



Royal Commission
into Violence, Abuse, Neglect and Exploitation
of People with Disability

Voices of people with disability

Book 1



Final Report
Volume 1



Painting a vision for an inclusive future, Group mural, Melville WA

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Acknowledgement of Country

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) acknowledges Australia's First Nations peoples as the Traditional Custodians of the lands, seas and waters of Australia, and pays respect to all First Nations Elders past, present and emerging.

We recognise their care for people and country. In particular, we acknowledge the Traditional Custodians of the lands on which our offices are based: the Gadigal people of the Eora Nation where our Sydney office stands, the Jagera and Turrbal people as Traditional Owners and Custodians of the lands on which the city of Brisbane is located and the Ngunnawal and Ngambri peoples upon whose land the city of Canberra is located.

We pay our respects to all First Nations people with disability and recognise the distinct contributions they make to Australian life and to the outcome of this inquiry.

Acknowledgement of people with disability

The Royal Commission acknowledges people with disability who fought and campaigned long and hard for the establishment of this Royal Commission.

We acknowledge the courage and generosity of people with lived experience of disability who shared their knowledge and experiences of violence, abuse, neglect and exploitation with the Royal Commission. Their contributions to the Royal Commission have been indispensable in framing recommendations designed to achieve a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

Content warning: These stories are about violence, abuse, neglect and exploitation and may include references to suicide or self-harming behaviours. They may contain graphic descriptions and strong language and may be distressing. Some narratives may be about First Nations people who have passed away. If you would like to know about available support, please see the [Contact and support](#) webpage on the Disability Royal Commission website.

Introduction

More than 9,000 people with disability, their family, friends, supporters, advocates and others shared their experiences and recommendations with the Royal Commission.

Many gave consent for their accounts to be published as short de-identified narratives that capture the authentic voices of people with disability and provide an insight into their daily lives.

This volume contains a selection of these narratives.

Individual narratives often describe multiple themes and cover a large number of topics. For this reason, we have not attempted to group the narratives and there is no Table of Contents.

The purpose of these narratives is to give a voice to people with disability and to help the public better understand the issues that people with disability may encounter in their daily lives.

We hope they will assist to bring about transformative change to help make our society safer and more inclusive for people with disability.

The voices of people with disability reflect the language and diversity of the Australian community. Narratives draw heavily on direct quotes of participants and their individual language choices. They sometimes include strong language, and language that may be at odds with polite or preferred usage.

To fulfil our legal obligations and to protect the identity of people who shared their experiences, we have used pseudonyms. We may have excluded or changed other details, including the jurisdiction where events took place, to further protect the identities of those involved.

Some experiences could not be converted to a narrative because the participant did not consent, or their experiences were impossible to de-identify. Whether they were written as narratives or not, every experience informed the Royal Commission's work.

The people who shared their experiences were not witnesses. They did not give evidence, take an oath or give an affirmation. Nothing in their stories represents a finding of the Royal Commission and any views expressed are those of the person, not of the Royal Commission.

The Royal Commission would like to thank each and every participant who has shared their experiences with us. This information has been vital to our work.

Earl

‘They say to me, “You’ve got to go see a counsellor.” I said, “Here, you give me a counsellor that’s walked in my shoes and has survived what I survived, and I’ll listen to them. But if they never been there, done that, they don’t know. How are they going to counsel me?”’

Earl is a First Nations man in his 50s. He acquired a brain injury in a car accident when he was at primary school.

‘After I got killed by the car and brought back to life, I had trouble with everyone. I had trouble sitting in the schools. And they classed me as uncontrollable,’ Earl told the Royal Commission. ‘They treated me different because I was uncontrollable. They didn’t look at my medical reports.’

Earl’s mother took him to the city to live, where he continued to struggle at school.

‘I used to go skating, and everyone loved me and all that. [But] I had brain damage, and I couldn’t fit into school. You know, I wasn’t a normal kid. They put me in special class, and I couldn’t even sit in special class. I wanted to jump out the window when they said, “Where’s your homework?” I didn’t know what homework was. I felt threatened.’

Earl and his siblings were removed from their mother and taken to a home run by a religious organisation.

‘They hounded us like dogs. And ... they locked me underneath the stairs when they went to church and let me out when they came back.’

Later, he was placed in a detention centre.

‘They locked me in cell ... And I used to sniff three tubes of glue a day. And then they used to lock me in the cell nearly every week, away from everybody. And that was my life.’

As an adult, Earl ended up in jail where he said correctional officers ‘bashed, gassed and tortured’ him. He was often placed in isolation.

One day, he was asked to take part in a university entrance education program.

‘And these people did these tests with me, these special things called “mind works”. And it helped me focus and taught me things ... And that helped me.’

Earl said professional tutors taught him ‘literature, communication and mathematics’.

‘I got high distinctions at university.’

While in jail, Earl helped set up counselling and disability employment strategies for First Nations people in the correctional system.

Eventually, Earl was released. One day, he was with a relative on her birthday and they went to a casino.

'I don't drink. So, they accused me of refusing to leave the premises. I was just watching my niece. And they smashed me to the ground, and then they arrested me. They took me to the watch house. They stripped me naked and put me in a cell and left me there for eight hours.'

Earl said police charged him with being drunk, even though he had a zero blood alcohol reading. He said sometimes people thought he was drunk because of his 'cross eyes' caused by his brain injury.

'I wait for my door to get kicked in every day. That's how I live. And I still think I'm a prisoner, and I've been out for ... years,' Earl told the Royal Commission.

Earl wants more liaison officers to help people with disability in the correctional system.

'I found that people in the mental health system and people with disability have not much support and advocacy. They're lost, lost people.'

Sufjan

Sufjan is in his late 20s and has autism and epilepsy. He told the Royal Commission about his experiences in the education, justice and mental health systems.

When Sufjan was in year 7, the school had a teacher whose role was to assist students with disability to integrate.

‘I would be sent to his office ... and he would make me have sexual intercourse with him,’ Sufjan said. This was a ‘frequent occurrence’ that continued for about two years.

The teacher told Sufjan, ‘No one will believe you, you have a disability.’ He called Sufjan ‘a retard’.

Sufjan can’t understand why the teacher was allowed to spend extensive periods of one-on-one time with him when he was so young.

Sufjan reported it to the police but ultimately decided not to pursue justice in the courts.

‘I don’t feel I can go through the criminal justice process, having to go to court with him and all of those sorts of things.’

While at school, Sufjan was bullied by other students. He was physically assaulted, kicked to the ground and called a retard.

‘It’s had quite a significant impact on my life.’

The bullying occurred at two different mainstream schools.

When Sufjan’s parents complained, one school said he should go to a special school if he’s not happy being bullied.

‘My parents described it at the time as a battle with both of those schools ... They were in sort of war just to have me go to my local public high school where I was gazetted and zoned to go.’

The schools were concerned about the cost of supports and told Sufjan and his parents he ‘would slow down the class’.

‘It was quite hurtful to my parents at the time and also to me as I was drawn into some of these meetings where they were complaining about the costs of things.’

When Sufjan was 15 he went to a party.

‘I was robbed at knifepoint ... Some kids from the school put this 18-year-old guy up to it, to rob me. He forced me in his car and drove me around the area for about half an hour also.’

The incident was reported to the police and the man was arrested. But the prosecutor 'did a deal' and the person 'received a backdated custodial sentence of four months and a good behaviour bond for a year'.

Sufjan didn't feel supported to be included in the process.

'The prosecutors didn't consult with me or my family as this was going through court. We found out he was sentenced after the fact. We had no idea that there was a sentence hearing.'

Sufjan would have liked to have made a victim's impact statement to the court because he was 'experiencing a lot of flashbacks ... nightmares'.

'I wanted to tell the court about those experiences because I felt quite scared going out in the area by myself.'

Meanwhile, Sufjan's parents requested that Sufjan go to a different school 'because the 18-year-old was clearly brought in by other students at that school'. The response from the education department was, 'oh well it was just a practical joke in a social setting'.

Sufjan stayed at the school until the end of year 10. He changed schools but completed his senior year via distance education because he was 'quite scared and fearful'.

Last year Sufjan was experiencing a 'severe episode of depression'. The local community mental health service refused to treat him saying, they 'don't deal with people who have autism'.

Sufjan told them he wasn't there for behavioural issues but for depression. The doctor asked, 'why do you want your depression treated if you have autism, what's the point in doing that?'

Sufjan was shocked by the doctor's comments, but when he spoke to friends with dual diagnoses he discovered 'the response is not uncommon'.

He believes there is an attitude that medicating an autistic person for mental illness is inappropriate and akin to chemical restraint.

'If someone has a mental illness like depression or schizophrenia or bipolar and they also have a disability, they're entitled to the same sort of treatment [as a person without a disability].'

'My GP had a lot of challenges finding someone in the private sector ... to refer me to because there's very limited ... psychiatrists who will see patients who have dual diagnoses presentations.'

Bryson and Arabella

‘At no point did they ever consult him – he’s a 14-year-old boy – about what he wanted in his life.’

Arabella has cared for Bryson since he was 10 months old. He is a First Nations child who has been in out-of-home care (OOHC) since he was born. Arabella told the Royal Commission that Bryson has faced many barriers and hurdles because of his race, his disability and being in OOHC.

Bryson is autistic and has attention deficit hyperactivity disorder, anxiety and limited mobility in his left arm, which makes writing almost impossible. Before Bryson started high school, Arabella asked his specialists to observe him in the classroom and determine whether he should attend a mainstream or supported education school.

The specialists agreed Bryson’s ‘best opportunity for whole life outcomes’ was to attend a mainstream school with support. If he wasn’t in a mainstream school he ‘would be bored ... go backwards ... and it would be harmful to him’.

Arabella met the principal of the local state high school and ‘got a reasonable reception’. However, a few weeks later the education department asked her to attend a review to discuss the supports Bryson needed. Staff from the high school were also present.

Instead of discussing Bryson and his strengths, they showed her three pieces of student work. One was a ‘B’ standard student, the next, a student with a disability and the third piece belonged to Bryson. All pieces were handwritten. They told her that based on this test it would be impossible for Bryson to ‘meet the curriculum’ of a mainstream school and he needed to attend an autism specific school.

Arabella was confused. They knew Bryson needed a scribe to support him with assessment tasks. ‘Basically they’d taken away his supports ... and used his disability against him.’

They ‘proceeded to harangue’ her about moving Bryson to the autism specific school. If she didn’t, they said, Bryson would get beaten up and laughed at because of the strange noises he makes and teachers wouldn’t care.

‘The whole thing was incredibly insulting and designed to marginalise, discriminate ... and prevent him going to his local school.’

Nonetheless, Arabella was determined to follow the specialists’ recommendations and enrolled Bryson at the local school.

Arabella said that, despite an initial first quarter that was ‘not too bad’, the school was relentless in its push to remove Bryson.

Every time there was a new OOHC case worker – which was often – the school would have ‘secret meetings’ to convince the case worker to move Bryson to another school. Bryson was ‘out of control, not performing, not engaged in his education, failing all classes and not doing any work,’ they said. Yet by the middle of the year, he was in the top three of his geography class.

When Bryson’s birth mother became critically ill, the OOHC case worker insisted Arabella tell him – in the middle of the school week – his mother might die. Arabella warned the school he might be reactive. Yet when he became upset and there was an incident, the school suspended Bryson instead of supporting him.

Suddenly, Bryson was offered a place at another high school.

Arabella met the prospective principal. She discovered most of the students were drug users and had criminal records – it was ‘the school of last resort’ before the juvenile justice system. The principal told Arabella that Bryson would be easily identified as ‘the weak link’. He would be taken advantage of and ‘learn behaviours most likely antisocial and criminal’.

‘So, totally not the school to send an anxious child with autism,’ Arabella said.

She firmly rejected the offer but the education department told her Bryson could no longer attend the local state high school. Arabella tried to enrol him at private schools but none would take him.

A series of dispute resolutions were held.

‘It was a really horrific process. The education department was incredibly demeaning, bullying, they talked over me constantly ... There was no-one who would stand up for him except for me.’

It took Arabella six months to resolve the issue and Bryson remains at his local school.

‘He has a right to go to his local school, he has a right to be heard and a right to make decisions in his own life.’

Glenn and Sariah

‘Our drama started ... when he broke his leg quite badly at school.’

Sariah told the Royal Commission she didn’t think too much about it at the time because her son Glenn was ‘a climber’. But she was surprised that no-one from the school knew how the injury occurred.

Glenn is non-verbal, has an intellectual disability and is autistic. His regular teacher was away when it happened and Sariah has never been told who was teaching that day. ‘We had our suspicions but we don’t know.’

Glenn needed to use a wheelchair while his leg mended. Sariah thought this wouldn’t be an issue for his special needs school, but they ‘couldn’t cope with him’. He was home for six months. ‘I think it was easier for them,’ Sariah said.

When Glenn returned to school, Sariah immediately noticed behavioural changes. He had never been a violent child, but he was now having frequent ‘melt downs’ and lashing out. ‘He just started to lose his crap and go into a screaming mess at the drop of a hat.’

Sariah constantly rang the school telling them ‘something’s wrong, something’s not right’. ‘All I got back from school was “Oh you know he’s 12 now and puberty’s here.”’ But there were no outward signs of puberty.

Then he started coming home with bruises, scratches and bite marks. A parent told Sariah that Glenn was being attacked by another student. Sariah was ‘jumping up and down like mad’, asking the school why there was nothing in the communication diary.

One afternoon when he got off the bus, Glenn’s face was bleeding. Sariah said it looked like his eye had been gouged. ‘I was like what the hell happened – why is he bleeding and why didn’t I get a phone call?’ The teacher aide on the bus was upset and said, ‘I can’t talk to you. If I talk to you I’ll get fired.’

Sariah searched Glenn’s bag and found a note in the communication diary. It said Glenn was a ‘bit red on the face, don’t know why’.

Then when Glenn took his clothes off Sariah saw bleeding scratch marks down his back and bruises on each arm. She was sure these injuries couldn’t have been made by another child.

Sariah took photographs and emailed them to the acting deputy principal, who told her nobody saw what happened. But Sariah finds this hard to believe. ‘There is no way this happened to him and he was quiet. He screams the house down.’

She decided to keep Glenn home until someone could guarantee his safety.

Meanwhile the teacher who was on duty when Glenn came home bleeding came to see her. The teacher told Sariah the staff had been warned if they talked to her they'd get the sack. But she wanted Sariah to know she hadn't hurt Glenn.

By this stage Glenn's anxiety was so bad he was 'a screaming uncontrollable mess'. Sariah took Glenn to the paediatrician and showed him all the photos. He said as a mandatory reporter he would report the injuries to the child protection authority and advised her to do the same thing.

'A couple of days later,' Sariah said, '[Glenn] pulled out his penis and tried to slam it in the shower screen door.' Thinking it might be a urinary tract infection Sariah took him to the GP who referred them to hospital. Medical staff looked over Glenn 'from head to toe' and asked Sariah to explain Glenn's injuries. A nurse informed her he had to report the injuries to child protection.

By now at least four people had reported Glenn's injuries to the child protection authority, yet no-one had contacted Sariah. A counsellor told Sariah if the injuries had happened at home she would have been charged by the police.

When a new principal started and the suspected teacher left, Glenn slowly returned to school.

Then unexpectedly Sariah received a phone call from an investigator in the education department. Sariah asked if it was about the broken leg or the other injuries. The investigator had no idea what Sariah was talking about. 'She knew none of it ... It's like nobody cared about what happened.'

The investigation came to nothing.

'They don't have enough evidence to go anywhere and that's just the end of it ... We're just expected to carry on like nothing has ever happened.'

Glenn, not yet a teenager, is still suffering. Sariah says he has regressed. 'His anxiety's through the roof, he's scared ... and lashes out at people.'

'To do this to him and make him cope ... as a parent it's heartbreaking.'

Sariah would like to see cameras in the classroom to protect the non-verbal students.

'I don't trust [Glenn] with anybody anymore.'

Anastasia and Beatrix

Anastasia lives with a severe form of epilepsy, cognitive impairment, autism and a bowel condition.

Her mother Beatrix told the Royal Commission that when Anastasia was 10, in the early 2000s, she was having up to 80 seizures a day. Beatrix needed support in order to care for her.

The disability department found Anastasia a place in a respite house for three days a month. Anastasia didn't want to go and Beatrix 'had to drag her there'.

At this time, Anastasia's capacity was such that she 'couldn't put her own shoes on, couldn't undress herself'.

One day Beatrix received a call – there had been an incident at the house. Anastasia had been found 'naked in the bedroom, bent over a bed, with three older boys ranging from 12 – 15 standing behind her'.

Staff told Beatrix 'nothing happened, there's no need to make a big deal about it'. But Beatrix took Anastasia to hospital and then to the police station where she made a statement. 'Nothing was done,' she said. 'I never took her back to respite.'

Soon after, Beatrix was approached by a disability service provider who offered to take Anastasia as a client for three months. The provider implied Anastasia's behavioural issues were due to poor parenting and they would help Beatrix with a parenting plan.

The provider proceeded to 'consequence' Anastasia. 'They were using consequences to get rid of her disabilities,' Beatrix explained. They told Anastasia she could only see her mother or speak to her if she behaved.

Sometimes Beatrix would 'do drive-bys and show up at the house' and find Anastasia sitting on the floor in the freezing cold in barely any clothing, while staff sat in the staffroom with heaters. Beatrix would wait with her and sometimes it could be up to an hour before staff noticed. The provider attempted to restrict Beatrix's visits and she was told to phone before she dropped by.

During this time Anastasia's behaviours escalated. By the end of three months Beatrix said the staff were begging her for help, saying, 'How the hell have you done this on your own this whole time?'

The provider tried to find a place for Anastasia in a children's mental health facility to no avail. So Anastasia, at 12, was placed in an adult mental health unit while doctors adjusted and changed her medication.

When she was discharged, the provider agreed to provide full-time care in a private rental, funded by the state government. Anastasia lived alone with a couple of support staff rostered to live with her.

Staff continued to try to 'consequence' Anastasia's behaviours and told Beatrix to trust them.

Sometimes Anastasia would come home from school to find everything she owned had been removed from the house. 'She would have nothing but a mattress on the floor and then she had to earn back all her stuff with her behaviours,' Beatrix said. This would go on for 10 days. Anastasia would try really hard, but if she slipped up on the ninth day she'd be forced to start again.

Over the years this resulted in Anastasia smashing every gift or anything new she was given. She told Beatrix, 'They can't take it off me now.'

The provider complained repeatedly about the cost of caring for Anastasia and pressured Beatrix to consider a group home or cotenancy. But Beatrix refused because of Anastasia's previous experiences.

Ultimately the state government took Beatrix to court for custody of Anastasia so they could place her in a group home. Beatrix said the judge was disgusted and said, 'How dare you put this family through this because of the almighty dollar.'

When Anastasia turned 18 she was forced to have cotenants. One tried to stab her. One stole all her things, and another destroyed them. Anastasia began to self-harm. One time she cut every tendon in her finger with a butter knife. Beatrix pleaded with the provider 'to stop this cotenancy, she's going to end up dead'.

Finally Anastasia moved to her own unit and shared support workers with a tenant in another unit.

Soon after, she rang Beatrix and told her she had a boyfriend who had kissed her on the lips. Beatrix was alarmed and asked the support worker to ring her the next time the man showed up.

Two days later the support worker rang Beatrix and told her Anastasia was very upset because the man had 'sexed her'. Anastasia told Beatrix 'he had his pants down and he pulled my pants down and put his penis there', pointing between her legs.

Beatrix took Anastasia to hospital where she underwent a rape kit exam. The hospital told Beatrix 'definitely, yes'.

The man was charged by police but when the prosecutor explained Anastasia would need to be cross-examined at trial, Beatrix decided it would be too traumatic.

Beatrix said it has taken years of counselling for Anastasia to stop self-harming following this incident.

Gabrielle and Doreen

Gabrielle is 10 and has autism. 'Her potential is unlimited,' says her mum, Doreen. 'She has these abilities, we don't know what they all are yet ... But school has stopped her social growth, school has held her back.'

'The system has failed Gabrielle,' Doreen told the Royal Commission.

When Gabrielle went to primary school, Doreen felt the head of the special needs department understood Gabrielle's needs and that she would be safe there.

As she moved into grade 3, Gabrielle was 'ready and excited to learn'. However her case manager was 'under supported and over worked' and was not able to implement the supports Gabrielle needed.

Then there was a change of principal and the head of the special needs department left the school. Her replacement, Doreen said, was 'a nightmare', and there was 'zero transitional support' for Gabrielle as she moved into grade 4.

'I have experienced first-hand how the replacement of a principal overnight can remove all supports that the student needs to engage.'

During the transition, the special needs coordinator was away on a school camp and there was no-one there to support Gabrielle. Within a couple of days her behaviour changed and she became very reluctant to go to school.

At the end of that first week Doreen was walking Gabrielle to the school when she became so upset she started to punch herself in the head. Gabrielle worked hard to calm herself down but when the school bell rang, Doreen said, 'she got up, looked at me, and fell down crying'.

'This is what happens when everything is taken away.'

Gabrielle's teacher was completely disinterested in Doreen's plan to support Gabrielle. He seemed to think he knew better. When the lack of appropriate supports in the classroom led to Gabrielle having meltdowns, he said she was 'making bad choices'.

Doreen says this victim blaming is common and is often couched in terms of 'resilience'.

'If another teaching adult says to me "Let's grow [Gabrielle's] resilience," ... I want to slap them! Because [Gabrielle] has more resilience in her little finger than their entire body. She goes back into that toxic environment every day.'

Then, with only one day's notice, the school removed the special quiet room used by children like Gabrielle.

'No transition, no alternatives, nowhere [Gabrielle] or other children could take time out to reset. The attitude seemed to be "she will either work out or she won't".'

Doreen tried to engage the school many times about Gabrielle's behaviours and supports. 'How often was she having meltdowns at school?' No response. 'What was the school's protocol for her meltdowns?' Nothing. 'What do you communicate to other children about her meltdowns?' Radio silence. Nor was there any communication with her parents when Gabrielle started to struggle in subjects she had previously done well in. They only found out after she failed.

Meanwhile, it took nearly two years to get Gabrielle's independent learning plan signed off on. 'And I had to fight, fight, fight,' Doreen said, 'to have her strengths put in there ... I fought and fought and fought to have goals in there. I said "we are growing this child".'

'The culture, that is deeply embedded, it's a combination of a perpetuated, unapologetic, segregational blend of superiority, arrogance, ignorance, entitlement, dismissiveness, stubbornness, change resistance, deceitfulness, closed mindedness.'

Gabrielle's parents are currently searching for a new school for her. They wanted her to be in a mainstream school, they didn't want her to be in a segregated system, but they now feel they have no choice.

'I don't want to force my daughter into a school that doesn't want her. How is that going to help her?' So Doreen is considering distance learning and applying to special schools.

'Our beautiful child who worked so very hard to be school ready and has wanted so desperately to belong has been deliberately sabotaged by the system that we were asked to trust. This school system has beaten us. Inclusion is a legislated myth ...

'She is a happy child, she is a curious child, who would love so much to be engaged in this world, she has unlimited potential ... but the way things are going she'll end up living alone and taking government checks ...

'The system has failed Gabrielle. It has to change.'

Dimash

Dimash represents Australia as an athlete. But because he arrived in Australia illegally by boat and has a disability, his future in Australia and the sport is uncertain. 'Uncertainty every day is with me ... uncertainty has destroyed me ... I can't express it in a way you can feel it,' Dimash told the Royal Commission.

When he arrived in Australia in the early 2010s, Dimash was detained in an immigration detention centre where he says he was abused and neglected.

Staff told Dimash there were no blind people in Australia and he would never be able to leave detention. They refused him a white cane in case he used it as a weapon. The only support given to him to learn English was a book of Shakespeare in braille. The old-style English was complex and made him sound comical. People would often comment on the words he used. Some staff accused him of faking his blindness for sympathy – Dimash wished that was the case.

When a group of human rights delegates visited the detention centre to speak to the children, Dimash sat with the children and told the delegates, 'I am a grown-up children. I am going to sit in the middle of here until someone answering me.' He wanted to know if there were people like him in Australia and learned there was a human rights commissioner with disability. A short time later the commissioner contacted Dimash and organised a white cane for him.

Two years after arriving in Australia, Dimash was released from detention with nothing but shorts and a t-shirt and \$400 to buy some clothes. A year later he was asked to repay the \$400.

While he waited for a protection visa he received a Status Resolution Support Services payment of approximately \$400 per fortnight. This was expected to cover everything – rent, food, transport and his sporting costs.

Dimash learned basic English through socialising and playing sport, but he wanted to improve his skills. He attempted to enrol in a university course, but wasn't eligible because of his visa status. Undeterred, he went to a class and the lecturer allowed him to sit quietly in the back, to listen and learn for free.

When his English improved Dimash tried to find work. He estimates he applied for more than 100 jobs. Organisations either didn't know how to support a person who was blind or didn't have the resources to do so. Dimash tried to get some support through disability service providers but often ran into problems because of his visa status. Most disability support is only available to Australian citizens.

Dimash felt refugee services and disability support services worked at cross-purposes. Disability services didn't know how to support a refugee and refugee services didn't know how to support someone with a disability.

Eventually he secured a casual position at a social enterprise. He described the feeling when he bought his first cup of coffee using his own money – ‘I was over the Moon.’

Despite the lack of resources and support, Dimash continued to excel at his chosen sport and was selected for national and international championships. But his temporary visa status remained a problem. Although he was granted permission to leave Australia, he faced immigration issues trying to return – one time he was threatened with deportation.

Dimash applied for a talent visa, which allows refugee athletes who represent Australia to work and live in Australia permanently. But his application was denied because he is blind. He finds the decision cruelly ironic – he’s representing Australia because of his disability but because of his disability he’s not eligible for a talent visa.

Meanwhile, he successfully applied for a job with a large company. Dimash said one of the best things about the role is he’s not employed because of his disability but for his skills and who he is.

‘We have to create opportunity for people with disability to just live a normal life ... If we get the right opportunity, right resources, I can do everything.’

Romeo and Sonia

‘He used to love school. There’s pictures of him really happy and engaging and doing things that are different, but now he doesn’t have that, and his life is very enclosed. It’s really crap.’

Sonia’s son, Romeo, is in his early teens. He is autistic and has an intellectual disability and epilepsy. He doesn’t speak.

Sonia told the Royal Commission that when he was in primary school, a teacher physically assaulted Romeo.

‘In one instance, he was pushed into the toilet stall and kicked in the shins, which is horrific.’ Romeo developed a fear of bathrooms. ‘He didn’t bathe for like six months.’

Sonia said the school didn’t tell her what had happened.

‘We didn’t get any information, apart from the principal told me on another occasion that it occurred numerous times, the physical assault, and in front of several staff members.’

Sonia told the police, who said there was nothing they could do.

‘They said, “Well ... it’s a school matter. We can’t interview [Romeo], he’s non-verbal. The school has to deal with it.”’

The teacher lost his job.

Another time, teaching staff left Romeo alone while he repeatedly banged his head on the floor. The school told Sonia they couldn’t intervene because that would be a ‘restrictive practice’.

A few years ago, Romeo developed severe epilepsy. The school couldn’t provide a full-time support worker to monitor his seizures. Sonia tried another school – they also couldn’t help.

‘That’s the only reason why he can’t access education ... you lose complete faith in the education system.’

Romeo developed a fear of school that remains with him. ‘You drive him past the street with the school and he gets really anxious in the car.’

When Romeo first developed epilepsy, Sonia took him to hospital. The hospital appointed a psychiatrist to treat him.

‘She ignored his seizures and saw that he was a child with high anxiety levels, and her recommendation was ... to trial him on stimulants.’

'He was beside himself ... If [Romeo] had been referred to the neurology team, he would have had access to better treatment, but he instead unnecessarily suffered for eight months.'

Sonia found a private neurologist, who gave him an implant to control the seizures. The implant caused an infection, and the hospital admitted Romeo to treat sepsis.

'[The neurologist] said to me, "Do you really want to do this? Do you really want him to go through this?" and I thought, "Yes." ... Then later on I thought maybe he was giving me the decision to end [Romeo's] life, and I just thought that's so wrong. If he had not had an intellectual disability, then they wouldn't have given someone that choice.'

Sonia said earlier and better-resourced medical and educational interventions would have prevented many of the challenges Romeo now lives with.

'In the long run, if [people with disability] had sufficient support in the beginning, it means that there's so much less needed when they're adults.'

Orlando, Eliana and Madeline

Orlando is in his 50s and has cerebral palsy, which affects his physical and communication abilities. He controls his computer with a pointer attached to his head, and his electric wheelchair with his chin.

For the past 20 years he's lived with five other men with similar disabilities in a block of units managed by an independent provider. Orlando's mother, Eliana, says it 'works very well and they all get on very well'. She and Madeline, Orlando's sister, describe Orlando's current support staff as 'sent from heaven'. But they told the Royal Commission this wasn't always the case.

In the early 2010s a staff member, Luke, bullied the residents. He would turn off the power to the wheelchairs and move things around in their rooms. When Orlando asked him to turn up the volume of the TV, Luke would turn it up full volume, leave the room and shut the door.

'Whenever we were in the house, we were never sure what sort of a mood this man would be in. He'd come in and be jovial one time and then he'd be sullen and you could hardly get him to speak,' Eliana said.

After a formal complaint from a resident Luke was moved to a different house.

Not long after this, Orlando attended a two-day camp with another resident and was surprised to find Luke was one of the two carers. Orlando said Luke was in a bad mood from the minute they got on the bus. He felt nervous and thought he'd try not to do anything to irritate him.

On the last day of camp Luke gave Orlando a urinal bottle while he was still in bed. He warned, 'if you spill that I'll get very angry' and then left the room. Feeling anxious, Orlando accidentally spilled the urine. When Luke returned, Orlando asked to have a shower because his clothes were wet and he felt sticky.

Orlando said Luke was 'pretty annoyed' and put him in the shower. The previous day a plumbing fault had been reported – the shower had been running hot and cold. Luke quickly tested the temperature and as it seemed fine he left to pack the van which was about 50 metres away and out of earshot.

Orlando was alone as the water heated to scalding temperatures. He began to spasm and wasn't able to get words out. 'I was in pain. I passed out.' By the time Luke returned Orlando had third-degree burns. He lost so much fluid he had to be taken to ICU and placed on a ventilator.

At this stage one of the doctors asked Eliana and Madeline if they wanted Orlando to be resuscitated. Eliana recalled, 'it was almost an assumption' that because he had a disability they shouldn't resuscitate him.

‘I did not want to die,’ Orlando told the Royal Commission.

After surgery to graft skin, Orlando returned home. He needed physical and emotional support but staff had been told not to talk to him about the incident.

‘I had a call from the house manager and the accommodation manager and do you know they’re the only two phone calls I had in the next four years,’ Eliana said.

The provider refused to accept any responsibility and suggested Orlando ‘might have kicked the hot tap’.

‘They covered everything up,’ Orlando said.

Eliana engaged a solicitor but the provider had more resources and ignored them. It took a court order and Eliana begging the CEO to ‘move this along’ to bring the matter to mediation.

‘We were turned into the big dragons you know, they acted like the victims and that we were being difficult, it was just horrendous ... At a time when we needed help, there was just nothing.’

Eventually, Orlando received a small financial compensation and an apology from Luke and the CEO of the accommodation provider. But Luke’s apology did not contain any admissions. ‘I think probably he was told what to write,’ Eliana said.

Orlando has post-traumatic stress disorder and anxiety and remains upset Luke was never sanctioned. In fact, Luke was promoted and is now a house manager.

‘They go right back to work after ... they nearly killed me,’ Orlando said.

Tyra and Bessie

‘All psychologists have said that the trauma will rear its ugly head later on when she becomes aware of what’s transpired.’

Tyra is autistic, has dyspraxia and was non-verbal until she was five. Initially, she attended a mainstream primary school.

About five years ago, Tyra came home from school and her mother Bessie noticed a grey discharge in her underpants. Bessie told the Royal Commission she had ‘the presence of mind’ to ‘bag’ the underpants.

Bessie took Tyra to the doctor. The doctor asked whether she ‘had been interfered with’. Bessie was adamant there was ‘no possible way because she’s never out of my sight’.

Over the next week Tyra started displaying sexualised behaviours. She asked Bessie to play with her vagina several times. She showed Bessie what she wanted her to do. Bessie tried to explain to Tyra ‘this is not appropriate and that our private parts are private’.

A few days later Tyra complained her vagina was sore. Bessie asked her if something had happened. Tyra said it was because Eamon touches her. ‘She put her finger in her vagina and she swirled it around,’ Bessie said. Eamon would touch Tyra when they were in the toilets before school.

Bessie went to see the class teacher who told her there was a boy named Eamon in Tyra’s class. She said she had not seen any animosity between them.

The next day the department of family services rang Bessie because someone at the school had reported an incident.

Bessie phoned the principal but he wasn’t in. She spoke to the assistant principal who put her on speaker phone. Bessie found it ‘completely intrusive’ recounting what happened knowing she was on speaker phone. She said he became quite defensive telling her it couldn’t have happened at school because there was a teacher on duty from 9 am. He said a boy near the girls’ toilets would stand out ‘like a rooster in a hen house’.

Bessie said the school’s response was neglectful and distressing. They shut her out and refused to investigate the incident. She believes Tyra’s disability had an impact on how the school reacted.

The department of family services investigated the incident and examined the home and the school environment. But the results of the investigation were inconclusive. ‘I’ve never been able to come to terms with that fact ... there was no transparency at all.’ The woman who did the investigation said, ‘It doesn’t mean it didn’t happen. It just means they can’t prove it.’ The department suggested Tyra see a psychologist and change schools.

Bessie had to request a copy of the report through Freedom of Information, but it was heavily redacted.

Meanwhile Tyra became increasingly traumatised, absconding and screaming when arriving at school.

At a parent teacher meeting, Tyra's class teacher disclosed there was animosity between Eamon and Tyra. Eamon often hit Tyra on the leg and 'was sneaky about it'.

Bessie removed Tyra from the school. She contacted the department of education, which was unresponsive. Later, the department apologised and offered to pay for counselling.

Tyra now attends a community school and is in a support class for students with moderate intellectual disability.

Curtis

Curtis is in his 40s. When he was in primary school, a car hit him. Curtis now lives with brain damage, hearing loss and some loss of sight.

‘As a person with a disability growing up, life was always more difficult,’ Curtis told the Royal Commission.

After the car accident, when Curtis returned to school, some classmates bullied him.

‘When I was in primary school, I was peed on.’

He transferred to a special school where the abuse stopped, but he was ‘still under the hierarchy of the kids’.

Curtis tried to head off abuse by educating other students. When he started high school, he stood in front of the school assembly and told them about himself and his disability.

Curtis said it worked. Rather than treating him as ‘that ugly guy over there’, students began to talk to him.

But when he moved to another high school, he was bullied again and kept to himself.

‘I kind of think of it as a dreadful nightmare, now I look at it.’

Until a few years ago, Curtis was his mother’s main carer.

‘I had to be a nurse for about four of those years. The last year, I had to shower her ... It just broke my heart having to do that for her.’

After his mother died, Curtis moved in with relatives. He got a job for a short time, but when he accidentally cut himself ‘just a little’, his boss told Curtis he was a ‘liability’ and didn’t want him working there.

‘People without disabilities, they go to work, they cut themselves, they’re still at the same job.’

Curtis is reluctant to look for another job. He’s now involved in community groups and enjoys acting, music and dancing classes.

His NDIS plan doesn’t cover all the costs of his classes. Instead, it covers things he didn’t ask for, such as ‘more help with walking’.

Curtis said he experiences discrimination when he walks down to the shops.

‘I have been told by people, “I don’t understand. Wait while I get my supervisor.” That’s in shops ... I have heard people talk about me, calling me spastic.’

Curtis is now an advocate for people with disability.

‘I believe to move on we need better education.’

Jacques and Addie

Addie is mum to Jacques, an autistic teenager with an intellectual disability. Jacques also lives with a neuro-degenerative disease, epilepsy and uses a wheelchair. Addie and Jacques live in a small rural town.

Addie told the Royal Commission that one night a couple of years ago she saw blood in Jacques's urine and suspected an infection.

Jacques was hospitalised for five days, in pain.

'They had no idea where the pain was coming from ... Tears were just rolling down his eyes. "Mummy stop it. Mummy stop it. Mummy stop it."'

Addie tried to explain to the doctors the nature of Jacques's disability and how it affects him. She told them – if he won't talk to you, talk to me. But the doctors didn't listen. One doctor called child protection officers, accusing her of lying about Jacques's disability.

Addie insisted the doctors perform an ultrasound. They discovered a benign tumour blocking Jacques's bladder.

Jacques has been unable to leave the house since Addie brought him home from hospital. He's supported by the NDIS, but has been waiting nearly two years for funding to modify his home so he can manoeuvre his wheelchair.

'There's no way of getting Jacques from his bedroom to the shower. There's no way of getting him into the shower in his wheelchair. I can't even use his wheelchair in the house because of his height and proportion. They're too wide for my doors.'

Addie said the COVID-19 lockdowns have made things worse by preventing his support staff from helping Jacques. He is too big for Addie to move by herself.

'[Jacques] is literally a prisoner in his own home ... [He] certainly can't get out with his wheelchair. He is literally grounded to home ... [Jacques] hasn't seen the sun in 18 months.'

Jagger

‘My time in the public and private [education] system has left me a bit of wreck.’

Jagger, 20, is autistic and has anxiety, depression and learning difficulties. He currently lives with his parents, but his goal is to live independently.

Jagger told the Royal Commission he was bullied from year 2 until he graduated in year 12. He said teachers didn’t do anything to stop the bullying no matter how much he complained. The teachers and schools always blamed Jagger because of his ‘behaviour’, and didn’t address the bullying. ‘This led me to develop anxiety and depression.’

One time, Jagger had a bad meltdown and banged his head repeatedly against the wall. He suspects he had a concussion, but the teachers and the assistant principal didn’t do anything except send him home. ‘Rather than dealing with the issue, they isolated me.’

In year 10 he invited the whole class to his birthday party and they all accepted. On the day of the party Jagger stood outside waiting, but no-one came. ‘It was a prank.’

Once while getting changed for PE, students shoved Jagger’s underwear and shoes down a toilet. ‘I was crushed,’ he said. The school suggested he change in the storeroom, not with the rest of the class.

Jagger was terrified of catching the school bus because the bullies caught it too. His dad made a complaint to police, who spoke to the bullies’ parents. The parents couldn’t understand why it was such a big deal.

Jagger said the school did not provide any individualised learning or encourage his talents. He was often isolated from the rest of his peers in a cramped ‘learning area’. Jagger’s dad made a complaint to the minister, who referred it back to the school.

Jagger moved to a private school which he hoped would give him more support. But he found it ‘worse’. The school denied requests for support because there wasn’t enough funding or resources. Jagger’s dad had to educate the teachers about autism.

For the last couple of years Jagger went to a different school in the public system. One teacher took an interest in him and ‘shepherded him through most of the problems’.

Despite all the barriers, Jagger graduated. ‘I didn’t think I would do well but somehow I did.’

He approached a disability employment service to help him find a job. They found him a night-fill job at the local grocery store. Jagger had to meet the same quotas as the other employees or the whole team would be penalised. Co-workers bullied Jagger, treating him as the ‘weak link’ in the chain. It reminded him of being at school and ‘really brought back bad memories’.

Jagger often came home from his shifts with bleeding fingers because he was opening the boxes with his hands. The store would not provide him with a knife or any other sharp tool because they didn't trust him, deeming him 'high risk'.

Jagger complained to the disability employment service, but they didn't do anything. His dad advocated on his behalf and forced an investigation. This led to an informal mediation where an in-principle agreement was reached requiring the store to implement various changes. But nothing happened.

Jagger now works at a local mechanic washing cars two days a week. He really enjoys working there.

Jagger is also at university. He said it is doing 'very well' and they accommodate his needs.

Jagger would like to move out of home. His NDIS plan includes funding for community engagement and he is trying to find a mentor to help him engage with peers. He needs someone to take him out, take him to the pub 'to watch a footy game'. But it is hard to find accredited services in the rural area where he lives. He says there is money to spend but no services to spend it on.

Rey and Mara

‘The cleanliness is not there. It’s a dirty, horrible, horrible facility.’

Rey was diagnosed with a brain tumour about 20 years ago. As a result, he is non-verbal, has memory loss and is physically impaired.

Initially, Rey’s wife Mara cared for him at home. After about seven years, his behaviour changed. Mara told the Royal Commission he would wake in the night and ‘try to strangle [her] with his good arm’. If their young daughter came near him he would ‘hurt’ her.

Mara spoke to her GP who suggested ‘it’s time that you think about doing something’. But there were no facilities in the area. ‘I needed him near me, and I needed him near his daughters ... and family.’ Rey moved into the only place available – an aged care nursing home. In his early 40s, he was the youngest resident. ‘That was the hardest decision and I regret it,’ Mara said.

Over time, the standard of care deteriorated. Mara said Rey was often in clothing that wasn’t his, dishevelled and dirty. When he rang the buzzer for assistance, he would be left waiting for long periods of time.

Some years ago, Mara and Rey were waiting to meet with an organisation to arrange some outings for Rey. Rey needed assistance and pressed his buzzer a number of times. It took 40 minutes for a staff member to arrive.

By then, Rey had defecated and was beside himself. Mara was so distressed she asked to speak to the manager. The manager told Mara that Rey ‘buzzes all the time, he’s annoying’. Mara reminded the manager Rey was continent and knows when he needs the toilet. She demanded staff respond immediately.

After this, the manager made an application to have Mara removed as Rey’s guardian. Mara had to go to the police station to read the manager’s report supporting the application. Mara said it was full of lies. The police officer quietly said to Mara to ‘gather what you can’ and ‘this lady is notorious for these’. Mara asked everyone who knew them to provide statements to resist the application. She was successful in retaining guardianship of Rey.

Mara said the current manager is kind and knows ‘the right words to say’ but nothing has changed.

Rey is unclean, often sitting in soiled pads and wearing dirty clothing. Mara said the medical care is ‘rubbish’ and the agency nurse who comes to the home is ‘incompetent’.

Not long ago, Mara noticed a number of bed sores and welts on Rey’s body. The nurse told her it was a rash and Mara had to fight to get him to hospital. Doctors said the welts were caused by bed bug bites. The home told Mara they’d washed the sling and changed his bed linen. Mara questions why that wasn’t done daily.

On one occasion Mara arrived to visit Rey and found staff 'saying goodbye' to him. The nurse, without any authority, had stopped Rey's food and water and had implemented end-of-life care.

Mara immediately called her GP and got Rey to hospital. Rey had sepsis due to a bed sore. Doctors treated him and kept him in hospital as long as they could.

During the COVID-19 lockdowns, Mara 'couldn't get in' to visit Rey. The home ignored a sore on Rey's leg and one on his shoulder. It wasn't until he was again hospitalised because of sepsis and dehydration that doctors examined the sores. They ordered tests and a body scan. The sores were skin cancers and the cancer had spread throughout Rey's body.

Mara is 'devastated' and is trying to get Rey out of the home.

'He's either got to go to the hospital or is coming home to me to die ... I can't have him in there ... I can't because they're incompetent, they're dirty, and I can't do it.'

Dalton and Lyanna

‘I’m fully responsible for him ... as his sister. That’s my job for the rest of my life. But it’s not a job, it’s just what you do. So, that’s been quite challenging ... because he’s been subjected to a lot of abuse with the services.’

Lyanna, a First Nations woman, raised her brother Dalton since he was a kid. Dalton lives with complex disabilities.

‘He’s very smart and I like that about him because I don’t want him to lose his attitude,’ Lyanna told the Royal Commission. ‘So, while he can’t talk, he can say some really poor words like “bullshit”, “horseshit” or “get out now, arsehole”. I don’t know where he learnt it, but anyway.’

Lyanna said Dalton ‘is a very nice-looking young man, and so people automatically really, really like him’. When he was living at home, ‘everybody was doting on him, so, you know, he really enjoyed that’.

Dalton’s mother died and he now lives in a supported independent living home where, Lyanna said, he ‘sustained some really horrific injuries’.

‘His whole arm ... was all black and like a really deep red. I’ve got all the photos and that because that’s the only thing that I can do, to take photos of evidence, otherwise it’s me against the service provider.’

Lyanna believes the service provider is neglecting Dalton.

‘He has no quality of life and some days he’s not even getting out of bed. I have concerns about his safety. He got out of the house and onto the road. He’s got no road sense whatsoever.’

Lyanna said his service provider is understaffed and ‘he’d be better off in prison’.

‘[Dalton] is hard work, right, without a doubt, otherwise he’d live with me. But when he’s in a caring and safe environment, he is, you know, he’s back to his beautiful self, and he doesn’t have to be in fight or flight. And that’s what he is at the moment, in fight or flight because he’s had so many injuries.’

Dalton has also started to wet the bed.

‘Not just that, but to soil himself as well, and again, he had never done that since we toilet trained him. Sometimes he’s just crying, and they’re saying that he’s doing it for attention, but that’s nonsense. It’s an emotion. He can’t control that. He’s sad. He’s really sad and he’s confused.’

Lyanna said the service provider has stopped giving her incident reports.

‘This breaks my heart, I had to stop going to visit [Dalton] because the service provider was claiming that ... I’m the problem, it’s not the service provider ... I will not apologise for holding them accountable when I go there and he’s severely injured and nobody has let me know, so that then I can get the doctor to come.’

Lyanna said she would like to change service providers, but she doesn’t have guardianship and doesn’t want to jeopardise Dalton’s NDIS support.

‘I don’t want to be continuing to have to prop up a service provider who’s providing no quality of care for him,’ Lyanna told the Royal Commission.

‘The NDIS without a doubt is outstanding, but it’s the service providers that’s bringing it down. I’ve been really lucky with the NDIS, you know, for [Dalton], so I’ve got nothing negative to say about the NDIS. We just need to make sure that people are doing what they’re meant to be doing.’

Lilianna and Alessandra

Alessandra and Lilianna were around the same age and good friends. Lilianna, who had cerebral palsy and used a wheelchair, died a few years ago in her early 60s.

'[Lilianna] couldn't feed herself, toilet herself, she had the most horrendous buckteeth you've ever seen,' Alessandra told the Royal Commission. 'It was very hard to understand her, so a lot of people thought she wasn't intelligent as a result of her speech, but she was a highly intelligent woman.'

Alessandra met Lilianna more than a decade earlier at her church, after another church had rejected Lilianna.

'They had said, "This probably isn't the right place for you ... Why don't you try the mob up the hill?" So, she did and she rolled into our church one day ... So, I introduced myself to her and we got talking and we became friends.'

Alessandra said Lilianna had lived in group homes where staff abused and neglected her.

'[Lilianna] often went hungry because she was reliant on people feeding her. And I would meet her at 9.30 and she'd say, "Can you feed me my lunch?" and I'd say, "[Lilianna], it's only 9.30. I'll, you know, feed you your morning tea," and she'd go, "Yeah, but I might not be able to find someone to give me my lunch."'

Alessandra took Lilianna home frequently to cut her hair and nails. 'It was just the little things, you know, just making her feel special that she never got from that house.'

'You know, they often would shave her head. And she couldn't even give me eye contact because she was so ashamed when they shaved her head, but that was an easy way for them to do her hair.'

Alessandra said a support worker sexually abused Lilianna at one group home. When she reported it, the support worker was moved to another home.

Lilianna eventually moved to another home. Here, a support worker punched her in the face giving her a black eye.

'I said, "[Lilianna], you need to complain about this," and she said, "Oh, they just get frustrated, you know what it's like," and I said, "I do, but they still don't have the right to do that." ... She didn't want to complain about him because he was one of the "good ones", and she just said, "He just lost patience and he just got frustrated."'

Alessandra said the home refused to let Lilianna have a cat 'because they didn't want to clean up after it'.

‘One of [Lilianna’s] greatest sadness, and this will always haunt me ... was that she desperately wanted someone to love her. She wanted a pet.’

One Christmas, Alessandra organised for Lilianna to go to a Christmas lunch, but the staff wouldn’t help her travel there.

‘She was absolutely distraught.’

When Alessandra visited after Christmas, she found Lilianna in hospital with a chest infection.

‘She tried to transfer out of that house to another house where she got accepted, [but] in the end it just all fell through and she realised that she was going to have to stay in [the group home] so she kind of said in herself, “I may as well die, everybody wants me to die.” So, she kind of stopped eating.’

Alessandra tried to smuggle Lilianna’s favourite food to her, but someone took an intervention order out to prevent her from visiting.

Lilianna was eventually moved into a palliative care unit.

‘She said, “Well, they’ve said to me I can’t go back to the house, that I’ve become problematic,” and, basically, she felt that she was going to be homeless and that they’d send her to a nursing home, so that was it. She just said, “Nuh, I’m not going to a nursing home.”’

Alessandra told the Royal Commission that Lilianna should not have died.

‘I just want justice for [Lilianna] and for all the other people out there who are in the same circumstances.’

Nikolas and Valery

‘It’s a hard road. A lot of these facilities that run these group homes don’t understand where the parents are coming from. I am an advocate for my son and they don’t like that. They like to be in control.’

Nikolas is in his late 30s. He has cerebral palsy, autism and is non-verbal. Valery, his mum, said he ‘understands 99 per cent of what you talk to him about’ and communicates using basic sign language.

When Nikolas was in his late teens he moved into a group home run by a disability service provider. At first Valery had a range of issues with management. She said there was ‘no compassion, no empathy’ and she felt isolated.

‘They were expecting me to let go and let them virtually run his life which I was not going to do,’ she told the Royal Commission.

At one stage Valery became upset with staff after seeing Nikolas had a broken front tooth and none of them knew how it happened. Management took out a restraining order against her.

When there was a change of management, the situation improved. For the next 20 years Valery had a ‘very good working relationship’ with the new managers. There was good communication, understanding, respect and empathy.

But a few years ago the managers were dismissed and the CEO of the board became the manager.

Valery described the new manager as an ‘absolute nightmare’.

There was a huge turnover of staff – the manager dismissed the old staff, often for petty reasons. Staff stopped communicating and interacting with Nikolas who – because he couldn’t express himself – started having behavioural issues and ‘became quite violent’. When Valery phoned and asked how Nikolas was he was always watching TV.

About a year ago staff reported bruising down Nikolas’s back – saying he fell out of bed. Nikolas had never fallen out of bed before.

Valery saw the bruises and photos staff took after his fall, but they didn’t fit with a fall out of bed. Staff then suggested Nikolas fell in the shower. But Valery said this didn’t seem consistent with the bruising either.

A support worker contacted Valery privately. He told her he had photos of other bruising Valerie hadn’t been shown. He said he couldn’t show her the photos because he was frightened he would lose his job. Valery went to the police, who said they couldn’t do anything without more evidence.

Valery complained to the NDIS Quality and Safeguards Commission, which investigated and made a number of recommendations. But the manager ignored them.

A short time later the manager cancelled Nikolas's service agreement and asked him to leave his home as soon as possible.

Despite sustained pressure, Valery refused to move Nikolas until she found a place he would be happy. Compatibility was an issue and it took almost four months to find Nikolas a new home. The NDIS support coordinator was 'brilliant' and extremely supportive, Valery said. 'I could rely on her 24/7.'

Nikolas's therapists recommended a transition period to help him adjust to his new environment but the manager refused to cooperate. In the end Nikolas had only two sleepovers at his new unit with the new staff until he moved 'cold turkey'.

Nikolas took some time to adjust and had a number of behavioural issues, but Valery said the staff and therapists supporting him have been fantastic and patient.

Nikolas is engaged and learning new skills such as cooking, and in the last few weeks Valery has noticed positive changes in her son.

'I am overwhelmed with the support,' she said.

Lena

When Lena arrived for her first shift as a disability support worker in a day centre, she expected it to be as advertised.

‘On paper the roster of programs looked fantastic,’ she said. Participants, some with high needs, could choose different activities – for example, cooking, sewing, woodwork and drama. ‘They should have been enjoying their life, but they weren’t.’

She told the Royal Commission she was confronted with 32 people, some restrained, some wearing face guard masks and some lying on the floor. There were only two staff and Lena was told to ‘get on with it the best you can’.

The restraints, she said, were ‘the old-fashioned chairs with belts on them ... and people that were ambulant ... would be strapped in’. The masks were forced on people to stop them spitting. Lena was shocked because this was in the mid-2010s and she knew there were restraint laws in place.

One man was lying on the floor eating chips. Lena was worried he might choke and tried to sit him up but was told, ‘Just leave him alone, there is nothing you can do.’

The participants also had set bathroom times. One man had already used his bowels and Lena told her supervisor he needed to go to the toilet. The supervisor replied, ‘We can’t take him now, it’s not his time.’

Lena’s second shift wasn’t much better and she put this down to the culture. The staff were old, institutionally trained or untrained, she said. ‘You don’t even need a certificate anymore for casual staff.’ Two shifts were enough. ‘It was revolting.’

The next place she worked was run by the same company and she did one-on-one support. All the residents had complex behaviours including physical violence, compulsive eating and absconding. All doors, windows and the kitchen roller door were locked.

The man Lena supported was a compulsive eater. Food soothed him, and he knew the staff kept their chocolates in the office. One day the supervisor found him there and yelled ‘what the fuck are you doing’ and told him to get out. When the man hesitated, the supervisor grabbed him and physically removed him. Lena reported the supervisor to her manager but was told it wasn’t her place to say anything. ‘I was casual and I didn’t want to lose my job.’

She supported the same man at a community centre during the day where the kitchen was open and lunch boxes were left out. With Lena’s help he learned not to touch food that didn’t belong to him.

Lena also recounted supporting a woman living in a residential facility for 30 men and women. Half the residents had a disability and half had been recently released from prison. Doors weren’t locked. For people with no support it was a place of last resort ‘before homelessness’.

The home kept 85 per cent of the residents' support pension for food, toiletries and health expenses. Residents were supposed to be given the remaining 15 per cent but this woman was lucky to get \$10 a week. Food was served at strict times and toiletries were restricted. Lena said, 'I had to go every week and ask for soap ... tampons ... shampoo.' Laundry was done only twice a week, so clean clothes were an issue. Rooms weren't cleaned. The residents' cigarettes were taken and kept in reception which was only open during the day.

The woman Lena supported had an acquired brain injury and was terrified of the dark. There was an issue with the electricity in her room and 'there was never a proper electrician called in to fix [it]'. She had no lights and no television. She was terrified, alone and unable to lock her door. A colleague told Lena multiple rapes had been reported.

When Lena left, the woman ran away. The police found her and brought her back. Lena returned and did a few shifts with her and the woman talked about feeling suicidal. Lena immediately told her supervisor. They responded that Lena was 'just a support worker'. 'It wasn't my business, and it wasn't their job to look after her.'

Lena says she tried to put clients in touch with disability advocates but found herself in a 'feedback session' and was told if she ever gave a disability advocate's number to a client again, 'I would lose my job ... they don't need advocacy.' She tried to report her employer but couldn't find an appropriate avenue.

Lena now also works as a disability advocate and is determined to support people who have no-one to speak up for them.

Paola

‘You end up hating yourself and your qualities because you’re told it’s wrong. You’re told the way you act is wrong, the way you feel, the way you think is wrong.’

Paola told the Royal Commission she had wanted to be a police officer since she was eight years old. But she always struggled with literacy and numeracy, and when she eventually applied she was unsuccessful.

At school, very few supports were available and different ways of learning weren’t encouraged.

‘They could see I struggled and then would punish you and put you in a locked room by yourself,’ she said.

Over time she developed anxiety and depression and when she couldn’t be a police officer, still wanting to help people, she enrolled in a social work degree.

With very few supports – she was granted an extra 10-15 minutes for exams – she continued to struggle. Not wanting to fail, Paola paid for a tutor who helped her structure her learning. The tutor broke down assignments into manageable parts and reframed questions so she could better understand them.

Paola passed the academic component of the course and completed the six-month social work placement. A month before graduation Paola was told she needed to repeat the placement.

‘There was no consultation with me whatsoever. They were aware I had some learning barriers but that was not taken into consideration.’

They agreed to provide extra support, but it didn’t happen. ‘Basically,’ Paola said, ‘I gave it another go and didn’t get the support.’

She was then asked to take a break from university. This prompted her to see a psychiatrist who diagnosed her with attention deficit hyperactivity disorder (ADHD).

The psychiatrist outlined a range of supports Paola required but the university refused to engage.

This resulted in a four-year battle with the university, ending with the state equal opportunity commission which found the university had discriminated against Paola.

‘The equal opportunity commission decided that I academically passed and [the university] were failing me based on my wellbeing.’

Paola said the university failed her because they believed it was their responsibility to protect the public from her ‘mental health stuff’.

‘What I had learned from that experience was that as a young person with anxiety, depression and undiagnosed ADHD and learning barriers, that I just listened to what they were saying to me, I had no confidence, I was scared, I didn’t believe I was worthy ... I thought, “yep I should fail.”’

Paola received compensation and was allowed to continue her studies. However because the experience had been so fraught, she decided to attend a different university and ended up completing a different degree.

A few years later she was discriminated against by an employer – ironically a disability employment service provider.

Paola’s supervisor ‘belittled and mocked’ her when she asked for information to be repeated and because she had to take medication every day. The supervisor would block Paola’s password preventing her from completing her case notes in her own time. She wasn’t allowed time off work to attend essential appointments with the psychiatrist and psychologist.

Ultimately, the employer advised Paola if her performance didn’t improve, she would be terminated.

Because of her experience with the university she immediately engaged an advocate.

The advocate helped Paola negotiate better supports and a reduced case load.

But Paola decided to leave and took her employer to court. The matter was settled and Paola received financial compensation.

Paola has been in her current role for more than two years and recently completed her social work degree. This time, the supervisors for her final placement spoke to her in a ‘strength-based way’.

‘When you don’t understand the way you think. If you can’t regulate your emotions. If you can’t regulate your thoughts, if you’re feeling misunderstood, then you’re going to fall into a trap of anxiety and depression.’

The placement supervisors understood this. They sat with Paola and helped her break down the work. They gave her feedback and time.

Paola said this made a ‘huge difference’.

She passed ‘with flying colours’.

Cynthia, Ellie and Siena

Since moving back home Cynthia has a 'really lovely quality of life'. She goes horse riding and swimming and will do some jobs around the house. 'She's still a bit naughty at times,' says her sister Siena.

But five years ago Cynthia was a different person. She was anxious, distressed and self-harming – the result of decades of abuse and neglect. Siena told the Royal Commission this began when Cynthia was a young girl.

From the age of eight Cynthia lived in an institution for children with intellectual disability.

The family visited every weekend and sometimes found bruising on Cynthia. Her mum, Ellie, said she would march into head office and demand Cynthia be moved, but options were very limited at that time.

A few years later, deinstitutionalisation was beginning and a place in a group home became available closer to the family home. At the time it seemed like a blessing.

The home accommodated five residents including Cynthia, all non-verbal. Siena remembers seeing other residents, who didn't get regular visitors, still in their pyjamas at 4:30 pm and never going out.

Bruising on Cynthia's back and arms continued. Ellie said they were often unexplained or the explanations were implausible.

There was one support worker who alerted Ellie to the abuse that was happening, but said she couldn't tell her everything because 'she would lose her job'.

Ellie peppered the department with complaints and eventually an enquiry was held. Recommendations were made but nothing changed.

Years later the support worker reported the abuse she witnessed at the house to police. This included staff forcing Cynthia to sit still against the wall for long periods. They would tape her fingers together to stop her movements and would tie her hands to the legs of the chair or behind her back.

The family also learned that some staff were stealing the clothes and food Ellie bought for Cynthia. They would also purchase items for themselves out of the residents' budgets and buy poor-quality food for the house.

Cynthia moved to a new house, but it was just as bad. Again there were unexplained bruises on Cynthia's knees and down her arms, food was stolen and Cynthia was neglected. The family would often find staff outside smoking while residents inside were running amuck or left sitting on the toilet.

Cynthia's health deteriorated and there were serious issues with her diet and personal care. More needed to be done for her but no matter what the family or doctors suggested, the house refused to implement changes.

The staff's convenience always came first. Instead of taking the residents to the park or the beach they would go to the same shopping centre every week where staff did their personal shopping. Rather than taking people out for a haircut they brought someone in because it was easier. Residents were deprived of all the little things that add up to a life.

'It became a constant battle,' Ellie said.

Ellie and Siena demanded action from the group home, the department and regulatory authorities. 'But they didn't solve anything, in fact they made things worse.'

Ultimately Ellie was banned from entering or calling the house and Siena was only allowed to call Cynthia three times a week.

Ellie and Siena didn't understand their rights and they were scared for Cynthia. They engaged a lawyer and were referred to an advocate who was a great support.

Ultimately, Cynthia was granted a large support package to move home.

Keeping Cynthia safe and happy continues to be her family's number one priority, but it has come at a cost. Siena explained, 'It has had a huge impact on both our lives and collectively. Mum and I can't go on a holiday and that's really impacted our relationship.'

Felicity, Houston and Octavia

In the early 2010s Houston received a letter from a 'whistleblower' alleging his sister Felicity was being sexually abused. Felicity had Down syndrome and was living at a group home run by the state government.

Immediately after receiving the letter, Houston and his partner Octavia took Felicity to the GP. Felicity disclosed someone had hurt her in the genital area. The doctor examined her and sent her to the hospital's sexual assault centre where she was examined by a forensic doctor. There was no evidence of sexual assault but, with Felicity's consent, staff notified police.

Houston and Felicity are twins and were born hard of hearing. Houston told the Royal Commission, 'I knew how [Felicity] spoke, what sign language she used and vice versa.' He believed he was the best person to support her during the police interview.

However the police refused to allow Houston to be present and, because of an outdated support plan, denied Felicity alternative communication aids. Inexplicably, the manager of the group home was allowed to attend the interview. Octavia believes this was a blatant conflict of interest.

According to police, Felicity did not disclose any sexual assault in the interview. Houston was not surprised. 'The police did not know [Felicity], did not know how to approach her, how to interview her and of course [she] was confused,' he said.

The alleged perpetrator was never interviewed. The government department responsible for the home allowed him to continue to work alone with Felicity.

Afterwards, 'he was very cocky, very arrogant,' Octavia said. 'It was almost like the smirk of, "you can't touch me." And he was quite right. You've got a whole system that was protecting him.'

Dissatisfied with the situation, Houston contacted a disability advocacy organisation. At a meeting with an advocate Felicity independently disclosed that a staff member had hurt her and pointed to her genital area. The advocate reported the disclosure to the department and police but the police refused to reopen an investigation.

Houston complained to the Office of the Public Advocate. But instead of fully examining the whistleblower's allegations they conducted a brief review. Their report discredited Felicity and her communication methods and vilified Octavia and Houston. Houston felt bullied into silence. He believes the strategy was 'to keep a lid on it' and protect the government of the day.

Meanwhile, the group home and department began a campaign of retaliation. Houston and Octavia were not welcome at the home and were excluded from all events, including Felicity's birthday party.

Without warning, Felicity was moved to temporary accommodation. The home told Houston they needed to modify her bathroom. But this never happened and after five months Felicity was moved to a new home. Houston says Felicity was devastated leaving the other residents – she'd lived in the home for almost her entire life.

The retaliation continued to have dire consequences for Felicity.

One time Felicity sustained carpet burns on her face, arms and knees. She told Houston a staff member dragged her along the ground. The home denied this telling him she'd fallen out of bed. This seemed so implausible Houston photographed the injuries. But ultimately he was too nervous to report the incident to police because of the way they'd been treated when they'd reported the sexual abuse.

Concerns around Felicity's dental health and hygiene had been ongoing. Her teeth had been removed because of decay and neglect. This allowed plaque to build up in her mouth to dangerous levels, putting her at risk of aspiration pneumonia.

Houston decided to take her to a private dentist. But when the home found out they intervened, telling him they would take her to her regular dentist. 'I was not invited to come to the appointment, I was only able to ask if [Felicity] had been.' The home also stopped him attending Felicity's GP appointments.

Three years after Houston learned about the sexual abuse, Felicity died from aspiration pneumonia. She was in her early 50s. Houston believes her poor dental health contributed to her death.

Houston and Octavia hope changes are made to group homes and the justice system so no-one else has to go through what Felicity went through.

'No system will be perfect. We are not asking for perfection. What we are asking is for people to do their job and we are asking for people to be made accountable.'

Verity

‘If I had access into buildings, if I had people treating me the same way you treated me before I hopped on this wheelchair, I would be fine.’

Verity is a single mother and a highly educated and experienced healthcare professional. A few years ago she started using a wheelchair.

Shortly after this, she needed to take her daughter to primary school for the first day of term. She told the Royal Commission the classroom was on the top floor and there was no lift.

Verity complained, and the school suggested moving her daughter to a different class. But Verity didn’t want her child to feel she had done something wrong. So instead the school moved her daughter’s class to a classroom on the ground floor.

This solved the immediate problem, but the school still wasn’t accessible – there was no lift or ramp. Verity pointed this out, and the school told her they didn’t want to put in a ramp ‘because there was only one disabled student’.

Frustrated by the school’s lack of understanding, she took them to court.

She said the school and the education department intimidated and bullied her and weren’t looking to solve the problem.

‘They used a QC against me when I was on the pension, a single mum.’

She wanted the school to apologise, agree to install a lift within 10 years and provide training for staff and students. The school refused, and the education department told her if she didn’t cease they would sue her for costs.

‘Not accessing the classroom seems like no big deal to most people but it’s this culmination of living in the community as a disabled woman,’ Verity said. ‘By the time I got to that classroom ... wow ... I can’t even see my own child in their classroom anymore. This sledgehammer hit me that I’m not part of society at all.’

And it doesn’t stop with schools. Verity can’t access most buildings, bars or cafés.

‘Once you become disabled you become excluded from society in every way, shape and form.’

Verity’s been at concerts and where she’s been told to move because people don’t want her up the front of the concert in a wheelchair.

Verity’s 18-year-old daughter asked her to assist her at Centrelink, but Verity said the staff member ‘refused to look at me ... refused to serve me’.

'The only problem was the fact that I'm in a wheelchair ... If I was standing next to my daughter they would have served me.'

Verity said she raised her voice, attempting to be assertive and she was labelled aggressive and they put a note on her file.

'If you raise your voice you're seen as being mentally ill.'

Around this time, Verity's marriage broke down. Being single left her fighting for custody of her children.

'It doesn't make sense. And all I can work out is ableism in society just means that they think a disabled woman cannot be capable of parenting.'

Verity says that everywhere she turns 'there is ableism towards a disabled person'.

'My dream is to have an inclusive education for everybody ... it won't look the same – it will have nursing staff ... quiet rooms. The bathrooms will be these amazing accessible bathrooms that everybody can use,' Verity said.

'What that does for the children is, it normalises disability. Disabled people aren't locked away and they can see that some kids do wear nappies still at eight years old, some kids will always wear nappies for the rest of their life ... and that's okay ... there will be grown adults who wear nappies ... there will be people without limbs and that's okay.'

And, she said, children will see there are other ways people communicate. Children will have conversations using communication boards and everyone will learn sign language. It will be a revolution.

'It blows me away that children don't get these experiences.'

Verity is determined to see this dream become a reality.

'Just because I use a wheelchair doesn't mean I'm ready to die, I'm not ready for that. I still have a life ... there are still things I want to achieve.'

'Why would I just sit in my bedroom and wait for death. That just seems so silly to me.'

Izabella

Izabella is an experienced disability support worker. For the past five years, she told the Royal Commission, she witnessed the organisation she worked for systematically abuse and neglect the people in its care.

One of the key problems, Izabella said, stems from the lack of experience and training of people working in the sector. So many of her employer's recruits were 'new workers coming straight into the workforce ... people who had never worked with disabilities and didn't know anything about disability'.

She spoke of one worker who, brand-new and with no training, was charged with the care of a client who had dementia and required regular seizure medication. The worker told Izabella she had 'never done this type of work' and had no idea how to manage the client or administer the medications.

Izabella said that all new staff should receive training on medications by a registered nurse, but this didn't happen. At a staff meeting she voiced her concerns about mistakes that were being made with medication and the substandard training.

'In front of everyone I was shouted down, and it really affected me. It taught me from that lesson not to say anything ... the fear from being humiliated in front of everyone.'

Izabella explained that around this time the service provider was starting to 'phase out' client medical charts.

'This is a systemic issue because ... medication is number one. Missed medications, dropped medications, medications disappearing ... I feel the reason they phased out medication charts was to stop the reporting of the medication errors that were being made. And serious errors – double dosing – and multiple issues over multiple years.'

The provider did get permission from guardians to remove the medication charts, but Izabella believes they only agreed because they were not aware of the kinds of errors that were being made.

'Had those families known ... I guarantee you those families would have said "No, we want to see what's going on."'

The lack of documentation extended to incident reports. Izabella said these often just didn't happen and, when they did, they were often meddled with or 'lost'. The employer used a paper-based system, making records 'disposable' and easily 'eradicated'.

One of Izabella's clients was Mindy, a young First Nations woman. Over the course of several years Mindy was abused sexually, physically and verbally by a cotenant multiple times. Izabella completed a number of incident reports that she delivered to her manager who was supposed to log them, but never did.

Once, when Mindy had been on an overnight visit at her mum's place, she returned to the group home with a black bruise on her arm. It was Mindy's mum who pointed it out to staff, saying she didn't know how it was caused but that they should be aware of it.

The manager asked Izabella to write an account about the bruising stating it was sustained while in the care of her mother – but Izabella knows that was a lie. 'Bruises don't show up that black overnight.'

Eventually Izabella learned how she could escalate the matter of missing or fraudulent incident reports by going around her manager. An investigation took place and the manager was sacked.

The next manager, however, acted in the same way – refusing to manage incident reports appropriately. They too were sacked and another manager appointed. The new manager was no different.

Izabella discovered that minutes of staff meetings in which abuse was discussed were being shredded – 'years of minutes, gone'. Those that were kept lacked information and did not record abuse or staff concerns.

'That's when I knew it was time to go. This organisation is deliberately hiding abuse, hiding things that would put them in a bad light, covering their arses.'

Just prior to leaving, Izabella became aware that the Royal Commission had requested the provider hand over certain information in relation to some of its houses.

'They were literally shitting themselves,' Izabella said. 'Because ... the information's not there.'

Walter

In his early 40s Walter was diagnosed with epilepsy. He told the Royal Commission about the impact this had on his ability to work and his struggle to get financial support.

Walter owned a successful small business and employed a number of staff. Initially his seizures weren't too bad and he continued to work.

Over time his seizures worsened and became more unpredictable. Eight years after his diagnosis Walter was in a car accident and as a result lost his licences – car, truck and motorbike.

Walter closed his business, moved interstate and found some subcontracting work. But he lost each job because he had seizures at work. Then at his last job, following a seizure, he attacked one of his workmates. He had no memory of the attack.

Doctors told him this was because of a 'post-seizure secondary state of ultra-consciousness' which can last 10 to 30 minutes.

'I don't know what I'm doing. I go crazy. I go running down the street and I abuse people and stuff like that and I don't know I've done it until somebody's told me I've done it,' he said.

Walter could no longer work and applied to Centrelink for financial support.

He received a Jobseeker payment, then known as Newstart, and because he had a medical certificate he was exempted from looking for work.

But after nine months and three medical certificates Centrelink told Walter he had to have an employment services assessment.

During this process a Centrelink worker suggested Walter apply for the Disability Support Pension (DSP).

He lodged a detailed claim which included 10 years of medical reports and letters from his GP and treating specialist who was director of neurology at a major teaching hospital.

Centrelink refused to accept much of the paperwork and misinterpreted some of the notes. They did not contact Walter's GP or specialist and relied on an internal medical assessment completed by a registered nurse.

Walter's claim for the DSP was rejected. 'I was rejected on the grounds my condition wasn't fully diagnosed, treated and stabilised, although it had been going on for quite a number of years ... To be honest I couldn't understand it.'

Walter appealed the decision and after five months contacted Centrelink for an update. They told him his appeal hadn't yet been referred to an authorised review officer. 'I got a bit stropky because it was taking so long.'

Then three days later he received an email upholding the decision to reject his claim for the DSP. Again no-one contacted his GP or treating specialist. Walter was told he needed an impairment rating of 20 or more to qualify for the DSP. His rating was 10.

Confused about the impairment rating tables, he asked Centrelink for social work support or assistance. Centrelink told him a social worker couldn't help him. 'They basically got me to sit down with a worker at the desk and try and work through things. By the time I walked out of the office after speaking to one of them I didn't really know what I was there for anymore.'

'I just could not get any help.'

Walter appealed to the Administrative Appeals Tribunal (AAT).

During this time Walter was becoming increasingly frightened by his post-seizure behaviour and was seeing a psychologist and psychiatrist.

One time he chased a young woman down the road and only knew about it when the police visited his home.

'I was quite embarrassed and quite apologetic to the person it happened to ... I don't know what happens – that's what scares me the most ... I don't know what to do.'

Walter told the AAT he was scared to leave the house because of his post-seizure behaviour, he was unable to shower or bathe without someone being in his home and he was no longer able to use the stove. But because the specialist stated Walter might be able to work 15 hours a week, although it would be 'burdensome due to the unpredictable occurrence of seizures and the inability to drive a motor vehicle', his appeal was rejected.

Walter applied for a second review from the AAT but was again unsuccessful.

Still unable to work or drive, and with the frequency of his seizures increasing, Walter applied for the DSP again. His application was rejected again.

Walter appealed, and this time he was assessed by a doctor. The doctor supported the application and, nearly two and a half years after his initial application, Walter was finally approved.

Walter has a little bit more money each fortnight and is able to live more comfortably, but the 'grief of all this stuff' has left him depleted.

'It was a nightmare,' he said.

Rosalie

Rosalie is a First Nations woman who has been a carer for children for more than 10 years. She spoke to the Royal Commission about the challenges of getting appropriate support for the children in her care from the relevant state department, starting with a failure to get their disabilities diagnosed.

‘The department doesn’t actively look to get children diagnosed. As a carer, you are left to your own devices to care for children who at times have really extreme behaviours ... Some of these kids who have come into my care I believe have FAS [fetal alcohol syndrome], but because of the delays in getting treatment, or even diagnoses ... these children then are pretty much going through life disadvantaged.’

Rosalie told us about one girl in her care. She was ‘hypervigilant’ and every day was ‘a battlefield’. Rosalie wanted to get this girl into a good school, but the girl was defiant and moved out. Then the department got her into her own unit.

‘She was only 15 or 16. She was too young. And all the problems that come with that freedom for a young person, living in a unit, having parties and getting themselves into strife. To me it was like the department had almost wiped their hands of this young person.’

Rosalie felt that if the girl had had a diagnosis ‘in her younger days’, she may have received the level of support she needed.

Rosalie finds it frustrating when, as a carer, she is not listened to. At one point she was looking after a pair of siblings. She kept ‘pressing and pressing’ the department to assess the oldest girl and she was eventually referred to a specialist. But after a brief consultation, the specialist sent them away saying ‘she’s just got behaviour issues’. Rosalie explains the problem: ‘They only see the child for a snippet of time in their whole life ... so that’s basically all that they really see.’

The siblings were reunited with their family, but Rosalie thought it was too early. She said to the department, ‘You know if you return these children back to their parents too soon, they’re going to end up not being able to care for them properly.’ Rosalie’s advice was ignored, and the children ended up back in care soon after.

‘These young children had no support whatsoever available and now they’re in the system ... So they’ve been let down in my opinion. It’s just really sad.’

‘Listen to us as carers,’ Rosalie says.

‘We know these children. We love these children day in and day out. Listen to what we are saying when we know that something is not right ... If we are going to avoid these children being in the system even as they get older, then they have to listen to us.’

Rosalie currently has a young boy in her care who came to her as a baby, and she noticed almost straight away that he seemed to have traits of autism. 'Thank God we were able to get a diagnosis through our local Aboriginal medical service,' she said.

Having a diagnosis helped Rosalie a lot, knowing what was wrong, how to respond to behaviours and where to get the right help. '[We need to] get these children diagnosed as soon as we possibly can,' Rosalie told us. 'That to me is the bottom line.'

Despite the early diagnosis, Rosalie has still struggled to get appropriate support.

'The problems we've had with the NDIS is that we went through all the process ... did all the right things, ticked all the boxes, did what we had to do, and the thing that upset me the most was that it was actually approved ...'

But the child safety officer never got in contact. Rosalie had to chase and continually push to get any response. 'The NDIS was approved for this little person in August, and by December I still had not got a word. So ... he had nothing. He had us, basically, for his support.'

Rosalie says there is insufficient support available within the department that is culturally appropriate.

'They really should be employing more ATSI people within the department ... really good grass roots people [who] can share the culture with these children.'

'I think of these little kids,' Rosalie says, 'and I just really honestly want what's best for them. Because we know that a lot of our young men end up in prison and I look at this little boy, and I think, I don't want that for him.'

Gunner and Emmanuel

‘That’s why we’ve got abuse and neglect ... People are too scared to speak up.’

Gunner developed a rare disease when he was a baby and has global brain damage. He ‘understands’, Gunner’s father Emmanuel says, ‘but he doesn’t walk, he doesn’t talk, he can’t defend himself.’ Now in his 30s, Gunner lives in a group home with four other people.

Not long after Gunner moved into the home Emmanuel became concerned about the house coordinator. She often yelled, screamed and swore and would bang her hand on the table to get Gunner to eat.

Then on Christmas day, one of the female residents wouldn’t eat her dinner and was making a lot of noise.

The coordinator declared she knew what was wrong with the woman and took a piece of cheese from the fridge and handed it to her. The woman took it and started to eat but the coordinator snatched it back and grabbed her by the arm, told her she wasn’t getting Christmas dinner and locked her in the toilet.

Emmanuel didn’t complain at the time because he was worried there would be repercussions for Gunner. By the time he did complain Gunner had sustained a number of unexplained injuries.

One time, Emmanuel noticed Gunner was in pain. He felt his bones and joints and knew there was something wrong with Gunner’s toe. X-rays showed it was broken and while Emmanuel accepts it may have been an accident, he was upset that ‘nobody would admit to it, nobody would own up to it, nobody wanted to know about it’.

Another time Emmanuel noticed a problem with Gunner’s ear. The doctor told him Gunner had cauliflower ear which is caused by blunt force trauma. The doctor said ‘There’s only one way you get that ... this is what boxers get when they’re boxed around the head.’

Emmanuel made a formal complaint about the coordinator but the provider refused to act. He escalated his complaint to the state disability department and the directors of the board of the disability service provider, but ‘it was just like walking into a brick wall’.

Ultimately Emmanuel engaged a lawyer and spent around \$12,000 trying to hold the coordinator and the provider to account.

But when the provider threatened to withdraw Gunner’s accommodation Emmanuel dropped the legal action.

During this period, some staff did speak up and complained about the abuse, swearing and yelling. The provider responded by transferring all staff to other homes.

Not long after, Emmanuel had to obtain medical guardianship of Gunner to prevent the provider from inserting a feeding tube directly in Gunner's stomach. Gunner needed his food to be prepared and he needed to be fed but he had no problem eating. Emmanuel successfully argued a feeding tube wasn't necessary.

Then when Gunner's grandmother was visiting she noticed he was fed exactly the same thing every day for lunch and dinner. Emmanuel investigated and discovered she was right – Gunner ate exactly the same food, blended into a mush, every lunch and dinner.

It took 'two years and a hell of a lot of arguments ... to get a menu book put in place'. Emmanuel also managed to get Gunner's meals separated so he could see and taste the different food he was eating.

Emmanuel then discovered the food was being served cold and he had to show staff how to heat it properly in the microwave. He said it took him three months to implement the procedure.

'I started visiting [Gunner] every day. I'd go every lunch time and every dinner time and make sure they were feeding him right.'

Recently, when Emmanuel arrived at the home, support workers were changing Gunner's pad on the lounge room floor. He was lying there naked on the floor while female support workers walked in and out of the room.

'That was a real shock to me,' Emmanuel said.

The support worker apologised and was dismissed. Emmanuel is concerned about what happens in the house when he's not there.

'These houses need cameras in them.'

Percy

Percy has schizophrenia.

Two years ago, Percy spoke to his mental health case manager about the progress of his complaint against a hospital psychiatrist.

The next day, Percy told the Royal Commission, he woke to find the police and his mental health case manager in his apartment. His mother, who owned the apartment, had given them a key.

The police took Percy to hospital still wearing his boxer shorts and nightshirt. 'They didn't let me get changed. I had no shoes. I didn't have my phone. They just took me away.'

When Percy arrived at the hospital he was having a pseudo-seizure. 'You're basically paralysed but you can see and hear what's happening,' he explained.

Hospital staff repeatedly flicked and jabbed Percy to bring him out of the seizure, and then left him on a bench in a small room for 12 hours.

Eventually staff informed him he would be transferred to another hospital more than an hour away. Percy was reluctant to go to a hospital so far away from his partner and cat.

Five security guards grabbed him.

'[They] got me in a wrist lock and drove me down towards the ground. My right knee dislocated ... [they] ripped my left arm out of its socket.'

Percy was yelling, asking for someone to call the police. One of the doctors told him, 'If you threaten one of us, this is what you get.'

The security guards then strapped Percy to a gurney so he couldn't move and drove him to the second hospital.

'I was in tears I didn't know what was going on. I thought they were going to kill me.'

The incident that had given rise to Percy's original complaint against the psychiatrist happened some years prior when his best friend of 28 years died. Percy decided to stop taking his medication so he could 'mourn properly'.

'Two weeks later they locked me up in hospital to put me back on my medication,' Percy said.

But he continued to mourn his friend, leading the hospital psychiatrist to conclude he had 'an additional mental illness'. The psychiatrist gave Percy 17 treatments of electroconvulsive therapy. 'I constantly wet my pants,' he said.

Not long after the treatment ended he had his first seizure.

Percy complained to the ombudsman about the psychiatrist and the complaint was referred to Australian Health Practitioner Regulation Agency. Percy believes that his recent treatment by hospital staff was retribution for this complaint.

He said his case manager later admitted that Percy was a 'reputational threat and that was the reason [he] was locked up'.

Officially, however, Percy continues to be detained for assaulting a doctor and making death threats against two doctors. He is adamant this never happened.

When Percy arrived at the second hospital he was in a wheelchair because of his dislocated knee. Nurses told him they needed the wheelchair more than he did. They threw him out of the wheelchair so hard he hit a wall and damaged his back. He was given an X-ray but was refused pain relief.

Percy tried to contact the ombudsman about the incident but staff confiscated his mobile phone and threatened to lock him up in the psychiatric intensive care unit.

Since then Percy has been too scared to complain to the police or the ombudsman about his treatment.

During this time, his partner of 11 years ended their relationship.

After five months Percy was transferred to a secure mental health rehabilitation unit closer to where he lived. He says, 'They've treated me pretty well here.'

Percy is allowed to leave the unit for short periods of time each week. He goes shopping and cooks for himself one day a week and spends time with his father. A support worker takes him bushwalking and fishing and to his mother's house to visit his cat.

He continues paying rent for his apartment and had hoped to return there, but a social worker recently informed him that's no longer possible.

Instead Percy will be transferred to a community care unit which he likens to a 'nursing home for 40-year-olds'.

'It's going to be crap.'

Nixon and Katlin

For two years, Katlin told the Royal Commission, she was unable to convince doctors and hospital staff to give her brother, Nixon, a soluble form of the drug Symmetrel.

‘It might not have made a difference but what upsets me is we’ll never know.’

Nixon had an intellectual disability. In the few years before he died his muscle tone deteriorated. This affected his balance and he had difficulty talking and swallowing. A feeding tube was inserted into his stomach.

Nixon needed Symmetrel to reduce muscle spasms and improve muscle tone. But because Symmetrel was only available in tablet form in Australia, Nixon had to take it orally. This required eating small amounts of food each day through his mouth to keep the muscles involved in chewing and swallowing active. As a result Nixon sometimes aspirated food into his lungs and had to be admitted to hospital.

One time, Nixon required surgery and had to be ‘nil by mouth’, which meant he could not take his Symmetrel.

Nixon became very unwell and experienced seizure-like activity – his muscles were rigid and his eyes rolled back in his head. Nurses assumed seizures were normal for Nixon.

‘Because he looks so disabled people made a judgement ... [it] influenced people’s decisions around his treatment.’

Eventually doctors ordered that Symmetrel be administered via the feeding tube in Nixon’s stomach.

‘They forced a waxy capsule down the ... tube,’ but this resulted in a medical emergency.

After Nixon was discharged Katlin spoke to Nixon’s private neurologist, explained what had happened and asked for alternate medication or clear protocol around the administration of Symmetrel.

The neurologist told Katlin he would look into it but nothing happened.

Meanwhile the number of times Nixon was hospitalised because of aspirated food increased.

The head hospital pharmacist identified a soluble form of Symmetrel, only available overseas.

Katlin asked Nixon’s GP for a referral to a hospital neurologist or other specialist who could order the soluble Symmetrel. The GP wrote the referral but didn’t indicate the appointment was urgent. Somehow when the hospital received the referral they ‘thought it was some sort of rehabilitation request’ and advised they didn’t do rehabilitation.

Katlin asked to see a copy of the referral but the GP denied her request.

Katlin then contacted the hospital liaison department to ask for an appointment. She told them Nixon was deteriorating and aspirating food more frequently.

They refused so she went back to the GP who sent a referral to a respiratory specialist.

'I gave him comprehensive information about the drug, about [Nixon]'s history, his swallowing and he told me he would do a case review with the pharmacist at the hospital.'

He told Katlin they would have a plan for Nixon in a few weeks. When she didn't hear anything she rang the specialist – nothing.

A couple of weeks later Nixon was admitted to hospital for the final time.

The nurse who was suctioning out secretions from Nixon's airways put the sucking device so far down his throat he started gagging.

Nixon coughed non-stop until his airways became blocked. He was transferred to palliative care.

Katlin wanted Nixon discharged so he could die at home but he was too ill to be taken home.

He died in the hospital with his lungs full of fluid.

The doctor tried to explain to Katlin that Nixon died because his low muscle tone prevented Nixon or the nurse from clearing his airway. Katlin, a qualified nurse, disagreed.

The doctor admitted there had been 'gaps' in communication and the hospital should have been able to get the drug from overseas.

'I was not listened to. If they listened to me things might have been better.'

Katlin finds it hard to believe someone with her knowledge of the health system was unable to successfully advocate for her brother to be given the drug he needed.

'Two years I was on about one thing non-stop and I still didn't get what I wanted.'

Winola

‘I know a lot of people who were doing sexual abuse, but it never got to the police.’

Winola lives with an intellectual disability and identifies as culturally and linguistically diverse.

For 30 years she was employed by an Australian Disability Enterprise (ADE).

When Winola was 16, her supervisors from the ADE took her on a number of holidays. ‘I was sexually abused when I went on these holidays,’ she told the Royal Commission.

The supervisors threatened to fire her from her job if she told anybody.

The abuse continued when she was at work and other girls were also sexually abused.

‘They were sexually abusing girls in the workshop during working hours, lunch time hours, morning tea hours. It happened. I’ve seen it.’

Two male co-workers with disability also sexually abused some of the girls.

Supervisors, some of them in relationships, began inviting Winola and at least one other girl to their homes.

‘I wasn’t earning much when I started working there and they knew my pay was low. So they gave me ... a pay rise, a lot of money.’

Winola was paid for sex.

‘I had to do sexual acts with these people then they’d give me the money. They also gave me gifts cards as well. They gave me a lot of gift cards.’

This continued for many years. ‘I shouldn’t have gone. It was a secret you see.’

One of Winola’s friends became pregnant and had twin daughters, another had a miscarriage. Winola didn’t want to get pregnant. ‘I had a hysterectomy and now it’s ruined my life. I thought one day I wanted to get married and have kids but now I can’t.’

One friend committed suicide.

‘Kind of affected me a lot because they were my friends ... They’ve been sexually abused ... committed suicide because nothing was done. So I’m really angry about this.’

Eventually Winola left the ADE and did go to the police. But they didn’t believe her and told her she didn’t have enough evidence.

‘But I’ve seen people being abused. I’ve seen it with my own eyes.’

Since she’s left the enterprise she’s been followed and stalked by her former supervisors.

‘When I was at the shops, in the park ... following me around and beeping their horns at me ... in my street, in front of my house when I was watering the garden.’

Winola is sure they’re stalking her because they want to continue the abuse.

‘Every time I see them following me I’m having flashbacks.’

Recently Winola has found an advocate and has approached police to stop the stalking.

But the police have again asked for evidence. She said the police are very disbelieving so she’s gathering evidence by filming and taking photos with her mobile phone.

She’s also trying to get access to her employment records to find evidence but each time she requests a record she has to pay large fees.

She has tried to escalate her complaint but authorities refer her back to the police or the NDIS Quality and Safeguards Commission. But because Winola wasn’t a client of the NDIS at the time the abuse occurred, they are unable to assist.

Winola is concerned some of the people who abused her continue to work with vulnerable people. She is determined to stop the abuse. ‘I want to stop it everywhere.’

‘I just would like people with disability to have a happy life, not a bad life getting sexual abuse.’

Yana

‘My experience may have prematurely ended my career, possibly 10 to 15 years earlier than I’d hoped. The social, intellectual and financial losses of this is immense.’

Yana was highly experienced, with a PHD, when she applied for a senior position at an Australian government agency. She told the Royal Commission when she read the agency’s disability action plan she felt confident she would be supported in the role.

Prior to the interview Yana disclosed she had a disability and required ‘flat-floor’ access. When no-one contacted her to discuss her accessibility needs she assumed everything would be fine.

However when she arrived for the interview and needed to use the bathroom, she discovered her wheelchair couldn’t fit in the doorway or the corridor to the toilet. The only accessible toilet was on a different floor leased by another tenant. As a result she had to sit through a one-hour interview needing to go to the toilet and was unable to sit the written test. Fortunately the panel chair arranged for her to complete the test at home and she was offered the job.

Because of the type of wheelchair Yana used, public transport was challenging so she was relieved when she was offered a car park in the building. But a week before she was due to start, she learned the car park was only temporary. When she raised her concerns, the HR officer asked if she wanted to decline the job offer. Yana didn’t but the response made her feel apprehensive.

At the orientation HR explained they planned to install an accessible toilet and automatic doors. Yana offered to involve Job Access – an organisation that can fund modifications – but HR wanted to do it themselves.

On Yana’s first day she spoke to her supervisor about the accessible toilet and car park. The supervisor was understanding and together they reviewed the Job Access website and made a request for Job Access to visit the workplace. When Job Access visited, they made a number of recommendations.

In the meantime Yana struggled to get to and from the toilet on the different floor. Because of the distance, the heavy doors and needing two people to assist, she tried to limit her visits. Often she had to wait 10 to 15 minutes for someone to open the doors for her. Sometimes instead of using her wheelchair she used a walking aid to get to the toilet, but it was difficult and she had to stop when she damaged her ankle. She felt embarrassed and humiliated.

‘That’s how my colleagues met me – when I was struggling,’ Yana said.

Yana believes HR blamed her for exposing the ‘rubbish disability action plan’, which she described as like ‘designing a car that you never expect anyone to drive’. They began to retaliate and discriminate against her. She found out they told staff she didn’t disclose her disability at the interview and blamed her for all the disruptions while the toilet was being modified.

‘[HR] had so much power over my body and my wellbeing and they were incompetent, they were mean.’

Eventually, Yana was offered the opportunity to work from home two days a week. On the remaining days, the other tenants agreed for Yana to work on their floor while the accessible toilet was finished. Yana also secured a permanent car park.

Four months after Yana started, the toilet was finished. However she still couldn’t use it because there was a delay installing the automated doors.

The situation came to a head when Yana was cautioned for having a public discussion in the staffroom about the length of time the building works were taking.

‘My two colleagues who were part of that discussion said, “Where’s our caution?”’

Yana began having panic attacks and could no longer continue working. ‘I’ve been through hell,’ she said.

Simone

‘The medications that I was given, I wasn’t able to think clearly. I was given everything from antidepressants to anti-anxiety ... which eventually turned into antipsychotics and sedatives. So between the age of 15 through to 25, it’s a blur.’

Simone is in her early 30s. She talked to the Royal Commission about her experiences in the mental health system for more than half of her life. Over that period she was given multiple diagnoses including depression, anxiety, attention deficit hyperactive disorder, schizophrenia, psychosis and bipolar disorder. Each diagnosis came with a new medication.

Simone’s interactions with the mental health system began at the age of 15 when she went to see a GP about the way she was feeling – sad, anxious, tired, devoid of energy – and with what she described as ‘extreme symptoms ... but mostly a deep disturbance in myself’. By the end of a 15-minute appointment the GP had diagnosed depression and sent Simone away with antidepressants.

Simone’s symptoms got worse. She went back to the GP who this time diagnosed anxiety, and sent her away with more medication.

Simone’s symptoms continued to escalate. She was now hearing voices and experiencing other ‘very distressing symptoms’. She went to a new doctor, who consulted with her first doctor. ‘Suddenly,’ Simone said, ‘I’d been diagnosed with everything.’

‘Of course the core problem wasn’t being treated and so my conditions were worsening ... At the early age of 22 I shut down, I stopped talking for a long time, probably about two years.’

The core problem Simone is referring to is that she had been subjected to psychological and sexual abuse since she was a child. The escalation of her symptoms at the age of 15, which had prompted her to see the GP, corresponded with her being raped by a family friend.

But none of the doctors who diagnosed Simone and prescribed medications ever looked further than her symptoms to understand that they may have been, as Simone now believes, ‘an appropriate response to trauma’.

Simone went to see the doctor about how she was feeling, only to be told there was ‘something wrong’ in her head.

‘In many ways the mental health system helped my abuse,’ she said. It reinforced the gaslighting being carried out by her abuser. ‘They tell you you’re crazy.’

‘It makes me wonder how many people are wrongfully diagnosed when they have a legitimate reason to be feeling what they are feeling.’

Following school Simone started university but she had become ‘phobic’ of her surroundings and ‘it just wasn’t working’. She was diagnosed with psychosis, given more medication, and then ‘just sort of collapsed’.

‘I was put in a program for people with disabilities ... the bin of society,’ Simone said. She was in the program for a couple of years.

Simone spent most of her 20s in a ‘blurred reality’ due to all her medications. But in the last couple of years she has begun to gain clarity around what happened to her. She has been able to reveal the fact of her abuse and begun to understand her abuser had targeted her.

‘Everything happened very fast, almost like my whole brain just started to rewire. And I was able to call out that person and shut down the whole abuse cycle. I immediately started to feel all of my symptoms disappear.’

Simone stopped her medications and found her own therapies, including stand-up comedy and other creative outlets.

‘Coming out of this by myself has been a lot of work,’ Simone told us. She now finds herself in ‘a brutal game of catch-up’. But she is also, for the first time, able to contemplate the possibility of a brighter future with ‘a loving home of [her] own, a career, a loving partner ... the anchors, the things that can help connect us to the world’.

‘It’s been a hell of a journey!’

Warner

From a very young age Warner was sexually abused by a friend of the family.

A First Nations man, now in his early 40s, Warner told us he didn't tell anyone about the abuse for many years and 'bottled a lot of things up'.

'I then became my own worst enemy. I carried around a lot of anger and guilt ... I was very ashamed. I wanted to kill myself at points in my life.'

When Warner was still a teenager the perpetrator moved into the house next door to his family. 'I couldn't get away from him.' This forced him to tell his parents about the abuse.

Not long after this Warner was falsely accused of robbery, arrested and charged. He was identified via an identification parade but was the only person presented to the witness. He served one month in a correctional facility before he got bail.

When Warner was released, he 'had a lot of anger' and started drinking heavily. He threw himself off a second-storey balcony, landed on a car and sustained an acquired brain injury (ABI), a fractured neck and paralysis on his left side.

Although doctors told Warner he would never walk or work again he eventually regained his mobility and got a job in a mine.

Then three months after he started, Warner's leg was crushed in a workplace accident and he started smoking 'hooter' – marijuana. He became aggressive and experienced psychosis. Warner told doctors he was hearing voices and he was diagnosed with schizophrenia.

'I was full of anger because of the things I've been through ... I didn't know where I was going and I didn't want to live because it was just too much for me.'

Doctors treated him by sedating him. During this period he remembers being locked in a small room while doctors trialled different medications. He felt like a guinea pig.

Eventually he was given fortnightly injections of a prescribed drug which he felt was too much. 'I wouldn't know whether I was Arthur or Martha, or whether the medications were giving me boils or what the go was.'

At times, police officers, doctors and security guards would show up at his house. 'They'd pull my pants down, hold me down and they'd jab me with a needle in the behind.'

This treatment would increase his anger. 'I'd get amped up even more. I'd think "what are they doing?" I was lost and no-one was really standing up for me or helping me.'

No-one ever spoke to Warner about the abuse he received as a child or his ABI.

‘One night I was ... feeling sorry for myself and I’d had a bit to drink. I was going off in town and carrying on like a bit of a pork chop.’

Police intervened. They handcuffed him and took him to the watch house. They didn’t speak to him or give him instructions. They slammed his head on the counter and wrestled him onto the concrete floor. Then a large officer knelt on Warner’s head and split his jaw in half. They took his clothes and cut his hair. When he was released he was naked except for a towel.

His mother picked him up and was ‘quite shocked’. She asked, ‘what the heck happened to you?’

Warner engaged a lawyer and was awarded compensation. He says his barrister did ‘an under the table deal’ with police and encouraged him to settle for a lesser amount rather than go to court.

After this Warner started going to church. ‘I’ve got a church family,’ he said. He feels ‘at home’ and credits his faith in God for the changes in his life.

‘I’m really happy with where I’m at today.’

Warner has a full-time job and receives his medication from his GP every three months. He hasn’t had any psychotic episodes or adverse reactions.

‘Life’s just not a walk in the park. Everyone has their struggles but life does get better with time.’

‘Time and God are good healers.’

Warner says, ‘Staying positive, putting in the work and you’ll reap the rewards’.

Bennett, Lakota and Paris

One afternoon a few years ago it was raining heavily when Paris, a First Nations woman, was picking up her children from outside school hours care (OSHC). She was anxious because her eldest son Bennett was hypersensitive to the sound of rain on a roof. 'It was quite frightening for him.'

Bennett and his younger brother Lakota live with intellectual disability and autism. Both boys were non-verbal at the time.

Paris explained to the Royal Commission that the OSHC was on the grounds of the special primary school the boys attended but was run by an independent provider.

Because of the rain Paris knew the children would be in a small undercover area with nowhere to go to separate from each other. It would be a loud, chaotic and 'very stressful environment'.

The carpark was about 200 metres from the undercover area. But as soon as Paris opened the car door she heard four-year-old Lakota screaming.

Paris raced up the footpath to the undercover area and saw children everywhere. Sitting in the corner on a little chair, crying and screaming, was Lakota. A male educator was crouched down in front of him with his hands on either side of the chair.

Paris called out to Lakota and the educator said, 'Mummy's here. Now we have to tell her you've been a naughty boy and explain to her what happened.'

The educator didn't release Lakota so Paris had to squat down to console him. 'He had snot running down his face and was highly distressed.'

The educator told Paris he had tied Lakota to the chair because he had kicked another child. He showed Paris the cloth he used as a tie.

Paris was horrified and picked up Lakota to comfort him. She challenged the educator and questioned the restraint. 'He's four, he's a tiny little boy.'

The educator told her that tying the children to chairs was standard practice at the school.

Paris was stunned but the undercover area was chaos and she was worried about Bennett who she could see wandering around. She needed to get the boys 'out of there' and told the educator she'd talk to him tomorrow.

As Paris was leaving, a different educator handed her a tooth. She told Paris Lakota was rolling on the mat, playing and the tooth fell out. Paris couldn't comprehend how this could happen but she was feeling overwhelmed and needed to stay calm for the boys.

That night she wrote emails requesting a meeting to the school, the OSHC provider and the education department.

The principal responded immediately but told her, 'It was not his problem. This happened at OSHC – that has nothing to do with him.'

Paris couldn't understand his point of view. 'I was really quite shocked ... at his dismissiveness, lack of care,' she told us.

Paris asked the OSHC provider to dismiss the educator but they refused. They were adamant it was a training issue. Paris disagreed. 'A person should not tie a child to a chair ... you don't have to be trained to tell right from wrong.' But OSHC stood their ground and Paris immediately removed both boys from OSHC.

During the meeting OSHC revealed that the educator also worked at the school, so Paris went back to the principal who now agreed it was a school issue. The principal terminated the educator's school contract. But when she asked him to investigate the practice of tying children to chairs, he said the educator was confusing this with the use of harnesses to keep children upright in their chairs.

Paris is still not sure of the truth.

The police interviewed Paris but were 'very dismissive'. They felt it was 'quite insignificant in the level of crimes people are committing' and said that because Lakota is non-verbal he couldn't be a witness. This made no sense to Paris because what happened was not in dispute.

The education department did a surprise inspection of the OSHC and discovered multiple breaches. For example, when teachers from the school brought the children to OSHC there was no 'hand over' and OSHC educators were given no information about the child's day.

Paris learned that on the day Lakota lost his tooth, he had hit his mouth on a trampoline at school earlier in the day. It's likely that's when his tooth came loose.

No-one told Paris or OSHC and it wasn't recorded in the communication book.

Paris is dismayed to think by the time Lakota arrived at OSHC he would have been 'stressed and unhappy and in pain'. And when he acted out, instead of consoling him, 'they tied him to a chair'.

At the end of the school year Paris removed Bennett and Lakota from the school.

Adeline

Adeline is in her early 20s. She lives with post-traumatic stress disorder, anxiety and chronic pain. She has no function in her legs, limited functionality in her arms and hands and uses a wheelchair.

Adeline told the Royal Commission that as a child she was sexually abused by her parents. At 17, she fled the family home.

Since leaving, she has had multiple hospital admissions to deal with chronic medical conditions. She said almost all her interactions with medical staff have involved neglect or abuse.

By far the most 'horrific' incident happened when Adeline was in a hospital rehabilitation unit for five months.

A male nurse was obsessed with Adeline and was physically inappropriate. He would often sit on her bed, stroke her legs and hug her without her permission.

One night, Adeline needed to go to the toilet. The nurse refused to take her because she was attached to multiple IV drips and 'it was too much of a hassle'.

The nurse told her to use the bedpan. Urine leaked onto Adeline's clothes and the sheets. To clean up, the nurse stripped Adeline and the bed and 'ended up' touching her sexually and assaulting her.

Adeline was 'horribly traumatised' and couldn't sleep. She was terrified of the nurse and 'would vomit and dry-retch' every time she heard his voice.

Eventually she reported the abuse to the nurse unit manager.

'She was not nice about it and treated me horribly because I'd accused a member of her team who was very well respected,' Adeline said.

The manager accused Adeline of wanting to get attention, saying 'Young lady, do you have any idea how damaging an accusation like this could be to a very well-respected nurse?'

The manager made it clear she didn't believe Adeline. But because she reported the assault the hospital conducted a mandatory internal investigation.

The investigation upheld several of Adeline's complaints but the nurse was only required to complete an online course about appropriate behaviour. Adeline felt this was 'a slap in the face'.

'I thought for a moment that this could be the one chance that it would be taken seriously and action would be taken and maybe it might be a safer place.'

But the nurse still has his job in the same unit. 'There hasn't been any real changes.'

After Adeline reported the incident she was treated badly by the other nurses.

'There are no words to describe how less than human you feel, that you're not worth anything happening ... They don't care what you went through, how grim it was and even when they believe you, they still don't care.'

Adeline's experience of the medical system is that most doctors and nurses ignore her, refuse to treat her or take advantage of her.

One doctor told Adeline 'to snap out of it and stop carrying on and that he has important work to do to save people's lives'.

Another time, Adeline needed to go to the bathroom and asked a nurse for a wheelchair. The nurse refused, telling Adeline her disability was 'made up' and she was 'doing it just to get attention'.

Adeline ended up wetting the bed. She was left in the bed for hours and then sent home in 'urine-soaked clothes'.

At one stage Adeline told her doctors she never wanted to be admitted to hospital again.

'I would prefer to die alone and at home rather than ever setting foot in a hospital ... because it isn't worth the trauma and the danger, the mistreatment.'

Jamal

‘I might be paralysed, but treat me like you treat anyone else.’

Jamal, a First Nations man, broke his back playing football when he was a teenager. He’s now in his 40s and living with quadriplegia. Jamal uses a ventilator and an electric wheelchair, and has a complex care routine.

‘Ever since my accident, I have been my own guardian,’ Jamal told the Royal Commission.

After his injury, when Jamal was in his early 20s and living in a regional town, he continued to go out with his mates.

‘One of my mates from school, we’d go nightclubbing at 12.30 until four in the morning. Instead of going back to my home to get back into bed, I’d just go to his place ... I’d have my doona there, my heater and my overnight bag, and I’d just sleep in my electric wheelchair. I’d just tilt it back like a La-Z-Boy.’

Jamal taught his mates how to use his ventilator and clear his lungs so that when he went out with them, they knew how to make him comfortable and safe.

‘It made you feel normal that you could go out to sporting games, do anything, and they were willing to do it, too, and all that. Even when they had children, their wives and all that, and it just made you feel normal.’

About five years ago, Jamal moved to a city to be closer to specialist care. He moved into a group home run by a private provider. There was little privacy.

‘I didn’t like it because when you go into the lounge, you’re sharing it with all the other clients and family, and you can’t watch what’s on the TV because other clients are watching TV or they’re playing games.’

Jamal said the staff were inexperienced. When a wound became septic, he had to explain to staff how to treat it.

‘I was managing a wound and all that myself.’

A few years ago, he moved into a self-contained unit in a facility with a large number of elderly residents. There were no other people with quadriplegia.

‘When I do get up with my electric wheelchair and go out of the unit, all I see is other clients and staff members down the corridor, and it makes you feel like you’re not normal.’

Jamal says the staff are so inexperienced in his ventilator and bowel care, he's reluctant to leave his room. He spends most of his days in bed.

'The last time I went out [into the community] was early 2019.'

One day, the fire alarm went off and staff evacuated the facility.

'And I told them, I'm in the middle of my care. They'd say, "You still have to go out."'

Jamal said the staff took him to the front gate and by the time he was allowed back into his unit he was 'lying in faeces'.

Jamal is applying through the NDIS to move into his own house with fully trained support workers. His care provider has already modified a house and installed his television, but Jamal said he can't move in until the NDIS agrees to fund the support he needs to be safe.

Jamal needs an experienced nurse with him at all times to keep his lungs clear. He said the package doesn't provide enough staff for him to be able to safely go out into the community.

'It makes me feel normal [when] I can still enjoy things I want to enjoy.'

When he spoke to the Royal Commission, Jamal was still negotiating a suitable NDIS plan.

Aliza

Aliza is in her 50s. She contracted meningitis as a child and now lives with cognitive disability, physical disability and cerebral palsy.

'I'm not frightened of the way I am because I know that my disability won't get better as time goes on,' Aliza told the Royal Commission, 'but I don't let anyone get me down because I know that I can do things that I've never done before.'

For example, after contracting meningitis, doctors had to operate on Aliza's spine and told her she may never walk.

'I proved everybody wrong. I threw my sticks [away] and I walked on my own.'

As Aliza got older her feet started to turn inwards and she now has difficulty walking.

She used to live with her mum. When she received a small inheritance, she bought her mum a car 'to help her with appointments and all that sort of thing to get around in'.

After her mum died, Aliza moved into supported housing.

'It was all right at first when I went there, but it just got a bit too much because I had to try and get to work, plus you had to do some stand up jobs and things, and it just got really, really hard.'

To live in the supported housing, Aliza's provider told her she had to work in a particular factory that packed products for kitchens and bathrooms.

'You're working there, you only get say \$10 a week.'

The work also required her to stand, which she couldn't do for long periods.

The provider of the housing didn't let her use her bank card unless she had a support worker with her. Aliza was living with her partner at the time and wanted to be more independent.

'It just got to the point that I'd had enough ... I had to do things for him and for myself, and I just thought it was time to move on my own, move into a place where I can just relax a bit.'

Aliza moved to a new provider and now keeps her bank card with her. She feels more independent, even though the public trustee controls her money.

'They swap people all the time and I get confused ... if I want clothes, money for clothes, then I have to ask. [But it's] better for me to be independent than not be independent.'

Aliza lives in her house with the help of the NDIS and 24-hour support. Her support workers help her shower and take her shopping, to appointments and 'sometimes ... for a drink or something'.

‘They do everything that I need done, and I don’t have to ask them, they’ll just do it ... They’re really good to me.’

They also help her cook. Aliza enjoys cooking.

‘At this moment I’m teaching myself cooking pancakes ... and I’m also learning how to cook my own vegetables.’

‘I want to say thank you very much for this special meeting,’ Aliza told the Royal Commission. ‘It hurts to know what happens to people with a disability or elderly people, for instance. And then you look and think, well, I’ve got a disability ... I think that people with disabilities, like me for instance, and other people, deserve better things.’

Nina and Frieda

‘This experience ... has brought us heartbreak beyond belief.’

Nina is in her 40s. She has an intellectual disability, little communication and a range of medical issues.

Nina’s mother, Frieda, made a submission about what happened a few years ago when Nina moved into a new home that had been organised by a disability organisation.

The family had spent five years planning and searching and getting Nina ready to go into supported accommodation. ‘But it has taken [them] 5 months to destroy our hopes and dreams, for [Nina’s] future and ours,’ Frieda said.

Frieda told us the home had a high turnover of inexperienced staff – 20 new staff, in a house with only two residents, in the five months Nina stayed there. During that time, Nina had two falls, bruises on her arms and lots of big mosquito bites that became infected. The meals were poor, usually frozen food.

Nina was traumatised by the lack of care. Frieda said staff routinely failed to give Nina her medications on time and would not follow her routine. This would make Nina angry and confused to the point where she started banging her head on the walls.

Meanwhile, Frieda felt like an ‘unwelcome guest’. The service provider seemed to expect her to dump her child and ‘let them deal with it’.

The family removed Nina from the home for good one day when they found her sick with vomiting and diarrhoea. Over the five months of Nina’s stay they had complained to the house manager and the area coordinator but were ‘fobbed off’. When they removed her, they wrote to the senior management of the organisation explaining why she wouldn’t be returning.

After that they went to the state disability complaints office. Frieda said the office took on the complaint but, as Nina had left the accommodation there was little in the way of resolution. There was no apology.

Frieda said that Nina is still affected by the trauma of what happened to her in that home.

‘My husband and I were also traumatised with this experience. As we are aging, we had hoped that we would find somewhere [Nina] could be cared for and have a good life.’

Amayah

Amayah, early 30s, has cerebral palsy. She comes from a culturally and linguistically diverse background and until a few years ago lived with her parents.

For much of her life Amayah used a walking frame and was 'very independent'. In her 20s, her mobility suddenly declined. She told the Royal Commission her mother couldn't 'cope with people with cerebral palsy' and sent her to respite every day.

Amayah married a man from the same cultural background and continued to live with her parents. She became pregnant with twins but had a miscarriage. '[My mother] hit me and then I lost my two twin girls,' she said. Amayah's husband left her.

Needing to use a wheelchair all the time, Amayah moved into a group home. She lived with four other residents, most of whom were elderly with dementia.

Amayah wasn't happy. 'I was crying all the time and ringing my dad all the time.'

Amayah said staff ignored her and prioritised the other residents above her. They routinely left her in bed or in her wheelchair for long periods of time. One morning she was left on the toilet for more than an hour. Staff said they didn't have time to do activities with her or take her on social outings.

When Amayah complained, staff called her names and told her she 'should be in a mental home'. Staff often made racist slurs referencing her country of origin. The more she complained the more staff and management punished her, labelling her 'the complainer'.

One time another resident was having a seizure and fell from his chair. Amayah 'panicked' and tried to help, ringing an ambulance. The support worker started 'screaming and yelling' telling her 'you go to your room' and 'you don't need to help other people'.

Staff regularly locked Amayah in her room. Other times, staff pushed her wheelchair into the corner of the room and turned the power off. She couldn't move because 'the switches are on the back of the chair'.

Amayah was often unwell with bowel issues. '[My] tummy was very big, it was a heavy kind of feeling.' She said her GP thought the problem was her diet. 'They were giving me lots of junk food, all unhealthy.' The GP contacted the home and requested they provide more nutritious meals, but nothing changed.

Another time staff forgot to put the belt on her shower chair and Amayah slipped and almost fell.

Amayah made a formal complaint to the manager. She discovered staff weren't writing incident reports. Rather than respond to her complaints, management asked her to leave. They gave her two weeks' notice, so she had to move to temporary accommodation.

The new service provider was better but Amayah had problems getting support workers each day.

'When I need a carer ... they don't message me. Like, who's coming, who's not? Please tell me. I need to know because I need a carer.' Often the provider told her they 'can't find a carer' or sent inexperienced staff. Amayah said support workers weren't trained and were 'mucking around' with her medication. They also didn't know how to cook basic meals. One tried to cook a boiled egg in the microwave. Another didn't know how to make a milky tea.

Amayah said neither group home understood 'about the culture ... about the religion'.

Amayah is Muslim and doesn't eat meat. A support worker bought a ham pizza for dinner. When Amayah complained the worker said she didn't know what to do. Amayah suggested a vegetarian pizza or a cheese sandwich. The worker said she don't know how to make a sandwich. 'She made me cry,' Amayah said.

Amayah now lives on her own in a supported disability unit. It has a large living room and she's 'very happy'. She has access to on-call support staff. While they can be 'a bit bossy' they 'understand what I like, what I don't like,' Amayah said.

Forest and Uda

Forest has an intellectual disability, is non-verbal and lives in supported accommodation. He used to work in a nursery and his sister, Uda, said he 'knew more about plants than anyone'. He had a girlfriend and travelled the world. He had a great life, Uda told the Royal Commission.

Then one day Forest had a stroke.

Forest had some paralysis on his right side but Uda was hopeful this would improve with rehabilitation. After two weeks, however, doctors told Uda that Forest's movement 'was as good as it was going to be' and rehabilitation was pointless. They wanted to transfer him to a nursing home.

Uda was horrified and contacted private and public rehabilitation centres but most wouldn't accept Forest. Eventually, he was accepted into a specialist neuro rehabilitation centre where he made progress. But then he was transferred to the mainstream part of the centre. Here, doctors pushed for him to be discharged and said 'he'd never walk, he couldn't do this, he couldn't do that'.

Many of the doctors thought Forest had always been in a wheelchair so Uda brought in videos and photos of him to show them what his life had been like before the stroke.

Unable to convince them, she arranged for a specialist doctor, who was a friend, to assess Forest. This doctor told her the brain could rewire and Forest was capable of making a recovery.

Under the pretence of taking Forest out for lunch on weekends, Uda started taking him to physiotherapist appointments. Forest began to improve. He was able to stand and, with her assistance, shuffle into bed.

Then one morning Uda received a call. The nurse told her not to panic but Forest had suffered a mild seizure overnight and had been taken to hospital as a precaution.

When Uda arrived she saw Forest was in pain. He hadn't passed urine for 24 hours. The doctors at the hospital said there was no evidence of a seizure or stroke and couldn't understand why Forest had been brought there. He was discharged and taken back to the centre.

But back at the centre that afternoon, Uda knew 'something was terribly wrong' and thought Forest was going to die.

Forest was then x-rayed, which revealed that his leg bone had been driven up into his pelvis. The pain would have been excruciating – he had been without pain management for three days.

Doctors at the centre were unwilling to operate and transferred him to the trauma department of a major hospital.

Doctors at the hospital were horrified when they saw Forest's injury. They decided to operate but soon changed their minds. The injury was worse than suspected and Forest needed a total hip replacement. He would not survive an immediate operation.

Unfortunately, the only place where he could be properly supported while he recovered was the specialist rehabilitation centre where he sustained the injury.

But the centre didn't want him. The head doctor fought against operating on Forest and wanted him transferred to a nursing home. In his opinion, Forest wouldn't walk again, the injury should be left alone and the pain managed with medication.

The head doctor tried to intimidate and frighten Uda. He told her, in front of Forest, that Forest would die. Ultimately, he threatened to take the matter to the state administrative tribunal.

Uda engaged lawyers and consulted one of the top orthopaedic surgeons in the state. The surgeon consulted colleagues and they examined Forest 'with a fine-tooth comb to make sure he was ready for surgery and wouldn't die on the table'.

Meanwhile Uda wanted answers about how the injury occurred. She suspected a nurse rolled him too far and he fell from the bed. But the centre had their own scenario – Forest had a major stroke and kicked the footrest on the bed causing the injury. Uda's experts said this scenario was ludicrous.

The operation did go ahead and was successful.

After rehabilitation Forest was able to go home. 'He's up and walking,' said Uda.

'All I want for him is a safe healthy life.'

Amelia and Carly

Amelia lives with a genetic condition, autism and attention deficit hyperactivity disorder. She is non-verbal, has complex needs and requires continuous support. A couple of years ago, when Amelia was in her early teens, her mother Carly made the difficult decision to place her in out-of-home care. Carly explained to the Royal Commission that she needed to consider the wellbeing of her other daughter.

Since then, Amelia has moved 12 times.

Initially she was at a respite centre. The centre catered for different sexes and ages, and if staff considered Amelia at risk they moved her back and forth to a caravan park. This continued for 12 months. Amelia's anxiety increased and her behaviour deteriorated. Sometimes Carly didn't know where Amelia was.

One time Amelia's finger was broken. Staff didn't give her any pain relief or seek medical assistance. Carly asked the centre for case notes 'but literally got no response'.

Fortunately, a stable place became available. Amelia settled down and was 'very content and happy'. But it only lasted six months because of an issue with NDIS funding. Carly explained that because the NDIS does not fund supported independent living for children under 18, the provider accumulated a large debt.

A new provider was found, but after four days said they couldn't continue. They told Carly 'some of their workers had basically left because of [Amelia]'s behaviours'. She believes the unfamiliar staff caused 'further regression and heightened behaviour'.

The provider gave Carly six hours' notice, putting her family in 'a position of crisis'.

Amelia came back to the family home with support from her special needs high school.

'It's like a family that school, really. They've got a very good understanding of disabilities, the family situation, the pressure it puts on families.'

The department asked Carly for her consent to move Amelia to another state but she refused 'because it would be a completely unfamiliar environment to her'.

With nowhere else to go Amelia moved back with Carly, but her behaviour 'was very disturbed, very heightened'. 'I had to pack my whole house up into mine and [my younger daughter]'s rooms so things weren't broken,' she said.

Amelia refused to go to school, and when she was at home she refused assistance from support workers – she only wanted Carly. She was very anxious and upset and 'definitely not the girl that left home'. Carly sent her youngest daughter, who was traumatised, to stay with the day care worker while she focused on Amelia.

After a while Amelia finally agreed to go to school but escaped to a neighbour's house. Police unsuccessfully tried to drag her out of the house before ringing an ambulance to sedate her and take her to hospital. She was sedated on and off for five nights.

Carly said the hospital system was totally unprepared to treat a child with Amelia's needs. The use of restraints was traumatic for Amelia and, rather than engage with her, staff stood back and watched. 'Some of them seemed very unsure and unsafe.'

When Amelia was discharged she was placed with another provider. When the provider conducted a risk assessment a few weeks later, it showed the home wasn't suitable for Amelia because of the extent of her behaviours. 'The risk assessment should have been done prior to her moving in,' Carly said.

With no alternative, Amelia returned to the respite centre. Carly feels 'really uncomfortable' about it, but 'there is literally nowhere else ... that will provide services ... because of her age'.

As a result of the constant moving and insufficient funding, Amelia lost most of her allied health support. A physiotherapist saw Amelia at school which is the stable safe place in Amelia's life. Carly believes other health professionals should follow suit.

'Up until recently I've had it pushed back on me to have [Amelia] living at home ... I've had to really stand my ground,' Carly said. She believes it is in the best interests of the whole family to see Amelia 'finally settled' outside the family home 'in a safe stable environment'.

'At one point she was really settled,' Carly told us. She believes if it wasn't for the funding issues, she might have remained settled.

Angelina

Angelina has a cognitive disability and has been a client of state-funded disability services her whole life.

Angelina was involved in an accident in the 1980s, when she was in her 30s. She and her friend, Bishop, were crossing a railway bridge when they saw a train coming. Angelina jumped off the bridge and sustained significant pelvic injuries and was in hospital for a number of months. Bishop was hit by the train and died.

Angelina met her advocate, Jen, for the first time in the early 2000s. She asked Jen about Bishop over and over again. Jen saw her every week and all Angelina would talk about was the accident and her friend.

‘[Angelina was] very clear about her grief,’ Jen told the Royal Commission.

‘No-one in that whole period of time had sought out the information about her friend and where he had been buried, nor had they done anything about grief counselling.’

Angelina wanted to see where Bishop was buried.

Jen drove Angelina to the area where the accident happened and Angelina identified the rail bridge. They went to the local library and found a newspaper article about the accident. They discovered Bishop’s surname and found where he was buried. Angelina and Jen went to the cemetery and visited Bishop’s memorial plaque.

Jen said that ‘knowing where he was and that she could visit him if she wanted to’ helped Angelina recover from her trauma, and she never mentioned Bishop in the same way again.

Not long after this, Angelina was able to move into her own home and she said she’s ‘very proud’ of her independence. She has a strong connection with her neighbours and cares about her community.

She walks to her favourite café every day and the people in the area know her and help her out.

If Angelina sees a path that is broken, or cracked because of tree roots, she reports the damage to the council. Several paths have been repaired because of her.

One of the roads she crosses every day is very busy. For pedestrians to get to the traffic island ‘it’s a bit like dodging traffic’. Angelina met with a man from the transport department and showed him the problem. There are now pedestrian lights at the intersection. She is happy that children and old people can cross the road safely.

Angelina also managed to get a covering installed over the taxi stand at the local shops. She told the local council and shop management that people shouldn't have to wait in the hot sun, cold wind and rain. Everybody tried to fob her off, but she was insistent and succeeded.

Angelina goes on a road trip every year with Jen and 'loves discovering new places'.

'I love quandong jam, lattes, sushi, egg and bacon sandwiches... and would like to ride a camel one day.'

Mikey and Ander

Mikey is in his 30s. He has an intellectual disability and is autistic. He has been working most of his adult life and he lives by himself. Ander, his dad, told the Royal Commission that Mikey's employer is financially exploiting him under the Supported Wage System (SWS) – a 'slave system' that is jeopardising his ability to live independently.

Mikey began working in a local store around 15 years ago. For the first 10 years or so he was doing 'the same or similar job as any other able-bodied co-worker without any extra support or supervision'. He worked for full pay.

About five years ago, the business embarked on a restructure. The employer told Mikey they had to reduce his hours and, to keep him employed at all, would have to move him onto a government-supported program, the SWS. The employer said this new program would provide Mikey with training and the opportunity to learn new skills.

'They advised me at that meeting that if you get on this system – the SWS – the government will pay for his wages,' Ander said. 'They will actually pay for his wages, for lost wages and whatever, and their retraining and support. So it was a win-win we thought.'

Ander explained that under the SWS, employers pay their employees according to a yearly assessment of their productivity. 'The whole assessment process is proven to be unfair and biased, lacking transparency,' he said.

In Mikey's first assessment, his productivity was deemed to be low.

'It wasn't because he was a bad employee ... [he worked] full pay, full-time. Never had one problem with his work performance, only that they want to save money, that's all. It's just a cost-cutting exercise.'

Immediately Mikey's wage decreased by almost half. The Disability Support Pension did not make up for this loss in wages.

Furthermore, within a few weeks of commencing in the system, the employer pressured Mikey to take his long service leave – but they would only pay it at the new 'below the poverty line wage'.

Ander believes employers and disability employment service providers both make 'a huge financial gain' by 'coercing' employees with disability 'into the system and keeping them on the system'.

'This employment service was not working to improve [Mikey]'s skillset or productivity and it's more focused on supporting the employer to continue offering a wage which is grossly under the award.'

Ander says that since Mikey has been on the SWS, he can barely cope financially.

'He couldn't afford it and nearly had to come home, so we've been supporting him with meals and stuff, and using his savings to keep him independent, living by himself, to have a quality of life and be a valuable member of the community.'

Arjun, Aila, Kaysen, Minnie, Sayda

Sayda is in her 30s and lives with an intellectual disability. As a child, she was placed in foster care.

Sayda told the Royal Commission that soon after each of her four children were born, child protection officers took them away.

‘I’ll give birth to a baby in a back alleyway before I will ever go back to a hospital, where I am clearly not safe.’

Sayda’s first child, Arjun, is now in his early teens. When he was a few weeks old, Sayda took him to hospital to get help feeding him.

Sayda said the hospital told her he was ‘failing to thrive’. Child protection officers took Arjun away.

‘If my friend ... had problems with her children [and] if she took her child to the hospital under the same conditions, they’d be, like, “All right, this woman’s having problems with her baby, let’s see how we can help. Let’s address her problems.”’

Sayda said the child protection service has since moved Arjun multiple times and police have arrested him for assault.

‘Because no-one is listening to him. And they’re going to lock him away until my child turns up dead or fighting for his life in the gutter somewhere.’

Sayda’s daughter Aila was removed when she was days old, when Sayda was still in hospital.

‘No-one would tell me where she was, how she was going. Little did I know that they had already discharged her to the foster carer. But no-one told me that.’

Sayda said she later learned that after the child protection service took Arjun away from her, it had placed her on a ‘watch list’.

‘They’d never made any effort to even check to see if anything had changed since then. They just made assumptions ... I did absolutely nothing wrong.’

Sayda said the child protection service placed Aila in long-term care because it claimed she had formed no bond with her mother. Aila has now passed through multiple foster families.

‘They just recently shifted her because ... the placement broke down as a result of her being in such distress. And they’ve denied me months and months and months of access to my baby.’

Sayda gave birth to her son Kaysen at home. Police took Kaysen away when he was a few weeks old.

'He had literally conked out through having such a huge big feed ... I had [Kaysen] in my arms fast asleep. Two police officers pinned me down to my lounge and ripped my baby out of my arms, fast asleep and literally tore him out of my arms. And they think this shit does not traumatise children or parents?'

When Sayda was pregnant with her youngest daughter, Minnie, she organised a support network to help her after the birth.

'My baby wasn't even two and a half hours old when they took my baby. I had done nothing wrong. Nothing.'

Sayda tried to commit suicide while still at the hospital.

'I never really got to spend any time with her at all. I've never been alone with her either, so how am I a threat to her? I've never been in a room with her alone ... What have I done to be a risk? I've done nothing.'

Sayda said the child protection service claimed during a court hearing that she was incapable of learning.

'How can I master parenting and get all the skills involved if no-one gives me the [chance]?' Sayda asked the Royal Commission. 'I did a full first aid certificate. Passed it. Rocked that ... A fully qualified first aid certificate. Does this mean I'm not capable of learning?'

Austin, Marilyn and Shane

Austin is in his late 30s. He has Asperger's syndrome and an intellectual disability. His parents, Marilyn and Shane, talked to the Royal Commission about the challenges Austin and his family have faced – from school to adulthood, to prison and life beyond.

Austin's parents were unable to get a diagnosis for him until he was 15. Meanwhile he struggled at school, academically and socially.

'He looked different, he spoke different and he was pushed aside by the group. It hurt him ... Kids would start calling him 'retard' and all of that. A lot of his anger to this day comes from a lot of that.'

After leaving school, a government department offered Austin a place in a house to live with a man who had an acquired brain injury. While living in this house, Austin started drinking.

During his early 20s, the drinking increased and Austin became 'more and more aggressive'. The department moved him into another flat on his own, but he started to refuse the community services the department offered. Becoming increasingly manic, he left and moved into a caravan park. 'He just told them "where to go",' Marilyn and Shane said. 'So they told him, "We won't help you if you don't want us to."'

His parents draw a direct line from Austin being able to refuse services and services being withdrawn, to him entering the criminal justice system.

'It's an incredibly important point,' Shane said. 'You're not allowed to impose help upon anyone. And really, it's a massive thing for us. Because he should have been helped by someone. We did everything we could, but they more or less said 'no' ... This story then jumps to [maximum-security prison] ... Where is the stuff in between?'

To get Austin out of the 'dodgy' caravan park and ensure no-one could evict him, his parents set him up in his own house. But without support, the situation continued to escalate.

'Things were about to explode completely ... he'd rejected all help and no-one would cross this line. No-one. Except the police. Once or twice they locked him up ... put him in a cell overnight.'

Meanwhile, Austin developed a friendship with a man in the area who had an intellectual impairment. He was on the disability pension, a convicted sex offender and, like Austin, an alcoholic. So they drank together.

'This is a very sad situation,' Marilyn said, 'because this man was a client [of the department] and he should have been better supported ... He was in a suburb and known as a sex offender. Kids and other people were throwing rocks through his home.'

He took refuge in Austin's house.

Marilyn and Shane believe Austin wanted to distance himself from this friendship but didn't know how. One day Austin lost his temper and 'bashed' the man. 'The guy was on life support. Austin could have been charged with murder.'

Shane and Marilyn believe there needed to be consequences for Austin's actions, but were disappointed by the lack of support available and absence of a specialised court that might assist him.

Marilyn said specialised courts have a 'really important role' and, if they are not available, you need 'at least a pool of legal people who have specific training and specific backgrounds'. Also, she said, judges 'need options'.

'While the judge was very understanding he was forced to treat Austin with no consideration for his disability and sentenced him accordingly.'

Austin was sentenced to five years in a maximum-security prison. While he was not sentenced with consideration of his disability, he was placed in a unit for people with an intellectual disability.

Marilyn and Shane said the unit turned out to be very positive for Austin because he was able to access much needed assistance. It was just 'unfortunate' he had to be sent to a maximum-security prison to get these services. They think there should be more such units available within a 'non-prison system ... not locked up within a maximum-security prison'.

Eventually Austin was up for parole. But he couldn't access parole until he had a house to live in, and he couldn't access a house without parole. Shane says there is no coordination between housing and the parole system. And there was no extra assistance given to Austin despite his being in the unit for people with intellectual impairment.

Marilyn felt there was an expectation that Austin would live in the family home, but that wasn't feasible. 'We had four other kids ... and we didn't know if he would start drinking again.' She knew they would have 'Buckley's' of getting him accommodation once he was living with them.

Marilyn and Shane spent months lobbying and advocating to find a suitable house for Austin. Even with all the work they put in, Marilyn said they only found him appropriate accommodation because the 'stars aligned'. 'Housing is dreadful,' she told us.

Having found him a house, Austin began parole. He complied with the rules and 'loved it'. The curfew, the tracking bracelet, having to report, alcohol testing – 'He loved all of that,' said Marilyn.

Shane observed that 'all the things that got done to him after he left jail' would have been of great benefit to Austin earlier on and helped him not end up in prison in the first place.

With the proper treatment and support, Austin was doing very well. However, his behaviour goes in cycles. The family is now back in the situation where access to services is again voluntary for Austin, and he has started to disengage.

His parents say there is a service gap for people like Austin who won't accept treatment or support. They would like to see services modelled on the parole system, but with more supports and freedoms.

As things stand, they are deeply concerned. Austin has started drinking again and is 'on his last warning' at his current accommodation. They will be 'back to square one' if he has to move out.

'We don't know what we would do.'

Samir

‘ADHD is a very bad secretary that I have ... She’s very inclusive, she invites everybody to the party until the whole head is so full, then she blocks everybody.’

Samir is in his 50s and lives with attention deficit hyperactivity disorder (ADHD). He told the Royal Commission he’s lived with ADHD all his life, but was diagnosed only a decade ago.

‘It’s really difficult to get a diagnosis because you can’t find the right people who have the expertise ... Even now there are doctors in Australia who will say “It’s nothing, you have nothing.”’

Samir said he was originally diagnosed with bipolar disorder, but the medication made things worse. He thought about suicide.

One day, he was in a doctor’s waiting room reading an article on ADHD thinking, “Are they talking about me? How did they know so much?”

‘Suddenly things seem to drop into perspective.’

Samir was a public servant at the time. He had always struggled to concentrate at work, and would sneak back after hours ‘to get through the job’.

‘[But] there was no problem in that role that I had because I was getting commendations.’

When a doctor diagnosed ADHD, Samir told his boss because ‘the narrative in those days was, if you come out and you talk about it, other people will be there [to help]’.

Samir said that after disclosing his diagnosis, his boss micromanaged him by watching what he did and reading his emails before he sent them.

‘I said, “What are you doing? I’ve been sending emails for the past [several] years. You do not need to read every email I send” ... It wasn’t that they weren’t trying to be helpful. It was just that they did not know, and I did not know, what help I needed.’

A few years later, he resigned.

Samir now helps people manage their ADHD, which he describes as ‘just a different human design ... just the way we process information’.

Avi, Harlee, Fay and Jeffrey

Fay and Jeffrey have been 'on-call 24/7' for their granddaughter Harlee since she was born. They described her as a 'strange child', and they struggled to find anyone to help her.

At 13, Harlee was diagnosed with bipolar disorder and schizophrenia. A few years later she became pregnant.

Fay and Jeffrey told the Royal Commission that Harlee was in a violent relationship when she gave birth to her baby boy. She was using drugs and slept most of the time. Avi was left to crawl around and if he woke Harlee she screamed at him. Raised voices are a 'big trigger' for him, Fay said.

By the age of two, Avi was starting to show signs of anger and frustration. At childcare he would 'get very angry and bite,' Fay said. By his final year he was 'very angry' and staff suggested 'something was wrong'.

Fay tried to get an appointment with a specialist, but it took more than a year for him to be diagnosed with attention deficit hyperactivity disorder and autism.

Fay described Avi's primary school as 'our family, our support'. Avi broke windows and equipment and kicked teachers, but the staff were 'brilliant'. The school engaged a psychiatrist and tried to coordinate as much support as possible. They paid for school camps and allowed Fay to accompany Avi.

Avi is 'mad keen' on cars and animals and now attends a high school with a workshop and farm. But the transition has been very difficult as staff are not sufficiently trained to manage him. He attends school on reduced hours, but rarely lasts more than 20 minutes. Recently Jeffrey had to collect him after he assaulted four teachers and smashed a printer.

'He can be an angel for a while,' Jeffrey said, 'but I've never seen a human being so complex.'

Avi has had four different NDIS behaviour management plans but they have never been followed through because providers and therapists discontinue treatment. 'Nobody's lasted,' Fay said.

One psychologist stopped halfway through an appointment and told Fay there was no point bringing Avi back because he wasn't listening. The psychologist made a coffee while Fay carried her screaming great-grandchild outside. Another psychologist did a one-off assessment but wouldn't take him on. Another refused 'point blank' to treat him.

As Avi gets older his behaviours are getting worse. He has destroyed his great-grandparents' fridges, TVs, doors and windows. The last time he stayed with them he gave Fay a black eye and she caught him looking up 'how to kill Nan' online.

'That scared me,' Fay said. She called the police and the officer said he wouldn't leave until they found Avi some respite or support. The officer rang everywhere but no-one would take Avi. Fay had no choice but to send him back to his mother.

Fay and Jeffrey believe Harlee's house is not a safe place for Avi to live. Harley is living with mental illness and a number of different people are squatting in her home, some of whom Fay describes some as 'dangerous'.

Recently Avi stole his great-grandparents' car. He had a weapon and said he was going to rob a fast food restaurant. Police told Fay and Jeffrey they could charge him but nothing would happen because he has a disability.

The school has sent child services to the house on a number of occasions but they don't do anything because there is nowhere for Avi to go. The department has advised Fay and Jeffery to give up guardianship. The family don't want to do this and can't understand why this is the only option for a child and family to access supports.

Fay and Jeffery would like to see Avi working with cars or on a farm. Jeffery said when he takes him carting he is the fastest around the track.

'There's got to be something out there for him,' Fay said. 'There's got to be a safe place for him somewhere.'

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Artwork by Peter Cox

Axel and Prudence

When Prudence gave birth to Axel 30 years ago, in Africa, she was a single mother working as a nurse.

Axel has an intellectual disability. When it came time for him to attend school, Prudence struggled to find a place where he could be educated, learn skills and maximise his potential. A friend suggested Prudence migrate to Australia because it had a good education system.

In the middle of the application process, Prudence fell pregnant. She gave birth to twins and a short time later restarted the migration process. She was approved to come to Australia to work as a registered nurse.

When Prudence applied for visas for the children, the twins were accepted but Axel was rejected because of his disability.

Prudence was shocked, but she didn't believe the government would really divide her family. She spoke to a friend and her priest – they advised her to come to Australia and work it out from there.

'Being a mother, I thought in the back of my mind I have three children ... I can't stop the life of two children because of one.'

In Australia, she immediately applied for permanent residency because she thought this would be the best way to bring Axel to Australia.

But Prudence was told 'you cannot get permanent residency in Australia because [Axel] has failed his medicals and if one child fails the whole family fails.'

Prudence couldn't understand why Axel's capabilities weren't being assessed. Axel was verbal, independent, could feed himself and go to the toilet himself. She submitted additional documents from Axel's psychologists and teachers.

'But each time we were told, "No, he fails his medicals."'

Leaving Axel in Africa was a 'crushing decision' for Prudence to make. 'So many times I've packed my bags saying I can't do this to my son.'

She spoke to politicians and members of her church to find ways to overturn the decision. Ultimately she had to stop her appeals because it was too painful. 'Rejection of your own child is a big thing.'

'Sometimes you feel like a person in ICU – you're suffering so much but you can't lift a finger because of the trauma you have. You've got to gather that courage to again go in ... and get another rejection.'

When Axel turned 18, Prudence removed him from the permanent residency visa application. She said it was the hardest decision but she felt she had to give the twins a chance in life.

‘I think my biggest problem has been why? How can they divide my family? How do they decide this child is good, this child is not good?’

Prudence works as a nurse and her husband also works. She pays taxes and every time she does her annual return she’s struck by the amount of tax she pays – ‘it goes to help other children, what about my child?’

She can’t understand why the government determined Axel to be a liability to the community when she was prepared to support him and pay for his education.

Ultimately, Prudence says, Axel was ‘denied something that would help him in the future’ and the twins were denied a chance to bond with their brother.

Prudence feels it is unfair for Australia to select her for skills as a nurse but reject the other aspects of her life – ‘if you want me, you want me as a whole.’

She says it’s ‘very sad’ that ‘a lovely country like Australia’ discriminates against a child because of their disability.

‘When I talk about my case I would hope I would be the last mother that has to experience this.’

Gracie and Camilla

Gracie and Camilla are Murri women. Gracie, Camilla's daughter, is in her late teens. She is autistic and has auditory processing issues, but she was only diagnosed recently.

'Our journey began when Gracie was in year 5,' Camilla told the Royal Commission. Gracie started to experience 'clandestine' bullying and, one morning, woke up weeping at the prospect of going to school. 'Why am I so different? What's wrong with me?' she asked her mum.

Camilla believes that bullying and a lack of capacity of teachers were both barriers to diagnosis. Camilla thought Gracie didn't like going to school because of the bullying. She got 'no feedback from the primary school teachers at all, nothing that would ignite a spark of "ok, maybe this requires deeper investigation"'.

There was also, Camilla believes, 'unconscious racism' at play.

'There was a lot of absenteeism due to the fatigue of having a disability and not knowing about it, due to having auditory processing problems and not understanding ... Rather than [considering] there could be a deeper underlying trauma that needs to be addressed, I suspect ... that they looked at us as a family and thought, "oh yeah, didn't realise they're Aboriginal ... "'

Camilla and Gracie described feeling 'so overwhelmed'. They didn't know where to start looking for assistance and support. They went to see a GP, who prescribed antidepressants for Gracie.

To relieve some of her anxiety, Gracie began homeschooling through a distance learning program with another school.

It wasn't until Gracie was in year 10 that they happened to meet a member of the teaching staff who had a daughter with autism. The next day the woman phoned Camilla and said, 'I met [Gracie], she's amazing, I just want to know if you have ever thought of getting her assessed. You might find she needs extra support'.

Now Camilla had some idea of what Gracie was dealing with, but there were still barriers. She couldn't get an independent learning plan for Gracie until she had the right paperwork. The cost of assessments was prohibitive and, before she could even do the assessments Gracie was required to have several sessions with a psychologist, which were also expensive. Camilla opted to get the assessments done through a university psychology unit. It was more affordable, but also involved a six to eight-month waitlist.

Camilla and Gracie hit yet another barrier. The Aboriginal Community Controlled Health Service focuses on early intervention and children under 12 years, but Gracie was now 15. 'We were in a kind of no-man's land,' Camilla said. 'There is just nothing around.'

During this struggle to get a diagnosis, the school asked Gracie to consider leaving.

‘Rather than help support us through that journey of getting a diagnosis ... instead they asked us to leave. Which was really traumatising, quite frankly. It rocked our world because we just felt like we were invisible, not being heard, you know?’

Now that Gracie finally has a diagnosis of level 2 autism, she is able to access support through the NDIS. But Camilla feels there is a ‘cultural disconnect’ between the NDIS and First Nations people.

‘Murri people ... [are] different to the normative society that talks about having people with disability living independently,’ Camilla explained. ‘That’s not really how our culture is. We tend to look after our families at home.’

Another area of ‘cultural disconnect’ is support workers.

‘I think we still are so deep in trauma from living as Murri people ... when you are expected to go out and get a support worker, it’s very hard to form that trust.’

Camilla believes some of the NDIS guidelines are ‘inherently racist’. ‘They don’t take into consideration our own unique experience of our culture,’ she said.

‘We have a greater number of comorbidities that exist within our community, and we are more vulnerable to, for example, diabetes and other chronic diseases ...

‘It’s crucial that we have our mob sitting on those reviews into how the NDIS is going, because I’m not sure that our concerns and our way of managing disability are being reflected in the guidelines.’

Brent and Trudie

‘I asked [Brent] what role he wanted to play in the Royal Commission. He consistently says the same thing. “Why bother? Autistic kids are never going to be able to go to school like other kids. Just give up mum.”’

Trudie is the mother of Brent, who’s in his teens. He has a high IQ, is autistic and lives with anxiety.

Trudie described Brent as an unusual baby.

‘In those rare moments that he wasn’t screaming when he was a baby, for example when I was breastfeeding, he wouldn’t look at me. I’d coo and make faces at his tiny little blue eyes, but he would just look off into the far corner of the room.’

When Brent was a few weeks old, Trudie asked her obstetrician about the screaming.

‘She looked me in the eye and said, “Welcome to motherhood, [Trudie]. You need to grow up and get over it. Babies cry.”’

Brent continued to scream as a toddler.

‘The episodes were terrifying. [Brent] would scream and scream, he’d go purple, he’d sweat, he’d run into walls, bang his head, he’d tear at his body and rock and sob.’

Trudie said she suspected autism and was placed on a waiting list to see a specialist. Two years later, a specialist diagnosed reactive attachment disorder. ‘Conforming with the medical diagnosis that it was in fact my parenting ... that was the reason for all of [Brent’s] distress.’

It would be years before other specialists diagnosed autism. Even then, schools blamed Brent and Trudie for Brent’s behaviour.

In preschool, Brent was suspended ‘for such offences as running away from noisy areas, rocking on his chair and not being able to do colouring-in activities quietly like the other children’.

Trudie said that when he started primary school, a teacher told Brent his family wasn’t disciplining him properly.

‘The [school’s] incident summary goes on to say [Brent] tried to explain how he loses control of his body when he gets upset ... [the summary then states] that the police would be called to imprison him if his behaviour didn’t change.’

Trudie said she tried various schools, but they suspended, restrained, segregated and humiliated her son.

‘School’s a harmful place where they hate him, and they hurt him.’

Sometimes when Brent was distressed he became incontinent. One time he was trying to clean up after an episode of incontinence. ‘[The school] lodged this as an incident of a code of conduct violation on the system.’

On another occasion, staff had segregated Brent in a room ‘where furniture was bolted [down] and the door locked.’ ‘[When he] asked to be allowed to join in with his old class, this was recorded as a violation of the department’s code of conduct.’

One day, staff had segregated Brent in an office. Trudie said that when someone told him to be quiet, they were ‘somehow injured’, and ‘arguably [Brent’s] limb or something’ made contact with the person. The police arrested and charged Brent with assault.

‘He was on bail for a year. My little skinny pale ... [boy]. He started wetting the bed again. He didn’t know what was happening. He stopped being continent during the day.’

Trudie said that when the matter came before a court, the magistrate ‘apologised personally that the matter was ever brought’.

Last year, Trudie gave Brent a birthday party where he and his friends played paintball.

‘We had the most amazing day in part supported ... through the NDIS. My son and nine other kids running around all day laughing and playing together. I never thought I’d see anything like it.

‘Now,’ Trudie says, ‘it’s almost guaranteed that it’ll never happen again.’ She told the Royal Commission she has ‘come to terms with the fact that because he was born different, he’s not welcome at school’. Brent now has a tutor and is homeschooled.

‘As we sit here, Brent sits alone in my apartment a few streets away alone and friendless ... I did what I could, but it just wasn’t enough.’

Brooke

‘Across my lifetime I had lots of things happen that I didn’t understand.’

Brooke is in her 40s. She describes herself as ‘one of those late-diagnosed women who was missed as a child’.

‘I’ve always wondered why people don’t like me,’ Brooke told the Royal Commission. ‘Now that I know ... it’s because I’m autistic.’

Over the years people labelled Brooke a drama queen, over-sensitive, a hypochondriac, precocious and obsessive.

At school, teachers called her stupid and yelled at her. She found it hard to sit still and focus. She would fidget, look out the window and sing to herself. Brooke remembers three male teachers cornering her and shouting at her which was confusing and terrifying.

As she got older she didn’t understand ‘the girl world’ and the other girls bullied her. She found it hard to manage big friendship groups and didn’t like to go out.

In year 10, Brooke had a breakdown. Her mother was so worried about her she moved schools. Brooke is an excellent musician so they found a school that focused on music. She met other neurodiverse people and felt safer. The new school was much more supportive but she wasn’t able to pass year 12.

The first time Brooke was sexually assaulted she was a child. ‘Socially I didn’t know when someone was being a predator, I probably still don’t get it.’

At university, Brooke was raped by an older man. ‘I woke up one night and thought I was suffocating. He was on top of me, I was terrified.’ She had another breakdown, became non-verbal and couldn’t look at people. She wasn’t able to continue her studies.

Despite these setbacks Brooke qualified as a music teacher. She said students love her and she has ‘always delivered’. She has run departments, staged great school musicals and put together wonderful bands.

Yet she’s been ‘bullied in every job’.

Staff rooms are too noisy and Brooke prefers to ‘hide’ in her office. She explained there is a lack of awareness of what ‘that noise’ does to autistic people. She described the sensation as feeling physically drained, ‘like there’s a cloud around my head’. It is debilitating and affects her work. One workplace said she was ‘insulting them’ by not going to the staffroom and told her ‘it’s too bad, everybody has to go’. They made her attend the staffroom every morning before school and at recess. She ended up leaving.

In Brooke's last job, she let them know that she has autism. The school liked to hold staff meetings in a café. She told them she couldn't participate because she couldn't hear and it made her physically sick. They refused to change venues.

Brooke ended a 'very unhappy' and abusive marriage, and now lives alone with her teenage children. She can't afford to buy a house and said rental managers take advantage of her. The last house she lived in had mould, was infested with insects and falling apart. 'They continued to take the money off us and then they took my bond ... it was horrible.'

Brooke's oldest child was flagged as autistic and attended school part time. Brooke didn't want him diagnosed because she didn't want him labelled. In hindsight, she said, she 'should have got it properly sorted'. He has anxiety and 'went through a lot of shit at school'. He's been waiting to see an autism specialist for six months.

Brooke's daughter was diagnosed with autism when she was young. She is non-verbal and uses Auslan to communicate which 'opens up a whole new world'. Brooke loves that her daughter is able to tell her to get out of her room.

Brooke said 'it would have been amazing' if her parents had known she was autistic. They would have understood her behaviour and she would have understood herself.

'I think I had a potential, and I think I still do have the potential to do what I want to do,' she said.

'I just feel like I haven't been looked after in the system.'

Calum

‘We’re not asexual ... we can have sex.’

Calum is a First Nations man in his early 30s. He has cerebral palsy and post-traumatic stress disorder and, until recently, was living in a group home.

Calum told the Royal Commission he ‘came out as gay’ not long after he moved to the home. He was 13, had no support and faced ‘pretty harsh disapproval’ from the people who were supposed to care for him.

Calum described living in the home as ‘being forced back into the closet’.

The home monitored all of Calum’s visitors and wouldn’t allow him to have a partner come to his home. A few years ago they called police to separate him from a man he was in a relationship with.

Two other residents were in a same-sex relationship and were having sex. Calum said the home refused to accept this. They moved them to bedrooms at the opposite ends of the house and ‘forced them apart’ if they found them together.

The home also restricts internet access for LGBTIQ+ residents so they can’t access adult content. Calum has successfully fought this but said none of the other residents have the capacity to advocate for themselves.

Calum said a support worker from a religious background has been openly ‘bigoted’ towards him. At the start of the COVID-19 pandemic they told Calum gay people caused the pandemic. Calum made a complaint but there have been no consequences for the worker.

Calum has never felt safe in the home and believes residents and staff need ‘proper’ sex education. He said the home thinks ‘if we just ignore all this, it’s going to be a better solution than educating,’ which is ‘just untrue’.

He asked the home to provide sex education that included LGBTIQ+ information and they said they’d ‘look into it’, but nothing happened.

A short time ago Calum, wanting more autonomy, moved to a flat at the back of the home. But very little changed – visitors have to come through the home to access his flat and he isn’t allowed to employ his own support workers. It’s ‘quite a frustrating thing,’ he said, to have no independence or ability to self-manage.

Calum recently told the provider he wants to find his own flat and employ his own staff. He said the provider has done everything to ‘block’ him doing this.

They now treat him with a lot less care and withhold cleaning and repairs. They told him 'oh you're going to move out anyway, what does it matter?' They stop him listening to his music and won't let him get another pet. They refuse to allow him to travel to look at places to rent and won't provide good references.

Calum said the provider sees him as an 'asset', a person to make money off, not a human being.

Recently Calum was assaulted by another resident, and he said staff 'did nothing' to stop it. He reported the assault to police but the home refused to cooperate and wanted to 'sweep the incident under the rug'. Calum said the police were 'very, very good, very understanding' but couldn't do anything because there was a lack of evidence. They continue to do regular welfare checks to make sure he is okay.

Calum is now working as an advocate. He wants to 'make the changes required so that people in the future don't have to go through these things'.

Everyone, he said, no matter their capacity, 'has a right to human connection'.

Damir and Estrella

‘The tape is ... distressing ... because you can hear him crying and pleading for help.’

Damir is in his late 20s. He has cerebral palsy, intellectual disability and is blind. He uses a wheelchair and has a feeding tube.

Estrella adopted Damir when he was a toddler. She told the Royal Commission that Damir is very social and loves going to the shopping centre because ‘everyone knows him’. She describes him as a ‘good kid’.

A few years ago, Damir’s behaviour changed and he started ‘playing up’. He didn’t want to go to his day program. Estrella would dress him and he’d undress himself. He was making himself sick every morning.

Estrella wondered if something was happening at the day program. A staff member told her some days Damir seemed ‘so scared he wouldn’t get out of the bus’.

Estrella decided to put an audio recorder in Damir’s bag. ‘It all came out what they’d been doing to him,’ she said. ‘I was shocked to hear what I heard. It was absolutely disgusting.’

On the recording, Damir is on a bus with three support workers. He repeatedly tells them he feels sick and wants to go home. The support workers tell him they’re going on an outing. Damir says he doesn’t want to go. They discuss their options and decide to trick Damir. They tell him they will take him home but instead drive to the outing.

On the way, Damir is distressed and crying, telling them he is sick and wants to go to the toilet. They swear at him and call him a baby. They tell him bad things will happen to him and his mother won’t want him unless he’s good.

At one point, Damir tells them he wants to go to the toilet ‘now’. He yells, asking them to stop the bus. Damir has a bowel motion and vomits. They berate him, calling him ‘disgusting’ and ‘lazy’. They tell him they’re not cleaning him up, he has to do it himself.

One worker says she hopes someone will ‘bite you and shit on you and rip your head off and shit down your neck’. Damir hits out at her and tells her to shut up. She taunts him, telling him she’ll keep talking just to annoy him. He cries and gets more upset repeating he wants to go home. One worker says, ‘Stop fucking crying. You have no right to cry. Are we beating you up? Are we hitting you? No.’ Another worker tells him if he doesn’t stop crying they’ll take him to her house and lock him in the back with the possums and the cats and they can ‘scratch his face off’.

When they arrive at the destination Damir won’t get off the bus. They leave him there without checking on him for at least 50 minutes. Damir can be heard yelling and crying and talking to himself. He becomes so distressed he pulls out his feeding tube and stomach contents spill over his clothes and seat. When the support workers return they’re furious and swear at him, telling him to close the tube. He asks for water but they ignore him.

