



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

Voices of people with disability

Book 3



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.

Elly and Pearce

Elly has an intellectual disability and mental health conditions that include post-traumatic stress disorder.

Her father, Pearce, said child protection put Elly into foster care when she was five, after her mother abused her.

Pearce fought to get Elly back, and regained custody after Elly was sexually abused in foster care. He raised her on his own for the next 15 years.

‘She’s a beautiful kid ... She shows me a lot of confidence that she can have a go at things,’ Pearce told the Royal Commission. ‘No-one’s perfect at raising any child that has some sort of disability, especially when I’ve got a disability myself – intellectual impairment. But I stand up. I done the best I can.’

A few years ago, Elly’s GP recommended she be fitted with an intrauterine device (IUD) for contraception. Elly loves children and the GP was concerned that Elly ‘wanted to have a baby’.

Pearce said Elly does understand where babies came from and what contraception does.

‘She knows everything because ... we used to get books.’

Elly signed a document agreeing to the IUD. However the device hurt Elly and caused mood changes.

‘I could not put up with watching Elly self-harming all the time over pain,’ Pearce said.

Pearce asked the GP to remove the IUD and Elly was admitted to hospital.

Around the same time Pearce, who has diabetes, developed an infection and was ‘in and out of the hospital’.

Elly told Pearce that, despite her severe reaction to the first IUD, doctors had ‘forced her to sign the document’ for a second IUD.

Pearce, ‘tired and burnt out’, asked an NDIS support coordinator to help get Elly discharged and ‘to get a bit of support’ so he could ‘have a rest’.

The coordinator suggested Elly’s affairs be placed under the public guardian. Pearce, still sick, agreed.

Soon after, Pearce discovered one of Elly’s NDIS service providers had filed a domestic violence order (DVO) against him.

'It got me a shock ... I found out when I got out of hospital ... that I was getting a DVO on me to get me out the way ... [But Elly] kept contacting me when she wasn't supposed to.'

Pearce said it meant Elly couldn't return home if he was still there, so he moved into a caravan. However, because he rents public housing in his name, the housing department considered he'd abandoned his home and he lost all his possessions.

Without a home to return to Elly was kept in hospital for several months, for which she was charged thousands of dollars.

'[Elly] was under the trustee. That was why she was living in hospital ... It was something to do with, like, rent.'

Pearce said an advocate helped him have the debt wiped and a lawyer helped Pearce have the DVO removed.

The guardian eventually found supported accommodation for Elly, but she is unhappy.

'[Elly's] got the capability of standing up. It's just she needed just a bit of, you know, some people in the real world [to help her]. She wants a job ... and her NDIS plan has not even worked, right? The guardian's not doing anything, even the provider, they're not supporting her.'

Pearce is worried what will happen if Elly does have a baby.

'I've already been through this with the guardian ... They're ready to pounce on her to take the kid away. Can't they give [Elly] a chance?'

Hans

‘I don’t think putting a 12-year-old in a detention centre should ever be considered reasonable. I needed safe and supervised accommodation. I lost my family. I don’t know my own parents, they’re strangers to me. I don’t actually know how old I am.’

Hans is a First Nations autistic man in his mid-30s. He also lives with anxiety, agoraphobia and complex post-traumatic stress disorder.

‘When I was growing up ... my family kind of knew there was something not right with me,’ Hans told the Royal Commission. ‘At the time, they didn’t know much about autism, so they kept, like, misdiagnosing me and then giving me wrong medications all the time, making me sick.’

Hans spent ‘months at a time’ in hospital having treatment for things like bipolar disorder and schizophrenia.

‘They did, like, isolation treatment on me at one point.’

When he was about 10, his mother ‘completely lost the plot’ and Hans was put into foster care. When the department of community services (DOCS) moved to become his guardian, promising psychologists and other help, his father accepted.

‘And it just ended up a nightmare ... They kind of lied to him. He gave up his custody hoping that will be better for me and he got screwed over just as bad as I did. Coz all they offered, they didn’t do. I ended up in refuges and dodgy foster homes with alcoholics and things ... who would take my DOCS money and spend it on booze, and then I would go to school with duct tape around my shoes because they had no money to buy shoes.’

When Hans came out of foster care – dosed up on ‘anti-schizophrenic meds’ – he was ‘completely off the rails’.

‘I was so angry ... At one point I was grabbing knives just to keep dad away from me ... It was just the medication.’

The department told his dad they were taking Hans to a refuge. Instead they took him to a juvenile detention centre. There, much older boys bashed and tried to rape him.

‘You had to fight them off and you’re screaming, just praying the guards would hear it. Their favourite thing to do would be to pin you down while others kick you in the head,’ Hans said. ‘I ended up staying in the cell 24 hours a day and refused to eat.’

After a few months, Hans returned to foster care.

‘Because I was in and out of foster homes, I did miss a lot of schooling.’

In his late teens, child protection services moved Hans into his own apartment – ‘a prison cell’ – but soon after, ended his supports.

Doctors didn’t ‘properly’ diagnose him until he was about 20. Since then Hans has been on a Disability Support Pension, but finds it ‘a joke’.

‘It should be minimum wage. You shouldn’t have disabled people living in poverty and feeling like they’re lesser ... I have to ration, I have clothes with holes in them because I have to figure out if I’m going to buy food or buy clothes.’

Hans has completed tertiary study and would have liked to work.

‘But I still can’t get a job. I’ve done everything I can to get better ... and I’m still stuck ...’

He now struggles to leave his house and is on ‘medication for suicide’. Hans says he really wants to ‘learn to live a life’ but feels he’s ‘being isolated and segregated’.

‘I should have a partner and a home and I don’t have nothing. I’ve been alone my whole life, never had a girlfriend, never even been on a coffee date ... I’ve never even held someone’s hand.’

Monty

‘Contributing to community and receiving some remuneration for that, and exercising my skill sets and my intellect and drawing on my social construct is important to me.’

Monty is in his 60s and blind. He was a primary school teacher until his sight started failing about 30 years ago.

‘The department of education ... left the responsibility for adjustments to the principal and that’s not his role or her role,’ Monty told the Royal Commission. ‘I was very fortunate for the last three years that I had a principal that was exceptional.’

When the department presented him with ‘changes of syllabus, all the pre-planning, et cetera’ in fine print and gave him ‘no ability to access anything’ to help him read it, he resigned.

Monty travelled for a year, teaching English overseas.

‘No-one asked me or doubted my professional capacity to do a job simply because I had a vision disability.’

When he returned to Australia more than a decade ago, he received a Disability Support Pension (DSP), but also started looking for work.

‘People with disability who can’t find work are often left socially isolated ... A workplace is the opportunity to get away from your home environment. The workplace is an opportunity to meet with different people.’

Monty, who lives in a regional community, went to a Disability Employment Service hoping to get a job for about eight hours a week.

‘[The employment agencies] were getting \$890 every three months to have me on the books ... but I was being parked.’

Monty said the agencies made no serious attempt to help him find an appropriate job. For example, he was asked to apply for a job at a welding works.

‘As a person with vision loss, I don’t know what they want me to do, but a welding works is fraught with danger ... I was asked to seek work as an usher in a cinema ... I was sent information to apply for training as a security guard driving around at night.’

Monty said when he complained, the agencies told him he didn't have to work because he already had the DSP.

'The worst part for me is that as a blind person I'm a voluntary client. And the number of times I've heard that, "You don't have to be here."'

Monty said all he wants is an office-based job for a few hours a week with assistive technology.

'Once I'm up to speed I can perform at the rate of any sighted person.'

Monty said he also asked the NDIA for access to assistive technology, but because he lives in a regional area it's too expensive to travel interstate to get the NDIA-approved assessment.

'I'm absolutely sure that with the right assistive technologies that I can function so much better than I am now. And I don't have any assistive technology outside my laptop.'

Clark and Laura

Laura wrote to the Royal Commission about the vulnerability of people with disability who are not able to advocate for themselves. 'We, as a family, experienced this for the first time when my son Clark was still at school,' she said.

Clark is autistic. He experiences high levels of anxiety and was given an additional diagnosis of social anxiety disorder during adolescence.

Laura told us about an incident 10 years ago when Clark was in year 8. He had been attending a local high school in a regional area for less than a year, enrolled as a student with special educational needs.

A couple of weeks before the end of term, Laura received a phone call at work to say a serious incident had occurred at school involving Clark. She was to come and pick him up immediately from the school as he was not to be on campus at all.

Laura arrived at the school to find Clark highly distressed. The deputy principal said that a female student had accused Clark of grabbing her on the breasts. As this was an extremely serious matter he was not welcome back until the matter had been investigated thoroughly.

Laura tried to find out details but the school wouldn't provide any. They said they would keep her up to date with what was happening, and if the matter was considered serious enough it would be reported to the police.

Laura took Clark home. For two weeks she rang the school every day to find out what was happening. Every day she was told the deputy principal was busy and would return her call later. But he never did.

When Laura would try to talk with Clark about what had happened, he would become extremely distressed and start self-harming.

'I don't think I did it. I don't remember doing anything,' he kept telling his mum.

On the last day of term, still having heard nothing from the school, Laura rang and made an appointment with the principal for the first morning back after the school holidays.

At this meeting, Laura told the principal she still had no information about the incident or the consequences for Clark, or even whether he was allowed to return to school. It was only then that the principal told Laura it had all been 'an unfortunate mistake'.

The allegation made against Clark was a lie. He had started talking to the young girl after school while waiting to be picked up. She didn't want Clark to talk to her and thought if she said he touched her, he would be made to stay away from her.

Laura asked what the consequences were for this young girl for making such a serious false allegation. The principal replied there wouldn't be any as it had just been 'a mistake'.

'It would not have been a "mistake" for my son if he had been falsely charged with sexual assault,' Laura responded.

'I feel that this is just one example of a young person with a disability being at significant risk because of their inability to advocate for themselves ... [Clark] will avoid confrontation at all costs and "loses" his ability to verbalise and "think clearly" when he is put into stressful or confrontational situations. He was not able to say with any clarity "I didn't do it" and he could not tell anyone what had actually happened. We were fortunate in this situation that the young girl decided to tell the truth about what had happened. It does not however, protect my son or anyone else from being victimised in this way in the future.'

Laura has never forgotten the feelings of anger, frustration and hopelessness she felt about her son being treated this way.

'I never officially reported this incident to any school governing body. At the time the incident occurred I was faced with the overwhelming task of dealing with my son's distress, my own distress, finding him a new school and maintaining my employment ... There needs to be easier access to advocates ... Having access to someone who could have helped with this at the time would have resulted in me making a report, and may have resulted in the school developing a greater understanding as to how to support students with disabilities and their families in a more appropriate way.'

Giles and Cher

Giles is a First Nations transgender teenager living with physical and psychosocial disability. He has had chronic pain and undiagnosed conditions all his life.

At the age of two, doctors treated Giles for arthritis. 'They put him in a wheelchair and said he'd never walk again,' said his grandmother Cher.

As a child Giles spent three months in hospital where, Cher said, he was treated like 'a guinea pig' and 'forcefully treated with physiotherapy' for his joint pain.

'It's caused more pain. It's so rough,' Giles said. 'When I got out of the wheelchair into crutches, they put me in the psych ward because they thought that it was in my head.'

Giles thinks medical professionals discriminate against him because he's Indigenous.

'Well I know there were lots of doctors that didn't really believe me.'

Two years ago, Giles went to see a paediatrician because his chest and stomach were hurting to the point he would cry.

'They said that they couldn't figure out what was wrong with me. They didn't even try and do anything. So they put me on a heap of pills and I was taking 13 tablets a day.'

Cher said the meeting at the hospital afterwards was 'appalling'.

'They turn around and they said, "How do you feel about [Giles] going back into the psych unit?" And I kept telling them the pain is not in his head. Like, I showed them photos of his legs – his kneecaps being swollen. I got into trouble and they threatened to dob me in to child safety for taking photos of my child's naked leg.'

Another doctor made Giles wait two hours to see him, then gave him opioids for pain.

'Sees him for about 15 minutes. He gets a lollipop and leaves,' said Cher. 'And we kept saying to him over and over what was going on? He couldn't give us a solution except for Oxycodone.'

Giles went to a specialist interstate who diagnosed him with hypermobile Ehlers-Danlos syndrome. His pain is getting worse and without proper treatment overseas he may soon need knee replacements, said Cher.

'We've been told that we've been treated like a third-world country. If we'd found a doctor that cared enough over here or believed us, they can't fix him but they could ease the pain and help him manage.'

Recently, one specialist kept promising to line up appointments for Giles.

'It didn't happen. It was bullshit. It was just to get rid of us. I don't understand. He must've had his licence from a Weet-Bix packet,' said Cher.

Giles has mobility problems.

'I'm losing my balance. I fell over twice the other day at school and I had my knees dislocated. I've been really weak,' he said.

He can no longer do activities he loves, like horse riding.

'The most I can do is go to school and go back home and sleep.'

He just hopes doctors will start believing him 'and actually try and do something'.

Babette and Rona

Babette, mid-30s, has Down syndrome and is hard of hearing and non-verbal.

She used to be 'quite outgoing', her mum Rona told the Royal Commission. She volunteered, loved playing sport, swimming and sailing.

Babette lives in a group home.

A few years ago, around the time of the NDIS rollout, casual and agency staff began replacing permanent staff.

Rona asked new support workers to introduce themselves and their role to Babette at the start of each shift, until she got to know them.

'If she doesn't know them, she is going to freak out. She is scared,' Rona said. 'But it didn't work.'

Babette's behaviour started to change. Staff began complaining she 'wasn't obeying the rules'. One time she broke a chair and another time she threw a cup.

Management suggested Babette see a psychiatrist. Rona agreed Babette wasn't 'coping too well'.

At the first appointment, the house coordinator pushed the doctor to prescribe antipsychotic medication.

Rona was shocked and refused. She agreed to giving Babette a course of antidepressants.

The coordinator scheduled a follow-up appointment without telling Rona.

'And the next thing, [Babette] is on antipsychotic medication.'

In 12 months, Babette was taking nine different antipsychotic drugs.

'The antipsychotic medication, as I saw it, was abused. It was used as a chemical restraint. They were high doses. [Babette] was walking around like a zombie, she wasn't able to function. You couldn't get a smile out of her. She just wasn't there. No personality.'

One morning, the home was short-staffed and the coordinator stepped in to shower Babette.

When Babette refused, the coordinator decided it was a behavioural issue.

'She tried to use the Mental Health Act to get [Babette] to the hospital, but that didn't work. [Babette] refused to get in an ambulance.'

Paramedics told the coordinator only a doctor or psychiatrist could force Babette to go to hospital.

A few days later, Babette again refused to have a shower. The coordinator tried to force her and Babette grabbed her clothing.

This time the coordinator rang the local GP, ambulance and police.

Officers handcuffed Babette, and paramedics took her to hospital heavily sedated.

'[Babette] has got a fear of ambulances, she has got a fear of police now.'

Doctors assessed her and sent her home.

'It was brought to my attention about hospital dumping. Well that scared me even worse. That they dump people at hospitals and get rid of them that way.'

One month later, the coordinator again attempted to send Babette to hospital.

'When [paramedics] arrived, [Babette] was fast asleep in bed,' Rona said. 'There were no behaviour issues ... They did her obs, they were happy with everything.'

A few weeks later, staff called the ambulance because they didn't think Babette had had enough fluid during the night.

'I got in the car and went to the house to try and beat the ambulance, because [Babette] had already been traumatised.'

Paramedics and police assessed Babette and felt there was no need to take her to hospital despite management's insistence.

'What they did is unforgivable. It is unforgivable. You don't treat an animal like that.'

Babette became so traumatised she won't leave her room. She won't let Rona put the television on or play a DVD. She has stopped eating, showering or going to the toilet.

'She has just totally shut down ... Everything was taken away from her. She has nothing. She spends 23 and a half hours in her room. Nothing. It has all gone.'

Rona made a complaint to the NDIS Quality and Safeguards Commission. They told her the provider has a number of 'red flags' but she doesn't know what that means.

The coordinator has since left and a behaviour support specialist is helping Babette.

Rona wants to move Babette to a new group home but 'it's quite difficult' because she is so unwell.

Katarina and Jurgen

Jurgen was ‘a citizen advocate’ for Katarina, who had an acquired brain injury and psychosocial disability.

Jurgen told the Royal Commission that before he met her, Katarina had engaged with psychiatric facilities, police services, organisations for victims of crime, housing services, public guardian and trustee services and disability service providers. He said all these services were aware of her disability, but did not keep her safe or support her to use services developed for people with disability.

Katarina’s mother had approached the advocacy service he worked for in the early 2020s. The agency deemed Katarina as the ‘number one most vulnerable person’ on its books, and her mother was ‘in a state of desperation’.

For about a decade, Katarina had been under an involuntary treatment order. She was ‘predominantly being treated by very long psychoactive drugs and psycho epileptics’ at dosages that were ‘impairing her cognition and decision-making functions and capacities’.

Katarina had ‘a long, long history’ of taking off interstate to see various family members when she was ‘becoming unwell’. Her mental health team knew of this, but ‘never actively intervened to prevent her from going’.

‘Nor would they ever follow up when they found out, for example, that she didn’t turn up for a deposit injection. So that would trigger in any system a phone call at least or a community visit ... [But] they were so detached ... [She] would invariably end up being hospitalised or put into a prison cell because she was psychotic.’

Jurgen said health systems in both states failed to communicate with each other in a ‘safeguarding capacity’ and Katarina’s condition ‘was obviously deteriorating further and further’.

One treating psychiatrist ‘had labelled’ her as ‘a lost cause’.

‘And her story is really one where she was desperately trying to reach out on multiple occasions to professionals to help her. And in the end, her deterioration had set in on such a profound level that to bring her back was really difficult. And this was evidenced by her more frequent cyclical hospitalisations.’

Katarina’s mother was constantly ‘trying to engage’ with mental health teams, but ‘they just labelled her a neurotic’.

Several months before her death, Katarina had left her home state and was ‘doing really badly’. Jurgen arranged for a clinical team from one of the hospitals she was known to to assess her, ‘but they deemed her okay’.

‘It beggared belief, it was obvious she was psychotic. You don’t have to be a psychiatrist to know that.’

Jurgen was trying to get Katarina on a plane back home, where she would at least have the support of him, as her advocate, and her mother. But he said services in both states ‘then became intentionally obstructionist’. They refused to recognise him as ‘an independent citizen advocate’.

‘That meant nothing to them. And as a result, they wouldn’t engage with me, and that’s why I had to become a nominated support person.’

Even then, Jurgen said, it was ‘clear they didn’t want to cooperate’.

Jurgen said the hospital left Katarina ‘wandering around floridly psychotic’. At a train station, two police officers realised she was ‘acutely unwell’ and took her to an emergency department.

After a lengthy period at the hospital, Katrina finally returned to her home state. The COVID-19 pandemic had begun.

‘Her clinical team wanted to put her into hotel accommodation rather than hospitalise her,’ Jurgen said. ‘And I thought to myself, you have got to be kidding me.’

The cause of Katarina’s death, at the age of 40, has not been determined. Jurgen believes it was ‘preventable’ and that a lack of care by health workers ‘contributed’.

He feels Katarina ‘needed a friend ... for someone with her consent to step in as a full guardian’.

‘Because she had been so damaged by this dangerously disorganised state-based mental health systems across two states over 20 years that ... it absolutely destroyed whatever remaining capacity she had because of the way that she fell through these jurisdictional cracks.’

Jurgen would like to see legislative changes to bring equitable balance in mental health by allowing people with disability to be supported by an advocate.

Sharney

Sharney is in her late 30s and lives with borderline personality disorder, schizoaffective disorder, trauma and depression.

'I grew up in a very violent household and I was on the streets at 12 ... which is where my personality disorder started creating itself,' she told the Royal Commission. 'Child protection ... they just sort of wiped their hands. They didn't offer me a home or a family, I just got left. So I literally lived in parks and what-not.'

Through her 'massive history' of mental illness, Sharney 'really struggled with public mental health systems'.

'They kind of used to put people with personality disorders in the too-hard basket ... I have two pages of single-line admissions to hospital to the facilities where I've been put on [treatment] orders and things like that.'

Sharney feels she's been caught in a cycle.

'The hospital will put you on certain meds and then, once you get out, your doctor changes it because he doesn't agree with the meds ... And then you go off your meds, because you're chopping and changing all the time. Then you end up back to hospital.'

A couple of years ago, Sharney was in 'a serious domestic violence situation' and ended up in a car accident.

Sharney said medical staff totally neglected her after labelling her 'a known drug seeker'.

'I don't know where they got that from, but that I feel is the reason that they treated me that way ... I was left 15 hours not strapped down and given not one single painkiller at all. My family weren't notified. I was in extreme pain. They ended up giving me mental health pills to sedate me ... It's not acceptable.'

Sharney believes her spinal cord injury stems from medical negligence.

'If I was strapped down and pain managed properly, I might not be disabled for the rest of my life.'

Sharney 'needed a safe place to go' because of ongoing domestic violence but every shelter refused her.

'There were beds available and I just kept getting told no, it's not suitable for my injuries ... It's not acceptable to be shoved aside because of my disability. I needed that help.'

After living in a camper trailer for about three months 'with no running water, no toilet facilities',

Sharney again wound up in 'a mental health hospital'.

'I went into a very, very dark place ... extremely depressed. I've been suicidal. I've been taken to hospital several times trying to overdose.'

Sharney is now trying to get NDIS support for the 'mental health stuff'.

'The NDIS said I definitely qualified, but they didn't give it to me because I was homeless and I didn't have a regular GP. So it got put off for another six to 12 months.'

Sharney feels everyone is 'passing the buck'. She now has an advocate and caseworker at a mental health charity and is hopeful that 'things are at last changing'.

'They're actually doing something outside of hospital for me. It's teaching me things I should have learnt when I was a teenager ... how to socialise and just be a kind of normal person. I've been seeking it my whole life.'

Nolan and Kimberley

Nolan is in his early 20s and is autistic. He also has an intellectual disability.

Nolan did specialist units at school.

'I wouldn't probably know what I'm doing if I were in regular classes,' he told the Royal Commission. 'I really need, like, help and everything.'

On finishing college, Nolan wanted to get some job skills with a local school leaver employment support service.

'It was a really dodgy kind of interesting place. There was only one guy who worked there ... He was very new and you could tell he hadn't really had a clue what he was doing.'

The manager gave participants Hangman word games 'all day every day'.

'Which is very uncalled for, because what he needed to do is really get us up and running.'

One day his mother Kimberley walked in. She told the Royal Commission, 'There was no staff there. There was just the people with disabilities huddled in one room with nothing to do.'

Kimberley called the provider who said, 'The guy is off sick or whatever.' They hadn't informed carers and parents as they 'didn't want to bother them'.

Nolan went on to another disability training service that he said was 'much worse'.

Things started out well. The support worker helped Nolan with his 'comedic ideas' and for a while 'he was absolutely a great help'.

'He was thinking we should go to the natural museum, inspire stuff for my drawing skills.'

But that never happened.

'And since then, everything just fell apart so quickly. He has the people with disabilities doing nothing,' Kimberley said.

The guy would 'vanish' and have coffee with his mate.

'We would have nothing on, and we were just these little extras which these guys just keep on and chat by themselves,' Nolan said.

Nolan registered with a disability employment provider. Staff would take people to shopping centres and parks and 'walk around with them all day'. The head office did nothing when Kimberley complained.

'I'd be ringing them all the time saying, "He doesn't need that," you know. "He needs to look for a job." ... They just didn't care.'

Kimberley enrolled Nolan at a vocational education provider with a disability support unit and provided the one-on-one support that 'the NDIS wouldn't fund'. He recently completed a certificate in animal studies.

'But no-one will employ him ... nobody will give him a chance ... My view is as soon as they hear him speak, they don't want him.'

Nolan's been volunteering for years at a couple of major charities 'but they won't give him paid work'.

'I'm down there trying my hardest,' Nolan said. 'I'm trying to get a job ... And everywhere I went it's just, like, "No. We're not going to get someone who has disabilities a job.'"

Kimberley is angry that employers discriminate against her son.

'There are all these opportunities. Why do they have to close the door for someone with a disability? Why do they have to block him?'

Nolan's last employment service provider was asking him to apply for eight jobs a fortnight, which 'is just impossible', he said. It was also sending his CV off for jobs he 'couldn't do' without consulting him.

The provider also asked him to fill out a form every month 'to prove that he still had a disability'.

'It was ridiculous. [He's] got a lifelong disability,' Kimberley said. '[The provider] kicked him out ... they didn't want him anymore.'

Following this, Nolan decided to launch his own business that utilises his creative talents.

'Just pay me for what I'm doing ... that's all I'm asking. Even if it's so little, just try to be fair.'

Lochlan and Etta

Lochlan has a speech impairment and became blind after being assaulted many years ago.

After a period of rehabilitation in the local hospital he was discharged. The discharge summary noted Lochlan's 'functional blindness', 'social isolation' and its assessment that he 'would not be able to manage in the community without significant risk to his safety and wellbeing'. It recommended a range of supports.

But with no community or public housing available Lochlan – then in his early 40s and 'with no social supports at all' – was placed into a private over-55s village. A community care service provider offered limited support.

Lochlan had been living in this place for about 10 years when Etta became his advocate. When she first visited his unit she was shocked.

'[It] was filthy, cockroach infested, the carpet was badly soiled with food debris that had not been cleaned for many years.'

She told the Royal Commission the unit was not designed for a person with complete blindness. Lochlan constantly bumped into things and often stumbled. Etta suspected he might also have a cognitive or psychosocial disability.

In the village Lochlan's social isolation had become 'extreme'. He kept himself locked in his unit, 'fearful for his safety and the outside world'. He relied on the radio to tell him the day and the time. He didn't sleep in his bed but in the lounge room chair so he could stay close to the radio.

Lochlan couldn't navigate the 30 metres to the communal dining room. The onsite manager delivered all his meals to his room. Because the manager didn't work on weekends, they delivered all the meals for the weekend on Friday afternoon.

'He has been starved in the past and is unable to regulate his eating, so he is in the habit of eating his weekend supply of food in one sitting and then going without over weekends.'

Etta discovered Lochlan had no teeth and couldn't eat some of the food. Neither the service provider nor accommodation provider knew this.

Etta found out Lochlan was entitled to five hours of support each week, but the service provider only provided two hours. When she raised this they told her, 'Lochlan can contact us at any time to request extra support.' However Lochlan's phone had been disconnected and he didn't make outgoing calls because of his speech impairment.

Etta demanded the provider increase the support. She arranged a community organisation to clean the carpets at no cost. She asked another organisation to engage with him regularly, but could only find someone to commit to 30 minutes once a fortnight.

The service provider and the accommodation provider blamed each other for neglecting Lochlan. They also criticised the NDIS – both had made unsuccessful applications on Lochlan's behalf.

Etta said the NDIS required evidence, but there was none.

Lochlan's medical records were almost non-existent or irrelevant to his disability and support needs. Health care providers and therapists had made recommendations over the years but they had never been implemented. Etta said 'the inertia of the bulk billing treating doctor' contributed to Lochlan's neglect.

Lochlan had fallen through the cracks.

Starting from scratch, Etta arranged medical and therapy assessments for Lochlan. He had no money so she had to find community organisations to fund the assessments.

It took several months to gather all the evidence the NDIS required. She told the NDIS Lochlan was in crisis and they fast-tracked some of the process.

Etta said the NDIS application process is too complex and the costs of all the required assessments too high.

'It is certainly not for the ordinary person to navigate such a complex system to achieve the best outcome for either themselves or someone with a disability who is acting on their own or being supported by a lay person.'

Lochlan now has an NDIS plan and eventually started receiving support.

'The joy he is experiencing at having daily support is overwhelming.'

Recently, Lochlan and Etta found out that about a decade ago Lochlan's siblings reported him as a missing person. His brother will visit him soon.

Meryl

Meryl is in her 60s and has cerebral palsy, bipolar disorder and depression.

'I got married at the age of 19, I have two wonderful children ... I've travelled the world,' Meryl told the Royal Commission. 'I've bungee jumped. You name it, I've done it.'

A few years ago, the NDIS was supporting Meryl with a cleaner for a few hours a week and a hoist to help her husband, who has arthritis in his spine, lift her when cerebral palsy caused her to fall.

A 'freak fall' a few years ago 'took away [her] ability to walk', and she rang the NDIS to ask for more support.

'I went through the fact that I was using a toilet commode as a wheelchair ... because I could not manage a manual wheelchair. I went through the fact that my husband could not care for me. He has severe back arthritis, he's a diabetic ... They seemed to understand. They seemed to not question anything.'

But instead of increasing her supports, the NDIS cut her funding.

'I was amazed. I thought, what? When I rang I was told that I should have supplied this document and this document and this document. No-one told me that in that phone call.'

Meryl asked them to review the decision and someone from the NDIS called to ask 'the most intimate questions'.

'So, yeah. "Are you really so disabled that you cannot toilet yourself?" Well, yes, I can toilet myself. "But can you still wipe all your areas?" Yes. I can still wipe all my areas. Yes. I still sleep in the same bedroom as my husband. Yes. We can still have sex. I have no idea what that had to do with anything, but she asked it anyway. I mean, really?'

Meryl said nine months later the NDIS agreed to increase her funding to several hours of support a day and no motorised wheelchair.

'We can't manage. I am showering using a shower hose in an ensuite because I cannot access the shower ... I'm actually recommended by every OT [occupation therapist] assessment for 24-hour care ... What we have asked for is 12 hours a day.'

Meryl said she appealed again and received an extra one hour of support a day. Instead of the powered wheelchair, she was allowed a mobility scooter to go shopping.

Meryl said she's now in a 'far worse state' than she was when she had the fall.

'The irony is their initial reason for not allowing the [motorised] wheelchair was that they didn't deem it was safe.'

An OT told her she now needs a motorised wheelchair with a lift function to help her transfer from the chair to the toilet or bed.

‘The initial chair, power chair was valued at \$15,000. The latest OT assessment that I had has now recommended a [far more expensive] one.’

‘The intent and implementation of the NDIS has set the standard world high. It’s been a long time coming and one I thought I wouldn’t see,’ Meryl told the Royal Commission.

‘For the last few years [the NDIS] worked. However, the system has now become broken, very broken. And for many, many people like myself that spend their lives with emotional and often physical nightmare, it seems to have no end in sight.’

Gordy and Lynne

Gordy, early 50s, has a genetic syndrome that causes cognitive disability and blindness. His parents placed him in state care immediately after he was born.

Gordy and Lynne met about 20 years ago when Lynne started working at the residential facility where he lived. She was horrified by the culture of abuse and neglect at the facility.

‘It’s really the staff versus the clients.’

Not long before she started, a staff member had physically assaulted Gordy.

The staff member was sacked and started working as a driver.

Other staff blamed Gordy and would book this person to take Gordy to weekly appointments. The person continued to assault and intimidate Gordy during these trips.

Staff also blamed Gordy for assaulting another resident. As a result, management isolated him for a year. Eventually the assault was investigated and they discovered Gordy had been wrongly accused. Nothing was done to address the false allegation.

After a government enquiry into the facility, it was shut down and the residents moved into smaller group homes.

Lynne said the facility destroyed all the client files.

‘All their details about their health throughout their life, their behaviour throughout their life, their family contact details. Like, [Gordy]’s mother’s contact details were in that folder. I can’t now find [Gordy]’s mother if I wanted to.’

Staff were relocated from the facility to the group homes, and the abuse continued.

When Lynne left her job, she continued to visit Gordy.

One time, Gordy was crying and telling her his eye was hurting. Lynne tried to get staff to take him to the doctor. When they refused she said she would take him, but staff threatened to call police, telling her she’d ‘be charged with kidnapping’.

After this, about 5 years ago, Lynne applied to be Gordy’s guardian.

‘That was a big relief ... We could get him to a doctor.’

While most of the abuse has stopped, she still struggles to get the provider to care for him properly. The house is filthy and many of Gordy’s things go missing.

Not long ago, Gordy broke his leg and was taken to hospital. The provider refused to send staff to the hospital to support him, and the hospital said it wasn't their job to feed him.

'While the argy-bargy goes on, [Gordy]'s sitting there with nothing, losing weight.'

The hospital wanted to discharge Gordy but the provider refused to take him back, arguing 'he was in the palliative stage of his syndrome'.

The doctors didn't agree and Lynne had to fight to get Gordy back home.

Lynne then tried to get the provider to develop a meal plan for Gordy to help him gain weight, but they refused.

Lynne is grateful for the NDIS.

'The NDIS has changed [Gordy]'s life. We got a [support worker]. [Gordy] goes out four or five times a week with non-government agencies. He has speech therapy, OT and physio support. He got new equipment such as a new wheelchair, a pressure mattress and things like that.'

Kia and Sheena

Kia is in her 40s and has an intellectual disability, anxiety and depression. Recently, she moved out of her group home to live with her sister, Sheena.

Sheena said Kia 'didn't feel safe' with the service provider she's lived with for most of her life.

'Other than meals or when she was showered, she really wouldn't come out of her bedroom because she was so afraid of the staff.'

'They would never talk to me or say anything to me,' said Kia. 'I was scared especially of [one support worker] ... she was a bit scary that woman at the house.'

Kia's support workers were intimidating.

One day, one of them punched Kia.

'He had a bit of a temper and he punched me,' said Kia. 'I ran away from him because he scared me.'

Another time a support worker exposed himself to Kia. He wasn't sacked.

Sheena said in the past few years support workers have neglected Kia. They failed to help her shower, take her medication or eat healthily.

'Soft drinks every single day,' said Sheena. '[Kia] is unfortunately obese. We have heart disease in our family. I had multiple, multiple, multiple meetings begging them to please stop doing that.'

'I was basically every day going out for takeaway and they would take me out for McDonald's, KFC, all that,' said Kia.

'She had a blood test recently,' said Sheena. 'She's got a fatty liver, high cholesterol. Her health is really not good. I also found out ... [Kia] hasn't seen a dentist in four years!'

Kia would visit at Sheena's house. When it was time to return to the group home, Kia often refused to go.

'Sometimes she'd get knives and say she was going to commit suicide. She'd run out into the street and the traffic. They knew all of this. And sometimes I literally couldn't get [Kia] to go back it just got so bad.'

When she did return, Sheena often stayed to clean.

'Meanwhile there'd be two staff members on sitting there watching TV. And I'd be doing things like organising her clothes, her laundry, I cleaned her room ... this was all while staff was on.'

One night Kia was in severe pain, but she was afraid to tell the support worker because he 'hadn't been very nice' to her.

'She didn't even feel comfortable telling a staff member "I'm in severe pain." That's how bad the relationship was.'

The next day Kia went to hospital where doctors removed her gall bladder. With the help of an advocate, Sheena sacked the service provider and brought Kia home to live with her.

'We're turning it around now. Like, she's been seeing a dietician. We've got a very good GP ... And she's not feeling emotionally abused and unsafe. Do you feel better now, [Kia]?'

'I do,' said Kia. 'I feel a lot better.'

'You don't do that as a sister if you have another option,' Sheena told the Royal Commission. 'I mean I love her, I'm happy to do it. But I'm saying this is the last resort. Because over the 20 plus years [the service provider] are a law unto themselves. There's nowhere to turn.'

Mckenna

Mckenna is in her mid-50s. She has multiple sclerosis and uses a walker to get around. She lives with post-traumatic stress disorder and depression.

A couple of years ago she decided to move to a villa in an aged care facility. She felt she would be safe there.

One night Mckenna woke at midnight to take her medication, as she routinely did. It was raining heavily.

‘As soon as I placed my feet on the carpet – I didn’t have any socks on, I felt all this water and the water was probably close to my knees, and my dog jumped off and all I saw was this brown water everywhere. I grabbed my dog, I grabbed my stick, my walking stick. I walked out to the corridor, I put the light on and I just saw this river of brown water everywhere.’

Mckenna was very frightened. She called the State Emergency Service (SES).

‘I said to the lady ... “Look, I’m disabled. I’m on my own. I’m very scared. I think I’m going to have an anxiety attack.” She said, “Look, go out the front and wait for the SES. They’ll be there in five minutes.” And I was in my pyjamas, I had mud all over my legs, all over my feet. It was slippery because I have hybrid flooring, there was mud everywhere. I was slipping and sliding. I was holding onto the walls. The water was up the walls.’

The SES arrived eventually and did what they could. But Mckenna couldn’t return to her home. A neighbour called the manager of the aged care facility for her.

‘He said, “[McKenna’s] got nowhere to live. Her house is unliveable” ... And she said, “I’ll deal with it in the morning.” And I was left outside crying with my dog and my pyjamas on, full of dirt, shaking. I’ve got nowhere to live.’

Mckenna ended up staying at another neighbour’s home. She says the manager of the aged care facility failed in their duty of care.

‘Before I signed on the dotted line and they took [money] from me, they told me, “Oh, [McKenna], we’re going to give you the best care now you’re on your own, you’re disabled ... We’re here to help you with anything.” How could a woman just go back to bed? She just went back to bed. That’s not duty of care. She should have gotten in the car and come to my aid ... I’m left out there like a shag on a rock, crying.’

McKenna told the Royal Commission that in the days and weeks that followed, the management team were rude and dismissive.

They refused to take any responsibility for the damage to her home, though the flood was partly caused by their tradespeople.

They found her alternative accommodation, as they were legally obliged to do, but it did not meet her access and other disability needs. They provided no additional support.

McKenna felt bullied by the management team, and her mental health deteriorated. She considered taking her own life.

'I ended up at a psychiatrist. And I've got a psychologist, my GP, my neurologist – everyone said, "You've got to get out of there. You're going to lose money but you need to just get out."'

McKenna sold the villa at a loss, on terms very beneficial to the aged care facility.

'I know a lot of my friends have said to me, "You've opened our eyes. We will never want our parents or our friends go into any of these places because they're just a money-grabbing organisation." It's just all about money.'

Sinead

'I think society as a whole has not made it easy for people like me to thrive. In fact, it's been very, very difficult.'

Sinead is in her late 20s and has just been diagnosed with autism. She also lives with psychotic depression, anxiety and attention hyperactivity deficit disorder (ADHD).

'I never thought there was anything wrong with me until people started telling me that ... I had a sickness or whatever,' she told the Royal Commission. 'I just thought it was my personality ... I thought that my differences were a strength.'

Not being diagnosed had 'a big impact' on her as a child.

'Because you don't get any of the supports you need as a young kid, you don't have any understanding of what's going on with you and why. School was very, very stressful. Like teachers didn't like me and my grades suffered, I guess because my brain was wired differently.'

Because she didn't 'act socially appropriately', others saw her as 'a bit of a weirdo ... mentally ill'.

'So, I've been bullied my whole life. As a kid in school and not just by students but by teachers, by people in the workplace, in relationships, all of that. It's led me to be very isolated and my mental health has suffered a lot ... I've been suicidal a lot of my adult life ... And all because I've never really gotten the support I need for those conditions.'

Sinead tried to seek treatment earlier.

'Most doctors aren't educated on neurodivergent conditions ... Instead of them looking into it further I would just get told to try harder ... I would sort of get dismissed as, like, my character flaw.'

Sinead was afraid to see a psychiatrist about a diagnosis because of the cost.

'And as a young person, 18 or whatever, I didn't have any money. So I couldn't do that ... Even after you are diagnosed, you can't really do much with it,' she said.

'I think there really needs to be more support services for adults on the spectrum because when society just keeps treating you like crap and always putting you down, you're not going to want to contribute.'

The lack of support has left her feeling 'quite helpless'.

'It's a bit hard on your self-esteem.'

That's been exacerbated by a lack of work opportunities. When she was younger, Sinead saw a campaign that suggested if you were unemployed you were 'sort of a dreg of society ... a failure'.

'That was pretty scary to hear when you are having legit mental struggles and having challenges. Instead of getting support, you just get shamed by the government.'

From employers, Sinead has experienced 'general inequality just for being disabled'.

'You get discriminated against if you announce that you're autistic when you are trying to look for a job, and the needs that you have aren't accommodated ... I get exploited in the workplace because I struggle with communication and listening.'

Sinead hasn't applied for the NDIS, but can't afford to get the help she needs alone.

'I think it would just be nice if the NDIS would consider ADHD just as disabling as autism.'

She was living below the poverty line until a couple of years ago.

'I'm lucky that as an adult I've had someone to advocate for me, but if I didn't have that, I'd have no money, I'd have no Centrelink, because it's been impossible for me to communicate.'

Just getting that 'extra bit of money' has really helped her 'get back on track'.

'It's not even just about paying for the essential things to survive, it's about doing things to make you happy ... and have a good quality of life. To sort of just to do things I enjoy.'

Bea and Addy

When Bea was an infant, Addy knew there was ‘something different with her’.

‘She has sensory issues ... Very highly intelligent. But her outbursts when they happen could be extreme.’

Initially Bea was diagnosed with persistent defiant disorder, and then a couple of months ago she was diagnosed with autism.

Addy has been trying to get the school to support Bea for many years.

‘The school have continuously said, “Yes, she can have social issues, however she’s at the top of the class so there’s nothing wrong.”’

About a year ago, another student started to target Bea and bully her physically and verbally. The school pulled him up numerous times but the bullying didn’t stop. The boy’s parents didn’t think their son was doing anything wrong.

‘They’ve taken retribution against us by trying to exclude us in the community.’

Bea became more anxious and Addy struggled to get her to school.

‘She started having anxiety attacks when she went to school, she’s never had them in her life before.’

This year, two other students started hitting Bea when she tried to walk away from them. She came home with punch marks on her back.

‘The school didn’t necessarily handle it in a very proactive way ... We had to medicate Amelia because of her anxiety ... It’s quite confronting having to put your very independent [child] on benzodiazepines because she can’t function or go into a situation in a place where she’s loved before.’

Addy reported the incident to police, who interviewed all the students in her year. The principal reported they were ‘absolutely horrified from the things that they heard’, namely that many students in Bea’s class ‘pick on her’ because of her disability.

Since then things have started to improve. There’s been ‘a real push’ for her classmates and the school more broadly to understand that ‘not all disabilities are visual and they can be debilitating’.

Bea’s teachers are starting to notice she has ‘amazing workarounds’ to cope with her disability in class.

'Focus on one task at a time. She will make sure that she finishes that task first, be ready before everybody else, watching the next child start the task.'

The school is starting to provide more support.

'It's proved invaluable for children like [Bea] who are struggling in that situation that now we're being seen and given the supports that she needs.'

Marcella

‘For me NDIS stands for Nightmare Disaster Insane System. I would like it to stand for Nice Delivery in Service. There is no service.’

Marcella lives in rural Victoria with physical and psychosocial disabilities after an accident in the 1990s.

‘I ended up with a hole in my face, it fractured my eye socket cheekbone and jaw, pinched nerves in my vertebrae and back and neck,’ she told the Royal Commission. ‘Since then I have lived with PTSD (post-traumatic stress disorder), anxiety and constant pain.’

For two decades, Marcella was receiving supports from a regional health centre and hospital.

‘I had home help, weekly cleaning, weekly counselling and regular physio. I had services in place that worked and supported me. When the NDIS took over, I did not know what to expect from them and trusted that the service would help me.’

The NDIS cut all Marcella’s ‘other services’ when she got her first plan four years ago.

‘The physical disabilities weren’t included at all. As a result, I’m taking more morphine-based painkillers, up to 15 a day ... If I can minimise the number of painkillers, use therapies to support my pain management, the better physical and mental quality of life for me.’

Marcella has found dealing with the NDIS ‘like hitting a brick wall’.

‘It’s challenging getting appointments generally with doctors and specialists. Even catching up with plan managers and support coordinators is difficult as we live some distance away.’

She’s been through several service providers.

‘There was no consistency in the services that I needed – I couldn’t rely on them.’

One provider billed her for assessments she never had.

‘They didn’t show up to scheduled appointments ... They cancelled all my current supports and put their own in at a dearer rate which was not approved by me.’

Once, a support coordinator left her ‘alone with no supports’ for weeks but continued to charge for their work.

Marcella says plan managers ‘create their own rules to suit themselves’ and ‘one area doesn’t communicate with the other – it’s disjointed’.

None of them have addressed her needs for physical treatment.

‘One planner said I’ve got to prove that my disability is permanent. And I just replied, is 25 years permanent enough? She didn’t even bother to look at my medical stuff and I just came away shattered.’

Recently, a provider was billing the NDIS while refusing to explain to Marcella ‘what the invoices were for’.

With her new support coordinator, Marcella has spent the past six months trying to organise a review of her plan.

‘The NDIS has been a never-ending saga from my experience, which has added to the trauma and I feel like a hamster on a treadmill. I want my life back, because all I do is spend all my time on NDIS.’

Marcela says the past five years have been ‘detrimental’ to her health mentally and physically, leaving her ‘wanting to step in front of a train at one stage’.

‘I’m now deciding whether to continue with the system or walk away with my sanity. I didn’t expect NDIS to fix everything in my life, but it would be great if it worked for me as a support.’

Dagmar

‘Interacting with the NDIS became really mentally draining. Your funding gets used actually trying to find out what services you can have.’

Dagmar is in her 60s and lives with post-traumatic stress disorder, hypomania and fibromyalgia. She’s had an NDIS plan for a couple of years.

‘When it first came in, it’s actually like a shiny new toy that makes a lot of promises,’ Dagmar told the Royal Commission. ‘But not so much now. I mean it’s quite difficult to manoeuvre, understand and manage.’

Because of ‘unclear criteria on what’s funded and what’s not’, providers often give her conflicting information – or none at all.

‘You’ll talk to three different people, you’ll get three different answers. It’s very inconsistent ... The staff don’t understand what criteria and you tend to sort of get pushed a bit from pillar to post. I’m paying them for their time, just to sort out something that should be actually really easy ... For example, when I first came into the scheme, I had \$5,000 for therapeutic services. Now, I was not told at all by anyone that I could actually use that for physiotherapy, and also for exercise physiology. I eventually found that out ... but they just say, “Here you go, you sort it out.”’

In one year Dagmar ‘went through six different local area coordinators’ before she found ‘someone who’s consistent’.

‘I sort of persisted and probably spat the dummy a few times ... I think it took me 20 phone calls to even say, “Look, I need someone I can talk to. Who do I talk to?” ... It’s sort of taken almost a year and a half out of my life. And really, the organisation should be providing the training, not using my funding.’

Dagmar is also concerned about the ‘really poor skill level’ among support staff.

‘There’s lots of small private organisations often who employ people ... who don’t understand the sector. They don’t even understand the difference between psychosocial and physical disability. I just think it’s really important for carers to actually have qualifications or at least be moving towards them.’

This has impacted the ‘quality of care’ Dagmar receives.

‘I had a mental health care worker who gets paid, or I get charged, a high rate ... For most of the medical appointments, she actually stayed on the phone and wouldn’t interact with me ... I was a bit astounded. And I just felt like she seemed totally unprofessional ... She was just using me to get paid for the shift.’

Dagmar said the problem is ‘worse’ with mental health care providers.

‘They just are just a little bit slacker about who they employ.’

This has led to providers ‘being a little bit exploitative’ with her.

‘At the moment, anomalies in the system means it’s quite open to providers to take advantage of people’s disabilities and not be very accountable for what they do.’

Despite ‘really poor standards’, she often feels she’s being overcharged.

‘Your budget gets chewed up really, really quickly. I’m sort of actually now financially reasonably vulnerable ... I really was considering dropping out of the scheme.’

Tyrone and Carlotta

Tyrone is autistic. He started kindergarten about a decade ago.

‘Academically I’d never worried about him at this point,’ his mother Carlotta told the Royal Commission. ‘As a four-year-old he was writing books, he has been read to since a baby, so he was really good with shapes, with numbers. I had a book that was 167 pages ... If I was to read that to him and miss a word, he would bring me back. That’s how much of a memory, and he was quite amazing for his age, way above level.’

But Tyrone had to ‘stay back’ at kindergarten.

‘He was continually absconding ... if he felt scared or frustrated.’

The school psychologist kept testing him ‘well below his capabilities’. The assessments involved ‘a truck sitting on a page’ or a cat.

The school provided him with ‘no real academic teaching’. Carlotta asked for more support, but the school refused.

Tyrone then went to a special school ‘where he was with seven children that couldn’t speak’. It had locked doors and high fences to stop students absconding, but the learning ‘was two levels below a mainstream school’.

Carlotta quickly noticed ‘he’s not flourishing, he’s going backwards’.

‘There was less talking from him, he started to get animal-like noises and grunts and became angry and a little bit aggressive. There was no longer the communication.’

Carlotta said Tyrone knew he was ‘in the wrong environment’.

‘He was saying, “I don’t like the school, I don’t want to be there. When is school going to sort out?”’

Tyrone wanted to go to the local public school instead.

‘We can’t support him and we don’t want him here,’ was the school’s response.

Carlotta explained that all Tyrone required was a shared aide ‘outside mainly, in the playground’.

‘If you want to pursue this, I’ll make sure that he never comes here,’ said the principal.

Carlotta turned to the education department and lawyers to intervene.

‘And everywhere discrimination. It’s just been relentless and fallen on deaf ears,’ she said.

‘This is my little boy and it is neglect. He’s got a human right. He could clearly be in the school, he just needed support.’

Carlotta kept advocating to get Tyrone to his school of choice. Eventually, the school let him attend one day a week.

‘They’ve very, very supportive. The principal is above and beyond. She is so understanding, she is so inclusive, she has a sensory room. She builds things to help out children with extra needs.’

But Tyrone has missed the ‘massive part, the foundation’ of his education.

‘Till this day, he still can’t read ... He’s given up on life, he’s virtually non-verbal right now. He’s a mess mentally, socially. He was loved at kinder and popular when he went to school, and kind, caring, protective, funny, smart. But he’s had it taken from him because he just hasn’t had the support and the encouragement and the inclusion.’

‘Money should be put into education because the ramifications of a child not being supported and not being socialised, not being in an educational setting, it sets them up for lifelong failure. It’s terrible.’

Bexley and Kristie

‘Nearly everyone’ bullied Bexley in primary school, Kristie told the Royal Commission, because of her daughter’s ‘difference of behaviour’.

‘Sometimes she was hit and kicked in the playground, isolated, not allowed to play with other kids.’

The school blamed Bexley – ‘If only [Bexley] was different. If [Bexley] did something differently things would be fine.’

Bexley became suicidal.

‘I was driving her home from school one day and I looked in my rear-vision mirror and she had a ribbon around her neck and she was pulling it tight.’

Bexley saw the school psychologist but didn’t feel comfortable talking about what was happening. The school didn’t offer any further support.

Bexley moved to another school. Teachers were more supportive but the bullying continued.

‘She used to cry a lot and she said she was told she was a cry-baby ... She also fell behind at school because she was so anxious at school that she wasn’t able to learn.’

In high school the abuse and isolation continued.

Bexley was uncomfortable doing oral presentations and became distressed if she made mistakes.

Kristie asked teachers for an alternative form of assessment but they believed it was important to make Bexley do the presentations.

Bexley became extremely anxious. She began self-harming and restricting her food intake.

She saw a specialist who diagnosed her with a number of mental health conditions and autism.

The school didn’t know how to support Bexley and she fell behind. She needed to repeat year 11 and decided to change schools.

At an extracurricular event, another student raped and assaulted Bexley.

‘He’d threatened her that if she told anyone that he would come to our house, so she was fearful of even being at our house.’

Bexley became suicidal and spent time in a mental health unit.

After a short while Bexley reported the rape and assault to police. Police interviewed her alone.

'She didn't involve me in her police sessions and I think what she heard from the police was, "You shouldn't take this any further."'

Bexley relapsed, she became suicidal and had to return to the mental health unit.

When she was ready to return, the school made it hard for her to come back. Kristie insisted the school keep Bexley and the perpetrator separated so she didn't have to live in fear.

Their solution was to isolate Bexley – a young autistic person – in the library. They also insisted she had to make up 'ever single hour' of the work she missed. She was overwhelmed with classwork and assignments and couldn't cope.

Bexley dropped out of school.

A short time later, she reengaged with a sport she loved and moved to a new club.

Initially they were accepting of her mental health conditions and autism.

But when she made the team and it came time to compete, they tried to exclude her. They said they were really worried Bexley would self-harm in the toilets or quit a week before competition.

'They were just mean to her a lot of the times. They were rude. If she asked any questions, they'd make her feel like she was an idiot. They'd point out a lot of her autistic behaviours. It was like, "I don't think she's very nice because she doesn't have eye contact, or she doesn't eat food."'

The club dropped Bexley from the team. She was traumatised. 'It was basically the bullying that she had at school,' Kristie said.

Bexley joined another club and started competing as an individual.

Her former coaches would turn up to competitions and 'intimidate and harass her,' Kristie said. 'It was terrible.'

Bexley, now early 20s, recently completed year 12.

Kristie helped her access the NDIS and she is getting the support she needs.

'There are a lot of things that she wants to achieve in her life.'

Dolly

‘I took a flight [between cities] and they left me on the plane ... They actually only discovered I was on the plane because the cleaners got on and wanted to clean the flight for the next sector.’

Dolly is in her 40s, has spina bifida and uses a wheelchair.

‘I have learnt to accept it, and this has come a lot from my partner,’ Dolly told the Royal Commission. ‘When I met him I hated myself, I hated my life, I hated my disability ... If someone picked on me I’d just take it ... I wouldn’t tell people to eff off when necessary. Without him I wouldn’t be the person I am now.’

Dolly’s partner died several years ago.

‘I miss him every day.’

When she was a child, Dolly’s mother insisted she attend a mainstream school.

‘She had piles and piles of letters between her and the education department fighting to get me into a proper school as opposed to a school for handicapped children ... She fought tooth and nail.’

Dolly said a lot of kids bullied her.

‘Practically every day I either had my equipment taken away from me because kids thought it was funny or I was left out of activities because teachers didn’t know how to handle me. I was just picked on constantly.’

Dolly later, as an adult, contacted some of the people she went to school with.

‘A lot of them have apologised and realised that they were totally stupid at the time and, you know, that’s fine. I mean it’s water under the bridge and so that’s okay, but at the time it was dreadful.’

Dolly now works in administration, where she said her main hurdle is the job interview.

‘I’ll turn up for the interview and all they do is look at the chair. They don’t look at me. And they either see me as a burden because they’ll have to make access changes to the workplace, or they see me as a cash cow because they get money from the government to have me as an employee. But either way I don’t get the job.’

Recently, however, she had a promising interview for a customer service job.

'I mean it's obvious that I'm in the chair and they're curious about how it affected my daily life, [but] they didn't make a big fuss of it. And they were more interested in me and my experiences, my qualifications, what I could do for them, what I could bring to the job ... I just came out of there having one of these experiences where I just knew it was good.'

Dolly is supported by the NDIS. She managed her own plan for the first year, but said a plan manager took over the next year, against her wishes.

'I've vehemently tried to get myself back to self-managed. They won't do it ... it's a great struggle, you know? They don't listen. I don't feel that they do what I want. I don't feel that my needs are taken into consideration.'

Dolly also told the Royal Commission that while the community is becoming more accessible to people with wheelchairs, 'the world has a long way to go'.

For example, there's a shortage of wheelchair accessible taxis and disability-trained taxi drivers.

'I have been thrown out of my chair so many times by inept drivers and have to ask for assistance from passing footpath people because the drivers have no idea. And they drive off,' Dolly told the Royal Commission.

'[But] I had a very lovely experience last week. I was in a cafe and a lady was sitting across from me with a toddler, would have been two, three maybe and a lovely looking little girl. And she kept staring at me and I'm thinking, okay. And then she suddenly said, "Mummy, she's got red hair." And so, of course, she had to toddle over to me and investigate my red hair ... I mean, they have to learn somehow.'

Stew, Landyn and Trixie

Stew, early 30s, is autistic, non-verbal and has attention deficit hyperactivity disorder (ADHD).

He lives with his parents, Landyn and Trixie, and has a support worker six hours a day, five days a week.

Trixie told the Royal Commission that Stew can read and understand, but he's never spoken a sentence in his life.

'He can't communicate his needs so he has outbursts of frustration,' she said.

Someone needs to remind Stew to wash himself and get dressed. He knows you're not supposed to walk around naked, but at the same time he 'doesn't quite know'.

Stew's not able to go into the community by himself. Once he was in a library pretending to scan books and the librarian called police.

The librarian told Trixie, 'Having people like that in here puts people off coming into our library.'

Landyn said over the years Stew has been in all sorts of employment-ready programs.

'He knows money can buy him chips, for instance, but he'd give you a \$100 bill for a bucket of chips and then leave the room.'

Since his early teens, Stew has been taking antipsychotics and ADHD medication. The drugs calm him but because he can't communicate, and won't submit to blood tests, 'it's just roll the dice really,' Trixie says.

Stew's psychiatrist believes they've reached a point where there won't be any positive change in Stew's behaviour.

But the NDIA fails to recognise Stew's disability is permanent.

'We feel like the intractability and the permanency of his disability is something that the NDIS has to have some mechanism for dealing with,' Trixie said.

'At the moment, particularly with these behavioural support plans that we have to comply with ... you have to always prove that he's got this disability and that he will have this disability going forward.'

Each year the NDIA requires a new behaviour support plan because Stew takes 'reportable drugs'. The plan costs more than \$10,000 to prepare and involves multiple trips to doctors and therapists. Landyn said the plan gets 'put in a drawer, ticked off', but it's not useful.

The NDIA wrongly believes Stew's behaviour will improve because of the plan, and his reliance on medication will 'fade out'.

'We just find that so insulting,' Trixie said. 'It's like saying we just put him on all these drugs. We have tried and tried and tried to get him off the drugs because they make him fat. He gets pimples and thrush in his mouth.'

The NDIA used to be 'very individually focused and they used to listen', but now it's a constant fight. Small changes cost time and money.

'In the complexity of it, it just becomes rules,' Trixie said. 'One time they just changed the rules about transport, and they totally slashed [Stew]'s budget. And we had to fight and get a review. And because we live rurally, transport is a critical issue.'

Landyn and Trixie said managing Stew's NDIS plan is like running a small business.

Stew receives different supports and services from a large disability organisation. Landyn has to fill out the same paperwork each time they engage with a service because there is no centralised database. The billing is often indecipherable and they have to constantly query which service item relates to which service.

Trixie said they now regret keeping Stew at home for so long because of the damage it has done to their other children and the family. At times the family had to separate to keep Stew from physically harming his siblings.

'His volatility and high needs skewed our family life in ways that we weren't even really conscious of ... It would have been really good if there was somebody who was experienced in disability who could have given us some guidance when [Stew] was young about what we would have to watch for, if some of the services provided, took into account the whole family.'

Athol and Cecily

‘I just wasn’t sure why we had to fight for somebody’s basic human rights, like accommodation.’

Cecily’s father, Athol, is in his 60s and has early onset dementia.

‘He didn’t really have a stable living environment,’ Cecily told the Royal Commission. ‘Because of his undiagnosed dementia he found it very hard to hold down a job.’

By the time doctors diagnosed Athol’s dementia several years ago, he had no assets or income and lived hundreds of kilometres from Cecily.

‘It was a bit of a tricky situation financially for him and for us.’

Cecily moved her father and his partner to her regional town where she helped him apply for the Disability Support Pension and the NDIS.

‘The first time we applied for the NDIS we were denied and they gave the reason of the medical reports weren’t sufficient. So we had a neurologist’s report that sort of gave the diagnosis of early onset dementia ... [We] applied again and were denied again.’

The third application succeeded.

‘I don’t know what was different.’

Cecily said her father’s partner, after organising respite care in a nursing home, ‘basically said she couldn’t have him back’.

‘So that made dad homeless, effectively. So he stayed with us for a while, but I’ve got young kids and it was just horrendous trying to care for an elderly father with dementia and having kids and trying to work.’

The NDIA agreed to fund supported independent living (SIL) accommodation and Cecily found a service provider.

‘They had very young staff members not trained in dementia. So there was a couple of times where dad was unsettled and became verbally aggressive.’

One night the support workers called an ambulance to take Athol to hospital.

‘He didn’t have anything wrong with him ... The supported independent living company refused to have him back [and] then wouldn’t answer my calls any longer. So it was really, really quite stressful.’

Cecily found another SIL provider, but the NDIS slashed Athol's funding.

'We got to the point where the funding in the plan ran out. So we put a review in, but again that evidence got knocked back.'

Although Athol couldn't pay the rent, the SIL provider continued to support him while Cecily appealed to the Administrative Appeals Tribunal.

'Even through the tribunal, the NDIA representation was hostile. It's stressful enough going into that environment where you're up against lawyers ... There is no disability advocacy down here so I just did it myself.'

Cecily said the experience damaged her health.

'It was full of legal jargon, it was via the telephone which, you know, that's not accessibly okay ... There was one point when we were ready to go into the second teleconference and I rang one of my family members and said that I can't do it. You know, "That's it. I'm done, I'm at the lowest point of this journey that I've ever been." And thankfully they gave me a pep talk and off I went and I did it.'

Cecily won the appeal but is still trying to recover from burnout.

'Not only has this whole experience shaped dad's health and his decline in his dementia, but it has had tremendous effects on me and my family as well,' Cecily told the Royal Commission.

'I'm a fully-functioning able-bodied person. I cannot even imagine what this would be like for someone to have a disability and have to advocate this stuff for themselves.'

Cecily said the process felt like an attempt to remove her father's human right to accommodation.

'Basically, a government organisation that is there to provide these supports and had done so for that person previously, for them to then say, "Oh no, we can't provide that now," you know, it just flabbergasts me.'

Inga

Inga is in her 30s. She is autistic and has schizoaffective disorder.

'I only found out I was autistic ... last year,' Inga told the Royal Commission. She had tried for years to get an autism diagnosis.

'Not one person would send me for an autism assessment because they believed I was already diagnosed ... Yes I've got mental illness, but when I was a child there were [other] problems as well.'

Inga said she masked the autism 'quite well'. When she was in her late teens, she also experienced auditory hallucinations and delusions.

'I had two doctors tell me to find God ... I thought it was maybe a cultural thing, but yeah, bit bummed to be told to find God when you're hearing voices.'

Inga said about a decade ago a doctor prescribed an antidepressant that had previously triggered psychosis. When she refused to take it, the doctor threatened to detain and sedate her.

When she had a psychotic episode after taking the medication, the doctor admitted her to hospital where she was given another drug that caused hallucinations.

'It was in the sixth or seventh week that I had a period of lucidity where I asked them what medications they gave me and I said, "No, I'm not taking that drug."

Inga said at one point, when staff were trying to restrain her, someone stepped on her face. Another time when staff tried to sedate her, her mother 'walked in to visit at that point in time and argued with them'.

'If she hadn't have been there to advocate for me I probably would have been psychotic for longer.'

Inga said she found a psychiatrist who stopped the medication.

'He told me that there's nothing wrong with me, basically. Keep a mood diary, stop my meds.'

Inga said she couldn't work for several years after she was released from hospital, but was unable to access the Disability Support Pension.

'Fast forward to last year, I get diagnosed with autism [and] it's approved straight away because I guess they don't want to appear to be discriminating against autism, but they will discriminate against schizoaffective disorder.'

Inga also has an NDIS plan, but is struggling to access supports because her support coordinator 'disappeared for four months'.

'Wouldn't answer emails, wouldn't answer text messages.'

When she found another support coordinator and emailed the old one to say their 'services are no longer required ... they replied within five minutes'.

'So they'd obviously been getting my emails and requests ... If you're unable to provide the service you're being paid for then you should be outsourcing that to someone who can.'

Shannon

Shannon is a First Nations woman in her 30s. She has intellectual disability, attention deficit hyperactivity disorder (ADHD) and other mental health conditions.

Early in 2022, Shannon moved into a supported independent living home where she was residing with one other person. She told the Royal Commission she thought it would be 'a good place' with '24-hour care'. But that didn't happen.

'No, not at all – they didn't care, nothing.'

The neglect by support workers started from the moment she moved in.

'Like they wouldn't be doing their duties, like what they're supposed to be doing ... There was a time when, like, I fell sick and ... I had two workers on and they didn't even do anything. They were sitting in the lounge room and the kitchen. They were just, you know, laughing and whatever.'

Shannon got no help with cooking, cleaning or getting to appointments. She said staff spent a lot of time on their phones. And they weren't 'following policies and procedures' for her treatments because '99.9% of them' had no qualifications.

'I was told to take depot [injections] when I don't have schizophrenia! And not to take my ADHD tablets by one worker. They said, "Do you need to take it?" I said, "Are you serious?" But willingly said [I] should have a monthly injection for a mental health condition I don't have!'

Shannon had to 'fight' with support workers to get food because they were 'skipping' the shopping.

'There was nothing there for anyone, not even the staff.'

She lost almost 50 kg during her 8 months there because workers were restricting her access to food.

'Especially at the start. It wasn't like until the sixth, seventh week, then they did shopping.'

After several months, Shannon told her counsellor about the mistreatment, who 'betrayed [her] confidence' and told the manager. The manager said if Shannon was upset, she should 'put a dummy in her mouth'.

Shannon said she tried to flee the home to escape the verbal and physical abuse, but they were 'holding [her] hostage'. One support worker tried to strangle her.

'Then after that, um, I ended up going to hospital and then I came back and [the support worker] had gone.'

The support worker was fired, but police never asked Shannon if she wanted to press charges. She feels that's because of her disability.

Shannon's behavioural therapist, who witnessed the abuse, organised for her to move to a new home. But the 'abuse and neglect' has left Shannon 'exhausted' and impacted her 'severe trauma'.

'My anxiety has worsened. Overall my mental health has deteriorated badly. I can't function through the day properly nor think properly ... It all catches up with me.'

Shannon says the former service provider is calling her 'non-stop, every single day' asking for money.

'It sounds like a scam. I need to get a second telephone so I can change my number ... Just yesterday, um, they sent ... one of their workers and said, oh, you owe the director this much money, blah, blah, blah ... It's actually fraud.'

One invoice claimed she 'had seven workers' and travelled '500 plus kilometres' on a day she'd been at home. Shannon wants to make sure others aren't treated the same way.

'It was toxic. It was too toxic. This provider needs a watchdog.'

Lawrie and Ginny

‘We have all these plans, all these strategies, but when the rubber hits the road, how are we supporting people with disability or their carer? The blunt answer is we’re not doing a great job of that.’

Ginny’s son Lawrie is autistic and deaf in one ear.

‘We want him to participate in school and to feel a sense of belonging and connection,’ Ginny told the Royal Commission. ‘He’s quite a bright little guy ... [but] there’s some challenges surrounding how he’s experiencing inclusion.’

Lawrie was born deaf and doctors didn’t diagnose autism until he started school. Ginny, a former teacher, helped his school apply for funding to support him.

‘What I’ve repeatedly seen both as a teacher and... a parent is that the child isn’t necessarily benefiting from the funding that they’re eligible for.’

Lawrie’s support funding is spent at the school’s discretion. Ginny said the school keeps telling her that Lawrie is ‘doing great, he doesn’t need any support’, so it allocates the money he gets to support other children.

‘Because there’s other children in his class that are not diagnosed that ... almost certainly do require additional support ... the teacher’s assistant is used for other children to support the other family.’

Ginny said Lawrie’s school focuses on academic outcomes, ‘not necessarily the social and emotional wellbeing of the child’. Lawrie’s doing well academically, but struggles socially at a school that doesn’t have a policy of inclusion. He needs a quiet space in the classroom as well as staff who have disability training.

‘Our school has a chaplain but they’re, like, a day a week [and] again not trained in disabilities so have very limited skills to support students.’

Ginny said she shouldn’t have to move Lawrie to another school to get better support if the funding’s already there.

‘One school might be a positive behaviour school and they might have a beautiful plan and policy available, and then the next school it doesn’t. So I think that needs to be mandatory for all.’

During the COVID-19 pandemic, Lawrie became more anxious and refused to go to school. Ginny asked her government employer if she could transition from full-time to part-time work to care for him. Her employer refused to make the adjustment and she had to resign.

‘It really goes hand in hand – education and employment, the impact on carers and families – because we as a family can’t meet [Lawrie’s] needs if I’m not working. But I can’t work if I’m not supported in order to be able to work. Some adjustments are needed.’

Maura

‘I’ve really learnt what support coordination isn’t, rather than what it should be.’

Maura is in her 60s and lives with post-traumatic stress disorder, depression and anxiety.

‘I would not be still here if it wasn’t for the NDIS,’ Maura told the Royal Commission.
‘It keeps me alive.’

The NDIS has supported Maura for several years, but she said it’s also causing ‘additional challenges’ to her mental health.

‘I’ve gone through with a lot of people being assigned to support me that don’t have any understanding of mental health.’

Maura said none of her support coordinators are qualified.

‘[What] I’m finding really challenging is people that are out there that are hanging up a shingle that say that they’ve got support coordination, but they might have a certificate four in aged care or something like that.’

One of her support coordinators had 80 clients and worked only three days a week.

‘It’s not possible for her to support that many people. So the support just wasn’t there.’

Maura complained and was given another support coordinator.

‘She wasn’t over-promising and underdelivering. She was promising and not delivering!’

Another support coordinator insisted she use a cleaning service run by an NDIS service provider owned by a close family member.

‘When the cleaners would come they’d be complaining about, you know, the owner spending money and buying new BMWs and not paying their super. And I thought, I just can’t deal with this anymore, you know? Like the cleaning’s not great anyway.’

Maura said another support coordinator with no appropriate qualifications ended up ‘making a lot of money’ from her NDIS plan.

‘She’s looking at things she wants to do and then convinces me to do them when it was that you got paid travel. Like when I asked to find me [a therapist], she found one in [another city] so that she could ... visit her family ... so she was making sometimes \$5,000 on a trip.’

Maura lives on a Disability Support Pension. One day, the support coordinator encouraged Maura to take her and her daughter to dinner.

‘Her daughter wanted to have dessert. She said, like, “[Maura’s] paying for this.” And I’m thinking ... “Like, why am I paying out of my plan for all of this?”’

Maura later discovered that the ‘support coordination’ consumed half her NDIS funding.

‘She literally reduced my plan by half ... you know, it’s really hard for me to get that this is a reality. I have been abused.’

Maura changed support coordinators again, but has discovered that some of her new support workers are also relatives of the coordinator.

‘You’re seeing a pattern, so the story’s bigger than my story.’

Lew

Lew, late 60s, has physical disability and epilepsy.

In primary school, Lew's seizures increased and the school couldn't handle him. He told the Royal Commission no-one understood epilepsy at the time, and he was taken from his mum and dad and placed in a home for boys.

'Mum and dad had no choice,' Lew said. 'I was sexually abused and physically abused and we didn't get an education.'

Lew said 'the only way out of the system' was to go overseas.

But when the family tried to return to Australia, Lew wasn't able to join them.

'Even though I was born here, I wasn't allowed to come back under mum's passport ... because of my disability.'

After some years Lew returned and devoted himself to working with children and adults with disability.

Over the years he has worked as a support worker, team leader, manager and official community visitor.

'Eighty per cent of group homes are okay,' Lew says. 'The problem is they don't get community visitors like they used to.'

Lew explained that official community visitors report to the public advocate. These days, they only visit the homes the advocate wants them to visit, and 'they don't visit them enough'.

'I would come in at 6.30 am in the morning when it's time to get clients up. I would see how handover gets done, then I might come in at 6 pm in the evening and normally that's dinnertime and I would see how many staff were on.'

Community visitors used to be able to access all the files to see where the money is being spent. Lew used to teach them to 'read between the files'.

'I showed them how the department write things up. And if they see things repeated too often, it's just a cut-and-paste ... I taught them to read the case files and make sure you talk to the clients and, if possible, you talk to them individually because some clients won't open up while the workers are there.'

Lew said some community visitors don't know how to communicate with people who are non-verbal, deaf or blind.

‘If we don’t have community visitors that are trained or senior investigators from the public advocates that know how to do it – I do get annoyed about it.’

Lew believes part of the problem is the public advocate has become ‘more like a private company now than representing those people with disability’.

‘They should really be looking after the people in care a lot more.’

Gatlin, Callahan and Samina

Gatlin, in his mid-40s, is autistic and has an intellectual disability. His father Callahan described him as a 'very gentle person'. 'Pleasant natured,' said his mother Samina. 'And we get a lot of smiles out of him,' said Callahan.

When Gatlin was about 16, his parents realised they needed to find a long-term home for him.

'We decided we're getting no younger to provide 24/7 care for Gatlin, and that getting a good home place would be long and difficult,' Callahan said.

Callan and Samina wanted a home for Gatlin that offered more than 'minder' care, that provided meaningful support.

They were particularly interested in 'person-centred active support' (PCAS), a personalised program which would give Gatlin the opportunity to interact with others through a range of appropriate activities. They felt this was important given the nature of Gatlin's disability.

'If left alone, people with autism are mostly incapable of occupying themselves constructively and will soon resort to obsessive and unsociable behaviour patterns,' Callahan said.

Callahan said Gatlin has had one experience of 'A-team' care, which lasted for about two years.

But these staff moved on and Gatlin's parents have had to return to their previous vigilance, monitoring the care Gatlin receives and ensuring his needs are met.

Callahan and Samina shared a list of issues where staff had not followed agreed procedures and practices.

They discovered that Gatlin had not had a bath for more than five years, despite his personal care plan listing this as a twice-weekly activity.

'These sort of things you can do, still continue to do, is things like a bath which helps them to relax ... It didn't happen because the staff condemned the old bath but never told anyone.'

Support workers didn't read notes in Gatlin's communication diary, entered by staff at the day service he attended. One time, this resulted in a medical emergency.

Gatlin's parents said when the NDIS was introduced they felt optimistic that care would improve. Now, 'despite the good intentions of the NDIS process', they are disappointed. Too often, Callahan said, both management and staff see the NDIS system as 'just carry on as usual'. Their mindset is, 'Parents, leave your family member with us, go away and don't bother us.'

Callan and Samina still don't have the confidence in Gatlin's care they had hoped for.

'In other words, we are parents that need to – to live forever. This is how a lot of parents look at it. They need to live forever to make sure that things are being done,' said Callahan.

Landry and Braelynn

Landry lost his mobility and capacity to speak after a medical event about 20 years ago. He is in his early 60s now, living in disability supported accommodation managed by a community healthcare provider.

Landry's sister Braelynn is his legal guardian. She had to fight to secure the role after it was initially taken up by the public guardian.

When Landry left the hospital, the public guardian organised for him to enter an aged care facility. Braelynn told the Royal Commission that in the nearly 10 years Landry was there, no-one from the public guardian visited him.

Without any oversight, Landry's treatment and care were neglected and his physical issues greatly exacerbated.

'They never checked on his existence. When I applied for guardianship, they didn't have a piece of paper in a file on him ... He would have been a lot easier to manage if they hadn't had that time to allow all of those things to happen to him that caused him so much harm permanently.'

When Braelynn became Landry's guardian, she organised his move to his current residence. He has had a 'plethora of injuries' since he moved there and she has many concerns about the care he is receiving.

Braelynn believes support workers take advantage of communication issues to ignore him and mismanage his care. Neither the service provider or individual staff members are held accountable for failures in his care.

Braelynn reported issues to the NDIS Quality and Safeguards Commission. This triggered the involvement of a community visitor, which resulted in time-consuming and onerous demands for documentation. She has not had any positive outcome in response to her complaints.

'Anything the community visitor writes, it gets sent to the service, and then the service has the ability to respond to those complaints. That's why they do it. But really, in effect, they're telling the service everything you said about them ... And so there was no protection for [Landry]. And then, what that did was it made it so I felt like I couldn't say anything, because that just fed the staff with their bullying about me,' she told the Royal Commission.

'And that's how this situation has built up, is now these carers – who have no training, no supervision, completely unaccountable – are sitting outside smoking most of the day. And they resent you saying to them, "Can you give him breakfast?" And that's the point that I'm raising with that bullying, is there doesn't seem to me to be anything that anybody can do.'

Braelynn is reluctant to move Landry because of his anxiety.

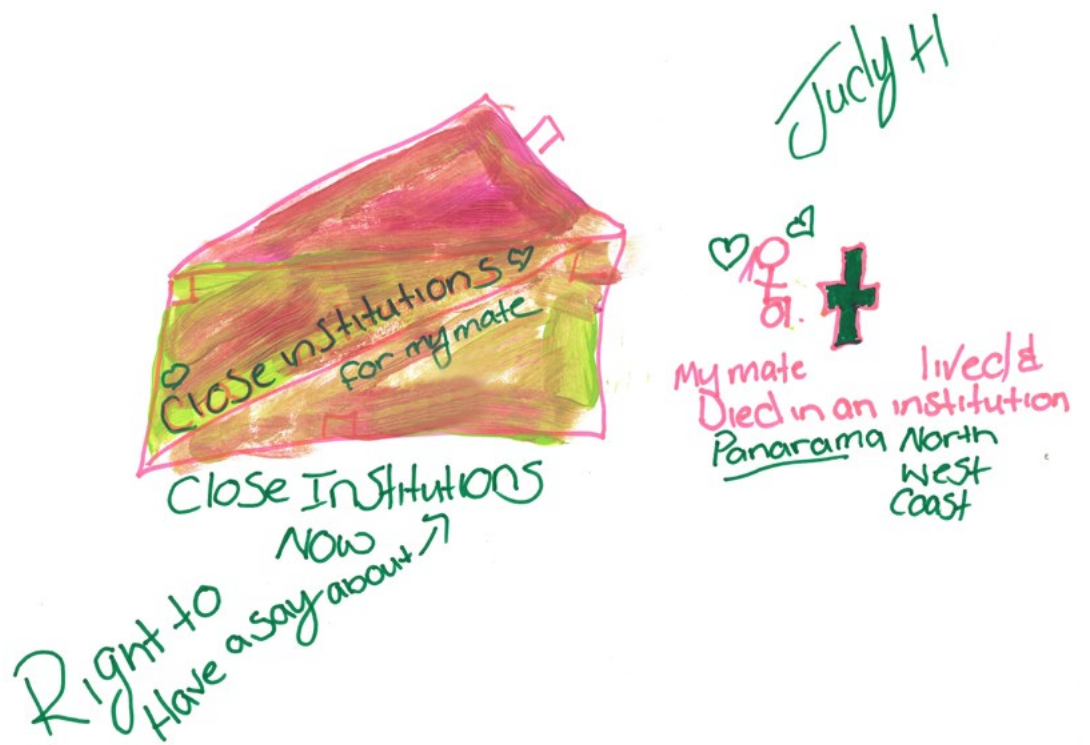
'For him to go somewhere else ... would be so self-defeating. It would be stressful for him to be somewhere else. And ... the system is the way it is – there's no guarantee it's not going to be the same somewhere else.'

Braelynn says she doesn't have 'a lot of faith and trust in the system'.

'[Support workers], they think I'm horrible because I'm the only person they're accountable to. I'm the only person that's doing any supervision of any kind over them.'

At a human level, she wishes for more understanding.

'They seem to forget that this guy that I'm asking them to change the pad on or give oats to is my big brother. He taught me how to swim, taught me how to write. He protected me all my life as his little sister. I know everything about him. I know what he likes, what he doesn't like. And you know ... sometimes I just drop to my knees, and I weep at how hard it is to get people to just do simple things that they're paid to do.'



Artwork by Judy Huett

Taya and Leia

Taya, mid-teens, has Down syndrome.

She is very athletic and loves to dance, her mum Leia told the Royal Commission.

Taya attended a mainstream primary school. She participated alongside her peers and was able to access the curriculum with some adjustments.

‘She thrived. She thrived academically. She thrived socially. Her grade 6 report was really reflective of how well she was going.’

The mainstream high school, however, refused to offer the same adjustments.

Leia said that Taya’s independent education plan (IEP) was ‘not appropriate for anyone in high school’. Taya had to do prep level work such as counting animals, pretend shopping and dot activities. She couldn’t sit next to her peers and had to sit at a desk to the side of the class.

‘She was really sad. Really, really sad. She’s gone from loving maths in primary school to absolutely hating it. She was very distressed about the fact that she was treated differently.’

Taya couldn’t socialise with her friends in the playground.

‘At recess and lunch, she was locked in a room with other kids with disabilities.’

Leia met with the principal, who argued the school was inclusive. Leia tried to negotiate Taya’s IEP goals but he refused. ‘This is how we educate students with disabilities at the school,’ he told her. He warned if she complained they would ‘fight [her] all the way’.

The school banned Leia from talking directly to Taya’s teachers.

‘I couldn’t phone her teacher. I couldn’t write to her teacher or email them. Every other parent at the school can, but we’re not allowed to.’

Leia made a complaint to the education authority, but they acted as if it had nothing to do with them.

She made a complaint to the state equal opportunity commission but they advised it didn’t fall under their jurisdiction.

Leia then made a complaint to the Australian Human Rights Commission.

‘It was on the grounds we had no input into her IEP. We weren’t consulted. There was the segregation. Not accessing the curriculum. Not being able to talk to teachers. Not being able to see her work.’

The school acknowledged the complaint, but was otherwise unresponsive. A conciliation meeting had to be cancelled because the school refused to sign the confidentiality agreement.

A caseworker said they had ‘never come across a situation like this’ and there was nothing further they could do.

‘We achieved nothing from it, other than we had consequences.’

The following year the school threatened to expel Taya, arguing she wasn’t engaging. They told Leia they were investigating the year 6 teacher who had given Taya a good report.

A few months later, the school’s lawyer demanded Taya undergo a psychiatric assessment within three weeks or the school would cancel her enrolment. She couldn’t comply because the waitlist was so long. The school then insisted on an IQ test.

‘Our daughter hadn’t done anything wrong, neither had we. All we’d done was put in a human rights complaint.’

Leia took the matter to the Federal Court, but a few months later the lawyer withdrew, leaving Leia to navigate the court system on her own. Legal Aid was unable to help.

‘We were only asking for very basic things. We just wanted our daughter to stay at the school and to have an inclusive education.’

The school isolated Taya and refused to allow her to attend excursions and camps or participate in the athletics team until Leia signed the IEP.

Taya became unwell.

The school demanded Taya complete a list of things or her enrolment would be cancelled. Taya was too unwell to comply and provided a medical certificate.

The school terminated Taya’s enrolment.

‘Everywhere we turned we just had barriers. The school had fought all the way.’

Leia withdrew the proceedings in the Federal Court.

Three weeks later Taya started having seizures.

‘It’s left her absolutely devastated. She’s lost all her friends. She had really good friends. She had really nice teachers ... She didn’t do anything wrong, and neither did we.’

Marise and Amoura

‘It was just horrendous. She would ring us up and just swear at us, and tell us that she wanted to get out of that place, that it was like a prison.’

Marise is in her 60s. She has an intellectual disability and epilepsy.

‘Mentally she’s like a child,’ her sister Amoura told the Royal Commission. ‘She’s never gone past the teens.’

About five years ago, a disability service provider offered Marise a place at a new purpose-built accommodation.

Soon after moving in, Marise ‘started to get some behaviour disorders’. Amoura learnt that a housemate was ‘harassing’ her.

‘He would take her belongings and hide them in places. And then he wanted to sit where she sat and, you know, all of this sort of thing.’

He was ‘the alpha male’ and Marise the eldest resident.

‘And there came a bit of toing and – yeah, conflict about who was in charge.’

Marise was refusing to go into the bathroom she shared with the man, because he was leaving ‘faeces and urine everywhere’. Management wouldn’t put a lock on the bathroom door to stop the man walking in on Marise.

‘Because her behaviours got a little bit out of control, and we had never seen this behaviour ... we took her to the psychologist,’ Amoura said.

The psychologist suggested a variety of signs and visual aids that would help the two residents manage their interactions with each other.

The provider again said no.

‘Because they said that it would look tacky in a brand-new house. They were given information to fix some of the problems for both of them and they – they ignored them.’

Amoura believes many of the problems in the house came down to staff not being trained, particularly in behaviour support plans. They let things escalate, and eventually Marise hit the man.

‘She walked past him and had her knuckle out, and she just hit him on the back of the neck. [His sister] went to police and laid an assault charge.’

The home tried to evict Marise. During a lengthy tribunal process, Marise spent most of her time with her parents. The provider continued to charge her full rent.

‘Until today we still have not got any of those arrears,’ Amoura said.

‘Unfortunately, when you’re vulnerable with disability, to take an organisation on you’ve either go to know someone, or you’ve got to be really strong-willed to just stand up to them.’

Marise is now in a new home with a new flatmate and a new service provider. Her support worker has ‘a huge background in disability’ and is ‘well known for her training ability’.

Kelli

‘I’m going through the motions of living my life. I’m just going through the motions.’

About five years ago Kelli, late 30s, had an accident and acquired a brain injury.

The public guardian began managing her affairs and moved her to a group home.

Kelli didn’t get a choice about the people she lived with or where she lived.

‘There just wasn’t consultation. It was really – there’s a vacancy here, go there. You know? From hospital straight to wherever there was a vacancy.’

Kelli hated the group home.

Staff members called her fat and one of the other female residents bullied and physically assaulted her.

At the time, Kelli’s two kids were living with their dad. Once every two weeks they came and saw her for a few hours and had dinner.

Kelli wanted her kids to be able to stay overnight but the group home wasn’t a nice place for them to stay.

Kelli moved to a different home, but again had no say about where she lived. Her children still couldn’t stay.

Kelli was the only female resident and had no privacy. She often woke in the middle of the night and found a male resident standing over her. It was ‘creepy’ and wasn’t safe.

‘I would not choose to live with these people if I had a choice.’

About a year ago the children’s father died and Kelli became more desperate to have them live with her.

She agreed to ‘a short-term solution to be closer to [her] children’.

She moved to a new two-bedroom unit that shares a common area with other residents. It is a long way from the shops but the kids can catch a bus.

At the moment she is the only resident and management have told her she will have a say about who lives with her. She only wants to live with another woman.

Kelli has been on the waitlist for public housing for a couple of years. She really wants her own home so her children can live with her.

Kelli has put as many location preferences down as possible to maximise her chances of getting a house, but 'there's just nothing'.

She regularly contacts her local member of parliament and the premier. 'I email them every day.' But she's 'fobbed off'.

Kelli believes the housing department is discriminating against her because they think a group home is 'the best place for her'. They are not prioritising her because she already has a roof over her head.

Kelli would like to return to work, but says no-one is helping her do this.

Before she had her accident, and was working, people treated her with respect. Now she feels she's treated like 'a piece of shit'.

'I no longer have a guardian because I do have capacity to make my own decisions. I want to live in my own place.'

Kelsie

‘[We need] mandatory minimum educational requirements [and] a registration of all carers, NDIS and aged care. And there needs to be a reporting structure.’

Kelsie is a registered nurse working with people with disability and advising service providers.

‘I’m totally shocked that disability workers are not required to have any experience at all to work in the community, in people’s homes on their own with them, with no supervision,’ Kelsie told the Royal Commission. ‘That is an accident waiting to happen. I’m really, really concerned about it.’

Kelsie, who’s investigated fatal incidents in aged care, described the lack of mandatory training for NDIS support workers as ‘scary’.

‘There is no accreditation process for these [support workers] to make sure that they are following guidelines and the standards ... Basically every NDIS worker should know these standards. They should be able to say, “Okay. If you were going to assist with medication, what standard is that within?”’

Kelsie said she is particularly concerned about small organisations and sole traders advertising their services online.

‘You’re relying on somebody to do the right thing, but there is no accreditation process for these people to make sure that they are following guidelines and the standards ... It could very easily be somebody who thinks, “There’s a lot of money in NDIS. I’m going to become a carer.”’

She said all support workers need some training and clinical management to prevent disasters.

‘Say Joe is on a modified diet and say he might have a little bit swallowing difficulty and he starts getting a lot of chest infections. That is a sign that this person has inhaled something into his lungs and got a chest infection.’

Kelsie said that without training a support worker might think he ate too quickly and will give him a drink of water.

‘And then it keeps happening and happening and happening until he gets aspiratory pneumonia and dies ... Probably that’s happening and they’re not even identified as incidents.’

Kelsie said all NDIS organisations need a senior nurse on staff.

‘There needs to be somebody in those organisations that can do the clinical governance and they can educate ... Do carers understand what is abuse? ... If you have somebody’s bed up against the wall and then they’ve got a cot side at the side, that’s restrictive practice. And if that person wants to get out to go to the toilet they crawl at the end of the bed and they fall out of the bed.’

‘All NDIS ... workers need to be registered. Just as nurses do. Just as everybody else has to be. There should be minimum educational requirements and that would include medication assistance.’

Siobhan

‘I think society as a whole has not made it easy for people like me to thrive. In fact, it’s been very, very difficult.’

Siobhan is in her late 20s and has just been diagnosed with autism. She also lives with psychotic depression, anxiety and attention hyperactivity deficit disorder (ADHD).

‘I never thought there was anything wrong with me until people started telling me that ... I had a sickness or whatever,’ she told the Royal Commission. ‘I just thought it was my personality ... I thought that my differences were a strength.’

Not being diagnosed had ‘a big impact’ on her as a child. ‘Because you don’t get any of the supports you need as a young kid. You don’t have any understanding of what’s going on with you and why. School was very, very stressful. Like teachers didn’t like me and my grades suffered, I guess because my brain was wired differently.’

Because she didn’t ‘act socially appropriately’, others saw her as ‘a bit of a weirdo ... mentally ill’.

‘So, I’ve been bullied my whole life. As a kid in school and not just by students but by teachers, by people in the workplace, in relationships, all of that. It’s led me to be very isolated and my mental health has suffered a lot ... I’ve been suicidal a lot of my adult life ... And all because I’ve never really gotten the support I need for those conditions.’

Siobhan tried to seek treatment earlier.

‘Most doctors aren’t educated on neurodivergent conditions ... Instead of them looking into it further I would just get told to try harder ... I would sort of get dismissed as, like, my character flaw.’

Siobhan was afraid to see a psychiatrist about a diagnosis because of the cost.

‘And as a young person, 18 or whatever, I didn’t have any money. So I couldn’t do that ... Even after you are diagnosed, you can’t really do much with it,’ she said.

‘I think there really needs to be more support services for adults on the spectrum because when society just keeps treating you like crap and always putting you down, you’re not going to want to contribute.’

The lack of support has left her feeling ‘quite helpless’.

‘It’s a bit hard on your self-esteem.’

That's been exacerbated by a lack of work opportunities. When she was younger, Siobhan saw a campaign that suggested if you were unemployed you were 'sort of a dreg of society ... a failure'.

'That was pretty scary to hear when you are having legit mental struggles and having challenges. Instead of getting support, you just get shamed by the government.'

From employers, Siobhan has experienced 'general inequality just for being disabled'.

'You get discriminated against if you announce that you're autistic when you are trying to look for a job, and the needs that you have aren't accommodated ... I get exploited in the workplace because I struggle with communication and listening.'

Siobhan hasn't applied for the NDIS, but can't afford to get the help she needs alone.

'I think it would just be nice if the NDIS would consider ADHD just as disabling as autism.'

She was living below the poverty line until a couple of years ago.

'I'm lucky that as an adult I've had someone to advocate for me, but if I didn't have that, I'd have no money, I'd have no Centrelink, because it's been impossible for me to communicate.'

Just getting that 'extra bit of money' has really helped her 'get back on track'.

'It's not even just about paying for the essential things to survive, it's about doing things to make you happy ... and have a good quality of life. To sort of just to do things I enjoy.'

Madden, Silver and Alen

Madden is 11 and has Down syndrome. His hearing and sight are impaired and he has an auditory processing disorder, working memory and executive functioning issues and fine and gross motor skills delays.

Silver, his mother, said it helps to think of these as separate issues.

‘Even though he’s got the Down syndrome disability, I guess what we have worked out is if we break them down we can work out how to address each of those concerns.’

Madden went to a mainstream kindergarten and is now at a mainstream private primary school.

‘We believe mainstream schooling is the best environment for [Madden],’ said Alen.

In theory, he said, he and Silver agree with expert advice that says children with disability ‘are best served by attending mainstream school and it also provides benefits for their peers at that school’. But in practice, ‘the systems aren’t there to support a child like [Madden] at mainstream schools’.

They are happy with Madden’s social experience at the school.

‘We’re very lucky the school he goes to is quite a nice community,’ Alen said. ‘The kids there keep an eye out for him generally. Yeah, he hasn’t been bullied or anything like that. So that, that’s been a positive ... that all the other kids there really look after him.’

But Madden’s educational experience has been a mixed bag. His parents have observed that there is a lot of educational policy that talks about the inclusion of children with disability – using language like ‘address the child’s needs,’ ‘modify’ or ‘adjust,’ ‘collaborate with parents’. But the reality does not match the rhetoric.

‘This is not effective and is either not happening, half-heartedly happening, disregarded, ignored or something put in place regardless of whether it is really addressing the child’s needs or not.’

Silver told the Royal Commission that in Madden’s prep year he had a teacher who was ‘really good’.

‘She included us, she found out ... what impairments, you know, [Madden] had, what his struggles were and she put things in place for that.’

Other teachers are not so open.

‘We’ve proposed a lot of things to the school to help [Madden], and quite often that’s just disregarded,’ she said.

‘Just about every year we go in there and say, “He learns by repetition.” You know, there’s the slow talking, he learns through videos, he learns through all the things we’ve worked out to address the needs. And what happens is [the teachers] don’t really adjust ... I think the expectation is for him to listen, learn and be able to do it. I think the amount of time that he gets to process and be able to learn is very minimal. It’s the same as everybody else, and then they’re moving on ... With his disability, that’s not achievable.’

Silver and Alen described some of the teaching tools they successfully use with Madden at home, including assistive technology that Silver has adapted to meet Madden’s needs. They would like to see such technologies adopted by schools, with support teachers trained to customise programs for individual students.

‘There’s never been a strategy for teaching [Madden]. Obviously [Madden’s] different to your typical child but I’ve never seen anyone sort of come up with an approach, “How, how are we going to modify what [Madden] has to learn?” We’ve never really had that.’

Gabe and Anette

Gabe, early 50s, has Down syndrome.

For many years, he lived in a group home managed by the state government.

About 10 years ago staff told Gabe's sister, Anette, they were arriving at the home to find him with no clothes on or with ripped pants, and deep scratches on his back.

Staff believed he was doing it to himself.

Then one night a staff member heard Gabe crying in distress and saw another resident running out of his room. It turned out the resident had been sexually abusing Gabe and another resident in the house for a long period of time.

The home refused to remove the perpetrator from the house.

Anette made a complaint to the department but the manager lied that there had been no further incidents of abuse.

Anette continued to make complaints and discovered the home was aware the perpetrator had a history of sexual violence. The department eventually moved the perpetrator to another unit.

Police were unwilling to investigate because Gabe and the other resident are non-verbal. They told the families there were no legal avenues available, which Anette has since learnt was incorrect.

Anette told the Royal Commission some staff started to treat Gabe and the family badly after this incident.

'Sometimes they were really rude, the staff, it was like a bullying mentality.'

One time, Gabe had dental surgery and needed a modified diet. A support worker refused to feed him soft food and follow the post-op care instructions. When Anette arrived to visit, the support worker was roughly pulling a jumper over Gabe's head, hurting him.

Gabe's mouth failed to heal properly and he was in pain, so Anette took him back to hospital. Doctors x-rayed his mouth and discovered he had a fractured mandible resulting from a 'deliberate blow to the jaw'. The support worker eventually left the home.

Another time, Gabe slipped on the kitchen floor. The staff member on duty didn't tell anyone, gave him a shower and put him to bed. The next day the staff on the morning shift couldn't get him out of bed and eventually called an ambulance. Gabe had multiple fractures of his pelvis.

A few years ago, Gabe had unexplained cold and flu symptoms for several months.

Anette told staff there was a musty smell in his room, but they failed to investigate. Anette found fungi growing from the wall behind a chest of drawers and soiled carpet. The bathroom next door had been leaking and mould had grown in the wall and floor.

Anette had to make several complaints to get the home to act.

The manager then sent Anette a threatening email advising they were implementing 'family engagement guidelines'.

'These weren't guidelines, they were restrictions. It felt like a dictatorship.'

The home wouldn't allow Gabe to go out with Anette and other family members. The family could only visit briefly and had to stay in Gabe's room. This wasn't feasible because he likes to wander and struggles remaining in one place.

'There was just such a lack of respect, not only for [Gabe] but for his co-residents. Because I interacted with a lot of these people because they didn't have family.'

Staff refused to provide verbal updates on Gabe and told Anette she would have to wait for the weekly email.

'I believe it was a punitive response to attempts to advocate for [Gabe].'

Anette and her husband removed Gabe from the home. Anette provided no notice because she was fearful the provider would try to prevent Gabe moving.

Gabe is temporarily living in an aged care facility while Anette modifies her house.

'Generally, things are okay. They're so far better than what they were in the group home.'

Maryanne

Maryanne is a physiotherapist who recently started a community practice.

‘I see people who have autism that work in community that, say, have a job versus people who are wheelchair-bound, nonverbal. So the spectrum is huge,’ Maryanne told the Royal Commission. ‘Some of those people ... their family are very involved, and others might not have family or friends advocating for them.’

Maryanne said some injuries and bad practices are unreported because service providers employ staff who are inexperienced or afraid to speak up. For example, in her first week in the community Maryanne visited a woman with an intellectual disability who uses a wheelchair.

‘She has a speech impairment. It takes a very long time to get information out of her ... I was just chatting to her really, and she told me about her sore leg.’

Maryanne discovered the woman fell from her wheelchair a few weeks earlier and her support workers didn’t report it.

‘They picked her up, put her back in her wheelchair and left her.’

Maryanne insisted the woman be taken to hospital, where doctors found she had a broken leg. She said the support workers probably didn’t realise the danger, ‘but they should have reported it for her to be assessed’.

‘You could get a support worker that has a nursing background or you can get somebody that walks in from the street with no disability or no caring background and they are expected to do the same job.’

Maryanne also described a man who had a stroke and was severely depressed because he was placed in a group home with a person who had ‘severe behaviour disturbances’.

‘I arrived to this person’s house in the middle of January this year and it was a very hot day, close to 40 degrees ... The man’s room had no air-conditioning and the food in the house was locked away.’

Maryanne said the man couldn’t leave his room because of the other person’s violent behaviour.

‘He was actually urinating in a bucket next to his bed ... He has a package that they need to shower him every three days, provide him with meals, this, this, this. And my first visit I realised they weren’t giving him what he was funded for.’

Maryanne took the man’s complaints to his service provider.

‘They weren’t happy that I did that ... [They were] refusing to communicate to me and they cut his care. So they punished him for dobbling on them.’

Maryanne said service providers sometimes fire allied health professionals who raise concerns.

‘So then you lose contact with the family. And so that’s why these things keep going. And it happens the same if a support worker speaks up or anything.’

She said it means cases of abuse and neglect aren’t reported.

‘I think what is happening quite a lot of the time in the community [is] companies hire quite inexperienced, say, physios ... They charge the full rate that they can claim. There’s no direct supervision. And they go out. So they are already overwhelmed by just the job itself ... Not blaming them. I think it’s a lot of the companies [employ inexperienced staff].’

Kris

‘Children with disabilities were always an afterthought at my primary school and the worst part of it was that they never tried to hide this.’

Kris is a teenager and has Ehlers-Danlos syndrome, which makes him prone to joint dislocation, injury and infection. He uses a wheelchair.

‘I have experienced hundreds of micro traumas over five years or so in my primary school years that left me extremely depressed, anxious, isolated and considering self-harm,’ Kris told the Royal Commission.

‘I would turn up to class and the other children were excited about doing a certain activity ... and nobody had thought of choosing something that all children could do. I was sent to other classrooms, to the office, or mum would simply keep me home.’

During one school excursion that was supposed to be inclusive, the school made the kids with disability take a different tour to everyone else.

‘Rather than trying to include everyone they ended up segregating people. That kind of left a lot of people with the wrong message, that this is what inclusion looks like ... which is obviously not the case.’

Although the school had a support team to help kids with disability, Kris said activities were often planned without consulting them.

‘A lot of the time they’d ... do activities down on the oval. I couldn’t do that because the oval was uneven and all that other stuff. They never consulted with the support team because mum would go and ask the support team, “Hey, were you consulted about this?” and they’d just be like, “No, we were never told.”’

Kris said every day something would happen in which he’d be forgotten.

‘They would quickly come up with something for me to do as I was forgotten 10 times out of 10. I became increasingly depressed and lonely.’

Kris said he never went on a school camp because the school never planned camps with activities that he could do.

‘The school was really stuck on the idea that because a location was marked as “wheelchair-friendly” it was deemed to be inclusive and that was all they needed to worry about. There was no thought given to other factors.’

When Kris’s mum complained, the teachers would ‘get angry about [her] asking them to make changes to their plans’.

‘During these times of being forgotten I felt like they were angry at me for being unhappy.’

Kris said he’s still traumatised by the experience, but he’s now at a private high school which is more inclusive and the teachers are ‘very open-minded’.

‘Even from year 7 they pretty much treated you like a young adult.’

Kris plans to study social work at university, ‘mainly just because of all the stuff that happened in primary school’.

‘I’m not going to stand for this. I have a very strong moral compass, to my detriment sometimes.’

Erynn

‘I think if organisations really understood what disability inclusion means for them ... they would know that it’s actually going to help their business.’

Erynn, early 40s, is autistic and has complex post-traumatic stress disorder.

She told the Royal Commission that growing up she didn’t fit in. Her classmates made fun of her, didn’t invite her to parties or pick her for a team.

‘In high school, I spent every lunchtime by myself.’

In her 20s, Erynn started working for a development company and said she found her niche.

‘The way my autism spectrum manifests is laser-focus, racehorse-speed problem-solving.’

She was very successful and made a lot of money for the company.

A few years ago, while working on a big project, Erynn told her boss she was autistic.

Her boss began to bully and isolate her and made disparaging remarks.

‘He hated the fact that I was on the spectrum. Everything I did is always wrong. “Oh, it’s great, but it’s all wrong because she’s on the spectrum and she doesn’t know what she’s doing. So everything that she’s done to date is wrong and you have to change it all.”’

Erynn had mentioned she was noise and cold sensitive.

Her boss moved her to the noisiest place in the office under an air-conditioning vent.

‘It couldn’t get any noisier. I was surrounded by 16 people, printers, it was a thoroughfare, it was behind reception, people coming and going, really loud doors slamming.’

One day in a meeting, her boss became very angry and Erynn thought he was going to hit her.

‘His hand was that close to connecting with my face.’

Other people in the meeting told her ‘the way he treated [her] was disgraceful’.

Erynn ended up with burnout fatigue and became suicidal.

One night she had a mini stroke and was admitted to hospital.

She returned to work and the bullying continued.

'I had an outburst after two years of being absolutely brutalised.'

Erynn told the HR manager what was going on and that she didn't feel safe in the workplace. 'He's been bullying me. Everyone knows he's been bullying me,' she told them.

An hour later they 'marched [her] out the door'.

The company told Erynn it was because of her outburst. 'It beggars belief,' she said.

Erynn has not been able to work since.

'I cannot physically be in an office building. It has traumatised me so much I lost my ability to function. I can't open a laptop.'

Dixon

Dixon, mid-30s, was born with a hearing impairment. He has post-traumatic stress disorder, depression and anxiety.

Dixon told the Royal Commission that he has been homeless, on and off, since he was a teenager, making it difficult to apply for the Disability Support Pension (DSP) or Job Seeker allowance.

He said he applied for the DSP 15 times before he was successful.

About four years ago Dixon was living in his car. Suddenly, he couldn't urinate.

'The pain is so awful, it's still excruciating every day.'

Dixon was admitted to hospital but 'still hasn't got proper answers for it'.

Doctors inserted a permanent catheter.

'I gotta have things like catheter tubes, catheter bags, like all the cleaning products.'

When he is homeless, Dixon has to change his catheter in public toilets.

During COVID-19, the council shut the public toilets and Dixon had nowhere to go.

'It was getting real bad for me. I had a tube coming out of my belly from the hospital doing the wrong procedure, and every public toilet in Australia was shut.'

Dixon's health deteriorated.

'I could barely walk up the street without, like, almost fainting.'

One day Dixon collapsed while out in the community. When he explained his situation to the people who came to his aid, they found him emergency accommodation.

A month later the public housing agency told Dixon they had a property for him. He couldn't inspect it because of the COVID-restrictions. The property was a 'six-hour roundtrip' from Dixon's GP, the hospital and his mum. He didn't know anyone nearby and felt the area was unsafe.

'They basically didn't give me a chance to give them a list for my needs or what areas [I wanted to live] or anything. It was basically like, "Oh, you know, you're lucky we're even doing this for you."'

Dixon said his new neighbours are very violent.

'I've been bashed by them, I've been robbed by them.'

He has made complaints but that has made things worse.

The neighbours broke his windows which took more than a week to fix.

'I've got like hundreds of hours of recordings of them like smashing, bashing.'

Dixon has given up hope about his housing situation.

'A lot of people would not have survived this. I'm only lucky I did have a sort of rough upbringing, I have managed to handle it. But look, so many people wouldn't, would've taken their life by now.'

Boris

Boris, mid-50s, is autistic and receives a Disability Support Pension. He describes himself as autistic, not 'a person with autism'.

'That insinuates it's a disease, like a person with cancer or a person with HIV or with COVID, just to be topical. It's not right. We are autistic. I call myself an autistic person for that reason. That's how I self-identify and that is in my opinion at least truthful.'

The last time Boris had a full-time job was 25 years ago. He told the Royal Commission he lost that job because of discrimination.

The job, which he started prior to having a diagnosis, was in an Australian Government training program.

He received his diagnosis six months into the role. When he told his manager about it, she 'completely changed her behaviour'.

'She ceased to be cooperative entirely and I was subjected to what I see now as the bullying that is typical of [that department].'

The office of the Commonwealth Medical Officer (CMO) became involved and prepared a report about Boris that eventually led to his dismissal from the training program. It was because of his social skills, Boris said.

'I tried to take it to the Human Rights Commission but basically the message was [the training program] did the right thing because of the unjustifiable hardship clause of the Disability Discrimination Act.'

The clause states that employers are not required to make adjustments to their workplace for people with disability if they can prove that an adjustment would be too expensive, difficult, time-consuming or cause some other hardship.

'I am of the very firm view that that particular clause is being abused against the disability community in general, but in particular ... against the autistic community because of our issues with social skills. And there are some jobs where unjustifiable hardship is justified and that's in jobs in retail and hospitality. In other words, jobs where you are dealing on a regular basis as an inherent part of the job with the general public. You can't control the general public,' said Boris. 'Fellow employees, on the other hand, it's a two-way street.'

Boris believes the CMO report has left him unemployable.

'If you can't work for the public service you can't work for anybody. That's the – that was the saying that was around and I think it's still valid now. And that is basically the reason why I haven't worked full-time since.'

He sees it as a '50/50 situation'.

'We should not expect society to adjust to us 100 per cent ... We need to meet in the middle. Society has to do their share but we've got to do our share as well within reasonable parameters. I'm prepared to do it.'

Boris wants to see the unjustifiable hardship clause in the Disability Discrimination Act strengthened to require employers to do more.

'They do it too easily, particularly when it comes to social skills. When it comes to – to the employability of a person. That's what cost me my job.'

Fabien and Ginger

'I thought I might have a part-time job by now like other kids. I am very hurt about everything and that I can't do what I wanted to when I grew up. I feel that it was taken off me.'

Fabien is in his teens. He was diagnosed with autism and anxiety in prep.

Ginger, his mum, told the Royal Commission his school 'had no idea what autism really was or how it affected a child living with it'.

'There would be times when I used to be called early in the day to come and collect [Fabien] because the teachers would not be able to handle him.'

Ginger refused to do this after a while as it 'was becoming a learnt behaviour'.

'He knew if he played up he would be able to come home early. He needed to stay.'

In primary school, at Ginger's insistence, the school eventually agreed to provide Fabien with teacher aide support for part of the week. But the aide was 'taking off', filling in for other teachers, and had 'no idea about kids with disability'.

In year 8, Fabien was coming home with lots of bruising. Ginger knew he was being bullied, but the school said it was not their 'problem'.

'The school did have a no-bullying policy but just didn't seem to do much when it came to us.'

When Fabien returned to school after a break, there were 'more incidents with the bullies'.

'They were always being rude to him prior to school starting, calling him names like retard.'

The principal ignored Ginger's emails as the bullying got worse.

'One boy said he would kill him if came to school,' Ginger said. The same boy stabbed Fabien with 'a very sharp pen' and punched him 'multiple times'.

It wasn't just the students.

One teacher would make fun of Fabien's stutter in front of the class.

'He mimicked how he was speaking to him when asked a question. The teacher made the whole class laugh ... to the point [Fabien] left the classroom crying.'

Ginger said the principal 'was aware of everything' that was going on. Ginger wanted the school to take disciplinary action against the teacher, but nothing happened. It 'seemed to be just dropped'.

Fabien was so 'physically and emotionally hurt by bullies and teachers', he was 'too scared to go to school'. He was upset every morning and 'blamed' Ginger for taking him there.

'He felt if I kept him home he would not get bullied. He did not feel safe. He even said to his therapist that he would rather kill himself rather than go back to that school.'

Fabien did attempt suicide. He was prescribed antidepressants.

Ginger said that after further incidents of bullying and inappropriate teacher behaviour, the school effectively forced Fabien out.

'We were a liability they had to get rid of. It has really damaged my son.'

Fabien told the Royal Commission he doesn't want this 'to happen to any person with autism at any school'. He and Ginger feel the 'educational neglect' has diminished his chances of getting into uni.

'When I graduate this year, [at least] I know that I did my best to earn my certificate,' Fabien said.

He is thinking of going to TAFE instead.

'He was robbed of the education that he should have been given to be able to live his dream of going to university,' said Ginger.

Rafe

‘These people walk in with this attitude to think they can dominate disabled people. And I have seen it time and time again.’

Rafe, mid-50s, has a cognitive disability.

He started receiving supports from a large disability service provider about five years ago.

Rafe told the Royal Commission that one of the support workers regularly abused him.

The support worker would bend him over her knee and hit him with wooden paddles and wooden spoons.

‘I added up one day that I think she belted me on 17 occasions,’ Rafe said. ‘She made me get on my knees and hold my hands out like a little child, and all this was for drinking a couple more beers than I probably should have drunk.’

After this, she would make him write out lines 100 times about the evils of alcohol.

The support worker regularly made sexual comments to him and spoke to him using sexualised language.

‘She said, “You need to get laid. When was the last time you had a good you-know-what?” It was just continuously things that she would say. And when I was at my weakest point she said, “Do you love me?” And I, unfortunately, I said yes, but I wasn’t aware what I was saying at the time.’

The support worker always kissed and cuddled participants when saying goodbye or hello.

‘I have since found out that you’re not really allowed to do that.’

Sometimes the support worker made him give her cash in exchange for taking him places.

She told him she took other clients to her house and asked if he wanted to go.

Rafe discovered she would get her children to ‘babysit’ the clients while she left the house to do other things.

He said the support worker should have been suspended for breaking the rules.

‘The fact is, she’s gone outside the rules and made her own rules.’

Rafe made a complaint to the provider but they ‘didn’t consider the issue to be very serious’.

He then reported the support worker to police. Rafe said police treated him badly and yelled at him. They told him it would be his word against hers and because he had a disability people would believe her.

Rafe has moved to a new provider, who is better.

'If you've got a problem you can give them a ring and they're quite helpful. And if there's any problems people are dealt with like they should be,' he said.

'This company doesn't allow any physical touching of their clients whatsoever, it's one of their rules.'

Felicia

Felicia is a First Nations woman in her late 30s who is autistic and lives with mental health conditions. A few years ago, she was about to take her own life.

'I had a big meltdown and I was panicking and I went to go to [a place known for suicides]. And somebody had seen me and called the police and ambulance. The police came first and they was really good ... He was helping me feel better.'

Felicia sometimes becomes non-verbal.

'And I can't talk and I can't tell them things. The ambulance man get really angry ... because I didn't want to go to the ambulance ... and I couldn't tell them.'

The paramedic 'just grabbed [her] and started dragging [her]'.

'And I got really scared and, because it hurted me and he was a man, so I was already scared ... But then the policeman told him off and the police said I don't have to go with him and I can stay with the safe police.'

After this, Felicia developed a fear of ambulances.

'Then I was just starting to get a bit braver ... and then about a year ago, the ambulance got a call ... As soon as the ambulance man got out of the ambulance, he was really rude and said he remembers me from a few years ago and that I'm just being silly and it's going to take forever.'

Felicia 'didn't want to go near the ambulance'.

'We were sitting in the police car and I said I needed my dog, because my dog's my assistance dog and they go everywhere with me. But I was non-verbal, so I was trying to sign and trying to write it down, and the ambulance man said no.'

A support worker offered to meet Felicia at the hospital with her assistance dog, and the officer again refused.

'And then, they just closed the doors and started going.'

Felicia's neighbour rang the ambulance service and insisted they allow access to her dog. Eventually they agreed. She wanted to wait with the police until the dog arrived. The paramedic told her if she didn't get out of the police car and into a wheelchair, he would 'throw her in it'.

'And then the ambulance man was – he keeps saying ... I was just bad behaviour ... He said to the police, "I would just grab her and drag her." And that scared me because that made me think about that time the ambulance man did.'

The paramedic was 'really mean and scary', yelling at her to 'use her words'.

Felicia made a complaint. The service said it 'investigated ... and couldn't substantiate' it. They didn't talk to her support worker or other witnesses, only to the officers.

'That's only taking their side, because they should talk to everybody.'

Afterwards, Felicia said the paramedic started 'bullying' her on a Facebook community page and at community events. He referred to her attempt to take her life as a 'waste of resources' because 'she wasn't really going to do it'.

'Because of what the ambulance man did, I can't – I can't go into town. I can't even go in to get a coffee ... I can't go down to the park. I just can't do anything. Because he has spread so many lies about me and – and because he's ambulance, everybody just believes him.'

Felicia said she faces a lot of discrimination because of her dog. It makes her feel like she's 'not good enough to be part of society'.

'Like I'm not worthy enough to be able to go out and do stuff.'

Katy Jo and Sabine

‘Money, time and emotions are wasted.’

Katy Jo is autistic and has cri du chat syndrome, a genetic disorder that causes intellectual and physical disability.

‘[She] is an amazing little girl,’ her mother Sabine told the Royal Commission. ‘We were told when she was diagnosed that she would never walk or communicate in any way. She can walk quite well. She communicates using a communication device.’

Katy Jo is in her fifth year at a specialist school.

‘I did sort of want her in a mainstream school. The schools around here weren’t that open to it because she is still in pads, not toilet trained yet ... She’s hard work, basically. It’s going to be hard work to get her included.’

Katy Jo has had NDIS supports for three years. The first two years were ‘amazing’.

‘We had enough funding for all of her therapies, we had enough funding for the Saturday community access, which she really thrives on. But then the third year they cut her funding in half, so there wasn’t enough for her continence aids, it wasn’t enough for her therapies ... Not too much at all.’

Sabine’s ‘biggest argument’ with the NDIS is about funding for Katy Jo’s talker, which costs less than \$5,000.

‘They have said that’s not value for money. That’s the only way she can talk. That’s her voice! It needs to be replaced because it’s old technology. So it’s making her not want to use it at all, which is causing quite a few behaviour concerns because she can’t communicate.’

The NDIA said, ‘Why don’t you just get her an iPad?’

‘But this is a dedicated device. I’m not going to start again teaching her how to speak differently just because they don’t want to pay for the voice that she has got.’

In the past six months, as Katy Jo’s behaviours ‘have regressed’, the calls from the school have increased.

‘And it has been awful. The therapies are dropping off and she is going through puberty. So, if anything at the moment, we need more therapies ... But we’re just not getting any support.’

Sabine has sent ‘countless reports’ from therapists validating Katy Jo’s needs.

'I've got letters from the occupational therapist and the speech pathologist ... And still NDIS were like, "Nope." They've said no to everything ... We've jumped through all the hoops.'

The agency also cut funds for a support worker to take Katy Jo to the shops or out for lunch, and classes to 'teach cooking and social skills' and manage money.

'Everybody in this town knows her because of that community access. I don't want her to fall through the cracks.'

'Two years ago I would have been singing NDIS's praises, because what they did for us then, it was such relief. And then for them to just cut it in half and leave us heartbroken.'

Chantal

Chantal, early 40s, has cerebral palsy, epilepsy, asthma, osteoporosis, arthritis and recurring tendonitis. She uses a wheelchair and needs help to dress, prepare meals, and clean.

About 15 years ago, Chantal moved out of her parent's home into disability accommodation.

She told the Royal Commission the house manager and a support worker were 'emotionally and mentally abusive'.

The support worker would tell Chantal everything was her fault and she hated working with her.

Chantal didn't know how to stand up for herself and would get upset.

'She used to tell me that I used to bring it on myself and I was a difficult client and no-one wanted to work with me.'

The support worker was always changing the roster and Chantal didn't like it.

One time, Chantal was getting ready to have a shower and asked about a roster change.

The support worker got annoyed and left the room.

Chantal was able to walk short distances at the time, and got herself into the shower.

Soon after, she heard the front door slam.

'I knew that I was going to be on my own and I was still in the shower. So I tried to get out of the shower and because it was wet I slipped and I fell. I tried to ring [the house manager] and her response was, "Well, what did you do to piss her off?"'

The support worker refused to complete her weekend shifts and the manager was unable to find anyone to fill in.

'I had to sort of deal with it and try to get myself up for the rest of the weekend and whenever. But by Monday, I was unable to walk.'

Chantal was admitted to hospital and doctors treated her leg. However, support workers failed to attend to the injured area during the recovery period and her leg deteriorated.

'Now I've got a lifelong condition and use an electric wheelchair because I can't walk anymore.'

Chantal made a complaint to the CEO, but the house manager and the support worker said she was lying about what happened.

Chantal made a complaint to the department.

‘I wanted to end the silence and speak up and say hey, look, I don’t want this to happen to anyone else.’

Sometime later Chantal was able to change providers and move to a different house.

‘I was again labelled a difficult client because all my shifts were all over the place and sometimes I didn’t get shifts at all.’

One of the support workers accidentally sent her an email meant for the regional manager.

‘It was four little words saying, “Can we hit her?” and I was absolutely horrified.’

Chantal said it is hard advocating for herself.

‘I get worried, you know, am I going to get labelled again? If I don’t do anything or if I don’t say anything am I going to get labelled?’

Since the NDIS, the rostering of support workers has become a lot better. But Chantal has to jump ‘through a lot of hoops’.

At the moment she lives in an unsafe area in a public housing unit that is falling down. She wants to move to a unit in a disability complex closer to her work.

The public housing body refuses to move her because she has NDIS supported independent living (SIL) funding. But Chantal says her SIL funding is inadequate.