Estrella reported the abuse to the state government disability commissioner who directed the day program provider to report it to the police. The commissioner investigated and found the three support workers violated Damir's 'worth and dignity'. Estrella said one worker was sacked, one left, one is still working for the organisation.

It took Damir about a year to trust support workers and to be able to travel on a bus again.

Damir is now at a smaller day program and is much happier. Estrella said, 'He's got a really happy life ... so, it's just a shame what happened to him.'

Di

Di is in her 40s, is hard of hearing and has partial paraplegia. She lives with mental illness and has been prone to dislocated joints, broken bones and infections since she was a child.

'I was extremely clumsy all my life and would break bones with not much effort. I couldn't participate in sport or ride a bike,' Di told the Royal Commission. 'I was unwell with a lower immune system [and] multiple ear infections.'

In her 20s, Di began to self-harm and was admitted to a mental health clinic where doctors diagnosed borderline personality disorder. They told her that she 'would need a high level of care for the rest of [her] life'.

'I had people telling me that I needed care, and that actually caused it to continue. Instead of what should have happened, which was them to say, "Okay, you have a few issues, let's sort them out and get you back to your career."'

Di said that, despite several years of treatment, she didn't get better. So she left the clinic and stopped her medication.

Several years ago Di developed a complex series of symptoms including vomiting, heartburn, chest pain, anaphylaxis and unexplained seizures.

'All the medical specialist doctors said to me when I started to get physically unwell that, listen, you're never going back to work, you've got a psychosomatic condition called FND or functional neurological disorder. Which I'd like to point out, a lot of medical people and myself believe there is no such disease.'

One night several years ago, Di rolled over in bed, 'heard a horrific crack' and felt intense pain.

An ambulance took Di to hospital. There, a doctor told the ambulance officers to leave her in the corridor because she 'had a past history of "psych" issues [and] was probably faking it'.

'No-one believed that I'd moved over [and] severed all the nerves.'

Di was later told she'd injured her coccyx, causing nerve damage and requiring a catheter. The catheter has been the source of several infections.

A couple of years later, a specialist treating one of those infections told Di she might have Ehlers-Danlos syndrome, which makes her prone to joint dislocation and infections.

Another doctor referred Di for genetic testing and she was diagnosed with a rare type of Ehlers-Danlos syndrome that includes osteogenesis imperfecta, also known as brittle bone disease.

Di said doctors had for years minimised her physical symptoms because of mental illness.

‘The most important thing is that people with mental illness can get sick too [and not be] heard simply because [they have a mental illness].’

Di told the Royal Commission that during a procedure to change her catheter, she contracted an antibiotic-resistant infection at hospital.

‘This has ultimately cut my life shorter than it should have been as ... this infection is untreatable [and] my care is now palliative.’

Adelle, Rania and Amir

‘It seems to be that perhaps someone has to lose a life ... before incidents such as this will be taken seriously ... At present it seems to be a case of government departments looking after each other rather than the people they are supposed to be supporting.’

Rania volunteers as a citizen advocate with a not-for-profit organisation that facilitates advocacy and independent relationships for people with intellectual disabilities.

Rania is advocate and friend to Adelle, who is in her late 40s and lives in a group home. Rania told the Royal Commission about an incident at Adelle’s group home that occurred about five years ago. Rania tried to escalate the issue at the time, through management and then through government, but said ‘the people at the top weren’t interested’.

One day, Rania arrived at Adelle’s group home for a visit. As she approached the entrance, a staff member came out and told her: ‘Adelle is going to tell you that she got sausage stuck in her throat and we didn’t do anything about it. That’s not true, because Maree took her to the doctor and got it out.’

‘So sure enough,’ Rania told us, ‘we are in the car and Adelle said, “I got sausage stuck in my throat, and them bastards did nothing about it. They just told me to go for a walk.”’ Rania quizzed her about Maree taking her to the doctor, but Adelle insisted that Maree wasn’t at the barbeque when this happened. She was adamant.

Rania called Maree, who confirmed that Adelle was telling the truth. At the time of the barbeque Maree was not there. The three staff on duty had laughed at Adelle but otherwise ignored her. It was only in the evening that Maree came on duty and – when Adelle told her about the sausage – encouraged her to drink some water.

When Maree realised Adelle could not swallow water because of the obstruction, she went straight to the supervisor and said she was taking Adelle to see the doctor immediately.

At the doctor’s, Adelle coughed up a huge piece of sausage. If not for Maree, Rania said, Adelle would have gone to bed with her throat still blocked. ‘Lord knows if she still would have been alive the next morning.’

Rania and Amir, a coordinator with the citizen advocacy group, told us that the lack of care with which the staff treated Adelle in this case is common in group homes.

They spoke of their belief that for a period Adelle, and possibly other residents, were being sedated just to make life easier for the staff. Rania would take Adelle out and she would fall asleep at the coffee shop, which was very out of character.

Amir had witnessed similar incidents. Adelle was for a while on the board of the citizen advocacy organisation and she loved attending the meetings – she was treated with respect and like a ‘normal’ person. But there was a period she started falling asleep during them, despite her best attempts to stay awake. Rania and Amir believe she was being sedated in order to subdue her ‘loud and boisterous personality’.

Rania and Amir said that Adelle feels a lot safer having Rania in her life. Rania is Adelle’s only friend. Adelle trusts her and knows she can tell her anything.

Amir explained the significance of this relationship, that it not only gives both women a more meaningful role in the community and a more fulfilling life, but also offers some protection from things that can happen when a person is ‘just part of a system’.

‘That’s really what’s lacking in a lot of people’s lives, the freely given relationships ... Imagine your life if the only people you had contact with were paid to be there ... In these houses, people are clearly treated as clients ... [With] citizen advocacy ... all of a sudden they’re with somebody that’s not a paid worker, that’s more as a friend. And no matter what degree of disability, they realise it. They know.’

Dylan and Megan

Dylan is in his early 20s and has lived on a rural property by himself since he was a child. He keeps sheep and chickens and sells meat and eggs to the local shops and people in the community.

Dylan's advocate, Megan, told the Royal Commission he has a lot of energy and wouldn't cope if he had to live in town. He has an intellectual disability and is supported by two support workers 24/7.

A couple of years ago, a support worker – Casey – assaulted Dylan. Another support worker witnessed the assault.

Dylan wanted to put his chickens back in the barn and put the lambs in the paddock and asked Casey to help him.

Casey snapped, 'I'm not your slave, use your manners and put the chickens away yourself.'

Dylan turned towards Casey and swore under his breath, telling him to shut up.

Casey demanded Dylan repeat what he said. He did, and then walked to the paddock.

Casey followed and shouldered Dylan, turned him around and pushed him in the chest with both hands.

Dylan stumbled. He didn't say anything – Megan thinks he was probably in shock.

Casey then grabbed Dylan around the throat and squeezed. The other support worker intervened saying, 'That's enough.' Casey turned on him and asked him 'Do you want a go?' He told his colleague, 'You're bad for him, you're babying him.' Casey then got in his car and left.

Dylan had red marks on his neck. The support worker who witnessed the incident took photos of the bruising and reported the assault to the police and the disability service provider. The service provider immediately dismissed Casey and reported the incident to the NDIS Quality and Safeguard Commission.

Dylan had not done anything to provoke the assault, but Casey told police Dylan had behavioural issues, 'trying to use his disability to get out of the charges,' Megan said.

Police took statements from the other support workers and charged Casey.

Megan expected the prosecutor to be on Dylan's side but she said they were 'tough ... questioning Dylan's behaviour and whether he was a credible witness'.

Initially Casey decided to fight the charges, but pleaded guilty the day before the trial. Dylan didn't need to go to court but the process was very stressful, Megan said. 'I don't know if it was a game from the support worker ... it caused more trauma to a young man who had trauma from issues related to childhood.'

The judge fined Casey and made him promise not to work in the sector again. The safeguard commission said it would revoke his yellow card. Casey has since moved states again and Megan has her 'fingers crossed' he's not working with vulnerable people.

Dylan wanted Casey to go to jail but told Megan he's 'glad that people heard'. She said, 'I know when he was younger he felt people never listened to him.'

Since the assault Dylan had come along 'in leaps and bounds behavioural wise,' Megan said. 'He's like people actually do listen to me and I am being heard.' She feels he's confident that if there is an issue, people will follow through.

Edison, Graham and Jayda

Jayda has never met a more curious person than her son Edison. 'He will ask a thousand questions of a stranger about anything. He is a learner ... who shows up in curiosity.'

But Jayda says the school system 'squashes these qualities' and has left Edison with 'a lasting legacy of shame'.

Edison is autistic and was non-verbal until he was three. He has profound issues with fine motor skills, attention deficit hyperactivity disorder and paroxysms.

'[Edison's] story started in kindy ... this woman pinched him,' Jayda told the Royal Commission. At another kindy, a 'parent witnessed him being flung against the wall by a carer'. The carer was instantly dismissed but a few weeks later the kindergarten asked Edison to leave.

When Edison started primary school, Jayda and Edison's dad, Graham, agreed to six hours per week, thinking it would increase over time. But it took a ruling by the anti-discrimination commission for the school to enrol him full time.

During his first year of full-time school he made significant progress. But the next year there was a change of principal and key special education staff. 'The agenda was clearly for him not to be at the school,' Graham said.

New part-time staff and new routines were 'a massive trigger' for Edison. He cried and didn't want to go to school. When asked why he was crying, he said, '[The teacher aide] always says she pities me.'

One day an incident escalated and Edison started spitting.

'[Edison] was held down by the two staff,' Graham said. 'He's screaming out "get me the police, get me the police, help me, help me." So then they rolled him over, so he was face down, so his screams for help could no longer be heard and sitting on his back.'

Graham considers spitting 'an abhorrent behaviour – no ifs or buts'. However he questions why the staff restrained his son like this instead of using non-violent intervention strategies.

The school expelled Edison and the education department offered him a place at the only 'autism friendly' school in the city. The enrolment was part-time and Graham and Jayda were told to accept they 'have a difficult son'. Only when they threatened to return to the anti-discrimination commission did the school allow Edison to attend full time.

The first year progressed well. Edison and his teacher 'got on really well'. One of the strategies in place for when this teacher was absent was a one-page document – '15 things to know about me'. It was designed so any relief teachers could be aware of Edison's triggers and know how to assist him.

One morning Edison was particularly anxious because his teacher would be away at a conference. Graham reassured him, reminding him of the one-pager, and drove him to school.

The deputy principal rang Graham later that morning about an incident with Edison. Graham asked if the one-pager had been used, but the deputy principal had no idea what he was talking about. Graham demanded a meeting.

A teacher opened that meeting with a statement, 'Your son is disgusting and shameful.' They then read out 'a litany of [Edison's] crimes'. The principal told Graham and Jayda they should be 'grateful' to the school, and threatened to call the police to deal with Edison in future.

'Both of us felt sick ... the way we're spoken to, the way our son's spoken to ... I had quite a lot of anxiety just turning up to the school,' Jayda said. Exhausted, defeated and fearful for their son, who was now expressing suicidal ideation, Graham and Jayda decided to homeschool Edison.

Now a teenager, Edison attends a religious high school. Jayda said they are kind. 'They depersonalise, they are flexible, they do whatever they can to make it work.'

'I do believe [Edison] will one day be working and doing stuff and contributing and it won't be because of school it will be in spite of it.'

Haven and Lucian

Lucian's daughter, Haven, is autistic.

'She's the most likeable person in our family we often say,' Lucian told the Royal Commission. 'She has the most friends out of all, like all the parents at [kindergarten] know her and she's always getting [invitations to] birthday parties.'

Doctors diagnosed Haven when she was 18 months old.

'Then started our journey on the NDIS,' Lucian said.

When he first applied for the NDIS through a service provider, Lucian 'really struggled'.

'The first thing that happened was they lost that application for a year ... We were being told that we were going to have to resubmit ... It really felt like we were being made to suffer and it was already a very confusing time.'

Lucian said he had to quit his job to navigate the bureaucracy and care for Haven.

'It got to a point where we were spending so much time trying to find a path through and it was taking a lot of time away from [Haven], trying to give her services and trying to tend to her, that there was just a point where we threw our hands up.'

When doctors first diagnosed Haven with autism, Lucian said public hospitals were a 'one stop shop' for services. He said now, even with an NDIS plan, accessing suitable services is more difficult.

'We've had lesser supports, we've had lesser quality, the prices of things have gone up.'

Lucian said many providers are 'really about trying to sign you up, trying to take the max amount of money off you ... like being circled by a gang of sharks'.

One service provider, for example, charged \$370 for an interview, but wouldn't provide the services Haven needed.

'So we ended in this horrible loop where we would ... end up getting two sessions in and none of the things that we asked for would we get.'

Lucian said his family is still suffering financially and emotionally.

'It's been three years [and] the only money we've been getting is government money for our being carer, and so we've suffered. We're in a shitty rental. Like, it's put our lives on hold.'

Lucian said the NDIS, in supporting people with disability, needs to support families.

‘The mental and physical health and wellbeing of everyone in the family contributes to [Haven’s] wellbeing. [Haven] needs to have happy parents who are able to get up and meet every day with positivity and strength. [She] needs to have a brother who doesn’t feel depressed and overwhelmed with a lot of what’s going on. That’s part of her wellbeing.’

Despite the family’s struggle, Haven is about to start school and Lucian is ‘overjoyed’.

‘I’m a very lucky man,’ Lucian told the Royal Commission. ‘I didn’t want my testimony to be really dark. There’s a lot of positives to our situation and we’re living a beautiful life with a beautiful family and that’s the cornerstone. The NDIS should be helping us do that, ultimately.’

Elodie

‘In Australia we are meant to be in one of the luckiest countries in the world, unless you have a disability.’

Elodie is in her early 30s and lives with complex post-traumatic stress disorder.

‘I’ve been on a disability pension for probably over 10 years,’ Elodie told the Royal Commission, ‘because of childhood trauma that was over a very long period of time, and also institutional child abuse, sexual abuse.’

Elodie takes antidepressants. One day, when her doctor was away, a new doctor refused to renew her prescription.

‘He looked at my file and said, “Why are you still on antidepressants? You shouldn’t be depressed anymore.”... He wouldn’t actually give it to me. He kept lecturing me and yelling at me, and I actually broke down in tears.’

Elodie went to another doctor, who renewed the prescription.

‘It’s just shocking that a psychiatrist can diagnose me, other mental health professionals can diagnose me, but then ... I go and see one doctor, and ... they feel that they have the right to undermine a whole bunch of other people who specialise in mental health.’

Elodie’s disorder prevents her from working. She receives the Disability Support Pension.

‘But after a few years and working with my therapist, I thought I might like to go off and try and study, get a job ... because it would make me feel good, and I wanted to integrate into society.’

She asked Centrelink to reassess her, and was told she could work 15 hours a week.

‘I went out and I tried, and I couldn’t do it. It didn’t work.’

Elodie told Centrelink, which insisted she keep looking for work.

‘They sit there, and even though you have an exemption, they sit there and lecture you and tell you, “You could sell books on eBay. You could do this. You could study,” and you’ve stood there, you’ve handed them the letter from the psychologist saying I cannot work, and they still sit there, and they make you feel like shit.’

Elodie told the Royal Commission that she’d prefer to be ‘working, making a hundred thousand dollars a year’.

‘I would feel so much better about myself if I could be that person.’

She and her husband, who has a physical disability, have been saving to buy a house. However, Elodie says, 'banks don't like to loan to people who are on pensions, a disability pension'.

'The problem with rentals is that they're not stable. You can be here for a year and then they kick you out.'

When Elodie asked her member of parliament if there was a scheme to help people with disability buy their own home, they suggested she move to the country and get a job on a farm.

'I brought up that there was an issue with the housing, and their only solution was to move me out into the middle of nowhere. To me, that just goes to show that people with a disability are just seen as a massive burden on society. They want us out. They want us gone. They don't want to deal with us. We're too much of a problem.'

Elodie said many people don't understand the difficulties people with disability face trying to access services and stable housing.

'People with disability don't want to be disabled. We want to go out and do these things, but here is something stopping us from performing in society in the same way that other people can perform, and it's not a choice.'

Ayla

'I felt I didn't belong for a long period of my life. I was bullied a lot in secondary school and I sometimes felt really, really alone and not included ... It is very difficult because all you want to do is be a normal human being.'

Ayla has cerebral palsy which affects her speech and movement. She has a PHD and is an advocate yet, she told the Royal Commission, people continue to underestimate and bully her. Sometimes, she said, the disability is all people see.

For as long as Ayla can remember she wanted to go to medical school. Despite having an honours degree in science, she has failed the medical entry test twice. Not because she doesn't have the knowledge, but because she is required to handwrite, quickly – the test must be completed within a certain timeframe.

During her undergraduate degree and PHD she was allowed more time for exams and was able to use a medically trained scribe.

Ayla requested 50 per cent more time to complete the medical entry test but the external body administering the test would only agree to 25 per cent.

'We have only one per cent of people with a disability in the medical field,' Ayla told the Royal Commission. 'Most of these people acquired their disability after entry into medical school ... How is this fair?'

Ayla said there are many fantastic examples around the world of doctors with cerebral palsy. There is a doctor in New York who had severe speech and mobility concerns. He became a rehabilitation psychiatrist, was a chief medical officer and department chair.

'We need to make sure we are giving people the supports that they need to be able to achieve what they want to achieve.'

This includes having good support workers who 'understand their needs and give them the independence they deserve'.

Ayla says support workers with the right skills are needed to help people with disability make connections in the community, because 'it is really hard to make a good friend'.

Even with her study and advocacy, lack of connection concerns Ayla. 'I do worry if my parents die I am going to be alone.'

She tries to look at the positives but 'sometimes it is very hard to live in a world that is so judgemental and cruel'.

'No matter the difference, no matter the age, no matter the disability, we all need to be treated with respect and to have good friends and to have a useful life.'

Erika

‘When I stopped being allowed to see my daughter, I thought I was going to have a heart attack ... I went to the hospital. And they said, “It’s not a heart attack. It’s like a broken heart.”’

Erika has cerebral palsy and is Deaf. She lip-reads and uses Auslan. She told the Royal Commission she is often ‘mistaken for being intoxicated’.

One time she was assaulted and robbed. She went to the police who thought she was drunk. ‘I couldn’t report a crime until I went to the doctor’s and got a medical certificate saying that I’m not intoxicated, and I’ve got cerebral palsy.’

Another time Erika was in court and the judge assumed she was drunk. The judge ‘yelled at her’ and told her if she ever came to court ‘in that state again’ she would hold her in contempt of court. ‘Guess I’m going to jail then,’ Erika responded. ‘Because I’m coming back next time in the same state. I’ve still got cerebral palsy. There’s nothing I can do about it.’

‘This is my life,’ Erika said. ‘[This] stuff ... happens every day.’

Erika believes the department of child protection removed her daughter, Mia, from her care because of ‘the way she presented’.

Five year ago, Erika and Mia were living in the country. A friend was staying with them while his sister was sick. At the time, Erika was working 12-hour night shifts and a babysitter stayed with Mia during the night. Mia asked if the friend could look after her instead of the babysitter. ‘I didn’t have a problem with that ... I trusted this guy. I had known him forever.’

Alone at night, he sexually abused Mia.

Two years later, Mia’s behaviour became ‘very violent’. She told Erika about the abuse and Erika immediately reported it to the police. Erika and Mia went to counselling but Mia’s behaviour escalated and she became suicidal. She would attack Erika telling her, ‘I want to die, mum. But I want you to come with me.’

Desperate, Erika contacted the department of child protection for help. They didn’t offer any support and assumed Erika ‘lacked the capacity’ to care for Mia. They immediately removed Mia.

The department continued to refuse all contact. ‘I haven’t seen her for three years ... I can’t imagine what they told my daughter.’

Erika has tried everything to reunite with Mia. At one stage a child protection officer suggested her best chance was to leave the house where the abuse occurred. Erika sold her house ‘for a very low price’ and moved to a different area. ‘But that still didn’t result in [Mia] returning home.’

Erika has worked as a disability support worker for 20 years. 'I'm allowed to work with extremely vulnerable people, but I'm not allowed to look after my own daughter. That's unbelievable.'

The department told Erika's older daughter that if she wanted to maintain a relationship with her sister, she should take out an intervention order against Erika. 'I've lost ... everyone. My friends, my family.'

Not long ago the perpetrator phoned, telling Erika he was having a party because police had dropped the charges. Erika contacted police who said there was nothing they could do and told her to speak to the department. The department told Erika that Mia wasn't 'mentally fit enough' to testify in court.

'I was so angry ... He got away with raping my seven-year-old daughter.'
Erika said when she asked the department about 'the next child he rapes', the response was 'It's none of our concern.'

Erika had two necklaces she used to wear every day. When she thought she was having a heart attack she asked the department to give them to Mia. Recently, Erika asked about the necklaces. 'They told me that she hasn't got them ... they told me they've misplaced them.'

Fiorella

‘No choice, no say, no nothing.’

This has been Fiorella’s experience for most of her adult life.

Fiorella has cerebral palsy. She moved into a group home when she was 18.

There was a woman living at the home who physically abused Fiorella on a daily basis. ‘[She] pulled my hair ... kicked ... called me names ... pinched me ... They tried to stop her and they couldn’t stop her ... She was a nasty piece of work.’

Fiorella told the Royal Commission the staff were unable to keep her safe. ‘This went on for a very long time and I couldn’t take it.’

Eventually she was moved to another house. But one of the residents struggled with depression and screamed day and night. ‘I found it very distressing,’ said Fiorella.

Next, she moved to a house with three other residents.

‘None of them could talk or communicate with me in any way, so communication was only with staff and often they didn’t have time to just have a chat. I was not happy there. I was very lonely.’

As there weren’t many services in the region, the disability coordinator decided Fiorella should move to a house in the city where she could access more day options programs and possibly find employment.

But at the new house, Fiorella did not get on with the staff. She said they didn’t listen to her and behaved as if they didn’t like her. They constantly entered her room without knocking.

‘One worker in this house told me off for looking at her.’ Another refused to give Fiorella her medication as prescribed by the doctor. ‘I had to fight very hard with that supervisor to stop her as she was trying to insist that my medication should be given separately and not together.’ Eventually they involved the pharmacist who agreed with Fiorella.

‘I felt very upset and uncomfortable at that time.’

Fiorella attended a day options program, but found it to be no better than the one she attended in her regional area. She found the activities boring, but she went anyway to get away from the house and staff.

Then Fiorella attended a self-advocacy training session. She said it changed her life.

First she decided to do something about staff entering her room without knocking. 'I called the manager and asked her to make a sign for my door instructing people to knock before entering ... The sign was made, laminated and put on my door and actually worked.'

The course also inspired Fiorella to start telling everyone she was unhappy where she was living and wanted to move.

'Eventually I was listened to.'

Fiorella was offered a place at a new home with three other residents. This time, she wanted to see the house for herself and meet the residents before she made any decision.

'When I was in the house I felt comfortable ... I was able to make my own choice. This was something that had never ever happened to me in the past.'

Fiorella moved in and says she is really happy there.

'I have my own room, my own TV.'

The residents decide what they want to eat and share the cooking. Fiorella cooks two nights a week and likes to cook schnitzels and sausages.

Fiorella also changed her day options program and is now on the organisation's board.

The participants have choice about what activities they want to do. Fiorella enjoys singing, cooking, barbeques and shopping.

As well as being on a board she works three days a week assisting other people self-advocate. 'I want them to have choice,' she said.

Fiorella shared her advice for staff who work with people with a disability. 'Don't put the ear pods in your ears and turn up the music but listen to them. They know what they want.'

Cecilia

‘Last year when the lift didn’t work ... I couldn’t get access to my floor unless someone came to the carpark and helped me jostle up a few stairs and we went around the long way. I understand things need to be maintained, and it’s costly, but it wasn’t just a couple of days, it went on for months.’

Cecilia lives with a muscular disease resulting in muscle weakness. She says she doesn’t ‘bend along the waist like everybody does’ and needs to be lifted in and out of standard chairs.

She works in a large organisation. When she started several years ago she asked for a modified chair to use in the canteen so she could go with other colleagues and have lunch, morning tea or a cup of coffee. Her request was ignored.

Celia told the Royal Commission that it has now become almost impossible for her to move from her office to other parts of the building. ‘There are filing cabinets in walkways, there are screens with feet jutting out ... there’s boxes in the walkway. It’s not only a danger for me, it’s a danger for other people.’

Cecilia asked for the walkways to be cleared more than 12 months ago.

‘I cannot visit all my colleagues. There are some sections that I just can’t physically get to. They have to come to me. If they have a meeting in their section I have to send someone else.’

Cecilia says change must come from senior management. At the moment ‘there’s no understanding of what it is to work in an inclusive environment’.

Cecilia worked for one manager who made it clear they did not want to work with someone with a disability. ‘They made statements that were witnessed and documented,’ Celia said. But it was Celia who was transferred.

‘As it turned out they probably did me a favour because staying with someone with those attitudes can take a toll on anybody.’

She finds it galling the number of ‘policies and procedures around access and equity ... that are never actually implemented – they’re just a tick and a flick’.

In addition to being excluded from parts of the building, Cecilia and staff with disability are rarely considered when planning events and conferences. ‘I’d have to take my own chair, my own laptop, there was no consideration about where I was going to sit or anything like that.’

Cecilia feels like things are getting worse rather than better.

When she first started, there was a formal support network for staff with disability. Staff assisted other staff with day-to-day practicalities and mentored staff who were interested in promotion. But the funding was cut.

Recently she was on an interview panel 'where it was clear [an applicant] needed reasonable adjustments because [of] a significant hearing problem'. Cecilia said no-one from human resources had contacted the applicant to find out what they needed and the convener was 'clueless'.

Cecilia said it was up to her to sort out support. She was surprised by how ignorant people on interview panels are about assistive technology.

During her long career, the only time Cecilia was given an opportunity and promoted was because of one manager.

'I was very fortunate ... someone tapped me on the shoulder and told me that I could do this and it was just because of someone's attitude.'

She can't imagine how her life would have been without that individual, but 'it shouldn't be just luck'.

'It is isolating,' Cecilia said, not being able to attend conferences, meetings, have a cup of coffee with a colleague, walk down a hallway or street. All these experiences have affected her quality of life and made her feel less valued and relevant than other people who do not live with a disability.

But Cecilia is passionate about changing things for people with a disability. 'I am a person who is fairly empowered. I have education. I have a job that pays well. If I can't raise these issues how does someone else?'

Gage and Frances

Gage, Frances's son, is in his early 30s and lives with cerebral palsy, an intellectual disability and epilepsy. He doesn't speak.

A few years ago, Gage lived in a group home where he was sustaining bruising and scratches. The provider told Frances that Gage was clumsy.

'You know, tripped up the stairs ... banging himself on the bed and all these things, so every time I asked there was always an excuse for it,' Frances told the Royal Commission.

Then one day, another resident pushed Gage, who fell and broke his hip. After Gage was admitted to hospital, Frances discovered the resident had assaulted her son many times.

'When I got the files there was 64 incidents where this other young man was beating the crap out of my son. That explains the bangs on his head, the lumps on his head, the black eyes, the cuts on his arms, the bruises on his legs.'

Gage's hip healed in six weeks, but doctors kept him in hospital for eight months while Frances searched for new accommodation. During that time, the NDIA stopped Gage's funding. Without support, he was unable to leave the hospital and access the community.

Frances said that with Gage confined 'within four walls', his behaviour deteriorated. This made it difficult to find him a new home because 'no-one would take him'.

Gage did eventually find a new group home, but Frances said she shouldn't have to 'keep banging [her] head against a wall for years and years and years just for something to happen'.

She told the Royal Commission carers should 'feel that they can do something without having to jump through these hoops and red tape, and put their life on hold when they are looking after people with disabilities'.

Gary

‘If we’re not positive about neuro divergence, then these kids are going to keep suffering. That’s what I’m here for, I just want to try and help the future for these kids.’

Gary is autistic and has taught in more than 100 high schools as a permanent and causal teacher. He told the Royal Commission he is fed up with the way autistic students are treated in school. ‘They’re put in the “too hard” basket, they’re being taught rubbish,’ he said. And they are regularly being suspended.

One of Gary’s year 8 students, Frankie, was suspended four times. Each suspension lasted for two weeks which meant he missed eight weeks of school. In the monthly staff meeting teachers complained about Frankie, saying ‘he’s horrible, he mucks up, he throws things around the room, he throws tantrums’. Gary felt the suspensions were unnecessary and possibly even illegal. ‘I found this kid was absolutely brilliant ... great in my class,’ he said.

Frankie’s behaviours were a result of Tourette syndrome, attention deficit hyperactivity disorder and autism. Gary explained to his colleagues, ‘He’s not mucking around, he’s having a meltdown and Tourette rages’. He encouraged them to provide more support.

But the school leadership refused to provide support for Frankie because he hadn’t been diagnosed with autism. Gary couldn’t understand this reasoning and suggested they treat Frankie as an autistic kid anyway – he did.

In Gary’s class there was a quiet corner with a comfortable couch. Frankie loved fishing and Gary allowed him to sit on the couch and practice tying fishing knots. Gary told Frankie, ‘The only thing you need to do is sit there and listen to everything I say because I know you’re going to absorb this information.’

Frankie excelled, scored 94 per cent in the exam and topped the class. But Gary’s approach was dismissed by the other staff. ‘If they’re not neurodiverse themselves, they really don’t understand it,’ he said.

The suspensions really affected Frankie and on a science excursion ‘he had an absolute Tourette’s rage, pushing kids and was very upset’. But the teacher blamed Frankie, labelled him undisciplined and said he knew what he was doing.

Another time, Frankie was thrown off the school bus because he was swearing loudly, which is part of his Tourette’s. Gary said, ‘These are the sort of things these kids are experiencing every day. No wonder they’ve got mental [health] issues.’

No-one was listening to Gary about Frankie, so he started to post messages on the school’s internal message board – for example, ‘this kid needed extra help’ – to let staff and other students know what was going on.

The deputy principal demanded Gary remove the posts and gave him a formal warning about his performance. 'It was like they were trying to find something to get rid of me,' he said.

Gary felt it had been this way since he told the school he has autism. Almost as soon as the school agreed to his list of reasonable adjustments they began to ignore the agreement and use the list to bully him. At times Gary felt they deliberately did things they knew would provoke him.

Then another autistic student told Gary he was having a birthday party after school and was anxious his friends would miss the bus. Gary was thrilled for him and told him to leave five minutes early and go to the bus stop and wait with his friends.

The deputy head saw the boys at the bus stop and immediately emailed Gary telling him this contravened school rules and gave Gary his second formal warning. Gary tried to explain, to no avail. He involved his union and the school offered him a package to resign, which he accepted.

'It's the best thing I ever did.' Since then has been teaching casually in schools with specialist autistic units. He hopes to get a permanent job.

Gary wants to change the way autistic students are educated, starting with the curriculum. His advice – replace life skills with topics the student enjoys. 'Each individual autistic kid just ... concentrates on what they are really good at because, honestly, if you find what they are good at, they will be the best in the world at it.'

Lilyana

‘A lot of doctors don’t seem to understand ... people with disability and how to work with them. They think it’s too hard.’

Lilyana is autistic and lives with intellectual disability and epilepsy.

She told the Royal Commission many doctors and dentists do not understand how difficult it is for people with disability to access and pay for medical services.

Each year Lilyana has to undergo a number of medical reviews. The NDIS requires evidence of her disabilities each time her plan is renewed. Specialists require a new referral from a GP every 12 months. Licensing authorities need yearly documentation for her to maintain her driver’s licence and mobility parking scheme permit.

Lilyana’s GP knew her well and was able to handle most of her documentation requirements. However, he recently retired and she needed to see another doctor at the clinic. Although Lilyana’s been going to the same clinic for almost 20 years and all the information is in her file, the new GP wanted her to see a specialist.

Lilyana said the specialist didn’t know her and the GP didn’t give him any information about her. The specialist ‘messed up the form’, restricting the distance she could drive. This affected Lilyana’s independence because there is no public transport near where she lives.

‘[I had to] do a review and get two more specialists to back me up to make me unrestricted,’ she said. ‘People with disabilities should have a choice whether they see their GP or specialist for documentation and evidence.’

Lilyana also spoke about the barriers people with disability face accessing dental services.

For many years Lilyana visited a local dentist. He knew she was on the pension and charged her half the standard fee. ‘Not once along the lines did he have to increase it.’

When he retired the business was sold and the new owners ‘didn’t even care’. She said they refused to negotiate a reasonable increase and would only accept the full fee. Lilyana was forced to find a dentist further away.

‘Unless changes are made people with disabilities will continue to face barriers.’

Glynn and Orra

‘Not treating him differently means not treating him appropriately.’

Glynn had cerebral palsy. ‘He couldn’t speak or walk without aids,’ his sister Orra told the Royal Commission, ‘but he was not intellectually disabled and was very bright.’

Glynn attended mainstream primary and secondary school and ‘participated in everything’. He loved his communication devices. The first one had a ‘Yankee accent’ but the next had an Aussie accent and his friends liked it much better.

Following school, Glynn worked as a communication accessibility assessor, rating public spaces. He assessed signage, the communication environment and whether people talked directly to him and didn’t rush the conversation.

Glynn was ‘somebody who didn’t let his disability get in the way’.

Two years ago, Glynn, in his mid-20s, began experiencing ‘a lot of pain’. Orra said, ‘He was never, never unwell so my parents took it very seriously.’ For about a month Glynn’s local GP treated him for constipation. Glynn’s health deteriorated and his parents took him to the local hospital. The staff didn’t take their concerns seriously and sent Glynn home.

Orra, who was living interstate, flew home. She was shocked when she saw Glynn and took him back to emergency. It was Christmas time and Glynn was left to wait. ‘During that time ... the staff were hanging Christmas decorations ... it just wasn’t right.’ Orra said there were constant delays in getting the tests doctors needed to diagnose Glynn.

‘I think because he wasn’t the type of person to be screaming out in pain or walloping or anything like that and because he doesn’t speak ... he was just seen as, “oh he’s fine”.’

The hospital eventually admitted Glynn and treated him for dehydration and constipation. Late that evening, although Glynn was distressed and in pain, staff told Glynn’s parents to leave.

The next morning a specialist from another hospital saw Glynn vomit blood. He looked at Glynn’s notes, saw something was seriously wrong and told staff to transport Glynn to his hospital.

Staff classified Glynn as low risk. When his condition deteriorated five minutes down the road the ambulance transporter didn’t have the appropriate equipment. They turned around and asked the hospital to readmit him. The hospital refused because Glynn had already been discharged. He had to wait for another ambulance.

Orra said when they arrived at the new hospital ‘things completely changed’. For the first time staff spoke to Glynn and asked him how he communicated. The nurse asked how he would like her to communicate with him. ‘They put him in a room by himself and ran a series of tests that weren’t even considered’ by the other hospital.

Less than 24 hours later, doctors diagnosed Glynn with stage 4 cancer and told his family he had days to live. The hospital managed Glynn's pain and extended his 'end-of-life care' to ensure everyone who wanted to visit could get there in time. When Glynn died there were about 30 people in his room, which was 'amazing for [Glynn] and us as well'.

The health complaints authority investigated the first hospital's treatment of Glynn. The hospital maintained Glynn wasn't treated differently because of his disability. Orra said that was the problem. 'Not treating him differently means he wasn't given the adequate care and attention he needed.' Glynn should have been 'approached differently based on his special needs'.

Orra wants hospitals and medical practices to have their communication accessibility assessed.

If Glynn had assessed the first hospital, Orra said, 'they would have failed'.

Since the investigation the hospital has apologised and made some changes. Orra is confident Glynn would be proud his death has resulted in positive change.

Gracelynn

'I would have loved to stay with my parents as a child but I could not. I would have loved to have my own place and choose who I live with but it is not possible now.'

'I'd like to tell you my story,' Gracelynn told the Royal Commission 'of having lived in an institution and group homes for most of my life.'

Gracelynn is in her 40s and has cognitive and physical disability.

When she was five she went to live in a home that provided accommodation and education for children with disability. She didn't want to go but her parents lived in the country and there was no school for her in the area. 'I was very upset and I cried but I could not do anything about it.'

Gracelynn slept in a dormitory with 12 people and was made to do 'hard and painful' physiotherapy. Things improved when she became a teenager and had her own room. She made some very good friends but 'it wasn't home'.

When Gracelynn was about 18 the organisation sold the home without telling the residents. Everyone had to move and Gracelynn was separated from her friends. She didn't want to go 'because it was like my family', but she said she had no choice.

Gracelynn then moved to a group home for six people. 'It was horrible.' Staff were bossy and residents had no choice. Everyone had to get up at the same time and go to bed at the same time. All the doors were locked. Residents couldn't choose what to eat or when to have their meals. If they didn't do what they were told they couldn't go out. 'It was like a prison,' Gracelynn said. Some residents were aggressive – 'it was a hard time.'

A year later Gracelynn moved to another group home and stayed there for about 15 years. It was a bit better but 'bad sometimes'.

One day she did not want to have a shower but was forced to. 'Three staff carried me and put me in the shower with my clothes on. It was not nice at all.' Gracelynn didn't think it was right but didn't know what to do which made her feel 'angry and upset'.

Staff forced Gracelynn to work in what she described as a 'sheltered workshop'. She didn't like it and doesn't know how much she was paid.

Gracelynn now lives in a group home with three other people. It is much better but she still doesn't get to choose who she lives with. A woman came to live in the house a few years ago and Gracelynn doesn't like her very much because 'she's a bit bossy' and 'thinks she is my mum'. Gracelynn's not happy but said 'What can I do? I cannot ask her to leave.'

On the upside, staff listen to Gracelynn and she feels she has more control over what she does. 'I go out when I want. I go to the footy and the pub.' When it's her turn she can choose what to eat and help prepare the meal. She uses a wheelchair and said staff are respectful when they help her with her bath and other personal care.

'But people were not always respectful,' she said, remembering a therapist who told her she was 'too fat' and could not get a new wheelchair. 'It hurt my feelings and I cried a lot.'

Gracelynn doesn't like having so many different staff in the house all the time. 'They change often and I do not have a choice on who supports me,' she said.

'I do like my place and most of my support staff are good but not everything is perfect. It will never be home. Home is where my heart is and it will be forever with my mum and dad.'

Hadlee and Hailie

Hadley has developmental issues and is small for his 10 years. He can be ‘unco-ordinated’ and moves his jaw around noticeably in order to talk and sometimes adjusts his language to avoid challenging words. He also has ‘many strengths’ and is his parents’ ‘pride and joy,’ said his mum, Hailie.

Hailie told the Royal Commission that when Hadlee started school at a private college about five years ago things were ‘moving along very happily’. The principal and teaching staff considered Hadlee’s ‘worth as an individual’ as ‘primary’ – not his disability.

‘Everyone was working together in collaboration, there was open and frank dialogue between everyone.’

Hailie gave credit to the ‘stellar’ principal of the school who was well studied in disability education. ‘She saw the whole child and responded to the whole child.’

Year 1 was ‘a joyful experience of celebrating all of [Hadlee’s] successes ... And, because he was being ‘supported in his needs and interests’, [Hadlee] was allowed to ‘travel along with the rest of his cohort’.

‘He was catching up apace. His literacy and numeracy was just going through the roof ... he was just so well taught, so well looked after. He was happy, he was a popular little boy as well. He really enjoyed his year there and we enjoyed it too.’

But from year 2, ‘it all really started to slide downhill’. The principal left and a teacher new to the school was assigned to Hadlee’s class.

The new teacher told Hailie that her son couldn’t do all the things the previous teacher had said he could do and she was putting him on a new curriculum.

Instead of joining the class as he had always done, Hadlee now sat in a space between two classrooms with a special needs education assistant, all day every day. He was given ‘baby work’ that was ‘far below his level of understanding’.

When Hadlee sometimes became upset about this, it was taken as ‘non-compliance’. The education assistant would take him for a ‘brain break’ to play on the climbing gym or go to the library. Hadlee quickly learned that if he was bored with his work he could be naughty and get play time.

It was around this time teaching staff started ‘sneaking in’ language associated with autism in reference to Hadlee – mentions of ‘meltdowns’ and ‘emotional regulation’ – even though these things ‘never were and never would be part of Hadlee’s disability’.

It was also around this time the bullying began.

‘The segregation was sort of what caused it,’ Hailie said. He became an ‘easy target’ for older kids. They threatened and chased him. On many occasions they punched him.

Hailie reported the bullying but the school did nothing. 'They just continued to reframe it as a [Hadlee] emotional regulation issue.'

Then the school came out with it – they wanted Hadley to get a diagnosis that attracted funding. 'They made no bones about it,' Hailie said. They gave her a list of disabilities that got funding, which included autism.

By the end of the year, the school made it clear they wanted Hadlee to leave. 'They basically told me that because they hadn't got a funding diagnosis they were going to withdraw all support for [Hadlee] the following year.'

Hadlee's parents withdrew him from the school. 'We had no choice,' Hailie said.

The next school was 'just shocking'. Hadlee's teacher was a bully. He would single Hadlee out for criticism and shout at him. He would make him sit with kids four or five years younger and tell him, 'That's your level, mate.'

One day Hailee was at the school to collect her son and a teacher approached her. She said Hadlee had 'had a little fall' and had been 'very dysregulated' but was ok now.

As he came limping towards her, Hailee could see that her son was covered in blood. It was his own blood, coming from a severe gash on his leg. She could see the bone underneath.

'They made him walk around like that,' she said in disbelief. She took him to the hospital where they closed the wound with stitches.

Hailee found out that when Hadlee was hurt, all the teachers wanted to do was 'police his emotional regulation'. 'They weren't interested in the injury. They hadn't looked at it.' So they let him sit there bleeding.

Hadlee's parents withdrew him from the school. They received no correspondence from the school other than an invoice.

Hailie is angry, but has decided to 'walk away'. 'I would love to pursue it. I would love to hold some people accountable ... but I've got to protect [Hadlee].'

Hadlee is not currently enrolled. Every school his parents have approached requires reports and assessments.

'[Hadlee] spent a lot of time in doctors' surgeries, clinician surgeries, allied health surgeries having the deficit poked and prodded, and he has said to me "no more". So we are going to respect that. Unless and until he says "Mum, I need a better understanding of myself," we are going to respect that.'

'Unfortunately we can't find a school who will respect our informed decision on that.'

Briar

‘In my life, the biggest concern is being believed and being seen as capable.’

Briar is in her 50s and lives with multiple mental health conditions.

Briar said that when she was a child, before she came to Australia, a person known to her family sexually assaulted her.

‘My behaviour was seen to be the result of immigration rather than what it was, which was being a child sexual assault survivor,’ Briar told the Royal Commission.

Later, in Australia, she was sexually abused on her way to school. Her parents didn’t know about it.

‘I ran away from home quite a bit, because I didn’t feel safe and protected at home from these things.’

In her teens, Briar was gang raped. Her doctor prescribed medication for anxiety.

‘[The medication] was the only advice I was given, despite the fact that I went to him and told him about what had happened.’

Later, she was admitted to a hospital mental health unit, where she said a member of staff raped her.

‘I will not go into it further because I have brought it up with people in the past and nothing’s been done.’

Briar told the Royal Commission that mental health unit staff held her down to inject medication and told her if she didn’t comply, she’d be isolated.

‘It feels like child abuse again. It doesn’t feel like treatment. And it doesn’t feel less than violent. And that brings up a lot of the old feelings. And I’m then unable to represent myself effectively.’

Briar said coercive treatment put ‘people in positions where they learn helplessness instead of developing coping strategies and ways of doing things that are sustainable’.

When she was able to she left the unit and moved interstate, to escape the state’s mental health system. She married a man who abused her and later left him, but she struggled to escape his controlling influence because they had children together.

One day, Briar’s son threw something at her and she slapped him.

'My reaction was not an adult parental reaction, and I shouldn't have done it. I slapped him on the face. But my ex-husband called the police.'

Briar was arrested and taken to hospital. She said her ex-husband denied her access to her children until she took medication.

'When people like myself, child abuse survivors [who] have witnessed situations where we're forced and coerced and pushed into getting treatment, we don't feel that we have any rights left.'

In another abusive relationship, Briar said the police saw her as 'the perpetrator' because of her medical history 'when, in fact, that was not what was going on'.

'I have felt defensive and that I'm not going to be believed, and I ramble, and I feel scared that people are not going to hear what I've got to say, are going to judge me through the lens of mental illness. And therefore, I won't be able to have my rights honoured and respected, and people won't hear what I've got to say and understand the situations that have contributed to what's going on.'

Briar said forcing treatment on people living with psychosocial disability, and punishing them if they don't accept it, is damaging.

'I've been better than I have been for a very long time because I'm not dealing with the power and control at home. And I have people around me who love and support me rather than people who challenge my right to do what I want to do and what I think is important.'

Harlem

‘I think she was after the money.’

Harlem, early 50s, has bipolar disorder, dyslexia and depression.

He told the Royal Commission he employed a woman, Saskia, as a cleaner. Over time she started involving herself more and more in his life.

When the NDIS was introduced Saskia took Harlem to his first planning meeting. ‘I hardly got a word in. She ... put me down quite a bit in the conversation that she had about my abilities.’

When Harlem’s plan was approved Saskia became his support worker.

Initially she was supposed to work a few hours a day, two days a week. Before long she was working six hours every day. She was supposed to help Harlem and take him out. Instead, Harlem said, ‘she sat on a chair and played with her mobile [phone]’.

Saskia didn’t understand Harlem’s disability. She complained on social media he was unmotivated. She often called him ‘lazy’.

Each morning Saskia called Harlem to wake him. She charged him \$100 for the call. Harlem said she called weekends and public holidays and he didn’t even want the call.

One time, Saskia attended a mental health appointment with Harlem. She spoke about him, and over him. After the appointment the nurse called Harlem and said she was worried about him and did not want Saskia coming to any more appointments. When Harlem told this to Saskia she blamed him.

Another time Saskia agreed to take Harlem to see a concert. She made Harlem pay for expensive accommodation. Worried about his therapy dog, he was unable to sleep and got out of bed a number of times. Rather than offering emotional support, Saskia scolded Harlem for disturbing her sleep.

Returning from the concert, Saskia told Harlem to go to a large grocery store. Harlem wanted to go home to his dog but he didn’t feel strong enough to say no. She really wanted to shop for herself and convinced Harlem to buy things he didn’t want. She charged him for the time she spent in the shops.

Saskia was very dominating and organised things without consulting him. Harlem became so stressed he ended up in hospital.

When Harlem eventually stood up to Saskia, refusing to allow her to charge the hours she wanted to, she resigned. Harlem told his support coordinator what had been happening and she is helping him prepare a formal complaint.

Harlem has been a lot happier since Saskia left. His new support workers are ‘fantastic’ and make him realise how unprofessional Saskia was.

Max and Dawn

Max is in his mid-20s and lives with a rare genetic disorder that affects his organs. He has autism, intellectual disability and is non-verbal. Max's mum, Dawn, spoke to the Royal Commission about the challenges in accessing adequate care for Max's complex health needs.

Dawn said there is a 'domino effect of health issues' when doctors failed to look at 'the whole picture of Max'.

For example, when Max was 16 he underwent surgery for scoliosis. Dawn said the doctors did not take time to understand him and assumed he had cerebral palsy and spasticity. They gave him large doses of Diazepam to relieve suspected muscle spasms. This sent Max into a coma for two months.

One day at the hospital a visiting international orthopaedic surgeon pulled Dawn aside. He showed her Max's file. Under his current medication, he said, Max would 'be a vegetable for the rest of his life'.

Dawn insisted on taking Max off all pain medications. Finally, seven weeks later, he started to open his eyes.

Following the surgery, Max developed a spinal injury. The surgeon gave Dawn a range of hypotheses about how the injury happened – each related to poor post-operative treatment by staff. The hospital files are now missing, so no further investigation into what happened is possible.

'At 16 ... he walked in that hospital and never walked out.' Max was now paraplegic.

Once he was discharged, Max's parents were keen to get him into rehab but were told 'there was no point' – Max wouldn't be able to follow the instructions or persevere through the treatment.

But Max's parents knew better. 'He's just got this amazing determination, resilience and attitude,' Dawn told us.

'No-one ever should assume that a young person, who they do not know, they've met that person in minutes and read the disastrous complexity about him, and made this enormous assumption that it would be a waste of time.'

Dawn was able to successfully advocate for Max and he did the rehabilitation for six months.

On another occasion, Max was hospitalised for two patella reconstructions. He was in plaster from ankle to groin for three months. When the plaster was finally removed Dawn could tell something was severely wrong. The doctors insisted that he was fine, 'because [Max] wasn't presenting as unwell, because he's such a bloody trooper'. But Dawn knew how to read Max's signs – he was 'freaking out'.

'They sent us home, not listening,' she said.

Max was discharged and went to another hospital for rehab. 'We were into the sixth week there doing physio and rehab ... And then I got a call from the [patella reconstruction] surgeon to say "stop everything".'

'We've discovered he's got two broken tibias,' the surgeon told Dawn. Dawn had been right all along.

'There was something wrong with our son. From the six weeks prior when we said there was something wrong, we were told I was a fussy mother, the over reactive mother, you know, that mother. Max was showing signs, very clear signs that he was not right, but no-one was listening.'

The surgeon apologised, telling Dawn he learned his lesson – he 'should have listened to mum'.

Dawn is concerned for people with disability who don't have people to advocate for them.

'We've watched various people with disabilities come and go and it's been horrific for them when they don't have the advocates around them ... you've got a medical team around that person who know nothing about them, knowing no way of how to communicate with them and trying to deal not only with their medical issues, not only their pain, but the behaviours ... The risks to the safety and the health of people with disability who are in a similar situation to my son is enormous if you don't have the voice or allow the voice to speak. And to rule out what the assumptions will be.'

Since the spinal surgery, it has been an ongoing battle getting Max access to either of the two units in the state that have the knowledge and skill to deal with spinal cord injuries. Dawn believes Max would receive a higher level of care if he were not a person with disability.

'It's appalling,' she says. 'And I know, if I wasn't the person I am – I can find the bitch within sometimes, and I hate that bitch when she has to come out ... it's the only way you can get to be heard.'

Hayes and Arielle

'I think being an Aboriginal person – and this can't be understated when it's mixed with disability – is that you are subjected to an extraordinary amount of discrimination. I think it's tenfold. Or even more.'

Arielle is a First Nations woman with disability and mother to several children – all of whom are 'high achievers'. Her son, Hayes, has Asperger's syndrome, attention deficit hyperactivity disorder and other health issues.

Arielle told the Royal Commission that Hayes's disability did not 'become a school matter' until his final years. She and Hayes approached two of Hayes's teachers about reasonable adjustments for HSC exams and assessments in consideration of his disability. One responded, 'Oh, if he's that bad, why does he do well at school? He doesn't look too retarded to me.' Arielle told the teacher she found his language offensive, but 'let it go'. 'I didn't want to cause problems for my son,' she said.

Then Hayes told her the teacher was making 'really discriminatory comments in class about Aboriginal people'. Hoping to empower her son, she urged Hayes to make a complaint to the principal, but that 'didn't go down well'.

Hayes reported to his mum that the two teachers were continuing to make 'snide comments about his disability and about being Aboriginal'. Arielle made a complaint to the principal, who was reluctant to engage.

When a teacher wrote negative comments about Hayes in a school report, Arielle went to the principal again.

The principal called the teacher into a meeting with Arielle. He refused to remove the comments and stormed out, slamming the door on Arielle's arm. The principal called the teacher back. He said 'I'm not apologising to anyone, and particularly an Aboriginal person that thinks they can run a school.'

'Anyway, this went on and on and on and on,' Arielle said. 'I made complaints. They did nothing. I made complaints. And in the meantime, my poor son was just really suffering, was crying, didn't want to go to school.'

Things came to a head when the teacher texted another student. He was giving them extra marks, telling the student 'that means you come first, and you beat [Hayes].'

Finding out about this, Arielle contacted the minister and insisted all of Hayes' exams be re-marked. This revealed under-marking of Hayes's assessments in two subjects.

'I just couldn't believe it,' Arielle said. 'I was just beside myself. I was sick. [Hayes] was doing his HSC!'

'[Hayes], in the end, was dux of the school. Sucked in to all of them ... But it's been a really terrible, negative experience ... the teacher is still there being racist.'

Arielle told the Royal Commission that, in dealing with the NDIA, she too experienced discrimination based on her disability and Aboriginality.

Prior to becoming an NDIS participant, Arielle had been on a support package that allowed her husband of more than 30 years to be her paid carer.

This arrangement was really important to Arielle. She had been sexually assaulted as a child and then, some years later – at the time she was paralysed in her arms and legs and unable to speak – she was raped by a carer. 'And so, I am incredibly frightened of care workers,' she explained.

But when Arielle was transitioning to the NDIS, the case manager suggested Arielle's circumstances were not 'exceptional' enough to warrant a family member being a paid carer. Arielle recounted her traumatic history, but the manager implied she should get better therapists to help her.

'How do I know you're just not trying to make money?' the manager asked her. 'We know that Aboriginal families can't really be trusted with, you know, having family as carers.'

Arielle was furious.

'I'm not working at the moment because I'm sick – but I've worked really hard. I've done everything that society could expect someone to do ... Still, she was there acting like I was trying to scam or ... it was just racist and discriminatory based on disability.'

Ilan and Farrah

Farrah is a First Nations woman in her early 30s and a sole parent. She told the Royal Commission that schools and hospitals aren't meeting her son's disability and cultural needs because they don't have the resources or training to deal with his behaviour.

Ilan, her son, was born with hydrocephalus and lives with level 3 autism spectrum disorder. He doesn't speak and sometimes bangs his head against objects.

'That behaviour is very confronting ... but he's not dangerous to anybody else. It's just to himself.'

Ilan started school a few years ago. When his own occupational therapist visited the special school to see how he was settling in, she found he'd been placed alone in a small room because he'd been banging his head.

'The principal said they were trialling this method of kind of taking him away from his situation ... giving him that time to kind of self sooth, self-regulate, but nobody was in that little room with him,' said Farrah.

Ilan sometimes comes home with bruises. 'When [his regular teachers] aren't with him ... that's when I see restraint marks. So I have to piece so much together. How come this is on my son's body?'

Farrah said she wants cameras in classrooms so she can be sure teachers always treat her son appropriately.

Part of the problem, she says, is a shortage of teachers trained to work with children with disability. Ilan's school has only one occupational therapist and one speech therapist for 150 children. Ilan's behaviour is linked to his inability to communicate, so access to speech therapy is important.

'You're going to get those behavioural outbursts if you're not attending to their needs. That's why they're at special school.'

Farrah said hospitals and clinics also seem to lack staff trained to help people with disability.

'Even to our own clinic, and when I see how much the team has to adjust to [Ilan], I mean if he's trying to escape the clinic they lock the whole clinic down and everyone's frantic because they're not too sure what to do.'

The lack of trained staff means Farrah has to work harder as Ilan's advocate.

‘No-one really cares for the carer. I can’t really open up to my family because I’m the strong one, so if I’m crumbling they’re like, “No, stop, don’t cry.” And so that’s really tough for me, finding that support outside of family and relying on health professionals ... So all these things I’m kind of battling against. [But] it’s what I have to do for [Ilan].’

Farrah told us there’s ‘a lot of toughing it out as a special needs mum’. She’d like more government help, but because she’s a First Nations woman she’s reluctant to ask.

‘That’s a risk for Indigenous mums because if you are vulnerable you might trigger something to alert them. You don’t want to lose your child to child safety. So that’s a big fear.’

Zaria

‘I don’t want anybody to treat me any different from someone else. I’m just a lady that loves my husband and my dog and my boys, that wants to be happy, that wants to know that everything is going to be safe and secure.’

Zaria, a First Nations woman in her late 60s, has only recently ‘come home’.

Zaria has psychosocial and mild intellectual disability. Her husband had been her primary carer until she had a stroke causing her ‘never to walk again’. At that point ‘it got a bit too much for him’, so Zaria moved into a nursing home.

Zaria hated the nursing home. ‘I was not happy there. I felt very depressed, suicidal and that,’ she told the Royal Commission.

She described being made to wait for more than an hour to go to the toilet, and being made to wait, wet, in soiled bedclothes for long periods. The meals were ‘absolutely disgusting’, she said. ‘I wouldn’t give them to a dog.’

Zaria desperately wanted to go home, but said the NDIA stood in her way.

Zaria had been an NDIS participant before moving into the home, but received a letter ‘out of nowhere’ saying her access was being revoked. Zaria had to go through an independent assessment and get ‘lots of evidence’. But when her support was reinstated, it was only for her psychosocial disability, not her physical disability. Since the stroke Zaria was no longer able to walk. She said the NDIA was withholding support that would allow her to return home.

Zaria and her advocate, Meg, told the Royal Commission about the actions of Zaria’s NDIS support coordinator during this time. ‘[The support coordinator] wasn’t doing her role,’ Meg said. ‘It was found out that she was using all the support financial funding, but not using any of [Zaria’s] supports to actually support [her] ... We asked to understand where the money was going, and they couldn’t account for where it was going.’

With Meg’s help, Zaria took her complaint to the NDIS Quality and Safeguards Commission. As part of the resolution, the provider assigned a new support coordinator to Zaria to ‘start supporting [her] with her goal to move home, which was a very achievable goal’.

‘It took two years for the NDIS to give [Zaria] a plan that was suitable for her to be able to start planning to go home,’ Meg said.

Zaria was still in the nursing home when COVID-19 hit and was subject to the home’s ‘really strict lockdown’. Meg said that ‘under the mandate there were exceptions ... in relation to mental health needs’, but that the home ‘just flatly refused that for [Zaria]’.

'We had to escalate that to the ombudsman to get them involved to try and get some movement to negotiate and allow it. Some of the things that they said was that [Zaria] just has to be like everyone else and put up and deal with it. But there was just no awareness of [her] mental health needs at all ... It was a very, very traumatising time for [Zaria].'

Meanwhile, without her knowledge, Zaria was accruing significant debt. The state trustee manages Zaria's finances. While she was in the nursing home the trustee failed to pay a number of invoices, despite the funds being in Zaria's account. It was 'honestly shocking' to Zaria when the nursing home told her she owed them a large sum of money.

Meg told the Royal Commission that Zaria 'lives fortnight to fortnight'. The state trustee acknowledged their fault in the matter and negotiated a payment plan for Zaria. But Zaria now has to pay '\$40 a fortnight for the rest of her life because of that error that state trustees made'. Zaria and Meg are trying to get the debt waived or have the state trustee take responsibility for the debt. 'We're still in that process,' said Meg.

Zaria hopes one day she can be an advocate for other people with disability.

Jaden and Mattie

Jaden has anorexia, which his sister Mattie describes as a 'slow death'. He has cerebral palsy, uses a wheelchair and is non-verbal. Mattie said he has an eye gaze device, and if you take your time you can have a 'regular' conversation with him.

Now in his early 50s, Jaden has spent most of his life in institutions and group homes.

Mattie told the Royal Commission his 'entire life in care has been terrible, he's been abused so many times'.

About five years ago Mattie accessed some of Jaden's files. She discovered he has had medical procedures without his or his family's consent and his image has been used without consent. One home deliberately took him out on the days his mum would come and visit.

Jaden has been assaulted multiple times. One time a support worker hit Jaden after he laughed at him. He had red welts across his backside. Another resident witnessed the assault but the worker 'got away with it' because police refused to interview Jaden. Mattie remembers police told her interviews 'could be very upsetting for "these kinds" of people'.

A few years ago Jaden moved closer to Mattie so she could better support him.

A short time later when Mattie visited him, he 'looked like a prisoner of war'. He was so thin, barely 40 kilograms. 'It was just awful,' she said, 'extremely difficult to watch.' Jaden told her he thought he was going to die.

Mattie consulted Jaden's GP who told her there was no medical reason for his weight loss. She then spoke to the CEO and accused the staff of neglect. The CEO was adamant this wasn't the case.

Jaden didn't improve and told Mattie he 'was going to bed hungry'. The CEO disputed any resident would be going to bed hungry.

Jaden has been admitted to hospital twice because he was malnourished.

Jaden's mum thinks his anorexia may be linked to trauma. He has a history of refusing food and drink when he is distressed and frustrated.

Mattie asked the home if they could organise some mental health support but nothing happened.

When COVID-19 forced everyone into lockdown, Jaden suffered. He is very social and became frustrated because he couldn't see his family or go out. He began to self-harm.

The home promised Mattie they would help Jaden face-time his family more, but they didn't follow through. One time she organised a pavlova for Jaden and staff promised to pick it up. A week later she discovered no-one ever did. Jaden can only sleep with his TV on. When it broke, the home didn't inform Mattie until more than a week later. Jaden's dental health deteriorated. Mattie said he 'went in there with a mouthful of teeth that were perfectly fine' but has had to have 'every tooth ripped out'.

Mattie spoke to Jaden's support coordinator. The coordinator insisted the home employ a dietician to help Jaden gain weight during lockdown and he gained 20 kilograms. Mattie said this proves 'he was absolutely being neglected'.

Now lockdown has ended and normal life has resumed Mattie is worried staff will not have the time to feed Jaden properly and he will lose weight. When she visits, his eye gaze device is rarely set up.

Mattie asked Jaden if he wants to move to a different home, but he said he doesn't.

'He feels like he's been with so many organisations and they've all been pretty much the same.'

Moving forward, Mattie wants Jaden's life to improve. 'I just want to make sure that he's fed, that when he's funded for one-on-one support he has access to that ... I'd really like for him to be heard.'

Raelynn and Wynter

Raelynn is a First Nations woman in her 60s.

About five years ago she had a stroke and was admitted to a hospital stroke rehabilitation unit. Wynter, her daughter, told the Royal Commission that Raelynn was ‘one of the poster people’ for the newly opened unit.

Raelynn had made great progress and regained her capacity to walk, but had not entirely recovered. ‘In all honesty,’ Wynter said, ‘[the hospital] actually pushed her out earlier because they wanted to promote their short time period.’

Raelynn moved to a nursing home while she waited for disability housing, on the understanding ‘all the rehabilitation’ would continue in transition care.

‘As soon as she got into transitioning care her daily therapy stopped immediately ... so she started to immediately decline,’ Wynter said.

In the nursing home, Raelynn ‘was immediately cut off from her previous GPs’. This was difficult for Raelynn, who had experienced repeated sexual abuse as a younger woman. After the stroke, a lot of unfamiliar people were suddenly having ‘intensive access’ to her body. ‘[This] reopened a lot of trauma for her personally,’ said Wynter.

The hospital had given ‘extra consideration’ around female staff and ‘privacy issues’, but as ‘soon as she moved into the nursing home, that was completely ignored’.

‘If that understanding [of her needs] was there, that would alleviate a lot of deadly trauma that mum has to go through.’

An incident in the nursing home led to Raelynn being hospitalised for fractures in her leg. Wynter wanted her to have rehabilitation at the hospital so it would ‘be seen to properly’, but again there was ‘pressure to get her out’. This time Raelynn moved to the ‘highest care level nursing home’, with assurances ‘she would be given all of her rehabilitation’.

Again, this didn’t happen.

The physiotherapist at the new home refused to provide physio services. She said her insurance wouldn’t cover her to work with Raelynn because of her weight.

Meanwhile, the nursing home decided it was not work-safe for their staff to assist Raelynn to use the standing hoist, which was facilitating her to move short distances.

‘Never to be able to use the toilet again or to ... shower properly or to sit in a normal chair. That one decision made an immediate halt to any of that.’

Raelynn's rehabilitation immediately after the stroke had given her back the capacity to walk. Without ongoing physio she could not sustain that capacity. Now she was told she should 'just accept that that was what was gonna happen, she was never gonna walk again'.

Wynter said staff exhibited a 'quite aggressive attitude' towards Raelynn.

'She was told daily that she's too fat ... that "Because of your own self – it is your fault. Because of your weight you will never walk" which is an impossible situation to remedy if you're stuck in a bed and you have no control over your eating habits or anything at all.'

Wynter believes staff 'racially profiled' her mother. When Wynter met the placement officer at the second nursing home, they asked 'how did your mother get to this facility?', then said 'I don't know how that happened'. 'Because apparently it's the top facility,' Wynter said. The officer was 'very rude' and told her 'your mother is very difficult'.

Wynter said the nursing home provided very little support to her mother. For example staff refused to assist her in and out of taxis, to clean or even help her use her crucial breathing machine. The home was charging for a 10-minute fortnightly massage – a service other residents seemed to get for free. The home had been 'taking care of the entire disability pension' but charging Wynter for 'some basic things'. 'I don't seem to see [these things] happening to other residents within the nursing home,' Wynter said.

Raelynn, however, is determined. 'I've got things that I want to do before my times up,' she said.

She recently watched Ash Barty on TV. Ash had a photo of Evonne Goolagong Cawley.

'No-one's pushing me anywhere. And I keep going and I'm gonna be like Ash Barty and I'll go for that Olympic Gold ... [my] story hasn't come to an end yet.'

Jazmin and Lucas

Lucas is in his early-40s and has intellectual and psychosocial disabilities. Jazmin, his mum, talked to the Royal Commission about Lucas's experiences – and her own – with health professionals, government agencies and the broader community.

Jazmin had been Lucas's primary carer for most of his life. About 10 years ago, she was really struggling, with carer fatigue and with her own mental health issues. She had been asking the relevant government department to find accommodation for Lucas for some time because she wasn't coping. But they kept fobbing her off, telling her 'You're doing a great job – keep it up.'

Meanwhile, Lucas was going through a really bad episode, but the hospital was ignoring him – they kept saying there was nothing wrong with him. Jazmin broke. 'I just left him in the hospital and said to them "well, you take him." All I remember was getting in my car and then the next thing I remember is I was in hospital myself.'

'That should never have happened,' Jazmin told us. 'They knew how stressed I was because when they came to visit me I was crying, I was saying "I can't do it." And I would go and see them privately so that Lucas didn't know and I would beg them. And they honestly just said "But you're doing such a good job and we'll get some respite." But Lucas wouldn't go to a respite place ... and I just wanted to be at home on my own, you know, not having to think about going somewhere.'

It was only once Jazmin had the breakdown, after they found her in her car, that the department found accommodation for Lucas. 'They don't do anything until you get to that point,' she said. 'For Lucas to see that happening to his mum, thinking he may have caused it is awful. And for him to leave home that way ...'

Since then Lucas has done 'extremely well' living on his own with support from the NDIS. He loves having the freedom to select his support workers and make his own choices. 'He feels so in control,' Jazmin said. Lucas said, 'I've been let out of prison.'

Recently, however, both the NDIS and the state guardian have been encroaching on Lucas's freedom of choice.

The state guardian took over management of Lucas's finances after an incident where someone took Lucas to an ATM and stole his money. Now they have begun to limit his independence and autonomy. Jazmin said the guardian is 'doling out the money, dollar by dollar, and Lucas is almost having to beg'.

Recently, when Jazmin queried the budget the guardian had allocated for winter clothing, they suggested Lucas buy his clothes from op-shops.

'I said, "do you buy the bulk of your clothes at an op-shop?" Why should my son have to buy clothes at an op-shop just because he's disabled?'

Meanwhile, the NDIS recently threatened to cut back Lucas's funded support worker hours unless he starts attending group activities. Lucas doesn't like group activities.

'For some reason, if you've got an intellectual disability, or any kind of disability, you've got to go and join a group ... nobody does that to us, but they do that to people like Lucas.'

While the NDIS has given Lucas more control overall, he remains vulnerable to people in the community who would exploit his intellectual disability and need for connection. Jazmin says that people befriend Lucas and 'once they've won over his confidence, then they start stealing from him'.

'There needs to be some way to continue to protect vulnerable people in the community.' Jazmin told us. 'When we contact the police, the police will say "Are they there now?" We say "no" and they say "well when they come back, ring us". There needs to be some way ... even if it's just a trespass order ... That they can get that protection quickly, and it stays in place.'

Jazmin connected Lucas's vulnerability to how society regards people with disability.

'Because he's very social and he loves company, and there are no other people that come to socialise with him, that's all he's got, these other people ... The general public won't engage. They either fear because of lack of knowledge, or they feel inadequate in how to communicate or whatever.'

Jazmin believes this attitude has negative impacts for everyone.

'The community is missing out on a lot of wonderful variations, variety, wonderful humour, creativity – the creativity is gobsmacking! ... They have so much to offer.'

Nathanael

‘If mum and dad had looked after me in the proper way, half the stuff would never have happened to me.’

Nathanael, in his 50s, has a cognitive disability. He told the Royal Commission his father was a ‘bastard’ and ‘treated the family hard’. Nathanael was particularly vulnerable. ‘I had a disability – he thought he could get away with anything.’

One time Nathanael was helping his father build a shed. His father told him to hold something steady, but it was difficult. His father drilled the drill bit through Nathanael’s arm, into the tendons. He didn’t say sorry and didn’t take Nathanael to the doctor. Nathanael still has a very visible scar.

At school, the other boys bullied Nathanael relentlessly. They ‘picked on’ him because of his voice and the way he spoke. He was slower than the others and they taunted him because he wasn’t smart. ‘I was very scared.’

Nathanael told his parents. His father called him ‘soft’ and told him to stand up for himself. Nathanael became ‘too scared to say anything’.

Nathanael never went to secondary school.

In his 20s, Nathanael delivered catalogues to homes in the area. A gang of kids would take the catalogues and throw them on the road. One time they assaulted him and tried to ‘rip [his] head off’. A passing motorist intervened and asked him if he wanted to go to the police. He was too scared.

‘Every time they picked on me it got worse and worse and worse.’ Nathanael thought they would kill him and asked his father for help. His father told him to tough it out and ‘just be a man’. ‘When it came to me he wouldn’t do anything for me ...that hurt me so much.’ Nathanael ‘lost it’ and ‘went off his head’. His mother called the doctor who gave him drugs to calm him down. ‘I was forced to leave home, otherwise I would kill dad.’

Nathanael went to live in emergency disability accommodation. He was suicidal and asked for help. Disability services assessed him as ‘too smart’ and told him he was not eligible for support. He stayed for three months but said his mental health was worse when he left.

After some time in respite accommodation, Nathanael lived in supported accommodation with two other men. In those days, he said, he didn’t know how to say ‘no’. One of the other residents pestered him to get involved with a woman who already had a boyfriend. Nathanael didn’t want to and tried to ignore him. The man ended up damaging Nathanael’s car to get his attention. Nathanael reported him to the police but they couldn’t do anything because there wasn’t enough evidence.

Nathanael was distressed and ended up having a 'second breakdown'. The doctor viewed him as 'a danger to life' and medicated him. Nathanael was desperate for more help but the accommodation provider said he was too dangerous and refused to support him anymore.

A few years later, Nathanael became involved in a sexual relationship with a co-worker at the disability enterprise where he worked. He tried to end the relationship but she threatened to tell her mother. Nathanael was scared he would lose his job so stayed in the relationship.

Two years later the woman told her mother about their relationship. Her mother asked the enterprise to sack Nathanael and tried to obtain a restraining order. Nathanael attempted suicide and cut his wrists.

Nathanael's employer and his social worker helped him to get mental health support. He continues to work for the same disability enterprise and lives on his own with disability support five days a week. He likes a woman who treats him like a 'real person' and hopes one day she will be his girlfriend.

Nathanael says he has learned 'the hard way' to say no to people. 'The last seven years of my life have been the best years of my life because I've got myself what I needed to get through.'

Sonny and Veronica

Veronica is mum to 13-year-old Sonny, who has autism, dyslexia and dyspraxia. He should be in school but, now at the end of a four-week 'exclusion' period, his parents are fearful of sending him back.

'He's suicidal,' Veronica told the Royal Commission. 'It's the school environment. He is so anxious and he feels so much pressure to do the right thing, and then when he doesn't do the right thing, he just feels awful. I don't know if I can put him in that environment again, but I don't know what else to do.'

The problems started early. In kindergarten Sonny was already using violence 'to regulate himself'. The school's answer was to remove him from the classroom.

Veronica explained to the school that Sonny's behaviours were a result of him feeling uncomfortable. If they removed him every time he felt uncomfortable, they were simply reinforcing the behaviours. But the school persisted in removing him.

Sonny reached year 5 without being able to read. 'He was so far behind in his work because he'd just never been in the classroom.' His parents decided it was time to 'give another school a shot'.

The new school acquired funding for a one-on-one teacher for Sonny, on his own, five days a week. At recess he had a student support officer who followed him around and was with him the whole time.

'He was learning to read and get an education, but they weren't allowing him to get in normal social situations ... they basically just "caged the lion".'

When it was time for Sonny to go to high school Veronica argued he was not ready, but was told he had to go.

Sonny had numerous 'meltdowns' at high school and twice he was sent to a behaviour management school. Veronica said it was not set up for 'kids on the spectrum', but for kids from violent backgrounds with a lot of trauma and aggressive behaviours.

'He actually came out worse than when he went in. He learned some really bad behaviours ... They wanted to send him a third time, and I said "No, no way. I'll have him home but I'll not send him back there."

In the most recent incident, during the COVID-19 pandemic, the principal called the police because Sonny was spitting. Sonny's father arrived at the school to find six police officers on top of him trying to handcuff him and making the situation worse. Sonny received a four-week exclusion from school.

The last meeting Veronica went to at the school before he got excluded 'broke' her.

'I basically had them telling me [Sonny] is choosing to make the decisions he's making, he's choosing this behaviour. Now we're talking about a child that suffers anxiety, depression ... he has suicidal thoughts, self-harming behaviour ... He hates that he's different. He hates that he gets angry. He absolutely hates it. And he hates it so much that he hates himself ... I was gobsmacked by this comment, that he is "choosing" to behave this way ... I'm so angry.'

Veronica said the department has 'these behaviour support people' who go to the school to give teachers strategies to manage Sonny, and one was present at the final meeting. Veronica asked them 'how many times have you actually come out and observed Sonny?' They never had. Never.

'They come to the meetings when he's suspended and expelled – that's when I see them.

'I just feel so let down by the education department ... You know my son, he loves to learn. He still says he wants to go to school.'

Jazmine and Melody

‘Disability starts in health care ... I think that’s where the starting problem is – low expectations of people with disability.’

Jazmine was in her 20s when she was diagnosed with a benign brain tumour. Following surgery she underwent extensive rehabilitation and was able to return to living independently, driving a manual car, and working. However 18 months later, in the early-2010s, a scan revealed another mass on Jazmine’s brain. She needed more surgery.

During the second operation Jazmine acquired a severe brain injury. When she regained consciousness she was non-responsive, had very limited memory and no ability to form new memories.

Her sister Melody told the Royal Commission she later learned ‘cotton wool was left in [Jazmine]’s brain during the [first] surgery ... and a misdiagnosis may have led to the surgery which resulted in [her] disability’.

In the days and months that followed, medical staff repeatedly told Melody that Jazmine would never improve. The head of social work urged her to ‘find a nursing home that will accept your sister ... because you are never going to get the help you need to bring her home’.

Melody said this attitude influenced the standard of care Jazmine received. Medical staff treated her very differently to how they treated her after the first operation. Melody, Jazmine’s legal guardian, raised multiple concerns with the treating team. They dismissed and blocked her.

Melody recalled Jazmine was constantly nauseous after the operation and needed anti-nausea drugs. She noticed Jazmine gained a significant amount of weight, which was puzzling because she had no appetite and struggled to eat small amounts of food. Melody also noticed unusual hair growth on Jazmine’s body.

Eventually the treating team organised further investigations, but neglected to tell Melody. She arrived to visit Jazmine and found an endocrinologist trying to consult with her. The doctor suggested Jazmine had a germ cell tumour on her reproductive organs. She ruled out pregnancy because Jazmine had been in hospital for five months.

The next day an ultrasound revealed Jazmine was 21 weeks pregnant and was possibly one-week pregnant when she had her operation.

‘[Jazmine] had been in the health care system in a non-responsive state for the entirety of her pregnancy and the hospital failed to diagnose the pregnancy,’ Melody said.

The hospital immediately applied for permission to perform a ‘special procedure’ which Melody learned was code for a termination.

She asked for information about Jazmine's health, the health of the fetus, the risks of a full-term pregnancy and a late-term termination. Instead of providing this information, the hospital applied to remove Melody as Jazmine's legal guardian. They suggested Melody felt unable to make decisions for Jazmine, citing her distress, being a single mother and her health – Melody has multiple sclerosis.

'I had never provided any indication to any representative of [the] hospital that I was unwilling or unable to continue [as legal guardian],' Melody said.

Melody tried to get Jazmine discharged from the hospital because she was 'literally scared for her life'. When this failed she engaged lawyers to keep Jazmine safe and sought a second medical opinion. The doctor advised it was safe for Jazmine to continue the pregnancy.

Following her baby's birth, Jazmine transferred to residential aged care. However, she didn't respond well. 'She started cutting her arms up. She didn't know where she was. The only thing she knew in the world was me.' Melody left her job, brought Jazmine home and became her full-time carer.

Worried about what would happen to Jazmine if anything happened to her, Melody decided to pursue a compensation claim. But after years of protracted and traumatising legal battles she ran out of funds.

'We were never compensated. We never got an apology ... I will never know what actually happened to my sister in that hospital. I will never know.'

The NDIS now funds Jazmine's supports and almost 10 years on she no longer needs 24/7 care. She's able to manage her chronic pain and is more independent. 'I'm no longer my sister's full-time carer and as of about two months ago [Jazmine]'s actually started volunteer work,' Melody said.

'If you have a decline in function, if you're born with a disability everything comes from the healthcare model ... If you've got people at the coal face with low expectations of people with disability ... it can send people in the wrong direction ... "Oh you may as well find a nursing home," is still going on.'

Jimmy and Lukas

‘What is out there in terms of assisting autistic people, assistance seems to be lacking, broken, heading in the wrong direction, seems to be full of unworkable practices and policies.’

Lukas is dad to Jimmy, who is in his mid-20s, autistic, non-verbal and has ‘high needs’.

When Jimmy left school and was at home full time, Lukas organised in-home support from a specialist autism service provider. Lukas told the Royal Commission the support provided was ‘bloody inadequate’. ‘They were sending pretty much anybody around,’ he said. ‘Just tick the box, shift’s covered.’

This was detrimental to Jimmy who was ‘going backwards’ with ‘people who didn’t understand him and couldn’t meet his needs’. He was gradually disengaging and his behaviours were escalating.

Lukas consulted with a psychiatrist from the service provider, who prescribed risperidone to treat Jimmy’s behaviours. Six months into the treatment, Jimmy started having dystonic episodes – ‘on his feet, locked up rigid, eye balls rolling back in his head, he’d basically have a seizure and just rock there’.

The psychiatrist acted like it was no big deal. ‘We’ll just keep an eye on it,’ he said. Jimmy continued having one of these episodes every two months or so.

Still dealing with inadequate in-house support, Lukas arranged for Jimmy to attend a trial at a group home run by the service provider. Lukas described the home as ‘chaos’, with staff who had no understanding of how to support the residents.

‘The staff couldn’t handle [Jimmy]. He wasn’t being bathed for two weeks. He wasn’t eating, they couldn’t get his nutritional vitamins into him, he pretty much confined himself to the room. His self-injurious behaviour was really escalating.’

Jimmy was still being medicated with risperidone. When he had dystonic episodes in the family home, the psychiatrist had been ‘so flippant about it’. But when Jimmy had his first dystonic episode in the group home, ‘all of a sudden it was a major medical emergency’.

The psychiatrist called Lukas – he had to take Jimmy off the medication urgently. This seemed dangerous, and Lukas wanted a second opinion.

He arranged for two other experts to see Jimmy. A ‘leading psychiatrist’ advised he should stop taking the medication. But a ‘leading neurosurgeon’ said ‘double it’.

Lukas had no idea what to do. Meanwhile he was having meetings with the team at the group home who were advocating additional medications, suggesting ‘half a gram of this, half a gram of that,’ like they were ‘dreaming up a cake recipe’.

Lukas researched the side effects of the suggested medications – ‘they were pretty wild’. When he expressed his concern the doctors ‘smiled’ and told him not to worry – they had drugs to deal with the side effects of the other drugs. Lukas told them he didn’t think more drugs were the answer.

By the next day, the service provider had bought on an emergency guardianship hearing in the Administrative Appeals Tribunal, claiming Jimmy’s parents weren’t fit to care for him because they were refusing to provide him with medication.

Lukas and his wife had to appear before the tribunal the following day.

‘It was quite a scary moment ... They can snap their fingers and bam, there’s a hearing the next morning. And that really concerned me ... how much power, as a parent, can be taken away from me. And I don’t want the power to be in the hands of these people who pretty much advocate one line, and that’s just drug, drug, drug, drug.’

The tribunal found Jimmy’s parents to be capable guardians.

They withdrew Jimmy from the group home and within six weeks were able to get him off the drugs, ‘inching it down’. They ‘exchanged the drugs for nutrition’ and ‘gave him a calm environment’.

Lukas found another organisation to provide in-house support. ‘Couldn’t believe the difference,’ Lukas said. ‘I have two fantastic support workers who are incredible ... They really have this compassion and passion to help.’

Jimmy is now doing well. After leaving the group home it took a year and a half for Jimmy to leave the house. Now he goes out every day.

Nicklin

‘We’ve got a disability but we can talk, we can communicate.’

Nicklin moved into a group home almost 30 years ago when he was in his early 20s. He has spina bifida and uses a wheelchair.

Initially he felt ‘quite happy’. He told the Royal Commission, ‘I was with friends.’ The house was centrally located and he was able to access the community independently.

But the house wasn’t designed for wheelchairs.

After a few years Nicklin asked management if they could build a house nearby – he wanted ‘a place where I could wheel around’. Management said they had no money.

Then one day the manager showed Nicklin a house with a ‘lovely view’ some distance away. The manager tried to convince him it would be a great place to live. Nicklin disagreed. ‘I said that’s your opinion.’

Nicklin didn’t want to live there, but they ‘just moved [him]’.

‘I thought you bastards, I was furious.’

Nicklin says the house is cold and noisy because of the high ceilings and hard floors. He lives with three other people who are ‘not good to live with’. With four people and support staff it’s like living with ‘raging bulls’.

The house is not accessible. The bedrooms are small. Nicklin said it’s ‘damn hard’ to get his wheelchair around his bed. The outside paths are half cement and half grass, making them impossible to navigate in a wheelchair.

Over the years Nicklin has ‘just shut up and put up with it’.

About a year ago Nicklin developed pressure sores because his wheelchair no longer supports him properly. He has no feeling below the waist and didn’t realise the sores were opening and getting worse. ‘Community nurses were coming in and they weren’t doing their job properly.’

The sores became so infected Nicklin was bedridden for nine months. He said it was a terrible time and he felt his life was ‘crap’. He had ‘some horrible thoughts’ and wanted to suicide.

For a short time staff moved him to the large bedroom at the front of the house. He said this room was much better because he was closer to staff and ‘could communicate and talk to them’.

Nicklin is slowly getting back to the things he did before he had bed sores. He goes bowling, to the movies and spends time in the community.

But he is back in his small bedroom. The cramped conditions and the noise in the house continue to irritate him. One of the women in the house chooses the food they eat and tells the staff how to cook it. She chooses very fatty food. 'She's stuck in the 1940s,' Nicklin said. Although he's 'not one to start arguments over food' he would like to live with just one other person.

'It'd be a step in the right direction if I could choose. It infuriates me because we should have our rights to say who we want in the house ... but we don't.'

Katina

‘When you listen to your clients cry and you hold them in the night, when they’re telling you their concerns and there’s nothing you can do, it’s heartbreaking.’

Katina worked as a support worker, coordinator and team leader in several group homes for 20 years. She told the Royal Commission the organisation that ran the homes refused to deal with serious issues.

Domestic violence was a common problem because management didn’t care if the residents were compatible. ‘It’s just fill that bed ... that’s the goal,’ Katina said.

Whenever she reported domestic violence management would tell her to ‘downgrade the incident, the incident did not occur’.

On one occasion one of the male residents sexually assaulted a female resident. Management told Katina to ring the woman’s mother and ask her to drop the intervention order so the man could continue to live in the house. Katina refused.

Another time, a male support worker ‘formed a fond liking’ for a female resident. Katina didn’t think it was appropriate for the worker to continue to deliver the woman’s personal care and asked management to move the worker to a different facility. Katina was told she was being over protective.

The worst case of management neglect was when she was working as team leader in a house with five young adults and one older man. All were autistic and non-verbal and, except for the older man, could be violent.

When Katina arrived she couldn’t find any documentation for the clients, just a few out-of-date behaviour support plans.

She soon discovered the house was ‘blacklisted’ by all medical services in the area. ‘I couldn’t get anybody to work with these people.’

The older man was the victim of regular sustained abuse by other residents. He would be thrown to the floor, his head trampled until he was bleeding all over. Katina reported the abuse and classed it as domestic violence but management asked her to downgrade it so it fell into another category.

The older man was eventually able to leave the home and management accepted a new client. This new client required two-to-one support at all times, which was impossible as only two staff were rostered on at any one time.

Katina couldn't understand why the new client was in a house with five other people when he had a well-funded NDIS package to enable him to live alone. She later learned the provider not only received the NDIS funding, but the state government paid an additional \$1.2 million to the provider to place this young man somewhere.

Katina contacted the state government and advocacy groups. 'I said to them somebody has to act for this man because putting him in a group home not only threatens him but threatens everybody else that lives in this home.' She told them it was also a danger to staff.

Katina asked the behavioural support manager to provide safety training for the staff and requested protective sleeving to keep their arms safe from attacks. Management refused.

One night, Katina stopped by the house on her way home to drop off some training materials that might assist the staff. She knocked on the staffroom door and when she didn't get a response used the security code to enter the house.

One of the workers, a big tall man, was covered in blood from head to toe. 'He was standing in the room crying at me saying, "I don't know what to do – what am I doing here? What does this company do to us?"'

The other support worker was looking after two other clients who were bleeding. Katina took the injured worker into the staffroom to assess his injuries and ring an ambulance. The offending client managed to get into the office and attacked Katina. At one stage he held her in the doorway by her neck.

'If I didn't have my male workers I probably wouldn't be here to tell you this story but that client should never have been placed in that home.'

Katina carries physical and emotional scars from that day. She now needs to work in a quiet environment where she won't be startled and says she 'will never work in disability services ever again'.

'I have 20 years of knowledge that will never be put back into [the sector] ... There are so many workers like me who wear their heart on their sleeve, that do it because you know, they have an empathy and ... you fall in love with these people that you work with.'

Henrik and Ingrid

When Henrik was a toddler a doctor told Ingrid, ‘Your son has autism, good luck with that.’ Ingrid said she and her husband were left ‘to figure out what to do’ themselves.

This was almost 20 years ago, ‘at the time when there were very few services for people with autism in Australia’.

‘It struck me,’ Ingrid told the Royal Commission, ‘how biased health professionals were against children with severe autism.’

Ingrid said the prevailing attitude was ‘your child is not going to progress and it would be a waste of your time to try’.

Ingrid needed access to reliable, evidence-based information about treatment options for autism. All she found was ‘a lot of disinformation’.

At the time a child had to have an intellectual disability to be eligible for services, so Henrik took an IQ test. Ingrid said she didn’t then understand that this IQ test would label Henrik as ‘not having potential for learning’ and would exclude him from some services.

Initially Henrik attended a special school. When he started coming home with ‘unexplained injuries’, his mother moved him.

But the same problems started to occur at the new school. When Ingrid asked staff about the unexplained injuries they said they didn’t know what happened.

It was only later, after going to court, she learned from staff affidavits that the school had brought in a martial arts expert to teach staff how to physically restrain Henrik.

‘I felt distressed and sick knowing that a group of professional educators exploited my son’s inability to communicate to me what was going on for him at school.’

Ingrid homeschooled Henrik for a while, but found it exhausting and felt she was neglecting her other child. So she opted to send Henrik to a state school a couple of hours a week.

But this didn’t help because the school looked to Ingrid to be the expert.

‘I would have to hire professionals to go in and try and work with the school staff – I don’t think that’s a reasonable request to make of parents yet the school expected it of me.’

Ultimately Ingrid felt the only way to have Henrik’s education needs met at school was to make an official complaint.

She complained to several bodies but they lacked the power to direct the school to provide adjustments, so she took her complaint to court.

Ingrid found herself up against a state department with unlimited financial resources, prepared to 'play legal hardball'. She feared losing her house if the case went to trial.

'The state portrayed me as a very demanding, unreasonable mother, I was a perfectionist who was never satisfied with anything. I was wanting the school to "cure" my son.'

'Instead of educating my son,' Ingrid said, 'teachers were focused just on building the case against him.'

She believes there is something 'profoundly wrong' in a system that 'brings out that kind of behaviour'.

Ingrid feared for Henrik's future and it seemed the only option was to take him out of the school.

The move made Henrik ineligible for the NDIS or disability support, but Ingrid said he 'got his life back'.

Now almost 20, Henrik 'is a talented artist and has his own business in collaboration with a few of his peers'. He has learned to manage his own behaviour and independently goes to the gym and library, shops, cooks and volunteers. He has friends and is still acquiring language.

'I am glad I did not listen to Australian experts.' Ingrid wanted to reassure other parents in a similar situation 'that they should have hope for their child'.

'You must never give up on trying to promote language and communication.'

Kenji and Adley

‘If we have an animal who can’t communicate with us, but we know something is wrong, we give them the full gamut of tests to determine what it is, but that is not afforded to my child.’

Kenji, 20, is autistic, non-verbal and has an intellectual disability. His mother Adley told the Royal Commission, ‘His inability to speak, it’s often mistaken as not having anything to say ... in his silence he communicates more clearly than most.’

If Kenji is in pain or distress, he injures himself. The level of damage he inflicts ‘is ferocious’ and ‘quite unbelievable,’ Adley said.

Kenji was about six when he had his first episode. He had ‘some sort of accident’ at school. Nobody thought anything was wrong until he started self-harming. Adley took him to hospital and asked doctors to give him a full body scan. They didn’t ‘see the point’ and sent him home.

Adley continued to seek help. Three months later she convinced a private specialist to order a scan. Kenji had a broken leg.

At 15 Kenji had another serious episode, banging his head repeatedly. Adley took him to the children’s hospital, told them it was a medical problem and asked them to do a number of tests. They refused and sent him home. The next day he injured himself so badly he lost sight in one eye.

Adley rang the school principal for help. The principal took Kenji to hospital and forced them to admit him.

At first doctors said Kenji was constipated, but he became so unwell he spent three months in hospital. It was a fight ‘every day’ to keep him there, Adley said. Different government departments argued about the cost of his care and who should treat him. Ultimately the hospital appointed a medical team that included physicians and psychiatrists. ‘They found multiple things wrong with him, constipation was not one of them.’ Kenji had a ‘massive infection’ and 15 broken bones.

Adley could no longer care for Kenji at home because of the level of support he required, so he moved to respite accommodation. After the NDIS was introduced, the house he was living in became a group home. Three other men moved in.

A few years ago, a new house manager decided Kenji was overweight. She limited his food choices, including his favourite foods, and put locks on the cupboards. Kenji lost 25 per cent of his body weight. His self-injuring escalated and ‘was just horrific to watch’. Adley repeatedly asked staff to take him to hospital but they didn’t believe it was a medical issue.

‘And there he was, destroying himself and his head and his body while everybody watched on.’

Eventually Kenji went to hospital, this time to the adult section. Adley asked doctors to put him in a general ward but they refused. ‘Because [Kenji] is complex, in that he can’t tell you where the issue is, nobody wants ownership of him ... nobody wants to be his doctor.’ The only bed they offered him was in the mental health unit which was ‘at best, horrific’. They changed all of his medication and Adley said ‘overmedicated him’ to manage his behaviour.

When he returned to the house, the house manager continued to limit his food and use large amounts of medication. ‘He couldn’t stand, he was virtually bedridden and emaciated.’ Adley made a formal complaint and the house manager moved to a different home.

Things have improved but staff continue to assume Kenji’s self-harm is a behaviour issue. He recently had an undiagnosed ear infection that burst. ‘I can only begin to imagine what the level of pain was, for that ear to burst, and they were just drugging him because they wanted his behaviour to stop.’

Adley doesn’t want to ‘walk away’ from the service provider because the staff know Kenji. ‘If I can get it to work for him, I think he’s better off, and he has a long life ahead of him.’

Lina and Olva

Lina is in her mid-20s and has autism, Down syndrome and low vision. Her mother, Olva, told the Royal Commission about the 'shocking bullying' and neglect in Lina's group home.

When she moved to the group home in her late teens, Lina was the first resident who was mobile. This annoyed the staff who were accustomed to leaving residents sitting in their pyjamas watching television until late in the afternoon. Lina's mobility and some of her behaviours made her more time consuming than the other residents. One staff member told Olva point blank, 'We don't want Lina here.'

Staff also resented parent involvement.

'I think they had been very used to an institutional type situation, where essentially they controlled the situation. To have an involved parent coming on board was obviously quite traumatic to them, and their response was to react in an antagonistic way towards us.'

Olva first found out from the team leader about the little 'tattle' stories the nurses had started spreading about her and her husband. 'They started in "schoolyard ways" ... about little things that we were doing.' The team leader tried to reassure them that staff would soon 'get over' it.

But the storytelling escalated. The team leader who had tried to be helpful moved to a new role. The new team leader 'very much collaborated' with the nurses.

'The stories started to grow about what Lina did and about what we did in the home ... They wanted Lina out ... so they went on strike. The nurses decided they weren't going to have anything to do with Lina anymore and the management agreed.'

Olva was left to work with the support workers to help them and show them how to care for Lina.

Meanwhile, the stories were 'getting bigger and bigger'.

'They said we were interfering with them doing their work, raising voices in the common area, disturbing other clients – often at times when we weren't even there. Basically just a schoolyard type ploy to make life difficult for us.'

But Lina's parents did not realise how serious it would get.

'Based on all their false stories, they considered that I wasn't a fit parent,' Olva said. Staff filed an application for guardianship of Lina, and in the six-month period leading up to the hearing Olva was denied access to Lina's house.

The tribunal threw the case out straight away, but it cost Lina's parents \$50,000 in legal fees to defend the application.

Lina receives NDIS funding for one-on-one support and for community access, which Olva organised with another provider. Olva said the home's management – who are 'desperate' to get funding for these hours back – give these support workers 'a shocking time'. 'They jump up and down like crazy over this – they don't like the one-on-one carers.'

Olva says it is important Lina gets this support from external providers because of the neglect within the house. Prior to moving into the home Lina had no dental problems. Now she has loose teeth and gum disease.

One time, Lina's parents returned from a one-week holiday to find she had developed bed sores. Staff don't move her properly, and sometimes they don't move her at all. They have left her sitting in wet nappies for hours.

Meanwhile the stories have started again and letters have been sent to the general manager of the home's governing body alleging Lina's parents have been rude and aggressive to staff and other clients.

Lina's external support workers who are often at the home with her have written to the general manager insisting none of it is true. There is to be an external investigation, but Lina's parents are sceptical it will result in any positive change.

Despite everything, Lina's parents are reluctant to remove her. She has her own room, which she loves, and she doesn't adapt well to change.

'It is just a continuation of this very sad antagonism that reflects directly on Lina's care – that's what worries us ... that we have to have a constant warzone going on in a situation where we just want a home, a safe home for our daughter.'

Michelle

Michelle was born Deaf in a country town in the mid-1950s. Her parents thought a boarding school for Deaf children would give her the best education.

At the time, every Deaf child had to learn to speak. 'It was just "oralism" and spoken language,' she told the Royal Commission.

But Michelle, who also had impaired vision, couldn't lip-read very well. 'So communication ... was really, really hard.'

Some of the older students knew sign language but 'were forced to never use it', Michelle said. 'We were punished for using our hands in any way at school.' Girls would hide in the toilets or under the bedsheets and make up signs to communicate.

Michelle said the teachers were cruel and would physically punish the girls.

Once she woke and discovered she and other girls had green paint in their hair.

'This [teacher] grabbed me by my clothing, picked me up and threw me onto the floor.'

Five teachers interrogated her and she kept telling them, 'I didn't use any paint.'

'[One teacher] got very angry at me ... got a belt ... tightened up that belt and ... started hitting me repeatedly.'

The school expelled the girls and rang their parents to collect them. Her uncle suggested Michelle should see if she could pick up the paint tin.

'So I tried to pick it up and physically it wasn't possible because I was a little girl.' Her dad spoke to the school and all the girls were allowed to stay.

Michelle didn't want to stay, but she had no choice.

'I told my parents I saw all sorts of cruelty and physical things. You needed to protect yourself. You needed to be careful ... it was just horrible.'

When Michelle was 15 or 16 the school moved her to a vocational training home for people with disability.

Michelle didn't want to go and thought she was too young to be there.

'I just wasn't comfortable staying there and a man there ended up raping me. It just felt awful and abusing.'

Michelle went to hospital and police were called but she was unable to communicate with them. They brought in a sign language interpreter but Michelle couldn't sign. The man 'ended up going free'.

Michelle was struggling with learning the basics of education, 'so sex education was never going to happen'.

'I didn't know that kissing led to sex and sex led to babies. That was never part of anything that was taught to me.'

A short time later a friend of the family raped Michelle. When her mother found out she didn't want to hear about it and told Michelle if anyone found out 'her name would be dirt'.

'So the things that I learned about sex and rape were not because I was educated but because I experienced it. I didn't understand this sexual abuse was going to affect my whole life.'

After school she went to a residential hostel for Deaf people. There were some girls from school at the hostel. 'I saw them using their hands and I was like, "are we allowed to, is this something we can do now?" and they said, "yes you can, school's over."'

Michelle quickly learned to sign. 'Being with Deaf people every day ... it changed my life.'

When she started work 'there was no such thing as interpreters'. She had to write everything down but she found there was always a couple of girls at work who were happy to learn sign language. 'Then at least I had someone to talk to.'

Michelle would like everyone to learn Auslan. She said it will help hearing people understand 'they're no better than Deaf people and everyone is equal and should be treated equally'.

Bodhi and Tayla

‘I think it is really important that he get the best care in the limited time that he has, and if I have to beg, borrow and steal to get it, I will.’

Tayla’s son, Bodhi, was born prematurely and is now in his teens. He lives with spastic quadriplegia cerebral palsy and uses a wheelchair.

‘We were made aware really early that he had quite a lot of brain damage,’ Tayla told the Royal Commission.

Tayla, a single mother, said doctors at the time gave her no indication of ‘what his disability would mean for his life or [hers]’.

‘He essentially breathes on his own, and everything else is supported.’

When Bodhi is sick, Tayla takes him to a children’s hospital, where she said the level of care has ‘greatly declined’ in recent years.

A few years ago, Bodhi hurt his leg.

‘It was uncomfortable to the touch. He was wincing when I touched him.’

The hospital’s doctors took an X-ray and sent him home with painkillers. Nine months later, she discovered in his medical history that his leg was broken.

When Tayla complained, she said her ‘concerns were not addressed’.

‘If he had been a child who was not in a wheelchair, was standing up ... with a sore leg saying, “Mummy my leg is sore, oh my God, I’m in pain,” what would have been the level of care then? Because clearly he was in distress because that was why I took him in there.’

Tayla said the hospital appeared to consider her a troublemaker for advocating for Bodhi.

‘I’ve received in writing a letter that says that, due to my “anxiety”, I am unable to communicate with the hospital. I don’t have a mental health history.’

Bodhi is supported by the NDIS, which Tayla said has dramatically increased his funding and access to services. She told the Royal Commission that some service providers are exploiting it.

For example, Tayla recently called an occupational therapist out to adjust Bodhi’s wheelchair.

‘So this person comes out, we had a bit of a chat, she had a look at him in the wheelchair and rather than just adjusting the wheelchair herself then and there, [she] indicated that we were requiring that the manufacturer of the wheelchair come out ... in case she needs to order more items.’

Tayla said it ended up costing \$800 ‘to do an application’. ‘And then, of course, under the requirements of the NDIS, she can then bill me another \$452 to come back to supervise that gentleman putting that piece of equipment on that wheelchair.’

Tayla said she manages Bodhi’s NDIS funds responsibly, but some providers were ‘putting parents in a really awkward situation’.

‘Someone can run out your funding very quickly.’

Tayla worries about what will happen to Bodhi if she isn’t around to manage his funds and care.

‘It would be vastly open to exploitation. I’m almost positive he would be neglected in some level ... so those are the sorts of things that worry me.’

Tayla said she sacrificed her career to ‘advocate for him and to care for him’, leaving her with no superannuation or financial security.

‘I almost have no pride left. It’s terrible. It’s taken a huge toll on my family, myself ... I don’t want to think that if I can’t afford to rent or if I get evicted that I might be homeless.’

Miles and Phil

‘The people who failed [Miles] have been there for over 10 years ... they’ve been doing it for so long and getting away with it for so long.’

Following a stroke a few years ago, Miles moved into a group home. His brother Phil lives nearby and sees him almost every day.

Phil told us Miles is non-verbal but clearly communicates his preferences. For example if staff give Miles a dinner he doesn’t like – ‘curries and stuff like that, that’s covered in chillies ... [or] doesn’t look appealing’ – he doesn’t eat it. He shakes his head.

But staff at the group home will ignore Miles and give him the same meal the next night. Phil has seen Miles’ reaction – ‘[He] looked at it and chucked it on the floor.’ Staff then label Miles as ‘non-compliant’.

Phil said the staff at the home think the job is to ‘get [Miles] up, give him breakfast, put him to bed and give him a shower if he’s lucky. In between that there’s nothing’.

Miles’ stroke left him with paralysis on one side of his body. He was making good progress with his physiotherapist until there was a sudden change in his behaviour. He didn’t want to be touched or moved and he refused his medication and food.

Staff at the home told Phil that Miles was depressed because of the stroke, but Phil didn’t agree. He thought Miles was trying to tell them something.

A doctor investigated and discovered Miles’ hip was broken and had been broken for several months. His behaviour changes were due to pain.

Phil suspected that Miles’ broken hip was the result of staff incorrectly transferring Miles from his bed to the chair, as he had witnessed this before.

The home denied any knowledge or responsibility and refused Phil’s request to see incident reports.

Frustrated, Phil installed a camera in Miles’ room. What he saw shocked him.

‘A lot of time [Miles] would spend days and days and days in his room alone doing nothing ... some of his basic needs were not even covered ... they weren’t showering him or ... getting him out of bed and things like that.’

Phil said staff stripped Miles of his dignity.

‘I used to walk into his room and I used to smell a urine smell ... I now know [it’s] because more than likely he’s not getting showered, and his linen on his bed is not getting changed.’

When he raised these incidents with the home they denied it. Or they said Miles would not want a shower and become abusive, or they blamed his seizures.

Phil asked staff to sign forms to indicate they had showered Miles, taken him for a walk or to hydrotherapy.

Staff signed the forms, but the videos revealed 'the staff lie, they're liars'.

Phil bought Miles a new wheelchair with GPS. Staff signed the form saying they'd taken Miles for a walk. But the GPS showed Miles hadn't been anywhere.

Unable to 'sit back and watch anymore', Phil told the home about the camera.

'I've had to work really hard to get some help,' Phil said. 'To make a complaint it's really, really hard ... unless you're really determined, you get nowhere.'

Phil is in the process of moving Miles to a new place and getting some good staff around him. 'All the damage from the past is done now,' Phil said. But he hopes the move and the 'good network of people' he's employing will improve Miles' quality of life.

Kennedy

‘Before NDIS ... I was effectively left in the situation where the person who was being paid as my carer was taking drugs and ... had absolute control of my finances, control of everything.’

Kennedy is blind, has anxiety, depression and lives with chronic pain. For 25 years she lived with a man who was violent. She relied on him for food, medication and some personal care. Without him, she believed, she ‘would be unable to survive’.

When the NDIS was introduced Kennedy received some limited support based on having a live-in carer. For the first time she felt she could ‘get the support she needed to live’ and end the relationship. But that hasn’t happened. ‘I have gotten rid of him and now I’m battling,’ she told the Royal Commission.

Kennedy asked the NDIA to review her plan based on her change of circumstances.

‘I was basically going to be left in a situation where I was looking at running out of funds and no longer having a live-in carer. I was in a situation where I can’t even leave the house on my own let alone get ... my shopping ... anything that I need to live.’

She said the NDIA told her, ‘There’s a lot of people waiting. Get in line.’ Until she was ‘down to \$500 in funding’ they ‘don’t consider that to be an emergency’.

After several months of ‘stress upon stress ... and uncertainty’, Kennedy contacted her local member of parliament. A few days later, an NDIA staff member phoned her – Kennedy assumed to schedule a review meeting. But the woman wanted to review the plan immediately over the phone.

Kennedy wasn’t prepared but said the woman ‘was very understanding’. The woman agreed to include additional support worker hours and other items. Kennedy was ‘so relieved’ and ‘felt she could breathe again.’ However, two days later the woman rang and told Kennedy she could have half of what they’d discussed. Kennedy said this wasn’t enough for her ‘day-to-day survival, let alone accomplishing any goals’.

One of the items the NDIS wouldn’t fund was a small wearable camera device. Kennedy explained it attaches to her sunglasses, is a portable screen reader and has facial recognition software. ‘One of the things that is really scary when you’re blind ... is having people coming into a room and you don’t know who it is.’ She believes, this device would make her feel safer and allow her to work again. An occupational therapist recommended the device, but the NDIA argued this wasn’t enough evidence. They asked Kennedy to supply an assistive technology assessment. Kennedy said this assessment costs thousands of dollars, ‘nearly as much as the device’.

The NDIA told Kennedy support worker hours could be reduced because medication can be delivered. She said this isn't correct. 'You cannot send a driver to a blind person to give them morphine.'

Kennedy found the 'lack of empathy or understanding was really terrifying'. She said, 'There's just this assumption – well you're blind, you need this much.'

Kennedy is in the process of appealing the NDIA decision.

'It's just another battle again and wasting more money on more assessments again ... asking for more evidence ... I'm tired.'

Kennedy is also battling the state government housing authority. Her ex-partner had kicked in the front door. She asked the housing authority to fix the door and change the locks. She also asked for modifications to enable her to live there without 24/7 support. The authority agreed but the work has stalled. 'They say they'll escalate it, and nothing happens ... I had to ring and make a complaint about the complaints officer.'

Kennedy has a history of 'self-harming really dangerously'. She is 'worried every day whether [she] can survive'. She said the uncertainty and the thought of being isolated in her home has 'led [her] to self-harm again'.

'What do I do? Do I ring my abuser back up and say come back?'

Murphy

‘People my age are being told to go to the scrap heap and sit there sucking eggs all day.’

Murphy contracted polio when he was three. He spent 12 months in an iron lung and ‘nearly died’. He is unable to walk without aids. He told the Royal Commission he’s always been determined to be self-reliant. He’s had a successful career and productive life. Now 70, he continues to work part time and wants ‘to keep contributing to society and paying taxes’.

For much of his life Murphy has worn a ‘straight leg brace’ or splint to help him walk. Over the years his knee has rotated outwards. His leg is unstable and bangs into doors and furniture when he walks. He has to use a wheelchair more often.

Murphy said the use of technology in mobility aids has been ‘going gangbusters’. There is now a C-Brace that uses technology to ‘mimic walking’. The knee is able to bend.

‘It stops the knee from ever rotating wrongly again and the other thing it does is helps your back. As you get older walking with a straight leg for any amount of time, you hurt your back because you’re always hitting the ground hard.’

Murphy’s doctor told him he was ‘the perfect candidate’ for the C-Brace and his life ‘could be restored to full quality’.

First, Murphy needed an operation to straighten the knee and lengthen the leg.

The operation cost \$15,000, which he ‘happily’ paid himself.

‘It was a very painful surgery and recovery was long but I decided to undertake it in the belief that I would then be able to access the NDIS.’ The C-Brace costs \$80,000.

Murphy’s application to the NDIS was rejected because of his age. ‘This policy arbitrarily determines me to be an elderly person unworthy of a brace that would restore my quality of life for productive work.’

When the NDIS was rolled out in his area, Murphy was 63. He said the government knew about his disability and had a ‘duty of care to fully inform [him] of the requirements of any new system’.

Murphy said the government directed him to the My Aged Care scheme. But the funding can’t be spent on assistive devices and it is means tested. Also, the maximum a person can receive each year is \$52,000. Even if he could use the funding to buy a C-Brace it wouldn’t be enough.

He discovered some state governments do fund mobility devices for people over 65. However the state Murphy lives in will only fund another straight leg brace. He said this is ‘inconsistent, confusing and discriminatory’.

Murphy contacted an Indigenous disability advocate who helped him appeal the NDIS decision. The NDIS agreed to put the age limit to one side if he could prove he had been accessing disability services before he turned 65. Murphy gave them his medical and hospital records, but 'this didn't count'.

Murphy wrote to a range of government ministers. No-one could help him. The Indigenous affairs minister said they could give him \$1,000. Murphy said, 'I feel pretty humiliated by this whole exercise to tell you the truth.'

As a First Nations man with a disability Murphy has experienced 'lifelong subtle discrimination' his whole life.

'The NDIS was meant to be a great shining hope for all Australian citizens with a permanent disability ... It is a sad reality that now, like thousands of other polio survivors, I find myself caught up in a bureaucratic mess with the NDIS and for the first time in my life I am the direct victim of discrimination because of my age.'

Natasha

Natasha has a cognitive disability that affects her language, spatial and thinking processes.

She told the Royal Commission about a period in her life, about a decade ago, when she was separated from her husband and living with her adult son in the family home.

During a camping trip with her son, a frightening incident caused Natasha to collapse. She began vomiting uncontrollably and became incontinent. She couldn't walk or stand.

Several hours later at the hospital, the triage nurse asked her a number of questions and Natasha gave her a detailed medical history. Natasha noticed that the nurse didn't take any notes. She was anxious that the nurse understand she is allergic to aspirin.

But the nurse kept suggesting Natasha had a migraine. 'She'd say it over and over again ... and I didn't have a migraine I only had a headache.'

When Natasha was finally assisted onto a bed to lie down, the nurse asked her if she was pregnant. This seemed like a ridiculous question, considering her age, and Natasha was confused. She felt a prick in her wrist and was lifted back up. No-one told her what was in the injection.

When the doctor appeared Natasha was sitting up. 'I thought he knew I couldn't walk or stand but I don't believe he did know.' He looked her up and down, spoke to her briefly and left. The nurse then told her she needed to leave.

Thirty-four hours later, Natasha said, 'my son finds me on the floor'.

Natasha had collapsed and believes this was due to the medication she was given. She had a large blood clot in her brain and required a craniectomy.

When she came out surgery, Natasha's language and comprehension had deteriorated significantly. She said she's now aware this is 'the first indication of somebody with brain damage'. But no-one told her she had an acquired brain injury (ABI), and she was offered limited rehabilitation.

Meanwhile, without her knowledge or signature Natasha's husband transferred considerable sums of money from the joint bank account. He also moved back into the family home.

Natasha had explained to the hospital social worker that she 'was separated and ... intended to divorce' her husband, but hospital staff allowed him to see her several times. 'I cried and cried and cried hysterically,' Natasha said, but no-one did anything to stop him.

Without consultation, the hospital appointed Natasha's husband her 'supervisor'. When she was discharged from hospital he made her live with his parents. Her in-laws were uncaring and forced her to sign her car over to them.

After a while Natasha moved back to the family home. She thought her son would be there but discovered her husband had evicted him. She told us she was terrified to be alone with her husband.

‘I was afraid he’d do something really bad to me ... I was scared for my life.’

Natasha found out recently her husband had opened three bank accounts and moved the money he took from the joint account into these accounts. He bought a car in her name. ‘I never saw a contract, I never signed a contract,’ Natasha said.

Natasha’s GP advised her to leave for her own health and safety. She fled to her brother’s house and took out an apprehended violence order against her husband, eventually divorcing him.

Natasha said she found the family court terrifying and the divorce settlement was ‘totally unfair’.

Not long after, Natasha became homeless and moved to a caravan park. She became unwell and required quadruple bypass surgery. She believes that during this hospitalisation she was given incorrect medication for her existing illnesses and said her ABI affected her ability to assess her options. When she questioned staff, she was isolated and dismissed as delusional.

Natasha received compensation from the health department but said because she had no legal support or advocacy, the amount wasn’t sufficient.

She has since found an advocate who is properly investigating her allegations of medical negligence. She believes advocates can make a difference.

BETTER LIVING

BETTER HOSPITALS

LIVING IN YOURS WITH

SAFETY CROSSING ROAD

MORE TRAFFIC LIGHTS

MORE WORK
FOR PEOPLE

MORE
JOBS
PETER

SPAIN & TIME

BRINGING YOURS AND OTHER

BIRD LIFE

DOING YOURS OWN WORK

YOURS WRIGHTS

GETTING ON WITH LIFE

PETER

Artwork by Peter Ramsden

Zion and Aldari

‘This is like a fire. If you are not going to stop the fire when it begins, it is just growing bigger.’

Zion’s parents adopted him as a small child about 40 years ago. The family migrated to Australia about five years later.

Zion has cognitive disability and is autistic, however he was only formally diagnosed with autism as an adult. Zion attended a mainstream school. As he was entering his teens his mother, Aldari, ‘recognised that something is going wrong’.

One day she received a call from the business where Zion used to ‘help out’ after school. Zion had told the manager he had been sexually abused. Aldari was ‘stunned’, and immediately took Zion to the police station to make a report.

Aldari told the Royal Commission her English at that time was ‘sub-zero’.

‘I couldn’t communicate with all those people at the police station, with everyone ... I don’t think we used interpreter because my ex-husband was taking that part over.’

The police questioned Zion and other children who had been to Zion’s home. They determined he had ‘made it up’, but then gifted him a mountain bike. Aldari finds it hard to make sense of this.

‘They said to me that your son is liar and the story is not true ... but they presented with the mountain bike. So I thought, oh, you’re not presenting someone with a present who is actually telling the lies.’

Aldari feels that whether her son was telling the truth or not, the police should have done more.

‘They didn’t connect my son to seek out psychological help or they didn’t give us any – any hint that look, you need to take your son, or we are going to refer your son ... because this can grow up into the issue.’

For a while ‘life went on’. Then, Aldari noticed ‘warning signs’, such as Zion having an unusual interest in babies and nappy changing. Then in his late teens, he began watching children at a kindergarten near the family home. Teachers at the kindy reported him to the police, who informed Aldari.

Aldari sent Zion to see psychologists. She told them everything she knew, but said ‘still nobody reached any positive outcome regarding to prevent all the issues which has further developed’.

Meanwhile, Aldari’s married life was breaking down. She had a baby daughter and felt it was not safe for the baby to be in the same house as Zion. So she and her daughter moved out, leaving Zion to live with his father.

‘So I had no family here. I felt lonely. I felt totally lost ... I love him as my son, but I love my daughter as my daughter, so the internal war inside me made my mental health actually very bad outcome.’

About five years ago a serious incident occurred. Zion was arrested, placed on an 18-month-long corrections order and listed on the sex offenders register.

Aldari said that following his conviction, nobody provided Zion with any referrals for support. Aldari tried to find help herself, contacting around 40 professionals. ‘Nobody wanted to take him on,’ Aldari said. ‘And I was stuck.’

Aldari’s ex-husband went overseas. ‘So now I am looking after – I have become, you know, a sort of carer,’ Aldari said. She is effectively Zion’s minder, checking where and when he is at all times. ‘[It] is a constant monitoring. It is never-ending and it’s very constant.’

Aldari sought help from a service provider specialising in support for people with autism. But Aldari says they provide little support to adults, or ‘high functioning’ people. ‘This is a system issue,’ she said.

Aldari believes that Zion’s sexual offending is linked to his disability. She also believes the police were negligent in not taking Zion more seriously or referring him for appropriate support when he was a teenager.

‘I reported. I connected. I put him into a professional’s hands, so and eventually nobody, nobody cared. Nobody take that issue seriously until he ended up in front of the Magistrate.’

Niklaus and Zuri

Niklaus and Zuri are long-term partners in their 50s. Niklaus has a disability that effects his speech and movement and uses a wheelchair. He worked in the IT sector for almost 20 years. Zuri has a physical disability, is speech and hearing impaired and lip-reads. She is a talented artist and also provides social support for people with disability.

Niklaus and Zuri told the Royal Commission they are frustrated by the increasing obstacles they face accessing the community.

Like everyone, to enter a café or shop they need to scan a QR code using their phone. This is physically difficult. There is often no table or hard surface where they can balance their phones. Increasingly, there are no staff to help them or complete a written check-in.

Niklaus and Zuri are exempt from wearing a mask. Zuri said people give them 'dirty looks'. Niklaus went into a government office and staff initially asked him to leave. He had to give an in-depth explanation for his mask exemption. He felt uncomfortable drawing attention to himself and having everyone looking at him. Taxi drivers often insist he wear a mask not understanding how difficult it is for him.

Zuri has designed a sign she wears around her neck explaining she is unable to wear a mask due to her disability. It also explains she is deaf and requests people remove their mask when speaking to her to enable her to lip-read. Some people dismiss the sign. 'If they don't have time they don't care,' she said.

Niklaus suggests when premiers give daily COVID-19 updates they should remind everyone that people with disability are exempt.

'It's too hard, with the face mask and the QR code. It's just too hard. So now I stay home ... I only go out to do my food shopping and that's it, back home,' Zuri said.

Niklaus and Zuri used to love going to a café every day. They use a straw to drink because they don't have full control over their movements. Cafés no longer provide single-use plastic straws because of government regulation. Cafés can provide plastic straws to people with disability but 'they don't and they don't care,' Zuri said. One time she found a plastic straw in her bag and asked the staff if they could rinse it. They refused and told Zuri to go to the bathroom and rinse it herself. Staff sometimes offer metal straws but these straws can cause mouth injuries and chip teeth. Cafés won't provide silicon straws because they are difficult to clean. Niklaus said people 'need to be educated'.

A couple of years ago Niklaus had a car accident – he described it as a 'small bingle'. When police arrived they wrongly assumed he'd been drink driving. Niklaus was required to modify his steering wheel by adding a knob, and this restriction was added to his licence. Niklaus and Zuri like to travel but he can't hire a car because of the restriction. Niklaus had to re-sit a driving test and have a series of medical checks for authorities to remove the restriction. 'It just caused so much distress,' he said.

Niklaus would like to spend his retirement travelling while he is physically able. He has accumulated a significant amount of superannuation but is unable to access it for a number of years. His life expectancy is less than a person without a disability, he said, and the government should lower the preservation age accordingly.

Meanwhile Zuri continues to work. She was working for a disability employment enterprise until she discovered she was being significantly underpaid. 'I loved that job but I was working very hard for nothing.' When she made a formal complaint the enterprise increased her pay by reducing the other workers' pay, so she left.

She now runs her own business. 'I get more an hour than I got in a whole day. I can't believe it. I can have a holiday.'

Pablo

Pablo is in his 60s. He was ‘a normal person, an able-bodied person’ until a couple of years ago when he acquired a brain injury. He told the Royal Commission his ‘whole life changed from that point on’.

‘What it’s meant for me is a huge life-changing situation where I have to depend on unscrupulous people that are coming at me for my NDIS funding. So, like, I’ve hired providers to provide me with services and they plundered my funding and have given me no services.’

Pablo described his first provider as a ‘toxic organisation’ that ‘targeted’ him while he was still in hospital after acquiring the brain injury. A social worker offered to help Pablo apply for NDIS funding. Much to his surprise, it ‘was approved in three days’. ‘[Then the provider] came and told me a great story about how they were going to help me when I left hospital.’

Prior to the incident, Pablo had been living in his own home, but it was no longer accessible or safe for him. Pablo ‘signed over everything’ to the provider so they could set up a place for him to stay.

The organisation rented a large house for Pablo with ‘a huge garden’. They put in ‘brand-new leather lounges’, a ‘huge widescreen TV’ and brand-new whitegoods.

Pablo kept asking them, ‘Why did you rent this house? It’s too big for me.’

‘I was only new on the NDIS. I didn’t understand. But since then, I’ve learnt ... and I can tell you that they were playing a confidence game with me.’

‘They took one-third of my funding to set the house up,’ Pablo said. ‘Then after three weeks they gave me a weeks’ notice to find somewhere else to live ... The intention was to set up the house and get rid of me.’

Pablo has experienced exploitation and poor service from ‘a number’ of disability service providers. For example he told us about one female support worker who insisted on sitting in the bathroom and watching him shower. Another support worker called the police on Pablo when he wanted to hang on to the group home phone for a bit longer because he was waiting for a specific call.

Pablo said he made ‘a lot’ of complaints directly to the organisations. ‘I was asking to be treated like a human being.’ But he believes most providers have the same attitude: ‘You’re disabled. You’ve got a mental disability. We will call the shots. You have no choice and control.’

He said he also made a range of complaints to the Quality and Safeguards Commission but believes it to be ‘totally useless’. He says that for some within the Commission, the ‘agenda’ is ‘to protect service providers from participants’ complaints’.

Right now Pablo is doing well. He has found a provider who is ‘like-minded and understands’ and is ‘doing the right thing’. ‘They’re following the guidelines.’

Sophie

Sophie was in her 40s when she was diagnosed with early onset Parkinson's disease. She had three children, was working as a teacher and in a new relationship. At first the symptoms were mild, but as her tremors began increasing she needed more and more medication. 'I became unable to think clearly and for the first time in my life, dependent on another person,' she told the Royal Commission.

At the time, deep brain stimulation (DBS) was the 'gold star' treatment for early onset Parkinson's. However, no-one ever informed Sophie it might cause changes to her personality.

'I woke up and I did feel different to what I normally felt and I couldn't understand it. I asked the doctor "when do you think I'll get better, because I'm feeling a bit strange" and he yelled at me, "You need to be grateful for the things we can offer you."'

The doctor told Sophie to try harder. 'I went home ... and from that moment on, I saw the look in my kids' eyes ... that's not our mother anymore.'

After researching DBS and attending conferences, Sophie discovered 'there are a group of people who are sensitive to the electrical stimulation that's put through the brain during this procedure ... [who] develop things like suicide ideation [and] personality disorder'.

'If [the surgeon] had communicated to my family beforehand that there's a possibility that their mother could develop this stuff, then we could have talked all together. I wouldn't have felt as though I was odd and they wouldn't have felt afraid.'

Sophie's research revealed her surgeon had been mentioned in an inquest into the suicide of a man. Sophie read the man's story and about the symptoms he experienced. '[His] story up to the point where he killed himself was exactly mine.'

She learned the reason her doctor didn't speak to patients about the possibility of psychosocial complications was because he didn't believe the research.

Sophie decided to change doctors and asked for her medical records to be transferred. But the doctor refused, forcing her to apply to the medical ombudsman. At first the doctor told the ombudsman 'he preferred to pay the fines than hand them over'. The doctor said he felt Sophie was 'too emotionally unstable to be able to handle the information that was in the medical records'.

After six months the doctor eventually released Sophie's records, but they were heavily redacted. The ombudsman told her it was impossible 'to find an independent medical clinician in Australia capable of interpreting them'. Sophie said 'it was very upsetting'.

‘When you enter the world of Parkinson’s disease, or any disease that involves the brain, it’s very easy for the medical world to say or suggest, “you’re not a reliable person” or “you’re too emotional to be able to have your records.” You’re treated as a child ... that was a big surprise.’

Sophie requested her medical records from every doctor who treated her following her diagnosis but was blocked until she made a Freedom of Information (FOI) request.

Reading her files, Sophie discovered the way doctors and clinicians talked about her. Despite her history of Parkinson’s disease, cancer and pain, they often dismissed her as ‘irrational’ and difficult – the message throughout seemed to be ‘this woman is a pain in the behind, be careful.’

Because Sophie had gone to the ombudsman and used FOI, other specialists refused to treat her. Without specialists, GPs were at a loss. ‘I was given a cocktail [of drugs] and the result was continual pain, brain fog and serious infections.’

Sophie thought she was going crazy. Around this time her partner left and Sophie had end-of-life discussions with her children, who responded by organising a mandatory detention order.

Sophie successfully appealed the order. She moved states and found a new specialist, who explained her delirium had been caused by the medication.

Sophie is now working to ‘rebuild relationships with [her] kids’ and has a message for medical staff. ‘Don’t write medical notes unless it informs the next person – don’t make judgements – if it’s going to do harm, don’t write it.’

Reese

‘I was acting psychotic and no-one did anything, but when I put on some make-up and cross-dressed they wanted to section me.’

Reese, late 20s, is non-binary and gender diverse. When they first started experiencing hallucinations and paranoia a few years ago, they weren’t ‘taken seriously’, they told the Royal Commission.

Reese was ultimately diagnosed with psychosis due to schizophrenia. They’ve also been diagnosed with anxiety and depression. One doctor told them they had borderline personality disorder. Reese is not so sure about this.

Reese doesn’t know whether people abuse them because of their disability or gender diversity. But they know, either way, it’s ‘not good’.

Not long ago, Reese was experiencing psychosis and was in crisis. They rang a mental health service and two people arrived at Reese’s home. They told Reese that Reese needed to exercise more. Reese asked to speak to their manager. When Reese rang the number they provided, a person from a TV news desk answered the call. Reese made a formal complaint but said it was dismissed ‘because of [their] condition’.

Reese was in hospital when their grandmother died. They were upset and told a nurse, who said ‘good’. Her colleague looked shocked.

‘A lot of services ... staff have value systems that demonise gender diverse and psychotic people and there’s not much accountability or ways to complain.’

Doctors and nurses have called Reese a ‘faggot’ and have ‘smirked’ at Reese because of their gender presentation.

‘[At] another service, I was trying to fill out my information as non-binary and gender diverse. I later found out ... they hadn’t listened to anything and just put down male.’

Over the years, Reese has had multiple misdiagnoses. They have been over medicated and at one point were on more than six different drugs, causing a number of adverse medical issues. They’ve also signed a lot of forms ‘in impaired states’. ‘On reflection,’ Reese said, ‘[it] kind of seems wrong.’

Reese described ‘a cycle’ of hospital, work and relapse.

If Reese relapses they go to hospital. There, they are ‘tranquillised and restrained’. No-one treats the ‘causes or experiences that led to the psychosis’. ‘Once you’re stable [you’re] sent away.’

To continue to receive a Jobseeker payment, Reese has to engage with a disability employment agency. Reese is required to 'apply for so many jobs' they're not qualified for and 'don't have the mental health to manage'. They said they're often pressured to accept a job before they are ready. Most of the work available is low paid. The employers are often 'unscrupulous' and don't give consideration for their disability. Reese said they've been forced to work extra hours unpaid and take on significant more responsibility without being renumerated. Reese's health deteriorates and they relapse.

Reese has broken the cycle for the moment and 'feels lucky'. 'I've been able to come out of that and hold down a job for a while. A lot of people in my situation don't have private health cover or relatively supportive families.'

Recently, Reese described the emotional and physical abuse and neglect they experienced at school and in relationships to a new doctor. For the first time a doctor acknowledged 'there's a lot of trauma which could be the root cause'. Reese is trying to access trauma treatment. They feel community treatment would be better than the medical model.

'Supporting people economically while they get community treatment, learn about their illness, learn how to manage their illness ... when they're not worried about managing their house, food and bills.'

Reese wants greater 'respect and dignity given to people with psychotic illnesses'.

Paulina

Paulina has post-traumatic stress disorder, severe depression and anxiety as a result of her experience in the mental health system almost 40 years ago.

Paulina had three children under seven when she fell pregnant with her fourth child. Three months into the pregnancy she began to experience 'persistent suicidal thoughts'. She immediately went to the GP who referred her to a psychiatrist.

Paulina told the psychiatrist she asked for help because she 'was very frightened' by a thought she had about the children. 'If I was going to commit suicide I would take them all with me to heaven.' But, she stressed, she had this thought 'once and once only'.

After revealing this, she spent 10 days in a private hospital. Not long after returning home, she 'took a minor overdose of tablets' and was voluntarily admitted to the psychiatric unit of a public hospital.

One month before the baby was due, despite 'still having suicidal thoughts', Paulina was abruptly told she could go home. 'I was not given any offers of help or support.'

Back home, unable to cope, she took an overdose and was rushed to emergency in a coma. The baby was delivered by caesarean section.

Following the birth, Paulina stopped having suicidal thoughts and was no longer depressed.

Despite this, she was admitted to a locked ward in the psychiatric unit and a child abuse and neglect team removed her baby. No-one in the mental health unit spoke to her about what happened and no-one listened to her when she told them how she felt.

The obstetrician told Paulina 'it was not [her] fault and this sometimes happens during pregnancy and once the baby is born you tend to feel much better'.

Paulina believes if she'd had access to health checks and been informed about prenatal depression after the minor overdose, the situation might have been different. She would have had 'some reason to not despair of ever getting better and would have had a real incentive to hang in there until the baby was born'.

Without consulting Paulina, the child abuse team proposed placing the child with foster parents unless Paulina's husband 'could prove he could provide for [the baby]'s care at home'. Fortunately her husband's parents were able to move in with the family and after three months the baby went home.

After six months, Paulina appealed to the Mental Health Tribunal. She appeared for 10 minutes. The head psychiatrist was present but Paulina was not allowed to remain in the room to hear the psychiatrist speak. She believes the process was unfair and weighted against her.

Suddenly, a week after the appeal, she was discharged but the treatment order remained. She was required to attend regular appointments with a psychiatrist, the baby's specialist doctor and her GP. The head psychiatrist wrote to Paulina's GP informing him Paulina continued to have 'persistent suicidal and homicidal tendencies'.

'That was a lie. I would like them to tell me, if it was persistent, then who I told it to, because I didn't tell it to anyone.'

After 12 months the treatment order was lifted but Paulina was badly damaged and too frightened to seek help. Several years later when she did ask for help, a psychiatrist told her, 'You need psychiatric help to get over your psychiatric help.'

Paulina said when she returned home she was met with 'total silence' and was shunned by friends and family because 'mud sticks'. 'They think they know something so they generally keep me at arms-length or exclude me.'

'I have had to deal with the ramification of this trauma for 40 years.'

Paulina is now caring for her husband who has a disability following a cancer operation. She is amazed at the support and help he receives. 'People actually talk to him about his disability and illness and always ask how he is.'

She is glad that 'a person with a mental health issue' is now recognised as 'a person with a disability'.

Priscilla, Lyla and Noel

Priscilla is in her early 40s, autistic and non-verbal. Her parents, Lyla and Noel, told the Royal Commission Priscilla is unrecognisable from the woman she was when the family first moved to Australia a decade ago.

A few years after they arrived, Lyla's health deteriorated and she was no longer able to care for Priscilla. As Priscilla was not an Australian citizen, she was not eligible for the NDIS.

The family was advised the only way Priscilla could receive government support was for her family to relinquish her into state care.

Initially Priscilla was placed into emergency respite care. 'This would have been a frightening situation [for Priscilla],' Lyla said, 'and difficult for her to understand.' When residents who posed a risk to Priscilla's safety arrived at the emergency respite, staff moved her to another centre. After one move, Lyla noticed Priscilla had 'severe bruising on her upper thighs'. There was no incident report and no explanation.

After two years of being moved back and forth, Priscilla was placed in a home with a male housemate who lived in a granny flat. Priscilla's family hoped this home would be permanent, but it didn't work out. Lyla and Noel soon discovered the support workers, who were mainly male, were taking her food and stealing her possessions. '[Priscilla] regressed to living in her bedroom,' they said.

Around this time, Priscilla reported two incidents of sexual abuse to a nurse. Priscilla told the nurse a male support worker had taken naked photos of her, and there was a second incident involving a dental visit. Priscilla used mime – her method of communication – to make these reports to the nurse.

The nurse reported both incidents to the police. Police would not permit family members to support Priscilla during their interviews with her. They told Lyla and Noel they couldn't lay charges because Priscilla's evidence, given non-verbally, 'couldn't be substantiated'.

Priscilla moved house again, this time to live with an older lady. 'On the face of it everything looked great,' Lyla said.

But when the woman moved out, the service provider talked Lyla and Noel into allowing two teenage boys to move in – they were 'kind, gentle, loving boys who would love [Priscilla] and look out for her'.

As weeks went on it became clear both boys were violent. The abuse was 'non-stop' and it 'became impossible' to protect Priscilla. When Lyla and Noel insisted the provider take action, the provider cancelled Priscilla's agreement and relinquished her care.

Since then Priscilla has lived at another house run by a different provider.

Over time, staff at this house began to neglect Priscilla's personal hygiene. Lyla would arrive to take her home each Sunday, only to find Priscilla in bed, filthy. She hadn't been showered and her clothes were dirty.

Staff told Lyla that Priscilla didn't want a shower and didn't like her hair being washed. If they tried she would become aggressive and threaten to slit her own throat. But Lyla and Noel said it was just easier for shift staff if Priscilla said she didn't want to shower – 'they just leave her for the next carer.'

Constant staff changes and inexperienced support workers led to Priscilla 'having melt downs and progressing to self-harm'.

'Her behaviour has grown worse over the years because she's been ignored and abused ... The huge mistake carers have made is that she cannot talk, so she is excluded from any participation.'

Noel and Lyla also reported incidents of staff stealing food. They have seen support workers in the shops with trolleys full of food but there is very little in the house.

Complaints are redirected back to the service provider and the response is 'if you don't like it, leave'. But as Priscilla is not eligible for the NDIS, her options are limited.

Noel has recently had a serious health scare. He and Lyla are terrified about what will happen to Priscilla if they die.

Kolton

'I did not understand the way my mind worked.'

Kolton is in his 40s. He is deaf and autistic, and has attention deficit hyperactivity disorder.

'I was kind of in my own world,' he told the Royal Commission.

At three, Kolton's mother took him to the city for intensive speech therapy. They stayed in a hotel and he spent some time in the hotel's childcare facility. A man led Kolton away from the facility and sexually abused him. Kolton attributes his 'hypersexuality' to the abuse. 'I believe that has made my life difficult for me in some parts and led me to some confusion.'

In primary school, Kolton was adventurous and began running away from home. He caused his parents 'a lot of grief and frustration' because of his 'behavioural problems'. He said he lacked empathy, didn't understand people and thought people's personal property 'didn't matter'.

One time, when he was about seven, a teacher found Kolton with his hand in her bag. To teach him a lesson she told him to put his hand back in the bag. He did and she slapped his hand. He quickly pulled it out and the teacher told him to put it back and she slapped him again. She made him do this repeatedly, but all it did was confuse him.

Because of Kolton's 'out of control' behaviour he was prescribed different medications. He experienced some debilitating side effects and he felt 'more out of control'. He couldn't think clearly.

At 16 he was admitted to a psychiatric unit. After he was released he left home and stopped taking medication.

Kolton's said he's 'very, very frustrated' and 'disappointed' by how he's been treated in the workplace. He's been underpaid, called names and unfairly blamed.

One time Kolton was working at a sawmill. A group of workers were playing cricket. 'I wanted to try and be involved and join in' so threw a small piece of wood, like a ball, at the bat and went back to work. The next day he was fired because the others told the boss he started the game. 'I had no opportunity to explain what was going on which was very disappointing for me.'

Kolton's mental health deteriorated and he started using alcohol and pharmaceutical drugs. He described his approach to life as naïve and feels people took advantage of him. A friend encouraged him to break into an animal surgery and steal drugs and after that his drug addiction 'started spiralling down'.

Kolton was often in trouble with police and went to prison several times for about a month each time. One time, he was placed in the protection unit 'but even there, people with disabilities were not cared for,' Kolton said. The 'influence there is not very healthy' and he 'suffered a lot of abuse'. He was pulled down, out of sight, in the laundry room and raped. Prisoners 'put things up [his] backside', and just before he was released they held him down and shaved his eyebrows.

Kolton said prison officers sometimes saw what was going on but did nothing to protect him. Other prisoners tied him to a fence with socks and stripped him naked – officers watched. One time, officers deliberately locked him in a room with another prisoner who raped him. 'I was afraid to call for help because I didn't know what the repercussions would be.'

When he was released from prison Kolton made a complaint, but nothing was done. The prison system needs to be 'fixed for people with disability,' he said. 'I have no idea what other people have suffered.'

About five years ago Kolton was watching a movie. It 'sort of broke me' and 'I realised I needed to get my act together'. He stopped smoking, drinking and taking drugs. 'I broke free and I've never gone back since.'

Priya

Priya is in her 40s. She lives with bipolar disorder, myalgic encephalomyelitis (ME), fibromyalgia, depression and anxiety.

Priya was 10 years old when she began experiencing severe throbbing and pain that would move suddenly from one limb to another, along with near constant soreness in her back and neck. During the day the pain limited her movements and activities, and at night it would cause her to wake in tears. But doctors dismissed her complaints. They put it down to 'growing pains' and suggested she was just 'school-phobic'.

Priya was made to feel 'naughty' if she complained, so she 'tried hard not to ... show any visible signs of the pain'. She endured four years of this before finally being diagnosed with severe fibromyalgia and ME.

Priya's diagnosis meant there was now a lot more support available to her, but the trauma of not being believed by medical professionals and their failure to take her illness and disability seriously followed her into adulthood. 'Ever since then I have internalised self-blame,' she said.

As an adult, Priya says medical professionals have continued to 'neglect and devalue' her because of her disability. In particular she has experienced 'systemic abuse and neglect with the NDIS application, review and appeals processes'. It has been 'a battle' to be recognised and obtain support and the 'stress and trauma' it involved has impacted her health issues and disability.

Priya first began applying for access to the NDIS about three years ago, primarily on the basis of her bipolar disorder and anxiety and secondarily on the basis of her ME. Over the next three years, Priya and her care team were required to give evidence proving her disability on eight different occasions.

'Analysing and describing my disability to strangers with no compassion for my wellbeing is not just paperwork, it's traumatic and dangerous. I was not ready to face it, let alone over and over ... to faceless bureaucrats who just want to avoid paying money. It's systemic abuse.'

Having to repeatedly prove her 'incapacity' and 'constantly focusing on the negatives over and over again' took a huge toll on Priya's mental health, with 'flashbacks, paranoia, fear, existential depression and trauma' on a scale she had not experienced before.

A big part of the problem 'proving her disability' was to do with the language used by the NDIA. Priya told us that despite English being her first language and being university educated, she struggled to interpret the language used by the NDIA.

'I had a care team of eight doctors and specialists and they also struggled to express my needs in appropriate NDIS disability language as opposed to the health language they are experts in. They supported me and bent over backwards to try and give evidence, however their words were misinterpreted and used against my case ...

'It's like the NDIA have a checklist that they're not fully revealing to us. To them it's pass or fail. It doesn't matter what your actuality is – if your language is not spot on, you're gone. It's an exercise in semantics, not diagnostics.'

When Priya was granted access to the scheme, it was for her psychosocial disability only, not for her physical disability. She had no funding for the longstanding supports previously provided by the local community organisation, such as cleaning, shopping, cooking and transport. She was only able to cope with the support of her mother and friends.

After several reviews over two years, a new plan was approved. It contained adequate core supports, particularly for social participation, but with no counselling and only very limited funding for therapy. The plan when to review again, this time by the Administrative Appeals Tribunal.

Reflecting on her experience with the NDIA, Priya said:

'Subjecting applicants to trauma is systemic violence. Taking away all core supports is systemic neglect. Living with multiple severe permanent disabilities is traumatising. Applying for care should not be more traumatising than dealing with the disability itself.'

Reda and Dot

‘I know parents are petrified to speak their mind, to say something, or to hold organisations to account.’

Dot understands this fear. She told the Royal Commission she too has experienced the terrible consequences of ‘saying something’.

Dot’s daughter Reda is in her 50s and has intellectual and physical disability. She has lived in group homes since her late teens.

About 20 years ago, Reda sustained severe burns in one of these homes and was, after some delay, hospitalised.

Staff on duty tried to tell Dot the burns were a rash, but doctors at the hospital said the injuries were consistent with being in a scalding bath.

The organisation denied any fault for the burns or failure to respond with urgency, and Dot felt the investigation that followed was ‘grossly inadequate’.

All these years later, Dot still doesn’t know exactly what happened but she is certain that the burns were inflicted in retribution. Prior to the incident, Dot had lodged a complaint about the home employing a new member of staff who had no professional registration. Following the complaint, senior staff had tried to intimidate Dot.

‘[One of them] tried to prevent me from leaving Reda’s room one weekend. She blocked the doorway and said “Please don’t speak about what goes on in [here] outside”. I replied “I will speak to anybody when, where and why I like”. I didn’t think anything would come of me saying that, but it obviously did.’

At the time, however, Dot says she ‘didn’t recognise it as retribution’. ‘When [Reda] was actually burnt, I truly could not ever believe that one human could do that to another, deliberately.’

But then there was another incident.

‘A woman who was sharing the room with [Reda] ... her mother rang me and said “[Dot], my daughter has come home with cigarette burns”. It struck me, vividly ... it’s obvious that it was retribution for both of us ... because [the woman’s] father was quite outspoken.’

This remains a source of trauma for Dot.

‘When I read through the material about her burning, and I re-read it, the word that stuck out to me was “retribution”. I burst into tears because I felt I’ve done this to my daughter. My beautiful daughter. How could I possibly have caused her such damage? That disturbs me to no end.’

Reda moved to a new home managed by a different organisation.

At this home, staff gave Reda another resident’s medication with terrible consequences – ‘From that day onwards, she has never walked.’

‘When a meeting was called with the superiors,’ Dot said, ‘I was made to feel that I was super sensitive and that I was really complaining over something that wasn’t of any importance.’

Dot reported this incident to the ombudsman and was soon after upbraided by board members of the organisation managing the home. ‘All they could talk about was “we won’t be able to get any funding now” ... there was no care.’ Dot was appalled.

‘How uncaring, how disrespectful of other people’s lives.’

When Reda moved to another home, staff gave her the wrong medication again.

‘It resulted in my pleading for incidents reports,’ Dot said. ‘That’s another issue – incident reports will never be given to a parent or a guardian ever by any organisation ... it is important that incident reports are dealt with objectively and honestly between the parents and the organisation.’

Dot would like to see support workers get better training and support so that these kinds of incidents are less common.

But she says cultural problems in ‘the upper echelons’ are also a common theme.

‘Every organisation had an attitude of ownership. That is incorrect and it should never happen. They don’t listen to parents. They own the individual. They own the [incident reports]. They do what they like. We do need to have that changed.’

Dot also said there needs to be better support for carers, particularly women.

‘Many women are left on their own to take charge and to care for their son or daughter ... all of these people need respite care. Every one of them. But there are no facilities available ...

‘It’s a lot of heartache and distress that people go through ... I just want to see a better life for them. A better life of happiness and joy.’

Kailani

‘At the ... place I worked ... their basic human rights and needs were not getting met.’

A few years ago Kailani worked for a disability service provider across several different homes with residents who required 24/7 support.

Kailani told the Royal Commission the provider didn’t treat the residents with ‘respect or dignity’ and spoke about them ‘very poorly’. She said, ‘When I raised that, I ended up in a HR meeting where I was reprimanded.’

One time, Kailani worked with Jess. She has a cognitive disability and is non-verbal. Kailani found some white powder in her cupboard and suspects it came from another resident.

Kailani was worried Jess had ingested the substance and called an ambulance. She reported it to the team leader and called Jess’s father who wanted the substance tested. The team leader took 40 minutes to arrive. He berated Kailani for calling the ambulance and scooped up a small amount of the substance.

The team leader later told Kailani it was soap powder. Kailani does not think this is true – the substance did not smell like soap powder. Kailani discovered the substance wasn’t tested and believes the team leader did not notify police.

The team leader removed Kailani from the house because she was ‘too emotionally involved’. He forced Kailani to do ‘pages of reflections on [her] behaviour’.

Next, Kailani supported two elderly men with development disabilities. One client had lived there for 15 years and was having epileptic seizures during the day. He had not seen a neurologist for years.

Another time, Kailani raised a complaint after a client was forced to catch buses despite previously having issues with public transport. Her supervisors bullied her for making the complaint and performance managed her. Kailani said reports were paper-based. This meant reports could go missing or be amended without the author’s knowledge.

Support workers did not assist clients with personal hygiene. Kailani believes they had the capacity to do this but chose not to. Kailani said oral health was badly neglected. One client had a fungal infection that spread from the sinus into the teeth. Kailani took him to dentists and specialists and had to send the invoice to his sister. It cost \$23,000 to fix his teeth.

Kailani is now working for a different service provider. She said the service is ‘amazing’, very supportive with a strong focus on client safety. Clients are happy and safe.

‘It’s just such a different atmosphere,’ she said.

Roman and Nico

About five years ago Roman had a severe stroke that left him quadriplegic, non-verbal and incontinent. He was hospitalised for 10 months. His father Nico told the Royal Commission that during this time Roman was abused and neglected.

In the first few months there were a number of serious incidents. These included nursing staff failing to administer blood-thinning medication, resulting in a blood clot. Then a surgeon 'nipped' a blood clot in a vein, causing a brain bleed.

About three months in, a doctor from Roman's neurology team approached his parents. 'He stopped us and told my wife and I that he needed to talk to us and if we ever discussed the conversation with anyone else he would deny it,' Nico said.

'He told us it would be in [Roman's] best interests and our best interests to be out of that hospital ... that [Roman] was not receiving the treatment that he should receive.'

Roman's parents tried to speak to the neurologist in charge but were told 'he doesn't speak to patients'.

'We would go to the hospital every day and night ... We would find [Roman] in soiled sheets, dried urine sheets, blood ... On one particular occasion the nurse was having difficulty ... getting the machine for the PEG [percutaneous endoscopic gastrostomy] feed to operate. She ripped it out, threw it in the bin and walked off in disgust ... so my wife and I taught ourselves how to look after and monitor Roman while he was in hospital.'

On one of their night visits, Roman's parents found bruising on Roman's forearm clearly outlining four fingers – it was a handprint. Staff said the bruising was a result of blood-thinning medication. But Nico and his wife were sceptical.

'We'd been looking after Roman for six months by now and there had been no bruising at any time by any of us who were his family that were helping out in the hospital.'

After a few more months, Roman's parents approached the hospital to discuss Roman's treatment and rehabilitation.

But staff considered Roman to be a 'nil candidate' for rehabilitation. The paperwork had been completed, they insisted, and Roman would be transferred to a nursing home.

Roman's parents fiercely resisted this. Over the next two weeks they did as much training as they could so they could safely care for their son at home.

Roman has now been home for four years. He is doing well, but his successful rehabilitation in the family home has come at a huge emotional toll for his family and has ruined them financially.

Nico's business had started to fail when he began spending so much time by his son's side in hospital. When Roman came home, Nico accessed his superannuation and all his leave entitlements to finance Roman's support needs.

Roman's family decided to build an extension on the family home to accommodate Roman and his support equipment to ensure he would never have to go into a nursing home. They used \$300,000 of Roman's total and permanent disability payout to build the extension.

At some point, a lawyer advised Nico to contact the relevant tribunal to explore guardianship with respect to Roman. Following this advice turned out to be disastrous.

'We went to the hearing and our world just fell apart.'

The tribunal ordered them to repay the \$300,000 and deemed the \$150,000 they spent of their own money to be a gift to Roman.

'We're seen as the enemy ... because we took \$300,000 off a person with a disability. But we bought him a home, and [Roman] and his sister, in our will, get this home. He will live here until he dies. And he will have the care, the support and the love of everyone in this home.'

Roman's parents lost their business and re-mortgaged their home. Nico has been unemployed for more than two years. He applied for a carer's pension but is only entitled to a \$130 per fortnight, despite providing 130 hours of care a week.

They think there should be better protections for families like them. 'We're at the mercy of bureaucracy at extreme levels,' Nico said.

They also think the government should provide more accommodation for young people with disability, instead of sending them to nursing homes.

Marcos and Madalyn

Madalyn is the mother of Marcos, who is in his teens, autistic and living with Tourette syndrome, attention deficit hyperactivity disorder and anxiety.

Marcos is gifted at maths.

'He can solve a Rubik's cube in about three minutes,' Madalyn told the Royal Commission. 'He's a wonderful, wonderful human being. Although, unfortunately, not everyone in society thinks that.'

When Marcos started school, Madalyn tried to enrol him in the after-school care program his sister attended. After she applied, the organisation running the program told her it couldn't accept Marcos.

'This person that didn't know my son used the words and said, "Your son is dangerous." I said, "Well, how do you know this? You've never met him, and he doesn't have a dangerous bone in his body." And the response was, "Well, he has autism, so he must be dangerous." I'm like, "Well, no, he's not dangerous".'

The organisation eventually agreed to enrol him, but said Madalyn would have to pay a higher fee.

'They said, "Oh, we're just a not-for-profit organisation. We need to cover extra costs. You need to pay more," and they thought they were perfectly justified in charging us more.'

Madalyn said she sought legal advice and the education department 'ended up paying money directly to the provider'.

When Madalyn tried to enrol Marcos in a private primary school, the school told her she had to pay for an extra staff member for the class.

'We were quite shocked. ... Basically all the costs associated with employing that person we would pay; their leave, their long service leave, their sick leave, superannuation, everything ... We are not made of money. We are just a regular working family with a mortgage.'

Madalyn said she instead enrolled Marcos in the public primary school down the road.

'He had a fantastic experience ... What made it successful, I think, was the mindset of the school principal. He was just really welcoming and flexible, you know. Just nothing was too much trouble. Not that we needed that much, but he was just, we felt welcome there.'

When Madalyn more recently tried to enrol Marcos in the private high school his sister attends, the school 'started to ask us for additional information'.

'At first, I was giving them this information, and then they would ask for more information, and it was getting quite ridiculous.'

For example, the school wanted the details of his NDIS package.

'Why is that relevant to his enrolment in school? It is absolutely not relevant at all ... All of his peers were receiving offers of enrolment, but he wasn't.'

When Madalyn refused to give the school the details of his NDIS package, they said they 'would not progress the enrolment.'

'And they never rejected Marcos, but they refused to progress it. ... Yet I provided everything that every other parent provided and more ... In the end, we walked away from that.'

Madalyn said Marcos is now thriving at a public high school.

'He goes to a mainstream school and is, in fact, in the gifted and talented stream.'

Ronnie and Freida

Ronnie was a happy, healthy baby until, at the age of two, he had a terrible accident that caused serious damage to his head.

Ronnie was raced to the hospital where he had a CT scan. The results were 'normal', so doctors discharged him within a few hours and sent him home with painkillers.

However over the days and weeks that followed, Freida, Ronnie's mum, noticed her child 'wasn't himself'. He wasn't maintaining eye contact or using words he had been using prior to the accident.

Doctors dismissed Freida's concerns, so she took Ronnie to see a private paediatrician. She told the Royal Commission that 'after asking some questions and ticking a few boxes', they diagnosed Ronnie as having autism.

Within two months of the accident Ronnie had lost all his speech and recognition of familiar surroundings and family, and appeared to be almost in a 'state of dementia'. Ronnie's GP eventually made a referral for him to see a paediatrician and allied health professionals in the public system.

Ronnie underwent MRI scans, skin biopsies and various blood tests, all under general anaesthetic. He had several hospital admissions and underwent four lumbar punctures within a year.

Freida had done some of her own research. She pleaded with the treating team to stop re-running the same tests, and instead conduct different scans that could potentially eliminate or identify reasons for Ronnie's continued deterioration. She said she would privately fund such a scan, but the treating professionals denied her requests.

Ronnie had appeared to be experiencing pain in his head ever since the accident. Things took a dramatic turn when, at the age of six, he began to suffer on a daily basis and lost control of his bowel and bladder. His health deteriorated to the point that he required multiple ambulance transports to the children's hospital. On each occasion Ronnie was treated for neurological behavioural disorder.

Currently Ronnie is in a very bad state of health, suffering severe physical and vocal tics and will often 'collapse in pain crying'. Freida is desperate to get help for him, but none of the many specialists or treatments she has been able to access over the past 10 years appear to be helping.

Freida says her biggest frustration is that she knows there are other medical tests and investigations available, but the state health department will not allow these to occur.

She believes Ronnie's brain injury and chronic pain have been overshadowed by his diagnosis of autism.

'It's never been noted that Ronnie suffered a traumatic brain injury ... because it wasn't classed as a major bleed and happened within five years of age and that's where the autism spectrum disorder comes in at ...'

Freida would like to see medical professionals 'actively listening to the family of disabled and vulnerable children'.

'We may not have medical degrees and qualifications, but we're living day in day out with this little person. Our concerns and questions regarding possible other treatments may be of benefit ... [We should] be taken seriously and not just classed as neurotic parents.'

Freida is still searching for answers and ways to alleviate her son's pain. She is determined to go overseas to seek independent specialists that might consider her son's case from a fresh perspective, however COVID-19 travel restrictions put that plan on hold.

Stefan and Frida

Frida told the Royal Commission about the abuse and neglect her son has experienced in the care of disability service providers. She says a lack of consequences has been a common theme in their lives. 'When you look at our history, our private history, how can we have confidence in moving forward?'

Stefan is in his late 20s and has Down syndrome. Some years ago, as a client of a disability service, he was indecently assaulted.

'We went down the court process and unfortunately ... they argued technicalities all day and it was thrown out of court,' Frida said. 'So the perpetrator got away with it and there were no consequences.'

When Stefan was in his late teens he was involved in a car accident.