Chantal has had to make a number of submissions and applications to the public housing body and the NDIS to work out a solution.

It is taking a lot of time and effort and she is ‘tearing out her hair’.

‘It’s a lot of stress and it’s a lot of worry when you don’t get the right allocation for what you need. It’s a lot of heartbreak for people with disabilities as well as their families or their support workers who really want what everyone else wants – to live as comfortably and independently as you can.’

Shandra

‘There’s no accountability. There’s still a lot of coercion going on and invalidation. And you know, it’s not mental health at all. It’s just, “Do what we say and shut up.”’

Shandra is in her early 50s and lives with schizophrenia and psychosocial disability.

‘My illness started when I was 17 and I’ve always been in public systems,’ she told the Royal Commission.

About 15 years ago, Shandra was admitted to a psychiatric ward ‘after being suicidally depressed’. One morning she woke up with dishevelled clothes and bruises. She said one of the staff had drugged and raped her.

Shandra reported the assault but said the police didn’t take her ‘seriously at all’. They took photos that showed ‘black bruising under [her] buttocks’, but she felt they ‘bungled the investigation’. She found the whole process ‘absolutely humiliating’ and felt ‘abused’.

A few weeks later, a detective called Shandra in for further questioning.

‘And he basically was just really abusive ... It was like he was gonna attack me ... And he said, “It didn’t happen. There was no semen found.”’

The matter did not go to trial and a lawyer told Shandra the photos of her injuries ‘had gone missing’.

‘The detectives and the hospital and everybody failed in their duty of care ... They’ve gotten away with it. There’s no accountability of night staff particularly.’

During involuntary admissions to mental health wards, Shandra said police were ‘totally insensitive’ about her disability.

‘I’ve experienced police brutality.’

One time, she said, they handcuffed and manhandled her.

‘There was no need for handcuffs. And no need for abuse ... It was violent. I think they gave me kidney blows to my left kidney. I was bruised in my wrists from the handcuffs being too tight. My shoulder’s still out... years later.’

At the hospital, an officer was ‘standing over’ her abusing her. An emergency doctor told him to get out and took an X-ray of Shandra’s ribs.

‘And there were no broken ribs, but it took me about six months to get over ... And it’s swept under the carpet. And, hey, most people just don’t even want to engage with the systems, because they’re so cruel and nasty.’

Another time, police took her away in her ‘little pink nightie’. They wouldn’t let her get her personal belongings.

‘It was just so inappropriate. No clothes, no nothing ... I still freak out thinking police might turn up at my door again.’

Shandra has never had an advocate during these involuntary admissions and ‘absolutely nothing is explained’ to her.

She wants measures taken to stop abuse ‘that you can’t prove’ in the mental health system – ‘cameras that work, phone calls to be recorded.’

In her experience, public psych wards are ‘totally untherapeutic’.

‘I have been there overnight, and it’s horrible. There’s no outdoors. It’s like a prison. The tables and chairs are like cemented to the floor ... There’s no interaction with the staff.’

Colleen and Debra

Colleen is in her 40s and has an intellectual disability and schizoaffective disorder. She's been living in the same supported independent living (SIL) house for more than two decades.

'I used to feel like I was free to pop in there,' said her mum Debra. 'I felt welcome in there. I felt like it was a little bit more like a home.'

Debra told the Royal Commission things changed when a new service provider took over a few years ago. It's 'just not a home' anymore.

Before the change, Colleen's old service provider persuaded Debra to become her daughter's guardian.

'[They] could foresee the problems ... Without guardianship I would have been completely ignored as a parent.'

Debra said the new staff appeared untrained and unable to manage Colleen, and after a few weeks she became concerned for Colleen's safety.

'Special needs kids – they're lovely but they can be difficult too. I suppose we all know that. But ... [Colleen] won't just conform [and] if they couldn't get her to do what they wanted her to do, then she would be bullied and abused.'

Debra said staff always had an excuse not to take Colleen out into the community, even though they were paid to take her out.

'One staff member just in the last few months actually verbalised to me, "We don't want to take her." ... So my daughter's sitting there. She's told me, "Mum I feel lonely."'

Debra said Colleen's clothes were often dirty and she may not have been showered. She also appeared to be overmedicated and her behaviour deteriorated. One day she drank cleaning fluid and was rushed to hospital. Another time staff called the police, who used capsicum spray.

'Even if she was rough and angry and everything, it doesn't justify giving a special needs child capsicum spray and throwing them in the back of the [police van].'

When Debra complained to the disability services department, the service provider launched its own investigation and accused Debra of being 'controlling' and 'bossy'.

'I am an active person and I like to be like that because I want to know how my daughter's going, and I want to tell the truth of what's happening.'

The service provider banned Debra from the house.

‘They don’t respect it anyway, actually, the guardianship.’

Debra said the provider also keeps ‘coming up with excuses’ why Colleen’s behavioural specialist can’t visit the home.

‘Why is it that we can’t work together as a team? Team being me, [Colleen’s support workers], the house, the staff. Why isn’t it better to [help Colleen] living a better life? But it’s not like that.’

Jamir

‘I’m so fatigued from having to explain myself ... You’re on this sort of process of educating people about your particular needs so often.’

Jamir, early 50s, has progressive congenital spinal stenosis and attention deficit hyperactivity disorder (ADHD).

About five years ago, his spinal stenosis started to compromise his capacity to work full-time.

‘I’ve had to increase my dependence on different technologies and different set-ups to do things,’ Jamir told the Royal Commission. ‘It takes me time because I fatigue, and the pain is also fatiguing.’

Jamir recently enrolled in a postgraduate course.

His doctor suggested he ask for additional time to complete assessments because of his pain and fatigue.

The university told Jamir he needed to meet with an officer from the disability unit to discuss his needs and set up a learning plan.

As soon as Jamir started to explain his needs, the officer interrupted.

‘The young woman said to me, “Okay, so what we’re going to put on your form is that you need help with being organised, because you’re not good at time management and you lose concentration. And you need some help with – you’ve written ‘fatigue and pain’ – so I would say concentration issues.”’

Jamir told the officer she was making assumptions and stereotyping him based on his ADHD. He asked her to read the doctor’s report properly.

She kept insisting she knew what she was talking about because she’d done this many times.

Jamir asked to speak to another officer but she said it wasn’t possible. He then asked if he could give feedback about the process.

She told him to email the general email address.

Jamir didn’t feel comfortable sending his medical documents to a general address so emailed asking for an opportunity to give feedback on his experience.

The coordinator replied telling him to use the general email address and they expected ‘respectful communication’ as per the student charter. She also arranged an interview with two officers and gave him the time and date.

‘You’re being moved around like an object. I’m asking for an opportunity to provide feedback. I just want a situation where I’m going to be listened to ... She decided to appoint two people to work with me, without having heard any feedback, without explaining what that process was.’

At the meeting, Jamir explained that people using the service have had a lot of challenges talking about their experiences.

‘They just want to be met with a service that’s going to be supportive and person-centred, and I didn’t experience that.’

Jamir said the officers seemed receptive, but when he asked about the next steps they said ‘there is no next step’.

Frustrated the disability unit was unwilling to accept feedback and change their processes, Jamir made an official complaint.

The investigator, ‘who again, didn’t understand the challenges that face people with disabilities’, became defensive.

He told Jamir that the officer said he’d been rude and she felt intimidated.

Jamir explained he was assertive but not rude, and suggested they record the conversations.

‘You do want to go to a service that’s actually going to understand and will have the training and understanding to work with you, because you want to feel you’re going into a place that’s going to be safe ... It was a bit of a shock to me that the [disability unit] was actually where I would have the difficulty.’

Jamir sent his doctor’s report to the head of school apologising for how long the process was taking.

The head of school told him, ‘Don’t worry about our systems, take the time you need ... We are here to support you. What you have sent through is more than enough.’

‘That’s what I expected from the [disability unit],’ Jamir said. ‘That ability to hear me and see exactly what was going on. “Oh, okay, this person’s overwhelmed because they can’t meet the requirements because of this medical situation, their disability. And what we need to do is make our system actually accommodate this.”’

Melanie and Babette

Twenty-year-old Melanie is autistic and non-verbal.

Babette, her mum, told the Royal Commission that when Melanie attended a mainstream primary school, she witnessed staff 'being extremely inappropriate' to children with disability.

'Down syndrome children, screaming at them. My daughter would go to school and they would mix up her incontinence aids and put a two-year-old's incontinence aids on. When she would come home, she would be all red. When I asked about it, they didn't like that.'

Babette's complaints led to an investigation, which found that there was 'abuse ... and a lack of care for the children'.

Melanie then went to a special school, but her class had a high turnover of teachers.

'And that just didn't work. And she regressed to almost a vegetable lying underneath a blanket the entire time. Became about 40 kilos.'

For the next four years, until she was 13, Melanie attended a supportive class and 'progressed fantastically'.

Problems began when she joined the NDIS and needed support workers at home. 'Basically, the support system outside the school environment for a person with level 3 autism is lacking intensely,' Babette said.

Disability service providers constantly let her down.

'They can just tell you overnight, "We don't have somebody for your daughter," or "We don't want to give her support." They don't even have to tell you why. This industry is a casual-based industry, so all their workers come and go.'

Melanie needs someone to help her manage her behaviour – 'to predict what she's about to do, or how she's about to escalate or deescalate.' But her support workers see the work as a 'stepping stone' and have no long-term commitment to her.

'The last provider was getting a ridiculous amount of money. And they had no intention of organising the consistent workers that we agreed to. In a month she regressed dramatically. There was in actual fact no trained person for her at all,' Babette said.

'This is the culture of calling a human being "a million-dollar baby" because they've got a disability like [Melanie]. In other words, providers are looking for million-dollar babies.'

Babette also points the finger at support coordinators.

‘In reality, all that they’re happy to do is take the NDIS funding to ring you once a month ... and then they will take the money out for that phone call. But if you tell [them], “Look, I need a new program for [Melanie]. Can you go and investigate that, make some appointments?” They can’t do that.’

Melanie is onto her tenth NDIS plan. A support worker kept getting her behaviour support plan ‘all wrong’. ‘And sending invoices when she hasn’t got any input from me. The plan goes less than 5 per cent to addressing her needs. It has basically no effect on her life.’

Shanna

‘When it comes to people in charge of organisations who are looking after vulnerable people, they need to have some training or education ... But it is more what they put in their back pocket.’

Shanna is in her 40s and lives with a degenerative neurological disease. She’s been on a Disability Support Pension for about eight years.

A few years ago, she began working part-time for a disability advocacy group.

‘When I first started with them, they knew exactly what my disabilities were,’ she told the Royal Commission. ‘They knew how they had to support me. I’ve always been open with everyone because if I’m not, then people are going to expect too much.’

But then a new manager came aboard.

‘And one of her first discussions with me on the phone was, “Can you even do your job? Can you coordinate?”’

Shanna’s team was behind on a job because of COVID. But the manager ‘needed someone to blame’ and got the idea of pushing Shanna out.

‘She was always criticising and questioning my ability to perform my duties. This made me feel like I had to prove myself worthy. It made me very anxious and I started doubting my own abilities.’

Shanna said the manager was demeaning to her and a colleague with intellectual disability.

‘She openly said to both of us that we don’t have disabilities. And then she said, she believed him. She looked at me and said, “He’s got a lot more disabilities than what I have.”’

Shanna told her boss, ‘That’s all on record.’ A week later, the manager spoke with them as though nothing had happened.

‘It was almost like she just dismissed how she made us feel the week before.’

Shanna’s colleague told her, ‘I don’t want to be in a meeting with her by myself. Can you always be there?’ He feared being ‘mistreated’.

‘An organisation like that, someone needs to step in and teach them that you’re supposed to be set up to look after people with a disability and have that empathy, understanding, not put unrealistic goals on people. It’s just not fair.’

The organisation was receiving significant government funding to boost open employment for people with disability, but Shanna said the company was exploiting her.

‘I’ve seen the budget and it makes no sense. I should’ve been getting paid more. So I don’t know where that money was going.’

The stress at work had an impact on Shanna’s health.

‘It ended up being that bad that my disability took over.’

She had a week or so off work, and when she started feeling better met with her manager online.

‘And I was trying to ask what I need to do to return to work, but she kept talking over me. There was no, “How are you going?” ... It was just, “When are you coming back to work? Because we can’t pay you for doing nothing.” I actually wasn’t expecting to get paid when I was sick. My health comes first.’

Shanna felt she had to resign.

‘I have been left feeling used and abused.’

A trauma counsellor is helping her and Shanna has found another job.

‘Because I love my work. I love working for these people and helping.’

Ryk and Tofi

Ryk is in his early 20s and lives with Asperger's syndrome, dyspraxia, trauma and other physical and neurological disability. He needs 24-hour care.

His mother, Tofi, told the Royal Commission that a few years ago Ryk was raped while at a respite facility.

“You're a retard, no-one's ever gonna believe you” – That's what the rapist said to my son.'

After being rushed to hospital, Ryk was admitted to a mental health ward. The hospital didn't do a rape test even though Tofi 'asked multiple times'.

A victims of crime investigation confirmed that Ryk had been raped, Tofi said, and Ryk gave 'the exact same account' to six different psychologists.

'He was black and blue. We have it on video, he has marks on his legs that his legs were held down. You could tell that they're fingerprints, indentations. He had cuts and scratches and things like this.'

Ryk spent a year in respite care. Tofi said the hospital 'forcefully medicated' her son and made decisions about his health that she did not consent to. Tofi had warned them of his low tolerance to drugs.

'They injected him to try to sedate him, and it had a really bad reaction. My son went into psychosis. And they just kept on pumping him full of medication, and they would not listen ... It's like parental alienation. They've just walked all over the guardianship order. And my son's the one that pays for it.'

The hospital took Tofi to a tribunal to get guardianship over her son because she 'disagreed on the way they handled the whole situation'.

Meanwhile, 'nothing's been done' about the rape. 'Where's the justice?' asked Tofi.

'No-one has said diddly squat, that this is okay for a 15-year-old disabled person being raped in the bathroom by a support worker. The whole thing was about keeping them all safe. It was never about my son.'

Tofi recently moved Ryk out of his third supported independent living house because she suspected he was being physically abused.

'He's so traumatised, his mental health was deteriorating. And now, the biggest slap in the face was that this service provider took it upon themselves to report me to [a tribunal] questioning my competency and my capacity because I dared to speak out about their unprofessional practice.'

Tofi says incompetent providers make the family scapegoats 'once they're called out on something'.

She is still trying to help Ryk through his 'trauma reaction'.

'He has everything that he needs. He's got a psychologist, he's got an OT, he's got a behavioural therapist, he's got a physio.'

Last year, she was able to get him 'off meds'.

'I'm talking about heavy duty antipsychotics. Now he's able to speak about things. He's doing pretty well, taking into consideration all the things that he's experienced. And that's why he's my hero. He was just a victim of the broken system.'

Callum, Saul and Allanah

‘We are trying to make disabled people look like able people. By being inclusive, we are ignoring what they really need.’

Allanah is in her 40s and is the mother of two boys with intellectual and physical disability. Callum, the eldest, has level 3 autism and a genetic disorder that effects his speech and mobility.

‘He could not gain access to a special school,’ Allanah told the Royal Commission, because his cognitive impairment fell short by one point.

‘To get into a special school is so hard and our education system is not supporting children who are disabled. It is killing them. Stuffing kids into mainstream school is not inclusion. That excludes my son from learning. He can’t learn in that environment. He doesn’t actually want to.’

Students physically and verbally abused Callum from preschool to year 3. Allanah felt she was sending him into the ‘lion’s den’ each day knowing he would be ‘kicked, pushed and punched’.

‘He was bullied and beaten until he tried to kill himself when he was eight years old.’

Allanah felt the mainstream schools ‘wanted to blame him for what was happening to him’.

‘They felt that he needed to change his behaviour so that other children wouldn’t bully him. But he has an intellectual disability. He was never supported. For five years, every single day until I pulled him out and we were forced to homeschool. And I am not Robinson Crusoe you know.’

Allanah works as an NDIS support coordinator and says she has witnessed many children with disability ‘in the same boat’.

‘If you have an intellectual impairment, it is not set up for us at all. That leads to our children being abused at school and they are being neglected by our schools every day.’

Meanwhile Callum’s younger brother, Saul, has been attending special schools. He has high support needs, which Allanah says the schools have neglected.

‘They weren’t changing his incontinence aids, they were not doing his tube feeds, he was coming home half naked.’

Allanah said that when she wanted to move Saul ‘from one special school to another’ to get the right care, the education department ‘outright threatened’ her. She had to sign a statutory declaration saying she would not ask for extra supports, otherwise they would not process his enrolment.

‘So at the [new] special school he wasn’t provided with a chair to be fed in, so he had to roll around on the floor. He had major medical emergencies and I wasn’t contacted.’

Saul missed out on some of his schooling because the special schools didn’t have the staff for high-needs students. Outside school hours care was non-existent, Allanah said.

‘We don’t have before-school care, we don’t have after-school care. So you are stuck. When I am sick and I can’t get up, [Saul] doesn’t get fed.’

Allanah is advocating for more funding for informal support networks around children with disability.

‘Having paid workers as the only option to support our kids is not the answer. The standard line we get is parental responsibility. We are screaming for help and are made to feel that we are just being lazy and shirking our responsibility. And that is not the case ... It is a community responsibility.’

Yareli

Yareli, in her late 50s, is profoundly deaf and uses Auslan. She moved to Australia some 20 years ago.

When her partner became physically abusive she left the relationship, taking their child and 'moving all around'. Yareli told the Royal Commission that the police were involved and tried to help, but they didn't provide Auslan interpreters, making communication difficult and 'very frustrating'. 'It was emotionally really hard,' she said.

'We had to write notes back and forwards and I wasn't able to get to – it was a lot of effort to try and write notes with the police. And nobody supported us because we had no family supports here in Australia. All of my family were back in [my home country] still.'

The difficulty of communicating was 'very frustrating'. 'It was emotionally really hard,' she said.

Yareli said there have been many times in her life people and systems have disregarded or exploited her disability.

For example when she approached Centrelink for help finding employment, they referred her for inappropriate roles, such as receptionist.

'Often they'd tell me just to call different offices. And I got no support as a Deaf person and I was incredibly frustrated.'

She started 'just door knocking' – 'going into different shops and offices asking if I could, you know, get a job. I was desperate to work.'

Eventually she found a job, but her employer made her do a lot of tasks that were not part of her role, like putting out heavy rubbish. She asked for an interpreter but her employer said the business couldn't afford it.

'It meant that a lot of the time I had no idea what was going on in that workplace and I wasn't able to access information ... I got paid very little, I was struggling, I could barely pay the bills. And I'll never forget how difficult and traumatic that time was and how I was treated in that workplace.'

Yareli receives a Disability Support Pension and recently had a letter from Centrelink telling her she owes them tens of thousands of dollars.

'I didn't understand the letter at all. I was so distressed. I didn't know what to do and I thought I better start paying this money back. So I started paying off the [debt] in tiny little bits.'

She asked Centrelink for an interpreter to help her understand what the debt was for. They told her she needed to provide one herself.

‘They had a terrible attitude, the people who worked there ... It was absolute rubbish what they put me through.’

Centrelink staff didn’t believe Yareli was deaf and kept giving her phone numbers to call. She had to go to an audiologist to ‘get a piece of paper’ confirming she was deaf.

‘It took getting that – paying out of my own pocket for that bit of paper – for her to believe me. It was incredibly stressful.’

Yareli still doesn’t know why she owes the money. But she is looking for work though a support agency so she can continue to pay the debt off.

‘I’m doing my best. But I feel like my brain, as I’ve got older, I’m losing capacity. And, you know, I’m getting very depressed ... I feel like sometimes the barriers I face just completely discombobulate my mind, I’m not able to think clearly.’

Yareli said she wishes people who can hear would learn a little about the Deaf community and sign language.

‘And don’t assume that I am just like them except for my ears. I belong to a different culture, and I would like them to understand that deafness is a part of who I am, so it changes the way I behave. So it’s not just about my ears, but it’s about who I am, and if they could understand that, that would help me a lot.’

Beeba

Beeba is in her early 70s. She has struggled with different issues over the years and found it a relief when she was finally diagnosed with Asperger's syndrome and attention deficit hyperactivity disorder (ADHD) much later in life.

'I really feel that I was lucky, even though it didn't happen until I was 60 ... I'm a bit like Pollyanna where I'm trying to turn a bad thing into a good thing.'

Beeba had worked as a journalist and described Asperger's syndrome as the 'perfect skill set' for someone in that occupation.

'You have to be a loner, you have to be objective ... you have to be interested in facts.'

But she did experience personal difficulties, such as an inability to make friends and form lasting relationships. Now she mostly avoids socialising with others.

'I find just going to random places where I've got no control over the people. Like, even a book club, that is a potential hazard for me because people are going to judge me ... because I'm not like them. You know, I'm not married, I don't have children and I'm not planning overseas trips.'

Beeba's dog was her closest companion for many years.

'He just died and I realised how much I put all my emotional needs and my social needs onto him ... Now I've lost him, I realise I have to be more proactive, but try and make more contact, but do it more selectively.'

She has connected with other people with autism and ADHD through Facebook, one group in particular.

'It's about adults who make the most of the enthusiasms, our quirkiness, how we view the world differently, how to make the most of it. And I think that's – that is definitely the way to go.'

While positive about her diagnosis, she still feels distressed about the shame and rejection 'dumped' on her over the years.

'And that's really almost – well, it is – it's worse than the actual disability. Because the disability, once you know about it, you can learn how to manage it.'

Beeba is considering moving interstate to access more support.

'You try and get help for people my age with autism – I don't think that's ever going to happen. Too hard. They're putting all the resources into the children. Fair enough,' she said.

Liddy

Liddy, early 40s, has multiple sclerosis (MS) and lives with depression. She told the Royal Commission that MS affects her ability to think clearly and her brain sometimes ‘switches off completely’.

‘If you imagine you’ve had quite a lot to drink ... You wake up in the morning and you’ve gone, “Geez, I don’t remember that conversation. I don’t remember that.”’

Liddy said her ex-husband used her MS as an excuse to control her.

He wouldn’t share his bank account and tightly controlled their credit card.

‘I wasn’t able to access money to buy things.’

He also isolated her from her family and friends, telling her they didn’t care about her.

Following the birth of one of her children, Liddy experienced postnatal depression.

One day she was at an appointment with the maternal health nurse.

‘We talk about our experiences, they ask how we are, and that’s really when someone first pointed out to me, “I think you’re going through domestic violence.”’

A short time later. Liddy’s ex-husband came home drunk, became violent and started to strangle her.

The children were ‘screaming and crying’.

Liddy rang police.

Seeing the marks around her throat, police suggested they ring an ambulance. Liddy declined because she didn’t want to leave her children.

In hindsight, she wishes she’d accepted the offer – there would have been a medical record of her injuries.

Police took her husband away and took out an apprehended violence order, but didn’t charge him.

Liddy decided to divorce her husband. She didn’t have the money to hire a lawyer and represented herself.

‘He could afford two lawyers and a barrister, and then there was just me. Sometimes I was standing at the front, brain switches off completely, because it’s quite a frightening place.’

Liddy believes the court didn't consider her disability or the family violence. She was advised not to mention she had MS.

'If I did mention the MS, it could go against me. It was too risky with the judge. It was too risky.'

Liddy had heard stories of women with disability who had lost custody of their children and was terrified.

'Those stories still sit in my brain.'

Liddy wishes she ignored the advice because her ex-husband ended up using her disability against her.

His legal team told the judge they had 'concerns about her looking after her children' because of her 'severe mental health issues'.

The barrister framed her regular MS treatments as electric shock therapy.

'I just sat there. You can't stand up and go, "I object." It's really hard when you're representing yourself ... You want to say, "That's a lie." You can't say anything.'

Liddy felt she didn't have the opportunity to explain everything properly.

'I did not have a voice. I had no voice.'

When negotiating the financial settlement, Liddy was still traumatised and said she didn't care about the money. She believes the settlement was very unfair. She now realises the system didn't support her.

Liddy has recently started studying and gets 'extra supports' because she has MS.

'I get direct one-on-one chats with the lecturer. That is going to help me excel and pass this course. So why can't the court system be the same?'

Jeanette, Ann and Raimondo

Jeanette is in her early 40s. She has an intellectual disability and is non-verbal, but 'understands everything you say to her', her mother Ann told the Royal Commission.

For a decade Jeanette has lived in a government-run supported independent living home and has 24-hour care. A few years ago a new resident moved in. She was regularly aggressive with others.

'One of the ladies there, her glasses were smashed out. A carer got hit, had a black eye,' Ann said.

Ann and her husband, Raimondo, felt 'that this lady was in the wrong place with the wrong people'. House staff acknowledged 'it was a poor placement decision' to put the woman 'in a home with other fragile and vulnerable residents'.

Once, the woman hit Jeanette across the head in front of staff. Ann spoke with a manager about it. His response – 'Oh, it's got nothing to do with me.'

'Our daughter's being hit. Our daughter's being belted. They let it happen,' Ann said.

Not only did management let it happen, they made Ann and Raimondo feel guilty for wanting the woman out.

'We keep getting it thrown down our throat that, you know, the particular person in question has got rights ... that we're attacking this person.'

Ann and Raimondo were told about other incidents, but they often felt they weren't getting 'the full story'.

'I think we get a sanitised version. They tell us what they want to tell us.'

Most incidents occurred when 'casually employed people' were in the house, said Raimondo.

'They're not skilled, not interested in being there.'

When the woman hit out at Jeanette again, her parents tried other legal avenues. Police, lawyers and disability commissioners all said 'there wasn't much they could do'.

A couple of years ago the home was privatised. But the disability provider 'knew nothing about the safety issues'.

'We've jumped from the frying pan into the fire,' said Ann.

The provider suggested Jeanette move out – ‘despite her being the victim of violence and having housemates in this house she had grown up with and were equivalent to her siblings.’

Since then the woman has been into Jeanette’s room and destroyed property, and has again assaulted Jeanette.

‘It’s been traumatic for her,’ Anne said. Jeanette is showing signs of anxiety.

The manager refuses to sit down and talk. Raimondo wants to ask him, ‘Why have you allowed this to happen?’

The provider has never responded to ‘very detailed letters’ outlining their distress over Jeanette’s situation. Yet under the Disability Act, it is required to ensure ‘a resident’s right to privacy and enjoyment of their home’, said Ann.

Ann and Raimondo made a complaint to the NDIA and there’s finally ‘light at the end of the tunnel’.

‘They’re looking for a place for this other woman,’ Raimondo said, ‘coz we’ve been fighting this pretty hard.’

Marcelo and Uwe

‘The providers just brush, brush, brush abuse to the side.’

Uwe is a community care worker in his 40s who lives with bipolar disorder.

‘I deal with people with mental health issues plus the elderly and the disabled,’ he told the Royal Commission. ‘The main thing is you help people with their independence. The old-school providers, they don’t do that ... They act like they rule your life, don’t treat you like a human.’

Uwe described the things he’d seen in his seven years in the industry as ‘absolutely disgraceful’. Until recently, he was working with a provider offering in-home supports for people with ‘very high needs’.

One client, Marcelo, has cerebral palsy. He is a wheelchair user and lives in a housing estate.

‘He should have been put in a home,’ Uwe said. ‘He was falling all over the place. Yeah, ambos there all the time.’

Marcelo has a problem with his bowels.

‘So you walk in there first thing in the morning and he would just be in his own diarrhoea. In his own mess.’

Other support staff were ‘very cruel and spiteful’ to him. One woman was in charge of buying Marcelo’s food and cooking for him.

‘She basically had food in there that even the dog wouldn’t eat ... Wouldn’t take [him] out shopping. And she was doing really spiteful stuff in the house so he can’t get to his food.’

Another employee was supposed to help with housework.

‘She comes in, says “I don’t clean,” and locked herself in the bathroom for an hour and a half. So, yeah, dangerous.’

The family and other staff complained about the abuse, but the agency did nothing.

‘It is just a poisonous environment. And everyone winds up poisoned. The staff end up poisoned, clients end up poisoned.’

Marcelo eventually got accepted into a group home.

‘Which everyone just said it would be better for him. If he has an accident, he goes to the shower straight away ... People can help him out when they can.’

But Marcelo's sister and mother who were managing his finances decided against it. Uwe couldn't understand why. It was a 'brand-new home' adapted to Marcelo's disability.

Uwe said he 'pretty much took over' Marcelo's affairs from there.

'The bills weren't getting paid ... I always thought he was broke ... He had no clothes ... But then I started seeing discrepancies on the statements.'

Uwe discovered Marcelo's family were 'misappropriating funds'.

'Once again, you report, they don't do anything.'

Things got so bad, he had Marcelo 'on suicide watch'. Marcelo was asking to see a doctor about euthanasia.

Uwe alerted the office.

'No-one cared. The office didn't care. Absolutely no-one.'

Uwe went to 'absolute war' with the NDIA and the ombudsman to help change Marcelo's circumstances. 'He is good now,' Uwe said.

Uwe is 'a lot more optimistic' about his current employer.

'I have seen people getting treated nicely. They don't put you in a box to tell you what to do and tell them what to do,' he said.

'What I saw before was that bad, I just thought every care provider was just the same. I'm allowed to just do my job. Just help people out, give them a bit of a giggle and if they need a hand. Caring for people isn't hard.'

Boyd and Dorothea

Boyd, a First Nations child, is autistic and has attention deficit hyperactivity disorder (ADHD). He recently started primary school.

‘[Boyd’s] incredibly intelligent,’ his foster mum Dorothea told the Royal Commission. ‘He’s very good with mathematics. He is a very good reader ... He’s a great runner. He’ll tell you he’s the fastest runner in the world and he’s aiming to be faster than Cathy Freeman.’

Boyd’s been living with Dorothea since he was a few months old.

‘There was a lot of planning that went into choosing and selecting the most appropriate schooling for [Boyd]. However, when we started school we ran into issues immediately.’

Dorothea said the school ignored Boyd’s behaviour and learning support plans.

‘We were constantly called to pick him up at either recess or lunchtime. In that time we were having behaviours where he would abscond from school. They weren’t focusing on, I guess, strategies that we were trying to implement.’

Instead the school developed its own plans.

‘They were trying to implement a behaviour support plan that worked for the vice principal rather than one that worked for the child ... They were saying ... that he could control the behaviours of concern if he would just listen.’

Dorothea said the school ‘worked quite tirelessly’ to exclude Boyd’s support team, including child protection. When Boyd’s behaviour deteriorated, one staff member wanted to change Boyd’s medication ‘to fit in with schooling’.

When Dorothea suggested a sensory space for Boyd, the school put him in a locked room with toys. One day she arrived at school to find him sweeping concrete while the other kids were playing sport.

‘He was completely unaware that the children were participating in sports activities, and he’s a kid that loves sports activities.’

Dorothea said the school often sent him to the library alone to play computer games because it ‘didn’t want him to interact with other children’. When the other children went to the library to borrow books, his teacher assumed Boyd wouldn’t be interested and didn’t include him. Dorothea insisted he be included.

'He came home absolutely ecstatic going, "I went to the library and they actually have library books." And he didn't realise ... that you could actually borrow books from the library. He was just thinking that he went to library for Minecraft.'

One day Boyd told her he shouldn't be playing with other kids because he was naughty.

'You shouldn't love me because I'm the naughtiest kid in the school,' he told Dorothea.

'And I'm like, "No. Where are you hearing that? That's not true and we love you very much.'"

Eventually, Dorothea persuaded the school to include Boyd's support team in its behaviour and learning plans.

'We've actually done quite an amazing job to get him to where he is at the moment. He's not absconding from school anymore at all ... He's building meaningful relationships with both his aides and children.'

But Dorothea said the school still treats First Nations foster children with disability differently to other children with disability.

'We have seen other kids in that school with disabilities who have been handed everything. You know there's been amazing things done with a deaf child who has severe disabilities ... but then I've seen another [First Nations] child [with disability] who has been told he can't use the disability toilet.'

Dorothea said there are still teachers who believe autistic and ADHD kids are 'just naughty'.

'The attitude ... [is] really hard to shift without ongoing, formal education and training. It can't just be a once-off. It needs to be ongoing, especially for I think the older generation.'



Artwork by Alice Fullerten



Artwork by Alice Fullerten

Gregg and Antoinette

Gregg is a First Nations primary school student who has an intellectual disability and global developmental delay. Antoinette is his foster mum.

‘I’m trying to facilitate a lot of his world so he can be independent,’ Antoinette told the Royal Commission. ‘He makes you smile so he’s a good kid.’

Antoinette is a disability support worker who decided to foster Gregg several years ago when she learnt his carer was dying.

‘You form a relationship with the person you look after or the client that employs you.’

A few years ago, despite the recommendations of Gregg’s support team, the NDIA cut his funding.

‘I would break down and cry because I’m a single mum on my own so I didn’t have any support from my parents. And I understand it’s not about my support or anything like that, but then you know I could see my son missing out on things.’

Antoinette said she has had to take over the work of his physiotherapist so Gregg ‘doesn’t go backwards’.

‘Then we’ve got OT [occupational therapist] where we’re looking at his fine motor skills. So you know we’re trying to relay this to the NDIS ... we had to like call them up and go, “Hey look what’s happening? What ... evidence do you need in order for you to understand what’s happening with [Gregg]?”’

She said the NDIA ignored Gregg’s support team.

‘I’m coordinating with people so I am understanding what’s happening. I’m a professional ... I’m going over the [NDIS] website trying to understand ... and we’re trying to get the point, “What do you want?” Not in a bad way, just more like, “What’s the evidence that you require?”’

One day Antoinette called to question a 50 per cent cut in his funding for support workers. An NDIS representative told her, ‘We’re not here for you.’

‘Even though I was still very emotional I learnt not to talk. And when they did ask me a question, I kept it minimal. Because I was trying to relate to them how it’s unfair that he gets to miss out on things.’

Gregg has trouble walking. When Antoinette applied for a device to support his leg, no-one could tell Antoinette how long approval would take.

'I just said to them, "Look I'm not understanding your process here ... I'm calling you every week. My coordinator is calling you. What can I do? What's the next step? If you're telling me there's a waiting period, great, I can work with that. But you're telling me it has escalated and to call back next week. I've been doing this a couple of months.'"

Several months later, someone called to say the funding was approved.

'I didn't want to rock any boat. I didn't want to say how frustrating the process was. I was just like, "Yep that's okay.'"

Antoinette said Gregg would also benefit from more contact with his First Nations community, but the NDIS has been 'silent on that'.

'They don't understand complexity.'

Antoinette said that after 'fighting' with the NDIA for several years, Gregg now has an appropriate funding plan. She worries about people with disability who self-manage their NDIS plans.

'I did work with a client that had suffered a head injury ... I said to him, "Mate you can't remember things and even for me it's a lot, the budgeting aspect of it,'" Antoinette told the Royal Commission. 'I have a caseworker and a coordinator and they're all fighting for my son, you know, and then the people that I work with don't have that.'

Braylen and Rhonda

Braylen had a stroke in his early 60s. He is now paralysed on one side and uses a wheelchair.

The wheelchair was almost impossible to manoeuvre in the home where he and his wife, Rhonda, lived at the time. The house is in the country, and the couple loved it.

'We bought the house thinking that we were going to – with a view to retire and that we were going to basically die there. And it was our forever home. It was peaceful and quiet, and we don't have that anymore,' Rhonda told the Royal Commission.

Several years after Braylen's stroke, the couple sold the home because if they stayed they wouldn't be able to meet the costs of Braylen's care.

'Well, it got to the point where I either had to stay at the house and we would lose everything, or sell it so that we wouldn't lose everything,' Rhonda said.

Rhonda explained that their difficulties are due to reductions in Braylen's NDIS support. This includes the decision to stop funding taxis to take Braylen into town, despite there being no other option.

'You know, you just get a letter – and you go, "What the –?" you know. And there's no explanation,' she said.

'And when you do ask for an explanation, they just run you around. You know, you don't get somebody saying, "Well, [Rhonda], this is why," you know. They won't physically ring you ... There's no compassion there whatsoever to actually, sort of, explain to help you understand.'

When Braylen first came home from hospital, the NDIS helped meet the cost of equipment such as his wheelchair and a hospital bed, and contributed to the cost of modifying the kitchen. But the NDIS did not agree to help meet other necessary expenses, such as modifying the bathroom.

'They kept saying, "No, we can't do this," and "No we can't do that part of it," and "No, that's your responsibility." And that went on for about seven or eight months,' said Rhonda. 'So I funded the things.'

A review of Braylen's support package resulted in a cut to funding for physiotherapy sessions.

'Since that's happened, [Braylen] basically can't walk on his stroke walker anymore because he hasn't got that support and that, you know, exercise regime.'

Braylen's health has deteriorated since the move. The NDIA also reduced his funding for mental health care, further impacting his wellbeing.

Rhonda said getting information about why these and other decisions are made is like 'pulling teeth'.

'My feelings are that they really don't care about the people who they're providing the packages for. And they're not willing to actually listen to anybody. And when you go to them and say, "No, you've got it all wrong," or "You're not listening," or anything like that, it's all above their head, and they just don't want to listen.'

Sheryl and Walt

Walt's wife, Sheryl, had complex post-traumatic stress disorder, borderline personality disorder, depression and anxiety.

'She had a really bad childhood. Her parents separated and [Sheryl] was ... sexually abused a couple of times as well,' Walt told the Royal Commission.

A psychiatrist diagnosed Sheryl several years ago and prescribed medication.

'[Sheryl] had some relapses ... I think of numerous times I called triple-0, and the police or the ambulance were always coming and taking her to the hospital, never to the police station. They were treating her like a mentally ill person, giving her the help that she needed.'

A couple of years ago Sheryl took too much medication and collapsed.

'The ambulance came, they took her, but for some reason they just let her walk out. Without even informing me. She was the kind of person that she didn't like going to hospitals so she checked herself out and they just let her walk out.'

Walt said Sheryl became aggressive after that and one day threatened him.

'I thought I did the right thing, what my psychiatrist always advised me, "Always call triple-0. Never try and force the issue ... Let the police do these kind of things." So I did that.'

The police found Sheryl on the road and told Walt they'd called an ambulance to have her assessed and taken to hospital.

'About 20 minutes later, [the police officer] comes back and told me that the ambulance came, assessed [Sheryl] and they decided not to take her [to the hospital].'

Instead, the police took her to the police station. Walt said he later learnt that when the ambulance arrived the police told the paramedics they weren't needed.

'She was interviewed [at the police station] alone – which I found out later that they shouldn't have – because she should have had an appropriate adult with her and support or taken to be assessed by a doctor before being interviewed.'

Sheryl told police she had a mental health condition, but the police kept questioning her. It was after midnight when they released her. They warned her not to go home or contact Walt.

'She was homeless and that would have triggered [childhood] memories ... That would have made it even worse.'

Later, Sheryl had to appear in court and a police lawyer asked Walt what outcome he wanted.

'I told him the outcome I was looking for from the beginning. I want my wife to be taken to the hospital to be seen by a doctor there and let the doctor decide if she's right to come out or not. She needs help.'

Sheryl was granted bail on condition she take her medication, see a counsellor and not harm Walt.

Walt took Sheryl home, but she refused to go to hospital and he struggled to help her. One day, she took too much medication again and collapsed.

'I saw her on the bathroom, on the floor, blue lips, no breathing.'

Walt called an ambulance, but paramedics couldn't resuscitate her.

'All this would have been prevented. All they had to do is take [Sheryl] to the hospital or if they couldn't do it, call the [crisis assessment] team. They would have come and assessed her and they would have taken her [to hospital] ... They didn't do that. None of my wife's doctors have been contacted by police.'

Paddy

Paddy was badly injured in an accident in his late teens and became paraplegic. Nearly two years later he experiences episodes of breakthrough neuropathic pain, sometimes in clusters, about every two weeks.

‘This is one of the awful side effects of paraplegia and a common experience for many people with paraplegia or quadriplegia,’ Paddy’s support person Angela explained.

Paddy told the Royal Commission that during hospitalisation after the accident, the nursing staff bullied him. He now has post-traumatic stress disorder (PTSD) associated with hospital visits. When he goes to hospital to manage neuropathic pain, Angela goes with him to help mediate his interactions with medical staff and manage his PTSD.

During a COVID-19 lockdown, Paddy had a pain episode and went to hospital in an ambulance. When Angela got to the emergency department (ED) soon after, staff would not allow her to see him.

‘I had explained to the paramedics and to the doctors within the hospital ED that [Paddy] needed to have a support person. He’s got specific trauma related to hospital presentation ... And they refused entry to me. They said there’s no way that you can be admitted to go to [Paddy’s] bedside,’” Angela recalled.

‘The supervising nurse even said to me, “The only situation is if a person is dying. And he’s not dying, is he?” So, yeah, a fairly average tone.’

Paddy had been put in a room on the ED ward. Staff put his wheelchair outside the door. After several hours he rang the call bell and waited for 45 minutes, but no-one came.

‘And, I’ve been, you know, sort of yelling – not yelling, but, like, saying, “Hey, like, see if anyone could come into the room?” ... I was in a lot of pain. So I started getting quite angry,’ he said.

‘The nurses were yelling back at me. They weren’t providing any calming process or anything. They were slamming the door and restricting my wheelchair from me.’

Eventually, staff placed Paddy’s wheelchair within reach. ‘And he wheeled himself out of Emergency, still in 10 out of 10 pain,’ said Angela.

After this, Paddy submitted a complaint to the hospital. It did not respond. The state’s health oversight board is now following the matter up.

‘It’s not like I went in there, you know, getting angry and yelling. I was – I understand it. Emergency departments especially at that time they’re very, you know, busy and hectic places. But, it was – it reached a whole new point, three hours with no pain relief, 45 minutes with the call bell being on, my wheelchair being held from me. Like, you know, that’s when it’s not cool for me. I couldn’t put up with that,’ said Paddy.

Since this experience, Paddy has started having anxiety attacks. He no longer attends that hospital and is consulting a private specialist about a pain management plan. He wants to see improved training for nursing staff so they better understand people in his situation.

'I'm just dumbfounded that they would have so little idea of disability and what I'm going through, in terms of pain and stuff. I think there should be much more attention going into that ... I get that disability and chronic pain is a tricky thing to deal with in ED. But, I think there needs to be – as a nurse, you should be able to deal with something like that,' he said.

'I think they just think, you know, "I'm a nurse. And it's just a 19-year-old kid" ... but somehow I know more about this stuff than public nurses do, which is not how it should be at all.'

Kristine

Kristine, mid-60s, is short-statured, has vision and hearing impairment and uses a cane. She also has a number of medical issues.

Kristine has been an NDIS participant for about six years.

‘My experience in the six years is there’s constant changes that I have no power over or no input,’ she told the Royal Commission. ‘I just sort of feel very much done to, and very much in a place of having to ... fight constantly, if I’m going to achieve anything. And that’s really exhausting.’

A few years ago Kristine requested home modifications. She had to wait a really long time for the occupational therapist (OT) to do an assessment, and then more time for her to do the report. Kristine had to follow up with the OT several times to make it happen.

Kristine submitted the report to the NDIA and didn’t hear a thing.

‘There were no updates, no feedback, absolutely nothing.’

She contacted the NDIA several times and, while staff were ‘helpful in general’, they were not able to give her any information about her application.

Eighteen months later the NDIA phoned her and told her ‘the home modifications have been knocked back’. The staff member was very unhelpful and didn’t seem to know why.

‘That was a really, really stressful and really difficult time where I was just not told anything.’

Kristine contacted another NDIA staff member, who couldn’t tell her a reason or summarise the decision.

‘I had this email saying, “I can send you a 360-page document” – and I really struggle with my vision and with lots of words on a page.’

Kristine’s support coordinator and OT discovered the NDIA had issues with the kitchen and bathroom modifications.

Kristine put in another application. This time the NDIA approved the bathroom and ramp but not the modifications to the kitchen.

Kristine couldn’t understand the decision.

She said she’s four feet high and can’t use the benches, oven, top storage, dishwasher or microwave.

'It was just the cheapest revamp of the kitchen that was possible and lowering all the lower part, and a redesign, putting a lower bench where I can sit down and work, particularly cutting vegetables, because I get really dizzy standing up.'

Kristine ended up paying for the kitchen herself.

'It just showed a complete lack of my needs and ... a complete disrespect to all the hours that the OT had put into this, with measurements, photographs of me and a 40-page report.'

Kristine said she receives insufficient support coordinator funding, and the constant turnover of support coordinators makes things more difficult.

One support coordinator overspent Kristine's core funding and refused to pay the OT, her doctors and other services. One service provider cancelled her supports. She was without hearing aids for several months while she tried to sort it out.

'I then had to fight for another six months to try to get information to try to get those people paid. And, of course, that's not my job.'

Kristine unsuccessfully tried to get the local area coordinator to help.

'She just said, "I can only have contact with you during your planning meeting. End of story."'

Kristine said dealing with the NDIA is difficult because 'it's quite complex'.

Perry

‘Last year we had the deaf awareness workshop at my workplace. Someone came and went through the process, but the issues continued. It didn’t solve anything.’

Perry, late 50s, is Deaf and uses Auslan.

He’s worked in different teams in a government department for the last 20 years.

Perry told the Royal Commission no-one takes the time or effort to communicate with him respectfully.

Occasionally, the department provides interpreters.

‘They accepted it [my request for interpreting] because I was nagging them, not because they wanted to provide me access.’

Co-workers often make rude gestures and yell at him. They make fun of his signing and say or try to sign, ‘How do you sign deaf and dumb?’

One time, a co-worker thought it would be funny to leave Perry stranded up in a mechanical lift.

Another time, a co-worker made a hand-gun gesture at his head.

‘That was such an awful experience. I did not want to go back to work ... Once I returned to work, I felt all eyes were on me.’

There was an investigation but the co-worker said he was gesturing that it was time for lunch. Everyone made fun of Perry for complaining.

Perry’s workplace has never celebrated his birthday or given him a birthday card despite doing it for others.

No-one bothers to invite him to social events.

‘I saw food laid out, and there was no email, no tap on the shoulder, no-one letting me know. All I noticed was there was a whole stack of people who were gathered around having something nice, but I had no idea what was going on ... But a few weeks later the [boss] said, “We invited you, you were rude for not coming.” And I’m like, “But no-one actually told me that I was invited.”’

Perry started to keep a diary of these incidents.

Recently, a supervisor asked him to put some boxes away. Perry put the boxes where he usually puts them but the supervisor started yelling at him.

'Yelling and swearing at me, right up in my face, but I have no idea of course what's going on.'

Perry started to make a note in his diary. The supervisor 'absolutely lost it', telling him he was stupid.

'I was scared. I was shaking ... I just left. But it was scary. And because this has happened so many times in the past, I'd just had enough. I went off to my doctor and let them know what had happened ... This is happening for like 20 years, this same situation, over and over and over again.'

Perry spoke to HR and his union. He received a belated apology but doesn't think things will change.

Perry has tried to find another job.

'I just don't know how to work out finding another job ... I'm putting through all these applications to find a job and of course I'm not getting it because I'm Deaf. Well, I think it's because I'm Deaf. It's hard to tell, right?'

Ollie

Ollie, a First Nations man in his early 40s, is autistic.

A couple of years ago he was living in supported independent living (SIL) accommodation operated by an independent provider.

Ollie lived with people with physical and cognitive disability, people with complex psychosocial disability and people with substance abuse issues.

'You're living around people who have massive problems with drugs. And they're not getting any help that they need. But they're housed in with people who are just really, really quiet and just trying to live life. And you spend most of your mental energy trying to live around that instead of trying to develop yourself and then be a part of the community and integrate yourself.'

Ollie told the Royal Commission the accommodation was in disrepair and there were rats and rat faeces near the food.

At one stage Ollie slept in a garage and had no choice but to sleep on the floor.

Ollie said the provider took 85 per cent of his disability pension. They also made him do manual maintenance work, building tasks and lawn mowing in exchange for a reduction in his rent.

After a while Ollie realised the arrangement wasn't fair.

'I used to be able to be manipulated very, very easily. Or at least, I'd just be very quiet about it ... It's not employment because I was a resident. I was a client, so it's exploitation.'

Ollie told the provider he didn't want to do the work anymore and they threatened him with eviction.

The provider's lawyers said they would 'bury' him in legal costs if he ever told anyone what was happening.

Ollie reported the provider to the police, but they didn't believe him.

He also made a report to the NDIA, who told him that the conduct was in the past and the provider had changed their practices.

Ollie made a complaint to the Australian Human Rights Commission but said they passed his complaint back to the provider.

Ollie is frustrated no-one has taken any action and feels as though he has not been listened to.

Benedict

‘This is not a place for anyone with any type of mental health problem. They just treat us like we’re not even humans.’

Benedict is a First Nations man in his early 20s, currently in prison.

Benedict has mental health problems but prefers to keep quiet about them.

‘It makes you feel vulnerable ... I’m not really open to people much, I just kind of hide it.’

He thinks this is why he ended up in prison without getting the chance to speak with a lawyer.

‘I think it was my disability. I didn’t talk to no-one. I didn’t talk with my family and I was always by myself.’

Racism has made it worse.

‘I feel like racism is a part of my life ... When you see the way they treat you, it just kind of puts me off. If you have a disability and you’re in jail ... some people put you down.’

The lack of support makes him more depressed and anxious.

‘With my mental health, I do get stress. And I try not to show it ... That’s why I should have talked to somebody ... Just speak to someone. Bit of help.’

Prison conditions exacerbate psychosocial disabilities for inmates. Benedict said prison officers treat them like ‘a piece of dirt ... like shit’.

‘They swear at us, we can’t swear at ’em. They give us food that – it’s leftovers ... We all grew up in a hard life ... I’ve seen things happen on the outside, I’ve seen things happen on the inside. Some people don’t understand, like, what’s happening in here.’

Benedict has friends with disability who also get a tough time.

‘Just yesterday, one of me good mates went to the DU, which is the detention unit. Just because the officer swore, and he swore back. And so they took him ... Well, he has disability, meaning he couldn’t control it.’

Benedict wants the system to ‘deal with disability’.

'Not just for myself... for everyone. We do need more support ... especially in this place. There was one bloke, he couldn't actually speak or walk. He was in a wheelchair for a while. They just left him in here and didn't care about him. Officers didn't actually give a fuck about it. It was just sad to see him, like they don't have a place for people with disability ... I felt stressed. I felt anger. I wanted to tell the officers he's in a very bad way. Put him in a place where he'd be cared for. Not this place. Pretty weird.'

Benedict spends his spare time writing songs for church and playing the guitar. He would like to see a group therapy session set up in prison.

'I reckon it would help us all, sort out problems ... Everybody in here, we all want to go home. Some of the men in here are really stressed ... I just want them to share for themselves.'

He likes to help other inmates when he can.

'Well if you could see the men's faces in here. I'm trying to keep 'em happy. In a place like this, it's really hard to cope. I see people ... they've lost a lot. I've been here for seven years and I lost a lot of people that I really care about. But I didn't share no emotion, because what can you do? That's life. You just need someone to talk to.'

Brycen and Caiden

Brycen is in his 30s and has an acquired brain injury (ABI) after a haemorrhage at work several years ago.

'He had several hours of brain surgery and he was in a coma,' his father Caiden told the Royal Commission. 'The prognosis was not good. The surgeon was preparing us for ending life support. [Brycen] must have heard that because the next day he woke up.'

Doctors transferred Brycen to a hospital rehabilitation unit, which failed to provide any cognitive therapy.

'They had all of the clinical data, but they didn't have any of the ... input from allied health ... He was [also] refused permission or access or support for using the toilet and instead was forced to use the bed pan.'

Brycen had been in the unit for more than a year when the hospital 'started making noises' about him moving out.

'We said, "No he's not being discharged. He's got a lot of work to do yet." ... [but] they were absolutely focused on discharging him.'

The NDIS was being rolled out at the time and the hospital, unable to find a service provider willing to take Brycen, tried to put him into residential aged care. Caiden fought the move because it would be 'extremely detrimental to his wellbeing and recovery'. The hospital applied to have a public guardian appointed.

'A guardian would be more cooperative with them on putting [Brycen] into residential aged care ... And it wasn't until we backed down and said we would consider the aged care options before they withdrew the [guardianship] application.'

Caiden said that while the hospital looked for nursing homes that would take him, it neglected Brycen.

'Once he was out of bed into his wheelchair he could move around, but he couldn't even get support to get out of bed at times because as far as [the] hospital was concerned he was just taking up space.'

Brycen met a young woman in hospital who also had an ABI and they 'developed feelings for each other'.

'They asked the nursing staff if it would be okay for them to have some privacy in [Brycen's] room so that they could extend their relationship, and immediately there was pandemonium.'

Caiden said the hospital moved Brycen into a ward with locked doors and security guards 'as a means of protecting her from sexual assault' by Brycen.

'[Brycen] was still so disabled that the only way that the two of them could have had intercourse was for him to lie flat on his back and for her to do all of the work,' Caiden told the Royal Commission.

'It's just so ridiculous as to be absolutely astonishing ... It was an absolute, blatant breach of human rights for both of them. And they justified it on specious legal grounds.'

Brycen eventually moved into a group home with the help of the NDIS.

'The hospital system needs to change to address the person and the outcomes for the person. [It] needs case management across the entire journey that focuses on the person. Not the facility. Not the funding.'

Pico and Larissa

Pico, from a culturally and linguistically diverse background, is in his early 40s and lost both his legs in a car accident a few years ago. He also has an acquired brain injury.

'I have not accept my son's situation yet,' his mother Larissa told the Royal Commission. 'My son was a beautiful tall man. And now to see him is really, really hard.'

Medical staff at the hospital where Pico underwent rehabilitation were abusive to him, Larissa said. Once a nurse was 'practically on top of him' when she walked in.

'When [Pico] saw me and my husband, he said, "Ma, she is slapping me." She had been slapping my son because he didn't want her to put his top on. But anyway, she denied that, but I saw the hand mark on my son.'

At a meeting with hospital staff, a neuropsychiatrist told her it was all in Pico's imagination and put him on tablets 'to calm him down'. The medication made Pico 'agitated and aggressive'.

'It was a very strong medication, which was not really doing what it's supposed to do. It was no good for him.'

A couple of years later, a doctor suggested a course of hemp oil 'to wean him off his drugs'. When Larissa informed the service provider, it tried to remove her as guardian for giving her son 'marijuana oil'.

A report to the tribunal relied on an account from Pico's neuropsychiatrist who 'repeated every single word' of his private conversations with Larissa.

'Not only wrong, it was humiliating. There were so many little things, you know, that made me look like I am a bad person, a bad mother, a person that cannot be a guardian to my son. It's been a nightmare ...'

A state government agency was providing for all Pico's care. After the proceedings, it left Pico without support workers for six months, said Larissa.

'I had to fight ... They say to me that they still were paying for the carers, so I don't know where that money went.'

Larissa met with the provider to ask them.

'This person stand up and physically pushed me out of the office. "Out. Out." I went to the ombudsman. I made a complaint ... but I never had any satisfaction whatsoever.'

Larissa's husband was very ill and she wanted to temporarily place Pico in a home. The provider put him in a hotel with two carers who 'were really unprofessional'.

‘They told me they have plenty experience for autism. A brain injury is not a person with autism.’

The agency moved Pico between seven different hotels.

Pico moved home recently and the agency is still not providing rehabilitation and other supports.

Larissa is building Pico adaptable housing in her backyard. She’s hoping to get him full NDIS support, but for now it just ‘fill gaps’.

Hedley and Kell

‘[If he had] the three years of speech therapy that he missed, I believe he would’ve been able to break that communication barrier. His life would be so much easier for him.’

Kell is the father of Hedley, who’s autistic and in a special education unit at primary school.

‘He’s a quick learner. He’s very smart, he really is,’ Kell told the Royal Commission. ‘[But] he couldn’t do the things that he needed for mainstream school like self-care and things like that.’

Hedley was diagnosed when he was a toddler and quickly received funding for early intervention therapies.

‘That was a weekly session of occupational therapy, and also speech therapy as well because he was having speech delay ... And my ex-partner and I, we went to a meeting with a service provider and we told them what [Hedley’s] needs were and they said, “That’s fine.” And they agreed. And they were to put that in place.’

When Kell and his partner separated, she took out an order against him. Kell had to rely on her to take Hedley to his appointments.

‘I would ask her regularly, like, “What’s going on?” and stuff. And she was unable to explain a lot to me ... she was saying, “Oh, he’s had the session” [but] ... she never took him.’

Kell said he discovered only a few years ago that for some time Hedley received little speech therapy and much of his NDIS funding was left unspent.

‘He needs physiotherapy because he’s fitted with ... ankle and foot orthopaedics, I think they call them, for his toe walking. And he’s required to have fortnightly visits to a physio so that he can do stretches for his ligaments ... She hadn’t taken him to that either.’

Kell said Hedley’s service provider failed to follow-up on his missed appointments and didn’t contact Kell to let him know what was happening.

‘The order doesn’t actually prevent me from going to the therapy ... but the organisation had excluded me after my ex-partner rang them and told them about the order.’

Kell said the service provider also knew Hedley’s updated NDIS plan from the previous year had not been approved because Kell’s former partner hadn’t provided the documents.

‘I’m really disappointed in them. Yeah. They knew [Hedley’s] needs. And I’m an equal representative for the participant in the NDIS. When [Hedley’s] not been taken to [the] therapy that we asked for, yeah, I assume that if they couldn’t contact the mother, I thought they would contact me. And they hadn’t.’

Kell said Hedley needed early intervention therapies years ago to help him at school and to reach his potential.

‘With the right therapy at the right age I was hoping that by even by grade 1 that he may be able to go to mainstream school. That’s always been the goal ... He has a communication barrier that the right amount of speech therapy would’ve been able to break. And I know he can do it.’

Kell told the Royal Commission his former partner moved and he now doesn’t know where Hedley lives.

‘My ex-partner ... doesn’t realise the importance of implementing these tasks.’

Gav and Reace

Gav is in his 20s and has cerebral palsy and spastic quadriplegia. He lives with his dad, Reace, in a country town.

'The thing he loves about the country the most is that he can talk to anyone in the street and they stop and they talk,' Reace told the Royal Commission.

Gav also loves football and flying.

'He'll happily get on a plane and fly interstate to go watch a game of footy because ... he can chew the ear off any of the flight attendants in relation to football, which most of them were happy to talk to him about, and he loves aeroplane food.'

Reace is separated from Gav's biological mother and when Gav turned 18, both his parents applied for guardianship. The office of the public advocate (OPA) instead appointed a public guardian.

Gav wants to buy a suitable house with the compensation he received from the 'botched delivery' at birth that caused his disability. However, Gav's guardian is 'intent' on moving him into a group home paid for by the NDIS.

Reace said the guardian also won't approve Gav's therapies 'until she had every report under the sun'.

'And then when she got those reports she'd say she needed additional reporting to say that it was beneficial for him even though he's been going through these therapies for [more than a decade].'

Reace said the guardian had only ever met Gav once and had never asked him what he wanted. One day the guardian phoned Reace to say she was applying for extended powers, and he asked her if she'd like to speak to Gav.

'I said ... "He's right here. I'll put him on the phone." Then she said, "No, that would be incredibly inappropriate." And I would've thought that would be the most appropriate time to speak to him and find out.'

Reace said the guardian's attempt to have the NDIS pay for a group home have caused his family stress.

'The place that we're [renting] was put on the market so we've had to move ... We were hopeful that OPA would've thought that a year was enough time to make up their mind as to whether or not [the regional area] was an appropriate place for [Gav] to live, that we could provide him with the services that he required.'

Reace said when he complained to the OPA about the guardian, the OPA forwarded his complaint directly to Gav's guardian. When Reace called, the guardian's manager threatened to remove him as Gav's NDIS nominee if he didn't 'toe the line'.

Reace complained to state administrative tribunal about the powers of the OPA. The tribunal gave Reace the power to decide where Gav lives. Gav also has a new public guardian.

'If they were going to change one thing about the way that OPA works is that they would have a panel of people looking after individuals, rather than individuals looking after individuals.'

Bon and Catrina

Bon, who is autistic, recently started primary school.

'He was a wonderful student and loved [preschool],' his mum Catrina told the Royal Commission. 'I didn't believe that there would be any concerns. His intellect certainly warranted for him to be in a mainstream setting, and I thought it would be a positive environment to assist his growth.'

When Catrina enrolled Bon at the local primary school, his attitude to school changed.

'He was hiding ... He was in a state of anxiety, he was crying. This was five weeks into school.'

Catrina asked to meet his teacher.

'She said to me to my face, "I don't have time to deal with him. I'm working with the normal children." And that's where things started to snowball.'

Catrina said the teacher put photographs on a school app showing Bon 'purposefully being excluded'.

'Other students are all sitting down on the carpet and [Bon's] sitting down on a chair staring into another classroom wondering why he couldn't be somewhere else.'

Bon likes his food in 'a very particular way', so Catrina would cut fruit into triangles for him.

'[The teacher] would purposefully chop it up on him and I would request, "Please leave his food," and I would come home [and] he hadn't eaten all day because she had been messing with his food.'

Catrina asked the principal and learning support coordinator to move Bon to another class.

'They basically said to me, "No. We're not going to move your child into another class. Tough luck. She is who she is."

Catrina said the school had also promised a support coordinator for Bon several days a week, but 'this didn't happen'.

'They took funding for a support coordinator and spread the budget out over the entire school system. And Bon got 15 minutes a week with a support coordinator, someone who was supposed to be there to support and help him bloom.'

Catrina withdrew Bon from the school and enrolled him in a special education school where he's 'thriving'.

'I've seen other parents who battle and battle and battle with the schools. And it doesn't end well for the child and I just didn't want to do that. I wasn't going to put him through any more trauma and anxiety in his first term of his first year of school. Hopefully he's got 12 years in him.'

Bramley and Augusta

‘It’s honestly been a nightmare and disgrace.’

Bramley, early 30s, has intellectual disability and a rare form of epilepsy.

Growing up, his stepfather was very cruel to him and his mum, Augusta. He would put an electric collar on Bramley and zap him, laughing as Bramley ran around the yard screaming.

‘You don’t know what it was like to be treated that way, treated like a pet guinea pig,’ Bramley told the Royal Commission. ‘It was painful. The power was a nine-volt car battery, a wire and dog collar on my neck.’

At the special school Bramley attended, an older boy sexually assaulted him.

The school knew the boy was a sexual predator and promised it wouldn’t happen again. But a short time later, the boy locked Bramley in the toilets and the assault was much worse.

‘Why do you put someone who is predatory in school? People have to be put in with people who don’t do that and do such things,’ Bramley said. ‘It has to change.’

In his early 20s, Bramley went to live in a group home with four other residents.

‘I was hoping for happy freedom until I was literally being destroyed.’

One of the residents repeatedly assaulted Bramley.

‘I had to lock myself in the room because he’d come back and back.’

One time Bramley locked himself in the toilet for four hours.

Staff did nothing.

‘Sitting there on their phone, ticking around not doing the job properly. And then at the same time I had to learn to defend myself.’

Augusta made a complaint.

‘We saw nothing change,’ she said. ‘And it got so bad that [Bramley] developed ideations as well, suicidal ideations. His psychologist was very, very scared.’

Eventually the provider moved Bramley to another home with two other residents.

‘One was good and one was more like an animal where he would just come back for more,’ Bramley said. ‘[He] was older and deaf and totally aggressive. Not a safe house.’

The resident would hit Bramley in the stomach and genitals.

‘He’d hit my door and then punch walls, throw furniture at people, like knives and everything.’

When the NDIS started up, Bramley was able to change providers and move to another home.

‘And then it happened again,’ he said.

‘A lot of same thing – abuse, and a client jumping on to you and then swearing at you.’

Bramley feels living with four other people is too many.

‘They put you in with that many people, and then not dealing with problems like that. Not very clean and safe, kept cutting corners, endangering my life again.’

Bramley loves gardening, but one of the residents would rip up his plants and destroy his property.

Bramley is now living in a new home.

‘Since he has gotten away from all the past horrible stuff, he has just pretty much been one-on-one in this house,’ Augusta said. ‘He’s starting to calm down. His PTSD is nowhere near as bad as it was, and he is actually starting to learn some things.’

Bramley loves living by himself and wishes the provider didn’t want other tenants to move in.

‘I can cook meals and I really want to do the old classics. I want to live free. I said to my mum and my new house company I’m with that I want to grow fruit to give them for free.’

Bramley now has a part-time job at the local markets but would love to work on a farm.

‘Helps me with my anxiety levels, it calms me and I love the smell and all the tools and stuff.’

Bramley wants to get a full-time job so he can take his mum on a holiday.

‘It’s been that sort of nightmare,’ Bramley said. ‘And for a parent to have a son or daughter to go through all of that crisis, we need to shape for the future, and put an end to it.’

Tenille

‘There’s a complete contempt for human rights in psychiatric wards. No accountability. They’re just really cruel. It broke me.’

Tenille is in her 50s and lives with mental illness, psychosis and complex post-traumatic stress disorder.

Her psychosocial disability developed while she was a medical intern.

‘The nurses, when I was tired, started me on Temazepam. And then I got depressed and so then they put me on antidepressants,’ Tenille told the Royal Commission. ‘And that started me off in my downward spiral.’

Tenille has been on a Disability Support Pension for two decades. In the housing estate where she lived, one of her neighbours was abusive. One night the neighbour assaulted her.

‘She was continuing to hit my head on the concrete while I was unconscious. Police attended and told me I deserved it and wouldn’t take my complaint.’

The neighbour continued to harass her. Tenille tried to get help from a community legal centre.

‘And they said it wasn’t their responsibility. I thought they were just rejecting me and I had a bit of a meltdown. They called the police and the police took me to the psych ward and I was locked up for three weeks and drugged.’

One of the drugs had a ‘black box warning for suicide’. Tenille said it caused ‘a prolonged suicidal psychosis’ and she tried to take her own life.

‘So they doubled the dose of the medication that was making me suicidal.’

Tenille ended up in ‘a clinical coma’ because of all the drugs. Since then, she’s been admitted to psychiatric wards several times on an involuntary treatment order. She said that each time doctors give her ‘mind-altering medications’ that make her psychosis worse.

‘I think there’s an absolute abuse of antipsychotics.’

Tenille found herself in a cycle.

‘Wandering the streets at night, picked up by police and taken to the psych ward again and locked up. Put on antidepressants and tranquilisers. Discharged.’

Tenille recently spent more than a month in a psychiatric ward. She described it as ‘absolutely shocking’.

'I had no rights as a human being. Jail's better than the psych ward. All they do is threaten you to increase your medication, and if you don't take it to give you an injection,' Tenille said.

'They have to help you with your social issues rather than just drug you up. I think that was abuse of power ... I mean, I was dribbling, I couldn't close my mouth, I was dragging my feet.'

Doctors denied Tenille access to an advocate.

'You need one person to stand up for you so that they will all back off, and nobody ever would. I had to fight them off at the Mental Health Review Tribunal. They were trying to keep me on prescribed medications indefinitely and take all my money and give it to the public trustee so [that] I had nothing.'

Lesley

‘When I was able to show them that I could do the job [the supervisor] was like, “Wow. And you’re Deaf and you did this job!”’

Lesley is in her 50s. Auslan is her first language, but in her public service job she’s expected to lip-read and write notes.

‘I’ve worked there for 30 years in the public service and in that time I’ve not been provided interpreters. Not for 30 years. No interpreters at all.’

As a result she missed meetings, work events and office conversations, and missed out on promotions.

‘My supervisors constantly refused and said, “You don’t need [an interpreter]. No, we’re not getting one.” They knew I had reasonable written English so they expected me just to write notes ... If I didn’t understand something I would ask someone to write it down for me. And they would write these very longwinded, complicated notes.’

Lesley said she was ‘blocked’ from getting a promotion despite often being asked to work at higher levels than she was paid.

‘When I was looking to apply for a promotion ... the job selection criteria that happens within government jobs was so very difficult to manage. There was no other option except to write written English to all of the responses.’

She would have preferred to apply through an interpreter using Auslan.

‘Many Deaf people who work for the public service have told me the same thing. It’s way too hard to make an application and there’s no flexibility to suit access needs.’

Lesley’s husband is also Deaf. He works in the private sector where he’s been using an interpreter for years, funded by the government’s Employment Assistance Fund (EAF). Lesley said she told human resources that the department wouldn’t have to pay for the interpreter if they accessed one through EAF, but they still said no.

Lesley said she’s lobbied for many years to be promoted and develop her career, but has come to ‘realise it’s just a waste of time’.

‘The public service doesn’t really have the opportunity for people with disability to progress. It seems to be the same old thing regularly.’

Recently, when her department was being restructured, Lesley was given an interpreter for the first time so she could understand what was being said at a meeting.

‘I was happy to leave my old [job] and move onto the new department. So I did have interpreters for that.’

Lesley was late on her first day at her new job.

‘I was on a train and ... the train stopped. And I said to someone, “What’s happening? Why has the train stopped?” And one passenger said, “Well there’s floodwaters on the track. We can’t get through.” But then I realised I’d been missing all of the audio announcements. I had no idea what was going on. I got no alerts on my phone.’

Lesley struggled to find alternative transport and had to wait at the station for the tracks to reopen.

‘Again, you know, there was nothing set up for Deaf people. There was no visual alerts. There’s nothing, no [messages] on my phone. And I worry about that. That’s a really dangerous position to be in.’

Stephanie

‘There’s no education on this condition and they seriously believe it does not exist. There’s a lot of stigma, mistreatments and neglect.’

Stephanie is in her late 20s and lives with complex post-traumatic stress disorder (C-PTSD) and Ehlers-Danlos syndrome (EDS).

‘It’s a connective tissue disorder, and I’m having quite severe symptoms associated with that,’ Stephanie told the Royal Commission. She has been fighting for two years since her diagnosis ‘for any type of adequate treatment’.

She said that when her symptoms first started appearing around 2015, doctors didn’t take her seriously because they have ‘miniscule’ knowledge of the illness. She was having ‘black-out episodes’, headaches and memory loss, yet most GPs put it down to her mental health.

‘For the first three years it was – oh it’s period pain or you’re fine, go home, you’re just hysterical, it’s in your head, you know. I just think it’s all too easy for them to blame psychosomatic disorders, especially when somebody has something like C-PTSD.’

Stephanie tried ‘about 140 places’ last year to get a new GP for necessary referrals. Most told her she was ‘too severe’, or that she had to come in for an appointment first.

‘And I’m like, “I can’t stand up to go to the toilet let alone come to see you.” I can’t leave my bed. I can’t get out. I can’t even be moved to a new place because moving me will exacerbate my symptoms and, without medical interventions, I might not survive it this time.’

Stephanie feels she has been ‘roadblocked’.

‘It is quite terrifying. This is not how I want to live, especially when there’s a lot of treatments and a lot of interventions that I should be getting. In every other country there are treatments for this condition. Just not in Australia. I’ve just been left in the lurch.’

Even her current specialists have ‘no idea what they’re talking about when it comes to EDS’. She believes they should ‘figure it out’ and help her.

Left untreated, Stephanie’s condition has worsened. She can’t move her head and wears a neck brace for support.

‘At the moment, I’m bed bound ... I’ve just completely fallen apart. I have 24-hour nursing services.’

During hospital visits, staff have 'dropped' her on to a bed and refused to allow her support workers to assist.

'The last hospital admission was quite horrific, I don't think I've ever been treated like that before. There was neglect and emotional abuse.'

One nurse told Stefanie that she was 'incompatible with life' and refused to treat her.

Stephanie was trying to avoid surgery at all costs.

'But now I've now been told by doctors that actually understand this condition that they need to treat this as if it's a traumatic car accident. They need to respond with the urgency and the care that would be required of that.'

Stephanie is on a waiting list to see a specialist about emergency surgery.

'It wouldn't have gotten to this stage. I could have prevented it if we'd done interventions years ago that would've stopped this progression of my disease.'

Sibyl

Sibyl, mid-40s, is autistic and has post-traumatic stress disorder and fibromyalgia.

She has assistance dogs that are trained to monitor her health.

‘I don’t really listen to my body at all,’ she told the Royal Commission. ‘Like I’ll just push through things, whereas [my dog], she’ll start actually indicating ... if I’m about to get a migraine. She’ll alert me just before I get an aura. She does heart rate alert. Anything above 78 beats per minute, which also helps if I’m about to have anxiety or panic attack.’

Sibyl’s ex-partner of many years was abusive.

He limited her access to supports and financial services by telling her ‘you’re too disabled to do things’.

He used her dogs to control her and keep her from leaving.

He would say, ‘You can’t leave the dogs. You can’t leave the house. Where are you going to go with your dogs?’

A friend helped Sibyl engage with domestic violence (DV) services.

She discovered DV services didn’t understand service or assistance animals and how to work with them.

They only looked for emergency accommodation that would allow pets.

Sibyl said this happened multiple times despite her repeatedly explaining the access rights of assistance animals. The DV services ‘couldn’t conceptualise this notion of an assistance dog not being a pet’.

DV services treated Sibyl differently when she told them she had a disability. One time, a staff member was looking at her information and noticed she was autistic.

‘They were doing the intake, which was all perfectly fine until they said, “You’re on the spectrum are you?” And I said yes. And their whole demeanour changed and they started dumbing down their language.’

Sibyl works as an academic and at times feels like she is walking in two worlds.

‘In one world I’ve got the hat of disability, assistance dogs, so on and so forth. And then the other world I’ve got as an academic, and they don’t seem to marry up.’

Early in Sibyl's career she was advised not to tell the university about her disability because it would be detrimental to her career.

She regularly hears staff make condescending comments about autistic students and feels nothing has changed.

Her current employer asked if she had a disability and needed reasonable accommodations. Sibyl would like to be able use her voice recognition software and have her assistant dog with her to help manage her anxiety. However being on a casual contract, she's worried about saying, 'Hey, I need some of that.'

'Even if you wanted to disclose [you have a disability] you're too concerned to actually disclose because then they might not renew your contract for the next semester.'

Sibyl says the pandemic 'has been fabulous' because she has been able to work remotely from home.

She believes if she didn't have flexible work she would be on the Disability Support Pension.

'To be honest, having money and being able to survive is way more important than actually getting reasonable accommodations.'

Macey and Netta

Macey has a rare genetic syndrome. She is non-verbal, uses a feeding tube, has global development delay, vision impairment and a heart condition. She requires support with her gross and fine motor skills and is unable to walk long distances.

A few years ago Macey's mum, Netta, enrolled her in a state government preschool program.

Macey's classroom was full of small objects for the children to explore.

Netta was concerned Macey would put the objects in her mouth. She told the Royal Commission that she wanted her placed in a smaller, younger group with more supervision.

The teachers said Macey had to be with children her own age and reassured Netta that the education aide would watch her.

In the short time Macey was at the centre, she swallowed several items every day.

One day she was playing with the dinosaurs and swallowed a rock.

'She got the rock stuck in the food pipe, luckily not in the windpipe, but required surgery.'

Macey was in hospital for a week.

Netta discovered the aide who was supposed to be supporting Macey supported the whole class and only worked one hour a day.

'How is it possible that a child with lots of disabilities, with a PEG feeding tube, was only given one hour a day?' Netta asked.

'I left my child in a safe place, that is supposed to be helping her and protecting her, and I got there with three ambulances out the front, trying to take something out of her mouth.'

Netta had to quit her job and stay home for a year until Macey was eligible for school.

During that time, Macey couldn't access therapy or support because her syndrome was so rare the state disability program didn't recognise it.

Netta hoped things would be better once the NDIS was rolled out in their area.

‘Now that NDIS is finally here ... [Macey] is still not receiving enough therapy, enough care hours. Everything falls under parental responsibilities. However they don’t look at the bigger picture. I am a single mum. I don’t have any family here ... If I don’t work, I am not able to feed my family.’

Macey receives one hour of support five days a week.

‘She is not independent for anything. She is not able to eat for herself. She is not able to dress by herself. [Macey] is non-verbal ... If she hurts herself, she cannot tell me. I have to be there. I have to look at her all the time.’

Netta has tried to find after-school care programs and school holiday programs for Macey, but the waiting list is too long.

‘I can’t divide myself into two people.’

Netta said the support workers are very good. They have taught Macey to sign and she is able to communicate her needs.

When she goes to school or out into the community, however, most people can’t understand her. Netta believes sign language should be taught in all mainstream schools.

‘This not only helps to include those who doesn’t have a choice, but helps kids when they feel so overwhelmed by things that they don’t want to talk.’

Lynn

Lynn, in her early 30s, has attention deficient hyperactivity disorder (ADHD), anxiety and depression. She was only diagnosed with ADHD a few years ago.

Lynn used to work as a casual salesperson.

‘It was the kind of place that for me working was good. Like, I can’t organise my own routine, so a job where you’ve got like a uniform and it’s nice and clean and you get to talk to different people all day every day was a good job for me.’

Lynn had been there just over a year when her GP suggested she ask her managers if they’d make the role permanent and full-time. The GP said the stability of a full-time job would make it easier to manage her ADHD. She could also then afford to see a psychologist.

At a meeting with her managers, Lynn explained her situation. She also told them she had been a substance abuser in the past and wanted mental health support to ensure she didn’t relapse.

‘After I spoke to them that day when I was upset, they pretty much signalled to me that they were going to end my employment. So the next day I came to work in uniform, like “Don’t worry I’ll be fine,” and they gave me a separation certificate.’

Lynn when home and spent a month ‘on the couch, like pretty catatonic’.

‘All I asked for was like a bit of help or for them to understand how important it was for me to go full-time so that I could see a psychologist. And instead I ended up not having a job at all. And they said something like, “You could join the circus.”’

Lynn filed a claim for compensation at the Fair Work Commission. She was offered a paltry amount and decided not to accept.

She lodged a claim in the Federal Court, but this process was onerous and took a long time. Lynn couldn’t access Legal Aid and represented herself. The judge found against her.

‘His decision ... was that I was an unreliable drug addict ... and that I hadn’t been fired, I’d been taken off the roster.’

Lynn has found it hard to accept the judge’s decision.

‘I don’t think what he did is right and it’s not fair and it freaks me out ... I at least like to think that the world has some [system] that makes sense. But it doesn’t feel like it does,’ she said.

Lynn believes her managers should have been held to account.

'There's just no recourse if they do the wrong thing by you. Which in my head, they did the most wrong thing that you could do, which was like totally like kind of shun me when I asked them for help.'

Lynn is on medication for ADHD and is still seeking mental health support. She is looking for work, but has little time for the job agencies Centrelink sends her to.

'They're, "You're a bit acute for us so go speak to this person down the road." And you just tell the same story over and over again. And you don't find the connections to like move forward because you don't stay with one person at all,' she explained.

'That's why the judge thing to me was big ... Like, this is wrong to get fired when you're suicidal. This is obvious this is wrong. But it didn't work out that way, and I'm still struggling with it ... I'm just angry that I did what everyone tells you to do, which was ask for help, and I just got, like, pushed away.'

Rhiannon

‘For the past eight years, I have become a guinea pig for every antipsychotic I could possibly think of. There was severe blood noses, I looked like a car accident victim. There were severe mood swings, suicide attempts.’

Rhiannon is in her 50s and lives with psychosis and other mental health conditions. She was diagnosed in her 20s with schizophrenia, then about eight years ago with schizoaffective disorder.

‘And I do believe that I have been misdiagnosed,’ Rhiannon told the Royal Commission. ‘And it could be autism spectrum disorder. ASD can be mistaken for schizoaffective disorder, so a lot of people are being re-assessed now.’

Rhiannon is on an involuntary treatment order. She said the doctors have put her on drugs that have turned her into a ‘zombie’.

‘I have been taking my medication, it is all bullshit. I have severe cognitive impairment. I have got vision problems. I am now suffering dementia-like symptoms. I am also sleepwalking. I have to barricade myself in my apartment every night.’

All this has a debilitating effect on her life.

‘I can’t function normally. There’s a lot of things I can’t do. I can’t go into jobs that I would like. I can’t drive. I am unable to have a child at all.’

Rhiannon has been admitted to psychiatric hospitals about 10 times during this period. Each time, her health deteriorates.

‘The doctors want to pump you up with drugs and, you know, they don’t care if you are suffering mentally or physically because it is a big money-making scheme. And every single one they have tried has not worked for me.’

Rhiannon described her psychiatrist as ‘a wolf in sheep’s clothing’ who gets pleasure from locking her in a secure extended care unit (SECU).

‘Now SECU is a ward where they have severe cases, people that have murdered, they are ice addicts. I was assaulted by two patients, I was verbally threatened. I was intimidated. I was frightened for my life. I was there for four months.’

During her stay, two nurses approached Rhiannon.

‘And they say, “You’re not psychotic. We don’t know why you’re here.” One of the nurses said I was being medically neglected.’

Once the head nurse and four security guards ‘cornered’ Rhiannon to give her an injection.

‘Then they grabbed me, slammed me into the bed and ripped my pants down with four men watching me.’

Rhiannon reported the abuse to police and received a payout as a victim of crime.

A couple of years ago, Rhiannon tried to get her mental health treatment order revoked.

‘I was refusing to see [my psychiatrist]. I was going to go cold turkey on the medication so I could choose whether to have antipsychotics in my system or not. She rang me and she said, “You’re completely manic and I am going to put you back on a community treatment order.” Without even evaluating me, she made that decision in 30 seconds.’

Rhiannon is on a waiting list to see a private psychiatrist for a diagnosis ahead of her next mental health review tribunal.

‘I do not have faith in my current psychiatrist. She is absolutely appalling.’

Meanwhile, Rhiannon is ‘a recluse’ in her apartment. She has supports 12 hours a week but is trying to get that increased.

Rhiannon would like to put her qualifications to work in aged care or childcare, but her ‘memory is shot’. One of her dreams is to be a mental health advocate.

‘To help as many people as I can in similar circumstances. Being up there and saying, “Hold on a minute, this is not right, this is human torture and human abuse.”’

Mel

Mel is in her 50s and has borderline personality disorder. She is a disability support worker.

'I walked in with no experience 10 years ago. I was put across five houses,' Mel told the Royal Commission. 'Forty per cent of the customers had quite high behaviours.'

Mel has since completed training courses and has several qualifications, but she said the industry is still hiring support workers who are poorly trained and have no experience.

'We're hiring the wrong staff. The good staff are going. We're not getting rid of the staff that we need to because we're so short-staffed ... We are going through staff like you wouldn't believe.'

Mel said new support staff employed by her service provider are given a five-day induction over the internet.

'We are no longer doing face-to-face ... We've got so many people that are coming on board with no experience ... newbies that have never worked in the industry. They're going onto floors of houses that are already damaged with staff that have been there too long.'

Mel said although many frontline staff 'do an amazing job', the high turnover rate leads to poor morale, more resignations and poor services.

'For our customers to get the support we need to have the right staff. To have the right staff, we need to be able to do the right thing by them, which means better training and also, you know, have them come back [each day to work]. We need to look at that.'

Mel said the lack of training and shortage of staff leads to errors. In one group home medication errors forced the company to conduct a training session, but this too was delivered online.

'[And] we're so short-staffed in some areas that we book it, maybe only three show up because so many people are either off sick or we don't have the staff.'

Mel said the move away from face-to-face training to online training started during the COVID-19 lockdowns and continues because it's cheaper.

'They save money this way.'

Despite her concerns for the industry, Mel loves her job.

'I love it with such passion. You know what? Without me heading into this sector I may not have even been able to get myself right. You know this industry has made me a better person.'

Iker

'I was born with this hearing problem which led to speech impediments and a stutter,' Iker told the Royal Commission. As a young child his family and friends accepted him, and it wasn't until he started school that he was marked out as different. 'That's when all the problems started,' he said.

With his hearing and speech difficulties, Iker learnt slowly. Teachers punished him by making him sit at the back of the classroom, which made learning even harder. His classmates bullied him, calling him 'spastic' and 'mongoloid'. Students continued to bully him in high school, and he left at 14.

Iker is now in his late 50s. He has been diagnosed with dyslexia and finds it hard to absorb information and to read.

These challenges, along with his hearing and speech difficulties, caused problems in Iker's working life. He was victimised and exploited in multiple workplaces, and left jobs often as he felt he couldn't defend himself.

'I can't communicate, like, I freeze up when people – I'd rather walk away.'

In the mid-1990s Iker began psychotherapy, and through this process was diagnosed with a work-related psychological injury.

'There was compounding things happening,' he said. 'So I first went in for work-related issues because of all the bullying, and then that's when I found I had a disability, once I started disclosing.'

Iker has been on a Disability Support Pension for several decades. He applied for the NDIS and was refused. He doesn't know why. The paperwork was 'just too much' for him.

Iker did not have any assistance with his NDIS application. He has had matters in court. A community housing provider once evicted him over a technicality in his agreement with them, rendering him homeless. Iker had no support in any of these matters.

Iker said that if he wants to make a complaint to an organisation or agency, they typically require him to do so in writing. They do not accommodate his difficulties with literacy or offer any support. Nor have any of them ever referred him to disability advocacy services.

Iker believes such organisations should be required to refer people with disability to services that can provide independent support and advocacy. He thinks housing providers should employ disability officers to help with forms and navigating the system.

Kaya

‘I still think that a lot of the stuff around disability inclusion is very surface level and very tokenistic and very much it turns us off. Because you’re pretending that you’re inclusive, but there’s not really action, the culture is not inclusive. That’s the problem.’

Kaya was diagnosed with autism several years ago. Now in her early 30s, she also lives with a disabling physical condition and the consequences of a car accident in her early 20s.

Kaya works in the public service, a workplace she believed would accommodate her needs better than the private sector. ‘I know that I have capacity if only given flexibility and chance,’ she said.

But Kaya has found that efforts of her workplace to build understanding about disability are ‘primarily focused on very visible disabilities, not hidden’. She says autistic people are ‘very much forgotten’.

‘What I’m hearing about the recruitment programs for autistic people is that most of them within a year have quit because the focus was getting them in and getting them set up and nothing beyond that,’ she said. ‘It’s not [about] getting us into the workforce, it’s actually setting our environment up and giving us meaningful work while accommodating our needs, because people don’t even understand our needs.’

Recently at Kaya’s workplace, someone who wasn’t autistic gave a presentation about autism awareness. Kaya says that it may be helpful to provide an understanding of the ‘general characteristics of autistic people’ but ‘preconceptions’ being formed ‘by people who are trying to teach workplaces how to support autistic staff’ are a ‘big problem’.

‘We’re all different and you need to ask every individual autistic person what their needs are and how they show up. Because those preconceptions are just more social expectations that are being put on us that we already have to deal with in a society that fundamentally doesn’t accept our natural behaviour.’

Kaya is now an advocate for people who are neurodiverse. She has been sharing her experience of autism ‘in the hope that it would help other autistic women especially to receive better care and have a better quality of life’.

Bobby and Abby

‘It has taken way too long for our family to be satisfied that [Bobby] is safe.’

Bobby grew up in the country and lived with his parents until they couldn’t care for him anymore. They were ageing and couldn’t manage his behaviours on their own. He moved to the only supported accommodation available – almost four hours drive away.

Abby, Bobby’s sister, became his legal guardian. She told the Royal Commission that since he moved he has had ‘multiple incidents of poor care’. She said in most cases the family couldn’t do anything because there was nowhere else for Bobby to live.

Her brother has an intellectual disability and needs one-on-one support.

‘He cannot understand consequences for behaviour and has no impulse control.’

She explained that when Bobby feels pain he lashes out in anger. He requires multiple behaviour management strategies to help him regulate his behaviour.

One time Bobby was unwell and had uncontrollable diarrhoea. Support workers left him outside on the verandah for most of the day.

Although it was 40 degrees no-one checked on him. No-one noticed he was groggy.

When the afternoon shift arrived they immediately called an ambulance. Bobby remained in intensive care for more than a week – his kidneys had failed.

Abby spoke to a disability advocate who helped her make a complaint. ‘The company has now been shut down due to more than just this infraction,’ Abby said.

At another house, support workers refused to acknowledge Bobby’s disability. Abby said he was ‘bullied out of supported accommodation because they were convinced he was just bad’. They moved him into a house without 24-hour support and Bobby set a fire in the laundry because he was cold.

Abby also discovered large sums of money had been removed from Bobby’s account. There were no receipts or explanations. She didn’t know what to do about this or who to report it to.

Abby said the NDIS has made things worse for Bobby. Prior to the NDIS he enjoyed a number of activities supported by a variety of different people. He loves to bowl, play the guitar and cook. However, his NDIS funding only covers the cost of his one-on-one support. ‘This means his opportunities for social interactions are now limited to carers and not peers,’ Abby said.

‘I hope that people with major intellectual disabilities get seen for their complex care requirements ... [Bobby] still misses out ... he still cannot visit his family in the country ... or participate in family events ... This is so horrific for a man who’s happy to be with his family and join in the festivities.’

Aislinn and Melissa

‘People with disabilities are just as able to look after their children as people that have no disability.’

Melissa’s daughter Aislinn has a learning disability and epilepsy.

Aislinn and her partner, who Melissa describes as having a minor disability, have two school-aged daughters. They are ‘great parents’ and have ‘lots of family support’.

Not long ago one of the children had a ‘slight facial injury’ and the department of child protection removed both girls from Aislinn and her partner.

Melissa told the Royal Commission that the department ‘offered no support whatsoever’. She thinks the department believes ‘people with disabilities should not be raising children’.

Melissa has spoken to a number of government departments and organisations but can’t get any help to overturn the decision.

‘[A youth mental health organisation] is the only one trying to help us at the moment,’ Melissa said. But it is difficult because the department ‘will not allow them any support in the courtroom ... to help with the case’.

Instead of judging them, Melissa wants the department to give them a chance.

‘I think there should be more support for people with disabilities and young families to be able to raise their children competently. We are all human and we all need support in these situations.’

Zack

Zack has an acquired brain injury and is largely non-verbal. He needs physical and first aid support for seizures.

As a young adult living in rural Australia, Zack volunteered with his family at the local fire service. His parents told the Royal Commission this was a positive experience. He attended trainings with his siblings and loved helping to wash the firetrucks after call-outs. Zack enjoyed being in nature and, through his involvement with the fire service, had 'a healthy respect and knowledge of the danger of fires ... [but] was not adversely afraid'.

However this all changed one very hot dry Christmas, more than a decade ago.

As the fire risk in their area intensified, Zack's parents asked the fire service to warn them if they planned to do any back-burning. They explained the importance of this for Zack and others in the neighbourhood with disability. They would need to make plans to evacuate and minimise anxiety.

As the threat of bushfires increased, Zack's family and neighbours began a 'massive property preparation regime'. Zack enjoyed being involved in this, helping with pruning and disposing of litter.

But one morning, the family woke to the terrifying sight of the next hillside ablaze – 'a huge blanket of smoke and leaping flames' not 500 metres from their house.

Believing these were spot fires from the main fire front, the family evacuated.

Zack thought his family would perish. During the evacuation he was in a 'constant very aggressive uncontrollable behavioural state calming only during tonic clonic seizures'.

It was only as the family drove out of the area they heard on the radio that the fire they were fleeing was actually controlled back-burning. The warning the family asked for had never come.

The family continued with their evacuation.

'The scene of such an inferno was terrifying to us so it was multiple for [Zack].'

Initially they went to a relative's house, but Zack was in such a state that the confined space was not safe for him. They took him instead to a caravan park where there were at least playgrounds and nature walks to divert him.

The family then took Zack to a respite facility, but there was evidence of the fires all around. They tried to find counselling for him, someone to help reassure him they were safe, but there was none available.

In the aftermath of the fires the family attended community briefings and programs for bushfire recovery.

‘Experts from various fields offered advice and counselling ... but not one thing was available to help [Zack] overcome his trauma.’

Even through his family’s extensive contacts in the disability sector, there was ‘nothing to meet [Zack’s] disability in the realms of counselling’.

Zack never went back to fire training or wanted to clean fire trucks. For years to come he would go outside every night to make sure there were no fires. And every Christmas he relives the trauma of that bushfire season.

Zack’s parents believe the failure of the fire service to ‘pre-warn vulnerable people’ about back-burning amounted to neglect.

They also believe it is the responsibility of governments to ensure sufficient and appropriate support is in place for people with disability during and after bushfires. This includes quite areas for people with disability to go if they need to evacuate.

‘The state [Zack] was in with his aggressive behaviour he would have been not only unsafe to himself but to others for he would have “attacked” anyone and anything out of fear and stress if he was placed in a normal evacuation site.’

They would also like emergency services personnel to receive training to counsel people with disability who have been traumatised by fires.

Berkley

Berkley is in her mid-20s and lives in a rural area. She is autistic and has attention deficit hyperactivity disorder, post-traumatic stress disorder and depression.

Berkley told the Royal Commission she was ‘bullied every single day in primary and high school’ and ‘not one person in staff’ supported her.

Berkley was still at school when her father died, sending her into ‘one of the worst depressive episodes’ of her life. She self-harmed while at school, but teachers did nothing.

‘No-one did shit. I walked out. And nothing was ever mentioned to me ... If any other person in that classroom had shed a tear, they would’ve been removed and spoken to.’

Berkley has a history of self-harming when she gets ‘overwhelmed’ and ‘can’t cope’. She said emergency services have only once treated her well.

‘I was 16 years old ... I answered the door with blood dripping down my legs and my arms. My mum came out and was like, “What the fuck is this shit?” blah, blah, blah. And, the ambulance officer took her away out of the room and said, “She may do this for the rest of her life and you need to support her no matter what.”’

Berkley feels police often fail people with disability.

About three years ago, after her sister punched her, she ‘drunk a litre of vodka, had probably 200 pills’. Police ‘dragged’ her out of her car and took her to hospital.

‘When you send the police to a mental health issue, you’re going to end up with problems because the police are only there to enforce. Their training is to manhandle people. Not to treat them like fucking human beings.’

Doctors pumped her stomach and discharged her, even though she told them she would kill herself .

‘I ended up back in the ED (emergency department) four hours later. I’ve never had such a depersonalising, traumatic, abusive, neglectful situation.’

By this stage, Berkley had an NDIS plan, but was homeless because I didn’t know how to use it.’

‘Educating’ herself has made all the difference. Berkley is trying to self-manage her plan and hires her own support workers. Recently she fired one who would come to work for five hours, work for one, then ‘sit on her ass for the rest of the day’.

Berkley says good supports ‘take away’ some of the stress of ‘trying to cope with life’.

Tucker

Tucker is in his 60s. He is in prison, where he says he is treated with neglect and his health care is disregarded.

Tucker requires a wheelchair for transit more than 20 metres. He also has anal fistula, a painful condition that can result in prolonged discomfort – exacerbated if seated for long periods.

Tucker told the Royal Commission that because of his disability and the fistula, he spends the majority of his time in his cell and is unable to work.

‘[I] spend most of my time bedridden or immobile like [an] elder. My day-to-day life is virtually my cell!’ he said. ‘[I] have always been very active but now I am drowning!’

Over the last year Tucker said he repeatedly reached out to government agencies for assistance. He also approached the ombudsman multiple times.

One day, as a result of the pain Tucker was experiencing, he commented that ‘life was not worth living’. He followed that up by saying he ‘was definitely not suicidal’. Nonetheless, he was ‘dumped into a special area’ and spent three days in solitary confinement.

Recently, Tucker was taken to the hospital. He assumed it was for an operation to remove fistula stitches. He was surprised to end up undergoing eye surgery, ‘more than a year after [his] expected notified time’.

Tucker acknowledges that the COVID-19 pandemic has affected the ability of the health care industry to process patients as efficiently as it previously did, but it’s ‘not the main problem’.

‘Simple case management would be a good idea,’ he said.

Bertrand

‘There were people in my life and other’s lives who were meant to protect us and who failed.’

Bertrand is in his 50s and has level 1 autism. He has a couple of tertiary qualifications, works part time, receives a disability pension and enjoys his independence. Reflecting on his life experiences, however, he told the Royal Commission about the ‘negative treatment’ at school and in the workplace that have left him with ‘emotional damage’.

Bertrand told us about the ‘intense’ bullying he received at school from other students, which ran from name calling and verbal abuse to physical abuse. It began in primary school and escalated in high school. It was so bad, Bertrand says, that sometimes he ‘would vomit from the feeling of going to school’.

Bertrand can forgive the kids.

‘School kids can be idiots and don’t know things,’ he said. ‘It’s harder to forgive the adults.’

Bertrand said teachers were often aware of the abuse by other students but did nothing. Sometimes, the teachers did the bullying.

For example, said Bertrand, ‘In year 8 my sports teacher used to constantly make fun of me to the point I was too scared to go to PE.’

Similarly, he ‘dreaded’ going to choir practice because the choirmaster would insult him and routinely kick him out for things like ‘moving his head’ or ‘not paying attention’.

Bertrand and his parents made complaints to the school, but the typical response was ‘boys will be boys’ and that Bertrand should become ‘more resourceful’. One teacher even said it was Bertrand’s fault because he was always ‘being different’ – he should ‘try to fit in, instead of insisting upon tolerance’.

Bertrand also experienced bullying and discrimination in the workplace. At one stage he was working in a government department. Colleagues would insult him and imitate his behaviours. Eventually Bertrand’s boss told him his work was not up to standard – the implication was that his colleagues were justified in bullying him.

‘All people with disability can experience issues,’ Bertrand told us, ‘but the problems can be compounded where it is an invisible disability ... people with invisible disabilities are often thought to be morons.’

These days Bertrand’s ‘self-worth is much more than previously’. He said he dealt with his experiences through his religious faith, but he understands why some people become desperate.

‘Society has a poor record of looking after people with disability.’

Neve

Neve is in her late 40s and has a psychosocial disability. Her now-estranged husband is in the police and, she told the Royal Commission, continues to exploit her financially.

It began about 15 years ago when Neve's father passed away and she inherited millions of dollars in shares. Neve's husband, co-executor of her father's will, got 'pissed off' and exploited the fact that she was 'depressed and grieving' to trade the shares under her name.

About 10 years later, Neve's mum died. Neve's husband tricked her into signing over her mother's house.

'Police removed me from my house. [He] said we were going to sell it and split the money but this didn't happen ... [He] also has our kids.'

'The wheels fell off and I had a breakdown,' Neve told us. She is now on a disability pension.

Neve believes her husband's position in the police force has helped him maintain his control over her.

'I have tried several times to take out an AVO against [him] for financial abuse but these were rejected and I was scheduled.'

Now, Neve's husband has an AVO against her. 'I can't go see my kids or house,' she said.

'[He] set my mental health label and led me into NDIS through conversing with my mental health doctors ... [He] gets into my mail, social security, hacks my computer ... Lots of money milked from my bank account ... I tried to report to police ... [He] gave me stigma so I am dismissed when I make suggestions. Because I'm labelled everything is seen as all mental health issues ...'

Neve would like to see better accountability mechanisms and oversight bodies that can provide people like her with more assistance.

She would also like to see better protection for whistleblowers so the media is better able to uncover and report on corruption.

Barrett

Barrett is a First Nations man in his early 30s. He told the Royal Commission about his experiences as an adult with psychosocial disability, post-traumatic stress disorder, intergenerational trauma, anxiety and depression.

‘People with psychosocial disabilities have no rights – they are rarely involved in decisions that impact them. I have been involved in this system for seven years and been hospitalised countless times against my will. People working in hospitals with mental health patients are cruel and take advantage of people with disabilities. The less you can stand up for yourself the more they exploit you ...

‘Drugs are misused to keep us “easy to manage” not because the medication will help.

‘There is nobody to report to ... you are treated like all of your thoughts views and beliefs are invalid because you are unwell – but it is often only very select thoughts and views that are impacted. Police won’t take [you] seriously. Hospital management won’t listen because it’s their staff.’

Barrett would like to see better education around mental health and psychosocial disability to reduce the stigma.

‘Look at countries that have favourable outcomes for people with disabilities, all disabilities, and learn from the evidence,’ he said. ‘Use social models to support people with psychosocial disabilities.’

Barrett hopes that people who knowingly exploit people with disability will be brought to justice. And ‘for those who mean well but don’t know how to do things better’, his hope is that ‘they are educated and are part of the change process’.

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, 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.

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 quality, 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 one day when they found her sick with vomiting and diarrhoea. 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. 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 ageing, we had hoped that we would find somewhere [Nina] could be cared for and have a good life.’

Adam

Adam is a 12-year-old boy with autism. His father told the Royal Commission the mainstream school Adam was attending refused to make reasonable adjustments to accommodate his disability. The school also repeatedly suspended Adam, more often than is allowed under the legislation.

When Adam had problems, the school would call his dad to pick him up. This happened dozens of times a year. If he failed to do so, the school called the police.

Adam's dad believes the school wanted to get his son off the roll, but it needed a police charge in order to have a good reason. It tried for months.

Adam had just turned 13 when he was arrested by the police at school. He was charged with 'threatening life', which his dad said was 'ridiculous'.

At the police station, officers formally interviewed Adam without representation and with no parental support. No-one had told his parents he had been arrested.

The charges were dropped. Adam's defence lawyer said it was the weakest and most inappropriate case he had seen.

The department of education ordered Adam to attend a special school. Adam's parents fought to allow him to go to a mainstream school and made an application through the District Court, but were unsuccessful.

Adam's parents moved him to a private school where he is doing well.

'My son left the public education system. We now pay \$8,000 a year in private schooling.'

They are angry about how their son and their family has been treated.

'It is too easy for [the department] to just trot out its records to malign students with a disability ... they will not make reasonable adjustments and hide behind "threats of violence" which give an excuse to ignore making adjustments because they can just say it's all about safety.'

Pia

Pia has motor neurone disease and uses a wheelchair. She told the Royal Commission she was 'treated like a prisoner' in a respite facility.

During her stay she 'lost over 20 kilos' because she wasn't adequately fed. Desperate, she ended up ordering online from a supermarket to deliver 'food and basic toiletries'.

During her stay, someone from the facility stole money from her. She believes staff were responsible because they knew where her money was kept and when she reported it they questioned her, asking, 'Are you sure you had money?' She felt she was 'treated like a child'.

There was an incident in which Pia sustained 'fractures and a broken toe' and was admitted to hospital. She said this happened because staff didn't have training in how to hoist clients.

Pia spent three months at the respite facility, during which time her partner 'wasn't allowed to show her affection'.

She felt 'frightened and unsafe'.

'My mental health deteriorated I ended feeling depressed and isolated being denied my basic human rights.'

Her psychologist rang the manager and told them Pia 'needed physical contact' from her partner.

Despite complaining to the respite facility, she said 'nothing was done'.

Pia believes she should 'get to live her life to the fullest without being treated like a prisoner by those who are paid to care as a profession'.

Jason, Mya and Kent

Mya and her husband Jason have Asperger's syndrome. Kent, Mya's father, told the Royal Commission that both have 'severe social disability' and trouble communicating. He describes them as 'feeling the whole world is against' them.

'Initial friendly contacts turn negative or even hostile.'

Jason and Mya have a son, Ty, who is autistic. His behaviours include 'head banging, screaming' and he has 'minimal verbal communication'.

Kent gave the family 'as much money as [he] as a pensioner could afford' to buy a block of land 'to get out of a rental poverty trap'. They purchased a block near a small mining town and were living in a caravan.

However, the family had to move after 'incessant council employee pressure'. At first there were complaints about the noise from a small generator. Then, after Jason erected a shed, council workers told him it was too close to the boundary and threatened to bulldoze it. They also repeatedly threatened to remove Ty's 'therapy special breed chickens'.

Council workers repeatedly trespassed on their land, scaring Mya and her child. Eventually the family felt compelled to move off their block and camp beside the road in a public reserve. Again they were told to move on as it was 'council controlled land'.

When Jason questioned whether the land was state land or council land, the council worker advised him they would call police to issue an order for the family to move.

Kent is disappointed the family has moved from their own land. When council workers move the family on, citing various regulations, they have little 'opportunity to understand their rights or laws they might be violating'.

He believes 'there needs to be a public helpline for people with disabilities', someone who can help them 'understand their rights regarding civil and property laws'.

Miranda and Wilson

Miranda has a rare neurological condition that affects her cognitive abilities and general health. Her father, Wilson, told the Royal Commission that Miranda and other people with disability receive inferior medical and health services, particularly in relation to diet and nutrition.

Wilson said his daughter had reached early middle age by the time genetic analysis determined she had mutation that puts her at greater risk of physical ill-health including cardiovascular disease, stroke, recurrent early miscarriage, migraine with aura, osteoporosis and some cancers.

Experts believe diet can reduce these risks.

Wilson said that, had he known about this sooner, he would have taken preventative measures with Miranda's diet.

Wilson has noticed more broadly that 'many people with disability have poor diet and nutrition' which 'can lead to poor quality of life, poor health, shorter lifespan'.

'[The NDIA] gives no attention to this matter,' he said. 'Seems to me that this matter is fundamental to everything else but it is the missing element!'

Wilson would like to see comprehensive research into the diet and nutrition of people with disability.

He would also like to see support workers receive education around nutrition, 'so they can focus away from easy to access junk food'.

Dean and Eva

‘All perpetrators of sexual abuse need to be accountable ... no matter what age.’

Dean has cerebral palsy, a cognitive disability and vision impairment. His mother Eve says ‘he has good speech and enjoys listening to music’. Now in his early 30s he lives independently in his own unit with the support of four workers. He is a busy volunteer, including with a community radio station and as a visitor at an aged care facility.

Eve told the Royal Commission that towards the end of primary school, Dean was sexually abused by another student at his mainstream school.

‘At lunchtime while my son was on his own in a playground of over 200 students, he was wheeled into the toilets by another ... student.’

Eve says the student pulled down Dean’s pants and tried to make Dean have oral sex with him.

Dean did not tell Eve about the incident until she was putting him to bed that night. Eve notified the school and Dean ‘identified his perpetrator ... after looking at all the photos of the boys in his class’.

The school notified the police, who interviewed Dean. Eve was not allowed to be present and he did not have an advocate or support person. He became agitated and ‘lost it’, but the case did go to court. Eve said that the judge believed Dean, but the other boy was not sentenced because of his age.

‘The School was most apologetic, however everyone was ... ashamed this had happened under their watch so communication was quite strained and we did feel quite isolated,’ Eve said.

The school asked Eve if they could shift Dean out of the shared classroom. She thought this was ‘most inappropriate as the other boy should move as he was the perpetrator’.

Eve asked the school to notify the high school the boys would transition to about the incident. The principal ‘stated that he was unable to pass this information on ... due to the Privacy Act’.

Eve believes what happened to Dean could still occur today because ‘funded time [for educational support workers] does not include supervising the playground which is where most of the bullying occurs’.

Eve would like to see all school playgrounds monitored so ‘all children can play in a safe environment’. She believes sexual abuse by minors needs to be disclosed to relevant future schools for the ‘safety of others’ and a perpetrator of sexual abuse should be immediately removed from any classroom they share with a victim.

She says a person with a disability should always have a support person or advocate present when being interviewed by police.

Eve also feels the young perpetrator 'should have been made accountable' for what he had done.

'This young man he was not sorry in the least, he knew exactly what he had done to my vulnerable son in a wheelchair ... Counselling or community service could have been ordered and may have assisted the boy.'

Mila, Asher and Nancy

Asher is a young First Nations man with a disability.

Mila works in an education team in the learning and wellbeing area where she manages suspension and expulsion. She met Asher and his mother, Nancy, following a referral from a First Nations education team.

Mila told the Royal Commission that Asher's school had suspended him for more than 100 days, about 'half the school year'. Asher was about to be expelled from school and his mum was trying to get him enrolled in another public school. She was confused as to what she should do next.

Mila emailed the principals of both schools to clarify the situation. She had received no reply by the end of the school year, and assumed the matter was resolved.

She was surprised when Nancy contacted her before school resumed and told her the matter wasn't resolved and Asher 'was keen to start school when all his peers returned'.

Mila met with Nancy and Asher. Nancy told her Asher had tried to end his life twice over the Christmas break 'resulting in hospitalisation and police involvement'. Nancy was 'distraught' and confided she had 'mental health issues and was not very literate'. She had trouble understanding the letters from the school and reports from counsellors.

Realising the matter was urgent, Mila contacted the proposed new school to progress Asher's enrolment.

The school refused to engage and referred her back to the First Nations education team as they were 'managing the issue'.

Mila emailed her supervisor, team coordinator and the area education director expressing her view that there had been 'noteworthy breaches to significant government legislation and departmental policy', and it was 'no wonder the family have no idea what is happening'.

A meeting was organised with the education director and both principals. Mila emailed her supervisor requesting she be included in the meeting. Her email cited the breaches to the relevant legislation she believed had occurred.

Mila's supervisor granted her request, but informed her she must make a formal apology to Asher's current principal, as he had been upset by her email. Mila was 'perplexed'. 'This has always been my role – "warn me when a train is coming",' she explained.

Mila refused to apologise.

'I was merely identifying potential breaches of policy and legislation.'

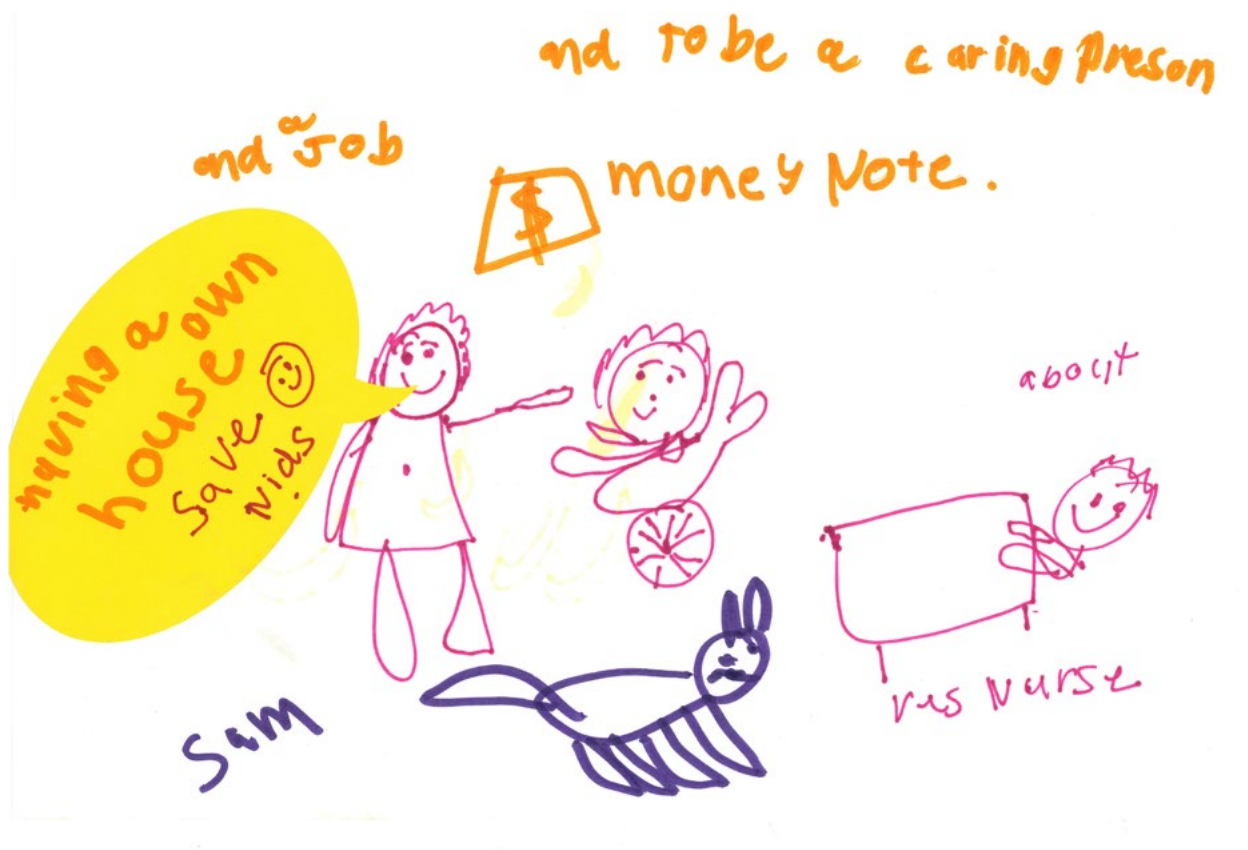
Nonetheless, 'things began to move'. After many meetings with departmental officers, Asher's enrolment in his original school was resumed. Mila believes her insistence, with Nancy's permission, 'that the attempted suicides be discussed openly with all involved ... changed the school's position'.

Not long after, Mila received formal notification that she had breached the code of conduct for her 'failure to comply with a request – apologising to the principal'.

She believes the situation shows how a large organisation has difficulty adhering to the Disability and Discrimination Act.

'When orthodoxy is challenged, the department fights back by looking for a scapegoat, rather than address its failures and engage principals with further training about their responsibilities.'

Mila says the 'sorry' incident represents the education department's ignorance and complacency when managing matters that involve students with a disability.

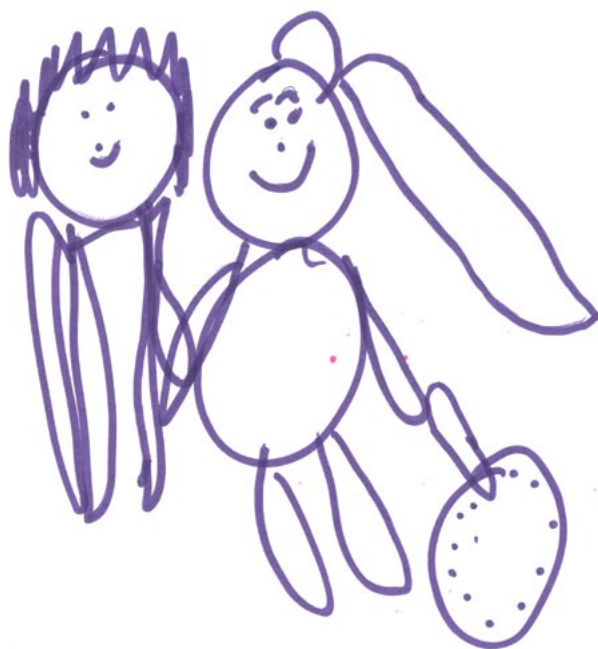


Artwork by Samantha Dyer

To get ^a Envisionable
for a vet nurse.



Samantha



Sam

Merry

Artwork by Samantha Dyer

Karla and Josie

Josie told the Royal Commission about the abuse her nine-year-old daughter, Karla, experienced in a 'special needs classroom' at the local public school in the early 1990s.

Not long after starting at the school, Karla complained to her mum about having a sore back, neck and arms. Then in the bath one evening Josie noticed 'bruising on her back and arms'. Josie asked Karla if she had fallen over or if someone in the classroom or playground had hurt her. Karla told her the teacher 'hurt her'.

Josie went to the school and asked the teacher if she had noticed anyone hurting Karla. She said she hadn't.

Over the next few months Karla kept coming home with bruises on her back and arms. Josie asked her again what had happened and she told her 'my teacher pinches me'. Josie found it hard to believe it was the teacher and kept asking her, prompting that perhaps it was another child. But Karla 'did not deviate from her accusation'.

Josie went back and questioned the teacher. The teacher said she had been looking out for Karla and hadn't seen any incident that would account for her bruising.

Josie found this strange. Karla 'was a special needs student in a special needs classroom'.

'She had high support needs and would have been well supervised, especially in the class as there were only nine students.'

They were also well supervised in the playground.

The bruising continued, and Josie asked the teacher directly if she was hurting or pinching her daughter. The teacher denied it, so Josie went to see the principal who said he would follow up.

While waiting for him to investigate, Josie spoke to some of the other parents. One revealed 'her son was also coming home with bruises' and a previous student also experienced the same abuse.

Nothing came of the principal's investigation. Not long after, however, the teacher was transferred to another school. Josie 'feared for the next students that were in her class'.

Josie decided to report the incidents to the police.

The police interviewed Karla and the other child. The children clearly explained what had happened and showed the police their bruising.

Josie expected the teacher to be charged. Instead, the police told her they felt it 'would not be advisable to proceed to court because even though the witnesses ... could tell what had happened in their own simple language, the defence lawyer would eat them alive ... and easily discredit them'.

So the case didn't proceed. Josie felt it was 'a very unjust, miserable end'.

Josie would like people with disability to have better support from the police. She would like to see 'abuse not covered up, nor the perpetrator moved on'. Instead they should be 'charged with a criminal offence'.

'To this day [Karla] remains a victim of abuse,' Josie said. It 'has had a deep impact on her' and she still talks about her time at that school 'with anxiety and fear'.

Avril, Rana and Jaci

Avril ‘sucks at hide and seek’.

Her mother Jaci says this is because Avril is ‘profoundly deaf in one ear ... and even if she hears the sound she can’t identify where it is coming from’.

She also has mild hearing loss in her other ear. Her ability to comprehend speech in noisy environments is ‘seriously compromised’. Yet, Jaci told the Royal Commission, Avril’s disability is often ignored. People ‘only look at the “better” ear, ignoring all the research showing detrimental effects of being profoundly single-sided deaf’.

When Avril needed a cochlear implant for her ‘profoundly deaf ear’ it took eight months and ‘excessive amounts’ of advocacy for her to be assessed.

When Jaci tried to enrol Avril in a public school with a hearing unit, she was told her daughter wasn’t eligible because of her ‘better’ ear.

Avril is also ‘not deaf enough’ to attend preschools or schools with bilingual Auslan programs, even though ‘she is likely to lose the hearing in her “better” ear and may end up dependent on Auslan’.

Additionally, Avril didn’t qualify for hearing aids until she turned five. ‘Why did she need them at five-years-old and not earlier?’ Jaci asks.

Jaci’s older son Rana is in prep. He has ‘mild bilateral [hearing] loss’ and uses hearing aids and the FM system in class.

But Jaci says ‘it takes hours, weeks every time he gets a new kindergarten teacher, school teacher, specialist teacher’ to bring them up to speed on how hearing aids and the FM system work. Jaci thinks Rana ‘should qualify for a teacher of the deaf to come and educate staff on his needs’.

Jaci also says there is ‘not enough access to Auslan at kindergarten or school’. There are only a few schools with Auslan ‘as either primary language, bilingual or Language other than English (LOTE)’ and she is unable to find a private Auslan children’s language class or private teacher.

Jaci wants ‘Auslan to be the LOTE for most public schools’ and the discrimination ‘against single-sided deaf children’ to end.

Keith, Jacob and Cody

‘Verbal and physical abuse was a daily occurrence ... These men were hostages in their own homes.’

Keith used to work in a group home as a support worker. He told the Royal Commission of the ‘boys culture’ he experienced in this home and of the routine acts of violence and degradation perpetrated on its residents.