He was supposed to participate in a day program on a farm where they pulled lawn mowers to pieces – he is obsessed with cars and everything mechanical. While Stefan waited at the centre for the others he looked at his favourite website – carsales.com. The transport left without him. 'No-one bothered to intervene and include him.'

When Stefan realised they'd gone he decided to catch up. He took a set of keys from the cupboard, 'clicked the clicker' and hopped in the car. But Stefan can't drive.

Frida received a call – Stefan was in hospital. Fortunately he wasn't seriously injured, nor was anyone else. But in his attempts to drive he had crashed into a building.

Frida was shocked at what happened, and even more shocked when the provider refused to take responsibility. They sued her for \$50,000 worth of damage to the building and car. She had to hire a lawyer and it took three years to resolve. 'The whole scenario was an absolute nightmare,' Frida said. When she made a complaint to the oversight body, the provider was simply told 'don't let it happen again'.

When Stefan moved out of home to supported independent living, he again encountered abuse, neglect and exploitation.

One time, another resident took Stefan to the pub and made him buy alcohol. 'They went back to this boy's unit and drank the lot.' Stefan 'was so drunk and totally unsupported'. He 'threw up all over the place', but nobody became concerned 'until he started throwing up blood'.

Again there were no consequences. The support worker assigned to Stefan was not supposed to work with him again, but a few weeks later he tried to take Stefan to a massage parlour.

Support workers have financially exploited Stefan. He has a 'tap and go card' and one support worker got him to pay for her meals and petrol. The coordinator denied it was happening, but Frida showed her the bank statements. She says that even when you provide proof of wrongdoing, 'nothing ever happens'.

Stefan decided he wanted to leave. In the 24 hours it took to move him out, half of his belongings were stolen. Frida had to go to the police to get Stefan's television returned.

Frida thinks part of the problem is that 'anyone can work in the disability sector'.

'To get your aged clearance or your disabled clearance takes two seconds ... I guess it's because we don't value disabled people.'

Frida has made many complaints over the years. 'I'm not an abusive person. I can be very firm ... I won't tolerate neglect or abuse or theft of his goods.' But she has found all the complaint bodies to be 'toothless tigers'. She learned that even if a provider is closed down, they can open up under a different name.

Furthermore, her complaints have made things worse for Stefan. None of the disability service providers in their area will have Stefan as a client.

Privately they've employed 'two excellent support workers' but 'unfortunately they don't stay'.

One support worker was with Stefan for two years and helped him develop independent behaviours. She tried to help him find work with a local car dealership – polishing cars. But when they tried to get the disability employment provider to follow up, it fell through.

Frida says the employment providers are hopeless. 'They don't go out and visit the community and try and get work for disabled people.'

Frida's most pressing concern is what will happen to her son once she is no longer able to advocate for him.

Vero and Goldie

Vero has an intellectual disability, autism and behavioural issues. Goldie, his mum, told the Royal Commission he has been segregated, suspended and constantly monitored since he started school.

In his first mainstream primary school, despite having no physical disability and being a good swimmer, the school wouldn't let Vero take part in the swimming carnival. Nor was he allowed in the playground, in case he fell down. 'At one stage he was even kept by himself for his lunch breaks because they were worried about his interaction with his peers,' Goldie said.

Feeling pressure from the school, Goldie decided 'with a heavy heart' to send Vero to a special needs school. But it was 'the biggest disaster' and 'very traumatising' for her son.

Vero was triggered by the noise of his peers and hated being isolated in a gated community. 'He started to climb fences and tried to escape which he'd not ever done in his life.' The staff tried to pull him off the fence which made him 'lash out'.

'They labelled him quite quickly as being violent. He was seven or eight ... so he was still very little,' Goldie said.

Vero's behaviour escalated and his learning declined. Then the suspensions started, 'endless suspensions'.

When three teachers physically restrained him for 45 minutes after a meltdown, Goldie decided to put him back in a state school.

Vero had a promising and happy start at his new school, but then there was a change in principal. Suddenly everything went downhill. Vero was relegated to the prep class, no longer allowed to share a classroom with his peers.

When a teacher found Vero in the library with his hands covering a damp patch on his shorts, they assumed he'd been masturbating. Vero was 10. Goldie said, 'I'm 100 per cent sure he had never masturbated, ever, at that time and I'm 100 per cent sure he actually wanted to go to the toilet and he just wet himself.'

Vero's toilet difficulties were known and Goldie 'found it heartbreaking' the teacher jumped to conclusions. She believes if it was any other child they would have assumed the child just wanted to go to the toilet.

From the age of 10, Vero was labelled a sexual predator. 'That record moved with him and is still moving with him,' said his mother.

There were more suspensions and he was segregated further.

Then another new principal started.

'He just turned it around,' Goldie said. The principal supported the teachers and changed the culture. Everyone welcomed Vero and he spent the whole year in the classroom with his peers.

'He left grade 6 on a real high. It was so exciting to see my beautiful boy graduating from primary school.'

High school, however, has been 'a nightmare'.

When Vero started year 7, the principal told Goldie it would only be a matter of time before her son started masturbating in public. 'All children with autism do,' the principal insisted. Teachers shielded other students from him.

Goldie said the record that follows her son from school to school is like 'a criminal record'. He never has 'a chance to have a clean slate'. Once when Vero's hand 'stroked past a teacher's breast, they were talking about sexual assault'.

Recently the school expelled Vero for pushing and swearing at a teacher during a meltdown.

His enrolment at his new school is again conditional – three hours a day for three days a week.

Now Vero has NDIS support, and support workers look after him after school and occasionally on weekends. He is learning to cook, do his washing and enjoys going on excursions. 'When he's at home there are no issues around his behaviour because they do really good support and keep him busy,' Goldie said.

'He needs to have people around that want to engage with him and let him be a part of things. One of his support workers says she has so much fun and enjoys his company so much. That's like music to my soul.'

Leon, Flor and Richard

When Leon was studying teaching he was diagnosed with a brain tumour.

The surgery and radiation left him with epilepsy and an acquired brain injury (ABI) that affected his memory, speech and hearing. A counsellor told Leon 'his head injury could make him impulsive'.

His parents, Richard and Flor, told the Royal Commission his mental health was also affected. Leon 'would compensate' and 'try to hide' his disabilities so they were 'not obvious to the casual observer'.

'Due to the social stigma ... it wasn't something he wanted to talk about,' Richard said.

Leon returned to his studies while undergoing radiation treatment. Flor said the students were 'fantastic'. But some of the staff were not supportive.

Leon overheard a practical supervisor say he 'was going to be supervising some goddamn epileptic'. When the two met and Leon was asked his name he said, 'I'm that goddamn epileptic'.

Leon completed his teaching degree, but because he was still having seizures and receiving speech therapy he decided to retrain and work as a rehabilitation counsellor.

It was more than 10 years later that Leon returned to teaching. He hadn't been in the classroom for a long time and there was no specific support for his disability, but it seemed to Flor and Richard that everything was fine.

It was not until his final payslip came to their house his parents realised Leon was in trouble.

Leon had been teaching for about 10 years and over that time students had made a number of complaints about him.

Leon admitted to tapping a student on the head and throwing an eraser in the direction of another, but he disputed other complaints. When Flor and Richard accessed the documents, they found staff and other students also disputed some of the complaints. Written reports contradicted interview transcripts.

They also discovered those investigating the complaints rarely interviewed Leon to get his version of events. When they did, they didn't encourage him to take notes. Because of his ABI he often had no memory of events, so notes helped trigger his memories.

'[There were a] number of people with "support" in their title,' Richard observed, but they 'didn't make any effort to support [Leon]'.

There was one principal who took a proactive approach. Following an incident, he began counselling Leon before school. This continued for two years and during this time there were no incidents.

But then a new principal came to the school who had no interest in continuing these sessions.

There was another incident, and Leon was supposed to attend 'code of conduct training'. This may have assisted him, but the school never followed through. Richard and Flor can't understand why the school left the situation to deteriorate.

Desperate for a solution, Leon applied for positions that would reduce his teaching load or take him out of the classroom. Richard and Flor believe this could have been a solution for Leon, but none of his applications were successful.

Leon lost his job and his teacher's registration was revoked.

Afterwards, Richard and Flor discovered there is a unit within the department to assist staff and students with health problems. They don't understand why no-one referred Leon to this unit so he could receive support and keep working as a teacher.

It was only when Leon appealed his termination that Leon and his parents saw most of the documentation for the first time. Leon had no support during the appeal process which was complex and confusing. At one stage his name was made public.

Losing his teaching job and registration has had lasting impact. Years later, Leon applied for a blue card so he could volunteer to work with children. He waited eight months for a decision, only for his application to be refused on the basis of what happened while he was teaching.

Flor and Richard have been advocating for Leon for nearly 10 years. They are angry and frustrated they haven't been able to help him or find anyone from the department or appeals tribunal who would listen to them.

Richard said talking to the Commissioner was 'the first time we've been able to talk to somebody about our problems'.

Leon had a stroke a couple of years ago and Richard and Flor are worried about who will help and support him when they die. '[We] don't want him hurt any more than he has been,' they said.

They believe that if the department had provided appropriate support to Leon, he would be in a very different situation now.

Flor and Richard 'want people to respect people with disabilities and consider their disabilities when making decisions affecting their lives and livelihoods'.

Wylie and Liliana

Wylie is in his early 30s and lives with autism, Tourette syndrome and a severe anxiety disorder.

‘He has always been a very very complex young person,’ his mother, Liliana, told the Royal Commission. ‘He’s always had a destructive behaviour. If things are old he will rip them apart, get rid of them, gone.’

Because of that behaviour, Wylie moved out of home and into supported accommodation in his teens. In his mid-20s he was ‘doing quite well’ and asked for his own unit.

‘He was left alone way too much,’ said Liliana. ‘And with that, the spiral began.’

Wylie began to demolish the unit and threaten his neighbours. It became so bad that one night health department staff moved him out of the unit and into a public housing apartment, where Liliana said he ‘continued to damage, pull down curtains, everything’.

He was moved to a caravan park, causing ‘tens of thousands of dollars damage.’ After that, he was deemed homeless and admitted to a mental health facility.

Liliana doesn’t have much control over her son’s care. Wylie’s legal guardian is the public advocate, but Liliana said that during his eight months at the mental health facility, the guardian had little contact. Neither did Wylie’s behavioural consultant.

‘So it was sort of left up to [the facility] to medicate him [and] he would not eat hospital food. I was cooking and taking it in every day.’

The facility kept Wylie in his room, where he chose to sleep on the floor.

‘I don’t think the health system knows how to deal with someone with autism and extreme behaviours.’

Liliana said there appeared to be no plan to move him from the facility, so she wrote to the Premier. After that, the health department modified a house for Wylie, installing such things as a steel toilet and an indestructible mattress.

Wylie is supported by the NDIS, and a support service eventually moved him into the modified house with a full-time team.

‘I think they underestimated what he was capable of, unfortunately.’

Wylie pulled the walls and floor apart. While demolishing a steel shed in the backyard, he injured his leg. Staff were afraid to treat him and the leg became infected.

Liliana arrived another day to find 'water seeping out from underneath the house because the showers in the house weren't connected to drainage underneath', and a sewer pipe leaking onto an area of artificial turf.

It was winter and Wylie had removed the walls. Staff told her they didn't fix the house because her son had told them not to, even though Wylie was unable to make decisions for himself.

Lilian complained and the home was deemed uninhabitable. While it was being fixed the support service moved Wylie to a hotel, where he ripped out the toilet. He was admitted again to a mental health facility.

He refused to eat their meals, so the facility gave him the takeaway food he demanded 'to try to keep him calm', even though Wylie had diabetes.

'They gave him three of those iced coffees a day ... triple cheeseburgers lunch and dinner, a meat pie for breakfast chocolate muesli bars, potato chips. And that was his diet for two and a half months in that hospital.'

Liliana said medical staff, police and service providers often held Wylie to account for his actions, but by failing to explain the consequences of his actions to him and giving into his demands, they made his behaviour worse.

While Wylie was in the mental health facility, his service provider withdrew its support. Wylie's support team resigned from that provider so they could stay with him.

'They all signed over to the new provider because they love working with my son. They're very special people ... And he's in a really good place.'

Wylie is now back in the house, but a more robust house is being designed.

'I don't want him in another mental health ward. Dumped for months.'

Harold, Katalina and Neville

Harold is in his late 20s and is unable to 'walk, talk or eat'. One night, two years ago – at his supported accommodation – he was severely injured. The support worker on duty didn't tell anyone.

Ten hours later, a different support worker noticed Harold 'was in extreme pain' and called an ambulance.

Katalina and Neville, Harold's parents, told the Royal Commission that when they arrived at the hospital, no-one was able to tell them what had happened.

When doctors touched or moved Harold he 'had a look of horror on his face'. So they x-rayed his legs and discovered his left leg was broken above the knee.

Harold was given additional pain relief but a short time later had trouble breathing and became unresponsive. The doctor asked Katalina and Neville, 'Do you want to continue or should we just leave him and not assist him to breathe?'

Neville was horrified.

'If one of my other boys had a motorbike accident or a car accident he would be in surgery straight away ... it was more of a fact, "he's got a disability, I think we should just let him pass" ... I got really cranky about it right at the start. He was here for broken legs ... to me it was black and white ... if it was one of my other boys, it would be no question.'

Harold was intubated and transferred to intensive care.

Katalina pushed the doctors to do further x-rays and scans and they discovered Harold also had two broken hips. The doctors did not believe the injuries were caused by a fall from bed, as the support worker on duty had said.

The doctors were reluctant to operate because they felt rehabilitation would be too painful. At a meeting, which Katalina described as like 'an interview or even a trial', Neville and Katalina had to justify why Harold deserved to be treated like any other person with broken hips and a broken leg.

'We had to fight every step of the way,' Neville said.

That night Neville rang the police. 'One leg ... there might have been an accident [but] when you've got breaks in his hips ... in my eyes there's some foul play there.'

The police investigated but, despite indicating there was a case of criminal neglect, never laid any charges against the support worker or the supported accommodation provider. They told Neville and Katalina that Harold was an unreliable witness, even though they never interviewed him.

Neville and Katalina made a formal complaint about the police investigation, which forced the police to interview Harold. With the assistance of a speech therapist Harold indicated that, contrary to the support worker's account, he did not fall out of bed.

But by then too much time had passed between interviewing Harold and the support worker for the police to consider criminal charges.

When Neville and Katalina discovered the service provider had dismissed the support worker because of negligence, they decided to lodge a complaint with the workplace health and safety authority. At the same time they made a formal complaint to the state government disability department.

Both bodies briefly investigated the incident but dismissed the complaint or refused to take it on.

The government department referred them to the NDIS but, as the NDIS Quality and Safety Commission hadn't been established at that time, the NDIS said the state government would need to take the lead.

Katalina said no matter who they spoke to, the 'first conversation' was 'are there charges laid?' Without charges, everything became more difficult.

Harold was caught between several bureaucracies and systems. Neville estimates 'probably about 10 of them'.

Katalina and Neville want justice for Harold but say 'an apology ... would go a long way'. They also want it acknowledged that Harold was significantly injured. The trauma left him 'very, very scared'.

'He was just not himself for a very long time ... He didn't smile for a very long time.'

Katalina and Neville would like a redress scheme which would include a 'direct personal response from the institution ... the perpetrator, counselling and financial compensation'.

They also believe a dedicated policing unit to investigate crimes against people with disability is needed.

'I think the biggest thing for us with [Harold] after he was injured, was how differently [he] was treated ... He wasn't seen as a person at all.

'The systemic failures that we experienced ... were actually quite shocking to us'.

Xan

Xan's 'whole dream was to be a nurse'.

He told the Royal Commission he wanted to be a nurse because he 'loves being by people's sides, helping people and being an advocate'. But while studying nursing, he was 'bullied, abused and set up to fail' and forced to let go of his dream.

'I have autism, Asperger's syndrome,' he said. 'I also was born to a migrant family. Being an only child with my mum and dad as family in this city, hence my interpersonal skills with people are affected.'

At school, Xan kept to himself and 'just studied really hard' to get into nursing. At university, he excelled in his studies but was worried about his first hospital placement.

He requested a meeting with both the subject and clinical coordinators.

'I detailed the concerns I had with clinical placement and my anxiety of dealing with patients, as well as my communication skills as a result of my Asperger's and dealing with people.'

The coordinators reassured Xan that an independent support person would be present during his placement. He also met with the disability support supervisor to develop coping strategies. The supervisor also assured him he would have support.

But Xan said he was given none.

He found his first clinical handover 'overwhelming'. Despite needing to step outside at one stage, Xan did what his 'buddy nurse' told him to do and completed the shift. 'The patients complimented my care – I was very gentle.' After the handover, Xan 'was left alone without any support' besides the buddy nurse.

The next day, the clinical facilitator took Xan aside to give feedback on his shift. It seemed the buddy nurse went behind his back 'without ever bringing the concerns to [Xan's] face'. The facilitator criticised Xan 'destructively' and humiliated him because of his disability, saying Xan 'wasn't suitable for nursing because of [his] disability, personality and interpersonal skills'.

Two days later, Xan's clinical placement was cancelled on the assumption he would fail in the future because of his interpersonal and communication skills.

'I'm not going to learn how to be a sweet talker or ... to communicate really well within three days,' Xan said. 'No, it's going to take three years ... Three days is just too short for somebody with disabilities.'

Xan complained and requested another placement, but the university told him he had to change courses or leave university.

'Basically they told me to leave ... because I had Asperger's syndrome and they told me I should pursue something not in health care ... It made me cry ... my whole academic life destroyed ... by this stupid behaviour.'

Xan filed a discrimination complaint, a formal grievance and an appeal to the university, but all of his complaints were dismissed.

Still hoping for some redress, he contacted the disability discrimination legal service. He was advised his complaint fell outside the statutory limitation period under the anti-discrimination legislation.

'I have received no apology, no remorse,' Xan said. 'And they say *my* interpersonal skills are so low!'

Xan is still waiting for the cost of the course to be refunded.

Reflecting on his experience Xan said, 'I was set up to fail by not being provided ... any guidance, no guidance whatsoever about how to relate to people.' He is adamant he is 'capable of caring and performing the job', he just needs adjustments and support.

Xan is now studying in a different faculty at another university and works part time at a pharmacy.

'My pharmacy role has allowed me to prove to myself that I can care for the most vulnerable in our society and communicate professionally in a team environment.'

Xan believes people with disability are an untapped resource.

'Having more people with disabilities, having more graduates with conditions, like me, working in the sector, this can mean increased awareness, increased adaption and better patient-centred care.'

Davion

‘It is our job to identify failings, but we are surrounded by people willing to do anything to escape responsibility, punishment and loss of income.’

Davion, early 50s, lives with post-traumatic stress disorder.

A few years ago, he worked for a disability services provider. The organisation wanted to become an accredited NDIS provider and asked Davion to review their policies.

Davion told the Royal Commission the organisation had not reported any incidents in approximately 20 years. He discovered unusual financial behaviour, no processes for handling complaints, poor staff training and poor accreditation practices.

Davion made a number of recommendations and the organisation offered him a 12-month contract to implement them. Davion assumed he had broad management support and expected managers to cooperate.

However, staff refused to share information and he found himself embroiled in bitter ongoing fights.

One fight was between two managers. An investigation found one of them, Ed, had acted unethically.

Davion tried to stay out of it, but Ed pressured him.

‘I became a target for his aggression resulting in a threat to my life in the work carpark.’

Davion reported the incident to police but there was insufficient evidence to proceed with criminal charges. Police suggested he file a violence restraining order. ‘It was granted the next day but under stress from [Ed’s] lawyer, I later withdrew in place of a legal undertaking,’ Davion said.

Although the organisation ‘completely’ believed Davion had been threatened, he said their support was ‘not genuine or comprehensive’. There was a culture of cover-up and they tried to silence him rather than assist him.

Ed and other staff left the organisation to work for another provider. Davion said they took a number of clients with them and erased NDIS data.

Davion is concerned Ed remains employed in the disability sector and now coordinates supports for people with psychosocial disability.

Davion decided not to renew his contract. He has struggled to find employment since, in part because the experiences still haunt him.

‘I wanted to join the disability sector and support people with disability to be free from abuse, but found that good intentions and skills are no match for an angry fearful culture of managers, support workers and board members willing to use NDIS training tools to escape responsibility, hide evidence and protect their colleagues and their own careers.’

Roxanne

Roxanne is in her 30s and lives with Ehlers-Danlos syndrome (EDS), a group of disorders that can affect the skin, joints and blood vessels.

EDS causes Roxanne pain and stops her doing things.

‘Can you hold two litres of milk? Well, if you held a gun to me, yes, I can do that, but I will cause myself damage, and that damage is both temporary and long-term and if I do that over and over again, I will destroy this body and then I will be unable to do things.’

Roxanne told the Royal Commission that when she was a child she had debilitating pain in her lower limbs. Doctors told her parents the pain was in her mind and not physical. It was only later, in her 20s, after a series of medical issues, that a doctor diagnosed EDS.

‘So you go through your teenage years and up into your 20s and 30s basically ... denied, dismissed and being gas lit over yourself. It’s just the most horrific thing.’

Even after her doctor diagnosed EDS, she couldn’t get other people to believe her.

‘You get this impression that the diagnosis is the key to everything ... you can’t get the NDIS without it. You can’t get to other types of disability services without it, you know, you can’t do anything without it. And you think that when it comes it will change things. But it doesn’t.’

Roxanne said the NDIS would only accept a diagnosis from an EDS specialist, but there are no EDS specialists in Australia.

‘They say, well you absolutely cannot access [the NDIS] without a specialist letter, and I said to them, “There isn’t any specialists, and literally nobody who can do that for me.”’

She said her previous diagnoses of psychological conditions ‘continue to be weaponised against [her]’.

‘If there was something I could have now, it would be a legally enforceable right to have ... those incorrect diagnoses removed from my medical record.’

Roxanne said she spent several years fighting for NDIS support.

‘I said to the man who had done the assessment, “Have you ever heard of my condition?” He said, “No”. I said, “Did you look it up while making this decision?” and he laughed and said, “If I haven’t heard of it, it can’t be that important.”’

Roxanne now receives NDIS support.

‘They’ve given me access to the therapies that I should have had for the first 21 years of my life, but I’m trying to improve my capacity with all the physio and all the [occupational therapy] and things that I should have had for decades before. That’s what I really needed, you know, because I want to keep the function I’ve got.’

Roxanne said people still question whether or not she lives with a disability, because they can’t see it.

‘And public transport is a problem for me because people take one look at me and say, “You don’t need an accessible seat,” and I’ve been physically assaulted on trains for daring to sit in one of those accessible seats. An older guy, like, beat me with his walking stick because I was sitting on that seat.’

Darcy and Rihanna

Rihanna's daughter Darcy is in her 30s and lives with bipolar personality disorder.

A few years ago, Darcy nearly died from a drug overdose.

Rihanna told the Royal Commission, 'The operator who assisted me on the triple-0 call was wonderful, although she quickly realised I was in no state to do CPR, as [Darcy] was around 100 kilos, and I just couldn't get her on the floor.'

Rihanna said Darcy spent six days in a coma and survived thanks to the 'attentive and committed' paramedics and public hospital staff.

'She was gravely ill, and I'm convinced she could not have received better care anywhere else.'

A few days after she woke up, doctors transferred Darcy to the public hospital's psychiatric ward. She has private health insurance and the psychiatrist told her she should go to a private hospital.

'As you can imagine, [Darcy] was in a very fragile state ... It upset her greatly, and I was quite gobsmacked at the audacity of the doctor to just even bring that up. Like, within the first five minutes of meeting her, "You shouldn't be here." Just blows my mind.'

Rihanna said the psychiatric unit offered Darcy no treatment.

'Nothing. I get it, it was between Christmas and New Year, and that's a busy time, but that didn't affect the normal hospital ... These people that go into [the psychiatric unit] go there because their life is in danger, mainly because they'd tried to commit suicide, so the very vast difference I saw was the incredible help of the public hospital, and then nothing, no treatment at the psychiatric unit.'

Rihanna said the only activities offered to patients were watching television and walking the grounds, so she brought in artwork and puzzles.

When Darcy entered the psychiatric unit she complained of a headache and saw a general practitioner, but the headache didn't go away. A psychiatrist suggested physiotherapy.

'He suggested she phone and make an appointment with a physiotherapist and make her own way there. She was three days out of a coma, she could hardly walk and she was suicidal. And he was going to put her in a taxi.'

Rihanna noticed Darcy's neck was swollen and told the general practitioner, who ordered an ultrasound. It revealed a large blood clot, which was treated with blood thinners.

Darcy moved to another clinic because she wasn't getting the treatment she needed at the psychiatric unit.

Darcy is supported by the NDIS. When she was discharged a couple of months later, Rihanna said she noticed that her service provider had charged her for services Darcy hadn't used while she was in hospital.

'It's just blows my mind. It's abhorrent, disgusting. I can't think of adjectives strong enough for how evil that is. And the sad thing is, the people I've spoken to have said she's not the only one this happened to, that it's rife.'

Niall and Lisbeth

Lisbeth is mum to Niall, who's in primary school. He is autistic and lives with attention deficit hyperactivity disorder, oppositional defiant disorder, anxiety and a complex range of other conditions.

Lisbeth said Niall's disability wasn't diagnosed until he started primary school.

'I got through all that period without a diagnosis, so there were obviously indicators, but it was really challenging to get help,' Lisbeth told the Royal Commission. 'He's actually quite bright ... borderline gifted ... So, I think if we can get through life, get him through school, he actually has quite good prospects to be employed in some, like, coding or engineering or some of these areas that are actually where he can contribute.'

Lisbeth used to run her own business, but gave it up to care and advocate for Niall. She now receives a carer allowance and hopes one day to go back to work.

'I do expect that I am going to have to support him at some level ... I don't want to be in the situation where rent is so high we can't afford to live in a rental property.'

Before the NDIS, Niall received support from a state government scheme for children with autism. To switch to the NDIS, Lisbeth had to pay for doctors' reports.

'I had to get a private paediatrician to get him diagnosed fast enough to access [a particular] program because obviously I didn't have any funding ... I maxed out our safety net. I was like in major trouble with rental issues because I was having to choose ... which things get paid first and keep this amount of money free. It was absolute hell.'

After submitting the evidence, the NDIS offered less support than he had been getting under the state scheme.

'It was really frustrating because even before NDIS I had evidence of how he was seeing weekly OT [occupational therapist], he was seeing a psychologist. All these, I was just asking them to maintain his current therapies, and they just cut them all.'

Lisbeth appealed. When she spoke to the Royal Commission, she was still waiting for an NDIS plan.

'I have been saying, "I'm not coping." ... I'm on a carer payment currently, it puts me in financial hardship and means I have to hold back money that I need to be paying out to other things like rent and ... because of this appeals process, I've just been sort of trapped.'

Lisbeth rents privately and has been waiting several years for public housing. Caring for Niall and paying rent was particularly difficult during COVID-19 lockdowns.

‘Single parents were provided with a COVID supplement federally, parenting payment and other payments, but [a person on the] carer payment was excluded from that, so I found it really challenging to again maintain rental payments.’

She said most housing supports are for adults with disability rather than families caring for people with disability.

‘Because there is no data captured on carers in regards to housing, there’s no way to challenge what’s going on ... So there are families with disabled children becoming homeless, basically.’

To find suitable housing, Lisbeth has moved further away from Niall’s school.

‘No-one has a plan for families with disabled children. We are not in any priority area. We just fall into the general insecure housing priority. That’s where I am.’

Juniper

Juniper was born in a South Asian country. She is in her 40s and lives with depression and post-traumatic stress disorder. A decade ago she damaged her knee. She can't lift heavy things or stand for long periods of time.

'I thought, I'm really too young to have a disability,' she told the Royal Commission. 'I've worked with the heavily disadvantaged community and disabled people ... I have so much empathy to the families, how the families [are] breaking up, how they can't go back to work.'

Juniper is unable to access the Disability Support Pension (DSP) because of her husband's income. 'We [are] barely surviving with my medical expenses and the house mortgage and the kids.'

Before she injured her knee, Juniper had a corporate job. During her time off work, she went back to university and completed a master's degree.

'I have physical disability, but my brain working fine. They can utilise it, right?'

Juniper has been unable to find full-time employment. She eventually took a part-time position with a federal government agency, but she said the agency treated her differently once she disclosed her disability. It agreed to provide reasonable adjustments, but never did. Her contract was terminated and she has not had paid employment since.

Juniper feels that disability job agencies are 'useless' and that employers discriminate against her because of her physical disability and mental health issues.

Now she chooses not to tell people she has a disability. Instead, she hides it.

'I haven't declared my anything, you know [but] my worry is if you don't ... declare it, they will expect you to perform in the higher level, so I don't know whether I can perform it as a normal person, because of the pain.'

Juniper told the Royal Commission she wants to work 'to contribute to society, contribute to [her] household financially', but struggles to find employment.

'It's come down to this disability, not my colour of the skin. I really think so, yep.'

Jase and Kynlee

‘We know that he is intelligent and capable of more than what he’s been able to achieve, and that’s why we never gave up on him, you know.’

Kynlee is in her 40s and has attention deficit hyperactivity disorder (ADHD). She’s also the mother of Jase, who is autistic and lives with ADHD and intellectual delays. Jase is in primary school.

‘He loves Roblox, Minecraft, pretty much every game that any [boy of his age] can play,’ Kynlee told the Royal Commission. ‘He’s just all over it and really, like, self-taught with all of it, just an absolute natural with technology.’

Kynlee is a special education teacher. Before teaching in Australia, she worked in countries where schools were more inclusive when it came to children with disability.

‘The UK have these inspections. They can be random. Schools have to prove that they’ve got inclusive practice in place and I don’t understand why we don’t have external bodies assessing [Australian] government schools.’

Kynlee said Jase’s first year in a government primary school in Australia was ‘a nightmare’.

‘His teacher was a first-year teacher without any experience working with or understanding autism and ADHD.’

The teacher reprimanded Jase in the classroom for his behaviour. Jase began ‘lashing out’.

‘I would pick him up from school. “Why doesn’t anyone like me? Why doesn’t anyone want to play with me?” and then start crying. And this went on for weeks until I had to basically just stop.’

Kynlee transferred Jase to an independent school.

‘There was only five in the class which made a huge difference. He was happy. He made friends. It was incredible. It was the best school he ever went to, actually.’

Unfortunately, Kynlee couldn’t afford the tuition fees, so she enrolled him in another government school. His new teacher had ‘no tolerance for his behaviour’.

‘[Jase] started to get worse. He’d bang his head against the wall.’

Kynlee said her son was ‘basically pushed out’ of the school.

‘The teacher almost triggered [Jase’s] behaviour on this particular day by ignoring him and not supporting him when he was having a meltdown and I think it was communicated to the principal.’

Kynlee later learned the school had been given funding to support Jase, but hadn't consulted her. When she asked what the school was spending the funding on, she was told it would be used for a speech therapist.

'This decision was made despite [Jase] already having a private speech therapist and not needing to see another.'

Jase now attends another private school with small classes and better support.

'They plan in a proactive way for the learning to be engaging and motivating. But more than anything, it's the smaller class sizes that really help him,' Kynlee told the Royal Commission. 'It's just become a haven for all the kids like [Jase], who are not being included [in other schools] ... I can see the private sector taking over where the government are not capable because they're just not getting funded properly.'

Seven and Dee

Seven is a young autistic boy who has attention deficit hyperactivity disorder (ADHD) and developmental delay impacting his speech and mobility. He lives in a rural town.

Seven thrives on repetition and routine. His mother, Dee, says she has 'little charts' at home to show him 'what he does in the morning, what he does after school, [and] in the evening'.

Before bedtime, Seven takes his medication, uses a weighted blanket and often watches his favourite movie with his parents to help him 'calm and settle'.

Seven also requires support with his fine motor skills, 'like being able to tie his shoelaces'. He 'really struggles with his social interactions' and finds team sports challenging. 'He doesn't like things in his face, and nor does he like to make eye contact.'

Dee told the Royal Commission that living in a 'rurally isolated' region means they have 'very limited' services available to them.

In the classroom, Seven requires 'visual guidance' to support his understanding of maths, grammar and handwriting.

Seven has access to a teacher aide for 30 to 60 minutes a day, but this is shared with other children in the classroom.

Dee was told that her son didn't need a full-time aide because 'the school believes it's important to encourage Seven to be independent'. She later discovered limited funding prevents the school being able to offer 'extra help and support.'

'The principal told me that the aide is supposed to be shared amongst a few students rather than just the individual with the disability,' said Dee.

Resources Dee had bought to assist her son in the classroom went missing, for example visual cues such as pencil grips, a cushion for his 'restless legs' and a 'time timer' to reduce the stress of trying to decipher the time on a clock.

Dee has had several support workers assist Seven at home. She says they either lacked an appropriate level of training, or were uninterested. She often saw agency workers 'playing on their [mobile] phones' rather than interacting with Seven, who 'should have been their centre of care'.

But more shocking incidents were about to occur.

'[Seven] told me that [one support worker] hit him with a [toy] light sabre between the legs more than once when they were jumping on the trampoline, pretending they were Star Wars characters.'

Seven also told his mother that while he was sitting on the couch, the same support worker 'started to tickle him ... more than once' in 'his private area'.

'We actually went through a police investigation but it's [Seven's] word against the individual support worker,' said Dee. The family has yet to receive a response or apology from the agency.

Dee said the incidents led to an increase in Seven's anxiety levels, and he began having nightmares.

In a recent incident, a support worker stole her son's anxiety and ADHD medications. '[Seven's] Lovan disappeared, his Ritalin at the time – as well as I was on some pain relief because I had had some surgery – so I had some Panadeine Forte or Endone ... and they disappeared.'

Dee reported the matter to the service provider. She is unaware how the agency dealt with the matter. She was told by a third party the support worker is no longer with the agency.

Dee says the agency's failure to provide quality support workers with appropriate experience and training is 'appalling'.

Shelby

Shelby is a support worker for a government-run disability agency.

She told the Royal Commission the mistreatment of clients is 'systemic', especially in group homes where 'they don't have family, they're from the institutions' and there's no-one to advocate on their behalf.

At one of her placements, Shelby noticed one of the residents was 'not allowed off the lounge, virtually for the entire day'.

The man was also 'continually hit over the head', and told to 'get back to the lounge' by a support worker. 'I was absolutely horrified,' she said.

Shelby reported what she had seen to her supervisor. 'To this day, the same staff [member is] still working with that man. Nothing that I know of was ever done about it.'

Support workers use derogatory language towards residents. 'Dirty old man, retard ... really disgraceful,' says Shelby, 'just horrendous.'

One incident that stands out for Shelby was the day she was called in to work at short notice because a co-worker had to leave early.

When she arrived the group home was in disarray, 'dishes in the sink, untidy, just dirty, really dirty'. She went into the staff office and saw money and knives out on the desk, not locked away securely as they should have been.

Among the items was her co-worker's lunchbox. When she opened the lid, she made a shocking discovery.

Inside was an ice-pipe. 'There was foil that had what looked like little bits of ice still left in it,' Shelby said. 'I sat down for about 10 to 15 minutes because I was so shocked.'

Once she had collected herself, Shelby rang her supervisor who escalated the matter to the regional manager.

Many hours later, a manager came to the house to remove the material. Shelby was given strict instructions: '[Do not] disclose this to anybody, do not disclose it to the next staff that come on.'

Shelby says the person continues to work for the organisation.

'It just blows my mind that that was allowed, when obviously that ice-pipe had been used that day at work. To me that's instant dismissal. I can't, I still can't understand it.'

She says even now, the co-worker continues to chastise the home's residents 'about how they make him sick, he can't stand them, can't stand people dribbling over him all the time'.

At another group home, Shelby has reported staff who continue to allow a resident to live in 'filth'. 'There's urine everywhere, he's standing in urine ... it looks like a room that just should be condemned. To me it's uninhabitable, no human should be living in it.'

Her growing frustration at the conduct of co-workers has led her to contemplate resigning.

'We're called carers, and it's just not caring, just not caring ... things that are reported, there's just no action. And there just seems to be this mentality ... [where management] just keep ignoring it.'

She says the neglect is systemic. 'There's a lot of people who've been with the department 25-30 years ... They're fully taking advantage of the clients.'

She believes the department needs a total overhaul. 'If I had a child or a family member with a disability, there's no way I would send them into a government organisation, or a respite, to be cared for.'

Len

Len is in his 50s and lives with a degenerative spinal disease and dyslexia.

'My father and my mother knew I couldn't read from grade 2,' Len told the Royal Commission. 'I got beat every time I brought home an English fail.'

Len was born overseas, but lived the first 20 years of his life in Australia. During that time 'nobody recognised or actually understood that [he] had a learning disability'.

Len was diagnosed with dyslexia only when he returned overseas to study at university.

'As someone with a learning disability, I'm not stupid. I'm quite intelligent, and I work outside the box ... I actually consider my learning disability a gift.'

After university, he started his own business overseas, but struggled with the degenerating discs in his spine. Walking became painful. He received a disability pension that allowed him to live with adequate support.

Len returned with his family to Australia several years ago and has since developed a functional neurological disorder.

'Coming back here I have been treated ultimately not even as a third-class citizen in this country.'

When he applied for a disability pension, Centrelink referred him to a psychologist.

'The lady fell asleep three times during our meeting ... I've never had someone insult me or treat me like I was inhuman as I have at Centrelink. The questions she asked me were disgraceful, disgusting and demoralising.'

Len said Centrelink denied him support.

When Len applied for NDIS support, he was met with a 'format of disbelief'. '[They feared] that I was going to rip the system off.'

He persevered and now receives NDIS funding for a support worker.

Len's back causes constant pain. He said he's often treated like a drug addict when he visits a medical centre to renew his prescription for strong painkillers.

'I've lived as a disabled person my entire life. I've managed my disabilities and succeeded through them, I've been abused since I was six ... moved countries and actually got into university, and then turned around and was successful in my own business.'

Len told the Royal Commission that since returning to Australia, he's become 'scared to do anything' because people are judging him on his disability, not on what he's achieved.

Olivia

‘I’m living with that fear all the time that [the NDIS] are suddenly going to give you one of these [eligibility] assessments and you can’t even find out why.’

Olivia, late 40s, has myalgic encephalomyelitis (ME) fibromyalgia, postural orthostatic tachycardia syndrome and severe endometriosis.

Prior to being diagnosed with ME about 10 years ago, Olivia worked in a senior position at an IT company. She told the Royal Commission she gave up work when her symptoms became debilitating. Her husband is her full-time carer.

A few years ago, Olivia applied for the NDIS. She said because the NDIS was new, her GP was unfamiliar with the process. The NDIA rejected her application because her GP didn’t provide sufficient evidence.

Olivia applied a second time and was rejected because her disability was ‘not permanent’. She asked for the decision to be reviewed and the NDIA instead argued she ‘had capacity’ and therefore was not eligible.

Olivia appealed the decision through the Administrative Appeals Tribunal. She said the NDIA was represented by Queens Counsel and ‘experienced legal professionals’ while she was assisted by legal aid lawyers. She said the NDIA threw up ‘every obstacle’ and ‘played lots of games’. They required her to have an independent functional assessment but refused to give her a copy of the report. The process took 22 months. One week prior to the hearing the NDIS conceded Olivia was eligible for funding.

Olivia requested a manual wheelchair and a medical bed. Initially the NDIA refused to fund these supports but eventually agreed.

Then, during a COVID-19 lockdown, the NDIA requested Olivia complete an eligibility reassessment. She said they didn’t give any reason, and she had to seek an extension so she could get reports from her specialists. She spent considerable time and effort attending telehealth appointments and allied health assessments to support her eligibility. She discovered the reassessment was triggered because ‘an assessor doing the manual wheelchair assessment decided [her] condition was a health condition’. She argued this should never have happened given the outcome at the tribunal.

‘These processes have had a profound impact on my disability. The stresses and the processes I have had to go through to get support, and to continue to get support, has made me worse physically, and means that I now spend more time bed bound than I was prior to getting onto the NDIS.’

Olivia said she lives with a 'real fear' the NDIA will put her through assessments again. She believes it is because of a lack of knowledge and understanding about ME in Australia.

Olivia believes the healthcare system is also prejudiced against people living with ME. At the local regional hospitals, doctors look at her chart, see the diagnosis and assume she is 'drug seeking' or a 'hypochondriac'. She said, 'They don't treat me with the compassion and care I deserve.'

One time, Olivia went to emergency with severe stomach pain and was given paracetamol and sent home. Later, doctors discovered her appendix was leaking. Another time she went to hospital with blood in her urine. Doctors told her this was normal and gave her anti-inflammatories. Four days later, tests showed she had a 'raging infection' and she ended up in hospital for 10 days.

'I don't now go to hospitals unless I'm absolutely critical.'

Olivia said the NDIS and medical professionals 'need to listen and understand the lived experienced of these disabilities' and not just rely on textbooks or articles.

Johnathan

‘I don’t think nurses should be playing pranks on people in their care. They’re supposed to be looking after me not using me as the butt of their jokes.’

Johnathan, late 30s, had a car accident on his way home from work when he was 20. He sustained a traumatic brain injury and spinal cord injury resulting in incomplete quadriplegia.

Following the accident, Johnathan spent two months in recovery at a hospital intensive care unit. He developed a pressure sore the size of a grapefruit and continues to experience a great deal of pain from the scarring and severed nerve endings.

A few years after the accident he moved to a regional city to be closer to his family. Johnathan told the Royal Commission that during this time he was taking a number of different drugs to manage his pain. He said doctors incorrectly prescribed ‘high doses’ of antipsychotics, antidepressants and opioids including OxyContin.

Johnathan’s mental health deteriorated and he decided to ‘get off the antidepressants and the pain killers ... cold turkey’. But the sudden withdrawal of the drugs negatively affected his behaviour. His relationship with his family broke down and he was ‘thrown into the psych ward at [the local] hospital’.

Johnathan said that when the nurses realised he was on antipsychotic medication they decided to ‘trick’ him. ‘I’m not sure where they learned this trick but they played a game, not with me but on me.’ Nurses told Johnathan drug smugglers were breaking into the hospital every night and stealing drugs. They repeated the story a number of times and Johnathan became scared and paranoid. ‘I started screaming this out to everyone in the hospital trying to alert them.’ He said the nurses were ‘too busy laughing’ telling him to ‘shut up’ while they quickly closed the curtains around him.

Johnathan was ‘really upset’ and wanted to report it at the time but he was isolated and ‘didn’t have ... supports in place’. If he’d reported it, there’d be a record, and he could do something about it ‘so it doesn’t happen to anyone else’.

He has good supports now. ‘I’m feeling better about myself,’ he says.

Rocky and Tripp

‘I’m a dog with a bone, and the bone this time is my little brother, and I would never let it go ... I’m going to continue to fight the battle.’

Tripp is Rocky’s big brother. Rocky, late 40s, has an acquired brain injury, vision impairment, attention deficit hyperactivity disorder, schizophrenia and diabetes.

Rocky lived with his grandmother until she died in the early 2020s. Support workers helped him with day-to-day tasks.

Tripp lives in a different town several hours drive away. About a year ago Tripp couldn’t contact Rocky and asked a friend to do a welfare check. Tripp’s friend found Rocky living in ‘squalor’. Tripp said he would be there as soon as possible and asked the friend to continue to look in on Rocky.

A few days later Rocky fell out of bed. The friend told Tripp the fire services found him face down on the floor. He had had a diabetic attack and had ‘worn the skin off his ... knees, his elbows, the bridge of his nose’ trying to get up. A support worker took him to the doctor but didn’t supply ongoing care.

Two days later, Tripp arrived to find Rocky unconscious in a diabetic coma. He was unclean, disorientated, underfed, soaked in urine and covered in faeces. The wounds from the previous fall hadn’t been looked after, were infected and ‘quite graphic’.

Tripp discovered the disability service provider wasn’t accredited and the support workers were from one family. They were charging for five hours of care each day but only providing 15 minutes.

Tripp took Rocky to the local hospital. He asked them to keep him there until he could address the squalor in the home and employ new support workers.

‘That was the start of ... the biggest nightmare I’ve ever experienced.’

Rocky was placed in a ‘makeshift psychiatric ward’. One of the social workers told Tripp there was no way Rocky was going back to his home and they would find a group home for him.

Tripp argued he was Rocky’s family and he felt Rocky would be better in his own home. Nursing staff and social workers told Tripp he had no legal authority and they would hold Rocky until a public guardian was appointed.

‘I do resemble your everyday, average pain in the backside motorcycle bkie,’ Tripp told the Royal Commission. ‘That’s why I was treated so horrifically, and so was my brother.’

At the administrative tribunal hearing, Tripp said the hospital made him out to be 'the bad guy'. The tribunal split Rocky's guardianship. They gave Tripp responsibility for medical matters and the public guardian responsibility for accommodation matters.

While Rocky was in hospital he had a stroke and his self-harming increased. When Rocky's health stabilised Tripp tried everything to get him discharged but the public guardian only listened to the hospital staff.

Tripp said Rocky's rights as a voluntary patient weren't respected and nursing staff and social workers 'detained' him for more than four months.

Tripp's wife contacted the brain injury ward of a nearby local hospital. They suggested Tripp go above the nurses, social workers and their supervisors and speak to the hospital management.

'We were like wild animals when we spoke to them. We were so broken and so shattered. And we said that he'd been unlawfully detained in their hospital for 18 weeks ... he was self-harming ... we had to get him out.'

The hospital agreed to transfer Rocky to the hospital near Tripp. Here, doctors established he didn't need to be hospitalised and discharged him.

Rocky is now living with Tripp but wants to go home. Tripp is determined to make this happen.

Meanwhile, they are waiting on the outcome of investigations into the conduct of the hospital staff, the service provider and support workers.

'This whole process has been horrific.'

Crystal and Corinne

‘Autistic people are amazing if they’re just given the opportunity and the right environment to learn.’

Corinne is mum to seven-year-old Crystal, who is autistic and requires complex supports. Corinne told the Royal Commission that Crystal is very intelligent but has ‘fallen through a very big crack’ in the education system.

Corinne explained that Crystal can’t attend the local state school because of her ‘sensory processing issues’. A mainstream school environment is ‘almost torturous’ for her because she has to ‘move, pace, backwards and forwards’ to be able to ‘listen and take information in’. However because she doesn’t have an intellectual disability, she can’t attend state special schools.

Corinne felt she had little option but to enrol Crystal in a specialist autism school. It is very expensive, the school day is shorter and it is a one-hour drive away. ‘It comes at a great cost to my ability to work because I don’t get left many work hours.’

Therapists tried to help build Crystal’s capacity to catch the bus, but had to stop because it was too traumatising for her.

Corinne is concerned the school has a ‘stagnant approach’ to educating children with autism and is not responsive to concerns or complaints raised by their school community.

‘I feel ... the purpose of that school is to turn autistic children into a mainstream product that can fit in, you know, fit in to this mould, this mainstream mould, which I find is really tragic, because all it is teaching them to do is to mask, or to pretend to be, neurotypical.’

Corinne is considering homeschooling Crystal. She said other families are even considering building their own specialised schools, where their children can learn in a manner that celebrates their styles of learning, instead of attempting to change them.

Corinne said the education department doesn’t understand why Crystal cannot go into mainstream schooling. She says their inclusive education policy is rigid and doesn’t work. ‘There is more to inclusion than just sitting in a room.’ Corinne wonders how families who can’t afford exorbitant school fees educate their children.

Getting Crystal to school has recently become more difficult. She is ‘very rigid’ in how she thinks about transport and will only drive in one car. Corinne was able to use Crystal’s NDIS funding to pay a support worker to take her to and from school in the family car. ‘It opened up a great opportunity for me to work ... it was really great for my mental health ... great for the family,’ Corinne said.

However, Crystal's NDIS funding for the next 12 months has been cut. The NDIA argues the education department should pay transport costs. The department believes it is Corinne's 'parental responsibility' and 'beyond their scope'. If Crystal's disability was physical, a special taxi would be funded. Corinne said it's wrong Crystal's 'type of disability is a disadvantage'.

Corinne is currently appealing the decrease in Crystal's NDIS funding and is managing this process herself, further straining her ability to work. If successful, the appeal will ensure another 12-month plan which, at the end, she worries may be followed by another mediocre plan. She says this 'bureaucratic nightmare' impacts the mental health of the whole family.

Corinne would like society to accept people with autism and stop asking them to modify their behaviours.

'I feel that a lot of money could be saved by putting that money into community awareness around what autism is, what it looks like and just simply radically accepting autism, as opposed to asking autistic people to modify themselves to fit in to a mainstream community.'

Zev and Waverly

Zev is a young autistic man with attention deficit hyperactivity disorder (ADHD) and anxiety. His mother, Waverly, told the Royal Commission about his 'struggles' and 'negative experiences' with medical specialists and his school.

During his first year at primary school, teachers reported that Zev experienced difficulty following written instructions. Waverly arranged for her son to see a paediatrician, speech therapists, occupational therapists, a cardiologist and several psychologists. 'But none of them diagnosed him ... no-one picked it up,' said Waverly.

One psychologist described Zev as a 'most unusual boy', which Waverly said was 'very hurtful'. Another told her son, 'If you want to be treated normally, you just need to act normally.'

Three years later, having consulted nearly 10 different specialists, Zev was diagnosed with ADHD and anxiety.

Zev's parents came to a decision. 'I thought, naively, that it would be best to transfer him to a private school,' said Waverly. She 'stupidly' thought that they would 'have cutting-edge strategies' and invest in students with disability. 'But that wasn't the case at all.'

During the admissions process, Waverly sent a copy of Zev's diagnosis and other reports to the school. 'I just assumed that I would be called to a meeting to discuss his needs.' She waited for weeks, but 'nothing happened.'

She approached Zev's teacher to enquire about classroom supports or potential learning adjustments. The teacher was unaware Zev had a learning disability.

'I don't know how [schools are] supposed to comply with their obligations under the law as to disability when they don't tell the teachers that they've got kids with disability in the classroom.'

Zev's teacher told Waverly 'the fact that he didn't come to her expressing difficulties ... indicated to her that he's failing to take responsibility'. He was 'very disorganised', the teacher said. 'And to be organised, he needs to want to be organised.'

'I kept insisting that they need to provide adjustments, and what were they going to do? And I could tell I was getting into the too-hard basket at that point.'

One senior staff member told Waverly the school had a diversity program, but at this school 'diversity does not mean disability'.

Meanwhile, Zev was becoming 'more and more unhappy and anxious'.

One day, he wrapped his school tie around his neck, ran out of the house, down the street, and attempted to climb over the wall to the train station, 'as though he was going to do something'.

Zev's parents called an ambulance, which took him to a nearby hospital. A psychiatrist assessed Zev's mental health and gave Waverly a stern warning that, as his mother, she needed to 'get control of him'.

After this incident, the school agreed to a learning plan. Things improved for a while and Zev seemed to be adjusting.

Then Zev moved into high school.

'That's when things fell apart,' said Waverly. 'He started complaining of bullying. And he was very lonely.' Zev told his mother, 'It hurts to go to school.'

When they approached the school, it was suggested to them that Zev leave. '[It's] a good school, but it's not for everybody. He should be at a special school,' they said.

Waverly felt let down. 'They have a certain type of student, I think, that they feel that they're servicing, or providing a service for, and that doesn't include people like [Zev].'

She lodged an anti-discrimination application with the Human Rights Commission.

One of the school heads got 'very angry about it'. 'Do you ever think it's you that causes [Zev's] anxiety, coming up here all the time?' he yelled at Waverly.

Waverly felt ambushed. 'It was just very intimidating ... I just couldn't cope with continuing the complaint.'

Deciding it was more important to support her son through high school, Waverly withdrew the complaint.

Two years later, Zev completed year 12. 'It was with great difficulty, but he did finish.'

Branson, Addison and Clarissa

Clarissa is a disability support worker. In the 1990s, when she was 16, she got a job with a service provider for children with disability.

‘I was too young to be working within the human services industry legally, so I was told to take the P-plates off my car and not disclose my age,’ Clarissa told the Royal Commission.

The service provider ran school holiday and weekend camps for children with disability.

‘Three-quarters of those clientele were kids that were through the [child protection] system ... Most of them were being thrown out of school at that point in time. There were not very many services that would take kids with severe disabilities or severe behaviours.’

Clarissa said there was little training for staff, except in how to restrain children.

‘It was quite horrific ... full on restraints for kids for just trying to run off to the playground ... We’re talking hand behind the back. We’re talking headlocks. We were told to hurt them under their fingernails and behind their ears because bruises wouldn’t show.’

One of the first children Clarissa met in her job was Branson, who was still in primary school. Branson was autistic. One day he choked to death.

‘[He] liked to flick light switches on and off, but he certainly didn’t have any eating issues, you know, in all the time I’d known him.’

Clarissa said Branson’s death was attributed to his disability. After his death she made a complaint to a government department about the provider.

‘And even after, you know, repeated complaints by me, by other staff, by parents whose kids were coming home ... with bruises and, you know, sexual assault marks on them and all the rest of it, nothing had really been done.’

When she was in her 20s, Clarissa tried to help Addison, a young girl living in a group home run by her employer. Addison lived with complex disability and behavioural issues, and couldn’t speak. Clarissa formed a strong relationship with Addison and looked after her.

Clarissa took leave to complete university studies. It was not surprising that Addison’s behaviour deteriorated during Clarissa’s absence. But the provider’s response was to increase her medication so much that by the time Clarissa returned about a month later, Addison looked like ‘a zombie’.

'It was a technical restraint ... she was drooling when I came back. She was just drooling.'

Clarissa quit. Addison's physical condition deteriorated. Clarissa was so worried, she applied to be Addison's guardian.

'I had to go down the path of showing that [the provider] was, in actual fact, abusing her, and that that's why they needed to provide her with a guardian.'

Clarissa said her application was rejected because she was too young. Addison's guardianship was vested in another service provider.

'Her behaviours became really horrific, and the self-harm really took a turn for the worse.'

The guardianship was withdrawn after staff restrained Addison with a tea towel and confined her to her room at night. Addison was made a ward of the state and another foster carer found.

'[Addison's] story is one of the reasons that I wanted to come and speak to you guys today,' Clarissa told the Royal Commission.

'That whole process of trying to report what was going on and trying to get help for her, and having government department after government department say that it wasn't their problem ... It's really scary. You know, [Addison] was lucky that she had me fighting for her because if she didn't, then she wouldn't be here.'

Jakob

Jakob is in his late 40s. He has myalgic encephalomyelitis (ME), idiopathic hypersomnia, gastric issues and sleep apnoea.

Jakob's doctors advised him to manage his ME by pacing himself. They warned, 'Ignore it, you pay for it.' He told the Royal Commission if he pushes himself too much he experiences muscle cramps, spasms, swelling around the neck and boils. He can suffer 'fatigue crashes' which can last weeks or months.

Jakob works as a software developer for a government department. His job is highly analytical and for many years he was well supported in the role.

Four years ago, Jakob started reporting to a new supervisor and manager. He said they both treated him poorly.

His disability was not understood or respected. His managers questioned his disability suggesting 'maybe it's all in your head'. They denied Jakob flexible work adjustments and refused his request to work from home.

At one stage Jakob's personal information was exposed to other staff.

Jakob can't understand why people who smoke are allowed to take breaks whereas people with disability are not allowed short breaks.

Jakob's supervisor forced him to attend a rehabilitation program set up to support people at risk of self-harming. He felt it was not an appropriate program for him but he wasn't given the option to refuse. 'I felt ... if I didn't, I would be moved on.'

As soon as the manager told Jakob to attend the program he refused to engage further. His attitude became '[he] could outsource this problem ... goodbye'.

Jakob made a complaint and the department carried out an independent investigation. He believes the final brief report was 'false and misleading'. 'It dismissed everything that I said. It makes me look confused,' said Jakob. 'That I didn't understand my role and [my managers] were simply trying to help me.'

The manager and supervisor have since left, but Jakob doesn't believe the issues have been resolved.

Jakob believes he is being 'managed out the door' and silenced.

During COVID-19 Jakob was allowed to work from home. He said this was a 'godsend' because he can take a short break every few hours. He believes it shouldn't take a pandemic to be given flexible work adjustments.

Callan and Kelly

‘I know parents that aren’t here anymore, but have kids still in care and, you know, I often say a prayer for [the kids] at night because ... it’s not right that there’s no-one to advocate on their behalf.’

Kelly’s son Callan is in his 30s. He is autistic and has intellectual disability and obsessive-compulsive disorder. He doesn’t speak.

Kelly’s husband was Callan’s main carer until he died more than a decade ago. After he died, Kelly had to raise all her children alone and couldn’t afford to stop working.

‘My husband was the strength and I was always the sook behind him,’ she told the Royal Commission. ‘And after my husband passed away, I had to find a place for my son – oh, geez, I’m going to get upset straight away. Sorry.’

Kelly put Callan into supported accommodation. He was happy, at first.

One day she saw a support worker assault Callan.

‘A male carer ... elbowed my son right in the stomach as he was coming up the hall to say hello to me ... I was shocked. I was a bit scared, so I didn’t say anything. I just got my son and just left the house straight away.’

Kelly complained to the group home’s managers, who told her they had moved the worker. She later discovered they had rostered the support worker on a different shift, so he wouldn’t be there when Kelly visited her son.

‘They’d only moved him from one weekend to another because I didn’t come on that weekend. I only came every fortnight because I worked all the other weekends.’

Later, the same worker called Kelly to tell her Callan had vomited in the house and she should take him home.

‘I said, “I can’t”. I said, “I’ve got to get to work”. And he said, “Well, that’s not my problem”. And I thought, “Why am I explaining this to this guy?”’

Callan’s brother brought him home.

‘[Callan] looked like an old man off the street. His pyjamas had a rope around his stomach ... the socks that weren’t his and so I said, “He’s never going back there again”.’

Kelly complained and the worker was removed.

Callan appeared happy for several years until a new provider took over the group home.

One night, when Kelly brought him to the group home from hospital, Callan refused to get out of the car.

‘So, the carer came over and grabbed him by his shirt and pushed him to go and said, “Get into your room” ... And then because he didn’t want to do it, she slapped him on the head and said get into his room, which he did do. I just left quietly [and] cried all the way home thinking, “Oh my God, why is she treating him like this?”’

Kelly complained, but she ‘felt like nothing was ever done’. Callan became more aggressive and Kelly moved him to a new home, run by a different company.

‘If you ring up and have a complaint, it’s fixed that day and they get back to you. If there’s a problem with the carer, they’re gone straight away. They don’t muck about.’

Kelly said that as she gets older, it’s becoming more difficult to advocate for him.

‘I just don’t have the strength that I had years ago ... I think life should be easier for Callan, but he’s never moving again, that’s what I can say.’

Andy

‘They don’t ... understand the language of Auslan, and how to book an interpreter.’

Andy is Deaf and uses hearing aids. His first language is Auslan, his second is English.

A couple of years ago Andy said hello to Carl when they were waiting outside a grocery store. Carl told him he was homeless. ‘He said that he was trying to support his family because they had no money, that they were poor, and they needed food and petrol,’ Andy told the Royal Commission.

Carl pleaded with Andy for money and asked to ‘borrow’ Andy’s bank card and PIN. ‘He kept asking me to give him money so many times.’ Andy couldn’t say no.

Over a short period of time Carl withdrew \$25,000 – most of Andy’s savings. When Andy realised what he was doing he was ‘shocked’. He asked Carl to return the card. ‘I said to him ... please, stop doing it. This is my money. But he kept taking it. And then he got angry and got frustrated.’

Andy went to his bank and asked them to ‘lock the card’. The bank immediately cancelled the card. ‘If I need money now, I go into the bank and I ask for cash, and I just pay for everything with cash now.’

Carl continued to message Andy trying to ‘manipulate’ him. At one point he asked Andy to put cash into his bank account.

Andy’s disability advocate was worried Carl would take more money from Andy and encouraged Andy to report the stolen money to police. Andy told police officers he was Deaf and needed an interpreter. They told him they don’t have interpreters. ‘I was shocked. It was awful. It wasn’t fair.’ Instead they gave him a piece of paper with writing he couldn’t read. He believes police expected him to lip-read to understand them.

Andy’s advocate made a complaint and after several months police finally arranged an interview for Andy with an interpreter. Unfortunately, on the day, Andy couldn’t attend because he had injured his back. His advocate unsuccessfully tried to reschedule the interview.

Despite Andy having threatening and intimidating Facebook messages from Carl, police refuse to investigate the complaint. They believe there might have been ‘some sign of a financial agreement or friendship’ between Andy and Carl.

Andy is ‘frustrated’ and ‘still needs [Carl] taken to court’.

Westley and Sloan

‘Pretty much I was in a domestic violence relationship with my son.’

Westley, 13, lives with his family in a small rural town. He has attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder, dyslexia, depression and anxiety. His mum, Sloan, told the Royal Commission there are ‘not a lot of supports’ available to help Westley or the family.

Towards the end of primary school Westley’s behaviour escalated. He saw a paediatrician and started taking medication for ADHD. Doctors adjusted the dosage and the medication seemed to help. After a long and difficult search, Westley started seeing a psychologist an hour’s drive away.

Around the start of high school, despite increased dosages of medication, Westley’s behaviour became violent. He ‘smashed up’ the home and repeatedly tried to strangle Sloan.

At times the family were so scared they called police. Police would walk in and say there was nothing they could do to help the family despite seeing the damage and other signs of violence.

Twice, Sloan was able to get police to take Westley to hospital. The first time he couldn’t access the mental health service because he was already seeing a psychologist. The second time staff wanted to give him sleeping pills and send him home. Sloan was very concerned because that morning he had held his young sister down and put plastic bags over her head. She told them she was too scared to drive the hour from the hospital to home with Westley in the car.

Various services told Sloan there was nothing more they could do for the family unless she relinquished care of Westley.

Around this time Sloan’s two older sisters moved out of home because of the violence. One is still at school.

At school, Westley was involved in many fights and has spent more time on suspension than in attendance.

Westley is often the victim of bullying. One time his teeth were knocked out and he had to have them wired. Other kids have also threatened and bullied him on social media. The school recognises it has a bullying problem.

Not long ago, students sent Westley messages saying they would bash him at school. Sloan showed the school the messages and they suggested she take Westley’s phone away. A short time later he was ‘majorly bashed’. Students filmed it and sent the video around in a group message.

‘The next day he got bashed again by the same people,’ Sloan said. The school asked Westley’s sister, who was also a student, to take him home. ‘I was really angry they were going to try and put a dysregulated boy, that’s just had head injuries, into a car with my ... daughter.’

The school is in the process of putting together strategies and supports for Wesley.

Sloan only learned about the NDIS a year ago. She applied immediately. The NDIS rejected the first application saying she didn't supply enough documentation. They rejected the second application because, contrary to the psychologist's report, they believe Westley's disability is not lifelong. Sloan submitted a third application and has been waiting more than two months for a response.

The impact on the family has been terrible. Sloan is working two jobs to pay for specialists and medication – approximately \$1,000 a month. Her husband has lost his job because he needs to help Sloan with Westley.

When Westley is suspended it is very hard. 'The hardest thing going through it ... there was no respite whatever.' She and her husband are socially isolated and she worries about the lasting impact on her daughters.

Westley is not as violent at home as he was a number of months ago. One of his sisters has moved home again.

Sloan believes services need to be better coordinated rather than 'handballing' the problem to each other and then back to her. She has been to countless meetings where people have said 'good luck'.

'I didn't need luck, I needed help.'

Aya

‘In my entire experiences and interactions with the police, I’ve never had an interpreter once ... I’ve actually got to the point where I’ve lost all trust in the police force.’

Aya, early 40s, is Deaf and works as a support coordinator for people with disability. She’s been using Auslan since she was young. Aya told the Royal Commission she has complex post-traumatic stress disorder. She explained it’s a ‘layer of repeated trauma’ that makes her react in a ‘very volatile way or an immediate way’.

Aya’s partner is also Deaf.

About a year ago Aya called police during a domestic dispute with her partner. ‘I called the police to help calm my partner.’ When they arrived, they tried to interview Aya without an Auslan interpreter. They also turned on their body cameras without asking her permission. Then without explanation, they arrested her partner and took him away.

The next day, Aya went to the police station to pick up her partner. Police did not communicate with Aya or arrange an Auslan interpreter. ‘It took me four days to find out he was in the jail, and he had been locked in jail for five days without an interpreter.’ Aya said she ‘lost it’. ‘Can you imagine being put into a cell and not knowing why? That’s why it’s imperative that we have interpreters.’

Aya emailed police on three occasions asking to arrange a meeting with an Auslan interpreter but did not receive a satisfactory response. Eventually, police showed her a statement they had drafted on her behalf. Aya disagreed with the statement and requested an interpreter to amend it. Police told Aya she did not need an interpreter to make a statement.

Aya has not had any contact with her partner since he was arrested. She believes he is being held at a correctional centre.

‘I’ve asked for communication repeatedly through an interpreter, and I’ve received absolutely nothing. So, I’m often not allowed to contact my partner to check in, are they okay. It’s like there’s this complete barrier that’s been set up. I have no communication. I’m just frustrated. It’s giving me trauma.’

Aya has to attend court and is unsure if the court will arrange an interpreter. Aya said the court system is impossible for Deaf people to access.

Another time, Aya’s adult daughter called police after an incident with Aya. A male and female officer wearing masks walked into Aya’s house while she was in the kitchen cooking dinner. Aya asked them to get an Auslan interpreter or leave the house. The officers refused and kept trying to communicate with her in English. The officers stayed for about 30 minutes and watched Aya. She told them she has complex post-traumatic stress disorder and they eventually left.

Two months ago, police arrived at Aya's friends' house who are also Deaf. The friends asked police to get an Auslan interpreter and gave them a card with details. The police refused to get an interpreter and instead attempted to get their children to interpret.

One time, Aya was pulled over by police. The officers did not believe Aya was Deaf and she felt targeted. She did not make a complaint because she was worried about retribution.

Since then, Aya has made formal complaints about her interactions with police but nothing happens.

'I feel like I've got no hope. I actually think that the police force do not care about the Deaf community.'

Kesha and Marisa

‘[Kesha] has really experienced that ‘otherness’ ... where if you are in a group of people, everybody will talk to everybody except her.’

Kesha is in her mid-20s. She has a genetic syndrome causing intellectual disability, development delay, issues with fine motor skills and mild dysmorphic features. Her mother, Marisa, told the Royal Commission Kesha doesn’t trust people because of her experiences in high school.

Kesha attended a primary school for children with disability. From year 3 to year 7 Kesha did very well. She also did well at outside school hours care. Marisa was particularly impressed with the art program and felt the school was dedicated to their students.

High school, however, was ‘totally traumatic’, Marisa said.

On the first day in the special learning unit of the local state high school, Marisa asked a teacher if she could help Kesha unwrap a feminine hygiene product. Kesha needs help because of her fine motor issues. The teacher told her they ‘should have had this sorted’ before Kesha started school.

Marisa said she had to constantly battle with the school to include Kesha. There were no adaptations or efforts to include children from the learning unit generally. The school held a barbecue commemorating the ‘laptop roll-out program’ but didn’t include the students in the special learning unit. The principal told Marisa he decided it wasn’t important for them to attend. ‘It was the most disgraceful act of discrimination you could imagine.’ When Marisa raised the *Disability Discrimination Act 1992*, the school wasn’t even aware it existed.

Marisa also had concerns about the level of work teachers gave Kesha. She said it was either ‘overcomplicated or colouring’. When Marisa raised this with the principal, they responded that Kesha did not have to attend any class she wasn’t comfortable in.

The school also failed to provide adjustments to the ‘late for school policy’ for students with disability.

Marisa made several complaints to the head of the special learning unit, the principal and the minister.

Eventually, the school ‘labelled’ her ‘that difficult parent’, and enforced a communication protocol.

Kesha developed anxiety and ongoing continence issues. Despite being funded to provide toileting support, the school didn’t offer any assistance. Marisa had to develop her own toileting program and plans.

Halfway through year 12, Kesha stopped going to school. Marisa said there was no support worker on duty one day when ‘something’ happened and Kesha had a meltdown.

Marisa is concerned students are still experiencing the same issues Kesha experienced.

'We are in the 21st century, we've got all the knowledge behind us, you know, and it is still going on. I think it is because principals aren't accountable, departments aren't accountable and politicians aren't accountable.'

Kesha has been trying to find work but feels let down by the disability employment service. Marisa and Kesha worry about the future.

'My darling daughter said to me, "Mummy, I don't want to spend my life throwing biscuits in boxes.'"

Derryl

Derryl is in his early 40s and has avoidant personality disorder, autism and depression.

About three years ago Derryl was sentenced to two years' imprisonment for offences relating to possession and distribution of child exploitation material (CEM).

Derryl told the Royal Commission that he believes people with autism and other developmental disabilities are more prone to committing CEM offences. He says this is due to a range of complex factors, which can include childhood trauma and the difficulty of forming close relationships.

He told us he never had a desire to break the law. At the time he did not think he was 'crossing the line' and believes that his disability allowed him to rationalise what the law actually allows him to do.

His disability, he said, should have formed part of his defence, and greater consideration should have been given to it when he was sentenced.

Derryl experienced serious depression and suicidal thoughts during the investigation, throughout the court case and his incarceration. He has been ostracised from his friends and family. Yet, he says, when he was released from prison he was not offered any counselling or assistance finding work.

Nylah

Nylah is in her late 60s. She has post-traumatic stress disorder, anxiety, a physical impairment relating to her spine and a rare and complex heart condition.

About 10 years ago, Nylah began to develop significant pain and sought treatment from a local GP. The GP largely ignored Nylah's reports of heightened pain. Nylah got 'sicker and sicker' but the GP just blamed this on her anxiety. She said Nylah should see a psychiatrist because she was 'imagining it', but continued to treat Nylah.

Nylah told the Royal Commission it wasn't until later that she found out this GP had determined that she had Munchausen syndrome – a rare type of mental disorder in which a person fakes illness.

'For six years I thought I was being looked after by my doctor ... I had no idea that a lot of information wasn't being passed on and that she was telling everybody I made things up.'

Nylah believes this was one factor that would influence future interactions with medical professionals.

Nylah's heart condition had been diagnosed five years earlier – a genetic heart condition that is extremely complex. Nylah said even general cardiologists don't understand her condition as it is very rare.

'It's very hard to get normal cardiologists to believe you. I've been laughed at and told it was the anxiety. My heart condition has been downplayed when I am having severe symptoms of it.'

Some of those symptoms included blackouts and collapses. 'I ended up having a complete collapse, and when I finally got to the hospital the cardiologists there found I had severe obstruction to blood leaving the heart.' Nylah had emergency surgery the next morning.

After the surgery, however, Nylah's health continued to decline. 'So I got sacked by my second cardiologist who after that first surgery didn't know what was wrong with me,' Nylah said. 'And because I continued to black out and my symptoms get worse, after that I'm sent to a psychiatrist.'

The only people who would listen to Nylah were some 'really good nurses who showed me some of what was printed because they could see how sick I was in my hospital circumstances'.

This was how Nylah found out her GP was telling other medical professionals she had Munchausen syndrome.

Nylah then went to great effort and risk to get herself to specialists in two states. Each time she went to a new specialist the first thing they asked was 'did she have anxiety?' and 'why didn't she trust her doctors?'

Meanwhile, for three years Nylah had been coughing up blood, yet no-one ever thought it necessary to take a sample or run any tests. Other physical problems were ignored.

'I was being treated like a piece of dirt quite frankly ... I would go to the ER and I'd be ignored and sent home and treated as a joke with them saying we can find nothing life-threatening wrong with you. Nobody was taking me seriously and yet the disease I had is progressive, it is incurable.'

Nylah eventually insisted certain tests be run and finally a test was done that showed there was still an obstruction in Nylah's heart.

Another surgery took place.

After the surgery Nylah was ok for a few months but then started to get sick again, with pain, nausea and depleted energy.

But Nylah is too scared to go to any more doctors. 'I just got abused and bullied and completely brutalised. I've just been laughed at ... I felt like a bug that somebody had just squashed underfoot.'

Apollo

‘I’ve seen it in every jail ... there are people in jail with disability that should not be in jail.’

Apollo is in his 20s and has an acquired brain injury and post-traumatic stress disorder. When he was younger his psychosocial disability would cause him to ‘blackout’ when he became stressed.

At around the age of 10, Apollo became a ward of the state. He was sent to juvenile detention a couple of years later.

As he grew older, the blackouts turned to anger and frustration and he often found it difficult to keep his temper in check. Apollo has spent most of his adult life ‘in and out of jail’.

The prisons where he has served time have had a disruptive prisoner protocol (DPP) in place. Under the policy, an inmate can be kept in solitary confinement for 28 days. They are entitled to three meals, one phone call, a shower and one hour of outdoor recreation each day.

Inmates in the general prison can be prescribed medication and have access to counselling services. Those same supports are not offered when they’re ‘down the back’.

Apollo has spent a lot of time ‘on DPP’, confined to a cell for ‘23 hours a day’.

During one stint, he went ‘eight days [straight] without the cell door opening, not for a shower, phone call, rec, nothing’.

‘You can’t put [people] in a cell for, like, a long period of time and not let them see no-one, not let them talk to no-one, not give them a TV, not give them a radio ... nothing at all.’

Under the policy, once an inmate completes their 28 days in solitary incarceration, they can immediately be transferred to another prison. They can also be ‘rotated’ every 28 days, for months at time.

Apollo told the Royal Commission that the protocol and other prolonged periods of solitary confinement should never be used to ‘punish’ inmates.

‘What they’ve done to not only me, a lot of other boys ... it stuffs with people’s heads mentally ... People kill themselves over shit like that.’

During one stint, he became so distressed that he set his cell alight. ‘I nearly died,’ Apollo said. He had already spent six months down the back. As a consequence for starting the fire, he was sentenced to another four months on DPP.

Apollo has recommended that inmates serving a ‘disruptive prisoner’ term have access to counsellors, psychiatrists and ‘more people to talk to’.

He recalled a situation where a prison officer helped him during a particularly difficult time while in solitary. Apollo had told the officer, 'Chief, I feel like smashing this cell up.'

The staff member sat down outside Apollo's cell, drank his cup of coffee and chatted with him. His proactive approach helped de-escalate what could have led to a violent situation. 'Some officers are good like that,' said Apollo.

He has also recommended that offenders with psychosocial disability appear before 'a mental health courtroom'. Not a criminal court he said, but 'a courtroom of their own'.

'The shit I went through I wouldn't wish upon ... my worst enemy ... yeah, it's [been] a hard life'.

Temperance

‘My university experience was like everything I had experienced, plus more, on steroids, the worst yet.’

Temperance, mid-30s, has a vision impairment, attention deficit hyperactivity disorder, scotopic sensitivity syndrome, photophobia and anxiety.

In high school, Temperance had to constantly remind teachers to provide reasonable adjustments. She had to organise and chase up materials in accessible formats, always ‘on catch-up’ with the information. She told the Royal Commission she found it ironic the school expected a person with executive function issues to organise, sequence and plan their own learning materials.

Temperance’s first time at university was an ‘okay experience from an accessibility perspective... not perfect ... but it was a lot better’.

In gaining her second degree, however, she experienced abuse ‘on a daily basis’.

Prior to commencing, Temperance gave the university comprehensive information about her disabilities and the reasonable adjustments she needed.

She required a screen reader and extra time to prepare for lectures and take exams. She also required lecturers to provide slides, handouts and exams in electronic format in advance so she could read the material using adaptive technology and software.

The university agreed but required Temperance to register for reasonable adjustments each semester, even though her disability is permanent. The university also required her to speak to her lecturers in person and explain her disability and the reasonable adjustments she needed. Temperance ‘struggled a bit’ turning up and introducing herself as ‘the student with a disability’ and ‘hoping they respect that’. She said most of the time they did. ‘But I was an inconvenience a lot of the time, too.’

Nonetheless, most of the time lecturers ‘forgot’ to provide the material in an accessible format beforehand. The lecturer would hand out printed notes and suggest Temperance email them after the lecture and ‘remind them’ to send an electronic copy. She got sick of hearing, ‘Oops, sorry. I forgot ... Oh, you’ll have to sit this one out and do it on your own later.’

‘I wasn’t able to learn. I wasn’t able to participate and do what everyone else was doing.’

Some lecturers told her they were trying ‘to save [her] from finding out the hard way’ she wouldn’t be able to work as a medical professional. At one meeting a staff member asked, ‘Should she really be at university with a disability?’ Temperance pointed out as it was her second degree, ‘it is possible’.

Sometimes the university paid other students to take notes for Temperance. These students were not trained to take notes and the notes often weren't good. Temperance was eventually able to hire a professional note taker. Some lecturers assumed the note taker was her assistant and could organise the reasonable adjustments.

'I had to complain. I had to drive the complaint. I had to take flak for the complaints ... I just became this problem they needed to get rid of and deal with.'

Temperance's mental health deteriorated. She couldn't go to class and was 'shaking and crying'. She started seeing a university counsellor.

Around this time Temperance made a complaint to an anti-discrimination commission. '[The university] played a very dirty game,' she said. They questioned her disability and refused to engage or comply. She believes the commission 'either doesn't have powers or doesn't use them'.

When the counselling service handed over Temperance's treatment notes to the university without her consent, it was 'the final straw'. She took the university to court, seeking an apology and for the university to change their processes. The university dragged the matter out for more than 12 months.

'[I was] shocked at the level of games they were playing and how hard they were working to cost me more.'

Eventually Temperance could no longer bear the financial and emotional costs. She settled and signed a non-disclosure agreement.

'I was discriminated against. I had evidence that I was discriminated against. I was not provided an appropriate justice process that did not cost money. And then I was the one who was silenced.'

Annalee

‘It just upsets me that ... in this day and age and in this country that people with disability are not treated better.’

Annalee is in her 50s and lives with fibromyalgia, trauma, anxiety and depression.

‘I know what it’s like not to have a disability, then to be given it,’ Annalee told the Royal Commission. ‘It’s very hard to take ... when you are not getting the help you need to cope.’

Annalee acquired her disability nearly a decade ago after her former partner abducted her son. Shortly after this incident, Annalee’s employer made her redundant.

‘And that was the start of my journey of this disease grabbing me.’

Annalee said she reached a point where she ‘couldn’t move really’ and saw a doctor.

‘Being an active person beforehand, and a mother of a son, it was hard for both of us. And my parents. It was hard for the whole family because it’s annoying, and you think you can beat it and you can’t.’

Annalee said when she tried to get help, the government made her disability worse.

‘I’ve worked all my life. Always worked, and I was a volunteer firefighter. And the way I’ve been treated by ... government agencies, has been disgusting.’

After Annalee was made redundant and her health deteriorated, she became homeless. She approached Centrelink for help.

‘You’re going to specialists, you’re getting this and that done, and when you are ringing up to get some help, you’re treated like a liar.’

She later applied for a Disability Support Pension, a process that took so long Centrelink lost her paperwork several times.

‘They said, “Oh, we’re sorry, we’ve made a mistake.” Now, that mistake took too long for anybody ... That was like a three-year wait.’

Annalee said the abuse from her former partner, and the difficulty finding support, made her disability worse and traumatised her son.

‘I’m just scared ... My son, he’s already got a disability, he’s got severe PTSD [post-traumatic stress disorder] ... I’ve got him at the psychologist. We both see a psychologist ... I don’t want him or anyone else to go through this.’

Dane

‘Sometimes I can go three, four, five days without eating because I am just too sick and just too upset with it all.’

Dane is a First Nations man in his 50s. He lives with post-traumatic stress disorder (PTSD) and a physical disability from several years in juvenile detention.

‘I have got complex spinal, broken spinal from long-term torture and sex abuse from when I was a child,’ Dane told the Royal Commission. ‘I can’t walk too far. I am also severe PTSD, still.’

Dane, who lives in a regional community, also has cancer.

‘So, medically wise I haven’t been very good.’

A few years ago, Dane was involved in a traffic incident.

‘I was doing 50 kilometres per hour in a 50 kilometres per hour zone and I was rear-ended.’

Dane said police charged him with dangerous driving. He isn’t sure why.

‘I am telling [the police], “I am disabled, I am not coping, what is going on?” ... I have been asking all the way along, “I need support, I am disabled.”’

Dane said legal aid initially agreed to help him defend the charge, but withdrew ‘because it wasn’t an incarcerable offence’. Dane said he has to represent himself.

While Dane was in another state being treated for cancer, the COVID-19 pandemic closed the border. Dane said the court agreed to postpone his hearing.

‘I have all the documentation to support this. They told me, you basically get well, and after I was well to come back.’

When Dane returned after the border reopened, police arrested him for failing to attend the hearing. At a later hearing, Dane said he was handed ‘a huge bunch of paperwork’.

‘I was told to go outside the court for 10 minutes to read it, and then come back in and defend myself.’

Dane said the magistrate sentenced him to several months home detention.

‘During the court trial, I am disabled and I am telling this, that I can’t function.’

Dane said that while he was stranded in another state, he was still paying rent for the home he couldn’t access and had to live on the street.

'I am still a month behind on my rent. I have still got bills coming out of my ears, and I just can't get out of it. I have been slowly chipping away at it. I got myself down to spending two or three dollars a day just to eat.'

Dane said he's applying to enter aged care.

'When the specialists are telling me I could have only two months to two years [to live], that is why we sort of, you know, went straight to aged care ... My health has deteriorated from this whole system failure over the last four or five years.'

Jarrad

Jarrad is a First Nations man in his 70s. He has chronic fatigue syndrome.

‘I’ve spent a lot of my life starting the day thinking, “Will I be able to manage this?” and thinking, “What needs to be done to get the maximum done to avoid going under?”’ Jarrad told the Royal Commission.

Jarrad had worked most of his life, but wondered why he struggled. In his 40s, ‘thinking there was something wrong’, he saw a psychiatrist.

‘At the end of two years he said, “Well, there’s nothing wrong with you, [Jarrad].” I’ve got this clean bill of health.’

Jarrad said he still felt something was wrong and was ‘driven’ to try to find it and fix it.

He heard of a large medical research project and signed up. Through the project, he was diagnosed with chronic fatigue syndrome.

Jarrad said it was ‘a relief, in a way’ to finally have an explanation for not just the fatigue, but decades of living with ‘all these funny symptoms’.

A few years later, Jarrad stopped working and began to receive the Disability Support Pension. He struggled to feed his family.

‘There was not enough money for the week, and I’m in this terrible physical shape, starving.’

He delivered newspapers ‘to try and make ends meet’.

‘[The disability pension] has got nothing to do about looking after people or that. It just gets them out of sight.’

In his 50s, wanting to get off the pension, Jarrad applied for an apprenticeship.

‘And then, of course, having a chat with one of their business managers, they get me out on the basis they couldn’t secure from me that I wouldn’t be one of these sticklers for working to the shift.’

Jarrad said people with disability want opportunities to work, but face an ‘uncaring society’.

‘I’m happy that I’ve been heard,’ Jarrad told the Royal Commission. ‘I just hope some good comes out of it for the sake of people who aren’t quite as dogged as me. There’s so much unnecessary suffering, and there could be so much contribution made in the country in so many ways.’

Jenesis

Jenesis is in her 60s. She has a severe congenital hip condition and under-formed knees. She has psychosocial disability resulting from her physical problems.

Jenesis spent most of her toddler years in a full body cast as a hospital inpatient, and every six weeks doctors used a circular saw to remove her cast. Despite the trauma this involved for a toddler, she was allowed only minimal visits with her mother. Jenesis believes that the loss of 'toddlerhood' affected her social development and made her 'vulnerable to anyone in authority'.

Jenesis met her local priest in her late teens. She told the Royal Commission he targeted her for a sexual relationship because she was isolated due to her disability. The relationship lasted sporadically for some years, as Jenesis did not know how to make it stop.

Jenesis does not like being described as 'vulnerable'. She feels that you are only vulnerable because you are targeted. And people with disability are targeted.

Jenesis later reported the abuse to the police but felt they had no understanding of how isolating it is to live with disability or how this can lead to targeting by abusers. She said the female officer she first spoke to was great. She came to Jenesis's home and compiled statements.

However, when the case was transferred to a male officer, the investigation was suspended. The police did not communicate with Jenesis.

Jenesis made an appeal to the Police Commissioner's office, which returned the matter to the local station. The local station upheld the suspension. By then, the Catholic Church had defrocked the priest. Jenesis made a further appeal, but nothing much happened.

Jenesis then reported the abuse to police in another state. Investigation by a specialist detective resulted in the priest being charged. The detective told Jenesis that police in that state undergo psychological training in sexual abuse. She believes this training helped the detective manage the case and understand what had happened to her. She strongly believes police in all jurisdictions need similar training and to 'catch up with the psychological literature'.

Despite the efforts of the specialist investigator, the matter did not proceed to court as prosecutors believed a conviction was unlikely. Some years later, Jenesis received compensation from the Catholic Church.

Jenesis left her career in teaching due to impacts of her disability and moved on to other roles. When she became unemployed, she applied for the Disability Support Pension (DSP). Jenesis said she found some Centrelink staff spoke very rudely to her on the phone and were condescending. However, one helpful staff member contacted Jenesis and told her 'the words' her doctor should write to successfully appeal Centrelink's decision. This appeared to work as she got the DSP.

Jenesis has since applied for support through the NDIS. She was continually 'knocked back' and has appealed those decisions. An NDIS officer told her, off the record, that she 'didn't tick the right boxes' and that 'if you are not in a wheelchair you won't get NDIS'.

When she was younger, Jenesis always felt people were staring at her because she walked differently. She had lots of operations so she could walk 'normally'. However, Jenesis finds that not using a wheelchair makes people think she doesn't have disability. People have challenged her right to use a disability parking space, despite her permit. Now, not being in a wheelchair may be the reason the NDIA is refusing funding. 'Invisible disability' is a real issue, she says.

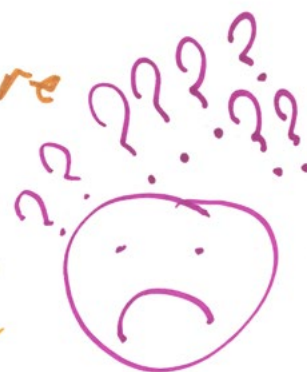
STOP ABuse, neglect, Exploitation

Ona PEOPLE with a disability
Everyone has Rights

STOP BULLYing

We all Have a choice where
We want to Live

ABuse IS NOT OK



Artwork by Sonia Hume



Artwork by Sonia Hume

Kaiden

Kaiden is in his mid-20s and lives with post-traumatic stress disorder (PTSD) and drug-induced psychosis. He is currently serving a custodial sentence in prison.

Kaiden told the Royal Commission that controversial ‘punishment’ rules are severely exacerbating his psychosocial disability.

Kaiden explained that these rules were introduced to bring law and order into the prison system. Inmates can be sent with little or no notice to another prison, where they spend up to 23 hours a day in solitary confinement. They call it being ‘sent down the back’.

Several years ago Kaiden was involved in an altercation with prison staff. ‘One thing led to another, I end up donging one of the officers,’ he said.

The next thing he remembers is ‘being woken up, 5.30 in the morning’ and dragged out of bed. He was handcuffed, taken out of his cell and strapped to what looked like ‘something out of some Hollywood movie ... like an asylum chair’.

‘[I sat there] like 11 and a half hours. No water, nothing. And just left there.’

Following an investigation over his assault of the officer, Kaiden was sentenced to several months of isolation.

‘I was only allowed out of my cell 15 minutes for a shower, [then a] 10-minute phone call ... not allowed to participate in any recreational activities.’

Many times while he’s been ‘down the back’, he recalls officers coming into his cell with riot shields and pepper spray canisters. Kaiden says officers ‘unloaded’ on him.

‘I’ve been pepper sprayed. I’ve been tasered ... I’ve still got scars on the back of my head from when they kicked the shit out of me.’

The ‘disruptive prisoner’ protocol is intended to ‘encourage’ more positive behaviours. But Kaiden says its implications are far more sinister.

‘It’s played a big big part of my mental health. I now suffer PTSD from being assaulted “down the back” ... It’s broke my mental persona severely ... it’s fucking ruined me.’

He says having spent many times ‘down the back’, he has become ‘programmed’ not to trust anyone. ‘We know if we say the wrong the thing, we’re automatically isolated and put into a chokey regime.’

Kaiden has also been to the prison's medical centre several times in the past few weeks. '[(They check)] everything other than what I need to be checked for, my mental health.'

He's been trying to see a 'psychiatric doctor' for months, without success.

Kaiden says he cannot wait until he is released to get the help he needs – he needs it now.

'It's all good me getting out and having a home and that to go to. But my mental health, if I can't get that ... levelled before I get out, then there's no hope for us when we get out.'

He says 'disruptive prisoner' protocols and solitary confinement should not be used as punishment.

'It's not the cure to keep boys out of jail.'

Kellan and Estella

‘You talk to any parent with a child with a disability, and their biggest thing is that they feel like they’re fighting, they are climbing up a wall all the time.’

Estella, mid-40s, has psychosocial disability. She is Kellan’s mother.

Kellan was born eight weeks prematurely and developed ‘pretty well’, but Estella knew from the beginning there were ‘going to be issues’. At two, he developed a ‘major’ stutter and stopped speaking. His speech improved with therapy, but he continued to experience a great deal of anxiety.

In kindergarten, Estella told the Royal Commission, Kellan’s anxiety increased. The following year he had a number of different teachers and ‘his separation anxiety just got ridiculous’. Estella knew, ‘something was wrong’.

Having Kellan assessed for autism would require assessments by speech pathologists, occupational therapists and a psychiatrist. Estella couldn’t afford all of these. The teachers and principal at Kellan’s school told her, ‘He’s fine, he’s just emotional.’ The school couldn’t provide additional support until Kellan was assessed, and Estella felt she had no choice but to remove him.

Estella homeschooled Kellan for the next few years. ‘He did amazing, he thrived.’ During this time she supplemented his meals with hospital formula to keep him healthy and he reached a good weight.

Estella ‘dipped into’ her superannuation to pay for Kellan’s autism assessment. He was diagnosed with autism, anxiety, dyspraxia and hypermobility – she wishes he’d been assessed earlier.

At seven, Kellan returned to school with some educational support. The school offered a healthy eating plan and refused to allow Kellan to eat the food he required.

On his first school excursion Kellan had a meltdown on the school bus. Three staff members, including the school principal, held him down and strapped him into the seat.

‘I said to the principal ... “I’ll take him on the train, there is no point stressing him out.” And her reply was “He will get on that bus and if he screams all the way home, so be it.”’

The principal told Estella ‘it was about power’. ‘They don’t understand it’s his brain,’ Estella said.

Kellan can no longer attend school because it gives him too much trauma. He has bitten all the skin off his fingers. ‘No-one sees the after effects of what we’re dealing with.’

Estella reached 'rock bottom' with her mental health. 'The impacts his disabilities have had on my disabilities [are significant],' she said.

She applied for the NDIS on Kellan's behalf. The NDIS funded a support worker one hour a week – giving Estella a little respite – but told her caring duties are her 'parental responsibility'.

Estella recently applied for NDIS funding to support her mental health. Her application was refused because she did not provide enough evidence.

Estella says she is 'a fighter' and will continue to seek appropriate supports for her family.

Lenny and Lorna

Lenny is in his 40s. He is autistic and has schizophrenia.

Lorna said she gave birth to Lenny when she was young, on her own and already had another baby to care for.

'I relinquished [Lenny into foster care] on the understanding that I was going to be giving him a better life than what I would be able to provide for him,' Lorna told the Royal Commission.

Later, when she tried to find him again, she was told he had a disability. A social worker also told Lorna off the record – she said she was not allowed to disclose the information – that Lenny's first foster father had sexually abused him. A teacher had reported suspected abuse to the police, who investigated the matter. They charged the man with child sex abuse offences, however the charges were later dropped.

At just under 10, Lenny was placed with a second foster family.

Lorna said the new family, who Lenny stayed with until his late teens, had many children in their care. Lenny seemed to have no possessions beyond a few sets of clothes.

'When I first met [Lenny] ... he had one Tonka truck and he slept on the couch. He didn't even have a bed.'

Lorna was granted guardianship and organised independent accommodation. The foster mother delivered Lenny to Lorna, then never spoke with him again. Lorna found it 'quite cruel'.

'That was it. That was so sad to see him standing outside waiting for her to pick him up. He'd been with them since he was nine.'

Lorna organised support services for Lenny, including a psychiatrist.

'Life was really going lovely for [Lenny] ... He was becoming very confident and comfortable with meeting new people, and I introduced him to singing and dancing with a private social group ... where he would go on Saturdays of his choice. Yachting, river cruises, horse riding, really living it up.'

Lorna said a government department then challenged her guardianship.

'They tried to portray that I was in Lenny's life for his money ... They tried also to portray that I was abusing him. His abuse happened way before I met him.'

Lorna said she felt bullied into giving up guardianship. Years later, she re-applied.

'He's been in terrible accommodation.'

Lorna said he was living in a house with several aggressive men and his support workers appeared to use Lenny's money to buy cigarettes. She also suspected he'd been sexually abused.

Lenny's service provider gave him five dollars each Sunday 'and \$10 to buy a takeaway lunch every second Monday'.

After she was granted guardianship again, Lorna moved Lenny into a new house. 'Just two guys, and he's got one end and the other guy has got the other. They just share the centre kitchen.'

'Today, [Lenny] has the best of everything. He has as much control of his finances as he can. I put into his account a certain amount and he operates from his debit card. Again, today he's proud of his financial independence.'

Matilda, Yaneke and Brea

Matilda is a young autistic woman who is non-verbal and has cognitive disability. She spent more than 10 years living in a group home before returning to live with her family a few years ago.

Her mother, Yaneke, told the Royal Commission that staff at the home created a 'culture' of sedating the residents – without the residents' or their families' knowledge or consent.

Yaneke said that when Matilda first moved into the group home, she was 'doing well'. The family's doctor would visit Matilda on a regular basis and supervise her medical regime.

When the family doctor retired, Matilda's family began to notice a change in Matilda's behaviour. All of a sudden, said her sister Brea, she would come home on the weekend and spend her days flopped out on the couch like she was 'comatose'.

The family later discovered Matilda had been put under the supervision of a new doctor without their authority. 'At no time were we ever consulted,' said Brea.

In addition to her regular medication, staff were giving Matilda 'a lot' of additional medication. Yaneke said these included psychotic sedatives – drugs routinely prescribed as a chemical restraint for disruptive behaviours.

Without warning, Matilda's behaviour changed again. She became 'very aggressive' and angry. She'd wake up the family in the early hours of morning, pulling them from bed and dragging them around the house.

'[It was] really, really terrible,' said Yaneke. Her daughter was in this aggressive state but didn't seem to know what she wanted. 'Nothing was helping.'

The family lodged a complaint with the home's management. 'They did a little investigating at the start internally, and then nothing went anywhere,' said Brea.

Yaneke did her own investigating. One day she noticed Matilda being loaded into the residents' minibus in 'a sedated state'. When it returned hours later, Matilda 'could hardly walk'. She stumbled into the house and went 'off to bed until morning'.

The family decided to seek independent medical advice on the use of chemical restraints. The psychiatrist said Matilda was being overmedicated and it could take years to wean her off the drug.

Brea says the family doesn't believe staff ever followed the policies and procedures around the use of restrictive practices. 'At no time were we ever consulted,' she said.

Finally, once the independent psychiatrist became involved, staff stopped dispensing the psychotic sedative to Matilda. 'They had no other choice. They had to stop,' said Yaneke.

In the end, the family decided to remove Matilda from the group accommodation. Yaneke said she would rather her daughter live with her ageing parents than a place where the staff and management 'are nothing but bullies'.

'I will never send [Matilda] there. I don't trust them because [of] what they did. It's a criminal act giving her medications like that. Might as well get a gun and shoot her.'

Micah and Halima

‘The staff should have a level of education that is specific to their care role ... They’re dealing with people with complex problems that they’re not trained for.’

Micah is in his 70s and has cerebral palsy and developmental delay.

He went into disability care when he was a young boy. He stayed at his last residence – a large state-run disability facility – for nearly 50 years.

The institution closed down a few years ago, as part of a government initiative to integrate people with disability into community care.

Micah went to live in a group home, which was eventually taken over by a private service provider.

Not long after the new managers took over, his sister Halima told the Royal Commission, Micah began to experience ‘violence ... elder abuse ... neglect ... [and] malnutrition’.

She said the group home had a toxic culture and ‘substandard’ living conditions. ‘It was the scariest time of [Micah’s] life,’ she said.

At times, residents bit him on the head and ‘shoved their fists down his mouth’. One time he was assaulted and ended up with a black eye. Halima said it was his ‘first of several’.

In one incident a staff member ‘punched [Micah] in the mouth’, leaving her brother ‘very badly bashed’.

In another, Micah had to be hospitalised after being assaulted. Doctors discovered he had sustained ‘severe carpet burns’ to his hips and buttocks. ‘It was just a horrific situation,’ said Halima.

‘We could never prove if it was the other residents or if it was staff belting him up. I do have my suspicions on that, but I don’t have any evidence.’

She also discovered the state of Micah’s living conditions. His mattress ‘was worn down, the cover was worn, and there was faecal matter ... filthy ... it was unhygienic’.

It was difficult for Halima to have daily communication with her brother, due to the home’s outdated telephone and visitation protocols.

Micah became so scared that he refused to sleep without lights on. Halima asked that a baby monitor be put in his room to provide him with a sense of safety and comfort. The service provider denied the request, considering it a form of ‘restraint’.

'It was climbing a mountain all the time,' said Halima. The staff lacked 'gentleness ... understanding and ... training.'

One of the 'saddest' moments she recalls, was hearing that Micah was often so hungry, that 'if anybody spilt anything on the floor he would pick it up ... and eat it'.

Halima reported these and a dozen more incidents of neglect and violence against her brother, to the home's managers. When her complaints were not listened to, she went to the state safeguard commission, which found that the service provider 'had nothing to answer for'.

Halima eventually withdrew Micah from the centre. He now lives in a small group home with just three other residents, who also previously lived at the institution. She is confident he'll 'live a lot longer ... a lot safer and a lot healthier'.

Halima said Micah's 'sense of humour has come back'.

'[His] latest trick [is to] hokey pokey down the hallway when he goes to bed ... an amazing turnaround.'

Alessia and Nash

Alessia is a mother in her early 50s and each of her children has disability. Alessia herself is autistic and has post-traumatic stress disorder and a neurodegenerative disorder. She told the Royal Commission she has struggled with social interactions most of her life, but has nonetheless built a notable career and ran a successful business with her partner.

As a teenager, Alessia was sexually abused by her mother's boyfriend. The abuse caused her to start drinking.

Alessia confided in the school counsellor about the abuse. When the information 'got out', the principal called Alessia a liar, and Alessia's mother forced her to leave home. She moved in with her father.

In her late 20s, a doctor prescribed antidepressants. Alessia had no support in managing this medication and believes it 'completely changed' her. Her marriage broke down and her drinking escalated.

Alessia began a relationship with another man. Together they had two children, Nash and a younger sibling. But the man was violent towards Alessia. She obtained more than a dozen apprehended violence orders, but he repeatedly contravened them. Even when he kicked Alessia's door in, the police took no action. Alessia believes the police dismissed her as 'paranoid' due to her mental health condition.

Alessia's son Nash has profound intellectual impairment and a genetic condition – Alessia describes him as 'a toddler in a large boy's body' who needs '24/7 care'. He has 'explosions', makes 'poo smears on the floor' and has attacked his sister.

Nash accessed the NDIS in his early teens, but did not obtain sufficient funding or supports for his needs.

At one point, Alessia took Nash to hospital. He was given an antipsychotic which caused his condition to deteriorate.

Alessia unsuccessfully sought more support and additional funding for respite. Eventually, due to lack of support, Alessia temporarily relinquished Nash's care to child safety authorities. He lived in a group home for around two years, but his condition deteriorated further.

Alessia said Nash has had 'lots of caseworkers' – he is now on his eighth support coordinator – but no respite. There were 'huge meetings' involving 'around 10 to 20 people' to plan changes to the family home to ensure Nash's safe return, but 'nothing happened'.

Alessia is now Nash's full-time carer. Her autism adds to the stress of providing this constant care. She requires an operation but cannot go ahead as there is no support for Nash while she is in hospital or in recovery. The NDIS has reduced support to three hours per day.

Alessia pointed out that through the business she and her partner had built up, she employed several autistic people, yet she has been unable to obtain help in caring for Nash. Being his full-time carer, Alessia sometimes had to take Nash to appointments with her clients.

Alessia said she kept 'shaking every tree' to get help for Nash, but this only resulted in reports saying she triggers her son's behaviour and suggesting her claims are a result of her own mental illness.

She feels she is 'walking around with gaping wounds' as a result of her childhood trauma and struggle to obtain supports.

Phoenix

‘There’s not supposed to be neglect. There’s not supposed to be abuse. There’s not supposed to be things paid for that aren’t received.’

Phoenix, late 20s, is autistic. They have chronic fatigue syndrome, fibromyalgia, postural orthostatic tachycardia syndrome and use a wheelchair.

A couple of years ago Phoenix moved into an apartment managed by a supported independent living provider.

Phoenix told the Royal Commission the standard of care was far lower than the provider promised. Phoenix was often left without support workers. The provider gave little or no notice when workers couldn’t make their shifts and charged Phoenix regardless.

Staff didn’t take COVID-19 protocols seriously. They pulled their masks down when they talked and didn’t practice social distancing. Phoenix wasn’t vaccinated at the time and was very concerned about becoming ill.

The apartment was unsuitable for someone with a disability. Phoenix couldn’t turn their wheelchair around easily. There wasn’t enough furniture and many items in the apartment didn’t work. The shower and laundry flooded regularly. The bed was ‘extremely old’ and caused Phoenix ‘a lot of pain’. They ended up sleeping on the floor.

The provider charged Phoenix \$300 a day. Phoenix asked for a breakdown of costs and an itemised invoice but they never provided one. ‘I contacted the NDIS to say can we halt these payments until we work out what services [are being provided].’ The NDIS initially agreed but Phoenix discovered they had already paid the provider in full.

Phoenix followed the established complaint channels, including making formal written complaints.

The provider either ignored the complaints or made Phoenix feel ‘guilty’ saying, ‘we are bending over backwards to help you’ and ‘you should be more grateful’. They kept promising to fix the problems but nothing happened. ‘That was just lip service.’

The situation increased Phoenix’s stress levels and they experienced suicide ideation. Phoenix called an ambulance and was admitted to hospital under psychiatric care.

Phoenix felt the only option was to find another provider. After the service agreement ended, Phoenix moved out and posted a negative review about the provider online. ‘I posted a picture of where I was sleeping on the floor.’ The provider threatened Phoenix with legal action if they did not remove the post. Phoenix had ‘lots of pictures and videos’ and their support workers and occupational therapist told them they would ‘back [them] up’. Phoenix obtained legal advice that there was enough evidence to challenge the provider.

However, it ultimately became too stressful and overwhelming and Phoenix's health deteriorated. They signed a legal agreement with the provider that they would not post any comments or speak publicly on social media. Phoenix felt the provider 'silenced' and 'bullied' them 'into not being able to speak up'.

Phoenix complained to the NDIS Quality and Safeguards Commission, but it 'made things harder' and 'was just another set of hoops to jump through'. They felt like the commission did not seem to care and 'cherry-picked' only a few issues to half-heartedly respond to. Phoenix found this lack of interest 'harmful' for their mental wellbeing.

'Almost every provider I've dealt with, unless they have a lived experience of disability, they don't really care about my wellbeing, they don't really care about providing the service or providing the care that's involved with the service.'

Addisyn and Valentina

‘[Addisyn] has never had an education, you know, that’s the terrible thing. I paid for an education. She never got an education – she got abused the whole way through.’

Valentina is mum to Addisyn, a teenager with autism, a cognitive disability, depression and anxiety.

Addisyn’s first two years at a religious primary school went well, Valentina told the Royal Commission. However, in grade 2 it ‘was obvious [the teacher] did not want her in the class’.

Around this time, the principal and deputy principal made a room available for Addisyn to use for occupational therapy. They assured Valentina an education support officer would be with Addisyn at all times. Addisyn increasingly spent ‘more and more time’ in the room. Later, Valentina discovered Addisyn was often locked in the room, alone, without any access to occupational therapy support.

Addisyn said it ‘felt like a jail’. Her brother would ‘hear her screaming’ from his classroom.

Valentina said the school made decisions about Addisyn without consulting her or Addisyn’s support professionals. The school introduced a course called A and B choices and rewarded Addisyn if she did something they considered correct. ‘If she did something wrong she’d be sent home.’

One time a member of staff filmed Addisyn having a meltdown using his mobile phone. Four adults stood around watching. Valentina only found out about the filming when Addisyn came home from school traumatised.

Valentina contacted the school and demanded the footage. The staff member said she had ‘no right to the footage’ and he had ‘every right’ to film Addisyn, maintaining the video was for training purposes. Valentina is sceptical because the video demonstrates no strategies to manage Addisyn’s meltdown.

Valentina, Addisyn and the support worker who was on shift, went to the police station to report the incident. No-one told Valentina that Addisyn could have a communication assistant. When she discovered it was possible she asked police for another interview. Police refused, saying, ‘You had that support worker.’

Valentina made an official complaint to the education authority who confirmed the recording would be destroyed. She removed Addisyn and her brother from the school. Addisyn experiences ongoing trauma ‘every single day’ because of this incident. Valentina was so distressed by everything that happened at the school she contemplated suicide.

Addisyn then briefly attended a different religious school. '[The other parents] hated our guts just for being there,' Valentina said. Here, the teacher never taught her, leaving it to the education support officer. On one occasion the teacher failed to inform Valentina and Addisyn of a planned excursion. While the rest of the class attended the excursion, Addisyn, dressed as an 'eco-warrior', picked up rubbish on the school grounds.

Next, Addisyn moved to an education facility for students with intellectual disability. Valentina said, 'They all look lovely but what goes on in there isn't that great.' Addisyn told Valentina the teacher put her in a small dark room on two occasions. When Valentina noticed bruising on Addisyn's arms, Addisyn told her 'big men' held her down and stopped her moving her head and mouth. She said this happened three times.

Valentina contacted the school who told her they have their own internal policies around the use of restrictive practices. She asked the school to adopt the positive behaviour support plan the external support workers use, but the school was extremely resistant and denied Addisyn's support team access to the school. Valentina was horrified they were able to use 'unauthorised restricted practices' on Addisyn and 'get away with it'.

Valentina believes a community visitor program would expose poor practices and make all schools safer.

Ashlynn and Davian

Ashlynn and her partner, Davian, are Deaf and communicate using Auslan.

Ashlynn and Davian told the Royal Commission it is difficult to access Auslan interpreters at their local hospitals.

In their health district, hospital staff must arrange interpreters through the health interpreting service. However, many staff don't know the booking process.

'When you speak to clinicians, they seem to think ... the interpreter will be there on the phone within five minutes, which does happen with spoken languages, but obviously they are not culturally aware of Auslan and the need to book ahead of time.'

At Davian's first chemotherapy appointment, the interpreter didn't show up. Davian had no choice but to exchange written notes with the nurse. However his written English is 'not good' and there was a mix-up with the medication.

'Luckily everything got resolved ... but it was a hugely risky business, not having an interpreter.'

Another time Davian broke a bone and arrived at hospital late at night. He was in pain and very unwell and immediately asked for an Auslan interpreter. Staff told him several times 'the interpreter is coming soon', but no interpreter arrived. After several hours the doctor found another doctor who knew some sign language and a nurse who 'could sign a little bit because [she] learnt from [her] cousin'. Ashlynn demanded a professional interpreter. Eventually the hospital found an interpreter who was able to interpret via Skype.

Ashlynn had a fall and broke her ankle. After they'd been waiting hours for an interpreter Davian happened to run into an interpreter he knew in the coffee shop. She had just finished work and was happy to help. The hospital became 'very upset' Davian organised the interpreter, making the interpreter 'very uncomfortable'. Davian asked the interpreter to make a complaint about the system with him but she said she didn't want to get involved.

'That shows you the fear amongst interpreters about not speaking up to the hospital system, but it also leaves Deaf people at a disadvantage of them not being able to get an interpreter.'

Davian and Ashlynn had a bad experience with an interpreter. 'We explained she was not qualified, she did not have the skill, she was not competent, she was not clear ... please take her off the list. We won't use her. It is too risky,' Davian said.

Despite this the hospital continued to book this interpreter, who ended up wrongly interpreting a serious medical procedure. Davian and Ashlynn only became aware of the misinterpretation because they filmed the doctor's explanation and sent it to their children so they too could understand the procedure.

Ashlynn and Davian have made a number of complaints but 'are just seen as complainers'. They say no attempts have been made to fix the system.

They have also made a complaint about the lack of skilled interpreters but the complaints commission told them they only deal with complaints against health practitioners – not interpreters.

Maximus and Ros

Settings and contexts: homes & accommodation, funding

Ros's son, Maximus, is in his 40s, autistic and lives with an intellectual disability, obsessive compulsive disorder and depression.

Maximus lives on his parents' property, in a bungalow in their backyard. During the COVID-19 pandemic, he spent 18 months isolated there.

'His attitude now is turning basically towards us, that he's starting to really resent us,' Ros told the Royal Commission. 'Hell, it is 18 months we've basically been controlling his life, as he thinks, trying to get him the services that he needs.'

Maximus was with the same service provider for about 20 years, until several years ago.

'We had no problems with them. Then when they amalgamated [with another provider] everything started to go, well, out the window.'

Ros said the new provider overcharged and was unprofessional.

'We had some invoices that were doubly charged, and when I requested for it to be changed, they turned around and said, "No, we can't change them and we don't re-issue invoices."'

The service provider also cancelled Maximus's support workers at short notice. Sometimes, workers didn't turn up.

'It was affecting [Maximus] because he was getting out of his routines and not getting the services that he actually needed.'

Ros said one day the service provider stopped Maximus from seeing his behavioural specialist.

'They just said, "It's finished as of now," and when we tried to find out what was going on, we got no information.'

The behavioural specialist told Ros they had to 'concentrate more on the community housing people than anybody else'. But Ros felt 'they were more interested in the dollar, getting more money with less service'.

Ros found a new service provider.

'They are, well, I'll say brilliant. Compared to what we were getting.'

Ros said the NDIA was also difficult to deal with, cutting Maximus's funding and not explaining why.

‘We’ve asked them and asked them, and they’re not giving us any information whatsoever. They disregarded [specialists] about the support he needs. They basically disregarded all of the reports.’

Ros said every time he asks for a review of Maximus’s plan, the NDIA reduces his funding. He and his wife felt they were being ‘punished’ for asking questions.

Ros is in his 70s and is worried what will happen when he’s unable to advocate for Maximus.

‘We are getting old, and we can’t be running around with all this ... We are trying to get some extra hours to have support workers to start to work for when he goes independent. These have all been knocked back on us. We’re not going to be here one day for him ... [Maximus’s] got a lot of complex needs and, as I say, they are basically just ignoring all those things, and it’s getting worse as he goes on.’

Amari, Boden and Sal

‘Nobody wants to know about it. It just goes straight into the too-hard basket.’

Amari, early 40s, has an undiagnosed, non-specific intellectual disability and has been receiving the Disability Support Pension since she was 16. Her parents, Boden and Sal, worry about what will happen to her when they die.

As a child, Amari’s physical and intellectual development was delayed and she missed regular milestones. She attended special disability schools and played Paralympic sport competitively.

Leaving school, Amari found a job in a restaurant. She enjoyed it initially, but didn’t like working on her own and stopped attending. She has had odd jobs since then, such as being a jillaroo, but nothing has worked out.

Amari is frequently abusive to Boden and Sal and people she lives with. Her relationships with her siblings have broken down because of her behaviour.

‘[Amari] doesn’t get on with people ... she distrusts people ... she gets in a tantrum and just fires up,’ Sal said.

Boden and Sal bought Amari a house on a large property. The house wasn’t properly finished inside but Amari doesn’t mind. She lets chickens in the house and has pulled up the flooring.

Amari trashes many of the items Boden and Sal give her. Her house is filled with broken appliances. She has been through about nine cars.

Recently, after a ‘blue’ with a neighbour, Amari moved out. She took her dogs and is staying in a caravan park. She’s happy where she is – she just wants to be on her own.

Amari told Sal and Boden she has been raped twice and when she reported the rapes to police they didn’t do anything. She refuses to give them any more information. Sal tried to arrange for her to see a counsellor, but it didn’t work out.

Boden and Sal suspect Amari has a mental illness, but she has never been assessed. They would like to get a formal diagnosis so that she can get treatment and support. Boden believes Amari ‘falls through the gaps’ because she does not have a diagnosis.

One time, Boden arranged a mental health assessment for Amari and requested the assessors let him know when it was happening so he could arrange accommodation for Amari’s pets. On the day, Amari called Boden ‘shrieking her head off, hysterical’ and said there were people at her house. About 20 minutes later, Amari called Boden and said they had left.

Boden discovered two doctors had arrived to assess Amari without calling him. They spoke to her on her driveway for 20 minutes and didn't look at the house or assess her living conditions. They told Boden, 'There's nothing wrong, [she's] okay.' Boden was disgusted. He argued, 'If there is nothing wrong with her why is she on a disability pension?'

Sal arranged a meeting with an NDIS officer at Amari's house. At the meeting, Amari said one of her goals was to work again.

The next day Amari called the officer confirming she wanted to sign up to the NDIS. The NDIS officer arranged for an assessment for Amari because she did not have a diagnosed disability.

During the assessment, the assessor told Amari she could not get the NDIS if she got a job.

Boden and Sal tried to contact the officer but received no response.

Boden doesn't know what more they can do.

'It's gone on for so long, I've just tried so many things. I've just given up now.'

Dream, Evelyn and Xanthe

Xanthe is a First Nations woman in her 30s. She has mild intellectual disability and, since a government department removed her children from her care, lives with complex trauma and anxiety.

One of her daughters, Dream, has an intellectual disability and is in primary school. Another daughter, Evelyn, is a toddler.

'They took the kids because of my disability,' Xanthe told the Royal Commission.
'They had no evidence to take [Dream]. They took her from school, didn't tell me.'

Xanthe said the department took Evelyn soon after she was born.

'I had all my disability supports in place ... I had everything from hospital saying I was doing everything right, even from my Aboriginal doctors. They were actually quite disgusted, because I was home for five days and [the department] took her at nine days old.'

Xanthe said she abused alcohol when she was younger, but she's since 'changed and become a better person'. She said the department officers agreed with her.

'They said, "Yes, you've changed." And then they come and take your newborn and go, "We don't think you've changed" ... They never were in it to help me at all. So, I just feel that they don't help. They just want to take the kids instead of putting the appropriate supports in place.'

Xanthe and Dream both receive NDIS support.

'My workers know that I'm not a bad parent, and they see you day in day out with those kids. And they know that I look after them and what's best for them.'

Xanthe said the department officers, however, treat her like she knows nothing.

'I know a lot more than what they think. And I would never put my kids in harm's way. I just want my girls more and that's all I want. I miss out on Christmases and birthdays. And I don't get to see them on my birthday. I don't get to see them on Christmas Day. I don't get to have them for a sleepover.'

Xanthe said the department placed her daughters in the care of her mother, who she said made her out to be 'a bad person'.

'When in actual fact she couldn't parent me. Like, because I had a disability, nothing was ever good enough for them ... my mum telling me I deserved everything I got ... and I'd amount to nothing.'

Xanthe only sees her children once a month.

'It's not enough ... I love them very much. And [Dream] wants to come home and she's asking for help and no-one's listening.'

Xanthe said she's now training to be a youth worker 'to make a change'.

'I don't want kids to be taken for no reason.'

Elyse

'I'm nobody. And I'm telling this story ... hopefully to benefit all the nobodies out there that have become nobodies. But my story started with me being somebody.'

Elyse came to Australia in the mid-2010s because her husband wanted to retire in the town where he was born. She'd had a 'very successful' and busy career, and when she relocated brought containers of valuables and family heirlooms with her.

Not long after they arrived Elyse and her husband 'started having some troubles' and her GP referred her to a psychologist in the small rural area where they were living.

Elyse told the Royal Commission that the psychologist 'took over [her] life', positioning himself as her 'saviour'. He 'jacked up' medications telling her 'it's for your own good'.

Elyse felt 'chemically restrained to where you have no brain'. The psychologist convinced her to take out an apprehended violence order against her husband and sign several documents. The marriage ended.

Over the next few years the psychologist financially exploited and physically abused Elyse. 'I went from being a very wealthy person that had worked my whole life to where \$10 is a lot of money for me.' He convinced people she was a hoarder and his staff removed items from her house. 'All the family heirlooms, everything is pretty well gone.' Her mental health rapidly deteriorated.

Elyse tried to tell people what was happening but no-one believed her. The psychologist convinced other health professionals she was ill. 'I lost all my rights to be a person because [of] ... the mental health label.' The health professionals were connected to each other and police officers. 'It's incestuous, frankly.'

Elyse was admitted to a psychiatric unit. Even though she was there under duress she said the doctors were 'decent'. A doctor saw some documents on Elyse's computer and realised Elyse was telling the truth. Doctors made an official complaint to the health regulatory body about the psychologist.

The investigation took seven years. Elyse had to disclose everything that happened to her but she was not entitled to any information because she wasn't the person who filed the complaint. 'I have no right to any information, but the perpetrator, the mental health people, the health professionals have a right to everything.' The psychologist was able to find out her current diagnosis, names of her doctors and where she lived.

'I was so suicidal and scared because I lived in a bed in a room for so long because I couldn't leave. He threatened my life, and his clients were threatening my life.'

During this time Elyse applied to the NDIA several times, but they refused funding on the grounds her disability wasn't permanent. 'The time I needed it most I couldn't access it.'

Ultimately, the regulatory body cancelled the psychologist's registration and prohibited him from providing health services.

A friend helped Elyse move interstate but she's still 'scared to death of this man' and terrified he will find her. 'I'm suicidal most days, it's very difficult.'

A support service is helping her and she successfully re-applied for the NDIS. Recently she got a therapy dog.

'The dog is my only family, my only reason that I get out of bed in the morning. So, I've made progress because she makes me get up.'

Jarrah

Jarrah, late 30s, has a psychosocial disability and receives the Disability Support Pension.

He told the Royal Commission that when he was younger he felt like he was ‘second class ... wasn’t equal to the rest of the community or workforce’.

‘Because of my disability people felt that I was a burden and they were obliged to help me.’

In his early 20s he took an overdose of sleeping tablets. Police found him unconscious and took him to a mental health facility. The facility liaised with his parents and, without consulting him, admitted him under an involuntary treatment order.

Three years later, after the order was lifted, Jarrah moved to a townhouse. His neighbour didn’t like him and ‘wanted [him] gone’. The neighbour punched him with a set of keys leaving ‘a scar on the side of [his] head’ and made a complaint to police. Jarrah’s lawyer told him to plead guilty even though he was the person assaulted. Jarrah was convicted and spent a few months in jail.

Following his release, Jarrah volunteered as a support worker at a drug council. He said it felt good ‘giving back to the community’. However he got into the ‘biggest strife’ when a police officer harassed and intimidated him because of his assault conviction. The officer ‘took it upon himself to totally degrade’ Jarrah by covertly recording him and sharing the recording with other people. Jarrah said the police officer made him ‘look foolish’.

Jarrah lost his job because of his conviction which was another ‘blotch on his record’.

Jarrah tried to find work through a disability employment service. ‘They were very unhelpful – that was the biggest insult I’ve ever had in my life, sitting in front of one of them fools’. He said they shared information about his disability and criminal history with employers, which hindered him finding work and made him feel as if his privacy had been violated.

‘They get referred a file and it’s got all this horrible, horrendous stuff about your nationality or your criminality or your disability.’

The only job they found for Jarrah was trolley-collecting at a supermarket. It was an informal arrangement and was two days a week. He would have preferred a full-time retail job, but said the trolley job provided ‘a bit of pocket money’ and it allowed him to buy ‘a bit of food, some steaks ... and stuff’.

Around this time he was able to secure public housing. But two years later the agency ‘tricked’ him into giving up his place in exchange for another one. However there was no other place – they just wanted him out. For the next five years the agency ‘blacklisted’ him and didn’t provide him any accommodation.

Jarrah would like to apply for the NDIS but believes he wouldn’t be successful. ‘Statistically there’s not that many disability pensioners with a mental health issue receive NDIS.’

Riccardo and Salim

Riccardo was legally blind and had dementia. Salim and Rafiq are his sons.

Until his death, Riccardo lived in the family home with Rafiq.

Riccardo's aged care workers became concerned Rafiq was not acting in his father's best interests. Salim applied to the state tribunal to appoint a public guardian for Riccardo, and the family supported the application. The tribunal found that Riccardo had lost capacity and appointed the Office of the Public Advocate (OPA) as guardian.

Salim soon became dissatisfied with the OPA's management of his father's case. The family believed that an aged care facility would be better for Riccardo's needs than the family home. However the OPA decided that Riccardo should continue to live with Rafiq. The tribunal ordered that Salim and his mother could visit Riccardo, but Rafiq denied access and changed the locks of the home.

Salim had concerns with the way Rafiq dealt with his father's health issues. Using Riccardo's money, Rafiq applied expensive 'natural' treatments for Riccardo's medical conditions, including one that was banned by government medical authorities.

Rafiq refused to treat his father's eczema with prescription medication, causing Riccardo considerable suffering.

In one instance, Salim asked the OPA not to allow Rafiq to accompany Riccardo to a specialist appointment. 'They let my brother take him,' Salim said. The specialist reported that Riccardo had 'no problems'. The OPA and the tribunal accepted the report, resulting in Riccardo going without treatment.

Salim also believes Rafiq emptied Riccardo's bank account.

Fearing Riccardo was experiencing elder abuse, Salim made many complaints to the OPA, but said nothing was done. He thinks the OPA is not equipped to deal with elder abuse.

Salim also complained to police who, apart from occasional welfare checks, refused to intervene. They said it was a guardianship issue, not a criminal matter, and directed him back to the tribunal. Salim feels he 'wasted five, six years' going back and forth to the tribunal.

Salim said that the OPA seemed unable to protect Riccardo from Rafiq's abusive behaviour and the tribunal would not intervene. He feels that some tribunal members were not impartial because of former associations with the OPA.

Salim believes there should be an inexpensive alternative to state tribunals for people with disability to seek redress.

'My father ... died having no proper contact with his wife and family for many years ... The OPA was supposed to protect him from abuse ... They failed my father ... and so did the [tribunal] system.'

Alayna

Alayna is in her early 50s and lives with clinical depression and anxiety due to the strain of working with challenging clients for around 10 years. She also has a heart condition and issues with balance and mobility.

Alayna told the Royal Commission she spent approximately 10 years working as a government employee dealing with 'high risk' clients. These included people who had recently been released from prison and required referral to a psychiatrist.

Alayna informed her employer that her work was adversely affecting her mental state and asked for support. But assistance never came. Her employer often ignored her medical certificates, meaning she lost pay when she couldn't work.

Upon leaving the job, Alayna applied for WorkCover. After many appeals to the Administrative Appeals Tribunal, Alayna finally received workers' compensation. Alayna believes she was being monitored during the appeals process.

Alayna has received assistance from Comcare for some things but not others. She finds having to engage with Comcare about her financial support exhausting.

Alayna believes Comcare has harassed her. She described having surveillance technology placed in her home, including automatic camera lights in her bathroom, lights in her bedroom and drones landing on her roof. She is also concerned that USBs containing information about her medical conditions have been stolen from her home.

Alayna feels like a prisoner in her own home and has 'a deep-down concern' that she is being monitored. She has moved house, but the problems have continued. Alayna believes her family and friends are also being targeted.

Alayna feels that Comcare is intent on 'sending [her] insane'. 'Comcare always argues if ... a new condition has superseded the current condition, then your payment with Comcare is no longer valid.'

Alayna has reported the incidents at her home to police and other agencies but little assistance has been provided. She feels that police have not taken her seriously and that emergency services staff have labelled her as 'psychotic' without any medical basis.

Alayna does, however, believe that her psychologist and advocate have helped her to regain some independence. She hopes that this, together with her own rehabilitation efforts, will assist her in continuing her university studies. She wants to exit Comcare and do the rehabilitation and study without Comcare's involvement.

**'I'm not going to be silenced. I'm not going to be bullied anymore.
And I won't stop until my last breath.'**

Colten and Dionne

Colten contracted the flu while on an overseas school trip a couple of years ago. He became very ill with 'severe seizures and incredible head pain' and, at times, paralysis.

Dionne, Colten's mum, told the Royal Commission they 'nearly lost him at one point'. Doctors diagnosed him as having autoimmune encephalitis and gave him medication which stopped the seizures. He was able to walk again. 'They were incredible, I can't thank them enough for what they did. They were there for him 24 hours a day.'

After three weeks Colten wanted to come home. The hospital contacted the children's hospital near where he lived and sent videos supporting their diagnosis. But the doctors in Australia didn't agree Colton had autoimmune encephalitis. They believed the seizures were behavioural, not epileptic. 'I didn't understand it. Neither did the [overseas] doctors.'

The overseas doctors reassured Dionne that as long as Colten continued the medication he would eventually recover and there wouldn't be any long-term damage.

'When the air ambulance people turned up they were awful,' Dionne said. They told Colten he didn't have autoimmune encephalitis and stopped his medication. During the flight Colten's seizures returned 'as bad as they were when they started'. Dionne 'begged' them to give him the medication, but they refused.

When Colten arrived at the children's hospital he had to wait in emergency for several hours despite the hospital promising he would be taken to a ward immediately.

Doctors diagnosed him with functional neurological disorder (FND) without conducting tests, telling Colten his symptoms were 'all in [his] head'. They refused Dionne's repeated requests for tests and reviews telling her she was exacerbating his FND and associated behaviours. Colten's father sided with the hospital. 'They said he couldn't get over his FND because of me, and I was not supporting them, I was causing more damage.'

Dionne felt like she was being attacked and vilified to the point where, for her own safety, she started recording the meetings she had with hospital staff.

Although Colten was still having seizures and using a wheelchair, the hospital allowed him to go home for a weekend to spend time with his family. On the Sunday the seizures became so severe Dionne called an ambulance. She begged them not to take him back to the children's hospital, but they told her they couldn't take him anywhere else. On the way to the hospital the ambulance officer rang the hospital. He told Dionne he would normally treat the seizure but 'they have told me not to'.

Colten's seizure continued for seven hours.

'They let my son have seizures and a doctor didn't even come and see him in emergency. We watched his brain shut down ... He couldn't speak. His paralysis was bad again. He just wasn't with us properly, so it got to the point where he was in a nappy.'

Dionne believes Colten acquired a brain injury as a result of the seizures. He experiences 'anger attacks' and frequently absconds. His school has tried to help him but his father refuses to have him independently assessed. When Dionne has contacted specialists, as soon as they see the children's hospital have diagnosed Colten with FND they refuse to see him.

Colten's father believes Colten's condition is 'anxiety from his mother'. He said it's a 'mental illness and blaming my family' – Dionne has attention deficit hyperactivity disorder and her mum has post-traumatic stress disorder.

Colten's father recently engaged lawyers to prevent Dionne and her family from having contact with Colten.

Colten, now 16, lives on the streets and is 'in trouble with the police'.

'He has got brain damage. He is no longer at school. He can't study. Where is he going? Where does he go next? To jail? Death?'

Kaleb and Bailee

‘[Kaleb] is just one of the cases where a lot of things went wrong, both personally, situationally, systematically. He just found all the cracks and he slips through them.’

Kaleb was 12 when he first went to prison.

Bailee, his mum, told the Royal Commission that Kaleb loves boxing, and when he’s drunk he gets into fights. By the time he was 20 he had a ‘30-page rap sheet for assaults’.

Kaleb’s been diagnosed with attention deficit hyperactivity disorder, autism, social phobia, Asperger’s, borderline personality disorder, oppositional defiance disorder, anxiety, depression and alcohol dependence.

‘Now, you would hope that all these diagnoses helped to help him,’ Bailee said. ‘But it hasn’t.’

The first time Kaleb went to detention he was scared. Police put him in the back of a van and he didn’t know what was happening. ‘There’s still trauma every time he’s in a van,’ Bailee said.

In detention Kaleb told staff he was so depressed ‘there was no use in living’. Staff trialled various medications but nothing worked.

At 14, Kaleb went to a rehabilitation facility in the country. They did not provide counselling or proper support. Bailee spoke to the manager who told her ‘they didn’t have time for the likes of [Kaleb]’. Kaleb ended up sniffing paint. Staff told him they were going to take him to McDonalds, but took him to the police. Kaleb ended up back in a correctional centre.

At 16, Kaleb was put in solitary confinement for three weeks, which was illegal. ‘When I got him out of prison after that, he was truly never the same. Something changed.’

Kaleb would punch the prison walls and injure himself. Bailee tried to help him see a psychiatrist, but prison staff told her ‘he will have to wait his turn’. When Kaleb asked for help staff taunted him saying, ‘What’s wrong with you? Are you a retard? Are you a moron?’

At 19, people filmed Kaleb without his consent for a program. He looked unwell, all his teeth broken. He was very distressed when he saw the film.

As an adult, Kaleb spent three days in solitary confinement in his undies, using a mattress for warmth.

Rehabilitation hasn’t worked – Kaleb continues to drink and use marijuana.

Bailee says he’s been ‘spat out of the system’ and it is up to her to support him. She left her job to be his full-time carer and he hasn’t been back to prison in 10 years. But it’s been difficult.

Bailee thought the NDIS was going to be great. People were positive saying 'we're going to do this, and we're going to do that'. But they 'put money in their pockets' and 'didn't care less'. 'It's damaged everything.'

She struggles to find support workers who are both experienced enough and willing to support Kaleb and his sometimes-violent behaviours. If he is violent, workers ring the police. Bailee is terrified Kaleb will go back to prison.

Now in his early 30s, Kaleb spends his days watching TV. He moves from the lounge room to the bedroom. He is scared of everything and doesn't go anywhere. He loves his dog, Will, who is 'his constant companion that he needs every day'. '[Will] is everything to him,' Bailee said.

Following a one-hour telehealth appointment, a forensic psychiatrist recently diagnosed Kaleb with schizophrenia. Kaleb needs to go to hospital to get his new medication. However the hospital doesn't recognise Will as a support dog and won't allow him on the premises.

Kaleb refuses to go to hospital without Will. Bailee has tried 'every which way' to have Will registered, with no success.

Bailee is frustrated so much money and time have been wasted and so many reports written, but nothing has worked.

'I'm getting older, I can't cope with how he is anymore, I just can't cope with it.'

Rupert and Mirabel

Rupert is in his 20s. He is autistic and has epilepsy and a severe intellectual disability. Mirabel is his mum.

‘He knows every name of every AFL player that you can think of,’ Mirabel told the Royal Commission. ‘He recognises people by their numberplates on their cars. He has a photographic memory for numberplates.’

Rupert also loves working in supported employment.

‘The guy that is in charge of his area said that the place would have to be burned down before [Rupert] misses work once ... He loves it, he likes to do a job, likes being helpful.’

When Mirabel and Rupert’s father separated about 10 years ago, Rupert lived with Mirabel.

‘[Rupert’s] father was still accepting the carer’s payment. Even though I was caring for him, so I had to go to Centrelink and report that.’

Rupert’s father was charged with fraud.

‘I applied for a guardianship,’ Mirabel said, ‘because I could make a, you know, list of things that I ... do for Rupert. And that was rejected. I think his father just says no because both parents have to apply, have to agree for any change.’

The public trustee and public guardian now control Rupert’s affairs and he lives in supported accommodation.

Mirabel says the public trustee isn’t properly administering Rupert’s finances.

‘So, I’ve got things here that really worry me. Okay?’

For example, the local pharmacy threatened to stop supplying Rupert with his medication because the trustee wasn’t paying Rupert’s bills. The trustee also failed to reimburse Mirabel for Rupert’s medical expenses.

During a COVID-19 lockdown at his group home, the trustee wouldn’t let Rupert pay for a television subscription service.

Mirabel said Rupert recently needed a new pair of shoes because his old shoes were ‘falling to bits’.

‘The response I got was, “Didn’t you buy a pair of shoes six months ago?” and I explained that he wears one pair of shoes. He wears them to basketball, walking, work, the whole thing.’

Although Rupert receives the Disability Support Pension, has more than \$10,000 in the bank and a larger amount invested, the trustee said no to the shoes.

‘I just, I fought and fought and fought for that, and the [public] advocate wouldn’t help, so I just had to go out and find shoes.’

Mirabel bought the shoes herself.

‘Both [Rupert] and myself are being treated unfairly. We have been made to feel our needs are trivial ... I have the best of intentions for [Rupert’s] wellbeing. [But the] system fails him through financial neglect.’

Florence

‘We don’t want to be complaining all the time and ask for extra things and special treatment, we really don’t. We want to just be independent.’

Florence is in her 30s and was born with her left forearm missing. It means she overuses her right arm, sometimes injuring it.

‘If I ruin this arm ... I’ll have to go in to care,’ Florence told the Royal Commission. ‘I won’t be able to wipe my backside or feed myself. To me, everything comes back to that – looking after this [right arm] and making sure it works.’

A few years ago, when Florence’s right arm became painful from overuse, a physiologist told her to avoid surgery. Instead, he helped Florence’s strengthen her right shoulder muscles.

Florence said that, as a result of that advice, she developed carpal tunnel syndrome that required surgery.

When she was in hospital recovering from the surgery on her right hand, a nurse placed food in front of her despite her not being able to use her arm. She was told to use a shower that had only a handheld hose, which she couldn’t use.

‘I said to them, it’s very difficult. I can’t wash my hair or anything ... All I got was, “Oh yeah, I’ll let maintenance know.”’

During subsequent surgery on her shoulder, a doctor couldn’t put a line in Florence’s left arm and scolded her. ‘As if it was my fault,’ she said.

‘I’ve never in my life felt so embarrassed, so belittled in front of everybody. Like, how dare I have a disability.’

Florence works as a disability advocate, but had to resign from her job because of ongoing pain in her right arm.

‘During this experience I have been dismissed, ignored and openly mocked for my attempt at advocating for myself. I’ve been labelled a drug seeker and a hypochondriac by able bodied people with absolutely no experience – lived or professional – of my disability.’

Florence is studying social work, hoping one day to work in a hospital where she can help people with disability and educate staff.

‘If I don’t like a surgeon ... I’ve got private cover, so I’ll just go and find another one ... But every time I do that I think about the poor people, like, in the public system, who don’t get a choice of surgeon [and] they’re not being listened to either.’

Alden and Conrad

‘I really celebrated the time that Alden said no, he wasn’t coming out with me. I just thought yes, we’ve done it right, you know, where he is able to actually advocate on behalf of himself.’

Alden, early 40s, has an intellectual disability. Conrad, his advocate, told the Royal Commission, people often wrongly assume Alden can’t communicate or can only communicate through signing. Alden answers ‘yes’ and ‘no’ and uses communication devices. The issue, Conrad said, is his support staff don’t bother with them.

Alden lived at home with his parents until his 20s. They started having health issues and Alden was forced to move into supported accommodation. Initially he lived in a respite group home with people of a similar age.

One time, staff found Alden and another resident, a person from his school, sharing a bed. Despite neither person reporting any distress, staff told the other person’s parents. They blamed Alden and he was ‘labelled a pervert’.

When Alden was living at home, his mum used to send him ‘off down to the shop’ and he would ‘come back by himself’. ‘He knows about road safety.’

However, most homes refuse to allow Alden to access the community by himself. Many homes have high fences, but Alden finds ways to climb over them and abscond. One time, he dragged a trampoline to the fence and jumped over.

Conrad doesn’t blame him. ‘I try and put myself in [Alden]’s shoes ... I think I would be very angry, but I think I would give up and give in, and that concerns me.’

Because of Alden’s reputation for absconding he is now ‘locked in’.

For three years, Alden lived independently in a unit with 24-hour support. He wasn’t able to choose his support workers and had no agency. He also was unable to socialise and was frequently lonely. ‘Living by himself is probably not ... suitable, because he is a social person.’

Following this, Alden moved to a group living facility. A support worker, who was off-duty, visited the home to collect something and left his children in the car. Alden took the children out of the car and showed them around. The worker accused Alden of attempting to abuse his children. Conrad said the home didn’t reprimand the worker for bringing his children to a worksite, and blamed Alden.

‘[It was] a black mark against him,’ Conrad said. ‘He is not an angel, but he is labelled with all these things that are not his fault.’

Currently, Alden lives in a group home with a number of residents with different behaviours.

Alden frequently locks himself in his room and has little opportunity for community access. It is difficult to find an alternative home for Alden as there is limited housing stock.

Conrad is frustrated people don't pay attention to Alden's own voice and wishes.

'Everyone knows me as Alden's advocate, which is nice, but it's not nice that Alden needs an advocate and has needed an advocate for 26 years ... I don't think anyone should need someone to be so vocal and involved in their life.'

Caspian and Daleyza

'I am feeling very dissatisfied with the way I have been perceived and the way that the word "disability", it somehow tends to make you lesser. And I feel that every time I go and do something in terms of being a disabled person, I've got to fight. And I'm tired. I'm tired of fighting.'

Daleyza is a single mother in her 50s. She has narcolepsy, which means she falls asleep without warning. She lives with her son, Caspian, who is in his 20s and is autistic.

Daleyza receives a Disability Support Pension.

'[Caspian] doesn't qualify for a Disability Support Pension, but he qualifies for the NDIS. I qualify for the Disability Support Pension, but not for NDIS,' Daleyza told the Royal Commission. 'I'm very confused about what evidence I'm supposed to be providing to what agency in order to qualify for all these things.'

Daleyza sleeps up to 18 hours a day and her disability prevents her from driving.

'The last time I caught a bus I was mugged, because I fell asleep on the bus. And somebody stole my wallet.'

Daleyza said the NDIS rejected her application for support because 'in their terminology' she's 'too mobile'.

'I feel extremely let down by the NDIS. I feel like I was put through a lot of unnecessary worry, a lot of unnecessary questioning and a lot of unnecessary judgement about what my needs were from people who knew nothing ... it was dehumanising.'

Because her narcolepsy leaves her only six waking hours a day, Daleyza struggles to support herself and Caspian.

'I'm trying to access the systems for both of us, which is extremely tiring. I feel very frustrated.'

Daleyza said many of the services she's approached for help misunderstand her narcolepsy.

'I've been dismissed a number of times because what I have is considered a neurological condition. And people think a neurological condition means you can't think for yourself.'

Daleyza told the Royal Commission she spends 65 per cent of her pension on rent. Meanwhile Caspian's NDIS plan is yet to be approved.

'[Caspian] thinks he's done this to me ... He feels responsible.'

Daleyza hopes Caspian will eventually 'be able to discover his talents and a world that he's comfortable in'.

'He's so, so smart ... I want to see him being more independent. I want him to find what he's passionate about ... I want to see him happy. That's my plan for him.'

Clyde

Clyde has permanent injuries from a road crash nearly 30 years ago. He has trouble standing and walking for long periods.

After the crash Clyde began receiving the Disability Support Pension, but he wanted to work.

'I did a vocational assessment at the Commonwealth Rehabilitation Service to see what sort of career to do, and it came through as film and media and TV studies.'

Clyde told the Royal Commission he received a study supplement to complete degrees in film and the arts.

When he graduated and tried to find a job, he was told it was 'too hard' to get work in that sector.

'It appears to me that they put you in this box so that you are ... studying, and then once you have done your studies you are back where you were.'

Clyde said he discovered he had 'too many qualifications' to qualify for the Disability Support Pension. He was encouraged to study aged care, 'a growth area' that would 'suit [his] disability'.

Clyde now works in aged care as a nurse.

'I work about an eight-hour shift and I'm on my feet for about six or seven hours, and it's pretty hard. I don't know how long I'm going to be able to keep doing this.'

Since his accident, Clyde had surgery on his knees and ankles 'to enable [him] to do the work', but he still wants a job that doesn't require so much standing and walking.

'I'm too worn out after I do my work at night-time to go look at work ... you sort of give up trying to find other work because you're only banging your head against a brick wall.'

Emersyn

‘A lot of people in my area are naive about mental illness. They think that if someone has a mental illness, they’re dangerous and should be watched and kept away from. I’ve never experienced so much discrimination and stigma in my entire life.’

Emersyn, mid-50s, has psychosocial and physical disabilities.

For most of her adult life she’s found it difficult to find secure, affordable housing.

Ten years ago, the department of housing built Emersyn a granny flat on her father’s property. She pays a portion of her Disability Support Pension as rent to the department.

Emersyn’s father and stepmother, Joy, live in a house at the front of the property.

‘I’ve always had a difficult relationship with my stepmother, and she’s got a tendency to be coercive and controlling.’

Lately, the situation has become untenable.

A few years ago, Joy discussed Emersyn’s mental illness with the neighbours. Emersyn was ‘deeply embarrassed’ and shocked Joy had ‘violated [her] privacy’. Every time she saw Joy or the neighbours they’d make inappropriate comments about her disability and snide remarks about the medication she takes.

Joy then began monitoring Emersyn’s movements. ‘It’s continual stalking,’ she said.

Emersyn tried to talk to Joy and suggested they all attend family counselling, to no avail.

‘[Joy] refuses to believe that she is doing anything wrong or anything that’s inappropriate and damaging.’

Emersyn no longer talks to the neighbours. ‘[I] attempted suicide a few times because of the distress.’

Desperate to move, Emersyn approached the department of housing. They offered her emergency accommodation in a shared facility, but she couldn’t bring her cat. She’s now on a public housing waiting list. Ideally she’d like to buy some land and move the granny flat to the land, something the department has agreed to do.

The NDIS has funded an additional support worker to help her find alternative housing, but there is nothing in the area she can afford. They’ve suggested a group home but Emersyn wouldn’t ‘feel comfortable living in that kind of situation’.

Recently she approached an aged care provider, but she’s not old enough to access their services.

Emersyn returned to university to get a job so she can buy some land. She said that’s her only hope – to be ‘as independent as possible’.

Harlan

‘The culture hasn’t changed – the culture of abusing clients, the culture of abusing staff.’

Harlan has worked as a disability support worker in group homes for many years. Initially the state government owned and managed the homes. When the NDIS was introduced, private disability service providers took over.

Harlan told the Royal Commission that irrespective of who manages the homes, the same issues with workplace culture and discriminatory policies remain. He said there is a ‘toxic culture’ in many of the homes.

Six years ago, a client assaulted Harlan. Harlan reported the incident to management and the police. Management suspended Harlan without pay while the incident was investigated.

This was the first time Harlan realised there was a strong disincentive to report any incident. ‘Essentially you will get stood down for reporting abuse’, even if the person making the report is the victim. Harlan was ultimately cleared of any wrongdoing. A union representative helped him and the home paid him back pay.

Harlan called one home he worked at ‘the hellhole’. He witnessed staff cooking their own meals during work time and taking residents’ food home with them. The area manager ‘completely ignored’ Harlan’s complaints and cut his shifts ‘as punishment’.

A few years later at another home, a staff member locked a resident in her room overnight, wedging a towel under the door to jam it shut. The staff member told Harlan the woman was wandering during the night. Harlan took some photos and sent them to the area manager. The manager accused him of being a serial complainer and moved him to a different house.

Not long after Harlan left he heard a resident had died in the house. He tried to find out some information about her death but management refused to tell him anything on privacy grounds. Harlan is unaware if there was a formal investigation. He said the resident who died had little quality of care. She was malnourished, staff moved her in a ‘rough way’, and they kept her in front of the television for most of the day.

A few years ago, Harlan reported his supervisor for bullying him for making complaints. Management investigated and moved Harlan to a different house. Harlan lost clients he had formed good relationships with and his mental wellbeing deteriorated.

More recently, Harlan witnessed a staff member lock a resident outside in the middle of winter. Harlan reported the incident and management immediately cut his shifts.

Not long after this, a resident made a complaint against Harlan. Management formally suspended Harlan for seven months without pay. Although the allegation was unsubstantiated, management refused to allow Harlan back to the house.

At the last house Harlan worked in, a resident had a fall. Because of occupational health and safety procedures, the supervisor told staff not to help him up. The resident had to wait more than an hour on the floor, in pain, for an ambulance to arrive.

Harlan made a complaint about this and the work practices of some of the staff at the house. Management informed him staff had also made a complaint about him, and suspended him.

He believes these complaints are unfounded and staff made them up to punish him for speaking out.

Harlan believes management have breached his employment agreement.

‘We are not giving our best care to the people we are supposed to be supporting. And it is sad.’

Jayson

Jayson is in his 50s and has Asperger's syndrome and obsessive-compulsive disorder.

Jayson played the trumpet at his meeting with the Royal Commission.

'I have realised that I communicate a lot better with my music than with English. So that's been a huge learning curve – a great, fun learning curve to be able to communicate with music.'

Jayson was diagnosed with Asperger's syndrome about 10 years ago.

'And that was the first official time that I could actually identify that I had autism, Asperger's syndrome. Through my schooling I had huge difficulties in learning for understanding.'

Jayson described his brain as 'like a washing machine ... and all of the information gets jumbled up'.

'It's been only recent times I have realised that ... but it gives me a sense of who I am.'

For the past few years, Jayson has received eight hours a week of cognitive therapy funded by the NDIS.

'I still have huge difficulties in developing, say, close relationships, friendships, and I'm working on all of those sorts of things.'

Part of the funding helps him attend meetings of a stroke support group, where he plays the trumpet.

'This is a bit weird playing this at least once in the session, playing Happy Birthday. Why I play Happy Birthday is ... everyone remembers the words to Happy Birthday, so they can sing along ... It gets my neurons and gets my brain working and that is so important. It connects me with people.'

Recently, the NDIA reduced Jayson's funding package and provided no money for cognitive disability support. Jayson appealed and the NDIA reinstated the funding, but Jayson said it left him with 'grave concerns about their lack of understanding of cognitive disability'.

'If I want to be blunt and honest, I would say many of these people haven't got a clue about cognitive disability, which further increases the discrimination to people like me with my cognitive disability. And it's, well, I feel that it's, what's the word? I just feel further discriminated against on many, many levels.'

Jayson says people often think he has 'a mental illness or even an intellectual disability'.

'So, hugely misunderstood. And this is talking about obviously a huge gap for people with Asperger's, with autism and other cognitive disability ... As I said at the beginning, it's like a washing machine with all of the information spinning. That is an important point to get across to people to start to understand me. If they can see that I live in a state of confusion, it's a big start.'

Kaiya and Marisol

Kaiya is in her 30s and has cerebral palsy. She has also been diagnosed with post-traumatic stress disorder, generalised anxiety disorder and chronic depression. Marisol is her mum.

'[Kaiya] had been walking since the age of three,' Marisol told the Royal Commission. 'So I had spent [more than 30 years] getting her to the stage of life where she was educated, physically able, very competent and very confident.'

Marisol said when the NDIS was rolled out and Kaiya moved into supported accommodation, she 'weighed 60 kilos' and 'ambulated with two walking sticks'. Since then, she has sustained injuries, lost mobility and had a 'massive weight gain'.

'What came into play at that time,' Marisol said, 'was the NDIS, the NDIA and a deterioration of her health needs by the public health system.'

Nearly a decade ago, Kaiya fell from her electric wheelchair and broke her arm.

'That was ignored for two weeks in the actual hospital ward, and it was ignored for four months in the rehabilitation section of that hospital,' Marisol said.

A couple of years ago Kaiya had another fall and broke her arm again.

'She was taken to hospital, the hospital lasted for two days, and then she was accepted into the rehabilitation section for a further two days, and then discharged with no grounds whatsoever.'

Marisol said the NDIS initially funded rehabilitation. 'Recently that has been reduced remarkably, by two-thirds. The reason being, it is a public health issue, not an NDIS issue ... [but] the public health system says it's the NDIA's problem.'

'Look, I get stuck in the middle and nothing gets done,' said Kaiya.

Kaiya's service provider told her she would lose other NDIS funding if she tried to access rehabilitation.

'I was threatened with eviction because I wanted to go to rehab and they said I would lose my housing.'

Since her falls, Kaiya has been unable to get physical therapy. The NDIA expects her support workers to 'be responsible for everything, such as therapy'. 'But the point is,' Kaiya says, 'they are not trained, plus they don't have enough time to do that.'

'I want to get out of this situation because it's affecting my physical and mental health. I can't stand it any longer. I just, I have to get out of here so that I can get a semblance of my life back at least, even though I don't feel like I will be. I'm just existing.'

Kristian

‘You’re a disabled person living in housing commission – you’re not important.’

Kristian, late 50s, has health issues and uses a wheelchair.

After the rollout of the NDIS, a private disability accommodation provider took over the government contract to provide Kristian’s accommodation.

Kristian transferred money from his account every week to pay the rent.

A couple of years ago the provider withdrew funds from Kristian’s bank account without his knowledge. When he queried this, the manager initially told him it was because he ‘was behind on his rent’. Kristian’s bank statements showed he’d been paying his rent on time.

Kristian reported the matter to police, who told him it was a civil matter and they couldn’t do anything about it. Since then he’s approached dozens of agencies for help. They all ‘brushed [him] off’, telling him to contact someone else.

‘I couldn’t get an explanation from anybody ... the people I relied on to help me did nothing.’

Eventually, Kristian refused to pay further rent until the provider explained how they gained access to his account. The provider has threatened to evict him.

Kristian says he no longer trusts anybody and rarely lets anyone into his home. He has resumed paying rent, but remains frustrated.

The provider recently forced him to re-sign his lease under duress and without advocacy support.

Kristian is not optimistic about the future.

‘I’ll live out the few years I have got left, hopefully not being annoyed by anybody.’

Mikaela

Mikaela, in her 20s, is autistic and lives with depression, anxiety and attention deficit hyperactivity disorder (ADHD).

Mikaela wanted to tell the Royal Commission about her supported employment. The employer went into liquidation around four years ago.

Mikaela began as a linen hand, earning \$5 an hour. She said that some workers with disability were only on \$1 or \$2 an hour 'even though [the employer] gets 15 grand off the government'.

Mikaela often worked in hot and dirty spaces and recalled having 'ice block' breaks when the temperature reached 35 degrees. The employer didn't provide workers in the laundry with masks or other personal protection equipment other than mechanics' gloves for sorting linen. The lint was never properly removed from machines, and Mikaela said she still has a bad cough and nosebleeds as a result. Linen was covered in faeces, urine, vomit and blood. Workers had to stand near old, dusty and noisy dryers with no hearing protection.

'The place was very unhygienic. The air quality was never tested.'

Mikaela's grandfather had warned her against working for the employer. His sister had worked for them some years before and had badly burned her hand in an old-fashioned manual press.

Mikaela believes that around half the workers were injured in some way due to the low safety standards. The linen bags weighed around 20 kilograms each. 'We had unsafe loading skills.'

Mikaela said workers sometimes came to work under the influence of alcohol and drugs. Some workers called Mikaela a 'retard' and made threats.

A while after commencing her employment, Mikaela became romantically involved with another staff member of similar age. The employer disapproved of the relationship and separated the couple.

**'They kept saying that he forced himself onto [me],' Mikaela said.
'I lost my rights to my body.'**

The employer threatened to take the couple's phones and close their social media accounts. They made Mikaela do a 'sexual knowledge' test.

The couple spent around six months working in close proximity but not allowed to talk to each other. Mikaela recalls coming to work crying and, one lunchtime, she self-harmed.

'They could see the marks on my arm,' Mikaela said. 'They never called an ambulance, they never cared ... they never gave a shit ... They could see – clearly see I was suicidal.'

Mikaela's partner finally had enough and left the employer, moving interstate. Mikaela experienced suicidal thoughts. She believes her support worker was aware that she was self-harming, yet still no-one provided any support.

Mikaela wanted training in the 'pack out' area doing computer systems work. 'Being ADHD I could memorise stuff ... like a little computer system,' she explained. Some senior staff backed her request saying, 'She's got a brain, she's smart and she should be paid like a normal worker.' However, the move never eventuated.

Mikaela feels the employer financially exploited her. She is uncertain as to whether she was paid the correct amount of superannuation and believes the amount paid to supported workers was 'wage theft'.

Nerida

Nerida, mother of two teenagers, is in her 40s. She has cerebral palsy and post-traumatic stress disorder. She shared with the Royal Commission her experiences as a person with disability in the family court system.

Nerida is a survivor of domestic abuse, having been 'emotionally, mentally and physically' abused by her ex-husband during their marriage.

'Our close friends knew that I had cerebral palsy and knew that I had falls and what not. So if I was covered in bruises [they would say] "oh yeah you fell again?" And I would say, "Yep." Dismissed.'

When the couple first separated, the children lived with Nerida. 'I was doing the best with the skills that I had at the time.'

After five years, her ex-husband made an application to the Family Court. His lawyers honed in on her psychosocial disability.

'It was all about "oh, you've got mental health, you've got anxiety and depression" ... nothing about the [cerebral palsy] as such ... There's no understanding or empathy of any of that.'