Keith told us there were two residents who seemed to receive the worst of this abuse, Jacob and Cody.

Jacob had sensory overloads which would sometimes cause him to lash out at staff. Instead of moving back, staff would ‘relish in the opportunity to physically engage’ with him. Keith witnessed a staff member pinning Jacob on his back to the bed, swearing and abusing him. When another member of staff came in and confronted him, he claimed Jacob had backed him into a corner and he ‘had no choice’.

Staff who ‘just didn’t want to deal’ with Jacob regularly used chemical restraints on him with no restrictive practice authority, and often locked him in his room. ‘These types of strong-arm techniques were regularly employed in the house and were way over the top,’ Keith said.

‘The residents were regularly verbally and physically intimidated by staff, who enjoyed the physicality of it all and often described their time in the house as “working in the trenches”. Their egos were completely out of control.’

Cody is autistic. Keith described him as ‘very literal’. Staff would ‘toy with him’ about changing his daily routine, saying he couldn’t go out to get his paper, for example. Not understanding ‘the joke’, Cody would, predictably, have a meltdown. If this caused him to display severe behaviours, they really would deprive him of his daily routine and schedule, ‘using his poor behaviour as a justification’.

Staff regularly degraded Cody verbally and physically. For example, Keith said, ‘staff would draw genitals on his hats or face and laugh at him, and Cody would just be happy to be a part of a joke’.

If Cody asked for the remote to change the TV station, one staff member would say, ‘Bring it back, not broken, or I’ll smash your f***ing face c***.’ He’d then laugh, said Keith, because ‘that was his idea of joking’.

‘There are dozens of these stories, over the course of 18 months,’ Keith said. ‘Incident reports were doctored daily so as to not reflect staff in a poor light, or reveal any illegal practices.’

Keith informed management about the abuse that some staff were engaging in, but they never escalated it to the area manager.

‘Because my claims couldn’t be corroborated and [Cody and Jacob] are either non-verbal or barely verbal, I was told the claims couldn’t be substantiated,’ Keith said. “‘Dobbing” on another staff member was seen as a totally hostile and disloyal action. I was essentially enemy number 1 for reporting on them.’

One of the abusive staff members was given a promotion and Keith had to work under him. Keith’s life ‘was made absolute hell.’

‘I was moved to a respite house, by myself, to work 16 hour shifts with a very violent client ... I asked to be moved, relieved, have SOME of my shifts somewhere else, but they refused to move me, citing that they had “no-one else to work with him”.’

‘It was there I developed Post-Traumatic Stress Disorder and I’ve not worked in 3 years, I lost my career, my house and my partner. I barely leave the house anymore, I’ve tried to take my own life several times. This has taken me a very, very long time to get around to writing.’

Keith said he hopes the Royal Commission can ‘open up the curtains’ to see what’s happening in these houses.

‘There are now more shadows in the disability sector, not less.’

Jolene

Jolene has paraplegia from an injury 30 years ago. As a person with a disability over the age of 65, she says she is one of a group of people 'neglected in a way that amounts to abuse by the decision of the Government to have a cut off age for the NDIS'.

To date Jolene has largely managed without support workers. Her partner, who also has a disability, gives her some support around the house. She uses a manual and electric wheelchair, a hospital bed to help her sit up, and a pressure cushion to prevent sores.

'Once you get to the highest level,' says Jolene, 'your state funded equipment cuts out except for an electric wheelchair. Thus no pressure cushions, no hoists, no bathroom commodes, no manual wheelchairs, no pressure mattresses, no continence aids.'

As she continues to age, Jolene anticipates she will need help for personal care, mobility and other functions. Jolene has heard that she can only apply for personal care once she needs it, and then it will take two years to get funding. 'The inevitable consequence of this,' she says, 'is I would be forced into a nursing home, when I don't want to be in one.'

'Yet people under 65 can have funding for care, equipment, therapy, transport etc till they die. They can stay in their home with the help they need ...

'This is, to say the least, unfair. It is discriminatory on the grounds of age ... we do contribute to society. We are professionals, parents, siblings and friends. We are elders in the disability world and in general society.'

Jolene has approached government organisations, disability organisations and politicians but says nobody wants to hear about it.

'We have been banished to invisibility.'

Shelley

Shelley is in her 30s. She is autistic and has intellectual disability. Shelley told the Royal Commission her disability impacts on her life 'dramatically'. She is 'treated differently and constantly misunderstood'.

'I have issues socially and I feel that I'm not heard compared to others all the time.'

Shelley told us she doesn't get the support she needs, either from home or from her support providers.

She said her mother gives her no help and leaves her 'to stress and struggle alone'.

'My mother has failed to provide care or support for my autism and I feel it's also the reason I'm misunderstood and that my internal needs are not being addressed.'

Shelley told us she experienced domestic violence at the hands of her brother. When she told her disability support worker about it, she told Shelley it was her fault and she should take care of it herself.

'She let me down. Her bosses told me off. I have been tormented by her actions ...

'No matter who I tell or what I do or don't do, I'm in the same situation regardless. That because of family abuse or neglect I'm a victim of abuse all round as I'm left on my own to deal with things ...

'Things worked well when I have the right person and that they don't give up on me or make things my fault all the time.'

Shelley thinks there should be more support for adults with autism.

Colin

Colin is middle-aged and experiences anxiety and depression. He is angry about the government's response to COVID-19 in relation to people with disability.

'It's neglect and discrimination against the disabled that the Government has excluded the disabled from the temporary corona virus supplement of \$550 a fortnight for 6 months,' he told the Royal Commission.

'The Government acknowledge there are additional costs due to the pandemic social distancing and lots of allied health services (especially community-based services) being withdrawn or cancelled at the moment. Which means as a disabled man to stay safe and well during this pandemic I have to fund my health care out of pocket with private providers. I can't afford private health being on the DSP.'

Ian

Ian used to work in warehouses, with constant lifting and squatting, and developed a femoroacetabular impingement – a condition in which extra bone grows along the hip joint. Ian wrote to the Royal Commission about the challenges he has faced trying to work with physical disability, and in navigating Centrelink.

For a while Ian found employment with an organisation through a disability agency. However he feels that he was only employed as ‘free labour’, and his employment was terminated as soon as the government stopped its payments to the organisation.

‘Don’t let employers take advantage of the [money] you hand out to get people like me employed,’ he wants to tell the government. ‘It’s heart breaking and I’m already pretty broken.’

Ian struggled in his interactions with Centrelink. He felt like he was treated like a liar.

‘Even with scans and doctors certificates and physio certificates I was given grief.’

He felt like they were ‘interrogating’ him every time he went in and that interacting with Centrelink triggered his social anxiety. ‘I am defeated,’ he said.

Adding to the stress of his interactions with Centrelink, Ian was ‘pushed’ into jobs that he couldn’t physically do and which were likely to make his condition worse, and ‘then made to feel like shit by the employer’.

‘Like I really need that kick when I’m trying to restart life.’

Ian would like to see Centrelink employ people with more empathy and medical understanding, and ‘for no person young or old or any colour be made to feel inferior when asking for help’.

Kevin and Rosalyn

Kevin is an autistic student. His mum, Rosalyn, wrote to the Royal Commission.

‘I would like to share an experience with regards to my son’s schooling and how ultimately we were failed terribly by those who were meant to support us because they didn’t properly understand the concept of inclusivity.’

When Kevin began kindergarten, about 10 years ago, it quickly became clear he would require additional support within the class. The class environment was overwhelming for him from a sensory and demand perspective and he quickly became agitated, needing breaks from the room and permission to move.

‘The school and staff were wonderfully supportive,’ Rosalyn said, ‘and he was provided with a full time EA [education assistant]. This EA and my son developed a brilliant relationship and despite my son’s ongoing struggles she managed to support him to maintain a love of school and enjoyment of learning in his own way.’

Things continued happily in this way for a couple of years. Occasionally when Kevin’s behaviours escalated, the department of education would provide extra assistance via the special education needs and disability (SEND) team. Kevin also developed a great relationship with the SEND staff member.

Halfway through primary school, Kevin began having some violent outbursts. The SEND staff member suggested the school provide Kevin with a separate learning environment to reduce the sensory and demand impacts of the classroom.

‘This idea proved to be ideal for my son by providing an inclusive solution that took into account his disability requirements, and for two years, with support from the then principal he engaged in school life happily, with few issues,’ Rosalyn said.

‘He became increasingly able to engage and disengage from the school environment and learn on his terms. I was able to commence full-time study ... I no longer needed to be available to collect him from school at a moment’s notice.’

But then everything changed. The new school principal had Kevin’s room dismantled, and expected Kevin to return to class. The EA who Kevin had bonded with over the previous five years was replaced. Rosalyn told the principal this could be a catastrophic move for Kevin, but the principal said the SEND team would be coming in to help develop a behavioural management plan.

Kevin’s behaviour deteriorated within days and the calls to collect him recommenced. Both Rosalyn and Kevin’s new EA were excluded from planning meetings for the first time. The school ignored Rosalyn’s concerns.

Kevin's behaviours deteriorated further and Rosalyn was having to collect him from school on a regular basis. Eventually she had to remove him from the school.

'My son was devastated as he loved school, but could not contain himself once stressed and dysregulated.'

After that, Rosalyn homeschooled Kevin. She had to close her new business and sell her house.

'In conclusion,' said Rosalyn, 'a simple inability on behalf of the school's leadership to comprehend that inclusivity is not about forcing kids to do what all the others are doing ... The emotional and financial costs have been incalculable.'

'Nobody questions a wheelchair ramp for those who need it,' Rosalyn points out, 'so why question specific supports for those with neurological differences?'

Ryan & Brielle

Ryan is a young boy at primary school. He is autistic and has attention deficit hyperactivity disorder. His mother Brielle does 'everything' for him as an unpaid carer.

Recently, Ryan was diagnosed with extreme anxiety. Brielle told the Royal Commission it is directly linked to several acts of physical violence at school by staff.

Brielle complained to the school and reported the assaults to the police, ombudsman and the department of education. But her complaints were ignored.

'No-one took responsibility of actions. No justice or apology ... We have photos of marks and bruises of my son when incidents happened. This has greatly impacted my son, and our lives.'

Nothing has been done to address or prevent any further incidents of abuse or violence towards children with disability at the school, and Brielle says the lack of action is unacceptable.

Brielle is unaware of what else she could do to report the abuse, or prevent the violence from happening again. Concerned that Ryan is at risk of further violence and abuse, she removed him from the school.

Brielle thinks school staff should be properly trained on how to deal with children with disability.

Baker and Katherine

Baker is almost 60. He has cerebral palsy and cannot sit up unsupported, walk, talk or use his limbs. Baker needs assistance to eat, shower and use his wheelchair. Katherine, Baker's mum, wrote to the Royal Commission on his behalf.

Baker went into care 30 years ago and has been in a facility with four residents. Katherine says he enjoyed this 'enormously'.

'The shared accommodation gave Baker an opportunity to socialise with other people, which improved the quality of his life immensely.'

Recently, however, Baker was diagnosed with cancer, and the shared supported-living facility can no longer provide the care he needs.

'We were advised to seek a place for Baker in a nursing home,' Katherine said. 'This has proved impossible, however. No nursing home is willing to accommodate Baker due to his complex medical needs.'

So Baker returned home to receive cancer care. Baker's parents, however, are in their 80s, presenting a range of issues given their 'increased frailty'.

'Disabled peoples in Australia like Baker are living longer, due to improvements in medical care and other social and educational enrichments,' Katherine said. 'However, there are few facilities that currently cater for the intersection of disability, older age and medical care. What is needed is a dedicated facility for disabled people as they age, including medical staff who are educated in disability care.'

Katherine believes 'there has been a lack of policy discussion about disabled persons who require medical care for acquired health conditions, such as cancer'. This leaves Baker 'without a "place", in a system which fails to recognise the changing circumstances of disabled people as they age'.

'We feel strongly that Baker has been let down,' Katherine says. 'While any policy changes are unlikely to benefit Baker directly, we both understand the importance of communicating our story in the hope of helping other disabled people and their families in the future.'

Juliette

Juliette is a learning support teacher in a private college. She wrote to the Royal Commission about the inappropriate use of Nationally Consistent Collection of Data (NCCD) funding, which she says is a systemic issue.

NCCD is used to calculate the student with disability funding loading the Australian Government provides to schools, based on levels of adjustment provided to students.

Juliette told us that over four years she saw more than \$500,000 in NCCD funding come into her school.

‘I was so excited when I first saw the amount of money that was allocated to us through the NCCD funding. The possibilities for therapy and extra assistance were endless... but my dreams were shattered. I never saw a cent of that money in my department.’

Juliette and her colleague submitted proposals each year about how the NCCD funding should be used to support the school’s students with disability.

‘It has been soul crushing to be knocked back time and again,’ she said. ‘Unfortunately in my networking with other learning support teachers/heads it is not unusual for schools to allocate this money to buildings, buses etc. One teacher even said that her school charges the learning support department rent and electricity for using their premises!’

Juliette thinks spending of NCCD funding shouldn’t be at the discretion of principals, for whom students with disability are ‘often not the top priority’.

‘Learning Support/Special Ed teachers are often ... working ridiculously long hours with minimal resources, trying to provide the best possible education for our most vulnerable students. Burn out is high and mental health is damaged by the lack of priority shown to these departments by the Principals and administration staff.’

Juliette believes the government needs to allocate money to be spent directly on students with disability, and audit schools ‘to show accountability for how they spend this money’.

Seth and Ula

Seth was diagnosed with dyslexia, dyspraxia, dysgraphia and anxiety four years ago. He is 12 and has difficulty with literacy, numeracy and gross and fine motor skills. His learning differences are known as specific learning disorders (SLD).

Seth struggles to find balance and maintain correct posture.

‘Simple childhood joys such as swimming [and] bike riding were hard won skills,’ said his mother Ula.

Yet it is not SLD, but the ‘lack of education, empathy, skills and support within the education system’ that has ‘the largest impact’ on Seth’s self-esteem. His anxiety has resulted in physical symptoms such as skin rashes, headaches and bed wetting.

Ula told the Royal Commission that a person with SLD is not eligible for NDIS funding. There ‘is little financial support through private health funds’, so she funds Seth’s therapy herself.

Each week Seth attends speech and occupational therapy and sees a psychologist ‘to build skills and self-belief’.

He attends therapy outside school hours. They live in a rural area so it is a one-hour round trip to all therapies. Without therapy Seth regresses.

When Seth started high school, Ula investigated private tutoring options and ‘had to navigate a myriad of questionable providers’.

When she asked about a schedule of fees, tutors told her she ‘needed to accept “special needs kids are expensive”’. When she asked about realistic learning milestones aligned to the school syllabus, tutors tended to be ‘vague’.

‘I understand funding for these kids is challenging but the current situation where they simply fall through the cracks ... is not acceptable nor humane. Especially when others receiving NDIS can use funding for horse riding lessons, swing sets or trampoline purchases ... SLD kids receive nothing and their teachers do not have capacity, skills or knowledge to help.’

Fortunately, Ula found several school counsellors who have been supportive and provided key advice and guidance.

‘Without these individuals I would have given up on the school system entirely.’

Ula also found support groups provide ‘fantastic resources and recommendations and a sympathetic “shoulder”’.

‘Professional private services we have engaged have also been wonderful but I am conscious that I am in a situation where I have a well-paid job and have the option to take up these services albeit at significant sacrifice. Others are not so fortunate.’

Ula believes neurodiversity is essential and would like educational support systems to be truly inclusive – not for the few with certain diagnoses.

‘My hope is that, with support, all neurodiverse persons will feel they can lead fulfilling lives as valued members of our society.’

Jeff and Alec

Alec worked in a factory with supported employment, supervising employees with disability.

‘There were many good people trying to do a professional job with no resources,’ Alec told the Royal Commission. ‘I began to understand that the supported employees had nothing to aspire to.’

The factory packed and labelled cartons. Soon after Alec started, he met Jeff.

‘I liked [Jeff]. He was a bit of a stirrer and got into the odd fight or two, but did a great job. He was in another group and was constantly being disciplined.’

Jeff had worked at the factory for 40 years, packing cartons, wrapping pallets of cartons in shrink-wrap plastic, and labelling them. He was highly skilled, moving the pallets with a trolley jack and operating machinery.

‘[Jeff] was, unfortunately, covered by the [employer’s] supported wage system.’

Alec said the employer paid Jeff \$3.30 an hour. The highest pay rate under the wage system was \$6 an hour.

‘I was given training on this wage system and quickly discovered its aim; to keep wages low.’

Alec said the employer linked Jeff’s wage to his behaviour.

‘Unless his behaviour improved, he could keep getting paid \$3.30 an hour. I have seen worse behaviour in open employment with no consequences ... Even the employees that behaved well received little reward.’

Alec said one new employee, ‘highly skilled and highly intelligent’, who had once run his own business, ‘was offered \$4 an hour as a starting wage’.

Alec asked why the employees weren’t given regular pay rises and was told that they weren’t entitled.

Alec also questioned the employee superannuation payments. He wrote to the ombudsman, which told him it would not investigate his allegations.

‘They quoted privacy. I find it hard to believe that someone who tells the [ombudsman that] over 100 people with disabilities have received less than they are entitled to under workplace laws, is not even talked to.’

One day, Alec was told to give the group of employees he supervised a new, unsuitable job.

‘I knew [it] was not good for the group’s skills. I pointed out to my supervisor that most of the group had behavioural issues and this would upset them.’

Alec felt his supervisor was bullying him and his group.

‘I went in my office and almost cried.’

He resigned the following week.

Alec told the Royal Commission that businesses and governments should overhaul the supported employment industry.

‘Don’t put 100 people in a supported workplace together, and give them meaningless work and no hope. Put them in an open workplace, with the right support and training.’

Abbie

‘From my story it’s clear that my life revolves around PTOs, police coming to my house and taking me to the hospital, being pinned down by police and hospital staff. It is a vicious cycle that continues to negatively affect me and cause me more trauma and fear.’

Abbie recounted to the Royal Commission numerous examples, over the course of 20 years or so, of mistreatment she has experienced at the hands of police and hospital staff as a person with a psychosocial disability.

These have typically involved police turning up at her house and taking her to the hospital – for reasons that have ranged from allegations of assault on medical staff, to hanging out washing in her underwear, on her balcony, on a hot day.

Over the years Abbie has been placed under several psychiatric treatment orders (PTOs) and medical staff have locked her up and restrained her on a number of occasions – sometimes for hours, sometimes for weeks.

‘They simply assumed because I have a psychosocial disability, they can treat me however they wish. I was treated in an inhumane manner which was neither reasonable nor necessary ... This was a traumatic experience for me which has affected me whenever I am in a hospital environment.’

Abbie says she has been ignored and considered ‘aggressive’ on several occasions when she has tried to explain to hospital staff that the information they hold on her is incorrect.

Abbie’s advocate heard from Abbie’s support coordinator that staff at the mental health unit of this hospital do not listen to anyone. The support coordinator says she has tried to speak to some of the nurses and doctors about Abbie’s condition, but they do not listen to her either.

‘This has led to hospital staff and the police restraining me at every point when I am in hospital,’ Abbie said. ‘I believe there are better ways to treat people with psychosocial disability. Being treated like a criminal due to the nature of my disability is completely unfair.’

Abbie says that at times she has had information about her medications and her own health withheld from her.

‘I feel that I am not included in anything that involves my own health. I may have a psychosocial disability, but I have a right to be included in anything that revolves around my life and my treatment ... I am continuously left out and this makes me feel excluded and not having control over my life ... ’

‘I would like to live a full life where I do not have to feel discriminated against due to my disability. I would like to see the police and hospital staff as people I can trust when they are at my door and when I am in hospital, respectively.’

‘I would like to be treated in a humane way. I would also like to be able to make a complaint without fear of retribution. Lastly, I would like to be involved and included in understanding the decisions being made around my treatment.’

Oona

Oona is an autistic teenager. She wrote to the Royal Commission about the bullying she experienced at two different schools.

'I was bullied ... and the teachers would not do anything about it. I got called horrible names ... The teachers thought I was gay for this one student and that student bullied me and my friends ... I was called awful slurs like "Spastic" and other horrible names.'

Oona also says she was groomed by a paedophile, her 'boyfriend', in high school. She made a complaint to the police, but 'nothing happened'.

When Oona moved to another town, she 'was accepted by the boys and girls'.

'It was heaven.'

Ruby and Sue

‘Being involved with this sector has left me feeling overwhelmed, powerless and despairing much of the time. I strongly suggest that this story is representative of other hidden Australian citizens who do not have a spare relative to tell it for them.’

Sue is a retired health professional who supports her niece, Ruby.

Ruby loves art and played in a rock band in high school. After graduating, she had surgery for Crohn’s disease. Now in her late 40s, she lives with a number of neurological and physical disabilities. Ruby is unable to eat solid food, stand, or sit upright, and is confined to bed in a group home.

‘She literally never sees the sun or clouds overhead, nor feels a breeze on her skin,’ Sue told the Royal Commission.

‘In [Ruby’s] words, “Am I expected to spend the rest of my life hidden behind these walls?” ... She never sees beyond her door, which doesn’t face her. Her only view of the outside world is a window, but she is unable to open the curtains.’

Sue said that initially Ruby’s care was ‘adequate and kind’.

Then about 15 years ago, after spending a year in rehabilitation for assessment and treatment, the state government transferred Ruby to independent units in a regional town. The government also handed her support funding to the care provider who ran the units.

‘Within a very short period of time carer hours reduced and quality of care reduced with it ... For almost a decade, [Ruby’s] care consisted of staff constantly running in, rushing out, being called away, leaving half a leg washed, missing out on many basic tasks.’

The care provider removed Ruby’s princess chair, bought by her parents to help her move, for safety reasons, and stopped transporting her by van to a local doctor.

When Ruby and her family asked about the apparent cuts to her funding, the care provider told them they couldn’t reveal the amount for ‘privacy’ reasons.

‘A few years ago the family discovered that [Ruby’s] funding had not been reduced; only the services the [care provider] provided to her,’ said Sue. ‘What was this funded amount used for if not for [Ruby’s] care requirements?’

She said the poor care had profound effects on the health of Ruby and her parents.

‘I am at a loss to describe the sense of frustration, helplessness, and feeling completely

overwhelmed which existed without abatement during these years.'

Ruby also spent that decade on a state government waiting list for allied health support.

'She never rose to the top of that list for occupational therapy or psychological support,' said Sue, 'and when, finally, physiotherapy support arrived, it was unprofessional and damaged [Ruby's] health.'

A few years ago, after receiving an NDIS plan, Ruby gained access to better physiotherapy. An occupational therapist is assessing her for a wheelchair and an ambulance now takes her to see her doctor once or twice a year.

But Sue said many issues still haven't been fixed.

'[Ruby's] isolation is absolute. She is completely isolated from community and any semblance of a normal life.'

Sara

‘Police should ask people if they identify as having a disability as some disabilities ... can be invisible.’

Sara has a cognitive disability and says she has experienced ‘violence and neglect’ from the police.

Sara described an incident when she attended a peaceful protest with a new partner and was pushed to the ground. She wasn’t sure whether it was the police or her partner who pushed her.

‘The police officer refused to become involved and wouldn’t let me look at camera footage ... to discover what had happened.’

After this, Sara reported experiencing domestic violence from her new partner. She had ‘significant difficulty communicating with the police’ but she was ‘granted a domestic violence order’.

She said her partner breached the order but ‘police only spoke to him on one occasion’ and told her the ‘CCTV footage relevant to a breach went missing’.

Sara made an official complaint about the police but was told she was ‘being difficult’.

When she reported subsequent incidents to the police, the officer told her she was ‘being paranoid’.

Sara stopped reporting anything to the police even though the violence continued.

‘I feel as though the police are using my past against me and that there will be judgement and disbelief if I try to report anything again.’

Sara reported these incidents to support workers, a domestic violence refuge and lawyers.

‘These people all believed me, were supportive and recognised that the abuse has happened.’

Sara would like the police to improve their communication so they ‘don’t belittle and neglect people’. She wants them to ‘believe people and listen to their stories’. She wishes someone higher up in the police force had contacted her and spoken to her after she made complaints.

Denise

Denise is a child of deaf adults (CODA). Auslan was her first language, but the second language of younger siblings.

Denise describes her parents as having lived 'the Australian dream'. They had 'successful jobs ... their own home and ... a family'. They never 'saw their deafness as a disability, because both were quite capable to achieve almost anything'.

Denise explained to the Royal Commission that a CODA, such as herself, 'has the responsibility to speak on behalf of their deaf parents' from quite a young age.

'[This includes] making phone calls, interpreting appointments (general, medical and legal), interpreting job interviews, parent teacher interviews, weddings, disputes and even funerals.'

'You can imagine the emotional weight and responsibility,' she said. 'We had to quickly learn the responsibilities of adulthood ... not what you would class a normal childhood upbringing.'

Denise says this 'still continues today for many CODA'.

The main reason is cost. Denise said the fee for an Auslan interpreter for a minimum of two hours is between \$250 and \$300.

'Medical appointments are at no cost thanks to the wonderful service of the National Auslan Interpreter Booking Service.'

Denise believes the NDIS has made a difference for people under 65 because the funding package 'accommodates for interpreting for any type of matters'.

Her concern is for her parents and other 'deaf elders' over 65 who 'are assumed to have no life other than medical appointments'.

Denise says her parents are 'fit, healthy, active, retired, self-funded pensioners'.

'How can the Government expect a pensioner to pay a fee of \$268.20 for an appointment with a real-estate agent, solicitor, tradesman, bank manager and many more others?' she asks.

This means the children continue to interpret and her parents continue to feel 'guilt and strain' for needing 'to rely on their CODA to interpret'. Denise says it impacts every relationship.

'The relationship between CODA and parents, the relationship between CODA siblings not doing enough, whose turn it is to assist, and the relationships affected by the time spent away from family, work and responsibilities for CODA's immediate families.'

She told us relying on children to interpret increases 'loneliness, isolation, rejection, mental

health issues, financial burden and discrimination’.

Denise believes deaf elders need to feel ‘their identity is acknowledged’.

‘Access to communication, access to a one-to-one Auslan interpreter for a deaf person is so vital, and I believe, a basic human right.’

Denise would like to see a ‘My Aged Care supplement package for deaf elders over 65 ... who are fit, healthy, active self-funded retirees’. She believes they should be ‘provided with funding equal to NDIS eligible recipients ... not group funding and not in-home Auslan interpreting’.

Deaf elders deserve to ‘live independently [and] have control of their lives’.

Denise believes this ‘vulnerable group’ needs to be ‘acknowledged, accepted, included and given this opportunity to feel that they are contributing and making a difference in their community and society’.

Rylee and Safa

When Rylee was in year 1, she started experiencing anxiety and refused to go to school. A paediatrician diagnosed her with attention deficit hyperactivity disorder (ADHD), executive function difficulty, learning disorders and anxiety.

Following her diagnosis, Rylee started taking medication and the school implemented a detailed independent learning plan. In addition, her mother Safa paid for a specific learning difficulties (SPELD) tutor to work with Rylee in the classroom.

Safa, who also has ADHD, told the Royal Commission she found the acting principal and teacher to be supportive and encouraging during this period.

But in the final term of year 3 a new principal started. They would no longer allow Rylee's SPELD tutor on school premises. They told Safa the year 4 teacher was experienced with students with learning difficulties.

On the first morning of year 4, Safa did her best to settle Rylee in but her anxiety levels were 'clearly very high'. By the end of the second day, Rylee was in tears and refusing to go back to school.

Safa spoke to the assistant principal who agreed there should have been more interventions to manage Rylee's start to the new school year. He reassured Rylee 'she was very safe within the school, and that she could visit him at any time she felt upset'.

Rylee seemed to settle down, but it didn't last long. Her anxiety increased and she began telling her mum everything was 'too hard'. She often had meltdowns at home and refused to go to school.

Safa took her to a psychologist who was concerned Rylee was not receiving reasonable adjustments. They suggested this was likely a trigger for Rylee's anxiety.

'I pressed the school for a case conference ... to have the support reinstated that we had experienced previously,' Safa said.

A meeting was held, without the principal, and some 'fantastic interventions' were agreed on.

One strategy was to limit Rylee's choices to reduce her anxiety. However the librarian refused to do this, saying it wasn't her role to 'restrict and censor what the students can and can't borrow'.

Another meeting was held, this time with the principal and deputy principals.

The principal complained the requested adjustments amounted to Safa 'dictating to the school'. She told Safa she was 'becoming somewhat of a nuisance'.

Safa showed the principal a letter from the paediatrician explaining Rylee's disabilities and prescribing antidepressants. The principal refused to look at it.

Safa also questioned why NDIS funded tutors were allowed in the classroom but Rylee's SPELD tutor wasn't.

At this point the principal shut her down.

'[She] told me it was apparent that it was my anxiety that was ramping up,' Safa said. 'I felt incredibly offended that [the principal] thought it appropriate to call my mental health into question, and perhaps suggest that my mental health was somehow impacting my daughter's.'

Only a few weeks later the community went into lockdown because of COVID-19. Safa said that in lockdown Rylee's anxiety almost disappeared.

The paediatrician told Safa this suggested it was the school environment that was directly responsible for much of Rylee's anxiety.

When school was able to resume onsite learning, Safa made the decision to send Rylee to a new school.

'My daughter has a fundamental human right to an education. She is very bright, happy and extremely sociable. There has never been, at any point, anything to suggest our daughter's needs make her in any way unsuited to a mainstream classroom.'

Stan and Tyrell

One night in the early 2020s Stan, who was in a wheelchair, tried to reach a can of Pepsi on the floor. The safety belt was too loose and he slid forward, ending up slumped over the belt. He didn't have the strength to lift himself upright. Stan died in hospital a week later. He was in his mid-30s.

Tyrell had been Stan's support worker five years earlier. Stan had cerebral palsy and when Tyrell worked with him he was well supported by his service provider. Stan was in his 20s at the time and unwell. The provider helped him find a place to live and reconnect with his family. 'He had access to therapy sessions, timely doctor check-ups and ... easy access to available resources,' Tyrell told the Royal Commission.

Then in the mid-2010s a former employee of the provider set up her own business. She began to recruit clients and got Stan to sign a service agreement. Tyrell said she did this without consulting his next of kin. She argued Stan was capable of making his own decisions. There was nothing his old provider or the support workers who had been with him for many years could do.

The woman employed her family members as support workers.

'Some of them [were] even as young as 17-years-old without prior experiences, no training, no safety measures in place to deal with complex health needs of people,' Tyrell said.

When Tyrell tried to visit Stan, the new support workers abused him and told him 'to get out of their house'.

'The house was a total mess.'

Neighbours told Tyrell that Stan was using marijuana 'heavily' and the workers encouraged him.

'He failed to attend appointments and therapy sessions as [the new provider] considered "having a fun day" superseded the importance of his health.'

A former colleague did manage to see Stan a few times over the years and told Tyrell that Stan and his dog appeared to be malnourished. He said Stan 'had lost half of his body weight and his hand coordination'. He appeared to be surviving on Pepsi, burgers and chips.

'[Stan] had been totally neglected, his care rights taken away from him, deprived of dignity as he would wet his pants and he would sit in it for hours. He had been deprived of access to basic health care facilities, either by choice or by the failure to uphold their duty of care.'

Stan died because of neglect, Tyrell said. Left in the chair all night the pressure of the safety belt caused internal injuries.

'He would have been alive if [a support worker] had properly restrained him onto his chair, or would have put him to bed before [they] went home, or would have educated him on the use of a panic button.'

Norah

‘I want to remain independent in my own home and obviously a good part of that is to stay well. I have a job that I love and would like to keep doing.’

Norah has spina bifida. She lives in her own unit, with assistance from support workers several times a day for personal care and cleaning. Norah told the Royal Commission she is worried that her health and her independence are now in jeopardy.

‘With the Coronavirus pandemic at the moment, I am worried that most of my support workers don’t have masks. I don’t know where they have been or who they come into contact with in their daily lives and because I have spent almost three months in hospital/rehab, I don’t want my health to be compromised, but I obviously need the support.

‘Only one of my support workers wears a mask. I really think that agencies should give all support workers masks, for their own protection, as well as their clients’ protection, although I understand it could intimidate some clients.’

Kyla

Kyla finds it difficult to focus, is frustrated easily, talks too quickly and feels so bored it's 'almost physically painful'. She also struggles with verbal instructions and reading documents. She is 'always ridiculously early or late' and requires fidget gadgets in meetings or lectures.

Kyla told the Royal Commission it was not until she was in her mid-20s, after 'years of depression, anxiety ... and wanting to die' that a psychiatrist told her these behaviours were due to attention deficit hyperactivity disorder [ADHD]. She would need substantial support to 'keep [her] job, stave off another bout of depression and another severe psychiatric breakdown'.

She would also need medication, but having been diagnosed as an adult, her medications aren't subsidised. She spends 'approximately \$250 per month' on medication and in addition has to pay \$350 every time she sees the psychiatrist. The Medicare rebate is only \$120.

Meanwhile, Kyla was really struggling with her condition.

'I was having difficulties with energy regulation, I couldn't work past 3 pm without losing complete focus, even on my medication. Over-sensitivities were horrible, the light gave me headaches, [and] sounds screwed my concentration up for the rest of the day. My emotional dysregulation was severe. I wanted to cry, die, scream, sleep, laugh and more in rapid succession. I was managing, but it was taking everything I had.'

Someone suggested to Kyla that an occupational therapist could help her with strategies to manage her ADHD and she should apply for an NDIS package.

Kyla submitted an NDIS Access Request.

Three months later she received a response. Her request had been denied based on Section 24(1)(b) of the NDIS Act, which requires that 'you must have an impairment which is permanent, or likely to be permanent'.

Kyla felt humiliated.

'To be told that the condition I have struggled with, that has caused secondary depression so severe I wanted to die several times, was not permanent or likely to be permanent ... '

Kyla asked for a review, then waited another three months to be told 'the access criterion was unmet'.

Ultimately, the NDIS determined Kyla hadn't exhausted all her treatment options. This was the point of Kyla's application in the first place: she wanted help with treatment.

Kyla was told she could appeal through the Administrative Appeals Tribunal, but she was 'humiliated, dejected and had no fight left'.

Since then Kyla has been 'struggling in the same way with energy, emotional dysregulation, and all the other difficult to manage aspects ... on a daily basis'. She said her only supports are 'either highly costly', such as her psychiatrist, GP and psychologist or family.

Kyla told the Royal Commission the experience has left her disillusioned with the system.

'The fact that a system that is supposed to help people with disability managed to wear someone with a disability down to the point I got to is disgusting and proves that the system is broken.'

Kyla would like ADHD 'treated with the severity it deserves' and believes the NDIS should be 'a system for people with disabilities that doesn't judge them or belittle them for wanting help'.

Belen and Alexa

Belen had a difficult time at school.

Alexa, his mum, said he struggled from kindergarten when he started attending the local state school.

She told the Royal Commission teachers didn't offer any support, or make any offer or suggestion to have Belen assessed. They sought instead to manage his behaviours through 'public disciplining'. This led to 'escalating anxiety, self-harming and extremely low self-esteem,' Alexa said.

'The teachers clearly lacked any knowledge on "invisible disabilities", and they assumed that any non-compliance on behalf of the child was simply a result of bad parenting, not inability of the child to control their behaviour.'

During the second year of school Belen continued to experience 'emotional instability, delayed functioning at home and at school, impulsivity and social difficulties'.

'We were forced to seek help outside the school system,' Alexa said, and they 'paid a lot of money to get [Belen] assessed privately'. Alexa's suspicion of attention deficit hyperactivity disorder (ADHD) was confirmed.

With a diagnosis, the school offered Belen a place in its social skills training program. But there was not 'any other follow-up or any other special accommodation provided'.

Alexa explained that ADHD 'does not attract funding and is not enough to have individualised learning or a behavioural management plan, unless it comes along with another significant disability'.

The following year Belen was also diagnosed with anxiety disorder, 'which allowed [Alexa] to continue advocating for him'.

'We are lucky,' said Alexa, 'because we have time and money to seek diagnosis.'

'Many families cannot afford this or have to wait long time to see the specialist ... Without early diagnosis, early intervention is not possible. Lack of intervention leads to escalating problems, not only for the child, but it also affects mental health and ability to work of people around, as a ripple effect. That's why it is essential to have a sound mental health screening and support system that is easily accessible and affordable to all, ideally in the first year at school when most invisible disabilities start surfacing, making children with such disabilities to fall through the cracks.'

Wendy

Wendy immigrated to Australia from Asia. She has been a support worker in the disability sector here for almost 20 years.

Wendy told the Royal Commission her former employer dismissed her when she made enquiries relating to the death of a client. She believes the death was caused by her employer's negligence.

Wendy requested a conciliation process.

'The result of it was: I was not authorised by the participants, I therefore have no right to enquire about what was going on to them; and, I was no longer working in the house ... I have no need to know more about what will be happening in the group home. The case was thus closed.'

Wendy had worked mainly with people who have cognitive disability and are non-verbal and she shared some observations with the Royal Commission.

Wendy believes the quality of the support workers is the 'most decisive element in running a good service'. She also says trusted support workers should be involved in the decision-making surrounding a person's care.

She says 'it is important for medical staff to make the right diagnosis and provide the right treatment', but it is the support worker who works closely with a person and observes them over a long period of time.

Wendy doesn't know how doctors deal with a non-verbal patient 'with no adequate and updated information,' especially if the patient lives alone.

Wendy also believes the criteria for being a support worker needs to be raised. Poorly trained workers 'will do harm to participants'. She believes the support worker's job is 'to identify different issues [and] collect specific or general data [about the person] in order for doctors and specialists to make effective decisions'. 'At the moment the job is far from being satisfactory,' she said.

Regular meetings between 'support staff, medical staff, and management staff to exchange information' would give 'real benefit to the participant,' Wendy said. 'At the moment, the three groups of staff work separately, they don't even know each other.'

Wendy would also like to see the supervision and complaints system improved.

She has witnessed support workers provide doctors with incorrect information about a participant so they prescribe medications to make the participant 'quiet'.

She also has seen support staff show a 'different face' to a client in front of other people, then threaten the client about what they will do 'when it is only me and you'.

Wendy has made formal complaints about abuse and about the incident resulting in a client's death. The outcome in both cases, she says, was unsatisfactory.

Julianna

Many years ago Julianna was diagnosed with disabilities that included chronic fatigue syndrome and depression.

For more than 20 years she relied on welfare as her main source of income. 'I remained on Youth Allowance/Newstart allowance for five years... even though I was disabled,' she said.

These days Julianna has a full-time job. She loves working, but she becomes extremely tired by the end of the day and is unable to 'work around the house, socialise, or have any hobbies'.

Julianna told the Royal Commission that years of dealing with Centrelink staff – of being 'berated, belittled, and humiliated' – has contributed to her poor health and continues to have a negative effect on her self-esteem.

'[They] refused to communicate about what kind of information they needed about my disability,' she said.

This resulted in several of her Disability Support Pension (DSP) applications being rejected.

She says many of the work placements Centrelink required her to attempt were beyond her physical strength and stamina.

'Centrelink staff... repeatedly threatened me with cancellation of payments if I could not attend to their demands... which threatened my ability to pay my rent and exposed me to homelessness.'

Julianna says she didn't know that while she was unemployed she was entitled to see a social worker free of charge.

Now that she has a full-time job, Julianna no longer needs government support. But she still feels traumatised.

'I live in fear of ever having to deal with Centrelink again and I suffer from anxiety when answering the telephone to unidentified callers.'

Julianna recommends that applications for the DSP should be managed by advocates. And that Centrelink be required to tell recipients about their rights to a social worker.

Gregory, Beth and Maya

‘The fact that I experienced challenges related to access within health all through my children’s lives ... is evidence that the system needs to make changes.’

Maya has been working as a medical professional since she migrated to Australia in the 1990s.

Gregory and Beth, Maya’s children, had a very severe form of a neuronal migratory disorder. Their illness meant they were unable to move independently and required wheelchairs. Both children were non-verbal.

Gregory was diagnosed 12 days after he was born. His parents were told that he would die within a month, that he was ‘intellectually zero’ and would never recognise his parents.

Gregory did not die within a month – he lived into his early teens. Beth lived for more than three years. Maya said that over time they discovered that Gregory and Beth were actually ‘quite bright’.

When a person can’t communicate, or can’t communicate in a traditional way, Maya told the Royal Commission, ‘their lives are viewed as having poorer quality and they are viewed as second class citizens ... Many of our issues stemmed from communication breakdown or pre-judgement of a situation and decision-making that is not clinically based’.

One example of this occurred towards the end of Gregory’s life. Gregory had never had any urinary issues but suddenly he was having episodes that caused him great distress. He was groaning and crying – which was unusual because he was placid by nature and, having very weak vocal cords, rarely made a sound.

Maya and her husband knew something was wrong. Local clinicians reviewed Gregory and said he was dying. A few days later Maya realised that Gregory’s distress escalated whenever he was passing urine and that there was a white chalky discharge. The clinicians said it was probably semen and was to be expected for a boy his age.

Maya insisted on a scan or ultrasound to check what was going on. The ultrasound showed renal stones. The doctor said that the stones were in a location that would not cause any pain and she would follow up in a few days. The next day Gregory was still in distress, so his parents took him to an emergency department. The medical staff there talked to Gregory’s primary medical contact, then told Maya and her husband to take Gregory home because he was dying.

Maya refused to go home while Gregory was in so much distress, and asked them to investigate the cause.

‘I had to fight to have a request sent to the urology team to review the reason for his urinary retention.’

During his hospitalisation, Gregory's physical care needs were neglected.

'We went home for one night and came back to find Gregory lying in a bed soaked with urine and faeces. It was devastating that my own colleagues did not look after Gregory. I shudder to think about what others with no links to the hospital faced,' Maya said.

'This is only a small part of the challenges we faced ... We struggled to be heard and felt frustrated and angry about the lack of effort invested in helping us identify the reason for Gregory's distress.'

Because Maya worked in the health system she did not make a complaint. 'I did not have the strength to deal with the consequences and I was not confident about the outcome,' she said.

'I have really struggled in the bereavement period, because I feel that I let Gregory down. I feel that Gregory's pain and suffering at the end took away his passion for life and his will to live. Gregory and Beth were integral to our family and we miss them.'

Pearl and Miriam

Pearl and Miriam are sisters. Pearl has cerebral palsy, intellectual disability, epilepsy and reduced vision. She has been living in a group home for more than 30 years and for much of that time, Miriam and her family have been fighting to get the organisation that runs the group home to provide appropriate care for Pearl.

‘They seem to be able to run it without meeting the disability standards,’ Miriam said.

Miriam told the Royal Commission that staff negligence, inexperience and lack of training has resulted in numerous falls and accidents, jeopardising Pearl’s health and safety.

For example, inconsistent staff supervision of Pearl when she was using a walker resulted in her falling. Instead of improving supervision, staff now won’t allow Pearl to use a walker and she has to stay in a wheelchair.

Once, staff failed to read handover notes relating to Pearl. They sent her in a taxi to the wrong day program when she was sick, highly contagious and supposed to stay home.

Pearl has had to have numerous procedures on her teeth – losing four teeth at her last dental appointment – because staff aren’t helping Pearl brush her teeth.

Miriam said the family has made ‘endless’ formal complaints to the service provider.

‘They say they will action things but inevitably issues keep reoccurring. So frustrating that you have to keep fighting for our sister to receive a basic level of care, not [even the] high level which we expect.’

‘Our biggest worry is all the people living in this organisation ... [who] have no family to advocate for them like we do for our sister. They are the silent wounded with no-one to give them a voice or fight on their behalf.’

Pearl’s family would like to see better restrictions on employment in the disability sector and better training of health professionals dealing with people with disability.

‘My hope for the future, says Miriam, ‘is that people with disabilities are valued in the community and genuinely treated equally’.

Holland and Knox

Holland has a moderate intellectual disability and is autistic. When he left school a few years ago, his main focus was finding work.

Holland's dad, Knox, told the Royal Commission his son has tried to find work through non-government disability support services and NDIS programs, but so far everything has been unsuccessful. This has affected Holland terribly. 'He has no self-worth,' Knox said.

One employer paid Holland 'what they deemed his "work capacity" which amounted to \$15 – \$20 dollars a day (minus his bus fare)'. After a while he felt undervalued. He went to Centrelink for a work capacity review but it soon deteriorated, due to a combination of staff turnover, staff forgetting meetings and staff having 'nothing really to offer'.

At one point Holland took the initiative and handed out resumes in the local industrial area, but this came to nothing and he feels he has failed.

As a result, Holland's behaviours have started to spiral out of control. He is 'self-harming and self-medicating with alcohol' and engaging in 'risk taking behaviours'. At times he has become violent and aggressive 'to the extent emergency services have been called'.

When Holland was at school he used to regularly touch base with his psychiatrist, who would review his medication and help Knox with strategies to assist Holland. Knox found this 'highly beneficial and successful.'

Currently Holland is not seeing a psychiatrist. Knox's wife has contacted more than six in the area and has been told their books are full or, in one case, that Holland's needs are 'too high' to deal with.

Professionals have told Holland's parents that their son is suicidal, but they can't find any professional support for him. He needs to have someone with him at all times. An NDIS support worker is with him two days a week, his grandparents support him for two days and Knox's wife stays with him the remaining weekday.

'Caring for someone with a disability is hard work. Having a child with a disability is a challenge not just emotionally but financially and at times physically.'

Knox says he would like funding to be based on 'the real needs of the individual'.

'It is a struggle to have the NDIS acknowledge how desperate we are for support in this area and they can only work to a formula based on their framework and funding parameters.'

Holland needs help urgently.

'As parents, we are desperate.'

Braden

Braden is a First Nations man. He was a volunteer firefighter for almost 20 years and, as a crew leader, risked his safety protecting others.

‘[I] suffered several injuries and ... helped save hundreds of homes.’

Now, he told the Royal Commission, his ‘future looks grim’. After a serious workplace accident he has multiple injuries and lives with significant pain.

Braden has arm, shoulder and leg injuries, muscle wastage, weight loss, headaches and depression. He has ‘trouble lifting objects, typing and maintaining his property’.

Braden was unsuccessful in his applications for a Disability Support Pension and for NDIS support, so he has been relying on the Job Seeker payment, Newstart. This payment is conditional on Braden undertaking a number of job-seeking activities and appointments each month.

Braden has trade qualifications, but since the accident ‘cannot physically undertake the work’.

‘I have retrained and gained some non-trade-based qualifications but my body is holding me back.’

Braden’s payment has been cut multiple times because of his condition.

‘My benefit was cut 2 years ago for a 3-month period because I was attending a psychologist appointment, and cut for 6 months last year as Centrelink chose not to recognise the doctor’s opinion.’

Braden’s doctor advised Centrelink he could only complete eight hours of activity each week. Centrelink ignored this advice. ‘I have been pushed to do 16 hours,’ Braden said.

Braden appealed the decision. When he rang requesting an update, he was told no appeal had been received. After further investigation, a Centrelink employee told Braden the appeal request was on his file but ‘there was no information on the appeal process’. Braden believes this ‘indicates gaslighting by phone staff’.

After Braden complained to his federal MP, Centrelink accepted the medical certificate stating he was unfit to work for three months.

Centrelink resumed payments, but gave no back-pay, ‘creating massive financial pressures and stress’ for Braden.

Then Centrelink rejected the next three-month medical certificate.

Braden is currently 'suspended ... without income'.

'[I am] suffering from slow starvation, my peace of mind is under attack and my health is suffering in other areas also due to the cruel, heartless, inhumane and punitive treatment from the federal government and its welfare contractors.'

Despite volunteering as a firefighter, giving up hours of his own time, spending his own money getting to and from fires, Braden feels the government ignores him and treats him 'like a burden on society'.

Braden believes that until there are 'policy changes at a government level', people will continue to be 'unfairly treated, financially and mentally abused, ignored, negated and pushed to the edge of their existences'.

India and Farah

India has distinctive physical features and is small for her age as a result of a rare genetic condition.

When she was in her teens she needed to have some small operations at a children's hospital.

Her mother Farah said that one time, while India was prepped and waiting for surgery, 'one of the operating surgeons approached her and said straight off the bat, "So, do you go to a special school?"'

Farah told the Royal Commission she and India were gobsmacked.

'What a way to approach someone, anyone, let alone a person who was about to trust you with their life ... Not that it matters but, as it stands, my daughter obtained an almost perfect score in year 12 and is currently studying for a PhD.'

Farah said another incident occurred at the same hospital when India was in her mid-teens. A different surgeon was examining her. She was naked and vulnerable when he loudly observed to Farah, 'I'm not sure she has normal breast development.'

'[India] cringed ... what a crushing situation for her at such an impressionable age,' Farah said. She couldn't believe that these 'elite, trained surgeons' didn't understand that words matter.

'[India] has already entered this world with the odds stacked against her and the doctors purporting to care for her, who we are meant to trust, are doing their darnedest to undermine her.'

Farah wants to know why these doctors are working in major teaching hospitals without knowing their words matter.

'Words count almost as much as medical procedure.'

Cory and Kiana

Cory is a young autistic man who has attention deficit hyperactivity disorder, depression and anxiety. He also has a passion for music.

Just before Cory turned two, his mum Kiana became concerned about his lack of developmental milestones. She took him to a paediatrician who, in making his diagnosis, said Cory would 'probably die young due to social isolation and... live at home for his whole life'.

At first, Kiana says, her family felt like they had 'lost their son' before he had had any chance of a life.

Now she says the diagnoses was a gift. It meant Cory had access to early intervention, which was 'highly beneficial in helping [the family] deal with everyday living skills and managing his disability'.

When Cory got to high school he struggled socially. He was bullied by some of his peers who would spit on him on the school bus.

Cory began self-harming. 'We ended up changing schools which caused more depression and anxiety for the last years of high school,' Kiana said.

When Cory finished high school, financial assistance seemed to disappear. The family felt like they were all alone. Cory applied for the Disability Support Pension but was knocked back. Kiana says it was 'due to his disability being a hidden one'.

Cory has struggled to find and keep employment. He had a job but lost it after five months because he has difficulty concentrating.

'We would like him to be more independent,' says Kiana, 'but at present due to financial constraints while on Newstart allowance, this is not a reality.'

Kiana says for young adults like Cory, dealing with everyday issues such as Centrelink, Medicare and the NDIS is not something they can do alone.

'Living independently would be a huge benefit but not viable if [Cory] can't get a disability payment or a job with some security.'

For the foreseeable future, Cory will continue to live at home with his parents.

Nick and Yuan

‘From the moment I found out my child had Down syndrome, I spent some 300 days fighting medical odds for my son’s survival,’ Yuan told the Royal Commission.

‘I’ve heard stories from those who were pressured to abort their disabled babies, and from those whose special needs children were denied adequate care in hospital ... I’m adding my experience of both, from the perspective of a single mother and an immigrant.’

Yuan found out she was pregnant with Nick about 10 years ago. When she turned up at the hospital for her 20-week ultrasound to find out the gender of the baby, the doctors delivered the ‘bad news’ that the baby had a heart defect, a blocked bowel and it was very likely that he had Down syndrome.

Yuan was advised to get an amniocentesis test done before it was too late to terminate. Yuan told the doctors she ‘was satisfied to work with the assumption that [her] baby did have Down syndrome’.

‘I told them that termination was out of the question.’

At her next check-up, a midwife suggested Yuan take the amniocentesis test to help her better prepare for the baby’s level of disability. Yuan said she’d think about it.

At the next antenatal appointment, Yuan told the doctor she would like to get the test done. The doctor was excited, as though relieved that Yuan had come to her senses, and said they’d better get this done quickly because she was running out of time. Yuan corrected the doctor and explained she just wanted to find out the level of disability she needed to prepare for. The doctor stopped in her tracks and said the test only gives a positive or negative.

‘To this day,’ Yuan says, ‘I have no idea if it was pure ignorance by the previous person that led me to be misinformed, or if it’s just a symptom of the systemically coercive environment to terminate.’

After Nick’s birth, a doctor confirmed that he had Down syndrome, that he would need bowel surgery within a couple of weeks and one or more heart surgeries down the track. The doctor said to Yuan, ‘His bowel we can fix, his heart we can fix, but there’s no cure for Down syndrome – do you understand that?’

‘This kind of condescension,’ said Yuan, ‘... basically, the doctors think I’m stupid.’

Over the days, weeks and months that followed, there was a series of additional health complications requiring serious interventions. Yuan felt the hospital system was ‘hellbent on pressuring [her] to give up at each turn’, to withhold treatment and let Nick die.

At three months, the hospital wanted to transfer Nick to another medical team. Yuan complied because she didn't want to leave her son 'in the hands of professionals who didn't think he was worth saving'.

The new medical team came up with a breakthrough. At five months, Nick was finally strong enough for his open-heart surgery. After spending the first 217 days of his life in hospital, he was able to go home.

'Contrary to the doctors' doom and gloom even as [Nick] left the hospital ... he has thrived – all the residual holes in his heart have healed without need for further surgery, and he's the happiest little kid I know.'

Yuan told the Royal Commission, 'I made a choice to "hold it together" during this period, ... some of the medical staff interpreted my stoicism as stupidity ... I had to ask myself if it was my appearance that made them think I was some illiterate refugee, or if it was par for the course for them to talk down to everybody ...

'I'm still struggling; it still keeps me up some nights. It affects my relationship with medical professionals and with society at large (e.g. when anyone insinuates that I'm a bad or inadequate parent).

'I'm hoping that by sharing my experience, future parents can be better prepared for the insidious eugenics practised by some in the medical profession right here in Australia, accept that doctors often get things wrong, and claim their right to stand up to them when they do.'

Shawn and Teresa

Teresa is Shawn's legal guardian. Shawn has a moderate intellectual disability and went into care when he was a toddler. Now in his late 40s, Teresa told the Royal Commission, he has 'no support, no family and no friends'.

When Teresa met Shawn, he was living in a group home. She says the neglect he experienced there 'has been awful'.

There were four residents in the group home and 'often only one support worker'.

One resident was violent and constantly abused Shawn. Teresa says he would kick in Shawn's door, scream, tell him he hated him and threaten to kill him. Shawn lived with this for three years.

Sometimes, to get him out of the house so they could handle the dangerous resident, staff would tell Shawn, a vulnerable man, 'to go for a walk around the streets'.

The violent resident also assaulted staff and Teresa discovered they had evacuation plans. On one occasion staff organised to go out the window. 'But they had no plans to evacuate Shawn,' Teresa said.

Twice a week staff would send Shawn to the pub with \$20. One time a customer at the pub got Shawn drunk and 'attempted to rape him'. The house staff 'did nothing'.

Teresa says Shawn complained about his situation 'to anyone who would stand still and listen'.

One year, Teresa wanted to take Shawn interstate for Christmas, but staff at the home told her 'he couldn't leave the state as he was a state ward'.

When Teresa told them she was concerned Shawn might have a prostate problem, staff 'failed to follow up'. Teresa had to become Shawn's legal guardian to compel them to act. It turned out Shawn had a severely blocked prostate. His support worker 'didn't know what that meant' and 'failed to get his medication'.

Eventually Teresa removed Shawn from the house and he lived with her for eight months.

Shawn now lives alone in a granny flat because he is 'too frightened to live in a group home'. Teresa worries that he is lonely.

Teresa reported the situation to the state ombudsman. She wanted a record of the incidences of assault and to find out why Shawn was placed in the home. The ombudsman failed to produce anything and the case was closed.

Steve, Rebekah and Val

Four years ago, without warning, Steve didn't return home from his regular day program. Val, Steve's guardian, was frantic. After about four hours she discovered a government case worker had taken Steve to live in a home an hour's drive away.

Steve, in his early 30s, has a cognitive disability, obsessive-compulsive disorder and schizophrenia. Rebekah is Steve's advocate. She told the Royal Commission, '[Val] was deeply distressed because she realised how frightened and upset [Steve] would be at not going home.'

Steve had come to live with Val when he was a boy and thinks of her as his mother. Val taught him how to care for himself and interact with others. He went to school and was part of the community. He swam regularly, sang in a choir and played sport at state and national levels. Val helped Steve save to cover the costs of competition – he had thousands of dollars in his account.

Rebekah said Val was getting older and realised Steve would need to transition to independent supported living. She included the public guardian as a joint guardian and every few weeks Steve stayed overnight at a residential care facility. Val was not expecting the public guardian to remove him so suddenly, with no consultation or notice. She was so distraught she was hospitalised.

Steve too was in shock. 'He was totally bewildered and grieving for [Val].' The public guardian removed him from his social network, his swimming and sporting groups. 'Anything, or anyone that was familiar to him,' Rebekah said.

Val phoned Steve at the home every night to settle him. If he was too distressed the support workers would ring Val, sometimes late at night, and ask her to come 'to try and settle him down,' Rebekah said.

One time he was so distraught the support workers took him to hospital 'with his wrists handcuffed'. Rebekah said Val 'was horrified to see this young man, who in her home was gentle and responsive, had been handcuffed feet and wrists, and had two armed guards standing over him'.

Val gently told Steve to stop struggling and sit quietly and behave himself, which he did.

At the home, Steve's health suffered. He rarely ate fruit or vegetables and was constipated. He slept on a mattress on the floor. He repeatedly said he wanted to go home but was ignored.

When support workers told Val there was no money left in Steve's account, Rebekah contacted the public guardian and threatened to go to the media unless something was done immediately.

The guardian relocated Steve to a house closer to Val and his community supports. 'This was a great relief,' Rebekah said.

However, Steve's mental health continued to deteriorate and he began to self-harm. Support workers said they couldn't stop him. His personal hygiene, oral health and appearance declined. Support workers insisted they couldn't force him to clean his teeth. Rebekah said he was being restrained with medication. His exercise regime ceased and his social life was restricted.

Val asked if she could be involved in his care, but this was refused.

Initially Steve was able to have dinner at Val's home one night a week but this was stopped. He wasn't allowed to spend Christmas or Easter at her home.

Rebekah complained repeatedly to various authorities and eventually there was an administrative tribunal hearing. The tribunal found Steve's removal was unlawful and the restrictions placed on his movements were also unlawful.

'Not only was [Steve] removed, but he has been denied his liberty for four years,' Rebekah said.

'There has been constant negligence in the way [Steve]'s "care" has been undertaken, and an almost total lack of accountability by the government and those entrusted with his care.'

Gia and Mario

Gia is autistic. Mario, her dad, says most people and institutions don't understand her antisocial actions are not 'malice or explosive anger' but 'heightened anxiety, paranoia, delusions, psychosis and confusion'. As a result she has had numerous interactions with the justice system which, Mario told the Royal Commission, isn't working for people with autism or psychosocial disability.

Often Gia is violent at home. There are many triggers and 'she is very unpredictable'.

'She pinches, punches, kicks and spits, suddenly enraged over something minute.'

When the situation becomes uncontrollable Mario will 'lock the other kids in their bedrooms' while he tries to calm the situation. If he's not successful and the situation becomes dangerous, he calls emergency and prays the ambulance arrives and not the police.

If the police arrive, the problem typically escalates. If there is obvious damage, such as a smashed window, the police will lay charges. Mario objects, but 'it is apparently mandatory' in a domestic violence case.

Once Gia ends up in the legal system, her condition deteriorates.

If Gia is charged and fined, Mario has to pay the fine.

If Gia is jailed, her condition becomes much worse and she ends up in court.

The court sometimes orders medical reports and these are costly. Court attendances are time-consuming. Too often, because of funding, Gia is represented by multiple lawyers which create major problems and setbacks for her. Because Mario is the victim, Gia needs someone else as a support person, which often takes time and money to organise. If Gia is ordered to do community service, Mario is asked to organise it.

'Knowing this course of events often deters us from calling police ... and puts us at even greater risk,' Mario told us.

Mario would like a special court for people with psychosocial disabilities who 'lack capacity for medical reasons'. This court would have Legal Aid lawyers, magistrates and judges trained to understand autism. The person with autism would have the same legal representative from the beginning to the end of the process. A specialised court could organise medical reports.

In addition, Mario would be able to speak directly to Gia and her lawyer. At the moment, as the victim, he is required to bring an additional person to act as an intermediary.

'They act like an English-to-English translator, repeating everything I say to her lawyer so I do not speak with them directly.'

Mario welcomes Gia's NDIS funding, but says it is inflexible and does not cover all the care and support she needs.

Gia needs to be allowed to use her NDIS funding to give family caregivers additional support, to help in court when Gia's mental health spirals out of control, or to pay higher wages to ensure continuous quality care for Gia when she is triggered and needs specialised support.

'We have given up our jobs, and work full-time trying to keep our daughter from deteriorating further and becoming another mental health inmate in the prison system,' Mario said.

Josh and Regina

Regina is a primary school teacher in a regional town, and mother to two children with disability. She told the Royal Commission about her son, Josh.

Until recently, Josh was attending a local high school in the autism unit. He is a teenager, but Regina said he has the mental age of an eight-year-old.

To get to school, Josh was placed on a 'run' with assisted school transport. The transport picked Josh up from a location that Regina drove him to, then travelled a long route to collect all the other students and go to school.

The reverse was occurring on the way home from school. Josh was exhausted by the time he got home each evening, spending so much time in transport. Regina complained to the school about the situation for six months, but nothing was done until the grandparent of another child in a similar situation also complained.

Then Josh was placed on a run with a student from the autism unit named Tegan. 'To cut a very long story short,' said Regina, '[Tegan] began grooming my son.'

Tegan performed oral sex on Josh in the transport vehicle. Regina understands 'that some teenagers get up to all sorts of things when left unsupervised', but cannot accept that the driver of the sedan didn't know what was going on.

Regina believes the driver is still working for the transport service and is still driving other vulnerable children to and from school each day.

When she became suspicious about what Tegan was doing to Josh, Regina insisted that if they must be in the same transport, one must sit in the front and the other in the back.

But then Tegan made 'her own home-made pornography' which she gave to Josh in the transport. This was with a different driver, but with the same transport service. This made Regina fearful that the drivers were actually filming the sexual acts, or possibly even involved in the acts themselves.

'The very nature of all of this makes me sick to my stomach. My son is a vulnerable boy who has been abused and taken advantage of while I trusted that he was simply being transported to school. I am a working parent and needed to utilise a transport service to ensure my son was at school each day and brought back to me in one piece ... [Josh] is extremely distressed by the situation and my entire family has been rocked by what has occurred and no-one has been held to account over any of it!'

Learning of the situation, the school principal arranged a meeting between Regina, the welfare head teacher and the head teacher of the autism unit. This led to the local police viewing the USB with the pornography Tegan had given to Josh.

‘A child wellbeing report was generated, but nothing else happened!’ Regina said.

Tegan continued to attend the autism unit, so Regina removed Josh from the school and enrolled him elsewhere. Tegan, however, has continued to contact Josh by email. Regina is concerned because Tegan ‘has exhibited predatory behaviour and still has access to other vulnerable males in her class’.

Regina says she reported the matter to the regional director of education. She sent a letter numerous times, but never received a response.

Grace and Holly

‘No-one even told us that learning sign language was something that we might want to do, so that our daughter could have access to a culture and a group of people that could accept, support and celebrate her.’

This was despite Grace attending a ‘(not very) special development centre ... from the time she was 18 months old until preschool’ because of her profound hearing loss.

Her preschool teacher suggested Grace attend the local state primary school, but when Holly met the principal he told her, ‘Your child has a disability ... she’s not coming here.’

Holly was devastated and wanted to make a formal complaint. The preschool teacher was supportive but also suggested Holly may want to find a school that would welcome Grace. So Holly paid for Grace to attend a local religious school.

At first things were promising. The principal asked Holly to show him the technology Grace used, and told Holly he thought grade 1 was the most important school year for a child.

‘He said that he would make sure that his most experienced grade one teacher would be my daughter’s teacher. He made us feel welcome, and that we had a place there.’

But rather than set Grace up for success the school made the decision to purchase the necessary equipment only if Grace fell behind.

Grace was ‘so good at masking’ that she was several weeks behind the rest of the class before they discovered she wasn’t learning. Then they had to wait for the equipment to be ordered and for staff and Grace to be trained.

The school also failed to see past her disability and treat her as a ‘whole person’.

‘Grace wasn’t seen beyond her hearing loss ... only in relation to her disability.’

She was ‘bullied at school for several years’ because of her delayed start and disability and ‘now has a diagnosed mental health condition’.

Holly wonders, ‘If I had received support, and my daughter had been connected to the Auslan speaking Deaf community, perhaps I wouldn’t have pushed her so much to explore getting a cochlear implant.’

Grace kept refusing the implant and Holly ‘pushed her until it has become a source of anxiety and tension for her’.

Grace now receives excellent support and is getting on with her life.

‘Grace is a smart and independent young woman. She works full time, has a drivers licence, owns her own car and votes,’ Holly told us.

Holly would like teachers to stop focusing on what children aren’t doing.

‘Children should be set up immediately with the resources to succeed, rather than waiting for their teachers to notice that they are failing and falling behind their peers.’

Luis

‘As if we do not have enough struggles in our daily lives already.’

Luis wrote to the Royal Commission about his experience of the NDIA as an organisation with ‘abusive, neglect policies towards people with disability’.

Luis was born with ‘severe hearing loss’. English is his second language.

Luis works from home. He told the Royal Commission he waited a long time for NDIS support. When it finally arrived it covered only basic equipment to help with daily life and work, ‘even though this was clearly inadequate’.

The NDIS told Luis he needed to complete an assistive technology form.

‘[This] was a nightmare ... When it is finally clear that the service provider need to complete this form, for three weeks NDIS has not been able to provide any advice to the service provider about completing the form. I had to escalate and use national relay chat to continuously follow up.’

Luis lodged a complaint but, he says, the complaint process takes 21 days to run its course.

‘From the time I applied to now, 5 months have already passed – and now I need to wait another 21 days just to get NDIS to advise on how to complete a form which *they* created.’

Meanwhile, Luis says, he has been struggling through the ordeal of navigating ‘often inconsistent, incompetent and incomplete’ advice from NDIS officers with unsuitable equipment.

‘I don’t even know if I am really going to get any helpful response in 21 days either.’

Emery and Franco

About a year ago, Emery was admitted to hospital because of an ‘autoimmune issue with his kidney’.

Franco, his son, was concerned about Emery’s compromised immune system. When he was placed in a ward ‘full of infectious patients’, Franco pleaded with the hospital ‘to move him to a room with other non-infectious illnesses’. Any ward other than ‘a general ward with infectious cold and flu patients’ would have been a better option.

The hospital kept Emery where he was.

The man in the opposite bed had cellulitis – a common bacterial infection. Emery contracted this infection, causing permanent injury to his leg.

Emery also contracted ‘a lung infection which almost killed him’ and had to spend nearly two weeks in the intensive care unit. Not long after leaving intensive care he contracted another bacterial infection that ‘devoured his aortic heart valve’. Emery had to have open-heart surgery to replace the valve.

During his seven-month hospital stay, Emery told Franco ‘he was assaulted by being slapped during the night’ on three occasions. Franco reported the first assault.

‘The second time and third time, I stopped making complaints because of retribution against him while he is alone at night.’

Franco says Emery is now ‘essentially bedridden’. His leg muscles have atrophied and he finds it difficult to walk any distance. A hospital physiotherapist is working with Emery, but Franco says the exercises they are attempting are too hard for him.

‘He is dejected and deflated.’

Franco says staff threaten his father and tell him he will ‘go to a nursing home’ if he doesn’t walk.

‘He has started crying after his physio sessions, and in one case during the session, saying, “I can’t, I just can’t. I don’t want to go to a nursing home.”’

Emery describes it as a ‘torture session’.

Franco spoke with the physiotherapists about how hard it is for Emery, but says they did not listen.

GEORGIA COPPLEMAN



Artwork by Georgia Coppleman

Bryan

Bryan has Down syndrome, Alzheimer's disease and type 1 diabetes. He needs daily insulin injections.

Bryan lives in a group home managed by a service provider. He needs a support worker to carefully manage and administer the correct dose of insulin each day.

Recently, Bryan told the Royal Commission, one of the staff gave Bryan the wrong dose of insulin, which was also three years past its expiry date. This had a catastrophic effect. He had two hyperglycaemic events and required urgent medical intervention from the ambulance service.

Bryan and his mother complained to the service provider who 'conducted a full medication audit in accordance with their policies and procedures'. His mother also requested staff be given diabetes-specific training.

As a result of the training, the provider has implemented new policies and practices around the administration of medication.

While the provider has made changes, Bryan is concerned that it has a poor track record implementing verbal agreements. He would like a written document to guarantee the provider implements all action plans within an acceptable timeframe. There also needs to be 'accurate documentation relating to [his] wellbeing and any necessary requirements'.

Bryan believes much of the neglect and abuse in the group home happens because staff are poorly educated.

The vetting and training of support workers needs to be urgently prioritised and improved. This needs to include education about the rights of family members, enduring power of attorney, enduring guardianship and advocacy. 'On many occasions my caregivers have displayed a complete ignorance of these subjects,' he said.

He would also like the needs of family members to be better recognised, and for staff to 'actively develop sound relationships' with them.

Bryan hopes that one day there will be a disability system that gives him 'the same rights, monetary advantages, a safe living environment, recognises [his] social needs, physical and mental health provisions as that of an able-bodied person'.

Keaton

Keaton uses a wheelchair and requires a ventilator to help him breathe. For the past 12 years he has needed 24/7 personal care and support.

A few years ago his long-term care provider was bought by another provider. Clients were assured 'nothing would change' and 'services would in fact be better'.

Recently, however, the company advised they were ceasing services in some, mainly rural, areas.

Keaton told the Royal Commission the government department responsible and the NDIS should not allow this to happen.

Keaton's services have been substantially reduced. The 'amazing carers' who have worked with him for up to 15 years have been replaced with inexperienced support workers.

Sometimes when he has trouble with saliva or phlegm or a bloody nose, he is unable to speak and non-verbally indicates the problem that needs to be addressed immediately. Inexperienced workers 'panic when this happens'.

Support workers no longer deliver his medication or required meals via the feeding tube.

'This has put an enormous amount of stress on my wife who now has to do my medications three times per day.'

The company has also ceased support for Keaton to socialise in the community which has again increased his wife's workload.

'NDIS was supposed to be helping reduce the load on primary carers not increasing it.'

These changes affect Keaton's health, his quality of life, his relationships and marriage.

He has made several complaints and met with the general manager, to no avail. He believes the 'goal is PROFIT for the company and NO empathy for the clients'.

Keaton has also complained to his state and federal members of parliament. '[They] basically said that I would need to seek a new provider!' he said.

As a high-needs person living in a rural area, he and his wife are anxious about finding a new provider and training new support workers.

Keaton would like providers to be made accountable 'so they cannot use their clients like "pawns in a chess game" where they sacrifice them for greater rewards'.

Billy and Una

Una wrote to the Royal Commission about the experiences of her six-year-old son Billy, who has attention deficit hyperactivity disorder (ADHD) and anxiety.

Recently, a private school expelled Billy for 'non-compliance and safety'. But Una believes the fault lies with the school which did not adequately accommodate him or support him in the right ways.

'He was continually removed from class, and suspended. He fell behind academically, his self-esteem plummeted. Spoke of self-harm. HE IS 6!'

Now Billy is attending a public school, but is currently only allowed two hours of education each day.

Una says both schools were 'quick to mention' ADHD is not funded or recognised as a disability in the education system.

'Therefore not much help can be offered to what he requires to succeed.'

'Also,' Una says, 'ADHD is not funded through NDIS. Yet we (as parents) have zero funds to access the intervention he requires so as not to become a future statistic to depression, suicide and other mental illnesses associated with ADHD.'

'Our son's needs are neglected by the education system, and the NDIS system.'

'ADHD kids need better support,' she says. 'I hope ADHD is recognised for what it is, a disability.'

'This particular experience has had a huge negative impact on our family finances, mental health, and family dynamics.'

Taylor and Zara

**‘[Taylor’s] experience is not shocking or outrageous,’ says Zara.
‘It hasn’t been one or more big events ... [but] over years my child
had experienced many instances of unwitting exclusion at school.’**

Taylor has dyslexia. Zara told the Royal Commission there is very limited support available at school, but often her daughter is not able to access it. According to the school, Taylor ‘is not bad enough’ and doesn’t ‘qualify’ because there are other children who need the support more. ‘Our child still has a disability,’ says Zara, ‘it doesn’t go away.’

Zara also says that, despite arriving at school with a diagnosis of specific learning disorder and ADHD, Taylor was never issued with an appropriate individual education plan. Zara has ‘had to fight just for easy to implement things’, for example allowing Taylor to sit on a chair instead of the floor, or to access freely available assistive technology to allow equal access. ‘The school leadership is highly resistant to engaging with us on implementing meaningful adjustments and accommodations,’ she says.

‘The predominant literacy pedagogy, balanced literacy, does not work for my child, yet [Taylor has] been forced to try and learn using this. It failed and with the constant failure came poor self-esteem.’

Taylor’s school experiences include being threatened with suspension in grade 2, being made to pick up the class’s rubbish when she couldn’t draw neatly in grade 3, being told on a weekly basis throughout grade 5 to ‘just play games on the laptop’ because ‘what’s the point’, and kept in at lunch and recess countless times.

Taylor has developed performance anxiety as result of her school experiences, has taken extended periods off to deal with the anxiety and has spoken of ‘wanting to die’.

Tyson and Pru

Tyson is a middle-aged man with dyslexia. He can read only a little and cannot write at all. He also has attention deficit hyperactivity disorder and, in recent years, post-traumatic stress disorder. Pru, his mum, wrote to the Royal Commission to help her son tell his story.

Tyson had worked all his adult life and reports constant bullying and discrimination. He had managed to cope with this until a few years ago when, Pru said, 'the bullying from people who should have known better caused him to "snap" and he could not take it any more'.

Tyson was bullied by his co-workers, including his supervisors. Management did not take appropriate action when he complained, despite assuring him the problem would be 'fixed'. Tyson became aggressive at work 'with an "I will get them before they get me" attitude'. He lost his job and then began self-harming behaviour.

'He is now incapable of working and has become a recluse,' Pru said. '[He] will not socialise, does not trust people any longer, and will not go to places where there are many people ... He is a "broken" man.'

The events have also smashed Tyson's family life. His marriage has ended and he is estranged from his children. He has suffered financially too and is homeless — 'all caused by intense bullying because he had a disability,' said Pru.

'People with a disability get treated differently,' Tyson says, 'even when they are good workers. They get called names, like "spastic", and "stupid" ... I just need to be able to buy another farm and retreat to the country with some animals where nobody is going to bully me ever again. I will never be able to work again.'

Tyson is grateful for Pru's love.

'My mother has been the main person who has supported me, and has listened to me every day when I really needed somebody to talk to who understood.'

Jennifer

Jennifer has a disability and is also a support person for a friend with disability.

She told the Royal Commission about her recent experiences as a hospital inpatient. She said health professionals ‘will lie by omission of information, at every chance they get, in order to comply with their workplace policies and treatment practices’.

Jennifer experienced doctors and nurses leaving out relevant information when seeking patient consent for treatment.

‘They have also shown that they will neglect to inform the patient of their health progress if they feel it may reflect badly on medical procedures they have used,’ she said.

‘Further doctors will threaten patients with involuntary treatment orders if the patient questions their practices or tries to ask for clarifying information about their treatment.’

Jennifer said that in her experience, medical staff will often dismiss the concerns or questions of patients with disability in the belief ‘they know better’. She said they routinely fail to provide clear information at a patient’s communication level.

She also said unless a patient has someone aggressively advocating for them, medical practitioners will ‘simply railroad a disabled patient into their own goals’.

Sullivan

Sullivan told the Royal Commission that more than 30 years ago he was involved as a legal professional in a coronial inquest into the death of a toddler with Down syndrome. Now retired, Sullivan says this case 'still haunts' him.

Sullivan said that the 'well cared for and much-loved child' was described in the medical notes as a 'social problem'.

He said the doctor ordered that no intubation be provided, resulting in the child's subsequent death from whooping cough.

'The distraught foster mother took to imploring parents outside the emergency department to ensure their children were properly cared for,' he said.

'The coroner's finding was a whitewash.'

Kenny

Kenny is in his late 30s and has post-traumatic stress disorder. He has experienced violence and abuse at the hands of police and hospital staff.

‘On one occasion I have had my front door kicked in and been beaten by four police officers, and on another I was beaten by six officers ... both without justification, and in both cases the guilty parties knew that I was a vulnerable person,’ he told the Royal Commission.

‘I have also been beaten on a number of occasions by the security staff of ... [a] local hospital, on one occasion being thrown into the floor face first before the poor administration of a variety of drugs, and on another, I was thrown to the floor by six security guards and had a knee jammed into my back leaving bruising.’

One day, Kenny said, he was detained by eight officers for no apparent reason. One of them told Kenny, ‘I’d shoot you, but I don’t like paperwork.’

Another time, Kenny was beaten by a hotel employee on a cigarette break. He tried to seek assistance at the local police station. Kenny said the police officer asked him if he was homeless. Realising he wasn’t, the officer told Kenny to ‘go home and sleep it off’.

‘Police need to be correctly trained to deal with vulnerable people in a safe, calm and respectful manner,’ says Kenny. He wants to see victims of crime who have disability ‘respected and dealt with in a proper manner’ and ‘their concerns treated in the same way as anybody’.

Glenys

Glenys is in her 40s. She is autistic and lives with dyslexia and a work-related injury.

A couple of years ago, she turned to a service provider for help.

'I went there for counselling, nothing more, but somehow I ended up in the public trustee system,' Glenys told the Royal Commission.

The provider was the 'driving force' behind the move to have the public trustee appointed as her financial guardian. Glenys had no say in the matter and no-one informed her of the grounds for the decision. She said the government agency ignored her human rights and unfairly presumed she was 'incapacitated' because of her disability.

'They never approached my family or friends about my capacity, or my doctors. They just made the decisions on a paper hearing without even a face-to-face meeting with me. Originally when the public trustee got control, they wanted to sell my assets including my house and put me into a group home. And then take over everything and my family wouldn't have any say on anything either.'

She'd spent years trying to 'overcome' her disability with education and training.

'Not to be put in mental, financial or psychological prisons ... This goes back to people's prejudice and internal values, not what's legally right for me.'

But the public trustee threw a spanner in the works there too.

'They decided on my behalf to put me on disability benefit and the NDIS, when I wanted paid employment. They took me off further study plans that I had.'

The agency didn't pay her bills on time, incurring extra costs. Glenys said staff demonstrated 'coercive, controlling behaviours and unethical behaviour'. There was no duty of care, 'extremely poor communication, a lack of transparency and no internal complaints system'.

Recently, she succeeded in having the trustee removed as financial administrator. Initially it refused to relinquish control.

'I was flabbergasted when it sought a second and even a third order despite the evidence I had presented to the courts that I was capable of looking after all my own affairs.'

Glenys still has 'ongoing problems with the public trustee'. The agency is 'holding on' to her mortgage and banking details and is still on all Glenys's bills.

'It looks like I'm not capable, so banks won't deal with me directly. They just tell me to go away.'

Until the trustee hands back her files, she is unable to engage with a disability employment provider.

'It's not their right to choose if I'm employable or not, but they've made those decisions and now I can't re-enter the paid employment market and I'm stuck on volunteering. It's turned my life upside down and I'd like to forget it altogether, but unfortunately, I'm still caught up in it. And there doesn't seem to be any way out because no-one's taking responsibility or accountability.'

Glenys wants to see 'a conflict resolution system' set up within public trustees.

'So that court is not the only option. And an oversight body to keep public trustee systems honest and fair.'

Meanwhile, the service provider has never apologised for the harm and hardship it inflicted.

'So I presume they just don't care. They should reflect on what the client's needs really are and what is the person's wishes and goals.'

Instead of empowering her, Glenys said the provider used 'suppressive tactics' to take her choices away. It gave evidence to a tribunal and excluded her 'mentally, socially and emotionally' from decisions concerning her.

'The decision-making power needs to be given back to us. It's about what we need and what we want, not what the institution thinks we want.'

Gabriella

‘When I left child safety, I could have been taught how to be a mum, how to protect a child. I shouldn’t have been told I would have my kids taken away from me.’

Gabriella is in her mid-20s and has intellectual disability. When she was in primary school, child protection services placed her in care after her mother’s partner sexually abused her.

Later, in her early teens, they put her in a juvenile detention centre. ‘I was at a lot of different schools. I was hanging around with the wrong people,’ Gabriella told the Royal Commission. The agency warned her that if she ever had children, they would take them away from her.

‘I didn’t like it ... that they said that. That made me feel like I couldn’t have kids, that made me feel worried.’

But that is exactly what happened a few years ago when Gabriella fell pregnant with her first child.

Child services registered Gabriella’s mother, who she was living with, as primary carer of her daughter, despite their ‘problematic relationship’. Gabriella said it was ‘very stressful and confusing’ because the agency had seen fit to take her off her mother when she was a child.

‘It’s almost like double standards ... I couldn’t go anywhere with (my baby) if mum wasn’t with me.’

A couple of months after giving birth, Gabriella and her mum had a fight. The government removed the child from the family altogether. Gabriella’s social worker, Sarah, told the Royal Commission there had been ‘no allegations of neglect ... no signs of neglect’.

Gabriella said that in foster care, her child went from being ‘a happy, smiling little girl to a very sad looking baby’. She saw signs of neglect and abuse.

‘When she first went into care, she used to come to visit with really, really wet nappies. She had bruises on her toes ... she had lice in her hair. She never had bruises on her apart from when she went into child safety’s care.’

Gabriella told child protection officers she would not give her daughter back ‘because she’s been harmed’. She wanted to speak to her lawyer, but they refused.

The agency eventually placed three of Gabriella’s children in foster care. One child was taken from her at birth.

‘She did everything she could to fight to get them back,’ Sarah said. ‘Then bang, they’re home.’

The government recently returned the children to Gabriella without helping her get any supports in place.

'So they take the kids because she's got an intellectual disability, but they won't do anything to then help her because she's got an intellectual disability,' Sarah said. 'If you wanted to know the wrong way to go about doing things with someone with an intellectual disability, they've done it.'

Gabriella told the Royal Commission that people with intellectual disability can be good parents. She's finding it 'challenging but doable'. If she'd been given the right supports in the first place, things would have been different.

'Child safety should have found me a house, they should have found me people to have around me. They took my network away from me when they took my mum away. They should have made sure I had people who were like a family to me.'

Tahlia and Mauricette

Tahlia attended a high school with a special education unit for children with intellectual disability.

‘We felt that she would be afforded every opportunity to grow and develop and become the best person that she could be,’ her mother Mauricette told the Royal Commission.

There were ‘quite a few boys’ in Tahlia’s class who ‘displayed different behavioural issues’ and ‘were a lot bigger than her’.

Mauricette said that a year into her schooling, some of these boys sexually assaulted Tahlia in a classroom.

‘They were fondling my daughter’s breasts and vagina. They grabbed her hand and were putting it on their penises.’

Mauricette later found out that one of the boys had sexually abused several other students.

‘He had a history of sexualised and harmful behaviours and numerous suspensions ... We were led to understand that there was a support teacher who was supposed to be monitoring him at all times. So why was he allowed near [Tahlia] or any other girls given his previous behaviours?’

Tahlia’s parents met several times with the school following the incident.

‘[We asked] them what they were doing about, well, number one, supervising what was happening in the school. How they were educating our young ones regarding safe behaviours and being able to look after themselves ... They were never forthcoming with the information.’

During a session with a counsellor a couple of years later, Tahlia revealed that another student in her class had raped her.

‘Tahlia said her teacher removed her from class after the rape and told her to ‘pee on a stick’. When Tahlia expressed discomfort at being in the classroom with the boy who raped her, the teacher told her to just ignore him.’

Despite knowing about the rape, the school never told Tahlia’s parents.

‘We had no opportunity to have her medically assessed or to make choices about whether we kept our daughter in that institution. It just feels criminal that as a family we were never given that information.’

Mauricette learnt the school had also been aware, prior to the rape, that the perpetrator had been threatening Tahlia.

‘So, you know, I’m wondering, where is the person who is supposed to have eyes on him? Where are the teachers who are looking at what’s happening in the playground?’

She said the school failed in its duty of care and that neither the school nor the education department took responsibility for what happened to Tahlia.

‘The lifetime impact that it has on [Tahlia], you know, where education is to build us up, to make us stronger, to give us opportunities. The outcomes have been, well ...’

Today, Tahlia is dealing with the ongoing trauma and her family is ‘working on her anxiety and ability to be around other people’.

‘She’s a very bright, bubbly, happy by nature human being.’

Mauricette remains concerned that ‘underlying issues’ and failures of the school and the department are ‘not being addressed’.

‘And that’s scary.’

Laura-Jane and Katerina

Laura-Jane is in her 30s and has an acquired brain injury.

'My daughter was seriously injured ... in a car accident and received compensation,' Katerina told the Royal Commission.

Because Laura-Jane was a child at the time, the money went to the public trustee to pay for support services and accommodation. Katerina said Laura-Jane eventually bought a house with the money.

'I did have carers come in, but then my marriage ended and I said I would take over the care, but [the trustee] just abused that because they wouldn't pay for any extra care to come in.'

Katerina said she didn't apply for guardianship.

'Looking back, you know, I should have done that. But because she lived with me and I was her carer and her mum ... nobody ever said to me that that's what you need to do.'

The public guardian was appointed to oversee Laura-Jane's affairs.

Several years ago, Laura-Jane was assaulted in her neighbourhood. Because she and Katerina no longer felt safe, the trustee agreed to sell the house so they could move.

'They told me when the house sold ... to go find something else to purchase, which I did. Now they told me that I could only spend what the other property had sold for.'

Katerina found a suitable property, but because it was a few thousand dollars more than the previous house sold for, the trustee 'didn't follow through on the purchase'.

'They sold her property and did not purchase another one and left [Laura-Jane] and I homeless.'

Under pressure, Katerina asked a relative to take Laura-Jane 'for a few days'.

Laura-Jane never came home. The relative persuaded the trustee to let Laura-Jane buy another house, and moved into the new house with her.

'I'm going to try not to get emotional, but I feel like I've been living a nightmare for many years.'

Katerina said she hadn't seen Laura-Jane for several years until the relative recently invited her to visit.

‘She’s been neglected with what I’ve seen ... Her hair was sticking to her head it was that dirty ... She’s not allowed to come down out of her bedroom until [others] are fed ... She has to watch TV in her room on her own.’

After a few months, the relative stopped Katerina visiting. When Katerina contacted the public guardian, they told her Laura-Jane didn’t want to see her anymore.

‘I’ve never ever believed that to be true because [Laura-Jane] and I have always been so close ... [She’s] too scared to speak up in front of [the relative],’ Katerina told the Royal Commission. ‘Every time I went there she said, “Mum I’ve missed you so much. Where have you been? I want to spend more time with you.” And she’s struggling and I seriously do not know what to do anymore.’

Katerina said she’s applying for a review of the guardianship.

‘I have watched [Laura-Jane] struggle all her life with her disabilities. And for her to have to endure something like this on top of what she has to deal with, it’s extremely unfair.’

Solene

Solene is autistic and in her 50s. She lives with post-traumatic stress disorder and depression.

‘My first encounter with the mental health system was because I felt suicidal,’ she told the Royal Commission. Mental health workers gave Solene electroconvulsive therapy. They said it was in her ‘best interests’ because she was treatment resistant.

‘I didn’t fully understand. I knew by then the word schedule, I knew I could be locked up and things be taken away. And that’s when my story starts going downhill.’

Solene says the treatment gave her an acquired brain injury.

‘From that point on, it exacerbated my autism. As a result, I have a degenerative – like a dementia thing. So then, I needed the support.’

Solene was already on the NDIS, but the agency wouldn’t increase her support.

‘Then I become homeless and nobody cared.’

After staying in a couple of homeless shelters, Solene moved into a group home run by a disability services provider.

Solene said the way staff at the group home treated people with intellectual disability and mental health problems was ‘intolerable’. Support workers locked Solene out of the common areas when she was having a meltdown.

‘And that went on for two days. It was very abusive. I had workers yelling at me. Like, I’m in a meltdown and they’re keeping me in meltdown ... For an autistic person to have a meltdown for even an hour, like the toll on yourself it’s ...’

Solene went for days without medication because staff refused to give it to her.

‘I had a PRN [medication that is taken as needed], and I was able to say when I needed it, and I knew, like, I could have one tablet to calm me down.’

At the home, Solene witnessed the deaths of two people with mental health issues, that were ‘completely preventable’. One man barricaded himself in his room wanting to kill himself. Staff ‘dawdled around’ for hours before calling the police, by which time the man was dead. Workers ignored another man who was saying, ‘I can hardly breathe, I’ve got massive pain.’ The next morning, he was found dead on the kitchen floor.

At another home, Solene faced ‘repetitive, restrictive practices’ that included locked gates and doors.

'I was left in the house, I was in shutdown. I was left for months – no staff, no food, no anything, and the NDIS knew. I was completely terrorised.'

Once she rang the police in desperation.

'[The house manager] goes, "Well, it's behaviour, look what we have to put up with." And the police would leave and they would never believe me.'

She wants police to treat calls from people in disability accommodation as domestic violence.

'Police need to be aware that most if not all of these calls are not from people making it up. There's literally nowhere to help.'

Solene said the NDIS Quality and Safeguards Commission failed on its promise to fully investigate her complaints.

'A lot of this stuff is criminal. It's not, "Oh, we're going to just hear this and do nothing.'"

Soizic

‘If you are disabled then, by definition, it is okay for you to be hurt.’

Soizic is in her 40s and has cerebral palsy and complex post-traumatic stress disorder.

Growing up, her brother hated her because he was embarrassed to have a sister with disability. At school, children pushed her into animal faeces, chased and hit her and put her on the monkey bars and pulled on her legs.

Soizic told the Royal Commission her teachers contributed to ‘the normalisation of violence, harassment and abuse’ of a person with disability.

‘If the teachers hadn’t been so complicit in everything that was happening with the school, I wouldn’t have learnt that it was alright to actually be treated like that.’

Teachers warned her to ‘get used to it’ as she would be ‘discriminated against and treated badly’ her whole life.

‘It’s expected and therefore accepted, or at least kind of tolerated. We figure that it’s inevitable that disabled people are just going to suffer. And, I mean, the overall impact has been absolutely catastrophic. I actually think that if I hadn’t been abused, I would have had a completely different life.’

Soizic said she was raped and sexually abused several times as a young adult.

‘And then, once you layer in the abuse on top of disability and all of a sudden, my body’s not just something that’s contemptable, now it’s actually also become a crime scene.’

She ‘wound up further isolated and excluded’ and struggled for years to get adequate supports. Today she has far more support.

‘I’ve got NDIS funding and I’m very fortunate and I can get my therapy and that’s fine. But there’s a limit to what you can get.’

Soizic has a nurse support her for several hours a day, but finds it’s much harder to receive assistance and care for her trauma.

‘Because the mental health system is broken and there’s not enough money for everybody to get the therapy that they need.’

She believes this comes back to the ‘worthiness’ society places on individuals.

'There's an issue of us viewing disability as something that comes out of neediness. It's an able-bodied world and we're just going to try and tweak around the edges as best we can for disabled people. You know, that second class citizen thing, and we should be grateful for what we get. I've certainly had that experience in the NDIS.'

Soizic has overcome huge barriers of 'systemic ableism' to have a successful career.

'I'm just grateful to have a seat at the table at all in a world that fundamentally does not belong to me.'

But she said a lot more needs to be done to make work and public places accessible to people with disability. She can't access many education and health settings in her wheelchair.

'We're 18 per cent of the population. Every single place in society should be a disability setting.'

Recently she was at a rehabilitation hospital and 'couldn't find the disabled loo'. Then she realised that 'every single toilet in that building was a disabled toilet', so there was no need for signage.

'Part of me did not want to leave that toilet. I felt more dignified and seen and part of that community at a hospital than I feel anywhere else in my life, except my own house.'

Davey and Billie

‘I know people make petty comments and petty complaints. But this is about our sons or our daughters who are non-verbal. They’re not petty, you know, we just want them to be treated with respect.’

Billie is the single mother of several children with disability. Her son, Davey, is in his 30s, autistic and non-verbal.

‘I got cancer ... and after all the treatment I put [Davey] into care,’ Billie told the Royal Commission.

Davey needs a lot of support and it took Billie some time to find a service provider that that could care for him.

‘[Davey] gets overly anxious and he will bite or hit or headbutt and some of the staff wouldn’t listen to the triggers that would trigger him and basically said they couldn’t handle him.’

Davey eventually moved into a supported independent living (SIL) home with several other men. Billie said the home initially was poorly managed and many of Davey’s possessions vanished.

‘We’d lost probably, it would be over half a dozen iPods and headsets over the years, because staff would take them off him and you’d never find them again. And management would go, “Oh yeah we’re looking into it.” You never heard anything.’

It was only when a new house manager started several years ago that staff ‘started to treat the boys as human beings and as adults’.

Under the new manager, a small group of dedicated long-term support workers also made sure the home looked like a home and not ‘a sterile box with a couple of little wooden chairs’.

‘They put pictures up on the wall and all that stuff, which really for the first time ... it was kind of a bit more homely than what it had previously been.’

The regular staff ‘could read [Davey’s] moods to defuse any behaviours that might start’ and got to know what the residents liked to eat.

A couple of years ago, the house manager left and the service provider decided to move the group home’s long-time staff to another home.

‘They were switching houses and they were bringing in other people that didn’t have a clue about the behaviours of the boys and wouldn’t listen to the staff who knew the boys.’

The new staff also changed the menu.

'The regular house staff previously, for the last four years, had devised a way to get vegetables and healthy foods into the boys ... And [Davey] really ate really well at that time.'

Davey refused to eat the new food and one day staff found him unresponsive in bed. They called an ambulance, but later told Billie he was only 'a little sick'.

'[Davey] was in a bad way when he was brought to the hospital in an ambulance.'

Billie employed a dietician, who found the service provider's food wasn't appropriate or nutritious.

'After we got the report from the dietician ... within 24 hours I got a, "[Davey] is to move out."

The service provider evicted Davey. Because he needs 24/7 care, Billie struggled to find another SIL provider that could accommodate him.

'We ended up in the motel for eight weeks.'

Billie ended up employing Davey's long-time support workers, who quit the service provider to work unpaid helping Davey transition to a new SIL. The workers later started their own small service provider and still work with Davey.

'They are probably the most gentlest, caring people ... They're in my top three people who have dealt with disabled people over time ... They accommodate and treat him as a human being for a start and as an adult and I can't speak highly enough for these guys.'

Filippa

Filippa is a First Nations person in her 30s who has a rare congenital disorder, bipolar disorder and post-traumatic stress disorder.

After Filippa left an 'abusive relationship' with her husband, she became involved with another man who would 'quite often be forceful ... sexually'. A few years ago he tried to kill her.

'He punched me in the back of the head ... then he put his hand around my neck and started choking me.'

Police charged the man, but Filippa told the Royal Commission she received no support.

'I was told straightaway that I will be contacted by someone from domestic violence crisis service. And I didn't hear anything from them until eight months later.'

Around this time, she was diagnosed with bipolar.

'And I was still navigating that ... I expected that I would have some difficulty dealing with the trial.'

Filippa was unable to get an appointment with a psychologist so she 'could kind of prepare for things'.

'I kind of fell through the cracks and there was nothing out there.'

The office of the director of public prosecutions told her she could have a support person present while she testified.

'But then on the day, the court sheriff didn't let my mum come in with me. And we were made to leave as soon as I was finished. And I hadn't had time to even try to calm down. We got outside and I ended up wetting myself, which just make me feel even more humiliated about the situation.'

The trial was rendered invalid and set for another date.

'Everything just got too much for me and I ended up attempting suicide because I didn't feel like I could go through it all again ... That resulted in my children being removed from my care and I was in hospital for five weeks.'

Filippa said child protection services spoke with her mother instead of communicating directly with her.

'If they had actually come out and spoken to me and given me the assistance I had asked for, things would have been different.'

She feels the agency ignored her because of her psychosocial disability.

'They continually told me that they were there to help me and that they didn't want to keep me from my son. Then they handed him over to my ex despite the fact that he hadn't seen him since he was 7 months old and had made no effort ... I was made to feel like I had been the abuser.'

Filippa hasn't seen her children for months. She feels legal help should be more forthcoming.

'Having the mental health issues that I have, it's hard to be able to reach out when I'm struggling at the best of times. This year alone, I've seen my psychologist 14 times. If it wasn't for the fact that I had been approved for the NDIS, I really wouldn't have any supports in place.'

She's relying on that ahead of her next appearance at the children's court.

'I'm basically doing everything in my power to try and keep my mental health as stable as possible so that no-one has anything that they can use against me when it comes to me trying to get my kids back.'

Neill and Dervla

Neill is in his 50s. He is autistic and has epilepsy.

‘Before mum died I made her a promise that I’d look after [Neill],’ his sister Dervla told the Royal Commission. ‘And we lived together happily for, you know, nearly 15 years.’

Dervla gave up her career to care for Neill in a public housing flat, where for years she made up for the shortfall in his support services.

‘I was chief cook and bottle-washer for everything and we did the best we could with what we had and we were really happy. It was tough, but he was happy. He was independent.’

One night several years ago, Neill had an epileptic seizure on the toilet and fell. He didn’t appear to be badly hurt that night, but in the morning Dervla took him to hospital.

‘That’s where the doctor made the bad mistake and he said there was nothing wrong and he sent us home.’

The next night, Neill had another seizure on the toilet.

‘His neck, which was actually fractured, was bashing up against the cistern as he was convulsing. The fractured neck cut through his spinal cord.’

At the hospital, Neill’s heart stopped. Doctors resuscitated him but then told Dervla the hospital might not let the spinal injuries unit (SIU) treat him.

‘His life didn’t have that same value. He was going to make no economic contribution to society. He was going to cost the system and, you know, the only place for people like that’s a nursing home.’

Dervla eventually persuaded the hospital to admit Neill to the SIU, but after several months the hospital stopped his support services.

‘I’m dealing with these strangers who ... don’t know his life, who know nothing about him, who have subjective ideas, who work to a formula that they slot everyone into and I thought I had the right to say, “Well, no, I don’t want that.” And of course I did. So I was viewed as being obstructive.’

Dervla had been managing Neill’s finances to this point. After breaking his neck, Neill’s NDIS funding rose to nearly a million dollars. Dervla found a new wheelchair-accessible flat for the two of them so she could continue to care for him when he was discharged.

The hospital, however, applied to have a public guardian appointed – it didn’t consider Dervla ‘a suitable guardian’.

‘Shocking, terrible things [were] written about me,’ Dervla said.

After a tribunal appointed a public guardian, the hospital discharged Neill, against Dervla’s wishes, into specialist disability accommodation (SDA) ‘miles and miles away’.

‘I can’t get there. I don’t have my own transport.’

Dervla said there appears to be collusion between the hospital and the guardianship board, and between Neill’s public guardian and his service provider.

‘I’ve had that ability to honour that promise [to care for Neill] taken away from me ... He’s had so many infections since he’s been there, I’m fearful. I’m fearful that he’s going to die there without me. I want him back. I want him to be with his family.’

Davie

Davie worked as a builder for a large disability service provider for several years.

Not long ago, he began a major home modification for a client who uses a wheelchair.

It was an older home and Davie was worried there might be asbestos. He immediately contacted his manager who told him there was no mention of asbestos in the paperwork.

Still concerned, Davie spoke to the senior builder, also the team supervisor, who had conducted the initial inspection of the property.

The builder told him there was no asbestos at the property.

Davie and his colleagues began demolishing parts of the home and took the material to the local rubbish dump.

The client and his wife stayed in the house during the demolition and remained in the house that evening.

Davie and the other workers returned home to their families and children.

The next day, they continued the demolition.

Davie told the Royal Commission that he pulled off a panel of sheeting and found an asbestos sticker on the back.

He immediately stopped work and sent a sample for testing. The test result was positive for asbestos.

Davie told his manager that the builder had 'blatantly lied' about the presence of asbestos at the site.

'The response of, "Why do you care? You're a smoker," was just gobsmacking,' he said.

Davie lost it, and reminded his manager they had exposed the client – a person with disability – to asbestos.

Davie's manager agreed to file an incident report with the building authority.

Shortly afterwards, Davie received a written warning 'for using bad language in an aggressive manner'.

A week later, Davie discovered the manager hadn't filed a report. He contacted the CEO who fobbed him off, giving him information Davie knew to be false.

Davie decided to report the incident himself and made further enquiries about the job.

He discovered the builder had never conducted an asbestos assessment. Yet the quote for the home modifications included almost \$3000 for the removal of asbestos.

Davie found other irregularities in the quote, including charges for several hours of report writing that they didn't do.

'Multiple items on there that they're getting charged for that were never going to happen,' Davie said.

'[The provider] has been issuing fraudulent quotes to clients by including disinformation on items and services, and including additional, unnecessary hours on the quotes submitted to the NDIS and other funding providers.'

Davie continued to investigate and discovered the provider and another organisation had shared information about their quotes, agreeing to inflate certain costs.

He asked an independent builder to provide a quote so he could get an idea of what the job should have cost. He discovered the provider was charging the client with disability more than double market rate.

Davie resigned and gave all of the information to the client, telling him, 'If you ever get sick, or any of your family, this is yours.'

He reported the provider to a number of different agencies including NDIS Fraud Reporting and Scams Helpline, to the NDIS Quality and Safeguards Commission and police.

'Retelling the story over and over again is emotionally exhausting. Knowing how people with a disability have been deliberately taken advantage of, for personal and company gain. I was foolish that I believed my senior staff for years. The realisation that it is simply a money grab is enraging.'

Izz

Izz, early 30s, is Deaf and non-verbal. He doesn't lip-read.

He came to Australia as a toddler with his parents, who are from a culturally and linguistically diverse background.

Izz's first language is signed English. He learnt pidgin Auslan and Auslan in primary school but his signed English was stronger because that's what he used at home.

'As a Deaf student, every day people were nasty, pushing me and bullying me,' Izz told the Royal Commission. 'Some of the teachers weren't qualified in their communication style in signed English.'

In year 1, a new hearing teacher of the Deaf started. Her signed English and Auslan were poor.

'She was cruel and nasty and used to yell and scream and point her finger and would pick on me and the other Deaf students.'

The next year, the school moved Izz to a class with students with intellectual disability. His year 1 teacher taught the class.

'She would smack me on the bottom if I couldn't speak properly or she couldn't sign. I wasn't able to lip-read or communicate with her so she would physically hit me.'

Izz was a very active child and each time he moved, the teacher would smack him.

'I didn't have an interpreter to explain what was happening ... and there was no sign to explain what was going on.'

Over the next few years 'the physical abuse was worse and worse'.

Izz tried to tell the school but no-one believed him.

When he fell behind in his education, the school sent him to some mainstream classes with an interpreter.

'I cried a lot and I didn't want to go into the hearing class. It was a terrible experience.'

Class photo days were distressing.

'I just felt traumatised and crying and scared. I didn't have an interpreter. I didn't know what was going on, and they said I had to go there and smile and put on happy face and be part of that group.'

Izz's parents pulled him out and homeschooled him.

In high school, Izz was forced to learn Auslan.

'They said that I'd only pass if I used Auslan.'

Izz changed schools several times.

'I'd be in mainstream with no interpreter. I was very stressed,' he said. 'I felt really lonely ... I just didn't have any friends.'

University was much better, and Izz used Auslan.

Following university, Izz got a job at a government agency.

'I was so excited to be in there, [but] it was a horrible experience. This woman who was my boss ... was just abusive. She just did not understand how to work with people with disability. She thought I could just lip-read everything.'

Izz told his boss the law required her to give him access to interpreters.

'Every time that I raised this with her she would get really angry and say just do your job and just lip-read people. She would really make my workplace a living hell.'

Izz said people would tell him to get a cochlear implant, learn to lip-read, get some speech therapy and learn to speak.

'The government really needs to open up to people with disability who are Deaf and Auslan users. It was very hard.'

Izz became depressed, lost weight and couldn't sleep.

'But I wanted to work. I wanted to earn a wage and do my job.'

Izz spoke to a counsellor at his workplace. The counsellor suggested it might not be the right job because of his mental health issues.

Izz's GP disagreed, believing the agency's refusal to provide the necessary accommodations was the problem.

He encouraged Izz to make a formal complaint.

'My culture means that I should be quiet and I don't complain. That's how I was raised. And as soon as I've ever raised anything I've found that the bullying gets worse and that people don't understand.'

Izz left the job.

Jenni and Marcia

Jenni, early 30s, has a genetic disorder.

She has progressively lost speech and motor skills since childhood, and needs help to move and eat.

Jenni moved into a group home about five years ago. The home was a two-hour drive from her sister Marcia, but the only option available.

Jenni settled in and appeared happy. Staff were experienced and qualified and provided excellent care and support.

The following year, around the time of the NDIS rollout, there were several staff changes.

Marcia told the Royal Commission the quality of Jenni's care declined significantly.

Staff started to puree meals for all the residents.

'One of [Jenni]'s pleasures is eating and that would have been a massive change for her,' Marcia said.

'They are cooking one meal for everyone and it doesn't matter whether you can eat it or not. A stir-fry for instance, they are pureeing that and then trying to give it as a meal.'

During COVID-19 things got worse. Jenni wasn't able to go to her day program and staff rarely took her out of her room.

Jenni's health deteriorated.

The house doctor doubled her epilepsy medication and increased other medication. She became drowsy and sleepy and couldn't eat and her weight dropped below 30 kilograms.

Marcia complained Jenni was dangerously underweight and her medication levels were too high.

'It was met with defence from the manager of the house ... And then as we got further and further up the chain, it became more and more aggressive in how they behaved and how they spoke to us. Telling me that it was my perception that she was underweight, and it was to do with her condition.'

Jenni started to scream out in pain.

Marcia got her to hospital but doctors couldn't find the source of her pain and sent her home.

This continued a number of times until Marcia insisted they admit her.

‘We were told that it was behavioural even though it wasn’t. We were told ... if we did run tests and we did find out there was cancer they wouldn’t treat her because of her disability. It wouldn’t be worth it.’

In hospital, staff refused to shower Jenni or feed her and they refused to give her any pain medication.

‘The way in which they treated us and her was probably the most horrific thing that I have ever been through in my life.’

Staff told Marcia to ‘face the fact’ Jenni was dying.

One day, Marcia was changing Jenni and noticed stones in her nappy. She picked them up and googled them and discovered they were kidney stones.

Doctors refused to believe her.

‘My age was brought into it, the fact that I was not a doctor, the fact that I was female. I was basically told over and over again that I didn’t know what I was talking about.’

Instead, doctors decided to insert a feeding balloon into Jenni’s stomach.

Marcia did everything she could to stop the operation.

The hospital tried to have the family removed as guardians but were unsuccessful.

Ultimately, they ignored the family and operated on Jenni.

A day after the operation the balloon burst. Jenni had to wait days to go back to surgery to have it repaired.

Marcia contacted one of the world’s leading specialists in Jenni’s disorder. She discovered doctors should never have prescribed the epilepsy medication Jenni was taking because it is known to cause kidney stones.

The specialist spoke to Jenni’s doctors and they stopped the seizure medication and treated her kidney stones.

‘I even had one of the doctors say to me that the operation was probably unnecessary because the entire time it had been the kidney stones that had caused the pain.’

Marcia eventually got Jenni out of hospital and out of the group home.

She is living in a unit by herself with 24/7 support.

Jenni has gained weight and is slowly transitioning back to eating regular meals.

Angeline and Dora

Dora is in her 40s and autistic. Her teenage daughter Angeline is also autistic and has attention deficit hyperactivity disorder (ADHD), depression and anxiety.

‘While she was really young, we had huge behavioural issues with her,’ Dora told the Royal Commission. ‘[But] we didn’t know she had a mental disability until [she became] violent at school.’

Dora said Angeline is becoming more aggressive, but struggles to get help in her regional town.

‘If we were in [the city] they’d be able to send more qualified staff in to help us. We’ve been through about 21 carers in two and a half years, and five or six of those carers quit after their first day.’

Dora said Angeline appears to have an undiagnosed personality disorder and wants her admitted to hospital for an assessment.

‘I see this switch go on and off in her and she just gets this look on her face ... because then all of a sudden she’ll switch and she’ll be crying and apologising and then just start all over again.’

Dora said when the local hospital refused to review Angeline’s medication a couple of years ago, she took her to a city hospital.

‘Unfortunately she punched a nurse there and ended up in jail.’

The hospital discharged Angeline into police custody without a mental health assessment.

‘They pulled her hair the whole time dragging her from one cell to the other. They left her in a padded cell for over an hour with handcuffs on and she was crying out for her dad. She was banging her head against the wall.’

Dora said police held Angeline overnight because she refused to sign a bail form.

‘Why should a young child with a disability be expected to sign a bail form that ... she’s not understanding?’

After she returned home, police arrested Angeline for breaking into someone’s house.

‘I was begging for an admission just into the local hospital just so she wouldn’t end up in jail.’

Recently, Angeline tried to cut Dora’s throat.

'I saw her out the corner of my eye and I've turned around at the last second,' Dora told the Royal Commission. 'I didn't go into hospital. I thought I needed to, but I didn't. [The wound] pretty much closed up overnight. I didn't go into hospital because I was scared she would get arrested.'

Dora said although the attack was unprovoked, Angeline's psychiatrist refused to admit her to hospital for an assessment.

'And I said, "Surely this is the actions of a psychotic person." And [he said], "No." I said, "Does she have to kill me before you can give her a hospital admission?" I literally said that to him in a meeting. But there's just no response at all. He just won't budge.'

Dora has an appointment to see a new psychiatrist but 'it's a three-month waiting list'.

She says there is a program in the city that could help Angeline control her behaviour, but the NDIS won't fund it.

'They're saying this is mental health, so they're trying to handball it back to the mental health. The mental health team was saying, "No, this is behavioural." ... So I feel like there's a big issue between disability as national and the mental health services are state-run. And I don't even know what to say about that.'

Eveline

‘I had no choice who I lived with ... Mum got no say in it. I got no say in it.’

Eveline, a First Nations woman in her mid-30s, is autistic and has intellectual disability and obsessive-compulsive disorder.

Growing up in a small town, she had limited access to education and support.

A disability case worker convinced Eveline’s mum that a group home would be able to provide tailored support and training programs. In her mid-teens, Eveline moved to a group home in a regional city about 10 hours’ drive away.

Initially she was excited because she had her own room.

‘The next week it didn’t feel so good,’ Eveline told the Royal Commission.

One night, staff wrapped her up in a doona, put her in the back seat of the car and drove her to another house.

‘They put me in a little room, no windows, no door handle, felt like a cupboard. I think I was there about a week.’

Each time Eveline ‘had behaviours’, staff drove her to this house.

‘Once I heard them speaking to my mum and I started banging and screaming and yelling so my mum could hear. I was in there for weeks. It was just me.’

Staff would hold her down on the ground and pin her arms and legs behind her back.

‘Two workers ... took me to the laundry and put water in the sink and put my head under the water and tried to drown me. They didn’t say why they did this.’

Eveline’s mum discovered what was going on and tried to get someone to help her. Staff kicked Eveline out of the house and told her not to come back.

She was homeless for about eight months.

‘I was freezing cold or really hot, and hungry and thirsty ... I felt scared and alone, no help.’

Once, Eveline went to police and asked them to take her back to her mother’s house. They told her to go away.

A man found her and took her to his house.

‘He raped me in his house. I ran away and I hid. I didn’t tell anybody at first.’

A group of guys found Eveline and took her to their farm.

‘They kept me hostage there in a room for months ... They tied me onto the bed.’

If she ran away they would chase her and bring her back.

Eveline became pregnant and miscarried.

‘Blood went everywhere. I had no help, nothing.’

She eventually managed to escape. Someone found her and took her to hospital. Staff rang Eveline’s mum who came to pick her up.

‘I was really thin and my feet were all cut up.’

She was too afraid to tell police about what had happened.

Eveline’s mum made an official complaint to the disability department, and Eveline was placed in a group home for people with mental health issues.

‘There was lots of abuse, pushing me and restraining me lots, and I had lots of bruises. I got drugged up a lot to go to sleep, the workers spat in my food.’

Eveline’s mum made another complaint and Eveline went to another group home.

‘All other homes I saw a lot of bad things happening with other clients. It was scary ... When the staff don’t like you then that’s when they abuse you or attack you.’

Eveline tried to tell her mum what was going on.

‘If I was talking to mum, they’d say, “Hang up the phone right now!”’

Eveline started to see a counsellor and told her everything that had been happening. Staff got angry at her for ‘dobbing staff in’ and stopped her going.

Her mum continued to make complaints and eventually got her out of the group homes.

Eveline now lives by herself in a house with a big backyard. She has a licence and a car. Support workers help her shop and go to appointments.

‘I suffer from post-traumatic stress disorder ... I have painful memories and keep reliving the painful memories again and again.’

Mary-Lou, Pedro and Georgette

Georgette is mother to two autistic children under the age of 12, Pedro and Mary-Lou. Both have NDIS funding, but Mary-Lou's plan was reduced by half in 2021. This left her without vital supports just as she was starting back at school.

'We had just had my son's review and he'd got this wonderful package, Georgette told the Royal Commission. 'And when we got her report back, I just kind of looked at it and go, "What? You're kidding me." And I pretty much like burst into tears. And I'm just like racking my brain as to why her funding was cut.'

Mary-Lou has higher needs than Pedro because she has level 2 autism.

'He's level 1, so he's more functioning ... I feel like their plans need to be the other way around.'

Mary-Lou needs more speech therapy and respite care but the new plan overlooked that.

'We'd gotten reports from all her specialists, recommending all the things that she needed. Because she's missed out on two years of schooling. She started school in 2020 when the pandemic hit ... When we got her report back, I'm just like, 'What? Did they even read any of the information?'

The cuts to Mary-Lou's plan followed a 'phone consult' and relied on 'cookie cutter' decisions and outdated information.

'What I want to see is more of that face-to-face contact rather than over the phone ... because I feel like they don't believe you sometimes, especially after her last review.'

Georgette feels it comes down to the luck of the draw. Pedro's got a good support worker, which has made a remarkable difference in the standard of care he receives.

'But no-one's really telling me how to go about getting a support worker for [Mary-Lou]. And I'm watching this 8-year-old hate school and hate life, because she doesn't have those supports there.'

Georgette fears this is setting Mary-Lou up for failure.

'If she was given access to all these things, she wouldn't be such a burden on the general population as she gets older ... You don't want them to be reliant on, you know, government payments. You want them to be able to get a job and have friends.'

Georgette recently got a glimpse of the benefits of more outside-school supports for Mary-Lou, when she went on a camp.

'I spent the whole weekend on the edge of my seat going, "Am I gonna get a phone call?" But she had an absolute ball. And it's good to see the smiles back on their faces after missing out on so much. And just neurodiverse children being able to have those experiences and being supported in those experiences.'

Glen

‘She wanted rid of me because she was scared of me because I had a disability.’

Glen has intellectual disability, epilepsy and brain damage caused by seizures. He works as an assistant at a large professional practice.

About two years ago, a female colleague made a complaint that Glen had touched her inappropriately.

Glen told the Royal Commission the allegation was ‘complete crap’.

The practice manager immediately suspended Glen.

‘They did an investigation, they didn’t assume things and they found out it was completely unsubstantiated. Then I was allowed back at work.’

The woman wasn’t happy about the outcome and went to police.

‘Four police came to my work ... and they humiliated me in front of everybody. Staff were walking by.’

Glen asked to go someplace private but police refused. They immediately started reading out the conditions of the restraining order.

‘They were saying all this stuff that I’m not allowed to do ... and jumping to kind of conclusions, and people walking by,’ Glen said.

‘I was embarrassed and humiliated and intimidated ... People just jump to conclusions.’

Glen’s CEO came and spoke to police. Police gave the CEO a copy of the restraining order without asking Glen’s permission.

Glen phoned a friend and former supervisor, and police read the conditions of the restraining order to her.

‘I explained to them that [Glen] was a severe epileptic and the amount of stress and pressure they were putting him under at that point was unacceptable, and they needed to back off a little bit – they were really full on,’ Glen’s friend told the Royal Commission.

Glen’s lawyer said police did not have to behave that way and should not have given the restraining order to the CEO.

Later, Glen went to the police station with a friend who is a disability lawyer. Police didn’t want to listen to him or give him any information.

Glen feels police believed the woman and thought he was not telling the truth because he has a disability.

Glen wasn't able to go to work for several months because of the restraining order.

Glen's lawyer asked police and prosecutors not to contact Glen directly because of his disability.

But police visited Glen's house unannounced late at night to try to get more information from him. Glen says he felt harassed and pressured by police.

Eventually the court decided the woman's claim was unsubstantiated and the restraining order expired.

'There was evidence at work that [the woman] was lying. She kept on changing her story.'

Glen returned to work but people started treating him differently.

'I was looked at as some creep.'

He discovered the woman 'had told everybody at the clinic' her story.

About a month later a second woman accused Glen of touching her.

Glen was able to prove he had never met this woman – they worked different shifts.

'It seemed like a vendetta.'

Police turned up at Glen's home and were very aggressive. They immediately treated him as a criminal even though he'd never met the second woman.

'Apparently you can't make the same accusations a second time, you know, for another restraining order. So, they got another girl to do it.'

A second restraining order was issued, and Glen couldn't go to work.

Ultimately, police didn't have enough evidence and the magistrate ordered the restraining order to be withdrawn and dismissed.

Glen is scared he will lose his job even though he didn't do anything wrong.

'Now my work is saying, "Just because it's unsubstantiated, it doesn't mean that it didn't happen."'

Other women in the workplace are now saying they are scared of Glen.

Clarice

‘As far as I’m concerned, when I see the Prime Minister on TV I should see an interpreter. Because how do Deaf people increase their knowledge about the political system and be part of civil life in our country if Deaf people can’t access the information?’

Clarice is in her 50s and a child of Deaf adults (CODA).

‘I’m what you would call a CODA, growing up in a bilingual home where I learnt to sign before I could speak and then later learnt to speak in English,’ Clarice told the Royal Commission.

As a CODA, she was often expected to interpret for her parents.

‘My mother had quite serious mental health issues ... and there were many times that I would attend medical mental health appointments with her and interpret ... quite disturbing types of questions.’

Clarice became a professional Auslan interpreter in schools. She said it’s ‘baffling’ that education departments don’t employ more interpreters and teachers fluent in Auslan.

‘Deaf children are more and more integrated into mainstream schools and there is no standard of provision of access for those signing students to qualified interpreters. I just think that is absolutely abominable.’