She felt the legal system expected her to be 'Wonder Woman', able to perform various physical feats despite being hemiplegic on one side of her body.

'I don't want people to feel anything less of me because I can't do them things. But I am who I am.'

She said she went through a 'whirlwind of emotions' during the court process. At no time was she ever asked, 'So what does cerebral palsy actually mean to you?'

'On the whole, I've never thought that someone thinks any less of me because of my disability,' Nerida said. But in the court system, it's 'a whole new ballgame'.

Ultimately, Nerida lost custody of her children. 'I just feel that my rights have been violated so much ... I am who I am ... I can't fit in this box that I'm not.'

She has an hour of contact with her children each week, but has not physically spent time with them in more than two years. 'I definitely think there was absolutely no understanding of a disability, to be quite honest ... I now don't have a relationship with my children.'

Nerida is disappointed with the court system, and feels it 'manipulates' people with disability.

'I don't understand when we tell young people "don't be ashamed of your disability", because in reality you are [made] ashamed, and you are used and abused because of it. It's false hope.'

Neve and Jarrod

Neve, mid-30s, was diagnosed with epilepsy when she was young. As a teenager, her seizures increased. Doctors further diagnosed her with a range of complex cognitive, physical and psychosocial disabilities. She requires 24/7 care. If her seizures aren't managed carefully she is at risk of injury and death.

For the last 15 years, Neve has been living in disability residential facilities.

Jarrod, her brother, said that with the coming of the NDIS, the home Neve had been living in for about 10 years 'dropped the ball'. Management reduced staff numbers and refused to provide additional support workers for Neve. She became malnourished and her medical care deteriorated. Management allowed an occultist to visit Neve when she was experiencing psychosis.

Jarrod and his wife, Rachel, engaged a new disability services provider. There was a three-month transition period and, at first, they found staff warm and accommodating. But very quickly Jarrod noticed errors and a 'lack of basic competence'.

Staff lacked training and would often not show up for shifts. The inexperienced manager would call in Jarrod and Rachel to cover these shifts, but still invoice them for support workers. Two support workers took maternity leave at the same time and management failed to replace them, despite Jarrod and Rachel approving potential candidates.

Jarrod engaged a support coordinator who worked hard to improve the provider's performance, with little success.

Jarrod made a formal complaint to the NDIS Quality and Safeguards Commission. He said the process was 'totally unsatisfactory'. He received a single phone call in three months to ask how it was going. Neve's parents felt disheartened and felt the commission was 'basically a swamp'.

'They lead you off into the swamp and kill you there,' said Jarrod. He believes the process is 'useless'.

The next provider was 'extremely hopeless'. Staff failed to keep basic records or follow Neve's medication protocols. Some staff did not have sufficient literacy and language skills to communicate, read charts or keep records. They disregarded Neve's diet schedule and fed her sausages and beans on a regular basis.

A few months after Neve moved, the provider terminated Neve's agreement with two weeks' notice. Neve had to spend time in hospital until she was able to move to her new home. She had to share a room and was distressed, but there was no other option.

Jarrold said the new home is unable to provide the level of care Neve requires. There is no consistency of support staff because of the high turnover. In one year Neve has had more than 30 support workers. The workers are not sufficiently trained, do not understand her 'complexities' and do not follow procedures. Neve had a major fall walking down steps in the wet room alone, without shoes.

Neve's mother, Rachel, increasingly felt her daughter's living situation was 'hopeless' and that there was nothing she could do.

Rachel suicided.

In his distress, Jarrold felt he had no option but to relinquish Neve's guardianship and her financial administration to the public trustee.

He now regrets the decision and feels 'shut out'.

He says the public guardian has a 'culture of antipathy between parents and guardians' and is 'the enemy of the family'. He is concerned Neve is in a 'very dangerous place' at the moment and the public guardian is not taking sufficient steps to keep her safe. He feels there is nothing he can do.

'We are committed carers ... but we are disregarded.'

Paulette and Leonard

‘I have advocated for many other victims of the guardianship racket in several states. Basically, there is only minor difference in execution but the intent is identical ... find victims and milk them dry with no concern whatever for the consequences.’

Leonard is Paulette’s spouse and unpaid advocate.

Seven years ago, Paulette, then in her 50s, was admitted to hospital with aphasia – loss of language. Doctors suspected, incorrectly as it turned out, Paulette had had a stroke.

Within days of admission, a social worker at the hospital convinced Paulette’s sister to ask the state administrative tribunal to appoint the public guardian to manage Paulette’s legal and financial affairs.

Leonard told the Royal Commission that hospital policy at the time required doctors to wait until at least a month after admission before writing official medical reports on brain injury patients. Also, the senior neurologist had to approve all reports.

The social worker completely ignored the mandatory one-month requirement, did not consult the senior neurologist and did not consult Paulette. Instead, Leonard said, the social worker coerced a newly qualified registrar to bypass the hospital system and write a report supporting guardianship.

Lynette appeared at the hearing, recently discharged from rehab, less than three months after she acquired her brain injury. Leonard said, ‘Other than the speech disorder aphasia, [she] had no significant disabilities.’

The guardianship application was granted.

Leonard lodged an appeal against the decision and for the next two years fought to have guardianship revoked. He had to lodge an appeal against the original decision and apply to have Lynette declared as having capacity.

Almost immediately the public guardian charged Paulette \$20,000 for ‘representing her interests’.

Leonard obtained more than 40 positive reports from a number of health professionals to support Paulette’s claim she had capacity. During this time, as a result of intensive therapy, her speech improved. Leonard said the public guardian and the administrative tribunal ignored the health professionals and Paulette and ‘fought them all the way’.

During hearings lawyers ‘verbally attacked’ Paulette – on one occasion ‘with such ferocity that she was rendered catatonic’ for almost a week.

‘You’ve got to be thick in the head to challenge it, because the pressure against you, the resistance is unbelievable. Only someone with desperation, I suppose, in our case, I was prepared to fight, we were going to win this.’

Eventually the appeal was heard by the Supreme Court and was successful.

‘By the time we received final statements several months later, [public guardian] costs exceeded \$200,000 over 27 months. There is no possibility of recovering this by using any Australian law.’

Reuben and Edna

Reuben is in his 30s and has a brain injury, epilepsy and weakness on his right side.

Edna, his mum, told the Royal Commission that when Reuben was a toddler, doctors discovered a tumour in his brain.

The first procedure, an 'eight-hour gruelling surgery', removed 'hardly any tumour ... because it was in a very deep-seated area of the brain'.

Reuben began experiencing seizures, but the hospital sent him home to the family's regional town.

When the wound in Reuben's head became infected 'he was then airlifted back to the children's hospital'.

Edna said treatment of Reuben's tumour in Australia seemed to be 'substandard' and she sought opinions overseas.

'I had to try and find a neurosurgeon who could remove his tumour and save his life, so I was informed about [a doctor in the United States] and that's where we ended up going.'

The doctor removed most of the remaining tumour, and Reuben's seizures stopped.

About 15 years ago, a car hit Reuben while he was riding a pushbike. He had been wearing a helmet, but the seizures returned.

Several years ago, Edna was evicted from her home. Police arrested Reuben and Edna and placed them in the watch house.

'They specifically didn't want [Reuben] anywhere near me. And he was being tormented, where he was refused to go to the bathroom, and they kept him and I there for eight hours, during which time his medications were due.'

Reuben said they never retrieved his medication and 'treated [both of them] like shit, like animals'.

Reuben said that when he asked to be with his mother, police assaulted him.

'The shock [Reuben] was going through when he was being dragged by the throat, his left arm – you know, because of his neurological damage – it was straight up to his side and it was as stiff as a board.'

Edna said police dismissed her complaint, but Reuben's seizures 'came back with a vengeance'.

'They haven't stopped.'

Roscoe

Roscoe is in his 50s and has an intellectual disability. His grandparents left him an inheritance and he also receives a Disability Support Pension. Roscoe told the Royal Commission that the public trustee controls his money and, after paying rent to his parents, it gives him \$90 a week to spend.

‘I can’t even go for a counter meal with my mates and all that stuff.’

When Roscoe was a teenager, he was sexually assaulted. Afterwards, he was sent to a psychiatric hospital, ‘a nasty place’, where he stayed until his 20s.

Roscoe told the Royal Commission staff at the hospital abused him and locked him in a ‘time-out’ room. It made him sad and lonely.

After leaving the hospital, Roscoe lived in boarding houses until his parents bought a house for him to rent.

Because the public trustee won’t let him access more of his own savings, Roscoe now collects bottles and cans to supplement the \$90 a week he’s allowed from his pension.

‘I’ve got all that money in [the bank]. They’re not even giving me any of it ... I’m unemployed and I’ve got no other money.’

Roscoe said that when he asked the public trustee and his parents for access to more of his money, they said ‘No’.

‘I’d like them not to be greedy. I’d like them to give me my money more often ... I’m happy with \$80 extra a week.’

Seneca and Bensen

Bensen is in his 60s and lives with physical impairment and psychosocial disability and has difficulty walking. However, Bensen primarily wanted to tell the Royal Commission about his 25-year struggle to provide the best possible care for his partner, Seneca.

Seneca was diagnosed with Crohn's disease in her late teens. Alongside other complex medical issues, she also had chronic obstructive pulmonary disease. She used a wheelchair and scooter, and a colostomy bag.

Seneca was not eligible to receive NDIS support, despite her health issues. Bensen said the NDIA believed Seneca had medical conditions, not disability. Bensen could never get any further than the switchboard when he called the NDIS. '[They] didn't want to know.'

Without NDIA support, Seneca relied on Bensen 24/7 – including for her personal care. He funded most of her treatment and bought her wheelchairs, a scooter and other special equipment. Bensen struggled to find suitable housing and said he is still waiting.

The stress of trying to access support for Seneca, and of caring for her without even one day of respite, caused Bensen to consider suicide.

'If I'm not there,' he thought, 'someone's gonna have to provide the support she needs.'

Bensen told the Royal Commission about the accessibility issues Seneca continually faced.

About five years ago, Bensen and Seneca embarked on a much-anticipated cruise. '[Seneca] had saved all our change for over two years for a holiday,' Bensen said.

But the holiday quickly became 'an absolute nightmare'. On the voyage out, Seneca could not go outside on the ship because her scooter could not get over the humps at the doorways. Much of the accommodation at their destination had stairs and narrow walkways that her scooter could not manage, and bathrooms or toilets she was unable to use on her own.

The return journey was on a different ship. On arriving at the new cabin, Seneca found there was not enough room for her to get off her scooter. Management gave them a different cabin in which she could at least get off the scooter, but the bathroom was still completely inaccessible. Seneca had to wake Bensen in the middle of the night, 'panicking that she was going to wet herself'. With Seneca in tears, they 'set off in search of a disabled toilet'.

At the end of the journey, there were further difficulties.

'We took the lift down and there was no ramp access for [Seneca], so I set off to find one. When I returned [Seneca] was in tears. She was being abused by other passengers as there was little room.'

Seneca told Bensen she would never go on another holiday.

‘What was supposed to be a holiday for us to enjoy was a nightmare and humiliation.’

In her mid-50s, Seneca was admitted to a hospital renal unit suffering acute kidney injury. Her condition quickly deteriorated and she died soon after.

Bensen is angry about events leading to Seneca’s death, believing that ambulance and medical staff at two different hospitals failed to provide appropriate care. An autopsy was performed, but no inquest was ordered. Bensen is not satisfied with the coronial findings or the information provided by the hospitals.

These experiences and struggles have been detrimental to Bensen’s mental health. He ‘is struggling to fight’ and is living in ‘a mental nightmare of guilt, anger and loneliness’. The eight visits to a psychologist provided by his My Aged Care package is, he says, not enough.

Shiloh and Keo

Shiloh is a First Nations woman in her 30s. She has attention deficit hyperactivity disorder (ADHD), complex post-traumatic stress disorder, obsessive-compulsive disorder, borderline personality disorder and an eating disorder.

Shiloh's son, Keo, also has ADHD.

Shiloh told the Royal Commission she grew up in a dysfunctional household where her mother, a 'sexually perverted, dangerous woman', let her drink alcohol and take drugs when she was young.

Shiloh said she later became involved in the adult film industry and abused drugs and alcohol.

'I looked at addiction on every level from like, you know, going to the gym, binge eating ... so I can tell any alcoholic why they drink alcohol, is because it's just too easy to access.'

Several years ago, Shiloh left her violent partner.

One day when she was visiting her ex-partner's home, her son Keo drank from a bottle of dishwashing liquid thinking it was soft drink.

'He was taken to the hospital and ... they called child protection. So, child protection said that they wanted me to get an intervention order on [the ex-partner], which I did, as it was unsafe for [Keo] to be at the house.'

A few years ago, child protection services removed Keo from Shiloh's care and sent him to live with Shiloh's mother.

Shiloh said her mother's partner sexually assaulted Keo.

'My child got sexually abused whilst their intervention was taking place ... Child protection do not accept that there was any sexual abuse ... but how can child protection accept that when, you know, we've got my child demonstrating it via play and also under a six-month ... assessment?'

Shiloh is worried that Keo's abuse at his grandmother's house is 'affecting [his] mental health'.

Shiloh said she's allowed to see Keo only four days a week, but 'they haven't been occurring'.

'I've been able to see my son through my mother ... but basically ... I've had to mend a relationship with an abuser just to have contact with my child.'

Tristen and Gabriel

‘One of the single biggest issues for people with disability is the overprescribing and dangerous prescribing of medications that causes significant harm and death.’

In the late 2010s, Tristen, then in his late teens, injured himself at work. His GP prescribed opioids to treat his pain.

Tristen’s dad, Gabriel, told the Royal Commission that Tristen’s injury prevented him playing sport and his mental health deteriorated. He struggled with depression and anxiety and, unable to exercise, became obese and developed sleep apnoea. His GP gave him sedatives and an antidepressant.

Gabriel said Tristen’s GP failed to ‘monitor the amount of prescriptions or the quantity of medications’ and Tristen became addicted to the opioids and sedatives. ‘His GP never explained the extremely dangerous risks of respiratory depression, coma and death, especially with someone with sleep apnoea.’

Tristen began experiencing suicidal ideation and twice was admitted to hospital after overdosing on his medication. Although he was ‘in crisis’ the public hospital wouldn’t admit him to the psychiatric unit. The treating psychiatrist said the unit was filled with ‘violent, dangerous patients ... and he would likely come out of the facility more distressed’. He suggested a private psychiatric hospital would be more appropriate.

After a five-month wait, Tristen was admitted to a private clinic. He stopped taking opioids and started taking a different antidepressant. Gabriel said Tristen’s mental health appeared to improve.

When Tristen left hospital eight weeks later, he was taking six different drugs. They included an antipsychotic, two antidepressants, an antihypertensive, an anticonvulsant and a sedative.

A few days later Tristen bought an over-the-counter antihistamine.

A week after that, Tristen aggravated his injury playing sport. His GP prescribed two opioids, even though he’d promised Gabriel he wouldn’t give Tristen opioids ever again.

Two days later Tristen experienced a panic attack and the GP prescribed a sedative. That afternoon, Tristen seemed confused and drowsy and had difficulty walking. Gabriel immediately called an ambulance to take Tristen to the emergency department of a private hospital.

Despite the emergency doctor noting ‘a red flag for addictive substances’ the doctor gave Tristen another opioid script.

The next night Tristen stayed with Gabriel because he was concerned about how much medication he was on. He asked Gabriel to book him into the private psychiatric clinic again so the psychiatrist could review his medication.

Gabriel was worried about Tristen and checked on him multiple times during the night. When he checked on him the next morning Gabriel found him snoring loudly. However when he checked again a short time later, Tristen was unconscious. Gabriel immediately started trying to resuscitate his son and called an ambulance.

Tristen couldn't be revived. He was in his early 20s.

The autopsy concluded Tristen 'died due to the toxic reaction of his prescribed medications, taken as directed, exacerbated by his existing health conditions'.

Gabriel believes the mixture of medications prescribed by multiple practitioners caused his death. He particularly blames Tristen's GP for continuing to prescribe opioids, despite knowing he was addicted, and for not monitoring him appropriately. Gabriel said the GP never referred Tristen to a pain management specialist or investigated alternative treatments.

Gabriel says consumers are not given adequate information about the risks of taking certain medication, particularly opioids and sedatives.

'I blamed myself for what happened to [Tristen], I felt that I'd failed him. After doing my research and finding out the medications he was on and how they all interacted with each other and interacted with his sleep apnoea ... I soon realised that there was no blame on my shoulders, I'd done everything humanly possible to help him and to protect him and to ultimately try and save him.'

Wilf and Meriam

‘I have jail workers who say to me, “He is the most beautiful boy, he is so gorgeous, he shouldn’t be here.” And yet that is what we seem to allow. We have to protect these people better.’

Meriam is the mother of Wilf, who’s in his 30s, is autistic and has an intellectual disability.

When Wilf was born, he couldn’t breathe for several minutes.

‘He was left like a stroke victim ... he has dyspraxia and autism, as well as an IQ of only 59. However, he was brought up to be the most beautiful soul. That’s what he is.’

Meriam said that after Wilf’s birth, her doctor told her to ‘put him in a home and get on with [her] life’.

‘That was my first contact ... with what we do to people who are disabled. We pretend that they don’t exist. We put them away. So, that is the beginning.’

Meriam said Wilf ‘will never be more than a 5-year-old’. He was bullied at school and people still take advantage of him.

One time a woman approached Wilf, telling him to sign a contract for a new phone or she would ‘start making a noise here and now’. Wilf did as he was told and printed his name. ‘My 5-year-old grandson writes better,’ Meriam said.

‘I went down the very next day to the shop and said, “How could you have someone like this sign a contract?” And they said, “No, it’s nothing to do with us, that’s a management decision,” and so it just went on and on and on.’

Meriam says the telephone company is still demanding payment for a telephone Wilf never used.

One day, someone Wilf knew accused him of touching a child’s bottom. Meriam said Wilf was innocent, but the police interviewed him.

‘He couldn’t speak for himself, because he wouldn’t be able to cope with the stress or pressure or understand the language that they put on him. He wasn’t able to speak, but they wouldn’t let anybody else speak for him.’

Wilf was charged and appeared in court. The court procedure confused him. ‘The intellectually disabled ... can’t play that game. So we need something different within a court system,’ said Meriam.

Wilf was 'judged guilty without any look at who he was, without any understanding [of his disability]'.

The judge sentenced him to several years in prison.

Meriam said Wilf was transported to prison 'handcuffed in the back of the van, not understanding what was going on'.

'[But he] heard the two police making a joke as they found potholes, went over speedbumps to see his head smashed, to see him thrown around in the back of the car. When I first saw him, he was broken.'

Meriam said she's been unable to see Wilf since because of COVID-19 lockdowns. The prison system removed his support network.

'In a justice system where someone has not so much as had a littering fine in their whole life – because he is an innocent and lives by what he is taught – that that person can end up incarcerated is quite horrifying.'

Antonella

‘You never know what you’re walking into in terms of mental illness, and control is a big thing for me and to have that taken away is huge.’

Antonella, early 40s, told the Royal Commission she is a recovering addict.

A year ago, she became confused and disorientated and was admitted to hospital. She was diagnosed with a neurological syndrome that affects memory and the central nervous system.

Antonella was in a coma for more than a week. ‘They didn’t expect me to live, and I had a period after I came out of ICU which was like, I call it my crazy period, about a week or so and I had absolutely no idea what was going on.’

During this time, somebody – Antonella is not sure who – made an application to the administrative tribunal, which placed her under the guardianship of the public trustee and guardian.

Two weeks later Antonella started to recover some of her cognitive function and met with a woman from the public guardian’s office. ‘The only thing going through my head at that particular point of time was I don’t want to go into a home. I don’t need to go into home.’

The trustee and guardian withdrew all Antonella’s money from her primary account – she had several millions of dollars in accumulated wealth. They gave her a small weekly allowance for necessities and she sent them all her bills to pay. ‘But they were falling behind, like months and months and months’ and she spent ‘hours on the phone’, convincing her landlord and medical specialists to ‘bear with [her]’.

Antonella tried to contact the trustee and guardian but they refused to communicate with her.

‘The lack of control was really quite difficult for me, and I didn’t want to give them more information than, you know, I had to actually give. I was in the process of buying a house, so I couldn’t buy a house without them involved.’ Ultimately the trustee and guardian made it too difficult and the sale fell through.

Antonella was shocked by the fees the trustee and guardian charged and believes they still have around \$45,000 of her money.

Antonella spoke to the social worker who told her ‘she had no idea this was actually the process’ and told Antonella she was ‘so, so sorry’.

After 10 weeks in hospital, Antonella had regained most of her memory and the feeling in her hands and feet and was discharged.

She then set about trying to 'get out of guardianship', but said it was 'very very difficult'.

After 'multiple assessments' her psychiatrist wrote a letter supporting 'the revocation of the guardianship', but it wasn't enough.

Antonella engaged a lawyer and eventually, after spending thousands of dollars and undergoing more assessments, the guardianship was revoked.

Antonella worries about people in a similar situation who don't have the resources or the ability to advocate for themselves.

'I just think about people that aren't able to speak up for themselves, it's awful.'

Brennan, Nala and Allen

Brennan, mid-30s, has Down syndrome and verbal dyspraxia. He lives at home with his parents Nala and Allen and has a younger brother, Jack.

For 12 years Brennan attended a day program run by a disability service provider. In the last few years the provider started claiming the cost of the program from his NDIS funding.

A few years ago, when Nala was expecting Brennan home, the provider phoned her to say there'd been an incident at the day program and Brennan would be late.

By the time Allen got home that evening, they still didn't know where Brennan was.

A short time later, police called informing them 'certain disclosures' had been made against a family member and Brennan was at an undisclosed location for his protection.

Police told Nala and Allen the provider had used an 'app' to question Brennan, and determined Brennan had been abused. Later, Nala discovered the 'app' had come from the state ombudsman and was 'like a children's app and had illustrations'.

Police did not provide any further information about what happened, the allegations or who they believed was responsible.

Some time later, Nala found out two 'child' trained officers had interviewed Brennan but had not been able to communicate with him successfully. They took away his phone during the interview so he could not ring his family.

Nala and Allen ended the call believing there would be further questioning in the next day or two. The next day they made a number of phone calls trying to find out where Brennan was.

Then two days later, police asked Allen to come to the station. They served him with an apprehended violence order listing a 'sting of grotesque allegations' in words Brennan would never use.

'You can imagine my shock when I read these,' Allen told the Royal Commission.

As a result, Brennan was not allowed to return home.

Allen's other son Jack made some enquiries and discovered, 'At no point did [Brennan] make the allegations. Effectively the provider made the allegations.'

Brennan was still attending the day program, and the manager allowed Nala to see him.

‘He shuffled, he’d lost weight. He said he was sorry but didn’t know what he was sorry for.’

She asked him where he wanted to live and he told her he wanted to come home. Brennan tried to get in her car to go home with her.

The provider advised Nala they planned to initiate guardianship proceedings.

Nala was alarmed to find Brennan was living in one of the provider’s group homes. They would be charging \$600 per day and claiming it through his NDIS funding until the guardianship matter was resolved.

She contacted the NDIA – they were also concerned.

Allen moved to a hotel so Brennan could return home. He remained in the hotel for approximately six weeks, unable to have any contact with his son.

Nala contacted a legal service and a disability association. They told her that Brennan should have had someone with him at the police station and police should not have interviewed him on his own.

Nala contacted the state ombudsman, but they never returned her call. She believes the ombudsman had advised the provider to seek guardianship of Brennan.

During the tribunal hearing a month later, the provider refused to release the incident report. To this day Allen and Nala do not know what the report said or the procedures the provider followed.

The tribunal awarded guardianship to Nala and Allen’s other son, Jack.

A few weeks later Allen went to court for the apprehended violence order hearing. Police withdrew the charges and the order was dismissed. The NDIA terminated the service agreement with the provider.

‘It was really a traumatic experience,’ Allen said. ‘And I still feel the trauma of [Brennan] being whisked away from his home to go and live in a house full of people he didn’t know.’

Charmaine

Charmaine is legally blind. She volunteers as an advocate for people with disability, mainly for blind people, to help them access the best available NDIS packages. She also works to promote disability awareness.

Charmaine receives NDIS support. She told the Royal Commission that she has a 'really good plan' now. She has around 36 hours of support each week including support workers, a gardener, a cleaner and someone to cook and shop. 'I can't complain.'

However, Charmaine has encountered difficulties each time she needs to review her support package. NDIS staff 'do not understand about blindness,' she said.

Charmaine spoke about NDIS staff bullying her. She believes it is because she told them what they offered was not enough to live independently. She escalated her concerns about bullying to the relevant minister and the head of the NDIA but said it was hard to get somebody to listen.

Charmaine gave examples of unreasonable costs under the NDIS.

As Charmaine is 'plan managed', to be reimbursed for costs she must buy products from specialised providers, who may have 'very limited products'.

For the NDIS to cover the cost of a microwave, she needed a report from an occupational therapist. But for an occupational therapist to visit her home and write a report, 'it's \$190 an hour'. This fee was taken out of her NDIS plan. With support services dipping into a plan in this way, Charmaine says, it 'doesn't last as long as it should'.

Charmaine finds the NDIS a complicated system.

'They need to reorganise and restructure the NDIS to make it a better service ... It's so difficult for people to access, it's not funny.'

Charmaine spoke about her attempts to find paid employment through a disability employment service. A woman at the employment service said, 'If you look blind, people won't employ you.' She told Charmaine she needed to present as though she can see.

Charmaine has qualifications as a trainer and assessor, but the employment service wanted her to pack boxes. She eventually gave up on paid employment. She now has her voluntary work.

Charmaine said that when she refused to attend a day program, believing it would not help her, the service provider bullied her.

She said they also took money out her NDIS package for services she didn't use, although the money was eventually given back.

Charmaine has difficulty interacting with basic services, such as telcos and banks, due to their lack of accessibility.

‘Everybody who’s blind has trouble with the ATMs ... Then when I got inside the bank, they want me to pin and sign. And I told them “I can’t pin and sign.” “Oh, do you have a driver’s licence?” “No ... They won’t let blind people drive.”’

Similarly, Charmaine’s telco refused to discuss her bill with her over the phone because she was unable to read the pin they messaged to her.

Charmaine says getting around in the community is difficult for blind people. Public transport often fails to provide announcements about where to get off. She has also fallen on occasion because of a lack of tactile warning about stairs or ramps. As for traffic lights, she says, the ticking indicator does not always work or cannot be heard.

Finley

Finley is in their 60s and lives with bipolar disorder.

‘Apart from having gone into hospitals at various times ... I always worked and just led what would be deemed as a normal life.’

Finley told the Royal Commission that a decade ago they were in a hospital mental health unit.

Shortly after the hospital discharged Finley, they discovered that someone had withdrawn nearly \$2000 from their bank account.

‘The ... bank did reimburse me and all the rest of it, but I thought, look, really people need to know about this because I am just a conscientious person who found out about it by reading my statement ... But there are many people in those places who I know, and I’ve seen before who are very, very vulnerable.’

Finley complained to a state government commission. A month later the commission told Finley the hospital believed it was [a relative] who had taken the money and they ‘wouldn’t take this any further’. Finley said it wasn’t possible for a relative to have taken the money.

A couple of years later, Finley was admitted to the unit again. This time, patients’ belongings were stored more securely in a safe.

Finley said thefts in mental health units appeared to be common.

‘They think, oh, the person’s very heavily medicated, they won’t know the difference. We can just sort of bamboozle the whole, you know, situation to make it look as though they don’t know what they are talking about or doing.’

Finley also said they knew of staff who punished patients by overmedicating them.

‘They really can make life hard for you because they have power over you, you know? They can play, and they do play, all sorts of mind games, you know, with you. And, “Oh, okay, so you won’t do that. All right, well we are going to give you another injection ... This sort of thing does go on, or it did when I was there.’

Hemi

Hemi is in his 30s and lives with schizophrenia. He's been in a psychiatric hospital for more than five years under a forensic order.

'I do not feel safe here in this hospital,' Hemi told the Royal Commission. 'I'd rather be back in the community where I belong.'

Hemi has his own room at the hospital, but doesn't like the food, which he calls 'dog food'. Hemi said the nurses bully him and other residents.

'They should be treated as human beings and I've seen people who've been bullied ... I had one of the nurses put his foot on my head.'

Hemi said the hospital restricts his access to nearly everything. He's not allowed a mobile phone. Hemi has a significant heart problem, but was told to remove his medical bracelet.

'You can't have this, you can't have that.'

Hemi said he was sexually assaulted when he was younger, but the nurses don't respect his preference not to be touched.

Once, when they tried to sedate him, he objected to being touched and they put him 'into seclusion'.

'I ended up getting hurt. The other nurses blamed it on me, but it's not my fault.'

Hemi hopes to move into supported independent living. To do that, he needs the forensic order lifted. He said there was a hearing recently, but he wasn't invited. Hemi told the Royal Commission that he went anyway, but 'didn't feel welcome'.

'I want to get out [of the hospital] as soon as possible ... and get the rights that I wanted all along, and to live in the community as a human being.'

Jensen

‘It’s almost like now the disability and medical sector are at each other’s throats.’

Jensen is a First Nations man in his 30s. He has an acquired brain injury from an accident when he was 13.

Jensen told the Royal Commission that, as an adult, he was ‘conned into some unnecessary surgery’ that left him in a wheelchair.

After his experiences in hospital, he became a disability advocate.

‘You know, to have no support at that stage, for there really to be no-one within the hospital that could actually come and advocate for me based on the disability stuff, was really quite scary.’

Jensen said people with disability often struggled to find support in the health system.

‘I find that really trying to access government services, supports and other sort of things the government should equitably provide to every citizen, not just you know a select cohort, it’s very, very difficult as a disabled person to often access a lot of those services.’

Jensen told the Royal Commission that after the surgery that put him in a wheelchair, he returned to hospital several times to try to fix it.

‘It was just a mess, you know. From one doctor yelling at me while saying that I shouldn’t be in a wheelchair and if I tried to walk I could, other doctors just treating me like ... somebody without any brain capacity. And, you know, if I was to bring a support person I would be completely ignored and often the support person would be communicated with.’

One night, Jensen was talking to a First Nations hospital liaison officer.

‘It was past visiting hours, of course she works at the hospital, and one of the nurses comes up and says “Oh, sorry, you have to leave. Visiting hours are over” and she actually had the name tag [with] the hospital’s name but, yes, she basically just got fobbed off because people didn’t think that she was an employee at the hospital.’

Jensen said the health system labelled him a ‘frequent flyer’ because of his frequent visits to hospital.

‘These are often people with a lot of comorbidities, disability, perhaps drug and alcohol issues, a very complex cohort that are regularly appearing in hospitals. And often once you’re labelled as a frequent flyer, as I was, ... you get treated really badly. From being denied medical treatment, not being believed, being accused of being an opioid seeker.’

He said that instead of the health system being an ally, people with disability became ‘another burden [in a] cruel cog caught in the wheel of government’.

Jensen said that after several failed attempts to repair the damage that put him in a wheelchair, the hospital was reluctant to extend his rehabilitation.

‘You end up in the scenario where you’re already being neglected in the acute system, you’re neglected in the rehab system and then you’re almost left in a scenario where the disability sector then has to pick up all these pieces and you’re actually sort of a bit behind the eight ball.’

The hospital discharged Jensen and, unable to find anywhere that could support him, sent him to a nursing home.

‘It was not the right place [for a person with disability]. It does get very depressing when you’re in an aged care facility. You know, basically [people] that become your friends are constantly dying on you.’

Kade and Zenni

‘Abuse and neglect are very broad terms and I beg you not to look the other way just because there is no gaping wound. It’s often covert abuse and neglect that’s brutally insidious.’

Kade, early 60s, was formally diagnosed with an intellectual disability last year.

Zenni, Kade’s sister-in-law, told the Royal Commission that two of Kade’s siblings intentionally delayed a diagnosis and hindered him from obtaining any form of disability support throughout his life.

About 40 years ago Kade’s mother died in a car accident. Kade, a passenger in the car, inherited his mother’s estate. Zenni estimates the estate is now worth more than \$4.5 million.

In the late 2000s Kade’s father died and his siblings ‘made’ him appoint them as his legal guardians and joint enduring powers of attorney. Zenni believes Kade lacked capacity to understand what he was signing. ‘[The solicitor] did not take any steps to safeguard [Kade]’s interests,’ she said.

A few years ago, Kade’s sister took him to a financial planner and he signed a financial management plan. Zenni believes Kade didn’t understand the document.

Zenni said Kade’s siblings do not want Kade to spend money and rarely act in his interests.

Kade has been working as a kitchen hand at a hospitality venue since he was 18. He does not use a mobile phone and, walking home from work late at night, he often gets lost. Kade’s siblings refuse to allow him to use an Uber or taxi service. Zenni purchased a hi-vis safety jacket for Kade. She also organises and personally pays for his transport to and from work.

Kade continues to live in the family home. The house is in a ‘very poor’ condition and infested with pests. Mice have eaten through his mattress and Zenni suspects Kade sleeps upright in the hard dining chair. A recent occupational therapy assessment confirmed there was ‘no safe place’ for him to sleep.

It is also extremely difficult to move about the house because Kade is a compulsive hoarder. Zenni organised and paid for a deep clean of his house. This professional clean took four days and cost \$12,000.

Last year Kade was admitted to hospital with untreated kidney stones. During his stay Zenni connected Kade with medical professionals and social workers. Kade was formally diagnosed with an intellectual disability. The medical professionals recommended a number of services and therapies to improve Kade’s quality of life.

Kade will have his first NDIS planning meeting soon.

If the NDIS refuses to fund Kade he will miss out on these services. His siblings will not permit him to fund the services himself despite him having ample resources and no dependents. When Zenni raises her concerns, she feels 'intimidated and bullied'.

Kade's siblings are depriving him of basic liberties, Zenni says, because they want his estate to be as large as possible when he dies.

Zenni's lawyer advised her to make an application to the administrative tribunal to have Kade's guardianship and financial management orders reviewed. However, she is concerned that this would damage Kade's family relationships, exacerbate the psychological abuse and isolate him further.

Zenni feels like she has run out of options. 'What can I do to protect him?'

Kenzie and Celine

‘It became more and more obvious that [the school’s] acceptance of [Kenzie] was becoming less and less.’

Kenzie has a cognitive disability and is non-verbal.

In the mid-2000s, a year prior to starting school, the local school principal approached Kenzie’s mother, Celine, to enrol Kenzie at the school. She told Celine they had all the funding in place and could give Kenzie the support she required. ‘We were so happy,’ Kenzie told the Royal Commission.

Celine said the school was ‘very open’ to children with disability – each class had one or two children with disability and a ‘heap’ of ‘wonderful’ aides.

However, in grade 2 a new principal started and advised Celine, after reviewing the finances, they could only fund an aide for Kenzie for one hour each morning.

Celine was concerned and contacted the department of education who spoke to the principal. Celine says she’s unsure what they discussed, but it was the start of a ‘downhill slope’. At the time, Celine considered herself a confident person but over the next four years, dealing with the school, she became ‘a blithering mess’.

Kenzie’s aide resigned in term 3, leaving her with an aide only one day a week. The school advised a replacement aide was ‘not a priority’. Her classmates tried to help her as much as they could, but then Celine started hearing from their parents their grades were suffering because of the time spent helping Kenzie.

Two weeks before the end of the school year the new aide started. By this stage, after spending so much time on her own, unable to communicate, Kenzie’s anxiety was ‘quite bad’.

In grade 3 the principal called Celine to collect Kenzie because she’d had a toileting accident and ‘really smelt’. The aide attempted to clean Kenzie in the disability toilet until the principal told her to stop. The principal considered the disability toilet her personal toilet and when Celine arrived, shamed her about how ‘dirty’ it was and put up an out-of-order sign. She told Celine if Kenzie soiled herself again the aide would not clean her and she’d be sent home.

In grade 4 the principal told Kenzie to stand near the ramp. Kenzie misunderstood and after a while sat down in the shade. The principal called her ‘naughty’ and as punishment made her stand near the ramp until she told her she could leave. But the principal forgot about her and left her on her own for three hours. A teacher found her crying in a corner. Later that year she was sent to the ramp again and refused to go back to school.

The grade 4 teacher instructed an aide not to allow Kenzie to go to the toilet during class as it was 'distractive for students'. Kenzie had to 'hold on', but she has no concept of trying to stop the urge to go to the toilet. That year she had more toileting incidents than any other year at the school.

In grade 5 Kenzie came home with two black eyes. Celine demanded the school investigate. At first they maintained it happened on the weekend but then said they didn't know what happened because Kenzie 'couldn't say'. Celine spoke to Kenzie's friends who told her another student hit Kenzie in the face with their school hat. It was the second time she'd been assaulted.

Kenzie's paediatrician prescribed medication to stop Kenzie vomiting and wrote detailed instructions for the school to follow. However, the principal refused to administer the medication. Kenzie spent more than 100 days vomiting in one year.

Celine took Kenzie out of the school in grade 6. She said by this stage most of the children with disability had been 'pushed out' – only one child remained.

Kerrin

‘Having a disability and neurodiversity has put me in lots of positions where I have vulnerability, either as a child or because there is such an imbalance of power when you’re needing help.’

Kerrin, mid-40s, has a degenerative genetic condition affecting her mobility and physical health. For much of her life she couldn’t stand for too long without ‘passing out’ or having seizures. She uses crutches and a wheelchair. She is neurodiverse and has complex post-traumatic stress disorder.

When Kerrin was a child a family member sexually abused her, twice over a six-month period. Kerrin told the Royal Commission she ‘became aware over time that people who have a predisposition to being abusive are able to spot, sense vulnerability’. She said she was ‘more of a target’ because of her troubled history – her mother was ‘in and out of hospital because of depression’.

When Kerrin reported the abuse, nobody believed or supported her. Instead they ‘pathologised’ her, misdiagnosing her with mental illness. This ‘discredited’ her and made it harder to get help.

At 14, Kerrin had anorexia. She was hospitalised for five months, during which time doctors ‘didn’t even want to know’ about her trauma. She described the treatment model as ‘punishment and privileges’ and ‘being punished for having trauma’. She said it set her up for ‘further vulnerability going forward’.

Some time later, Kerrin was an inpatient in a ‘locked special ward’ at a different hospital. Here, a male nurse sexually assaulted her numerous times. She asked a female nurse how to report the abuse and the woman responded, ‘I wondered when you were going to ask.’ However, when Kerrin reported the abuse the nurse ‘didn’t back [her] up’.

The head psychiatrist at the hospital tried to convince Kerrin the abuse didn’t happen. She felt extremely unsafe and asked the hospital to remove the male nurse from the ward. The hospital refused, and instead moved her. Kerrin phoned the official visitor service and the sexual assault service, but no-one came to see her.

Eventually Kerrin decided to ‘submit completely to what their picture of being dischargeable looked like’ in order to leave.

Kerrin said the hardest time in her life was seeking justice for sexual assault that occurred in her 20s. The trial was ‘worse than the initial experience’. She’d ‘never ever recommend, ever’ anyone report an assault.

It began with the police officer who took her initial statement using his own words instead of hers. Police didn't give her a copy of the statement until she was in court, where she was asked to read it out loud. But Kerrin 'couldn't read it' because she felt the language 'of intimacy' the police officer used didn't reflect what happened.

Kerrin felt confused giving her testimony. Under cross-examination, the lawyer asked her to recount events in the order they happened. She couldn't remember the order and contradicted the statement. They questioned her about her sexuality and psychiatric history. To discredit her, the defence called as a witness the head psychiatrist at the hospital where she'd been assaulted. Despite having 'forensic proof' and 'proof of damage', the court found her perpetrator not guilty.

'What I saw when I was in and out of psychiatric wards, was so many women with and without disabilities who were abused as children and then misdiagnosed with borderline personality disorder.'

Kerrin says her medical record makes it impossible for her to get help for her physical disabilities in the public system. She is treated as 'drug seeking' or 'there for attention' and her physical symptoms are 'in her head'.

'It's awful,' she said. 'No-one should have to experience that ... If there is a way that I can contribute ... making sure other people don't go through that, then I would like to do that.'

Lorelei and Gerardo

Lorelei, early 40s, has attention deficit hyperactivity disorder (ADHD), post-traumatic stress disorder and borderline personality disorder.

She told the Royal Commission she is from a culturally and linguistically diverse background, and in her culture her disabilities were perceived as shameful. As a child, no-one sought any support or treatment for her. Lorelei experienced child sexual abuse and, as an adult, her partner physically abused her.

For the past decade Lorelei has been working in the police department. Following the birth of her son Gerardo, around eight years ago, Lorelei took maternity leave. When she returned from leave there were issues with Gerardo's behaviour and she couldn't obtain full-time care for him. She had to take extra time off work and noticed her colleagues started bullying her.

They made 'racist comments' and 'tampered with her computer and work things'. Staff would move her mobile lockable work drawers and she would spend the first 15 minutes of her shift looking for them. Her manager openly reprimanded her for being 'distracted' and wasting time.

She explained that because of her ADHD she 'couldn't stay still' and would get up and go to the bathroom more frequently than other people. Staff made 'hurtful' comments about this. Lorelei asked to see an onsite psychologist but her manager refused to allow it because it would be 'taking time away' from her duties. The manager also warned her there was 'stigma attached' to a staff member needing help from a psychologist. She asked to move to a different unit but her manager refused.

Lorelei's mental health deteriorated and she took sick leave. She attempted to report the bullying but avenues were either not available or blocked. People didn't think she was a 'credible witness' because of her disability. Lorelei said there was 'no transparency' within the police department.

Ultimately, she made a workers' compensation claim but her claim was rejected. Lorelei said the police department interfered with the process.

Meanwhile Gerardo's behaviours were becoming more challenging. He would have 'violent outbursts' and often 'strip naked in public places'. In preschool he was diagnosed with autism. Mainstream schools wouldn't accommodate his behaviours so Lorelei sent him to a special school.

In 2018 Gerardo received NDIS early childhood intervention support. He made progress and music therapy helped him become verbal. With the assistance of an exercise physiologist he was able to do regular exercise and his coordination improved. Two support workers helped him go to the toilet, shower, dress himself for school and feed himself. An occupational therapist helped him with his diet.

However, the support was short-lived. After six months a review 'was triggered'. By the time it was completed, four months later, Gerardo had turned seven and was no longer eligible for early childhood intervention funding. All supports were removed 'immediately' except for 53 hours of occupational therapy a year. Gerardo started 'regressing in his behaviours', lost speech and 'became antisocial'.

At one stage Lorelei was getting a phone call from the school every second day to come and collect Gerardo. He'd lock himself in the bathroom and there would be a 'siege type situation'.

Lorelei requested multiple reviews, to no avail.

'My frustration is, the way that NDIS reviews are, the delegate doesn't have contact with you so they wouldn't know how the person's disabilities affect them in their day-to-day lives. They just go off pieces of paper.'

The NDIA said Gerardo's supports 'fall under parental responsibility' and accused Lorelei of trying to 'shirk' her responsibility. Lorelei disclosed her own disabilities and provided a psychiatric report. 'They just said, "too bad".' She is appealing through the administrative review tribunal.

'As a taxpayer, I'm frustrated that rather than seeing the funds go towards getting support for people with disability, it's being spent on lawyers.'

Madilynn

‘These organisations have the power to work with [the workplace safety regulator] to not support their staff who are trying to do the right thing, [but] rather support their staff who are helping them to cover up. And that for me has been a very difficult journey.’

Madilynn lives with post-traumatic stress disorder, depression and anxiety after managing group homes for people with disability.

Madilynn told the Royal Commission she started her career two decades ago full of optimism.

‘I enjoyed it so much, and found a lot of reward and just happiness doing that kind of work ... It was my whole life.’

Madilynn volunteered with a large number of charities helping people with disability before getting a tertiary qualification.

‘I wanted to give back because I received a lot and enjoyed a lot of what all of those jobs brought to the table for me personally. So I wanted to, I guess, hone those skills.’

Just over a decade ago, she became the manager of a group home with poorly trained staff and residents newly arrived from an institution.

‘They had just been put out in the community with no choices as to who they get to live with, the type of people they might have things in common with or their capabilities or their interests. It was really a recipe for disaster.’

Not long after starting, Madilynn witnessed a violent assault. When she tried to intervene, she was beaten and thrown through a wall.

When she reported the incident, the service provider told her ‘it was an internal matter’. She was not to tell parents what was actually going on with their adult children.

The service provider transferred Madilynn to another home, where she again encountered poorly trained support workers and overmedicated residents.

One day, when Madilynn had a weekend off, support workers left residents unsupervised while another worker left the home in a car to buy cigarettes. One of the residents crawled out of the house onto the driveway. The returning support worker ran over him and the resident spent several weeks in hospital.

‘I was advised by management not to disclose any information to the family of [the resident] ... around the suspected intoxication of the staff member who had run him over in the driveway.’

Another time, a support worker locked a resident in the bathroom because he was 'very agitated by her vocalisation'.

When Madilynn made him open the door, she found the resident with her face bleeding and 'a flannel stuffed down her throat'.

When she reported the incident, the service provider was 'dismissive of what [Madilynn] was saying, and more interested in the impact that it would have on the service if those incidents were shared'.

Madilynn took leave.

'I began not sleeping and having nightmares about what I had seen.'

Madilynn felt her managers were less interested in the welfare of the individuals in their care, and more interested in 'dollars and cents, budgets, rostering, limited rostering'.

'Everything that happened was horrific in its own right,' Madilynn told the Royal Commission, 'but then to be judged and questioned and have your character questioned and have [the workplace safety regulator] rain down on you and have [the service provider] take no action to make these people accountable ... it leaves a person wondering what hope is there for people.'

Maximo

Maximo is in his 60s and has a spinal injury.

‘I can’t tell you how it happened, but I can tell you this much. It made me into a vulnerable person,’ Maximo told the Royal Commission. ‘That’s what I say about every person that has a disability. They are vulnerable.’

After his injury, Maximo’s partner became his paid carer.

‘She did nothing but leave me without any money every week. She left me in bed, you know, every day ... she didn’t give a stuff about me at all.’

Maximo now lives alone in government housing. He said the housing department staff treat him like a ‘lesser human’.

‘They’ve known that I’ve been disabled ... They don’t care.’

Maximo said he struggles to access his kitchen.

‘I’ve got a dishwasher and it sits in the laundry, right? ... And I’ve got to walk all the way into the kitchen to bring the plates that have been done. Sometimes I drop everything.’

Maximo recently began receiving NDIS support. He’s shocked by how much service providers charge.

‘An OT [occupational therapist] came over, she only came over for two hours. Her whole bill has now gone up to \$1,780, I think it is, for two hours work ... Let’s see if I can actually open up a bill,’ Maximo said during his teleconference call with the Royal Commission.

“‘Therapy report writing – \$630.47’ ... This makes me laugh. ‘Phone call – \$13.35 ... Phone call to [Maximo] – \$28.37.’ Come on! ‘Support coordination email to call physio’ – still haven’t seen no physio – ‘\$13.35.’”

‘The NDIS is really good for all these providers. Jeez, I wish I was getting that type of money.’

Raul and Anya

‘The individual houses ... from my experience, they’re mini institutions.’

Anya is in her 70s and the mother of Raul, who has an intellectual disability and epilepsy.

‘He was a perfectly normal, healthy child until he was three and had a virus,’ Anya told the Royal Commission. ‘Progressive brain damage caused uncontrolled epilepsy, loss of intellect and other faculties.’

Anya said surgery to reduce the seizures paralysed one side of Raul’s body and damaged his sight.

Anya and her husband cared for Raul at home for nearly 30 years. ‘We were pushing the envelope a bit at that stage.’

A decade ago, they placed Raul in a government-supported group home.

‘I don’t think a mother is ever ready to part with a child.’

Anya said the government told her Raul would be the first resident in a new ‘purpose-built’ group home, but didn’t show her the plans. She didn’t see Raul’s room until the day he moved in.

‘It was only a standard-sized room ... [Raul] has a king-single hospital bed, so it’s large. He’s a large man in a large wheelchair, so he wasn’t able to move freely around his room ... he can’t access the window side of the bed at all. There is no room in there for him to have a chair and sit and, say, watch TV and have time out.’

Anya said that when she and her husband complained, the government department tried unsuccessfully ‘to override [their] guardianship’, saying Anya and her husband weren’t working in Raul’s interest. ‘After nearly 30 years of your life down the drain. No career, nothing.’

Anya said that once in the home, the service provider continued to ignore her concerns about how Raul’s support workers treated him.

One day, Anya was visiting and found Raul alone in the shower.

‘He’s never to be left alone in the shower. He didn’t have a strap on restraining him in the chair. He had access to the hot water tap ... if he’d fallen off that chair and struck his head from that height – the shower chair is quite high – that could be fatal.’

Anya told the house manager.

‘The response to that was, “Right, you came in when we were showering him and so it’s your fault, so you can stay away between 5 and 8 pm any day of the week”, and we were banned.’

So, we could not enter the premises ... I think that was about 12 months.'

Another time, Anya received a call saying Raul had fallen, but 'wasn't hurt'.

'Then we got the incident report ... What happened was that [Raul] was on the toilet on his own and someone came in and found him on the floor non-responsive. He was unconscious ... they didn't call any medical help and finally they got him and put him to bed with no medical help. They just put him to bed for the night.'

Anya said staff also ignored his dietitian's advice and fed Raul party pies and pizza.

'They would purchase the takeaway food with [Raul's] personal expenditure funding. He was paying board and lodging for the food already, so they were doing a double dip on that.'

Anya believes the neglect and abuse stems from inadequate staff training.

'I'm sad to say, but it does seem to reflect society's attitudes towards those with disabilities, or older [people], not necessarily being valuable. And that's the intrinsic bottom line ... Not everybody is respected for who they are. And give them care that they need, not what, you know, the budget's going to allow for.'

Amaris

‘Instead of locking people up in institutions there should be a social and emotional healing centre for people to go to, for families or individuals, 10 acres each, hobby farm, horticulture, parenting classes, not being treated like animals.’

Amaris is a First Nations woman in her 50s currently subject to a compulsory treatment order for a psychosocial disability.

‘I do not identify as having a disability,’ Amaris told the Royal Commission. ‘I was treated like a criminal when I wasn’t one. There was racial discrimination, sexual discrimination as a woman who has no voice, [I] was tagged and discriminated against.’

Amaris worked as a public servant in education and training for many years, but took a redundancy after a back injury more than 20 years ago.

‘I wanted to spend more time with the kids.’

After child protection officers took her children into care, Amaris ‘had a breakdown and went to hospital’.

Amaris said doctors and police had her involuntarily admitted to a number of hospitals where she was restrained and overmedicated.

Once, after police arrested her, she said they ‘pulled [her] pants down and proceeded to jab [her] with needles’.

‘They overdosed me two years ago in [hospital] and I can’t recall anything else. There was a nurse, a security guard that sat with me for over 24 hours, because I was overdosed and nearly died.’

Between hospital admissions, Amaris was homeless, ‘but back and forth mainly to [her] daughter’s where [she] was abused, physically, mentally and financially’.

Amaris now lives in government housing and is hoping to overturn the compulsory treatment order.

‘I’m an elder in this country now ... but I don’t feel it. I don’t feel it.’

Benson and Everly

Everly is mum to Benson, who is 18, autistic and has a moderate intellectual disability. Benson also has low muscle tone and a limited vocabulary.

Everly told the Royal Commission that, about a decade ago, a teacher at Benson's specialist school hit him with a ruler.

'We were lucky because [Benson] told us. He was able to communicate it to us.'

Everly spoke to the principal, and someone at the school reported the incident to the police. Everly said that without evidence, and because Benson has difficulty speaking, nothing was done.

'I sort of felt like, ok, well then that's the end of that. You know, because it was his word against hers. And for me the thing is, he wouldn't know how to process a lie.'

Benson 'turned from this boy who was very independent' to refusing to go to school.

'We would never have imagined that would happen, and it did. You put your trust into these schools, thinking that your child is safe, in a safe environment, but they are not.'

Benson spent nine months being schooled at home and receiving counselling.

During that time, Everly heard little from the school. She refused to pay Benson's school fees for the time he was away. She said the school then wrote to say 'good luck with the future', and that was it. 'So nothing was done, obviously, about this particular teacher,' she said.

Everly enrolled Benson in another school for students with disability.

'Now he's flourished ... Out of all this ugliness, as much as this teacher has kind of gotten away with it, [Benson] is in a happy place, and I know he is in a safe place, too.'

Calliope

‘We have put complaints into the NDIS, and it is like speaking to the door. I get more feedback from my door than the NDIS.’

Calliope is a double amputee in her 60s. She has cardiomyopathy and uses a wheelchair.

A few years ago, the NDIS arranged to extend a ramp so Calliope could more safely access her yard.

‘It was just too narrow for the wheelchair,’ Calliope told the Royal Commission, ‘and I come off it and I end up in the hospital with broken hips and femurs and stuff like that.’

Calliope said that, before starting the work, the NDIS sent a plumber to map the drains.

‘He put his head around the corner and I was doing the washing at the time ... and he said “I flushed your drains for you”.’

Calliope left the house for some time. When she came home the house was flooded.

‘[But] having no legs I had no idea that the floor was soaked. The carpets were soaked ... The house was wrecked, and I didn’t know.’

Calliope said she wasn’t aware until days later when the house ‘started to smell musty’. The NDIS sent a cleaner, who subcontracted the job to someone else.

‘And the only cleaning they did was removing stuff, that’s about it, from my house. And I’m talking about hundreds of thousands of dollars.’

Calliope said the cleaners took her valuables. The council fined her for the rubbish left in her front yard. Calliope said nobody is taking responsibility for the damage.

‘I’m living in hell! The place is filthy and I can’t do anything about it. I can’t bring anybody into my home, I’m too embarrassed.’

Clancy and Amaia

‘I cannot tell you how angry I am. There is no justice for a man like [Clancy].’

Clancy is in his 40s, has cerebral palsy and speaks with the help of a communication device. Amaia is Clancy’s mum.

‘The severe communication impairment is what impacted him the most,’ Amaia told the Royal Commission. ‘He also has a visual impairment. They say that he’s legally blind, but he has a lot of useful sight and has learnt to read with glasses on.’

Clancy felt he couldn’t retell his traumatic experiences. ‘It hurts too much to make myself think about it,’ Clancy told the Commissioner. ‘Mum can tell them how much it hurt. Moving on is what I want.’

Amaia told the Royal Commission that it was only when Clancy started school that she realised he would never speak.

‘So, he had six years of life when we didn’t know what was going on except that he wasn’t speaking yet and was clumsy ... He was placed in a school where signing is taught, and they tried to teach, but then the dyspraxia [a movement disorder] was diagnosed, and signing was clearly not possible for him.’

The regional town in which they lived had no speech or occupational therapists or physiotherapists.

‘[Clancy] was the only speechless kid in four primary schools. So, to get the support, we had to send him to [the city]. That was a very difficult four years.’

Unable to continue the commuting, Amaia decided to ‘have a shot at the local school’. Before starting school, Clancy had a holiday in a respite care centre where, unknown to Amaia, ‘one of the staff members repeated sexually assaulted him over a 10-day period’.

Amaia said that by the time Clancy started at his new school, his behaviour had changed.

‘He started grabbing everybody and everything and that became a really serious behavioural problem that determined his next 10, 15 years of life ... we recognise it, after he disclosed [the abuse], as fear.’

Clancy was still a teenager when he tried to kill himself. Afterwards, he told a psychiatrist about the man who abused him over several years at holiday camps at the respite centre.

Amaia said Clancy told the police, but his allegations ‘went nowhere’.

‘When I look back at the hurt to [Clancy], what’s most salient to me, is his speechlessness has caused him to be a non-proof to people. People assume that he cannot understand them ... and that disability has been a huge source of pain.’

When Clancy became an adult, he entered a government-run group home. At the time, Clancy had no means of telling people that someone was abusing him.

‘Nobody knew how bad it was. I utterly got hurt. My parents didn’t know. Mum didn’t know,’ Clancy told the Royal Commission in his statement.

‘I was bitten most days. I got no help. The community visitor never helped me. The staff just left the room. I couldn’t move. Dyspraxia and fear just made it impossible. The staff didn’t understand either. Never felt so nobody. But I’m not nobody.’

One Christmas, Clancy told Amaia that a support worker at the group home sexually assaulted him. Clancy and Amaia worked with advocacy groups and the police to take the case to court.

Amaia said the prosecutor wouldn’t accept Clancy’s statement unless he ‘had his intelligence, his cognitive ability tested and his communication tested’. Clancy’s psychiatrist said that would be ‘too damaging’ for Clancy, who was already traumatised.

‘I am angry at how hard we tried, and yet how much we failed,’ said Amaia.

Clancy now needs regular counselling, but the NDIA is considering cutting his funding.

‘How do you compensate for what has happened to [Clancy]? This is impossible. But recovery is possible, and counselling is needed to make it possible.’

Dougie and Cherry

Dougie is in his 40s and has cerebral palsy. He uses an electric wheelchair with chin controls for mobility. He is also a world-class player of a Paralympic sport.

Dougie has difficulty hearing and speaking and brought his advocate, Cherry, with him to the Royal Commission.

Dougie used to live in a group home that he 'loved', but recently his service provider told him to move out.

'I don't know why,' said Dougie.

It happened so fast, he was forced to find emergency accommodation and then moved into an unsuitable share house.

Cherry said the house was noisy with a lot of 'shouting and banging'.

'I didn't like it,' said Dougie.

Cherry said it was a long way from where 'all of Dougie's friends lived', which was also close to where he played his sport.

'That was really hard,' said Dougie.

Dougie had to move again, but still lives a long way from his friends and his sport.

Dougie used to compete internationally. His travel used to be funded, but Cherry said the NDIS now considers his sport 'just a hobby' and 'not a financially viable service'.

'This is a highly competitive athlete,' Cherry said. 'This is his job.'

Dougie still has to travel to where he trains, and it's expensive. He can no longer afford to compete at major interstate and international tournaments.

Although he still plays in local competitions, there are now 'so many less opportunities to keep doing the things that were really, really meaningful to him'.

Dougie also misses his friends. He's applying to keep a cat, but the new house has a no-pets policy. 'He just wants some company,' said Cherry.

When Dougie recently applied to move to a house in the area he used to live in, he was knocked back because a staff member at his previous house wouldn't provide a suitable reference.

'We got no explanation. Just "not suitable",' said Cherry.

Dougie feels it's 'not fair' that he can't choose where he wants to live, and that his ability to play competitive sport has been taken away.

Ford

Ford, in his 70s, is a medical professional with a busy practice.

About 15 years ago, Ford told the Royal Commission his marriage broke down and he started seeing a psychiatrist. The psychiatrist diagnosed him with attention deficit hyperactivity disorder (ADHD) and prescribed a central nervous stimulant. Ford started taking the drug but immediately experienced heart arrhythmia.

Ford went to another psychiatrist who confirmed he had ADHD and prescribed Ritalin. Ford took the medication every day. Initially it helped him enormously and 'life became beautiful'. He said the drug 'shut down the noise'. He was less impulsive, inattentive and fidgety. He no longer felt like he was trying to process everything at once. His 'inability to read the subtext of a conversation' and understand body language improved. He felt he could organise his thoughts and 'put his thoughts down on paper'.

But after about six weeks, Ford was 'on the floor' and experiencing suicidal ideation.

He went to third psychiatrist who suggested he continue with the Ritalin but only use it when required.

Ford now manages his ADHD. While Ritalin is not a 'cure', he has learnt 'to live with it'.

As a medical professional and a father to a child with ADHD, Ford is concerned doctors are overmedicating people. He said they rarely ask children 'how is this medication working for you?'

In Ford's experience, there are huge profits to be made in medicating people with ADHD. He worries drug manufacturers are driving overmedication, giving 'suggested doses' higher than required.

Ford said it is difficult and expensive for people with ADHD to obtain an initial diagnosis from a psychiatrist. These services are not bulk-billed and people have to attend ongoing appointments to receive medication. He said it's 'extremely profitable' for medical professionals. Meanwhile, a large percentage of the population can't access treatment.

Ford is also critical of the education system. He feels many children and young people with ADHD are 'lost' by the 'rigidity' of the system. Children with ADHD are often mentally and socially isolated, put in 'time out' or 'in the corner'. They are often disciplined for 'not listening' and told they are disobedient.

Teachers used to tell Ford he was 'just lazy' and to try harder. They smacked him often to 'teach him a lesson'. 'I eventually wagged school because I was caned every week for misbehaving.' The teacher punished him for wagging by caning him.

Ford is also critical of examination and university entrance processes, saying they are full of 'discrimination' and 'neglect'. Good candidates are overlooked because most universities or higher study programs consider exam results only. Generally, universities do not make reasonable adjustments for students who do not respond well to written examinations.

Ford believes students should have choice about how they will be examined, and computers should be permitted. Text to speech is a 'godsend' and should be used. Ford said multiple-choice questions are a form of discrimination and a 'major problem' for people with ADHD because of 'impulsiveness'. 'The examination has to change. It can't just be written. Giving a person extra time is destructive.'

Ford believes the government should supply computers with speech-to-text software to every person diagnosed with ADHD. 'We need to allow the tools for the brain to develop.'

Recently, Ford was attending an ADHD conference and found himself sitting next to a woman with a child. They started chatting and Ford explained he was attending as a medical professional, and as a person with ADHD.

'She said "there's hope for my kid yet, thank you." But I felt like saying, "it's a bloody hard road."'

Hazel

Hazel, early 50s, is autistic. She told the Royal Commission she's 'a stickler for numbers' and loves spreadsheets. 'I love rules.'

She's worked in the state government for more than 30 years, always in roles that are black and white.

'I love budgets, I love finance, treasurer's guidelines, instructions and the like. I guess I'm not the most popular person because you need to make decisions based on facts, data and guidelines.'

About seven years ago the department asked her to use her bar licence to operate a bar on a Friday afternoon for senior staff. Hazel agreed, but would only operate within guidelines and wouldn't do anything 'that didn't feel right'. She became known 'as a bit of a problem child' and 'rain man' for her adherence to the rules and regulations.

Then two years ago one of the executive assistants told her to buy the wine from her husband. Hazel refused because it was against the rules. The assistant started threatening her, calling her 'a retard' and told her 'I'm going to make you pay'.

Not long after this the department boss decided to provide alcohol free-of-charge every Friday afternoon. Hazel told him he couldn't do this because it was outside department guidelines.

'A fight sort of ensued between him and myself, where he said I had no political or social acumen, which is right in a sense, because I don't understand why he couldn't understand he shouldn't be doing it. It sort of all got a little bit out of hand.'

Hazel was upset her boss couldn't understand he was doing the wrong thing. Friends and colleagues told her the department could do what they wanted and she needed to do what she was told. 'I'm happy to do that, but it's supposed to be in writing or it's not correct.' She lodged a complaint about the misuse of public funds to buy alcohol.

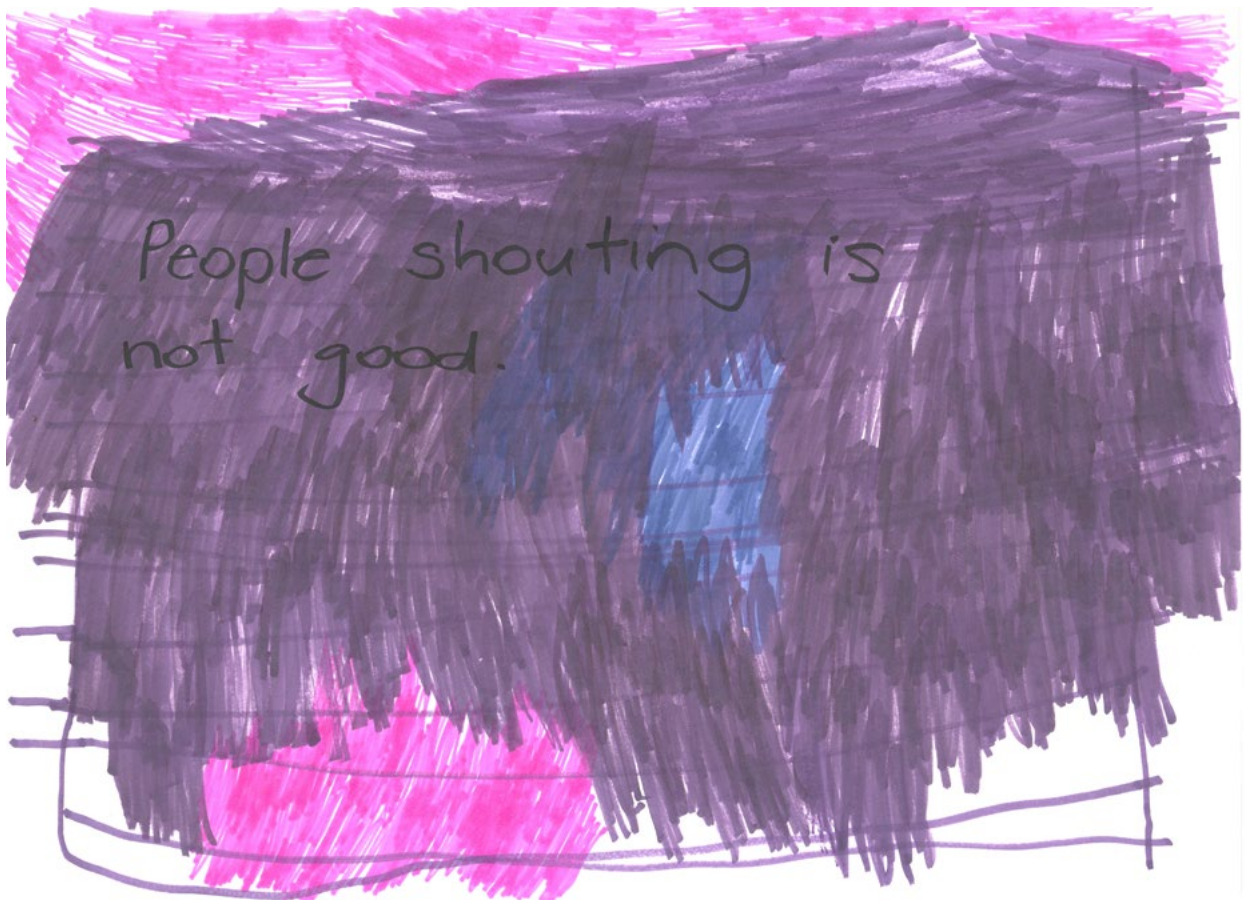
Hazel became so distressed she went to her doctor who prescribed anti-anxiety medication.

Not long after, a new person started and 'befriended' her which she 'found strange'. The person then accused her of sexually harassing him 'which was not true'. Her boss launched an investigation and found she had 'sexually harassed' the person 'for her husband's sexual gratification'. This led to police raiding her home and seizing her and her son's computers. Police charged her with 'criminal activity' and the matter went to court.

‘It was thrown out of court by the magistrate, because they could tender no evidence, because I actually haven’t done anything wrong ... Then they allowed me back at work, but I had to put signs on my door to tell everyone I was autistic.’

Immediately after she returned to work the department initiated another investigation and told her to return home.

‘All I’ve wanted was that the public should not be paying for the [department] to have unlimited use or abuse of resources such as alcohol, or anything else that they choose fit.’



Artwork by Eric Kwong

Jodi

Jodi is in her 30s and has attention deficit hyperactive disorder (ADHD).

'My family made it out like it's a disease that doesn't exist,' Jodi told the Royal Commission. 'I'm actually very intelligent and my family have always told me that I'm nothing.'

When Jodie was in her late teens, a psychiatrist diagnosed ADHD and prescribed medication, which helped her 'learn for the first time in [her] life'.

'I was always a kind girl at school. I was nice, but I wasn't really smart, you know ... When you start to learn, you start to realise that, "Oh wow, this is what it's like to be alive."'

Jodi started her own business, married and had a son, who also has ADHD.

'He doesn't want to learn ... he's always tired, his brain doesn't focus unless, you know, it's video games or something that he can hyper focus on.'

Jodi was determined to intervene early with tutoring.

'I had [him] twice a week going to occupational therapy and I really pushed him hard and that year he got an award from the school.'

Jodi is estranged from her father, who she said still doesn't believe she has a disorder. Jodi said recently he told her psychiatrist she was overusing her medication. Her prescriptions stopped.

'My life was on a path that, you know, we were just cruising along and just because my father didn't believe me, yeah, everything has fallen apart.'

Jodi said without medication she's struggling with anxiety and the ability to focus on work and personal tasks.

'It is a massive setback for someone who was doing so well.'

Jodi recently separated from her husband. She said her family is now trying to prevent her son from receiving medication.

'I'm going up against my family, and my family have said they'll take me to court if I try and put him on medication.'

Kori

Kori is a disability support worker in her 40s. She migrated to Australia several years ago, after working and training overseas.

‘I was very, very lucky in my career,’ Kori told the Royal Commission. ‘I had wonderful people guiding me all the time. And I suppose that’s what encouraged me to go back and not just do my degree, but do my honours degree and then do my masters.’

When she arrived in Australia, Kori found a more ‘clinical approach’ to disability support and a largely untrained workforce. She discovered she was more qualified than most Australians she worked with.

‘You cannot have an uneducated workforce. When you have an uneducated workforce – and this is what we found [overseas] – abuse is going to happen. Because staff don’t know how to report.’

Kori’s first job was with a disability service that welcomed her because she ‘fixed things and made them look good’.

She managed a team, but was shocked by the abuse she witnessed.

‘What I saw was absolutely dire. Participants were being screamed at, pointed at, I heard one staff turn around and say “If I had my ... rings I’d put them on and give them a smack around the face”. This was the type of language that was being used.’

One of her staff members was sacked for reporting abuse. Kori confronted a company manager.

‘I said if this doesn’t stop I can’t stay and she said, “That’s fine.” So they gave me a redundancy package.’

Kori told the Royal Commission she was trained overseas ‘to stop abuse’, but in Australia, the law didn’t protect her for doing that.

‘I got sacked from my last job for reporting up abuse and neglect.’

Kori said she reported a client who threatened to kill themselves. Managers didn’t act and the client died. When Kori made a complaint to a government authority, she was bullied and eventually sacked.

‘It is very, very hard to do your role, because you are working for the agency, but you want to support the participant, and I’ve always had to play a person with two hats ... I actually serve the community. That’s my role.’

Kori told the Royal Commission many people in the disability industry are focused on the money.

‘There are a huge amount out there that don’t know what they’re doing and they are not helping families, and they are just taking the money basically, and rorting the system and families are looking distressed, they’re looking broken.’

Kori said the industry needed better trained professionals and more governance, accountability, enforcement and transparency.

Lance

'I have been treated differently as a result of my disability. I find that not everybody, but most people, when they hear the word disability it's like they look at you differently, like there is something wrong with you.'

Lance is in his 40s and lives with severe anxiety and post-traumatic stress disorder.

Several years ago, Lance was admitted to a hospital psychiatric ward.

'I had a mental breakdown,' he told the Royal Commission.

Lance spent several weeks in hospital and a medical recovery centre before being discharged.

'When I left, they told me that if I was still having trouble in three months' time that I could come back.'

However, a few months later when his doctor advised he return to the centre, the centre said 'No'.

'The official reason given was because ... they felt that I would become reliant on the system.'

Lance complained and 'they finally gave [him] access a second time into the facility'.

But a few days after the centre admitted Lance, management told him to leave.

'They told me that I had to leave because a staff member felt unsafe. And I had no idea why, but I did what I was told. I packed up the room, I cleaned up the room and then I left.'

Lance said that the next day, the centre contacted his mum and told her Lance had 'threatened to kill a staff member'.

Lance denied this. Lance's support worker was so concerned he called the centre to find out what happened.

'They told him on the phone that the reason I was told to leave was because I threatened to kill two staff members ... I've never threatened to hurt anybody. Really, I'm not that kind of person. And I just don't know why they would come up with that.'

Lance said despite his protests, the false allegations remain on his file.

'I'm classified as dangerous, and I've been denied medical treatment. I've tried ever since then to try and get the legal ways and every different way I possibly can, to try and get these off my record.'

Lance said he learnt later that someone accused him of putting a threatening note on a car.

'On the day that they said I did it, I was with my support worker, and he said, "Yeah, I can prove that I was with him at the day and the time" ... but they're still accusing me of doing it.'

Lance said when he accessed his medical records, sections were redacted.

'It's kind of hard for me worrying that if my disability plays up again or if, say, I have another mental breakdown or that sort of thing, I've got to worry that I've got nowhere to go.'

Matieu

Matieu is in his 60s. His primary diagnosis is paranoid schizophrenia and he has been an inpatient at a psychiatric ward for the last few years. Matieu is unsure why he is there, and even more uncertain as to how long he'll be staying there.

'I've been locked up unnecessarily,' he said. 'I have stress problems and sometimes ... I overreact, I get a bit wild, [and] I raise my voice.'

Matieu told the Royal Commission his disability has been 'mislabelled', and that he was admitted to the psychiatric hospital against his will.

Matieu's wife raised concerns following an argument where he picked up a butterknife and held it against his stomach. 'That's ridiculous,' he said. 'I'm no threat ... I've never hurt anybody.'

Matieu says there is very little to do in the ward. He is not allowed to raise his voice with the staff, the food is bland and he is 'sick of doing the same thing[s]' all the time. He shares a room with another patient, with a fabric curtain for privacy.

'I shouldn't even be here, you know, I haven't got schizophrenia, I've got stress and they – they've had me here for three years ... it's very restrictive.'

Matieu's NDIS package provides for his support worker to take him shopping once a week and drive him home for a couple of hours on the weekend.

Matieu says 'shopping' is not his idea of fun, and it 'would be a lot better' if he could spend more time at home.

Matieu has been to the Mental Health Review Tribunal twice, seeking to be released from the ward. He says he wasn't 'given enough time and consideration to speak' at the hearings, and he's uncertain what his future holds.

'[I] don't know when I'm – I'm not told anything,' he said. 'All I want to do is go home to my wife ... and live at home.'

Mullins and Jericho

‘I wanted him to be able to access the community with dignity, and to not have this embarrassing total bladder loss that could have been so easily prevented.’

In the 2010s, Jericho worked as a community access worker helping group home residents with a range of activities in the community.

Mullins, who is autistic and non-verbal, was one of Jericho’s clients. He exhibited ‘hitting behaviour’ and had incontinence issues. Staff at the group home believed he deliberately wet his pants ‘to sabotage an outing’ and called him ‘a naughty boy’.

Staff refused to allow Mullins to use incontinence aids. If he wet his pants once, staff told Jericho to change his clothes and continue the outing. If Mullins wet his pants twice, Jericho had to terminate the outing and take him back to the home. If Mullins hit Jericho, he had to terminate the outing.

Jericho wanted to build a relationship with Mullins. So, when Mullins hit him he decided to ignore the instructions and continue the outing. Jericho also decided to manage his toileting and introduce more frequent toilet breaks. Eventually, ‘after some very intensive work’, they were able to complete a whole bushwalk circuit. They went to a museum, bakeries and different shops. Jericho established a routine so Mullins felt safe. The hitting behaviour disappeared. Jericho’s employer told him Mullins was ‘thriving’.

‘The adult guardian was able to reduce the restrictive practice that he was under ... his chemical restraint was reduced during that time.’

However, incontinence continued to be an issue and Mullins would rush to the toilet and become very distressed, to the point of crying. Jericho didn’t believe the behaviour was ‘naughty’ and deliberate.

Jericho noticed that the more Mullins exercised the more he needed to urinate. The home dismissed these observations. One staff member felt Mullins was urinating because the outings were the same and he was showing he was bored. Jericho didn’t agree.

Regardless of why the incontinence was occurring, Jericho believed a grown man who emptied his bladder in public needed incontinence aids. Mullins was getting a reputation for urinating in public and wasn’t welcomed in public spaces.

Jericho continued to advocate strongly and eventually staff gave Mullins incontinence aids on four outings. On two occasions Mullins experienced full bladder loss and the pads contained the urine. However, when a senior staff member found out, they put a stop to the pads because they hadn’t been medically prescribed.

Jericho discovered staff kept Mullins in urine-soaked clothing so he 'learnt consequences'. Jericho reported this to management, but they believed this was an appropriate response to incontinence.

'I was told that under my watch he had developed an autistic-like obsession with going to the toilet.'

Jericho continued to speak up on behalf of Mullins, but management told him they would terminate his employment if he didn't stop. Ultimately, they moved him to another home and he wasn't able to appeal the decision.

Jericho resigned and made an official complaint.

'I reached out to the adult guardian and I found out that they take a very dim view of people being kept in wet clothing as a kind of punishment and that anybody with continence needs should be referred to a continence nurse.'

Alaric, Hester and Zeb

Alaric is in his mid-30s. He has epilepsy, intellectual disability and is deaf. He lives in a group home, uses a wheelchair for mobility and requires around-the-clock care.

Alaric is also non-verbal and communicates by 'showing distress, crying ... [and by] the occasional smile,' said his mother Hester. All of the residents, including her son, are 'totally dependent on others for every aspect of living'.

Over the years there has been a large turnover of staff at the home. 'They must find the job soul-destroying,' said Alaric's father, Zeb.

Alaric's parents told the Royal Commission that having a group of non-communicative residents isolated in a group home leaves them open to exploitation. 'They're just sitting ducks,' said Zeb.

On a number of occasions, night staff left the house before the day staff had arrived for their shift, leaving residents alone in the house for three hours. 'Their carers had no notion of duty of care,' said Hester.

In another incident, a support worker physically abused Alaric, kicking him for not following instructions. Zeb pointed out that verbal instruction may not be the most appropriate form of communication for a person with profound deafness.

Zeb and Hester are both in their 70s and 'manual handling' is 'getting to be difficult'. They have an electric hoist to help them move Alaric in and out of his wheelchair, but 'it's very awkward to manage'.

Their 'greatest fear' is that the NDIS is failing people with 'severe, multiple disabilities'.

'[What will] happen when I go, when we go,' said Hester. 'Who will provide for Alaric then? And I also want Alaric to have care by kind people so when we're just too old and feeble to see him anymore, he's being looked after.'

Zeb says the NDIS needs to change so Alaric's parents are not being relied on to 'administer his care'.

'We actually need the care to be independent of us, so that when we are old and infirm, [Alaric will] be safe, primarily to be housed and well cared for whether we're there or not, whether we're overseeing the scheme or not.'

Remy and Payton

‘I was made out to be the crazy parent. I was made out to be mentally unstable. I had police ring me. I had security at my daughter’s [intensive care] door. They made me feel like the crazy one, when all I was simply trying to do was save them from killing my daughter.’

Payton’s daughter Remy was born in the late 2010s with a rare chromosomal disorder. She had the features of Down syndrome and additional features of delayed growth in the womb.

‘I felt from day one that she was being treated differently from all the other babies in the neonatal intensive care unit.’

Payton told the Royal Commission that staff treated Remy as a baby with a disability rather than a baby. She noticed other premature newborns in the unit had feeding plans and speech therapy plans by the time they were 24 hours old. Remy was ignored.

At 12 days old she was transferred to a different hospital. For the next two weeks she received the ‘best care [she] got’.

After that, Payton said, the quality of care declined. Staff routinely told Payton babies with Down syndrome don’t handle various treatments well and babies with the particular chromosomal syndrome ‘don’t respond well’. After a few weeks of hearing this Payton ‘lost it’ and told them, ‘You will treat her like any other baby in the hospital.’

While attending to Remy a nurse accidentally burned her. It took 45 minutes for staff to get her to ICU to treat her. The next day the doctor told Payton that Remy had ‘a couple of days’ to live. Payton asked if her rapid deterioration was because of the burn. The doctor was ‘gobsmacked’ – he knew nothing about the burn. He then admitted it might have been, but later other specialists disagreed.

Payton said her ‘issues’ started that day. She wanted another opinion and asked the hospital for Remy’s medical records, but they delayed. ‘It was just one lie after another.’

Meanwhile, Remy needed a canula inserted into her body. For most procedures Remy would scream but then quickly settle. The doctor inserted a needle and then inserted another needle to make the hole bigger. He then dragged the wire down, making two stitches to keep it in place. ‘All of this without any sort of nasal sedation.’ Remy ‘screamed and screamed’ and wouldn’t settle for hours – ‘she was that traumatised.’

Payton was so angry she threatened legal action. She said a senior doctor told her if she threatened the organisation they would cancel Remy’s life-saving surgery.

Remy's surgery proceeded, but soon afterwards her arm became 'puffy and swollen and changed colour'. Payton repeatedly told the nurses the wound was infected and she wanted a doctor to review. Nursing staff told her that doctors were aware of her concerns. Remy's arm was left untreated for three days. When the surgeon eventually saw Remy, he was 'disgusted'. He told Payton the nurses never informed him about her concerns.

Doctors discussed needing to amputate Remy's arm to stem the infection. However, they were reluctant to do it until the arm 'died' so they didn't have to remove more of the limb than required. 'Five times I demanded they amputate,' Payton said.

That evening Remy had two seizures and she sustained brain damage. 'You couldn't even touch her bed. She would cry because she was in that much pain.' Payton decided 'enough is enough' and told doctors to turn her life support off. Doctors provided enough pain medication to keep her comfortable. Remy died a short time later.

Payton requested an autopsy. The hospital refused because of Remy's underlying heart issue. Payton contacted the coroner's office who agreed to investigate. They found Remy died because of multiple organ failure. Payton is adamant this confirms Remy died from severe sepsis, which could have been avoided if medical staff had amputated Remy's arm at an early stage.

'They murdered [Remy] ... because she wasn't a typical child.'

Lillee

Lillee is in her 30s and lives with autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), bipolar disorder, post-traumatic stress disorder, obsessive-compulsive disorder (OCD) and anxiety.

Lillee is also a single mother of several children, in primary and high school, who also have disability.

‘We all have diagnoses from ASD, ADHD, anxiety, depression, OCD, bipolar ... So we’ve got quite a lot going on in the house.’

Lillee described for the Royal Commission a recent, fairly typical, day.

‘The other day [one child], she decided to leave the school and sit just near the road ... so then we have to go collect her. So [another child] was holding everyone hostage at school. He was outside throwing everything, whatever he could get his hands on ... so then I have to get him ... I’ll do that meltdown, that meltdown, and then a lot of the older kids, and so, like, it’s just a constant battle where I don’t actually get time to work on myself because I’m constantly stretched.’

Lillee relies on the NDIS, but struggles to get all the support her family needs.

‘All the reporting, getting all documentations for NDIS ... that is quite exhausting and time consuming because I have to do that [for each of the children] ... I was doing that with OTs, psychologists, speech therapists, dieticians, like everything. And I got all that information and all the reports were saying, “Yes, the children need this amount of support, 100 per cent,” and then we’d give it to NDIS and they are like, “Well, sorry, we don’t agree.”’

Lillee said the NDIS is funding one support worker for the family, despite doctors saying one child alone needs round-the-clock support.

‘So, if I was to say this is what each individual child needs, we are not even close to getting that help or support.’

Lillee said when she asked for respite care for herself, an NDIS officer told her, ‘All your children go to school, that’s your time, respite time.’

‘Whereas some days I don’t even get a second because there are so many meltdowns ... I mean, I am trying to do it because they keep saying, “It’s your parental role,” so I kind of feel shamed into going, “Well, I should be doing all of this.”’

Lillee said without the supports she needs, she recently ‘turned to alcohol’. To control her drinking, she and her support worker asked the NDIS to fund Lillee’s rehabilitation treatment.

'We checked with one person and they said it was okay. They have got to go through so many different channels to get the money paid to them, so NDIS were very well aware of what I was doing and they approved it and paid for it.'

Halfway through the rehabilitation, an NDIS officer called to tell Lillie they considered her to be on a 'holiday' and the NDIS was withdrawing that funding. Lillie was left with the rehabilitation bill.

The NDIS now manages Lillie's plan so she doesn't 'overspend' again.

'I kind of got punished for an error that they had made.'

Lillie doesn't think the NDIS understands her circumstances.

'I personally feel that me sitting here and saying all this stuff really doesn't give half of the picture that's in the house, you know, right now,' Lillie told the Royal Commission. 'It would be really nice, you know, if someone came out from the NDIS and did the review or revision in situations like this so that they can kind of have an understanding of what's actually going on.'

Milena

Milena, late 50s, has complex post-traumatic stress disorder and a dissociative disorder. She has a physical disability as a result of her adoptive father physically abusing her when she was a child.

In the late 2000s, Milena worked as a youth support worker and was attacked by clients several times in the space of six months.

Milena told the Royal Commission the attacks triggered memories of her childhood and she had 'a mental breakdown'. She lost her job and thought about ending her life.

Milena was living in a regional area and went to a nearby private hospital for help. In hospital she experienced flashbacks of her childhood abuse and became physically immobilised. During these 'episodes', Milena would scream but was unable to press the alert button. Sometimes another patient would press the button to help her. She said the nurses responded slowly and instead of helping her, 'started yelling' at her to open her hand for medication. She couldn't because her hands were 'quite clenched'. Milena felt 'quite terrified in that moment to be treated that way'.

A few years later Milena went to a doctor because she had a migraine which signalled the onset of an episode. The doctor refused to treat her and called her 'a waste of space'. Distressed, Milena ended up taking an overdose of some medication she had in her bag.

Milena made a complaint about the doctor, which led to the department of child safety becoming involved. Being a child of forced adoption she found this very upsetting. The department quickly decided she was capable of looking after her children and offered her support.

Around this time Milena's carer started living with her. Her carer was able to 'speak for her' when she went to hospital. If her carer wasn't with her, hospital staff treated her badly. To avoid this, they approached the hospital and explained what happens to Milena when she's having an episode and asked the hospital to add a note to her file explaining her history, diagnosis and soothing techniques. The hospital agreed but staff routinely ignored the note and continued to treat her poorly.

A short time later Milena attempted suicide. She said the hospital kept her carer away from her. The nurse on duty decided Milena needed to be 'taught a lesson' and made sure Milena had no privacy. This triggered a major episode but the nurse didn't care. She told Milena, 'We want to deal with real accident emergencies. Real patients.' Milena couldn't speak and 'froze'.

After this Milena decided the hospital was not a safe environment for her.

‘I would rather die than go to hospital for help ... and be treated like garbage like I was treated all my life in this adoptive family.’

Milena stopped accessing supports and self-managed her mental health. It worked for about four years until her teenage son died. ‘For two years I didn’t seek any help or support though I knew that I was struggling.’

Recently Milena connected with an adoption support service which has helped her access the support she needs.

Niko

Niko is a First Nations man in his 40s living with post-traumatic stress disorder (PTSD).

Niko told the Royal Commission that doctors wrongly diagnosed bipolar disorder because he was 'somehow delusional' and had 'all those aggressive symptoms'.

'I was bipolar [but] it's pretty much complex PTSD. That's what I have.'

The NDIS supports Niko with therapy, but a few years ago it cut his funding.

'I started to get support and I liked myself. For the first time in [more than 40] years I liked myself. And then I was stupid enough to think that I was entitled to some form of justice, so they turned my health off.'

Niko and his partner run a business, but it suffered when his mental health deteriorated.

Niko said he'd like to 'get well again'.

'The problem is I can't find that therapist.'

Niko told the Royal Commission that because his partner also has a disability, the government took their children away.

'They banged on saying she had an intellectual disability when she had a learning disability, and they wouldn't even comply with the court order to make reasonable adjustments because they don't have to. That's what happens when you deal with justice, mate, they'll do whatever they want.'

Niko said that when he was younger, he was in trouble with the police. He now worries that the government is perpetuating 'a very vicious cycle' by taking away his children.

'They're the ones that are growing up, you know, square peg when they're a round one. They're never going to fit into life, they have destroyed them. That's as simple as that. They've destroyed them. Disconnected them, rebirthed them, they're ... finished. It's just a matter of when they're either going to get chemically restrained, killed, in jail, one of those wonderful, wonderful flow on effects from the systems.'

Niko said he doubted the Royal Commission would be able to 'do anything' to help him, but 'maybe someone can help the next poor bastard'.

Ryder

Ryder is in his 60s and lives with post-traumatic stress disorder from childhood sexual abuse. He also has an acquired brain injury, after being struck by a car when he was in primary school.

‘I was run over from behind on the bicycle and somehow woke up three hours later in the gutter.’

Ryder told the Royal Commission that after that, he struggled at school.

‘Before the bicycle accident I had been a good student and coped well with life. However, after the accident I did not get the support that I needed, and I failed the rest of my schooling.’

Ryder said he tried to get his injuries assessed at the time – ‘however, this never occurred.’

‘The government did not want to pay any compensation. I was bullied and my parents were also threatened.’

When he was in his late teens, Ryder was involved in a car crash and, unable to work, became homeless.

When he tried to get compensation, Ryder said he received bad legal advice and a doctor ‘misdiagnosed [him] with schizophrenia’.

‘I was disbelieved and discredited.’

After another car crash and an assault, Ryder spent a lot of time in mental health facilities where he said he was forced to take medications that caused him to ‘feel like a zombie’ and lose his memory and his hair.

‘I really wanted to get married and have children, however this has not been possible due to the damaging side effects of medication and mistreatment on my mind, body and sexual functioning.’

Ryder said the abuse and his attempts to seek compensation left him ‘living in poverty’.

‘I was bankrupt twice from court cases and I have been living in social housing for many years.’

Siobhan

Siobhan is in her 60s and lives with bipolar disorder.

'I was diagnosed in the 1970s and, of course, you didn't disclose, ever. It was a shameful secret,' Siobhan told the Royal Commission. 'It's a bit depressing that after all of these decades we still have, despite language becoming a lot more guarded, we still have this insidious discrimination that goes on.'

Siobhan said medical discrimination contributed to the nerve and bone damage that has reduced her mobility.

'I think that when a person with bipolar presents at a doctor or a hospital, automatically there's this assumption, "Treat it with a grain of salt." We don't even get the benefit of the doubt. And if you are unlucky enough to have a physical disability or chronic illness as well as mental illness, you might as well just go and shoot yourself.'

When Siobhan was in her late teens, she contracted meningitis and nearly died 'because everyone thought [she] was faking illness'.

'No-one even took my temperature for four days.'

In her 30s, she lost hearing in one ear when a doctor – believing she was lying about the pain to get drugs – refused to treat an infection. A decade later, when she had an eye infection, a nurse lectured her 'about wasting time and resources'.

'It was two weeks until I saw a specialist who prescribed antibiotics to treat the infection. By then the damage was done.'

A few years ago, Siobhan was living in a regional town and went to the hospital to get treatment for a sore shoulder and hip. As she was leaving, she fell.

'Despite my increasingly-anguished pleas for help, I was never examined by a doctor there. Instead, over the phone, I was told by the hospital that I must have wrenched a muscle.'

A few months later, she went back to the hospital where a doctor told her 'there was no injury and that the pain was in [her] head'. The doctor tried to refer her for psychiatric evaluation.

A scan later showed her hip was broken.

'The bone in my left hip had died and disintegrated – avascular necrosis – due to the delay in diagnosis and treatment, with the only solution then being an urgent total hip replacement.'

Siobhan said she had to borrow money to travel interstate for the surgery, and is still in debt.

‘We belong in a rubbish bin ... Every single professional I came in contact with disbelieved me, resulting in the loss of part of my body. And it didn’t need to happen if the injury had been treated in that 24-hour window of occurring.’

Siobhan has lodged complaints but said, ‘It’s very difficult to prove when things come down to “he said she said”. The person with reduced credibility is going to lose every time.’

As a result of her experiences, Siobhan now has generalised anxiety disorder and post-traumatic stress disorder.

‘I would like to see something like a presumption of truth,’ Siobhan told the Royal Commission. ‘When a person with a psychiatric disability makes a complaint or an allegation of discrimination they should automatically be believed rather than the other way around, you know, like we have a presumption of innocence under the law.’

Xavy and Judi

**‘Once they’re lost in the education system they’re lost forever
... This is where [Xavy] is now, he’s completely lost.’**

Xavy, now in his late teens, missed development milestones growing up, his mum Judi told the Royal Commission. At school he ‘wouldn’t talk, wouldn’t engage’. He didn’t like change in routines and struggled when he had two teachers. ‘His writing was just scribble.’

When Judi raised concerns with the school they told her not to compare Xavy to other children. She asked if he could be tested but the school told her to wait. Doctors and teachers said Xavy just needed a ‘slap on the bum’.

Xavy had very particular behaviours. He wanted his clothes and breakfast laid out a certain way. He couldn’t tolerate other people touching his belongings and he wouldn’t eat his lunch if other people were watching him, ‘breathing on his food’. If something happened to upset him he would ‘go off, yelling and jumping on desks’. He also had sensory sensitivities.

Teachers told Judi they did not have the energy to deal with Xavy. One teacher told Judi they didn’t want him in their class because he would pull their NAPLAN score down.

The school was not transparent or truthful about incidents involving Xavy. One time the school principal forced Judi’s nine-year-old daughter, who witnessed one of these incidents, to change her story. She told her mum the principal was ‘getting angry and [she] was frightened’ so ‘said it his way’.

The school would not make any adjustments for Xavy and instead excluded him, putting him in a room by himself. He was given toys to play with and sometimes he would be in there for half the day. The school didn’t tell Judi when this happened.

Judi, not knowing where to go for help, ‘jumped up and down and swapped doctors a lot’. Eventually, Xavy was 10, a doctor referred him to a psychologist who diagnosed him with autism, dyslexia, anxiety and an intellectual disability.

With a diagnosis, Xavy was able to access supports in school, including a teacher’s aide. However, his learning did not improve because his teacher’s aide support was shared with other children who did not have diagnosed disabilities.

The family moved interstate for 12 months and Xavy attended a special needs school. Judi said it was a very positive experience. The school was about an hour away from where they lived and arranged transport each day.

Xavy learnt how to spell, count and deal with money. He spent time at the mainstream school and built friendships. The school communicated with Judi about any concerns and provided progress reports.

When the family returned to their home state, Xavy attended a local state high school. His reading levels declined. Judi discovered Xavy would spend the whole day on the computer.

The school separated Xavy from other students and excluded him from excursions. Teachers said he was too hard to teach. The principal regularly suspended him, with the suspension periods increasing.

On one occasion, the principal suspended Xavy for 20 days for fighting. The fight was filmed and showed a student walking up to Xavy, calling him a name and punching him. Xavy retaliated and punched the student. Xavy's father confronted the principal with the footage, who eventually revoked the suspension.

Xavy often absconded and sometimes went missing for days.

The principal told Xavy's father that as soon as he turned 16 he had to leave school or he would expel him. Judi pulled Xavy out of school.

Xavy continues to have problems with writing and recognising numbers. He wants to join the army but he is not eligible. He's had some odd jobs but they don't work out and people often exploit him financially. He receives the Disability Support Pension.

At 16 Xavy became an NDIS participant, but Judi says the system has failed him. Recently a support worker told him he did not have a disability. Xavy did a test online and no longer considers himself autistic. The NDIS has stopped his funding.

Adalee

‘Everywhere I go I’ve been disliked ... I don’t think people understand me ... being vision impaired.’

Adalee, mid-50s, is vision impaired. Her eyes make repetitive uncontrolled movements. She has epilepsy and, more recently, anxiety and depression.

In the 1970s, Adalee’s family migrated to Australia and she attended state primary and secondary schools. She couldn’t see the board or read notices in glassed-covered noticeboards. In secondary school she had to climb up on a chair and put her face against the glass to read the timetable.

Adalee told the Royal Commission students continually bullied and harassed her. One student chased her home growling at her. Another repeatedly punched her in the genital region until she cried. ‘The students kept bullying and bullying but the teachers didn’t do anything about it.’

Because of the bullying and lack of support, Adalee failed year 12 and had to repeat the year.

Repeating year 12 was a much better experience. A teacher noticed the bullying and Adalee’s vision impairment. She arranged for someone from the department of education to come and assess her. As a result, the school made reasonable adjustments for Adalee, which included extra time and a separate space to complete her exams. Students became ‘much calmer and much more accepting’ of her disability.

Following school, Adalee went to university and completed a social work degree. She then got an administrative job with a large government department.

Adalee enjoyed her work but said the department was not supportive. They didn’t understand her vision impairment and often ‘berated her’ for making mistakes. One supervisor told her she ‘belonged on a farm working with animals’.

The staff who completed the medical assessment prior to Adalee starting work didn’t comment on her vision impairment. Soon after she started, the department arranged another assessment. She feels they did this ‘just to get rid of [her] from the job’. They moved her to a high-pressure call centre where all her work involved using computer screens. Without supports, Adalee’s mistakes increased. ‘At the end they were so happy to write a bad report about me.’ The department didn’t extend her probation.

Adalee went back to university. She did a teaching degree and taught English as a second language.

In the 2010s Adalee worked for a neighbourhood centre. Her first manager was very ‘understanding’ and ‘helpful’. But the next manager didn’t understand her vision impairment.

When Adalee asked for an interactive monitor and a laptop, her manager refused. At one stage Adalee's manager told her she was 'scaring people' when she interacted with them in person. Adalee knew he was talking about her eye movement.

A short time later, the manager terminated her employment after she gave her opinion on another teacher's lesson plan. Adalee made a complaint to the Fair Work Ombudsman and received compensation for unfair dismissal.

'I got into a deep deep depression,' Adalee said.

Adalee's GP diagnosed her with work-related depression and anxiety. She made a complaint to WorkCover. She had to attend various medical assessments and appear before a medical panel. The panel decided she was 'exaggerating' her injury and gave her 15 per cent incapacitation.

Adalee is disappointed by the outcome. She says the weekly payments are a constant reminder of what happened. If the panel had given her 30 per cent incapacitation they would have made a lump sum payment and Adalee could get on with her life.

Briella

Briella is in her 40s and lives with functional neurological disorder.

'It impaired my ability to read, write, walk, hear, see, my muscles, and anything connected to your nerve system, your bowels, your cognitive function, your bladder,' Briella told the Royal Commission. 'My brain stopped functioning.'

Briella said she didn't know when it started or what caused it.

'I had a few accidents and had a traumatic upbringing as well with abuse and trauma and violence as a child as well. And we didn't wear helmets in the 70s and I did hit the concrete at one stage.'

Briella said she struggled at school.

'I learnt to be a pleaser and I was very good at doing things for them and I believe I was intelligent, but I couldn't do the work they required.'

Briella later married a man who physically and sexually abused her.

'I didn't learn how a man should treat you and so I guess that's how I fell into being abused as an adult as well. One of my psychologists said, "Someone taught you to be submissive."'

After many years, she left him.

'I wanted to get away. I was frightened and he said, "If you leave me I will destroy you. You're alone and I will destroy you if you try and get away." That's how it happened. I was scared.'

Briella said that during the divorce, her lawyers allowed her to be financially abused by forcing her accept a smaller share of the property settlement even though she was raising the children without an income.

'I actually said no I didn't want to sign the form and when I refused to, he took another five per cent off. They pointed out all my faults and separated me from my other kids who had come to help me. And then they would yell at me and I would do as I was told, but I didn't want to do it ... My lawyer, their lawyer. They'd say they're friends with the other lawyer.'

Briella said her disability prevents her from working. When she applied for a Disability Support Pension, Centrelink wouldn't accept her original diagnosis and requested a new one.

'I just have symptoms of trauma and violence and hurt that take over my body intermittently like seizures and stuff. And people don't see that. They see strong, healthy, "You look good, you can work."'

Vincenzo and Mila

‘There needs to be a better way, because we need to change these children’s lives ... We need to find a way to help them cope in the world.’

Mila is in her 50s and cares for Vincenzo, the son of her niece. Vincenzo is in primary school. He is autistic and has complex trauma. Mila and her partner cared for Vincenzo after child services removed him from his parents when he was a baby.

‘When he first came to us – I have three adult sons – and I didn’t know what I was looking at. My children are neurotypical and I had never met such an angry young child,’ Mila told the Royal Commission. ‘Before his first Christmas with us, I had bought him a blackboard and whiteboard and whatever. He decimated that. He completely and utterly broke it apart and his room was trashed.’

Because she brought Vincenzo from another state, she struggled to access government services.

‘That made it incredibly difficult to find the right help for him or even try and find out what was going on for him and that was probably the biggest hurdle to begin with ... I fought so hard.’

Vincenzo’s autism diagnosis took years, because specialists disputed what caused his behaviours.

‘I’m going to cry. I’m sorry, but I was going to psychologists that probably weren’t as knowledgeable as they should be for a child in this situation.’

When Vincenzo was eventually diagnosed with autism, Mila and her partner had good jobs and could pay for Vincenzo’s supports including speech therapy, psychotherapy and occupational therapy.

‘I, unfortunately, had an accident and fractured my neck and partially disabled myself, which meant I couldn’t work in my role anymore and that meant that we no longer had the money.’

Then, Mila’s partner was killed in an accident.

‘It’s just been a battle from beginning to end.’

Mila said she could no longer afford the supports.

The state child protection agency is Vincenzo’s guardian.

‘There’s always this threat that [the agency] will take him away and then I worry about the long-term effect that would have on him.’

Mila wants to enrol Vincenzo in a special live-in program that can help modify his challenging behaviours.

'It's a lot of money. It's worth more than my house is, you know, because I would have mortgaged it if I could ... because I think that would be the only thing that will change the trajectory of his life.'

Mila said the NDIA and the child protection agency are disputing who should fund the program.

'If I was still working and earning, you know, great. If [my partner] was still alive and earning money, you know, then maybe things would be better. We would find a way, but there's this whole battle between [the child protection agency] and the NDIA and they're forever pushing back on each other. I don't care who bloody well funds it. The child needs it.'

Because of his challenging behaviours, Vincenzo struggles at school. Mila said the first half-a-dozen schools she approached wouldn't accept him or, if they did, warned her they would probably suspend him.

'This whole integration and moving away from special ed schools and special ed units, in trying to integrate a child. That's all well and good to talk about integrating a child, but when they can't integrate, what do you do then? Suspend them? So, then they live their life at home, gain no social skills, have no education?'

Mila moved to a regional area where she's still struggling to find a school for Vincenzo.

'What would I need the most? I need [schools] to give [Vincenzo] what he needs because I need to concentrate my energies on the child, not fighting for the child. You know, I'm good at advocating for what he needs and I'm not saying that I'm unwilling to do so, but I need to be less worn out. You know, I need to be less tired.'

Sarah-Jane, Farris and Vikki

Vikki, who was born overseas and is from a culturally and linguistically diverse background, had two children, Sarah-Jane and Farris. Both had epilepsy and other disabilities and attended at the local hospital regularly.

Several years ago, Vikki and her husband caught the flu. When Sarah-Jane and Farris, still young children, developed fevers that led to seizures, Vikki took them to hospital.

'The doctor in the emergency was very concerned about [Sarah-Jane's] blood pressure, because it was extremely low,' Vikki told the Royal Commission.

Doctors tested both children for influenza but, when their temperatures fell, discharged them before getting the results.

Sarah-Jane, however, didn't get better. Two days later the hospital still hadn't sent through her test results, so Vikki took her to the general practitioner. '[He spent] most of the time explaining the difference between a cold and the flu,' Vikki said.

'He just examined her with the stethoscope and said she's fine, it's just a cold.'

Vikki was exhausted from having the flu herself when, that evening, her daughter developed a dry cough.

'I held her until about close to about 2 o'clock in the morning ... I fell asleep. I fell asleep. Oh God. I woke up ... and it was so quiet.'

Sarah-Jane was dead.

The following day the hospital, unaware of Sarah-Jane's death, called Vikki to tell her Farris had tested positive for influenza A.

'I asked the doctor, "Can you please tell me about my [Sarah-Jane]" ... and he told me she, too, had influenza A.'

Worried Farris might also die, Vikki took him back to the hospital. Doctors gave him an antiviral drug and his condition improved.

Later, Vikki discovered the hospital hadn't completed a discharge summary for Sarah-Jane, or informed the general practitioner of the positive influenza test.

Vikki believes the hospital did not take her concerns about the health of her children seriously because of her racial background.

'They don't expect [a woman like me] to be explaining to them about [her children's disability] ... It's not the first time they have neglected my [Sarah-Jane].'

She is reluctant to complain because she doesn't want to jeopardise Farris's future medical treatment at the local hospital.

'I am actually very scared ... It's the people, it's their mindset, it's their attitude, and I can't change that.'

Vikki told the Royal Commission she is still waiting for the coroner's report into Sarah-Jane's death.

'I'm still waiting ... It is two years and seven months, and I'm still waiting.'

Piri

Piri is in her 20s. A few years ago, after her relationship broke down, Piri became homeless.

'I was under a lot of stress at the time and I probably wasn't making the best decisions for myself,' Piri told the Royal Commission.

Piri said that although she knew she wasn't safe when she was homeless, she had made decisions not to live in certain places because of a 'lack of cleanliness or [she] didn't feel comfortable emotionally or mentally in that space'.

Piri self-harmed and was admitted to a hospital mental health unit for six months. Staff in the mental health unit believed she had an intellectual disability and wouldn't let her leave the hospital.

'So that's when they put a guardian and a trustee on me ... Because I wasn't making decisions to get myself safe, I was put under guardianship, which I still to this day don't approve of.'

While in hospital, Piri discovered she was pregnant. When she was discharged, she was placed in a private rental property for the duration of her pregnancy.

'I was made to go [back] into hospital and ... forced into a caesarean. I told my guardian that I didn't want that caesarean and I wanted to give birth naturally and I knew what I was doing.'

Piri said there was no reason for a caesarean because her midwife said the baby was healthy and wasn't breached. The guardian made the decision, 'which has very badly traumatised' Piri. Her baby was placed in foster care.

Piri's guardian found a group home for her. At one time she tried to leave to see her parents. 'The minute I stepped foot off that property I was thrown to the ground,' she said.

'I had to stay there. If I tried to take off and go somewhere else I was restrained basically which was really horrible ... It was actually not a very nice place.'

Piri has since moved into her own apartment, but said the guardian and public trustee still control her life. She receives a disability pension and despite having thousands of dollars in personal savings, she told the Royal Commission, the public trustee gives her just \$100 a week for food and hygiene products.

'Sometimes that's not enough and when I found myself not having food I've had to go to food places, such as [charities], soup kitchens basically because I haven't got food.'

Piri receives an NDIS package of more than a million dollars, but the money goes straight to her new provider. She has full-time support workers, but doesn't understand how all that money is being spent.

'One of the biggest things I want from my package [is] to help me with ... learning how to live in the community and stuff like that because one of the biggest things that I need to do in order to get my son back is to learn to live in the community.'

Piri said she's getting no help to do that. Her only activities are escorted trips to buy food, and to a park.

'If I'm not getting that help with my current coordinator and guardian, I'm never going to spread my wings and live in the community myself. I'm never going to have my baby back.'

Mina, Camille and Nikolai

‘One day [children] are ... in the class. Tomorrow they’re going to be lawyers, judges, police officers in our society. If we have the disabled people in the classroom in the mainstream, we’re going to accept them in our society from the start.’

Nikolai told the Royal Commission his daughter Mina was barred from mainstream education and ‘didn’t learn nothing for 13 and a half years’.

Mina, early 20s, has a mild intellectual disability. At six, her mum passed away and Nikolai, who spoke little English at the time, took his family to live in a regional town. Camille is Mina’s stepmother.

Mina attended the local state school and was ‘put into the unit’. Nikolai ‘can’t call it a school because it was a prison in the school’. Children with disability were separated – ‘locked up away from everybody else,’ Camille said.

Teachers gave Mina the same work from year 1 to year 6 and never taught her anything constructive. Nobody helped her change her clothes if she wet herself, and she would arrive at after-school care in wet clothes. Mina continues to be incontinent from being in wet clothes all day.

Nikolai repeatedly tried to advocate for Mina, asking the principal to move her to a mainstream class.

‘Literally, the way they treat us personally was we don’t know nothing, especially because I didn’t speak much English ... Laughing in our face when you’re asking serious questions ...’

High school was more of the same. Mina was placed in a unit, fenced off from the rest of the school – even her sister couldn’t talk to her or visit her.

Every report from year 7 to year 12 said Mina couldn’t concentrate and was messy. ‘If that is the case,’ Camille said, why didn’t teachers ‘focus on that and try to actually improve it’. Often teachers ‘copied and pasted’ reports and Mina’s report was littered with other students’ names. ‘That’s the type of care that this school gave. Zero,’ Camille said.

The principal ignored Nikolai’s pleas to allow Mina to attend sewing and cooking classes. Mina said she really ‘wanted to do the childcare class’ but ‘was denied’. In year 12 Mina wanted to attend a work placement, but again the school refused.

By year 12, Mina’s self-esteem and confidence were so low she felt like she was ‘no-one’. Nikolai had ‘had enough’ and removed her from school.

‘She couldn’t even look someone in the eye,’ Camille said. ‘It took her a very long time. She’s still not confident ... It’s still very, very hard socially for her ... It really damaged her.’

Mina has one suggestion for schools wanting to do better. ‘Remove the fences,’ she said.

Mina now attends classes and activities in the community funded through her NDIS package. She works in a café one day a week and hopes to be able to live independently.

‘That’s what we are working towards,’ Camille said, ‘but it’s making sure that she is ready plus we find the right type of ... housing.’

Emani

‘If I had had the disability support and the right advice when I first became sick with ME, I would never have ended up in aged care. I think I would be pacing, working part-time, living a quiet but much, much richer life.’

Emani, mid-30s, has myalgic encephalomyelitis (ME), chronic fatigue syndrome and lives in the dementia ward of an aged care facility.

She told the Royal Commission that prior to having ME she was a ‘young and healthy woman’ who travelled the world.

Initially doctors advised Emani to exercise and push herself rather than rest. This caused her immense pain and suffering.

‘There was a point when I was living at home ... I was in a completely dark room. I was lying on my bed. I couldn’t talk to people. I couldn’t hold a conversation.’

Emani needed 24/7 support and her mum became ‘absolutely exhausted’ looking after her. She applied for disability support from the state government but wasn’t eligible because they deemed she ‘didn’t have a disability’ but a ‘health condition’. Emani considered suicide.

Out of options, she moved into aged care accommodation. The facility has provided the nursing support she needs and ‘have done their best’. At times though, it’s been ‘horrendous in terms of trying to manage living with sensitivities and ME and trying to stay safe’.

When the NDIS was established, Emani applied for support but they also told her she had a medical condition, not a disability. Eventually she was able to convince them her disability was neurological and she received funding. However, the NDIA rejected her application for a wheelchair saying she couldn’t ‘demonstrate she could use it’.

The NDIA has threatened to ‘kick her off’ several times. One NDIA planner told her, ‘You’ve got chronic fatigue syndrome, you don’t deserve our help with that.’ They question whether her ME is curable despite her medical specialists saying it’s not. Recently, they told her she needed to undergo specific treatment such as graduated exercise therapy and cognitive behaviour therapy. Emani said her medical specialists are against these therapies and believe they cause more harm. She believes NDIS medical treatment guidelines need to be updated.

Emani has applied for specialist disability accommodation (SDA) so she can move out of aged care. It took nine months to have the first planning meeting and the outcome was her having to pay ‘more money’ for ‘more reports’.

After almost three years, the SDA funding has been approved. She intends to custom-build a home suitable for her needs.

In the last few years Emani’s been ‘using science to rest and recover and not to push too hard’. She is able to pace herself and her quality of life has improved.

Casen

‘It makes me feel dehumanised. It makes me feel like having autism’s a curse.’

Casen is in his 40s. He is autistic and has an adjustment disorder with anxiety.

Casen told the Royal Commission he wasn’t diagnosed until after he completed a degree, more than a decade ago.

‘I’ve always had anxiety ... When I first started to work out what was going on [it] ultimately led to getting an autism diagnosis, which was about two months before I started [a new job] ... I didn’t know anything about autism before that at all.’

Before starting his degree, Casen worked as a labourer. After finishing his degree, he found a job in the public service.

‘So, this is the first time I’ve ever stepped into an office and worked in that sort of environment.’

Because of his diagnosis, he was placed in a government disability employment program.

‘And that’s when the problems started because ... I was given all these forms, and I had to tick that my job was [at risk]. And that’s when I first started to get worried at work.’

Casen said it made him feel unsafe at work.

‘I just sent an email to the inclusion guy saying, “Why am I, you know, is this the appropriate support?” ... And then he called me saying, “No, your job’s not [at risk], but it probably will be because you’ve got a disability.”’

Casen said he was assigned a support worker who began advocating for him.

‘The inclusion manager basically berated her and said that, you know, “Your job is just to listen to him in these sessions and, you know, leave the rest to me.” ... and [he] asked me to tell him any information in our sessions where she [said] anything about the government. And that’s when I had my first breakdown at work.’

Casen said the workplace disability program didn’t provide any support ‘other than having a place where you can go debrief and talk to someone’.

‘I needed something from a cognitive perspective that could, you know, help explain the issues I was having, to help develop strategies and also to help the workplace to better understand my autism.’

Casen struggled with his workload, working long hours without appropriate support.

‘And the distress just got worse over time.’

He had to stop work. That’s when a psychologist diagnosed Casen with adjustment disorder with anxiety. ‘It came from the trauma of doing that work,’ he said.

‘Everything is all related around the support I didn’t get and the adjustments that weren’t put in place and the lack of autism awareness.’

When Casen returned to work, his employer didn’t want to talk about autism.

‘There’s nothing in this process that recognises neurodiversity. You are put through the same process that neurotypical people are ... so, for me, things like the massages, float tanks and dealing with the trauma and the stress and the body is a really important part of recovery.’

Casen said the system ‘seems to just hope’ that counselling for anxiety and depression will help someone living with autism deal with stress.

‘The process doesn’t even recognise the disability to start with, because there’s nothing in the documentation that talks about my disability. Nothing, you know, about the lack of support, about the conditions that led to my breakdown. So, I’m basically screwed.’

Alonzo

About 20 years ago, Alonzo crashed his motorbike and injured his spinal cord. He now has paraplegia and uses a wheelchair.

His employer at the time supported him.

'They stood at the end of the bed after my accident and said in front of my family, like my mum and dad, that no matter what happened, I would always have a job. And they were actually true to their word.'

Alonzo told the Royal Commission that before his accident he treated people with disability differently.

'If I saw somebody with a disability, I didn't know how to talk to them. I thought they were somebody different and I thought, well, you know, I'm a caring kind of person, I didn't want to say the wrong thing.'

After the accident, he learnt what that was like.

'My wife used to wheel me around the place, people would just look straight over my head and say, "What does he want?" and she'd said, "Why don't you ask him? He's got a brain, you know." Then she'd force them to talk to me. But most of the time, they would just think, "Oh, he's in a wheelchair, he must have some sort of intellectual disability.'"

After a few years, Alonzo's employer closed its office and he was out of a job. He volunteered for a number of organisations involved in youth justice and disability services, as well as with the police.

One day, Alonzo was driving his modified car when a police officer pulled him over.

'The officer said, "One of your lights isn't working." He said, "Come out here and I'll show you." I said, "Well, I've just got to get my crutches." So, I reached around behind my seat to grab my crutches and the next minute he's dragged me out of the car. He's kicking the crap out of me on the side of the road.'

Alonzo said the officer told him to get up.

'I said, "I can't." And he said, "What do you mean you can't?" I said, "I'm a paraplegic," and he said, "Crap. I don't believe you.'"

Alonzo told him to look at the wheelchair in the back of the car.

'He looked down and said, "I've stuffed up, haven't I?" I said, "Yes, you've stuffed up." I said, "But I'll forget about it if you forget about it," and he just got in his car and drove off.'

Alonzo said he has since spoken to the officer and decided not to pursue the matter. '[I] didn't want to ruin the man's career because, you know, I think he needs help.'

Alonzo told the Royal Commission that police and government officials need training to better understand people with disability, especially psychosocial disability.

Alonzo said he once worked as a volunteer with a young man who'd been either in jail or 'on the streets' for 15 years. 'He was ... tired of it. He was dealing with schizophrenia [and] everyone was scared of him because he was such a big guy.'

No emergency accommodation provider would take him in, so Alonzo helped him find a place to live.

'Housing didn't want to know him, so I said to him, "Well, look, we've got to prove ... that you can be responsible." I was just honest with him, you know, and that's all he wanted. People had been, you know, telling him crap his whole life.'

Alonzo helped him prove to the government housing authority that he is a reliable tenant.

'He was a neat freak ... in the end they gave him a brand-new unit ... so, yeah, he had every ability to be able to look after his problem even with his disability.'

Kirk

‘My family didn’t understand why my life was the way it was, like I was pretty much drooling on the floor of the house.’

Kirk is in his 40s and has schizoaffective disorder. He also lives with post-traumatic stress disorder, having been sexually assaulted when he was younger.

Kirk told the Royal Commission he is overmedicated and his family struggles to understand his behaviour.

‘They don’t understand because, to them, they don’t have the condition. They don’t know how it affects you. They don’t always understand why you aren’t socially as, you know, like when you are younger ... and then they can’t understand why your social existence has become pretty much non-existent.’

Kirk said the medication ‘takes a lot of toll on [his] body’ and he struggles ‘to maintain a certain level of, you know, just social function’.

Kirk lives independently, occasionally being admitted to mental health facilities for several weeks at a time. During one admission, Kirk asked if he could take his medication as a tablet, rather than an injection.

‘They said, “You don’t always get what you want” ... [The nurse] threw me into the wall. Not on purpose. They just shoved me in the back and then that didn’t resolve well. So, I got squashed on the bed and then they give me the needle.’

Kirk said people with disability should be given a choice of treatments if they’re available.

‘As a patient, you actually have the right in the choice of what medication you take, and if they just wilfully choose what medication you take without giving you that advice, then that’s also a breach of a right.’

Kirk said he saw other patients forced into treatments that seemed excessive.

‘I watched a 74-year-old woman in hospital who has had a high state of anxiety ... because the situation was she was feeling insecure.’

Kirk said she was given ‘electroshock therapy’.

‘I don’t feel 74-year-olds really need shock therapy ... I said to them, “If you actually took her out and made her feel secure in her situation by giving her one-on-one support care, so you’re giving her someone in the morning to have a cup of tea, or something in the afternoon that made her feel secure in her situation, she might actually progress to not actually feeling someone is going to break into her house.”’

Julissa

‘At my age, at this age now, like, I don’t know what’s going to be there for my future. Like, who’s going to look after me when I can’t look after myself anymore?’

When Julissa was in her teens, she crashed her car. She’s since had surgery on her hip five times. Julissa is now in her 50s and has an acquired brain injury (ABI), chronic pain and post-traumatic stress disorder.

‘I hit a pothole. The last thing I honestly remember was something black going past my window,’ Julissa told the Royal Commission. ‘So my injuries sustained at that point in time where I had laid in petrol – that ate the skin off the back of my legs. I had a compound fracture to my left hip. I had a shattered pelvis, lacerations and I was cursing at everybody when I went to hospital.’

Julissa said doctors at the time didn’t diagnose the ABI.

‘If someone has a traumatic brain injury they quite often are extremely vocal when they get to hospital ... I remember the doctors getting a nurse to come and put ice into my mouth to make me be quiet.’

Julissa said that later doctors put her on ‘all these medications’ after misdiagnosing her symptoms for bipolar disorder.

‘I have an ABI. Sorry, I’ve gone blank ... acquired brain injury,’ Julissa said as she described her symptoms. ‘So I say sometimes it’s like a computer processing problem. It’s like, you know, if you put too much stuff into the computer it gets a little bit muddled up and it freezes.’

Julissa said the relevant government agency tried to minimise the amount of compensation she could claim.

‘In my court case, there were things that were brought up from my past that had nothing to do with the car accident at all. So it was very messy. I’ve got the court transcripts. I still haven’t finished reading them because it’s just, I just can’t believe the bullshit. I’m sorry. I can’t think of another word to use.’

A tribunal decided her disability was more significant than the government agency claimed. Julissa said the agency now pays her a fortnightly amount that ‘isn’t really all that much better than being on, say, Centrelink’.

‘At least with Centrelink ... I’d have a concession card and I could also earn as much money as what I earn now, if not a little bit more, and be better off without it coming out of my pay.’

Julissa said that if she earns extra money now, the agency reduces her payment by the same amount.

‘And I still have to fight really hard for [the agency] to get things done.’

After her latest hip replacement, Julissa struggled to get the support her surgeon said she needed to recover.

Julissa instead relied on a neighbour.

‘She brought me dinner every night. She helped me shower. She changed my sheets. She did everything for me when I got home from hospital.’

Julissa said she applied to the NDIA for support, but it rejected her ‘basically because I’m not on Centrelink and because [the agency] is supposed to pay for most of those services’.

‘[The agency has] made me feel so many times that my life isn’t worth it and that, you know, there is no point to going on because life shouldn’t be this hard. And it shouldn’t be this difficult to be supported.’

Julissa said when her physiotherapist was injured recently and couldn’t visit, she applied for her driving licence.

‘I’ve had to go and get a whole lot of medical stuff done to make sure I was safe enough to drive again. And also sit for my learners. Which I have done. I have completed all of it ... You know, I’m kind of really proud of myself for that at the moment.’

Julissa said she would prefer the agency pay her out with a lump sum so she could regain control over her life.

Eliza

‘There were four times I went to the police, and each time I got basically ignored.’

Eliza, late 30s, has functional neurological disorder, bipolar disorder and uses a wheelchair.

For six years, Eliza was in a violent relationship.

‘Every time I went to report it to the police, they were like, “How do we know it wasn’t an accident because he is disabled?” ... I felt ignored, and I felt trapped.’

Eliza told the Royal Commission that, during the first 12 months of the relationship when she was living with her dad, her partner was ‘like [her] knight in shining armour’. However when she moved into her own place the relationship ‘went downhill’.

If Eliza refused to have sex with him he would withhold her medication. In public, he loudly and graphically talked about wanting to have sex with her – ‘it was embarrassing’. He accused her of cheating on him and raped her twice.

When Eliza reported the first rape to police they told her if the matter went to court lawyers would interrogate her about the mechanics of the rape – ‘who put what where’.

‘I felt dirty, and it’s like they didn’t believe me, because he is disabled, and then they decided to tell me that the definition of sexual assault is when someone pins you down, and forces themselves on you. Now, they are not recognising that coercion is also a form of rape. At least that is how I felt.’

One time in public, Eliza’s partner rammed his wheelchair into her walker. He pinned her in place refusing to ‘get off her’, only releasing her when her friend called police. The next day Eliza reported the assault to police and asked for an intervention order. Police told her because she went home in the same taxi with her partner she had to obtain her own order from the courts. ‘I know I went home with him but I had no other way of getting home,’ Eliza explained. Police told her she should have called another cab. ‘But how do you call another cab when you’ve got no money?’

Eliza felt ‘so let down’ and ‘didn’t do anything because the police weren’t going to do anything.’

Through a domestic violence support group, Eliza found a female police officer who supported her.

‘She helped me come to the conclusion ... would you rather be lonely but happy, or would you rather have somebody but be unhappy ... that was when I decided that I had had enough.’

Eliza decided to proceed with her complaint and the matter went to court. She didn't have a lawyer, but her ex-partner did. The judge asked her why she didn't report all of the incidents with her ex-partner to police. She 'felt stuck' trying to justify her feelings and actions.

Eliza eventually did get a restraining order but said it wasn't worth the paper it was written on. It didn't make her safe. Her ex-partner has intimidated her and made threats his family members will hurt her. She continues to be scared of him.

Alanna

‘If we don’t speak up nothing’s going to get done ... I just want to make it right for these children of ours.’

Alanna, a First Nations woman, has a psychosocial disability. She also has a daughter with disability.

For almost 20 years she worked across two disability support units at a secondary college.

In the mid-2010s, at a staff party, a teacher’s aide shared explicit photos of students with disability.

One photo showed a First Nation’s boy with his shirt off in the toilet. Another showed a student running away with his nappy falling off. He also showed photos of students banging their faces against things.

Staff thought it was funny and laughed. Alanna was horrified – the students were all non-verbal and couldn’t tell anyone what was happening. She told him to ‘put the phone away’ and ‘shove it where it fits’.

The next morning Alanna spoke to the teachers who were at the party and asked if they were going to report the incident. Not only is it mandatory, she told them, but it was ‘the right thing’ to do. ‘They just looked at me and shrugged.’

Alanna reported the incident to the principal.

From that moment on, Alanna said, they ‘really bullied’ her.

Staff turned against her, ‘sticking up’ for the teacher’s aide. The principal moved her to another disability unit, banned her from talking to the parents of the children she taught, and walked her out of the gate each afternoon. She told her to remove the ‘Aboriginal people’ from her phone so she couldn’t tell the children’s parents. When Alanna applied for another job the principal told her, ‘Don’t think you’re going because you’re not leaving here.’

During this time Alanna saw the teacher’s aide watching children with disability using the toilet, through a partially open curtain. She believes he may have sexually abused a student, but she was prevented from talking to the student.

‘They stopped me being with him and he’s an Aboriginal boy. I wasn’t allowed to talk to him at school. I wasn’t allowed to help in class anymore.’

One day Alanna walked past several of the staff who had been bullying her and they started laughing at her. She snapped. ‘I’ve had enough of you now ... You’re not hurting me, you’re hurting the kids ... You watch me. I’ll push this till the day I die.’

Alanna reported the incident to the department of education. The teacher's aide resigned from the college before disciplinary action could be taken.

Alanna contacted the children's guardian and was led to understand they were investigating the matter.

Later, she attempted to report the incident to police, but there was nothing they could do because children were over 18 by that stage and had to report the matter themselves.

Alanna believes the teacher's aide still works with children with profound support needs.

'I tried my hardest to stop him working with kids. I don't think people should work with kids when they're doing that.'

Alanna has left the college.

Brantley and Marissa

Marissa is the mother of Brantley, who is in his 20s and has developmental delay and intellectual and physical disability. Brantley uses a wheelchair and is non-verbal.

'Very early on we discovered he had lots of disabilities and lots of medical problems,' Marissa told the Royal Commission.

When Brantley turned 17, Marissa placed him in a group home run by the state government.

'We were really happy. It was all in one spot, you know, where he had the care that he needed ... your physio, your OT [occupational therapist], your speech therapist, they were all there and worked with everyone in the group home. Now that really worked well for us.'

Marissa said the home was 'a community' for the residents and families. 'We're a community for each other, as well.'

When a service provider took over the home several years ago, things changed.

'I'm not here today to say that [Brantley] himself has been abused or anything like that in any way,' Marissa told the Royal Commission, 'but I just really feel that there is underlying discrimination.'

When the government managed the home, the families of residents were consulted when new staff were employed.

'The staff that were there were absolutely fabulous.'

Marissa said family members helped choose new staff.

'If we really want people like [Brantley] ... to have real say, we have to be involved in that process.'

Marissa said the new service provider didn't seem to understand why that was important.

'So, we had a situation where we sent a family member along to what we thought was a panel. What had happened is that the two people [from the company] had pre-interviewed this person and then presented it [as], "This is a person we've picked, you can ask them questions," but it was a done and dusted deal.'

Marissa said 'there was a lot of problems' with the new staff member, which included them 'bullying and harassing [other] staff'.

‘We tried to explain to [the management] that the staff were like [Brantley’s] family ... They were the people there, day in and day out looking after him, caring for him, making sure he was okay. So, they are the second most important people to us as the families, because we wanted to make them happy, and the fact [was] we ended up in a situation where they were being bullied and harassed.’

Marissa said the service provider, without consulting the residents, recently turned the home’s family room into an office.

‘I explained, “Your landlord or your bank can’t walk into your house and say, I’m now taking this room over for an office” ... It’s [the residents’] home. And they’re very keen to say that’s their home, but when it came to something like that [the management] could not understand, I think, until I very blatantly pointed it out to them by saying “You’re discriminating against people with disabilities.”’

Brantley has calcium leaching to his kidneys and two metal rods in both legs. He needs regular pain relief. Marissa said that despite Brantley’s increasing need for support, the NDIA recently cut his funding.

‘We’ve asked for an internal review of the nursing levels for [Brantley]. Which, for us, is just another element of stress and anxiety ... Now that we’ve moved to the NDIS, it just feels like a huge fight all the time to get what [Brantley] needs.’

Dom and Jess

Jess's son Dom has cerebral palsy and significant vision impairment.

'If you look at [Dom], you think he could see, but he can't,' Jess told the Royal Commission. 'So, when he first started preschool, I was lucky ... They said "Of course, he's going to come here. We will take him on."'

Jess said Dom went through the first years of school with no-one understanding how to teach him how to read and write.

'They were always trying to make him read ... and he had a wonderful memory. He remembers everything. He could recite, you know, little books, that you start reading [to him] ... It was like he was reading, but he wasn't reading at all.'

Near the end of primary school, a teacher suggested they should stop trying to teach Dom, 'a really bright boy', how to read and write, and instead help him to learn by listening.

'I thanked her at the end of the meeting and I said, "You've given me a new way of looking at [Dom]."'

Dom became good at languages and in senior high school wanted to study German.

'[The school] said, "[Dom] can't do German ... and if he attempts to do senior [studies] he's going to fail." And I said, "How can that be?" And they said, "It's the way the syllabus is set". I said, "Well, they are going to have to change the syllabus."'

Jess went to the education department. They told her that even though Dom had a gift for languages, he couldn't compete academically because of his disability which prevented him from reading and writing.

Around this time, Dom developed an interest in the law.

'[Dom] is very resourceful and he loved the law, so he was going down to the High Court of Australia.'

Dom told a legal professional that his school wouldn't let him finish his education.

'[The legal professional] was just gobsmacked. And he looked at him and said, "[Dom], how do you know so much about the law?" And he said, "I just listen." And [he] said, "Look, I'm going to get someone to represent you because this boy has to do senior."'

With the legal professional's help, Jess lodged an antidiscrimination complaint against the school, but it was unsuccessful. She transferred Dom to another high school where, with help from a vision impairment specialist, he graduated.

Dom's now studying law at university.

'He still goes to court every day – he's in the Family Court at the moment – and listens. He just loves the law, [but] he can't get work.'

Jess said the next hurdle is for Dom to find a job, even 'one day a week as an assistant parole officer, just something to make him [feel] worthwhile'.

Candace

‘I was in a coma for six days. They were honestly shocked I didn’t die and I think the reason is I’m supposed to be a fabulous painter. That’s what I’m going with. So that’s my purpose and meaning.’

Candace is in her 30s and lives with bipolar disorder, borderline personality disorder, attention deficit hyperactivity disorder, anxiety and depression.

A few years ago, Candace’s psychiatrist tried to wean her off a medication that makes her sleepy.

‘The brain fog was awful and I couldn’t really function and I got a bursitis injury due to just sleeping all the time.’

Candace enrolled in a teaching course.

‘I was doing really great. I really love children ... but then with the titrating off the meds everything was wobbly and by midyear I hit a depression,’ Candace told the Royal Commission. ‘I mean, that’s how bipolar works. And we were having trouble treating it. I just couldn’t – is swearing allowed? Yes? Cool. I just couldn’t fucking stop crying all day, every day.’

Candace struggled with her studies and admitted herself for treatment to a mental health unit. Before she did, she told her course coordinator.

‘I was being a really good student about it in letting them know.’

She didn’t disclose the nature of the treatment.

‘Huge stigma. So I went in. The treatment didn’t work. I got worse because it’s hard to sleep in those places and I’m a chronic insomniac.’

When she returned to her classes ‘everything had changed’. She felt as if she wasn’t prepared. She also felt rushed by her father into returning to study.

‘He does not understand mental illness at all. Sadly, I think that a lot of the older generation don’t, which is really sad because they have untreated mental illness. Anyway, so yes, I was trying to prove that I was a good student at the school. I was trying to please dad and, yes, I ended up having like a massive panic attack.’

Candace returned to the mental health unit for a few days. When she was discharged, she was unsure whether she could return so quickly to her study. Candace met the course coordinator again.

'He was like, "So considering that you have been in, you know, the psych ward or you have had this mental hospital admission, does that ... invalidate the validity that you are safe to work with children?"

Candace said the question 'paralysed' her.

'He really, really put that in my head when I was literally the most frigging vulnerable mentally ... I did look into making a written complaint to the school, but it felt too traumatising because I was already so traumatised.'

A few months later, after her parents separated, Candace tried to kill herself. During her recovery, doctors gave her medication that worked.

'We were going to get back on track and do the classes again and this time it was going to work better because I was on the right meds. Right? A week later the pandemic was announced.'

Candace said she is only a few subjects away from getting her qualification and is trying to re-enrol.

'I called them midyear and they were like, "We will call you back," and they didn't. They didn't. They don't want me there.'

Evelynn, Indie and Adriana

‘[The hospital] saved them from dying ... but then they wiped their hands of their rehabilitative needs.’

Evelynn and Indie were assaulted when they were very young and sustained traumatic brain injuries and cerebral palsy. Evelynn has epilepsy and is non-verbal.

Adriana, their aunt, applied to foster the girls. She told the Royal Commission the department of child safety fought her ‘every step of the way’. Ultimately, the department deferred to a medical team who decided the girls needed full-time medical care and couldn’t live with family.

Now young teenagers, Evelynn and Indie still live in a small private hospital where, Adriana believes, they have limited quality of life.

Indie has fewer health complications than Evelynn. She can sing and say some words. But she’s never had access to any type of therapy. Adriana says that with rehabilitation, Indie could be using a standing frame or walking.

Indie had to wait years for spinal surgery and another three years for a custom-fit wheelchair. While waiting, she had to use a wheelchair she would slide out of. Adriana believes if she hadn’t ‘jumped up and down’ Indie would still not have a supportive and safe wheelchair.

A few years ago, Indie dislocated her knee. Doctors placed her on the bottom of the surgery list because they thought that, as she couldn’t run, it wasn’t important to operate on her.

For Evelynn, the last few years ‘have been a horror’.

Evelynn’s ‘great love’ was food, but because of health complications she needed a feeding tube. Doctors at the hospital said it would be temporary, but because she’s a slow eater the hospital has never removed the tube.

Two years ago, Evelynn was in severe pain. A doctor at the hospital diagnosed her with constipation even though she was using a feeding tube – ‘which causes the opposite problem,’ said Adriana.

After one week a nurse intervened and sent Evelynn to a large public children’s hospital. She did not have constipation – she had a chronic infection and had developed sepsis. Her brain swelled and she went into kidney failure, needing a ventilator and dialysis. The hospital told the family, ‘Say your goodbyes.’

The doctor who’d dismissed the pain as constipation told Adriana it would be ‘a blessing’ if Evelynn died because ‘the poor thing’s already been through so much’. Adriana was incredulous the doctor would make such a comment.

Adriana said that ever since Evelynnn turned eight, the palliative care team at the public hospital has been pushing Adriana to sign an end of life plan. No matter why she was there, even for a stubbed toe, staff talked about end of life plans.

During the treatment for sepsis, Evelynnn would repeatedly 'crash' and need resuscitation. Adriana said the public hospital used this as an opportunity to get her to sign a 'do not resuscitate' document. She thought it was limited to the sepsis admission, but has since discovered it is ongoing. Adriana now lives in fear the doctors will let Evelynnn die even if she can be saved.

A year ago, the private hospital took Evelynnn to emergency at the public hospital and left her there. After a short time in intensive care, medical staff transferred her to a ward. Adriana says they expected Evelynnn to die in that ward and ceased all observations.

Evelynnn can move her right arm and uses it to express herself. While in the ward, staff restrained her arm so she couldn't touch the tubes and cords. Adrianna arrived at the hospital to find Evelynnn alone and restrained. She feels the doctors wanted Evelynnn to 'hurry up and die'.

Adriana says she will fight for Evelynnn until Evelynnn 'is ready to not fight anymore'.

The department has found a group home where both Indie and Evelynnn would have their own bedrooms. But the private hospital continues to delay the transition.

'The girls are seen as cash cows,' Adriana said.

Jad

In the late 2000s, Jad had a car accident and sustained a brain injury. He was paralysed on one side of his body and spent many years teaching himself to walk again. He told the Royal Commission he continues to have memory issues as a result of the accident.

A few years ago, Jad wanted to work again and participated in a return-to-work program through Centrelink and a disability employment service. Jad worked one day a week at an equipment hire and grass cutting business. The company was happy with his work and, when the program ended, employed him directly.

Soon after, Jad's boss started verbally abusing him calling him a 'disabled idiot' and other derogatory names. Despite working more shifts, Jad discovered he wasn't being paid. The boss told him there were some 'cash flow issues' and he would be paid soon.

After about six months Jad became so frustrated he 'lost it' and told his boss to 'stick his job'. The boss tried to physically restrain him and Jad pushed him away. Jad said his boss threatened to kill him.

After many texts Jad received his final pay, however the boss withheld monies saying Jad didn't provide adequate notice.

Jad was furious because he was a casual worker and not required to provide notice. Jad rang his boss and told him what he thought of him. The boss rang Jad several times over the next few days screaming at him.

'I sent him a text saying, "I'm going to take you to Fair Work" and then the next thing I know he sent me a text saying, "Don't threaten me and my family," and I'm like, you know, "What are you talking about? You're making stuff up now."'

The boss contacted the police telling them Jad threatened to kill him. Five police officers in 'full riot gear' burst through Jad's door, took him to the police station and detained him for four hours. Despite being aware of his brain injury, they refused to allow him access to a support person. When police asked if he'd threatened to kill his boss he said he couldn't remember. Jad believes police took this to mean he did make the threats but didn't remember.

Police subsequently charged Jad and he went to court. '[The judge] told me that he found me guilty because of the fact I had a disability, which I was stunned at. I mean part of my condition is I get sort of annoyed, my brain takes over, I can't stop it.'

Jad decided to appeal to the Supreme Court. The matter was 'thrown out' but Jad was ordered to pay costs.

'I was abused through my working with him, and then tried to ask for help from the police and they basically abused me as well.'

Jarvis and Enid

Jarvis is in his 30s, has cerebral palsy and uses a wheelchair. Jarvis spoke to the Royal Commission with help from his advocate, Enid.

Jarvis and his partner bought a house in a regional area. Enid said the NDIA has since refused to fund a ramp so he can access his house.

‘The problem is both the front and back door have steps, so he was wanting a ramp for the front door only,’ Enid told the Royal Commission. ‘It’s been rejected a couple of times ... It’s only about two or three steps.’

Jarvis uses a powered wheelchair that’s too heavy for anyone to lift up the steps. To get into his home, Jarvis has to go to his mum’s house nearby.

‘[I leave my] power chair at my mum’s,’ said Jarvis.

Jarvis is then driven back to his house where he pulls himself up the front steps using the handrail. He has a manual wheelchair inside the home.

‘If he wants to go out for the day,’ said Enid, ‘he has to go back to his mum’s the next day to get his power chair to go out.’

Enid said it appears the NDIA rejected the ramp because Jarvis didn’t consult them enough before he and his partner bought the house, even though they paid for the house themselves.

‘So, I think the reason for rejection was there was not enough evidence to show they looked around before they purchased this one.’

Enid said Jarvis did a lot of research before buying the house, and consulted his occupational therapist.

‘I’m not sure what justifies enough evidence, to be honest.’

Annabel

‘Apparently I stick out like a sore thumb. Like, everyone knows that I’m different.’

Annabel, early 40s, told the Royal Commission she ‘shifted around schools a bit’ and was bullied and treated poorly in every school she attended.

Despite Annabel’s difficulty with reading, writing, ‘sitting still’ and concentrating, doctors didn’t diagnose her with a disability until year 5. Initially doctors incorrectly diagnosed her with attention deficit hyperactivity disorder. Later, she was diagnosed with Tourette syndrome, obsessive-compulsive disorder, a short-term memory issue, learning difficulties and depression. She was also diagnosed with stigmatism and long and short sightedness and needed glasses.

Annabel said she’s ‘quite angry’ she didn’t get ‘the initial help that she needed’. Schools treated her the same as all the other students. She found writing painful and difficult. ‘A note taker would have at least been good so I could focus on what the teacher was saying.’

At the time, Annabel believes, the schools were better at supporting students with physical disability.

The bullying in high school became worse. ‘It was terrible ... it really ramped up.’ One student deliberately tried to push her down a flight of stairs. The school did nothing.

Her mother moved her to a different school. Nothing changed.

‘I was called retard a lot,’ Annabel said. Students threw things at her but, when she complained, the most the schools did was give the bullies ‘a talking to’. ‘I think that’s completely unacceptable.’

Annabel’s tics increased because of the way she was treated, and the school gave her detention.

Neither high school she attended provided any supports. ‘No note taking, no nothing ... which didn’t help at all.’ Annabel felt ‘like a number’. The schools provided no adjustments and she got ‘snowed in with work requirements’.

Annabel left school at year 10. Most of the teachers told her going any further was ‘a complete waste of time’.

At TAFE, Annabel did an office administration course. TAFE provided some note taking support, but she was already so far behind because of her poor schooling she wasn’t able to fully engage.

After completing the course, Annabel tried to find a job. She volunteered at a 'sheltered workshop' but it didn't lead to job. She went to an employment agency who told her there 'wasn't any jobs for disabled people' in the regional city where she lived. Annabel has been on the Disability Support Pension since leaving school. She said her lack of schooling has significantly limited her life choices.

Annabel receives NDIS support. She initially found it difficult to register and thinks this might be because she has a neurological disability rather than a physical one. She has had at least three plans in four years. Each plan has had varying levels of support, without any rationale for the discrepancies. For example, the NDIS approved transport funding in her first plan, but not in her second.

Annabel finds it challenging to live on the Disability Support Pension. The \$1,100 she receives fortnightly needs to cover rent, food, bills and other life costs. She said she is constantly living in a world of 'not enough', and it is always a 'struggle to make ends meet'.

'If I'd had more support at school and paid employment I wouldn't have to rely so heavily on mum ... It's had a huge impact on my life really.'

Ayleen

Ayleen's father taught non-verbal children with intellectual disability from the mid-1980s to the early 2000s. He was very well educated and appeared to be good at his job. He moved from school to school, telling his family this was the result of making 'the right noises to the right people' and being promoted.

Recently he became ill and Ayleen needed to go through his papers. She discovered 'a heap of child pornography' and a history of complaints alleging he had abused children in his care.

Ayleen told the Royal Commission she found her father had physically and sexually abused children in every school he taught in. He would lock himself in the sick bay with the students. The schools thought it was 'too hard' to deal with him and 'shuffled [him] from school to school to school'.

Ayleen had concerns about her father's interactions with children for a long time but assumed there was 'some kind of protection in the schools' to keep children safe.

'To find that the education department knew about these complaints, when he was still working as a teacher, and all of these earlier complaints and comments from other people who had worked with him and had done nothing about it – it just horrifies me.'

Ayleen 'hates to think' how many children he 'preyed upon' who had no ability to communicate what was happening let alone 'necessarily understand what was happening to them'.

Only one school – the last school her father worked at – took any action and didn't allow him 'to have direct interaction with the students unsupervised'.

'I kind of get the feeling that he was protected by a lot of people as well, who maybe didn't think there was anything wrong with his behaviour.'

Ayleen handed all the documents and materials she found to the police.

'It just appals me that this was able to happen.'

Bronte

‘Where I live is basically a funeral yard to me. You get put there and you stay there till you die. That’s it. And there’s no support.’

Bronte, mid-50s, was involved in a car accident when she was in her late teens and acquired a brain injury.

Soon after, she formed a relationship with a violent man who had substance abuse issues. He regularly assaulted her and threatened her children.

Bronte told the Royal Commission that her partner would kick her and tell police, ‘I didn’t lay a hand on you.’ One time he threatened her with a knife and when her daughter went next door to get help, he ran after her telling the neighbours he was ‘going to kill them’.

‘So the girls and I were ... living in a very serious, dangerous position.’

When Bronte received compensation, 10 years after the accident, her husband took the money and ‘took off’.

‘So we ended up living in a garage beside our house, someone’s garage.’

After some time, Bronte was able to access public housing.

The house is now ‘filthy’ and has ‘dust and holes and cockroaches’. Bronte believes the house has made her sick and she’s often in pain.

Bronte finds it difficult to make a complaint and advocate for herself. ‘[My paperwork] does look like a child did it. I can’t spell.’

If someone does come to fix something in the house, the agency charges her even if they haven’t fixed the problem.

‘I asked them to fix a toilet seat. They can’t even do that. It falls off again and it’s been a week.’

A couple of years ago Bronte went to hospital to have a tooth extracted. When the doctor came in to perform the extraction, he did not have her X-ray. As a result, the doctor removed five teeth instead of one. Since then, Dianne has been taking nine Panadeine Forte a day and is still on the waitlist for implants.

Bronte is very concerned about her daughter. She believes her daughter’s mental health has ‘been affected’ growing up in a violent household. ‘She needs to get help. She can’t get the help. She has breakdowns and she can’t even go to a shopping centre without screaming.’

Bronte's daughter recently moved out of the house because it was making her sick. She would lay in bed and 'feel the dust over [her] mouth and eyes'.

Bronte believes her life and her daughter's life would be better if she'd had 'somebody ... who can help ... somebody for brain injury people or disability'.

Instead, she feels people take advantage of her because of her brain injury.

'They manipulated me, they were telling me things that I believe was wrong ... I had a brain injury. Lost my house. Lost the brain injury money I had ... Any money I had he took.'

Cesar and Henrietta

‘This was our child. And yes, he had a disability, but he was still a person and he still had rights and they ignored it ... He ended up dying from the very thing that we said was happening.’

Henrietta’s son, Cesar, had an intellectual disability, bipolar disorder, epilepsy and schizoaffective disorder.

He was born nearly 30 years ago with a hole in his heart.

‘We knew something wasn’t quite right,’ Henrietta told the Royal Commission. ‘He didn’t reach any of his milestones.’

Cesar didn’t walk or talk until he was four.

‘Then we actually saw full-blown seizure activity and then, of course, he went backwards, so even further.’

Henrietta said the seizures, and the drugs he was given to control them, sparked other disorders.

‘So, basically, that’s where it started – when he was about 14, I believe.’

Cesar was frequently admitted to a hospital mental health unit. The doctors told Henrietta that, because his condition was ‘medical, not disability’, Cesar wasn’t allowed to have assistance from hospital staff to eat and shower.

‘So, he was left to his own devices and I had to go in and I had to care for him ... So, if I didn’t feed my son and shower my son and care for my son while he was in there ... it wouldn’t have happened.’

When Cesar turned 18, the doctors put him on an antipsychotic drug that caused lesions on his body.

‘He was having tachycardia. He ... couldn’t concentrate. He had drowsiness. See, he had all the symptoms of rejection of the drug, basically.’

When Henrietta asked the doctors to take him off the drug, they told her that because he was over 18, ‘it was none of our business’.

Henrietta said Cesar had the ‘age capacity of a 10-year-old’.

‘So, my argument there is, would you tell a 10-year-old that doesn’t have any clear understanding of a drug, “Take this drug, it’s going to make you better”? And [Cesar] repeatedly asked them even to come off the drug and they threatened him with community treatment orders.’

Henrietta said she hadn’t applied to be Cesar’s legal guardian because she ‘wanted him to have that independence’.

‘Even though he was limited, he was still a man and he still had rights ... They ignored him and they ignored us.’

Cesar received NDIS support and lived independently in his own house with the help of support workers. One day a couple of years ago, Cesar told Henrietta over the phone he wasn’t feeling well.

‘I told both [Cesar] and the carer just to go to the local GP at that point and check what’s going on.’

At lunchtime, when she phoned to check, Cesar said he still hadn’t seen the doctor. Henrietta spoke to the carer and told him to take Cesar to the doctor. The third time she rang, Cesar said he felt worse.

‘I [told the carer], “If you don’t ring an ambulance, I will” ... Eventually, they finally did ring the ambulance. By the time he got to the hospital, everything had shut down. So, his whole body had literally rejected the drug that he was on and he suffered a major heart attack.’

Cesar died in the ambulance.

‘So, he’s asking for help and [the service provider is] not giving it. I’m saying to get him help and they’re not doing it. So, it’s the story of his life basically, yeah.’

Henrietta said the coroner found that systemic inflammatory response syndrome caused Cesar’s death.

‘We still want answers. That’s the problem. We still want to know why and how come the system failed him. Why they didn’t listen to us? Why they didn’t listen to him?’

Holden and Hadley

Hadley is mum to Holden, who's in his teens and has a learning disability and an acquired brain injury caused by a tumour.

For several years after he was born, Holden didn't put on weight and had other health issues. The doctors blamed his mother.

'I kept on taking him to the doctors and saying, "This is happening, and this is happening." I got told, like, when I finally got the report years later, the doctors they have written down, "She is suffering postnatal depression."'

When Holden was three, Hadley persuaded the doctors to do a brain scan.

'He was getting worse at this stage,' Hadley told the Royal Commission. 'They kept on saying, "He is going to grow out of it, don't worry." They were treating me like I had a problem and was making up all these symptoms.'

The scan revealed a tumour in Holden's brain stem.

'They said, "We have to operate to see what type it is" ... I wanted more information. They said, "No, no, no we have to do it." So, they diagnosed on the Thursday, they told me they had to operate on him on Sunday because it was life and death for him.'

Hadley said they didn't explain to her the risks of the operation.

After surgery, Holden developed an infection which 'contributed to his brain damage now'.

Holden struggles at school and has meltdowns when he's frustrated.

'He can't follow rules properly and he forgets rules ... He started to learn reading and he couldn't do it. They kept on forcing it upon him without modifying.'

Hadley said one school, rather than focusing on what Holden was good at, encouraged the worst aspects of his behaviour to get more funding.

'The school said ... they could apply for the funding under severe behaviour ... So, they decided to expose him to situations that he couldn't cope with ... It was so they could say, "Look how bad he is, look at all these things he did."'

Hadley said the school also asked medical specialists to change the wording of their reports.

'I call it bullying in the process of the funding application ... They wanted to get the highest amount of money they could ... They would give me a note saying, "You have to take these back to the specialist. You have to get them to word their report with these words in these ways.'"

Hadley said she had to ask the hospital to make doctors change the wording of reports because that was 'the way the education department will accept it'.

'They don't want to know what the child can do, which is what doctors say. They want to know what the child can't do, and the worst-case scenario this child can be.'

Holden is now in high school.

'He could have a conversation with you about a nuclear bomb and how it works, do you understand? Or something very technical, he can verbalise a lot of things. His written skills, his reading skills are still back at like grade 1 or grade 2. He never progressed. So, I keep on saying, even with all the struggle with him for all these years, there was no point him going to school ... It was all a big battle. It only caused him stress.'

Kylee and Paula

‘[Kylee] had many friends and ... she was talking and she was communicating with me ... But she’s lost all of that now.’

Kylee, a First Nations woman in her 50s, has lived with her mother Paula most of her life.

As a toddler Kylee achieved typical developmental milestones, had good speech and play skills. She was shy, but socialised with family and friends and had no behavioural issues.

Kylee attended mainstream classes for the first couple of years. Then a school counsellor administered an intelligence test which showed Kylee had a moderate level of cognitive disability.

The headmaster transferred Kylee to a special school without consulting Paula.

In the few years Kylee spent there, her behaviour deteriorated dramatically. She would sweat, move her hands about and wring her hands constantly. She became withdrawn, with severe anxiety and depression.

When Paula asked Kylee what was wrong she wasn’t able to speak about it. Paula told the Royal Commission she suspected Kylee was being sexually abused at school and ‘took her out of there’.

Kylee left school when she was a young teenager.

Many years later, a psychiatrist confirmed Kylee’s behaviours at the time were likely related to sexual abuse and ongoing trauma. More recently, police contacted Paula and advised they’d located the abuser and were considering prosecuting him.

Over the next 20 years there were a series of medical assessments and incorrect diagnoses, including Tourette syndrome, personality disorders and childhood schizophrenia. Doctors prescribed a cocktail of antipsychotic medication causing Kylee to jump around, kick walls and hit Paula. Other times she’d be ‘walking around like a zombie’.

Her family, through all this, was ‘on a merry-go-round’, trying to find answers to the cause of Kylee’s behaviour and get her some help.

Paula believes government policies at the time failed Kylee because ‘no-one wanted to touch the Aboriginal mental health area’.

‘Any Aboriginal person or child with a mental health issue couldn’t move into disability services, they had to stay with DoCS which meant that they never got any help, any support.’

By the time Kylee received help she was in her 30s and no longer able to communicate. With a diagnosis of autism, she was able to access some support.

Paula's experiences with Aboriginal health services have been disappointing. 'The rating I'll give them, one out of 10 ... you hardly ever see them.' At one stage, Paula asked a doctor to come and assess Kylee, however the doctor didn't attend for the six scheduled sessions they were supposed to. The doctor saw her for the initial consultation and then once a few months later.

Paula said staff need more understanding and awareness of people with disability. 'They need more training in the area and non-Aboriginal have to be more understanding of Aboriginal people when they come in contact with them.'

In 2017, Kylee acquired ongoing NDIS funding. Paula says the funding has made it easier to get support for Kylee, but 'again there is lack of understanding of her cultural needs'. The NDIS does not provide support for cultural activities.

Kylee is eligible for specialist disability accommodation with 24/7 support. However, because she's a First Nations person the NDIA is refusing to fund her.