She said when Deaf students leave school, they still struggle to find good interpreters. For example, in most hospitals there’s a telephone interpreting service for spoken languages, but nothing similar for Auslan. There are also few interpreters in the legal system, especially for Deaf First Nations people.

The COVID-19 pandemic was a boom time for Auslan translators, but Clarice said the media often ‘cut them off or [didn’t] show them in an appropriate size on the screen so that Deaf people could view the information’.

‘The people that they appointed for these roles were absolutely inappropriate. They did not have the skills and ... I was actually told by one agency that we’ve got to give these interpreters a go, give them some practice, and I was just horrified.’

Clarice said there should be a minimum standard of training for interpreters. For example, the NDIS is ‘fantastic’, but some poorly-trained interpreters are taking advantage of Deaf people.

‘People who have NDIS packages can hire people who are not qualified to interpret as interpreters. Now I don’t know what is in the legislation for the NDIS or other professionals such as OT [occupation therapists], speech therapists, but I would be sure that people cannot hire those professionals without them having some form of a qualification.’

Clarice also said there are too few interpreters in government.

'If Parliament wasn't accessible to those in wheelchairs then, you know, there would be a big uproar, so changes need to be made,' Clarice said.

'I don't see the same uproar about the [Deaf] citizens of this country being unable to access our government ... I just find that absolutely shameful and discriminatory.'

Leonna

Leonna is in her 30s and has post-traumatic stress disorder (PTSD) and myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome.

She told the Royal Commission that doctors diagnosed her ME nearly 15 years ago when there was 'no medical pamphlet ... so [she's] just been discovering what it is'.

'I would describe life for me like living a tunnel with no light at the end basically. And you just have to keep going because you know that if you stop that's it.'

Since her diagnosis, she's struggled to find appropriate support. Leonna doesn't qualify for the Disability Support Pension and only recently received an NDIS package for the physical and mental injuries ME causes.

'I would collapse, I would faint. I couldn't make it through the shifts ... The thing that scars you, that gives you the PTSD is how you're treated by medical people and how you don't have a future and you have no security or stability.'

Leonna said she now struggles to feed and care for herself.

'I've had the NDIS for a whole year and I have support coordination and I have fought so long to just get jointly recognised with my physical disability and the mental disability.'

The NDIS supports Leonna for a couple of hours a week 'for transport, medication, doctors' appointments'.

'I am not entitled to nursing through the NDIS or home care that I need. And I go into hospital and then the hospital people say, "Well it's your disability. It's the disability [provider's] role to do the follow-up and to do the home care." And then the disability people will [say] that's the health care people.'

Leonna can't afford rent and lives with her mother, who is violent.

'She encourages me to suicide. Earlier in the year she tried to choke me, but I couldn't report it because there was nowhere for me to go.'

She said she still struggles to have her disability treated appropriately.

'I'm not asking or expecting a solution or a cure or anything like that, but I just want my existence, and other people that have this, [recognised] ... There's plenty of scientific evidence and plenty of people have it and it's well-documented. And so I just think that the needless suffering should stop.'

Aj and Renae

Aj, in his 50s, has Korsakoff syndrome and an acquired brain injury.

After acquiring the brain injury about five years ago, Aj was in hospital for six weeks. The hospital then discharged him to an aged care facility.

Renae, Aj's ex-wife, said the hospital gave the family no choice. It was either the aged care facility or home.

'We couldn't take him home – he needed 24-hour watching.'

Renae said the facility was 'awful'.

'The smell, the food quality, the treatment of the patients, they would be made to sit on their beds all day, every day ... It was just so sad.'

Aj's next home was a supported independent living (SIL) unit with four other residents. When he acted aggressively one day, management called police who arrested him and then had him admitted to hospital under an involuntary mental health order. No-one called the family.

'I had to ring around all the police stations and find him ... I found him and I copped it from the police. They were like, "It's not our fault. We, you know, we seen him, he was angry." And I was sort of like, "Did you not realise you picked him up from a care facility? Did you ask any questions?"'

Eventually Aj was able to tell Renae why he'd been aggressive. He and other residents had been doing physical work for the manager 'all day' and when he asked for a can of coke she wouldn't give him one.

'So the whole thing, he got arrested over this can of Coke,' Renae said.

Aj had no mental health issues so the hospital put him in a general ward. He spent weeks there while the family tried to find new accommodation for him. Finally he moved into another SIL unit.

'The workers were lovely, we enrolled him in a gym program for socialisation and he was going shopping ... We felt like we were moving forward.'

Aj was receiving a Disability Support Pension and NDIS funding and had been approved for additional support. But there was a delay in the payments. One day when Renae arrived to visit him, Aj wasn't there. The manager had moved him to another unit.

'I went to that unit and I opened the door, the place was filthy, there was no furniture in there, not a fridge, not a lounge ... The smell in there was horrific, it was just horrific ... I was just broken by it – even today, you know, four years down the track. It was so cruel, so cruel. And then, you know, [Aj's] just standing in the corner crying because he didn't know what to do either.'

The manager was unapologetic.

'He was like, "Well, you know, I needed my funding," blah, blah, blah. "If you haven't got money, this is what happens."

After that, Aj moved into a privately rented unit. He had different care providers and new problems of bullying, negligence and or exploitation. Renae made two formal complaints to the NDIA. The agency took months to respond and did not take any action.

Aj is finally in a better situation now, with care arrangements that are working well.

Renae told the Royal Commission that there is no help for people like her.

'When we start out, we've got no idea with this stuff. No idea whatsoever. We're relying and trusting these people and they're letting us down. They're charging extraordinary amounts of money ... and they're getting away with it. If we put in a complaint, we get nothing out of it,' she said.

'That's the biggest reason that I've actually wanted to join in here today, to highlight the amount of people in a short period of time that have ripped me off, and caused me anguish, and they've delayed the process of these people in their healings and settling wherever they may be.'

Blythe

‘I have a lot of friends on the [Disability Support Pension] DSP as well who are looking at properties and all of us face the same issues. We’re all just trying to get by and we shouldn’t have to only live in share houses.’

Blythe is in her 20s. She has rheumatoid arthritis, fibromyalgia, chronic fatigue syndrome and anxiety. She has trouble walking, but lives in a flat on an upper floor.

‘Currently my mum pays half my rent,’ Blythe told the Royal Commission. ‘I have a two-bedroom place and I have support workers and it means I can have, like, my art space on the floor, and I can have a friend stay over, so I can be my own person.’

Blythe is searching for a new flat that’s affordable and has fewer stairs.

‘Trying to find like an accessible property, there were I think two places I found that I thought were ground floor. And so I’m lucky, in a way, that I don’t like have a wheelchair, I don’t have to have room for that. But going upstairs is tricky.’

When Blythe applied to rent the flats, she revealed her disability.

‘I did say, “This would be so good for me.” And while I recognise they can’t necessarily prioritise they, yeah, I was rejected for both of them even though I’ve got a [good] rental history.’

Blythe said to rent a flat she has to reveal her Centrelink income which shows that she has a disability.

‘Because they can’t ask “What disability?” they might automatically think that, maybe [I’d cause] property damage. Or, you know, they could assume anything. And I had no way of kind of proving to them that I’m disabled but well enough, or whatever.’

The NDIS supports Blythe and she has a support worker several hours a week.

‘Pretty much anyone can kind of become a support worker. I know there are NDIS little [training] modules and things [and] I literally signed up this afternoon and did two modules in like half an hour and I was like, “This is the training they get?”’

Blythe said some support workers sent to help her were unable to do much.

‘I’ve had one worker who ... was terrified of cats, she was terrified of main roads, she didn’t like elevators. And all individually are kind of fine, but I’m like, “Why are you a support worker?”’

Many of the support workers sent to her were university students who wanted temporary or part-time jobs.

‘It’s almost like a hospitality job kind of thing that they’re just getting into it for a couple of months and then leaving ... and for people with disabilities, like, I’ve been on NDIS for nearly a year and a half and I’ve had maybe eight workers so far, support workers.’

Blythe said she’s been ‘really lucky’ with her workers, but worries about other people with disability.

‘It feels like there should almost be a minimum qualification for workers, for example like mental health first aid.’

Toosey

Toosey is in her 30s and lives with bipolar disorder, complex post-traumatic stress disorder and alcohol dependence.

She told the Royal Commission that in her early teens she was sexually abused by the man she later married.

‘I was groomed ... I was entrapped essentially, because I relied on my abuser to provide me with alcohol and drugs.’

The marriage was a violent one.

‘He would continually abuse me physically and emotionally.’

A few years ago, she punched her husband while trying to escape. Toosey wanted to get a domestic violence order against him, but he convinced the police to turn the DVO around on her.

‘That’s what he does. When I tried to leave, he had me admitted to a psychiatric facility.’

Toosey had 10 admissions to mental health wards over the next couple of years. When the couple separated, the Family Court awarded him custody of their three children because of her mental health history.

Toosey felt the police and court system offered her no protection. She says that ‘any domestic violence victims who have a disability’ find it ‘incomprehensibly hard to prepare a DVO application by themselves’.

Toosey wanted police to issue a ‘cross-order, where two people have domestic violence orders against one another’, but they refused.

‘This provides for an environment where vulnerable and disabled people are not only ignored by the police service, but made to live in an unsafe environment ... Police were aware of historical child sexual abuse that occurred to me by my estranged husband. They have still not invited me to make a formal statement regarding that.’

Under state law, Toosey said, the child abuse she reported to police had ‘no impact’ on her ex getting custody. ‘It shouldn’t matter that it’s historical,’ she said.

Currently, Toosey doesn’t see her children.

‘I’m only allowed two phone calls a week. And sometimes they don’t happen. I have a letter of recommendation from my psychologist ... for me seeing the kids on a graduated basis.’

Police still haven’t acted on the allegations concerning her ex.

‘The fact is, he is now still controlling me. With my children.’

Talitha

Talitha's sons are autistic and have attention deficit hyperactive disorder (ADHD).

'They're both also identified as gifted and that's not some kind of humble brag,' Talitha told the Royal Commission. 'That means that there's a high IQ which is identified through testing.'

Doctors diagnosed Talitha's sons with autism only after they developed anxiety and struggled at school.

'My eldest son was about 10 by the time he was diagnosed ... If something had happened sooner perhaps we would've been better able to handle this. Perhaps better accommodations would've been made. Perhaps a lot of things.'

Talitha said a number of doctors told her not to worry as she struggled to cope with her eldest son's behaviour.

'We had a family GP who dismissed my taking him [for a diagnosis] and [me] saying I wasn't coping for a seven-year period ... We had already seen a specialist developmental paediatrician at two points over a 12-month period [who] dismissed it as, "Oh he's just a bright, sensory child.'"

Talitha said her eldest son started primary school as a 'beautiful, bright inquirer and he was gifted', but had his love of school 'knocked out through years of unmet needs'.

Her youngest son, who is advanced in reading and has a high IQ, also developed anxiety.

'He had a teacher who ... focused on red lining everything he had written and that's because [he] couldn't spell well ... And I would say to her, "Are you sure there's not some kind of hidden disability here? You know, what is going on? Why, if he's having trouble picking up spelling, is his reading so advanced?"'

When he failed a couple of subjects he was 'forced out' of his private school.

'It's so terrible because he thinks he is dumb and he won't to go school ... He reads many years above his age level. His understanding of concepts is profound. But he's failing.'

Talitha said gifted children with autism who have no visible intellectual disability are 'slipping through the diagnosis system'.

'They might get labelled instead as the ADHD, autistic, dyslexic child and that masks their giftedness. So you might think, "Oh well that's not a big deal because, you know, they're coping. Obviously that bright intellect is helping them cope." But it's masking, actually, trauma.'

Talitha said the education system can't meet her sons' needs and to prevent more trauma she is homeschooling them.

'The number of women who are hidden with children at home because they cannot attend school, [women] who are so highly qualified, have so much they desperately want to do and can't.'

Sid

Sid is in his 50s and is partially paralysed. He lives with chronic pain, post-traumatic stress disorder, anxiety and depression.

A few years ago, after an operation, he asked his service provider for a support worker to drive him to an appointment.

'I didn't think it would turn into what it did,' Sid told the Royal Commission. 'It was terrifying.'

Sid said when the worker picked him up she at first drove 'very gently' around speed humps because of his operation.

It was a hot day and when she couldn't find the address, she became aggressive.

'She went into three businesses asking, "Is it here? Is it here?" ... she'd left me in 37-degree sun, and ... I just said, "Look can we just go home?" ... She lost the plot.'

The support worker drove fast and aimed for the speed humps.

'She would accelerate into the base of them and the car would launch and then she'd accelerate again when it landed so it would go "bang". And I'm there screaming because my body's had enough.'

Sid said she drove past his street and kept going. When she started to slow down several minutes later, he reached for the door ready to jump out 'and she took off again'.

'I just kept saying to her, "Why are you doing this?" ... She just wouldn't stop the car. And then at one point she turned the music right up full bore and she said, "I drive better like this."'

Sid said she eventually turned around and left him on the street near his house.

'I got out of the car, [she] threw my backpack and my iPad on the driveway and smashed it, got in her car and drove off.'

Sid said when he reported the incident to the service provider, the provider told him the support worker had 'received appropriate feedback and [been] counselled'.

'I just wanted someone to say that she's not going to do it anymore to anyone. I don't know if she's even still working there. I don't know.'

He said a service provider executive told him to replace the broken iPad using his NDIS package. The provider then charged Sid for several hours of support work at \$165 an hour, even though the car trip was less than an hour.

Deirdre

Deirdre used to work as a manager in different organisations providing NDIS-funded services. She left the sector after six years.

‘I just couldn’t deal with what was going on within that industry any more,’ she said.

Deirdre identified two main issues common to all the organisations she worked at.

‘Firstly, the training is, I was going to say poor but non-existent is probably a better way of putting it.’

She told the Royal Commission that widespread labour shortages make it very difficult for service providers to find workers.

‘There’s no people to hire ... At one organisation, they literally just have people on the street and go, “Oh, would you like to come in and work for us?” And I’m not actually being flippant about saying that. It did happen.’

‘So we’ve had unqualified people, we’ve had people who have been 18, 19, 20, quite young, no experience with people, with some quite severe behavioural issues I suppose that they had to manage. And that wasn’t a good experience for the employees but it definitely wasn’t a good experience for our clients either.’

She described this as one of the ‘biggest issues’.

‘That people just didn’t have any training going onto their first shift and they just had to wing it, which would explain why sometimes things just aren’t done right because they formed bad habits from other people who have formed bad habits. And it just is a roll-on effect basically.’

Deidre is also concerned about the ‘really poor governance and oversight’ within the organisations she worked for.

‘By poor governance I mean poor financial management, poor people management. There’s a lack of integrity and transparency in some of it as well, around the way that they seek their funding, or they report things or not report things depending on if they think they’re going to get in trouble for it.’

Deirdre told the Royal Commission about an incident at a supported living home, where CCTV footage showed a support worker bullying one of the residents. When Deidre and her team investigated further they found the supervisor at the home was absent for much of the time.

‘When we looked into it, we could see other incidents or heard about other incidents that had happened, but nobody in the home was going to actually raise it and say, “Hey this is a problem.” It wasn’t until we had a new starter come on board and say, “Hey, you know, this isn’t right. I’ve been other places and, no, no, I’m not okay with this.” If it wasn’t for that person, this could have continued indefinitely.’

At another home, restrictive practices were common. The residents were supposed to be taken on outings but actually didn't leave the house for months at a time.

'The lives of the staff were made easier by ignoring the needs of the residents,' Deirdre said.

Deirdre believes leadership in the industry needs a 'really big cleanout'.

'They understand the nursing side and they try and focus on that, but then the leadership side and the governance side starts to fail. Whereas if you get someone in there who's got leadership experience but not really the nursing side of things, then the nursing side can start to fail. And trying to find those people who have got both skillsets is like a unicorn in an industry that doesn't have enough people to start with,' she said.

'And there very much is a culture, I'll say, of coverup, but it's actually got more to do with the oversight of it. They don't even really need to cover it up because no-one's looking. There is no safety check in place to make sure that these things don't occur.'

Suzie

Suzie, in her late 20s, lives with schizophrenia, obsessive-compulsive disorder (OCD), fibromyalgia and other health issues.

Suzie said she has been stigmatised because of her 'invisible' psychosocial disabilities, especially by the medical profession. One doctor told her she was just using her OCD 'as an excuse' to avoid work. When she presented with suicidal ideation at a hospital emergency department, a nurse told her that if she really wanted to take her own life she would have succeeded by now.

'I was seeing a regular GP who was treating me for my mental health issues and I was seeing her for years and years and I started developing chronic pain,' Suzie told the Royal Commission. 'Didn't want medication or anything like that, I was just like "Can we do tests, can we explore it?"'

The GP told her it could be fibromyalgia or it could be psychosomatic.

'They were convinced it was all in my head because of my previous history and I couldn't get them to do any tests.'

Suzie consulted another GP, without revealing any of her mental health history. The GP referred her to a rheumatologist, who told her she had a 'textbook case' of fibromyalgia.

'Life is a lot simpler without having other diagnoses clouding – it's quite tricky,' Suzie said.

Suzie's psychosocial disability has also made her vulnerable in relationships. At one point she had an abusive partner – 'someone who preyed on me being heavily medicated ... someone who used that disability to isolate me, to remove me from my family.'

Suzie was dependent on this person.

'I had no understanding of NDIS at that point. I didn't know I could get support workers. I had no-one checking up on me. And I don't think the hospitals really gave me any information about that either. I had no info.'

Suzie only became aware of the extent of the abuse after taking herself off her medication. She had a habit of doing that, she said, and 'for once' it worked in her favour.

'It wasn't really doing much for my symptoms but it was clouding my cognitive function to the point where I was a bit of a zombie, so I was very easily manipulated and was just a bit of a potato. So as I came off that I was a bit more aware of what was going on.'

With the support of her mother, Suzie left the relationship and moved back in with her parents.

About a year later Suzie reported her ex-partner's assaults to police, who told her there was nothing they could do. She believes this was because of her mental health history.

'He was able to get away with everything that he did because of my disability. The police didn't take me seriously,' she said. 'It was crushing.'

Suzie is the single parent of a young child. She told the Royal Commission this makes her fearful of 'broadcasting' her disabilities.

'You hear horror stories where people don't think that you can be a decent parent with a disability. If I didn't think I could be a decent parent I wouldn't be doing it, but it's very tricky.'

She is reluctant to seek support for the same reason.

'There's too much stigma around at least this kind of disability to even ask for support. Because the minute you ask for support they start going "Well, you're not a good parent then," and it's just not worth it.'

Rowena

Rowena is in her late 20s and lives with schizophrenia, post-traumatic stress disorder, anxiety and attention deficit hyperactivity disorder.

‘On a more personal note my interests are volunteering in the LGBTIQ community, riding motorbikes and partying on the weekend,’ she told the Royal Commission.

‘I’m someone who has a pretty well-rounded tertiary education. I have financial stability that a lot of other disabled people don’t. I have a strong support network who really look out for me and I’m in a reasonably well-paid job ... Even so, I experience a lot of risks and vulnerabilities that members of the general public never have to deal with or understand.’

Several years ago Rowena admitted herself as a voluntary patient to the mental health unit of a city hospital. The process required an initial assessment. ‘People usually spend less than 24 hours in that assessment unit. I was there for four days,’ she said.

Ten minutes into their first meeting, a psychiatrist told Rowena she had borderline personality disorder (BPD). In front of Rowena, she discussed with nurses the possibility of administering a medication just to get her out of the hospital.

‘At the end of the first meeting I was highly agitated and distressed.’

Rowena said that in the days that followed the psychiatrist was ‘dismissive’.

‘She felt that my severe distress was funny.’

Rowena’s employer supported her to work while she was in the mental health unit, but the psychiatrist was ‘outraged’.

‘[They] said that if I was really someone with a psychosocial disability I’d be unemployed like the rest of the patients.’

When the hospital discharged Rowena, it offered her no assistance.

‘I was lucky that a friend was able to pick me up at no notice.’

She also found that in her discharge notes the psychiatrist had written she considered Rowena to have a cluster B personality disorder. Rowena said she made this assessment without any formal diagnostic process.

'I don't consent to this being on my record and no-one has ever explained to me how this could be removed. I consider this to be an abuse of power and, to be honest, when you're a neurodiverse person the world is antagonistic because of the way that we engage, communicate, move our bodies for example. We don't react well to micro-aggressions because after a lifetime of them we get sick of it. But that doesn't mean that we have BPD!'

Rowena shared several recommendations with the Royal Commission.

'Number one is treat us like human beings. It's a really basic one but it's one that so many people get wrong. One example that comes to mind is by giving us choices.'

Another is to ensure psychiatric facilities are 'more livable'.

'It's important for us in psychiatric facilities to have access to therapeutic and recreational opportunities that support that recovery model and don't disempower us the way that the staff did to me.'

As well, value lived experience.

'Unfortunately, I find that the health system does continue to privilege that clinical experience and professional qualifications above lived experience.'

Rowena remembers one nurse at the hospital who did support her. His partner had bipolar disorder.

'He actually told the psychiatrist at least once that how she was talking to me was not okay, and that made a big difference.'

Laurinda

‘It’s not direct bullying, it’s more like, “Oh we have to make adjustments for you. We have to make adjustments.” It’s the unsaid things.’

Laurinda, mid-40s, has cerebral palsy and uses a wheelchair.

Growing up, everyone encouraged her to walk.

‘If you didn’t walk you weren’t normal. You had to make yourself able-bodied, like you had to hide everything about you.’

Laurinda pushed herself to do the same things her siblings and friends did.

‘Whether it meant that you stayed up all night preparing your stuff, you just did it.’

Laurinda studied to be a teacher and had a positive experience at university.

‘I lived on campus, it was fabulous. I made the best friends of my life because all of a sudden everyone had grown up, and everyone was close by – my mobility issues weren’t a problem.’

The university provided reasonable adjustments and gave her extra time to complete her studies.

Not long after she graduated, she got her first job.

‘I went in as an able-bodied person – I didn’t actually declare that I had a disability.’

Laurinda tried to hide her disability as much as she could. She never went to the staffroom because she couldn’t carry coffee cups and other items and didn’t want to ask for help.

‘I really didn’t understand the implications of my disability. I was just so busy trying to focus on getting through every day. I didn’t really realise that it wasn’t normal to get home and just crash on the couch and have no social life.’

After a while ‘it was very obvious’ she had a disability.

She started to experience more pain and lost mobility.

‘I set the classroom up in a way that meant the children could help themselves to a lot of things.’

Eventually she broke multiple bones in her feet and toes trying to walk, and needed to use a wheelchair.

‘Schools are not accessible. They have stairs. And for the children with disabilities there might be one room in the school that is accessible, but it doesn’t mean it’s accessible for staff.’

Laurinda told the principal she had a disability and asked for reasonable adjustments.

The principal wasn’t sure what to do and put her on limited, non-teaching duties. The principal didn’t understand that reasonable adjustments ‘did not mean less’.

One of the students used a wheelchair, and the principal would make comments to Laurinda that she wasn’t as disabled as the student.

‘At the time I went, “Well no, I’m not.” But I am. I just have longer arms and longer legs.’

After a while, Laurinda asked to return to the classroom.

The principal refused because she didn’t believe Laurinda could set up the classroom to accommodate her wheelchair.

Laurinda applied for a permanent position hoping things would improve if she didn’t have to apply for jobs so frequently.

The department refused because she wasn’t ‘able and willing to work anywhere at any time’ because of her disability.

Laurinda ended up leaving teaching.

‘I’d love to do it again, I’d jump at it.’

Donnie and Rachelle

Donnie, now late teens, was diagnosed as autistic in early primary school.

The principal refused to accept the diagnosis.

‘He honestly believed Donnie was a behavioural problem. He was a bad kid,’ Donnie’s mum Rachelle told the Royal Commission. ‘So that’s how he continued to treat him. And he had the teachers believing the same.’

Rachelle organised the autism association to come to school and speak to the principal.

‘He still refused to accept that my son had any issues.’

In year 3, Donnie’s anxiety became so bad he couldn’t leave the classroom.

‘He would shut down. Not make eye contact. Not speak. Not engage with anybody ... It was very hard to connect with him once he was in that state. And it could take an hour for him to actually come back and acknowledge people, or talk to people ... That was his coping mechanism.’

The principal saw Donnie’s behaviour as defiance and refusal to do what he was told.

‘He would actually pick him up by the back of his jocks and the neck of his shirt, and carry him out of the classroom kicking and screaming.’

Several parents at the school contacted Rachelle after witnessing the way the principal treated Donnie.

Donnie’s anxiety escalated and he refused to get out of the car at drop-off. Rachelle would walk him in and sit with him for 20 minutes until he got comfortable and relaxed.

‘But the principal said that this was unacceptable, and I wasn’t allowed to hang around. He would actually restrain [Donnie] ... and would make me leave the school.’

Donnie stopped going to the toilet at school.

‘His toileting issue worsened and he experienced many stomach pains and accidents.’

Donnie became frustrated and his meltdowns increased.

Rachelle tried to get the school to develop and follow an independent learning plan for Donnie.

But the principal didn’t support the plan and teachers only participated on an ad hoc basis.

Rachelle made an official complaint against the principal.

She believes there was an investigation but the department didn't communicate with her or offer Donnie or her any counselling or support.

The education department reassigned the principal to administrative duties, but after a couple of years moved him to another school.

Initially high school was okay, but teachers failed to consider Donnie's history and what he had been through.

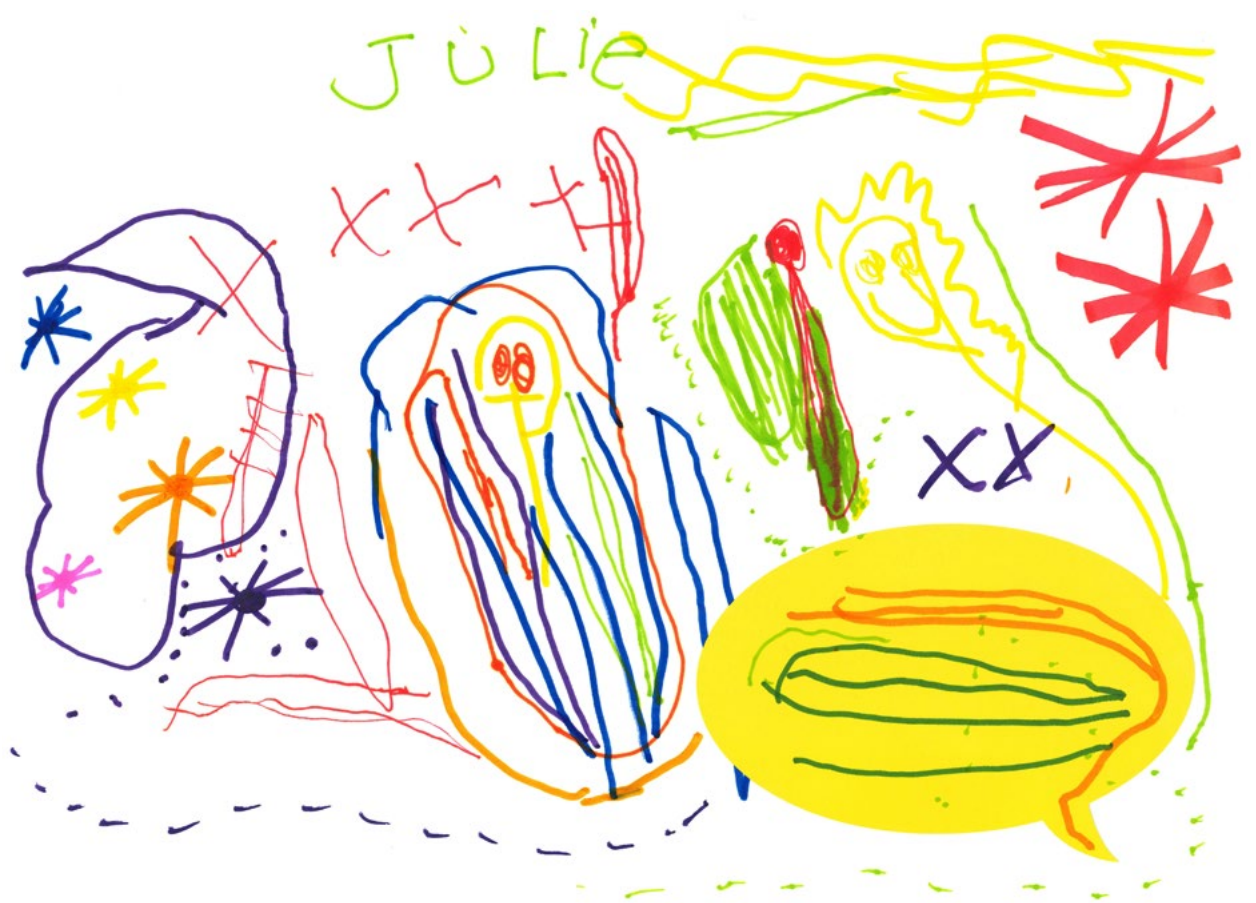
'My son struggled with his education and school attendance.'

Strategies that were meant to encourage him – such as playing chess – were used as punishment.

'And from years of being misunderstood, mistreated and misjudged, he actually started self-harming.'

At 15, Donnie stopped going to school. He rarely leaves the house and spends most of his time gaming or watching videos.

'I believe he was robbed of an education and respect and a chance to grow and learn with his classmates and enjoy his school years. He has deep-seated issues with all aspects of authority now, minimal education and limited social skills.'



Artwork by Julie Rosendale

Lambert

Lambert, mid-50s, has physical disability, is hard of hearing and has medical issues.

He is in a correctional facility.

‘I broke my leg in several places and I do struggle to walk. I limp really badly.’

Lambert told the Royal Commission the facility refuses to give him mobility aids.

‘They don’t like giving you crutches or a walking stick or anything. They just don’t hand them out.’

Lambert has broken his wrist several times. Recently he developed involuntary muscle tremors. He finds it difficult and painful to use his hands and hold things.

He has to clean his own cell, which he says ‘is acceptable’.

Recently, however, the correctional facility moved Lambert to a different division. Cleaning his cell in this division is ‘a different kettle of fish’.

‘They have got a stainless-steel sink and toilet. It’s all one piece and it’s polished like a mirror and they expect you to keep it polished like that ... You’ve got to get on your hands and knees and scrub the toilet and the sink.’

Lambert can’t kneel or squat or grip the polishing cloth.

He said the only reason the facility requires him to polish the toilet and sink to such a high standard is to torment him.

To clean the floor, he has to use a dustpan and brush.

Lambert asked the officers for a broom because he can’t bend and get down on his knees.

‘I was told in these words, “Fuck off, that’s not happening dickhead ... Talk to the hand, don’t want to hear it.”’

The officer said Lambert would find a way to get on the floor, ‘if he knows what’s good for him’.

Lambert uses his feet to clean the floor but it is very painful.

If the officers aren’t satisfied they make him clean his cell again.

The facility gives Lambert ‘finger food’ because they don’t allow cutlery. He says it is horrible and difficult to eat.

One time in the exercise yard, an officer spurred on a guard dog to attack him.

‘They stirred the dog up to attack me ... They shouldn’t do it. They made sport out of a disabled prisoner and they shouldn’t have done that. I made a complaint about it. Nothing happened.’

In winter, the officers wear scarves and jumpers and taunt Lambert about the cold.

‘They take your clothes off you and they give you a canvas bag with armholes to wear. It could be three or four degrees in the cell because there’s no heating there ... It is freezing cold in winter but you’ll be left there with no shoes, no socks and a canvas bag with armholes to wear.’

Lambert said the officers treat prisoners with intellectual disability and prisoners with schizophrenia or mental health issues very badly and enjoy tormenting them.

‘This is what goes on over there. People don’t understand. People don’t see it. They don’t know about it. This is how they treat you.’

Gayel

‘I feel they tried to put me down because of my disabilities.’

Gayel, mid-40s, has intellectual disability, anxiety and depression.

A few years ago, Gayel’s social housing unit started to flood. She contacted the housing agency and told them sewerage water was leaking into her unit.

‘I was told because of my disability I was having delusions and things weren’t real about me living in six inches of sewerage water. It couldn’t have happened.’

Gayel had to keep reporting the problem.

‘When you try to follow up they put you back at the bottom of the list again.’

Some of Gayel’s furniture and other items were destroyed because of the water.

Gayel contacted a lawyer who helped her take the matter to the state administrative tribunal.

The tribunal ordered the housing agency to fix the problem. Gayel had to move out while they did the repairs.

Soon after she returned, the unit flooded again. Gayel had at least six inches of water over the floor.

‘There’s pictures of me living in that water.’

Gayel became unwell and developed an infection in her foot and her arm.

‘I had to have a vaccination which helped prove it was from the sewerage water, walking around in the house.’

She discovered the housing agency only painted over the water damaged wall because they couldn’t find the problem.

‘It’s like I didn’t exist, it didn’t happen. Just swept under the carpet.’

Gayel had to go back to the tribunal.

The housing agency tried to argue Gayel had refused to give their tradesperson access to the property. But the tradesperson only tried to contact her by phone, which she can’t use because of her disability.

The tribunal ordered the housing agency repair the property and pay Gayel compensation for her damaged property. They also ordered the housing agency communicate with Gayel by methods other than telephone and give her reasonable notice when attending the property.

Eventually, the housing agency determined the cause of the leak. Inspectors believe it is fixed, but Gayel and her lawyer are concerned that the plumbing may not have been properly repaired because of cost.

Gayel believes there is still a leak.

Mindy

Mindy is in her 40s, has spina bifida and uses a wheelchair.

‘The majority of people with spina bifida [who use wheelchairs] end up in hospital quite regularly,’ Mindy told the Royal Commission.

The trouble is that ambulances usually can’t take wheelchairs with them, so patients become bed-bound in hospital.

‘Some end up staying there longer if they don’t have their chair because of pressure sores.’

Mindy said she knows people with spina bifida who won’t go to hospital ‘because they want to avoid not having their chair’.

‘If you show up to hospital without a chair ... if you’re in a bed and being wheeled in, they don’t know you can’t walk. I’ve had friends who were told to, “Get up and walk around,” said they can’t and actually get yelled at.’

People using wheelchairs usually have to organise a friend or family member to bring in their wheelchair to hospital.

‘[But] a friend of mine ... didn’t have family or friends that could help him ... and the ambulance took no responsibility for taking his wheelchair and they said to him, “Well you can put it in a taxi.”’

To transfer between hospitals he also had to pay for a taxi to take his wheelchair separately, which he couldn’t afford.

‘If he wasn’t in the taxi with his wheelchair he couldn’t use vouchers so it would’ve cost him over \$100 to get from one [hospital] to another.’

Mindy said there needs to be a better policy for ‘letting the first responders know there’s a wheelchair’ and having a way to bring it with the person who needs it.

‘[But] that relies on the person being conscious enough to be able to say, “This is where my chair is,” and having a support network and having an NDIS plan. Not all people have any of those,’ Mindy told the Royal Commission.

‘It’s complex and it’s not easy to fix, but it’s unreasonable to expect that people just leave their wheelchair [behind].’

Tolly and Marg

Around 15 years ago Tolly – he was 19 at the time – had a scholarship to go to university.

Days before his scheduled departure a car ran him over. He spent months in hospital but did not fully recover. Along with other physical issues he now has aphasia.

Tolly told the Royal Commission that aphasia is a relatively common disability but few people know about it.

‘That is very frustrating,’ he said. ‘No-one hears of what it is and no-one is really understanding of what it is.’

Aphasia affects Tolly’s ability to speak, to read and write and to process information. He also has problems with short-term memory.

‘Everyone has got a different kind of flavour of aphasia,’ he explained. ‘And I got the full monty of everything – global aphasia – so I can’t talk, I can’t read or write. And it is difficult to understand ... Normally I just say “Yes, I understand,” but I don’t.’

When he was hospitalised after the accident, Tolly couldn’t speak at all. He was supposed to receive 24-hour care, but one night he woke up alone. As he struggled to get up he fell out of bed. No-one told his mother, Marg. She only found out when one of the nurses mentioned it in passing.

‘He is not able to say anything and so they don’t have to bother saying anything to anyone. And so, I mean, that is horrible negligence, but it is also just the neglect that it is someone who is not able to advocate for themselves so they get lower priority,’ Marg said.

Tolly has had many experiences of neglect since then.

‘Because aphasia is a communication disorder, it is easy to ignore him,’ said Marg.

‘You get really zero help,’ Tolly said. ‘Doctors I believe have no clue about aphasia, zero understanding. And they treat you like a five-year-old ... They treated me this way and, yeah. Doctors have no clue. So awareness, that would be a very good start.’

Marg recalled attending medical consultations with Tolly and specialists who just ‘talk and talk’.

‘Well, [Tolly] can’t process the language the way they are talking. Or they write things down and give him a bit of paper. Well, he can’t read that.’

She believes notes about his aphasia should be at the very front of Tolly’s medical file. Every interaction he has with a doctor or specialist should begin by making a communication plan.

Tolly told the Royal Commission his dream is to read and write again.

'[But] you get zero help and you don't know what to do. You just have to find it on Google and you just hit and miss. You just don't know,' he said.

'And it is an invisible disease and ... they just want me to just stare at the wall and watch TV in my life. And I do that, but I want to do a little bit more in my life. And I don't ... I don't like it but I do need help. And I tried many times and it just so – it is tiring, it is exhausting and it is just like, yeah.'

Donny and Susannah

‘[Donny’s] a completely normal bloke. He just wants to have a chat with you. It’s not that difficult. You know people need to have a little bit more understanding on asking what helps. A lot of people won’t ask him.’

Donny is in his 50s and has trouble talking and walking after a motorbike crash. He brought his support worker Susannah along to the Royal Commission to help him tell his story.

‘I guess the biggest thing is his aphasia in the sense that he can’t speak to people and a lot of people aren’t willing to speak to him,’ Susannah told us. ‘[Donny’s] got a lot of physical injuries and stuff also. He does have a lot of pain ... a lot of mental health and frustrations as a result of the aphasia.’

Susannah said that before the crash Donny had ‘a lot of good things going for him in life’, but now people tend to ignore or patronise him because of the way he speaks and moves.

‘People insult his intelligence because they think ... he is dumb as a result even though he is fully intellectually capable.’

After Donny received a compensation payout, the state’s civil and administrative tribunal decided he didn’t have the capacity to manage his own money.

‘They can’t see past the disability.’

The tribunal appointed a company to administer his finances.

‘[They] just did not help him at all with anything in, I think, the three to four years that they were his administrator.’

Susannah said Donny felt he was alone because financial advisers weren’t ‘understanding fully how to work with someone with a disability’.

Donny found an advocate to help him get the tribunal to revoke its decision and give him back financial control.

Susannah also told the Royal Commission about Donny’s struggle to use public transport.

‘Bus drivers in particular ... just don’t seem to know what to do when someone with a wheelchair comes on the bus ... So, you know, pull up in the correct spot for a start. Lower the bus down. Put the ramp. Go do the seats. Just little things like that.’

Donny has a card for drivers to read, but Susannah said many refuse to look at it.

‘It’s exhausting because they just don’t listen ... often other passengers actually end up helping him, not the bus drivers.’

Rosabelle

‘They don’t believe the person with the psychiatric disability because what would we know? We’re not really in touch with reality. If you have a PTSD diagnosis, you’re second-rate in the psychiatric world as well.’

Rosabelle is in her late 50s and lives with psychosis, post-traumatic stress disorder (PTSD), depression and anxiety. She had been sexually abused as a child and was in an abusive marriage for nearly 30 years.

Rosabelle told the Royal Commission she has had seven different diagnoses, including ‘some rotten ones’.

‘The treatment for each one is totally different. I had the diagnosis of borderline personality disorder at one point. And whoa, don’t ever tell anyone in the mental health system that. The discrimination and the assumptions are things like, “You are manipulative. I cannot believe one thing that you say.”’

An emergency department once threw Rosabelle out at 2 am and she walked for miles in her pyjamas to find a motel.

‘Because they decided how I had borderline and what I was really there for was a room for the night ... I mean, there are psychiatrists that refuse to treat people with borderline. And as it turns out, it’s not what I have anyway.’

Doctors have put her on 15 different medications in the past two decades.

‘They sedated my life away, and that sedation was the reason my husband was able to sexually abuse me.’

Rosabelle said specialists used ‘antipsychotic drugs to control behaviour’ instead of understanding the cause of her anger.

‘They don’t try and help you other than, “Here, try this medication.” And for trauma, that doesn’t work. And it was just this rotating door of coming off one and then going onto the next. Because the depression, which I clearly had, was a result of life. It wasn’t a result of chemical imbalance up here. But they don’t ask that question ... All of this results in neglect. My physical health has been neglected since I got a mental health diagnosis.’

Selina

‘It feels like there is discrimination against Deaf children, you know, by putting us in a subpar environment and expecting us to perform on par. There are no options to fit our needs.’

Selina is in her 30s and has been deaf since she was a toddler. In her early childhood she lived overseas where she had a cochlear implant and used sign language at school.

‘When I moved to Australia I moved into a high school that was mainstream and educated through the oralism method,’ Selina told the Royal Commission, referring to the use of speech and lip-reading rather than signing. ‘When I was growing up I never was taught to speak ... then I went to a high school where you couldn’t sign.’

One day in the playground she tried to teach her friends how to sign.

‘A teacher walked past and had muttered something and I didn’t catch what she said. But then there was a strange vibe. The kids then looked at me [and] said, “We’re not allowed to sign.” And that really confused me.’

Selina said the school offered her little support apart from someone occasionally taking notes for her.

‘There wasn’t any sit-down consultation about what support I need ... I wasn’t sure what support I was allowed to ask for or what support I was going to get. Over time I taught myself how to speak and how to lip-read.’

Selina struggled in senior high school when her teachers expected her to ‘perform on par with [her] hearing peers’ even though she struggled to follow what they were saying in class.

‘The teachers would often think that I would have what they would call “selective hearing” ... because I responded to my name ... but any other things I wouldn’t understand. So the teachers often thought I was being deceitful or being sly in terms of how I responded to spoken English.’

She said high school was ‘a bit of a fail’ because of her poor access to information.

‘If I had access and support particularly with maths I would have been fine. But I didn’t.’

Selina is now studying to be a teacher.

‘I know that I’ve got a huge road ahead of me in terms of advocating for students, and I’m already tired. I’m not looking forward to that challenge ... I don’t want to have to fight the system to advocate that [Deaf] students’ needs [must] be equal to that of their hearing peers and go through all of that again.’

Lem and Sepp

Lem, early teens, has a tremendous sense of humour and a deep curiosity about the world. He is autistic, has attention deficit hyperactivity disorder, oppositional defiance disorder and anxiety.

‘I’ve learnt through our experience with his primary school,’ Lem’s dad Sepp told the Royal Commission, ‘that he can be a really productive member of the community. And he can feel a great sense of belonging if people are prepared to accommodate his needs.’

When Lem started primary school, he was a ‘square peg in a round hole’. The school had never experienced someone with such complex behaviours.

‘They didn’t have much knowledge of autism and they most certainly didn’t have the skills to navigate autistic behaviour.’

The principal – ‘one of the most spectacular human beings you would ever encounter’ – was determined Lem would have the same opportunity as the other children and graduate with his peers.

‘It led to a lot of difficult conversations with parents. It led to a lot of honest conversations with students. It led to ultimatums with staff members.’

The principal employed a learning mentor to help Lem, and an additional vice principal to help him and the teachers.

He upskilled staff to see challenging behaviours as the child’s reaction to their environment.

The school provided accommodations such as a low sensory retreat and more visual materials. They also allowed Lem to leave the classroom for regular breaks. His learning mentor would take him outside and play basketball or ping pong with him.

When it came time for high school, Sepp chose a religious private school with a very good reputation for inclusive education.

The primary school principal offered to be involved in the transition and share resources, but the high school principal declined – they would do it their way.

‘I just thought, “That’s a strange response, bit arrogant, but they’re entitled to do it their way,”’ Sepp said.

Lem’s behaviour deteriorated. He started having regular meltdowns and lashing out.

‘He was behaving in a way that we’d seen in the past when we didn’t meet [Lem] where he was at.’

Sepp expected the principal to admit their way wasn't working and start collaborating with the primary school.

Instead, the principal began suspending Lem.

Lem's behaviours escalated, and the principal told Sepp that Lem couldn't return to school.

'I said, "Is he expelled?" And they said, "No, we've never expelled a student." I said, "Well if he's not expelled, he'll be returning to your college because he's got disabilities and you haven't made the adjustments that we recommended." They said, "He's indefinitely suspended."'

Sepp contacted the principal of the local high school who agreed to work with the primary school principal and learn what he could.

'We're sort of working together to find better, more experienced staff to help support him.'

The new school has introduced a flexible learning plan for Lem, and he enjoys going to school again.

'It's not been perfect ... it's a bit of a journey ... I'm optimistic we can achieve it,' said his father.

Lynette

Lynette, late 50s, was born with spina bifida and had her first hip replacement in her 20s. She has spinal issues, knee issues and arthritis, cataracts in one eye and glaucoma in the other eye. She needs support to read and write, and cannot walk unassisted.

Until recently, Lynette lived independently with 'drop in support'.

Then she had a couple of falls and needed more support.

'I had live-in support at home and then it became too much because I was on oxygen 24/7.'

Lynette moved into supported accommodation with two men.

She found it very difficult to give up her independence and to say goodbye to her pets. Most of the time she felt unsafe and vulnerable living in the house.

Staff spent their shifts sitting on the couch talking to each other, or on their phones.

'They would just do their own things, muck around and chat and all that. That's constant all the time. It felt like you would be lost in your house.'

When staff did help her they never spoke to her.

'They would talk over you. They're dealing with you but they're talking about what they've done and what they're gonna do. It's like you're just a bit of meat.'

At night time there was only one staff member on site, and they were allowed to sleep because it was a non-active house. There was no way to contact them during the night.

Lynette would sing out or bang on doors to try and get their attention when she needed to use the bathroom. They either didn't hear her or chose to ignore her. Lynette was given bottles to urinate in, and most nights she was left alone for 12 hours with no support.

By the time it was morning Lynette was a mess.

A lot of the staff were 'dodgy'. They were meant to be provide one-on-one support but they'd go to the pub to play the pokies while they were being paid to support Lynette. They would only come back towards the end of their shift when it was time for them to handover.

Once, a staff member dropped Lynette's medication on the floor. They picked it up off the floor, wiped it on their pants and tried to give it to her. Lynette refused.

Staff regularly smoked outside her bedroom, despite her being on an oxygen machine.

There was no fire evacuation plan for Lynette. When she told staff she was worried about what would happen to her if there was a fire, they joked and told her they'd put the hose on her.

'If I made a formal complaint about anything, they'd never look into it. Nothing ever got done about it.'

Staff would treat her like a troublemaker.

One staff member told Lynette, 'Piss off from this house and get out. This is our house.'

After a few months, the provider told her that they didn't have the staff or the equipment to help her transfer in and out of bed.

'I was in bed the whole three months. I had not had a shower in three months. I had not been taken to the toilet in three months. I've not even washed my hair.'

Eventually the provider told Lynette they could no longer care for her and tried to get her to transfer to their aged care facility.

Lynette didn't want to move to aged care.

She had NDIS supported independent living (SIL) funding and asked them to help her find somewhere else.

The provider refused to help and continued to push their aged care facility.

Lynette changed SIL providers and was able to find a property in the same area.

Lynette is happier and feels like she's looked after better and is more supported by the staff.

Wenley

Wenley, in her early 50s, is Deaf. Auslan is her first language and there are many situations that are extremely difficult if she doesn't have an interpreter.

Wenley receives NDIS support. At a recent meeting with her support coordinator, Stephen, she requested more money for interpreting services. She has an injury that prevents her from doing physical work, so she asked for a cleaner. She doesn't always feel safe at home because she can't hear if someone is on the property, so she asked for a security camera.

Wenley's funding in the new plan was reduced by more than half and all her requests were refused. Stephen told her she couldn't have a cleaner but she could have remedial massage. She was funded for one session with an interpreter per week. Stephen said her children could interpret for her at other times, and they could also listen out for intruders at night.

'I got really cross,' Wenley told the Royal Commission. 'This is wrong. They're children. They don't have to be my interpreters, and I shouldn't have to rely on them. And just because they can hear and I can't, it doesn't give them additional responsibility.'

She was 'really upset' by the idea that 'the NDIA thinks that's all right'. She was also 'shocked' by the allocation for interpreting services.

'Once a week only for interpreting, and I knew that was wrong as well, and that that was a poor decision.'

Wenley needs an interpreter for medical appointments, meetings at her children's school and other commitments.

'It's vital that any time I head out into the community and have these interactions, these important interactions, I have interpreting access,' she said. 'But [Stephen] had no idea about a Deaf person's needs and what interpreting requirements I had.'

Wenley's relationship with the NDIA got off to a rocky start when the agency called and left messages about her upcoming appointment. When she didn't respond they cancelled it.

'They'd never read my actual file to see that I'm deaf, and that it had to be text or email only. Like, that's pretty basic information.'

Such disregard for her needs happens often. At work she has funding for an interpreter, but meetings are called at such short notice she doesn't have time to book one. Hospital appointments are often delayed or rescheduled, so the interpreter is unable to attend.

After experiencing domestic violence she went to police. A police officer came to her home to get a statement, but without an interpreter.

‘They wanted my children to act as an interpreter for me, but I didn’t want my children to hear what I was going to be talking about. It was very private and sensitive, and I refused.’”

Wenley described many other difficult and frustrating situations. These included using an intercom to get into a building, ordering takeaway food where the customer’s number is called out, poor captioning on films and TV, and news events where the Aslan interpreter is cut out of the frame. Going to the airport, catching a train or bus or being anywhere that announcements are not made visually is stressful.

‘I have Deaf friends. [We] have this conversation and go, “Look at the world and how they accept people with disability, but they don’t understand us.” Deaf people don’t seem to fit within the disability sector, and the wider community just don’t understand a disability they can’t see,’ she said.

‘It makes sense to me because there is more and more access considered for people with physical disabilities, with wheelchairs, but why aren’t developers and builders and the government thinking about Deaf people and what their access needs are as well? That would make society a much fairer place for Deaf people to be.’

Lil and Marian

Lil, mid-20s, is autistic and has a genetic syndrome that affects her vision and health.

After finishing university, Lil applied for a job. She was very open about her disability in her written application and in the interview.

Soon after she started, the mandatory training was interrupted because of COVID-19.

Lil was surprised when they started giving her shifts, despite not having finished the training or having a uniform.

When she asked about the training, her supervisor told her it was too late. Lil thought, 'It's silly to say it's too late.'

Lil told the Royal Commission her direct supervisor was very condescending and critical of her work.

'I just felt like I wasn't getting the support that I needed and I felt like I was doing everything wrong.'

Most of the time Lil worked on the front desk, greeting customers.

One day, a customer started verbally abusing her.

Lil didn't know how to deal with the situation – she hadn't received any training or advice on how to deal with difficult customers.

The customer continued to rant until Lil broke down crying. Her supervisor sent her home.

No-one gave her feedback about the situation or provided guidance about how to deal with challenging customers in the future.

Instead Lil's supervisor micromanaged her.

'We would be on the floor and you'd have a visitor come in and I was going to approach the visitor, but then my supervisor just swooped in and took over the job.'

The gallery started giving her fewer and fewer shifts and her uniform never arrived.

'I asked about the uniform because we were all given a uniform ... And they were like, "We're still waiting."'

One of the other supervisors contacted Lil and told her to come in for a meeting. She suggested Lil bring someone with her.

Lil asked her mum Marian to come.

‘I thought it would just be me and my supervisor but it actually turned out to be me, my supervisor, the other supervisor who was micromanaging me and being condescending, and then someone from HR.’

The HR person told Lil she was not suitable for a customer-facing role and they were terminating her employment.

Marian was shocked.

‘I listened to it and eventually I said, “Well, I’d really like to make some comments.” And I said, “You’ve got a policy on disability and yet you haven’t followed through ... and that was one of the reasons [Lil] applied.”’

The HR person said she didn’t know Lil had a disability.

Lil didn’t know how to respond – she had been open about her disability during the hiring process.

The supervisor who’d been involved in the hiring process accused Lil of lying. She said Lil had never mentioned her disability.

‘[Lil] was devastated by that comment,’ Marian said. ‘First of all, she doesn’t lie. She doesn’t know how to lie.’

Lil was very upset.

‘It’s a hard thing to deal with a difficult customer, let alone if you have a disability,’ Marian said. ‘I don’t think she deserved the way she was treated.’

Lil started seeing a psychologist.

She would still like to work in customer service.

‘One bad experience shouldn’t affect how I view customer service.’

Cally

‘The amount of people with disabilities that I encounter in the public service has diminished over time. So people with vision impairment that I know have moved on because it’s just become too challenging.’

Cally is in her 40s, has vision impairment and is colourblind.

‘I quite often come across as looking non-disabled. So, you know, I’ll wear sunglasses during the day and I just get out there in the world and do my thing,’ Cally told the Royal Commission.

Cally went to a high school special education unit where teachers told her she couldn’t study science because there were no staff to supervise her.

‘I could not do art because I am colourblind. I couldn’t do geography because it would be too difficult for me to read the maps ... I felt like I had this constant rhetoric around, “You can’t do that because of your vision.” It creates a huge amount of doubt in my mind.’

This made Cally’s transition to the workforce difficult.

‘This has set us up to think we can’t do as much as everyone else ... Especially when explaining to an employer that I can do the job of my able-bodied competitor in an open market situation.’

In spite of her restricted education, Cally went to university and joined the public service where she ‘experienced a fair amount of backwatering, bullying and harassment’.

‘People do not understand disability at all. There is an unwillingness to understand my needs and have them accommodated.’

For example, Cally is sensitive to light. One building was so brightly-lit she struggled to read and move safely about, so her manager gave her an office where she could close the blinds.

‘But then people would walk past and just say to me, “Why are you in an office?” and ... it’s basically if you get treated differently to somebody else then that favourable treatment ... doesn’t go down well with some of the other people.’

Another manager told Cally she didn’t want her in that office and moved her ‘back out on the floor’.

‘That affected my work performance significantly.’

Managers also declined to pay for software to help Cally better read her computer screen. Cally said there is a double standard in the public service where some departments ignore the policies of inclusion they promote.

'When they talk about access and inclusion they don't talk about it in the sense of disability. They talk about it in the sense of, "We're going to give ... access for all," meaning everyone who works there,' Cally told the Royal Commission.

'It's not in the context of disability. It's like you don't exist ... so it's this shifting of disability issues [and] making them kind of, I guess, more about the people without disabilities, just about everybody. So you're ignored essentially.'

Madge and Jeanie

‘Even though she’s so mentally ill, right, she’s a real sweetie. So who’s to advocate for her if I’m not? Because nobody else is, right?’

Jeanie is in her 80s and the mother of Madge, who lives with schizophrenia.

‘She needs to have an advocate because, you can probably tell from my voice or whatever, I’m getting on,’ Jeanie told the Royal Commission. ‘I’m not going to be around too much longer.’

Madge lives in supported independent living accommodation and in recent years put on a lot of weight.

‘When she was slimmer she had friends and boyfriends. Even when she was ill, right, she still had the friends. But now this huge weight gain and she doesn’t dress appropriately.’

Jeanie blames Madge’s service provider for giving her poor food.

‘I think she’s prediabetic and she will end up in a wheelchair ... And if she does it means then the expense of a wheelchair [and] special living quarters.’

Jeanie said Madge’s home doesn’t have a proper kitchen.

‘Any cooked food is fried ... A few weeks ago I went there with some meat and some veggies, ready to microwave the veggies and ready to grill the meat. Well, you can’t grill. There’s no way of grilling anything.’

Jeanie bought some fruit for the residents and put it in the fridge ‘assuming that it would be used’.

‘Well it wasn’t, right? Because the next time I went there and looked in the fridge there was this fresh food rotting, rotting in the fridge.’

Jeanie said nothing changed even after dieticians came into the home to teach the staff how to prepare healthy meals.

‘The support staff, to be honest I don’t think they have enough time and I don’t think they have enough money there to do the right thing ... I mean, oh please, can we have the dietician more interventionist?’

Jeanie said the service provider also seems reluctant to repair things that break, such as the blind in Madge’s room.

‘It was 10 weeks, 10 weeks before that blind was fixed. And then it was the manager of the agency ... came out and he fixed it himself.’

Jeanie said when vaccines became available during the COVID-19 pandemic, she had to arrange Madge's vaccination herself.

'She has a mental health nurse, she has a psychiatrist ... at least six people hovering around. Not one of them, to my knowledge, made any inquiry about a vaccination for [Madge]. Not one of them ... and nor the GP. So in the end I set about it.'

Jeanie said the service provider only acts when she complains, but she's had to get so many things fixed she's now worried about repercussions.

'I try to sort of not complain too much because I'm concerned that, oh, they won't be kind enough with [Madge], right? Their little ways of cutting her out or ignoring her or whatever if there's too many complaints.'

Oskar

‘You kind of just become a piece of currency getting passed around and profited off of and never helped.’

Oskar is in his 20s and has attention deficit hyperactivity disorder (ADHD) and anxiety. He’s been looking for work since high school.

‘I have quite severe ADHD basically which wasn’t diagnosed when I was a kid,’ Oskar told the Royal Commission.

Oskar doesn’t qualify for the Disability Support Pension, but uses Disability Employment Services (DES) to find work.

‘I’ve never been referred to a job vacancy to apply for other than occasionally being offered full-time work in an industry that I have no experience in that is at a location nowhere near where I live.’

Rather than finding him a suitable job, Oskar said DES providers try to maximise the government subsidies they receive from having him on their books.

‘The government rewards providers that can have clients stay with them longer voluntarily when they don’t have to because they see that as being a sign that the client’s getting value from the provider and the provider’s doing a good job.’

Oskar said one DES provider promised him gift vouchers every three months he stayed with them, writing to thank him for his ‘kind support’.

‘I didn’t realise I was supporting them.’

At the end of six months, after the DES provider received the maximum government subsidy, it didn’t send his second voucher.

‘Their motivation for keeping me as a voluntary client is completely gone. They have no incentive for me to, after that point, be in a good position in terms of my employment, my wellbeing.’

Oskar said instead of gift vouchers he’d rather have support – buying clothes for a job interview, for example.

At another DES provider he had to explain to a consultant what ADHD is.

‘And I saw her scrolling through the list of conditions on their system and she was saying to herself, “I can’t find it. I suppose it isn’t really a condition, is it?” ... How is this my disability employment services consultant? How is the government paying hundreds or thousands of dollars for me to have the privilege of seeing this person?’

Recently, Oskar had an injury and for a few months wasn't required to deal with a DES provider. During that time he found 'probably the best job [he's] ever had'.

'I was in the right headspace as a direct result of, in fact, not having to engage with my DES provider. Yeah, the break from them is what I needed to get a job,' Oskar told the Royal Commission.

'I'm a pretty capable person outside of the symptoms of my conditions. The main barriers for my employment have been basically poverty and the fact that what little money I do have is tied to dealing with these [DES] providers ... there's got to be tens of thousands of people like me.'

Stu

‘I was a kid ... If I had the support then that I do now with my psychologist, I don’t think I would have ever seen the inside of a cell.’

Stu is in his 30s and recently discovered he is autistic and has attention deficit hyperactivity disorder (ADHD).