'[The NDIA] are saying that she can't have the accommodation, that she needs to stay in Aboriginal housing ... Aboriginal housing said they can't really have her because she needs 24/7 support.'

Paula's main concern is Kylee will end up in a group home, overmedicated like a zombie. 'They are setting up [Kylee] for future violence, abuse, neglect,' Paula said.

'It's only just me and [Kylee], you know, and I will support her, but I want to get her set up in her own place and she can have her own garden ... I'll support my daughter right up to the end.'

Lillian, Maxwell and Myra

‘The issues ... are systemic ... It is not about individuals, it is about the system that gives rise to their actions.’

In the late 1980s, six-year-old Lillian accidentally rode her bike into a cement wall. She sustained a brain injury affecting her development, speech and the way she expresses herself. Later, she was diagnosed with autism.

‘It created a level of difficulty for her which is almost unfathomable,’ her father Maxwell said. ‘The world is very hard for her to interpret.’

As a teenager, Lillian went through ‘an explosive period of violence’ and became very difficult to manage. She would go from ‘a state of tranquillity’ to rage in an instant. Lillian broke Maxwell’s nose a number of times.

Maxwell and Myra, Lillian’s mother, approached a number of state government agencies for help. The answer was always the same, Maxwell told the Royal Commission. They agreed the situation ‘was dire and terrible’ but ‘they could not help’.

Lillian’s behaviour affected the whole family. Vivian, her sister, overdosed on medication and was admitted to hospital. The hospital refused to discharge Vivian until Lillian was removed from the family home. ‘We had to choose between our daughters,’ Myra said.

Maxwell and Myra frantically searched for accommodation for Lillian, finding a place in a respite home. After a male resident exposed himself to her, her parents moved her to relatives and then a group home.

Lillian started taking antipsychotic medication and her outbursts reduced. However, after a violent episode the psychiatrist increased the dosage. A support worker, not familiar with the medication, increased the dosage further. Lillian collapsed on the school bus. She was humiliated and distressed and ‘from that day on’ refused to take any oral medication.

‘None. Not a Quick Eze, not an antidepressant, not an antipsychotic or a mood stabiliser. She would take nothing,’ Myra said.

This led to Lillian having increased outbursts and the home asking her to leave.

The only essential, non-oral medication she could take to help her mood caused chronic constipation, and Lillian developed a large bowel hernia.

For the next few years Lillian moved between mental health facilities and group homes, at one stage living in an aged care home. Nothing worked.

Maxwell and Myra built a bungalow for Lillian in their backyard. The arrangement wasn't ideal but it was manageable.

Then in the late 2000s Maxwell was diagnosed with a medical condition and could no longer support Lillian.

Maxwell and Myra decided to move states and found a disability service provider who ensured Lillian could transition into supported independent living three months after they moved.

Maxwell and Myra moved to set up their new home, but it took more than two years for the provider to find suitable accommodation for Lillian.

Lillian moved to a unit with 24/7 support. Initially she was only funded for a few hours of support each day. The accommodation provider and the disability support provider didn't communicate with each other. When Lillian was distressed she wailed and smashed furniture, but the accommodation provider would ignore her. Their attitude was 'she's not our responsibility'. Maxwell considers this a 'despicable form of neglect'.

At one point Lillian's toilet overflowed with faeces. She began toileting in an ice-cream container until she became completely incontinent. The accommodation provider told Myra that Lillian didn't want workers in her bathroom. Myra said some of the staff are 'lovely people' but they 'didn't know what to do' because they 'weren't trained'.

'Nothing was done to fix the problem. And when it happened again, they did say that they were afraid that [Lillian] would hit them if they went in there,' Myra said.

Lillian now has NDIS support. 'There are still problems, but it is a lot better,' Maxwell said.

Mica, Lisa-Marie and Jock

‘She has her whole life ahead of her. There needs to be big changes in our education system regarding children with disability.’

Lisa-Marie and Jock are the parents of Mica, who is autistic. Mica is about to start high school.

‘We knew things were wrong with [Mica] from a certain age, around three to four, but there was no help,’ Lisa-Marie told the Royal Commission. ‘There wasn’t much information about girls on the spectrum, it was all about boys.’

Mica was diagnosed when she started primary school. Jock said each school Mica attended was reluctant to accept her diagnosis or offer support because Mica doesn’t show some of the common physical conditions associated with autism.

‘Our experience is the mental, the hidden disabilities, are just being missed and ignored ... “You look fine, so just get on with it.”’

Lisa-Marie said the head of the special education unit at Mica’s first school ‘failed to understand how Mica could be diagnosed’.

‘[The teacher] still didn’t believe she was on the spectrum. And that is what we got. “She doesn’t show physical signs.” “She’s not lashing out.”’

‘And eventually when things got worse for [Mica] at school – with either bullies or where she wasn’t understood in the classroom, her emotional and social state, where she could not communicate – [Mica] would be left to meltdown on her own ... They would leave her on the stairs by herself to cry. And other children would make fun of her.’

Every day when Lisa-Marie picked her up, Mica would be crying.

‘And what we’d get told was that she needs to be more resilient.’

Lisa-Marie found another school for Mica.

One day, a group of boys verbally assaulted Mica in the bathroom.

‘The school did nothing. They kept those boys there. [They said Mica] was the problem. [She] needed to be more resilient. We needed to put more things in place for [her]. And [Mica] to this day has a fear of men and boys because of this.’

Mica made a number of attempts to end her life and spent time in hospital.

Lisa-Marie found yet another school for Mica.

Initially, in a classroom with an understanding teacher, Mica thrived. She began making friends.

But later that year, a new teacher arrived. They didn't understand Mica's disability and would embarrass her in front of her class. The teacher stopped Mica receiving support from the teacher's aide, even though funding for the aide had been provided to the school because of Mica's disability.

'Our understanding, and what we've been told by principals, is the funding they receive is there for the school to use as it sees fit,' Jock told the Royal Commission. 'So it could be used to make a new office for the principal ... I don't see how that's fair and just at all.'

Mica was admitted to hospital with a mental health condition. She didn't return to that school and missed her primary school graduation.

**'She felt she had that taken away from her,' said Mica's mother.
'She would have graduated with her friends. I didn't get that chance
to see her graduate. To go on stage and be proud and say you are not
a failure, your autism does not fail you.'**

As Mica prepares for high school, Lisa-Marie is worried for her future.

'I really feel our daughter has been failed by the education system.'

Nyah

‘I have been through hell, and when I came for help I got hell again.’

Nyah is in their 50s and lives with complex post-traumatic stress disorder (PTSD) and dissociative identity disorder (DID).

‘I came here today because I have experienced patterns of neglect and abuse within the psychiatric system,’ Nyah told the Royal Commission, ‘and it started at the very beginning when I actually went for help.’

Nyah became homeless as a child.

‘I was on the street and I was picked up. I was put in commercial brothels at that age by policemen.’

Nyah said that experience caused a range of mental health disorders.

‘I know nine people in the whole world who have been through what I’ve been through as a young person. And you know, out of them, seven are gone. That’s the pressure and the experience, and how it impacts our lives.’

Nyah was admitted to a psychiatric unit, where they were misdiagnosed with borderline personality disorder.

‘It was just something that was given to you on arrival. There was no investigation, no therapy, no process of diagnosis, just that label. I was never told during that entire experience what was actually going on with me.’

Nyah said that one day a male patient assaulted them.

When Nyah was released from the unit, a doctor told them to ‘go home and pretend to be normal’.

‘It’s where I sort of disconnected with the whole mental health industry. It’s like, these people can’t help me. I’m on my own, and I had to go from there ... I was frantically trying to figure out ways to save my own life because nobody else seemed to give a damn about it except me.’

Nyah went to hospital multiple times. On one occasion, after a suicide attempt with a drug prescribed to treat anxiety, a doctor prescribed more of the same drug.

‘He knew what had happened and where I’d been, he also knew that I was a single parent of a young child, and he gave me a bigger bottle of [the drug]. And a basically “Go kill yourself” attitude.’

It took four years for Nyah to find a psychologist who correctly diagnosed PTSD and DID.

'He put me on an antipsychotic, and actually things started to stabilise and get better. You know, there was this whole four-year period where it was just one continual neglect after another, where there was no referral to anybody that could help, no actual discussion.'

Nyah said they still struggle to find treatment for PTSD.

'Everywhere I go, all the patients have got anxiety and all the clinics are full. Even my psychologist, who I run to, tried for three weeks to get me in somewhere, and it's just full of anxiety patients. Even places that are supposed to do trauma are all full.'

Nyah needs specialist help, but said the NDIA denied them funding.

'All the cumulative trauma has never been dealt with, not in any substantive way, and every time I go for help it's just not there. So, the disability remains active and imposing in my life, as opposed to something that I just live with.'

Nyah said they felt 'completely abandoned by the mental health system'.

'I've done my best and I've done my job, but I feel like the system hasn't done its job.'

Paityn

'I struggle to believe this has happened to me. Sometimes I think this must be a dream, a really bad dream.'

Paityn is in her 50s and lives with post-traumatic stress disorder, anxiety and depression.

Paityn told the Royal Commission that after her marriage ended, her husband gained custody of her children.

'I was the worker of the family ... he was the prime caregiver, so the children were with him until we managed to get through court.'

Paityn said stress made her sick and she lost half her body weight in a few months.

'I'd been functioning really well in work, and it was just really the sadness had got to me ... My GP admitted me initially for an infusion. But then I came on the mental health radar.'

Paityn said after a psychiatric review she was forced to spend a weekend in a mental health unit.

'That whole weekend I didn't see any doctor, I received no treatment and I was not on any medication, so I do not understand why that was necessary. And, come Monday morning, I had an interview with a psychiatrist and I was discharged.'

Paityn said the experience 'derailed' her.

'For somebody who has survived 15 years of violence with my husband and to be locked up in a place like that is just, I can't even explain, you know. You're just putting me back in the lion's den with all these people ... it was a crazy place.'

Paityn was diagnosed with an eating disorder and re-admitted multiple times over the next few years to make her gain weight. She said security guards held her while a staff member inserted a nasal feeding tube.

'I've been dragged along the floor by my arms and stuff ... I've had security guards come behind me, I've been strangled in the past, come behind me and grab hold of my neck, and it's to drop me to the ground. It's just wrong, it's wrong that people are treated like that when they've come from a trauma background ... Every day I woke up there I just wished I was dead.'

Paityn tried to kill herself. She was re-admitted to the same mental health unit.

The day she was being discharged, someone gave Paityn chocolate cake to eat.

'I've never eaten cakes in my life. And there was no way that I could eat it. I'd put on the weight that I needed to put on and I was about to go home.'

She refused to eat it.

'They cleared the room ... and then a couple of security guys [came] to pin me down and it was just really bad and they inserted a [nasal] tube in the wrong place and then they just ripped it out, and it was just the worst experience ever ... it was just another torture.'

To avoid going back to hospital, Paityn 'went on the run'.

'I actually had a lot of backing from people who probably shouldn't have backed me. I had people in hospital tell me whatever you do, don't let them get hold of you because once you're in here nobody can help you. And it's true, you have no rights at all.'

Paityn told the Royal Commission that although she'd been diagnosed with an eating disorder, 'there has since been some talk whether that initially was a misdiagnosis'.

'Other psychiatrists have also noticed that it was due to trauma and post-traumatic stress of how my marriage ended ... So, kind of the misdiagnosis at the beginning ... has really escalated the problem.'

Paityn says she has 'just got [her] life back together' and is trying to support herself.

Quentin and Reyna

‘He was Deaf, that’s all. They treated him horribly. These people treated him like [he was] nothing.’

Reyna is in her 60s and has mild intellectual disability. Her partner, Quentin, was a Deaf man in his 70s. The couple had been together for nearly 20 years.

Quentin relied on Reyna to be his interpreter and carer. She was ‘by his side all the time’.

Reyna told the Royal Commission their lives were destroyed when, without their knowledge or consent, the public trustee took control of Quentin’s health decisions and financial affairs.

‘He was an independent man ... [who] wanted me to look after him. That’s what he said.’

Quentin had lived in a retirement unit for several years. He was ineligible for NDIS supports, so he applied for an Aged Care Support Package. The GP who assessed his eligibility told Reyna that Quentin would need a brain scan ‘to see if he’s okay’.

‘He was going all right,’ said Reyna. But then he had a vomiting episode and had to be rushed to hospital.

Reyna arrived at the hospital the next day to visit him. She was surprised to find that staff were moving Quentin to ‘the ninth level’.

She didn’t understand what that meant. As he approached the ward’s entrance, Quentin spotted signs on the wall. He asked, ‘Are we in the dementia ward, [Reyna]? Why am I in the dementia ward?’

Reyna was also confused. ‘[Quentin] did not have dementia,’ she said. ‘He had hearing loss.’

The couple were unaware a social worker at the hospital had contacted the public trustee.

Quentin stayed in the dementia ward for more than two months with no interpreter to help him communicate with medical staff.

One day, they received a visit from an administrative tribunal officer, who introduced herself as Quentin’s ‘new guardian’. Without having consulted either of them, she told Quentin he would be moving into a nursing home.

Quentin responded, ‘I want to go home.’ Reyna said the officer ‘didn’t take any notice’.

‘[Quentin] didn’t have any say at all ... They just dumped him in a nursing home with the dementia residents.’

Reyna learnt much later that the public trustee did not consider her suitable to be Quentin's full-time carer.

Reyna says staff at the nursing home were 'not much better'. They did not assist him to shave or arrange for him to get a haircut. 'Just left it long, that's the nursing home for you. And they're telling me I can't look after him!'

Reyna went back to Quentin's unit to collect some of his personal items. But when she opened the door 'all his stuff was all gone'. 'All empty!'

Neither the public trustee, nor the nursing home, had consulted Reyna or Quentin. Reyna is certain she knows why. '[It's] because he's Deaf. That's how they treat Deaf people. They don't care about them.'

On one occasion, Quentin gave Reyna his ATM card and asked her to withdraw money from his bank account. 'What's the good of [that]?' asked Reyna. 'You've got no money in it. The public trustees have taken it.'

Quentin responded, 'That's not fair, that's my money.'

Reyna said that the intrusion of the administrative tribunal, the public trustee and the nursing home in his life left Quentin feeling 'useless'. 'Everything was taken from him.'

After a year of residing at the nursing home, Quentin had a stroke. He died a few days later.

'[Quentin's] rotting ... in the cemetery now ... I miss him so much,' said Reyna.

Sawyer and Marianna

‘These children have abilities ... There’s so much potential there but if you can’t un-tap it ... you lose it. And society loses it, because these kids ... they end up in jail, they end up committing crime.’

Marianna told the Royal Commission her 16-year-old son Sawyer ‘thrived’ when he was young. However once he started school the education system failed to support him.

Sawyer struggled to learn to read. He became agitated and anxious and refused to go to school.

The school could see Sawyer was struggling, but told Marianna he was ‘lazy’ and ‘needed to try harder’.

Sawyer’s school refusal became difficult to manage and Marianna questioned the school’s teaching methods.

She moved Sawyer to a smaller private school. She said the new school’s attitude was ‘leave it to us’. They were confident they could help him learn to read. He didn’t refuse to go to school and seemed more settled. But over the years Sawyer fell ‘further and further behind’.

In year 3 Sawyer was diagnosed with dyslexia. Marianna was ‘over the moon’ because finally Sawyer had a concrete diagnosis explaining why he was falling behind. Marianna approached the school armed with the expert’s recommendations.

The school had ‘very little understanding of what dyslexia was’ and the type of instruction required.

‘The first thing the teacher said to me was “Oh well, we won’t get him to do NAPLAN then.” That was the very first thing she said.’

Marianna realised the school was simply incapable of implementing the recommendations. While teachers have good intentions, she says, they are not graduating from university with an understanding of contemporary evidence-based teaching methods.

Marianna said Sawyer’s individual lesson plans were inadequate, non-specific and lacked accountability, making his progress hard to measure. Sawyer was quiet and ‘flew under the radar’ and because he didn’t cause trouble, teachers were happy.

Marianna paid for therapies and literary coaching as there was no government funding available. ‘Dyslexia doesn’t fit anywhere,’ she says. As a single parent she has found it very difficult financially. She says both she and Sawyer would benefit from seeing a psychologist and occupational therapist, but the costs are prohibitive.

‘I know that my son has not reached his potential from an educational point of view.’

Bode and Violetta

Violetta has several children. One of her teenage sons, Bode, is autistic and has cerebral palsy, psychosocial disability and other health issues.

Violetta told the Royal Commission that educators in regional schools lack disability training and awareness.

When Bode attended an early learning centre, staff told the family that parents ‘were getting very upset’ because he was ‘biting’ other children.

The family engaged occupational therapists and other early intervention services, but staff insisted the family ‘remove’ Bode because he was ‘difficult to manage’.

Violetta felt she had no option but to keep Bode at home until the family came to a resolution with the centre. She sought a commitment from the centre to train the staff in working with children with autism. After three months of negotiations, Bode went back to the centre.

‘It was their training that was lacking, not so much [Bode’s] disability,’ Violetta said.

By the time he finished at the early learning centre, Bode had transitioned from using a wheelchair to a walking frame. He started primary at a ‘fabulous’ special school.

Then the family moved to a regional area ‘and everything changed’. Violetta enrolled Bode into the local special school. The principal told her the school had no ‘children with behaviours’ in attendance.

One day, Bode came home in tears. Violetta was ‘absolutely shocked’ to learn the principal had ‘stormed into the classroom’ and forced Bode and two other children to stand in front of the class until one of them confessed to shoving toilet rolls into the toilet.

‘I don’t want to go back to that school anymore. I’m going to kill myself,’ Bode told his mother.

Violetta believes the principal’s actions reflect a lack of disability training and awareness. ‘You can’t attack the children, especially if you want a proper response. You don’t attack them, they’re not going to answer you.’

The family recently learnt that Bode had been misdiagnosed and actually has Prader-Willi Syndrome, a genetic disorder that affects a child’s growth and development.

The family is concerned about the medical consequences for Bode. Had doctors diagnosed him accurately, Bode would have been eligible for 'early intervention' measures, such as hormone injections to improve his muscle mass. They are also concerned about the impact it will have on his NDIS supports.

'I've been in shock for a couple of weeks, and I don't know where to go with this ... it's blown me away,' said Violetta.

Watson

‘I want to tell my story to the Royal Commission because it shows how the child protection system can trap parents within its reach, make damaging claims against parents and ultimately ruin lives. The department discriminates against parents with slight disabilities, even if those disabilities result in minimal impairment.’

Watson was abused as a child and lives with post-traumatic stress disorder, anxiety and depression. ‘Despite my history of trauma and mental illness, I have managed throughout my life okay.’

A couple of years ago Watson moved interstate for a new start. He got a job which he described as ‘hard physical work’, but said ‘It felt good to make some money and start my new life.’

He soon met Katie who, like him, had a traumatic past. He was aware she had some psychosocial disabilities, but it was only later he learnt the child protection department labelled her bipolar with autism and attention deficit hyperactivity disorder.

Katie already had a young child when they met, and Watson became his stepfather and provided for the family.

Katie had also had two children with a much older man when she was still in high school. The man had a history of substance abuse and violence. Watson said that when the relationship broke down, the man’s family targeted Katie. The child protection department became involved in the custody dispute and, despite the man’s history, had removed the children from Katie.

Watson and Katie were happy together and, a few months into their relationship, she became pregnant. ‘I was in a new relationship, had become a stepfather, was living in a good home, had a full-time job and a young son on the way,’ Watson said.

About a month before Katie was due to give birth, the department began to appear in their home. Katie was scared and felt they were targeting her. ‘It was like she turned into a teenager,’ Watson said. ‘I thought that it must have been from the trauma of already having two of her children taken away from her.’

Katie’s fears were realised. Child protection removed her newborn child and told Watson he would need to quit his job to be the baby’s primary carer – he did.

The department then made Watson and Katie see a psychologist.

‘It was a fifteen-minute conversation that focused entirely on negative points, such as my childhood abuse and the small amount of cannabis I smoke. There was nothing about my work, about our household. Or about how I was paying off a new car for the family.’ Watson felt the psychologist’s report ‘completely demonised [him] as a person’.

The department made an application to remove Watson’s son. Watson challenged the order in court but the department argued Katie was not a fit person to parent, and Watson could not parent because he did not understand their concerns about Katie.

Although Watson completed two parenting courses he has been unable to overturn the order.

Watson and Katie’s relationship broke down.

‘An entire department weighed against me to remove my son and funded questionable psychological reports that undermine my character as a parent. My “impairments” were exaggerated to justify an 18-year removal order ... I worry about my son’s trauma from the whole ordeal and the impact it will have on his future.’

Bill and Carrie

Bill had cerebral palsy. Carrie, one of his support workers, told the Royal Commission he had been ‘neglected by the whole system’. He died at the age of 23.

‘He died alone, his family not contacted until after he died. Bill should never had to go through what he went through.’

Carrie first met Bill when he was 18, just after he had moved into a government-run share house for people with disability. She worked for Bill’s day service provider and described him as ‘full of life’.

During his time at the share house, Bill had a lot of health concerns. These included pressure ulcers and bruises and scratches from unknown causes.

She said when Bill arrived at the day centre, his poorly maintained wheelchair was often dirty from dropped food.

‘It was so badly broken and did not fit him and was causing injuries to his arms and legs. It was so badly designed he no longer fitted through doorways and could not be safely transported in the community.’

Carrie’s day service regularly reported its concerns to the share house.

A couple of years later, Bill broke his leg. The house manager didn’t say how it happened. Bill spent six months at an extended care centre before the health department transferred him to a hospital geriatric evaluation management ward.

Then, one day, Bill reappeared at the day service. Carrie washed his clothes and cut his hair.

‘[Bill] was malodourous, unkempt, neglected,’ said Carrie. ‘[He] had not had a shower since leaving the [extended care centre].’

Bill still had the same broken wheelchair that made showering difficult. The hospital suggested the day service wash him in the change rooms of a local public swimming pool.

‘We found this to lack dignity and refused.’

Instead, staff bought a shower trolley so they could wash Bill at the centre. They told the hospital they had serious concerns for his welfare. ‘He had developed pressure wounds on his elbows due to the poor condition of the chair.’

Bill had been waiting for a new NDIS package that would replace his wheelchair and provide 24-hour care in a new home.

‘He finally had his NDIS meeting. At this stage his chair was so broken he could not sit in it.’

Bill did not get his new wheelchair. Two days after his NDIS meeting he died in hospital from an infection in the wounds on his elbow.

Scout, Aubrielle and Fred

'I fear for [Scout]. I fear for her every night. I'll fear for her for the rest of my life ... We just want to make it right for her.'

Scout, mid-40s, has an intellectual disability, limited verbal communication skills and requires 24/7 support.

Aubrielle and Fred, her parents, have looked after her all her life. They told the Royal Commission they worry about what will happen to Scout when they die.

A few years ago, after spending five years preparing Scout, they transitioned her into supported accommodation.

Just before the move, they visited the house which was close by. They met the other resident but didn't have a chance to meet any of the staff.

'That concerned me because [Scout] just doesn't relate to new people at all. She never has. She takes a while to study people, and she works them out pretty well,' Aubrielle said.

Although the house was brand-new it wasn't purpose-built for people with disability. The hallways were tiled, and Scout can slip and fall easily.

Straight away, there were issues with staff. The home 'churned through so many' and Scout 'didn't know who was coming into the bedroom the next morning'. She started to rebel – banging her head, throwing things out of her room and refusing to get out of bed.

All her life Scout has had a set routine. She showers to help her wake up, then has breakfast and then takes her medication. Although Aubrielle explained the importance of the routine, staff ignored it to suit themselves. When she raised her concerns, the house manager shut her down telling her Scout preferred the new routine.

One time, Scout showed Aubrielle her knee and told her she'd fallen. The house manager called out from the hallway, 'Oh yes, [Scout] had a fall.' Staff hadn't provided first aid or written an incident report. Another time Scout was covered in mosquito bites and the doctor prescribed antibiotic cream. A week later the bites were all infected and Aubrielle discovered staff hadn't even opened the cream.

One evening Aubrielle found Scout 'whimpering in the bathroom'. She had bruises on her arms that looked like thumbprints. Aubrielle met with the area manager who told her Scout must have 'done it to herself', but Aubrielle didn't believe this.

Aubrielle became increasingly concerned about other aspects of Scout's care.

The food the home provided was often pre-made or frozen. Scout is a type 2 diabetic and it is important she has fresh nutritional meals.

Staff rarely took Scout out into the community. One weekend outing was a 10-minute drive.

Scout needs help to clean her teeth properly and staff refused to assist. After seven months, Scout's teeth were 'terrible' and she had to have a general anaesthetic to remove a tooth.

When Aubrielle and Fred made complaints, management told them 'outright lies' or ignored the issues. Aubrielle contacted an advocate who helped her make a complaint to head office, but instead of addressing her concerns they told her she could not visit the house without ringing first.

Fred said 'the situation was intolerable' and they moved Scout home.

Scout is now living in a new house with four other people. It is better, but while she loves the company and social aspect, it is still hard to get the support she needs.

'I want to die knowing [Scout] will be looked after for the rest of her life. I don't want to die thinking oh well, she's with such and such now, what happens if they die?' Aubrielle said.

Abuse is never OK



Print of my fist



↑
This represents
my previous relationship.
"Abuse is NEVER Okay"

⇒

right to have the same pay as everyone
else

better health care -



Artwork by Kiara Lavin

Adaam and Henrie

‘We say that we’re trying to normalise people with disabilities like the rest of the community, but it’s not happening.’

Henrie is the father of Adaam, who’s in his 40s. Adaam is autistic and has intellectual disability, epilepsy and post-traumatic stress disorder. He uses a wheelchair and can’t speak.

‘My son is not able to defend himself. And when [he feels threatened] what he does is he hurts himself,’ Henrie told the Royal Commission. ‘That’s his sort of way of showing to people that, “I don’t like that.”’

About 20 years ago, Adaam was living in a government-run group home. Another resident sexually assaulted him, but Henrie said nobody told him until after the police tried unsuccessfully to question Adaam.

‘That is my biggest concern at that time, that they didn’t call me in time to help my son to communicate with the police and with the other people involved in the incident.’

Henrie said staff tried to downplay what happened.

‘I didn’t get any help from them. They were trying to tell me that nothing really happened, which I didn’t agree with.’

The government department running the home investigated, but closed the case after finding no evidence of sexual assault. Henrie moved Adaam to another group home but, several years later, another resident assaulted Adaam.

‘That particular resident had my son in a headlock, and he was punching him in his head. And another time he threw three chairs against him, and most luckily missed him. That situation was going on for a long, long time.’

Henrie said Adaam began self-harming. The service provider took no action against the other resident.

‘Most of the people I complained to were sympathetic. The only thing is that it seems they didn’t have the power to intervene.’

Henrie said the same resident assaulted him a decade later when he went to Adaam’s rescue.

‘He smashed the door in my face. Closed the door. So, I had to call the police. So, I called the police and they arrived in about 15 minutes, and they helped me ... to go inside the house and get my son out of his room.’

Henrie applied for a court order to protect Adaam, but the magistrate denied it. He told Henrie, 'These people do not know what they are doing.'

'So, I'm just thinking that if we are trying to sort of say that disabled people should live normal lives as the rest of the community, what would happen in a normal house if there were family violence? The police will be called [and] they will take the person away.'

Henrie said Adaam is not receiving that same level of protection.

'My son is being abused, being intimidated, he is being physically assaulted, and he still has to live with the person – and even sit on the same table – to have dinner with him.'

Adaam still lives in the same house, but currently with only one other resident.

'I am hoping that the next person who steps in is not the same as the other two that I described before, because that would be devastating for everyone concerned.'

Cyrus, Anais and Colson

Cyrus, who has attention deficit hyperactivity disorder (ADHD) and a sensory processing disorder, is in high school.

His mother, Anais, told the Royal Commission that Cyrus is interested in engineering and computers. 'He is self-taught and he has just got an interest and enthusiasm for those sort of things.'

Cyrus struggled at high school and felt 'lost in the system'. His school gave him an individual education plan, but some teachers didn't follow it.

'There was this complete lack of consistency about it and he felt blamed for his own ADHD. Like, he couldn't concentrate, and so they [were] all constantly on about him not concentrating. Well ... are you engaging him? Why are you letting him sit at the back of the class? He's sitting at the back of the class on his laptop playing games.'

Anais said some teachers considered Cyrus 'a pain in the butt'. Cyrus felt excluded. His concentration and behaviour at school deteriorated. Doctors increased his medication.

'This is a bored student. This is a disaffected student,' said Colson, Cyrus's father. 'That's why we find ourselves here talking to you guys today, because the lived experience is that those events of last year are connected to everything that went before.'

'He didn't just wake up one morning and go, I'm going to do this stupid thing,' said Anais.

One morning, Cyrus took a toy gun to school after another boy beat up one of his friends. Some students reported the incident to the police. Cyrus ended up in juvenile detention for several weeks.

'They wouldn't give him his medication when he was first in, and that was when I thought, "Oh, he's actually quite lucid." We had talked to him on the phone and he seemed happier, almost, I mean, scared ... but just a little bit more able to talk things through and everything.'

Anais said it turned out that Cyrus had been overmedicated.

'We thought he wasn't concentrating, so [doctors] increased the medication. But in actual fact what it was, was that they increased the medication so much that he wasn't sleeping at night, therefore he couldn't concentrate during the day.'

Anais and Colson believe if the school was more inclusive, if it did more to engage with children with disability, listened to them and made them feel safe, things would have been different.

'At the end of the day, we just don't want anyone to have to go through this kind of experience,' said Colson.

'And it's not [about] what happened on that day. The problem is why it got to that,' said Anais.

Deacon and Nataly

Deacon is in his 50s and has intellectual disability, cerebral palsy and epilepsy.

He has been living in hostels since he was 17 and his relationship with his family broke down. 'My mum kicked me out,' he said. For the past 40 years he has moved from one hostel to another.

Nataly is his advocate. She says Deacon is a 'very strong and determined man'. He often talks about finding somewhere else to live that is 'safe' and 'private'.

Nataly knows that Deacon 'could live a different life', independently and free from violence. Together they inspected 'quite a few' rental properties. But without a character reference from the hostel manager, Deacon stood no chance of being approved for a lease.

Nataly told the Royal Commission that hostels are reluctant to support people with disability to live independent lives. 'They tend to say residents can't move out because they can't do this and that,' said Nataly. Trying to get Deacon a reference was a 'massive hurdle'.

Deacon had been living in the hostel with 30 other residents. They never needed a house key because the 'back door was always open'. He paid \$400 a week for a shared bedroom with no privacy. Some of his personal belongings, including a suitcase full of DVDs, were stolen.

Deacon was hospitalised several times because he was 'bedwetting at night', said Nataly. It may have been caused by social anxiety and the prospect of having to 'interact with people' on the way to the toilet. 'It was a 'nightmare,' said Deacon.

He would often spend his days at a sheltered workshop, or 'chilling out' at the local shopping centre, to avoid getting 'hassled' for money back at the hostel.

Although Deacon had been a resident at the hostel for several years and had a good reputation, the hostel manager refused to give him a character reference.

He insisted Deacon undertake an assessment to prove that he had the capacity to escape an emergency situation, such as a 'house that was on fire'.

Nataly came up with a way to 'flip' the scenario. She found Deacon a service provider willing to identify any supports he'd need to move out, and what further supports would be required to keep him safe. They wrote a recommendation 'about who [Deacon] was, and that he would be a good tenant'.

Deacon is now living in a private rental. 'I love it,' he told the Royal Commission. He bought all of his own furniture brand-new, and has memorabilia of his favourite football team throughout the unit. 'I can do whatever I like!'

Support workers help him 'do shopping, clean up and do his chemist runs,' said Nataly. And he does a good job of 'keeping the place tidy'.

At night, Deacon walks to the bathroom and back to bed without interruption. 'It's amazing!' he said. 'It's a miracle, now I don't wet the bed anymore! I cannot believe it!'

And while he finds it a bit lonely living on his own, Deacon says he will never return to hostel or group housing.

Ellison and Addilyn

‘I have learnt while I was going through all this, if you’re a female and you’re disabled you have 80 to 90 per cent chance of being sexually assaulted. I mean, if our government’s aware of that, why are they running the risk?’

Ellison, mid-40s, has Down syndrome and an intellectual disability and requires 24/7 care. Addilyn, her mother, is her primary carer.

In the mid-2010s Ellison was attending a day program and staying in respite care on the weekends.

One Monday, when Ellison came home, Addilyn noticed changes in her behaviour. She seemed withdrawn and angry and ‘started to wet the bed’.

‘She hadn’t wet the bed for years,’ said Addilyn.

Three weeks later Ellison told a staff member at the day program that a male support worker had sexually assaulted her when she was in respite care. The day program ‘took her seriously’ and notified Addilyn, who notified police.

Addilyn told the Royal Commission police conducted a ‘relatively thorough investigation’, but this was the ‘beginning of the problems’.

Police initially interviewed Ellison, with a public advocate as support, at the station. Ellison felt she was in trouble, ‘sat with her head down’ and was reluctant to speak about what happened. Police then spoke to Ellison in her home, which Addilyn felt was better but still confronting for Ellison. The police officers had little to no experience interviewing a person with disability and no ‘insight into a person with a cognitive disability’. Ultimately, the case did not proceed, however, the worker resigned from his position.

‘Basically, it came down to her word against his.’

Addilyn felt ‘very alone’ and ‘isolated’ and didn’t know where to get support for Ellison or for herself. She asked the provider for information about the assault, but they refused. She made a Freedom of Information request and received ‘pages and pages of redacted information’ that oddly included the support worker’s pay rate.

‘I rang them and said, “Are you serious? You are telling me how much an hour a person has been paid to rape my daughter?” And she said, “Oh well, we had to be seen to be open and honest.”’

Addilyn did discover that the morning after the assault, Ellison told a female staff member she was bleeding. They put it down to her having her period, but if they'd read her file they would have seen she was on medication to prevent her period. Addilyn believes if the staff member had acted the perpetrator would 'be behind bars'.

Addilyn contacted the relevant government department but said they 'played the adult card'. They wouldn't release information about Ellison because she was an adult.

Addilyn engaged a disability legal service who she describes as a 'godsend'. They launched a civil case against the provider, but she feels the provider 'got off lightly'.

Addilyn is now a hypervigilant parent and does not allow Ellison to stay overnight in respite care. Ellison is much more 'clingy', but a psychologist is helping her process the assault. Despite this, Addilyn is very concerned about Ellison's future, particularly as she herself gets older and less able to care full-time for her.

'She is a beautiful person, and I thought, you know, she would be happy anywhere. And now, that has all changed. I'm terrified. In fact, I would rather she went before me, and that is the reality.'

Halo and Mac

Halo is in her mid-40s, has an acquired brain injury, post-traumatic stress disorder and experiences seizures and vertigo.

She told the Royal Commission that when the NDIS was introduced, she thought it would be about 'getting people back out into the community', doing things that 'enrich your life'.

Instead, she has found the scheme's rules and processes 'arduous and taxing ... like pushing treacle up a hill'.

Because she lives in a rural location, waiting periods for services can be months or years. Halo says the idea of going without specialist care for so long fills her with dread.

A few years ago, Halo's occupational therapist recommended a number of home modifications to make it safe to access. 'If we had a fire, and if I had to go out the front, I would fall, and the back is nearly just as treacherous,' she said. The therapist's report went to 'different people', but Halo has heard nothing further.

Halo constantly feels 'let down', abandoned, and with a sense of having to 'fight every step of the way'.

Halo described her experience with support workers as 'a debacle'. One particular worker 'was always on her phone' and would 'sit in her car' while Halo was shopping. When the support worker introduced Halo to other people, she would say, "she's got a brain injury. You can't tell, can you?"

One day, Halo fell as she was getting out of the support worker's car. The worker was on a phone call and had not helped Halo out of the car. As a result of the fall, Halo sustained an injury.

Halo's husband, Mac, says he feels unable to leave his wife alone with support workers. He now stays at home when carers visit, to ensure they are taking good care of his wife.

'That's pretty hard. It limits my life, it limits [Halo's] life and that should not be the case.'

Iyla and Adalynn

‘Her whole life has been taken from her and they control everything she says and does, basically.’

Adalynn is the older sister of Iyla, who’s in her 50s. Iyla has Down syndrome and an intellectual disability.

Until a few years ago, Iyla lived independently in her family home in a regional town. At times, she lived in her own unit.

‘[Iyla] has had a pretty happy life,’ Adalynn told the Royal Commission. ‘She has achieved many things in her life.’

Iyla had a job and used public transport, did her own shopping, attended yoga classes and was part of a dance group.

‘I’m very proud to be her older sister. And we’re not just sisters, we’re best friends. We used to do a lot together, actually.’

Several years ago, their mother became ill. A family dispute over guardianship ended with the public guardian taking over.

‘They moved [Iyla] out of the house. [Iyla] didn’t want to go.’

Adalynn said that, at the time, the NDIS funded a support worker.

‘It was \$70,000 at the time and that was ample for what [Iyla] was needing.’

The public guardian placed Iyla in a group home.

‘She’s, I believe, now worth millions of dollars under NDIS, [to the] service provider, because she’s confined 24/7.’

Adalynn said her sister ‘didn’t want to live there’. The service provider supervised all their meetings. A couple of years ago, the public guardian moved her to another provider.

‘It’s an organisation that popped up, as they call them, “pop ups”. When NDIS was started. And they’re actually larger now in the three-and-a-half to four years that they’ve been going than other established ones before NDIS.’

Adalynn said the public guardian gave the service provider running the group home the power to make decisions about Iyla’s health.

‘I was not able to know information about any of [Iyla’s] health matters, any of her life.’

Adalynn said the service provider didn't like her visiting her sister.

'She's not allowed to go to the yoga class at all now. She's denied that, denied her community, her access to friends she's known for over years. Many things she's been denied, not by her choice. It's not her choice.'

The service provider also prevented Lyla from spending Christmas with Adalynn.

'She was having to stay in the house. Her first Christmas ever. And this is somebody who still believes in Santa Claus ... She was just quite distraught.'

Adalynn said that after she sent Lyla a cake for her birthday, the service provider asked the police to issue an apprehended violence order, on behalf of Lyla, against Adalynn.

'[Lyla] would have no idea this is happening.'

Adalynn is trying to overturn the order. She said she fears Lyla is now 'a commodity' because of the size of her NDIS plan.

'This is my sister,' Adalynn told the Royal Commission, showing us a photograph. 'That's [Lyla] and I two years ago. I think she looked pretty happy. She's so gorgeous. She doesn't deserve what's happening in her life.'

Jace and Kas

Jace, early 20s, is autistic and has attention deficit hyperactivity disorder and an intellectual disability.

Three years ago he was living by himself in supported independent living (SIL) accommodation managed by a disability service provider.

Jace would often get erections. Staff 'scorned him' and referred him to Kas, an occupational therapist specialising in sexual health.

The first thing Jace told Kas was that he was unhappy. He said, 'I want to get rid of [the service provider].'

Kas told the Royal Commission Jace was on a number of antipsychotic drugs. Despite this, she found Jace engaging and personable. He participated well in sessions with her, but she noticed his level of alertness diminishing as the day wore on because of the antipsychotics. Jace has no history of psychosis and Kas believes his GP was overmedicating him as a form of 'badly managed chemical restraint'.

Kas said that before she could address Jace's sexual health, the provider needed to address the neglect. Jace was 'baby sat' and didn't 'live a meaningful life'. No-one was addressing his continence issues. He had no activity programs.

Kas was shocked when she saw his apartment. 'He didn't have a bed that fit him, he didn't have air-conditioning ... there was no furniture.' He didn't have any money yet there was \$11,000 'building up in a bank somewhere'.

'[Jace] was exploited and seen as a way to get money ... He had no therapists despite the sizeable plan.'

Boredom is a trigger for Jace, and when he's bored he has outbursts. He can read and write but needs reading glasses, yet the provider didn't bother taking him to an optometrist. They also refused to allow him to use a mobile phone or tablet. During lockdown, Jace didn't even have a television to watch.

Support staff ignored Jace and spent most of their shifts on their mobile phones. One staff member posted an online dating profile for Jace with 'disgusting' comments about what he'd like to do to women. Kas knew Jace was 'respectful to women' and wouldn't have been involved with this.

With Jace's consent and after talking to some of the support workers, Kas arranged for him to see a psychiatrist.

Kas asked Jace for his consent to speak to the NDIS Quality and Safeguards Commission on his behalf. Jace told her he wanted to make a complaint too. He wrote 'people are mean to me' and 'people steal my things'.

Kas drafted both complaints and at the same time spoke to the provider's CEO and care coordinator about their 'passive neglect'.

Almost immediately a guardian was appointed to act for Jace. The guardian banned Kas from treating Jace and refused to allow her to hand over to a new occupational therapist.

The provider has since moved Jace, and Kas is unsure where he is. '[He is] missing ... because he is worth money,' she said. His NDIS package went from \$300,000 to \$550,000 and is slated to become more than \$1,000,000. Kas believes if the provider developed Jace's capacity he wouldn't need such a large package with so many support staff and could live in shared accommodation.

Kas believes Jace is 'a cash cow for a company that is expert at profiting within the disability sector'. The provider 'has a long history of poor management, burning out its workers and unsafe practices', but is 'well connected to the NDIA, the offices of administration and guardianship and alternative SIL companies'.

'Working together, they are successfully draining the financial resources of the scheme and bringing misery both to people with disabilities in their care, and the support workers they employ.'

Kamryn and Star

‘The carers are totally overwhelmed because the client-to-carer ratio is not sufficient to provide the care they need to give every individual.’

Kamryn, late 30s, has lived in a group home with three other residents for almost 20 years. She has Down syndrome, a vision impairment and other disabilities.

Star, her mother, told the Royal Commission the neglect Kamryn experiences at the home is ‘endemic’.

Kamryn is a ‘super carrier’ of a skin infection and has been seeing a skin specialist for seven years. She must have a bleach bath three times a week to control the infection, and her NDIS plan provides funding for one-on-one support for this to happen. Star has provided detailed instructions for staff to follow.

Both Star and Kamryn’s doctor have repeatedly asked the home to do the baths, but they don’t. Recently, at an appointment, the doctor asked the support worker present, ‘What don’t you understand? I have written it, year in and year out.’

Star believes the home is severely understaffed. She recently discovered Kamryn’s file doesn’t contain an up-to-date comprehensive health care plan.

One time, Kamryn and Star were at the movies and Kamryn needed to go to the toilet. Kamryn told her mum it was ‘really painful’ pulling up her undies. Star discovered she had a huge pus-filled infection from her stomach to her pubic region. No-one at the home had told Star about the infection or taken Kamryn to a doctor. Kamryn had to be ‘drained of the pus at an emergency admission’ in hospital.

Another time, without consulting Star, staff took Kamryn to a different skin doctor who prescribed a medication her regular specialist has expressly told them not to use. Staff like using this medication because it is quick to apply and takes less time than giving Kamryn bleach baths.

Staff also fail to apply the fungal medication prescribed for the repetitive fungal infections on Kamryn’s feet.

Kamryn does not have the strength or skills to brush her own teeth. Prior to living at the group home Star had taken very good care of her daughter’s teeth. Without them, she would be unable to eat anything but pureed food. Also, Star says, it would affect her speech and her years of speech therapy will be wasted – the teeth stop the tongue from lolling out.

A few years ago, Star employed an advocate to support the family. The advocate told Kamryn’s support worker they had to help Kamryn clean her teeth each day. The worker said they have a ‘no touch policy’ and couldn’t assist. The advocate suggested they use a hand over hand method to help her clean her teeth. Workers continued to refuse and stopped taking Kamryn to dental appointments.

‘[Kamryn] has a big NDIS package and that package is not being used for [Kamryn].’

Two years ago, Kamryn’s eyesight began deteriorating rapidly. She needed an operation and Star had to book a pre-operation appointment a year in advance. Star arranged to meet Kamryn and her support worker at the specialist’s rooms on the day of the appointment. Star turned up but Kamryn didn’t. Staff either weren’t answering their phones or, if they did, didn’t know where Kamryn was. Later that evening the support worker called saying they had cancelled the appointment. Kamryn was distressed because she knew the appointment was important and had been booked a year in advance.

Star made a complaint about the support worker and requested they be removed as one of Kamryn’s workers. The home agreed, but after a couple of months reinstated them.

Recently, a new house coordinator started and things have improved. Star is worried if the new person leaves all the improvements will stop.

Lara-Rose

‘I don’t want a free handout ... All I ask for is a little bit of help.’

Lara-Rose is in her 40s and was sexually abused as a child. She now lives with post-traumatic stress disorder, depression and agoraphobia.

She also has an eating disorder. A few years ago she fell, injuring her spine.

‘I can’t feel from my waist down,’ Lara-Rose told the Royal Commission. ‘Sorry, I normally never cry. I normally never get teary.’

Lara-Rose uses a wheelchair and lives alone. Since the fall, she’s gained so much weight from lack of exercise she can hardly move and is unable to leave the house.

‘I miss the basic day-to-day things in life, like just going for a shower, just going to the toilet. Being able to go to the kitchen, just little things I can’t do.’

Lara-Rose lives in a regional town and said the local hospital won’t treat her because of complications associated with her weight. She said the NDIA believes her physical disability is ‘only due to [her] weight’ and won’t help her until she can prove the disability is permanent.

‘Four times they’ve knocked me back ... They just keep going on about my weight, but the thing is I’ve got spinal injuries and I’ve just been diagnosed with two broken hips.’

Lara-Rose said that despite numerous medical reports, the NDIA now wants her to have an MRI scan to show the damage to her spine. The problem is, Lara-Rose can no longer fit into the machine.

‘It’s not the weight, it’s the actual width. And I keep putting on more weight each week ... I can’t get an MRI to prove what’s there that makes it a permanent disability.’

Lara-Rose receives a disability pension and the NDIS provides her with less than two hours’ support a day for her mental health disability.

‘The worst thing is that I had some money for therapies and they’ve used all that up for reports [on her physical disability]. I’ve got nothing now.’

Lara-Rose said she asked for surgery to control her weight, but her doctor said she doesn’t eat enough for surgery to work.

‘I haven’t been able to eat solid food since I was 12 years old ... I eat once a day, sometimes twice.’

Lara-Rose said pool therapy helped her to lose weight in the past. What she needs, she said, are support workers to help her access physical therapy.

'The hospital wants the NDIA to sort it, the NDIA wants the hospital to sort it, but in a way I find they're both responsible.'

In the meantime, Lara-Rose said she's trapped in her small apartment.

'All I do is sleep and stress, thinking what are they going to ask me next, what more do they want from me? I don't get it ... It's really embarrassing because I was never the person to sit around.'

Lara-Rose has a master's degree in counselling and wants to get back to work.

'I don't want to sit on the system forever. It's not me. I want to learn how to live with my new disabilities.'

Lara-Rose said she's a victim of a bureaucracy that wants her to prove her disability by having a procedure that her disability prevents her from accessing.

'I know I haven't got much left in life. I did fight for ages, you know what I mean, and I gave it my best shot.'

Orla

‘Agencies are filled with people that don’t have disabilities. And it’s like they’re telling you “you can have this” or “you can’t have that”, so it’s really like they’re dictating to a person with a disability ... you can have social activities if we say you can, or, you know, you can hear properly if we decide that you can.’

Orla, 50, has had a vision impairment for about 10 years and more recently, a hearing impairment.

A couple of years ago, Orla asked the NDIA to fund new hearing aids that her audiologist and occupational therapist recommended. Orla provided their assessments and reports explaining why she needed the hearing aids and outlining the risks if she didn’t use them.

Orla said the NDIA ignored the reports, telling her to use the standard hearing aids funded through a different government agency.

Orla told the Royal Commission she feels unsafe when she wears the standard hearing aids. If someone speaks behind her she is unable to hear them. If there is a lot of background noise she cannot hear properly. Orla says just trying to get across a busy road is challenging as she cannot hear the traffic properly. ‘Every day they put me at risk and I’ve had a lot of near misses with being hit by cars.’

The standard hearing aids have button batteries. If Orla drops the batteries she can’t pick them up because she can’t see them. Orla has a guide dog and fears her dog may ingest the batteries.

Orla applied for an internal review of the decision. After 12 months she hadn’t heard anything and contacted the NDIA. She discovered a staff member had made a decision but had left the agency. She had to apply again, but was unsuccessful.

Orla appealed to the Administrative Appeals Tribunal. She engaged a solicitor, and a barrister represented the NDIA. Orla believes the barrister’s fees alone would pay for the hearing aids she needs ‘three, four times over or more’. Meanwhile the NDIA continued to ‘really put [her] through a lot of anxiety, a lot of high stress, a lot of risk’.

‘[The barrister] was allowed to question me like a criminal ... because I was asking for something that was, to me, really vital to stop me from getting hit by a car or other risks to my guide dog, or if I had a fall.’

Meanwhile, Orla ran out of funds because her NDIS package ‘didn’t quite cover her needs’. She had to stop all services and supports. ‘I can’t clean my floors, I can’t clean my shower, just socially isolated. I’ve become depressed and ... I can’t really go out into the community.’ She has asked for an urgent review.

Orla would like to return to paid work but ‘keeps getting knocked backed’. She’s applied for at least 10 jobs at the NDIA and – although she’s highly qualified, has a postgraduate degree and a disability – has been unsuccessful.

One prospective employer emailed her a link for a virtual interview but it wasn’t accessible. Her disability employment service organised a phone interview but Orla never heard anything further.

Another employer shortlisted Orla for an interview but when the employment service asked a question about Orla’s guide dog, the employer withdrew the offer of an interview.

Orla believes government should take the lead and employ more people with disability.

‘That’s where the government needs to take responsibility because nobody else will.’

Raphael

Raphael is in his 40s and has an acquired brain injury, anxiety, depression and a spinal injury.

'I was initially trained as a disability support worker. Which is a bit of an interesting perspective, being a professional and a client,' Raphael told the Royal Commission. 'What I like to do is help people.'

Raphael said the low standard of care in the disability sector reflects the low level of qualifications needed to work in the sector.

'I mean, the fact that you can get a [certificate], which is ridiculously easy, then go into the sector with, you know, just a driver's licence and a blue card. I have seen that people ... treat the work as easy money.'

Raphael said his original service provider tried to discourage him from obtaining a driver's licence and become more independent.

'I originally had a very generous budget with the NDIS. You could see the dollar symbols dancing in their eyes ... They were pretty much in panic mode when I was going to get my driver's licence. They actually tried to physically stop me from getting my driver's licence. It was unbelievable.'

Raphael overheard a team leader refer to him as a 'cash cow'.

'I have actually heard a site manager use that term, "This is one of our cash cow clients." I was just gobsmacked by that.'

Raphael said the service provider would coach clients about what to tell the NDIS to get larger packages.

'What to say, what to exaggerate, to try to get the most funding for your budget. Obviously, they had an invested interest in you having a bigger budget.'

Despite his service provider trying to stop him, Raphael passed his driving test. When he realised he didn't need 'half of [his] funding for community access', he asked the NDIS to reduce his funding.

'I got the feeling that someone asking for less [was] a bit of a breath of fresh air.'

Raphael now manages his own funding package, but said providers still see him as a 'cash cow'.

For example, when Raphael needed physiotherapy for his back injury, he asked a physiotherapist the price for an initial consultation. He didn't mention he was funded by the NDIS.

'I think it was \$80 or something like that.'

When his wife later called the same physiotherapist and told them it was for someone on the NDIS, the price doubled.

'That was pretty unnerving. I was having to conceal that I had NDIS funding for fear of being grossly overcharged.'

Summayah

‘You are doing me an injustice ... and I have to fight for myself as a disabled person. Because if I’m not going to fight for me who’s going to fight for me?’

About 20 years ago, Summayah had a serious car accident in the country where she was born. Her right arm was paralysed. She told the Royal Commission she faced challenges learning to live with reduced motor-function, but she quickly adapted and lives independently without assistance.

After the accident, Summayah worked as a social worker with children. She held a full manual driver’s licence and drove every day as part of her job. She said her paralysis was ‘never an obstacle’ in her life or career.

A few years ago, an Australian government department sponsored Summayah to work in Australia. She told them her right arm was paralysed and signed a declaration of a pre-existing condition. She said no-one from the department mentioned or discussed her physical impairment again.

When Summayah started work, she informed the team leader about her arm. ‘Ever since then everything tumbled around me.’ Management insisted on weekly meetings to discuss her ability to perform her duties. Summayah requested a support person but management refused saying the meetings were ‘informal’. No minutes were taken.

Summayah told them she drove government vehicles in her home country in all her roles without issue. Her home country’s licence is recognised in Australia and has no restrictions. She had successfully applied to lease a car.

Management weren’t convinced and made her drive them to the transport department ‘to personally tell these people I am disabled’. It was a ‘heartbreaking experience’ and she felt ‘shattered’ and ‘humiliated’. Transport staff asked to see Summayah’s licence, noted there were no restrictions and confirmed she could drive in Australia.

Summayah engaged a lawyer and demanded a formal meeting. At the meeting, in addition to raising concerns about her ability to drive, management questioned her ability to safely perform her duties with respect to children. They said she wouldn’t be able to pick up a baby or fasten them in car seats. They also doubted she could handle difficult situations without assistance, such as needing to remove a child. She said she has never had an issue performing these duties when working in the same role in her home country. Furthermore, Summayah reminded them, she would not be doing the role alone because the policy is to conduct client visits in pairs.

Management demanded a department-appointed physician medically assess Summayah. The preliminary report found she was 'unfit to perform the inherent requirements of the role'. She said this was 'highly distressing'. She felt like the department wanted her to fail, and she had been discriminated against on the basis of her disability.

'I suffered a nervous breakdown as a result of the findings, with my self-worth and image devastated,' Summayah said. 'There was never any support for me while I was fighting this battle.'

The department transferred Summayah to a different office to work in an office-based role. They said they would assess her capacity in the role, and if they decided she could not manage the workload, she would be dismissed. Summayah felt enormous stress and pressure because her continued employment is a condition of her visa.

A few months later, the department told Summayah her contract would not be renewed. Also, they said they would not provide a recommendation letter to apply for permanent residency because she was in a contract position. Summayah's colleagues, who were sponsored by the department at the same time, were given recommendation letters.

'It was just a horrible experience ... I couldn't make peace with the injustice.'

Ted

‘My Aged Care has financially become a nightmare ... We feel we are totally discriminated against.’

Ted, mid-70s, contracted polio as a young boy and completed all his primary and secondary education in hospital. He has had a successful and varied career. He wore calipers until he had a relapse with post-polio syndrome in his 50s. He now uses a wheelchair and, until recently, continued to work and live independently.

Four years ago, Ted was hit by a bus. He was seriously injured and spent many months laying on his back in bed. He told the Royal Commission he lost the independence he had ‘fought so hard for throughout [his] life’. He now needs 24/7 care.

Ted sought compensation for his injuries and had to deal with a large insurance company. He said the insurance company’s interrogation tactics were ‘deplorable’ and ‘discriminatory’.

The company constantly accused Ted of lying and downplayed the value of his life. They told Ted he deserved a smaller payout because he had a shorter lifespan because of his disability. They also told him that because he was already in a wheelchair his life wouldn’t change much as a result of the accident. Ted cried through most of the ‘interrogation’ and left mediation meetings in tears. He couldn’t believe the way they were treating him.

Ted and the insurance company finally agreed to a settlement. His solicitors advised him not to accept the offer and to take the matter to court. ‘My mental health was at the lowest ebb and I just couldn’t go any further.’ He said the settlement monies were enough to cover a vehicle with a hoist and some items he needed to live comfortably at the time.

However, he’s since discovered it may not be enough for him to continue to live in his own home. People over 65 aren’t eligible for the NDIS. Ted says people with disability over the age of 65 are discriminated against by being ‘lumbered into’ My Aged Care with everyone else.

He says costs have skyrocketed since the rollout of the NDIS, directly impacting My Aged Care funding packages. Ted’s wheelchair prior to 2019 cost around \$12,000. His most recent wheelchair cost more than \$26,000. ‘That’s an enormous amount out of your package when you have the service providers charging anywhere between 33 and 42 per cent of your package.’ Ted’s shoes increased from \$100 to \$260 a pair in two years. The NDIS would fund these shoes, but My Aged Care does not cover the cost.

Ted says disability specialists are more difficult to find now as a large proportion of allied health professionals only operate as NDIS-funded services.

Ted feels pressured to move into full-time residential care because the costs are becoming ‘unmanageable’. His service providers charge him around \$56 per hour, but only pay the support workers a maximum of \$26 per hour. Night-time and weekend care can be up to \$300 per hour. ‘Service providers have a culture that the money from a package belongs to them.’

Ted's full-time carer receives a Centrelink Carer Payment. Ted said he's 'lucky' because without this payment, he would be without a carer and couldn't afford to live at home. One time his carer had to go to hospital at short notice. Ted did not have enough money in his My Aged Care package for another carer and had to rely on friends and family. Ted is worried he may soon have no choice but to go into a nursing home because his family live in a different city. He said he is 'far from ready' for that.

Ted said older people with disability live with 'an enormous amount of emotional stress' concerning their ongoing care.

'Anybody over 65 with a disability, regardless of their disability, should be on the NDIS.'

Valeria and Wesson

Valeria was murdered by her husband. He tried to make her death look like an accident, but was charged and convicted. Her son, Wesson, told the Royal Commission about the failure of guardianship and medical systems to safeguard against the abuse that led to her death about five years ago.

Valeria suffered a stroke in the 1990s leaving her with an acquired brain injury, speech impairment and mobility issues. Following the stroke, her husband's verbal abuse, which had always been a feature of their marriage, increased.

In his late teens Wesson left home and settled overseas. Over time, it became increasingly difficult to contact his mother and he realised other family members were having the same problem.

Eventually, the family made an application to the civil and administrative tribunal. This, Wesson says, started a 14-year process that commenced in relation to access, but morphed to include other issues, including his mother's personal care, health care and financial independence.

'We were quite worried about Mum's welfare in terms of when we would meet her, she would be in dirty clothes, or clothes that were too small, shoes that were too small, she smelled quite bad, so obviously she wasn't – she wasn't being washed. She never had any money ...'

Wesson lost count of how many times the family went to the guardianship board.

'[It] was very much up and down in terms of their interest. My father is quite a difficult person, I think often it was just put in the too-hard-to-deal-with basket. So we would go to the guardianship board, and then he would make undertakings, and then it wouldn't happen. Then another year or two would pass where nothing had changed, we'd go back to the guardianship board, he would make new undertakings, nothing happens again and again and again, and I could basically say this process continued for 14 years.'

Valeria's home was not accessible and, as her mobility declined she had lots of falls. Eventually, she moved into aged care but was put in a ward where there were few activities and no mental stimulation. Wesson wanted to move Valeria to a facility with more activities but his father refused.

Following the stroke, Valeria received a pension from her previous employer representing two-thirds of her salary. She had the means to make the house accessible, to buy nice clothes and many other things, but never seemed to have any money. The public trustee would not give Wesson any information about how Valeria's husband was using her money. But he later learnt that Valeria had apparently bought farm machinery while in living in aged care and had paid for her husband's legal representation for his guardianship applications.

'Why is the public trustee not asking questions? "Why aren't you paying for your own lawyer? Who is representing Mum's interests? Why doesn't she have a lawyer? What's going on here?" These kind of basic questions ... Who was protecting her interests?'

Fearing her husband was financially abusing Valeria, her family made an application to the tribunal to take away control of her finances from the husband, and for the public trustee to become her financial guardian. Wesson believes his father, who stood to inherit her pension upon her death, feared losing access to her money. '[He] was so dependent on her income that he was willing to kill her for it.'

He believes that 'if any of these issues had been taken seriously' earlier, his mother's death may have been prevented.

'This lack of any accountability and follow up. I mean, ultimately, it's cost her her life. And I think that's where she's just fallen through the cracks of the system. Because these cracks and this lack of follow up, it has consequences, and I think Mum just completely fell through them. This system that was meant to protect her, she just fell straight through it.'

Zayn

‘Suffering from extreme anxiety with no intervention from an early age means that I missed out on a huge amount.’

Zayn, mid-30s, told the Royal Commission he feels ‘angry’ that his parents, teachers and doctors ‘had their heads in the sand’ and never ‘picked up’ his disabilities when he was young.

From a young age, Zayn’s father, brother and then stepfather physically abused him. Once, his brother tried to drown him and his parents didn’t intervene.

Zayn didn’t speak until he was four. Countless school reports describe him as ‘extremely quiet’ and having ‘difficulty speaking’. One time two older boys seriously assaulted him. When teachers asked about his injured ribs he wasn’t able to speak.

No-one ever investigated Zayn’s behaviour to determine if there was an underlying cause or issue.

When Zayn was about 13, he climbed onto the roof of the house to escape his brother’s abuse. Medical specialists didn’t ask why he climbed on the roof and incorrectly diagnosed him with bipolar disorder. In his teenage years, doctors treated him for depression but didn’t ask him questions about his life growing up. They didn’t ask if anyone was harming him.

Eventually, in his late 20s, he was diagnosed with post-traumatic stress disorder and ‘extremely severe’ generalised anxiety. He said if he’d received help earlier he would have the tools and strategies to manage his disabilities more effectively. He would have been able to ‘enjoy life’ instead of being ‘constantly on edge’.

‘All I have ever wanted is for a doctor to explain things to me, to talk to me, rather than having to find out years later that they have written something about me which isn’t true.’

He has recently applied for an assessment for autism but there is a 12-month waiting list in the public system. A private diagnosis is too expensive, costing \$1500.

Indigo and Kerry

Indigo is an autistic teenager with chronic disease and psychosocial disability.

She ‘very rarely’ leaves the family home because of her anxiety. ‘She has maybe one or two friends ... and the rest of the time it’s more at home with [me],’ said her mum, Kerry.

Indigo is now on her third NDIS plan. Each plan went to review due to insufficient funding which failed to capture her ‘real needs’. Kerry says the system isn’t set up to support people with disability.

‘You advocate your ass off, and you get all the reports you can so that you can tick all the boxes ... [to] try and meet what the system wants.’

During the COVID-19 pandemic, Indigo’s mental health and wellbeing went into decline. ‘COVID was sort of the catalyst that really brought everything to a head,’ she said.

When school restrictions began to lift, Indigo told her mother, ‘I still really want to learn, I’m just – I’m really struggling to actually go out.’

Kerry tried to arrange remote learning for her daughter, and the school initially agreed.

However, a few months later the school wrote to the family informing them ‘teachers already have enough work to do in the classroom’ and they’re ‘under no obligation to mark [Indigo’s] work’.

The family met with the school and advocated for adjustments such as letting Indigo use the library as a quiet ‘safe space’ to study during classes. They were told what they were asking for ‘wasn’t reasonable’.

The school said Indigo already received ‘regular breaks’ when she needed to use the bathroom. ‘Apparently, that is classed as a sensory break ... that was [considered] time out,’ Kerry said.

The situation became ‘incredibly’ difficult as Kerry continually had to justify Indigo’s needs.

‘She is my daughter, she is my world. I love her ... [and] have to focus on her wellbeing. It is not realistic to expect her to go to school [any longer].’

Indigo has enrolled in a pilot education program that offers online schooling that focuses on the student’s level rather than their age. Kerry said ‘they understand that kids quite often learn at different paces with different subjects ... [and they] meet you where you are at.’

The family has now decided to focus on Indigo’s mental health and build her ‘capacity to explore and find herself and find her way in the world ... and build those skills so that she can do so safely’.

Indigo's latest plan had been locked in for the next few years. Now that her support needs have 'exponentially' increased, Kerry will need to request another review.

Kerry is in the process of 'collating all the evidence' so that she can 'put the strongest case forward'.

Kian and Eithan

‘The social and emotional support is the thing that is going to suffer.’

Kian, 60s, was born with quadriplegia and cerebral palsy and is non-verbal. His brother Eithan told the Royal Commission that Kian loves to swim and is in good health. He requires 24/7 support.

From a young age Kian lived in different institutions and group homes.

Thirty years ago he moved into a state government-run purpose-built duplex home for people with high care needs. Each house had five residents.

Initially each house had two disability support workers every shift. The houses shared a floating supervisor who helped out and did all the administration. Eithan said the staff provide a very high level of care and are incredibly hard working and caring people. ‘We’ve been really lucky as a family, we’ve had some very good staff.’

A year ago, without consultation, management axed the supervisor position. The support workers are now required to spend 30 per cent of their time on administrative duties. At night, only one support worker is rostered to each house.

Management did not inform residents about the changes. ‘We found out informally through the staff.’

When Eithan spoke to management they told him they are working within the NDIS funding model. ‘The state government needs to adjust the care they provide based on what the NDIS gives them.’

Eithan is very concerned because the funding is not transparent and he’s unsure how it will affect Kian going forward.

Kian needs two staff to help him get in and out of his wheelchair and to shower, bathe or use the toilet. This means there are no staff available to supervise or support other residents at these times. Previously the floating supervisor filled the gaps.

‘It really reduces the amount of supervisory oversight ... for new staff and making sure the procedures are followed.’

The loss of a staff member also reduces the residents’ ability to engage in community activities. Only one resident can be out in the community at a time, as opposed to two or three. Staff no longer have any downtime to take residents to the beach or the shops.

‘When you hear the stories of what has gone on in aged care, it makes you worry for the whole sector ... we’ve seen examples of that starting to happen.’

Eithan is concerned too many changes are happening ‘while the screen is still up’ and there needs to be greater transparency and consultation.

Deidre

‘If you grow up with people with disability [and] they go to school with you, you work with them, you won’t have that bias or discrimination, we hope. Well, I think so.’

Deidre is a retired teacher.

‘I worked for 25 years in schools, both in special education and inclusive education, and primary and secondary,’ Deidre told the Royal Commission. ‘I’m lucky enough to have also worked in disability-specific units at a regional level, and also in leader roles in schools.’

Deidre’s son is autistic and has intellectual disability and obsessive-compulsive disorder.

‘I suppose what I’m trying to do is have a helicopter view over that time and look at some themes as I have seen them ... It scares me that I look back to what my classroom was like in 1983 and ... not a lot has happened ... to enable inclusive practice.’

Deidre said the segregation of children with disability in schools is ‘a form of abuse and neglect’.

‘The segregation, particularly here in Queensland, is getting worse. [I’m] seeing more special schools being built.’

Although a special school can be inclusive and welcoming, Deidre says, ‘at big society level that is segregation’.

‘I don’t think what we are doing at the moment is reflecting the society I think most of us would agree we want to live in.’

Deidre says many parents are now discouraged from enrolling children with disability at their neighbourhood school, particularly the local high school.

‘You are faced with the principal or a deputy that sort of goes, “Oh, you know, the school down the road, the special school is for you.”’

Deidre says that while parents are often told their children have a choice of where they go to school, ‘it’s not a free choice’.

Deidre resigned from her teaching job because she had ‘a bit of disagreement’ over the lack of inclusion. She became an academic and trained teachers.

‘I remember one student put up his hand and said, “[Deidre], I have never met a person with a disability. How do I talk to them?” That is a reflection of our society.’

Rochelle and Marnie

Rochelle is a teenager with autism, intellectual disability, schizophrenia and bipolar disorder. She was in foster care when Marnie adopted her.

‘She was six years of age when a teacher said, “Oh, that’s a foster child, and she’s got mental health problems,”’ Marnie told the Royal Commission. ‘My daughter came home and told me what they said. I said to her, “Don’t listen to people like that.” But [the teachers] should learn – they are in education.’

Marnie said that a couple of years ago, Rochelle was rushed to hospital after harming herself. After several hours, a doctor sent Rochelle home with a prescription. ‘So, I rang up mental health [services] to see what the prescription was for and they said, “Oh, just take it down to the doctor.”’

Marnie’s doctor told her the medication treated schizophrenia and bipolar disorder.

‘And I said, “How long is she going to be on it for?” He said, “I don’t know” ... So, I rang up mental health [services]. I’m still waiting and I’ve got no response from it.’

Marnie said the local hospital has limited mental health facilities and staff avoid Rochelle ‘because they are not sure’ how to treat complex psychosocial disability.

One day, staff put Rochelle in an empty room with a cement floor.

‘There are no cushions or anything to sit on ... And Rochelle sat on that cold floor without a blanket, without going to the toilet. They just left her there. For two and a half hours she sat there.’

Rochelle was cold and started shaking.

‘So, when the doctor came past I grabbed him and I said, “Have a look at my daughter, there is something wrong,” and I told him what happened. He said, “She’s in a convulsion. How long has she been like that?”’

Another time when Rochelle was admitted to hospital, a doctor assumed she was in labour.

‘They throw her on a bed, they pull her legs apart like she’s a flaming piece of sheep, and he said, “Oh, she’s in labour, first stages.” I had a policeman with me who told them to keep their hands off her.’

Marnie said Rochelle was sexually abused at school and her treatment at the hospital traumatised her.

‘They talk about her as if she isn’t there and neither am I ... I would never, ever go back to [that] hospital again in my whole life and neither will my child.’

Hayley

‘When a person is diagnosed with a significant condition, the next step should be for someone to help them ... If they stop working, how do they access funds, how do they live, what changes do [they] need to make to do well and live a life that is doable?’

Hayley, late 40s, has degenerative conditions that affect her sight, mobility and short-term memory. She also experiences profound incontinence and mood instability.

When she first became unwell 10 years ago, she ‘really struggled’ to figure out how to look after her kids.

‘I was on the couch, not really able to get up ... and the kids were locked in the loungeroom with me. We had a lunch and a morning tea there and waited for dad to get home and sort of take the kids, and bed, bath and everything else that needed to happen.’

Desperate, Hayley contacted the department of child services and reported herself for neglect. The department provided a nanny for a few hours on a temporary basis. Hayley told the Royal Commission this was helpful, but she had to constantly reapply for the nanny.

‘Every 13 weeks I needed doctors’ letters to support the ongoing issue, so it was quite a lot of effort to help keep her there.’

The children missed out on ‘a bunch of basic things’. They didn’t have play dates. No-one came to the house. They didn’t participate in sport or after-school activities.

When Hayley could no longer turn the taps on and off, she realised she needed more support. An occupational therapist assessed the home and recommended a number of modifications.

The department approved Hayley’s development application and put the work out to tender. The builder they choose quoted \$98,000 to modify the bathroom. Hayley believes if she’d contracted privately, it would have cost \$20,000.

It took two years for the builder to finish the bathroom and then widen the doorways for wheelchair access. He told Hayley he would complete the landscape stairway with a staircase and chairlift within a few months.

But there was a breakdown between the builder and the engineer, and the work stopped.

Hayley contacted everyone involved, eventually making a complaint to the disability minister. The minister sent her back to the department, who in turn told her to contact the builder.

‘The builder was quite aggressive with me,’ Hayley said.

He would yell at Hayley, call her names and tell her to stop getting involved – she should be grateful that she was getting a publicly funded staircase. At one stage he told her he was not progressing her modifications because he was helping ‘people who really needed it’ – she was healthy. Hayley started recording their phone calls.

Then, Hayley’s development application expired.

The department told her that for the work to continue, they needed to hold a mortgage over the home. She wasn’t in a financial position to agree to a second mortgage and made a complaint to the state ombudsman. Eventually the department agreed to remove the mortgage condition.

It has now been more than 10 years and the work has still not been completed. This has placed a huge strain on Hayley and caused her immense stress. She is terrified of falling down the stairs and her family becoming homeless.

Hayley’s husband began losing his temper during the disputes and their relationship broke down. He no longer lives in the house and stopped supporting her financially.

Hayley is worried he may want to sell the home. There is a 6-year waiting list to get social housing where she lives, and any house will need to meet her increasing accessibility needs. She is not able to move out of the area because she relies on her parents, who live locally.

‘If you weren’t having a hard time emotionally from the loss of your abilities, then ... the process of getting assistance is so convoluted that it would definitely take you out, and it has done me on many occasions.’

Carlo and Analia

‘There should be rights for people who live in supported accommodation ... There’s nothing in law to say what the protections are ... Service providers are able to just move people around and do what they like.’

Analia, early 50s, lives with chronic depression. She is a full-time carer for her brother, Carlo, who has cerebral palsy, diabetes and schizophrenia.

Analia told the Royal Commission that Carlo’s dream was to have a ‘home for himself’ and not to have to live with her or their parents. For about 10 years he lived happily in supported accommodation with two other men.

‘They were like their own little family,’ Analia said. ‘They would do things for each other. Like the other person had a motorised scooter, so he would do the shopping while [Carlo] would hang out the washing.’

Then, about five years ago at a routine meeting, the house manager told the men the provider was breaking up the house and moving them to other accommodation. The two men who had recently turned 65 would move into an aged care facility and Carlo would move to another house.

Carlo, who’d been unwell, was very upset. He told the house manager he did not want to move and ‘did not want to separate’.

He immediately contacted Analia, who contacted the provider. They told her the decision had been made and there was nothing she could do.

Analia contacted the health complaints commission, telling them any move would seriously jeopardise Carlo’s mental and physical health.

The commission ordered the provider to consult Carlo. As a result, Carlo was allowed to stay in the house until they found suitable accommodation.

‘The chief executive, it felt like she didn’t even really understand [Carlo] or his circumstances or his disabilities,’ Analia said, ‘even though he had been a client of that service for 10 years. She seemed to not even understand that he had cerebral palsy.’

Carlo’s health deteriorated.

He could no longer cook for himself and bought biscuits, chips and pet food to eat. He became confused and stopped taking his medication regularly. He also became increasingly paranoid, not wanting to leave his home.

Analia met with a new provider who was ‘supposed to be all amazing and have lots of programs’, but ‘they didn’t do anything’.

The new provider was only concerned with 'housing people' and was 'out of touch' with Carlo's needs. The provider placed him in homes with other residents who had violent behaviours. One man 'dominated' Carlos, forcing him to stay in his room. The home hadn't been modified for a person with physical disability. Carlos had to walk up a set of stairs with no rails to get to the bathroom.

Carlo's behaviour 'changed significantly'. He became concerned people wanted to hurt him and his family. He started hoarding.

Analia made formal and informal complaints to no avail. She felt she had no choice but for Carlo to live with her.

'The dream of having his own place ... is now lost. And [Carlo] has been left traumatised by our experiences of trying to sustain that dream.'

Yara and Sunny

‘I have been through a lot of very stressful things in my life, but absolutely nothing has mentally crushed me the way the interactions with the [public] trustee and guardian have ... It crushes me mentally, emotionally, spiritually because they just won’t fucking listen.’

Sunny and her daughter Yara, a baby at the time, were involved in a serious car accident about 30 years ago.

Sunny sustained injuries to her legs and pelvis and continues to experience significant pain. She has post-traumatic stress disorder and borderline personality disorder.

Yara acquired a brain injury and has vision impairment and physical and cognitive disabilities.

At the hospital, doctors told Sunny that Yara would be ‘a vegetable for life’ and would be better off in a home.

Sunny disagreed.

‘I learnt about how an uninjured brain works. Then I learnt how an injured brain’s difference might be. I learnt about different ways of communicating. I learnt about developmental steps and processes,’ Sunny told the Royal Commission.

‘My daughter now walks with assistance, can pick a cup up and drink from it, and can pick finger food up and eat that by herself. She has gained all these levels of independence that we were told would never happen.’

After decades of neglect and abuse, Yara now has a good support team in place.

She wants to be more independent and ultimately move out of home.

Yara received significant financial compensation as a result of the accident. The public trustee manages her finances.

Yara is conscious of her money and is very frugal. When Sunny asks her how much she wants to spend on certain items she goes through a list of choices and chooses the cheaper options.

The public trustee assumes Yara doesn’t understand her finances. They refuse to provide Easy Read documents and financial statements because the existing documents are ‘how documents are’. Sunny finds this nonsensical.

A couple of years ago, Yara and Sunny started looking for a house for Yara.

They found a place that could be modified in the area Yara wanted to live, and asked the public trustee to release the money. But it has been a 'two-year battle' for Yara to be able to buy the house.

Every time Sunny thought she had done what the trustee required, they told her, 'No, we still haven't approved it. You have to do this or that, or something else.'

Sunny was at the 'point of suicide'. She said it was only the fear that the public trustee might never let Yara buy her own home that stopped her. 'I certainly felt that I couldn't mentally cope with one more thing.'

Recently Yara wanted to stop attending her day program. It was an 'abusive environment', Sunny said, and Yara didn't want to be there.

'I had to fight them to get my daughter out of the day program.'

The guardian felt Yara needed to be with her peers.

'She in fact belongs to dozens of peer groups,' Sunny said. 'Young women ... people who love music. She likes swimming – she might find peers who are at the pool ... Yet their entire focus was on her disability.'

Eventually the guardian agreed she could stop going to the day program and spend her day doing what she wanted to do.

Meanwhile, Sunny says, Medicare refuses to give Yara her own card because she can't sign her name.

She has a stamp with her signature and can stamp her name. Sunny wants Medicare to accept this.

'For me it is just abusive that they keep making me responsible for areas of her life that she wants to be responsible for. She wants her autonomy and independence over that. It is like they won't let apron strings go. She wants to, and I want her to. She is forced to be mummy's little girl forever because these government departments won't cooperate and provide her with what she needs.'

Abner and Gulliver

‘There’s people being abused everywhere.’

Gulliver is in his 60s and lives with post-traumatic stress disorder, anxiety and depression. He is the legal guardian of his nephew, Abner, who has cognitive and physical disabilities following a motorbike accident about 20 years ago.

More than a decade after the crash, Gulliver helped Abner’s mother move him into a group home in a regional town closer to where they lived.

Gulliver told the Royal Commission the manager of the group home tried to take control of Abner’s finances by keeping his bank card – ‘To the point where she refused to let me or [Abner’s mother] use it.’

Gulliver said before the manager went on holidays, Abner’s mother demanded the bank card back.

‘[The manager] didn’t want to hand it over. So [Abner’s] mother insisted, and when she got it off [the manager], she said, “And you’re not getting it back either.”’

Gulliver said he discovered discrepancies in Abner’s accounts, including the use of Abner’s card to buy food such as pizza.

‘[Abner] doesn’t eat pizza. So, I don’t know who ate the three large pizzas. It’s a pretty sad story, isn’t it?’

Gulliver was appointed Abner’s legal guardian and power of attorney. He then had ‘a lot of trouble from the staff up through the ranks’ to the service provider’s senior managers.

‘They considered me an affront to their authority and duly let me know. And from then on, it was more or less a nightmare.’

Gulliver said, for example, that staff ruined the carpet in Abner’s room by failing to empty his urine bag. He demanded the service provider change the carpet.

‘From that day on, their staff were brutal to me and [Abner’s mother] ... They were calling the police on me. They were calling the police on [Abner]. I believe beyond a shadow of a doubt that they were psychologically abusing [Abner]. They were bullying me and [his] mother.’

Gulliver says other residents are being abused, including a man who had his finger caught in the bus door.

‘They bandaged it up and left it for about a fortnight, I believe it was. It went gangrene, and he had to have his finger removed.’

The experiences have left Gulliver anxious and depressed. To help him 'get out of this' feeling of helplessness, he started his own business.

'My goal is to have a successful business that employs people on disability employment, and I've just employed my first young man.'

Gulliver also moved Abner to a group home run by another service provider in another town.

'I'm absolutely thrilled with the way he's being looked after. And the manager there is as straight as a gun barrel. She doesn't take any rubbish from the employees. And [Abner] is a different person altogether ... He's happy.'

Gulliver told the Royal Commission that some service providers 'absolutely abused' the government resources allocated to help people with disability.

'Years ago they ... didn't have these facilities and people died, died living on the streets, or ended up in mental asylums where they should never have been. All that's changed ... but the attitude has gotten worse.'

Serenity

Serenity is in her 40s and is autistic.

'I'll straight up refer to autism as autistic spectrum condition, not autistic spectrum disorder,' Serenity told the Royal Commission. 'I don't believe that autism is disabling. It is disabling [only] because of attitudes towards autistic people in society.'

Serenity also has attention deficit hyperactivity disorder (ADHD) and post-traumatic stress disorder as a result of domestic violence.

Serenity said that several years ago, her husband assaulted her.

'He started being violent to my daughters as well. And because of that ... the police got involved. And then child protection because of the domestic violence, [although] they weren't aware that he was also being violent to the kids as well.'

Serenity said she didn't tell child protection services of her husband's violence towards the children because she was 'scared of losing the kids'.

'But I mean I thought ... knowing that he was violent to me in front of the kids would be enough to get support to deal with his violence without losing the kids and without making the situation worse.'

Serenity said she has 'the female presentation of autism'. 'We tend to be loud and awkward and hand waving.' She said her husband is manipulative and was able to convince the police that she was the abuser.

'One of the incidents they attended ... he slammed my arm in a ... door and I had bruises from mid-forearm right up to nearly my shoulder ... They definitely saw them. They claimed that I was the aggressor.'

Serenity made a complaint to the police about the violence, but says they 'won't even look at the evidence'.

'Even when I've reported some of the other assaults from my [now] ex-husband with evidence, with witnesses, it's just been swept under the carpet.'

When Serenity took out a domestic violence order (DVO) against her husband, he took one out against her.

'He made complaints to the police that text messages about my daughter's welfare breached the DVO. And the police charged me.'

Child protection services then became involved.

'They took the attitude of, because I'm weird and awkward and talk loudly ... I must be the bad guy and my poor, poor husband was the sweet innocent little victim. And this continued even after he admitted to punching me in front of the kids and incidents like that. They still acted like I was the bad guy. I must be mentally ill because he said so.'

Serenity said her ex-husband has custody of her daughter while a custody case is before the court. She is representing herself because she can't afford a lawyer.

'It took [several years] to get a final hearing ... And the judge's constant criticism saying that my affidavits were poorly written and jump all over the place, which is part of my ADHD, which is why I needed a lawyer. But I didn't have one.'

Serenity said that during one hearing, a psychologist told the court that people with autism and ADHD were 'basically ... a danger to children'.

'And my worry is that if he gets what he wants, which is sole custody and to cut me out of her life, that he will go back to physically abusing her.'

Bernie

Bernie is in his 30s and has attention deficit hyperactivity disorder, diagnosed a couple of years ago.

Bernie is a disability advocate. He told the Royal Commission about working in regional and remote communities.

‘The barriers in place for any person like me accessing the Disability Support Pension are already enormous. Add to that a thousand kilometres of unfathomable roads, and also the fact that there are no mechanisms to get the things that are needed to make the application in the first place. It’s purposefully designed to be inaccessible.’

Bernie said remote First Nations communities are especially disadvantaged because ‘poverty-stricken groups ... don’t fight for themselves a lot because they don’t have [the resources] and they don’t know how’.

Bernie said people with disability in remote communities are more prone to losing their independence and being ‘predated upon’.

‘It’s all service provision out there. The [service providers have a] very maternalistic, paternalistic idea of what health care should be like, rather than involving people in their own journey.’

Bernie said before the NDIS was rolled out, services in remote communities were already expensive ‘just by the fact that it is so far away’. Now, there is often only one service provider for a community, removing an individual’s choice and control.

Bernie said, for example, conversations about an individual’s needs often stop after they’ve seen their doctor.

‘[The doctor] will have this conversation with the participant, and then they will put that into their report, and that will go down to the service delivery people.’

Bernie said because there is little privacy in small, remote communities, participants often turn up to NDIS meetings alone, without a key support person.

‘If someone has shame or guilt about what is wrong with them, and what they need help with, then they are going to leap at any opportunity to not have to talk about that in front of people.’

Bernie said participants are often ‘prevented from accessing the thing that they need’ and given supports they don’t need because they go to meetings alone, without a key support person. They feel powerless to object.

Bernie said support people should be mandated 'for NDIS interactions of any kind' in remote communities.

'Whether it is mum or grandma, or uncle, or, you know, a school teacher, or a case manager or someone who knows them who they feel comfortable with talking about it.'

Bernie said it would help stop 'pencil-pushers from burying or disagreeing with health practitioners' recommendations and treatment plans and advice'.

Bernie said recently an NDIS officer told a client to 'lose weight' before she could access supports for her disability.

'Osteoporosis and osteoarthritis ... make it hard for her to walk around or cook her own food, or go and do her own shopping. And the decision officer, who was not a health practitioner person, told her she needed to lose weight, and then she wouldn't have a disability anymore. That is happening a lot.'

Nath and Odell

Nath has severe intellectual disability, limited physical movement and is non-verbal. He uses a wheelchair because his walking is unstable. His brother, Odell, and his mother are his appointed guardians.

Nath entered full-time residential care in 2005 as a teenager. He had previously lived at home, but when Nath's father died his mother could no longer cope. Since then, he has lived in two separate residences and had four different disability support providers. Odell says they had few 'good experiences' with any of the providers.

The first disability support provider didn't understand Nath's needs and wouldn't allow his family to be involved in his care for the first six weeks.

Nath moved to a different house managed by another provider. Odell described a history of unexplained injuries to Nath while living at this home.

One time, Nath hit his head on a wall. His head was bruised and the wall had cracked. Two support workers claimed Nath had been banging his head on the wall, but Odell believes a worker hit Nath's head against the wall. The family reported the incident to the provider but is unsure if it was investigated.

A few years ago a support worker was involved in a car accident. Nath was a passenger. While the worker was dealing with the accident, they left Nath unattended in the hot car until he 'was on the verge of collapse'. The worker tried to blame the collision on Nath, saying he had distracted her.

The family contacted police about this incident but were told that leaving Nath in the hot car did not meet the criminal negligence threshold. The family made a complaint to the provider, but received no response. Odell feels there is a lack of accountability by disability support providers in responding to or following-up complaints, and they often don't tell families about the outcomes.

When the next service provider took over, a support worker told Odell that Nath had broken his leg falling out of bed. Odell says the cushioning around the bed would have made this unlikely. The family had placed a camera in the house, and the footage from the day before the incident showed the worker 'out the back reading a book having a ciggy', instead of inside watching Nath. Odell believes Nath fell while trying to walk without support.

The hospital said it could not provide the rehabilitation Nath needed to recover. The family wonders if the hospital took this position because of Nath's disability.

The family transferred Nath to a private hospital where he received the care he required. While there, the family reviewed footage from a dashcam they had placed inside Nath's car some time before. The family noticed the same support worker had taken Nath out on various occasions, leaving him alone in the locked vehicle for around 20 minutes while they went and bought coffee.

The family gave the support provider the footage. It took two months for them to investigate the complaint and they did not inform Odell of the outcome. They terminated the worker's employment, but Odell believes she is still working with people with disability.

Throughout his time in care, support workers have ignored Nath's dietary and feeding requirements, thinking 'they know better'. For instance, an operations manager designated Nath as 'nil by mouth'. Without any water, he became dehydrated.

Odell believes many support workers lack appropriate education and training in understanding people with intellectual disability, and many have the wrong attitude.

Abel and Adeline

Abel rode his pushbike into the back of a truck when he was in his teens. Now in his 30s, he has an acquired brain injury and vision impairment.

‘He was found unresponsive,’ his mum Adeline told the Royal Commission. ‘They pulled into the hospital, they got a pulse and they kept working on him ... And then an hour later when I turned up at the hospital and I spoke to him he snapped out of unconsciousness and he sat up.’

Adeline said Abel ‘completely changed’.

‘He was one of my nicest, politest boys. He used to help with the housework. He used to want to vacuum the house. He was always “please” and “thank you”. And all of a sudden it was just, “I want food. I want it now.” ... I realised really quickly that he had hardly any long-term memory and less short-term memory.’

Abel also became irritable and increasingly violent. The hospital told Adeline to contact a brain injury organisation. Adeline and Abel live in regional Australia and the organisation told her it had no-one nearby who could help. It suggested asking a government mental health service for help.

Adeline said the mental health service staff told her that, to get their help, Abel would need ‘a mental health diagnosis ... Or else [they] can’t get funding’.

‘They said, “Well look, what we’re going to do is we’re going to diagnosis schizophrenia because he’s having aggressive behaviours and that would most suit that diagnosis.” ... I had no idea that it was a lifelong diagnosis that can’t be removed once it’s been given to somebody. And I just went along with it.’

The doctors prescribed antipsychotic medication. Abel’s behaviour became worse.

‘And then two years passed and he didn’t get better, he got worse. He just continued to get worse and worse and worse.’

Abel started drinking and smoking cannabis. After several years on antipsychotic medication, he began having seizures. Adeline asked the mental health service to take him off the medication because he was ‘not truly schizophrenic’.

‘They all knew this. They all knew they took him in as a brain injury ... They kept using the excuse, “There’s not enough funding. He falls through the cracks. We can’t do anything.”

When a new service provider took over Abel’s care, a manager labelled Adeline ‘neurotic’ and ‘hysterical’ for questioning his medication and diagnosis.

When Abel began to destroy Adeline’s public housing home, he was evicted and started living on the streets.

'I used to drive around looking for him. In summer I would take him water. In winter I would take him blankets. I was forever trying to find him to feed him to give him food. [Abel] became dirty and malnourished.'

Adeline said Abel stole food and was sent to prison, spending 'the entire year in there hitting his head against the walls'.

While in prison, a neurologist diagnosed him with a condition caused by antipsychotic medication. When Abel was released, another neurologist prescribed new drugs. Abel's behaviour improved in three months.

Abel is now being treated for an acquired brain injury. The NDIS provides him with 24/7 support.

'He's just now a big gentle giant ... He's going to gym five days a week. They take him fishing and on barbecues. He's got a beautiful house ... He's living a normal life and thank God for the NDIS. Without the NDIS none of this would be possible.'

Adeline said the mental health service won't take responsibility for the misdiagnosis.

'They actually have a standard story that, "Oh yes, your child fell through the cracks." Well, they had known the cracks have been there for 20 years because I've been hearing that for 20 years. They haven't fixed the cracks. Some of us feel like they allow those cracks to be there.'

Geraldine and Karina

Geraldine, late 40s, has a genetic syndrome and needs 24/7 support. For most of her life she lived at home with her mother who was her primary carer. When her mother became unwell and could no longer care for her, she moved to the first of many group homes.

Geraldine's sister Karina said the NDIS support coordinator was very inexperienced and didn't understand the system. Often homes turned Geraldine away because she didn't have enough NDIS funding.

Sometimes homes relinquished care and sent her to hospital. Hospital staff could not communicate with Geraldine, and Karina would arrive to find her 'drugged up and drooling'. Doctors told Karina her sister was violent and should be in a mental health facility.

'I was bringing in her reports, and trying to get them to understand that when you speak to her, it has to be slow ... If you say something too fast, or if she doesn't understand you ... then that would cause her to get anxiety, and then she's going to act out.'

One time a group home sent Geraldine to hospital after she was sexually assaulted. Karina asked staff to do some tests but they refused because police had not requested it. Karina had to make a formal complaint to get staff to take the assault seriously.

At one group home, Geraldine went without a shower for more than a week and developed bed sores. At a different home, staff left her in bed in wet soiled sheets. Karina said staff refused to 'acknowledge that she was a human being' and failed to check on her.

'In another home she was held against her will in a hospital bed, and they were putting the rails up and keeping her there for long periods of time, and she was staying in her own urine and faeces.'

At the same group home, staff medicated Geraldine to prevent her from having her period so they did not have to use hygiene products.

Geraldine now has a large NDIS package but this means service providers look at her like a 'million-dollar baby'.

She lives by herself in supported independent living with 24/7 care. Karina said Geraldine's 'thriving' living on her own.

Geraldine's NDIS planner wants Geraldine to move into a group home because it will be cheaper.

'I would hope that she stays safe. She's got good staff now ... they do have more education, so I would hope to see that continue. I would hope the NDIS just don't turn around and say we're not going to fund it anymore and you have to move her into a group home because it's cheaper.'

Agatha

A few years ago, a small company providing accommodation for people with disability hired Agatha as a cook.

‘When I first got there, the boss was ... getting me to blend [food that was off] and chuck in a sauce because “these people don’t care”. That was what she was saying to me. “These people don’t care.”’

Agatha’s job was also to dispense medication. When the company became an NDIS service provider, they asked her to clean as well as help with personal care and support for residents.

‘I was only getting paid \$21 an hour or something.’

Agatha said initially the residents paid other NDIS service providers to take them to appointments and on outings, but ‘once the bosses realised they could make a lot of money, they’ve asked the residents just to cancel everything’.

Agatha said most of the residents didn’t realise what they were doing.

‘They got some of the residents to sign over ... Like, they’d written notes, some as simple as, “I don’t want you to be my provider anymore. I want to be with [the company]”, like that effect, and they got the residents to sign an X or a scribble ... [Some residents] lost their art classes, they lost work participation because these people don’t care if they do those things ... They want all the money in-house.’

‘The caring for people, it just doesn’t come into it. They’re just a money-making machine.’

The company provided the services for which it could bill the NDIS.

‘I know guys that are being dragged down the tobacco shop. They don’t even smoke, you know, and they’re just being carted around in little groups for money ... For example, like, one support worker drives to the local shop with one participant who then buys soft drinks for two other participants at home, and they charge three hours for that 10-minute ride.’

Agatha said the residents ‘don’t know where to complain’ and can’t change providers again. Many have no family support.

‘They can’t speak out because of the fear of the consequences from the staff, exclusion, eviction.’

Agatha said the company usually employs inexperienced staff.

'A lot of them are friends of friends, or friends of staff. They've got no qualifications with medications ... I've seen medications not being administered at times, or outside scheduled times.'

Agatha said the company asked her to sign 'bogus reports' on 'things that hadn't happened or outings ... that don't happen, just to fill with hours'.

'They've all been bodgie. Backdated. They're not true. They wouldn't match to any rosters. If someone audited that company, they would just fall apart. I don't know why no-one has.'

Agatha said she became distressed and a psychologist advised her to 'leave the job so [she] could actually sleep'.

'I developed such friendships and, oh gosh, I miss them. It was such a hard decision to leave,' Agatha told the Royal Commission. 'I'm worried about these people.'

Vincent

‘If I had had these reasonable adjustments in the beginning ... it would not have ended the way that it did, and perhaps I would be a productive member of that team to date.’

Vincent is in his 20s and is blind. He reads braille and uses special software to read computer screens.

Vincent worked in retail for several years before applying for a casual job on contract at a federal government department.

‘I’d read through the position and I thought, “I think I could do this job well.”’

Vincent got the job.

‘The challenge began around working with [the recruitment company] and the department, being two big entities, in trying to work out for me what reasonable adjustments I required.’

The department didn’t give him a workplace assessment or provide any technology to help him. The office he worked in had no braille markings on lifts, in meeting rooms or in toilets. Vincent needed someone to escort him every day to his office. He couldn’t read the department’s training material. He often relied on colleagues to read documents aloud. Neither the department nor the recruitment company permitted flexibility to working hours.

For example, Vincent was forced to take breaks at set times.

‘If you were on a phone call, you had to go at that specific time or else you were in trouble ... None of those [computer alerts] would read to me ... You know that your lunch is at 1 pm, and you know that you’re going to miss it today, and you know that next week you’re going to be called in for an adherence meeting.’

Vincent said that because the employer did not do a workplace assessment or provide adjustments, he fell behind.

‘Not being able to read information, and being given information again in inaccessible or graphic format that I had to try multiple steps in order to read things, and not being able to pick up things as fast as other people, really made me slip down the chain and just led to an awful ending.’

The employer abruptly sacked Vincent.

‘I was pulled into a room and essentially they said, “It’s over, you haven’t met your targets. You’ve got 10 minutes to get out of the building.”’

Vincent said his complaint to an anti-discrimination body wasn't heard because he was a casual employee on a contract.

'One of the things that I really struggled with, as a person with a disability, was if I ask for this reasonable adjustment, I'm going to get the flick because I'm only on a casual position and they can get rid of me quickly,' Vincent told the Royal Commission. 'It's better off me not asking for the adjustment and just take what I can get without sort of trying to rock the boat at the beginning. And when I did try and rock the boat I got into trouble for it.'

Aldo, Sloane and Amora

‘I think there are some real opportunities for Tassie to be a very special place. It’s quite unique and it’s just got to get some resources.’

Amora is the mother of two primary school children, Sloan and Aldo, who are both autistic. Amora, who’s in her 40s, recently discovered she is also autistic.

‘There’s a lot of women that are undiagnosed and a lot of research that’s catching up. There’s clinicians that lack experience and understanding and there’s a lot of misdiagnosis,’ Amora told the Royal Commission. ‘So, I was lucky to be smart enough to do my own research.’

Amora and her children live in Tasmania, where she said getting a diagnosis, as well as support, is difficult because of a shortage of specialists. For example, Sloane had to wait eight months for an initial appointment to see a paediatrician.

‘I don’t think this paediatrician in [a nearby town] sleeps. I’m not complaining about him. I just think he shouldn’t have to service 100,000 kids.’

The NDIS initially rejected Aldo’s application because the overworked paediatrician ‘didn’t tick a box’.

Until recently, Amora lived in a small rural town where Sloan and Aldo went to the local primary school.

‘The biggest problem with [the town was] unbelievable amounts of trauma and bullying at school.’

Amora said Sloane was ‘barely ever able to walk past this kid without him kicking her physically’.

“‘You’re fat.’ ‘You’re ugly.’ ‘You’ve got no friends.’ Other kids ... were not coming over on the weekend anymore [because] other people were going to find out they had socialised with [Sloane], so the boys were going to tease them as well.’

Amora said the school principal and teachers struggled to control violent behaviour at the small school.

‘My son witnessed another little boy who’s also very troubled ... he’s picked up a pair of scissors and stabbed a little kid with it in front of [Aldo].’

Amora said the school had numerous principals in a short period.

‘There were several kids in there with behavioural issues that weren’t good. Another family left there only last year after being there three months ... Their young son was threatened or shown a knife, basically.’

Amora said the bullying became so bad, Sloane and Aldo refused to go to school.

‘All I could do was move.’

Amora moved to another town, and her children now attend a private school with better support.

‘I’m so grateful and happy and I celebrate that, and I worked hard to get there [but] it’s a double-edged sword. I am disgusted that it’s such a different planet. It’s not fair on the rest of the kids over there [at the other town] that deserve better.’

Amora said the new town was beautiful.

‘Hence don’t, please, tell anyone how lovely it is ... because it can’t service their needs medically, mental health-wise,’ Amora told the Royal Commission. ‘Getting appointments is really hard. I haven’t got my kids engaged yet with any of the services through NDIS.’

She said she hoped one day to return to the former town ‘without crying on the drive in’.

‘I think we will. It just takes time. It just takes a bit more patience and this opportunity helps me lie straight in bed at night knowing I’ve done absolutely everything I could. And I don’t accept that this is normal for any kid.’

Robyn

‘Everyone discriminates against disabled people, and especially if it’s something you can’t see. If you can’t see it, it doesn’t exist.’

A few years ago, Robyn’s psychiatrist diagnosed her with attention deficit hyperactivity disorder (ADHD). Robyn is in her 60s.

‘I have been seeing psychiatrists on and off since I was at university, so I don’t know why it took so long,’ Robyn told the Royal Commission.

Robyn has multiple university degrees, but has struggled to fill in forms to apply for jobs and support.

‘So many of the forms online I find extremely difficult,’ Robyn said. ‘The way these websites are written to deliver a simple message, it’s so complicated and so hard to read. I don’t know how they find these writers. They are so bad, giving reams and reams of details and it’s actually quite hard to understand.’

Robyn has been permanently locked out of the federal government’s MyGov website because she ‘made too many mistakes’.

‘So, that’s pretty funny isn’t it? You can’t even contact them by email and you can’t actually talk to them because no-one answers the phone.’

Robyn lost her job several years ago.

‘Your income and your job control so much of your life.’

She applied for a government job that she’d already done, and for which she had all the qualifications and experience.

‘The skills you need to [apply for the job] are often totally different from the skills you need to do the job.’

She said it took her seven hours to fill in the forms and she didn’t get an interview.

Recently, Robyn moved interstate and applied for a new driving licence.

‘I had to have a letter from a doctor to say, you know, I had ADHD and I was okay to drive. Like, I haven’t had an accident for, like, 40 years.’

Coen and Aspen

‘Child safety needs to be held accountable for the support it doesn’t provide.’

Aspen is a single mother and foster carer of her grandson, Coen, who is autistic and has global developmental delay.

Aspen’s daughter, who has bipolar disorder, became pregnant as a teenager and struggled to raise Coen.

‘By the time [the child safety department] became involved I was exhausted,’ Aspen told the Royal Commission. ‘I felt totally inadequate because, you know, a good parent is able to provide all the supports that a child needs. I couldn’t. I didn’t have the resources. I didn’t have the time.’

Aspen had other children to care for, but had to give up work to support Coen.

‘I can remember when I took [Coen, the department] said, “Oh yep, we’ll provide supports, you’ll get a carer allowance.” You’ll get this, you’ll get that. I was pushing shit uphill ... trying to get things. Like, I will pay for OT [occupational therapy] if you guys pay for psychology ... I was seriously negotiating continually with them to help me out and their attitude was, “Well, you know, you do get a fostering allowance.”’

When Coen turned 17 a few years ago, government support stopped and Coen went to live with his mother.

‘These young ones who don’t have anyone, it is horrible, absolutely horrible what happens ... A majority of young people when they leave the care system, they go home to be with their parents. There are no supports put in place around that psycho-education to parents around providing adequate supports for the young person, understanding their disability, understanding how they operate.’

For example, Aspen’s daughter wouldn’t let Coen access government support.

‘She wanted him to get a job. She didn’t want him to go on Centrelink.’

Coen lived in a tent until someone else helped him apply for a Disability Support Pension.

Aspen said because of a shortage of foster carers and residential care, child safety departments increasingly rely on relatives to foster children.

‘Training is not mandatory for kinship carers. So, therefore, those foster carers [who are] kinship carers don’t know their rights, nor their responsibilities in lots of ways.’

Aspen told the Royal Commission the government exploits kinship carers.

‘Blood is thicker than water and you will do anything for your kids. You know, lots of grandparents out there ... who are in poverty themselves, or single women, and it’s pushing them further and further into poverty.’

Aspen enrolled in a social work degree.

‘I went to university because of him. I learnt what I learnt about early childhood development. I’ve met children with the most horrific disabilities, but I see them. I see who they are because of him.’

Alister

Alister has an intolerance of certain sounds and vibrations.

'I have a mental disability with sound that few, if any, people understand,' Alister told the Royal Commission. 'My physical and mental disabilities include hyperacusis, misophonia, misokinesia, tinnitus and phonophobia.'

Alister is in his 50s and lives in public housing.

'Dealing with [the housing department] has just been really, really hard for them to accept the things that I go through. I don't think they take my mental disabilities seriously.'

Alister said the housing department hasn't found him a suitable place to live in more than a decade.

'During that time, I have been trying to impress on housing ... that where I am living significantly affects my mental health, for better or worse ... They have chosen properties that they have forced me to accept or that I have accepted out of desperation. This has increased my distress and trauma extremely.'

For example, the housing department offered him an apartment in which he couldn't always shut the doors to block the sound.

'Every morning at 5 am, firetrucks drove down the street to get a coffee at a cafe around the corner, with sounds vibrating and echoing inside the whole apartment. The neighbour above me would thump his feet when he walked, day and night. The neighbour beside me often had loud parties.'

Alister said housing department staff 'didn't want' to understand his disability.

'I've said, "Look, I've got this mental illness around sound because it makes me panic." They think, "He is just making an excuse that he wants to be in a quiet area." And it's like, "No, you don't get it." ... It's like no-one is listening, and it just makes the mental illness worse.'

Alister said housing department staff pressure him to take unsuitable accommodation.

'They want to force me to take it because they think it is suitable, but it's not. And then you have only got two tries ... And if you get three strikes you are out, yeah? It's nothing to do with helping me, but everything to do with putting me in a box.'

Alister said the housing department needs empathetic staff.

'They've really got to be more empathetic. If not empathetic, sympathetic. They don't have to understand it, but just respect that it is happening and go from there.'

Daniella

Daniella is in her 50s and has vision impairment. She is autistic and has attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD) and anxiety.

Daniella was born overseas and moved to Australia more than a decade ago.

'I migrated here to marry my husband,' Daniella told the Royal Commission. 'After about three years of getting to know him, not face-to-face but online, we both said we loved each other on the same day. I don't know how that happened but, anyway, six months later I find myself here and married.'

Daniella said her husband lied about having two jobs. 'So the financial abuse actually started prior to me moving over here,' she said.

'Even though I found out he was an alcoholic, about a year or so later, I didn't know what to do ... I was embarrassed, I was ashamed, so I decided to stay married to him. I decided as a Christian that's what I should do.'

Daniella said she often missed social cues. One of her friends told her she might have autism and encouraged her to get an assessment.

'My husband ... was not happy that I was getting checked out for this. He was not happy. He was very resistant to that.'

When her husband hit her, Daniella left him. She struggled to find support.

'Even though I went to a domestic [violence] program ... they basically kicked me out after two [counselling] sessions maybe. So I got no help there.'

Daniella was studying at university at the time and was advised to see a university counsellor.

'The counsellor ... she's not specialised in autism and ADHD. She's not specialised in conflict resolution. She's not specialised in domestic violence.'

Daniella eventually received her diagnosis for autism, ADHD, OCD and anxiety. When she told friends at the university, they told her she was a 'drama queen'.

'Like, "[Daniella], you shouldn't really make excuses ... " Basically, I should have just been able to overcome whatever the problem was. Yeah. Without my medication. It was really difficult.'

Daniella was working at the university while studying. When a student 'complained about [her] behaviour', the university fired her. She said they didn't provide her with disability supports and she couldn't afford private counselling.

'[Students] can't afford to access the help that you need. Especially if you're living on your own, you can't.'

Clayton

‘It made me feel really, really bad. As a young person I could not achieve my goals to keep myself safe from getting hurt sexually.’

Clayton, mid-30s, has cerebral palsy. He uses a wheelchair and needs 24/7 care.

Clayton told the Royal Commission, identifying as a gay man with disability makes him an ‘easy target’ for abuse.

In the mid-2000s Clayton, then a teenager, dreamed of living safely and independently. He ‘fled’ his parents’ home and moved to a group home managed by the state government.

One time, Clayton was showering and another resident came into the bathroom and tried to have sex with him. Each time Clayton showered he would check the locks on the door but they were always broken. He told management but they did nothing about it.

The abuse escalated and for three years Clayton was ‘assaulted by the other residents in any room that they felt comfortable doing it in’.

On one occasion, after Clayton complained, the group home allowed him to sleep next to the manager’s office. That night the manager was drunk and tried to have sex with him.

Clayton reported the abuse to police.

At first Clayton felt the police supported him and tried to protect him. But over time, he said they became frustrated with him and other residents for not ‘standing up for themselves’. One of the officers told Clayton to tell the perpetrator to ‘put his dick away’, or otherwise to leave the group home.

Clayton made a complaint to the state government department. The department denied there were any issues with the group home despite reports from police and the public.

Clayton said the department would ‘shrug [him] off’ and make him feel he had asked for it because he identified as gay.

Too traumatised to live in a group home Clayton moved back to his parents’ home. ‘I gave up my dream.’ He felt he ‘had to trade the abuse of the group home’ for ‘the abuse of [his] parents’. It has taken him many years to find safe, affordable, accessible accommodation.

Clayton has also found it difficult to find adequate long-term mental health support to deal with the trauma.

‘I’ve asked for psychology to be included in my NDIS funding package, and all I get told is that I have post-traumatic stress disorder, so I have to learn to live with it basically, and all I can do is just control my future, stay focused on my future rather than issues of the past.’

Clayton says that as a person with a disability who is gay, one of the biggest challenges is finding support networks he can access independently of his support workers. When he talks to support workers about sexual issues, they generally 'shut down' the discussions very quickly.

'I want to be able to know someone that loves me, or falls in love with me on my terms, not on their terms, and realise that sometimes what I really need is more time, not to be rushed to having sex against my will.'

Steph

‘This work is uncomfortable. This work is challenging ... You need to deal with that, and that’s your responsibility. If you’re going to use black humour and these horrible stigmatising ways of trying to distance yourself, that doesn’t work. And actually, it creates more damage and it perpetuates stigma and shame.’

Steph, mid-40s, has psychosocial disability. A few years ago, she worked as a mental health peer support worker at a community health organisation.

She told the Royal Commission she had been ‘excited’ to use her experience of mental illness to support others. She was the only peer support worker within the organisation.

Steph immediately noticed staff using ‘a great deal of black humour, inappropriate language, stigmatising language’.

Staff would make crude jokes about clients. ‘You name it, they joked about it.’

Steph felt they were probably ‘letting off steam’ and tried not to take the jokes and comments personally. But being a trauma survivor, she started to internalise the things they were saying.

‘I took them home with me and so, over a period of time, that started to really affect me.’

When she attempted to challenge her colleagues about what they were saying, they would ostracise and exclude her. ‘I would get laughed at, at things that I would say or suggest.’

When the organisation moved into a new office, Steph’s supervisor asked her to move out of the team space. She had to sit at a desk isolated from everyone else.

One time, Steph was in high spirits after a successful session with a client who, like her, was a survivor of child sexual abuse. When she told her supervisor about the session, they responded with an inappropriate joke about paedophilia. It left Steph ‘gobsmacked’.

Steph made a complaint to her team leader about the workplace culture. He was very defensive and didn’t take any action.

Steph said she had realised by now her role was ‘tokenistic’. She became quite unwell, had to commence medication and take leave from the workplace.

Steph is now employed by a new organisation and is well supported.

Lloyd

Lloyd is in his 60s and has bipolar disorder.

'I have a broken mind that can be wonderful at times and absolutely zombie at other times,' Lloyd told the Royal Commission. 'I spent three and a half years as a zombie and other times the mind can be quite quick-firing and full of ideas and coming up with solutions.'

A doctor diagnosed Lloyd in his 20s.

'That was a shock to my system and I suffered the consequences of that diagnosis ever since.'

Lloyd had a successful career in finance until a family member disclosed his diagnosis to his employer. Lloyd said he eventually lost his job, 'which had a massive financial impact'.

'I lost a minimum of half a million dollars and I went into, what I call, financial suicide.'

Lloyd said the government appointed a financial manager while he was interstate on holidays. They gave him no money to live on.

'All my accounts were frozen. All I had was a few spare dollars in my pocket and somehow I managed to get back [home] ... They did my council rates and other expenditure. But as far as stuff for myself to eat, I had no money ... I took out loans left, right and centre ... Bugged up my credit rating.'

Lloyd slept in his car to save money when he travelled to see his psychiatrist.

'[The psychiatrist] knew I slept in the back of the car. And his frame of reference is, "That is unusual for a professional person to sleep in the back of the car."'

The psychiatrist gave him two choices – 'You can voluntarily go into the psychiatric ward of hospitals, or you can go in as an involuntary patient.'

Lloyd went voluntarily but said, once admitted, he wasn't allowed to leave. He spent three weeks 'locked up' in the ward.

'The best nurse [treated] all of us inmates [who were] incarcerated, whether voluntarily or involuntarily, as human beings regardless of the fact that we were suffering from the hidden broken brain and various stages of repair ... She would ... go into the kitchens and scavenge cheese, sandwiches, sweets, crackers, and then come to a table and share the food with us as human beings, not as inmates.'

Andi

‘If someone could have just been on my side. Instead of trying to prove me wrong all the time, trying to prove me right.’

Andi, late 40s, has multiple sclerosis (MS). She is also needle-phobic.

‘I still drive. I still live alone. I’m looking after myself.’

Andi told the Royal Commission people are a ‘little bit discriminatory because [they don’t] really understand MS and [don’t] really understand how [she] experiences MS’.

For Andi, MS affects her mobility and makes her extremely intolerant to heat.

Some years ago, while driving, she was struggling with the heat and began experiencing severe pain. She pulled over and because she didn’t have a friend to call, rang an ambulance to take her to hospital.

At the hospital, doctors wanted to take some blood to find out what was going on. Andi refused, explaining she usually needs a week ‘to get [herself] ready’ to give blood. ‘They immediately sort of got really nasty and then thought that I was on drugs.’ Andi told staff she wasn’t ‘crazy’ but needle-phobic. ‘I can’t cope with it. I’ve never been able to.’ Andi asked them to treat her for heat intolerance and let her go home.

The situation ‘became a bigger thing than what it ever should have been’. Doctors diagnosed her as ‘manic’ and kept her in hospital overnight under observation.

‘After, they’ve marked my medical records with me being manic.’

Since then, every time Andi seeks medical help staff treat her as if she has a mental illness and rarely investigate further.

Over the last few years Andi has been dealing with a bug infestation in her home. It became so bad it was in her furniture, clothes and hair. She has had to go to extreme measures such as shaving her head to keep herself bug-free.

Initially she asked the rental agent to organise a pest control treatment. It didn’t work but the agent kept trying to reassure Andi they’d dealt with the pests, saying, ‘It will be fine, don’t worry about it, it will be okay.’

Andi contacted the pest control man directly and asked him if he could do a more thorough job and treat the ceiling and insulation. He told her it was her MS and she should see her doctor.

Next, Andi contacted an insect specialist to see if he could identify the insects so she could organise a more targeted treatment. After a brief discussion the specialist also told her it might be her MS and she should see her doctor.

When Andi spoke to one doctor 'he'd already sort of discriminated against [her] because [she] was walking with a stick'. When she pleaded with him to help her and started to cry, he looked at her records and told her she had 'mental issues'.

'I feel that now my rights are relatively non-existent and no-one listens to me and they think I'm crazy and I can't prove to them without getting someone to actually help me.'

Gracen and Eleanor

Gracen is about to enter high school. Her mum, Eleanor, told the Royal Commission about Gracen's experience in primary school.

'She was a nine-year-old with intellectual disability and autism, in a place where it is meant to be safe. Sorry, it's just mind blowing.'

Doctors diagnosed Gracen with autism a week after her second birthday. Eleanor enrolled her at a special education school when she started kindergarten. A couple of years later, she moved Gracen into a mainstream school with a special education unit.

'For four years she was attending that school with no real [issues].'

Then, a new teacher and deputy principal arrived.

'There were a few big changes in the school. Kids with autism don't do change very well ... There were almost issues straight away.'

The school suddenly re-characterised Gracen's behaviour as 'defiance and attention-seeking'. 'She got seen as the naughty kid,' Eleanor said. The school began to punish her.

'She was regularly excluded from assemblies, other special things, even the whole school excursions. There were ... things that she was not allowed to attend. I think it was an Easter excursion, so she had to go to the office for that. She was taken out and put into the office quite a lot.'

Eventually, the school stopped Gracen playing with her peers.

'She had to go into the little special place that ... had a sandpit – a small area, high supervision.'

The school increasingly suspended Gracen.

'I would see the phone – school, oh, what is it now? ... The day that I was going into hospital, she was actually suspended at 9.30. School starts at 9 o'clock. She was suspended at 9.30! And that was for three days, I believe. And the suspensions got longer.'

Eleanor tried to teach staff appropriate strategies to manage Gracen's behaviour, but they felt these strategies rewarded 'bad behaviour'.

One day, Eleanor saw Gracen's teacher with her arms around her daughter, 'pushing her down towards the timeout chair that was down by the toilet and away from the classrooms'.

When Eleanor made a complaint, the school stopped communicating with her.

'The teacher wouldn't tell me what was happening, or how her day was ... Even the behaviour

support stuff that we had in place wasn't happening, the forms weren't being filled in any more. So, I had no idea what was happening in her class, absolutely no idea.'

Eleanor said the school deleted Gracen's photos and projects from its shared website.

'I lost two years of photos and memories from that school.'

The school's behaviour made Eleanor fear for her daughter's safety. She enrolled Gracen in a new school.

Gracen's new school is more inclusive and has appropriate strategies to manage her behaviour. 'I cannot believe that two public schools ... can be so different,' Eleanor said. 'And they are both special education units in a mainstream school.'

Gracen has been at the new school more than a year now, and graduates soon.

'Her first day back after Christmas holidays, she was up at 7 o'clock. She was, "Where's my uniform?" ... She really wanted to go to school. She was happy.'

Eleanor had asked Gracen what she wanted to tell the Royal Commission.

'She said it "hurt her heart" that they were just pretending to be nice [at her old school] ... To have her lose her friends, to lose her school, to lose her peers, to start a new school, being at a new school for a graduation and going up to high school. Yeah, we have lost a lot actually, as a family. [It's not] what you would expect to happen at a school.'

Romi

‘We have all these specialist family violence services ... but no-one actually is equipped to deal with people with disability, nor is the concept of accessibility [explained] to them.’

Romi, an experienced family violence worker and trauma counsellor, told the Royal Commission about two ‘individuals in [her] lifespan and experience that stick in [her] mind’.

Jan, who had disability as a result of several strokes, had experienced domestic violence. At the time Romi met her, she was using a wheelchair and living in a care facility.

Jan’s husband would come to her residence in the evening, take her medication and sexually abuse her. ‘Some of the care workers were fantastic because they were so proactive in marking down bruising that they saw that was unexplained.’

Romi helped Jan obtain a family violence intervention order.

Romi wanted to continue to support Jan by providing trauma counselling, but her employer wanted her to refer Jan to another service. However there were long waiting lists, and counsellors were reluctant to see Jan because they didn’t have the skills to work with people with disability.

Romi ignored her employer and provided support to Jan, until her employer suspended her.

Romi found another job working with children in the foster system.

The case management system couldn’t locate Asa, one of her clients. ‘There was nothing in our system for this young boy with disabilities to say that he’d moved.’ Romi tracked him down through his previous foster family.

When Romi met Asa she discovered he wasn’t getting the disability supports he needed.

Asa needed glasses, but the department hadn’t done anything about it. The department hadn’t bought him new splints for his shoes for more than two years. They had also failed to fund a helmet, which his therapists had repeatedly requested to keep him safe during epileptic fits. He’d also never been to a speech therapist despite being ‘referred to as non-verbal’. ‘No-one took any notice,’ said Romi.

Asa’s foster carers were a same sex couple. His brother’s foster carers had homophobic views and wouldn’t let the boys see each other.

Romi said the new foster carers were fantastic. She has been able to review Asa’s case and get him some of the support he needs.

‘Every time I would go and see him in his new foster placement, he was just moving in leaps and bounds. His speech, he was talking more. He was helping in the kitchen. He had modified little knives and everything. He was going out!’

Anton and Tamara

‘The experience of having him and me ignored, and him and me being told that our experience is not what we’re living but what they are telling us is happening, was the most silenced I’ve ever, ever been in my whole life.’

Tamara has attention deficit hyperactivity disorder (ADHD). Anton, her son, has ADHD and speech and language impairments. At 15 he was diagnosed with autism.

‘I knew right from the get-go that there was something going on with him,’ Tamara told the Royal Commission. ‘He just wasn’t developing at the speed that he should have. And everybody said, “Don’t worry, he’s a boy, he’ll catch up.” I knew that that wasn’t right, but what I found was, that anytime I tried to raise it I was told ... “you’re worrying too much.”’

When it came time for Anton to transition to high school, Tamara contacted ‘many, many’ schools trying to find one that would support him.

Most independent schools had no programs and told Tamara she would have to fund supports herself. She could not get him into a state special school or special education unit with the diagnoses he had at that time.

Eventually a religious school offered Anton a place, and he started high school in the late 2010s. Anton still hadn’t received a formal diagnosis of autism, but the school was aware of his learning difficulties and ADHD diagnosis.

However when Anton started, the head of learning support repeatedly told Tamara that Anton was not entitled to any additional funding or supports. The school couldn’t locate his education adjustment program verification. Tamara said Anton had been verified when he was in primary school, and the primary school confirmed they had forwarded the documentation.

At the beginning of term 1, Anton was bringing home English homework that was well beyond his capacity. Within a few weeks he was becoming aggressive and agitated at home.

Anton started to refuse to go to school and his non-attendance escalated.

‘He was terrified at that school, and he was terrified of his teacher, because he said that he would shout all the time.’

When Tamara asked for help, the school told her that unless Anton attended every lesson every day, his enrolment would be withdrawn.

Tamara discovered the different departments in the school didn’t communicate with each other. Anton struggled to read and was supposed to have a modified reading program. However, library staff told her Anton was in a normal classroom program with no modifications and no learning support strategies.

At parent teacher interviews Tamara became aware teachers didn't understand what Anton's needs were. They didn't seem to comprehend that Anton could not cope with the classroom and the approaches being used to teach him.

'[Anton] was being accused of being lazy, and the school refusal being his fault ... If he only tried harder he'd be fine ... And if it wasn't for [his] mother he'd be fine.'

By the time Anton received his formal autism diagnosis, his ability to engage in education was severely diminished.

Anton is now attending a specialist learning centre.

Tamara said he has not received an education that is even a fraction of what other children receive.

'The implications for [Anton] are that he has missed years of more knowledge that could have made his educational experience much better, and ... this enormous waste of money, trying to make [Anton] write essays about 17th century educational reform in Ireland – that is a waste of money. That is a waste of [Anton]'s precious life.'

Therese

Therese lives with complex post-traumatic stress disorder, schizophrenia, anxiety and bulimia.

Therese told the Royal Commission about her physical, financial and emotional abuse by a support worker, her problems with supported independent living arrangements and securing funding under the NDIS.

Therese became friends with her support worker shortly before her disability services provider assigned him to work for her. Therese said that his attitude towards her soon changed from friend to abuser. He hit her with his belt, punched and kicked her and called her a 'fat pig'. Therese was so scared of him that she agreed to make him a signatory to her bank account from which he took large sums of money.

Therese wanted to have a baby. Her support worker manipulated her to use him as sperm donor. Therese fell pregnant but miscarried.

'The beating that I got the day that happened ... I kept asking him to take me to hospital but he wouldn't.'

Therese could not understand why her disability services provider did not know what was happening, but when they found out about the miscarriage, they cut the support worker's shifts. '[They] finally decided to ring [the NDIS Quality and Safeguards Commission] and ... the Commission did nothing.'

With the help of an advocate, Therese made her own complaint to the Commission. It told her that the matter was closed because there was insufficient evidence to progress the complaint. The Commission said the provider had taken all reasonable steps when informed about the support worker's conduct.

'Making complaints to [the NDIS Commission] is a waste of time ... You either don't get a real response or it sits ... for months,' Therese said.

Therese had no replacement worker for around three months. During that time, she could not leave the house or attend appointments.

Therese now has funding for support but she finds the arrangements unstable. 'I had 24/7 one-on-one support ... I still have it, but I've run out of money.' The NDIS plan changes every quarter. Therese has asked for a 12-month plan rather than the stress of facing the same hurdles every three months. She is being helped by a support coordinator and is awaiting an outcome.

When Therese seeks internal review of a care plan, the process takes so long that she has the new plan before the current plan is considered. She complained to the Commission about the plan structure but they told her nothing can be done while her plan is under review.

‘I know it’s a lot of money ... and I’ve got to prove why I have to have it, but ... it’s really, really, really hard.’

Therese currently has a service provider but says ‘they’re terrible’. She is often left to coordinate workers’ shifts.

The support worker who had abused Theresa killed himself. Following his death, Therese had a breakdown and underwent hospital psychiatric care for around three months. Her supported independent living (SIL) provider evicted her, with four days’ notice, because it didn’t get any NDIS funding while she was in hospital.

Therese found another SIL provider. After requiring further hospitalisation, the new SIL provider also evicted her, offering no help to find alternative accommodation.

The NDIS removed Therese’s SIL funding because she was spending too much time in hospital.

Therese has unsuccessfully attempted to secure SIL with the help of a support coordinator. She now rents a unit. Therese is desperate to ‘get back into SIL’ as she cannot manage even with support workers.

Therese said that service providers should not be able to ‘pull their services’ because ‘they’re not getting enough money out of [her]’.

Ariadne and Kitty

Kitty is the mother of three children, two of whom have disability. Her daughter, Ariadne, is autistic and has cerebral palsy. She also experiences anxiety and post-traumatic stress disorder (PTSD).

Ariadne's first primary school offered some support for Ariadne, but seemed unable to properly manage her support needs. The school decreased supports further the following year, so Kitty moved Ariadne to another school.

The second school had a specialist unit for children with disability. It was a small multi-age classroom with one teacher and two teacher aides. The next two years were 'incredibly happy' for Ariadne. Then Kitty was told that, under a new government inclusive education policy, Ariadne would move into mainstream schooling.

The school assured Kitty they would manage Ariadne's transition to mainstream schooling properly and meet her support needs. However, the promised supports never came. The children were taken from their familiar multi-age classroom and put into different classrooms according to age. There was one teacher aide between two grades. 'So there's one aide basically running around the school all day, and the children with disability ... getting half an hour here or there.'

Kitty said teachers 'didn't understand ... the complexities of [her daughter's] diagnosis, and were unwilling to give her reasonable adjustments' to help her cope.

Teachers never explained to Ariadne's classmates what it meant to be autistic or to have cerebral palsy, so some children excluded Ariadne or made 'certain comments' to her. Kitty believes there was some resentment from classmates because of needing to wait for the children with disability to catch up. An inclusion officer told Ariadne not to tell others if she was depressed or kids wouldn't be friends with her.

'[She was] being taught about resilience and how to put a smile on your face even though you might be feeling depressed.'

Some teachers openly said they didn't want to teach children with disability. There was one teacher who did want to support Ariadne, but the school didn't provide him with the assistance he needed to do so.

Kitty said Ariadne's anxiety increased on school mornings. She lost the motivation to learn and, one day, held a knife to her wrist during an anxiety attack. Her psychiatrist diagnosed Ariadne with PTSD.

Kitty communicated her concerns to the school but felt that she was an 'annoyance'. She sent the psychiatrist's report to the headmaster outlining her daughter's declining mental state and suicidal ideation. She approached the education department, but got no response. Autism education specialists stepped in and made recommendations to the school, but these were never implemented.

The school's headmaster told Kitty 'what we needed for our daughter, she was unable to supply', and the only options were distance education or homeschooling.

Ariadne now attends an independent school with small class sizes, many teacher aides and an onsite psychologist. The school is supportive and will try something new if a certain approach isn't working. There is a focus on Ariadne's mental health and she feels safe. The school fees are 'quite expensive', but the outcomes have been positive.

'If you're putting a child into mainstream [classrooms], the schools have to make sure the teachers are properly trained and that the neurotypical children are actually informed ... what's going on.'

Theodora

Theodora has cerebral palsy and has a communication impairment. She communicates using an alternative scanning communication method.

For almost 20 years, from her teens, she lived in a large residential care home where, she told the Royal Commission, she was sexually abused twice.

The first time, when she was still a teen, a security guard sexually assaulted her. Theodora's family reported the matter to police and the care home terminated the guard's employment. The guard was acquitted following a trial, possibly due to a lack of evidence.

The second incident occurred in the 1990s when a support worker sexually assaulted Theodora in her bedroom. She told the home straight away but didn't have the chance to tell her parents until a few days later. The police were informed but nobody took Theodora to hospital for a medical examination or offered any health checks to ensure she had not become pregnant or was otherwise injured.

Theodora feels that the police were dismissive at first and didn't treat her with respect, but they eventually believed her story. She doesn't know if the matter proceeded to court but she never went to give evidence.

Theodora believes the home swept the matter under the carpet, transferring the perpetrator to an aged care facility. She says it is so important to have a family for support in these cases or the abuse might have continued.

Theodora feels this care home was unsafe. It was a big facility with lots of visitors coming and going. There was ample opportunity for abuse to occur undetected.

Theodora now lives in a government-run house with four other people with disability, but she says it feels like an institution. She 'feels shit' when staff don't bother to learn to communicate with her. She feels left out and that nobody is listening.

Theodora said one of the support workers at the home emotionally abuses her. She will ask him for things, which he then refuses to give her. For instance, when she was 'dying' for a drink he put the glass in front of her knowing she couldn't pick it up.

Theodora complained to the worker's supervisor but was told there is nowhere to transfer him to. They said he would undergo more training, but nothing has really changed.

Theodora questions the effectiveness of the Community Visitors Scheme. Staff 'hang around' during the visits leaving residents fearful of disclosing their concerns. There is also a high rotation of community visitors, so they don't get to know the residents well.

Theodora would like to live independently and intends to work with her support network to negotiate with the NDIS about facilitating this. She is keen on a particular accommodation that has accessible, independent units. She believes she will be able to choose her support staff, entertain friends more freely, and feel safer in such a place.

Artemis and Madilyn

Artemis had cerebral palsy, intellectual disability and epilepsy, and was non-verbal. She was in her early 20s when she died. It was the mid-2010s.

Madilyn, her mother, told the Royal Commission she hurt her back when Artemis was still young. She felt she had no choice but to relinquish her daughter into state care.

About a decade ago, Artemis was moved to a new residential care unit. Her mother was fearful as Artemis's support workers warned her the manager, Betty, was known as 'a butcher'.

For a few years all seemed to be going well. But then someone informed Madilyn that Artemis was being abused. She phoned Betty who told her everything was fine and 'not to listen to anybody'.

One time, Madilyn decided to turn up at the house and check for herself. When she arrived, she saw Artemis through the screen door. She was on the floor, screaming, hitting herself and banging her head on the ground. Despite the bruising on her face, Betty played it down. 'She's always like that,' Betty said. 'You know ... we just let her go, she's fine.'

Madilyn asked that Artemis be removed from the accommodation. Betty told her there was nowhere for her to go, and Madilyn didn't know where else to turn.

Around this time, she noticed Artemis was losing 'a lot of weight'. The support workers hadn't informed her.

She complained to Betty that Artemis was only getting fed 'chips and sauce' for dinner. The home was taking money from Artemis' Disability Support Pension for food, but Madilyn started bringing homecooked meals to her because of the substandard food the home was providing.

One day, Artemis was admitted to hospital with a bone infection. Madilyn said no-one at the hospital informed her because Betty had deliberately given them her old phone number.

The hospital discharged Artemis two days later. Soon after, Betty asked Madilyn to attend a medical clinic to approve a change in her daughter's medication.

Madilyn arrived at the clinic on a very cold day to find Artemis 'sitting on the wheelchair soaking wet'. Betty explained they had left Artemis outside 'because she loves water'. 'You left her under the rain in that cold weather?' Madilyn asked, incredulous.

'And while I am arguing with [Betty], the doctor ... said, "Can you please sign this paper?" She put a paper on the table, because we were standing up when we were talking, three of us, and it is a little clinic, like a little – so she grabs the paper, she goes, "Quick, sign here." And I just grabbed it and I signed it.'

A few days later, Artemis returned to hospital still fighting the infection. She also had a severely lacerated tongue and was in septic shock.

Madilyn only learnt Artemis was back in hospital from her son. Medical staff had not contacted Madilyn and refused to provide any explanation about her daughter's injuries. She overheard them say Artemis had fallen. One support worker told her on the phone, 'We found her on the floor and the room was full of blood.'

Artemis died 10 days later.

'And I will tell you what,' Madilyn said, 'no-one attended her funeral. No-one.'

The coroner found that Artemis had extensive bruising 'on her shoulders, on her back, everywhere'.

'The day that Artemis hurt her tongue, she'd been abused, she'd had a fall ... she'd been abused physically and everything,' Madilyn said.

Madilyn later learnt that the form she had signed at the clinic – that she assumed was about changes to medication – agreed to end of life 'comfort measures only' for Artemis. The doctor had not explained what the Advanced Care Plan meant. Madilyn said she had signed her daughter's life away without knowing.

She wants her daughter's story heard 'to warn people to look after their children'.

'These people, the one who was doing it to my daughter, are doing it to other kids too.'

Ric and Debbie

Ric, 13, is autistic and non-verbal. 'You don't think he's paying attention or listening, but he's taking in every single word you're saying,' his mum Debbie told the Royal Commission.

Ric uses showering to self-soothe when his emotions escalate. 'The hot water just kind of settles him down where he can gather his thoughts and get back to thinking straight.'

As Ric got older, Debbie insisted he be with a male education assistant if he needs to use the shower at school. 'Being Aboriginal, when the boys get to a certain age, the father figure takes over tending to them.' Debbie later discovered the principal 'didn't even bother writing this down'.

When Ric was in the last year of primary school, he 'started acting strangely'. He was weeing over the furniture and 'painting faeces on the wall'. He was often distraught. He didn't want to go to school and would get upset when he arrived.

The school started contacting Debbie to collect Ric because he was 'putting the other children at risk'. When Debbie picked him up the teachers and education assistants would look at her 'weird'. 'I felt like they were judging me as a mother and I've done something wrong.'

Debbie's mum had passed away earlier in the year. Ric was very close to his grandmother and Debbie thought he might be grieving. She let the principal know Ric was going through 'this grieving process' and might need some help.

A couple of days later, the principal showed Debbie a video of Ric that had been recorded three months earlier. He was 'in the shower and naked'. A female education assistant was recording him, and another was showering him down with the shower hose.

'I just fixed on him ... he knew they were recording him. He was getting more and more distraught.' Debbie's first thought was to pull Ric out of school immediately.

She was shocked the education assistants had filmed Ric in the shower, that the education assistants were female and that the principal had taken so long to show her the video.

Debbie discovered there were three videos of Ric in the shower. The principal told her the education assistants were filming him throughout the day to create 'an escalation profile' to see what was triggering him. 'But on that actual iPad, there was no other recording of that day. It was just three recordings of the bathroom.'

The principal said she didn't see 'any sinister intent' in the recording and wasn't going to report it to police.

Debbie made a complaint to the education department. The department didn't apologise and insisted it was 'the family's expectations' that Ric be showered by a male.

‘But it wasn’t our expectations – it was [Ric]’s needs ... They weren’t acknowledging our cultural needs and the way that we are as family, for our boy to be showered by males, not females.’

Debbie tried to explain to the teachers and principal how Ric felt. ‘The teachers laughed it off’ saying they didn’t have enough staff ‘for our expectations’.

Debbie would like a ‘formal apology from those involved’ so Ric can ‘move on’. But the education department ‘won’t even allow’ the education assistants to apologise.

Ric has transitioned to high school and is ‘doing really well at the moment’. He has a male First Nations support worker at school. Ric is gradually attending school more often. ‘This week is the first week that he’s actually gone to school the whole day for a whole week.’

Bee

Bee is in her 20s and has muscular atrophy and an intellectual disability. She uses a wheelchair and needs 24-hour support.

Bee's grandparents cared for her when she was a child. Since her grandmother died, she has been living in a hospital.

'I was admitted initially because I was sick, and then they kept me there, yeah. Then they kept me there, but I was living on the adolescent ward,' Bee told the Royal Commission. 'There was like a back room where you could sit and just look around and I would sit there on my own sometimes and just watch people and I would talk to the nurses at the nurse station. I would draw pictures ... I had birthdays there and I had Christmases there.'

In her late teens, Bee moved into a group home where she shares a kitchen and bathroom with another person.

'I have dolls that are my children ... I have always wanted to be a mum, and so because it's not safe for me to have real human children, I decided to treat my dolls as children. And I take them out and I dress them and I look after them.'

Bee dresses her dolls, which she calls her 'kids', and takes them shopping and to the playground.

'It's a kind of a therapeutic thing for me. When I dress them, when I hold them, it gives me a sense of ... You know?'

Bee said that since she's had her kids, she's become more assertive and asks for help. She said the support staff don't seem to like it.

For example, the dolls live on a table, off the floor, in her room for safety. Bee said one of her support workers moves them around 'without asking'.

'She came in and said to me what the manager of the house says – babies are not to sleep on the table. But the manager didn't actually say that, [the support worker] just said that, and I got upset. Because ... when they're sleeping on there, I can actually go up and, you know, interact with them in my height. When she said that, I got emotional because it took that independence away.'

Bee said another support worker has become 'very snappy'. Others are rough when they move her on her bed.

'She kind of pulls harder to get me over quicker.'

Bee said she'd like to be more confident, but fears the quality of her care will be affected if she speaks up too much.

'I don't expect everyone to like it, but you just have to be more respectful to me about it,' Bee told the Royal Commission. 'Because I'm asking for a lot more nowadays as well. Before my kids, I would just sit on my iPad all day and do nothing.'

Ash, Kristy and Garth

Ash had a rare condition that caused complex behaviours, cognitive impairment and digestion issues. Kristy, her mum, told the Royal Commission that people didn't understand Ash's disability. Because she could 'walk and talk' and 'presented beautifully' people assumed she was 'sweet and adorable'.

'[Ash] could not be left ever on her own. She would be like a two-year-old upending everything because she was confused about the world,' Kristy said.

In her late 20s, Ash moved from her family home to a group home with four other residents.

'It was new, it was right there. We could still have her home once a week overnight, which was a big thing for us, and she would still stay in her day program,' Kristy said.

A few years later, not long after the NDIS was established, Ash's father Garth got a job in a different city.

Kristy and Garth decided to relocate Ash so she could be near them. They found a home they thought would be a good fit because the other residents had similar intellectual disability.

The transition did not go well. The new provider did not know how to care for Ash and didn't provide adequate support. Other residents would pinch and scratch Ash, and her behaviours escalated.

One time, staff 'backed her into a corner' and she reacted aggressively. Staff called police, and the provider evicted Ash without any notice. Kristy and Garth were 'gobsmacked' this could happen. 'On the back of this incredible trauma, she was then without a home,' Garth said.

Ash had to move back home with Kristy and Garth. 'This is the first time [Ash] felt the full trauma of that rejection,' Kristy said. Her anxiety, obsessiveness and incontinence increased. Kristy and Garth enlisted the family to help her recover.

A year later, Garth and Kristy rented a house for Ash and very slowly transitioned her into it. They started by driving past the house and working on her separation anxiety.

After a month, Ash was in the house full time supported by a small handpicked team of female support workers.

A short time later, the provider managing Ash's NDIS funding told Kristy and Garth that her funding was inadequate. They threatened to withdraw their services unless another resident moved into the house.

Kristy and Garth were shocked by this request and were concerned Ash was still recovering from the trauma of her last group home. The relationship with the provider deteriorated, until eventually Kristy terminated the agreement.

After protracted negotiations, the NDIA reviewed Ash's plan and the family found a new service provider. Ash was able to remain in her house with her support workers.

This arrangement ended abruptly when a worker made a workers compensation claim after an incident with Ash. Within days the provider sent all staff an email terminating their employment and suggesting they talk to the family.

The NDIS Quality and Safeguards Commission intervened and instructed the provider to reinstate the staff and provide 90 days' notice – which they did.

For the next four months, Ash remained in the home and the family took over managing her NDIS funding. Ash's sister had to drop to part-time work to properly manage Ash's supports.

The NDIA finally assessed Ash's needs as 'complex' and funded the appropriate supports.

A few months later, in her mid-30s, Ash died unexpectedly.

Kristy and Garth said that they have not heard from the NDIA, despite being promised that a bereavement team would be in touch.

They described the NDIS as a 'marketplace' where the providers that succeed are those in the 'strongest position to bargain'. They believe people with cognitive disability are at a significant disadvantage because they are not able to advocate for themselves within the complex NDIS system.

Ashton, Chanel and Karson

Ashton, 30, has intellectual disability and is non-verbal.

In the mid-2010s his parents, Chanel and Karson, decided to transition him into supported independent living in case anything happened to them.

The disability service provider told them not to visit Ashton for three months to make the transition easier.

But after six weeks Ashton was still pining and anxious. Chanel said it was cruel letting Ashton think they had abandoned him.

As soon as they walked into the house they noticed signs on the wall warning staff that Ashton's co-tenant, Jay, bites and is capable of breaking jaws, shoulders, arms and fingers.

Chanel and Karson were horrified no-one had told them anything about Jay's behaviours before Ashton moved in.

'We had [Ashton] settled in the house by then,' Karson said. '[We] couldn't do anything about it.'

They discovered that around the time Ashton moved in, staff began restricting Jay's eating. Jay liked to 'eat and eat' and when he couldn't, blamed Ashton. He started a 'biting spree' against him.

During the next six years, Chanel and Karson estimate that Jay bit Ashton seriously about 50 times, although there were probably many more not reported. The provider tried to tell them some of the bite marks they saw were acne.

Trying to find a solution, Chanel and Karson asked the service manager to relocate Jay. The manager said they couldn't move Jay because he might bite other residents.

At one stage the provider asked a consultant to investigate Ashton and Jay's compatibility. The report concluded they should not cohabitate because it wasn't safe for Ashton. Still, the provider refused to act.

Ashton was forced to live constantly in fight-or-flight mode, and his behaviours escalated.

Jay enjoyed standing in the bathroom watching himself in the mirror while swinging his arms and yelling loudly. Ashton became too scared to go to the bathroom and began defecating in his bedroom. Staff would then get angry with Ashton for soiling himself and refuse to clean it up.

Chanel and Karson demanded the provider address the issue. The provider insisted there was nothing they could do, so Chanel and Karson tried their own solutions.

First, they covered the bathroom mirror and put another mirror in the living room for Jay to enjoy.

Karson then installed an alarm on Ashton's door that would sound when Jay entered his room. However staff rarely responded to the alarm, so Jay continued to enter Ashton's bedroom, sometimes dragging him from his bed. Staff, meanwhile, spent their shifts sitting in the locked office, using their computers or phones. They rarely engaged with either resident.

Ashton spent most of his time sitting on his bed, watching television and trying to keep to himself. He wasn't able to access the community because staff couldn't cope with Jay's behaviours in a public setting.

Over the years Ashton's parents made multiple complaints to the state disability department, but said the department was 'useless'.

Eventually the provider suggested an alternative property for Ashton. However Chanel discovered it was completely inappropriate and failed to address any of his safety requirements.

When the NDIS was introduced, Chanel and Carson were able to change providers and move Ashton to new accommodation.

Ashton is now happy, calm and cared for, and likes his staff.

'He's living the life,' Chanel said. 'He's got a better social life than anybody. He's loving it. And that could've been all those years ago.'

Berenice

Berenice, late 30s, has an intellectual disability. Her partner also has an intellectual disability, and they live together in a private rental.

Berenice told the Royal Commission that over the years she has found it difficult to find suitable full-time work.

‘My experience has been up and down with the disability [employment] agency because they haven’t been hearing me out about what I need and what I want in life. They just go according to what my disability is.’

Berenice was with one disability employment service (DES) for about 10 years. She said they didn’t give her any interview training, and when they sent her for an interview it felt like they were ‘putting [her] in the deep end’. When she ‘failed the interview’ they never gave her any feedback, ‘just some excuse’.

The DES only found her one job, as a sales assistant, in 10 years. She worked in the role for two years but the company closed and she was ‘back to square one’.

The DES had high staff turnover. Berenice had to have numerous 30-minute sessions with each new consultant explaining her job history, her capacity and what work she wanted to do. She felt these meetings were a waste of time because the consultants never found her any work.

Sometimes she’d turn up for her meeting with a consultant only to be told the meeting was cancelled.

About a year ago she moved to a new DES and explained she was looking for work in office administration or hospitality. The consultant found her a potential role as a sales assistant in a gelato bar.

The consultant went to the interview with her and sat ‘sour faced’ while the manager asked Berenice questions she couldn’t answer. ‘[Afterwards], she looked disappointed and very angry that I didn’t get the [job].’ Berenice felt the consultant wasn’t trying to help her find a suitable job, that she only wanted to ‘hit her KPIs’ by finding Berenice any job.

After this, Berenice was forced to attend back-to-work training sessions to be ‘job-ready’. She said these were a waste of time and thinks the DES benefited financially from this training.

Berenice decided ‘to ditch’ the DES and look for work herself. She’s currently working for a food delivery company. ‘It’s a fun job for me to, just drive myself around, clear my head and do work.

I do like the work. I’m happy.’

Boone

Boone is a First Nations man in his 20s with psychosocial disabilities, including post-traumatic stress disorder and depression. Boone has spent a lot of time in mental health units since he was a child. He's now in prison.

'I have been a lot of trouble,' Boone told the Royal Commission. 'Because of my history, past history, they don't like me out of the [prison] unit, so I've got to stay in the unit all day behind the grills, locked in. I'm pretty much used to it because I've been doing it for so long.'

Boone said prison makes his disability worse.

'I had no support. I've always asked to see mental health ... and I used to get knocked back all the time. Like, I was denied of mental health, seeing the psychs and stuff, so it was hard, yeah. And I had to go off a lot. And then the only time they'd actually do something is when I'd smash something up.'

Prison officers consider Boone 'disruptive', so he spends a lot of time in solitary confinement.

'I hate confined places now, I done so long down the back in solitary confinement. Since I've been in prison it's got real bad with my mental health. I struggle a lot down the back ... I think about self-harm, especially down the back.'

Once, Boone spent two weeks in solitary confinement for speaking back to a prison officer.

'I just told him not to talk to me like a kid and I got two weeks on close supervision, which is solitary confinement down the back, just for saying, "Don't talk to me like a kid." Like, I felt the whole time I was there they were trying to break my soul.'

Boone said he once spent 10 weeks in solitary confinement.

'I suffer from depression and anxiety a lot, so that just made me feel ... like I was treated like an animal.'

He said it's worse in summer.

'They didn't give me no fans. I had to suffer in the cell for, like, over three weeks without a fan in the cell. I couldn't sleep. I was going through that much heatstroke and that my nose was bleeding every night from the heat ... They turned my taps off. Couldn't drink water. It was that hot in the cell.'

Boone told the Royal Commission the prison system prevents his rehabilitation.

'I was doing painting courses, general education like maths, English. I was doing a lot of that.'

After being transferred between prisons, ‘they just stopped all [his] education’ and some mental health supports.

‘They stop everything because they think I’m going to do something wrong. Most of the time I’m just getting pushed to the edge because I’ve got nothing going for me. I want to change my life around while I’m in prison, like, and the treatment I’m getting, it’s pushing me to the edge. I don’t think I’m going to be changed. I’m going to be even worse when I get out.’

Boone says his main support in prison are First Nations elders who are also in prison.

‘It makes me happy, I like being around my elders, like learning and stuff, so I get that real good connection and healing. So, yeah, I love it, yeah. At least being stuck in the unit all day, I can be around them, you know ... My elders actually keep me out of trouble, so I listen to them.’

Marjorie

Marjorie is in her 50s and has bipolar disorder.

She was working in a regional town as a support worker when, one day, one of her clients developed shingles.

'She was really really very unwell. And one morning, she actually collapsed in my arms. I had to catch her, and she was literally hanging in my arms drooling on me.'

Days later, Marjorie became ill.

'I woke up with a sore throat. And I thought, okay, maybe it's from the cold wind the previous day or something. But I just let it go. And on the way home I really started feeling very tired, but I just brushed it off ... And the headaches started.'

Marjorie became confused.

'On the way to work I started feeling my fingers going numb. And I thought, "Oh, that's strange."

Marjorie struggled to walk. A doctor at the regional hospital said her symptoms were 'psychological' because she 'had a diagnosis of bipolar'. 'That's why you can't walk and can't stand up straight, and if you can walk then you can go home,' the doctor told her.

'And I was very stubborn, so I decided well even if I fall ten times I'm walking out. I will never forget that little bit. I had to walk to get to the car.'

Marjorie's symptoms worsened. When she went back to hospital, doctors insisted the unexplained condition was linked to her bipolar disorder.

'They keep on going back to the bottom line, "Oh, you have bipolar." No matter whether the bipolar was well-managed, well in control the whole time.'

Doctors eventually diagnosed meningitis caused by the shingles virus. Marjorie now uses a wheelchair.

Marjorie discovered her town lacks services and support for people with disability. She can't access many of the services for which she has NDIS funding.

'In town if you're disabled, whether it's mentally or physically disabled, you've lost. You have literally lost because there are just no services.'

Marjorie says the town 'is not disabled friendly'. For example, many shops have no wheelchair access.

'There's no safe access for drop-off or pick-up for the wheelchair taxi. So, they take chances and you really [are] unsafe ... And another thing that's frustrating here is the disabled parking. They make it the same size and width as a normal parking. And then you try and park in such a way that you can get out of the passenger side with your wheelchair being in place. You can't do that.'

Braylon and Arianna

‘I see him once a month and sometimes when he comes I cry. Well, I should be enjoying my son. I should be able to be relaxed knowing he’s being supported well. And he’s not.’

Arianna is in her 70s and is mum to Braylon, who has a cognitive disability and is non-verbal.

Braylon lives in public housing and is supported by the NDIS through a service provider.

‘I would be told, “If you aren’t happy, [Arianna], I’m happy to find you another service,” knowing full well that I am struggling with debilitating health issues and I’ve ... no energy to do that. I’m totally burnt out,’ Arianna told the Royal Commission. ‘That’s why I handed [Braylon’s] support over to [the service provider].’

For more than two decades, Braylon lived in a government-run institution.

‘Abuse by staff was horrendous ... There has been no compensation, no class action or anything in regard to those horrendous injuries that he suffered. Emotionally and physically to this day [Braylon] still suffers.’

Nearly 20 years ago, desperate to get him out of the institution, Arianna started her own service provider.

‘That service worked extremely well. [Braylon] had a much better life, everybody that saw it was impressed by the way it was set up, by the way we did things, how the house looked, everything.’

Arianna ran that service provider unpaid for more than a decade.

‘I had to learn and process wages for staff ... interview people, hire them and train them over long, full shifts day and night up until 10 at night ... I filled in as a support worker when staff were ill, away or on leave and was a mentor to the staff. I researched extensively ways to improve [Braylon’s] health and overall health issues, which didn’t leave a lot of time for me to be [Braylon’s] mum, which is what I craved to do at that time.’

‘Burnt out’, Arianna retired and looked for another service provider to take over. She found one, but says they now employ poorly-trained staff.

‘[Braylon’s] personal care is shocking. Quite often he’s not shaved properly ... Sometimes [Braylon] had been hospitalised and the hospital even queried the abuse. The doctor would say to me, “What was going on, where were you, what happened?”’

Arianna said the service provider appears not to be concerned about his welfare or enjoyment.

It is slow to report injuries. It stopped Braylon's horse-riding lessons.

'Staff are not trained in how to prepare Braylon for a ride so he's missing out on the joys in his life, after more than 35 years riding. Staff stopped [Braylon's] swim in the pool ... He's not encouraged to do many things that he did before and staff are surprised when I say, "Oh, but he can do this or he can do that." "Oh, we didn't know that," would be the comment. Most staff have no idea what he can do, so the level of participation for [Braylon] in the house is lost.'

Braylon was recently rushed to hospital with a food blockage, 'a mistake made by staff giving bigger food'.

'Staff are not trained properly. They've been working with [Braylon] for several years. They just stick with what they know and nothing new is learnt and nothing new is passed on.'

Arianna said that being 'in fear for your son's life' isn't what she expected from modern service providers.

'I can't do any more than I have done now. That's the way I feel,' Arianna told the Royal Commission.

'I can't do anything about what goes on at [the new service provider] anymore. I just look at him and just say "Sorry [Braylon], I've done my best, I can't do any more for you, mate."'

Kalyani

Kalyani, mid-40s, was sexually abused as a child and again as a young adult. She has complex post-traumatic stress disorder (PTSD), anxiety, depression and experiences periods of dissociation. She also has a spinal injury and is severely allergic to multiple medications.

Kalyani told the Royal Commission that when she goes to hospital her 'chronic physical conditions' are rarely 'addressed or recognised'. Doctors tell her it's her PTSD 'over and above anything else' and she's 'streamed into mental health'.

Over the past three years Kalyani has gone to hospital because of allergies. 'They see my PTSD and harass me about panic attacks and my mental health and disbelieve [me].' Recently, Kalyani spent half an hour trying to convince doctors she was 'having an allergic reaction' and was 'not crazy'.

Despite being aware of Kalyani's PTSD, medical staff often make decisions that retraumatise her. They have 'happily stuck [her] in wards' with patients who 'weren't in control of themselves'.

Not so long ago, Kalyani was admitted to a mixed ward. Within five minutes, a male patient was 'screaming at [her]' while her breasts were exposed.

Staff moved her to a different bed around the corner. The man in the next bed 'exposed his genitalia' and 'masturbated'.

Kalyani made a complaint but the hospital 'wanted to sweep it under the rug'. Ultimately, they said they weren't responsible. 'I wasn't supported. I was just harassed to make a statement to the police.'

The next time Kalyani went to hospital she insisted she be admitted to a female-only ward.

Kalyani wants doctors to take her physical symptoms seriously. 'I'm actually concerned I will end up back in the mental health [ward] for having an allergic reaction and drop dead.'

Brendan

Brendan, a veteran, lives with complex post-traumatic stress disorder, severe depression, anxiety, a spinal injury and a mild traumatic brain injury.

His assistance dog, Kami, wears a yellow vest that clearly identifies her as a registered assistance animal.

‘My dog is a piece of medical equipment, you know, she is like a wheelchair.’

On Anzac Day last year, Brendan ordered a car through a ridesharing app. As soon as the driver saw Kami, he told Brendan he couldn’t get in the car. ‘I don’t have to take pets. [The company] said I don’t have to take pets.’

Brendan told the Royal Commission he was shocked that a driver would refuse to take a veteran wearing his medals and his assistance dog on Anzac Day.

‘I did order another vehicle, and he took me to the parade. But when I got home later that day, I felt absolutely worthless.’

Brendan made a complaint to the rideshare company. He felt their response was ‘atrocious’ and ‘indifferent’.

His mental health deteriorated.

‘To be discriminated against based on my military service disabilities on any day is bad, but to be discriminated against on Anzac Day was way too much for me to bear.’

Two weeks later Brendan tried to suicide.

When he was feeling stronger, he messaged the company telling them about his suicide attempt.

A ‘full week’ later, the company sent the police to conduct a welfare check.

‘I’m sorry,’ Brendan said. ‘That’s not a welfare check, that’s ticking a box to say, “Yes, we did that.”’

Since the Anzac Day incident, three rideshare drivers have refused to take him and Kami. ‘Two of the drivers actually told me to leave my dog on the side of the road.’

Each time, the company has failed to deal with his complaint adequately.

Brendan then made a complaint to the state equal opportunity agency.

At mediation, the company said they were sorry it happened but they were not responsible for their drivers who were 'driver partners', not employees.

They maintained their drivers were adequately trained.

Two of the drivers have since written letters of apology, but referred to Kami as a pet.

'They're still not acknowledging that she's an assistance dog and she actually has a job to do. The training's not working.'

Brendan said the company has since changed their app so a person can identify that they have an assistance dog when they book a ride. The company immediately counsels any driver who refuses a ride explaining it's against the law to do this.

'Anzac Day caused a wound that got stitched up and was starting to heal, and then each time this happens again the stitches get ripped out, and the wounds festers and gets infected, and gets bigger. And it's at the point now where I don't want to leave my house.'

Kaylene and Nathalia

‘It’s very difficult to get them to break out of that cycle and to look at [the residents] as individuals, not dollar signs.’

Kaylene is in her 20s and has Rett syndrome, a disorder affecting brain development. Nathalia is her mum.

Kaylene uses a wheelchair, can’t speak and lives in a group home run by a service provider.

‘They’re an old disability service provider and they’re really struggling to get with the modern ethos of the NDIS which is, you know, choice and control, not institutionalised living,’ Nathalia told the Royal Commission.

Nathalia said staff are often new and inexperienced. They have over-medicated Kaylene and withheld meals as punishment.

‘There’s been, you know, instances where people have given her foods that she’s not allowed to have, which is a high aspiration risk ... I’m consistently having to have my daughter home. She is home with me today ... because the service provider cannot provide familiar staff.’

Nathalia said Kaylene sometimes has to sleep in her own faeces when the house is short-staffed.

One day, the service provider’s car was involved in a crash. Kaylene, in the wheelchair in the back, broke her teeth. To claim insurance, to have the teeth fixed, Nathalia asked the service provider for the car’s details.

‘I kept ringing up saying, “Can you just give me the registration of the vehicle because I need that information to pass on to the third party, you know, to put in the claim.” They wouldn’t give it to me. I actually had to go get a lawyer, and when the lawyer wrote them a letter that’s when they gave me the information. It was terrible.’

Nathalia said the service provider makes the residents pay for new furniture.

‘For example, a couch, a TV, although the girls’ money is paying for it, it remains property of [the service provider] ... So, out of that pool of money that they keep from the girls, which is their pension, they pay insurance on all the items, for example, the TV, the couch, this and that which don’t belong to the girls, yet they’re paying insurance for it ... And when I questioned this, they can’t really give me an answer, they are just, “Well, that’s just the way it is.”’

Nathalia said the service provider charges more than \$7000 a week to look after Kaylene.

‘I’d get amazing carers for that money, right? It’s just ridiculous, they’re charging so much money and not providing the service, absolutely not. It’s all about management, you know, big

CEO salaries. [The service provider] posted a [multi-million dollar] profit last year. They were not-for-profit.'

Nathalia said she made multiple complaints to the NDIA.

'To me they're a toothless tiger, they don't do anything.'

Nathalia said she's now considering bringing Kaylene home, so she can care for her herself.

'I don't know how long that's going to last. Yeah, very sad. Because I kind of figure, Commissioner, if all of this is occurring while I'm alive and involved in her care, she's going to end up being another [victim of neglect], she really is, because that's what happens when there's no-one involved. It's very sad.'

Brigitta

Brigitta is in her 50s and has spinal muscular atrophy, a degenerative disability that causes muscle wasting. She uses a wheelchair and needs support for everyday activities.

‘Very few know of my fears. Appearing vulnerable and risking being abused again haunts me constantly,’ Brigitta said in a statement she read to the Royal Commission. ‘It has never been more important for me to tell my story and play a part in evoking change and creating a future free from fear.’

Brigitta said that when she was growing up, her home ‘was rarely a safe place’. Her mother, who lived with psychosis, was violent.

‘She would often become extremely agitated, and it was during these times that I would be physically abused as her manic reality took over.’

Brigitta remembers one day, as her father left for work, her mother screaming ‘We’ll all be dead by the time you get home.’ She also remembers a Christian group coming to her home and placing their hands on her to rid her ‘of the devil that lived within’.

‘[It] left me terrified and questioning, “Am I bad? What’s wrong with me?” Still today I am stopped and confronted in the street by those that believe through the power of prayer I can be saved, I can be healed.’

Brigitta said she struggled to find ‘a safe place to belong’ at high school. Although she was a high achiever, her school wouldn’t let her continue to years 11 and 12.

It was around then that Brigitta was ‘thrown out of home’.

‘To stop the physical abuse, I instinctively locked myself away in the bathroom, but with continual threats to break down the door and the escalation of the rage on the other side I hesitantly unlocked the door to cower once again to slaps to the face and then without thought of consequence I reactively fought back, resulting in me being sent away.’

A couple of years later, a boyfriend raped Brigitta and she became pregnant.

‘I was a young, naive, broken woman and saw no other option than to have an abortion.’

She resumed her studies and started partying, but ‘struggled to find a sense of belonging’.

When she became pregnant at university, her doctor thought her symptoms were related to her disability.

‘At no time was I ever questioned or was it entertained that ... I could be sexually active.’

Several years later, Brigitta left her children's father.

'Financially, we struggled and I would often go without a meal to ensure my children were fed and our rent and bills were paid. I missed out on many of my children's schooling and sporting events as I did not have the means and the support to attend.'

After another abusive relationship, during which her partner controlled and punched her, Brigitta finished her studies.

'Gaining independence and achieving some of my lifelong goals came at a cost.'

Her muscular atrophy has worsened and she spends more time in her wheelchair.

'Not only have I lost mobility and function, but I have also lost my role as a mother, as my ... daughter has today become my carer.'

Brigitta told the Royal Commission she fears becoming vulnerable again to abuse.

'Optimistically I pray for a future free from neglect, abuse and violence for people living with a disability. However, realistically, I feel as though there will always be those that prey on some of our most vulnerable. I hope the Royal Commission can bring about better safeguards, practices and support systems for those that experience all forms of abuse and violence.'

Camden

Camden is a First Nations man in his 50s. He developed post-traumatic stress disorder (PTSD) from having undergone 11 medical procedures over the last 12 years, including knee replacement and shoulder reconstruction surgeries.

Camden told the Royal Commission that he has 'lived not an amazing life'. He worked at various trades after leaving school. '[I] met a girl, had a child, separated, the normal things ... in life,' Camden said.

With a child to support and hoping for a stable job, he joined the public service as a driver assessor. But over the course of a year, 'racial taunting, harassment ... and bullying' became a staple of Camden's daily work life.

Camden asked management for assistance, but help 'was not available'. A manager then told Camden that clients had made complaints about him. He was said to have sworn at someone and made a girl cry during her test. He was able to explain those incidents, but 'was very confused' and felt singled out as not being suitable to be in the public service. 'I ... was going through a complete mental breakdown.'

Camden's doctor gave him a medical certificate to take some time off work, but his supervisor kept contacting him. He insisted Camden should return to work as there was nothing wrong with him, ignoring the medical certificate.

Camden says that he has had anxiety, panic attacks and bowel problems since a meeting about his workplace performance. He has had endoscopies and is on nine medications to manage the anxiety and panic attacks.

When Camden's sick leave ran out, he made a workplace injury claim. He received some monies, but soon realised they would barely cover his bills. A free financial counselling service told Camden that, as a former public servant, he might be entitled to disability insurance through his superannuation. Camden applied. 'The insurer replied that ... I hadn't proved ... I had a disability and I wasn't able to access any of it.'

Camden approached a lawyer for help with the insurance claim and was told he needed a new psychiatric report. However, this would cost \$5,000 which Camden couldn't afford.

Camden cannot understand why he was denied insurance though his superannuation because he couldn't prove he had disability, yet qualified for a full disability pension with Centrelink.

He finds dealing with government systems challenging, particularly trying to contact someone in a government agency for help and having his queries followed up.

Vada, Bo and Trinity

In the early 2020s, Trinity fled the family home with Bo and Vada and her other two children to escape her violent partner.

Bo, 8, is autistic and has attention deficit hyperactivity disorder. Vada, a few years older, has anxiety and obsessive-compulsive disorder and, more recently, has been diagnosed with post-traumatic stress disorder.

Trinity told the Royal Commission she and her children went to a refuge. However it was full, and staff sent her to a motel. 'We had to stay in one room with five beds pushed together. There was no internet ... very minimal emergency food. There was no support worker to come and assist with the children.'

Trinity and the family lived at the motel for some time while she obtained a domestic violence order and police removed the children's father from the family home.

Child protection services spoke to the children and they all spoke about 'physical violence, psychological abuse, emotional abuse, from their father'.

A couple of weeks after Trinity and the children returned home, Vada told Trinity her father had sexually abused her over a number of years.

Trinity immediately advised child protection services and took her to the police station.

A child protection officer spoke to Vada on her own without any other support. 'She was overwhelmed and uncomfortable.' Police 'believe my daughter' but felt the information she gave was not enough to take the matter further.

A few days later Bo told Trinity his father had sexually assaulted him. A child protection officer interviewed him. When the officer asked Bo open-ended questions he said 'the elephant hurt me'. After a short while the officer told Trinity they weren't 'really getting anywhere' and asked her to come in but not look at Bo. When the officer asked a question about the elephant, Bo repeated the elephant had hurt him and 'pointed to his backside'. Bo started getting hungry and they ended the interview. The officer told Trinity to 'bring him back in a few years'.

Frustrated, Trinity asked the officer what training they have in interviewing children with disability. The officer said they weren't trained and they ask potential victims the same questions 'no matter what'.

Trinity was shocked. 'If you have difficulty with communication and language there is no interpreter. There is no communication assistance. How is that justice?' The officer agreed 'the protocol is wrong ... particularly for people with autism, children with autism' where it is clear there are 'communication and social challenges'.

Trinity returned home without any referrals for supports.

Trinity is angry health professionals didn't recognise what was happening to her children. Vada has had frequent urinary tract infections, a preanal tear and stomach issues for a number of years. The local GP sent Vada to the children's hospital where she was provided a referral for 10 sessions with a psychologist but nothing else.

Trinity applied to the NDIS for funding to support Bo and Vada. Bo's application was successful but Vada's wasn't. Vada's disabilities are not considered permanent.

Trinity has been able to access some funding from a victims' support program and, after a long search, found a psychologist who specialises in trauma. The psychologist said the children are telling the truth and Bo is 'incapable of lying'.

Social workers have reported seeing the children's father driving around in a new car and 'believe he's grooming again'.

Trinity is concerned that as Bo and Vada grow up they'll remember what happened and 'wonder why didn't anyone do anything'.

'My children have been raped. What about their future? What about now? There's not one person doing anything. No follow-up. Nothing.'

Camilo, Kamiyah and Julio

Camilo is in his 30s. He is autistic and has intellectual disability. He lives with his parents, Kamiyah and Julio, in a regional city.

Kamiyah was born in Thailand.

‘The Thai culture very strong, respectful and never like to complain, and always appreciate anything people have done for us,’ Kamiyah told the Royal Commission. ‘But from the past many years, I never want to complain. But then I start to learn to complain.’

Camilo’s experience at school was positive, but after leaving school his behaviour deteriorated. Camilo is often lonely and isolated. Julio said his son’s service provider doesn’t help him learn social skills.

‘Basically, they get driven round town on their own, driven to places and then lunch and then afternoon tea, and then more driving around town.’

Kamiyah said the service provider does not provide a safe environment. One time, Camilo ran away from his care facility and was returned in a police van.

‘They haven’t got any fence. It should be maximum concern first for this many people ... They frighten us a lot.’

Camilo’s support workers are poorly trained. ‘They always take advantage and ignore us,’ Kamiyah said. ‘They should do the best for our family. That [is] what we need.’

Camilo’s frustration at not being able to express himself has led to him self-harming and becoming more aggressive. Julio said he’s not been able to find a specialist doctor in the city to treat his son’s autism.

‘I did speak to my GP about would he look after [Camilo] as well. So basically he said because [Camilo] is so aggressive, he said if [we] wanted him to see [Camilo], he had to see him outside in the car park.’

Kamiyah worries that the family’s difficulty with English means they are not advocating as well as they could for Camilo. When Camilo was injured in care, for example, she said she didn’t know why no-one could help them or who to turn to.

‘Sometimes you think, oh, it’s something wrong with our English ... that is very difficult for us, yeah. And may I add ... we don’t know where to go to. We don’t know the people to approach ... to do something, you know, where to start.’

Leonie and Renee

Renee is a First Nations woman and aunt of Leonie, who has cognitive impairment. Leonie can't talk, needs a lot of support and lives in a group home in the city.

'We'd go down, visit her. Every Christmas, birthday, we'd pick her up. But as she got older, she was a little bit more difficult ... She was always having injuries and things.'

About 15 years ago, Leonie spilled a cup of tea, severely injuring her legs.

'That was a boiling hot cup of tea. What did they do? It was just wipe her down with a wet towel ... They did not even look at her, do anything, until another worker came in the next day or whatever, and [Leonie's] leg was stuck together.'

Renee was teaching in a remote area at the time. Because Leonie's mother 'didn't know about guardianships', Renee applied for and was granted guardianship of Leonie.

'I'd come back and look after their kids and look after [Leonie]. Then I'd go and work again.'

Leonie's family is large and very close.

'I don't sleep,' Renee told the Royal Commission. 'What's involved now is, [Leonie's] got nieces and nephews – she's a granny, you know – and as soon as I go anywhere they ring me up, "[Renee] ...?" So, I've got to drop that and go help the family again, you know. All these people that I've got to deal with. And I just don't say no, because that's how we are, family.'

Several years ago, the manager of Leonie's group home sent her to respite care in a house with four men for several weeks.

'When I went there, she was in the home with non-Aboriginal men, and I said, "I don't want her there."'

The service provider then sent Leonie to a nearby caravan park. But when Renee visited her a few days later, she discovered signs that Leonie had been assaulted while in respite care.

'When I had a look she had a bite mark on her breast, which was five centimetres. And they said it was self-inflicted. Self-inflicted?'

Renee reported it to the police.

'I had photographs and doctors' reports and everything, but ... as soon as the investigation was over, they sent a letter to the [service provider's manager] and he said they couldn't be identified, they couldn't lay any charges.

'It hurts ... Now, she can't talk. She's non-verbal. So, that hurt not only us, but our whole family.'

Leonie spent four weeks in the caravan park before returning to the group home. Two weeks later, she slipped getting out of the shower and broke her ankle.

‘So, then I had to go through the process again of putting the complaint in.’

Another time, Renee checked Leonie’s account and found the service provider had overcharged her rent by thousands of dollars.

‘Took a month to put that extra money back again.’

Renee said the service provider has improved in the past few years.

‘There’s been a lot of changes, a lot of staff isn’t there. [Leonie] is quite happy there ... We’ve got a good relationship with the people now.’

Alfredo and Lorella

Alfredo is in his late teens. He is autistic and lives with anxiety.

Alfredo had an 'horrendous experience at kindy', his mother Lorella told the Royal Commission. 'It just became really clear that he wasn't going to cope. He was non-verbal at that time and kids were very mean to him.'

When Alfredo started prep, the school knew he had a diagnosed disability.

'His first two weeks of prep he had no support whatsoever. When he just became completely non-verbal and shutdown, and the kids started targeting him and being mean to him, he started biting, which was something that he had never done.'

The school made it 'very clear' they were unhappy with his behaviour, but did nothing to help. 'But the reason that [Alfredo] was biting was because he wasn't supported. His communication was stifled, blocked completely.'

Classmates 'seriously bullied' Alfredo.

'I was witness to him being physically assaulted by one of the young boys in the class who was learning taekwondo. He taught two other boys the moves and then he floored [Alfredo who] faceplanted the dirt.'

When the school ignored the bullying, Alfredo turned his favourite book character, from *Where's Wally*, into his 'protector'. Wally accompanied him everywhere, Lorella said, 'whenever he felt threatened'. His classmates taunted him even more.

Things started looking better when the school created 'a safe space' for Alfredo. 'It was just a tent,' Lorella said. 'We think we're rocking it ... [Alfredo's] getting his adjustments.'

But then, while at camp, a teacher bullied Alfredo. Lorella spoke with the 'bully' teacher and the principal and 'started actively advocating' for her son. But this caused the relationship with the school to sour.

Things again went downhill when Alfredo attended high school. Alfredo 'was forced to leave school at the beginning of year 9' when his new principal 'stripped him of many of his educational adjustments'. '[He was] cut off from his friends and now learns from home.'

'A substandard education is actually a form of gatekeeping,' Lorella said.

Today, Alfredo is on the Disability Support Pension, and his mother said they had made a 'new life' in the countryside. 'We've created a new dream.'

Hezekiah

‘I became homeless at the age of 50. I am living in social housing. For what? For daring to put the trivial request [for reasonable adjustments].’

Hezekiah started working in a major retail call centre several years ago. He told the Royal Commission that after a career in finance it was an ‘easy job’ with flexible hours. Soon he was working on a full-time basis.

Hezekiah excelled, received regular bonuses and was ‘the first winner of the customer compliments award’.

Then a few years ago he began having problems with his lungs and was diagnosed with chronic obstructive pulmonary disease. He asked to work fewer hours and to have a rostered day off each week to see his doctor.

Hezekiah said from then on management’s attitude towards him changed. His manager suggested he might want to speak to his union, but Hezekiah couldn’t understand why.

Some months later, Hezekiah received a letter outlining allegations of rudeness to customers and colleagues dating back several months. He was shocked to hear about the allegations. In the years prior to him identifying as having a disability there had never been any complaints or workplace issues.

Hezekiah attended a meeting and almost immediately a manager abruptly accused him of misconduct. He believes the manager attempted to intimidate him so he would react with an angry outburst. ‘I was petrified to say something wrong or to make anything wrong.’

Hezekiah made a complaint to the state antidiscrimination body and over the next year attended eight hearings. He feels there was a power imbalance between the parties – he represented himself whereas the retailer had a team of lawyers. His complaint was ultimately unsuccessful.

Hezekiah was ‘completely smashed’ and he was diagnosed with anxiety and depression. He resigned from his job and when he couldn’t pay the rent, lived in emergency housing and went through a period of homelessness.

Since then he’s been able to access the Disability Support Pension and is now seeing a counsellor.

‘I was a complete mess ... I am much better now ... I am going to rebuild myself brick by brick ... I am going to rebuild myself 10 times stronger.’

Cath

‘When an NDIS participant has a family member or guardian caring and managing the financial distribution, the differences are startling.’

Cath has worked in the disability support sector for almost 15 years. Her clients have supported independent living (SIL) funding and require 24/7 care. ‘To pull a wage’, Cath works for a private client 16 hours per week and for a large disability service provider 24 hours per week.

Two of Cath’s clients receive roughly the same amount of SIL funding which is managed by the same SIL provider. She told the Royal Commission she has noticed ‘the private client funding allows a lot more opportunities to do physio, private activities, staffing hours and access to ... COVID-safe activities and exercise’.

Cath believes this is because the private client, Mari, has a family member who advocates for her. Cath’s wages are higher when she works for Mari and all staff ‘pull together’ if there are any issues. Mari is able to do a variety of activities and therapies at least six days per week.

Cath’s other client, Manu, receives a substantial amount of funding but ‘he’s very poor’. He relies on his plan manager to allocate his funds. Cath discovered the plan manager was affiliated with the SIL provider and did not provide ‘independent information or allocation of funds, but rather, sent funds to company preferences’.

Manu had no money for physiotherapy and the public guardian gave him ‘very little money’ for clothing or activities. Manu is ‘home a lot’. He goes to a day program and that’s it – ‘taxi there, taxi back.’

‘There is nobody advocating for him other than us, and we’re not necessarily heard,’ said Cath.

Manu needs two staff members to hoist him from his wheelchair to the toilet. The day program can’t assist Manu use the toilet so he would go as soon as he arrived home. The provider decided they could save money if they changed Manu’s toilet time from 4 pm to after 5.30 pm when there were two staff members there for the shift change over.

This meant Manu sometimes had to wait 12 hours to use the toilet. His bowels became impacted and he had to go to hospital many times. His urine bag and stoma would be pushed out. He began to self-harm.

Cath said staff offered to change shift times, but the provider refused.

‘Companies adjust staffing and services according to profit margins and company projects ... Definitely not client-focused, only profitability-focused.’

Staff became so concerned about Manu's health they encouraged him and his friend, who had family, to change providers.

Cath was able to move with Manu to the new provider but some staff were sacked for helping him.

'[Manu and his friend] seem happier and the company certainly pays them a lot of attention.'

However, Cath's aware 'they're a profit-making company' and is concerned when they 'figure out' how they can increase their profits, Manu's care might deteriorate.

Cath believes clients without family or advocates need to have 'their voices heard more'.

Zoie

Zoie is in her 50s and lives with psychosocial disability and lipoedema, an abnormal and irregular build-up of fat cells under the skin.

‘My entire life I’ve been bullied by the medical profession for being fat,’ Zoie told the Royal Commission. ‘I’ve had doctors say, “I can see that you eat too much and don’t exercise enough,” and I say, “That’s not true ... let me tell you what I eat, let me tell you how I move.” They’re not interested ... the thing about lipoedema is that it is completely resistant to weight loss, including with stomach banding.’

Zoie said she also has undiagnosed autism.

‘I have enough symptoms of autism to say that I’m autistic, but ... I can’t get a diagnosis of that, which is a problem, because it means that I’m not treated correctly by medical professionals.’

About 20 years ago, Zoie began losing her sight and asked a doctor for a referral to see an ophthalmologist. The doctor accused her of being a hypochondriac. She saw another doctor, who arranged an appointment with an ophthalmologist, who sent her to hospital.

‘They diagnosed me with benign intercranial hypertension. For a start, it’s not benign because you can go blind from it, and you can get dementia from it.’

Several years ago, Zoie’s house burned down.

‘I thought that my parents would ... be decent. I went over there, and they put me into hospital, and the hospital said, “We can’t look after her,” and they decided to put me into aged care.’

Her father was given guardianship.

Zoie said the nursing home staff ‘wouldn’t let [her] walk’ and tied her to a wheelchair.

‘Of course, I lost all mobility eventually and became completely paralysed. I think that would probably happen to anybody who was tied to a chair.’

Zoie eventually left the nursing home. ‘They were already threatening me with eviction anyway, because of my behaviour, which was basically I defended myself against attack by the staff.’

Zoie said that after struggling to have her bond refunded from the nursing home, she bought her own house and is now supported by the NDIS.

Chantelle and Suzanne

As a baby Chantelle began having catastrophic seizures which affected her ability to walk and talk. She is non-verbal and uses a wheelchair. She can walk short distances if she is properly supervised.

Suzanne, her mum, told the Royal Commission that Chantelle's primary education, at a disability support school, was 'quite good'. There were 'some wonderful teachers' and 'a lot of care shown for children'.

However, when Chantelle moved to the high school campus of the same school she 'lost her spark and happiness'.

Chantelle started putting on weight and became less mobile. She would often come home from school soaked, covered in large bruises and with unexplained injuries.

One time the mother of another student told Suzanne a student vomited on Chantelle and hit her when they were on the bus.

Another time the bus driver was pushing Chantelle off the bus and trapped her leg under her wheelchair. Someone noticed and stopped the bus driver before Chantelle's leg was more seriously injured.

Staff were supposed to receive training to operate Chantelle's wheelchair, but this didn't seem to happen and it was often damaged. One day, a repair person went to the school and found Chantelle strapped to the chair in the classroom. A young staff member had attempted to get Chantelle out of the chair by lifting her front-on with the foot pedals down. When the repair person intervened, the staff member apologised and said she had worked at the school for a month but had not had any training in manual handling and safety.

Although Chantelle could walk around her classroom, most days she was restrained in her wheelchair and left in the corner of the classroom. During breaks teachers wheeled her to the playground and left her restrained while they supervised other students.

When Suzanne made a complaint to the principal he responded, 'We don't have enough staff to allow [Chantelle] to walk.' Suzanne couldn't understand how a school set up for children with disability didn't have enough staff 'to support our children to practise their skills'.

Suzanne said the principal became 'emotionally abusive'. He didn't like having his authority questioned and wasn't receptive to feedback. 'If you stand up and complain you're labelled as a problem parent.'

Suzanne made a complaint to the education department but said it was 'a law unto itself' and refused to take any action.

‘No place is perfect. I recognise that. But our children should never be locked in a wheelchair. Our children should never come home in bruises. Our children should never come home limping. Our children should never come home in urine. Our children should never come home afraid of a man’s voice.’

Suzanne withdrew Chantelle from the school and began to homeschool her.

She approached the NDIA about additional in-home support for Chantelle. They refused because support during school hours is the responsibility of the education department.

Suzanne contacted the education minister to no avail. ‘I’ve tried to encourage them to support me to support my daughter’s education but there are no options outside of that school and that school isn’t an option.’

Todd

Todd is autistic and has agoraphobia.

‘It was hard for me to leave the house and also, like, I was at home by myself,’ Todd told the Royal Commission. ‘So, it was suggested that, you know, I get a dog or assistance animal.’

When Todd went to prison, he asked that his dog be allowed to visit.

‘I explained the situation and that, because they do ask you is there any issues we should know about and things like that. I got the prison medical people to agree, and forensic care – who do like the mental health stuff in prison – to agree that this is something that should be provided.’

The visits never happened. Todd made a complaint, and the ombudsman agreed the dog should be allowed to visit him in prison.

‘And the ombudsman was like, “You know, it is something that should be provided because it relates directly to health and wellbeing.” And then basically, you know, it got to the stage where I was released before a decision, or anything, had been made about access.’

One day several years ago, Todd said police approached him and he misunderstood what they were telling him. They arrested and charged him.

‘The language and that they were using – and I felt threatened and so forth – and ... so I had a psychologist report that says, “Well, because of his disability, that’s why the interaction with the police went this way.”’

Todd took the police to court for discriminating against him because of his disability. He said the judge ‘threw it out’.

‘The assistance offered to me was none. Like, they said, “Oh, we can’t do a grant for legal aid. We can’t do this. We can’t make orders for that.” ... So, it’s like I wasn’t even given a fair chance.’

Todd says people with disability facing discrimination do not usually have the money to assert their rights.

‘[The government] should make a system that ensures equal access to it, you know what I mean? Otherwise what’s the point of having the process? ... Where there’s a discrimination matter brought up for someone with a disadvantage – not saying necessarily just disability – the government should be obliged to put up equivalent legal costs to whatever the other party is.’

Cohen and Leslie

Cohen is in his 20s. He is autistic and lives with depression, anxiety, chronic reflux, schizophrenia and incontinence. Leslie is his mum.

‘He’s a pleasant, friendly, well-mannered young man. [Cohen] is a loving son, brother, cousin, uncle and grandson, and desires to get on with his life,’ Leslie told the Royal Commission. ‘But he is held back by his disability and other medical conditions. That has a significant impact on his life.’

A few years ago, Cohen was misdiagnosed with an eating disorder and admitted to a regional hospital.

‘[Cohen] was crying out for someone to listen to him about his autism and sensory issues with food choices. He was crying out about pizza ... when up to six people were holding him down and forcing [a feeding] tube into him while he was screaming. Autistic people do not like to be touched.’

Once, a security guard pulled Cohen out of the shower because he was taking too long.

‘Long, long showers are calming strategies ... Security guards need training. The security guard told me that autistic people are dangerous, and I should be very wary of my son.’

After a few months, he was transferred to a city hospital ‘in a catatonic state’.

‘I got a phone call from a doctor, who told me this. She asked, “What are his likes? We can’t get through to him. We can’t communicate with him. He can’t communicate with us.” So I told her all the things he liked, and I said, “If you get on a subject he would normally be able to talk,” but they weren’t able to communicate with him.’

‘Medical professionals in hospitals need to have more training and knowledge of how to deal with patients with autism.’

Gavan

Gavan has cerebral palsy, attention deficit hyperactivity disorder and post-traumatic stress disorder (PTSD).

Gavan's father was his main carer growing up, helping him shower and dress. His father died when he was 10.

'After that time, my mum became increasingly more abusive,' Gavan told the Royal Commission.

Gavan's mother controlled his finances. One day, when Gavan was in year 12, his mother took his wheelchair away.

'She said, "Why don't you go into the big wide world and, you know, see what it's really like?" She then took my wheelchair, stuck it in the back of a four-wheel drive and locked it up.'

Gavan moved in with his older brother, but said his mother wouldn't let him have his equipment, including a modified vehicle that had been provided as part of a disability support package.

Gavan spent most of his Centrelink support on taxis to and from school. The taxis were often late.

'If I or any other student was late, [the teacher] would make us stand outside the classroom, and she would literally go around to each of us and go, "Why were you late?" and my excuse was the same every time.'

Gavan needs help dressing and showering, and can't use public transport with his wheelchair. Getting to and from school was a physical and financial challenge.

'Okay, even if I get to school, how am I going to get home again? And even if I get home, how am I going to afford to get to school the next day and complete the whole process?'

When he told a teacher he couldn't afford a textbook, the teacher told him to 'lift [his] game'.

'I said, "Well, I can't do any better than I'm doing. I'm currently living with my brother. I'm potentially going to have to look at shifting out ... I said that I was struggling to even get to school. He basically told me in no uncertain terms, "If you can't handle it, just drop out."'

When his brother moved away, Gavan was homeless. Two members of his church invited him to live with them. They then applied for a carer's payment.

'[They] ... mentally abused me for months ... The primary reason I'd agreed to move there was because they were meant to take me to school instead of getting a taxi, but they ... after a couple of weeks, just went, "Nuh."'

Gavan finished year 12 'by some miracle', but the stress triggered PTSD. He moved out and later tried to continue his studies at university, but couldn't find suitable student accommodation.

'I literally couldn't get anyone to rent me a room because as soon as they found out that I had [cerebral palsy], they basically didn't want to take me on.'

The NDIS provides Gavan with a support worker for a few hours a day.

Gavan recently married, but the NDIS rejected his application for specialist disability accommodation. Gavan said his support coordinator has suggested he and his wife move into a group home.

Darrell

Darrell is in his 40s. He is autistic and lives with chronic anxiety.

'I suffered many challenges as a teen, which are more comprehensible in the light of my subsequent autism diagnosis,' Darrell told the Royal Commission.

Darrell's autism wasn't diagnosed until he joined a government department and found 'extreme difficulty in taking actions that fell out of a set routine'.

Darrell said, despite this difficulty, he performed highly at work until a manager bullied him for what he's been told is his 'interaction style and manner'.

'She was very clear that my manner was a key part of her contempt for me, criticising factors like my "subtly negative body language", and the fact that there was "something off about my manner". I broke down relatively swiftly.'

Darrell said the manager manipulated where he worked and his job prospects, denying him transfers.

'She acknowledged that she'd never supervised me, never worked with me ... and that, I think, just shows how dangerous things get when you let people sloppily operate through social influence and informal power.'

Darrell objected, but nothing was done. He said the government department breached its own legislative requirements to treat him fairly.

The bullying increased Darrell's anxiety and destroyed his relationships.

'Every day going to work I sign up for torture because open plan offices are noisy. And I'm even cut off from certain forms of entertainment. There are characters in TV shows whose manner or a physical appearance remind me of key people involved in this, and it's actually really upsetting to watch.'

Darrell said the department's senior managers became aggressive towards him even though they knew he was 'an ongoing suicide risk, had significant mental health issues'.

'They still launch into me because that's what they do.'

He said the public service, which should be a model for inclusion and fairness, isn't.

'It's not just small businesses being dodgy. In big departments, in all sorts of other places, horrible stuff does happen to people.'

Darrell now works for another government organisation.

'It's been a much better place to work. So, workwise, everything is going well. It's just, obviously, the personal and symptomatic issues have never resolved. And years on, honestly, my prospects aren't that great or improving noticeably anymore.'

Gideon and Afiya

‘They make you feel selfish for using any services whatsoever. And, you know, it’s a privilege that you’re getting services, but then they promise you the earth and never deliver.’

Gideon is in his 20s and is autistic. Doctors recently diagnosed him with schizophrenia. Afiya, his mother, has two other sons with autism, and she’s the main carer for her mother and father.

‘So, it’s been a bit of a difficult time, shall we say,’ Afiya told the Royal Commission.

Gideon lived at home until his schizophrenia diagnosis a few years ago. When he became ‘too much to handle’, Afiya looked for respite care.

The first provider told Gideon to leave after a couple of months, giving ‘no supporting reasoning’.

‘They gave us two days to find another provider, which also included accommodation.’

Gideon’s next provider changed its mind when it discovered it didn’t have enough beds.

Afiya said his current provider neglects him.

‘There were also times when they didn’t provide food in the house, and the food that was being left in the house was minimal and it was expired.’

Afiya said all providers promised to develop Gideon’s skills, to help him become independent, ‘but they don’t do anything for the participant, for their client’.

‘They’re getting all this money, and ... you don’t seem to have any comeback. Like, you’re just at their mercy, whether it’s the provider or whether it’s NDIS, you have no real power. I don’t. My son certainly doesn’t.’

For example, when Gideon’s house recently flooded, his service provider moved him without support into a motel.

‘Without contacting me ... they dumped him there. They hadn’t fed him all day. He’d had no access to food. He had no medication with him. He had no belongings with him. And they’d taken his support service dog.’

Afiya said one of Gideon’s goals was to find a job and become independent, but the service provider ‘never took him out into the community’.

‘They cancelled his transport at the last minute. Staff wouldn’t show up at all.’

Afiya said that, because he wasn't using the money set aside for transport, the NDIS 'slashed' Gideon's funding.

'The NDIS said in their wisdom, "Well, he's not participating in the community. He doesn't need transport." So, they took it away from him. So, I just feel like you're just constantly battling all the time and you're getting nowhere. And I can't get anyone to help me. It's just a terrible system. You just feel so helpless and hopeless. And if I feel like that at times, how does my son feel? I feel like I'm failing him all the time.'

Afiya said the NDIS and service providers have ignored her complaints.

'If I'd had the proper supports and the communication so I knew what was going on and I could work together with them and feel actually listened to, and I could resolve issues and get some results, I could help him be the most independent person that he can be,' Afiya told the Royal Commission.

'It would actually save the system in the end because he'd be a lot more independent and I could actually use less support services. But I seem to be frustrated at every turn to achieve that goal. So, the system is working against me.'

Delaney

‘As a house coordinator, I was constantly in battle with upper management in regards to people’s choice and control.’

Delaney, in her early 50s and an NDIS participant, has worked in disability group homes for more than 20 years. She worked in one home as a house coordinator for 15 years, but resigned two years ago. ‘I left totally broken, worn out.’

Delaney told the Royal Commission residents did not get a choice about who could visit the home or what activities they did. Often staff would only let residents use their iPads if they did an activity with other residents, such as go to a barbeque. ‘To me that’s manipulation and coercion,’ Delaney said.

Over the years, Delaney became increasingly concerned about the behaviour of staff. Money would regularly go missing from residents’ bank accounts. Staff would take the residents out to lunch and use the residents’ money to pay for their own lunches and drinks. Staff would encourage residents to buy and drink alcohol. One staff member ‘hooked up’ with a next-door neighbour and started ‘having sexual relations on the premises’.

Whenever Delaney made a complaint, instead of protecting the residents, management sided with the staff member. The organisation believed staff members could be ‘rehabilitated’ through their ‘good work’ with people with disability. Delaney finds this idea offensive.

Delaney said management continued to employ and protect a particular member of staff. In the late 2000s the staff member brought illegal drugs into the home. Despite complaints, management took no action. A few years later a neighbour called police after witnessing the staff member violently shake a resident. The resident had bruises on her arms, which a doctor said were consistent with being shaken.

The organisation refused to notify the family, so Delaney did. The next day Delaney found the resident unsupervised in the kitchen while dinner was cooking. The same staff member was outside on his mobile phone, smoking. Delaney wrote a report but her manager asked her to change it. ‘So, I bloody well did. I took it out and I knew it was wrong.’

Delaney said she had to fight ‘tooth and nail’ for the staff member to be removed from the house. She believes they still work for the organisation.

The organisation ‘started to fall apart’ about two years ago. The roll out of the NDIS gave Delaney ‘permission’ to ‘really push’ the residents. She asked them where they wanted to live and what they wanted to do. Using pictures of activities, she asked non-verbal residents to select activities.

Management did their best to ‘undermine’ Delaney, but she kept going. ‘Pressure was applied, and pressure was applied really hard,’ she said. It was stressful ‘doing it all on [her] own’. Ultimately it became too much for her and she left. Five residents left at the same time.

The organisation now appears to have ceased providing disability support services.

‘People just want to live a free life. They want to live a life that you and I have. They want to be able to go, “I want to do this, or I don’t want to do this.” You know, they want to have complete control.’

Dianne

‘They literally used my disability against me.’

Dianne, early 40s, has an intellectual disability and finds it hard to read and write. She has three children, two of whom have disability.

About 10 years ago, Dianne came home from work late at night and found her children and their father gone.

Someone had told the department of child safety the children hadn't been fed. Their father was passed out on the couch, drunk and under the influence of illegal drugs.

Child safety took the children into emergency foster care.

Dianne told the Royal Commission she tried to get them back but the department said the children weren't safe to 'be around [her] because of [her] intellectual disability'. Dianne had to 'push' for them to go to their grandparents – her parents.

‘For 10 months, and in that 10 months I proved to them that I was fit enough to have the girls back reunited to me as their full-time carer.’

The following year Dianne had a miscarriage, her house flooded and her health deteriorated. ‘I was dealing with the constant abuse from my ex-husband. It was verbal, it was physical, it was mentally, emotionally, you name it, I copped it.’

The department again removed the children. They didn't believe the children were safe living with either parent.

For the next few years the children moved between the foster system and their paternal grandparents.

Dianne fought to regain custody but the department did not consider her a safe option because of her intellectual disability. She found the process very difficult especially when she had to read and complete so many forms. The department and courts rarely explained anything to her and never provided Easy Read documents.

When her eldest daughter was diagnosed with fetal alcohol syndrome the department blamed her and, Dianne says, used it to continue to deny her custody.

Dianne's ex-husband told the court she was 'verbally abusive' and 'physically abusive' towards the children and they were 'at risk of being emotionally harmed by [her]'.

The court awarded Dianne's ex-husband custody of the children and they lived with him for several years.

Dianne's eldest daughter has severe depression, anorexia and self-harms. As soon as she turned 16 she returned to live with Dianne.

'I now have a 16-year-old daughter that needs to learn how to be a child again, because her father literally made her – the way the doctors have put it – he made her his slave. She had to cook his food, clean the house, be a mother to the other two kids.'

Not long after this, Dianne's other daughter came to stay.

Dianne is working hard to turn her life around. 'There is no such thing as a perfect person. Everyone makes mistakes. I stood up. The only way I knew that I would be able to change myself was, I stood up ... I admitted all the stuff-ups I did.'

Raven

‘When a person is admitted into the mental health ward they are intimidated. I was intimidated and deceived into signing a voluntary admittance form.’

Raven is in her mid-50s and lives with Sjogren’s disease, an immune system disorder, a back injury and congenital hip displacement.

She told the Royal Commission a ‘history of family dysfunction’ and a violent ‘psychopathic’ father are responsible for symptoms that include difficulty recognising faces and forming friendships. She has had delusions and often feels isolated.

Raven said she ended up in a hospital mental health unit about a decade ago after she slapped her sister on the face. Her family had her charged her with assault and health professionals misdiagnosed her with schizophrenia. She said the diagnosis was ‘inaccurate’ and ‘negligent’.

‘Family members are using the mental health diagnoses as a weapon during family dysfunction.’

Raven feels the way she was treated highlights failures in mental health services. She says psychiatrists use intimidation to ‘detain’ people in mental health wards. They exert ‘too much jurisdiction’ over patients without properly informing them of treatments.

She says they also misdiagnose mental illness and administer ‘continuous lifelong medications’ that have ‘a debilitating effect on people’.

‘When I had an interview with one of my psychiatrists about medications, I said to the person “Well, am I going to be 80 years old in a nursing home and still getting medications enforced on to me?” And he turned his head, shrugged his shoulders and changed the subject. So, I gathered from that, yes.’

Raven said mental health workers had breached her privacy when she was an inpatient by sharing information with her family members but withholding it from her.

She also had difficulty accessing her medical records. She applied under freedom of information to access case notes relating to her diagnosis, but all she received was ‘mostly a lot of garbage’.

‘Mental health patients are unlikely to ever know the full reason for their diagnosis, and they’re not properly able to challenge their diagnosis.’

Psychiatrists again admitted Raven to a mental health facility a couple of years ago. She appealed unsuccessfully to the health ombudsman about her diagnosis.

Because she put up a sustained fight, the hospital released her with her doctor's support. 'It was only [with] my persistence that they succumbed.' Since then, she has been free of the antipsychotic medication and has become an advocate.

Raven wants to see widespread change to the mental health system.

Raven's experience with relationship support services has been more positive. Psychiatrists had ignored the family dynamics behind her symptoms and simply medicated, whereas counsellors focused on understanding the family dysfunction, building coping mechanisms and changing negative beliefs.

For this reason, she wants independent counsellors to be part of the mental health tribunal hearings that decide on patient treatment 'to act as advocates during a diagnosis ... [and] balance out the psychiatrists' propensity to diagnose mental illness'.

Dre

Dre lives with paranoid schizophrenia and depression. He receives the Disability Support Pension and accesses supports through the NDIS.

During his several admissions to a mental health facility, Dre was sexually abused, put in solitary confinement, shackled to his bed and medicated without explanation. Dre's psychiatrist told him that this same facility has been the focus of inquiries and media attention.

Dre told the Royal Commission that he was admitted to the facility 'at least four or five' times over an eight-year period from the late 1990s. Some admissions were voluntary but, on most occasions, he was 'brought there in an ambulance.'

Dre said a particular male nurse sexually abused him 'more than once' during his stays at the facility. It was always when he was alone in his room at night. Two other nurses were involved. Dre thinks the facility had a culture of abuse. He 'can't believe how [other staff] wouldn't know'.

He cannot recall much about events in the early days because staff heavily sedated him. They never told him what medication they were giving him and had him 'shackled to beds and kept in ICU for weeks at a time'. Dre said fellow patients had similar experiences.

The last time Dre was admitted to the facility, he felt 'very uncomfortable with the nurse'. 'I remembered who he was ... and I asked to be discharged to [another mental health facility].' Dre complained to a head staff member about the abuse when he left the facility but believes it was 'brushed under the carpet' because he was 'a mental patient ... making up stories'.

Dre was satisfied with his care at the new facility. He felt the nurses were professional, they gave him more information about his medical care and he felt safe.

Dre has ongoing negative effects from his experiences, which, he says, are 'still a nightmare' almost 20 years later. They have affected his relationships and his work, and he hates leaving his house – a private rental unit where he lives alone. He uses alcohol and illicit drugs to cope.

Dre is reluctant to divulge his mental health situation to government bodies. He has his own psychiatrist and uses private services, but he has lost faith in the mental health system. He says he doesn't want anyone else to go through what he has.

'I don't have much of a life anymore and the system ... does need some help.'

Rosario

‘These people have to change. People have to be brave enough – when someone calls out, “I need help, I am being bullied” – to do something about it. What I found is that people are scared of losing their jobs.’

Rosario, early 60s, lives with post-traumatic stress disorder (PTSD).

About 10 years ago, she worked for the Australian government dealing with confronting and extreme situations in overseas countries. When she returned to Australia, she was diagnosed with PTSD as a result of her work.

Her employer provided psychological support, but it was ‘useless’, Rosario told the Royal Commission. She experienced a complete breakdown a short while later.

‘I was crashing and I didn’t realise it. I crashed.’

After she recovered, Rosario returned to work. But her employer and colleagues ‘ignored her’ and ‘walked on eggshells’ around her as if she was ‘a danger’. ‘They moved me from room to room, from team to team ... It was horrible.’

Then, out of the blue, Rosario’s employer ‘ambushed’ her, accusing her of privacy breaches. Her employer gave her 20 minutes to formally respond to the accusations. ‘They put me in a fight-or-flight mode.’

Rosario believes it was an intimidation tactic to traumatise her further, and an excuse to take her security pass and work computer from her.

While the employer investigated the accusations against Rosario, her colleagues and supervisors bullied her. ‘[They] were openly demeaning and degrading to me ... treated me like I was a piece of dirt.’

Rosario believes her employer used her PTSD against her to make it seem like she was of ‘unsound mind’.

Rosario was eventually charged, ‘frogmarched out’ and formally dismissed. The charges, however, were later dropped.

Rosario lodged a fair work claim against her employer for unfair dismissal. ‘I didn’t have money for a lawyer. I couldn’t get advice.’ She ended up representing herself. Two barristers and several solicitors represented her employer.

‘They offered me a pittance with a gag order,’ Rosario said. She felt she ‘couldn’t compete’.

‘I dropped the case for health reasons. I needed to make a stand and put it behind me. Now, I want to find a job and get on with my life.’

Dwyer

‘It proved to me that they didn’t have the system, they didn’t have a way to let blind people know what was going on.’

Dwyer, later 40s, is autistic and visually impaired. He lives independently but relies on support workers to help with almost all daily tasks.

In 2020 Dwyer ‘had a nasty cough’ that wouldn’t go away. His disability support agency cancelled all his support workers until he had a COVID-19 test. Dwyer rang around trying to get an in-home test to no avail. He contacted the agency, ‘very frustrated’, and they agreed a worker could take him to a drive-through testing clinic. The clinic told him he would have the results within 24 hours.

Dwyer asked the clinic to telephone him with the results rather than send a text message. He explained, being blind, he would not be able to read a text message. He also asked the clinic to send his result to his support agency and expressly provided his consent for them to do this.

Dwyer spent the remainder of the day isolating at home. He would usually go out with a support worker but understood the necessity of staying home to ensure everyone was safe.

Twenty-four hours later Dwyer had not received a result. He became increasingly worried because his support workers were not able to come to his home and he had no other support. He asked the support agency to help him track down his test results.

A few hours later, still no result, Dwyer phoned the government agency responsible for testing. They couldn’t provide any information and told him he just had to wait. They encouraged him to contact the clinic the following morning.

The next morning, the clinic told him they could only send the results by text message.

By this stage, Dwyer was feeling ‘very isolated and frustrated’.

Dwyer’s support agency also started hassling him. They needed his test results because the support worker who had taken Dwyer to be tested could not work with other clients until they knew Dwyer’s result.

After several more phone calls, including to his advocate, the clinic finally told Dwyer they had sent the results. Dwyer had not received them and asked them to tell him the results. The test was negative.

Dwyer told his support agency the test was negative but they needed the results in writing. Eventually Dwyer’s doctor was able to confirm the results.

Dwyer was very relieved because his support workers were able to return.

He then tried to book a COVID-19 vaccination but found the only way to book was online. 'I don't even have the internet, I don't have a computer full stop.'

Dwyer rang the COVID information line and, after being on hold for 35 minutes, 'gave up'. He tried again after work and this time was able to access the call back feature. A COVID hotline staff member rang while he was shopping with a support worker. The staff member confirmed he needed to book his vaccine appointment online.

'I said, "I'm blind, I'm visually impaired, I don't even have the internet" and she said, "You need to book online" and I was getting pretty ropeable.'

Ultimately, Dwyer's support worker made the booking for him using her computer. If she had not offered to help, Dwyer said, he 'really would have been snookered'.

Emmanuelle and Wilma

Emmanuelle was in her 80s and blind when Wilma met her.

‘She was the youngest of three spinster sisters with a very domineering father and a mother that had died when she was very young,’ her friend and former carer, Wilma, told the Royal Commission.

‘I think her disability came about because she hadn’t got the right care prior to her getting cataracts, which then led to blindness which then isolated her.’

Emmanuelle lived ‘in a very well-to-do area’, but ‘nobody seemed to notice her, to the point of [her] living in squalor’.

She was religious and belonged to the church.

‘But no-one ... was prepared to actually look out or do the neighbourly thing,’ Wilma said. ‘Somewhere in the system she got lost ... [and] had become a bit of a recluse.’

Wilma worked for a company that was providing Emmanuelle with disability support at home. ‘I ended up resigning from my job to be able to care for her [privately] ... because no-one was really taking care of her.’

The NDIS service provider wanted to move Emmanuelle out of her home. But that was ‘against her wishes’. ‘It was a family house that she had lived in all her life from 16,’ Wilma explained.

One day, Wilma was driving past and went to check in on her Emmanuelle. ‘And I got in and there was no sign of her. And then alarm bells rang.’

She phoned Emmanuelle’s support manager, who said Emmanuelle had been taken to hospital after a fall. Wilma was ‘livid’ – the manager had agreed to inform her if an emergency arose.

Arriving at the emergency department, she saw Emmanuelle ‘being heaved around by these great big blokes, stripped and washed and, sort of, disinfected’.

‘It was such abuse,’ Wilma said. ‘[She] turned into a piece of meat. No value, no nothing, no person.’

The hospital moved Emmanuelle into its aged care facilities. ‘I just found the whole place so neglected,’ Wilma said. ‘I was just so upset.’

Wilma did her best to make sure Emmanuelle ‘was alright’.

‘[I’d] play her YouTube services by the Pope in Rome because I knew that would give her some comfort because she couldn’t do anything.’

But she was 'angry and upset' at the 'abuse and neglect' of her friend.

'One day I walked in and she'd had a stroke, and they hadn't even picked up on it. I was ropable. I mean, I just couldn't believe these people, neglecting her so badly.'

Wilma said the mistreatment was widespread. She observed that women, in particular, were 'invisible'.

'They were so neglected these people ... Little ladies there who perhaps had a fall ... So, I decided that I will go around chatting to them all ... because they were so scared because no-one was really telling them anything.'

During her visits, Wilma would 'paint their nails, or do something kind like that'.

'I really feel ... that if we could somehow bring in that sort of nursing approach into those wards in the hospital, there would be so much joy in those rooms.'

Stewart

Stewart is in his 50s and lives with complex cognitive disability, schizoaffective disorder, post-traumatic stress disorder and oppositional defiance disorder.

‘I have a history of childhood sexual abuse from different adults,’ Stewart told the Royal Commission. ‘The reason I’m here is to create an awareness of complex cognitive disabilities. The biggest problem for me is the need to be needed. I was in a lot of dependent relationships where people will take advantage of me.’

Stewart said his disability made him ‘a poor decision maker, especially with finances, business and employment’, and the target of con artists.

‘I’ve done a lot of jobs. I found, because of my low confidence, I’ve been in a lot of industries that I suppose are what we call “dead end”. I worked in the cleaning industry for many years ... I bought a cleaning franchise and got ripped off \$20,000 ... I seem to be on the up and up, and suddenly that self-destruction kicks in.’

Stewart said he is especially vulnerable when he’s under financial pressure. For example, a few years ago a man approached him to start a cleaning business together.

‘I was totally taken in by him.’

Stewart said the man also claimed to be a member of the mafia and tricked him into paying him hundreds of dollars a week for several years.

‘I was catfished into believing that things happened. And he would introduce me to people who would say they were with the mafia ... Then eventually, I met his housemate ... who said, “No, he’s a conman.”’

Stewart said one time when he was out of work he used a disability employment service. It sent him to low-paying jobs where he was often bullied.

‘I was making certainly less than \$20 an hour.’

When he found a better job himself, he said the employment service rang his new employer and got him sacked.

Stewart now receives a Disability Support Pension. He told the Royal Commission he’s ‘probably lost nearly half a million dollars’ to people who’ve taken advantage of him at work.

‘I feel that there really needs to be a lot more done regarding assisting people with [complex cognitive disability] in holding down jobs.’

Emmeline

‘Getting help was the worst decision of my life.’

Five years ago, Emmeline, then late 20s, had a ‘big mental breakdown’. She told the Royal Commission she attributed her breakdown to the death of two of her babies – one died during labour and one was stillborn.

Emmeline developed insomnia and anxiety. She started experiencing flashbacks of her babies’ deaths and had auditory hallucinations. She also had flashbacks about her own childhood abuse. Over time the hallucinations became more frequent and intense and Emmeline feared she ‘had died’ or ‘was going to die’.

Emmeline, supported by her husband Saxon, went to a local mental health service hoping to receive therapy and ‘strategies for the flashbacks’. She explained her symptoms to the psychiatrist and was clear she ‘wasn’t suicidal’ but ‘really tormented’. After about 15 minutes, a nurse handed her some medication. She wouldn’t say what it was and Emmeline refused to take it.

The psychiatrist told Emmeline she had psychotic depression and placed her under an involuntary treatment order (ITO). He threatened to call police if she didn’t take the medication. Emmeline and Saxon were ‘so shocked’. Emmeline wasn’t ‘violent or threatening’ and couldn’t understand why the psychiatrist was talking about the police. Saxon told her to ‘just take the medication’ so she could ‘get out of there’.

After several weeks of taking the medication Emmeline was still experiencing the flashbacks, felt groggy and had gained a substantial amount of weight.

‘I began to argue that my treatment just seemed extreme, and harmful.’ The psychiatrist decided she had borderline personality disorder.

Emmeline asked for a second opinion but the psychiatrist told her it ‘does not work like that’. He said he no longer ‘trusted her’ to take the medication orally. From then on, four staff members would hold her down and forcibly inject her. ‘Afterwards, I just cried like a baby.’ She felt incredibly isolated, powerless and hopeless.

Over the next five months Emmeline was hospitalised involuntarily several times. ‘I was hospitalised for missing an appointment at the clinic or refusing to speak about my symptoms, such as hearing voices. They said because I wasn’t being honest about my psychosis, they couldn’t trust that I was safe.’

In hospital Emmeline wasn’t allowed to participate in any group programs and had to spend the entire day in her room with no access to her phone or other belongings. Her mental health deteriorated further and the isolation made the voices in her head louder.

Emmeline began to feel unsafe. ‘I received quite a few sexual remarks, like being asked for sex.’

She asked nurses to lock her door at night but they told her if she was anxious, take antianxiety medication.

One night a male nurse accused her of hiding her phone and searched her. 'He started to touch my breasts, go under my clothes. And I realised it was becoming sexual. I began trying to push him off me ... and he began to hit me.'

Emmeline tried to find a lawyer to help her challenge the ITO. No-one was willing to take her case because they believed, with her diagnosis, there was limited chance of the order being lifted. Emmeline represented herself at a review hearing but was 'overwhelmed and crying'. The tribunal decided the ITO should be continued 'indefinitely'.

Despite the possibility of being charged with a criminal offence, Emmeline and Saxon decided to leave the state. They were homeless for several months, terrified police would find them.

Emmeline has now found a psychiatrist she trusts and sees him every week. He has diagnosed her with dissociative disorder, stemming from trauma. He does not believe she has borderline personality disorder or schizophrenia. She no longer takes medication.

Emmeline has also joined a peer support group for mothers who have lost their babies. 'It's been really good to know other people that have gone through the system and suffered like I have.'

Francisco and Anthea

‘If we don’t do anything to get him out as soon as we can, we’re going to lose him. And he’ll be another death in custody.’

Anthea is a First Nations woman. Her son, Francisco, is in his 30s and has schizophrenia and bipolar disorder. He’s never been convicted of a crime, yet has spent a decade in prison.

‘He’s a very intelligent young fella. He’s attempted to study at universities,’ Anthea told the Royal Commission. ‘His mental behaviour, he didn’t acknowledge that it was an illness. He didn’t acknowledge that it was an issue that was going to crack him. You know? And this is where we’re at.’

Francisco was a promising athlete in his teens. His brother, Kev, told the Royal Commission that a leg infection stopped his sporting career. Doctors diagnosed Francisco with schizophrenia and bipolar disorder when he was 18.

‘And from that point in time, [Francisco] slowly started going downhill ... Like mum said, he’s pretty highly intelligent. Was really good at sport. Good in the community. And then the system just basically failed him.’

When police arrested Francisco for a property crime, a court found him unfit to stand trial on the basis of mental impairment. He received a custodial supervision order which he’s serving in prison. State authorities say they don’t have a suitable facility for him.

‘We don’t want to lose him in the prison system,’ said Anthea. ‘We want him home so he can live amongst us as normal as possible.’

Anthea said Francisco was not getting appropriate treatment in prison.

‘He’s not involved in any mental help recovery program whatsoever, because that centre does not provide that for people suffering with mental illness. In particular, our people. The First Nations.’

Francisco’s father, Hans, recently visited him in prison.

‘I was quite shocked at the treatment that he was getting from the prison officers ... And to me, anyone with or without a medical, and specifically with mental, illness, if you keep pushing someone like in a corner, they’re going to retaliate.’

Once, when he was released with a tracking device, Francisco travelled interstate to be near his family. Police returned him to prison.

‘Now, if you are looking at the wellbeing of a patient ... he was in [his home state] when he was arrested. Why wasn’t he taken to the [local] mental health facilities? ... It’s still a political move to take him back ... and lock him up again.’

Francisco went on a hunger strike when he was sent back to prison. 'He was not in a good way. His organs weren't working properly,' Hans said.

'Ten years in this system ... If you weren't totally mental before, you probably would be after being incarcerated in that place for such a long period of time.'

Hans said the family is trying to have Francisco released 'so that he can get the right treatment and right support' closer to home. If it's a matter of cost, Hans said, he's willing to escort Francisco home for treatment 'and save money to the taxpayer'.

Andrea told the Royal Commission the family doesn't know what more they can do to get Francisco out of prison.

'It is very emotional for all us, Commissioner. We want our family man [Francisco] to come home.'

Haydn

‘I’m essentially having to act as my own doctor any time I go anywhere because there just is no understanding of what needs to be done by half these doctors.’

Haydn, mid-20s, has chronic pain, attention deficit hyperactivity disorder (ADHD), anxiety, depression and regularly dislocates his bones. ‘If I sneeze or cough I’ll dislocate a rib.’

Ten years ago, he was hit by a car and required five surgeries. His disability got progressively worse and ‘things just kind of unravelled from there’.

When Haydn was released from hospital the pain ‘just never went away’. The hospital didn’t give him a referral to a pain specialist or follow-up support.

‘No-one picked up the fact that I was part mobile,’ Haydn told the Royal Commission.

It took several years for a pain specialist to finally diagnose him with a rare syndrome. ‘It was kind of like a bit of a lightbulb moment ... as to why I’ve always had all of these problems.’

Haydn said GPs have limited knowledge of the syndrome and don’t understand the symptoms. Doctors only want to treat his mental health issues and fail to address the constant pain he is in.

‘I get to the end of the day some days and I’m literally balled up on the ground crying I’m in so much pain.’

Haydn applied for the Disability Support Pension but wasn’t successful. Despite having letters from his psychiatrist and pain specialist, Centrelink assessed him capable of working 16 hours a week.

Haydn has tried to apply to the NDIS for funding to pay for physiotherapy, hydrotherapy, massage and a support worker to help him cook and do some tasks. But he gave up because he couldn’t afford to pay an occupational therapist to complete an assessment.

Haydn is also worried about getting involved with the NDIS. ‘It’s just been bad thing after bad thing in the news,’ he said. ‘If it does get knocked back there isn’t really much avenue for appeals and what not and if you appeal a decision you can be sitting there waiting a fucking year for an answer.’

Haydn has two small children.

His partner’s ex-best friend recently told child protection Haydn uses illicit drugs.

Haydn said the accusation was ‘ridiculous’ and she was being ‘malicious’. Child protection made him leave the house for a week and drug tested him.

'I'm on ADHD meds and ... I've got to do the drug test and it's come back positive for amphetamine and even then, it's not methamphetamine, it's very clearly amphetamine, like what I'm prescribed.'

Haydn had to go to court. He was allowed to return home but child protection have to see the children once a week.

'A lot of their concerns got disproved and they're still involved.'

'The one good thing that's come out of the stuff with [child protection] is we've got a support worker.'

The support worker is helping Haydn make another application for the Disability Support Pension.

Rod and Murray

Rod, early 60s, acquired a brain injury in a workplace accident in the late 2000s.

About two years ago, he was at a shopping centre and was hungry but didn't have any money for food. Murray offered to buy him something to eat and they became friends.

Rod told the Royal Commission that he has money but is unable to access it. The public guardian manages his Disability Support Pension and the compensation money he received as a result of the accident. The trustee pays Rod's rent and bills and gives him \$220 per fortnight for food, transport, everyday living and dog expenses.

'Not only does he not have access to his money ... they're barely paying him anything at all,' Murray said.

One time, Rod had to go to a charity for food, but was turned away because he is under the care of the public guardian.

Murray lends Rod about \$200 each week to help cover his expenses. 'If it wasn't for my support he would be starving and dead in the street somewhere, I suspect.'

Murray has also repaid Rod's outstanding loans. Rod owes Murray about \$40,000, which he intends to repay when he gets access to his money.

Rod said the public guardian doesn't communicate with him and is rude and abusive when he asks about his money. The annual fees have increased from \$3,400 to \$4,300 per year.

Five or so years ago, the public guardian released more than \$300,000 so Rod could buy a house for a woman he's known for some time. Rod doesn't live in the house and doesn't know the address. He is not sure if his name is on the title and hasn't been able to contact the woman for many months. Murray believes the public guardian should not have released money for something that doesn't benefit Rod.

Murray can't understand why the public guardian doesn't seem to care about Rod. 'This is a guy who has had a brain injury. You'd think someone would have checked up or even see how's he's going.'

Garry and Rea

Garry's in his 30s and lives with Asperger's syndrome, anxiety, depression, post-traumatic stress disorder and avoidant personality disorder.

Garry's mum, Rea, supported him when he spoke to the Royal Commission. Rea said Garry struggled at school and although the teachers knew he needed help, nothing happened.

'It appeared that he would drift off at times and stuff ... they wouldn't help him. They were giving up on kids because it was complex. That's when they should have been having interviews with parents saying, look, you know, this is where you can go for help.'

'They knew that I had depression and anxiety,' said Garry. 'Like I told them, you know, I'm depressed all the time because my dad's being, you know, verbally and physically abusive in the mornings.'

Instead of helping, the school phoned his father, 'which escalated the domestic violence at home'.

Garry's disability wasn't diagnosed until after he left school.

'He could have been diagnosed with his autism many, many years ago,' said Rea, 'but you know, there was no guidance for parents with what to do. Some of the teachers would get frustrated and just say, you know, "he's lazy this and this."'

Garry was recently diagnosed and began receiving NDIS support. However, he wasn't able to use it for several months because it didn't match his needs.

'That's been a bit of a nightmare ... They knew that I needed to book an occupational therapist to try and access more funding, and also for housing ... The local area coordinator knew that I needed the occupational therapist report, didn't contact me, didn't return any of my calls for about three months or so.'

Garry wants to keep working, but said his health lets him down. Recently a boss sacked him because his hands were shaking.

'I explained to him ... that, you know, it's my antidepressants. I'm getting side effects that I've never had before. I was warned that this can happen ... And he goes, "You're a junky, you're on drugs." I said, "No, I'm on medication" ... and he goes, "I don't believe in that stuff, it's against my religion ... I'm a Christian, I don't believe in this stuff." I said, "So you don't believe in medicating?" He goes, "No." And then I got sacked.'

Garry's now on a Disability Support Pension.

‘The reality is I don’t want to be on a pension. I wanted to be working, but I’ve consistently been let go based on my physical health and my mental health ... I’m not happy getting by on breadcrumbs, you know, every fortnight. Like I would like to do more with my life, but unfortunately that’s not the case right now.’

Esme

Esme is in her 70s and lives with bipolar disorder.

'I am a working-class girl and the only thing I ever had really going for me was I was smart, you know. I had a high IQ, I could apply it,' Esme told the Royal Commission. 'And the thing I wanted least to mess with was my brain. The thing that I thought [was], "Don't take this away from me."'

Esme said that, as she aged, the emotional lows of bipolar disorder became harder to treat. Several years ago, her usual medication wasn't working and a doctor admitted her to a clinic where she was given electroconvulsive therapy (ECT) 'over 30 times in that three months'.

'I was waking up and not being able to remember the names of my grandchildren, not remember language and knowing that that was happening, and me saying, "Please stop this."'

Esme said the psychiatrist at the clinic coerced her to continue treatment when she didn't want to.

'I was asking, "Please stop this." I was being ignored.'

Esme said she originally consented to the ECT when she was 'at [her] worst'.

'You know, you're depressed, you don't care, your family have walked away from you ... If [the psychiatrist] believed I was in good enough condition to say yes to 48 treatments, when I said "I don't want anymore" I should have been [considered] in good enough condition to make that decision.'

When Esme asked for a second opinion, the psychiatrist refused to make a referral.

'I mean, it was bullying, it was intimidation, it was threatening. It was a total abuse of power and it got to the stage where it was not even hidden. It was, "If you stop having this now and you want to start again I won't see you through the system, you'll have to start all over again."'

Esme described the clinic as an 'ECT factory'.

'I can remember sitting in a line, there'd be three of us in a line, one of us would be taken in, the two would move along and another one would join the line ... if you look at the bill that I got, it ... is about \$300 or \$400 every time.'

Esme said she attempted to kill herself between treatments, but a friend saved her.

'I woke up every day wanting to die ... The things I've forgotten are half of my life ... I don't lay down memories now.'

Esme said when she tried to find another psychiatrist, she discovered the industry was 'a closed shop'.

'It's, "I don't want to know about that."'

When she did find another psychiatrist to treat her, Esme had to promise she wouldn't complain about her previous treatment.

'All I really wanted to do is to be heard, [but] it was made very clear to me if that was what I wanted, one, he wouldn't help me and, two, he would think twice about whether he wanted me [as a patient],' Esme told the Royal Commission. 'Now, he is a decent man, but that is the accepted and standard behaviour in this small community of people who have total power over people.'

Trish and Ali

Trish, early 30s, has epilepsy and was recently diagnosed with functional neurological disorder (FND).

Not long ago Trish left an abusive relationship and, since then, has had sole custody of her two children.

Trish's son, Ali, has sensory processing disorder, speech and language delay and can become overwhelmed. Trish told the Royal Commission she is struggling to access enough support for her and Ali.

'I'm trying to push myself to keep doing things, but without that extra support, mum can't keep being my carer and my backup forever.'

As a child Trish was 'spacey' and in her teens started having absent seizures. A GP advised against treatment and suggested she wait to see if things improved.

Trish continued to have epileptic seizures. She couldn't work and started receiving the Disability Support Pension.

At 35 weeks pregnant with her second child, Trish was away from home when she had a grand mal seizure.

A specialist diagnosed her with FND without considering her full history.

Trish said this diagnosis puts her at risk of losing the disability pension. She's concerned FND is treated as a mental health issue rather than a neurologic disorder.

A Centrelink staff member encouraged Trish to apply for NDIS funding. Trish paid hundreds of dollars for multiple assessments and the staff member helped her complete the forms. When Trish followed up a few weeks later, the NDIS hadn't received them. NDIS staff told her she had to complete the forms again and said they would post them to her. Trish has not received anything and has given up pursuing it further.

Meanwhile Trish has been trying to get an autism assessment for Ali. She paid \$2,500 for an assessment but discovered it wasn't recognised. 'Autism has become like a buzz diagnosis and a lot of places, there's no regulation ... a lot of places will take your money but what you're paying for is like clay therapy, they're not actually doing assessments.'

Ali's current NDIS plan is due for review. He does not have a plan manager because the funding ran out about three months ago. Trish is not sure how to submit reports because she doesn't have access to the portal.

'He legitimately needs weekly speech, he needs weekly OT and he's getting fortnightly psychologist sessions. And without that routine, he goes downhill very quickly and all schoolwork at home stops.'

Although Trish's mum helps her and her children, Trish is struggling to manage homeschooling Ali, keeping the house clean and dealing with the children when they have meltdowns.

'We're linked in with domestic violence services ... but without that additional support ... it is making it very, very hard for me to apply and do everything. I can't keep doing that and trying to homeschool and trying to look after mum – cause mum and I look after each other.'

Everlee

Everlee is an elderly woman with an intellectual disability. She lives in a community-based group home with three other ladies. She has an active social life, volunteers in the community and is very positive about her experiences in her group home.

Everlee lived most of her life in a large residential centre run by a company that provides housing and support services for people with intellectual disability. She moved into the centre as a small child. The staff would hit her with spoons and give her 'a hiding of the tail'. 'It was rough, those days,' she said. In one of the homes, 'they got pins put in [her] head'. This may have been a type of electroconvulsive therapy.

Everlee's father was president of the company's board and didn't want Everlee to leave the centre. She stayed there until her parents died about 12 years ago.

Everlee's current accommodation is run by the same company but it is a community group home and she describes her new way of life as 'very good'. Everlee has her own bedroom and ensuite and can live her own life, very different to her past experience.

Everlee enjoys living at the community home even though the three other women who live there are much younger, have significant physical disability and cannot verbally communicate. She is reluctant to move to new accommodation where she might be with residents her own age, because she would have to leave behind her support staff, who she thinks highly of. They ensure her needs are met and take her out every day to her volunteering work, to socialise or to shop.

'I don't want anything changed. I want things to stay the same ... The staff are good ... They care for all of us and ... do [a] very good job.'

Everlee's support worker describes Everlee as a social butterfly who loves travelling. She does volunteer work twice a week, delivering meals and helping in an op shop. She has social activities, is involved in a church group and likes movies, crafts and playing the piano.

Everlee met her fiancé some years ago. She misses seeing him because of the lockdown during COVID-19. 'We've got to wait ... I'll see him soon.'

Gianni

Gianni, 60s, has a hearing impairment and physical disability. He works as a disability advocate in a regional area.

Gianni told the Royal Commission about one of his clients, Jen, who has an intellectual disability and lives in a group home.

When Gianni started working with Jen she was having a sexual relationship with one of the male residents in the home. The male resident was physically violent to other residents and staff. He also masturbated on one of the other female residents.

Support workers told Gianni 'not to worry' about Jen because the relationship 'was consensual'. Gianni said this 'raised alarm bells' and he questioned whether Jen had the capacity to give 'informed consent'.

'Everyone else still stuck their heels in and said it's consensual, leave it alone.'

Gianni made a report to police.

Management arranged for an in-house social worker to conduct a capacity assessment with Jen via Zoom.

Gianni felt this was 'ridiculous'.

'How can you know someone by doing an assessment by Zoom? And I questioned whether a social worker is actually qualified to make that type of assessment.'

Gianni asked management to send Jen and the support worker most familiar with her to a doctor, for the doctor to assess whether Jen could consent.

The doctor concluded Jen could not give informed consent.

Management contacted the public guardian who said the doctor was not qualified to decide whether Jen had capacity to consent to a sexual relationship. Gianni pointed out Jen only had a public guardian because the same doctor had said Jen couldn't make complex decisions.

The provider continued to argue Jen had a right to have a sexual relationship. Gianni agreed but also believed Jen had 'a right to safety' and staff have to 'make sure that she can make informed consent'.

Ultimately the provider moved the male resident to a different home.

Gianni said the other residents were much happier after he left.

Jewel and Adrienne

Jewel has attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder and is autistic.

Adrienne, her mum, told the Royal Commission that Jewel didn't receive her autism diagnosis until she was almost a teenager. She believes specialists 'don't recognise the symptoms' as quickly in girls.

Jewel's experience at her first primary school was 'very positive'.

The family had to relocate for work and Jewel attended the local state school.

Adrienne told the principal Jewel had ADHD and asked if her psychologist could observe and support her in the classroom. The principal refused. Only the school psychologist or NDIS funded psychologists could attend school. The waiting list for the school psychologist was very long and students with ADHD can't receive NDIS funding.

Adrienne asked if she could have regular meetings with the principal and Jewel's teacher, but again they refused.

Teachers complained Jewel was 'loud and distracting and moving too much'. One teacher made her sit at the teacher's desk 'behind a wall of books'.

The principal would often scream at Jewel for minor things such as not sitting still on her chair.

Jewel's skills declined. At the start she was able to do multiplication and division. When she left, after three terms, she couldn't even do addition and subtraction.

Adrienne tried to make a complaint to the education department but discovered 'the principal is king and that's it'.

Adrienne enrolled Jewel at a new school in term 4 but she only stayed for one term.

Jewel began asking Adrienne sexually explicit questions such as, 'What does fingering mean?' She discovered older boys in year 4 were talking about sex and 'making sexual movements' encouraging her to remove her clothes. 'It was really awful.'

Adrienne told the teacher who was 'horrified' and said she would keep the boys and girls apart. The principal, however, was dismissive, telling her 'kids will be kids'. 'Kids play doctor, it's not a big deal,' he said, suggesting Jewel 'not hang out with them'.

Jewel developed compulsive thoughts about sex and suicide for about 18 months, requiring psychiatric intervention and support.

Jewel's new school was 'much better' and she felt 'more included'. The deputy principal also had ADHD and made himself available to Jewel whenever she needed him. There were some incidents with boys showing her their genitals and wanting to touch her. Adrienne reported this immediately. She said the school 'was great' and 'handled it really well'.

Two years later the deputy principal left the school and Jewel had a difficult final year.

Jewel had 'sensory issues related to her hair'. She found it very difficult to wash and comb her hair and 'it caused her a lot of pain to have her hair pulled up'. The new deputy principal decided to enforce the regulation that students tie up long hair. Staff targeted Jewel.

One time the deputy principal grabbed Jewel's hair roughly and pulled it into a ponytail. He told her it wasn't a sensory issue, 'she's just lazy'. Jewel was very embarrassed. After this, teachers wouldn't let her in class unless she tied up her hair. Students started bullying her.

'She started talking about killing herself again,' Adrienne said. 'I was close to being fired ... How can I focus on my job when [Jewel] is suicidal, when I'm fighting with principals? ... It's not just time, but it's your emotional energy and your intellectual energy.'

Selecting a high school for Jewel was very difficult.

'We were looking to take out personal loans so that our daughter would not be harassed because of her disability.'

Instead Adrienne decided to relocate so Jewel could attend a school that had a reputation for inclusiveness and fostering independent learners.

Jewel enjoys going to school now and was sad when she couldn't attend because of coronavirus restrictions. She told Adrienne she's surprised the teachers don't yell at her.

Silas and Leilani

‘They keep telling me that they were perfectly within in their rights to put him in this sensory isolation room simply because he had a diagnosis, and they didn’t need to tell us or consult with us or medical professionals.’

When Silas started kindergarten in the mid-2010s, teachers assessed him as academically gifted and ‘grade accelerated’ him to year 1.

Around this time, he was diagnosed with autism.

Leilani, his mum, told the Royal Commission that Silas had a successful first two years. The school was very good at making classroom adjustments and Silas excelled academically.

At the end of year 2, Silas ‘changed almost overnight’. Teachers dismissed Leilani’s concerns, blaming Silas’s autism.

In year 3 Silas’s wellbeing deteriorated further. ‘He just started to sink, becoming really, really sad.’ The school tried to build a case that he was not suitable for mainstream school. They used his disability ‘as a weapon against him’.

About halfway through the year, Leilani found out about a sensory room the school used to manage Silas. Staff sent him there three or four times a day. On at least one occasion, they locked him in the room without supervision. Leilani was devastated when she found out about the room.

She also discovered the deputy principal would film Silas and threaten to show the video to his mother.

Silas became withdrawn, did not want to attend school and began having meltdowns. He developed a fear of the dark, was having nightmares and his anxiety increased. His academic privileges were removed and teaching staff often sent him home from school.

Silas went from attending school full-time to only two hours a day, under the proviso Leilani supervised him during this time. There was no continuity of lessons and the teacher didn’t send work home.

Leilani homeschooled Silas for the final term. The school never contacted his parents to find out why he was not attending.

Leilani made several complaints to the school and the education department to find out what was happening to Silas. ‘[The school] shamed us and our child. And they didn’t hesitate to use their lawyers against us.’

Recently, Silas told a therapist about an incident that occurred in year 2. A teacher 'dragged him along the floor by his underpants' and the carpet 'burned his bottom'. His pants were 'pulled so high they cut into his bottom, and it was really painful, and he was crying'. The teacher locked him in an area with a tiled floor with no water.

Two medical professionals told Leilani that the sensory room has caused Silas psychological harm.

Leilani has made a complaint to police but it is currently on hold pending Silas's recovery. She does not want Silas to be traumatised further.

After a brief period at another primary school, Leilani enrolled Silas in distance education.

Silas's confidence has grown and he has demonstrated that he is academically capable. He has successfully completed the full curriculum for years 4 and 5 and is currently undertaking year 6.

Although Silas is excelling academically, Leilani worries he is missing friendships with his peers.

'He's missed out on all that friendship for three years, four years now. And this didn't need to happen. Sensory rooms should not exist in the way that this was implemented. And no child should be locked down.'

Giovani and Fortuna

Giovani, mid-20s, is autistic, has intellectual delay and requires 24/7 support.

Fortuna, his mother, lives with anxiety and post-traumatic stress disorder.

Fortuna was married to Giovani's father for 20 years. He abused her, Giovani and the other children.

When Giovani was about 16, Fortuna could no longer look after him. She contacted the relevant government department for help, but staff advised her they could only provide support if she relinquished guardianship. Fortuna told the Royal Commission that she agreed, but believed the arrangement was temporary.

The public guardian placed Giovani with his father. When his father abandoned him, they placed him in emergency respite. Giovani lived in a motel with support workers for a year. Fortuna wanted him to come home but the guardian refused.

During this time the conflict between Fortuna and her ex-husband escalated. She believes he has used – and continues to use – the guardianship system to abuse her and Giovani.

'The father was able to use him as a weapon against me. And every hearing wasn't about [Giovani], it was about my relationship.'

The public guardian unilaterally makes all Giovani's decisions, including community access, health care, support services, medical consents and accommodation.

Fortuna said Giovani has steadily regressed. At 16, he had some speech, could read and write, enjoyed swimming and was able to access the community safely. Now, Fortuna said, he can't do any of these things, is heavily medicated and his behaviours have become more aggressive. 'He had a different trajectory of life ... He was a happy young man.'

Fortuna says no-one is advocating for Giovani.

'Once he became under public guardian, not only did he lose his mother, he lost his advocate.'

Eventually Giovani moved into a group home and was able to go stay with his family on weekends.

One time, Fortuna was helping him get into the shower and noticed bruises, marks and bite marks near his genitals. She photographed the marks and demanded to know what had happened.

The provider investigated. They acknowledged there was a pattern of abuse and said they would move Giovani to new accommodation.

Fortuna asked if he could move home, but the guardian refused. 'The father kept saying no, so for that reason, he could never come.'

Giovani moved to another house but the violence continued. Fortuna has noticed Giovanni's behaviours have also become more violent.

He arrived home one weekend 'in a heightened state'. Fortuna rang the home for assistance but they refused to send someone. The situation escalated and Giovanni attacked Fortuna's partner. Fortuna had no choice but to call the police. When the police arrived, the provider sent a support worker to take Giovanni back to the home. Since this incident, the provider won't let Giovanni stay with Fortuna unsupervised.

Fortuna has made multiple complaints to the public guardian about the incidents in the home, but they brush her off 'as a complainer'.

**'I've questioned so many decisions. I've asked to meet with them.
I've asked for evidence to support the claims against me ... How do
you work with the public guardian that won't meet with you, who won't
acknowledge and discuss concerns?'**

Glenda

Glenda, mid-50s, has intellectual disability and epilepsy.

At a young age, Glenda and her brothers were placed into care because her mother was not well enough to look after them. Glenda was sent to a girls' home and her brothers went to a boys' home.

Glenda stopped talking when she was in care, which prompted authorities to investigate her father for sexual abuse.

Glenda told the Royal Commission she confronted her father when she was older. He denied abusing her and blamed her mother for making false allegations. Glenda will never know for sure what happened, but believes 'something had happened'.

Glenda has three children.

'I knew what to do when they were babies and I never got the chance to do it.'

The department of child protection removed Glenda's children immediately after they were born and placed them with her father and stepmother.

'[Glenda]'s disability was part of the reason they decided to keep the custody with the stepmother and father, despite being made very aware about the father's history of having sexually assaulted [Glenda],' Glenda's advocate said.

No-one offered Glenda any parenting support. '[My stepmother] only ever offered to take the children away,' Glenda said. She never offered to help. 'It was just all or nothing.'

Glenda initially had visiting rights and would see her children regularly. One day she found her father sleeping with one of her daughters. She raised her concerns but no-one did anything.

Glenda said her stepmother is 'really awful' to her and very critical of her. 'She thinks I'm not capable of looking after my own child.' Not long ago she stopped Glenda from seeing her children. One time she 'raced out' and told Glenda to leave. 'I'm not allowed to come on their property.'

Glenda feels her children were 'stolen' from her.

'When they first moved in, when they did get a chance to speak, they started saying "granddad" and "grandma". And then after a while, when they got to start to go to school and that ... they started saying "mum" and "dad".'

Her father and stepmother have never let her be involved with the children's schooling. She's

not invited to school events and they don't give her any information about the children's health.

Glenda's father has blocked her from attending family gatherings. Her brother stayed in touch with the children and would make reports to Glenda, but her dad has now blocked him too. 'Now no-one has any ties to the children.'

Glenda has attempted to gain custody of her children and has attended court on several occasions. She had legal representation. Glenda's stepmother accused her of being 'promiscuous' and said the children would not be safe in her care.

The court took Glenda's intellectual disability into account and didn't return the children.

Glenda doesn't understand why her children have never been returned to her.

Gus and Alexandria

Gus is in his 40s and lives with schizoaffective disorder. His mum, Alexandria, lives with anxiety and feels Gus's behaviour also stems from anxiety.

'I got him to a psychologist who could diagnose him in three hours with anxiety with defensive mechanisms,' Alexandria told the Royal Commission.

When Gus finished high school he experimented with drugs, staying out late and 'burning his candle at both ends'.

'He took 10 months to have a breakdown.'

A doctor diagnosed Gus with schizophrenia when he was 19 and prescribed medication.

'He came home like he was kicked in the head by a horse.'

Alexandria said the medication caused Gus's life to 'crumble'. It ruined their relationship.

'They've trashed it. They shattered it to pieces.'

Alexandria said that, since then, numerous case managers and doctors have changed Gus's medication.

'He was saturated in psychiatric pills. Saturated to the point where he's had a seizure ... I don't even know to this day if my son has got cognitive impairment due to his seizure.'

She said doctors saw Gus not as a person, but as a medical problem to be labelled and medicated.

'Those people have a single-minded focus in their clinical setting of looking for how much the chemicals are actually balancing.'

Alexandria would prefer doctors give Gus less medication and teach him emotional, cognitive and social skills.

'I wanted to raise him ... to be connected, to be outgoing, [a] loving person who could be what he wanted to be, but they ruined it. They ruined it.'

Hailey and Gabriela

‘I was told ... that just because they have a disability – intellectual disability – they couldn’t understand what it meant to be an Aboriginal person and they couldn’t understand what it meant to understand culture and connection and spirituality.’

Hailey is a young First Nations woman with an intellectual disability. Gabriela, a First Nations social worker, has known Hailey for nearly a decade.

‘I wanted to provide voice for some of the many people that I had the privilege of working with,’ Gabriela told the Royal Commission. ‘[Hailey is] a beautiful young person I started working with probably around the age of 13 ... She was taken from Country. She never returned.’

Gabriela said that after years in foster care, Hailey ended up in out-of-home residential care in the city. While living in care, Hailey used illegal drugs.

‘The staff that were put on to care for her were completely inadequate ... I’m aware that at times they even transported her to pick up drugs from local dealers.’

Gabriela said the service provider gave Hailey a support plan identical to other residents in the home.

‘It ... said the exact same thing. They just changed her name out of it ... Sometimes they had actually left the name of another child. So, nothing in her behaviour support plan was actually true to her behaviours and to her experience.’

Gabriela said the poorly-trained staff didn’t know how to support Hailey’s complex needs.

‘She had the highest tier of money for residential care ... Just doesn’t make sense to me. You would have a quite unqualified youth worker supporting her that at times became “her friend” and was taking her out to use drugs, hiding drugs in her room.’

Several years ago, Gabriela tried to help Hailey visit her dad in jail.

‘I was told she can’t see her dad because he’s in jail ... They’d be like, “She won’t be able to handle that environment because she has a disability,” or “She won’t understand.”’

Hailey’s dad died in jail soon after.

‘She was devastated that she didn’t get to have a relationship and see her dad. And the only time she was allowed to go and have a connection with her dad was when they allowed her to go to his funeral and speak.’

Gabriela said that one day, another resident of the home recruited Hailey to take part in an armed robbery. Hailey was arrested.

‘I had to fight for her to be recognised as a person with a disability and also an Aboriginal person.’

After Hailey was released from jail, Gabriela organised support services for her back on Country.

‘On paper she looked like a troubled kid that needed, you know, two-on-one support, and she was high risk and all of those types of things. But really, she needed connection. She needed somebody who would listen to her.’

Hailey now lives near her grandmother.

‘She was hanging out with her friends and her cousins. She was reconnecting with her family basically. She was spending time with [her] nan. Her little brother was up there as well ... And she wasn’t using ice anymore, so she was doing really well.’

Hamish and Meara

Meara is in her 70s and lives with post-traumatic stress disorder (PTSD), depression, anxiety and mobility issues. Her son, Hamish, lives with schizophrenia, obsessive-compulsive disorder, depression, PTSD, generalised anxiety disorder and epilepsy.

'I picked up that he had these problems, but his father didn't recognise it,' Meara told the Royal Commission. 'Different people commented on it, you know, childcare, schools, teachers. I took him to doctors, took him to different places, but nobody put the pieces together.'

Meara said Hamish's father 'did not want to believe that he was less than perfect, so he interpreted those as signs of genius'.

When Meara and her husband divorced, Meara was granted custody. But after 'merciless manipulation and gaslighting' by her former husband, she let Hamish live with his father.

'So, I sent him up there, and I hoped that things would be better, but they weren't.'

Hamish was admitted to a psychiatric hospital in his late teens. Meara said Hamish's father had thrown out the antipsychotic medication doctors had prescribed.

'He said, "No son of mine is going to take that schizo stuff."'

During one psychotic episode, Meara had Hamish admitted involuntarily to a mental health unit.

'[He] has held that against me ever since.'

Hamish used cannabis in his 20s and was admitted to a substance abuse program. While in the program, he disclosed his father had abused him as a child.

'It was minimised and discounted, and he was told that all fathers do those sorts of things.'

Meara said later in life, Hamish reported '17 times' about back and abdominal pain. Doctors initially brushed it off.

'He'd been told it was chest pain, it was just an infection, it was a bug, it was cannabis ... Then he coughed up blood.'

Doctors eventually diagnosed stage four lung cancer.

Hamish is supported by the NDIS. Meara said the NDIS initially refused requests to fund his transport for cancer treatment.

'There was nothing he could spend money on, he had \$60,000 at that point, and [they said] that he wouldn't get the transport ... unless it's for mental health treatment.'

Meara said she had to get a psychiatrist to write a report explaining why the cancer treatment was important. It took nearly a year for the NDIS to fund Hamish's transport to get treatment.

He has now completed his cancer treatment.

Clive

Clive is a First Nations man in his late teens who lives with complex post-traumatic stress disorder (PTSD) and attention deficit hyperactivity disorder (ADHD). Clive's mother died when he was 10.

'Before my mother died, I was a good kid,' Clive told the Royal Commission. 'I was going to school and all that, like, wasn't getting in trouble with the law and that. But when my mother died, that's when I went into [child services]. I just went downhill, you know?'

Child services placed Clive in a series of foster homes where he was 'bashed by the carers'.

'Then they called the police, and then the police would flog me there, too.'

While Clive was in foster care, his father died. Clive didn't know his father well.

'My father was 50 minutes down the track ... When I turned 18, they give me a book about him and when he died and where he was from. And I was thinking, they had it all this time, there's not one conversation. They could have said to me, "We'll take you for a visit" or something, you know? They did nothing about it.'

While in foster care, Clive said he was 'constantly in trouble'.

'I started using methamphetamine at 13 years old. Because, like, there was no way to escape it, all the stuff-ups going on in the care, you know?'

Clive went to jail when he was 14 and, when released, became homeless. He stayed in hostels for a time. 'But it got to a point where the hostel wouldn't take me.'

'I haven't had an address since I was 10, you know ... They just leave me to hang out and dry, basically.'

Clive is now back in jail, where staff won't let him have his ADHD medication.

'They only put me on sleepers ... Up all night, get up, agitated from no sleep. Yeah, they couldn't care less.'

Without his medication, Clive sometimes acts impulsively. Prison staff send him to solitary confinement as punishment.

When Clive spoke to the Royal Commission, he was several weeks away from being released. He was planning to live with a relative.

'My [relative], right, where he lived his whole life, he's in university ... I could have potentially done the same. He went all through school, he's got everything, you know ... And that's the environment [child services] deprived me from. You know what I'm saying? They say it's better in [foster] care. But look where care got me.'

Jerome

Jerome is in his 30s. He is autistic and has Down syndrome and post-traumatic stress disorder. He is non-verbal and spoke to the Royal Commission with the help of text-to-speech technology and a support worker.

‘I would like to talk about my experiences with trauma ... I just so wish that it is truly that easy, but I struggle with trauma.’

Jerome said he was abused when he was in high school by a staff member at a respite home. He said his mother didn’t believe him and didn’t report the abuse.

Jerome told the Royal Commission he will never overcome the trauma.

He is now an advocate for people with Down syndrome and employs staff ‘who are great’. Jerome said it’s hard, however, to find good staff.

‘I just want non-verbal people to be respected.’

Iluka

Iluka is a First Nations man in his 50s who has early onset dementia.

‘When I’m talking here and now it’s fine, but you ask me what I said 20 minutes later, I won’t be able to tell you,’ Iluka told the Royal Commission. ‘I can remember all the old stuff that happened to me, no problem, but short-term I’m gone.’

Iluka’s mother was a member of the Stolen Generations. Iluka lived with her at a convent until they sent him to a boys’ home ‘for not going to school’.

‘All my life I have been bashed by, like, boys’ homes and all that, raped, all that sort of stuff.’

Iluka said he ‘kept escaping and escaping’ and was sent to prison when he was a teenager.

‘For escape from [the boys’ home] ... shaved head and scabs all over me head.’

Later in life, Iluka developed early onset dementia and a few years ago was granted a government aged care package. Iluka has little control over the package, which a service provider oversees.

‘They’d never give me things that I really require as an Aboriginal person. I need to go to the country, like I asked to go to a place [that] just has four cabins on it where there is no alcohol, no smoking ... It’s \$140 a night and I wanted to stay there for four nights and they said, “No, you can only stay with us at a thousand a night.”’

Iluka said the church-based service provider is expensive and insists he use only its services.

‘And that’s one of the problems I have completely had is finding out why can’t I ... get proper respite that me doctor writ letters for, and stuff like that because of me mind.’

Iluka said the service provider once charged him for a shopping trip on Good Friday.

‘These are the sort of things they have been charging me for. Going shopping when there are no shops open, and stuff like that. I’m sure they do it to a lot of people.’

Iluka said another time, when he needed new tiles in his house, he found a quote for \$1,800.

‘[The service provider] charged me \$4,000 ... but three times they took the \$4,000 out, so they took \$12,000 for an \$1,800 job.’

Iluka said when he complained, the provider retaliated.

‘Every time I made a complaint against them, they would do something drastic to me, like just not turn up, not ring me and say no-one’s coming today, and I would be waiting, and waiting, and waiting, and no-one come ... And I had an appointment at the hospital, and it took me three more months to get in, stuff like that. And they don’t ring you and confirm, and they were just so bad, all they wanted was money. They weren’t caring about me and my needs.’

Iluka said during COVID lockdowns the service provider abandoned him for weeks.

‘It’s not good. Like I don’t sleep for days when they do things like that to me, like just forget to come and don’t ring me. For four weeks I sat here depressed. I didn’t have a shower for two and a half weeks. I just sat in the lounge and ate from the [local service station], and I would starve for the last two days of the week because I was buying from the garage, which is, you know, \$6 for two sausages and stuff like that.’

Iluka said he would rather self-manage his care package, but he’s ‘got no way of filling out forms’.

‘I don’t understand the words. I understand old language, but not the new wordings they have changed around to today.’

Mat and Maureen

‘Talking about this is quite distressing and ... the distress of parents doesn’t ever go away.’

Mat, mid-20s, is autistic. Maureen, his mum, is a GP and has a brother with paraplegia.

Maureen told the Royal Commission that over the years she has had to ‘constantly advocate’ for Mat because his disability is invisible.

She believes things are worse since under the NDIS because funding is based on a person’s disability, not their ability. She said the NDIS works better for her brother because his disability is measurable.

When Mat was young, his parents ‘just thought he was this fairly hyperactive full-on kid that needed a lot of maintenance’.

He started school in the private system but the school ‘couldn’t manage’. Maureen said they didn’t have the funding.

After one term Mat moved to a local state school. Things weren’t much better, but when Maureen contacted the education department they told her they had ‘nowhere to put [Mat]’.

A year later Mat moved to another state school. Maureen discovered he had been placed in the unit for emotionally disturbed kids.

In year 5, the education department moved Mat to a new school with an autism unit.

A short time later a new deputy principal started and didn’t want an autism unit. Almost overnight the classroom was segregated.

‘Him just going to school is one of the biggest traumatic events in my life,’ said Maureen.

Throughout primary and high school Mat was often suspended. Maureen said there was no allowance for his disability.

‘The education department is very, very bureaucratic and it seems to have blanket rules in regard to why children should be suspended.’

One time, Mat picked up another student’s school bag and ran off. Teachers chased him and told him to put the bag down. He threw it down and the Mother’s Day gift in the bag broke. Mat was suspended for wilfully breaking someone else’s property.

If Mat tried to defend himself and spoke back to teachers, they would suspend him for being aggressive.

In high school, Mat noticeably lost skills. He'd had two months of orientation with his teacher, but when he arrived the teacher had left.

Maureen had donated a touch type program to the school. Mat liked to write in colour and use multiple colours and use multiple coloured notepads. But the school wouldn't let him use these and forced him to use a led pencil.

'So, he stopped starting to want to write and problems ensued.'

When he started learning cursive writing, he liked to do it in a particular way. The teacher continually criticised him, so he stopped writing.

Mat spent more and more time in the autism unit, with little opportunity to participate in mainstream classes. 'He ultimately felt like he was in prison.'

'A lot of his capacities were destroyed in school, rather than nurtured.'

Mat still remembers the way the teachers treated him and is working through 'the trauma around school'.

Maureen feels 'burnt out'.

'All of those parents who do care ... just live on with being I guess traumatised by what our kids go through and what you go through to advocate for your kids.'

Jaylah

‘When you’re already feeling vulnerable, already feeling exploited, disempowered, that total weight is on the employee to then defend themselves that they have an entitlement to be at work.’

Jaylah, early 50s, has multiple sclerosis (MS) and chronic fatigue syndrome. She experiences speech and mobility issues, extreme sensitivity to heat and has difficulty swallowing.

When Jaylah received her diagnosis she decided not to tell her employer – a large disability service provider.

‘There was this fear that I would be stereotyped,’ she told the Royal Commission. ‘I would be limited in opportunities in employment. I would be put into a box.’

Jaylah had heard her employer demean people with certain types of disability. They would call clients with mental health issues ‘fucking crazy’.

Jaylah became so concerned about the culture in her workplace she filed a complaint as part of an internal review process. No-one followed up with her, but soon after her employer started isolating her.

Up until then Jaylah had had ‘glowing, perfect, model employee reports’ and ‘promotions at different stages’.

Following her complaint, her employer ‘ordered’ her to move to an office with ‘no ventilation’.

Jaylah challenged the move because she knew it would be too hot and trigger her MS. Her employer refused to budge, telling her there was no other office available.

Still reluctant to tell her employer about her MS, she managed the situation by negotiating to take unpaid leave during the ‘super-hot’ months as a ‘preventative strategy’.

Around this time, she became aware people were gossiping about her. Some colleagues speculated she was having a nervous breakdown or had been involved in misconduct.

Jaylah confronted her employer about the rumours. They told her another employee had reported that she looked ‘fatigued’.

While on leave, Jaylah had an MS relapse and was admitted to hospital. She had to provide a medical certificate to her employer, which is how they discovered she had MS.

Shortly after she was discharged, Jaylah’s employer contacted her telling her she couldn’t come back to work. They said, ‘The workplace is unsafe. MS, we believe, makes you unfit for work.’

Jaylah was shocked and couldn't understand what she had done, or 'had been unable to do in [her] job', that made them believe she was unfit for work.

Jaylah made an application to the Fair Work Commission, but had to represent herself because she couldn't afford a lawyer.

Her employer demanded she have an independent medical examination, which she agreed to. Jaylah said the report was 'completely in [her] favour' – MS did not make her 'sensitive to robust conversations'.

Jaylah was excited, thinking the report meant she could go back to work.

But she received another letter from the employer telling her, 'We're concerned about your behaviour. We can't have you in the workplace.' They also said they were concerned about how she might speak to clients, as other people with disability.

Jaylah made a complaint to the state human rights commission. Her employer offered a cash settlement, but Jaylah declined as it required her to sign a confidentiality agreement.

Jaylah believes she has a psychological injury because of her experience.

'It's been incredibly distressing to find out that we have legislation which I feel is powerless. It has no power over employers. Particularly employers that are very, very big, who use one of the largest litigation firms in the world.'

Joanne

‘We’re not the enemy. We were born. That’s not our fault. And it sometimes feels like that is, like we’re being punished for existing. And I don’t know what the answer is, but I certainly would appreciate feeling more valued, I guess, instead of a burden.’

Joanne is in her 30s and has Ehlers-Danlos syndrome.

‘I am in pain 24/7,’ Joanne told the Royal Commission. ‘Like, right now my feet hurt. My fingers are okay ... But I look fine because I have learnt to function at this level.’

Joanne and her husband have two children. Until a few years ago she received the Disability Support Pension.

‘They judged that my husband was starting to make too much money ... It didn’t make me any less disabled, but now he’s completely responsible for my care, which is archaic ... I’m incredibly lucky, we have a wonderful relationship, but it makes people with a disability completely reliant on a partner for care and money.’

Joanne said that although her husband earns a modest wage, the family lives ‘week to week’.

‘When they took my pension, they took my pension card, which gave me affordable health care. And I go to the doctor on average more than the average person ... We are only surviving. We rent because we can’t afford to buy a house.’

When her husband lost his job during the COVID-19 pandemic, the family had no income. Joanne re-applied for the disability pension and was told ‘maybe’ she’d receive it. By the time she’d filled in the paperwork, he was re-employed.

‘They have created this atmosphere where if you are disabled, you have to be alone. Because if you’re not alone then you have to be dependent and someone else has to look after you. And it feels wrong, it feels humiliating.’

Joanne wants to start her own business, but is still ‘too disabled to work’.

‘Which puts an incredible amount of pressure on my family, on my husband, on me, because I would like to work. I would like to be able to contribute or bring in some sort of money and not feel so guilty.’

Joanne said she pays for private health insurance because most of the surgery she needs is considered ‘elective’ in the public system.

‘The public system is not designed for people with chronic health conditions. It’s designed for acute moments. You break a leg, you go to the hospital, they take care of you. But you know, the system is not built to help disabled people. It’s only designed to keep us around.’

Joanne describes her disability as ‘invisible’.

‘My last doctor thought I was a hypochondriac because I kept coming back with more and more problems that I couldn’t solve. And she would say, “Okay, go and try this,” and I would and it wouldn’t do anything, and then she’d say, “Go and try something else,” and by the end of it she just stopped trying because it was easier.’

Joanne is supported by the NDIS, but ‘they don’t help with medications, and they don’t help with doctors or any surgeries or anything like that’.

‘So, while the NDIS does have its benefits, there is still a massive gap that it doesn’t cover either.’

Joanne said the NDIA recently denied her request, through an occupational therapist, for an assistance dog.

‘There’s no reason they shouldn’t approve it, so then you have to take them to the [Administrative Appeals] Tribunal. They pick top lawyers ... to defend them at the tribunal. They are spending NDIS money on very experienced lawyers, denying people with disabilities access to aids that they are entitled to according to policies of the NDIS.’

Ross

‘Always about cost cutting.’

Ross, late 50s, has cerebral palsy and double-scoliosis. He is mobile and independent, lives in a semidetached house next to a family member, drives his own car and self-manages his NDIS fund. He’s had a diverse and successful career in IT, health and rehabilitation.

Ross told the Royal Commission he applied to the NDIS a couple of years ago because of his declining health.

He said it took seven months for his application to be approved, and since then he has been through three separate review processes. In six months, he’s had four plans. He has found the process highly bureaucratic, opaque and lacking any accountability.

‘I’ve dealt with bureaucracy before, but this is taking it to the next level.’

During the application and review process, Ross has had to provide large amounts of personal information to anonymous people, and wait arbitrary amounts of time only for someone suddenly to tell him the information is inadequate and he needs to provide more. When he asks what information they need, they tell him he needs to determine this. ‘The goalposts keep moving,’ he said.

Ross has had to personally pay for two advocates, upgrade his computer on three occasions and maintain overly meticulous records to navigate ‘the most bureaucratic system’ he says he’s ever encountered. He has had to save more than 400 emails because the NDIA often deny stating something until he sends them proof of what they said.

Recently Ross requested a therapeutic chair. A staff member telephoned him to ask if she could look at his plan. He said ‘yes’ and she ended the call.

A week later Ross received a new plan. The plan was for three years instead of 12 months, but cut his funding by \$43,000.

‘When you get the email, you don’t get a new 1800 contact number. You don’t get the email receipt. You only get the first name. You don’t get a surname. So, then you ring up this 1800 number and say, “Look, this happened. Why has it happened?” And the answer always is, “If you have any issues with your plan, you have to go to an internal review.”’

Ross requested a plan review. The NDIA sent a single page letter which was identical to the original decision. ‘It was purely a cut and paste,’ Ross said. They did not answer his questions or address his issues.

Ross believes the NDIA is either incompetent or purposely amended his plan to save money.

Ross is also concerned about the cost of NDIS approved services. His regular physiotherapist charges \$60 per hour whereas an NDIS physiotherapist charges \$200 per hour. Occupational therapy (OT) reports, generally cost around \$2000, and in his educated opinion are poor quality. Often NDIS OTs are not qualified in many areas of disability. He has been with two OTs who have had to search cerebral palsy online for a basic understanding.

Ross's next step is to apply to the Administrative Appeals Tribunal for a review, but he is concerned the NDIA might make further cuts to his plan.

'People who are making these decisions have zero accountability, none. They make life-changing decisions and there's no accountability for it.'

Jocelyn

Jocelyn is in her late 50s and has physical and psychosocial disability. She also has mobility issues and heart problems.

Jocelyn shared with the Royal Commission her experiences as a disability support worker and her problems with the police and the courts after failing a breathalyser test.

Jocelyn used to work as a disability support worker, but has not worked for more than 10 years because she 'was a whistleblower in aged care'. Jocelyn said she lost five jobs because she tried to help people and made complaints on their behalf.

Jocelyn has argued with hospitals over their treatment of patients with disability. She has also made complaints about various bureaucrats involved with the NDIS.

Jocelyn is concerned about non-disclosure agreements which prevent support workers who have settled their legal action against their employers from discussing the case. She believes the agreements prevent important information from being shared.

The breathalyser incident began when Jocelyn was waiting for her son to collect her in a park after an exercise session. She noticed a car but did not know it was an unmarked police vehicle. Being uncertain who was inside, Jocelyn felt 'at risk'. She followed the car, intending to memorise the numberplates and then contact police.

'Anyway, it resulted in me being put on a breathalyser,' Jocelyn said. She was unable to perform the test properly, which she believes was due to an undiagnosed health condition.

Jocelyn asked to do a blood test instead, but the police arrested her and took her to the station for another breathalyser test.

'I have a very chequered history with police ... because I have advocated against them for death in custody, restrictive practices stuff.'

At the station, Jocelyn refused a second test because she did not wish to use 'the same machine' a sick man had just used – she thought he might have COVID-19. She told police, 'I'm happy to give a blood test,' but they declined.

Jocelyn was charged and, following court proceedings, convicted, even though she now had the relevant medical certificate for the health condition that prevented her from performing the breathalyser test. She received a fine and 'they added extra disqualification' – she was banned from driving for five years.

Jocelyn was frustrated with delays in the court proceedings and that she was not provided with legal assistance. Jocelyn represented herself and struggled. 'I was escalated by their behaviours towards me.'

Jocelyn is unhappy with how the police and court system treat people with disability.

Amber

‘People with disabilities are not a resource for [able-bodied people] to exploit.’

Amber is in her 50s and lives with complex post-traumatic stress disorder, a major depressive disorder and dissociative identity disorder.

‘My journey actually started in [the 1970s] where I experienced a gay bashing from family members,’ Amber told the Royal Commission. ‘But because of the support that I received within the school environment, I achieved a good level of health and that receded into the background.’

Amber became a social worker and in the 1990s worked with an intellectual disability service ‘advocating for people with disabilities and their families’.

‘This all started to unravel after I advocated very strongly for a little Aboriginal girl who was in the child respite centre. She presented with severe intellectual disability, lots of behavioural issues, but more significantly she also had continuous bowel movement which wasn’t being managed by the centre.’

Amber said she made the centre send the girl to hospital, which treated her for several medical conditions. Amber developed a program to help residential staff identify medical issues in people with intellectual disability.

When she told her manager about the poor level of care at the centre, they said she was ‘being insubordinate’.

‘I think that I was simply doing what I was trained to do as a social worker.’

Amber said that in retaliation, her manager sent her to work in a home of ‘high risk male clients’.

‘The male staffer there at the time said to me that he was very surprised that I was visiting as no female staff were allowed in on the premises. I had to endure, I guess ... a conversation with him with the young men who were engaged in explicit sexual acts, and it was extremely intimidating and quite overwhelming.’

Amber felt bullied and traumatised. She eventually resigned to start her own counselling business and continue her university research into levels of care in disability services.

When Amber told colleagues her research found families weren’t getting the level of service they needed, they ridiculed her and someone made a complaint to the university.

‘The research was confiscated, and I was subjected to what I can only describe as organisational violence.’

Nonetheless, Amber completed her degree.

After a series of traumatic events, she was diagnosed with dissociative identity disorder linked to the 'gay bashing' she experienced as a teenager.

'One moment I would be me, myself as I present today. Other times I would be presenting as a 15-year-old. Other times I would be presenting as a 30-year-old, without necessarily being aware that that was going on.'

Amber said that when she applied for accreditation to practice within the mental health industry, a supervisor used Amber 'without informed consent' as a subject for her own research.

'I eventually had a complete fragmentation in my personality which resulted in the manifestation of a dissociative identity disorder.'

Amber told the Royal Commission that when she complained about being exploited, the industry body dismissed her complaints and acted 'in a way that protected their interests, but didn't do anything to look after [hers]'.

Amber said it destroyed her reputation.

'I think you can see that there's not a lot of benefit attached to patiently attempting to address issues of the mismanagement of people with disabilities. You're likely to end up with a disability yourself, which is my story.'

Kayleigh

Kayleigh is a registered nurse who has worked in community psychiatry for more than 30 years.

She told the Royal Commission she works with a number of clients who refuse to engage with health services.

One client, Ava, has chronic physical and mental health issues. She refuses to go to hospital for treatment because of how staff treat her when she gets there.

‘Hospitals are too traumatising to people,’ Kayleigh said.

Not long ago, Ava had an ectopic pregnancy and was in severe pain. At the hospital, she experienced ‘high levels of trauma’ because of her previous hospital experiences.

Kayleigh said for Ava ‘alarm bells are going off all the time’ telling her she’s unsafe.

Ava left the hospital and walked home.

She continued to experience terrible pain in her abdomen but refused to go back to hospital.

Ava’s mother wanted to ring the ambulance, but Ava threatened to ‘never talk to [her] again’ if she did.

‘Her mother is placed in this difficult position all the time of going against her daughter’s wishes.’

Ava’s support worker, who had worked as a chef, didn’t know how to help her.

Kayleigh believes a multidisciplinary approach is needed to help a person get the services they need ‘when their judgement is impaired’.



Artwork by Maxine Flakemore

Jodie and Christine

‘My experience with the mental health system, that [Jodie] unfortunately got into, was no support, just medicate, medicate, medicate. That made my quite intelligent daughter feel like she was stupid, like she couldn’t function anymore.’

Jodie’s mother, Christine, told the Royal Commission her daughter was ‘very different’ from the word go. She did not talk until she was four and would ‘run off into the bush’ and ‘climb up trees’.

Jodie struggled at the start of primary school. The school suggested Christine get Jodie assessed for autism. But Christine wanted her to have a mainstream education at the same school as her sisters. Things improved the following year because Jodie had a very supportive teacher. She thrived and began to do very well.

At 13, Jodie’s dad left home and her grandparents died. She became ‘really anxious’, refused to go to school and had a ‘big mental breakdown’.

Jodie entered the mental health system for the first time and was ‘treated very poorly’. Doctors didn’t investigate if Jodie had a disability and heavily medicated her. Christine wanted someone to support Jodie, ‘work with her, not take her away and heavily medicate her’.

After a while, Jodie returned home and completed her secondary education. The school supported her and ‘she functioned really well’. She didn’t take medication, ‘blossomed’ and made friends. She left school, got a job and for nearly 10 years she ‘was good’.

In her early 20s, Jodie began having problems with her boyfriend. One day he took her to hospital and told staff ‘there was something wrong with her’ because she wanted to harm herself.

Again doctors medicated Jodie. Christine was able to get her assessed and she was diagnosed with autism. However, it was too late – ‘there was no support for adults.’

Jodie, now early 30s, has been in and out of hospital for the past decade. ‘She would get worse and worse until she became quite suicidal, really quite unwell, then go into the hospital again.’

Three years ago, Jodie started attending a regional hospital. Every admission, doctors would heavily medicate her – often to the point where she couldn’t walk – and send her home. ‘Not home to me, just home to live on her own, and she just could not cope.’

Two years ago, Jodie was admitted as an inpatient at another hospital, where ‘she was basically a prisoner’. Her treatment plan allowed doctors to heavily medicate and physically restrain her.

‘She was like a caged animal. They had her tied up ... there were faeces all over the floor.’

Christine tried to get Jodie some NDIS support. ‘But we had meeting, after meeting, after meeting with the NDIS and no, she doesn’t qualify for the support.’

During COVID lockdowns, Jodie was still an inpatient and Christine wasn’t allowed to see her. A social worker visited and told Christine that Jodie was living in putrid conditions with faeces through her room and all over her clothes. Staff refused to clean it up. When Christine was allowed to visit she asked staff for a wash bowl and cleaned Jodie and the room.

Christine engaged a barrister who wrote a letter to the hospital threatening legal action because of their neglect of Jodie. Following this, staff started becoming ‘friendlier’.

At the time, Jodie was under the care of the public guardian. Frustrated by their lack of oversight and action, Christine applied to become Jodie’s guardian. She was unsuccessful but tried to make the public guardian more accountable. They refused to deal with Christine labelling her, ‘chaotic and difficult’.

Eventually Jodie did get some NDIS funding, but Christine said supports were inadequate because the NDIA and the provider did not understand Jodie’s needs.

The barrister wrote to the provider and Jodie’s services have since improved.

Christine said people are now working towards getting Jodie out of hospital. Jodie ‘sees a way out’ and has ‘started improving’. Jodie is ‘trying really hard’ and has transformed.

‘I have got my old [Jodie] back. She can see some hope.’

Kellie and Margie

Kellie, 40, is autistic and has cerebral palsy and an intellectual disability. She's lived in the same group home with mostly the same five people since she was 18.

Margie, Kellie's mum, told the Royal Commission that one of the residents, Ian, has continuously harassed the others from the outset.

Ian is verbal, quite articulate and computer savvy, but has not been given the opportunity 'to do anything with it apart from cause mischief'.

Ian is the only resident allowed to stay in the house by himself and the only one with a lock on his door. When the others went out he would go into their rooms and steal their favourite things. He stole jewellery from Kellie and would constantly steal the batteries from her walkman. Kellie loved listening to music but it got to the point she thought the walkman didn't work and stopped using it. When Margie made complaints staff accused her of 'picking on' Ian.

Ian routinely teased another resident calling him a baby, over and over again. 'In the end, this guy smashed 16 windows in the house, because he was just being tormented.' The group home asked him to leave. 'The tormentee was asked to leave, not the tormentor.'

Ian hassled and goaded a resident with Down syndrome. The resident snapped and threw a cup of coffee at Ian. Margie said staff were more worried about Ian's wellbeing than the other resident.

Kellie's routine is very important to her. Each morning she has to have cornflakes for breakfast. Ian would deliberately take her cornflakes. This would trigger a meltdown and staff would blame Kellie. 'She can speak, but because of her autism she never criticises other people, and she will never say what the matter is, she just screams and throws things and breaks things. So, she was being blamed for being the victim.'

Margie said she's seen Ian not pay taxi drivers, make international phone calls from the home phone, and listen in on staff conversations.

If staff reprimanded Ian, he would go to the local police station and make a complaint about the staff member.

One time Ian made false accusations against Kellie's favourite support worker to 'get rid of her'.

The provider ignored all of Margie's many complaints and she felt like 'a failure'. She felt the provider 'disrespected, disbelieved, deceived ... and insulted [her]' for trying to advocate for Kellie. One time they told her she 'didn't love' her daughter.

A few years ago Ian followed Kellie into the shower and took her bathroom bag to provoke her. Kellie became very upset. Ian videoed the entire incident and uploaded it to YouTube.

Seeing the video of Kellie so distraught on the internet was 'the straw that broke the camel's back'. 'All hell broke loose for me,' Margie said.

Margie decided to 'use the legal system' and applied for a protection order. A disability legal service assisted her. Ian's parents paid for a barrister to represent him.

Margie said the magistrate was very understanding and after some negotiation Ian signed a legal undertaking to stop harassing Kellie. The magistrate said if Ian didn't change his behaviour he would be back in court.

Margie said the undertaking and the threat of the criminal justice system worked and Ian stopped targeting Kellie. The court experience made Ian's parents finally understand the terrible affects Ian's behaviour has had on Kellie.

'It was a shocking situation, and it had a huge toll on my husband and I but mostly on my daughter, who shouldn't have had to endure that.'

Margie said if the provider had addressed Ian's behaviour in the beginning the harm could have been avoided.

'Just amazingly creative, diverse, all-encompassing harassment which wasn't addressed for so many years.'

'Hopefully now it has been addressed. But my big concern, as with many parents of disabled children, is what will happen when I die and there is no-one to advocate for my daughter anymore.'

Teena, Polly and Helene

Teena is in her 20s and has an acquired brain injury, depression and chronic pain. She has two children – Polly, a toddler, and Helene, who's in primary school.

Teena told the Royal Commission that, when she was a teenager, her boyfriend's family forced her to marry him. She said she was made to clean for the family and look after their other children.

'Looked after two lots of kids, basically. And my ex was like a kid, so all my life I've been raising kids.'

Teena's ex has an intellectual disability and is violent.

'He's got anger management. He's got anger management really bad. I still can't sleep because of him. And all the trauma I'm still going through.'

She said Helene is also scared of him, and can't sleep.

'He used to drug me and my daughter.'

Teena moved away from her former husband and his family several years ago and into a refuge. Recently, she moved into her own house with assistance from NDIS support workers.

'I've got the oldest [daughter] living with me permanently. I just want my youngest one to live with me permanently.'

Child protection officers removed her youngest daughter, Polly, a week after she was born and placed her with a member of her former husband's family.

'Child protection still won't let me have my kids here, my youngest, and I hate it. Because I've done nothing wrong.'

Teena sees Polly several times a week, but only if there's an NDIS support worker with her. Sometimes support workers aren't available, which means Teena can't see her daughter.

'That worker quits and it's another worker, and then we go back to square one again. And all the other workers are saying I'm doing everything fine, and next minute I get told that, behind my back, it's different.'

Teena wants Polly and Helene with her all the time.

'My main concern is my kids. That's what they keep telling me. But they want to take my kids away.'

Nicola

‘I think that it is very important that you don’t have a singular carer, because it is not safe.’

Nicola, late 50s, has a genetic neurological condition that affects her coordination and muscle control. She experiences severe vertigo and has an acquired brain injury (ABI) as a result of multiple head traumas. She wears a medical alert bracelet.

About 18 months ago, Nicola’s NDIS service provider sent a support worker to clean her flat. The provider told the support worker about Nicola’s diagnosis, which Nicola felt was a breach of her privacy.

After a while the provider offered the support worker additional work without consulting Nicola. Nicola had concerns about the support worker and didn’t really want her in her home.

The support worker started staying longer, for tea and biscuits. Nicola said the provider was using the social funding in her package to ‘rent a friend’, but she ‘didn’t need or want that’.

Over the next few months Nicola’s lease expired and the owners told her they were selling the flat.

The support worker offered Nicola her granny flat.

‘Once I had moved in there, she gave me a proposition. She said, “Oh, why I don’t become your carer and we split the money 50/50.” And I said, “No, that’s illegal.”’

Nicola said that was when ‘bells started ringing’.

She believes the support worker was submitting false invoices to the provider for bogus services.

Then the support worker started running errands with Nicola in the car. Nicola felt like she couldn’t say no. On one outing, she picked up that the support worker might have issues with her licence.

Nicola went to the police station and asked if the support worker had a valid licence. They confirmed their licence had been cancelled.

Nicola told the provider, but they didn’t take any action. Nicola stopped hiring the support worker and switched to a different disability service provider.

When the support worker found out, she was angry at Nicola and kicked her out of the granny flat.

Nicola stayed at a homeless shelter, where she felt very unsafe. One time someone threatened her with a knife. Another time someone choked her.

The stress of the situation caused her to have a heart attack.

At the hospital, Nicola said the hospital staff didn't believe she was having a heart attack. They refused to ask questions about her ABI and how it affected her.

Nicola asked to go to a quiet room. Staff refused, telling her she 'needs to be seen to be seen'. So they left her under bright lights. When Nicola's arms started shaking and she had problems breathing, staff panicked and finally paid attention when she pointed them to her medical alert bracelet. They took her to a quiet room.

Nicola wanted to see a cardiologist. A nurse told her she had probably had a panic attack and that the cardiologist refused to see her.

'The whole time I kept asking for a patient advocate to come to my bedside, because nobody was helping me.'

Nicola said that while in hospital, staff didn't give her the correct food and left her to starve. Staff humiliated her, and one staff member abused her. She made complaints but nothing was done.

'Complaints people are only there for the hospital. So, the patient advocate needs to be made available for patients.'

Hospital staff discharged Nicola with prescriptions for 11 different types of medication. Nicola has issues with numbers and struggled to understand the instructions.

'They didn't show duty of care.'

Kirsten, Ensley and Mitch

‘It cost an incredible amount of money to go to through the courts. That money could’ve been so much better spent providing appropriate services to [Kirsten].’

Ensley and Mitch say they have spent most of Kirsten’s life trying to keep her out of prison. Kirsten, now in her 50s, has an intellectual disability.

‘From the moment she was born she was a difficult child,’ her mum Ensley said. By the time she started school she was ‘troublesome ... always into mischief ... stealing other people’s things’.

When Kirsten turned 18 she ‘demanded to leave home’. Ensley didn’t believe she had the skills to be independent and wanted her to wait. ‘From that moment, the stealing escalated, challenging behaviour escalated and her relationship with me deteriorated.’

After much persistence, Ensley and Mitch were able to find Kirsten a place in a mental health unit for ‘behaviour monitorisation’. But after a few weeks Kirsten escaped. ‘She was a very determined young woman,’ Ensley said.

Kirsten then moved to a group home managed by house parents. But when the house parents’ marriage broke down the house ‘fell apart’.

One day Kirsten ‘just walked out’ and moved in with her boyfriend, sleeping on his couch. She lived with him for 14 years. Ensley and Mitch tried to support Kirsten and her boyfriend but it was a ‘very stormy unpleasant situation’.

During this time Kirsten’s stealing escalated. She couldn’t use the things she stole, ‘she just had to steal’. Ensley felt she was trying to please her boyfriend. The relationship was very violent and ended when Kirsten’s boyfriend tried to kill her.

For the next few years Kirsten moved between different disability service providers, at one stage having more than 12 managers in a few years. One provider told Ensley that Kirsten ‘was a burden’ and another said she was ‘a waste of their time’.

‘There was no consistency, no continuity and there was no transfer of information to the next person, so we had to reinvent the wheel every time.’

During this period, her stealing continued and police would often detain her. On several occasions her support services would ring police and ask them to keep her in the watch house to ‘teach her a lesson’.

Kirsten’s behaviour did not change but she became ‘terrified of the police’.

From the mid-2000s to the early 2010s Kirsten appeared in court more than 50 times. Lawyers advised her to plead guilty. The judge – often it was the same judge, with ‘no understanding’ of disability – showed no mercy. One time the judge made Ensley and Mitch stand in front of him and promise they would make Kirsten behave. This was despite knowing Kirsten lived more than 100 km away from them at the time. They were not allowed to speak.

Another judge ordered state disability services to provide substantially more support to Kirsten. But disability services ignored them. ‘There’s a real disconnect between the courts, the disability services and it was just unacceptable to us,’ Ensley said.

Through a chance encounter, Ensley and Mitch found a criminal barrister who ‘had a passion’ for seeking justice for people with disability. He told them Kirsten didn’t need to plead guilty. He successfully managed to have Kirsten’s matters referred to the mental health court. However, this applied to only some offences and Kirsten considered the punishments, such as packaging food, more a reward than a punishment.

Despite these setbacks, Ensley and Mitch successfully advocated to have Kirsten’s criminal record expunged.

For the past few years Kirsten has received NDIS funding. She has 24/7 support, lives in her own unit and hasn’t been back to court.

Brenton

'I own this ... I felt like no-one could make me homeless. If I end up somewhere else, there goes my little protection from being homeless which is just terrifying for me.'

Brenton, early 30s, has bipolar disorder, anxiety, depression, suicidal ideation and paranoia.

He told the Royal Commission that as a child he was sexually abused by his father, and did not receive any assistance from his mother.

As a young man, Brenton lived in a campervan. He had a number of negative dealings with police and is wary of them. He said a police officer accused him of selling drugs and broke his arm.

Brenton now owns a caravan and lives in a caravan park.

Recently, his caravan needed repair and he wanted to fix it from the 'ground up'. He was working at night digging out dirt from underneath the van. He wanted to get under the van to remove the flooring.

'Stupidly, I was dumping the dirt and I wasn't doing it clandestinely, I wasn't trying to be sneaky about it.'

The caravan park manager became suspicious. He accused Brenton of ruining a garden bed – Brenton described it as a 'patch of dirt'.

Brenton believes the manager told police he was burying a body underneath the caravan.

Police arrived 'under the guise of a welfare check' and '[bullied] the hell out of [him] for about 15 minutes'. They threatened to arrest Brenton if he did not disclose his mental health diagnosis.

'Keep in mind my embarrassment and shame about having to [talk about my mental health diagnosis] in front of my neighbours.'

Brenton felt this was a breach of his privacy. 'It was not a welfare check. There was not one instance where I was asked, "Are you okay? Do you need assistance?"'

He said the police officers made comments and joked about his disability. 'The policeman also bragged about not having mental health issues. He also insinuated that I should be medicated.'

Police cautioned Brenton and told him to stop the work.

'They went on their merry way, and I went and vomited up my breakfast and had an adrenaline seizure.'

A short time later, the caravan park manager cut off all amenities to Brenton's caravan. He then tried to enter the caravan without any notice. He took photos and tried to force Brenton to sign a document without giving him the opportunity to read it properly.

Brenton believes this was an attempt to have his caravan declared uninhabitable, which would have left him homeless.

Brenton started using the shared amenities until management locked him out, blaming COVID-19.

Brenton receives JobSeeker payments and can't afford to rent anywhere else.

'I cannot form a plan to get out of there. I don't have the mental capacity to form a plan ... I don't understand how I can get an in-between place to put all my stuff.'

Kristi

Kristi is autistic and has Tourette syndrome and attention deficit hyperactivity disorder. She also has a physical disability and uses a wheelchair.

‘At 12 years old, I was home schooled and training 60 hours a week for karate,’ Kristi told the Royal Commission. ‘I was very active, and now I use a wheelchair all day, every day. Like, that’s been the progression of my disability over the past, you know, six years.’

Kristi is supported by the NDIS but says they ‘don’t like that [her] support keeps changing’.

‘NDIS ... don’t seem to like that because it’s been progressive as well. But my condition isn’t medically defined as progressive, it’s just the effects of it are.’

The NDIS initially rejected Kristi’s application for a power-assist wheelchair.

‘They’re like, “You don’t need one, like you can still use crutches,” We’re like, “Well, I’m getting to a point where I’m not going to be able to.”’

Kristi said the NDIA tried to give her a more expensive electric wheelchair. Kristi persuaded them to fund the less-expensive, more suitable chair, but waited three months for approval.

‘I was bedbound for those three months, and the only reason it was approved is because my mother rang every day for about six weeks. And they’re like, “These things take time, like, you know, we can’t just hurry these things up,” and mum was like, “She’s bedbound, she’s regressing.” ... I couldn’t get to physio. I couldn’t do anything.’

The NDIA also told Kristi that she didn’t qualify for specialist disability accommodation (SDA). Kristi at the time was living with her mother, who also has disability.

‘And every time, you know, I had to go to the hospital, mum couldn’t move me, so we have to ring an ambulance and I didn’t really need an ambulance. If I had the wheelchair I could’ve moved myself around.’

One day, Kristi fell and dislocated her shoulder.

‘I’d run out of funding and done my shoulder and no support worker was there, so I had to call an ambulance from my watch. And the hospital was not very keen to have me there, but they also weren’t keen to send me home, because I didn’t have support workers.’

Without suitable supports, Kristi’s condition deteriorated.

‘It’s not the hospital’s job to provide that sort of physio ... so I have declined quite a bit in hospital simply because NDIS couldn’t make up their mind.’

Kristi said she has since been approved for SDA and recently moved into her own apartment with support workers on call.

‘That took a while.’

Len and Constance

Constance is in her 80s and has a hearing impairment. She's the main carer for her son, Len, who has relapsing-remitting multiple sclerosis (RRMS). Len uses a wheelchair, is sensitive to heat and noise and has trouble speaking.

Len separated from his wife about 10 years ago. Doctors diagnosed him with RRMS about five years ago.

**'He could hardly walk,' Constance told the Royal Commission.
'He couldn't speak. And he couldn't even cook his meals and there he was trying to look after [several] kids. He was in debt, he couldn't pay his rent.'**

Len was assessed as being totally and permanently disabled and received an insurance payout. One of the conditions was that he 'purchase a place that will be suitable for [his] deteriorating condition'.

Len bought a house and modified it for wheelchair access. When Len divorced his wife a couple of years later, she applied for a share of the home.

'What the judge ... said in the Family Court [was that] it didn't matter about the [total and permanent disablement] TPD payment. Didn't matter about any of those things.'

Constance said that, because of his disability, Len is unable to attend court.

When Constance tried to represent him in court, she said the lawyers 'brushed [her] aside'. Because of her hearing impairment, she 'couldn't hear what was going on. It was terrible ... a nightmare'.

'The law was listening to [Len's former wife], not to me. And I hold an [enduring power of attorney] EPA ... but the law would not accept them. Now, my hands were tied in trying to help him in the court or anywhere.'

Constance said the court ignored Len's disability by ordering him to give his former wife a share of a payment he received to help him live with disability.

She said her other children are now trying to borrow money to pay the settlement, so Len can keep the house.

'His life is livable in that he maintains a certain amount of independence here. He wouldn't get that elsewhere.'

Whitley

Whitley, a First Nations woman in her 60s, has borderline personality disorder. She also has osteoarthritis and uses a wheelchair or scooter for mobility.

Whitley told the Royal Commission she was raised in an orphanage and foster care, so making her 'home life a safe one' has been her 'whole intent'.

However, Whitley said physical abuse by police and unjust treatment from housing authorities has led to her being evicted from government housing and becoming homeless several times in the past few years.

Whitley first moved into public housing in the early 2000s.

In the first house, she said police physically abused her after she had problems with a neighbour. '[My] right wrist had been fractured from being slammed and manhandled.'

Whitley said there were lots of 'police callouts' over the years.

Once she was walking to her weekly psychiatric appointment when police pulled up.

'They suspected I was carrying drugs in my anus, and they pulled my shorts and my underwear down on the public main street.'

'There was me slammed on the concrete ... with a physical disability that has gotten worse.'

The housing department evicted Whitley. 'Then they placed me into another disability unit.'

There were ice dealers living in the area. Whitley made calls to the police, but they repeatedly ignored her. 'I thought I was doing something – you know, to keep the community safe.'

It got to the point where Whitley 'had had enough'. 'So, I picked up my percussion instrument and knowing that they were going to do a runner, I assaulted the dealer, struck him once.'

Police detained Whitley. 'They were all laughing at the instrument,' Whitley said, 'having a joke.'

Soon after, she was told to 'get out' of the unit.

Following this eviction, Whitley moved through a string of support accommodation facilities. One of these had 'third world conditions'.

'It was horrible,' she said. 'I resided there ... with alcoholics, criminals. I was assaulted on day four, three times by the same mentally unwell man.'

Early in the COVID-19 pandemic, Whitely was placed in an Indigenous aged care facility. 'That was frightening. It's a prison.'

One night, a support worker accused her of threatening violence on a resident, and called the police. 'I had to go away to be mentally assessed.'

Management gave her 48 hours to 'get out'. Whitely became homeless again.

Today Whitley is in stable accommodation, but she is having problems with a tenant who is sexually harassing her.

'Because I was sexually abused in the orphanages ... it's like living with a paedophile above me.'

She says the housing department refuses to take her calls, and feels they have 'failed her'.

Whitley describes herself as 'a person that keeps getting knocked down and getting back up again'.

'It's been a pretty intense journey,' she said. '[But] I have now finally unpacked and have a home.'

Lex and Doris

Lex is a First Nations man in his 40s. He has an acquired brain injury (ABI) and lives in a rural town.

‘I was hit in the head with a baseball bat about five times and had a totally shattered skull,’ Lex told the Royal Commission. ‘I got told by a number of psychologists and psychiatrists over the years that I would never have full brain, or brain capacity function come back, and that I have an ABI.’

Lex recently applied to the NDIS for support but was unsuccessful. ‘They told me I didn’t fit the criteria because of how functional I am.’

Lex said that when the hospital discharged him after the assault, he developed depression and ‘started using drugs heavily’. However he has now been clean for several years. ‘Since I’ve been clean, the chronic depression has sort of gone away.’

A couple of years ago, Lex and his partner, Doris, had a baby. Doris has epilepsy. Like Lex, she had been a drug user but, at the time of her child’s birth, was clean.

There were complications during birth. ‘She had a very sort of brutal ... birthing experience. Forceps were used. It was very rough and very hard. The baby came out black and blue.’

The baby spent three weeks in intensive care. Lex said the hospital failed to support Doris because she had a disability. He made a complaint and was later told by child protection that he had been aggressive.

‘[The hospital] made no suggestion of aggression from me at the time, and no suggestion of anger.’

When the hospital discharged Lex’s son, child protection took him into care.

‘They said that the reason they were taking [my son] was due to drug use. But that was found not to be true ... They had a target on me, you know. At the same time, I’m dealing with a premature childbirth, a partner with a disability that wasn’t coping, with constant depression. Every time I went anywhere I was getting pulled up by the same particular police officer continually.’

Lex said that although the NDIS didn’t recognise his ABI, police and child protection officers used it to discriminate against him.

‘It’s a small town, bigoted community. If you’re black, you are bad. If you are disabled, we’ll take your kid. Or if you’re Indigenous we’ll take your child. If you’re white, not a problem.’

Lex’s son now lives with him and his current partner.

‘If I didn’t have a supportive partner, which I’ve got now, some days I would struggle. I would really, really struggle.’

Pieter

Pieter is in his 60s. He has diabetes and, as a result of a workplace accident nearly a decade ago, a physical disability. He has a metal implant in his spine, uses a walking stick and receives the Disability Support Pension.

'If I raise my voice a lot [and] seem to be a little bit abrupt, I apologise because I'm in a lot of aggravated pain,' Pieter told the Royal Commission.

A couple of years ago, a neighbour verbally abused and threatened him. Pieter said he's worried about his safety.

Once during an incident with the neighbour, police arrived. Pieter said they took away his walking stick, 'brought [him] to the ground', handcuffed him and 'dragged [him] by the elbows across the carpark in front of everybody'.

'They humiliated me. Hurt me is the worse part of it. And then when we got to the back of the van, I said, "Listen, uncuff me and I'll get into the van on my own recognisance. As I explained to you, my back is hurt. I've got a metal implant. I'm hurting all the time. Don't force me in." No, three heroes threw me in.'

He's made several complaints, but says the police haven't responded.

'They're not even bothering to answer the online complaint, the feedback form that I lodged, 22 emails, and so many phone calls, and they've gone to ground.'

Pieter now fears the police are following him.

'Everything that's happened just ruined my life. I, you know, I don't know what to do.'

Lillie

‘I’ve still got more to contribute, and people with disabilities also can do the same, [but] we just shut them out and put them in a corner and forget all about them, but they’re human beings.’

Lillie is in her 50s. She has type 2 diabetes and a physical injury from surgery.

‘Something happened, I needed an operation. I was told that it was something they do all the time. It turned out the doctor wasn’t qualified, he butchered me,’ Lillie told the Royal Commission. ‘That one day destroyed my life. I am not going to get emotional, it’s quite sad. I have been kicked from pillar to post since then.’

Lillie said that before the surgery, she had a successful career as an engineer.

‘I worked really hard and I loved my job. I was good at it.’

After the surgery, Lillie said, she lost her job and is now ‘mostly incapacitated’ and needs medication for pain.

Lillie is supported by a charity, but said its staff have abused her. For example, when her washing machine broke, she was given a replacement that was faulty.

‘I just didn’t use it, and that appliance could cause a fire and could kill somebody because it was arcing, and I was told by this woman ... to cop it and shut up.’

Lillie said some carers from other service providers stole ‘rings, gold chains, computers, CDs, stuff that they could either use themselves or sell on’.

Lillie said she’s had little help to access the NDIS.

‘Nothing happened. I am now receiving \$50 help a week from a friend of mine to get by, because I normally run out of food on the Monday before the Wednesday when my pension comes due.’

Luisa

‘Just like we build a ramp for people with physical disability for them to easily access a building, we do need to accommodate [people with other disability] even when it represents only a small number of the population.’

Luisa is in her 50s and has Asperger’s syndrome. She was born in China.

‘Since I was three I always wonder what’s wrong with me,’ Luisa told the Royal Commission. ‘But I’m very bright when I was a kid, you know. It’s just the social side of it, I just couldn’t navigate it.’

A decade ago Luisa enrolled in a university psychology course. She told staff she has a disability and asked for small classes.

‘I cannot process conversation. Like multiple conversations ... so it’s very hard to, you know, grasp in a big group.’

Luisa said she was placed in small classes, but felt labelled and harassed.

‘From there they just start to look at me in a different way ... they just started stalking.’

Luisa transferred to another university where the harassment continued.

‘They just give me a hard time ... they’re hacking my phone, hacking my computer, and it’s just horrendous. I don’t know why they are so into this kind of thing.’

When she complained, the university expelled her.

‘I was thinking, “Oh my God, I’m actually excellent student,” you know. I love those content. Why you expel me, you know? And all I’m lonely. I just want a good environment for me to learn better.’

When Luisa moved to another university, the harassment stopped. She’s now halfway through her course, but regrets telling them about her having Asperger’s syndrome.

‘I just feel like if I hadn’t provided them my diagnosis report, next to nothing would have happened ... I thought maybe I shouldn’t let them know. It’s damaging me ... I can hide it. But the thing is if people have to hide that condition in order to be able to fit in, I think then society is wrong.’

Luisa said students with Asperger’s syndrome are highly intelligent, but ‘have this deep ability [to] often mask their ability’.

‘I think that society needs more of us ... if you don’t have people like us that go to the classrooms or you know, to do whatever, there would be even less chance to understand us.’

Maleah

When Maleah came to Australia in the late 1990s, she got a job as a support worker in the disability sector.

‘Ninety-nine per cent of us were from a migrant background,’ she told the Royal Commission. ‘We needed a job and not knowing Australian laws, not knowing about human rights at this time, we had to follow procedures.’

Maleah discovered some of the procedures violated her clients’ human rights.

One client, Georgie, liked to get up at 2 am, have a shower and wake everyone else so they could have a shower.

Support workers were expected to implement a behaviour management strategy that had been in place for many years.

If Georgie wouldn’t go back to bed, support workers had to carry her outside and leave her there.

‘It didn’t matter whether it was four degrees outside or one degree or whether it was a warm summer’s evening ... We physically carried her and took her outside.’

Sometimes, even though it was freezing, Georgia would strip off all her clothes and run around.

Maleah, increasingly concerned about Georgie’s safety, spoke to the other support workers and they decided to allow her to have a shower when she woke up. The supervisor on duty helped them make sure she didn’t wake up the other residents.

‘That strategy actually worked very well. And then she came to the understanding that, “Yes, if I want a shower at 2 am in the morning, that’s my right but I don’t have to get anyone else up.”’

When the provider found out what was happening they disciplined Maleah for changing the behaviour management plan.

Maleah became the occupational safety representative for the provider and studied the relevant laws to better understand its obligations to both staff and clients. She told them, ‘While you have to provide a safe working environment for the staff, you have to provide a safe living environment for our clients and a safe system to manage their behaviour.’

More recently, Maleah supported another client. Alwyn was blind, had intellectual disability and pica behaviours. He would pick up anything on the ground, usually grass and dirt, and eat it.

Alwyn was ‘an absolute beautiful, beautiful man’ and staff didn’t let him out of their sight.

'Sometimes if we had a casual staff that was unfamiliar with him, some of us regular staff, we won't even take our lunchbreak. We were so scared.'

Maleah repeatedly asked the provider to fence off part of the backyard and install a gate so Alwyn could go outside safely.

'I think we fought over a 12-month period, and we did not get the gate,' Maleah said.

One day, a casual staff member who'd never worked with Alwyn before lost sight of him.

They found him outside, unconscious. Alwyn's mouth and throat were stuffed with so much grass and dirt that neither staff or paramedics were able to perform CPR. They were unable to revive Alwyn, and he died.

A short time later a young woman, also with pica behaviours, moved into the home.

Maleah demanded the provider put in a fence telling them 'We are not allowing another young person to come in this house and lose their life.'

The provider agreed and finally installed a fence and gate.

Alwyn's death still 'weighs heavily' on Maleah.

'[It was] a blatant breach of his rights ... He needed to be safe in the house. He needed a gate. He needed the fence. That's all.'

Harrison

‘We’re working in their house. They’re not living in our workplace.’

Harrison, mid-50s, lives with depression and anxiety.

A few years ago he started working for a disability service provider, supporting people with complex needs.

Harrison told the Royal Commission the provider treated residents in the group homes ‘like second class citizens and a cash cow’.

One of the homes was ‘very clinical’ and looked like a ‘wet room’. Everything was covered in linoleum, perspex and beige paint.

Two of the residents, Luca and Jono, had violent and aggressive behaviours and required two-to-one support. But the provider only employed one support worker to support both men during the nights.

Staff gave Jono and Luca excessive psychotropic medication.

Harrison said staff ‘programmed’ Luca to ask for a ‘happy pill’ if he was upset. But the medication affected his bowels and he would get constipated for days. The pain would cause him to behave aggressively.

Staff ignored violent incidents, even when police attended, because they did not want to ‘look bad’. If they couldn’t ignore incidents, they downgraded them to a ‘category one’ so the team leader didn’t have to escalate them.

Harrison said that compared to Luca, ‘the neglect of [Jono] was astronomical’.

Jono had faecal incontinence because of the psychotropic medication.

Staff wouldn’t provide Jono with incontinence pads, but would then refuse to take him out into the community because they didn’t want him in their car. He would spend long periods of time in bed in unwashed clothes and sheets. He often had large painful bedsores that needed medical attention.

Staff blocked Jono’s access to the kitchen. They believed if he had limited access to food they wouldn’t have to clean up after his incontinence.

Staff members ‘groomed’ Jono so they could get more hours. They would buy him cigarettes and soft drinks and tell him the other workers weren’t nice and he should request them. They also would incite Jono and Luca to fight each other so they could work more.

Jono confessed to Harrison that two female support workers told him and Luca to attack Harrison and another support worker.

‘[Jono] was asked to beat me up because I was a liar and a thief, and I was the reason he wasn’t allowed to do certain things. [Luca] was told to use his fishing knives on me.’

Harrison made a report to the provider and police. The provider conducted three internal enquiries and stood down two staff for a few months. The police refused to act because there was no attack.

In retaliation, the support workers made allegations against Harrison.

They complained Harrison was ‘grooming’ a client by allowing him to call him ‘Mr Sweetie Pie’. Harrison didn’t think this was fair because the client’s behaviour plan said staff should allow him to give them ‘pet names’.

Jono changed providers and asked Harrison to continue working with him. Harrison said the new accommodation wasn’t appropriate and there were similar problems with staff, including staff stealing grocery money.

‘There’s no safe room for the staff if he acts out. And it’s a standard unit that’s carpeted, even with his bowel problems. And it wasn’t long before I noticed the similar things, all the staff meals are paid for by the client through his groceries. He is being yelled at, bullied, manhandled.’

Harrison made a number of complaints to the provider. Just before his probation period ended, the provider terminated his contract.

‘[Jono] is still in that house and is still being treated the same way.’

Mason and Laney

Mason is in his 30s. He is autistic and has global developmental delay and an intellectual disability.

‘Until he was about six years old, [Mason] was completely out of touch,’ Laney told the Royal Commission. ‘He didn’t really know that I was his mother. He wasn’t really aware of anything very much at all.’

Laney said it wasn’t until Mason was seven that ‘a little light came on’.

‘Mason sort of had an understanding of what was going on around him, and he did make some progress.’

In high school, where he attended the special education class, Mason had ‘the innocence of a three-year-old’.

‘He was just like a really delightful three-year-old, but he was, you know, by the time he was about 15, he was nearly six foot tall.’

Back then Mason attended respite care, sometimes for several days at a time.

One day, just after Mason returned from respite care, his school called Laney to tell her Mason was upset and curled up in a corner.

‘He was just so completely traumatised ... He didn’t talk after that and he started to regress really badly, and he was incontinent and stuff, and I had no idea what had happened to him.’

Mason began to ‘act out behaviours ... he started pulling his pants down and he’d get really distressed’.

When Mason later became violent, his government support worker told Laney she thought something had happened to Mason in respite care.

‘She said to me there were no records, there was no information that would lead to any allegation or any suspicion that anything had happened to my son, and then she said — and this was the trigger — then she said, “Anyway, he was over 16 so it was consensual, whatever happened.” And I said to her, “No, it couldn’t have been consensual, you know, because he’s got a disability,” and she said, “No ... if you are over the age of consent, and you give consent, it’s consensual, and that’s all there is to it.”’

Laney said she later realised that Mason, on trips to the beach, would use a particular public toilet.

'I used to always call out, "Is anyone there?" and no-one would answer, and I naïvely used to let him go in ... I didn't realise at the time that it was actually a place where men used to hang around for sex.'

Laney told the police she feared Mason had been sexually assaulted.

'They told me that under policy changes, they could no longer arrest these men, because the men would say that it was consensual, and [Mason] would not be able to contradict them. And the police said, "We can no longer charge anybody with these offences, because your son can't testify anyway.'"

Laney feels Mason cannot consent to a sexual relationship.

'[Mason] does not understand any consequences of how a baby is made, even though they have showed him,' Laney told the Royal Commission. 'The dichotomy that used to exist between people that needed protections and those that didn't has been removed.'

Isador

Isador, mid-30s, has a number of disabilities that weren't diagnosed until she was in her 20s.

Isador's parents fled to Australia because of conflict in their home country. She told the Royal Commission her mother lived with 'generational trauma' and psychosocial disability.

As a toddler, Isador sustained third-degree burns. A government agency removed Isador and her siblings and placed them in a children's home, then moved them to a foster home.

The foster parents changed the children's names. 'A lot of the reports said that we did not identify as ethnic or Asian, and that we didn't want to have anything to do with our parents.'

Isador and her siblings were moved through different foster homes. 'There was a bit of abuse,' she said. As soon as she turned 14 she left home.

After finishing school, Isador found work as a consultant. She was earning a high wage, but was also being bullied and harassed. Management 'drove her to the ground' until, about six years ago, she sustained a mental health workplace injury. She was pregnant at the time.

'I just couldn't get out of bed, so I just shut down, didn't want to go back to work, and just never went back.'

Isador made a worker's compensation claim and had 'a lot of counselling'. She was diagnosed with complex post-traumatic stress disorder, anxiety, depression and adjustment disorder.

'I had private investigators on me throughout my whole pregnancy. I didn't leave my home. It was bad, you know. I got put through assessments when I was eight and a half months pregnant to do return-to-work activities.'

Isador was admitted to a perinatal ward because of 'maternal exhaustion', and was diagnosed with attention deficit hyperactivity disorder. The psychiatrist suggested her husband's demands and the way he spoke to her 'resembled domestic violence'.

Not long after returning home, Isador had a 'mental health breakdown'.

Services and police arrived and a police officer told her that the way her husband treated her was family violence. 'You need to make a choice,' the officer said. 'He stays or he doesn't, but you're putting your children at risk.'

Isador's husband struggled to adapt during the COVID-19 lockdowns. Isador threatened to separate if 'he wasn't able to stop himself from abusing [her] and the kids'. He started to receive counselling, which led to both him and Isador being assessed for autism.

'I had an autism diagnosis. My husband came out without one – he said he knew how to answer those questions.'

Isador obtained a family violence order against her husband. He then initiated child custody proceedings, alleging she was a threat to the children.

'He put in copies of my psychiatric statements, all of the things that were written for me to get support.'

Isador eventually reached an arrangement she would have custody five days out of 14.

Isador's children have been diagnosed with a range of disabilities and now receive NDIS funding. Isador, however, is ineligible – 'she ticks too many boxes' because of the workers compensation payout.

'I was so traumatised by these processes.'

Maude

Maude is an allied health professional working with people with disability.

Several years ago, Maude's father, who now has Alzheimer's disease, made her his legal guardian.

'He chose me when he had capacity,' Maude told the Royal Commission. 'I was happy to be his guardian, but my sister ... didn't like me in that role.'

Maude told the Royal Commission her sister moved into the family home 'to save rent' and applied for a carer's payment, but neglected her parents and 'took a lot of money' from them.

'So, when I started saying, "You can't do that. If you're going to be the carer, you have to be the carer. There's certain criteria around accepting that work." That's when it all started going pear-shaped.'

After Maude suggested employing professional carers, her sister challenged Maude's guardianship in the state administrative tribunal.

Maude said she sent the tribunal a submission, but it failed to read it before the hearing.

'They literally said at the beginning, "We haven't read it because it was too long."

Maude's father attended the hearing but wasn't able to speak. Her mother's voice was affected by Parkinson's disease.

'I was saying [before the hearing], "What sort of disability access can she take advantage of? You know, can she get extra time? Can she get a microphone? Will there be a disability support person there to support her?" And they said, "No."

Her mother supported Maude's guardianship, but told the tribunal she'd be her husband's guardian if Maude couldn't. Maude said the tribunal told her she was 'too disabled'.

'In those sorts of words – "You're too disabled to do it."

The tribunal instead appointed a public guardian 'based on what they call "family conflict".'

'For me it's not family conflict. It's, I'm the whistleblower. I'm telling them about the abuse and supporting my mum in telling them about the abuse.'

Maude's sister still lives in the family home with her father. Her mother moved into a nursing home 'to get away from' her.

‘There were so many systems in place to protect the residents there. There were whistleblowing posters on the staff toilets. There were complaint procedures ... But at home, my parents were left, you know, in squalor, yelled at ... I’m just finding it really quite shocking how little support there is for someone in that setting where the systems I would see in place in formal care just don’t exist.’

Maude’s mother recently died. Her father’s public guardian has not yet visited him, but restricted Maude to three supervised visits a week.

‘I’m not allowed to touch him, I’m not allowed to care for him ... I find that very strange in that I’m a professional carer myself ... I said, “Is there some sort of violence order against me” or, you know, “Why?” And [the public guardian] goes, “No, but you’re not a carer so there has to be a carer there while you’re there.”’

Maude discovered the tribunal had accepted her sister’s allegation that Maude was a ‘liar’. In its report based on the hearing, Maude said the tribunal alleged she also ‘manipulated’ her father’s doctor to write a report saying her father was being abused.

Maude said the tribunal later apologised to the doctor, but wouldn’t change its decision.

‘The whole process has been extremely traumatic because I’m really just trying to help two disabled people to get away from this abuse and yet, now, it’s being turned on me.’

Ramon and Alora

Alora is a single parent with three children. Her son Ramon is in primary school. He is autistic and lives with anxiety and obsessive-compulsive disorder.

Doctors diagnosed Ramon's autism a few years ago. Alora had known for many years 'something was up', and had already quit her job and university study to care for him.

'He eats a pair of socks every day, literally eats the whole pair of socks, it's bizarre. He'll eat his shoes, it's severe, severe. He'll chew up cables. And the costs associated with that is huge. During meltdowns he's broken down doors ... he'd have these massive meltdowns and he'd smash his head and knock himself unconscious.'

After waiting years for a diagnosis through the public health system, she borrowed money for a private assessment.

'We were at crisis point ... There seems to be such a big shortage of people who can help with diagnosis at a decent cost. I mean, it was like two and a half grand out of pocket for me to pay for that and on a single parent pension that is a massive amount of money.'

Ramon's diagnosis gave him access to the NDIS.

'They've given us funding which I'm very grateful for, don't get me wrong, for support workers. It's just not working.'

Alora said Ramon won't let the support workers dress or feed him, or give him his medication.

'He refused to eat it because [the support worker] touched it, so it was contaminated. Only mummy's allowed to touch it. Just everything they tried just didn't work.'

Alora said better support would be helping with housework and the other children while she feeds and dresses Ramon, 'because my house is just a disaster'.

'I basically don't stop between the three kids and [Ramon's] appointments and everything going on. And they said, "No, that's parental responsibility."

Alora said the NDIS doesn't understand Ramon's complex behaviours and how to help her manage them.

'They kind of clump together each disability and [say] like, "Yeah, kids with autism need this, this and this" and then when you ask for something outside of that, they're like, "No, well he doesn't need that."

Alora says managing Ramon's NDIS plan is 'more stress than it's worth'.

'Every time they want me to do carer's statements and this and that, and I've got to gather all the reports and it's just very stressful ... I don't have time to sit down and read and understand fully all the legislation. It's not explained. It's not clear what you can claim and not. I'm constantly worried.'

Alora said she survives as a single mother only because her parents let her rent a house that Ramon is 'destroying'.

'I can't work. I can't earn an income. I can't earn any more super, and I've had to withdraw it all, so I've got like zilch left ... There's no near point in me returning to work. I've got no assistance. The stress.'

Alora said if she had more money she would choose Ramon's supports and pay for them herself.

'I would just be like, "No, I'm not dealing with [the NDIS] anymore." ... Obviously, I don't have the money to get him private therapy and so I just kind of have to accept it.'

Kimia

Kimia, late 40s, has physical disability, epilepsy, complex post-traumatic stress disorder, anxiety and depression.

She was born overseas and came to Australia before she started school.

Kimia said that, as a toddler, her mother and someone outside the family sexually abused her. The abuse continued until she was in her mid-teens. When she tried to tell people what was happening, they didn't believe her because she came from a very Christian family.

Kimia told the Royal Commission her family didn't seek treatment or support for her physical disabilities. She believes if she'd received the appropriate support, 'it would not be a problem today'.

'Somehow,' Kimia said, 'I managed to get through.' She went to university and got a job. She said she became very good at masking.

Kimia got married in her 20s. Her husband began to physically abuse her, but Kimia hid her injuries. She would tell people she had fallen and hurt herself. 'I became very, very depressed – more than I already was.'

She tried to end her life.

'You can end up self-harming, and you can end up making very silly mistakes by being in a relationship which clearly is not good for you, and clearly ignoring your health. And when you are like that you're not able to speak to a doctor, you're not able to get any supports.'

Kimia was admitted to hospital. Her husband told staff she was an alcoholic.

'To this day, as a result of that, my name is tainted and I'm considered an alcoholic in some of the reports. There was no alcohol in my blood.'

Kimia attempted to report her childhood abuse and her husband's abuse, but police said it would be 'too much for her' if they investigated her allegations.

Kimia left her husband and stopped working. Her family promised to support her, but they controlled what she ate, where she lived and what she did. She lived with almost no food, four cats, in freezing conditions and with mould throughout the home.

When she tried to see a doctor, her family attended the appointments. Doctors dismissed any physical symptom as a mental health issue.

Kimia recently reached out to support services for help. 'To have to repeat myself over and over again has been so traumatising.' She finds it 'very hard to trust' and is 'petrified of information getting leaked out' and her family or ex-husband discovering things about her.

'I have no idea how I've survived. There's lots of grief there.'

Nikita, Moses, Ajax and Noor

‘I think that something really needs to happen in the police force. They need specialised training to deal with individuals with autism, like myself and like my children, and give people the opportunity to speak in their own language in their own individual way.’

Nikita, early 30s, and her children – Moses, Ajax and Noor – have autism and post-traumatic stress disorder. Ajax has a speech and language impairment and epilepsy. Noor has a heart condition. Different support workers worked with the children at home.

A few years ago, Nikita ‘started to see a change’ in Ajax’s behaviour. He had more ‘behavioural incidents’ at school and ‘suspension after suspension’.

At home, a fill-in support worker saw one of the regular support workers sexually and physically abuse Moses, Ajax and Noor. They reported the abuse to the provider. The provider notified police and suspended the offending support worker.

Nikita told the Royal Commission that her family has been ‘devastated’ not only by the abuse, but by the failings of police and legal systems that followed.

Moses refused, and continues to refuse, to talk about what happened. He spent time in a mental health facility and no longer lives at home. The support worker had groomed him, and Nikita says he now has ‘a hatred’ towards her for ‘taking away that particular support worker’.

Ajax, who was seven at the time, is non-verbal. Nikita said the police weren’t ‘willing to try’ to help Ajax give a statement. Instead, they had his three-year-old sister do it for him. Police interviewed Noor three times, without Nikita present. Using trauma dolls she had to ‘relive what was happening to her brothers’.

Police charged the support worker for sexually and physically abusing Noor, but took no action in regards to their abuse of Ajax.

Nikita felt she had no option but to pursue a civil claim. She recently agreed to a financial settlement believing it would give the family closure, ‘but it didn’t’.

‘Despite the abuse that happened to him and the things that he dealt with ... we cannot prove that it would be very much of an economic loss, because [Ajax] is an autistic child who is non-verbal.’

Over time, people who said they had seen the support worker touch Ajax inappropriately ‘started to come out of the woodwork’. If they’d made reports at the time, Nikita said, the abuse ‘wouldn’t have gone on for so long’.

Nikita said the fill-in worker who had reported the abuse was ‘traumatised’ and no longer works as a support worker.

Nevaeh

Nevaeh is in her 40s. She is autistic and has attention deficit disorder (ADD), post-traumatic stress disorder and complex health issues. Her children are autistic.

‘My oldest is actually doing very well, though,’ Nevaeh told the Royal Commission. He’s actually started uni now ... Never ever thought that would happen, so it is a huge deal.’

Nevaeh owned her home before she met her former partner. At the start of their relationship, she said, he was ‘so romantically wonderful’.

‘Like, in hindsight, too good. I can see all the points now, but at the time I couldn’t see them.’

When she became pregnant, Nevaeh refinanced the home and put her partner’s name on the mortgage.

‘That’s actually the first day that he put my head through a wall. That night after he signed the mortgage papers ... that’s when [he] started telling me very weird things, like with a smile on his face, that he had me trapped now.’

One day, after her partner assaulted her again, she went to the police station bleeding from her face.

‘The police ... told me it was my fault. One of the policemen said that he knew my ex. They both grew up in the country together and he didn’t know him to be a violent man, even though I was bleeding.’

Another time, Nevaeh’s partner dislocated her arm. She called the police.

‘I was screaming for help and then he had grabbed the phone out of my hand and smashed it on the ground. He even went out front, cut the phone lines, so I couldn’t contact anyone and the police.’

Nevaeh hid with her children. When she went to the police station the next day, an officer asked her if she was ‘the girl on the phone yesterday’ and laughed.

One night, her partner put her head in the oven and turned on the gas.

‘I was trying not to breathe in ... His hand was there so I just bit down hard. I couldn’t even tell you now where I bit him, I just bit on whatever I could to get away.’

The police served an intervention order on Nevaeh’s partner, and sent Nevaeh to a women’s refuge run by a church-based service provider.

‘Which was worse than going anywhere else. There was like a lot of drug addicts in there and it was quite scary for me and the kids.’

A support worker told Nevaeh she ‘was putting too much focus on [her disability]’.

‘And then I felt like if I ever mentioned the autism or anything, they actually looked down on me, or the ADD, you know, that I was then looked at as being – this is a terrible word, it’s the only word I can think of – as being retarded. And so, then I just shut down and just smile and nod to get them away from me, because I was always so afraid that they would take the children away.’

Nevaeh said that after her former partner started sending her photographs of dead animals, a government program supporting people with disability helped her take out an indefinite intervention order against him.

‘[The judge] said that I shouldn’t have to be so afraid for my life, because this was like the fifth intervention order I think. So, that was wonderful. That was just the best day.’

Noella

'I've seen things that I can't un-see ... I'm like one of the most relatively normal people you'll find in public housing, [but] it broke me and I've never been the same since.'

Noella is in her 30s and lives with borderline personality disorder and complex trauma, including post-traumatic stress disorder (PTSD).

'I felt a very urgent need a few years ago to tell my story because I didn't feel like anybody was listening,' Noella told the Royal Commission.

Noella struggles with depression and anxiety.

'It affected me a lot in school, and it affected my attempts to go to university ... I think I've attempted to get every single form of help available that there is. Sorry, I get a bit emotional.'

Noella is now supported by the NDIS, but lives in public housing.

'I feel like there's a great divide between the system and people, and it's weird because it's meant to be a social services system, but it's completely devoid of humanity.'

When she first moved into public housing, many of the residents in her apartment block were elderly or had disability. As those residents moved out, the block became more dangerous.

Noella told the Royal Commission she was sexually assaulted. A police community liaison officer advised her not to report the assault.

'[The liaison officer] basically said to me, "If you report this, we'll have to investigate and then they'll know that you've reported it, and we can't be there 24/7 to protect you." And that's the sad truth of this situation.'

When a woman moved into the apartment above and filled it with rubbish that attracted rats, Noella said the housing department 'did nothing'.

'I have emails from them saying, "We suggest you contact your local MP."

One night, the apartment upstairs caught fire.

'Obviously they had to put the fire out, so my apartment's flooded and, you know. After that they moved in a guy who was a drug dealer and he brought in about five people off the street with him.'

Noella tried to move.

'Then the situation really escalated ... I was trying to get out which meant that I had to report incidents. But in order to do that I had to, like, report on people in the building and they all knew it was me. So I became a target after that.'

She was stalked and threatened. One morning, Noella heard someone drilling into the lock on her front door.

'I looked through the peephole ... and I yelled through the door and said, "What's happening?" And then I realised that one of the guys was wearing a housing [department] name tag, and they were all yelling at me for some reason ... "We've got to come in. We've got to check the smoke alarm."'

Noella told them to wait until she got dressed.

'They didn't wait. They broke it, and they came in ... just to check the smoke alarm.'

Noella said the men claimed to have mailed her a notice that they were coming.

'I said, "Do you understand? People leave needles in my mailbox all the time. This is a very unsafe building. You can visually see for yourself that the mailbox is broken open." ... It was insane. It took me a long time to get over that.'

Noella attempted suicide. After she was released from hospital, she eventually found a senior manager in the department 'who behaved like a human being'.

'He got me out and if it hadn't been for him, I'm not sure I'd be sitting here today,' Noella told the Royal Commission. 'I guess he kind of stepped outside a bit of the bureaucratic lines to try and get me out ... I don't know why there aren't more like him.'

Noella said the housing department was aware of her disability. She was a good tenant and paid her rent on time.

'But it was like, why bother doing the right thing when I didn't get treated the right way in return, you know? Why bother?'

Mitchell and Tegan

Mitchell, 14, is autistic, has muscular dystrophy and uses a wheelchair. Tegan, his mum, lives with depression and anxiety.

Tegan and Mitchell used to live in the city to be close to supports. But Mitchell's school treated him in a way that 'really appalled' Tegan, so they moved back to a regional town.

Initially, the school wasn't very accessible. But as soon as the occupational therapist and physiotherapist told the school they needed to modify the ramps and the doorways, 'they were on to it,' Tegan told the Royal Commission. The local community pitched in and built a ramp in two weeks.

Mitchell has a full-time teacher aide and, while he's behind in maths and English, he's made 'fantastic' progress.

The school includes Mitchell in everything. 'He has been to camps ... They took the wheelchair.' On another trip to a remote location, the aide 'went out on a limb' and organised a golf buggy.

However, the rest of the town isn't 'wheelchair friendly'.

To get to school Mitchell needs to drive his wheelchair across the train tracks. A couple of times the wheelchair stopped right in the middle of the tracks. It 'freaked him out' and he 'lost his confidence'.

Tegan contacted the council to do something about the crossing, but it became 'a big uproar' between the council, main roads and the grain company that built the track. Eventually they smoothed out the surface of the crossing, but Mitchell 'still won't go through it' because he doesn't think it's safe.

The town is divided by a busy highway.

'[Mitchell] doesn't feel safe crossing ... I think they should reduce the speed limit ... There is a crossing for the school, but that is only working during school hours.'

Getting around the town is challenging. 'Some footpaths are good, but other footpaths are just non-existent, and ramps that go onto the road are not safe.'

Tegan said it's not just an issue for Mitchell but for older people with mobility issues.

The disability parking spaces in the main part of town are on a hill. 'Whoever put that there has no idea. If you have a van, you've got a ramp down the back ... A person in a wheelchair is going to take off down the hill.' Since Tegan pointed out the problem council has added new parking spaces on safer ground.

Buildings are also inaccessible. There are very few ramps, mainly steps. 'You always need a support worker with you.'

Tegan has raised the issue with council but they're not willing to address the problem, saying 'it's down to the private owners'.

'Working with the shire and getting them to acknowledge it more ... is a work in progress, but it definitely wasn't friendly at all.'

Jody and Nic

‘There’s no getting over that the end of [Jody]’s life was pretty bad. And it really highlighted to us some of the barriers that people ageing with cerebral palsy face particularly in the healthcare system, but also in the funding of support needs.’

Jody was born in the mid-1960s with cerebral palsy. Her brother Nic told the Royal Commission that Jody was ‘an amazing human being’ and lived a ‘passionate, engaged life’. She was independent and travelled into the city daily in a motorised wheelchair.

At 28, Jody had a serious accident. Her wheelchair toppled off a train station platform. She fractured her leg and lost two front teeth. Doctors immediately treated her leg, but not her teeth.

Jody had an ineffective bite and facial disfiguration. Nic said specialists decided it wasn’t practical to fit a dental plate because of Jody’s disability. No-one investigated an alternative.

Because of her daily travel, Jody’s wheelchair often broke down.

One time, Jody’s chair stopped while she was crossing the train tracks. Another time it broke down in the middle of a busy intersection. Luckily members of the public helped her get to safety.

Each time Jody’s chair broke down, a support worker had to help arrange its repair and Jody had to stay home.

Jody was fiercely independent and tried to find a way to fund a new wheelchair. At the time, state government disability services funded equipment. She tried to negotiate a solution but they were inflexible and refused to address the issue.

‘She was actually told by the funding people that she needed to be more careful with the use of her chair because she was getting too many breakdowns, which just is really not acceptable,’ Nic said.

In her mid-40s Jody started to gain a large amount of weight. She asked disability services to fund additional support worker hours so she could go swimming, but they refused.

Jody thought the weight gain might be related to her hormones. She worried about the affect it might have on her health and mobility and tried to find coordinated medical support to help her. She discovered the adult cerebral palsy clinic stopped treating people when they turned 40.

About five years ago Jody, then in her early 50s, started having frequent falls while transferring from her wheelchair at night when she was home alone. She also began to experience considerable pain in her shoulder.

Jody's GP recommended she see a neurologist. She had to wait 10 weeks and continued to have falls. The neurologist admitted Jody to hospital for a series of complex tests including an MRI. She had to stay in the hospital for more than six weeks waiting for the tests. 'That was one of the first highlights of where her disability was really a massive barrier to diagnosis,' Nic said. 'As soon as she got into the system, they couldn't really adapt the system to cope with both her day-to-day needs, but also then to give her some priority.'

Jody was in a standard hospital bed. She couldn't use the button to call the nurse, so the hospital gave her adult diapers. Jody told Nic she found this quite embarrassing because she knew when she needed to go to the toilet.

'She was just so upset, she was lying in bed, she couldn't see TV – and it was just purely because they had not positioned the bed in a way that she could actually physically see the TV ... She was convinced that they just look at her body and just think that there's no hope.'

Jody had to have spinal surgery and remained in hospital for 13 weeks. The hospital told Nic they couldn't deliver a rehabilitation program because of her disability. The senior rehabilitation doctor said Jody was 'past her use-by date'.

The hospital transferred Jody to an aged care facility. She died unexpectedly one month later.

Phill and Patricia

‘In the children’s hospital system, it’s expected that parents and carers are part of that whole team ... Suddenly, you turn 18 ... Everything is new and there’s no carry-over. It’s just a really dangerous period.’

Phill had cerebral palsy, was non-verbal and used a wheelchair. He used a feeding tube which caused constant issues with his digestive system.

Two years ago doctors diagnosed Phill, then late teens, with lymphoma. They told his mum, Patricia, they were reluctant to give a conclusive diagnosis because it involved invasive testing. They said Phill wasn’t ‘a candidate for treatment’.

Patricia wasn’t sure if this was because of Phill’s recent bowel surgery or his disability.

Patricia cared for Phill at home and tried to make him as comfortable as possible. She changed his diet which worked ‘really well’. ‘His bowel ... vomiting, his mucus that he was choking on all the time, improved. The only thing that hadn’t improved was he wasn’t adding on weight.’

Patricia had been trying to get Phill a better wheelchair. ‘He was in pain trying to sit in this seat that they’d created. It was like it was made out of cement almost. It was so hard. And he was sitting wrong.’

Phill developed a pressure sore and Patricia took him to hospital. ‘Suddenly there was all this blaming,’ Patricia said. ‘How on earth did [you] let this happen?’ staff asked her.

The hospital was also concerned about Phill’s weight loss. Patricia tried to explain it was due to the lymphoma and bowel issues. The hospital didn’t believe Phill had lymphoma, despite being the same hospital that had given him the diagnosis. They accused Patricia of lying. Eventually staff found a note in his records that he had lymphoma, but dismissed it because it was not a formal diagnosis.

‘A social worker ... jumped in ... put in a request for a guardianship order.’

While this was progressing, the hospital refused to let Patricia see her son.

She begged them to change their mind and they eventually let her see him for two hours a day. She said staff watched her like she was a criminal. Meanwhile Phill wasn’t allowed to go for walks and spent all day lying in his room.

‘[He] was distressed. He was in a room on his own where no-one could see him. [He] had no means of pushing a buzzer.’

Sometimes when Patricia arrived, Phill would be screaming, his head stuck in the rails of the bed. No-one supervised his feeds.

Hospital staff told Patricia on several occasions that if Phill got an infection they would not treat it because it might be better to let him die.

Phill continued to lose weight. The hospital refused to provide palliative care because he didn't have a formal lymphoma diagnosis.

At the guardianship hearing, the person conducting the hearing said they respected Patricia's care for Phill. However, as Phill was losing weight and the family and the hospital couldn't agree about his care, they appointed a public guardian.

The guardian allowed Patricia to take Phill home. The hospital was angry and didn't provide her with a formal discharge plan, support or give her any medical supplies.

After six weeks, Patricia arranged a district nurse to start visiting Phill. The nurse told Patricia she was doing a great job for him.

Patricia tried to organise palliative care at home, but many services refused because of the allegations of neglect and the guardianship order.

Patricia prevailed, and Phill died peacefully at home a few weeks later.

Prue

‘Discrimination laws, they’re not going to fix discrimination. They’re too inaccessible ... Just writing these laws it’s not worth much if people can’t access them.’

As a teenager, Prue, now mid-30s, had anorexia and self-harmed. She was diagnosed with borderline personality disorder (BPD), depression and anxiety.

She engaged with ‘a lot of health services’ and they ‘saved her life’ numerous times.

By her mid-20s she was ‘doing quite well’. ‘[I’d] overcome the eating disorder, overcome self-harm, hadn’t had any crises.’

Prue told the Royal Commission she felt she ‘was starting slowly to get there’ until she began experiencing ‘some very severe physical health problems’. She was in terrible pain and couldn’t walk. ‘For around six years I was mostly in a wheelchair or using crutches ... I couldn’t even pick up a pen. It was in my hands as well.’

Doctors said her symptoms were psychosomatic and diagnosed her with conversion disorder. Hospital staff told her she couldn’t have disability services because ‘that’s just going to encourage you to be ill’.

Prue had to ask her friends for help but after a while they wanted to know what was going on. She told them, ‘They say it’s in my head, but I don’t know if it is.’ It affected her friendships and she ‘stopped asking for help’.

Prue’s relationship with her parents broke down because she needed more help than they could give.

When she fell or couldn’t move she would ring the ambulance to help her.

In emergency, staff were rude and would humiliate her. One time she was told not to come back unless she was dying. Other times they told her she could only see a doctor if she walked into the cubicle. She told them she couldn’t walk but they ignored her saying, ‘We know you can walk, so walk.’

‘I really think they believed I was faking the symptoms.’

Prue later found out there were alerts on her file warning she had BPD and should not be treated in hospital. They also warned she was a drug seeker searching for morphine.

‘If I’d come in without any of this history, I wouldn’t have been treated like that.’

Prue started experiencing severe, recurrent urinary tract infections and needed hospital treatment. Although she had a letter from her GP saying, 'her pain is real, her symptoms are real', the hospital refused to treat her.

Staff routinely called security guards to remove her.

'I would be sent home in a taxi and ... there were times I had to ask a taxi driver to help me get inside.'

Prue's mental health deteriorated and she experienced a breakdown. 'It was the worst period of my life.'

Prue made a complaint to the hospital. They defended their staff telling her she had BPD and needed to be treated in the community.

Prue's psychologist encouraged her to file an anti-discrimination complaint.

When she tried to access her medical records the hospital refused to release them and tried to intimidate her.

They told her, 'Your mental health is so fragile, and a discrimination claim is a really stressful thing to do. We think that if you do that process, you'll die.'

Prue had to make an application to the state human rights commission to get access to her records. She found it incredibly difficult to find legal representation and navigate the process. She said the commission didn't seem to care about her discrimination complaint – they just wanted her to settle. She really felt that they just wanted it to go away.

At mediation, the hospital agreed to remove all the alerts off Prue's file.

During this time Prue applied for a credit card so she could access private health care. Specialists continue to treat her for rheumatoid arthritis and bladder retention.

It took more than five years to pay off the debt, but Prue's glad she did it.

'I'm really doing quite well. I feel mentally healthy, happy. It's great. I'm back in work.'

Rajesh and Ahmir

Rajesh, 12, is autistic, non-verbal and has intellectual disability. Ahmir, his dad, is a single parent of three boys and Rajesh's full-time carer.

A few years ago, not long after the NDIS was introduced, Ahmir had a meeting with the NDIS local area coordinator to discuss Rajesh's support needs and funding.

Ahmir had all the relevant information and was well prepared for the meeting.

The coordinator arrived one hour late. By then Rajesh had become increasingly bored and 'was off his tree', running around the waiting area.

Ahmir told the Royal Commission he could smell alcohol on the coordinator's breath. The coordinator did not want to listen to him or review the paperwork. 'He didn't bother. He'd already pre-prepared what the case was.'

The meeting lasted 15 minutes.

Afterwards, the coordinator escorted Ahmir next door to personally introduce him to a service provider. He told him the provider was 'a very nice guy' and he could get 'all the services' from him. Ahmir discovered the coordinator and service provider had been at lunch together prior to the planning meeting.

The initial funding was \$20,000 and was totally inadequate for the supports Rajesh required.

Amir contacted the coordinator asking him to come to his home to see 'the living situation'. The coordinator said there was 'no option for that'.

Ahmir made a complaint to the NDIS about the coordinator's conduct. He discovered 'there is a clear option' for a coordinator to visit the home and 'see the real situation and ... assess the situation'.

The NDIS apologised and increased Rajesh's funding to \$100,000.

However, it was a 'cut and paste' of the previous plan. The additional funding could not be used because it was not allocated to the therapeutic supports Rajesh needed.

A short time later, Ahmir discovered the service provider was fraudulently claiming an online course they'd developed as speech pathology. 'I did not agree with that. This is illegal.'

Ahmir made a complaint to the NDIS Quality and Safeguards Commission.

The service provider was 'not happy about [his] complaints' and he didn't feel they were 'honest people'.

‘I have much time for the NDIS ... It is good for the parents to help with the kids. I appreciate[it]. And there are good people – only one or two bad people.’

Ahmir moved his family interstate to find a new provider and to send Rajesh to a school a friend had recommended.

Rajesh now has an appropriate plan and can access the therapies and supports he needs.

However, Ahmir is under a lot of stress providing support for Rajesh. ‘It’s very hard to look after [Rajesh]. Nobody can take care 24/7 as a single parent.’ He says that his attention is required at all times and it is having an impact on his mental health.

‘What happens to [Rajesh]’s future? Who will look after him? At least if the NDIS can promise me a better service and insurance, then I’ll be out of that stress.’

Patrick and Ophelia

Patrick is in his 20s, autistic and has mild intellectual disability.

‘He’s my pride and joy,’ his mum, Ophelia, told the Royal Commission. ‘Biggest blessing, but we’ve had our challenges.’

Although Patrick could read and write before starting school, Ophelia struggled to find a school willing to take him.

‘We finally managed to enrol him in our local public school ... They made it clear from the beginning they didn’t want him there. They excluded him.’

Ophelia, who was born in Sudan, said one of Patrick’s teachers asked his aide if his family was Muslim.

‘[The aide] said, “No, they’re Catholic. But what’s that got to do with it?” And he said, “Well, we all know what people of that culture and race are like with their boys. Their boys have their parents wrapped around their finger, as this boy does.”’

Kids bullied Patrick at school.

One day, a group of boys pushed him into the toilets, flushed his hat down a toilet, and slammed his arm in a door. When he tried to get away, a teacher saw Patrick kicking. The principal suspended him.

‘I was told that the school doesn’t tolerate violence and kicking. So, it was okay for him to be subjected to violence, but when he was defending himself he was suspended. His words were, “Mum, please let me go back to school. I promise not to kick the boys even when they are putting my head down the toilet.”’

Ophelia transferred Patrick to a private school.

‘He was lonely at school, but the bullying was bearable up until a certain point. But ... the thing that upset me the most is they had no expectation that he could learn, so they didn’t teach him.’

Instead, he was put in a room ‘to waste the day away’.

‘They would tell us that there was a program, but there was nothing. Other than what we taught him, he learned very little at school.’

After leaving school, Patrick became good at public speaking and now speaks at conferences about bullying and autism.

‘If the schools just developed the skills he had, where could he be?’

Reed and Kellen

Reed lives with schizoaffective disorder.

His dad Kellen lives in a caravan and tries to support Reed, who lives nearby.

‘I’ve seen the deterioration in my son’s treatment,’ Kellen told the Royal Commission.

When doctors admitted Reed to hospital with psychosis, Kellen travelled several hours every day to be with his son. Doctors at the hospital had told him they’d let him know what was happening with Reed’s treatment.

Kellen said that one day, when he wasn’t there, Reed was ‘wheeled off against his will, the first of a course of a dozen ECT [electroconvulsive therapy] treatments’.

‘They stopped me from seeing him, you know. I stopped a doctor. I tapped on the window of the door, they took me into a room, [Reed’s] eyes looked crying, they were red. He was the most upset I had seen him dealing with what the doctors [were] putting on him.’

Kellen said he had to do his own research to find out what ECT was.

‘There’s lots of pros and cons, but the thing that concerned me greatly was ... a nurse or something, she said it done him good. That was utterly hogwash. He’s [still hearing] the voices, still through heavy sedations. They just made him speechless and turned him into [a zombie]. He used to have an excellent memory, you know, yeah.’

Kellen said he tried to stop the treatments.

‘I didn’t do a good job ... He got it done anyway.’

Kellen said many patients in hospital mental health units had no-one to speak up for them. He made a point of talking to other patients when he visited Reed.

‘It’s nothing special, it’s just being a sincere friend. But it was special to them, you know?’

Navya

Navya is in her late 60s and lives with a major depressive disorder, an autoimmune disease and a range of other conditions. She injured her lumbar spine working as a clinical nurse in a busy hospital, and subsequent surgeries exacerbated her bowel and bladder issues impacting her physical and mental wellbeing. She is incontinent.

Navya was temporarily placed in an orphanage as a young child and isolated from her sisters. Staff would not call her by her name and punished children for wetting the bed, an issue for Navya who had bladder problems.

Navya told the Royal Commission these experiences led her to believe she is 'nothing and no-one', which has made it difficult for her to assert herself and seek help for her medical conditions. Navya has problems speaking and, while she won scholarships to attend university, she felt unable to choose a career where she had to speak to people, such as the law or psychology.

'I know I can speak for myself ... but it's when I am stressed I become that nobody and no-one, with no name.'

Despite her difficulties with communication, Navya became a nurse, and then a continence nurse specialist. '[My patients] really enjoy seeing me as a clinician to assist them ... they can relate to me very well because I can listen.'

Navya's marriage was marked by sexual, physical and financial abuse. The couple had four children before her husband left.

Her initial attempts to access counselling to discuss the abuse were 'quite horrific'. She lost faith in counsellors after one of them tried to seduce her. She now sees a private psychologist who has helped her greatly.

Navya suffered a perforated bowel while holidaying overseas some years ago. She had a lifesaving operation in Greece but developed extreme pain on her return to Australia.

Navya attended hospital but said she was refused medication, treated like a hypochondriac and told she was a 'waste of space'. Her pain was so great she felt she was about to die, and believes hospital staff would have allowed her to. At no point did they contact her children. Fearing she was going to die, Navya messaged them to say goodbye.

Navya says she doesn't know how to stop this happening again and feels very vulnerable. She feels that vulnerable people should not have to feel afraid of going to the hospital and being seen as time wasters. They should be 'treated politely'.

When Navya was admitted at another hospital for a different illness, medical staff gave her medication she is allergic to, including penicillin. The hospital did not ask her about her allergies and Navya did not know what medications she was taking. Two days passed before her daughter realised and intervened. Navya believes the penicillin may have caused the oedema that developed at the time.

Salwa

Salwa was born in regional NSW in the early 1960s. She told the Royal Commission that she was raised with the attitude that people with disability were ‘faulty humans’.

In her early 40s, Salwa was diagnosed with fibromyalgia syndrome, a condition she describes as an ‘invisible physical disability’. It left her feeling like ‘a faulty human being’.

In the early 2010s, Salwa had a medical procedure that left her feeling exhausted and in deteriorating health. Her GP referred her to a psychiatrist. ‘Within one hour of meeting me, [the psychiatrist] said, “You have post-traumatic stress disorder from your childhood.”’ The psychiatrist didn’t recognise the diagnosis of fibromyalgia.

The psychiatrist prescribed an antipsychotic drug and, when Salwa’s health didn’t improve, added an antidepressant. When her symptoms got worse, the psychiatrist replaced one of the drugs with another medication. This caused Salwa to experience chest pains that, over several days, became so intense she called an ambulance.

Salwa was suffering an allergic reaction to the new medication and symptoms of withdrawal from the previous one.

However, based on the psychiatrist’s advice that Salwa had a history of psychotic depression, the hospital determined that Salwa was suicidal and transferred her to a mental health facility.

Salwa remained in the facility for the next five weeks, detained under a misdiagnosis that became the basis for three involuntary treatments of electroconvulsive therapy (ECT). Salwa believes the ECT changed her brain and has caused irreparable damage.

Salwa told the Royal Commission that staff at the mental health facility pressured her to accept she had a major depressive disorder.

‘They started to try and bully me into accepting a diagnosis of bipolar and then all these other personality disorders. They just kept adding over the weeks, more diagnoses, more medications and more and more.’

Salwa said she has made complaints to the relevant regulatory agencies in her state about her treatment at the facility, with no positive outcome.

‘It’s still going all these years later, and the decision letters are very biased, dishonest, based on my medical records which hold false information.’

Salwa said managing the different complaints processes has been a full-time job. Now the regulatory agencies are telling her they can’t investigate the matter because too much time has passed.

Salwa believes her psychiatrist was 'incompetent and reckless' and failed to understand her as a person with a disability. She says disability needs to be recognised whether it's visible or not.

'Sometimes I would like just a card to carry around with me, to say that I am a person with a disability that I ... don't have to explain my life and my story and my symptoms. This is just what I am.'

Instead, Salwa carries a letter from her GP that explains that she has fibromyalgia. She takes it everywhere with her.

'I feel like I need to protect myself and I think that's wrong that I have to carry this letter in my handbag every time I go out. Even when I take the dog for a walk in the evening, I have my letter with me.'

Marion and Rob

‘What I’ve learnt is having a diagnosis of autism is not the worst thing in the world, and actually, [Rob]’s autism is the last thing I’d probably change of him. I would certainly change ... a lot of people who have been in his life.’

Rob, late teens, is autistic and non-verbal. He has intellectual disability and lives with complex trauma.

Marion, his mother, told the Royal Commission that Rob has a great sense of humour, can be ‘quite jokey’, very playful and is ‘the best judge of character’.

Rob attended early intervention behaviour programs and six different independent and public schools. Almost all of them used restrictive practices.

Marion believes the early intervention programs were financially exploitative and says she spent around \$300,000 believing their ‘big promises’. Rob would fight the restraints. He transformed from a relatively placid child to a child who learned to fight back.

When Rob was five, he was locked in a school toilet for two hours. Staff didn’t contact Marion and, when she arrived to collect Rob, they couldn’t find him. Marion found her son ‘cowering in a corner and crying’, and he continued crying for hours afterwards. He had bumps on his head and he’d been biting his arms so much that he’d torn the skin off. Rob never went back to that school.

‘That was the beginning of his journey, unfortunately, with self-injury, which he still has to this day.’

Next, he went to a state primary school. They called Marion on a daily basis to collect Rob. Marion said the school and education department failed to provide enough support to Rob’s full-time aide, who had a breakdown and took extended leave.

Marion moved Rob to another special needs school. When Rob’s support worker came to collect him, she witnessed several adults restraining him. Rob was so distressed after one incident he was hospitalised for more than 100 days.

While in the hospital Rob refused to wear clothes, would only sleep on the floor and would smear himself with his faeces to keep staff away. Staff had no idea how to deal with him.

The hospital social worker badgered Rob’s parents to relinquish him to the state. ‘[But Rob is] a very loved and valued family member,’ Marion said, and the family ‘stood firm’.

Marion asked the state disability department to give Rob more support, and the hospital paediatrician supported her. But the hospital CEO didn’t, and made ‘inappropriate comments’ about Rob on discharge.

Marion believes the hospital put an alert on Rob's file. Three months later when he was having seizures, hospital doctors refused to conduct any tests, telling Marion to take her son home.

Rob eventually went to a group home run by a service provider, but he is the only resident.

The initial weeks were highly distressing. One of the provider's psychologists instructed staff to wear armoured gear when dealing with Rob. They forced him to get dressed, have a shower, wear nappies and a onesie. One time, Marion saw six adults with shields, helmets and other padded gear surrounding him. Extremely confused, Rob tried to fight them off.

When the CEO heard what was happening he acted immediately.

Rob now has 'some of the best people [Marion] has ever met' supporting him. He refused to leave his bedroom for nine months, but staff were extremely patient and would enter the room quietly and clean him.

Marion says Rob is now in a really 'good place'. He leaves his bedroom and has even ventured into the backyard.

'I just want all the staff to treat him humanely and kindly and act in a trustworthy way, and hopefully with time he will learn to trust people again.'

Roy and Talia

‘If Roy was left in [the child protection department’s] hands, he would be in a residential, in a five-point harness being fed mash. Instead he is walking, talking, contributing and loving life.’

Talia is Roy’s foster mother. Roy is in primary school and has an acquired brain injury and epilepsy. He is also a double amputee.

‘He was in hospital for about 14 months and he came straight to me just before his second birthday, straight from hospital to my care.’

Talia was granted long-term guardianship of Roy a few years ago, after a six-year fight with the child protection department.

‘I was told that [I] was not going to get long-term guardianship ... due to his complex needs,’ Talia told the Royal Commission. ‘And my response to the statement was that complex needs equals disability. Therefore it’s discriminatory to deny [Roy] the long-term stability, security and permanency to which all children have a right, simply because he’s disabled.’

Before she was granted guardianship, Talia said the department ‘consistently neglected [Roy’s] health, education, emotional and physical needs’.

Talia said she struggled, for example, to get the department’s consent for Roy’s childhood vaccinations.

‘There’s still one outstanding consent to this day. The [children’s hospital] just took it upon themselves and went, “No, this is ridiculous. Just going to give it to him.”’

Talia said she spent three years asking the department for a wheelchair for Roy. It never provided one. When the NDIS was rolled out, the department cut Roy’s services and left him unsupported for months.

‘[The department was] cutting off the complex needs allowances to children 12 months before NDIS was in the area, so that was leaving children in limbo.’

The NDIS refused to talk to Talia because she wasn’t Roy’s guardian at the time.

‘When I finally got guardianship of [Roy], his NDIS package ... had been sitting for five months. No-one did anything ... [the department], who was his guardian, didn’t know anything about him, so his first plan was an absolute mess.’

Talia said she had to fight the NDIS for prosthetic legs because the department had identified Roy’s primary impairment as ‘intellectual disability’.

‘They were not going to give him blades, wet legs and articulated legs because of his intellectual disability. He did not need them. Those words weren’t what was said, but that was the impression and implications of what was going on.’

When Talia pushed to become Roy’s guardian, the department resisted.

‘When you find that lawyers don’t want to take on [the department] ... how do children stand up to this? Who advocates for children? ... The point of this is that [the child protection department] is far too powerful, and they just take the law away from children and that is so wrong.’

Talia was eventually granted guardianship, and Roy now lives an active life.

‘He’s a kid that is learning to walk, learning to talk, enjoying life, loves school, loves socialising, loves going to picnics, loves walking in the park, loves talking to people. He wants to sing, he wants to run.’

Angus

‘The way that they get rid of people is not by firing them. They just make things so bad that you’re forced to quit ... They just make the workplace environment so toxic that most people would give up.’

Angus, late 30s, has been working in information technology for almost 20 years and is now in a senior role. ‘I’ve been able to get to that position, but not without a whole lot of side effects ... things like depression, anxiety.’

Four years ago, following an autism diagnosis, Angus began to understand ‘some of the problems [he’d] been having at work’.

‘Once I got the diagnosis, I thought to myself, well, maybe I’ve been going about this the wrong way. Maybe instead of trying to change myself to adapt to the environment, I should be using this diagnosis to try and help adapt my environment to me.’

Angus told the Royal Commission he asked his employer, a retail company, to ‘make a few small adjustments’ in the workplace. He requested regular one-on-one meetings with his manager, more time to complete specific tasks and disability training so staff could understand his disability. But the HR manager refused and ‘scoffed’ at him.

Angus felt the company might take him seriously if he provided more ‘evidence’ of his disability and found someone to advocate for him.

Angus applied for the NDIS but found it difficult to navigate services. ‘[Despite] all these services out there,’ he said, ‘[its] hard to figure out what you need.’ He had to go through ‘dozens of intake processes’ for various therapies and advocates and ‘explain things over and over and over again’.

Angus felt so overwhelmed and distressed he sent out an email saying he was going to ‘jump off a building’. Police arrived and took him to hospital for the night. He had to increase the dosage of his anxiety and depression medications.

Eventually Angus found a disability employment service who assigned him a case worker. After meeting with his employer’s HR manager, the caseworker told Angus, ‘I don’t think they believe you.’ Angus provided updated occupational therapy (OT) reports but the company remained ‘highly resistant’ to providing reasonable adjustments. Instead they commissioned a report from a specialist autism consultancy. The consultant recommended ‘almost the same thing as [the] OT’.

‘If they’d just done those things, I wouldn’t have had to go through any of this.’

Despite the report, the company refused to provide reasonable adjustments.

'I think there's a system in place to actively stop people such as myself from getting our rights, similar to what was happening with underpaying staff. It's an informal system, it's not going to be written down anywhere, but it's a kind of informal construct within the company.'

The company began to warn Angus about his performance and instructed his line manager to performance manage him. 'My line manager has his hands tied and he's told me that.' Angus believes the company is trying to force him to leave rather than engage with him regarding his disability.

Angus refuses to quit and has contacted his union which is providing legal support. He said he's prepared to go to court to 'drag them kicking and screaming into these reasonable adjustments'.

Samuel and Coraline

Samuel is autistic and has moderate intellectual disability. He has expressive and receptive language delays and is 'predominantly non-verbal'.

His mother, Coraline, is a special education teacher. She told the Royal Commission she 'watched his development like a hawk'.

When she enrolled Samuel in a special school for children with disability, the principal promised 'they were more than equipped and experienced to meet his needs'.

'So, I felt quite assured by that.'

But soon, she noticed Samuel 'was so distressed by school'.

'He would hit and hit and scream as soon as he saw his uniform ... he would run away from me. He would take it off me and he would throw it. And it was quite horrible to get him ready every day and send him off like that.'

Samuel loves buses.

'But he'd sit in his seat, and then he'd slide down, screaming, sobbing, and he'd end up on the floor ... It was like he was conflicted by, "I want my bus ride, but I know where the bus is taking me."'

Then came 'the real sign something was wrong'.

'[Samuel] would come home and for three-plus hours he would get on the ground and smash his head against the wall ... And he would just be crying, and he would scream, "What now? What now?"'

The penny dropped for Coraline.

'So, I was just thinking when he cries, someone says, "What now?" and I just thought what a disgusting thing to say to someone crying.'

After watching a *60 Minutes* program, she sent Samuel to school with a hidden voice recorder.

'I ended up just popping it in his pocket.' Coraline and her husband 'sat up all night and listened to the entire six hours of that audio.'

They were 'shocked' at what they heard. Teachers were screaming at Samuel – 'Stop it,' 'Stay there,' 'You're not going anywhere' and 'Get up, you are walking.'

They called him 'a little shit', 'a nightmare' and 'disgusting'. They talked about how 'he is ruining it for everyone else' and 'he's a challenge alright'.

Coraline said she could tell from his screams that his teacher ‘had abused him’.

‘My son does not scream like that. I have never, ever heard him scream like that ... For him that’s, like, incredibly, incredibly distressed. Also, a lot of the language just crosses a boundary. Why you would talk to a child that way ... that’s just beyond me,’ Coraline said.

‘This obviously happened more than once, but I sent him day after day after day. And this is what was happening, but he had no way to tell me. And that just absolutely breaks my heart.’

She said the audio reveals a ‘culture’ of ‘systemic abuse’. ‘There are other people in the background of that audio, and nobody says anything. Nobody alerts a supervisor.’

Coraline finds it ‘devastating’ that her complaints to ‘many agencies and departments who are designed to keep children safe’ got nowhere. Even the ombudsman told her, ‘[You’re] out of luck, because you chose an independent school.’

‘The way the school dealt with it was incredibly upsetting,’ she said. Its excuse was, ‘This staff member may have just been overwhelmed.’

Samuel is now at a public special school and ‘just doing beautifully’. ‘He’s in the right place ... The communication is excellent.’

Caroline describes it as a nurturing environment. ‘[Samuel] likes organising things. He quite likes to put all his peers’ artwork up and line it up and make it beautiful, so ... he’s valued for what he can offer the school community.’

Tate and Thalia

Thalia is a mother of two boys, Tate and Atticus, who are both autistic. Thalia is autistic and lives with post-traumatic stress disorder.

Thalia talked about her sons' experiences in public schooling.

Her eldest son, Tate, attended his school's 'child development program ... for special needs kids'. '[It] seemed wonderful,' Thalia said. 'They helped him a lot.' However, because he was doing well academically, they 'pushed' Tate into mainstream schooling despite his poor social skills.

When Tate entered mainstream schooling, Thalia told the teacher about his difficulty remembering to drink without someone telling him to. The teacher and the special needs unit assured Thalia 'it wouldn't be a problem'. However, it was an ongoing problem. Finally, the head of the special needs unit told Thalia, '[If you are] going to complain ... I'm just going to pour his damn bottle down the sink.'

Thalia and other parents noticed that, at first, the 'special needs teachers ... took every special needs child out and did extra teaching ... every day for an hour or two, and then they would go back into their classroom'. After a month or two, however, 'this suddenly stopped'.

Thalia says that while each student with disability is allocated a certain amount for educational support depending on need, she thinks schools are 'recruiting the kids into the school' by promising support. They provide support 'for the first few months ... or weeks, and then ... it disappears'.

Teachers rarely walk Tate through tasks, wrongly assuming he knows what to do. Teachers tell Thalia that Tate does not need help because he is smart and has good grades. However, he has few social skills and becomes anxious, often freezing up.

'I don't care about the grades ... My son wants to go to university ... how is he supposed to do that when he can't communicate ... because teachers left him in the back row.'

As Thalia was organising Tate's transition to high school, she found out that although he was 'verified' as having disability for supports such as physiotherapy and occupational therapy, he was no longer verified for educational support. Thalia believes it was because the school had stopped keeping records about the assistance they provided to Tate.

When Tate commenced high school, the school provided little support. Other students bullied him, and teachers became annoyed when he sought help. Thalia requested that teachers not ask Tate to do anything that focused attention on him, but they put him in the drama class – despite his request to join the computer and coding class – and told him he had to go on the stage. Tate became anxious and called his mum. When Thalia contacted the school, teachers were angry with Tate for phoning her.

On one occasion, when Atticus was in meltdown, the teacher asked Tate to come and help.

'Now [Atticus] at the age, even though he's four years old, younger than his brother, is literally bigger in size,' said Thalia. "He belt the crap out of his brother, having a meltdown. And his brother, who is very placid, just took it and kept trying to calm him down. "It's okay, [Atticus]. It's okay."

The principal and special education teachers 'watched on and didn't do anything'. Thalia was 'livid'. She made a complaint to the education department, but they seemed unconcerned.

Thalia withdrew Tate and began homeschooling him. She has 'had enough' of the public system and intends to send him to a private school.

Skylar and Brooklynn

‘These organisations ... just know how to work the NDIS system. They know what to say, they know who to butter up ... They’re spending their time just doing all that paperwork to get as much money as they can. They’re not spending the time actually properly managing the care of the individuals in their houses.’

Skylar is in her 40s and has Rett syndrome, which causes a gradual loss of motor skills and language.

Skylar’s sister and legal guardian, Brooklynn, told the Royal Commission that, until a few years ago, their mother cared for Skylar at home. When their mother was dying, Skylar entered supported accommodation run by a church organisation.

‘Overall, [Skylar’s] health deteriorated while she was there,’ Brooklynn said. ‘The staff weren’t actually organising any doctor’s appointments, dental appointments ... she wasn’t receiving any essential medical services the whole time.’

Brooklynn said the home’s support workers were poorly trained.

‘[Skylar] had facial rashes, always untreated ... and she would have food on her clothing, or she would always have dry spittle on her mouth as well and it was evident that had been there for a while because you could see dust was in it. And so her face just looked really dirty.’

Brooklynn said that once, when Skylar was dehydrated, a support worker ‘basically wet her sandwich in water and gave her a soggy sandwich’.

‘And I’m like, “You wouldn’t eat a sandwich like that, so why would you think it’s appropriate for someone who can’t speak, or do anything, to have it?”’

Skylar enjoys swimming, but needs two people to lift her. Brooklynn said that one day a new support worker whose ‘training consisted of buddy shifts’ took Skylar to a public pool.

‘She dropped her in the bathroom onto a cement floor ... In the policies, it was stated that two carers need to take Skylar swimming.’

After the accident, the worker ‘just took her home, put her into bed’.

Brooklynn said the next day a doctor recommended a scan, but it wasn’t done. When Skylar’s father visited two days after the accident, he called an ambulance. A scan showed Skylar had a broken leg.

‘She needed surgery ASAP.’

Skylar spent the next month in hospital before being transferred to a rehabilitation centre where 'they basically wouldn't do anything with her therapy-wise'.

'They were under the opinion from very early on that there is nothing they could do for [Skylar] because she's, you know, not able-bodied and she doesn't have that mental cognition.'

Skylar is supported by the NDIS. While she was in rehabilitation, the NDIS cut her funding, even though she needed more support.

'Because the NDIS planner didn't actually read all of the OT [occupational therapy] reports we sent in, she didn't approve any support for [Skylar's] new care requirements. She said, "No, that's a medical issue if she now needs hoisting because of that accident."'

Brooklyn said she appealed and the NDIS eventually increased Skylar's funding to cover the extra support she needs as a result of the accident. Skylar's father now manages her funding, cares for her at home and employs trained support workers.

'If the government ... care about money and how they're spending it, if they're actually wise about it, they would be making sure they're putting in skilled people to actually make sure things are being done properly, efficiently.'

Marleigh

Marleigh is in her 60s and has an acquired brain injury (ABI).

Marleigh told the Royal Commission a brain scan revealed the ABI after doctors misdiagnosed bipolar disorder and post-traumatic stress disorder.

'The wrong diagnosis caused me great distress and discomfort, especially when dealing with ... the police [and] not being listened to.'

Marleigh used to be a chef and worked in hotel management, 'looking after drunk people, closing bars and dealing with severe behaviour'.

'I saw people struggle, which motivated me. Drunk people have a choice. People with brain injuries don't. And they're wired different.'

Marleigh said it inspired her to become a disability support worker.

'I loved getting out of bed every day because I loved making a difference and impacting lives.'

A service provider employed Marleigh to help people with disability find work.

'I thought to myself, okay, if I can train them, get them job-ready and work with them on where they're happy, where they need to be ... I can match them with employers and I could make sure that employers are educated, [then] everything [would be] right.'

Instead, Marleigh said, she saw 'yet another side of a failing system'.

'Forcing clients into jobs and abuse when they're physically sick and lacking confidence, or ill prepared, was not a solution.'

Marleigh raised her concerns with the service provider.

'I knew [the clients] best and how to work with them. But no, admin always knew better ... I was told to stand down.'

Marleigh said when she raised concerns about the death of a client, the service provider dismissed her. She returned to hospitality. 'Because, you know, I didn't want to set anyone up for failure,' she said.

One night, when Marleigh was working in a kitchen, another employee attacked her.

'He threatened to slit me like a pig and my knife was just, like, on the corner of the bench.'

Although there were witnesses, Marleigh said 'no-one did anything'.

Marleigh felt unsafe and unsupported after the assault, and left Australia to live overseas.

'My choice was to leave my country so I could have freedom, because [I was] being victimised and, you know, just wanting to have a new life.'

Stuart

‘There’s been significant errors in care and inadequate assessment practices. [Hospitals] have also been very reluctant to acknowledge the need for carers to be present or to advocate for someone with a disability and that, I think, puts someone very much at risk.’

Stuart, late 40s, has multiple system atrophy (MSA). His automatic nervous system is progressively shutting down and he has been ‘in and out of palliative care’.

Prior to being diagnosed he worked as a medical professional.

He told the Royal Commission that he has ‘a unique understanding from being a patient and also being someone who advocated for patients’.

Stuart’s disease is complex, incurable and requires treatment from multiple specialists.

Despite having almost no understanding of MSA, hospital emergency staff don’t listen to Stuart and don’t let him see the specialist he needs to see. Although he has a neurodegenerative disease, staff often refuse to let him see a neurologist. The hospital has also blocked his attempts to move hospitals.

Staff often fail to read his medical records correctly and treat him for the wrong disease. He has been ‘triaged multiple times’ for multiple sclerosis.

‘But then you try to escalate it ... it creates a scene, and I don’t like scenes. And I didn’t create a scene until about 25 times.’

After Stuart complained the hospital organised a meeting with ‘every doctor, every person’. They agreed it shouldn’t happen and ‘they all sign off on it’ and put it in his notes. But the next time Stuart arrived in emergency, staff didn’t read the notes.

‘They don’t understand my condition ... I can’t even get triaged correctly. So therefore, I wait for 36 hours when I’m at a different triage level because they don’t want to understand it.’

When Stuart’s temperature reaches 36 degrees he is at serious risk. Hospital staff have refused him admission because 36 degrees is a normal temperature for most people.

Medical staff have inserted medical devices in him without his consent and without proper explanation. At the start of COVID, doctors inserted a different catheter without telling him. ‘This is having major ramifications for me. I’m wetting myself, I can’t sleep, I’m in that much pain.’ Stuart contacted the doctor, telling him it was affecting his MSA. The doctor told him, ‘I don’t have to treat your MSA.’

One time, Stuart's doctor told him he needed to admit him to hospital so a multidisciplinary team could treat him. Stuart's doctor 'lied' to get Stuart to have a mental health assessment. On admission, staff removed all Stuart's medication and locked it away. He was there for four days until the treating team discovered he had a progressive neurological condition. He was released without medication and had to wait to access new prescriptions. At the time he was part of a clinical trial. This had to be aborted because he hadn't taken the medication for a number of days.

When Stuart made a formal complaint, the hospital told him to contact the complaints commission. He discovered there would be a 'three-and-a-half month wait' to investigate his complaint. He went back to the hospital but they refused to listen. 'At the end of it all they don't apologise, they tell me to go shove it.'

'I personally would love to see changes to the way that complaints are managed through health ... You know, transparent communication of outcomes and timeframes for outcomes.'

Tanya and Marc

‘I do not believe there is enough protection for underage people with disabilities.’

Tanya, late 30s, has bipolar disorder. Her son, Marc, is autistic and has a cognitive disability.

Tanya told the Royal Commission that when Marc became a teenager he started to lash out and could be violent. Tanya had a friend called Jo who would often support her and Marc. If Tanya and Marc had an argument, Marc would often go and have ‘a break’ at Jo’s house.

One day Marc had a particularly big ‘breakdown’ and Jo suggested Marc spend the day with her.

Marc didn’t come home.

Tanya contacted Jo but she wouldn’t let her talk to Marc. She told Tanya that Marc didn’t want to come home. He was 16 and legally could do what he wanted.

Tanya rang police who were very understanding but said there was nothing they could do.

Tanya tried to see Marc at school but he wasn’t there. She thinks he is enrolled in a new school, but when she contacted the education department they wouldn’t give her any information and suggested she make an official complaint.

Tanya has since discovered that Jo had been messaging Marc for months ‘behind her back’ encouraging him to move out of home and in with her. Jo helped Marc get his birth certificate so he could open his own bank account and apply to Centrelink for a youth allowance.

Tanya believes Jo was grooming Marc so he would move in with her and she could take control over his finances.

Initially Marc’s NDIS therapists went to Jo’s home to provide supports. However, Jo refused to leave Marc alone with them and they couldn’t continue.

The NDIS support coordinator told Tanya she is ‘deeply, deeply concerned’ for her son. ‘They said he is at risk, he’s in danger, and ... they technically classified him as missing in action.’

It has been several months since Tanya saw or spoke to Marc. She is worried he has Stockholm syndrome and, because of his disability, may not even ‘miss’ her and his siblings or understand what has happened.

Tanya recently contacted the police again for help. They went to Jo's house but Marc was not there. Jo said he was in a rental property and she didn't have to tell police where he was. They have told her she must bring him to a police station so they can check on his welfare.

'Everyone is beside themselves because there's nothing we can do to protect him ... I don't sleep very well any more. I don't function very well any more. I'm dreading the day the police come walking in my door and tell me something bad has happened to him.'

Kailey

Kailey, early 30s, has vision impairment and post-traumatic stress disorder.

'I've had a lot of horror stories ... and have experienced great trauma, and it's through every aspect of my life.'

Kailey told the Royal Commission she's 'suffering still' and 'still not being helped'.

Kailey lives in public housing. The drinking water taps have not been maintained for a number of years.

She wanted to make a complaint but didn't know who to speak to. The only thing she felt she could do was to stop paying rent.

The department of housing threatened to evict her. She said they didn't ask why she was not paying rent or offer her any support.

Kailey couldn't get help to find alternative housing. She says there is a lack of consistency and accountability. She is now paying rent and is allowed to stay in the house.

A few years ago, Kailey had a support worker who wasn't providing the support Kailey needed. Kailey made a complaint to the disability service provider. '[The support worker] told me that I caused her undue distress – I'm the person with a disability!'

The support worker made a complaint against Kailey. 'I was in shock. I thought whoa, where did this come from?' Kailey said the allegations were 'concocted'.

Kailey attempted suicide.

Two years passed with no contact with the support worker, when Kailey accidentally texted them. The support worker applied for a personal protection order against her for harassment. They claimed Kailey lived with mental health conditions and was not taking medication. Kailey said this wasn't true.

Kailey describes the NDIS as 'a bit degrading' because she has to beg and beg for funding. She is not allowed to spend her funding on the things she needs.

Prior to the NDIS rollout, Kailey used to go to bowling. She is not able to do this anymore because NDIS will only reimburse her the bowling fees. Kailey does not have capacity to pay the fees upfront, so she misses out.

Kailey is seeking NDIS funding to undertake employment skills training. The NDIS has so far refused this support, having determined she doesn't have capacity to work.

Xander and Adelina

Adelina is the mother of Xander, who is autistic and has intellectual disability. Xander also has cancer.

'[Xander] had cancer of his lung, he had liver, and I don't know where else at the moment,' Adelina told the Royal Commission. 'But he's still alive. He's doing all right.'

Several years ago, Adelina used an agency to employ a support worker for Xander.

'She was not a registered NDIS provider, but she could provide NDIS services.'

Adelina said the support worker gave Xander amphetamines and may have sexually assaulted him.

'I did a home test, a home drug test when he smashed my house. That was proven a drug ingestion.'

Adelina lodged a complaint with the NDIS Quality and Safeguards Commission, which advised her to speak to the police. Adelina said she was too fearful to make a police statement because the support worker had a friend in the police service.

'But other people started to come forward about her.'

More than a year later, the NDIS banned the support worker for five years.

'When she did appeal – I just found out the result later on from somebody else – that it was reduced to three years. And I nearly fell over, because I just know how dangerous this woman is.'

Adelina said the NDIS should be more transparent about its inquiries, and encourage more people to come forward with complaints.

'A lot of people are too scared to come [forward] ... I know, I talk to parents. They're too frightened. Thinking that they might lose their service ... I said, "If you don't report this, this will continue to happen to other children and this woman will just walk away and be back in the workforce."'

Carmel

Carmel is an experienced social worker and support coordinator working in the disability sector.

She told the Royal Commission about two of her clients and their recent experiences in the health and justice systems.

Nisi is blind and has mild cognitive disability. When Carmel first met her, she was living with a man who was physically, emotionally and sexually abusing her and her daughter. She was 'in a desperate state'.

Carmel tried to help Nisi and her daughter get out of the house and get the police to intervene. But the barriers she faced were 'phenomenal'.

'In Queensland,' Carmel said, 'third-party organisations are unable to put an application in to get a protection order to protect people who have psychological injuries or have a limited capacity.'

Nisi had to apply for a protection order, which took time and was 'difficult'. Carmel found the delay intolerable – Nisi was being 'subjected to violence on a daily basis'.

Carmel believes the Queensland government needs to change the law.

'This is a phenomenon that I still can't understand, and the police have got their hands tied.'

Another client, Fi, had an acquired brain injury (ABI) as a result of falling off a balcony.

Her behaviours were 'quite volatile' and most staff were not sufficiently trained to support her.

Carmel got to know Fi over many months and noticed her behaviours becoming more violent and frequent.

She suspected 'something was wrong' and took Fi to hospital.

Hospital staff wouldn't investigate, telling her that Fi's behaviours were the result of her ABI.

Carmel knew that wasn't the case and requested an MRI. The hospital refused.

'We were begging ... and they put this lady aside.'

Carmel encouraged Fi's family to implement Ryan's Rule – a Queensland law allowing family members to request immediate medical intervention.

'When that was implemented, everyone came down. She had an MRI and it was found that she had atrophy of the brain and, subsequently, she passed away in two weeks.'

‘This is when I found out how the hospital treats people with a disability who have behaviours of concern.’

Carmel feels Fi’s quality of life could have been so much better.

‘They’re excluding any medical intervention – just passing it off, “No, no, that’s just part of [the ABI].” And in this particular case, this woman suffered, really suffered in the end.’

Trace and Darcie

Trace is a teenager living in a regional town. He has intellectual disability, sensory processing disorder and anxiety.

Darcie, his mum, told the Royal Commission she believes Trace has undiagnosed autism, but his school doesn't agree and won't support him.

'We did an autism assessment and my psychologist came back, "Yes, we're looking good," and then the school crushed it and said, "No, this child doesn't have autism."'

'He misses social cues and the rest of it ... The transition into high school has not been a happy one. Trace was failing. Since year 4 he has not liked school ... He doesn't know how to deal with bullies.'

Darcie said other students take Trace's food from his lunchbox to make him chase them. 'He would come home in tears.'

Darcie puts sweet items into Trace's lunchbox because he has an overactive thyroid. The school objects and takes regular photographs of his lunchbox.

'If they have taken the picture in front of his friends, that's food shaming and that's not going to help him because he doesn't already have a great relationship with food.'

Trace often refuses to take medication for chronic constipation. One day Darcie asked the school to help him take his medicine.

'That's when [child services] was called about the amount of medications he was taking. You know, it's kind of like, "It wouldn't hurt you just to help rather than to go ahead and just try prosecuting us."'

Trace refused to go to school so often that the school called the police.

'He had nightmares because he thought that they were going to take him away from me.'

Darcie took Trace out of school.

'If the school won't help me, and the education department won't help me and him attend school and get to the school and get through this pathway, there's really no point.'

Darcie homeschooled Trace and recently enrolled him in TAFE.

‘And, oh my God, half of the behaviours have changed. There’s no teachers growling at him. There’s no teachers yelling at him. There’s no teacher’s assistant sitting next to him, forcing him to do the work and write and read. He is sleeping better. He is eating better.’

Darcie said Trace hopes to do a computer course.

‘His superpower is technology. He used to go in to the school when they were teaching computers. He would be leading the class.’

Darcie fears, though, that because of his intellectual disability, Trace will be ‘forced into a pathway to get [another] job’.

‘He is going to have to, one day, at some point, move to [the city] because there’s nothing here.’

Jair

Jair is in his 30s and has a physical disability. He uses crutches and a mobility scooter and lives with chronic pain.

He is not confident speaking English, and talked to the Royal Commission with the help of an interpreter.

Australia granted Jair refugee status more than five years ago, and doctors diagnosed serious health concerns while he was in offshore immigration detention.

Authorities recently issued Jair a bridging visa. As a condition of the visa, Jair is expected to find a job and support himself.

But Jair says his disability prevents him from working.

'I don't have ... help outside. I don't know how they allowed me like this, and ask me to work and look after. I have medical problem.'

Jair has access to Medicare.

'Whenever I go to hospitals, I meet different doctors. Each doctor said different things. One person told, "You can't be cured". One person asked to take medication. So, they gave different medications time to time ... I'm scared I may get side effects. So, they initially did do some kidney problem side effects. So therefore, I have totally stopped taking medication.'

Jair is unable to access the NDIS. Because he can't work, he relies on community volunteers to help him live.

'I can't get back home also, and I have some food problem with those things. So, they get this visa and just left me, so I can't go home for this visa. For how long I am going to be like this?'

Darryn

Darryn is in his 60s and lives with anxiety and depression. He is a recently-retired disability support worker.

'I actually had a job that I liked with an NDIS provider, and because I complained about some health and safety issues there ... I got the sack,' Darryn told the Royal Commission.

Before the introduction of the NDIS, Darryn ran a hostel that provided accommodation for people with disability.

'The hostel operated on 85 per cent of the pension, and for that 85 per cent of the pension we provided everything, all right?'

Darryn said that since the introduction of the NDIS, more service providers are chasing 'a shitload of money at the end of the rainbow'.

'After having run a private hostel for 12 years on a shoestring, to see how money is poured into getting very little outcome these days is disappointing.'

Darryn says, in his experience, service providers employ poorly-trained staff with inadequate qualifications. He said he recently finished what was supposed to be a year-long certificate course in about two months.

'The problem with the course I did was everybody copied the answers from the board, all right? So, I complained to all sorts of government organisations ... and nobody cared that people have qualifications that are meaningless.'

Darryn said there may be 'hundreds, if not thousands', of people working in the disability and aged care sectors that have qualifications that 'aren't worth the toilet paper they're written on'.

'But nobody cares. Nobody seems to think it's a problem. That to me is a bit sad.'

Alondra

Alondra is in her 40s and lives with post-traumatic stress disorder (PTSD).

‘I developed PTSD, I believe, at around 12,’ Alondra told the Royal Commission. ‘My mother and father split, and basically they had an argumentative relationship, from what I can remember. I was only six when they separated, but my mother went on to become an alcoholic.’

Alondra ran away from home when she was a teenager.

‘I didn’t understand what was going on with me. I formed a very dysfunctional relationship with someone that I wouldn’t even have been friends with, to be honest, at the age of 14. And so by 16, I had my first child.’

While she was in an abusive relationship, the family services department took her children away and placed them with her mother. Alondra said the department gave her little support.

‘I was so confused and abused and hurt, and I had no idea.’

Alondra said department officers blamed her for her circumstances.

‘The psychologist said, “Alondra does very well to convince professionals that she is committed to change,” and, like, to me that looked like they were taking a swipe at my intelligence, because I’m not stupid, but it doesn’t mean that I’m immune to the effects of abuse.’

Alondra said her PTSD should have been obvious to the department, but it remained undiagnosed. The loss of her children made things worse.

‘Re-victimising a victim – I think it is one of the cruellest things you could possibly do.’

Alondra said the department gave her few tools to help herself.

‘When you’re not given the education and the resources to understand, you’re not just going to snap out of trauma, and it is just, like, disabling.’

Now living with chronic PTSD, Alondra is an advocate for families of people, including her son, who are in jail.

‘We need to start focusing on the solutions.’

Sarina

Sarina is in her 50s and has Down syndrome. She's a member of a theatre group. 'I'm just an actor, pretty much.'

Sarina's sister Ellery supported her when she met the Royal Commission.

'[Sarina] is an incredibly gifted dancer and comic,' Ellery told us. 'She has got amazing comic timing.'

Sarina lived at home until a few years ago, when she moved into a unit managed by a service provider. Her mother died recently and her father, who is her guardian, tightly controls her finances.

Ellery said their father's attitude to Sarina's care is that the service provider knows best. As a result, Sarina lives in an 'absolutely restrictive environment'.

'We are nearly the same age and they treat you like a baby, don't they?'

'Yeah,' said Sarina.

For example, Sarina's unit doesn't have a phone, and Sarina's not allowed to have her own mobile phone. She has to borrow a support worker's phone if she wants to call someone.

'I just need to learn the phone thing,' said Sarina.

Sarina used to catch a bus by herself, but her unit isn't close to public transport. Without staff trained to accompany her, she's not allowed to use public transport. Ellery said the service provider has a car, but Sarina's not allowed to go out unless her roommate also needs to go out.

'A number of times she has wanted to do things like go ice-skating and been told no, it is too dangerous,' Ellery told the Royal Commission. 'And there is a whole load of restrictions ... but nobody is taking the time to teach Sarina about money and managing it.' Sarina has to ask permission to use her own money.

Ellery said support workers also force Sarina to go to bed at 9.30 every night.

'Nine-thirty is a ridiculous bedtime for an adult, especially when it is midmovie. And [Sarina] loves watching movies.'

'If I want to stay up watching movies, [I should be] allowed,' said Sarina.

Sarina has an iPad, but no access to the internet in her unit.

'I don't think I've done anything with it yet.'

Ellery said that once, when a support worker was abusive, the service provider told Sarina that only her parents were allowed to discuss complaints.

‘It was a really impossible situation, and there is also a culture where if you complain you are trouble and difficult, and [Sarina] is rightly scared of being [evicted].’

‘And I want my [own] goals,’ said Sarina.

Melvin and Duke

Melvin is in his 20s. He is autistic and lives with epilepsy and post-traumatic stress disorder.

‘He was born prematurely ... and he was about three years of age when he got diagnosed with autism,’ his dad Duke told the Royal Commission. ‘So, my wife became his teacher. She more or less started schooling straight away with [Melvin] once she realised the implications of being diagnosed with autism.’

Duke lives in regional Australia. When he tried to enrol Melvin at the local primary school, the principal wouldn’t let him.

‘The principal basically said to me, “I know it’s the law, but it’s not going to happen on my watch, mate.” And I sort of took that on the chin.’

The family moved to another town so Melvin could go to school.

As Melvin got older, his behaviour deteriorated. Duke struggled to find service providers with appropriately-trained support workers.

‘They basically take people off the street. The next thing they are working with someone with God knows how many different types of disabilities ... I’ve had three or four carers bitten, and now it’s sort of got to the point where the last provider ... pulled the pin because they didn’t want to risk their workers. And I don’t sort of blame them.’

Duke said he decided to hire support workers privately. He found a behavioural specialist who had a criminology qualification.

‘So, under the rules as they were with NDIA – I sort of learnt this over time – anybody with a university degree that the provider decides is related to behaviour can become a behavioural specialist.’

Duke said the specialist spent ‘six months sitting in his office generating little bits of paper’.

‘Now, my support coordinator was looking at it, as was I, and we could not for the life of us see where the value was in \$20,000 worth of work.’

He said the art therapist and speech pathologist were also charging ‘top dollar’, but none of them would go near Melvin.

‘Everybody has taken the money. No-one is doing the work.’

Duke said when Melvin recently bit a support worker, he discovered the worker wasn’t covered by personal accident insurance.

‘Smart cookies that work in the care industry ... can charge at \$63 or \$64 an hour, straight out direct to the client. They don’t even have to have accident insurance which leaves them in a position, legally, where if anything goes wrong, they can sue the householder.’

A couple of years ago, doctors diagnosed Duke with a terminal illness. He’s been trying to arrange care and accommodation so Melvin can live safely after he dies.

‘It’s too easy for everybody to sit back and say, “Well, look, [Melvin] has got all these issues.” You know, where was all the support to try and help him deal with these issues?’ Duke asked the Royal Commission. ‘I really thought a couple of months ago I had finally gotten on top of things, and now I’m back to probably worse than where I started.’

WOULD LIKE TO SEE MY BABY NEICE



Artwork by Phil Coleman

Kathie

‘When I look back, in terms of all the teachers of the Deaf that I had, they were all hearing people. I never had a Deaf teacher of the Deaf.’

Kathie is in her 30s and Deaf.

‘I want to talk about my language access at school growing up,’ Kathie told the Royal Commission. ‘I moved to quite a lot of different schools through my time, and I didn’t have what I’d call perfect language access at all.’

When Kathie was in primary school teachers put her into what was then called a ‘hearing unit’.

‘That’s where it started to occur to me how much information I wasn’t accessing that the rest of the kids were accessing.’

During a sex education talk, for example, Kathie realised the information was being oversimplified.

‘I had read the book ... and I realised for the Deaf kids there was so much simplification of the information. And there were other Deaf kids in the class that were completely confused.’

Kathie said she had to explain to the other kids what the teacher meant.

‘There were a lot of things that they asked that I didn’t know the answer to, so I had to go home, do a little bit more research so I could come back to the class, to my friends, and explain a little bit more. I was 11.’

Kathie said that in high school, she slipped further behind because her interpreter wasn’t fluent in signed English.

‘They’d be constantly way behind where the teacher was up to ... And I’d be getting in more and more trouble for not watching the teacher and the teacher’s aide. And then in the end, the teacher’s aide ended up walking out of the classroom. So that means any kind of access I had was then denied to me. I had no access to language at all. I wasn’t able to ask questions of the teacher. I was left without any kind of access.’

In high school, she struggled to find fluent interpreters.

‘I still had to, you know, kind of dumb it down and go through secondary school trying to match [the interpreter’s] level of language to communicate with them, whereas that should never have happened.’

In her senior years, Kathie was given funding to find her own interpreter, but had ‘no takers’. Instead, she was given a teacher’s aide who ‘was actually learning how to sign’.

Kathie dropped out of high school in her final year.

‘It all came to a terrible crash ... My English teacher was a fabulous person and she was like, “You’re doing such a great job. What are you doing? Why are you quitting?” And I said to her I was just sick of fighting.’

One teacher told her she would ‘never go to uni now’. ‘That’s it. You’ve got no future,’ they said.

Several years later, Kathie did a bridging course to enter university, where she was given better interpreters.

‘Things happened so smoothly from that point ... I had that confidence to vet and scope to get the correct interpreter that I needed,’ Kathie told the Royal Commission.

‘What the key was is that [I], as a student, had the control. I was able to negotiate things with my lecturers, but also with my interpreters.’

Crosby

Crosby is in his 50s and lives with complex trauma.

'My sons have autism and [I] feel that I probably do have that, autism, but it never got properly diagnosed back then,' Crosby told the Royal Commission. 'I think because you acted up or you didn't sort of fit the mould, then you were classified as, you know, being "uncontrollable" or a naughty boy.'

Crosby's parents put him up for adoption after he was born. A large family adopted him.

'My [adoptive] dad wanted a son, but he didn't know how to be a dad. He knew how to provide education and all that sort of stuff, but there was no love, you know, no acceptance.'

Crosby's adoptive father physically abused him.

'If I was eating with my mouth open, he'd clench his fist and he'd go like that to shut my mouth. He used to flog me with a strap. If I did something wrong at night time, when he'd come home from work, and my mother would tell him if I'd done something wrong, he'd start flogging into me while I was sleeping.'

His adoptive mother also beat him.

'She used to kick me so hard up the bottom that I couldn't sit down.'

When he started sleepwalking, he was 'tied in bed with shoelaces'.

'That's how I slept at night.'

Crosby said he had learning difficulties at school, but was 'too scared to do homework because if [he] got it wrong, [he] would cop it'.

Just after starting high school, two men in a car abducted and raped him.

'I was put into that car by that guy and that door slammed and ... I thought, "This is it, this is how I'm going to die" ... And that still triggers me, when I hear a car door shut at night time or someone is walking behind me at night time.'

After being discharged from hospital the next day, the police took him back to the scene.

'They put me in a car by myself. I had no-one go with me as a support, at all. No-one ... There was no follow-up from them after that. Like, zero.'

The men were never found. Crosby said his parents gave him no support. He ran away from home.

‘I was locked up in a juvenile detention centre for being “uncontrollable”.’

After he turned 18, Crosby left home and lived on the street. He found a job, took night classes in maths and English and taught himself financial skills.

‘I reckon I could’ve gone further, but because of that disability, because of all the impacts of the adoption, the sexual assault, the abduction and all that sort of stuff, what happened within the institutions, that’s hindered me, financially as well, being able to achieve the goals that I wanted to achieve.’

Crosby told the Royal Commission he’s done his best ‘not to be a financial burden on society’, but struggles to have his trauma acknowledged.

‘I’ve lost a lot of family and friends over the time because of that, because of the trauma that I’ve been through. Some people think that you should just get on with it, get over it, you know? Forget about it, what’s in the past and all that sort of stuff. I’ve been working for [more than 30] years in the same job. Do you know what I mean? So, it’s not like I’m saying, “Poor me”, type of thing.’

Jan

Jan spent most of his life being abused and bullied because 'he thought so different to other people'.

He told the Royal Commission it wasn't until he was almost 40 and diagnosed with attention deficit hyperactivity disorder (ADHD) he understood his 'ADHD brain' worked differently.

Jan grew up in an abusive environment with a father who despised him and a mother who 'was a compulsive liar'.

When he went to school, the abuse and bullying continued.

'One teacher hit my backside in punishment and another would lock me in the classroom during lunch time because of my behaviour and not completing my school work.'

High school was much worse. The only difference was in addition to the 'teachers ganging up' on him, students would also bully him.

Jan felt the teachers approved and no-one intervened.

'Because you were disliked anyway ... they would turn a blind eye.'

With no-one to turn to, Jan dropped out of school 'after failing ... for a second time in year 11'.

Life didn't improve when Jan started work. He went from job to job, was bullied and 'spoken to in ways that grew [his] depression and anxiety'.

'I drank right through my 20s to escape the world of being disliked, bullied and the constant loss of jobs.'

Jan's relationships with friends and girlfriends also suffered.

He was aware he thought differently but felt he was smart and couldn't work out why he 'couldn't stay in relationships or jobs'.

Then last year his partner overheard a conversation at work about a person with similar traits to Jan. He 'read up on this condition called ADHD' and felt it explained 'why I was the way I was'.

Jan booked an appointment with a specialist and was diagnosed with ADHD. He started taking Ritalin.

'From that moment I thought my life would change and it did.'

But not in the positive way Jan expected.

'I went from the prison that my ADHD brain had created for me to the ADHD community where you are told that you are not worthy of treatments by professional doctors, not covered by the NDIS, which means no access to the disability job employment agency which means no support in the workforce.'

Jan wants ADHD to be recognised as a disability and for people with ADHD to be eligible for NDIS support.

'This is a disability ... that needs a strong voice and I will be that voice until we are heard and change is made in Australia.'

Yash

Yash arrived in Australia in the early 2010s on a student visa. Five years later he applied for a protection visa.

While waiting for his application to be processed, he lost his working rights. This left him 'living hand to mouth and homeless for the best part of that period'.

During this time, Yash was seriously injured outside a pub during an altercation. He was airlifted to a city hospital and went straight to surgery.

'This was the beginning of my woes,' he told the Royal Commission.

Not only was Yash facing possible deportation back to his home country, 'which is well known for its mistreatment of people with disabilities,' but the hospital discovered he didn't have Medicare or private health insurance.

Yash couldn't afford a wheelchair or rehabilitation and 'received little to no care from physiotherapists or occupational therapists'.

Without a wheelchair Yash developed health complications. He lay in bed for six weeks with no rehabilitation, so his chances of regaining motor and neurological functions were limited.

Fortunately, a hospital social worker managed to get Yash 'work rights' and Medicare. This enabled him to be transferred to the rehabilitation ward.

But by then Yash had 'racked up a \$115,000 hospital bill'.

Being on a bridging visa, Yash was unable to access any form of government support or community based funding programs. Without funding the hospital couldn't source a customised wheelchair suited to Yash's needs.

'This left me in limbo for a while until they managed to "Frankenstein" a wheelchair from the older parts of wheelchairs they had lying around.'

Once Yash was discharged, without any income or funding, he 'had to do without carers, nurses or support workers'. He also had to source his own consumables, such as medications, enemas, incontinence pads and catheters.

Yash now has a working visa he says it is impossible to find a job.

'All they see is the disability and the wheelchair, not so much me the person sitting in the wheelchair.'

The hospital recently contacted Yash and asked him to return the wheelchair because the loan had expired.

‘The stress and pressure as well as the toll that this had on me in the middle of a pandemic is just unexplainable.’

Yash would like funding to be available to all people with disability regardless of the type of visa they hold. Funding should cover equipment, consumables and support workers.

‘People with disabilities that are from culturally and linguistically diverse backgrounds should not have to suffer by not receiving adequate support that they require due to their visa or immigration status.’

Braxton and Nell

Braxton's mum, Nell, told the Royal Commission that Braxton is traumatised by the bullying, abuse and neglect he experienced at school in the late 1990s. Braxton is autistic.

Braxton's first school was a regional mainstream primary school. He had trouble socialising and completing tasks, and would wander around the classroom unsure what to do.

The teacher told Nell that Braxton was a distraction. She moved his desk to the back far corner of the classroom and faced it towards the window, away from the rest of the class.

In year 3, frustrated by school's inability to teach or support Braxton, Nell moved him to a school with a special education unit.

'What followed in the beginning was a gradual transformation in his abilities, with the introduction of one-on-one support in the special education room. For the first time he began to learn letters, read for the very first time, he also began to write and spell words including understand the basics of math.'

However halfway through year 4, the headmaster told Nell there wasn't enough room in the special education class.

Braxton moved to a mainstream class and experienced constant physical and verbal bullying. He hated going to school and Nell couldn't get the school to do anything. It was a very difficult time for them.

One day two students attacked Braxton while he was waiting inside the school grounds. They bashed him with his school bag and whipped him on his back and legs with an electrical cord. When he got home his sister had to scoop handfuls of water down his back to remove his shirt which was stuck to his back with dried blood.

Nell went to the police. They told her to talk to the school.

'The two boys were eventually made to apologise to [Braxton], and I was informed that their fathers were to "deal" with them which involved them both missing cricket practice and a game as this was hard for them as they loved cricket.'

When Braxton eventually returned to school he was frightened and anxious.

'He refused to leave the house to go to the shops, the local pool ... the park or any public place for fear of seeing these bullies or any children.'

Nell moved him to a private school but the bullying continued. Eventually she moved him to the same school as his sister.

The new school was supportive, but Braxton was traumatised. He washed his hands constantly and couldn't tolerate his uniform or school bag touching anything. He spent large amounts of time hugging the goalposts on the oval. The only person who could persuade him to let go was his sister.

Boys invited Braxton to play soccer but all he could do was hug the goalposts.

'[Braxton] could not distinguish the difference between the genuine invites these boys now offered and the previous traumatic ones ... the invites eventually stopped.'

Nell encouraged Braxton to attend counselling and they visited a psychiatrist together, but he couldn't talk about what happened to him.

Braxton refused to go to school and Nell paid for private tuition hoping he would return.

He completed year 10 at home but has been unable to attend any further education.

'He just could not bring himself to attend school anymore and I couldn't bring myself to force him.'

Braxton recently suffered a major breakdown. Nell said he was crying remembering the bullying and lack of supports.

'They didn't teach me anything. I was never taught anything,' he said.

Nell says Braxton is a 'bright, highly intelligent adult individual'.

'[He] could have had the opportunity to succeed with his disability diagnosis of autism to achieve a bright future for himself had the circumstances been different.'

Grayson

Grayson lives with a genetic disorder that affects his physical and mental health. He has congenital heart disease, a compromised immune system, a speech impediment, borderline personality disorder and insomnia. He is autistic and hearing impaired.

‘Despite all my health conditions I have been living independently in my own apartment for the past seven years, collecting my Centrelink pension, paying my bills, buying food, managing my personal hygiene as best I can.’

But Grayson told the Royal Commission he experiences regular abuse by the professionals who are supposed to help him.

He doesn’t know ‘the correct channels’ to get medical assistance, so often ends up at the emergency department of the local hospital.

There, he says, he is bullied and harassed by the doctors and nurses. He has been left in the waiting room without seeing a doctor. Medical staff have accused him of abusing substances and often call security to remove him from the hospital.

Mostly this happens because he is ‘treated as a mental patient’ and his physical health symptoms are ignored.

Grayson has also been overmedicated by hospital staff and psychiatrists. He has been accused of hearing voices and being a danger to others when he’s not.

‘I was forced to take antipsychotic medication against my will by doctors and family because of the diagnosis of schizophrenia for years, which turned out to be a false ... Hospital staff have called the police ... held me down then force injected me ... using chemical restraint against my will.’

Grayson says diagnostic overshadowing has had terrible repercussions on his health.

Cuts on his skin have been left untreated, become infected and triggered psoriasis. Doctors ignored swelling in his feet until Grayson could no longer walk. When he contracted cellulitis he was sent home with oral tablets instead of being put on intravenous antibiotics. Grayson said he ‘survived against the odds’.

‘Recently I lost the ability to walk and went to hospital to get help.’

Grayson had X-rays, but doctors still told him it was all in his head and he was ‘choosing not to walk’.

‘They ... forced me to go home even though I couldn’t walk ... I was forced to crawl outside and get into a taxi.’

It wasn't until Grayson's mother requested his medical records they discovered he had a 'bulging disks' in his back preventing him from walking.

'People with disabilities and/or mental health conditions should have equal access to health care,' Grayson said.

Ryann

Ryann is a First Nations woman who is employed as a support worker at a group home.

She told the Royal Commission one of the other support workers, Karine, is racist and bullies staff and residents.

On one occasion, Karine was overheard making racist comments to a person 'about her aboriginality'.

Staff complained to the manager but he did nothing.

The manager is Karine's nephew and Karine 'just does whatever she wants to do with no repercussions'.

For example, Karine changes the roster whenever she feels like it and she 'rarely turns up on time'. Karine won't do the residents' washing and instead does her own washing onsite. On night shifts, Karine will sleep on the couch. Staff and residents know not to disturb her.

'One resident won't even go outside for a smoke through the night.'

Ryann said some staff will take a stand but others don't feel they can.

'This is a huge conflict of interest – having a family member manage another family member.'

Ryann said the group home 'is a very toxic environment'. Karine's behaviour permits other staff members to behave badly.

'[One worker] spat in a [resident]'s meal ... because she doesn't like them and then thinks it's funny.'

The same person yells and screams at residents, and when she's not yelling ignores them – sitting in the office with the door shut.

Ryann told us she has made a complaint to her union and the NDIS Quality and Safeguards Commission.

'Something has to be done. This is dangerous for people's wellbeing and mental health. People are scared to talk to anyone for fear of reprisal and if you think this won't happen then you are all mistakenly wrong.'

Drew

Drew lives with psychosocial disability and experiences depression.

Drew told the Royal Commission there is systemic homophobia in the mental health system and, as a lesbian and someone who uses gender-neutral pronouns, they often feel judged.

Each encounter has made them feel 'stressed and anxious especially when attending clinics'. Many of Drew's friends feel the same way.

Drew has similar feelings about the police.

One time Drew's neighbours broke into Drew's home and poisoned the plants. But the neighbours told police Drew chased them with a knife.

'Since I am lesbian, I believe that my neighbours have used my "butch" appearance to paint me as the aggressor.'

The police charged Drew, who had no criminal history, with attempted murder. The case was 'thrown out of court'.

Another time Drew was seriously assaulted. When they reported it, the police didn't believe them and assumed they did it to themselves.

Drew has also been raped.

'I reported it to the police who said I was delusional and didn't even do a rape test.'

Recently somebody vandalised Drew's car. The tyres had been slashed, the mirrors and lights smashed and the exhaust removed.

Drew believes it was the neighbours and contacted the police. But the police told Drew they would only talk to the neighbours if Drew leaves the neighbours alone.

'I've not done anything to them or anybody.'

When the neighbours complain, however, the police seem to take the complaints very seriously.

One morning five police officers showed up at Drew's house because the neighbour had complained about Drew playing an instrument at 5.30 am. They disregarded Drew's denials, telling them to 'lay off the weed'.

Chloe

‘We desperately need to see changes from the bottom up to make sure no-one else slips through those cracks like I did.’

Chloe was diagnosed with attention deficit hyperactivity disorder (ADHD) in her early 40s. She told the Royal Commission that up to that point she spent her life ‘feeling confused and alone and being criticised and judged’.

Chloe shared her story with the Royal Commission because she wants teachers and doctors better trained to recognise ADHD.

‘I am an ADHD success story, but my success is only due to my own commitment to continue searching for help through a flawed system that disregarded my repeated attempts to find out why I struggled in many areas of my life, and why I felt and acted differently to others since childhood.’

After her diagnosis in adulthood, Chloe read through her old school reports and remembered the comments of her teachers.

“‘Try harder!’ [they said.] Stop twirling my hair. Stop kicking the leg of the table. Stop doodling when the teacher is talking. All these things allowed me to concentrate better, but no-one believed me. “Just sit still,” [they said] because I was distracting the other students ... “Stop asking so many questions.”

Chloe’s school days were ‘filled with angst, low self-esteem and having to work much harder to learn’. She felt ‘ashamed and embarrassed’.

At 15, Chloe’s parents thought she would never be able to go to university and suggested she leave school. She asked her teacher for a reference to help her get a job.

‘He scoffed and said the most humiliating, hurtful and harmful words ever spoken to me in front of my classmates; “Don’t waste my time or yours. You won’t get it ... You’re not good enough.”

Chloe left school and eventually ran her own business. At 40, she went to university to study psychology, and it was during her study that she was told she had ADHD. The diagnosis explained a lot.

‘I had an exercise addiction that wreaked havoc on my body physically and mentally and put pressure on my family relationships. I have suffered burnout and mental health issues ... [I would later learn] that women with ADHD are four times more likely to suffer with an eating disorder, and my exercise addiction, struggles with executive dysfunction, inability to start or complete some of the simplest tasks, my struggles with maths and other subjects are all due to ADHD.’

Chloe's two children have since been diagnosed with ADHD. Because Chloe and her son were both diagnosed after turning 19, the Pharmaceutical Benefits Scheme does not cover the cost of their medication.

'Yet we have all had this condition since birth. How is that fair?'

Chloe said there is still little recognition of ADHD in adults.

'Even after being diagnosed by a psychiatrist I had local GPs question the diagnosis, scold me for taking stimulant medication and question and treat me differently to what I had been treated before. Instead of understanding I was met with harsh judgement and criticism.'

Chloe's hope for the future is 'a society that doesn't stigmatise neurodiversity, but accepts its unique differences'.

Andrei

‘My injury does not mean I am “empty”. I have a wealth of knowledge, experience and acquired abilities by which I can still contribute to society.’

Andrei was in his late 50s when he sustained a traumatic brain injury and spent several months in hospital followed by extensive rehabilitation.

‘My traumatic brain injury left me with limitations to my vision and deprived me of short-term memory,’ Andrei told the Royal Commission.

Prior to the injury Andrei worked in several different sectors – as a tradesperson in a physically demanding role, and in a university. He also performed as a musician at international events.

‘I had at least a “normal” level of knowledge, intelligence and ability, along with good communication skills,’ he said.

In the 10 years since the accident, Andrei has experienced abuse and discrimination because of his disability.

‘There are some basic things in post-injury life which I am unable to do normally. This has caused others to engage in castigation and discriminatory actions based purely on their presumptions.’

Andrei has limited short-term memory.

‘I often ask someone a question and then repeat the question minutes and [sometimes] hours later because I cannot remember their reply.’

He said he is ‘told off’ with comments such as, ‘You are always asking me that’.

If someone asks Andrei to do something on a Tuesday, he doesn’t know when they mean. He can’t remember days of the week and has to ask more questions to work out when Tuesday is. People often reply ‘What? Don’t you even know what day it is?’

Andrei was a regular member of a hobby club and continued to attend after his brain injury. However he couldn’t remember faces or names from week to week. If he asked someone their name they said, ‘You know me. What’s wrong with you, we worked together for two hours ... last week’.

These incidents have affected Andrei’s self-esteem and he said he often has to find the courage to ask questions, knowing the person will belittle him.

‘I am still very capable of thinking and reasoning. Because I cannot remember a particular fact does not mean that I never need to use that specific fact. I simply do not have it available in my memory when I need it.’

Andrei believes sensitivity training should be taught in primary schools and beyond. Sensitivity training would teach everyone to carefully consider a situation and put themselves in the other person's place before they respond.

'By creating and promulgating a new paradigm of sensitivity we can actively reduce discrimination and do this without spending vast sums of money.'

Jonathan

Jonathan has hemiplegia, which is ‘one sided cerebral palsy’. The impacts of it vary from day to day, but generally it effects his ability to walk, causes medium to severe pain from the neck down on one side of his body, toileting issues and stomach problems. He requires frequent professional massages and physiotherapy appointments.

Recently, an NDIS physiotherapist suggested leg casts would help improve Jonathan’s spasticity (a condition in which muscles stiffen or tighten, preventing normal fluid movement).

Jonathan explained that after the cast is removed, ‘the foot’s movement ability is tested by pushing the foot in a variety of ways’. The physiotherapist records the measurements and the progress.

‘The last time the plaster cast came off, I was very sore ... the two physios pushed and prodded my foot to get the measurements they wanted, which was very painful,’ Jonathan told the Royal Commission.

By the time he got to the car he could barely walk. He rang the NDIS physiotherapist who ‘seemed to think there was no issue’.

The pain was so bad Jonathan visited his regular physiotherapist who he’d been seeing for more than 10 years. There was nerve damage to the foot, most likely caused by the NDIS physiotherapists ‘prodding and pushing for their own measurements’.

At the next appointment with the NDIS physiotherapists, Jonathan was going to challenge them but lost his nerve.

One reason Jonathan was reluctant to say anything is because ‘there aren’t many places for people with cerebral palsy to go’.

‘When I mentioned it to one of my disabled friends, he was shocked for me and very supportive. He and his wife encouraged me to not go to the provider anymore.’

Jonathan is not interested in doctors and physiotherapists taking measurements so they can evaluate how close he is to the ‘norm’. He needs them to act in his best interests.

‘I have cerebral palsy, and I’m not going to stop having it. Medical professionals need to stop trying to “fix” us. Instead, they should have an open dialogue with us to help us achieve our goals, not their goals.’

‘I have been pitied and stared at for having a disability, and judged for getting NDIS funding as I’m sure others have. I wish none of this on the next generations with disability.’

Bram

Bram is in his late 20s and is autistic. He describes himself as 'high functioning' and says he has worked hard to learn to control his sensory issues and anxiety and to 'use the benefits' of his disability.

Nonetheless, Bram told the Royal Commission, he still faces 'a lot of discrimination'.

'At school I was not allowed to be part of many events that all other students were allowed to go to! I was not allowed to go to sporting events even though I was one of the fittest students!

'I was not allowed to go on school trips, I was punished before I was spoken to! I was not told why I was being punished. Like many kids with autism, other students made a game of getting me punished!'

This discrimination continued when Bram went on to university, where 'staff refused to teach or help' him.

'One staff refused to communicate with me after I told her of my disability,' he told us.

'Because I have a disability I have to constantly jump through issues that other people do not and have to do more work because of systems and bureaucracy, yet I often am not provided with the essential help I need for the few issues I have not overcome! ... I spent over 1000 hours trying to get basic levels of help and proof that the university was willing to provide a service that would allow me to continue at university.'

Discrimination has also impacted Bram's ability to work.

'I have not been given the same level of opportunities in working in fast food outlets as others who are less qualified and not as hard working or reliable or even as able to do the job ... I was yelled at and insulted by managers because of my disability.'

Bram says he has not been given the same levels of training or learning opportunities as 'neurotypical people'.

'So many people with a label of a disability can be working in high paying jobs but are not provided the education to get the careers. The discrimination of people with a disability is holding back not just the people with a disability but our whole country.'

Arron and Philippa

After an incident at school, the principal told 13-year-old Arron he wanted to expel him because 'he was worried about the public image of the school'.

Instead he suspended Arron – who is autistic and has attention deficit hyperactivity disorder – for five days.

Arron's mum, Philippa, told the Royal Commission her son 'was confused, didn't understand, and had nothing explained to him in a way that he would understand'.

Philippa was baffled by the decision to suspend Arron because in the past the school had worked with the family 'using communication and appropriate consequences'.

Prior to the suspension Arron was on a modified timetable. He would spend the mornings one-on-one with an education support officer, followed by a few lessons in the mainstream classroom. In the afternoon he would spend time in the special education unit. Philippa said this had been working well.

Additionally, Philippa engaged a behaviour support specialist to develop a behaviour management plan. Arron started taking medication which 'helped immensely with his behaviours'.

But since returning from the suspension, Arron 'has been separated from his peers, with different recess and lunch times and put in the flexible learning unit on his own'.

Philippa said this 'massive change to routine' has increased Arron's anxiety and is affecting his mental health. He has regressed academically and his behaviours have escalated.

'It seems the school has gone from working with us, to just suddenly placing unrealistic demands on [Arron], saying he is bright enough and old enough to know better. It feels like they expect us to flick a switch and all the behaviours and challenges associated with his lifelong disabilities will disappear.'

The school did not communicate the changes to Arron 'in an autism friendly manner'. They told him 'all the students and teachers are scared of him'.

As a result Arron 'feels devalued, worthless'. He has expressed suicidal thoughts.

Philippa doesn't believe separating Arron from his peers is the solution.

'All children need friends,' she says.

Philippa made numerous complaints to the school to no avail.

She says the school has stereotyped her son as 'violent and dangerous' and told her 'he will not cope when he gets older and will end up in jail'.

'I know my son has many positives and strengths, he is brilliant with computers, and always compassionate and helpful with the other special needs kids.'

Philippa believes staff and students need better education about autism and how to accommodate people with autism in the classroom.

She says the unrealistic expectations and demands on children and their families 'to fit in and be perfect' needs to stop.

'[The school's attitude] has broken us and placed enormous stress of the family unit.'

Isadora

Isadora has epilepsy and, when she was 17, her mother put her in a nursing home.

Isadora is now in her early 30s. One day, after waking up with what felt like flu, she went to a doctor who gave her cough syrup and cold and flu tablets and told her to rest.

‘Because I am an epileptic, that night I had a seizure and fell out of bed and was on the floor with vomit all over me until morning, when my best friend found me unconscious in my room.’

Her friend called an ambulance and Isadora was admitted to hospital with bacterial pneumonia so severe she was placed in an induced coma for 10 days.

While in the coma, Isadora had a stroke that left her unable to move her right arm or leg, speak or open her right eye.

Isadora survived but now uses a wheelchair and wears a helmet for seizures. She told the Royal Commission she blames her current situation on lack of appropriate care.

‘What happened to me made me really angry because doctors are supposed to check you everywhere and be thorough and if my doctor had done that then she wouldn’t have missed the pneumonia. Also the carers neglected me by not checking on me enough. They usually checked on me during the night because of my seizures, but this night they didn’t.’

Isadora now has full-time support workers.

‘Please do not put your disabled children in some care home, cause if you have listened to my story you will understand why.’

Brady and Elsa

‘Even after finally revealing to my family about the long history of abuse, none of them talked about reporting it or confronting my ex-husband.’

Elsa told the Royal Commission her ex-husband abused her and their son Brady for more than a decade.

Brady is in his mid-20s and has physical and mild cognitive disabilities and significant communication difficulties.

Elsa said she feels ashamed and disgusted she didn’t do more to protect Brady. If her ex-husband had treated any of the other children the way he treated Brady she would have done more.

‘I somehow justified it, that looking after my son could be stressful and frustrating, maybe he didn’t mean to be rough, maybe my son did something to trigger it.’

It was only after leaving the relationship Elsa realised her ex-husband’s actions were calculated and deliberate.

‘And for that I really struggle to forgive myself that I didn’t have him charged.’

She said there were many factors that enabled the abuse to continue for so long. The lack of support – emotional, financial and physical – while not an excuse, was a contributor.

Elsa tried to leave the marriage many times – one time after her husband threatened to kill her. She had no money and knew it would be difficult financially. A social worker found her and the children, who were all under 10 at the time, somewhere to live. But Elsa couldn’t find work and discovered she wasn’t eligible for any home help.

After six weeks, she returned to her husband.

‘I couldn’t do it on my own,’ she said.

Another time, after ‘a particular scary incident of abuse’, she went to the police station to get an apprehended violence order (AVO).

Elsa said there was no privacy at the station – the police officer interviewed her over the counter in reception. The officer told her if she lodged a request for an AVO her husband would be charged and jailed. She asked if that was what Elsa really wanted.

‘Due to my husband’s mental health issues, I didn’t think him being jailed would be the best thing for any of us ... I asked if there was any other option. She said no. So I left the police station with nothing and returned home.’

When Elsa was finally able to leave her husband, most of her children were adults.

‘Although there are very clear guidelines about child support from divorced parents, there is nothing regulated about having to support an adult child with a disability,’ said Elsa.

Her husband is on a large salary and she is on a low salary and she has no legal recourse for financial support for Brady.

‘My lawyers chose not to mention the history of abuse in the settlement proceedings because they said it could prove that my husband doesn’t have a relationship with my son, so wouldn’t have to pay any ongoing support.’

Brady’s father has agreed to short-term limited support but can stop at any time.

Brady is now living in supported independent living accommodation. He is easily triggered and can get very distressed. Elsa has been able to find excellent counselling support for herself but has had difficulty finding someone to support Brady.

‘I’ve struggled to find a counsellor experienced in supporting people with a mixture of physical and some cognitive disability plus very significant communication difficulties.’

Elsa also remains concerned about her ex-husband visiting Brady and doesn’t believe the appropriate safety supports are in place. Her ex-husband has denied the abuse and Elsa has seen reports that have been changed to him ‘accidentally doing something’ to Brady.

‘I hope one day, attitudes and supports will change so domestic violence and abuse of people with a disability will be considered as serious as all domestic violence and abuse – no excuses or mitigating circumstances used to reduce the severity of the crime. And I hope in future people with disabilities who have experienced trauma will have the same access to appropriate, well trained support as everyone else.’

Elsa also wants financial support for carers, ‘something that makes it financially viable to leave an abusive relationship’.

Genevieve

Genevieve has multiple sclerosis (MS) and lupus. When she fell behind on her rent a year or so ago, she was evicted from her home.

'[The police] broke the door down and I was laying half naked on the floor having mini-seizures,' Genevieve told the Royal Commission.

When the seizures ended, Genevieve made her way to the toilet, which 'takes a while due to MS'.

'Thereafter I was getting dressed and was dragged out of the bathroom to put my underwear on in front of male police officers where they dressed me ... I was humiliated, by my disease and by everyone.'

Genevieve said that when this was happening she was 'heightened' by her 'previous complex PTSD which is triggered by the police'.

The police took her to hospital where she was involuntarily scheduled to a mental health unit for 28 days, something that Genevieve said could have been avoided if the police had a better understanding of her disabilities.

'MS is an invisible illness and one doesn't look sick, it is an immense illness ... There should be a police education program ... I shouldn't have been displaced from my home at all.'

During her 28 days in hospital, Genevieve arranged to have her belongings stored in a shipping container. When she was released from hospital, she found that the real estate agent who managed her former home had thrown some of her belongings away.

'All my items are determined abandoned goods and the real estate threw my valuable books and items from the house in a skip and deliberately took it away. I cannot replace my belongings.'

Genevieve is now homeless.

'The police gave me a T-shirt and didn't offer accommodation, they expected me to live in the car.'

Cate

Two years ago Cate had a heart attack and sustained a brain aneurism as a result of domestic abuse.

She was on life support for a number of days and in hospital for a month.

Cate told the Royal Commission she now has physical and cognitive disabilities.

'I have memory problems. I don't feel like myself which personally sucks quite a lot! Since my bleeding to my brain I've lost my spark.'

While Cate was in hospital her mother-in-law took custody of her children.

'So while I had to deal with learning to walk etc I had to deal with not having the care of my girls. So basically just getting my motherhood taken off me ... that's how I feel.'

Cate said she's 'been a complete mess – lost and confused'. She started taking illegal drugs.

'I didn't know how to deal with my emotions.'

Cate first experienced mental, physical and sexual abuse when she was a child. This caused her to neglect herself when she was a teenager.

If people haven't had a traumatic childhood, Cate said, they can be judgemental.

'Some people can't seem to understand about being abused, sexually and mentally also physically, or even having a disability or being neglected in their life.'

Sometimes she feels like giving up, but she doesn't.

'Life is way too beautiful to give up as I've learned now due to having a near death experience twice.'

Frederick and Jeremiah

In the first week of his first year at primary school, Frederick was assaulted so badly by another student that he was concussed and later diagnosed with post-traumatic stress disorder.

Frederick has speech apraxia, which makes it difficult for him to speak, and hip dysplasia, which can make it painful for him to sit. He also has some incontinence. His father, Jeremiah, told the Royal Commission that Frederick's public school and the education department failed to provide adequate support for his son's disabilities.

After the assault, Jeremiah asked the school to provide a safety plan for Frederick and to move him to another class.

'The school failed to facilitate these basic requests. During this time, [Frederick] was unable to attend school as he was frightened.'

Frederick was moved to another class only after two formal complaints to the education department.

'We should not have had to make such a threat, and the fact that we had to do so is extremely stressful,' said Jeremiah.

'In response, the school placed us on communications restrictions. They adopted a hostile position, and criticised me on numerous occasions. Unfortunately, this severely damaged the relationship between us and the school.'

Jeremiah said the school initially would not let Frederick use its separate special toilet, despite the recommendations in his hospital continence plan. The school allowed access to the special toilet more than six months later, after Jeremiah made two complaints.

Frederick's painful hip dysplasia prevented him from sitting cross-legged on the floor with his peers. Jeremiah asked for a special stool for his son to sit on.

'No action was taken. We made a follow up request months later. The school then required us to obtain medical recommendations before they would take action. We obtained the medical recommendations and submitted them to the school. Still, after all this and at our own expense, the school has failed to implement this reasonable adjustment.'

After Jeremiah told the school it was failing in its duty of care for Frederick, it responded by placing Frederick on a behavioural management plan.

'We viewed this unequivocally as a means of deflecting attention away from their failure to provide him the support he needed and meet their duty of care,' said Jeremiah.

The school also told Jeremiah his family's contact with the school would be restricted to 'a meeting once per term' and emails for non-urgent issues.

'Parents such as ourselves should not have to endlessly advocate and then suffer victimisation to try and protect the welfare of a child ... To have such stringent restrictions placed on our ability to communicate with the school is incredibly disconcerting.'

School staff told Jeremiah the education department's strict funding criteria meant that Frederick was not eligible for some of the support he needed.

He said he would like schools to receive the funding necessary to support all children with disability.

Newton and Lada

‘Please take the profit motive out of care for the disabled. We are all responsible to ensure that our fellow citizens have a life style which meets minimum standards. This is why we pay taxes.’

Lada is the adoptive mother of Newton, an adult with disability.

Lada told the Royal Commission that the transition from state-run disability services to the NDIS has been ‘a disaster’, with a deterioration in the quality of support services provided to her son.

She said that since Newton moved into NDIS-approved private accommodation, he has been exploited financially and staff have a mindset of ‘if I can’t see it, it’s not happening’.

‘My son is now served by undertrained staff who are left to manage difficult behaviours from four residents. Their response is frequently to call police or lock themselves in the office. Behaviour management skills are totally missing.’

Newton was first placed in state care in his mid-teens due to ongoing issues of domestic violence at home. By 21, Newton was living on the streets, using alcohol and illicit drugs and exhibiting dangerous behaviours.

Newton was appointed a case manager through the state health department. Lada said the case manager was incredibly supportive and found Newton accommodation in a supervised campus.

‘She supported us immeasurably and got to know my son well and the options open to us were always appropriate. I am indebted to her skill and commitment.’

‘The changeover to NDIS has never been of the same quality of service,’ Lada told us.

During the phase-out period from the state service, Lada had been advised to contract a private case manager. Their role was to take Newton to accommodation services and investigate their availability and suitability.

‘[The case manager] sent me a bill for \$2000 and the [health] worker and I subsequently discovered that my son had not been taken anywhere. I complained to the disability commissioner but they had no jurisdiction.’

Lada didn’t pay the bill and never heard from the case manager again.

Newton eventually moved into a supervised campus managed by a private provider. The experience has been traumatic for Newton and Lada.

Lada says she registered a complaint with NDIS about a staff member who was financially exploiting Newton. Nothing was done. It was only when she made a complaint about another offence that action was taken.

‘On the second offence only, the staffer was moved to another house. (I believe moved, not sacked),’ Lada said.

‘On a previous occasion when my son had again absconded, his unit was entered, and a computer stolen. Only staff had access to the unit. I didn’t report this. I don’t know how long these abuses had been enacted.’

Lada says the accommodation provider has a behaviour support team, but ‘to her knowledge [it] has never set foot on campus’. Previously there had been a full-time specialist who ‘constantly worked with clients and staff to settle issues’.

Lada feels the system now is ‘fractured’.

‘I deal with people who each have some training in a part of the chain but no overview. If I wasn’t here I don’t think my son would know who to turn to for help’.

Jacqueline

‘I hope that parents of adult people who have a disability will be able to have their own life without worrying about their children or being harnessed to them like me and my mum.’

Jacqueline, in her early 30s, lives at home with her mum. She is autistic and has attention deficit hyperactivity disorder and a range of complex health issues.

Jacqueline told the Royal Commission that the failure of the NDIS to take into account her health issues means she increasingly relies on her mother to care for her.

‘The NDIS has said that they can’t consider health issues and their impacts on my life in judging the amount of support that I need. This means that every year I have had either a panic attack or an autistic meltdown at the planning meeting.’

Jacqueline said her health and her disabilities have a profound effect on each other, and she fears that without more NDIS support for health care, she will end up in hospital.

‘They do not care that I need to see my GP at least once a week or other health care once a week either. They do not care that I have not been able to get out of the house and into the community for more than 18 months. They just say that “we do not do healthcare,” which shuts down the conversation.’

With more support to manage her health, Jacqueline believes she could eventually become more independent. She wanted to be a disability support worker and had finished a TAFE course, but could not pursue this career while she struggled with her health. Her mother helped as much as she could, but it was affecting both their lives.

‘She has not been able to have her own life. She has not been able to do her own activities in the community without having to worry about me. This would not be an issue if I had enough support.’

Jacqueline hopes that, in the future, the NDIS will consider the impact broader health issues have on the lives of people with disability and the family members who care for them.

Enoch

Enoch has peripheral neuropathy as a result of diabetes. He told the Royal Commission that he uses a walker because walking is 'difficult [and] painful'. His condition has progressed to a stage where steps and steep inclines are 'impossible to manoeuvre'.

Enoch regularly uses a hydrotherapy pool for exercise and rehabilitation.

In his local area there are two pools but both have steps leading down into the water. One pool has a lift chair but 'it has been out of order for some time'.

The waiting room is also poorly designed. The chairs, while a standard height, have no supports. Enoch needs help getting in and out of them.

Enoch said this may be a 'trivial matter' for a person without a disability but for him it is a 'major issue'.

'I am somewhat embarrassed ... I would have considered these issues trivial prior to my current condition.'

Enoch wants people with disability to be involved in designing facilities intended for people with disability.

Rafael

Rafael is a young First Nations man in his final years of high school. He wrote to the Royal Commission about his experience in the education system.

Rafael was born with cerebral palsy and sustained a brain injury as an infant. At that point his grandparents became his foster parents.

Rafael's grandfather took him to swimming lessons and hydrotherapy and each week an occupational therapist, physiotherapist and speech therapist came to the home.

His grandmother enrolled him in a First Nations kindergarten and he remains friends with people he met during this period.

'This has helped me to keep in touch with my Aboriginal background and I am very proud about my Aboriginal culture.'

When Rafael started school, writing became a challenge. He also had difficulties with decision-making and literacy and numeracy skills because of his brain injury.

His first local school received special funding to support him.

'But, in reality,' Rafael said, 'I got little, if any special support.'

Rafael's grandmother then enrolled him in a school with a special program but he was only allowed to attend part-time and he 'didn't receive much support'.

'In the end I received most of my education from my grandparents, as they taught me and spent extra time with me ... They are both teachers ... and they suspected that my funding had been directed into other areas, rather than supporting my needs.'

After a few years, Rafael returned to the local school but again could only attend part-time.

'I wasn't allowed to spend time in the library even with supervision.'

Rafael's grandfather would meet him at lunch and bring him home and his grandparents would 'fill in the other half' of his education.

Rafael's part-time schooling continued for several years until his grandmother attended a meeting with other grandparents and discovered what the school was doing was 'negligent and therefore illegal'.

His grandparents met school staff and department officials.

‘From this point onwards my school program changed immediately. I was able to attend full-time and I had a special teacher to support me.’

Even though Rafael was not well supported by the school system for most of his education, he considers himself fortunate.

‘I had the right people advocate on my behalf, especially my grandparents who did not give up on me or my education.’

Scott and Alma

Alma's son, Scott, has disabilities that include anxiety, autism and oppositional defiant disorder. It's difficult for Scott to work and make friends. He doesn't trust doctors. He can also be violent.

Alma has been his sole carer since she and Scott's father separated a decade ago.

'Because of this role, I do not have the opportunity to have a full-time job, nor time for social interaction.'

Alma told the Royal Commission that in recent years, Scott became 'increasingly aggressive and verbally abusive'.

'I have difficulty concentrating on tasks, I am constantly anxious, as I feel that any moment he may become upset if I say something that triggers him, which happens quite often and unpredictably.'

Scott's anger often escalates to 'explosions such as hitting walls, slamming doors, throwing items'.

'Many of my belongings have been damaged by throwing.'

To escape Scott when he's violent, Alma rents separate accommodation nearby.

'I ended up losing much of my savings as I was forced to pay rent for two private rentals and utilities for myself and my son, and all on a carer's allowance.'

Alma asked family violence services for support, but they told her she's not eligible for crisis accommodation, financial help or counselling until she leaves her son.

'I am unwilling to end my relationship with my son and to suggest I do this is incomprehensible.'

Church and community-based services also told Alma she was ineligible for help unless she separated from her son and 'have him put into an institution or potentially prison'.

'My son has a background of trauma and let-downs from services, alongside his disabilities. From childhood and teens until now he has experienced a world of trauma, feeling rejected, and disappointed ... I was unwilling to see his health deteriorate in this way.'

Alma said most services helped victims of violence escape the perpetrator of violence, 'but [this] is not an option for a parent who is a sole carer'.

'I can see that many mothers in my position would end up living with their family violence perpetrators as the services do not exist to assist them to support themselves and their children who have a disability.'

Alma told the Royal Commission that although Scott has an NDIS plan, it offers no protection to her as her son's carer.

'There is no assistance available for carers who suffer family violence from the person they are caring for.'

Joshua

'I have faced many varying struggles as a young openly gay man, but I have faced far reaching and more intense struggles as a young disabled man.'

Joshua is autistic. He has attention deficit hyperactivity disorder and experiences panic attacks, anxiety and depression.

'I started high school as a very overweight young man,' he told the Royal Commission.

In the first week, when Joshua was changing into his PE uniform one of the boys pointed to Joshua's large chest and everyone laughed and joked about how he 'jiggled'. The joking continued in class. As he was changing after class, one of the boys stole his shirts and he was forced to walk out of the locker room bare-chested. Everyone started laughing and when Joshua cried they laughed harder.

That same day a learning support assistant came into the classroom and asked the student sitting next to Joshua to move, saying they had to sit beside Joshua to help him learn.

'Any hope I had of a normal time in high school was very much dashed in that moment.'

From then on students called him 'insane', 'spastic' or 'crazy'.

Joshua went home in tears and his mother contacted the school who encouraged Joshua to speak to the counsellor. Joshua did this, hopeful the bullying would stop. Instead, it escalated.

'I would bite back, I would retort by calling people names, become agitated or simply scream.'

Teachers punished Joshua even when he explained he was being bullied.

'I was so lonely and would often spend lunch hiding in a cupboard so that people didn't tease me.'

On the first day of year 8, a student remarked, 'Damn it, the fat spastic didn't kill himself over the holidays. What happened? Did the rope snap?'

Joshua burst into tears and everyone laughed.

On the bus, students regularly called Joshua names, spat on him and stole his bag. One time he reacted and started yelling and the bus driver pulled over and made him get off.

Some boys he barely knew got off the bus with him and told him they were sorry he was being bullied and chatted to him.

'I explained that I was feeling suicidal, that I didn't want to live anymore.'

The boys reported this conversation and a counsellor spoke to Joshua about what was going on. The school maintained that they couldn't control what happened on the school bus and dismissed the bullying at school as 'friendship issues'.

Not long after this, students posted a video of Joshua reacting to students poking him. When Joshua complained to the school he was reprimanded for having the video on his phone and told to delete it.

Furious, Joshua's father contacted the school. The school ignored him so he wrote to the education minister. The minister directed the school to meet with the family.

'The school attempted to claim that all my issues were relating to "on again – off again" friendships, and that I wasn't reporting the issues and the school wasn't aware bullying was a problem. The school felt the real problem was of a social nature – that being autistic, I simply didn't understand the social aspects of high school.'

By year 10 Joshua began to realise he was gay.

'If the world was going to rip me to pieces for being disabled,' he thought, 'why not just also be openly gay?'

Unexpectedly, when students found out Joshua was gay, the bullying stopped.

'For once in my high school life, I was accepted, however, I realised that I was accepted not because of my disability but because of my sexuality.'

As a drama student, Joshua realised he might be able to 'act' normal. He started studying others and monitored and adjusted his reactions – not too loud, not too much laughing or hand movement.

Acting 'normal' and being gay enabled Joshua to complete high school, but it required a huge amount of energy and came at an enormous personal cost.

When Joshua went to college and studied drama, for the first time teachers encouraged him to embrace his different mind.

'I could be my full glorious autistic self ... I won awards ... I had friends, and a healthy love life.'

Which is not to say there weren't ongoing challenges.

'I have had times when my mental health has deteriorated significantly, and I become that boy stuck in the cupboard afraid of the kids outside. I am working on this every day, one step at a time, alongside my psychologist.'

Marcel and Philip

In Marcel's final year of childcare – he attended eight hours a day – a staff member from the local school came to observe his behaviour.

As Marcel is autistic, his dad Philip found this encouraging. He wanted Marcel's experience at school to be inclusive from the start. He shared Marcel's NDIS plan and speech and occupational therapy plans so the school could best support his son's learning.

Philip told the Royal Commission that Marcel is gifted and could already 'read, write in multiple languages and do cursive writing as well as addition and subtraction'.

Philip was surprised when the school advised they would only accept Marcel on a part-time basis for the first four weeks. He argued the varied times would increase Marcel's anxiety. But the school was adamant – Marcel could attend part-time for the first month or not at all.

A few weeks after Marcel started, the school said they had no funding to support him and he could only continue on a part-time basis – two and a half hours each day. Furthermore his teacher would not teach the curriculum and he would not be able to play with the other children at recess or break times.

'I explained that this was not acceptable, and that he was being discriminated against ... and that the school's approach was not inclusive, but in fact exclusive.'

A short time later, the principal rang Philip and directed him to collect Marcel – he had hit another student. Philip objected to the way she spoke to him and told her he couldn't get there until 11.30 am.

When Philip arrived he was taken into a meeting with several staff members. He told them he was there to pick up Marcel – he hadn't been advised there would be a formal meeting.

'At that point [the principal] began, irate, told me to sit down and proceeded to speak in a very aggressive way.'

She told him Marcel 'needs structure within an inch of his life' and he has no place at the school. She described Marcel's poor behaviour as happening 'repeatedly'. Philip argued he'd never been told this – the support teacher reported Marcel was mostly well behaved. There had been two incidents and on balance Philip felt Marcel was only partly responsible.

Philip reminded the principal Marcel has difficulty self-regulating and needs support. The principal responded, 'You're a liar and your son is a liar.' She told Philip either he sign a new part-time agreement for one hour a day or she would suspend Marcel.

Philip refused to be bullied – the principal was discriminating against Marcel because of his disability.

‘Being told the school is suspending your son for his disability was heart breaking.’

The principal then said Marcel could no longer attend his occupational therapy sessions at the school – she was banning onsite therapy.

‘At this point she got up and said, “That’s enough, I’m cancelling this meeting!”’

The principal’s approach has created anxiety for Marcel and the family. Philip said his son has gone from being excited about attending school to being upset and hesitant.

Despite repeated requests the school never supplied an individual learning plan, behaviour management plan or strategies to support Marcel integrate into the school.

They’ve made it clear they don’t want him at the school.

‘I feel they are failing to meet their disability strategy guidelines and disability and support requirements.’

Philip has lodged a case with the Human Rights Commission.

Diana

‘Imagine you are accused of a crime – perhaps a crime you did not commit, or maybe even a crime you were the victim of. The arresting officers use a different language; you’re unable to communicate what happened before you get brought to custody, lockup or jail. There is no way for you to contact your family or an attorney. Your legal rights are not accessible to you, how would you feel?’

Diana, who is Deaf, told the Royal Commission that she found herself in exactly this situation.

It happened about two years ago. She was in her car with a friend, returning from their lunchbreak to a facility where they were doing some training.

Randomly, Diana says, they were pulled over by police to a location where there were about a dozen officers and a K9 unit. The officers told Diana and her friend that they had been pulled over on suspicion of carrying drugs with intention to sell.

When the police asked Diana’s consent to search her car with the police dog, she said she wanted to talk with her lawyer first because she did not understand why she had been targeted.

While on the phone to her lawyer, the batteries in Diana’s cochlear implant went flat. She showed the officers the flashing orange light that indicates a failing battery and explained that she needed another rechargeable battery – in her bag in the classroom – in order to talk with her lawyer or the officers further. The officers, however, accused Diana of lying about being deaf.

Diana’s friend overheard the officers teasing her behind her back about her ‘made up disability’. They thought Diana’s lawyer had told her to pretend to be deaf so she didn’t have to answer questions. Diana’s friend told them several times that Diana was ‘110% deaf’ to no avail.

Diana’s friend described the scene.

‘I noticed that she was confused, embarrassed, upset and didn’t know what was going on, she was desperate to get her batteries out of the classroom and wanted them to go get it so she could hold the conversation properly with the police officers but they wouldn’t listen to her.’

Diana and her friend were then handcuffed and taken to the police station. Diana was fingerprinted, strip searched, photographed and had DNA taken all while she was ‘in deaf mode’.

‘I had no idea what was going on, and had a massive panic attack. The police kept questioning, talking to me and trying to force me to read their lips but I am Deaf and I don’t communicate without my working cochlear implant! ... this was unprofessional misconduct, discrimination and unlawful treatment against me, to be forced to somehow verbally “communicate effectively” with them without my hearing means.’

Diana said it took 'several requests and arguments' to get officers to write down their questions or answers. She wanted to talk with her lawyer again, but the police had seized her phone so the only way she could get her lawyer's contact details would have been to give the officers the passcode to her phone – and she did not trust them with that.

Furthermore, the police would not provide a video phone to allow communication with her lawyer, and at no point did anyone offer Diana interpreting services.

'The legal process can be overwhelming but for deaf people like me ... it was confusing, dehumanising, isolating, humiliating and treacherous,' Diana said.

'Aside from the shame and humiliation associated with searches, disproportionate stop and search practices can also cause people with a disability to feel a diminished sense of belonging, fear, insecurity, disempowerment, anxiety, intimidation, helplessness ...

'From scary, misunderstanding and dangerous arrests, to lack of access to re-entry services, our justice system fails deaf Australians every step of the way.'

Diana hopes that all those involved in the administration of justice will be given appropriate training to ensure effective access to justice for people with disability.

She would also like to see a diversity of people working in the justice system at every level – 'You know, deaf police, deaf judges, deaf attorneys, deaf prison officers.'

Ibrahim

Ibrahim has cerebral palsy and dyspraxia which affects his vision, speech and his ability to control his body and its movements.

When he was a child he was sexually abused and as a result has post-traumatic stress disorder (PTSD).

After Ibrahim left high school, in the mid-1990s, he moved to a community residential unit (CRU) hundreds of kilometres from his parents' home.

He was given no support at the CRU to use his communication devices, so he was unable to communicate with staff.

'I was totally alone,' he told the Royal Commission.

The residents had serious behavioural issues and Ibrahim was bitten repeatedly. Residents also pulled out clumps of his hair, threw things at him and deliberately pushed him into tables and chairs.

'This was utterly scary because I am legally blind and I couldn't see where they were pushing me. It is terrifying to be pushed when you have a visual impairment.'

Ibrahim told us staff were 'really scared' of one resident and when he was violent they removed themselves for their own safety.

'But they left me in the room and my dyspraxia meant I couldn't move away. They allowed me to be hurt.'

When Ibrahim's parents and other parents complained, the one resident was moved but the abuse from other residents continued.

Subjected to violence every day, Ibrahim says his 'life was lost' at that house.

'I really wanted to end my life. I couldn't because of my dyspraxia. All I could do was make myself numb.'

His mother took him to a counsellor, but at the time it didn't help.

'I couldn't think about what I needed to think about because I was too scared all the time. I was screwed. And I couldn't die. I hate that the caregivers didn't protect me.'

Finally, with the help of a community visitor, Ibrahim moved to a different CRU with calmer residents. His life was 'boring but safe' and he started to feel more hopeful.

But his hope was dashed when the house manager sexually assaulted him.

Ibrahim reported the man to police. A detective and Ibrahim's communication advocate initiated a protocol to support him to make a statement, and a specialist speech therapist helped him access his keyboard.

The assault was investigated and a case prepared, but it didn't go to court because of Ibrahim's PTSD.

Ibrahim felt the process was supportive, but he never felt hopeful the perpetrator would be held accountable.

Ibrahim only recently told his psychologist about the violence and neglect he experienced in the CRU and is getting help with his PTSD. He said that life is better now he is no longer in a CRU.

'Lonely and disabled adults were living watching fellow residents being injured. That is no kind of life.'

Ibrahim says he is 'the lucky one' because he could communicate and was able to move.

'The others are stuck for their whole lives.'

Jayleen

‘There is a pervasive attitude that service provided to people with a disability is a favour that they should be grateful for.’

Jayleen is the mother of an autistic child with intellectual disability and epilepsy. Jayleen is a bookkeeper, a skill that helps her manage her child’s NDIS paperwork.

‘I have spent many hours with organisations having to correct their contracts due to over charging for services they haven’t provided,’ Jayleen told the Royal Commission.

She said in her experience, overcharging is widespread.

‘The financial exploitation, and general attitude that people with a disability or families with a person with a disability have no knowledge and no right to query services, is endemic within almost every service provider I have dealt with.’

Jayleen said one provider had printed on their invoice that, ‘No returns or claims will be recognised unless made within 14 days,’ and sent the invoices to arrive 14 days late.

‘Complaints are treated with disdain, the accounting practices are sloppy, the reporting and recording keeping is sloppy, and often the attitude is that the company doesn’t have to bother because their clients and their families won’t know.’

Jayleen said that in one year she dealt with four different providers who were overcharging.

‘If my experience is an indicator, private service providers are charging for services they don’t provide and families who have no accounting experience or training are unable to keep up.’

She believed NDIS costs would increase without an audit of providers.

‘I am horrified to think how many people without the knowledge or confidence to deal with such attitudes are [similarly] treated and how much they are exploited.’

Antony

Antony has a genetic condition that in later life left him deafblind. He lost his career and now receives a Disability Support Pension.

Antony told the Royal Commission various government agencies have contravened the United Nations Convention on the Rights of Persons with Disabilities by not making information as accessible as possible.

‘The [convention] clearly states that barriers to information ... need to be decreased and information provided in my preferred format [as a person with a disability].’

Antony said one government agency’s website, for example, was difficult for people with disability to navigate and did not meet current international Web Content Accessibility Guidelines. He had to pay an accountant to help him fill in the ‘incomprehensible lengthy documents’.

‘The impact [of] these experiences have led to frustration, helplessness and hopelessness, besides having a financial impact involving accountant or carer support.’

Antony’s disabilities prevent him from using a phone. He would prefer to communicate with one of the government agencies by email, but can’t find a way to do so. This means he has to visit the offices with his guide dog.

A security guard once insisted his dog was a pet and denied him access. Another time, front counter staff redirected him to a disability telephone, which he could not use because of his hearing disability.

Antony complained and received a written apology.

‘Hence, if there is a need to attend, I now take these letters in case I need leverage to actually speak to a person.’

Antony said that as the population ages, service providers need ‘strategies that assist, offer respect and decrease bureaucratic frameworks imposed upon’ the increasing number of people with vision and hearing disabilities.

Hallie

‘I feel like I was treated like I do not deserve justice or to feel protected.’

Hallie has post-traumatic stress disorder (PTSD) and borderline personality disorder. She explained to the Royal Commission that this means she goes into ‘survival mode’ and flees when she is overwhelmed.

Recently, Hallie had to give evidence in court to have a restraining order against a violent ex-partner continued. The magistrate refused to allow Hallie’s support worker to sit with her while she waited to give evidence. This triggered a PTSD episode and she had to flee court.

Hallie went to police hoping they could help her and she could ‘settle and regain confidence’. She explained her ‘erratic behaviour’ was due to her disability and she needed support. Police didn’t listen and they ‘confused and traumatised’ her further.

Hallie returned to court and spoke to court staff, again explaining why she needed her support worker. They suggested she wait down the stairs with her support worker. She said she did exactly what they told her to do. Additionally she told security guards and administration where she was waiting and why she was there.

Despite this, no-one advised the magistrate.

After a while security guards told Hallie ‘she wasn’t needed’ and to talk to police.

Hallie’s case was dismissed because everyone assumed ‘she didn’t show up’ to give evidence.

‘I did everything I could to try to understand and cope under the circumstances.’

Hallie’s PTSD has become ‘impossible to manage’ and she has self-harmed and tried to suicide. She wasn’t able to attend court again and the restraining order was cancelled. Hallie, a single mum, said this decision also affected her children.

‘All they had to do was read my file, due to all the domestic violence reports they would have seen everything they needed to know about my mental health disabilities and taken more care to help me not cause me more harm.’

Hallie said she’s not sure if she will be able to trust police, lawyers or magistrates again.

Yolanda

After her mother-in-law had a series of incapacitating strokes, Yolanda felt it was her duty as an Arabic woman to take care of her. She was already caring for her husband, who had an acquired brain injury, and raising a young family of six children.

Yolanda is now in her 50s. She told the Royal Commission, through an advocate, about the toll all of this caring has taken on her relationships and health.

Yolanda has a brain aneurysm that she attributes to prolonged stress. She also has had epileptic seizures, major depression, anxiety and panic attacks, as well as back pain, diabetes and high blood pressure.

When Yolanda married her husband more than 20 years ago, her mother-in-law was living alone in a government housing unit. After her stroke, her mother-in-law was unable to climb the stairs to her bedroom and bathroom, so she slept on a couch downstairs.

Yolanda visited daily to care for her, bathing her in the downstairs laundry. The housing authority was told of the situation, but offered no alternative accommodation.

Yolanda found it difficult to access respite care. Her husband became distressed when anyone but a family member cared for his mother. When Yolanda did place her mother-in-law into respite care so she could take her children on a holiday, she had to return early because her mother-in-law developed a severe infection from bedsores.

Yolanda's family began to struggle financially. Her husband's brain injury prevented him from working, and between raising her children and caring for her mother-in-law, she was too busy to find a paying job.

When Yolanda's family lost their home, they moved into her mother-in-law's two-bedroom unit. When the housing authority found out, they evicted her family.

It was only when her mother-in-law was diagnosed with schizophrenia that Yolanda was referred to a disability support service. A support worker came for one hour in the mornings and one hour in the evenings.

Yolanda said that in caring for her mother-in-law, she had been unable to give her children as much attention as she would have liked when they were growing up. Her children also struggled to understand their father's brain injury and how much care he needed.

She believes the sacrifices she made contributed to her daughter leaving home and refusing to speak to her for several years. She also feels she neglected her own parents in the later part of their lives, because she was so busy caring for her mother-in-law and husband.

Yolanda told the Royal Commission that support for carers, including psychological support, should be included in NDIS plans for a person with a disability. Cultural practices also needed to be taken into account in NDIS plans, so families can care for their relatives at home for as long as possible.

She would also like to see family carers trained and paid at the same level as professional support workers, to help families avoid some of the pressures she experienced.

Lucca and Milana

‘It is no small thing to abuse a child with autism who does not understand what the problem is and whose confidence is likely to be undermined next time he goes out in public places.’

Earlier this year Lucca was shopping with his mum Milana. Lucca, not yet 10, is autistic.

It started out as a usual grocery shop, Milana told the Royal Commission, until one of the staff verbally abused Lucca.

Milana was shaken and couldn’t understand why the staff member behaved so aggressively. She tried to speak to the staff member, who eventually offered ‘an explanation of sorts’, saying another child ‘had misbehaved in the store previously’.

‘Clearly the staff member ... did not consider disability as an issue and acted in a way that suggested no small degree of insensitivity.’ Milana said.

A disability advocate is helping Milana make a formal complaint to the store.

Milana wants the store to apologise to Lucca and her. She also wants them to implement disability awareness training for all staff and managers ‘with an emphasis on greater understanding of the specific needs of children’.

Milana said all stores should have mandatory training because people with disability are engaging with the community more today than in previous decades.

‘My hope is that people with disability are encouraged to access the community and are treated with understanding rather than hostility.’

Kathryn

‘Just treat us like anyone else.’

Kathryn, in her 20s, has Tourette syndrome and several co-occurring conditions such as obsessive-compulsive disorder and anxiety. She’s studying to be a primary school teacher.

‘I have dreams of becoming a teacher, but the barriers to this have been so extreme that I have developed more issues than when I started university,’ she told the Royal Commission. ‘I had lecturers and unit coordinators try to scare me away from a career I have so much passion for.’

Kathryn completed a Bachelor of Arts. When she began her Master of Teaching degree, her supervisors told her she would be ‘mocked, bullied and teased by students’. She had by then been working for months with primary school students ‘without issue’.

‘I have been pulled into “hallway meetings” to be told that I may not get to my master degree.’

The university then asked her to meet extra conditions before a practical teaching placement.

‘[It’s] a requirement that is not expected from my peers and is only a requirement for me because I have an obvious disability.’

After completing extra tasks, Kathryn said the university ‘chose to move the goal post once again’. She was told her volunteer work, awards for student leadership and employment as a [Peer Assisted Study Session] facilitator wasn’t enough to show that she wasn’t a ‘danger’ to students. She had to complete a safety assessment.

Kathryn says she ‘typically can function well, attending university and living daily life’, even though she experiences unfair treatment because of her disability. This includes ‘being screamed at by bus drivers’ and being asked to leave the university library because of her tics.

The university’s attempts to stop her becoming a teacher have taken an emotional toll.

‘In recent months I have been hospitalized three times into a mental health ward due to situational related crises.’

She said she had tried to end her life and had regular panic attacks.

‘Now [I] fear that if I speak out naming myself or my university, I will face retaliation and be kicked out of my degree or have to face more barriers than I already do.’

Kathryn explained this fear to the university’s disability unit. They apologised, but told her it was ‘a necessary burden’ if she wanted ‘to be heard’.

‘People like myself shouldn’t have to prove we are able to do everything above and beyond that of a non-disabled person just to be given the same opportunities and respect you inherently give to non-disabled people.’

Ainsley and Sean

Ainsley is in her 40s. She has severe cognitive disability and epilepsy.

‘Our whole family have been affected by seeing and experiencing the way my daughter was cared for by the system,’ her father Sean told the Royal Commission.

Sean said restrictive practices, such as restraining and isolating Ainsley to control her behaviour, were particularly damaging.

‘I will never forget the look in my daughter’s eyes when I implemented some of the restrictive practices that doctors approved, and I felt were not appropriate, but you hope that what you are doing actually helps.’

Ainsley was an infant when she first developed seizures. She was having as many as 20 a day and didn’t respond to medication to control them.

A neurologist told Sean that his daughter would never walk and talk, and that he and his wife should consider placing her into an institution. They decided to care for her at home.

Doctors prescribed diazepam for Ainsley, which Sean said seemed to work to control the seizures, but ‘instead of calming my daughter down it was hyperring her up’.

‘It was at this stage our first “restrictive practice” was introduced,’ Sean said.

A psychologist told Sean to train his daughter to sleep.

‘I was to put my daughter to bed at an appropriate time and “hold her down” in her sleeping position until she actually slept. I did hold her down the first night and I was doing this for approximately two hours while she fought being held down.’

The next night Sean tried again.

‘You could see the anguish on her face as I continued with this procedure. It wasn’t working.’

He stopped the practice.

A few years later a doctor told Sean his daughter was ‘probably allergic’ to diazepam. When Ainsley stopped taking the drug, she slept normally.

Exhausted by her high needs, Ainsley’s parents made the difficult decision to place her – while she was still a child – in a hospital for people with disability.

‘The main reason we chose this facility was it was the only one who could cater for her medical needs.’

When Ainsley was older, the hospital moved her into a group home. The home implemented restrictive practices to control behaviours they described as ‘attention seeking, self-harming or socially not acceptable’.

When she banged her head or removed her clothes inappropriately, for example, staff moved Ainsley to a ‘time-out room’.

‘This meant the back yard. The neighbours called the police during one incident as my daughter was in the backyard, naked and crying ... Some staff just dragged [Ainsley] along the ground out of the room to the time-out area or man handled her by the arm.’

Sean said he knew ‘something had to be done’, but the discipline ‘only created aggression and defiance’. After Ainsley was injured several times, Sean told the hospital that the restrictive practices were abusive.

The hospital replaced restrictive practices with positive reinforcement in the 1990s.

‘This meant more trying to communicate with my daughter and to find out what she really wanted by her behaviour. This was extremely positive and incidents decreased dramatically.’

Sean said the abuse the family witnessed had, by then, damaged relationships. Ainsley’s younger brother ‘cannot really connect with her’, avoids doctors and ‘feels physically sick’ if he enters a hospital.

‘I am sure that the “old methods applied” have scarred my daughter’s relationship with me.’

Zac

Zac was diagnosed with attention deficit hyperactivity disorder (ADHD) at the beginning of the COVID-19 pandemic. He was in his 30s, working as a teacher and about to have his first child.

He told the Royal Commission, because of these factors, he decided to apply for an extension to his provisional teaching registration.

Six months after Zac lodged his application he received an email from the teachers' registration authority. They requested a letter from his medical practitioner to confirm that his 'impairment' did not prevent him from carrying out his role as a teacher.

Zac was outraged. After more than five years working as a teacher and more than a decade in the defence force, the teachers' registration authority considered four letters – ADHD – made him unable to do his job.

Zac did some research and found out that the registration authority requires all teachers to inform them of all 'physical and mental impairments'.

'This was part of a declaration policy that placed physical and mental impairment and disabilities between a criminal record and substance abuse, as if they were in some way similar,' he said.

He responded to the email and expressed his feelings.

'I pointed out the language was disgusting and would not be acceptable in a school if I described one of the students as "impaired".'

The registration authority responded saying they had a duty of care to student welfare. Zac couldn't comprehend how his diagnosis suddenly made him a danger to his students, but he submitted letters from his GP and psychiatrist.

'If it wasn't for the fact that the registration is a requirement to teach I would have taken them to court on the principle of the matter.'

When Zac spoke to his colleagues, many admitted they do not declare their mental health issues. One person had a similar experience and told Zac 'the process made her feel like a criminal'.

The school where Zac teaches has been supportive and view his disability as a strength.

Undiagnosed ADHD affected every area of Zac's life and he is determined to talk openly about it with students and staff.

'I firmly believe awareness and openness are the only ways to normalise mental health and ensure that people get the help they need. If just one person doesn't need to wait 36 years to find out they do not need to hide their oddness I'll take it as a victory.'

Kane and Leo

Leo, a teenager, is autistic.

His stepfather, Kane, told the Royal Commission that Leo had some difficult years in primary school.

Leo was having 'autism meltdowns' and, under the guidance of the principal, the school was calling Kane to collect him on an almost weekly basis.

The school was constantly suspending Leo, which interfered with his education and socialisation.

'[Leo] was not protected, other students learnt how to trigger him into a meltdown and would deliberately set him off,' Kane said.

One such provocation led to a string of behavioural incidents. The school called Kane to take Leo home and the principal told him he expected Leo to apologise for his actions the next day.

'Knowing [Leo], I told the principal challenging him directly would not be the way to get the desired result,' said Kane.

When Leo returned to school the principal confronted him anyway. This did not go well. Leo threw a few small objects and the school excluded him for the maximum allowed, 10 weeks.

Kane went to meet the principal about this exclusion and found police in attendance. A few weeks later, they charged Leo with assault. He was 10 years old.

The police eventually dropped the assault charge, but it was an 'incredibly traumatic time' for Leo and his family.

Kane believes a big part of the problem is that 'nobody is willing to learn how to help children with autism'. He would like relevant bodies to be funded to provide autism education sessions in schools. When he convinced two of Leo's teachers to attend an autism awareness course, he found it prompted 'a real change in those teachers'.

As Leo's stepfather, Kane has experienced this for himself.

'I never knew anything about autism until I met [Leo], but I did all I could to learn how to help him. We did a lot of informal therapy and he responded well. What I want is change so that these children with autism don't go through what [Leo], his mother and I went through.'

Darius and Lexi

Darius is autistic and has been at primary school for three years.

His mum, Lexi, told the Royal Commission she worked very hard with the school to assist him.

Darius was making significant progress until a class teacher, Mr Owen, began bullying him.

The first incident she heard about left Darius frightened and sobbing in the sick bay.

Darius was tapping his water bottle on the table and Mr Owen told him to stop.

When he didn't respond immediately Mr Owen 'ripped the bottle out of his hand' and 'smashed it onto the floor'. Mr Owen then stormed out of the classroom, telling the teacher aide to 'handle it, as I'm over it'.

A few weeks later Darius's name was pulled out of a hat for a class reward. He was incredibly excited, but Mr Owen said he felt 'too sick' to give Darius the award.

The teacher was making a sarcastic reference to the previous day when Darius said he felt too sick to complete some work.

The class laughed and Darius fell silent. When Mr Owen told Darius he could 'give it but he couldn't take it,' Darius burst into tears.

The head of the special education unit reported the incident to the principal. No-one informed Lexi.

On another occasion, Mr Owen returned from a camping trip and asked Darius to sit on the assembly line. Darius reminded him the special education teacher allowed him to sit to the side. Mr Owen replied, 'Haven't I missed you'.

There have also been incidents of body shaming. Mr Owen said if he had a stomach like Darius, he couldn't run either.

Lexi spoke to Mr Owen, but he dismissed her and told her Darius's behaviour 'is not autistic, just naughty'.

The daily taunts from this teacher set the tone for the other children to pick on Darius.

'Eventually my son went past breaking point, even spending one day under a computer table.'

Darius went from being frightened of being in the class to refusing to go to school.

Lexi complained to the principal, and Mr Owen was made to attend an autism training program.

Nothing changed, so Lexi wrote to the education minister and asked for an investigation into Mr Owen's sustained bullying of her son.

Eventually Lexi moved Darius to a different school.

Lexi said he is now 'doing brilliant' and the new teacher is helping him deal with the trauma associated with Mr Owen.

'I am amazed at how well his behaviour was in his latest report card.'

Darius is seeing a psychologist.

'Months after we have left the school he is still suffering the consequences of this teacher's actions.'

Lexi doesn't want this to happen to another child and is horrified by the thought another autistic child may suffer the same treatment.

'Their biggest trauma in life will be their schooling years, very very sad ... and no-one is doing anything to change this.'

Uri and Ivar

Ivar is a refugee on a Temporary Protection Visa.

His son Uri is autistic and non-verbal and needs 24/7 care.

Ivar told the Royal Commission that Uri enjoyed primary school but after transitioning to high school 'never settled in well ... was sometimes unhappy or badly behaved'.

One day Ivar noticed dark bruises on Uri's hands and arms 'with no explanation'. Sometime later, the school asked him to come to the school urgently.

School staff had reported the swimming teacher for 'aggressive and unacceptable behaviour' towards Uri.

'The teacher was seen several times squeezing my son's arm very hard and pulling him under water until his head was completely submerged and then releasing him coughing and choking.'

Ivar says Uri was traumatised.

The school reported the incident to the education department. A few weeks later the department advised Ivar the case was closed because the swimming teacher had 'resigned and was not in their employ anymore'.

Ivar went to the police and asked them to investigate the assault.

'Soon afterwards, I heard ... that they were not going to pursue the case further because they did not have enough evidence.'

Ivar went to the state's crime and misconduct commission to no avail.

'We didn't speak to a lawyer, firstly because we do not have enough money to pay for their services and secondly, we don't know the laws well enough to take legal action against the teacher.'

Uri's behaviour has 'significantly deteriorated' since the incidents.

'At times he has become uncontrollable with real risk of self-harm, injuries and damage,' Ivar said.

Uri hasn't been able to return to school.

Ivar believes if Uri received more support at the time of the incidents 'he would probably be more easily managed today'.

Ivar would like something to be done about the assault and for Uri to receive additional support and compensation.

‘My son cannot access any disability support programs and my wife as his carer cannot apply for any payments from Centrelink (such as a carer payment) because only permanent visa holders are eligible.’

The family struggles financially.

Uri’s parents worry about his siblings because ‘the high needs of the oldest brother leave us with very little time to spend with them’.

‘By denying us a Permanent Protection Visa [the government] has denied [Uri] his rights to receive the therapies that severely autistic children need.’

Sylvia

Sylvia is in her early 50s and has cerebral palsy. She has three university degrees.

For some years Sylvia enjoyed a teaching career. When she transitioned from using crutches to a wheelchair, her employer decided she could no longer cope with the physical requirements of the job. She told the Royal Commission she was forced to retire.

Sylvia applied for the Disability Support Pension (DSP) but was knocked back.

‘Several people told me it was a pity I hadn’t applied for the DSP earlier in my life, when it had been easier to get,’ Sylvia said.

‘I found it profoundly disappointing that rather than being rewarded for having a go and working while I was able to, I felt punished by a system which, when I needed it, didn’t seem to be there to help.’

Sylvia didn’t challenge the decision denying her the pension because she ‘found it too depressing and didn’t want to be rejected again’.

Sylvia says that while she had some capacity to work, she wasn’t able to find work in a market where ‘there was always someone else who ... was simply “easier” to employ because they wouldn’t require the “reasonable adjustments” that [she] either needed or was assumed to need’.

‘The government’s expectation for disabled people to work has changed much faster than the willingness of employers to hire people with disability,’ Sylvia said.

‘When I was looking for work, I contacted the Employment Assistance Fund (EAF) to find out what kind of assistance or equipment I could get, so that I could reassure employers that, with the right support, I could do the job.

‘There was nothing the EAF could do to help until I had a job offer – which I was unlikely to get without demonstrating that I could do the job.’

Sylvia said she was ‘condemned to long term unemployment, long term poverty and years of close government scrutiny’ because the government insisted she was able to work but employers wouldn’t hire her.

‘I wasted years of my [life] applying for jobs I was increasingly unlikely to get ... I found it extremely damaging to my self-esteem and mental health.’

Sylvia says Australia needs ‘an employment system that is about re-skilling workers not blaming them for being without employment’.

‘We need a system that provides pathways for people to change jobs and develop new skills ... We need a system that offers a support to every worker who needs a new job (disabled or not).’

Rohan and Margo

‘Turning 18 should be a celebration, but instead it opens up a minefield for the families of the person with a disability.’

Margo’s son, Rohan, is autistic and has attention deficit hyperactivity disorder and intellectual disability.

When Rohan turned 18, Margo said she was ‘cast aside’ and the institutions that took over Rohan’s care neglected him.

‘Parents need to be seen and listened to, even once the person turns 18,’ Margo told the Royal Commission. ‘They may be legally an adult due to the number of years they have been alive, but mentally they may be many years younger, very vulnerable and need guidance.’

Margo said Rohan’s NDIS service provider pushed to have a public guardian make decisions about his NDIS services, despite Margo and Rohan saying they didn’t want the guardian involved.

‘The public guardian, in the whole year she was assigned to my son, never met my son and spoke only once to him on the phone ... This is a person that is making very serious decisions about a person’s life that they don’t even know.’

Rohan lived with his mother, but when he became violent she paid for him to stay in a nearby caravan park.

‘He did not cope living on his own ... and this was communicated time and time again to the provider, [and his] NDIS complex needs coordinator.’

The NDIS told Rohan he was eligible for supported independent living (SIL) funding. Rohan waited more than six months for the SIL accommodation while his health deteriorated.

‘I begged the complex needs coordinator and the public guardian for the SILs process to be sped up, for anything that needed to be done to get started ... I just couldn’t get him out of the caravan park,’ Margo said.

As Margo and Rohan waited, the NDIS appointed a new complex needs coordinator for Rohan.

‘She came in and completely turned everything around, stated that because my son was living on his own in a caravan park that he may not need SILs anymore ... My son has never met the second complex needs coordinator, and has only spoken to her maybe twice over the phone.’

During this time, Rohan became ‘the victim of a very traumatic crime outside of the caravan park due to his vulnerability’. He also stopped taking his medication.

The NDIS agreed to place Rohan in a SIL house 'as an emergency placement which was meant to be for a short time'. After a few months, the SIL provider told him to leave.

'They said they needed him out. We were told that a new tenant was moving in, but I have since found out it was because his funding was running out so it wasn't financially viable for them.'

Margo paid for Rohan to stay at a motel.

'He stayed there for two months. His mental state deteriorated, and he became more depressed and suicidal.'

By the time he entered the supported accommodation, Rohan had attempted suicide three times.

Margo said she since discovered that the NDIS had changed Rohan's plan, removing some of his supports, including his two days of social activities.

'No-one had told either my son or I that he had lost his supports and services that he had prior to being granted the SILs unit, not his coordinator, not the NDIS complex coordinator nor the public guardian. It has been a disgrace with people not doing their jobs properly.'

Margo's now worried that, because Rohan has to 'constantly show the NDIS that he is "capacity building"', he will one day be forced to move into social housing where 'he wouldn't last a week'.

'[The NDIS] website states, "A participant has the right to make their own decisions about what is important to them and to decide how they would like to receive their supports, and who from." I am yet to see this happen,' Margo said.

Albert and Madelyn

Albert is a First Nations man in his 40s.

As a young man he was ‘very sports-oriented,’ his mum Madelyn said. ‘His room is full of trophies, he got accolades after accolades’.

At 17, doctors diagnosed Albert with Asperger’s syndrome. He started receiving a Disability Support Pension.

‘I went in to Centrelink time after time and said he’s a healthy young man, he doesn’t need to be on a pension,’ Madelyn told the Royal Commission.

She said the pension stopped Albert getting a trade. He has lived with his parents since then ‘because that’s all he’s known ... [although] he gets on with everybody, anybody’.

A few years ago, Albert’s behaviour changed.

‘He’s not a druggo, he’s never drank in his life, he’s never taken drugs, he’s never been that abusive person, but he’s become that person now,’ Madelyn said.

One day when Albert became violent, his parents called the police. They handcuffed him and put him in an ambulance to take him to the local hospital.

‘[It] broke my heart to be honest,’ said Madelyn. ‘We didn’t want this for our son. We just wanted help.’

While in the mental health unit Albert lost his clothes and didn’t wash, but a social worker told Madelyn he was ‘doing fine, he’s walking up and down the hallway’.

‘I said, “What’s that going to help him? He could walk up and down the hallway at home. We want to know where his problems lie and what needs to be done.”’

Madelyn told the Royal Commission no-one has provided any answers.

‘I’ve been waiting since October [last] year to tell me what my son’s diagnosis is and what happened to him in that hospital.’

When the hospital discharged Albert, he phoned his mum from another suburb.

‘I said, “What in the god are you doing over there?” And he said, “A taxi just dropped me off and I got no money and a paper bag with some dirty clothes in it.” [I said], “What is the taxi driver doing over there?” and he said, “They paid money at the hospital for me to get in a taxi over to here.”’

Madelyn called the hospital to ask why they had discharged Albert without support.

‘The phone just slammed in my ear with no explanation,’ Madelyn said.

The next day the police came to her door and arrested Albert.

‘They said, “We got a missing person out on [Albert].” I said, “Who did that?” [The officer] said, “Well, we were told they were missing. When they let him out of [the mental health unit] they were supposed to notify us.” ... So they had to take [Albert] away screaming and yelling in cuffs.’

The police released Albert without charge.

‘He’s not doing too good now,’ said Madelyn. ‘He’s homeless and mental health won’t have a thing to do with him because he doesn’t fit in the basket.’

She said Albert would be better off if he had been convicted of a crime. She works with the justice system helping First Nations youth access support services after they appear in court.

‘We set [them] up and I make sure that boy gets mental health [support]. He gets housing. He gets job assistance. He gets a worker allocated. I say, “I can’t even get that for my own son.” And I fight for these kids because I know my son will never ever get it.’

‘[It has] destroyed our life,’ Madelyn said of the lack of support for Albert and his family. ‘Our relationship’s in tethers.’

‘I’m just so tired ... there’s nothing at the end of that tunnel. It’s just a dirt road I’m looking at and it’s black. I can’t see anything further past that end of the road.’

Issac and Osman

‘It seems to be the policy of the police to, in all occasions, come in “gung ho, guns blazing” and escalate the situation – when in reality, the best way to handle a child with a mental disability in an aggravated state is most often via a calm and compassionate approach.’

Issac, 13, has intellectual disability, oppositional defiant disorder (ODD) and encopresis.

He lives in a regional area with his father Osman and attends a special school.

Osman told the Royal Commission Issac has experienced violence and abuse by staff at school and by police.

One time Issac had red marks on his face and told Osman a teacher had scratched him.

‘This scratch was hard enough to leave noticeable red welts, and I suspect occurred when the teacher was trying to catch him as he was running,’ Osman said.

The school told Osman that Issac ‘scratched his face on the school gate’.

This seemed implausible to Osman but the school principal continued to deny a staff member or the school was at fault.

Osman said this was just one example of the school’s inability to ‘de-escalate situations with children with disability when they become aggravated’.

‘Almost every second day [Issac] gets sent home from school for various incidents that could have been prevented with proper training, such as the breaking of windows. [He] has never broken any windows at home.’

Police often attend the school.

When Issac was 10, police arrived at school to deal with another student. Issac ‘was trying to stick up for this other student’ when police threatened to pepper spray him.

Another time ‘the situation resulted in a female police officer grabbing [Issac] by the arm and throwing him to the ground hard enough to fully knock the wind out of him’. Osman wasn’t told why the police were there but said ‘there is no situation in which such violent measures are appropriate to be used against a young child’.

A third and more traumatic incident occurred when Issac was 12. Police were dealing with another student when Issac grabbed a pair of scissors and threatened one of the officers.

Police put Issac in handcuffs, threw him in the back of their van and took him to the police station 'without any accompaniment by a teacher or other staff member of the school'.

Osman said the response was 'completely disproportionate' and the school did not intervene.

'When I arrived to pick [Issac] up, I found him crying and frightened, with red marks around his wrists due to the handcuffs having been put on too tight ... Ever since this incident, [Issac] has been too afraid to return to school.'

Osman has requested a full investigation of the incident and wants to see body-cam or other footage.

But he has been denied access to any footage that may exist and been told the incident is being investigated internally. He believes an open, transparent, independent investigation is needed.

Regional schools need to be better funded to hire and train staff to 'properly handle children with disability and ... de-escalate situations rather than immediately turn to law enforcement,' Osman told the Royal Commission.

Psychiatrists or psychologists on staff should be the first point of call when a child's behaviour is escalating, not the police.

If police are called, it should be a last resort and they need to be trained to deal with children in these situations.

Ultimately, Osman would like 'the general attitude and culture of the police force to be more understanding, kind and peaceful towards people with disabilities, particularly children'.

'Specialist schools should be places of understanding and education for children with mental or intellectual disabilities ... and the police force should be figures that all citizens – especially vulnerable children – can look to as a symbol of protection.'

Mavis and Dulce

Mavis had intellectual disability and epilepsy. She was one of six children and was about five when her mother put her into a psychiatric hospital.

Her sister Dulce explained that her mother was a single parent who 'could not read or write very well'.

'[She] relied on us kids for our help.'

Dulce and Mavis met for the first time in the 1980s.

'My mother had told us that we had a sister ... so I went out to find where she was,' Dulce told the Royal Commission.

Dulce found Mavis in a hospital in a regional city.

'They wheeled a person in front of me that had no hair on her head and was full of sores and very fragile with skin off her knees.'

A nurse told Dulcie her sister had 'fallen out of the wheelchair, and that they had to shave her hair as she ate it'.

'I was overwhelmed about what I was seeing and requested how I could get her out of the hospital, but was told that she was a ward of the state and that I would have to petition to have her removed.'

A staff member assured Dulce that Mavis was being cared for and warned her she was 'aggressive, so she would be hard to look after'.

Dulce kept in touch. One day the institution called to say Mavis was 'at death's door'.

'I was told she had eaten the leather off her chair, and it had become lodged in her bowel and they had to take part of her bowel out.'

Mavis survived the operation.

Wanting to understand why her sister behaved this way, Dulce asked to see Mavis's medical records. A nurse told her they were destroyed in a fire.

'I was upset and met with a head nurse at the hospital as I needed to be assured that she was being cared for. She said that I needed to accept that it was not easy having staff around the clock to keep an eye on her all the time.'

Dulce eventually arranged to transfer Mavis to a hospice near her so she could visit more regularly. When she asked that her medical records be transferred, the hospital told her 'they had nothing, and that nothing had been sent with her'.

Mavis used a wheelchair, but spent a lot of time in bed and could not walk or talk.

'The lack of medical history made it hard for me to try to explain why no-one could tell me or any professional as to why she was in that condition,' Dulce said.

When Mavis was diagnosed with breast cancer a decade ago, Dulce 'could not answer any of the medical or physical questions that the medical staff would ask'.

One day, Mavis's doctor phoned to tell Dulce that her sister had syphilis.

'I hung up and went to pieces. How does a woman in public care and private care who has been in care for 60 out of the 65 years of life and cannot speak or walk contract syphilis?'

Dulce contacted the police and tried again to find Mavis's missing medical records.

'I seemed to hit brick walls as everyone said, "Oh, that is awful, but it was so long ago do you really want to bring up the past?" People started to say things like, "Oh, you cannot make any decisions for [Mavis] anymore as you do not have guardianship of her."'

Dulce applied for, and was granted, guardianship. Freedom of information requests unearthed records from previous hospitals, but there were gaps in Mavis's medical history and no record of syphilis.

When Dulce complained about the lack of records, a government ombudsman suggested Mavis had contracted syphilis at birth, but could not show Dulce any evidence.

Mavis died a few months later.

'There is so much I do not know about [Mavis's] treatments prior to coming to me and to [the] hospice and I cannot imagine what has been done to this beautiful defenceless lady. I did not want to believe that someone had abused her.'

Isaak and Brianna

‘How could this happen to a young man who ... was effectively left to rot?’

Isaak acquired a brain injury at birth, has quadriplegia, epilepsy and is nonverbal. He lives in a large group home with 40 other residents. His sister Brianna lives interstate and became his guardian in the mid-2010s.

Brianna told the Royal Commission she noticed Isaak’s leg was swollen while she was visiting him five years ago.

‘His right leg appeared to be at least twice the size of his left leg.’

Brianna spoke to a staff member and remembers saying, ‘Something is very wrong here.’ The staff member dismissed her concerns telling her it was arthritis.

When Brianna returned home she contacted the nursing coordinator to check on Isaak. The coordinator told her she was applying heat and giving him spa baths. Brianna later learnt this would have caused Isaak immense pain.

Brianna wanted a specialist opinion and asked the coordinator to arrange a consultation. However the coordinator and then the CEO ignored her. After two months Brianna made a booking for Isaak herself. She emailed the appointment details to the CEO and told him the specialist needed the most recent scan of Isaak’s leg.

A few days before the appointment, months after Brianna noticed the swelling, the GP for the group home contacted Brianna. He informed her Isaak had a tumour in his right leg and would most likely require amputation.

‘I was shocked,’ Brianna said.

The doctor arranged for Isaak to see a specialist at the hospital and told Brianna he would keep her informed of Isaak’s condition and test results.

But the doctor never contacted her again. A few weeks later in utter despair she contacted the CEO.

‘I was not being kept informed of any test results and [Isaak] is still sitting around with a massive tumour in his leg.’

She was worried there might be secondary cancers.

Eventually Isaac’s surgery was scheduled. On the way to the operating theatre Brianna mentioned the family history of bleeding to a nurse. She assumed the home had given the information to the hospital. They hadn’t.

Isaak's surgery had to be cancelled. The hospital conducted tests and found Isaak has strains of a bleeding disorder and 'may very well have bled to death'.

Two weeks later – six months after Brianna first noticed the swelling – Isaak's leg was amputated.

'I did not know if he would even survive as the doctors informed me it was a very serious surgical procedure and [Isaak]'s epilepsy was high risk.'

Brianna was concerned about Isaak's prognosis and whether the cancer had spread. She requested copies of all test results. The CEO refused to give them to her and successfully applied to remove Brianna as Isaak's medical guardian. He told the guardianship board there were a number of family members contacting the home regarding Isaak's condition. He could 'not ascertain who could be regarded as the person responsible'.

A public guardian was appointed and the CEO told Brianna, 'I do not intend corresponding further with you.'

Brianna continued to request copies of test results and eventually received the results of a test performed five months previously. The report stated there was a possible metastatic lesion on Isaak's liver and suggested further scans.

Brianna asked to see the follow-up scans but the CEO refused saying 'all was clear'. She then asked the public guardian to intervene and discovered there were no scans.

'[The CEO] lied to me.'

Isaak eventually had follow-up scans and they showed lesions in his bowels and chest.

Brianna finds it incomprehensible that the people who provided Isaak's personal care failed to do anything about a large tumour growing on his leg.

'This is a shocking (and very sinister) indictment on a system that was meant to care and protect my severely disabled, helpless brother. When I chose to investigate such negligence and abuse and demand answers, I was totally victimised and continue to be, to this day.'

Jerry

‘In more than 50 years of struggling without success, I feel that any hopes I have for the future have been beaten out of me.’

For the past 30 years, doctors treated Jerry for depression. Now in his 50s, Jerry recently learned he actually is autistic and has attention deficit hyperactivity disorder (ADHD).

‘It was only with the help of my friend that I was able to get my current psychiatrist to take notice and realise that the standard treatments for depression had not worked,’ Jerry told the Royal Commission.

Jerry has difficulty expressing himself and struggles with anxiety. He is hypersensitive to loud noises and uncomfortable in crowds.

Jerry said a ‘mental health nurse made a tentative diagnosis of depression’ when he was in his 20s.

‘They sent me to see the psychiatrist at the local community mental health centre who suggested that I be admitted to hospital.’

Doctors told him he would get better within four to six months if he followed their instructions and took medication.

‘That four to six months has haunted me for years ... I was led to believe that my failure to recover was a result of me not trying hard enough. It left me questioning myself, “Am I just lazy? Am I putting it on to avoid responsibility, or avoid work?”’

While being treated for depression, Jerry spent 15 years completing his university degree.

‘I was still not “better” when I finished my degree and so was still not able to work and I now have a HECS debt that I can’t afford to pay back hanging over my head.’

Jerry relies on a Disability Support Pension.

‘As the months stretched into years, I watched myself fall further and further behind my peers. And in fact ... I have yet to achieve [a career and a family]. I’m not even sure if they are realistic goals anymore.’

Jerry said the original diagnosis of depression seemed to prevent his doctors ‘from considering any of [his] symptoms that did not fit with that diagnosis’.

When a friend’s child was diagnosed as autistic, Jerry asked them to ‘help [him] find the words to more clearly express what [he] was asking the doctors to do: To step back and reassess [his] diagnosis.’

A psychiatrist diagnosed Jerry as autistic with ADHD.

'I feel that if the doctors had been able to work with me as an individual, one on one, rather than pigeonholing me into boxes that I didn't entirely fit, years of stress and negative reinforcement of my already existing low self-confidence and self-esteem might have been avoided and the trauma that I experienced minimised.'

Julie

Julie has a neurodevelopmental disorder and one of her children is autistic.

About 20 years ago, the family moved to a regional area. Julie, a nurse, was soon headhunted by the local hospital.

'I was very happy when I was given a ward to run,' she told the Royal Commission.

Some years later, as a result of a medical procedure, Julie lost her upper frequency hearing.

'Since it was my upper frequency hearing, and hospitals don't use those frequencies, I was informed that there was no reason to submit for additional support at work. I definitely did not feel that my skills had been damaged in any way.'

Julie wore hearing aids at work but had difficulty wearing them at home. Her autistic child often yelled and screamed and with hearing aids the noise gave her headaches.

When Julie saw an ad promoting hearing dogs she immediately applied and was successful.

On the same weekend, the hospital offered Julie a permanent part-time job. She was thrilled and accepted the job immediately.

Kit the dog was trained to recognise 11 sounds which grew to 31.

'Mostly he was able to understand that I could not hear other people speaking when my son was screaming. I still wore my hearing aids at work with no comment nor concern.'

The organisation who trained Kit took a photograph of Kit with the family.

Julie's supervisor saw the photograph and told Julie she could no longer work at the hospital.

Julie argued her hearing hadn't changed since she last worked and Kit would be home during her shifts. Her supervisor was unmoved and refused to allow her to work.

Julie contacted her union and wrote to the anti-discrimination board who convened a conciliation hearing. She demonstrated her upper frequency hearing loss had no effect on her performance at work.

'By law I wasn't required to declare it as only disabilities that require adjustment need to be declared. You don't declare that you're an asthmatic or have ingrown toenails unless they affect your job requirements and mine did not.'

Senior staff supported Julie and told the board she was an excellent nurse and there had never been any complaints against her.

‘They wished there were more of me,’ Julie said.

The board ruled the hospital couldn’t dismiss Julie.

During the hearing one of the board members told the hospital they could only dismiss someone for not doing their job properly.

‘He basically coached them how to fire me and that is exactly what happened.’

The hospital insisted that Julie bring Kit to work and keep him in a cage. Over the next few weeks management shadowed Julie.

‘When I rang for my next fortnight shifts, I was told by the receptionist that shifts were no longer available to me, “because of the dog”.’

Julie contacted the anti-discrimination board again. This time the hospital insisted on a performance review.

‘They made a number of complaints – anonymous – and I answered their questions for over three and half hours with no break and no time out or legal advice. I knew I had not changed overnight.’

Julie’s union representative supported her during the hearing and told her she’d aced the meeting.

However when she contacted the hospital for work she was told she ‘could not work again until the investigation was complete’.

Julie hasn’t worked since and is unable to get a work reference or maintain her registration.

‘The anti-discrimination board, who is supposed to be there for disabled people, coached my boss how to get rid of me. Since then, my hearing has deteriorated and [Kit] retired ... I miss him every day.’

Derrick

Derrick has intellectual disability.

For the past 20 years he has lived in a block of units managed by a disability service provider – most of the time sharing a unit with one other resident.

A few years ago Derrick was given the opportunity to move to a unit at the back of the property and live by himself. He was able to listen to music and collect and repair record players. He took pride in his unit and loved living on his own.

Everything changed when Cath moved in.

Derrick's advocate told the Royal Commission the provider didn't give Derrick any choice about living with Cath.

From the outset Cath verbally abused Derrick. He tried to ignore her and retreated to his room. Cath also physically assaulted him, but the provider refused to intervene. Staff did their best to manage the situation. They often discussed their concern that Derrick, who is tall and well-built, may only be able to tolerate so much abuse before he retaliated.

Eighteen months after Cath arrived, the provider moved a third person, Abe, into the unit. Abe is very reserved and had experienced violence in two previous homes.

With three people in the small unit Cath's behaviour deteriorated. She regularly attacked Abe and Derrick and damaged the property. Derrick's advocate later learnt Cath repeatedly told her family and the provider she did not want to live with the men, but nothing was done.

The situation was further complicated because Derrick, Cath and Abe worked together at an Australian Disability Enterprise (ADE). Staff at the ADE reported conflict and incidents between the three workers.

One day Derrick did retaliate and pushed Cath to the ground. Derrick lost his job but Cath continued to work at the ADE, which increased tensions between them.

Soon after this Cath became unwell and her behaviours escalated drastically. She would 'explode' and the men were forced to leave their home for their own safety. For several weeks the men were forced to flee for periods of time each day. Despite requests from staff, the provider did nothing.

Then Cath assaulted staff. When ambulance and police arrived Cath ran off. Several hours later Cath returned and continued to assault staff and damage property. This time police and ambulance were able to assist and took her to hospital.

The next day Derrick's advocate supported him to make a statement to police. Police said they were unable to do anything because Cath 'was deemed as having no capacity'.

Derrick was terrified Cath would return. He required increased medication and support from his psychiatrist to manage his fear and anxiety. His advocate repeatedly argued the living arrangement was untenable. But the provider ignored her and after several months told Derrick that Cath was returning to the unit. Derrick was shattered and said, 'no, no, no'.

Derrick sought legal support and after sustained pressure the provider agreed to independent mediation.

Mediation raised questions the provider couldn't answer and Cath's return was put on hold. An independent consultant was engaged. After three months of phone calls and meetings, they determined the house was not suitable for Cath.

Finally Derrick did not have to live in constant fear and could relax.

Derrick's advocate is frustrated it took so much advocacy and legal support for him to be able to live without fear of violence. She believes the provider should be held accountable for the years of abuse and violence he experienced.

In the future Derrick says he wants 'people living in housing where they have choices with whom they live with, in a safe friendly home environment free from abuse'.

Jayden and Cadence

‘We never thought that seeking help from appropriate government services would make everything worse, much worse.’

Cadence’s son, Jayden, is under 10. He is autistic and has attention deficit hyperactivity disorder and oppositional defiant disorder.

‘When not hyper-aroused, [Jayden] can be a delight,’ Cadence told the Royal Commission. ‘However, despite much love and effort, we could not help [Jayden] sufficiently to make our home safe for his two younger brothers.’

When Jayden became violent, Cadence couldn’t find the help she needed.

‘When a crisis occurs, there is no place for parents of autistic children with behaviours of concern to turn to.’

Worried about the safety of her younger children, Cadence asked the state’s child protection service for help ‘in the hope of getting better expert advice and services’.

‘I want to make it clear that [Jayden], despite his behaviours of concern, was much loved and cared for at home ... The basis of this was not because my partner or I were neglecting or hurting [Jayden].’

Child protection ordered a review of Jayden’s circumstances and received a ‘positive assessment’ of his parents.

‘For a brief moment, I felt relieved that greater expertise would help [Jayden] and our journey would improve.’

Child protection then placed Jayden with a service provider that specialised ‘in helping children through family trauma. But, as Cadence pointed out, Jayden ‘had no trauma’, and the provider had ‘absolutely no expertise in disability’.

‘I soon felt that child protection was treating my partner and I as if we were irresponsible or bad parents, and the cause of [Jayden’s] behaviours of concern.’

Cadence said that to control Jayden’s behaviour, the service provider physically restrained him at school drop-offs and medical appointments.

‘It is beyond belief that child protection’s service provider justified to me the use of physical restraint as “therapeutic restraint”. The restraint was not “therapeutic”. There was no benefit to [Jayden]. It was simply an assault.’

Cadence said physically restraining him caused bruises and trauma.

'[Jayden] hides under his bed to seek a safe space. [He] flinches away from support workers when he is distressed.'

Cadence said the service provider conducted no behavioural assessment and child protection had no 'coherent case management plan' for him.

'If we had been provided with the evidenced-based practices that we had requested from the outset, I believe [Jayden] would have been supported to get on top of his behaviours of concern.'

Jayden was eventually reunited with his family 'because child protection realised that nothing they were doing was improving the situation'.

'Organisations like child protection need to understand the difference between parental neglect and children who display challenging behaviours as part of their disability.'

Cadence said that much of Jayden's NDIS funding was spent on the service provider that restrained him, leaving 'insufficient funding to provide appropriate services that were more likely to help him'.

'We have lost a number of years where [Jayden] could have received intensive evidence-based behaviour support ... It is incredibly distressing and frustrating to know what the next steps should be [and] to be inhibited by the very support services you entrusted your son and your family with.'

Norma

‘If you’re working with a child who has trust issues and when they get upset, you lock them in a room, on no planet would that be a good practice.’

Norma taught children with disability for more than 20 years.

‘I’ve taught in high school, special schools, high school support units, special skills, and primary school support units,’ she said.

A decade ago, Norma taught at a regional special school that was being renovated. The renovation included breakout rooms, ‘purpose built for kids to be sent with a door closed’ to control behaviour.

‘These sides [of the breakout room] consisted of metal panels that weren’t sealed at the top or the bottom ... which means, of course, they were open to the elements; the heat, the cold, and anything that would crawl in, could crawl in.’

Norma told the Royal Commission that the school placed highly anxious children alone in the breakout rooms.

‘I’ve seen kids rip their clothes, urinate all over the walls as a way of protesting about how awful [the rooms] were. I’ve been in a situation where there was a young boy that was hitting his head on the door and breaking the Perspex. It didn’t shatter it, but it sort of started to break up.’

Norma told the school’s principal to let the boy out.

‘She virtually said, “Well, you’re on your own there ...” and I said, “Well, okay then, you leave.”’

Norma put toys on the floor, and opened the door. The boy went to them and calmed down.

‘[Breakout rooms are] ineffectual because you were never allowed anything in there with them. So, there was no hope that they would be distracted. There was no calming. There was no sensory items. There was nothing except a metal box.’

Norma said teachers were required to record each incident, but it appeared nobody used the records to assess whether the breakout room ‘was useful or not’.

She said although some students did need to be physically restrained occasionally, the school taught the staff inappropriate methods. Norma said the school trained her using a program designed to restrain male American prisoners.

‘Which is not the demographic we use it for. We’re using it for very small people ... I’ve seen kids being restrained with two people either side for maybe 50 minutes. That is way, way too long.’

The school asked parents enrolling their children to consent to having them restrained, but Norma said many parents didn't understand what that involved, or felt they couldn't refuse.

'A lot of these parents are desperate. They're scared that their child is going to be expelled or removed from the school ... They're vulnerable themselves and that's becoming more and more evident as the face of disability is changing, we're getting more parents unwell and have their own issues. They're not in a position to take on the school.'

Norma said children enrolled in special schools increasingly showed signs of trauma.

'These students are coming from a place of mistrust. They don't trust adults because, to be quite honest and this is really blunt, most of the adults in their life have just fucked them over, really.'

Special education teachers need trauma-informed training, Norma says, not breakout rooms.

Dallas

Dallas is autistic and has an eating disorder.

Now in their 20s, Dallas was a high achiever at school and enjoys art and reading.

Dallas began to lose weight dramatically after starting high school.

'I had lost about 21 kilograms in total in a short period of time,' Dallas told the Royal Commission.

'Your brain, with the dysmorphia, it tells you [eating] will have this balloon effect and your brain will tell you that you will put on five kilograms if you eat a sandwich.'

When Dallas's health deteriorated, doctors admitted them to a hospital paediatric unit where the nurses 'didn't have much training' in eating disorders.

'I remember hearing the nurses on different shifts saying, "I have the eating disorder girls." That made me feel like I was nothing but my illness.'

Dallas, who now identifies as queer and 'at the time identified as a lesbian', said a psychiatrist told them they would 'get better' once they got a boyfriend.

The psychiatrist prescribed antidepressants and discharged Dallas. A change to the medication then 'led to a decline in [their] mental state'.

'My brain just felt like it was being shredded. It was just coming apart. I collapsed on the floor in the kitchen. Mum asked me if I needed to go to the hospital and I said yes.'

They were admitted to a hospital psychiatric ward.

'If you have an eating disorder and you present in that level of distress, you don't get to go in the eating disorder unit; you go into the psych ward. Psych wards have no training in, or understanding of, eating disorders.'

Dallas was given antipsychotic drugs and became suicidal.

'One of the nurses took me into a medical room and they just give you more medication. I was sobbing saying I didn't want to be alive and she told me suicide is the coward's way out and that I was being weak.'

After six months on a waiting list, Dallas was admitted to an eating disorder clinic.

'They had daily activities, occupational therapists, writing therapy, poetry. We had a wonderful psychologist who would come in and we would do classes on different psychology stuff.'

Educating us about it as well as giving us strategies for ourselves.'

That support helped Dallas take control of the eating disorder.

'This one psychologist would take me to the kitchen and work with me to make my sandwich. At meal times sometimes she would bring her own lunch and eat with us. This normalised having lunch and having a varied lunch.'

Dallas said the difficulty now is getting a job.

'It can ... be difficult when you apply for jobs and they just look at your resume and say no. You can't say, "These are my barriers," and "This is why I have these gaps [in the resume]".'

Martha, Mallory, and Julian

Martha, in her 40s, has intellectual disability, depression, anxiety and post-traumatic stress disorder.

‘Because of all I have been through ... I will have to take medication for the rest of my life,’ she told the Royal Commission.

Martha said her father sexually assaulted her when she was very young, while her mother ‘was in the same room laughing’.

‘I used to get physically abused by both parents.’

When Martha wet the bed her mother put her in a cold bath or her father sprayed her with a hose. When she argued with her sister, she was locked in a shed.

Martha said that both her parents were alcoholics.

‘And when my mother got drunk she used to bite me and pull my hair. I used to get smacked with the jug cord and wooden spoons really hard and then sent to my room. I didn’t know what I had done wrong.’

After Martha’s parents separated, her mother’s new partner raped her and her sister.

‘He even pointed a gun at us once and said if we told anyone he would shoot us. I eventually told mum and she didn’t believe me and then kicked me out of home.’

Martha was placed in foster care. She moved between foster families and was sexually assaulted again.

‘While my foster mother was at work, her husband was sexually abusing me. I eventually went out one day and rang the police from the phone box. They came and interviewed him. He wasn’t allowed to be alone with me after that.’

Martha continued to live with the family for another six months.

‘Nothing really happened to him because it was his word against mine ... I was never even offered any counselling or anything.’

When Martha left foster care, she began abusing drugs and alcohol.

‘I felt that I wasn’t worth anything because of what my family had put me through.’

Martha gave birth to her son, Julian, in her mid-20s.

‘He was a beautiful little boy, I loved him so much.’

But Julian died in an accident when he was a toddler.

‘I remember saying to the ambulance guys, “No, he can’t be dead.” ... That was the hardest day of my life.’

Martha met someone else and had a daughter, Mallory, who is now a teenager.

‘I love her to the moon and back. Her father and I are no longer together, but we are really good friends.’

Martha now works with an advocacy group for people with disability.

‘The message we are trying to get out is that parents with an intellectual disability can be caring and capable parents. I know this because I am one.’

She said her experiences have made her a stronger person.

‘I want to say that’s the end of my story, but I think it’s only just beginning.’

Ariya

Ariya is in her late 30s.

Throughout her childhood, she told the Royal Commission, she was physically and sexually abused by male family members.

By the time she was in her 20s she was dangerously underweight. She was diagnosed with fibromyalgia, osteoporosis, periodontal disease, post-traumatic stress disorder, anxiety and depression. Her father wouldn't allow her to get help or support and continued to expect her to work in the family business.

'When I was physically unable to work, I would be beaten.'

Eventually Ariya became so unwell she was admitted to a clinic to gain weight. She said she was 'lucky to leave the family home alive'. She learned to 'normalise' her eating and manage her 'extreme anxiety'.

After she was discharged from the clinic she did not feel safe going home. Instead she went to live in a nursing home.

'I naively assumed that I would be safe. Unfortunately that was not the reality. While I was in the nursing home, I endured horrendous treatment, was bullied by the staff, denied the recommended food to assist with weight gain and frequently denied access to drinking water.'

After four months Ariya left. She was 'financially destitute' and had no choice but to go home. Male family members continued to 'physically, psychologically and emotionally' abuse her.

A few years ago, she inherited some money and was able to buy her own ground-floor unit.

The owners' corporation held meetings on the top floor of the building – there were no lifts.

Ariya struggled to attend the first meeting. She told them she had a physical disability and asked if they could move the meetings to the ground floor.

The chairperson told her 'we always have the meetings upstairs'. Ariya questioned this decision and tried to explain her disability. They dismissed her by telling her she was 'overly anxious' and needed to 'manage her anxiety'.

Ariya's psychologist wrote to the owners' corporation explaining her 'physical distress to have to attend meetings on an upper floor'.

Ariya said the other owners interpreted her disability as a cognitive disability and as an inability to contribute in a worthwhile and equal manner.

‘The fact that I did disclose my disability has seemingly worked against me.’

Ariya believes her issues are routinely ignored and she ‘isn’t given a fair hearing’. For example, tree roots are blocking Ariya’s sewerage pipes. She needs the owners’ corporation to get a plumber’s incursion report before the council will allow her to remove the tree. Despite repeated requests, the owners’ corporation refuses to take action.

Ariya recently nominated to become a committee member. The chairperson informed her it would cause her ‘too much stress’ and he found her ‘too combative’. He also told her she uses her disability ‘as an excuse for expecting special and privileged treatment’.

‘The owners’ corporation seem to wield a lot of power and not always, on the face of it, in the overall best interests for all the tenants, especially so for someone who has a disability.’

Ariya’s mental health has deteriorated.

‘I now live in my own home, fearful, powerless and lonely.’

Ariya wants a ‘safe and secure life’, to be taken seriously and treated with dignity and respect.

Jared and Ivan

Jared is in his 50s and has severe dyslexia. He can't understand big words or complex sentences.

A couple of years ago, police arrested Jared for trespassing on a derelict property.

Ivan, Jared's cousin, told the Royal Commission that Jared had seen lights at the property and 'was curious'.

'Naturally, he regrets this now,' Ivan said.

Ivan said footage from a police body-camera during his arrest showed Jared telling the police several times that he was dyslexic and having trouble understanding what they were saying.

'They failed to ... take this into account and ensure that he understood his rights and what he was being arrested for.'

During Jared's arrest and a later recorded interview, the police didn't tell him he had a right to have a support person present.

'Persons with a disability need to be actively made aware of this right,' Ivan said.

'Even in a case where a person is not visibly or noticeably disabled on a surface level it is essential that the police still make them aware of this fact, as many disabilities may not be immediately distinguishable to the untrained eye.'

Ivan lodged a complaint with a human rights commission, which organised a meeting with the police.

'But this meeting was unfortunately voluntary and they opted not to attend. The matter was subsequently dismissed.'

Ivan lodged another complaint, with a corruption watchdog, which six months later referred it back to a police misconduct unit.

One day, a police officer knocked on Jared's door.

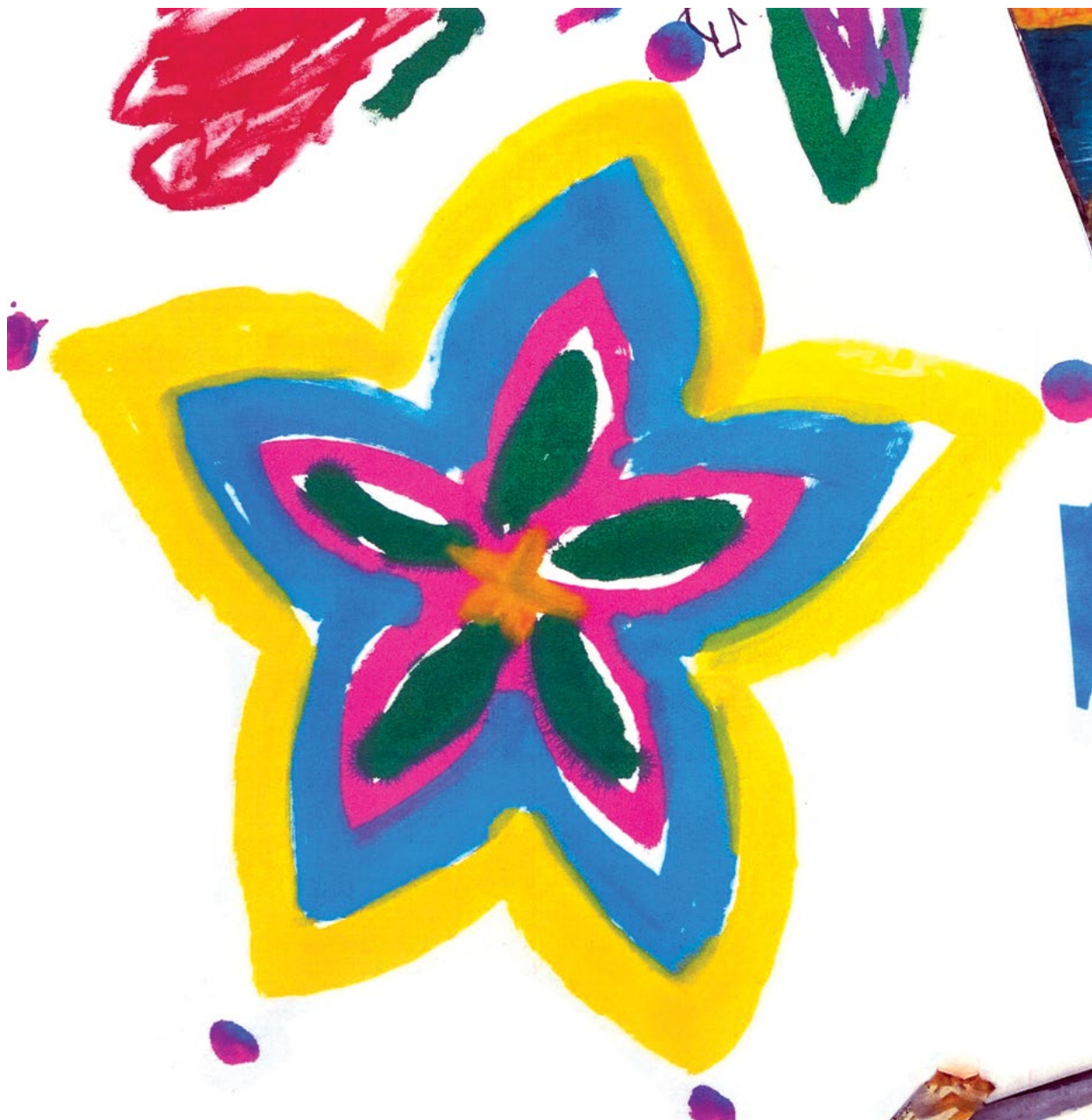
'[They] seemed to intentionally speak to [Jared] at a time when he had been isolated from myself – despite the fact that I was the one that lodged the complaint,' Ivan said.

The officer later questioned Jared's need for a support person and Ivan's authority to act on Jared's behalf.

‘The exhausting battle I have endured to try and have my concerns about [Jared’s] treatment listened to has been disheartening and fruitless, ridden with bureaucratic failure and a severe lack of empathy and care.’

Ivan withdrew the original complaint because it was causing him stress.

‘It is not as if I have been seeking anything significant or abnormal – a mere acknowledgment of my complaint and the issue it represents is all I have asked for.’



Artwork by Artist Unknown

Antonio

Antonio relies on his service dog, Bruno, for most day-to-day activities. Bruno opens doors, retrieves objects, turns appliances on and off and helps Antonio stand, balance and get ready for bed. Because of Bruno, Antonio has more stamina, improved mobility and greater confidence when he's out in the community.

Antonio bought Bruno in the US. He told the Royal Commission he immediately noticed people responded to him differently because he had Bruno. Instead of giving him piteous looks or comments, people engaged him and Bruno in conversation.

When Antonio moved back to Australia he needed Bruno to travel with him on the plane. But the airline wouldn't accept Bruno's US service certification.

Antonio contacted every dog certifier in each Australian state but no-one would certify Bruno without seeing him. Despite having videos of Bruno demonstrating he exceeds US and Australian standards, Antonio couldn't persuade anyone to give him even provisional registration.

Without Australian certification, Bruno had to travel as airline cargo and quarantine for 10 days in a facility with regular dogs.

Bruno's absence during this period severely affected Antonio. In addition to being without day-to-day assistance, Antonio needed to retrain Bruno. Bruno became overenthusiastic in response to other dogs, forgot he was working and needed a large amount of redirection to focus. Antonio estimates this took 16 months.

Antonio hoped once he was in Australia the certification process would be simple. But he says it's almost impossible. Most organisations are under-resourced and do not certify dogs who are not part of their programs. Antonio is still waiting for some companies to respond to his enquiries.

Without Australian certification Antonio is often refused service.

Once, at Centrelink, a security guard told Bruno to leave because he didn't have the state's service identification. Antonio showed the guard Bruno's US certification documents. He then had to show him vet records, medical evidence and evidence of his need for a service dog. The security guard went through the documents 'with a fine-tooth comb' and after 15–20 minutes Antonio was allowed to re-join the queue.

'The words and actions of the security guard were over the top.'

Antonio said the treatment he experienced 'brought back feelings of embarrassment and frustration at the level of discrimination'. Antonio's wife was with him and commented she 'felt very unwelcome in the Centrelink customer service centre'.

The lack of awareness and acceptance of the use of service dogs is also a barrier to employment.

Because Bruno isn't allowed on some premises, Antonio is unable to attend meetings with colleagues and clients. He has problems flying domestically because of the US certification and he has also experienced problems accessing some train services.

'There is nowhere to escalate the problem of access issues for service dogs in Australia,' Antonia said. 'There needs to be a chain of command and appeals process to seek redress'.

Antonio would like reciprocal certification standards between Australia and other international countries, and community education about the value of service dogs.

When Antonio is with Bruno he said people 'see him more as a person' rather than focusing on his disability. He appreciates being seen for who he is – 'someone who is capable, professional and approachable'.

Riley

‘Overloaded, overstimulated and feeling like just a steady stream of income ... As a disabled person, I felt like a number.’

Riley is in his early 40s. He told the Royal Commission that when he was in his 30s he became homeless after a relationship broke down. Living on the streets exacerbated his epilepsy and depression and he started having suicidal thoughts.

Riley moved interstate hoping to live with his father. His father refused to have anything to do with him because Riley is gay. He marked all Riley’s Centrelink mail ‘return to sender’.

Centrelink cut Riley’s unemployment payment and he became homeless again, with no money for medication or food. He had multiple seizures and became malnourished and dehydrated.

‘My memory of this period in my life is virtually non-existent.’

Eventually Riley was admitted to hospital and a psychiatrist diagnosed him with bipolar disorder. An MRI scan revealed he’d suffered a small stroke while he was homeless, affecting his mobility.

After he was discharged, he went to live in a supported accommodation facility for people with disability and people with substance abuse issues. For the first time Riley started receiving disability supports.

Riley said his biggest issue during this period was being surrounded by competing health care professionals – he felt ‘like a commodity’. Social workers wanted him to move out of the supported accommodation. Psychologists wanted him to stay. Riley’s psychiatrist wanted him to attend appointments on the days he had regular employment agency meetings. His support worker wanted him to go to the movies twice a week to meet his ‘social companionship goals’.

‘I was pulled in six different directions, feeling beholden to, and guilty about, attracting so many lovely and well-meaning people into my life. Everybody, it seemed, was competing for my attention to ensure they got paid.’

Riley said he didn’t feel supported but used. Organisations started using him as a photo opportunity because he is ‘well presented’ and ‘sounded educated’. He was paraded at seminars and support groups for gay people, people living with depression and people with cerebral palsy.

‘Honestly, being disabled felt like a full-time occupation.’

However, Riley wasn’t getting the support he needed. One time he was in extreme pain because of a toothache, but his disability support worker wouldn’t drive him in the company car to the dentist. The support worker prattled off a list of reasons but none of them made sense. It seemed the support worker’s role was to keep him company – not actually support him.

'The service they provide is ephemeral and tokenistic.'

Riley has become cynical about disability support.

'The relationship between the disabled client and disability support worker is based on obtaining signatures on contracts, not really about measurable outcomes or improving quality of life for the disabled.'

Rory and Esme

‘There isn’t a day goes by when I am not worried about what will happen to my brother.’

Esme’s brother, Rory, is in his 50s and has an intellectual disability.

Rory was made a ward of the state when he was a child, and placed in residential care in a regional town a long way from where his parents lived.

‘[He] was cut off from his family as our parents couldn’t drive. I still remember my mother ... crying, I never thought she would stop. I live with that memory.’

Esme said Rory once had a seizure in care and ‘almost died’. His care provider didn’t tell Rory’s parents until ‘months later’.

About a decade ago, Rory transferred to a group home closer to where Esme lives. One of the other residents, who was ‘known to eye gouge’, attacked Rory.

‘The other client went for his eyes and the gel in my brother’s eye was hanging down his face when another worker came in next morning and found out that my brother was left that way overnight.’

Rory’s doctor asked the public guardian to investigate the incident, as it ‘had happened so many times in the past’.

Esme said the investigation concluded that the home was short-staffed.

‘There was only one staff to manage the three clients and my brothers’ room and bathroom was upstairs.’

Another time, Esme thought her brother had a seizure. She learned later that it was a heart attack.

‘It took them a couple of years to tell me ... and I have been fighting [the care provider] since. It is like hitting my head on a brick wall.’

Esme said she saw a senior staff member verbally abuse Rory.

‘I am sure abuse goes on, but I am never told unless my brother tells me. Most of the time he is too scared to tell.’

Rory developed skin cancers and needed regular check-ups, but staff missed an appointment.

'After that I took over booking his appointments for his skin cancer. I am happy to say that I have kept on top of his cancer every three months. He now has had cancer spots frozen off. I feel that if I had left this up to [his care provider] I would hate to think what would have happened to my brother.'

Esme said she applied several times to be Rory's guardian, but 'every time [she] gets knocked back'.

'I am sure it is because [the provider] has blocked me,' she said.

'I feel my hands are now tied, I am not his carer; I am his next of kin and I don't have much rights to protect my brother ... Everything I do for my brother is not easy, it is a battle every time.'

Esme fears for people with disability in group homes who can't speak and have no family to advocate for them.

'I have seen things get worse in disability since the NDIS has rolled out, now I can say this is not about duty of care it is about money and I am sure this isn't only [Rory's provider], it is right across the disability sector.'

Tash

‘Chemical restraint and seclusion are absolute punishments. They are not therapies to help calm patients.’

In the early 2000s Tash was ‘extremely depressed’ and tried to take her own life. She was admitted to a hospital psychiatric unit under a treatment order.

‘This was my first real stay in a psych ward and I was very frightened,’ she told the Royal Commission.

Tash was in her late 30s.

At the end of her first week she experienced a thyroid storm which was misdiagnosed.

Instead of receiving treatment, the psychiatric registrar placed Tash in seclusion.

‘I was slapped in the face by a wardsman, who then kicked my legs out from under me ... then forcibly carried me to a seclusion room and held me face down.’

Tash said he pushed his knee into her back and she was ‘gasping for air’.

‘The registrar then injected me in the shoulder with a chemical that totally immobilised me such that I couldn’t move or speak.’

The staff then left the room and locked the door.

‘I cannot describe the level of panic I felt.’

After about half an hour the registrar checked on Tash and suspected ‘some deeper trauma’.

Blood tests revealed Tash needed an emergency thyroid ablation.

When Tash was discharged she complained to the hospital about her treatment but the doctor defended her actions.

The doctor said the thyroid problem wasn’t diagnosed before it became an emergency because there was a delay in receiving Tash’s blood test results.

The restraint and seclusion had been used as a last resort and while the doctor regretted Tash saw it in a negative light, ‘it had all “worked out well” in the end’.

But it didn’t work out well for Tash.

Tash said the treatment ‘deeply added to the trauma I was already suffering’.

When Tash was in her late teens she had been repeatedly locked in a small room, beaten, restrained and then left alone.

‘Many horrible and disgusting things were ... done to me.’

This included being ‘threatened with electrocution and murder if I spoke to authorities, at one time being strapped down and wired up with electrodes to intimate parts of my body’.

After about four months the police became involved.

Tash said she was shocked by the parallels between these two incidents.

Both included ‘slapping, tackling, being held face down, restricted breathing, absolute restraint, and being locked into a small room not knowing what was going on or what was going to happen to me’.

Tash no longer trusts psychiatrists and said she needed counselling ‘to get over what the psychiatric system did to me’.

Tash’s believes seclusion and chemical restraint never benefit patients and are only used to make patients ‘shut up and shut down in under-resourced and unpleasant working environments’.

She would like these ‘treatments’ to be banned. If they are used, ‘then the psychiatrist or registrar must be held to account’ and each incident must be investigated by independent authorities.

Theodore and Stevie

‘Is it right that the prison system is filled with chronic mental health patients who break the law because of their mental illness? Is it right that people with mental illness are incarcerated in the prison system for the behaviour that stems from their mental illness?’

Stevie is a First Nation’s woman. Her son Theodore, in his 30s, is autistic and has Tourette syndrome, obsessive-compulsive disorder, attention deficit hyperactivity disorder and autism.

When Theodore was in his mid-teens, a doctor gave him antipsychotic medication that Stevie said was ‘working well at stabilising him’.

When he turned 17, he asked a new psychiatrist if he could come off his medications. His psychiatrist said yes.

‘There was nothing I could do because he was considered old enough to make his own decisions,’ Stevie told the Royal Commission. ‘Looking back, this was really the beginning of a severe downward spiral for [Theodore].’

Theodore never saw that psychiatrist again, began self-medicating with illicit drugs, and lived on the street.

‘[Theodore was] at his worst with drug addiction and mental illness. He was charged with armed robbery and incarcerated for three and a half years.’

Stevie said Theodore received good psychiatric care in prison, where he was diagnosed with schizophrenia and given antipsychotic medication again. Once out of prison, the parole system organised housing and the NDIS gave him a treatment plan and a support worker ‘who was excellent’.

Theodore admitted himself to rehabilitation for his drug addiction. The rehabilitation centre gave Theodore a tele-consultation with a new psychiatrist.

‘The outcome of that one tele-consultation was that [Theodore] was taken off his medications.’

Stevie said this was against the advice of Theodore’s regular psychiatrist and psychologist, his GP and the mental health team that had been treating him since prison.

‘This marked the beginning of another severe deterioration of [Theodore’s] mental illness, the consequences of which are still playing out.’

Stevie said Theodore developed an ‘ongoing delusion’ to steal and crash cars ‘so his parents would not be killed’ and he would be returned to prison where he would be safe.

After stealing and crashing numerous cars, he was returned to prison.

'It seemed that his car stealing behaviour was deemed criminal ... not as a result of psychosis.'

Stevie said a pattern followed in which Theodore was released from prison, admitted to mental health units and discharged 'far too early'. He would then commit a crime, and be jailed again.

'I don't blame the prison system for having to take him in because of his crimes. I blame the mental health system for not being able to provide the care he needs, to keep him safe from himself and his psychotic episodes, and prevent him from committing crime.'

Cecelia

Cecelia has epilepsy and experiences headaches and memory loss as a result of domestic violence.

Her partner began assaulting her more than a decade ago. After he started assaulting their children, she stabbed him.

'I just couldn't get out of the relationship ... He'd beat me up when I'm drunk and then he bashed me and raped me ... So I thought I'll put a stop to that. He used to bash up my kids, too.'

Cecelia's partner survived. Their children were taken into care and Cecelia was sent to jail.

Cecelia told the Royal Commission that not enough is being done to help women avoid domestic violence.

'If they can give more help on the outside for women that get bashed, raped and all that. Give them a safe place, especially to get them away from wherever they are, fly them out or fly them somewhere, get them away from their partner.'

She said in the regional community in which she had lived, women often believed that domestic violence was their fault and didn't talk about it. It wasn't until she was in jail that she received help and attended courses to help improve her self-esteem.

'Women from the community need to open up more, tell others, let them know, like to other people, open up. So I think in here, we need more help for ladies, all of us in here. We need to do some kind of a course to make ourselves more empowered for when we're partnered outside.'

Cecelia would like to see more services available for women to help them leave abusive partners, as well as providing alternatives for women in jail, if they are returning to homes that are unsafe. Cecelia had chosen not to return to her regional community after being released on parole a few years ago, and became homeless.

'There was nowhere to go, I had no families to help me.'

When she asked domestic violence support services for help finding accommodation she was told she did not qualify because she was already homeless.

'They would try to help by ringing around to find a place to stay for a night or two and then you get a message back saying there's nothing available, do you have any families?'

While homeless Cecelia was admitted to a hospital mental health unit, which referred her to a neurologist for surgery.

Cecilia returned to jail before she could receive treatment.

Greg and Oline

‘I don’t know where to turn because everyone seems to think [psychotropic] medication is the only answer.’

Greg has a rare chromosomal disorder resulting in a cognitive disability and behavioural problems.

His mother Oline told the Royal Commission his behavioural problems have increased over the years.

Oline said Greg, now in his early 40s, is usually a happy person with a great sense of humour. However, this can change in an instant and he will yell, scream and self-harm.

Doctors and family members want Greg to take large doses of antipsychotic medication each day.

But Oline is opposed to this. She said the medication turns Greg into a zombie and he sleeps all day and night.

‘This is very peaceful but not a very good solution. He can’t live like this.’

Often Greg’s outbursts only last a few hours or days.

‘If he was on medication I would never know when he was okay,’ Oline said. ‘Even though these episodes are stressful for me, continual medication is not the answer.’

Doctors believe continuous medication might prevent Greg having psychotic episodes.

But Oline said Greg has only had a few psychotic episodes in his life. These can last from two to four weeks.

‘He goes for walks and throws things and yells,’ Oline said.

Not long ago Oline went on holidays and Greg had an episode while he was staying with his dad. By the time Oline picked him up she could see he had been overmedicated with antipsychotics.

Oline took him to the doctor who gave Greg another prescription. The pharmacist listened to Oline and suggested Greg reduce the medication until he was off it.

‘Within a couple of weeks he was back to his old self.’

Oline is not against Greg using medication. She knows he needs certain drugs to calm him down when he can’t regulate his behaviours.

Recently Greg needed to go to hospital for a general anaesthetic for dental work. They live several hours from the hospital and Greg needed to be there at 7.30 am. Olive wanted him to be admitted the night before so they could give him some premedication to calm him before the procedure the next day. But the hospital refused and Greg and Oline stayed the night in a motel.

‘This proved to be a traumatic time. He got out of the car and ran down the street and it took over an hour to get him to the motel room. I was worried he would run out on the road.’

Greg continued to scream and self-harm during the night.

Oline wants alternatives to psychotropic medication.

‘Behavioural support is helpful but does not solve the problem. I would like to know what’s causing it. But doctors are too quick to prescribe medication,’ she said.

Joey and Carmen

Immediately after Joey was sent to prison his lawyers came to visit.

The lawyers booked an Auslan interpreter – Joey is Deaf – for the hour's visit. They introduced themselves to prison staff and waited at the front desk.

After 40 minutes the lawyers asked staff if there was a problem.

'Apparently the staff had called [Joey] over the loud speaker,' his mother Carmen told the Royal Commission, 'which of course [he] couldn't hear.'

Two weeks later Joey was waiting to see a psychologist.

A professional looking woman came into his cell and sat down. She started speaking to Joey who signed he was deaf. After a few minutes the woman walked out of the room.

Carmen said the woman never returned and no-one explained who she was or what was happening. Joey continued to ask to see a psychologist. He told staff, 'he was not doing well mentally,' Carmen said.

'There was a misinterpretation or misunderstanding and staff thought he wanted to commit suicide so they locked him up in confinement for four days for 24 hour monitoring. He was very frustrated until he got his message through.'

Prisoners who aren't Deaf or hard of hearing are entitled to a daily phone call.

If Carmen rings Joey, staff will not pass on messages. She has to use the prisoner email system. But emails can take up to 10 days to arrive.

'If I need to talk to him regarding booking in visitors or court issues, I cannot inform him on that day.'

Lawyers also can't telephone Joey and have to see him in person. It is often difficult and has become very expensive for Carmen to find and pay for interpreters.

Carmen said there are many other issues that make Joey's life in prison harder than prisoners who aren't hard of hearing.

He has repeatedly asked to get subtitles on TV which still hasn't happened. He asked to do a course of study but they have refused because there is no interpreter. Joey also asked to work in the factory with the other prisoners but they said this isn't possible because of workplace health and safety issues. When there are changes to the mealtimes or the daily schedule the announcements are made over loudspeaker and no-one informs Joey.

‘One day he was not informed – said over loudspeaker – of 5 am breakfast and went to court and not had water and anything to eat till 12 pm after court. How is anyone meant to have a sharp mind in court with nothing to eat or drink in 15 hours?’

Carmen wants the prison to address the discrimination. She has contacted the warden, specialist service providers and the NDIS, but says she has not had a response.

‘This fight is not only for our son but any inmates now or in the future, who may have hearing impairment.’

Kendrick and Matthias

Kendrick is in his early 40s and has intellectual disability.

He lives with his mum and dad and has received NDIS funding for several years.

Matthias, Kendrick's father, and his wife are in their 70s. Matthias told the Royal Commission they are looking for out-of-home accommodation, to set Kendrick up to 'live an independent life'.

About a year ago, Matthias asked the NDIA to review Kendrick's plan and include specialist disability accommodation (SDA) funding. He also requested a modest increase in funding to support Kendrick during the transition. He supplied four independent medical and behavioural specialist assessments as part of the application.

The NDIA not only refused to increase support funding, it reduced Kendrick's core funding, telling Matthias they didn't accept the medical evidence he provided.

'Decisions on funding are made by someone in an office that has no contact or knowledge of the client's needs,' Matthias said. '[The NDIA] asks for these reports – which cost money and take no notice of them.'

Matthias asked for a review of the decision.

Meanwhile the NDIA approved SDA funding. They sent another plan, this time for two years. However 'there was no amount of funding in the SDA component' and the agency had further reduced Kendrick's core funding by almost \$60,000.

Matthias was shocked.

'To have funding reduced, this puts further health and mental stress on the carer or parent when they have to try and maintain the level of support for [their son] to allow him to live a life [he is] entitled to.'

Matthias asked for a review of this decision but was told he would have to wait two to three months for a decision about whether he could have a review.

'We think that [the NDIA] has lost its direction and has become more of a bureaucratic mess. It is more interested in the administration than the wellbeing of the disabled.'

He advised the NDIA he would take the matter to the administrative tribunal. He said the agency tried to 'bully' him into accepting the new plan, telling him that taking it to the tribunal 'would cost a fortune'.

Matthias has since found out the administrative tribunal process is free.

‘We’ve been misinformed so much.’

While the process runs its course, Kendrick doesn’t have a plan and his funding is running out.

‘We think this is a form of exploitation and abuse on the part of the NDIS.’

Matthias said he is frustrated by the delays, the waste of money and the confusing process.

‘We ended up having five reviews and it’s still not settled – we ended up losing a third of his funding.’

Tabitha and Valerie

Tabitha, late 20s, is autistic. She is trying to find employment so she can be independent. She and her mother, Valerie, told the Royal Commission about their frustrations with job placement services.

‘The centre refuses to match me with an appropriate job that suits my needs,’ Tabitha said. ‘This has happened several times.’

She feels like the agency is exploiting her to get funding from the government.

Valerie agrees, and says job placement services are an in-name-only service that do little to provide for the unique job needs of people with disability. She believes the financial incentives they receive encourage roting and inappropriate activity.

Valerie helped Tabitha submit a complaint to the job centre about its ongoing inability to secure her a suitable position.

Tabitha said, ‘We were fobbed off and told “a job is a job”.’

Valerie was also ‘very unsatisfied’ with the outcome.

‘It seems the job provider is more interested in the number of people on their books rather than what those people need.’

Valerie would like to see improvements in the regulation of job service providers so they are not simply acting on financial subsidies.

‘And the same goes with employers.’

Valerie said she is yet to meet a client who has had a positive experience with their placements.

Tabitha says the ongoing experience has left her emotionally vulnerable.

‘Too many unsuccessful job interviews and applications make for a negative impact on mental health both for the client and their family,’ Valerie said.

Lewis

Lewis, a First Nations man in his 30s, has intellectual disability.

He grew up in a regional community.

‘There was a lot of alcohol and drugs, a lot of criminal activity going on around me. A lot of violence. It wasn’t very good for a kid ... [I] had a hard time as a young fella.’

When he was in his mid-teens, a court sentenced Lewis to several years in prison for sex offences.

‘As a person with a disability, it was tough, rough,’ said Lewis. ‘Not good for anyone who’s got a disability, never taught me anything.’

Lewis’s lawyer told the Royal Commission that when Lewis was released after serving his full term, the state imposed an extended supervision order for another decade.

‘The conditions [of the supervision order] appeared to be punitive mechanisms of lifestyle control. The conditions imposed curfews. They controlled [Lewis’s] movement, which prevented him from visiting family and other members in his kin network.’

Lewis’s intellectual disability made it difficult for him to understand the terms of the supervision order. His lawyer said ‘the state was made aware’ of Lewis’s ‘low risk of sexual re-offending’ and that the supervision order was causing harm.

Lewis told the Royal Commission correctional department officers would visit to ‘check in’ and try to trick him into revealing breaches, such as visiting his mother. As a result, he was sent back to jail more than a dozen times.

‘They [the state] should be helping the people, not trying to breach them and trying to blackmail them, bully them, lie to them to benefit themselves,’ he said.

One time, after being sent to prison for breaching a curfew, Lewis became addicted to methamphetamine.

When he wasn’t in prison, Lewis attended art classes. He held an exhibition and sold several paintings, but breached the supervision order again and was jailed.

Lewis was in jail when a court found that the supervision order was punitive and ‘contrary to law’.

He said it was the first time he’d felt like ‘a free man’.

'I can actually sit down with my mum, sister, brother, uncle and cousins. I can go out bush and see all my family. They all haven't seen me properly since I was 16.'

The NDIS has since helped Lewis find a support network and cultural programs to help him continue his rehabilitation through art and contact with his family.

Zain and Toni

Zain, pre-teen, is autistic.

He recently needed to have dental surgery in hospital.

Zain's mother Toni told the Royal Commission her son is particularly anxious about needles and 'the unknown'.

They attended a pre-surgical clinic, so the anaesthetist could explain what would happen on the day of the surgery.

The anaesthetist used words like 'magic rocket and magic fairy dust' to describe the anaesthetic. This confused Zain and Toni asked her to use 'the proper formal words'.

The anaesthetist told Zain he wouldn't feel the needle because they would rub a numbing cream on his arm. She also assured him Toni would be in the operating theatre with him.

In the week leading up to the surgery, Toni repeated these assurances to prepare Zain for surgery.

On the day of surgery, one of the anaesthetists rubbed the cream on Zain's arm then began to apply a bandage. Zain wasn't expecting this. He doesn't like bandages being removed and became upset. Toni asked if she could hold the bandage in place. The anaesthetist said they were 'different bandages' and Zain wouldn't feel anything. But he did feel the bandage 'being lifted' and started crying.

The anaesthetist then made several attempts to insert the needle but couldn't find a suitable vein.

'I have never seen his face contort like that in pain and his tears flowed with the pain of it all.'

Toni told Zain he was being a brave boy and asked if there was an alternative to the needle.

The senior anaesthetist introduced herself and mentioned there was a drink that had a similar effect. But it needed to be given 45 minutes before the operation and they would need to reschedule the procedure. Zain didn't want to do that.

Toni asked the senior anaesthetist to 'give it one more try and then stop'.

The senior anaesthetist inserted the needle and found the vein the first time.

Toni couldn't understand why she hadn't done this at the beginning considering Zain was already upset and they knew he was autistic.

'I was comforting him and telling him the hard part was over now when the head anaesthetist told them to undo my gown.'

Toni wasn't allowed in the operating theatre.

'This was a huge change in the plan, and we were not given an explanation for the change.'

Zain was very upset after the operation.

He told Toni, 'I couldn't breathe when they put the mask on my face – I told them, but they did not listen to me. I couldn't breathe mum. Where were you?'

Toni wants a greater awareness of the needs of autistic children.

'I believe there may be a gap between autism and the anaesthetic area for surgery – especially pre-surgical clinics.'

Kole

‘I cannot remember a time in my life that I have not experienced some level of abuse, neglect or violence.’

Kole, in his late 30s, was born with cognitive disability.

He told the Royal Commission that when he was a child his father verbally and physically abused him daily for ‘the smallest of things’.

Kole said he acquired short term memory loss, a vision impairment, anxiety, depression and post-traumatic stress disorder as a result of his father’s abuse.

At school, teachers ridiculed Kole for answering questions incorrectly or being ‘too slow’ to answer. They ignored his ‘pleas for help’ and ‘turned a blind eye’ when students verbally and physically abused him. He went to school ‘fearful and apprehensive’ about what might happen to him that day.

Kole felt like ‘a second class citizen’ at school and never properly learned to read or write. He said he’s too frightened to trust someone to teach him these skills now.

Neighbours have abused and belittled Kole. One neighbour regularly swore at him, calling him ‘bludger’ and ‘loser’. Whenever he reported the abuse to property managers over the years they ignored him or told him, ‘he was the problem’.

A support worker recently ‘rough handled and assaulted’ Kole. He reported the abuse to the support coordinator but Kole said they did not take his complaint seriously. The coordinator gave him a new TV and told him to ‘forget about it’.

Centrelink has accused Kole of misreporting his living arrangements. They told him they had a letter signed by him proving he was living with another person. As Kole can’t read or write he said he couldn’t have done this. He was forced to repay a debt that was ‘not his to pay’ and he feels his reputation has been badly damaged.

Government could lead the way in changing the way people view and treat people with disability, Kole said, by increasing the amount of the Disability Support Pension (DSP).

Living on the DSP is akin to living on the ‘poverty line’.

‘I cannot afford many of the things that others regard basic ... like eating a steak ... not to mention having enough to visit friends or take part in the community.’

Kole has no savings and struggles in emergencies. He cannot afford to go to the major retail stores and was unable to buy shoes when thrift shops closed during COVID-19.

'Where I am meant to go?'

Kole contacted his local member of parliament to raise his concern about the DSP and the cost of living. He expected 'a listening ear and maybe even compassion' but was told to budget better.

'All I am asking for is to be given "a fair go". The NDIS is good step towards achieving this but the daily struggle trying to live on a pension that is not linked to a standard of living enjoyed by most Australians is a major barrier to a fulfilling and productive life.'

Kole feels government policies contribute to people with disability feeling devalued, rejected and isolated. Government could choose to 'make things right' for them.

Flore and Dulcie

Dulcie is a First Nations woman. She is a mother of three and lives in regional Australia.

Six years ago Dulcie's husband died suddenly, sending the family into crisis.

Dulcie was hospitalised with depression and had to relinquish care of her teenage daughter, Flore, who is autistic and has epilepsy, pulmonary hypertension and intellectual disability.

Dulcie told the Royal Commission that she made attempts to continue to care for her daughter, but said she received no support.

'I was never helped by any agencies to keep [Flore] ... with her family. Can you imagine what she felt, being off country, away from her people?'

So Flore lived in multiple residential facilities which, Dulcie says, failed to meet her medical and high support needs.

For example, staff at the last facility left Flore with an untreated urinary tract infection for weeks. The pain and discomfort resulted in 'escalating behaviour'. While showering her, staff used pure bleach to alleviate the smell of the untreated infection, causing Flore's seizures to increase.

During this period, family members of other residents told Dulcie they had heard staff calling Flore racist names, such as 'Black C**t'.

In her early 20s, Flore was diagnosed with an enlarged heart and was being treated by a cardiologist.

Dulcie warned staff at the residential unit that Flore was never to be given the dye used in angiograms – the tests used to look at blood vessels in the heart. There was a family history of adverse reactions to the dye. Flore also had a condition that prevented her body breaking down certain fats. This meant she was unable to fast for surgical procedures.

Flore's medical history was complex and Dulcie insisted on attending all Flore's medical appointments.

But no-one told Dulcie about the cardiologist appointment that would end up being Flore's last.

'What's killing me is I wasn't there that day my baby girl died. I would have been there if they'd told me there was an appointment.'

On the day Flore died, Dulcie missed a call from the manager of the residential unit. When she returned the call the manager told her she couldn't talk because something was wrong with Flore. She didn't elaborate.

Desperate for answers Dulcie rang the closest hospital only to discover Flore was in a different town. Hospital staff here told her not to come to the hospital but to go to the police station.

Travelling there, Dulcie vaguely remembers someone telling her, 'she's gone'.

The police told Dulcie she would not be able to see Flore until the next day. When she went to the hospital the next morning, her body was behind a glass screen and Dulcie was not allowed to touch her. It would not be until Flore's body was eventually returned home that Dulcie would be able to hold her daughter.

On the day Flore died, two male support workers from the residential facility had transported her to the cardiologist appointment.

'How would my girl have felt being undressed by men,' Dulcie asks. 'She didn't deserve that, they should have sent her with female staff. It's just not okay.'

At the cardiologist's, Flore was given a coronary angiogram. After 30 minutes the procedure was stopped and Flore was left in a dark room, unsupervised, 'to rest'.

Dulcie believes Flore died in this room and not in the hospital.

She wants to know who signed the consent form for the angiogram and if Flore was made to fast. 'They knew she couldn't fast or she would go into a fatal coma.'

Dulcie requested an autopsy and coronial inquest, but the coroner stated 'the date, place, manner and cause' of Flore's death 'was sufficiently disclosed'.

Dulcie tried to speak to the residential unit manager but no-one from the organisation would talk to her.

In fact no staff from the facility have contacted Dulcie since Flore died, not even to offer condolences.

'Her belongings were just packed in a removalist truck ... [Flore] meant nothing to them! She always carried a little bag with her personal belongings, and this was never returned!'

'I don't want to be this angry person,' Dulcie says 'but I want answers for my baby'.

Alexis, Cindy, Aden and Gina

Gina is a First Nations woman and a single mother of six. Two of her children have disability and they share a house with Gina's granddaughter, who also has a disability.

Gina's family rents the house from the local Aboriginal land council.

'There have been almost no repairs for 30 years,' Gina told the Royal Commission. 'The [council] always says they have no money for repairs. When my grandmother had a stroke, we had to use wooden boards to make a ramp so she could access her home.'

The house is a challenge for the three children with disability – Alexis, Cindy and Aden.

Alexis is autistic. She has difficulty speaking and needs help to eat and to manage her behaviour.

'I really need a fence,' Gina said. '[Alexis] has run away many times and been found near to a main highway.'

Gina's granddaughter, Cindy, has cerebral palsy. She uses a wheelchair and can't access the shower. Gina said the home's bathroom leaked for 10 years before it was fixed. The shower still spills water onto the floor.

'I just keep thinking, how do I get a break? There needs to be stricter regulations around the management of local Aboriginal lands councils, they just run their own shows.'

One of the few services in town supporting children with disabilities is the local primary school. Gina's son Aden is autistic and has trouble socialising. The school supports his interest in technology.

Gina thinks he may become an archaeologist, but outside school it's difficult to find support for his disability. The children have been waiting two years for physiotherapy, speech therapy and occupational therapy. Gina has been unable to access hydrotherapy for Cindy's cerebral palsy.

Gina also feels that her family's cultural needs aren't being met.

'There are no Aboriginal disability workers. Promotion of training for Aboriginal people in disability services could change this.'

Harriet, Ivey and Kiara

Harriet and Ivey have been friends since school. Not long after they turned 18 they moved into supported independent living (SIL) accommodation together. Six months later the provider evicted Harriet.

Their support coordinator, Kiara, told the Royal Commission she suspects Harriet was evicted because her mother repeatedly complained about the lack of choice and control the provider gave the girls over their lives.

For example, Harriet and Ivey had asked to attend a number of activities including a free concert in the park, a hiking trip and an overnight camp. Kiara said that despite providing comprehensive risk assessments, their requests were denied. Most puzzling to Kiara was the hiking trip – they were fit young women who exercised regularly.

Harriet didn't respond well to strangers, but the provider repeatedly ignored requests to limit the number of new staff in the house. Staff implemented a 'photograph system' to introduce Harriet to new staff before they arrived, but the provider refused to participate. Kiara suspects the provider was using the house as a training facility.

Around this time the provider increased the accommodation fees and informed Ivey's father staff would no longer accompany Ivey to medical appointments – he would need to arrange this himself.

Fed-up, Harriet's mother and Ivey's father met with Kiara and asked her to source a new provider who would also be interested in taking on some of the existing staff. Kiara investigated possible providers and spoke to two staff members who agreed to move.

The provider evicted Harriet the next day. 'The agreement had been seriously breached,' they said. She had to be out in 24 hours.

Kiara asked for evidence of any breach but the provider refused on the grounds 'they didn't need to provide any or justify their decision'.

The provider stood down the two support staff who'd agreed to move with Harriet and Ivey to a new provider.

Kiara was able to source emergency housing for Harriet. Ivey's parents immediately started the process to remove Ivey from the SIL accommodation.

Kiara described their being a 'sense of urgency' on the part of the provider to remove Harriet from the property. They engaged locksmiths to change the locks before the women had even left the accommodation, adding to the growing stream of strangers in Harriet and Ivey's home.

The provider made no attempt to support Harriet and Ivey who were becoming increasingly distressed.

‘At no point whatsoever did ... management consider the impact this was having on both the young ladies, their families and the regular dedicated staff trying to support the girls through this exceptionally stressful and traumatic process.’

Kiara wants the provider’s actions reviewed and strategies put in place to ensure that no other participants, their families and carers are put through this same stressful, needless process.

Ellis

Ellis is deafblind and has mobility issues.

They live in a suburb where there are frequent changes to the streetscape making it hard for them to participate safely in the community.

Ellis told the Royal Commission about a safety hazard not far from their home. The roots of a large tree push up through the footpath. Council regularly repairs the path, resurfacing it with a black tar substance rather than new cement.

‘This creates a hazard for those with impaired vision as the topography of the surface can no longer be easily discerned, and therefore navigated.’

It takes Ellis five minutes to navigate around the tree roots – a one-metre area – so they don’t lose their balance and trip. They said the only alternative is to walk onto the road. People with certain mobility aids have no choice but to do this.

‘This represents a significant safety risk and this situation illustrates the ongoing impact of council decisions on the safety of their vulnerable citizens.’

Ellis said the council doesn’t communicate with people who are deafblind when planning maintenance work or changes to traffic conditions.

The information is put in the letterbox and, Ellis said, ‘there is no way to tell the difference between important information and standard junk mail’.

If Ellis does identify the important information, the maps are often too small for them to read. They rely on other community members to let them know what is going on.

‘Similarly, the channels through which people with disability can communicate with council are difficult and time consuming to navigate or are inaccessible.’

Ellis said for many deafblind people voice calls are not accessible.

They suggest a single, dedicated and regularly monitored council email address for people with disability and council to use. Most people have access to computers with specialised software and braille displays.

‘I wouldn’t mind even if council could set up something where they text me the information.’

The council invited Ellis to be involved in a consultation process to establish a dedicated vision and hearing service in the area. But Ellis declined because they didn’t feel confident accessing the building where the meetings were held.

The new local service is located in a building with a bus lane directly in front 'meaning vehicles cannot park there and rideshare vehicles or taxis will also not pick up or drop off in front of the site,' Ellis said.

The one time Ellis accessed the service they were dropped off across the street and became disoriented. A member of the public had to help them find the building.

'People don't realise how tired you get. Just a couple of hours is exhausting. The extra steps to get there make you too tired to do the activity you've gone there to do in the first place.'

Ellis wants government and service providers to consult with people who are deafblind meaningfully and consistently.

Lilian and Gwen

Lilian is a First Nations woman in prison for domestic violence. She said her partner tried to strangle her.

'He was going to kill me, he was playing a game of cat and mouse with me all night. The only reason I did something was because I wanted to [live] to see my children.'

Lilian is helping a fellow prisoner, Gwen, who doesn't know why she's in prison. Gwen is in her 30s and doesn't speak. Lilian thinks she may have undiagnosed psychosocial disabilities.

'No-one cares that she's in this place. She's in the wrong place,' Lilian told the Royal Commission.

Lilian advocates for Gwen. Because Gwen can't talk, Lilian went with her to a court hearing to interpret for her.

'They couldn't even say her name ... she couldn't talk to them.'

Lilian said that Gwen gets angry because she can't communicate. When she gets angry, prison staff put her in a detention unit cell with 'the lights on constantly and people screaming all day'.

'So they've punished her for something on the outside she doesn't understand and is then punished in here for doing something she doesn't understand.'

Lilian said prison is making Gwen's disabilities worse.

'She'll go home worse ... We don't have any support in here. There's a psychiatrist who comes down, but they only come in when we've fucked up already, six months down the track.'

Because of a previous incident, Gwen is now kept in the detention unit. She is getting more depressed.

'This person comes from a remote community where they're free, they can go fishing and hunting and they come here and there are walls ... Everyone is screaming, they're angry violent people in there and she's there listening to it.'

Lilian advocates for a number of women in prison, including her aunt, who has diabetes. She monitors what her aunt eats and makes sure she takes insulin, so she doesn't fall into a coma.

'On the outside, ambos would come, sirens on, lights on for a diabetic, but in here there's nothing.'

Lilian said without help, prison makes things worse for already vulnerable women.

'Language, lack of education and knowledge, is making everyone disabled.'

Irving

‘I feel as though ‘everyday people’ would be shaking their head if they knew how the NDIA really treat people with disability.’

Irving is a below-the-knee amputee.

He told the Royal Commission prosthetic legs are unique to every individual and he requires a new prosthetic leg every couple of years.

‘Over the years, my stump changes in its size and shape, and the corresponding prosthetic must also change.’

A few years ago he applied to the NDIS for a new leg and was rejected.

Prior to the NDIS, Irving’s disability support was funded by the state government. He had been a client of one organisation for many years and they were flexible. After years of trial and error, Irving had found the most appropriate person to fit his prosthetic leg was an interstate doctor. The organisation funded Irving’s travel.

When the NDIS was introduced Irving was unable to stay with this organisation and he dealt directly with the NDIA.

Irving’s application was rejected because the NDIA believed the prosthetic leg should be fitted in his home state. After multiple rejections and internal reviews, his appeal for a new prosthetic leg went to a judicial hearing.

Irving said there isn’t a specialist in his state that is able to fit the leg he requires and he had multiple documents and an expert witness to prove this.

The appeal went for two years and ultimately he had to represent himself because of the cost. The NDIA had multiple in-house and external lawyers.

Irving said that during the hearing the lawyers made arguments that ‘belittled’ and ‘humiliated’ him.

‘They seemed to be implying that I wanted to travel [interstate] for a holiday, and not for a legitimate specialist appointment.’

The lawyers questioned Irving’s expert witness, presenting their own list of specialists who could fit the leg. It became clear the lawyers were ‘counting specialists in other prosthetic fields, wholly unrelated to prosthetic limbs’. Some were dental specialists.

At this point the NDIA conceded and Irving won the matter.

Because of COVID-19 restrictions, however, Irving has been unable to travel interstate. He has been living with his old prosthetic leg and relying on pain medication to get through the day.

‘The NDIA need to stop hiding behind bureaucrats and “red-tape”, and to actually listen to people with disability. Treat people with disability with the respect that they deserve. I have been an amputee for a very long time, so I know the complexities of my prosthetic leg. I know what works and what is painful. I know the specialists that can provide me with the prosthetic leg that I need.’

Irving said hiring private lawyers was unfair and the NDIA needs to improve the participant’s access to justice. He suggests the NDIA hire people with similar disabilities to mediate when a dispute arises.

‘The NDIS needs more compassion and understanding. Treat us individually.’

Odessa

Odessa, a First Nations woman in her 30s, has attention deficit hyperactivity disorder and anxiety.

When she was young she was a competitive swimmer. Things changed after she moved to the country and attended a religious school

At the end of the year 6 the school told Odessa 'she was not smart enough' to continue her education in the religious system.

She moved to the state school system but stopped going to school midway through year 7.

Odessa told the Royal Commission she disengaged from education early because she was neglected and no-one helped her transition from primary school to high school.

At 14, Odessa was 'kidnapped and held captive' for two weeks. She was 'repeatedly sexually assaulted and raped'. The kidnapper told her if she left the remote property she 'would be shot by the neighbour'.

Naked, Odessa escaped and hid in the bushes. The neighbour came to her aid, gave her clothes and took her to the police station.

Police took her to hospital and a detective interviewed her. The doctor was compassionate and the detective was understanding but no charges were laid and her case never went to court. No-one offered Odessa support and she didn't understand the criminal justice process. She would have liked someone to explain her rights and the importance of giving testimony.

Not knowing where to go for help, Odessa started drinking alcohol and taking illegal drugs.

A few years later she was violently raped again, this time by her dealer. She didn't tell anyone for weeks but when she finally did go to police, a female police officer told her 'she deserved to be raped'. Odessa assumed she meant because she was using illegal drugs. She felt the police officer condoned the rape.

Odessa recognises her drug use has impacted her life significantly.

Her journey to recovery has been difficult because she lives with domestic violence.

Recently her partner was served with an apprehended violence order.

Odessa's determined not to reunite with her children's father and breach the order for fear her children will be taken from her.

‘Support for victims of domestic violence and rape is inadequate or often non-existent in both rural and Aboriginal communities,’ Odessa said. ‘The subject of rape and violence remains “taboo” and ... people living with a drug or alcohol dependency are often excluded from support.’

‘Services didn’t want to help me, because I was using drugs, it was like I wasn’t good enough to get help!’

Betty

‘I wonder sometimes, who is designing public spaces, like roads and public toilets.’

Betty doesn't mind being known as 'the lady with the mobility scooter'. She lives in a good community, is well respected and nobody has ever said a 'bad word' about her.

Her main concern, she told the Royal Commission, is that the buildings and facilities where she lives are not accessible. She said people with mobility issues are too scared to complain or don't know how to.

Betty can't drive her mobility scooter on the roads and walkways in town because the curbs and gutters are high and steep. She said there should be more 'crossovers' – where they 'smooth out the gutter and create sloped concrete'.

Buildings rarely have automatic doors and Betty struggles to open them. The doors are often so heavy even people without a disability have problems opening them.

The local tavern installed a ramp but the railings jut out making the entrance too narrow for Betty's scooter. If she's there with a group of people, staff move the kegs out of the service entry so she can access the building.

'If it were me just visiting on my own, I don't want them to go through all that hassle, so I never go alone.'

Betty is also unable to access the sports and recreation building because there is a hairpin turn the scooter can't navigate. When she complained, management told her the ramp complied with 'wheelchair accessible standards'. Betty said if that's the case standards need to change to include mobility scooters.

Public toilets, including those designed for people with disability, are not easily accessible. The local hospital and the rehabilitation centre toilets do not have automatic doors.

'This means you have to ask people for help to get to the toilet, it is very demeaning.'

The tavern replaced sliding toilet doors with swing doors. Betty still can't access the toilet because one door swings in and the other swings out.

If Betty needs to use the toilet at one of the big shopping centres she has to ask a cleaner to open the door. The cleaner has to wait outside until she's finished to let her out again.

Other accessible toilets have shower spaces and are often wet and slippery. Some are used as storage rooms.

When Betty raises the issue the common response is, 'it's built to standard'.

'If things are built to the standards and the standards don't work – especially with new technology like electric scooters – they should be updated.

'I think it's really important that people who make the plans really think about the perspective from people who may require facilities and are living with disabilities.'

Elias

'If you don't have a stable home and nowhere to run to, you're fucked.'

Elias is in his early 20s. Growing up with his mum, 'it wasn't a good environment,' he said. He had easy access to drugs and was sexually assaulted.

Elias has been diagnosed with 'a heap of things,' he told the Royal Commission.

'I've got bad schizophrenia – not mild, and bad depression. I've got drug induced psychosis.'

The first time Elias went to juvenile detention he was 10. He's been in and out of prison ever since.

'Three weeks is the longest I've ever been out since I've been 15. Maybe a week or so here and there.'

At the moment Elias is in a privately run prison. He said the prison 'don't know how to deal with mental health'. He's been trying to see the mental health nurse for months.

'I put a request form in and they said you're on the list but heard nothing more ... You only get help if there's an incident and you hurt someone or slash them up.'

At times, he's been put in a 'dry cell' for a few days. There are padded walls, gowns and mattresses.

Elias said the disability support unit at the state run prison was much better. There were only 20 people 'in a pod' and everyone had their own cell.

'I can't be with a cellmate as I've bashed a few already.'

He could visit a psychologist and doctor as often as he liked.

'You just knock on the door and you get help.'

He was also able to go to school every day. And the prison officers were helpful.

Elias wants to go back to the disability support unit but says this won't happen.

'They say I can cope in a mainstream jail now.'

The few times Elias has been 'outside' he says he has been 'smothered' by support services, with no autonomy. Child services made all his decisions until he turned 18, and now the public trustee decides everything.

'Last time I was out I said I need some [money] and they gave me \$70 for clothes, \$50 for shoes and \$100 for a phone – it wasn't enough.'

A few years ago child services successfully applied to the NDIS on Elias's behalf.

'I like NDIS as I have control. I don't really have a whole plan, only half a plan as I don't get a chance to ask for help, I've been in jail all my life.'

When he gets out he wants to do things he hasn't been able to do.

'I want to learn Centrelink myself. Maybe I'll go to a footy game and find a job.'

Elias said what he'd like the most is a stable house and a stable routine.

'You can't fuck it up if you have stability. If I had a house, maybe not even a job but a structure, I could do it. At my own pace, no pressure and have things there if you need them.'

Emanuel and Lilliana

Late one night, not long ago, seven-year-old Emanuel was crying and in pain. His mum Lilliana wasn't able to determine the cause of his pain, so took him to the emergency department of the local hospital.

At the hospital Lilliana spoke to staff about Emanuel's disabilities – he is autistic, non-verbal, has an intellectual disability and is a flight risk.

She told the Royal Commission she explained to hospital staff that Emanuel finds crowded and unfamiliar rooms distressing and needed a quiet place to wait. She asked if they could assist, but no-one offered an alternative space.

Emanuel and Lilliana continued to wait in the main waiting area.

Emanuel became increasingly distressed and began attacking himself, Lilliana and others. It became difficult for Lilliana to restrain and calm him.

'I felt ashamed by the attention that [Emanuel] was receiving from other parents and patients because I believed they thought I was a bad mother for not being able to stop him from crying,' she said.

Every time a nurse appeared Lilliana explained why Emanuel was so distressed and asked how much longer they would need to wait.

At one point a nurse asked Lilliana what strategies she used to calm Emanuel down at home. Lilliana told her he didn't behave this way at home. She couldn't make the nurse understand that the environment was the main problem. She told the nurse she didn't know what to do.

The nurse was clear – Emanuel was Lilliana's problem and she had to find a way to calm him down.

'I asked her several times that night if she can help me in any way to make it easier for us to wait and the response was to ignore us.'

After seven hours Lilliana could no longer wait. Although Emanuel was still in pain, they left without seeing a doctor.

The next day they saw a GP who referred them to a dentist – Emanuel had a problem with his tooth.

Following the hospital visit Lilliana experienced severe back pain. She had injured her back trying to restrain Emanuel.

'When [Emanuel] next experienced pain, I was distressed by the idea of having to attend a hospital again because I was afraid that we would experience the same treatment.'

This time she called an ambulance who took Emanuel to a different hospital.

'[Emanuel] was given his own room to wait in where a doctor checked in every 30 minutes. He did not have the same behavioural problems.'

Lilliana would like emergency department staff to receive training about the needs of autistic children, and alternative waiting rooms for patients with sensory or anxiety symptoms.

Maddison and Karen

Maddison, in her 20s, is autistic and has cognitive disability. She lives in supported accommodation in a regional area.

Maddison's mother, Karen, told the Royal Commission she recently discovered that two support workers physically assaulted and emotionally abused her daughter.

In one incident, a staff member grabbed Maddison under the arm, lifted her off the couch, and put her in her room, closing a door on her hand. On another occasion a different staff member stood on her foot and put her in a room with loud music.

'These are only the [incidents] we know about,' said Karen. 'Her injuries were severe enough to warrant police investigation on each occasion.'

Karen said she first learned of the abuse when the house manager was replaced.

The new manager told her they believed the assaults had been occurring for a while. But as there was 'no evidence' they 'let it go on for a few months.'

'[Maddison] lived in fear every time this person was allocated to her care, most of the time at night.'

Karen asked for copies of the incident reports, but another carer told her that 'crucial incident reports have been destroyed'.

'Poorly trained staff, quick staff turnover, bullying from the top down contributed to the abuse.'

Karen said the police investigated, but suspended the investigation because they 'could not get a consistent statement' from Maddison about when the incidents happened.

'This is despite her telling a consistent story about the assaults to four different people. The nature of police investigation procedures are not appropriate for people with an intellectual disability.'

The provider also investigated, but wouldn't tell Karen the outcome for the staff involved 'due to confidentiality for the staff members'.

Maddison now self-harms and 'is anxious around men in her care environment'.

Karen is looking for new accommodation for Maddison, 'staffed with people who are appropriately trained in doing their job'.

Allyson, Sky, and Gwendolyn

Allyson, Sky and Gwendolyn told the Royal Commission about the discrimination they've experienced.

Sky has an intellectual disability. She used to work in a disability workshop where the workers with disability earned \$6 a day and were 'treated like animals'.

At Christmas, the employer gave the workers with disability 'cheap Christmas stockings with chocolates' and gave other staff 'better things'.

'They did not make us feel equal,' Sky said.

Sky left the workshop and now works for a disability advocate.

'This job is good because I am paid and treated equally.'

Allyson also worked in a disability workshop, as well as a factory. She enjoyed both jobs.

Allyson said that when she later worked at a government agency, she was 'treated like a second class citizen, harassed and bullied by staff'. She said the union and her family tried to help, but the bullying shattered her confidence and she stopped working.

Allyson said the government agency provides support services for people with disability, and she is afraid to return to the agency to access those services because the people who bullied her still work there.

Gwendolyn lives with post-traumatic stress disorder triggered by childhood experiences.

She used to be a piano teacher, but nerve damage from an arm injury prevents her from teaching piano. She is studying to be a yoga teacher.

Gwendolyn is supported by the NDIS, but the funding does not cover her needs. When she tried to access cheaper services, they weren't appropriate.

Gwendolyn lives independently and, because she has difficulty speaking, struggles to deal with support services.

She said people 'take over' when she asks for help, and do things she doesn't want them to.

Her support coordinator, for example, arranged for a gardener to do work she didn't need. He damaged her trees and charged her \$3000.

'This made me feel ashamed,' she told the Royal Commission.

Don and Essie

‘The school and TAFE system failed my son.’

Don has cognitive disability.

In primary school, a teacher’s aide helped him access mainstream education.

When Don transitioned to high school, the school told his mother Essie that he needed to go into a special education class or he would lose his teacher’s aide.

‘I felt like I had no choice,’ Essie told the Royal Commission.

She agreed but only if Don could attend some mainstream classes.

However this didn’t happen.

‘My son would do lots of car washing and cooking but no focus on academics or learning.’

In Don’s final year of high school the school psychologist assessed his academic progress. His academic level was the same at the end of high school as it was at the beginning.

‘He learnt nothing in all that time. It was very hard to take ... I was disgusted.’

Don was very good with computers and wanted to do IT and computer programming. Essie contacted TAFE and discussed Don’s strengths and challenges.

Don started studying a certificate III in computers. Essie arranged an aide to support him but TAFE said an aide was not required. Don failed two subjects. TAFE then convinced him to do a certificate IV. Again Essie arranged an aide and again TAFE told her it wasn’t necessary.

Essie couldn’t understand this.

‘Instead of supporting him to pass the work he had failed, they just kept moving him to harder work.’

One of Don’s subject teachers did provide support and Don passed this subject. Essie said this ‘indicated he can do the work if he has supports’.

Eventually TAFE agreed Don could have an aide but they told the aide not to tutor him. Most teachers agreed to this arrangement.

However one teacher was resistant and refused to pass Don because he had too much help.

Ultimately Don passed every subject except this subject. The teacher was adamant 'he had no right to pass because he had help'.

'[Don] passed every subject except this one, which just didn't make sense. It's not fair. Something needs to be done to help these kids. [Don] had worked his butt off. I am proud of him. I want him to have this certificate, it just means so much to him.'

Essie feels Don was targeted by this teacher.

'Fairness and equality is not happening for my son. Teachers need to know how to support people with disabilities. [Don] is so good at computers, he has even built his own computers. He is an amazing young man, he just need support and someone to encourage him and he will go places.'

Emilia

Emilia has a degenerative disease that affects her communication and mobility.

During the COVID-19 pandemic, Emilia's quality of life significantly deteriorated. Many of her activities were cancelled and she was confined to her flat. She couldn't even access her garden because the building needed repairs.

Emilia realised she needed more support but didn't have the funding and refused to go to an aged care home. Her husband is in a home.

'He hates it there and is unable to get out,' she said.

'I surmised towards the end of last year that soon I won't be able to live alone. So therefore, attempted suicide and am very cross to still be alive.'

Emilia told the Royal Commission she made a rational decision to take a suicide drug she bought overseas many years ago.

'Unfortunately although I took enough to kill a horse it had lost its potency.'

She spent a week in hospital and was interviewed by a number of psychiatrists.

'Silly me, I was my usual frank self, and this resulted in my being forcibly removed in a lock up van to ... [a different] hospital where I was imprisoned in the mental health ward.'

Emilia attempted to get legal representation but it was extremely difficult.

She felt trapped.

'I was treated like a criminal despite the fact that suicide is legal ... I was not allowed out of bed, not even to use my wheelchair.'

Visitors were turned away and she was denied access to her physical therapist because of COVID-19 restrictions.

Emilia continued to be interviewed by a barrage of psychiatrists and clinicians who refused to tell her what was going on or how long she would be there.

After three weeks flat on her back Emilia developed pressure sores and fungal infections.

'Fortunately, I kicked up such a stink at the time and knew my rights, I was eventually released.'

Back home she regained some strength, but continues to deteriorate.

'I am concerned that it is now very difficult to get me out of my chair and everyone who comes by to take me out has a real workout.'

Emilia doesn't expect this year to be much better than last year and says she 'must do it [suicide] again' to avoid 'the humiliation of high residential care'.

Emilia hopes no-one else has to go through the ordeal she went through.

Dave and Lori

Dave is in his 20s and uses a wheelchair. He has a cognitive disability and can't talk. He communicates through eye movement using speech-generating technology.

'I cannot talk, but I can understand what you say,' Dave told the Royal Commission. 'Give me time to understand and to answer.'

Recently, Dave had a bad experience at hospital.

'I had a sore tummy and back. It was making me vomit ... The doctors and nurses didn't ask me what was wrong, they only spoke to my support team and my mum.'

The medical staff gave Dave injections without explaining what they were for.

'They put a needle in my foot and it hurt a lot. It made me feel scared, hurt, frustrated, angry, sad. I didn't feel safe and I didn't know what was happening to me.'

Dave's support worker, Lori, helped him share his story with the Royal Commission. Lori explained that when an ambulance takes Dave to hospital, he has to leave his wheelchair and technology behind, 'so he would often not be able to physically operate the eye gaze system'.

'As soon as he's feeling a bit better, someone in the family brings it to the hospital and they set it up by the bed,' said Lori, 'and as soon as you start using it, the medics start going, "Oh!"'

Dave said the challenge is explaining to doctors and nurses how to communicate with him, even when he has the technology with him.

'I told them I can't speak, but I understand what you say.'

Dave said he needs the hospital staff to speak to him directly, not his mum or support worker.

'Ask what communication needs I have and ask me what is wrong and what is happening.'

When staff explain things directly to him, it makes him 'feel happy, not scared'.

Dave showed the Royal Commission the communication poster he uses to explain to staff how to communicate with him.

'This made it a good experience, as the doctor and staff spoke to me directly. They asked me the questions.'

Lori said the poster, and a smaller version in book form, includes a summary of things that matter to Dave.

'But not everyone reads it, hey. This book is often kept in [Dave's] room or on your bed, to inform any new staff who are caring for [Dave], but staff don't always have a look at it. That's the reason we have the poster as well. It's shorter, brighter, and [we] hope that sometimes if they read nothing else, at least they read that.'

Niles and Tessa

‘It shames and saddens me how uneducated jail [staff] are about people with a disability. It’s time the government realises, as a community we all have to make change happen.’

Niles lost sight in his right eye as a consequence of a firearm injury and required an operation to repair his skull. The incident also left Niles with cognitive issues and medical conditions, such as seizures, that require medication. His mother, Tessa, told the Royal Commission about her son’s experience as a prisoner with disability and her battles on his behalf.

‘I saw him in a state I find hard to write [about] – in a wheelchair, his left eye bulging and moving round and he could not see,’ Tessa said.

Niles was pushing his wheelchair into a wall and while there were three guards present it took some time before he was taken to the hospital. She said he was vomiting and dizzy but no observations or blood tests were done.

‘I [tried] all avenues to get help. [The prison guards] called him a ‘retard’ and he was put out in the yard while in his wheelchair without a helmet. At that time Niles had no plate put in [to repair his skull] so anybody could have hurt him.’

Following the procedure to fit a plate to Niles’s skull, Tessa said, her son was sent back to prison before it was safe. She was adamant Niles should not have been forced to return to prison without authorities considering the advice of his medical practitioners.

‘His neurosurgeon said he should never had been taken from rehab [as doing so would give Niles] a 10 per cent chance of survival.’

Tessa told us she thinks prison staff are not adequately trained, and are certainly not interested in maintaining the level of vigilance and care required.

‘He went down as soon as he was taken from rehab. He was doing good [in rehab]. Nobody understands the damage [done] is worse in jail.’

Tessa believes Niles was ‘poisoned’ with seizure medication while in prison, by guards both under- and over-medicating him. The resultant toxicity of medications in his system was so damaging that he became legally blind in his remaining eye.

‘One of the prison guards asked me not to say that she told me that Niles’ meds were given to him in [wrong] doses and would be on the [prison] cameras,’ Tessa said.

Sometimes Niles didn’t get his medication but his medical chart showed signatures indicating the medication had been administered.

Staff have not provided any assistance for Niles to read and write which is something he did before the injury. Tessa said he's been waiting more than two years for an artificial eye.

Tessa is also angry about the lack of clarity in communication she continues to experience while dealing with her son's health and wellbeing.

She would like to see prisons staffed 'with professionals in all areas' so that true rehabilitation of inmates requiring medical care can happen there.

'It's shocking [to see] Australia letting their own vulnerable people down.'

'He's no longer a violent offender,' Tessa said.

'[The] stress of being in jail is no good for his health. The environment is not calming [and Niles] is just treated like nothing, like nobody. Well, he's my son – he's somebody's – and [he has] a lot of support and a family who love him.'

Sienna

‘The ignorance surrounding gender dysphoria is the biggest problem I’ve come across in ... correctional facilities and in society in general.’

Sienna is a transgender woman. She has Asperger’s syndrome and ‘a number of mental illnesses’, including post-traumatic stress disorder.

Sienna told the Royal Commission that when she was a baby she was taken from her birth mother who was a First Nations woman, and raised by an evangelical Christian woman. ‘All throughout my childhood I was a girly little boy and I got bashed for it and I got bullied for it.’

Under this woman’s care, Sienna was physically abused, molested and starved. She sustained multiple injuries including broken ribs, broken bones and head injuries.

When she was in her 20s Sienna witnessed her own child being abused by this woman. In a fit of rage, she told us, she unintentionally harmed her.

Sienna was sent to a male prison and was confronted by prisoners with ‘their genitals out, stroking erect penises’.

‘I was afraid. I’d never been in prison before. I was afraid of getting raped. I was afraid of getting killed.’

Desperate to be transferred Sienna threatened to kill herself. She was placed in an observation unit but treated like a hassle. She said, ‘all they want to do is get you back into circulation’.

‘There’s no counselling, there’s no trauma support, there’s no mental health support.’

Prison staff have accused Sienna of using dysphoria to get attention and tell her to ‘act like a normal bloke’. A lot of them believe she chooses to be transgender and try to bully it out of her.

‘The gender transition was not to get attention or a lifestyle choice ... I am a female, I wear female underwear as a necessity, I have a female figure, I wear makeup and I have legally taken on a female name. Why would I choose to do this in a male prison full of predators if it’s a lifestyle choice?’

Sienna has had breakdowns in prison, been raped times and is constantly sexually harassed. One time the prison guards witnessed an attack but didn’t intervene. They told Sienna, ‘she brought it upon herself’.

She has heard prison staff make jokes about transgender prisoners ‘getting raped ... getting gangbanged to straighten them out’.

Sienna said she can't report the sexual harassment to the staff. 'If you do that in here you'll get killed'.

She wants prison staff to have training around dysphoria and mental health, and to call out and punish sexual assault and harassment.

Sienna had to fight to be given hormone replacement therapy which she has been taking for almost five years.

Ideally she'd like to be transferred to a female prison even though she's aware women prisoners can be violent.

'They've got to stop putting first time offenders with a gentle personality in with violent offenders'.

'You people out there have absolutely no idea what goes on in here. The misconception is that a lot of people in prison are violent criminals and have a criminal mentality. And I'm sorry that's wrong.'

Orella

Orella told the Royal Commission she's the happiest she's been in her entire life – she's in prison. For the first time she's feels safe and she's not looking over her shoulder.

When Orella was a child her mother was never there. Shunted from place to place she was always scared. One of the people she stayed with molested her and her brothers and sisters. 'My childhood was rough but somehow I made it through.'

Then she met a man who was nice to her. But not long into the relationship he started verbally abusing her – calling her horrible names and criticising how she dressed. 'Then it was physical, picking up heavy objects and hitting me with it.'

Orella tried to tell her family but they told her it was her fault because she stayed with him. She remembers feeling suicidal but didn't know where to go for help. 'We never used to talk about mental health in my family, it was just a joke.'

With nowhere else to go Orella stayed with her partner.

'The last thing he did to me is anally rape me with a glass bottle and I guess it was a trigger. I don't remember lashing out on him. But everything came out in the trial.'

Orella was convicted of manslaughter.

Around this time she was diagnosed with post-traumatic stress disorder and depression and started to receive treatment.

In the first few years she was often triggered – sometimes by prison officers. She remembered a time an officer called her names and made threats. He ran after her and grabbed her then told her to 'get' as if she were a dog. Orella said she was shaken and later cut herself.

'Some of the officers don't understand mental health, but they should know that they need not to bring their shit from outside into here.'

Orella said she has come a long way from the woman she used to be. She's become more patient and has learnt to do breathing exercises when she's triggered.

A community organisation has supported Orella and helped her understand domestic violence. She realises there was a lot going on under the surface for her mum. 'Mum was never a good teacher to me, would only be intoxicated or on drugs but she had her own trauma.'

Orella has also completed a number of courses in prison – including first aid, literacy and numeracy and vocational training. When she is paroled she plans to get a flat, get a part-time job and complete more study. She has lots of nieces and nephews and would like to become a teacher's aide.

'I've found myself, my self-esteem ... and my freedom behind bars.'

June and Charlie

June is profoundly deaf, has low vision and has significant physical disabilities. She has a son, Charlie, who is in his twenties. Charlie was born with physical disabilities and is autistic.

June told the Royal Commission she encounters abuse in the community on a regular basis. This abuse can range from name-calling and refusal of service to actual physical violence.

‘Due to being deaf and having a limited range of vision, I am unaware of people who are behind me or coming from the side. I have had experiences where I have been rammed by shopping trolleys, had people take control of my wheelchair and slam [it] into a wall to get me out of their way; and been regularly physically assaulted by people slapping, punching, spitting and hitting me with objects; whilst verbally abusing me.’

June recalled an incident in a queue at the post office.

‘A man leaned over the back of my chair in order to be served first ... He placed his hand inside my blouse and bra and fondled my breast. Not knowing what to do, I fled.’

While June was outside in tears, a witness flagged down passing police. June gave the police a statement of what happened, and the witness gave a description of the man. Police tracked him down quickly.

When the police spoke to the man, he denied what he had done. He said he wanted to charge June with assault because, he claimed, she had run over his toes with her wheelchair.

The police took June home and spoke with her husband. They didn’t have an interpreter and didn’t speak to June – only to her husband.

‘They told him’, June said, ‘that he needed to teach me better how to behave in public and learn to control my wheelchair in future’.

Charlie also experienced abuse and neglect in the mainstream school he attended.

June recounted that when Charlie was six a teacher put him in a wheelie bin with the lid closed because he was annoyed by Charlie’s repetitive verbal behaviours. The teacher sat on the bin for half an hour. Charlie passed out. He was then suspended for a month for inappropriate behaviour towards a teacher. Two days later, Charlie attempted suicide – the first of many attempts.

June told us that during Charlie’s schooling, teachers routinely excluded and isolated him. He was banned from all school camps, excursions and out-of-school activities. He was banned from taking a number of subjects. He was banned from the playground and was made to sit outside the staffroom during all breaks for all 12 years of his schooling.

For five years of his schooling Charlie was on a restricted enrolment, which meant he could attend school as little as three hours a week. June said she believes that this was because schools were unwilling to fund the support Charlie required, even though they collected enrolment and specialised funding for him as a full-time student.

June said that the abuse and neglect she and her son have experienced is 'minor' compared with the abuse others have suffered.

'It is my hope that this Commission will finally give a voice to people with disabilities, so that we may receive better treatment in our own homes, the community, places of employment and educational settings.'

Tommy and Anita

Tommy, a First Nations man in his 40s, has schizoaffective disorder, which means he has some of the symptoms of schizophrenia as well as a mood disorder.

Tommy lives in a group home.

His mother Anita told the Royal Commission he has a history of substance abuse and has been in jail several times.

‘Most of [Tommy’s] adult life has been dominated by what I would call the “white fellas” system,’ she said. ‘There was an obligation on the state to look after him as best they could, particularly as he has serious mental health issues. However, I don’t think he was looked after well.’

Tommy broke a rib and injured his lower back when the vehicle transporting him between prisons crashed.

In a home for men transitioning from prison to the community, he slipped on urine on the toilet floor and broke an ankle.

At a group home, carers left a tooth ulcer untreated, Anita said.

‘Even when Tommy’s troubles with drugs was becoming serious it would have been best for him to have gone out to country and be treated in the community by our elders,’ she said. ‘However, this was never an option. Instead he started to become engulfed in the “white fellas” system.’

Anita said that even though Tommy’s financial affairs were managed by the public trustee, some of his ‘friends’ defrauded him of about \$5000.

‘Again, this is a “white-fellas” institution. I believe that the public trustee did not take sufficient care over Tommy’s savings. The money was not recovered.’

April and Rosemary

April is a single parent. A doctor diagnosed her with autism, but April said she doesn't identify as autistic.

When April gave birth to Rosemary a couple of years ago, child protection officers told her she needed to undergo a parenting assessment to make sure she could take care of her daughter and had to be supervised until then.

'[The officers] didn't provide me with any support in arranging for this supervision and just expected me to find this kind of support myself,' April told the Royal Commission

April was living on her own when Rosemary was born.

'I was forced to move out. I had no family or friends that I could move in with, so I was forced to move in with a stranger.'

April said the stranger was 'unpleasant' and didn't want April to have visitors.

'This time was really hard, I had no privacy. Me and [Rosemary] weren't even allowed to have a bath together on our own.'

April and her daughter were confined to a room for the three months while they waited for the parenting assessment.

'We couldn't even see my family at Christmas because no-one would take us. I have had a better time during this entire COVID-19 lockdown than I had during those invasive three months.'

The parenting assessment showed that she was a capable parent.

'I was told I no longer needed to be supervised. That day I immediately moved out of the house I was living in with the stranger. I couldn't wait to move out.'

April said three months of supervision without support was too long.

'I feel like during this time [the child protection department] didn't help me at all, they didn't care about me and didn't listen to what I had to say.'

Despite being assessed as a capable parent, the hospital in which she gave birth still believed her daughter was at 'high risk'. They told April she had to return for regular 'check-ins', even though she regularly saw her maternity nurse and general practitioner.

'I'm asked to do this even though I don't live near this hospital anymore ... I don't think other parents have to do this.'

Lou and Ambrose

‘The school tried to “manage us” clearly putting the brand of the school above the needs of my daughter and ourselves.’

Lou attended a high school that prided itself on supporting students, like her, with mild to moderate intellectual disability.

At the start, Lou was ‘very happy, social and well-adjusted’, her dad Ambrose told the Royal Commission. But by her junior year she had developed anxiety, depression and ‘regressed significantly in many ways’.

Lou stopped being able to toilet herself and withdrew from every activity she had previously enjoyed. She started having panic attacks and sometimes ‘seemed to be in a permanent state of fear – not drinking, eating or sleeping’.

Lou’s psychiatrist repeatedly asked Ambrose if anything had happened to Lou which might be a cause of her mental health issues.

Ambrose eventually discovered something had happened. An older boy at the school had taken Lou to bushland on school grounds and sexually assaulted her on multiple occasions.

Lou’s parents were ‘heartbroken’. They felt they had ‘failed to keep her safe’ sending her to school every day.

The principal reported the abuse to police and ‘took it upon himself’ to interview the perpetrator. Other girls were involved but the principal told Ambrose they were ‘willing participants’.

The perpetrator returned to school after three days and the principal requested Lou also return. He tried to reassure Lou’s parents she would be safe because the boy would be kept in a separate class. But he was already in separate classes.

Ambrose discovered this wasn’t the first time the school had ‘covered up’ abuse. Had the school acknowledged their mistakes, Ambrose said, they could have worked with the community to make sure they were not repeated.

‘All children should be safe at school and safety considerations should be the highest priority for vulnerable children with disability,’ Ambrose said. ‘I remain appalled at how the school could have been so negligent as to allow this abuse to happen multiple times to multiple children.’

Lou left school and is being treated for post-traumatic stress disorder.

Jordan

‘I don’t think there is one deafblind person working at the NDIS.’

Jordan’s hearing aid batteries have to be replaced at least twice a week. The batteries and the hearing aid casings are very small. It’s easy to drop them – Jordan frequently does. As Jordan is deafblind, finding them again is almost impossible.

The batteries look like dog treats. Jordan told the Royal Commission they are concerned their guide dog will eat the batteries and become seriously ill, even die.

The component parts are small and not designed to be manipulated or operated by a person with a vision impairment. They are difficult to replace without damaging the casing or breaking the aid entirely.

Jordan is often forced to ask family members to help them change the batteries – limiting their independence.

If the batteries run flat when Jordan is out and there is no-one to help change them, Jordan can’t communicate or navigate spaces safely.

Jordan applied to the NDIA to fund rechargeable batteries, detailing all the reasons and providing supporting documentation.

But the NDIA rejected the request.

The NDIA suggested Jordan change the hearing aid batteries over a bucket.

They also offered to fund a streaming microphone instead. Jordan is at a loss to understand this.

Another suggestion was to use core support funding to pay for a support person to come twice a week and change the batteries.

‘Not only does this recommendation do the exact opposite of promoting a participant’s independence, but also represents a total cost over the life of the plan that is five times more expensive than the cost of funding the requested aids.’

Jordan said the NDIA’s reasons and suggestions demonstrate they have no understanding of being deafblind.

‘They don’t know enough about the person with disability to make judgements about what they need. I feel like I’m not being listened to at all ... I feel like a criminal for asking for something I need.’

Roland

‘I well know the fear one feels when the fire alarm rings.’

Roland lived in a high-rise building in the city for many years.

When the fire alarm sounded one time, a loud speaker message told residents to ‘urgently leave the building via the fire stairs’. It warned them not to use the lifts ‘under any circumstances’.

Roland has multiple sclerosis and uses a wheelchair. He told the Royal Commission he requires two support workers to get him out of bed in the morning, shower, toilet and dress him and put him in his wheelchair. Another support worker comes in the evening to put him in bed.

When the alarm sounded Roland and his wife were alone. All she could do was say goodbye, leaving him for ‘what felt like hours’ wondering what might happen next.

Roland said he wasn’t the only resident in the building unable to escape via the fire stairs. Some were vision impaired, used walking frames or had recently had hip or knee surgery.

It turned out the alarm sounded because of a technical fault and no-one needed to evacuate the building.

Recently Roland spent a few months in a respite facility while his wife was away. He was staying on the first floor and noticed a sign warning people not to use the lift if there was a fire.

‘So, I asked the manager what her advice was for people like me who couldn’t walk. And what about all the people in hospital beds? She said, “Oh don’t worry, the fire station is only ten minutes away”.’

Roland wasn’t comforted. He said the lives of people with disability who live in many types of buildings are at ‘considerable risk’ if there is a fire, earthquake, building collapse or other type of emergency.

He proposes governments develop a strategy to protect the lives of people with disability who live in multistorey buildings. He suggests people with disability develop a personal emergency plan that can be registered with emergency services.

The current situation is ‘totally unsatisfactory’ Roland said, and deserves the Royal Commission’s ‘urgent attention’.

Ray

Ray, who is in prison, sustained a brain injury when another prisoner punched him in the head.

‘Since then I experience pain, memory problems and difficulty speaking,’ Ray told the Royal Commission. ‘I have PTSD, anxiety, depression, adjustment disorder, panic attacks, suicidal ideation and nightmares since the assault.’

Ray said that when he was discharged from hospital after the attack, he was placed in a lockdown unit for more than a year ‘to put [him] out of everybody’s way’.

‘In there I was miss out talking to normal people, just conversation which I needed in early days because the way my speech is.’

Ray said he needed speech therapy to help him ‘find the words again’, and being isolated in the lockdown unit ‘wasn’t a help at all’.

‘I was put in a corner and told to shut up and that was that. Being in that unit, a lot of education program people don’t like coming down there.’

Ray asked for access to a speech therapist, but said it took ‘maybe two years’ to happen.

‘Then, I only had three meetings on video with the therapist. I still need more help.’

He asked for physiotherapy for an arm injury.

‘They can’t fix it ... it doesn’t work right ... They gave me an injection in the neck for it, but it didn’t cure it at all.’

Ray also wanted to speak to a psychologist.

‘There is a nurse that I can talk to monthly, but only if I’m really bad.’

He said it was an ongoing battle to get his disabilities treated in prison.

‘For drug users, they give them a lot of help, like methadone, but they don’t go helping people like me with a brain problem.’

Ray is worried about how he’ll cope when he’s eventually released.

‘There is no way I’m going to have a normal life when I get out that’s for sure. It’s going to be hard.’

Wade and Sterling

‘Workplace discrimination against disabled people is alive and well in a lot of workplaces across our nation. It only takes one biased person to discriminate in a workplace.’

Wade is in his early 30s and has cerebral palsy. He has a driver’s licence and works approximately six hours per week.

His father Sterling told the Royal Commission that Wade’s disability mainly affects his physical and fine motor skills. His cognitive skills are ‘affected to a minor extent’.

After leaving school Wade secured part-time employment with his current employer. Other people with disability were also part of the workforce.

‘Over the years [Wade] has enjoyed the support of several excellent managers ... Sadly this has not been the case in recent years due to changeover in managers,’ Sterling said.

Wade has completed a number of TAFE courses since leaving school and recently completed a certificate 3 in education support. Despite this, ‘he has been unable to secure any significant and meaningful changes to his ongoing employment’.

Wade has applied for countless jobs over the years to no avail. Sterling said despite legislation there is ‘an enormous amount of real discrimination against people with disabilities who are seeking employment’.

Sterling believes a more proactive approach to ‘help this group of people ... get into more sustainable employment’ is needed.

He suggests the government require companies to employ a percentage of workers with a disability and introduce tax incentives. For example, taxes paid by employees with disability could be reimbursed to the employer.

‘Workplaces would have to be visited regularly by inspectors to ensure that all arrangements are legitimate and working.’

Wade continues to live at home with Sterling and his wife who are both retired.

When Sterling reflects on their working and caring lives, he believes more ‘meaningful support’ should be extended to families of people with disability.

He believes Australia can do better.

Callen

Callen has multiple sclerosis (MS), and has had a stroke.

She lives independently and is completely reliant on support workers, who come from two different disability providers.

One morning, Callen's usual support worker was away and she was expecting a replacement.

No-one arrived.

Callen called the provider and continued to wait.

'They weren't here at 8.30 am,' she told the Royal Commission. 'They weren't here at 9.30, not 10.30, not even 11.30.'

By this time, Callen had been in bed for more than 13 hours. The bed was soaked, she was cold and her skin burned.

'I had even done a bowel motion in the bed, which is a first for me.'

Callen said she felt humiliated.

She rang the provider again and was told her situation had been escalated to someone she'd never heard of.

This person told Callen she wasn't on their roster and every time Callen asked a question she kept repeating, "You're not on our roster", parrot fashion'.

'I said, "As one human being to another can't you at least try and get someone?" And the answer was a curt, "No".'

Eventually the woman stopped taking Callen's calls.

Callen rang the other provider who said she wasn't on their roster either but would try to get someone.

In the meantime, Callen pressed her personal emergency alarm and a person from another provider arrived.

However they had no experience working with someone with a profound physical disability. The worker had never used a standing machine before and was unable to help Callen.

'Eventually at 12.30 pm – yes 12.30 – someone from [the second provider] came – 14 hours not turned, not toileted, not ANYTHING!'

Callen said the emergency worker ‘was appalled and disgusted’ she had been left in that state for so long. The worker who eventually arrived from the second provider was also disgusted.

Callen wants a written apology from the first provider.

‘This isn’t an isolated incident.’

Callen was given 24 hours’ notice she wouldn’t have a support worker on New Year’s Eve or New Year’s Day.

Panicked, Callen called the hospital and a community nurse but neither could help. Eventually she rang an MS organisation who contacted Callen’s two providers and brainstormed a solution.

Callen wants providers to ‘think outside the box’ when it comes to after-hours rostering.

‘In an emergency it is not good enough to say, “It’s not our problem”. It is your problem – it’s what you get paid for!’

Trenton

‘Being in prison is the punishment. Depriving people of the medical treatment they need isn’t the solution.’

Trenton is a war veteran. As a result of his service he sustained a back injury, post-traumatic stress disorder (PTSD), depression and anxiety.

After leaving the army he was involved in a car accident and shattered his leg and ankle.

‘I have what is called a “broken union”, which means that my leg won’t heal,’ he told the Royal Commission.

Prior to being incarcerated Trenton used Panadeine Forte or Endone to manage his pain, and sedatives to manage his PTSD.

Trenton is unable to access these medications in prison, despite his GP and psychiatrist confirming them as necessary medications.

He put in a request to see a doctor but was told to see a nurse, who was unable to prescribe medication. It took ‘a long time’ to see a doctor.

‘I had to say the same thing over and over again about what I needed.’

The doctor suggested instead of taking Panadeine Forte, Trenton join the methadone program so he would have ongoing pain relief.

‘That seemed too extreme to me. I just need pain medication when I need it. I am happy to do exercise to try to manage the pain until it starts affecting my mental health. That’s when I need the medication.’

Trenton is aware there are prisoners who will ‘stand over’ other prisoners and steal their medication.

‘I know that’s what the prison is worried about.’

He suggests that ‘if they segregated the people who genuinely need the medication and gave them proper medical and psychology services it would be better’.

The doctor also refused to prescribe sedatives for Trenton’s PTSD.

When Trenton told prison officers he was feeling suicidal they transferred him to a different prison. He had to spend eight hours in the back of a van and when he arrived he was ‘all stooped over and in pain’.

At the new prison they made him wear a gown and no pants.

‘It’s not the way to treat people who are struggling ... Now, I don’t tell them when I’m feeling suicidal because I don’t want them to send me there again.’

To avoid being transferred again he also has to be part of the work program. He does some cleaning, but the mopping aggravates his back pain.

Trenton was told he was scheduled to attend a pain clinic but it hasn’t happened. He was also told he would have an MRI scan of his back but he’s not sure when that will happen.

Trenton’s lawyer organised a new psychiatrist for him and Trenton lodged a request to see the psychiatrist, but he’s heard nothing.

‘I understand they have a budget but there needs to be compassion, particularly for people with physical disabilities or mental health problems.’

Scarlet

‘I believe the exclusion of over 65s from the NDIS is discriminatory and should be stopped.’

Scarlet is a polio survivor. She contracted the disease as a child in the 1950s.

‘It was a frightening era,’ Scarlet told the Royal Commission. ‘Theatres, football matches closed down. People were asked to keep away from crowds. We are reminded of this time with the current COVID-19 pandemic.’

Scarlet remembers the doctor telling her ‘polio is a life sentence’.

When she was a teenager a doctor said she would never be able to have children.

Scarlet described it as ‘a sad and difficult time’.

The sports Scarlet could play were limited and she had to wear appropriate shoes to accommodate what she calls ‘my unusual feet’.

All her life she has required regular physiotherapy, massage, acupuncture and other therapies to assist her mobility and treat her pain. She also uses medication.

About 10 years ago, not long after she turned 65, Scarlet developed post-polio syndrome. The symptoms appear many decades after polio and can include muscle atrophy, increased pain and difficulty breathing and swallowing.

Scarlet requires increased medical treatment and some assistance in her home.

‘The treatment I require to maintain my body so that I can lead an active life, and remain effectively in my own home is becoming financially difficult.’

Scarlet is not eligible for the NDIS. She said if she’d developed post-polio syndrome before she turned 65 she would be eligible.

Scarlet believes this is discriminatory.

‘It is contrary to the UN Convention on the Rights of Persons with a Disability and particularly unfair to those of us who acquired our disability as children.’

Scarlet wants people over the age of 65 who have post-polio syndrome to be eligible for the NDIS. She says people with post-polio syndrome should receive the same level of support regardless of their age.

‘Fairness should prevail for those still living and suffering from the late effects of polio.’

Christo

Christo is a First Nations man. He told the Royal Commission about his experience with mental health services over a number of years.

Ten years ago Christo decided to end his life.

'I put my surfboard in my car and decided I was going to get into the ocean and end my life by drowning.'

He was on his way to the beach when the police intervened.

'My phone was ringing, it was the police, they talked me into going and parking in a truck bay, they were great, they met me and arranged another police car to take me to the hospital.'

Christos was admitted to an acute psychiatric unit, where he stayed for a week.

He said the staff were 'terrific' and cared for him. They arranged for him to see a psychiatrist after he was discharged.

But things were different once he was home. Christo only saw the psychiatrist once.

'The follow-up was terrible,' he said.

Seven years later Christo tried to end his life again. His mate found him and called the police and an ambulance.

Christo was taken to the hospital emergency department. A psychiatrist spoke to Christo and said he would talk to him again later that morning.

A few hours later Christo saw a different doctor, who discharged him. Christo doesn't think the doctor was a psychiatrist.

'He ... didn't take me seriously – he said "Oh you look alright, you can go". He was too quick to dismiss me based on how I looked, but I was good at disguising how I actually was.'

Christo's brother was very angry the hospital allowed Christo to leave. No-one in the family knew what to do.

'All I cared about was dying. There was no follow-up for me.'

Two weeks later Christo tried to end his life again.

Sometime later Christo made his way to a First Nations health centre and joined their men's group.

'They stayed connected with me, they visited me at home, they have been my constant ... They have responded to me when I needed it. That's what has worked really well for me. Someone to call and check in every now and then.'

Waylon

Waylon, a First Nations man, speaks through an artificial larynx after having his Adam's apple removed.

'If my machine fails or breaks, I cannot talk to anyone.'

Waylon told the Royal Commission that his machine failed during a court case in which he was sent to jail.

'With legal proceedings, I had not been heard,' Waylon told the Royal Commission. 'When my machine failed my friend had to do all communication for me including phone calls ... My doctor also wrote a supporting letter for the courts that also wasn't presented that could [have] avoided me going to jail as I couldn't speak.'

One of Waylon's friends in jail helped him make his submission to the Royal Commission.

'If somebody smashes my machine I can't communicate other than through my friend.'

He's now worried that being in jail with his disability means he will lose his home, which is the subject of legal proceedings.

'I am afraid I will lose my home and my place of residence for 10 years ... I feel I can't get adequate support here other than friends in here.'

Arthur

Arthur was born in the early 1960s. He has dyslexia, which was only diagnosed recently.

Arthur told the Royal Commission his childhood was about 'survival'. After his mother left the family home he and his siblings were separated. Arthur was sent to a boys' home where he experienced constant bullying, abuse and sexual assault.

The boys' home had a school on site, and this failed Arthur too. He said the teachers didn't care if he could learn or not. If Arthur asked questions they would send him on jobs. If he sat there and did not talk they mostly ignored him. He could not understand letters or words. Looking at a page of writing was like 'looking at a moving picture'.

When Arthur turned 11, he was fostered out to a rural family. He was overjoyed to escape the boys' home, but he quickly learned he wasn't joining the family. He was there as unpaid child labour.

Arthur was sent to school with the local children but found it impossible to learn. The words 'kept moving' and he could not figure out how to read. Arthur recalls trying to ask for help from the teacher but he was dismissed. It seemed no-one cared if he learnt. The boys teased him every day about being 'dumb'.

After four years of hard work and abuse Arthur had had enough, one day knocking down one of the boys and threatening the other. He was sent away from the farm back into institutional care, this time at a 'half-way house'. He did not stay long. At age 15 he 'walked out of there and never looked back'.

Arthur was on the road alone for a decade, finding it easy to get jobs on farms and stations. In his mid-20s a station owner helped him enrol to vote. It was then his long-lost sibling found him. They had been searching for him for years.

Arthur's told us his traumatic childhood has had a profound effect on him. He has struggled with relationships all his adult life. His marriage ended, and he found it difficult to parent his own son, to show him love.

The dyslexia diagnosis is a recent revelation. Arthur says it is good to know but he is bewildered that teachers never listened to him when he explained that he didn't understand how they were teaching.

Arthur feels robbed of an education and all the opportunities this would have provided.

Makayla

Makayla was 'born to a drug and alcohol addicted mother' and was 'drug affected' as a baby. She has epilepsy, physical disability and post-traumatic stress disorder.

At the age of eight Makayla was placed with foster parents who had their own children and several foster children. This is when the violence and abuse started.

'The first time I opened my mouth ... they threw a plate at my head,' Makayla told the Royal Commission. 'This was the beginning of an ongoing pattern of throwing things at me, pulling my hair, hitting me and kicking me ... To protect myself I took the chuck out of the door latch on my room so I could see if they were coming into my room and stop the door from opening.'

When she was 12, Makayla's foster mother locked her in the shower and turned the hot water on. Makayla broke the shower trying to escape the scalding water.

In another incident Makayla's thumb was broken when her foster mum tried to kick her.

Makayla reported the abuse but no-one would listen.

'I tried to complain to social services and the police about what was happening to me. I also tried telling my mother but she didn't want to hear it. All I was told was, "You shouldn't tell lies".'

Makayla remained with this foster family until she was 15.

'At that time I remember going to bed then waking up in the hallway with a knife in my hand. It freaked me out and I put the knife back in the kitchen then went back to my room, too afraid to go back to sleep ... The next day I told the teacher's assistant at school what had been happening to me and begged not to go home.'

Soon after, Makayla and some of the other foster children were taken to the police station by an advocate to make a complaint about their treatment in the foster home.

The foster family was suspended from providing foster care, but Makayla found out that the foster mother who burned her went on to become a grief counsellor for child abuse victims in a charitable organisation.

'If there had been any follow-up to my situation she would never have got that job,' Makayla said.

Makayla would like to see an independent body that can advocate for children.

Sergio and Olympia

Sergio died while hospitalised for pneumonia about 10 years ago, in his late 40s. His sister, Olympia, told the Royal Commission she believes his death was preventable.

Five weeks after Sergio was born, he developed gastrointestinal problems and was admitted to hospital, where his treatment resulted in permanent brain damage.

Sergio would sometimes gulp while eating or drinking and was prone to aspiration pneumonia. He was admitted to hospital for treatment for this condition on a few occasions.

Olympia said that during these hospitalisations she had some ‘very difficult discussions’ with a particular doctor.

One time this doctor rang Olympia late at night and told her that ‘Sergio did not want any further medical treatment’. The doctor came to this conclusion because Sergio was ‘tugging at the intravenous line, trying to pull it out’. Olympia explained that Sergio was ‘like a very young, scared child that needed some calm reassurance’.

Olympia recalled another distressing conversation with this same doctor.

‘[The doctor said] people with an intellectual disability such as my brother should not be admitted to an intensive care unit, if their condition were to worsen, as that type of person “could not achieve much in life anyway”.’

The last time he was hospitalised for aspiration pneumonia the medication was not effective, and Sergio passed away. As he had been a resident in state care, his death was automatically the subject of a coronial investigation.

Those results took four years to be released.

‘I was dismayed to read in the Coroner’s Report that my brother died after doctors placed a “Do Not Resuscitate” (DNR) order on his medical file, even though instructions from the family were that all efforts should be adopted to keep my brother alive,’ Olympia said.

The coroner’s report revealed the decision to authorise the DNR order was made jointly by the medical registrar, the medical consultant, the ICU registrar and ICU consultant. Having prepared the report, the coroner indicated they would not get involved further.

‘From my perspective,’ Olympia said, ‘the death of my brother may have been preventable if appropriate medical attention had continued.’

Joyce

A psychiatrist diagnosed Joyce with schizophrenia when she was in her early 30s. Her marriage had just ended and her husband had left with their daughter.

'I went in myself. My aunty took me in. I was psychotic ... after the breakup, upset and everything. But that was the only time I have ever been psychotic.'

That was in the 1980s.

Joyce told the Royal Commission she believed the hospital psychiatrist had misdiagnosed her, because the hospital was at the time also treating her sister for schizophrenia.

'He said, "Okay, family history, you've got schizophrenia because your sister is here.'"

The psychiatrist prescribed medication and Joyce went back to work.

'I worked for 20 years in the workforce. I worked in the public service. And I never sort of questioned it really. I thought, yeah, they're right, I'll take the medication.'

She was re-admitted to hospital twice 'because when you go off the medication, sometimes you do end up in hospital.'

Joyce is now in her 70s. When the psychiatrist treating her died a year ago, she went to see her general practitioner.

'He said to me, "What are your symptoms, [Joyce]?" I said, "I haven't got any symptoms because I don't have it".'

She decided again to stop taking her medication.

'I have been off medication for 12 months doing fine, and nothing wrong with me and I always suspected that ... I am telling the government, I have got no disability, I never have had, okay.'

Mark

Mark has cerebral palsy which affects his movement and speech.

He told the Royal Commission he has experienced discrimination his whole life, but the most recent incident left him devastated.

‘[It] was a very serious matter that goes to the heart of my identity as a person with a disability and one that had dire impacts upon my independence and my dignity.’

As a young man Mark was determined to get a licence. Despite much opposition, after demonstrating his driving skills, he was successful.

‘People questioned the sergeant about why he approved my licence but he said, “This young fella can drive and you don’t have to worry about him”.’

Mark went on to get forklift, truck, long distance coach and bus licences. He worked in the transport and construction industry and was a professional driver until he retired.

‘These achievements were not easy to obtain because of people’s prejudice and judging me on my appearance.’

Last year Mark was driving to a shopping centre when he noticed a female driver speed up and tailgate him. Because she was dangerously close, Mark pulled over to let her pass. But instead, she pulled in behind him.

After a few moments Mark continued driving. The woman followed him to the shops and when he pulled in to the loading dock she parked him in. She then jumped out and took a number of photos and rang the police.

‘The male police officer came over to my car which was parked and put his hand through the car window and ripped out my car keys. I said, “Pardon me what is going on?” He said, “You might run off,” and I said, “How, I have a job to even walk?”’

The young woman told the police Mark was driving erratically. He said this was totally wrong. The police asked to see Mark drive but because he was ‘very shaken up’ he refused.

‘They conducted a breath analysis on me but not on the young woman and I feel like they made a fool out of me.’

Eventually the police let Mark drive home but two weeks later he received a letter – his ‘licence had been suspended pending an assessment’ with his GP.

The GP recommended an occupational therapist (OT) assessment which Mark said there was no need for as he 'hadn't caused a crash or had a poor driving record'.

Then he had to wait for an OT who had a vehicle with dual controls. Mark was very nervous during the assessment, but the OT told him 'don't worry you have done very well in a new strange vehicle'.

But this wasn't the end of it. After handing over \$750, the OT told him he needed to do an aged care driving assessment as well.

'I think this is undignified, particularly when I have achieved all these classes of licensed driving, even having completed advanced driving courses ... I always said that when I didn't feel safe on the road I would hand my licence in.'

Ultimately he completed the assessment and his licence was reinstated.

'To my annoyance I still have a restriction of only being allowed to drive within a 50 kilometre radius from home.'

Mark told us this restriction prevents him continuing his 'work as an advocate for people with disabilities and for older people' which is work he has been honoured for.

He finds it unacceptable the young woman was allowed 'to follow someone, park them in, verbally abuse someone and take their photo without permission'.

'The police judged me on my disability and not on my driving record ... I am used to being misjudged on my appearance but once you get to know me I am an intelligent, highly capable man trapped in a unique body from birth.'

Isla and Helen

Helen said her daughter Isla used to enjoy life and make the most out of every day.

‘She had a lovely smile and she always tried to make people happy and loved helping whenever she could ... She loved to sing every day.’

Isla died in her late 20s. Helen believes her death was preventable.

Isla had ‘mild’ cognitive disability. She lived an independent life. She couldn’t travel very far by herself but ‘was able to go to the local shops and back by herself’.

One weekend she was unwell. She was vomiting and had pain in her ear. Helen gave her paracetamol but it didn’t help. On Monday a doctor saw Isla at home. He said she had an ear infection and gave her a prescription.

A few hours after her first dose of the medication, Isla’s sister noticed something very wrong. Isla had spit bubbles on her lips and ‘appeared out of it’. Helen thought she’d ‘had a seizure or a fit because she was not herself and was not acting normally’. The ambulance took Isla to the local hospital.

At the hospital Isla complained repeatedly about her ear.

‘She was distressed and wanted to get out of bed all the time.’

Helen realised Isla was hot to the touch, but staff didn’t pay attention when she told them.

In the early hours of morning the treating doctor came to see Isla. Helen told the doctor she believed Isla had ‘had a fit or seizure’, but the doctor didn’t seem to believe her. The doctor wrote a prescription, told Helen to give Nurofen to Isla, and discharged her with a letter stating she ‘was having a temper tantrum’.

Helen knew Isla was in pain and she appeared to be in distress but the ‘nursing staff just told me not to worry’. Helen asked a nurse if Isla could stay in the hospital. The nurse was uncertain, but soon after the doctor walked past.

‘You’re still here?’ the doctor asked. Helen explained she could not get Isla out of bed. The doctor asked if she wanted security to help. Helen felt threatened and ‘stunned’. She ‘was scared and stressed’ because Isla needed help and ‘they did not seem to care’.

Helen approached a different nurse and explained they had been told to leave but Isla was still in pain. The nurse found a wheelchair, ‘manhandled’ Isla into it and wheeled her to the taxi rank.

A few hours later Isla was dead.

The coroner found Isla died due to meningitis. The hospital doctor had thought she might have had meningitis, but later decided Isla 'couldn't stand the pain in her ear because of her disability'. She admitted her diagnosis 'was inaccurate and inadequate'.

The coroner found Isla had been 'treated differently from the way they might have assessed and treated other patients and that staff made assumptions that her inability to communicate was due to "behavioural issues" associated with her disability, without investigating her symptoms further'.

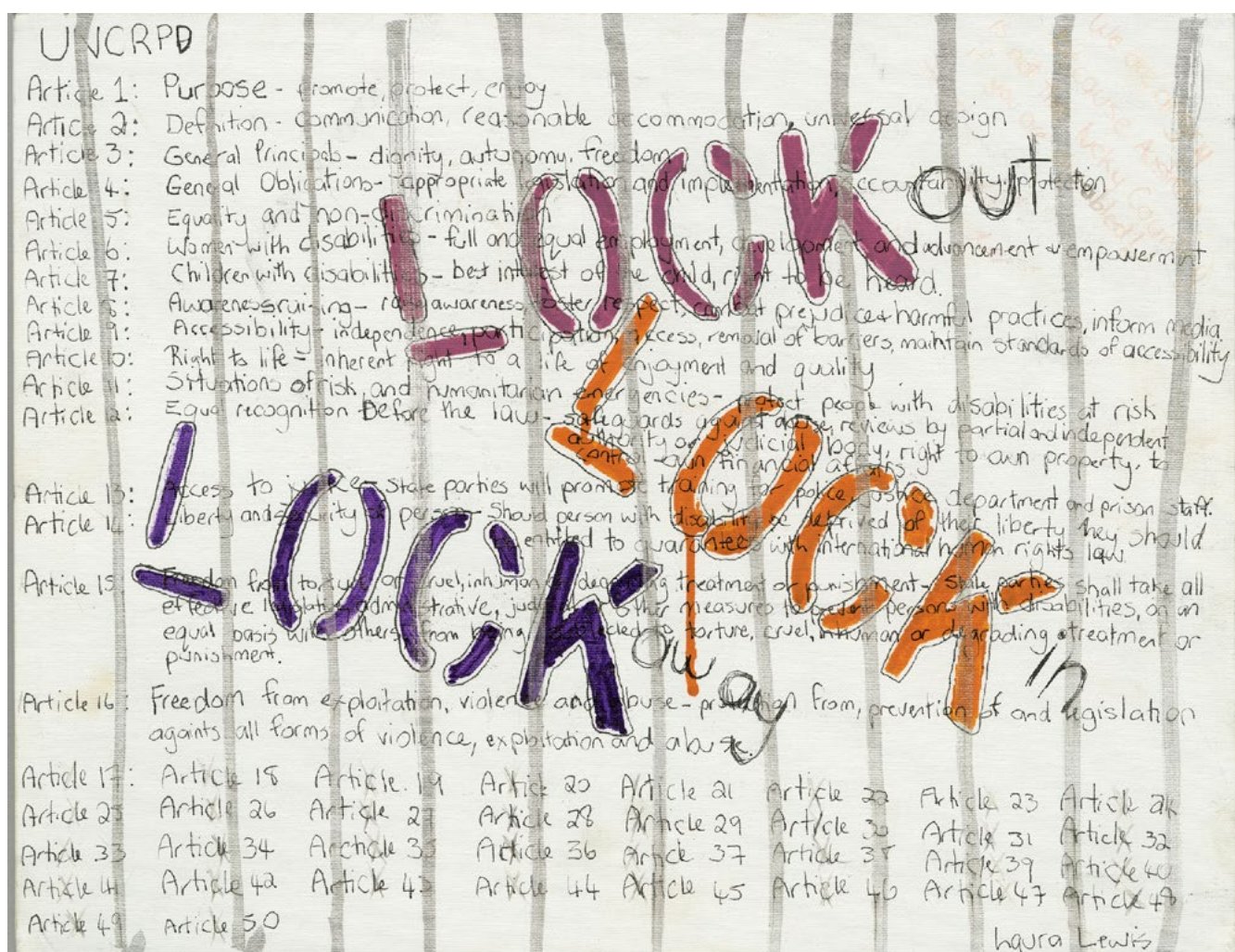
The coroner made recommendations for the hospital to improve the care of people with intellectual disability, including more assessments for people with intellectual disability before discharge or transfer, and where seizures occur. The recommendations also included more training and self-care for medical staff.

Helen returned to the hospital a few times after Isla's death to find out if it 'had followed the recommendations made at the inquest'. She remains in the dark, because on each occasion they 'called security straight away'.

Helen believes medical staff should 'listen to parents and carers who know their child best and how their child responds'. But above all they 'need to care more'.

'My family and I are still angry and upset,' Isla said. 'If a doctor discriminates in their treatment of a patient based on whether they have a disability ... [they should be] 'immediately stood down from their position.' Helen would like to see a change to the law to make this enforceable.

'I do not want any more families to suffer.'



Artwork by Laura Lewis

Cloe

‘Auslan is powerful and it empowers Deaf people. It is the birth right of Deaf people to have access to sign language. It is a visual, spatial language that fits Deaf people. With Auslan I can truly express myself and I can access the world.’

Cloe, in her 30s, is Deaf.

‘Growing up as the only person [in the family] who cannot hear was incredibly difficult,’ Cloe told the Royal Commission. ‘When I was born my parents assumed I could hear just like them ... The GP told mum, “I am very sorry, but your daughter is deaf,” upon which mum burst into tears.’

Cloe said after a few months grieving, her mum decided to learn Auslan.

‘The only person in my family who learnt to sign was my mum and I value her so much for doing this.’

Her mum enrolled her in a primary school where there were several other Deaf kids.

‘I was part of a community there and the students and staff were like my family. It was the beginning of my connection to the Deaf community too.’

One of her Auslan teachers was so good she inspired Cloe to help disadvantaged kids when she grew up. Cloe went to high school believing it would be like primary school, but said it was terrible.

‘I didn’t receive an adequate education and my access needs weren’t met. I was bullied relentlessly by the hearing students and I attribute this to being the only Deaf kid in my class.’

Because English is her second language she struggled to learn. In year 11 she switched to a school which employed full-time interpreters.

‘That school was excellent. We were treated like adults and everyone was lovely to me. There was still a small Deaf unit at that school and I got a lot of support from them.’

Cloe tried to pursue her dream of helping kids and did a tertiary course in community studies, but an agency couldn’t find her a job. Instead she was offered manual work at a disability enterprise.

‘I am Deaf, my ears don’t work, but that’s it. I do not identify with the broader disability community at all. As a Deaf person once my interpreting needs are met I have no disability and no barriers.’

When her mum developed cancer, her family didn’t think Cloe needed to know ‘all the details’.

She had to ask her mum's doctor what was going on.

'It was many, many months from when my family knew mum was dying until I stood up for myself and found out too.'

Cloe said even then she struggled to get information from hospitals.

'In all the medical and specialist appointments I went to with mum I never had interpreters present so I didn't know what was being said.'

Because her mum was the only one in her family who spoke Auslan, when her mum died there was no other family member she could talk with.

'I've become more independent since then, though.'

Cloe now teaches kids Auslan. She has also learnt to drive.

'Mum and dad would never let me learn to drive because I was deaf. I told them so many times that lots of Deaf people drive, and they would see my Deaf friends come over in their cars, but I was told I couldn't do it.'

She said many people in the community still assume she can't do things and ask her 'stupid questions'.

'I've had doctors question me about why I was bringing an interpreter to an appointment. I've had doctors talk directly to the interpreter like I wasn't there, like I was invisible. Even when the interpreters ask the doctor to address me directly they continue to look away from me.'

'I feel like jumping up and yelling, "Hello. Here I am. Look at me."'

Amiah

Amiah is blind and uses braille.

She grew up in a refugee camp with no access to special education or technology.

Amiah told the Royal Commission she never felt like she had a disability because her father encouraged her to do everything her siblings did.

‘My family and community were very supportive, and they have actively helped and assisted me to be independent ... This has made me very capable of living by myself and managing my needs.’

Amiah came to Australia in her late teens. Since then, she said, she has ‘felt discriminated against’.

‘The cultural differences and the isolation in school started to make my life stressful. I was more aware, conscious and anxious about being a blind person.’

Following school, Amiah started a relationship with a man who has vision impairment.

Amiah and her partner decided to start a family. Their GP referred them to an IVF clinic because ‘there were issues having a baby naturally’.

‘The consultations with the IVF clinic helped me make an informed decision. Several tests including genetic testing were done, and all tests came out good.’

Amiah was able to self-administer hormone injections by listening for the clicks the injection device would make. She said it would have been safer and easier if the instructions and markings on the device were in braille.

IVF was successful, but Amiah’s joy was crushed by people’s negative attitudes to her pregnancy.

People saw only a ‘blind lady who is pregnant’ instead of a person who wished to be a mother.

‘I have been discriminated against, judged and questioned by many people. I had to always say, “This is not an accidental baby.”’

She said health professionals were the worst.

They constantly questioned her capacity, asking if she was physically and mentally prepared to look after the baby.

One person demanded to know who was going to stay awake and take care of the baby at night.

‘I want to be that person, I wanted to be a mother.’

Another person told her she had ‘other options’ and could find someone else to look after the baby.

‘I wonder if they would ask the same of any parent who is in the same situation.’

Amiah’s baby was born a few weeks premature.

‘I was not able to hold the baby for 10 days, which was traumatising for me.’

Amiah’s partner overheard health professionals discussing whether Amiah would be able to care for the baby. Another asked him whether he or Amiah would cope. Amiah said people often treated them as if they were invisible, talking about their capacity in front of them.

‘As a blind person and a person with a disability, my whole life turns into a constant journey of proving self-capacity to everyone,’ Amiah said. ‘Everyone has a right to have a family and a baby.’

Amiah said that instead of feeling ‘harassed and constantly questioned and coming home being anxious about fear of losing [her] baby’, she would have liked practical support. For example, instructions for baby products, medications and supplies in braille would have been helpful.

Now Amiah’s child is a preschooler, people constantly express their surprise at how well he is cared for.

Amiah would like to have more children and hopes people’s attitudes will be more positive.

‘I believe I also have a right to be heard, have an opinion and have the same dignity as any other person.’

Jetta

Jetta, late 20s, has epilepsy.

She told the Royal Commission her seizures are triggered by stress. After having a seizure, she is so fatigued she can't get out of bed and attend to her personal care for several days.

Jetta worked in retail for almost 10 years. One time, she was serving customers when she started to experience pre-seizure symptoms.

She told her supervisor and asked if she could leave the floor and sit down, but they were dismissive.

Moments later, Jetta fell backwards, crashed to the floor and lost consciousness.

Witnesses later told her that her supervisor sounded the emergency alarm used for violent customers. Staff came from everywhere and evacuated the store. One staff member had a child with epilepsy and was able to administer the appropriate first aid.

Jetta needed several stitches in her head.

'The following week I returned to work and the team leader came up to me, and the first and only thing she said to me was, "Don't you ever do that to me again."'

Jetta moved to a different workplace and after some time became a team leader.

A few years ago, a new staff member started in Jetta's team.

She allocated him a number of tasks and was shocked when he told her, 'You cannot tell me what to do, you're female.'

Jetta spoke to her supervisor and the staff member was moved to a different team.

A few weeks later, he returned to Jetta's team.

He refused to complete his allocated tasks, again telling her it was because she was female.

Jetta immediately contacted HR.

'[They] had an unsupportive tone of voice and wanted to come and assess the situation as they doubted my rationale. The stress of this triggered me to have an epileptic seizure as soon as she walked into my outlet.'

The HR manager didn't know what to do, and tried to give Jetta water.

Jetta lost consciousness.

Another staff member, familiar with epileptic seizures, intervened and provided first aid.

‘I never got rostered for another shift after this day.’

Jetta contacted a lawyer who advised there was nothing she could do because she was a casual employee.

‘I had never seized whilst on shift for this employer and they were unaware of my epilepsy, making me think this was the reason why I failed to be rostered on again.’

Jetta has not been able to find work and relies on the Disability Support Pension (DSP).

She is not eligible for supports from the NDIS and struggles to pay her rent and bills.

Several of Jetta’s front teeth are broken because of falling during a seizure.

‘As a result of dental care not being included under Medicare I have been unable to get these repaired as I am restricted by the amount of savings I am able to accumulate whilst living on the DSP and rising cost of living.’

Every two years, Centrelink reassess her eligibility for the DSP.

‘The two-year reassessment period is a scary and stressful consequence that leads to further seizures.’

Jetta’s drivers licence has been medically suspended and she uses a discounted taxi service.

Drivers regularly question her eligibility for the service, suggesting she is too young and not disabled.

Jetta believes there needs to be increased awareness of epilepsy, including the impacts it has on a person’s daily life.

‘Furthermore, education on how to react when a person is seizing.’

Farangis and Robert

Farangis is in her 80s and is legally blind, with only a small amount of peripheral vision.

A few years ago Farangis was living at home, with her son Robert as her carer, when she went to hospital with an infection.

Such admissions had been 'recurrent' ever since a failed medical procedure at the hospital. Normally she would have 'a course of antibiotics' then come home 'after four to 10 days'. But this time, Robert said, the hospital 'refused to discharge her'.

'She hadn't even been treated for her [infection], which can be life-threatening ... She was arbitrarily detained. She had no other medical issues.'

The hospital said Farangis's home support was insufficient for her needs. However Robert was in the process of getting her high-level care package 'reinstated'. He believes the reason the hospital didn't want her returning home is that they 'didn't want her to be coming back in' for treatment during the pandemic.

Soon after, the hospital called Robert saying they 'were going to transfer her to an aged home'.

'And the basis of that was too many admissions ... I disagreed, my mother disagreed. I believe that's why they made the decision the following day to revoke my enduring power of attorney.'

Farangis stayed in hospital for months awaiting a tribunal hearing.

'Her stay there was just absolutely abhorrent. And the duty of care that was provided to her was not existent ... She was isolated in a room by herself. The room was dark because the overhead light was not working.'

The bed lifter didn't work either and Robert continuously found the nurse bell 'on the floor, under the bed'.

'That was quite distressing ... If you need help, that is your only lifeline. And yet there was wilful neglect towards her.'

Farangis told her son, 'They treat you less than a human being. They treat you less than a dog.'

Robert said 'on top of all the restrictive practices put in place', doctors gave Farangis lots of 'unnecessary medications that just knocked her out'. Some were 'experimental drugs', not yet approved.

'She then came out in full-body hives. Pain.'

The head registrar told him, 'It will be silly not to take this opportunity to trial her on a new diabetic drug.'

'I said, "What are you doing with her? She's drugged out. She's asleep every day. You call that duty of care?"'

Robert believes doctors 'sedated' Farangis so 'she couldn't do a thing' before the tribunal.

'Submissions were fabricated ... with basically misleading information. And it was all based around the fact that my mother had dementia, which she didn't.'

The social worker who 'authored' the submissions never spoke to Farangis and went by 'hearsay', Robert said.

'But [my mother] is a normal functioning person. She has full mental capacity.'

Farangis was also 'provided paperwork which she could not read, due to her disability'.

'They treated her as if she's not a person. They say, "She's legally blind, what does she know? There's no point." So they just totally ignore her.'

Robert said Farangis remains under the public guardian and in aged care because of 'doctors and their abuse'.

'She needs to come home with quality care ... They're just waiting for her to die.'

Jaimie

Jaimie has worked in his regional area as a support worker for more than a decade.

‘I’ve seen staff run from houses because they can’t handle the behaviour of a client,’ Jaimie told the Royal Commission. ‘I can calm a client down [but] ... I just feel like everything that I do is just not worth it anymore.’

About a year ago Jaimie worked with a non-verbal First Nations man in supported accommodation. Not long after he started the job, he saw another worker grab a jug of hot water and chase the man outside.

‘[The worker] said, “If he doesn’t want to participate in anything you have to get him up to do it. So what we do is we use a jug of hot water.”’

Jaimie said the man appeared to have previous burn marks and he reported the incident to the service provider’s manager, but ‘didn’t hear much after that’.

‘It’s very distressing for me ... He’s non-verbal. So when somebody’s chasing him with hot water, of course I’m going to try and do something about it to stop it. But I just couldn’t because the other staff member wouldn’t listen to me.’

Jaimie said the same service provider wanted to move another First Nations man to a town away from his family.

‘He didn’t want to move out there because his family was out here and he could see his children and his grandchildren ... I tried to intervene by advocating for him and sending an email to the CEO and all the other staff, and they said that this is a breach of policy.’

The service provider fired Jaimie, but still employs the worker who threatened a client with hot water.

Jaimie said there is significant nepotism in the disability sector.

‘I’ve seen in the many, many years of working in this sector that family members work in these organisations and get their family into work. I don’t think half of these people, maybe even three-quarters, have the qualifications to do it.’

He says some service providers cut corners by not properly training people.

‘Medication administration is pretty important. I did work for one organisation that put me through a course, but that was just for that organisation. And so when people find out my experience they’re just, like, “You’ll be fine with it, don’t worry about it.”’

One service provider told him to give the First Nations clients insulin injections.

'I know it's only insulin, but if I put in the wrong dosage, too much or too little, I'm responsible for it ... You know, I was assisting a lot of people in jobs that I was not qualified for. I'm not a nurse.'

Jaimie's said he's also seen service providers feeding people dreadful meals.

'I've witnessed over the years people mixing a [blended] steak with some milk to create a meal for somebody.'

Jaimie tries to make sure the residents he supports get the food they like to eat, such as fresh seafood and fruit.

'We got a huge bowl and I tell you two kilos of mandarins would be gone in about 10 minutes ... I got dragged over the coals for that because my weekly shopping bill was \$500 for four people in one house. Apparently I was only allowed to spend \$200 a week on shopping.'

Colleagues tell Jaimie he has 'something special' to offer, but service providers don't seem to value compassion.

'People stand over the top of me and say, "No stop, you can't do that. No, you can't do this. No, you can't do that." And I'm just like, "But we're trying to give these people a better quality of life.'"

Mary-Rose and Lettie

Mary-Rose, early 40s, has intellectual disability and is non-verbal. She has poor motor skills and needs help with meals and personal care, and lives in a group home with 24/7 support. Her mum and dad are ageing.

About a year ago, Mary-Rose fell and broke her leg. Support staff called an ambulance and she was admitted to a regional hospital. Doctors operated, inserting pins and screws to stabilise the leg.

Her mum, Lettie, hoped one of Mary-Rose's regular support workers would be able to support her while she was in hospital.

But the provider told her it wasn't possible because the NDIS doesn't fund support workers in a hospital setting. The NDIS expects hospital staff to provide this support.

Lettie told the Royal Commission that while individual staff did all they could, the hospital was severely understaffed. Mary-Rose was in hospital for more than a week 'before any nursing staff thought to do a patient profile for her so that all staff would be aware that she was non-verbal, needed support with her meals and support with her personal care'.

Mary-Rose developed an infection and had to have further operations. The last operation went very badly because staff didn't consider her disability prior to taking her to theatre.

'It seems very evident to me,' Lettie said, 'that nursing staff, as well as the shortages that they face, are also not given the time or the training that is required to deal with people with disabilities.'

Mary-Rose ended up staying in hospital for almost a month.

'This experience was extremely stressful for her and our family, and I am very concerned for her wellbeing if she should need medical care when I am no longer able to support her.'

Mary-Rose now has to have general anaesthetic administered at a major city hospital.

This means a long trip to the city for medical and dental procedures.

'She would be on her own in a strange place with strangers who are unable to understand her and would be unable to communicate with her, unless I or her father were able to make that trip with her,' Lettie said.

'It does really scare me ... that should I no longer be able to support [her] ... what would happen to her?'

Lettie believes the NDIS should fund the person's usual support workers to provide support in hospital.

Additionally, hospital staff need to learn how to care for people with disability.

'In an ideal world, all hospitals would also have dedicated staff and supports that they can call on when a person with a disability is hospitalised because often the person does not understand what is happening, nor why it is happening.'

Ephraim and Aja

Ephraim, in his early 30s, had a brain haemorrhage shortly after he was born. He is non-verbal and has very complex needs. He lives with his mother Aja and receives 24/7 care.

'We just went through a rough time,' Aja told the Royal Commission. 'Rough times in the last year, or three years with the pandemic, high level of autism, a lot of self-harming. But we try to battle on and, you know, face the day with optimism and things like that. And yeah, and keep going.'

Ephraim and Aja are Aboriginal, and Aja said they have had some difficult interactions with the NDIA, in particular with staff who lack understanding of First Nations culture.

She described a meeting with an NDIA planner which 'got off to a bad start'. Aja told the planner where her Country was, and asked the planner where she was from.

'It was like me saying, "Hey, where's your mob?"'

But the planner, 'lacking the cultural competency' to understand that, took it as 'a slight on her professionalism'.

'So, I've got to, kind of sit down with somebody like that and we start off on a bad footing ... because she doesn't understand that that was coming from probably my cultural way of talking, you know?'

That 'bad start' escalated, and Aja ending up walking out of the meeting.

'We had gone in really prepared because ... my son's got very, very good therapists and psychiatrists and allied health team. And we went into this meeting and basically it was as if [the planner] was prepared or instructed to shut it down right from the start. She never once asked me about Ephraim ... I think the thing that I still find good was – I don't know where I got the strength, maybe it's the Aboriginal woman in me – but when enough is enough, I just could not take it anymore, and maybe that was the best thing that I did that day ... I just said, "I have to leave."'

The encounter left Aja deeply distressed.

'It's almost like a weeping from, you know, our soul, that, when something – unkindness like that happens, and that unkindness has come from a lack of cultural competency and support ... I can say that this person that sat in front of me that day did not have the expertise that we would have expected her to have had,' she said.

‘And where do we ... where do people from culture sit with it? If they’re not like someone like myself, who’s had to fight hard for my son, and who is a warrior mother and who is a strong advocate, what happens to our people? Do they just kind of get flicked over?’

Aja sees the NDIS as a ‘fantastic thing’, but believes cultural awareness training for planners and other staff should be mandatory.

‘I think that we’re dealing with a serious lack of cultural capacity, or lack of cultural requirement, and the NDIS doesn’t seem to feel that it’s important. We all hear what is supposed to be being done, but when are we going to start having this really serious conversation about cultural competency where, you know, Aboriginal and Torres Strait Islander people from the lived experience can be offering that advice? Where are the Aboriginal trainers?’

Turner

‘Some of these drugs send you insane. You feel like you’re going to die. Under the guidelines of the pharmaceutical companies, they make you into drug addicts.’

For three decades, Turner told the Royal Commission, he has been a ‘victim of abuse’ in the mental health system, Psychiatrists have given him ‘mind-altering and dangerous drugs’ that make him ‘suicidally depressed’.

‘They bully people and they force drugs on people. They inject you with stuff that sends you absolutely crazy. It paralyses your body ... you can’t walk. Thirty years of drug abuse from mental health departments, you know, I’m lucky to be alive. They’re very aggressive people. They forced us to sign forms to get electric shock treatment. I’ve lost all my teeth from all the drugs and the electric treatment.’

Turner ended up on a Disability Support Pension.

He is under an involuntary treatment order and says he is given medications ‘known to be harmful’.

‘I’ve been subjected to this for 10 years, you know. Once every three months. Then you’ve got to try and reach out to all your friends to try and help you to stop you from, you know, necking yourself. All the evidence is there on what the drugs do to people and they don’t listen. They just keep abiding by the same protocol.’

Turner has tried to talk to his psychiatrists about this, but said ‘they just keep doing what they do’.

‘They don’t change it because they’re just aggressive bullies. It doesn’t matter what you say to them, they just override it and they force you, and they call the police around. Then they inject you with stuff. Like the last time they gave me an injection, I kept getting infections,’ he said.

‘All they’re worried about is their jobs. It’s created an industry of psychiatrists, drugs ... And the system, you know, they just use us like experiments for their own gain. Like guinea pigs. Like rats. It’s manslaughter what they do to people. They disable your mind.’

Greer

Greer is in her 40s and Deaf.

'My entire family are Deaf and they all went to Deaf school,' Greer told the Royal Commission.

She and her siblings used Auslan at home, and were the first in generations to go to a mainstream school where they had to sign in English. This was a 'new language' she had to learn.

'I'm not talking about the dark ages, this is very recent ... and because we didn't access our education through Auslan we had sub-adequate education. None of the teachers understood me.'

The teachers also insisted she wear a hearing aid even though it didn't help her.

'If you didn't have your hearing aid on you were forced to sit down at lunchtime and not go out and play with other students.'

Greer said because she was Deaf, teachers put her in a class below her skill level.

'Some of the other students who were Deaf needed a lot more support, and that work was appropriate for them. But I was never challenged and never given anything that was age appropriate ... That's why as an adult my education level is much behind the general public and my English is not so good.'

Greer said things haven't improved much since she went to school.

'I see [children] having qualified interpreters within the school, but, you know, the interpreters are usually lower-level interpreters because the school pay is not as good as freelance interpreting ... I see them and they are still going through the same issues that I'd experienced. The same barriers they're facing.'

Greer said the Deaf community often isn't considered in emergencies.

For example, one time she was in a public library when a staff member yelled at her to move.

'She had gone bright red. I didn't know if it was about the fact I'd booked a table or I hadn't booked a table, so anyway I took my time. I closed down the laptop and then this staff member lost it. She grabbed me ... I typed on my phone and showed another staff member ... "What's going on?" and she replied, "It's a fire alarm."'

'I could be sitting on a train and suddenly the train will stop and I've got to change trains and there's only been an auditory announcement, there's no scrolling message, so I just have to follow [everyone else].'

'It's things that just keep happening again and again and again. And we're all burnt out from living in these hearing worlds.'

Arden

Arden is intersex and neurodivergent.

Arden began losing her vision in primary school. Instead of supporting her, teachers made her repeat years. This affected her self-esteem.

'I never fitted in with my classmates and felt left out of everything, verbally abused and made fun of.'

Arden told the Royal Commission she was sexually assaulted as a teenager, and this led to 'mental health distress'.

In her 20s, she became blind.

'Losing my vision ... was a blessing as I didn't have to look at myself in mirrors and didn't have to cope with a world I felt alienated from.'

Arden struggled to fit in. Her mental health deteriorated and, at the time, she wasn't able to access support.

Arden said the 'train wreck' of her life continued.

About a decade ago, she decided to make some changes.

'I had to tackle the knowledge I always had deeper down – that I was different.'

Arden had surgery and transitioned fully to female.

'I was pleased to receive funding for my surgery but there was more that I needed, and it wasn't funded by Medicare or other sources.'

She felt her choices were limited because the medical system didn't fully consider her disability.

'Lack of in-depth counselling and lack of support for my disability also made me choose options and reject others that may have led to better outcomes.'

Arden's choices were also limited by a lack of savings or superannuation – her only income for most of her life has been the Disability Support Pension.

She feels fortunate to be able to access the NDIS but believes it should be 'a more flexible and fairer regime that puts people first'.

Arden is finally getting support for her mental health issues.

'We need the structures in place and the resources and opportunities to rebuild our lives.'

Sapphire

‘Ultimately, I can’t receive DSP until I take an antidepressant in Centrelink’s eyes, and that’s not going to happen.’

Sapphire is in their 20s and a few years ago ‘received an official diagnosis of fibromyalgia’.

‘Prior to my physical diagnosis, I had been diagnosed with schizotypal personality disorder which highlighted a lot of things about, I suppose, my anxieties and depressions and sense of paranoia,’ they told the Royal Commission.

Sapphire got counselling and medical care through a youth service organisation. At one point a hospital psychiatrist gave them an antidepressant.

‘To which I had an extreme allergic reaction ... And it was ridiculously scary this experience. And I spoke to him about that and he was understanding and he said that’s a really rare reaction. So I didn’t seek getting a script for that medication at all and I just continued with cognitive behaviour therapy and psychosocial therapies.’

Sapphire found the mental health services and activities at the youth community centre really helped ‘deal’ with their condition.

‘That’s where I was getting a lot of support ... And working a lot with their counsellors in – in trying to get the Disability Support Pension [DSP].’

Centrelink said Sapphire didn’t qualify for the DSP.

‘They just fully flat-out denied it at the start. They didn’t think that my illness had even affected me to a point of not being able to work. When I had doctors saying that I couldn’t work a certain capacity ... I still wanted to work but it needed to be reduced and a certain kind of work.’

A ‘very understanding’ consultant helped Sapphire get a youth disability supplement, which meant they weren’t ‘really required to look for work’. That lasted about a year.

‘Then all of a sudden I was required to do these things that were previously understood that I couldn’t do.’

Sapphire struggled ‘to meet those mutual obligations’ of a job active status, and ‘to find that support in employment’.

‘I was living on the edge constantly fearing that any Centrelink benefit would be cut off.’

Services Australia says Sapphire lacks the ‘impairment points ... for psychological impairment’.

‘They said it’s diagnosed, but not fully treated and stabilised and that was due to me not taking antidepressants.’

Sapphire puts her exclusion from services down to ‘a stigma’.

‘I have an invisible illness.’



Royal Commission
into Violence, Abuse, Neglect and
Exploitation of People with Disability