‘They thought I was just your typical uncontrollable young child that wouldn’t listen to things that were asked of them,’ Stu told the Royal Commission. ‘It’s frustrating that ... they ended up locking me up in the juvenile justice system.’

When Stu was a kid, child protection removed him from his parents and put him in foster care. Although many of the adults in his life tried to help him, no-one managed to arrange an assessment and diagnosis. He struggled at school.

‘I couldn’t succeed. Not because I was bad at school, but because the [autism] and the social challenges and my also now-diagnosed ADHD ... I could do the schoolwork, but I couldn’t hand it in. Like in hindsight that was ADHD. It wasn’t me not doing it, it was just me not getting it in on time.’

Stu had to leave school. He would ‘have a meltdown’, but his teachers didn’t recognise autism.

‘Being put in juvenile [detention] began to be a thing because my behaviour had escalated. And admittedly it was very challenging and in hindsight ... if I saw a kid going through that I would be challenged by it. But then dealing with that sort of challenge, the [detention centre] staff didn’t seem to understand what was going on.’

At one stage a doctor misdiagnosed bipolar disorder. To try to control his behaviour, detention staff gave him too much medication.

‘We’re talking at least two dozen, like, opioids. Like, not opioids, but that effect on slowing you down because that’s what they needed to be able to do, which was basically shoehorn me into this situation.’

The side effects of the medication put him in hospital. Stu said many of the other kids in juvenile detention also seemed to be autistic and were medicated and restrained.

‘Some of the stuff I do ... was the same for them, talking about [autism] and masking. How you behave a certain way to hide it. I can imagine a good handful of these kids, had they not gone through what they went through, like me, they would [now] be working in their own businesses.’

Stu said many of the kids in juvenile detention were talented artists, but the medication, violence and restrictive practices caused some to attempt suicide.

As a result of the abuse and delayed diagnosis, Stu says he's now 'unemployable'.

'I don't want to see others go through this. And if there was anything that came of this, from my part of it, it would be to make sure that if a kid goes in [to juvenile detention], shows a certain series of issues like anger issues or whatever, [their response] is not just, "He's being difficult. Let's medicate him."'

Rudi and Caley

‘We’re just saying the process probably needs reviewing and the people making these decisions ... who are playing God need more education.’

Caley is Rudi’s mum. Rudi, who is in his 30s, has cerebral palsy and epilepsy.

‘He’s a clown. He’s a really funny guy,’ Caley told the Royal Commission. ‘A very loving young man. Very social ... Not a lot of verbal so he communicates in a variety of ways, some with pointing, some verbal, some signs, some computer programs.’

When the NDIS took over state-based disability support several years ago, Rudi’s funding fell by nearly \$100,000.

‘It was put out there that nobody would be worse off financially than what they currently have ... but he actually was quite underfunded.’

Caley said she had to change the hours she worked when Rudi lost most of his respite care and community activities.

‘[And] he wasn’t able to do ... weekend activities because he didn’t have enough money because on weekends the charge-out rate is more.’

Caley asked the NDIA to review Rudi’s plan, a process that took nearly a year.

‘At times it was bizarre. It was designed to put people off.’

For example, the NDIA initially rejected funding to repair Rudi’s wheelchair because it said there was ‘no proof that the wheelchair was required for his disability’. It also told Caley that Rudi’s disability ‘affected him only 20 days a month, not 30 days a month’.

During the review, Caley collected more than a dozen reports from Rudi’s therapists.

‘They flew up an OT [occupational therapist] from Sydney for the day to do an assessment of [Rudi]. And I thought, “What does that mean? That means they haven’t believed all of our evidence.”’

During the review, Rudi missed out on many of the supports he needs.

‘And we’re having to go through hoops and do what we’re told or nothing’s going to happen. And it just seems an unnecessary process to me.’

The NDIA eventually accepted the therapists’ reports and Rudi now has a substantially increased NDIS package. He lives in supported independent living accommodation with full-time support workers.

‘Those carers take him out to various activities during the day ... they will often go sailing, they go out for lunch and listen to music. They go for a walk in the park where they meet people ... [he’s] getting out in the community.’

Caley said she’s ‘hugely grateful’ for the NDIS.

‘NDIS has, like, given so many opportunities to people, where under the old ... structure people would never have had this ... But it was just frustrating to have to go through that process.’

Dewi

Dewi, mid-40s, has physical disability and uses mobility aids.

He lives in a supported residential service (SRS) with around 20 other people.

Dewi told the Royal Commission the SRS provides accommodation, meals and a laundry service in exchange for about 90 per cent of his Disability Support Pension.

‘When I first moved in, there was mice shit and rat shit ... I didn’t even have a bathroom vanity. The toilet leaked nonstop to where it flooded all the time, same as the shower. I had to have a heater on all the time just to keep it dry until I tried to silicon underneath it, around the toilet. They didn’t like that. I didn’t have a lock on the door. You could use any key to open my door.’

Meals are served in a common dining room at a set time. They are ‘absolutely putrid’.

Dewi’s laundry is always returned damp and items go missing.

‘It’s meant to come back all folded and ready to put it all away but they just put it in garbage bags and throw in your room.’

Not long ago, the manager of the SRS set up her own NDIS accredited company. She told Dewi he had to sign up because ‘she signed everybody else up’.

Dewi refused. He had fixed his room up and was happy with the way things were.

The manager got quite angry.

‘When I didn’t sign the piece of paper she said, “Go pack your bags, you’re leaving.”’

Dewi refused to leave so the manager called police.

When police arrived, Dewi was on the phone to a family member who is a disability advocate.

She told police they couldn’t evict a person with disability from an SRS without an order from the state administrative tribunal.

As police were leaving, Dewi overheard them talking to the manager.

‘Police said, “You can make up a story and get a fake intervention order out on him and get him out that way.”’

Dewi left his room to go and get some food.

When he returned the manager prevented him accessing his room.

Dewi got upset.

Police returned and told Dewi the manager had accused him of being aggressive and wanted him to leave.

They suggested he come with them to the police station and they would help him find accommodation while the administrative tribunal sorted out the matter.

Dewi waited at the station and 'had to sleep in the foyer on the chairs'.

The next day different police officers swore at him, called him names and chucked him out.

Dewi went back to the SRS. He couldn't get into his room to get his things, including his crutches and knee brace. He spent the next few days homeless until family members could travel and take him to his parents.

A few months later, the administrative tribunal reversed the decision to evict him.

Dewi returned to the SRS.

He discovered his room had been rented the day after he was evicted. His belongings had been placed in garbage bags outside. Many items including his watch were missing.

The manager of the SRS gave Dewi a bill for tens of thousands of dollars for meals and laundry that were previously part of his board and lodging.

'I've been told the debt collectors were coming after me.'

The manager refuses to do anything for Dewi until he pays his bill and gives her access to his NDIS funding.

Dewi believes that all the other residents have signed contracts. He's the only one that refused to sign.

'They're getting a lot, they're getting a fortune off NDIS.'

Dewi hardly ever leaves his room because he's afraid they will change the locks and he will be homeless again.

Leandra

Leandra is in her 20s. She is autistic and has an undiagnosed neurological disorder.

Leandra's first seizure happened about eight years ago and became progressively worse.

'I couldn't continue attending school. I was having 25 seizures a day with it all.'

Once after being admitted to hospital, a doctor put her in an induced coma.

'And under his care, I endured a lot of malpractice ... I had two spinal taps that were unconsented. That was in ICU. Then I got moved across into the neurology ward, which is a very traumatic place. Instead of being comforted and consoled, I was strapped to the bed at one point because the hallucinations from the medication I was under were so severe.'

Leandra was in hospital for about a week.

'I just wanted to go home. It just really messed with my head at the time.'

The radiologist told Leandra if she had a seizure, she could leave.

'In my stupid teenage brain, I faked a seizure. I felt very bad about that.'

The doctor told her she'd wasted his time and would be lucky to have anyone give her support.

He didn't give me a diagnosis. He put down on my medical records I have pseudo seizures, which made a lot of complications in the future at emergencies.'

Since then, Leandra said she has faced 'a lack of care and support' and the treatment from health carers is confusing.

'Even though they tell me I don't have epilepsy or seizures, they still want to put me on anticonvulsants.'

Leandra gets very 'emotionally upset' during the ongoing medical assessments.

'I've been working very hard to get a diagnosis. All the assessments I've had, they've turned around and gone, "Well, yeah, you need therapy for dealing with the fact that you have a disability." But therapy is not going to solve these seizures ... "Can I have some support? Can I at least have a diagnosis? Can I have a seizure plan?"'

Leandra is hoping a new autism diagnosis might help her qualify for NDIS supports.

'I got diagnosed as a child, through the schooling system. But my dad, who I have no interaction with anymore, didn't want, in his words, "a retarded child". And he didn't want it labelled, so it got put aside.'

Bryant

‘Across my entire childhood, adolescence and early adulthood, I was subject to physical and emotional abuse from my father and siblings.’

Bryant, late 50s, has complex post-traumatic stress disorder.

His father, a war veteran, was an aggressive and violent man.

‘My father’s violence was extreme and unrelenting, and his coercive control over my mother and myself and my siblings was extraordinary.’

He routinely raped and tortured his wife, who ‘lived every moment in fear’ of him.

She made multiple suicide attempts and was ‘forcibly detained’ in a psychiatric hospital.

‘Her treating psychiatrists characterised my mother’s depression as a stress reaction to my father’s violence.’

Three of Bryant’s siblings became wards of the state and one was sexually abused in care.

Child services, police, the health and veterans’ affairs departments all engaged with the family on multiple occasions.

Bryant told the Royal Commission much of the violence and trauma was ‘completely foreseeable and preventable’.

His father ‘held [Bryant] captive’ until he died.

‘I have always been at heightened risk of re-traumatisation. That has made me vulnerable to abuse from teachers, peers, employers and others.’

Bryant hoped his life would get a lot better after his father died, but ‘it’s been extremely challenging’.

His mother developed early-onset dementia, and was placed in institutionalised aged care instead of a less traumatising facility.

One of his brothers suicided and another tried to suicide multiple times.

‘I live with constant stress, I have to actually manage suicidal ideation as part of my life – not on a daily basis, but it’s something I have to do. I get somatic symptoms such as chronic pain which comes from left field, and have to deal with that as well. I can be triggered into states of terror quite easily. And none of that is well-understood, and is highly problematic in terms of my day-to-day life.’

Bryan asked government departments and agencies for help.

‘I was pleading for long-term counselling and other support I needed, so I could start my life, coz I didn’t have a life. And to deal with all the trauma that I’ve been subjected to.’

Everyone acknowledged there’d been a lot of violence in Bryant’s life and he would need years of counselling support.

But no-one was willing to provide the support.

Bryant made a complaint to the Australian Human Rights Commission (AHRC) arguing the state was in breach of the Convention on the Rights of Persons with Disabilities.

He argued the state had a duty to promote his physical and psychological recovery by providing the services he needed, specifically because of his disability, as per the convention.

Bryant said the process was highly technical and extremely legalistic. He had to deal with not only the AHRC but a number of government departments and entities.

‘I had to go through the matter, in battle up against huge, almost insurmountable – well ultimately what were insurmountable – powerful government agencies. There was zero understanding of or empathy for my complex trauma.’

The AHRC ‘had absolutely no interest in [his] matter’ and after 18 months dismissed Bryant’s complaint.

‘I’ve been left vulnerable to further, multiple acts of violence and re-traumatisation, and deterioration in my physical and mental health. In other words, if I’d got that support, I would almost certainly be in a much better position than I am now,’ Bryant said.

‘If only, at the very least, the Australian Human Rights Commission had offered me fairness in their proceedings – rather than what they did, which was basically to build a false case to knock out my complaint.’

Arnie

‘This is not a disability issue, this is a societal issue. It is not about my disability. It is about me living an active, involved and engaged life.’

Arnie, mid-60s, has quadriplegia and describes himself as ‘an enquirer, researcher and optimist’. He is university educated, has a busy career and represents Australia as an elite athlete.

About two years ago, Arnie’s disability support was automatically transferred to the NDIS.

There was no planning meeting or discussion with Arnie about his needs.

By the time Arnie discovered he was with the NDIS, ‘providers were already claiming funds against [his] plan’.

‘I was disabled the day NDIS generated my participant number. I have not been included in the conversation let alone empowered to lead those discussions.’

Arnie’s plan was inadequate and inflexible and didn’t consider his needs.

The NDIS appointed agency couldn’t provide support workers before 6 am, and there was a constant turnover of staff.

‘I don’t want a different person coming into my life who has had no training ... I don’t want unskilled, I don’t want numerous ... I want a group of people that are happy to be here, happy to take direction.’

Arnie asked to self-manage his plan.

The NDIA refused but didn’t give him a reason.

‘I honestly cannot tell you why [they refused], other than they don’t want to. Why can’t I have self-management? I used to self-manage before NDIS.’

Arnie asked the NDIA to review the decision but they told him he would have to go to the Administrative Appeals Tribunal.

‘The NDIS promotes choice and control, but then does nothing about it. You end up in the tribunal.’

Arnie couldn’t find legal representation because of the long waiting lists, so he represented himself.

The appeals process has consumed his energy.

'It is an onerous bureaucratic nightmare, a system fraught with jargon, misinformation, bullying, stress-filled playground antics.'

The NDIA has questioned Arnie's capacity, honesty and integrity.

Arnie's plan was suspended because of the appeal. After a few months he ran out of funds and all his supports stopped.

Arnie had to sleep in his chair because there were no support workers to hoist him in and out of bed. He used adult wipes to maintain some semblance of cleanliness. He changed his own suprapubic catheters out of necessity when they became blocked.

The NDIA offered an expedited plan if Arnie stopped the appeal, but he refused.

They then threatened his plan would be agency-managed irrespective of the outcome.

'I was contesting my right to choose increased flexibility in a self-managed plan ... I would be placed under agency management, the most restrictive and least flexible plan option. We would just end up going around in a complaints circle.'

Arnie wrote to the minister who said they could do nothing while the appeal was ongoing.

After four months without support, the tribunal asked the NDIA why they hadn't used a provision in the Act to approve emergency funding for Arnie.

Arnie's supports resumed.

Two months later, the NDIA conceded they were unable to find any record or reason to substantiate the decision to refuse self-management, but that 'someone must have had a reason'.

The NDIA informed Arnie his plan would be agency-managed.

'Each time we have this flow-down effect of someone else managing the money. They pay someone, who pays someone, who pays someone and at the end I receive support that is not value for money. That is exactly what agency-managed is.'

Arnie refuses to accept an agency-managed plan. He wants the flexibility to negotiate with support workers so he can live the life he wants.

'Rather than listen to me and my aspirations and how we might overcome environmental barriers to my active community participation, NDIS has become my greatest all-pervasive disability.'

Conan

'I'm the poster boy for what happens when you kick the crap out of a kid, and then give them no help and then set 'em on their way and leave them to go through life.'

Conan is in his 50s and lives with 'major depressive disorder' and complex post-traumatic stress disorder.

He told the Royal Commission his brother and a neighbour sexually abused him as a child. He was 'institutionalised at a young age', and later joined the army.

'Which actually exacerbated all the illnesses ... So I mean, more trauma on top of more trauma. And I started saying with my mental health, there's something not right. I started having breakdowns, so I tried to get help ... Psychologists, they said, "There's nothing wrong with you."

Conan turned to various counselling services for veterans.

'One counsellor said, "It's not your mental illness, it's you." ... Or they say, "Oh, you're using your mental illness as an excuse." It's one thing to have all these illnesses, but then you go to the system for help and they fail.'

Conan eventually got some help at a private mental health hospital, but not 'proper care'.

'Because I was not diagnosed correctly. I got diagnosed in 2012 with borderline personality. And then I went to another psychiatrist who misdiagnosed me ... So then you get prescribed illegal amounts of Valium. Didn't help,' he said.

'I didn't realise that my whole life was gonna be a war pretty much. It's been exacerbated by the limitations of how people are diagnosed. I only just found out that I don't have an antisocial personality disorder. And that was an albatross around my neck in my life.'

Conan recently spent time in prison 'because of mental health issues'.

'You can't get access to critical health, mental health assessment, so they ring the police ... And they have no psych training ... See, if I got clinical help when I'd needed it last year, I would never have had to go to jail.'

He feels the justice system 'victim blames'.

'Because you can't articulate in a proper way because you're emotionally dysregulated, they discriminate against you, so you get angry, it's a cycle.'

Conan recently got what he feels is his first proper diagnosis.

'I've got PTSD from childhood and the services, and depression [and] major drinking dependency disorder.'

He is finally starting to access professional support, including a psychiatrist and behaviour therapy. For the first time, he has hope.

'They're fantastic. They have picked up on me and they stuck with me. And that's the difference. I think they just caught me in the nick of time. I don't think I would've gone on for much longer. I'm still trying to get on top of the whole lifetime of damage that's been done ... Catastrophic would be an understatement.'

Arturo and Christie

Arturo, mid-teens, has attention deficit hyperactivity disorder (ADHD), encopresis, sensory processing disorder and metabolic disorders.

He has attended multiple schools.

'[Arturo] has been subjected to exclusions, isolation, restraint ... rolling suspensions, being reported to the police,' his mum Christie told the Royal Commission.

Arturo's first primary school was unsuitable – it was big, open-planned and very chaotic.

His second school had very little understanding of ADHD.

'They were treated as wilful and defiant children ... It's just a punishment framework rather than a disability or a therapeutic framework ... I think the general approach is just keep punishing them, keep suspending them until they and/or their parents give up.'

When Arturo was eight, a teacher called him a sociopath.

Later that year, he threw a toy at a teacher.

'The teacher made a police report and said [Arturo] used a weapon. They locked him out of the school and they filmed him on their personal mobile phones. He ran away ... Luckily, the policeman who arrived had an autistic child and was able to provide him with some comfort.'

Arturo started to experience suicidal ideation and told Christie the world would be better off without him.

Christie asked the education department to recommend a suitable school that understood his disability and would support him.

Christie, an allied health professional, shared all her resources with the new school. She did one-on-one sessions with the education support staff and helped the school develop disability support plans for all children with disability.

But Christie soon discovered teachers were regularly removing Arturo from class.

'He pretty much didn't go to most classes – they had him playing Lego in the photocopy room. They had no independent learning plan for him ... They refused to follow the support plans.'

Rolling suspensions started.

Christie made a formal complaint, first to the school and then to the education department.

‘Every piece of advocacy that I did from that point on, actually turned out worse for my son, not better.’

The school increased the frequency and duration of Arturo’s suspensions.

‘That kind of behaviour is just to break a child’s will and the parent’s resolve.’

Lawyers started responding to all Christie’s emails.

Christie made a complaint to the Australian Human Rights Commission (AHRC) on the basis the school was in breach of the Disability Discrimination Act.

She discovered numerous different lawyers were involved in drafting correspondence from the school.

Christie said the AHRC has no power. It took 18 months for the department to action a request to involve a certified behavioural analyst, and a year of requests and appeals to get Arturo’s school records.

The school ignored the analyst’s urgent recommendations.

The analyst advised Christie to remove Arturo from the school.

‘The teachers have developed such a level of animosity towards him he’s at risk. He’s not been treated with any kind of dignity and all [the analyst] can see is a further deterioration in his behaviours.’

Christie tried to get the AHRC to intervene.

‘It’s a really impossible piece of legislation for parents ... it’s the kind of default pathway that you go through.’

The matter moved to the Federal Court.

The department used top tier law firms and barristers. Christie represented herself.

‘They fight a very aggressive campaign. They do not contribute to mediation with any kind of goodwill. They do not follow their model litigant obligations. And they spend millions of taxpayer money on fighting parents.’

After several years, the department settled and paid compensation.

Now Arturo ‘doesn’t trust any kind of authority figure’ and is barely hanging on in high school.

‘He believes that he is an idiot. He believes that he’s not smart. He believes that he’s a bad person ... He’s going to need a lot of therapy.’

Evette

‘The government is allowing age discrimination towards people who were born with disability, born deaf or who acquired deafness in early childhood. This form of discrimination is not tolerated towards able people.’

Evette is a child of Deaf adults and her first language is Auslan.

‘My father ... became profoundly deaf through a meningitis infection as an infant,’ Evette told the Royal Commission. ‘My mother was a rubella baby ... They have difficulty understanding and accessing information and have very limited digital literacy. My father does not own or use a mobile telephone.’

Because both her parents were over 65 when the NDIS was rolled out, they’re not eligible for NDIS support. They’re also unable to access most aged care services because they’re either ineligible or they can’t get past the technological barriers.

‘My father, for example, cannot contact [government services] on his own. He cannot use a telephone and he does not have computer literacy so he relies on a third party to communicate ... He still cannot call an ambulance today. He relies on running to the neighbours in the event of an emergency.’

When Evette arranged for her father to have an aged care assessment recently, the assessors didn’t book an interpreter. Evette said her father isn’t eligible for most aged care support anyway because he can still feed, shower and dress himself.

‘He is considered too old for NDIS, but he does not fit the criteria to get a home care package.’

The lack of support meant that during COVID-19 lockdowns, Evette’s parents were ‘completely isolated and overlooked’.

‘Everybody wore masks. They could not lip-read. When they did catch COVID in the middle of this year they were unable to follow instructions or understand how to take a RAT (rapid antigen test) ... They could not call their GP or the COVID lines. They were unable to go to a testing station as they could not read lips through the mask.’

When Evette’s mother developed a secondary infection during her isolation with the virus, she fell and cut her head.

‘My father stood by unable to call an ambulance or call for medical support or even call me. When my mother did regain some consciousness she sent me a scrambled message.’

Evette took her to hospital, which refused to discharge her until she had an occupational therapist (OT) home assessment. The hospital refused to supply an OT because staff assumed Evette's mother had some form of federal government support that would pay for one.

'Eventually the state agreed to pay for the OT as they thought it would be cheaper than keeping her in hospital. I ended up visiting my mother every morning and every afternoon at the hospital because everybody was wearing masks and it was impossible for her to know what was going on with her care.'

Evette said a nationwide shortage of interpreters means she is constantly on call to interpret for her parents.

'I am fortunate I have a very flexible employer, but I need to find an employer who is happy for me to constantly be on standby to go and interpret in the event there is a shortage.'

Evette said older Deaf people are 'the missing middle', ineligible for the NDIS and unable to access supports available to everyone else.

'Nobody wants to take responsibility for people like my parents. It seems that the government hopes that their death will be accelerated and they are phased out.'

Alvaro and Dixie and Mireille

Alvaro is in his late 20s and has a rare genetic condition that causes developmental and speech delays and behavioural issues.

‘He is non-verbal. He requires 24-hour care around all aspects of his life in terms of self-care, toileting, eating, bathing,’ his sister Dixie told the Royal Commission. ‘And he is a really vulnerable person. My mother and I looked after him until he was about age 18, until it was no longer possible for us to do so.’

About a decade ago, Alvaro moved into a group home. A couple of years later, Dixie and her mother Mireille applied to be Alvaro’s guardians.

‘The reason for this was he was prescribed a medication, antipsychotic by a psychiatrist without consulting my mother. And he underwent severe reactions and was hospitalised for a week. So mum wanted to have more formalised control around his care in all aspects.’

Concern about neglect at the home grew after a recent change in management. Staff were making errors in his medication, Dixie said. Once, they gave him a double dose.

‘So he is on a couple of medications which were for mood and general anxiety and insomnia ... There was clearly issues on safety and administration. Mum was upset about that and asked them to put it into the reporting.’

Mireille tried to speak to the manager about the errors. On one occasion, she requested the home not send Alvaro to his day program – ‘to stay at home to observe any dizziness’. But they ignored her.

Around the same time, Alvaro cut his neck on the seat belt.

‘And they asked me what to do. And I said “Don’t go to day program. Send him to GP, give first aid,” all those kinds of things. And they still followed through the same procedure putting him in a car – Tuesday, Wednesday and Thursday – without doing anything. It started bleeding and the cut went through the skin ... and he was struggling to get out and the more he struggled the more it cut. They did not give him any first aid for three days.’

In recent months, there have been signs of Alvaro being physically abused.

‘Usually finger marks, cuts or scratches, and there was one that appeared like a bite mark.’ Dixie said. ‘We contact [them], asking how this could have occurred ... We have asked for separate incident reports. We still have not got any ...’

The home never replied to Dixie’s emails ‘asking if there is a plan for investigation ... or some kind of follow up ... [to] avoid such a thing from happening again’.

Meanwhile, Alvaro's guardianship came up for review and the service provider tried to challenge it. Through this process, Dixie and Mireille learnt the provider had 'grossly overbilled'.

'It became very clear that it was never about [Alvaro's] interest and a lot of it is financially motivated,' Dixie said.

'We were very surprised and shocked at the behaviour of this organisation. Our concerns about care were justified.'

Dixie and Mireille want to move Alvaro somewhere 'safe'.

'Once we do, we will be making a complaint to the [NDIS] Quality and Safeguards Commission.'

Morrissey

‘Each of my psychosocial disabilities has become worse since joining the NDIS. I spend pretty much all day every day locked in my room because I’m too scared to interact with people.’

Morrissey is in her 20s. She is autistic and has post-traumatic stress disorder and a nervous system disorder.

‘I grew up with domestic violence and I have quite severe PTSD from that,’ she told the Royal Commission. ‘I have difficulty with executive functioning to a really severe extent.’

A few years ago, the NDIS assessed Morrissey’s support needs and decided to move her into supported independent living.

Morrissey has since lived in five disability accommodation houses. The first one kicked her out, when ‘all the money was drained’ out of her plan.

‘They had other participants who were more profitable than me who they were going to move into the house.’

She feels providers put the needs of other residents above hers.

‘The second time I was made homeless it was because of a gentleman who had more funding than I did. He was uncomfortable around me and his behaviour escalated to the point that it was no longer safe for us to live together. And the provider said to me, “Look, financially it makes more sense for us to keep him on.”’

Morrissey switched houses after getting a new provider and new support workers. But instead of giving her the 11 hours of dedicated support her funding provided for, the provider ‘rationed’ it out among residents. ‘So one support worker to three participants,’ she said.

Eventually, again, she was ‘booted out’.

‘Basically I wasn’t high enough needs to have enough funding to be worth providers’ time.’

Morrissey said it is unjust for companies to arbitrarily decide to end services to a person with disability.

‘One of the reasons is because in practice the accommodation is so rare. The need outweighs supply.’

Morrissey then moved into another house, sharing with a woman with 'severe psychosocial disability'.

'I think a lot of her meltdowns and stuff were triggering my PTSD. When she'd have a meltdown, she would scream in her room that she was going to kill herself. She would punch the wall in between our rooms and do stuff like that ... It's intimidating.'

When she wanted to switch homes, the provider accused her of being 'unstable' and turned the blame on her.

'Like, why do you have difficulties living with people? ... The issue is living where someone is punching the walls all the time, or throwing the furniture. And see how long it takes to have a mental breakdown. After living in the house share ... I ended up in hospital.'

Through all this, Morrissey believes the NDIS neglected her needs. The agency left her 'at the mercy of providers' with constant threats of 'a reduction in support'.

She wants funding reviews to be less of an 'adversarial process'.

'It's really damaging. I cannot tell you the amount of trauma I experience before every NDIS review.'

Morrissey feels the plan should stay the same 'unless there's a change in circumstance'.

Recently she won an administrative appeals case against the NDIS to live alone and feels 'incredibly lucky to have had such fantastic representation'.

'Legal Aid doesn't have enough funding to represent all the people who want to challenge NDIS decisions. So you end up with either an advocate or nobody at all and having to go up against, like, corporate level lawyers by yourself. Many people don't have the same advantages that I did.'

Renzo and Nathalie

Renzo is in his 30s and has 'severe autism and developmental delay'.

'He cannot speak and he cannot make any informed decisions of any significance in his life other than whether he chooses a certain piece of clothing or food,' his mother Nathalie told the Royal Commission.

About 15 years ago, Renzo got state funding to move into supported living.

'I didn't want to move him out of home ... We had in-home care and it worked very well,' said Nathalie.

But the government forced him into a group home. If he didn't go, his funding 'would be in jeopardy.'

The family was promised a say in 'the service provider ... and the residents he would be sharing with'.

'We never did. And that was the beginning of a really bad period,' Nathalie said.

The government placed Renzo in a home with three others including a young woman.

'And her particular disability and associated behaviours caused his to escalate further and further. Her outbursts were creating problems for him ... So it was like feeding fire to fire.'

Nathalie said the staff used Renzo 'as a tool to manage the female resident'.

'My son is a very big young man ... very strong. So she would attack him. He would then assault her'.

Management then tried to block the parents coming to visit unannounced, 'because they had problems with their residents'.

Nathalie noticed her son losing a lot of weight. He was 'fed like a dog'.

'They would make a pile of food and leave it on a table all day. If he didn't eat it, he wouldn't get fed.'

All the residents were subject to abuse, she said, because the manager was 'the most evil, despicable human being'. She stole furniture, food and other goods from residents, and was trying to run the house on minimal staff.

Once she ordered a support worker to ‘tackle’ Renzo to the ground ‘to teach him a lesson’. She also managed him through medication, increasing his dosage ‘to the point where he was a zombie’.

‘And she tried the same thing with all the residents ... To have their medication increased so they’d be tired and pliant ... I think that’s called chemical restraint now.’

One afternoon, Nathalie made ‘a surprise visit’. It was a very hot day and her son and the female resident were in the house by themselves with no air-conditioning.

‘They’d just come back from their day program. There wasn’t any food or drink anywhere. The staff were nowhere to be found ... I walked into my son’s room and found a filthy cup that he’d been using to get water. And I also at that point noted that there was dried faeces smeared over the wall and over the towel rack.’

Nathalie found the manager and staff in the air-conditioned staffroom. Soon after she complained, the provider replaced the manager.

Later, Renzo got ‘a catastrophic’ spinal injury at the home and ‘was so distressed, he would almost rip doors off from pain’. The staff member who was working with him had already caused similar injuries to another resident, Nathalie said.

‘So why not put cameras in? Because my son can’t meet the burden of proof to finger the guy who hurt him. But we know that he was hurt. Surely there must be different ways that people who are non-verbal, with disabilities, can have some justice and feel safe.’

When he recovered sufficiently, the government made Renzo go back to the home, but it was ‘hell on earth for him’. After five years there, Nathalie fought to get him out and Renzo has lived at home ever since.

‘I don’t want him to ever go to a hellish situation like that. I will never trust anybody again with him.’

Alain and Sybil

Alain is in his 30s and has intellectual and physical disability.

‘[Alain’s] brain didn’t develop when he was in utero, so his brain has an overall abnormality,’ his mother Sybil told the Royal Commission. ‘It’s given him rare medical conditions ... [and] his support is actually really complex.’

Alain attended special school for a few years, and in his teens spent time in a respite house.

‘There were lots of people that had been supporting him ... He’d be quite happy – loved everyone, always laughing. There were never any issues. I was never concerned about abuse, to be honest. I certainly didn’t know anything about the risk of abuse in group homes.’

Alain moved into a group home when he was about 20. Sybil realised after about 18 months that something was not right.

‘I started finding bruises and then he stopped eating. Like, on his wrist, there’d just be bruises that were just black and would actually go through the skin. He does not have the cognitive capacity to understand what abuse is, so he can’t tell us.’

Staff never informed Sybil of any problems.

‘The workers in the house, the team, were saying, “He’s fine, there’s no issues.”’

But she increasingly became aware of the mistreatment. Alain was showing signs of emotional distress.

‘He would self-harm by biting his wrists. The abuse he suffered included things like neglect, where he wasn’t being fed. He was frogmarched into a bathroom because he didn’t want to have a shower. He was hit by other residents in the house. One of the residents had a walking stick, used to call him “the clown” coz [Alain] makes a lot of noise. We know that at least on one occasion [Alain] was hit with the stick.’

Sybil said staff were neglecting his ‘complex medical needs as well as complex disability needs’.

‘With the physical disabilities that he has, and with the autism, if he doesn’t eat his dinner then his blood glucose will drop, which could cause him to go into a coma and die.’

Things came to a crunch when staff let his blood glucose go down ‘to near fatal levels’, Sybil said.

‘So an ambulance was called ... He could have died that day and there would have been no repercussions on the provider – and it was the provider’s fault. The workers weren’t trained ... They would have just filled the room. There would have been a new resident.’

Sybil removed Alain from the home, but the abuse left him with post-traumatic stress disorder.

'He has been diagnosed with PTSD. He's been diagnosed with generalised anxiety and also with situational anxiety ... I think part of the issue is that he liked and trusted them and then it came unstuck. For me, it's really sad to see because he was always the happiest person in the room, and now he's not that person. But we have managed to keep him safe.'

Alain is now living in a rental property with 24/7 care from support workers and his family.

'He has always liked being on his own. And he likes his own space. There's currently no real option other than what we're doing for him to be in a safe environment.'

But the NDIA wants to put him in a group home again because it's cheaper. Sybil says the agency should facilitate the right of people with disability to choose where they live.

Petille

‘The advocate should have the ability to investigate ... With domestic violence situations, the advocate should be able to help and represent the person with disability in court, or help them in other ways, like with changing housing or access to finance so that they can be independent of that controlling situation.’

Petille is in her early 40s and lives with depression. She was a lawyer until she incurred a work-related psychological injury a decade ago.

‘They terminated my employment ... because I became so unwell,’ Petille told the Royal Commission.

Petille spent several weeks undergoing psychiatric treatment. Her son’s father was supposed to be her carer. But the relationship led to domestic violence and she was in ‘survival mode’ while battling mental illness.

‘And then it just kept getting worse ... It was just really scary. And you keep quiet so you’ve got enough energy to look after your baby and yourself, keep going to your doctors’ appointments, keep taking your medication, you go to the hospital when you’re told to.’

Petille’s partner moved out about six years ago. During ongoing custody battles, she feels lawyers have ignored her requests because of her disability.

‘If you have a mental or an intellectual impairment, you’re either written off or you are steamrolled. Or you’re forced into agreements that you don’t agree with and that aren’t in your best interests or – where there’s a child involved – aren’t in their best interests. Because a solicitor, they’re working on billables.’

She wanted to use her ex-partners ‘long history of drug abuse’ to continue to block his access to their son.

‘I was trying to communicate that with solicitors, and it was just like, no-one wanted to press it. No-one insisted on drug testing when they should have, that sort of thing. My former solicitors didn’t issue subpoenas when I asked them to. They will ignore what you have to say, sort of force you into consent orders.’

Petille said her lawyers should have really been fighting for her, ‘not just pushing around paper’.

‘I’ve come across too many solicitors who are lacking in advocacy skills and that’s a real problem. Where there’s significant domestic violence, you really do need someone to help you and help verbalise what’s going on.’

Meanwhile, lawyers were charging her for things they weren't doing.

'It's just incredible. The last lot of solicitors, I had actually paid \$45,000 to them ... and I could barely feed us at one point.'

Petille sees an urgent place for highly-skilled legal advocates for people with disability who are present during all contact with lawyers.

'Litigation's a big thing for anyone, and dealing with, you know, large firms who have the power to wear you down with costs and paperwork. I've had so many advocates who – well, they're meant to be advocates, but they just don't have the skills, they're afraid to speak,' she said.

'When you have a disability, you may have good days and bad days. You really need someone to be able to fight for you consistently, a voice that's respected and treated on equal footing. Because sadly, with people with disabilities, there is a stigma.'

A lot of people with disability 'aren't believed' on domestic violence, Petille said, from the police to the courts.

'An advocacy service would be wonderful. If we're really going to make a change, I think that it comes down to the advocates being able to convince a judge or a magistrate of their case.'

She has found her times in court 'very challenging and quite humiliating'.

'I had to go in depth about my impairment and make the court understand ... If you had an advocate there who could be supportive, that would be great.'

Bryn and Davy

‘The only force behind me contacting you guys was respect to [Bryn] that at least someone on this earth will always advocate for her. And for me as a father, if I died tomorrow, that I could say on my deathbed that I did everything for you, sweetheart.’

Davy is the father of Bryn, a teenager who is non-verbal and has high support needs.

‘We were given the opportunity when she was born ... to switch the machines off. We didn’t,’ Davy told the Royal Commission. ‘The doctors and the consultants at the children’s hospital have said to us on multiple occasions [that] she only is living because of you parents, your commitment and attention to detail, love and care.’

Davy and his family live in a regional area where Bryn goes to a special school. One day a few years ago, her school phoned to say Bryn was ‘not well’. Bryn’s mother arrived to find an ambulance about to take her to hospital.

‘There was no aggressive, hysterical ranting and raving. [She] just asked, “What happened?” ... and so [the school’s] reply was, “We don’t know.” Then it changed to, “She rolled off the foam mattress.”’

The ambulance took Bryn to the local hospital, which transferred her to a city hospital for further tests. Bryn was in a lot of pain.

‘[When] the volume of her crying actually goes down, her lips go blue and her skin mottles. And so that’s when we know her pain level is off the charts. When it’s like that, her epilepsy kicks in and she goes in and out of hundreds of seizures per day.’

The hospital found Bryn had a broken leg, but Davy said the level of pain suggested ‘something really, really wrong’. His wife pleaded with the hospital to do more tests.

‘We rang the [school] principal and said, “You need to find out what actually happened because it’s actually impacting her ability to get this treated properly.” And we couldn’t get a story out of the principal. We pleaded.’

After 10 days in hospital, Bryn’s condition deteriorated. After being admitted to intensive care, further X-rays showed she had a broken back.

‘You don’t get [several] fractured vertebrae from rolling sideways off a ... mattress,’ Davy said.

Bryn remained in hospital for more than six months.

'We to date have never been able to secure from the school the honest, accurate account of the incident that caused these injuries. We received impossible and changing accounts of what occurred. This resulted in a delayed medical diagnosis which then resulted in admission to intensive care.'

The education department investigated the incident, but Davy said he was 'never privy to the investigation report and their findings'.

'The only communication we had from them is they wanted us to give them access to [Bryn's] medical files ... It was the biggest insult because we thought, well, wouldn't you just give us an answer to our question that was asked multiple times? Can you please just tell us what happened?'

Davy said Bryn's care still relies on understanding exactly what happened.

'We are not litigious people ... We actually said to the principal we understand things happen, it's not a perfect world ... [But] it leaves you feeling bewildered [about] an establishment that is meant to advocate and protect and actually specialise in dealing with children with a disability.'

Davy said he's telling Bryn's story to the Royal Commission to 'get the message out there' that prejudice against people with disability continues underground when there's no transparency, even in organisations that should know better.

'You can legislate anything in the world, but if you don't have a culture, a community, a society which rewards honesty and empathy, then it's only going to get pushed further underground.'

Maximilian, Rodrigo and Petula

‘There was just a complete lack of understanding of what was happening to him. And he was just seen as a ‘problem child’. A child that had behaviour issues and really needed some discipline.’

Petula is the mother of two boys with intellectual disability. Maximilian is in his early teens and has Down syndrome. The younger son is Rodrigo.

Petula chose ‘a very inclusive path’ for both boys, but a couple of years after Maximilian started primary school she saw ‘red flags’.

‘There were certain procedures and protocols that they had for children with disability,’ she told the Royal Commission. ‘They were doing special things for him that were a barrier to his academic and social inclusion.’

The school was pulling Maximilian out of class every day and putting him in a special education program.

‘They see it as more valuable doing, yeah, the targeted intervention in the special ed teacher’s room. And I’m asking for that not to happen.’

Petula wanted reasonable adjustments so Maximilian could stay in class, but the ‘non-inclusive practices’ continued. For example, he was being excluded from library time and put in a sensory room.

When Rodrigo started a couple of years later, the same thing happened. He’d just been diagnosed with developmental disorders including apraxia and dyspraxia, but Petula insisted he have an inclusive education.

‘So I was saying I didn’t want my boys taken out of language class, because I felt that was really important that they went ... like all of the other children.’

Petula tried to speak with the school about it.

‘My opinion wasn’t respected or appreciated. I was often made to feel like I was making decisions that were jeopardising their wellbeing and their education.’

With Rodrigo, the exclusion ‘got a whole lot worse’ and his ‘anxiety and behaviours started escalating’.

‘I was doing everything to try and provide evidence for appropriate adjustments and it just all seemed too hard or unreasonable. Even just in terms of little strategies, asking that he do his work on a laptop because he found it very difficult to write.’

In year 2, 'things started to really unravel'. Rodrigo was starting each day in a room next to the principal's office after playground incidents of Rodrigo 'kicking or throwing or pushing'.

'And we ended up just in this vicious cycle of behaviour and consequences. We could see the anxiety growing, skin picking, couldn't get to sleep at night. It just became unmanageable. He was in a bad state.'

Instead of helping him, teachers took issue and gave Petula a regular run-down of his bad behaviours.

'After the countless number of meetings that I've had to try and explain how he needs support in those situations. And then to see that the approach is to make him sit in the corner or to tell him that he's rude. I could just see how poorly the situation was managed and what an unsafe, unsupported environment that he was in.'

Meanwhile, Petula said, the education he was getting was 'ridiculous'.

'And the number of times he begged me not to go to school, how he could've been learning a new thing ...'

Even moving to a small rural school, the boys 'couldn't escape the behaviour protocol'. The school used a sticker chart for 'rewards and consequences'.

'Which again resulted in school refusal, escalations after school, meltdown after meltdown. [He was] covered in sores because of just picking his skin constantly. So that whole system just was not conducive to his disability, I guess ... It was extremely distressing to him and causing him harm.'

Recently Petula started homeschooling Rodrigo. She says he's thriving.

'Because it's an environment where he can be himself and feel as valued as everybody else. And he's not identified as being the naughty child that isn't as smart as everybody. He has freedom over his own self and his movements and he doesn't feel trapped. And so, for that reason, he's learning more.'

Gabbie and Rusty

Gabbie, late 30s, has a psychosocial disability and vision impairment.

About 10 years ago her husband – the father of her eldest children – died at work.

His children received a compensation payment. Gabbie started taking them to counselling but struggled with her own grief and mental health.

Some time later, Gabbie started another relationship and fell pregnant.

Rusty was born with a rare genetic development disorder. He has intellectual disability, sensitivities similar to autism, cardiovascular and musculoskeletal issues. He lives under palliative care.

Soon after Rusty was born, Gabbie ended the relationship with his father because he was abusive.

She told the Royal Commission that initially they tried to share custody, with limited success.

Rusty had a health flare-up while in his father's care, and had to go to hospital. His father became very angry, blaming Gabbie for the incident. He started making more and more threats.

Gabbie's GP suggested she go to police but she didn't want to escalate the situation.

Shortly after, Rusty's father commenced proceedings in the Family Court for custody of Rusty.

'The court system has been used to drain me financially. There has been blatantly false information.'

Gabbie said the Family Court has not considered Rusty's disability or her situation.

'That one blanket system does not work for children with high developmental and medical needs.'

Gabbie has not been able to access support or Legal Aid because of the way her husband's employer structured the compensation payment to his children following his death.

Gabby is also not able to access Centrelink support. She has had to work full-time, while caring for Rusty and her other children, to pay the legal fees.

She also had the financial burden of proving Rusty's disability to the Family Court.

'I had to financially pay to inform the court. My opinion and my knowledge was irrelevant.'

The court has required Gabbie to attend two-day hearings, on her own, unrepresented without adequate care for Rusty.

They refused her reasonable short extensions requests to allow her to find care for Rusty.

‘Even though I declared my own disability and my carer roles, the senior register ... refused to allow an additional two weeks.’

On several occasions, the Family Court proceeded with matters while Gabbie was caring for Rusty in hospital.

‘Instead of following the health needs of my child in order of priority, I’m required to react and respond to what the court needs at the time, based on whatever allegations the father might be making.’

Gabbie believes the court sees her ‘as a problem’.

‘That leads to the potential for orders to be made for a child that are not based around his needs, but are actually based around my ability to not offend people.’

Ayan

Ayan is in his early 70s. He had polio as a young child and has had post-polio syndrome (PPS) and associated physical disabilities ever since.

Ayan said the majority of people in Australia with PPS contracted the disease in an epidemic that took place in the late 1940s and early 1950s. They have now lived a long time with the aftermath of the disease. It leaves some muscles weakened, requiring others to work harder to compensate.

These muscles are doing work that 'they were not designed to do,' Ayan said. 'Because if you look at the human body as a piece of machinery, every piece of muscle has been created to do certain things for a certain period of time. People with polio have pushed those things to the absolute limit and, so, lots of people with polio find that their muscles are now giving up.'

Ayan told the Royal Commission that people with PPS need regular treatment from remedial health services such as physiotherapy and massage. But NDIS funding isn't available to people with the condition, and such services aren't accessible through My Aged Care packages.

'You might get an hour of cleaning or whatever, but you don't get any support to go and see chiropractors, massage people, physiotherapists, all those things which help polio people to keep going. And that's what is critical, that polio people need to have the right to continue going, otherwise we end up in a bloody nursing home.'

Ayan wants the NDIS to recognise PPS as a disability that warrants support. He believes that because it is a disease that has largely been eliminated in Australia, people don't appreciate its impacts on those who survived it.

'To many people, polio is a dead issue,' he said. 'What I've been pointing out to people is, yes, you're quite right. Polio is a dead issue, but those of us who had polio, we still live with the results and the longer we live, the more difficult it is with those things.'

He said another option might be to make changes to Medicare, to allow people with PPS additional subsidised visits to allied health professionals.

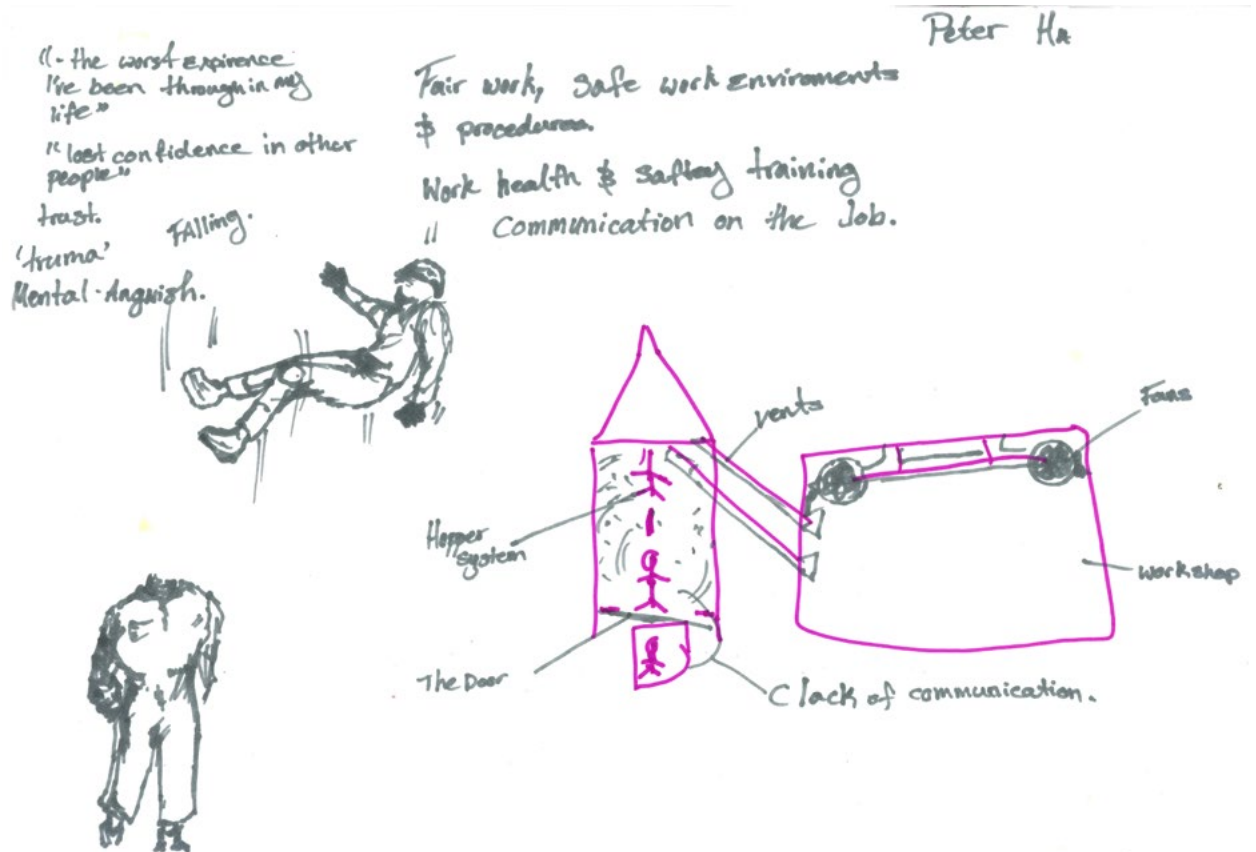
'Most of us have, despite our limitations – physical limitations, we have – well, to put it mildly, we've lived in the able-bodied world, we've played in the able-bodied world and we've paid taxes in the able-bodied world. But we don't get anything in return, especially under NDIS. So I think that whole program has to be revamped.'

Ayan said that throughout his life he has experienced able-bodied people making decisions about his disability.

‘You know, I have had doctors who tell me what’s wrong with me and I have to say to them look, “I’ve lived with my body, I know what’s wrong, can you please look at it from this point of view.”’

He hopes to see this change.

‘We need to include people with disability in any decision-making process, any changes that happen, so that it’s their point of view.’



Artwork by Peter Huett

Ritchie

‘We’re not a charity case. If you work with us correctly we can be the star or the gem of the company.’

Ritchie is in his 30s. He is autistic and has attention deficit hyperactivity disorder.

‘I was diagnosed with Asperger’s and I had an option for early intervention, but my dad said no,’ Ritchie told the Royal Commission. ‘My dad said, “Well there’s nothing wrong with my son so you’re not getting him help.”’

Ritchie was in a gifted class in high school, but in his final year ‘couldn’t study or focus’.

‘I left halfway through year 12, started working.’

He joined a large company working with computers. The company gave him awards, but after a relationship breakdown his mental health deteriorated.

‘I asked many times to get support because we were working from home as well, so to actually have face-to-face is difficult. So I asked to be kind of like buddied or something ... and they basically just sent me on these courses where you sit and listen.’

Ritchie struggled to concentrate on his projects.

‘I’m used to bullying in the workplace, especially when it comes to having a disability. People call you slack, people call you incompetent ... When I raised it with them, [the bully] basically put it back on me saying I was bullying him by raising the bullying. Which, you know, and then it just got dropped. So I felt very alone.’

The company eventually sacked Ritchie.

‘My career was progressing and then it kind of just collapsed. I lost my house, I lost my savings, I had to move three times. You know, I’ve nearly been homeless.’

Ritchie struggled to find another job and applied for the Disability Support Pension. Recently, he started an internship with another large company.

‘I almost cried. It was refreshing. I felt like I could just do my best, be honest if I wasn’t coping ... This is the first time in work I’ve actually felt happy or useful ... They provide flexible work hours and stuff.’

Ritchie said he has regular meetings in which the company gives him constructive feedback.

‘Like there’s options, [and] it felt like I didn’t have to fail. A lot of places you kind of push and you push and you push and you burn out trying to fit their expectations,’ Ritchie told the Royal Commission.

‘You have to put people in the right place. Not everyone has the same skillset. Same with disabilities. Not every person with a disability has the same skillset, but we can still flourish.’

Susanne

Susanne, early 40s, has spina bifida and uses a wheelchair. Support workers help her with daily tasks including personal care.

In high school, Susanne was interested in studying media and photography.

Teachers and the career adviser told her those subjects wouldn't help her 'get a job as a wheelchair user'.

'I was actually told that if I chose photography ... they wouldn't give any assistance.'

Susanne wasn't interested in the subjects she had to choose, and did poorly as a result.

'That was my first confronting experience of ableism and I didn't realise at the time,' Susanne told the Royal Commission.

'I do remember, though, a teacher coming up to me at the end of year and said to me, "Look, I want to thank you because," he said, "at the start of year, I didn't want you in my class. I didn't think a disabled person should be in the school system." And he said, "You have totally changed my mind."'

Following TAFE, Susanne contacted a disability employment service provider.

She told the caseworker she'd studied website design and multimedia and wanted to work in media and communications.

He told her she wouldn't be able to get a job in these fields.

'He said, "You need to take a good hard look at yourself, and realise what you can actually do."'

He told her he could get her a job at a government agency.

'He organised a meeting ... and said to me that I was not to speak at the meeting, that he would do all the speaking for me. And then I was just to say yes or no.'

Susanne worked at the agency for the next 20 years.

She said she only stayed in the role because she had no confidence in her own ability and 'nobody else had any confidence'.

'My mother, it was very much, "You have got this job, it is a secure job. Not everybody likes their job. Just be happy you have got a job."'

Almost immediately, Susanne started to experience workplace bullying. In the mid-2010s, the bullying escalated significantly.

‘It was a toxic workplace,’ she said.

Susanne’s psychologist told her if she didn’t leave, she would die.

She asked for time off due to her mental health. The agency wrote back and asked her to take out the reference to mental health.

Eventually Susanne left, and signed up with another disability employment service provider. She told them she was interested in marketing and communications – she’d completed a degree while working.

The caseworker told her they would market her to employers in the area.

After about three months of turning up for meetings and applying for jobs, she asked the caseworker for an update about the number of local employers they’d contacted.

They told her they didn’t have any contacts in the area.

Susanne also discovered the caseworker had no experience looking at resumes or job application letters.

Susanne made a complaint to a person in head office who told her they would find another provider, but there were no other providers in Susanne’s area.

Susanne decided to set up her own consultancy helping businesses employ people with disability.

She has enough work to pay the bills and is happy working for herself.

‘Working for somebody else, because of what happened at [the agency], scares the hell out of me. I don’t think I can trust anybody not to do what they did to me.’

Oksana

Oksana, in her early 20s, is autistic and experiences anxiety and depression. She receives a Disability Support Pension and NDIS funding. She also has mild cerebral palsy and uses a wheelchair she bought herself, second-hand. She gets no support from the NDIS for this disability, as she doesn't yet have the necessary official diagnosis from a neurologist.

'They're like, "Well, it's all just caused by your anxiety." I'm like, "I see why you think that, but I've had these same symptoms my whole life, since birth."'

Oksana was diagnosed with autism when she was about 10. Since then, doctors have attributed her physical issues to that.

'Like "Why does she walk really weirdly?" Oh, autism. Um, "Why can't she eat properly?" Autism. "Why are her limbs really floppy?" Autism. "Why does she have such bad fatigue?" Autism. Even though those are not signs or symptoms of autism. So NDIS, despite having many reports stating the functional need for a wheelchair, they will not fund one.'

Her current GP, occupational therapist and physiotherapist agree she has cerebral palsy, but the neurologists she's seen do not.

'I'm just like sick and tired of, like, paying so much money to go to these expensive neurologists and then just have them ignore me. They're not listening.'

At the moment Oksana uses her wheelchair 'most of the time'. It reduces the back, knee and lower leg pain she experiences. She would like a lightweight prescription model so it fits her properly and she can get it in and out of the car and push herself in it even when she's tired.

'It's just frustrating because I know NDIS is all about building independence. And I'm kind of like, well, if I have a wheelchair I don't need as many supports because I can actually go and do things on my own.'

Oksana told the Royal Commission she has a five-year goal.

'[To] be able to do pretty much everything by myself because I'll have the right tools and then, you know, I might only need someone to come over once a week to help me clean or something.'

At the moment Oksana's support workers drive her places, get the wheelchair in and out of the car and help her to 'navigate everyday life'.

‘I really want ... to be able to do what everyone else can do. I don’t want to have constant supports. I don’t want to have – like, I don’t want all of that. I really do want to be able to live independently and, you know, having a wheelchair and having the right tools in place I think would greatly benefit me in that sense.’

Oksana has recently started playing wheelchair sport and finds it very beneficial.

‘I got to a point where I felt like I was going to hospital every month because I really wanted to kill myself. I was having a horrible time. I’d failed uni ... couldn’t find a career, I couldn’t do anything – I felt like I couldn’t do anything right.’

People urged her to exercise. She didn’t think it would help, but gave wheelchair sport a go. She now loves it.

‘But I think what for me personally makes the biggest difference is the community. Having people that check in on you if you don’t show up to training and be like hey, are you all good? But also just, yeah, feeling accepted and not being self-conscious of my body when I’m playing coz I’m like, you know what? Everyone’s body here is weird. None of our bodies are the same. And just seeing everyone else use a wheelchair, and it’s so normal.’

Cherie

‘There’s no compassion. There’s no humanity. There’s no understanding there’s a human being trying to live and survive on the other end of that money.’

Cherie is in her 40s and Deaf.

About 20 years ago she was admitted to hospital for an eating disorder and asked the public trustee to manage her finances

‘Things like rent and bills you had to go to the post office to pay them, that sort of thing, and when you’re in hospital that’s very difficult.’

Cherie said she was told the trustee would make her life easier so she could concentrate on her health.

‘They never told me it would be impossible to get out,’ she told the Royal Commission.

‘The way they handle your money is they do up this budget and then they give you an allowance. So for food, clothing, transport, public transport ... everything like that I got \$80 a week.’

Cherie said it wasn’t enough, and she relied on charity for food and clothing.

‘You have to beg them for money for stuff. Like when I was pregnant with my son, “Please can I buy this cot? It’s on Marketplace. It’s a good price.” And by the time you get through the whole begging them and justifying it the cot’s gone to someone else.’

Cherie said the trustee stopped her allowance when she had to travel to another city to visit her dying father. Another time, they didn’t put her money into her account over Christmas.

‘They either forgot or it didn’t work – the automated payments that were supposed to go to people over the Christmas period. [And] most of the charities were shut,’ Cherie told the Royal Commission.

‘I went into the office crying on the day that they opened because it had been several weeks with no money. And they didn’t even apologise. I had to beg them to give me \$50 in cash.’

Cherie said the trustee often didn’t pay her bills on time.

‘I lost count of the number of times over the years that I got warning notices, final notice before eviction, notice from utilities that my utilities were going to be cut off.’

Cherie, who had been on the Disability Support Pension, said in the end she had to get a job.

'I didn't tell them. So they said like, "Oh, your Centrelink's been cut down. We can't pay these bills." So I started paying the bills and everything.'

Cherie then applied to have the trustee removed as her financial administrator.

'I've been told that to get out as easily as I got out [a few years ago] is rare, really rare. And it really is only because I could show that I'd been the one paying my bills.'

Cherie said she assumed the trustee had saved and invested the money it kept from her.

'At the end of it I got back ... I don't think it was more than \$2000 and something. And that was absolutely mind-blowing. Like, what happened to all those savings and everything over 15 years?'

Howie

Howie, in his early 30s, has attention deficit hyperactivity disorder (ADHD).

In the mid-2000s he served in the defence forces and was badly bullied. He was medically discharged and later diagnosed with post-traumatic stress disorder (PTSD), panic disorder and anxiety disorder as a result of his experiences. He receives incapacity payments through the Military Rehabilitation and Compensation Act.

In the mid-2010s, a series of difficult events in Howie's life and changes to his medication led to a period of suicidal ideation.

One night he took an overdose of pills and went to a bar. The police came, handcuffed him and put him in a paddy wagon.

'Rather than engaging with me as somebody who was clearly going through a mental health crisis, they started treating me as if I was a criminal,' Howie recalled.

The police took him to a local hospital. Staff there were also unsympathetic.

'Nobody sort of cared about what I was going through.'

When Howie asked a nurse what drug he was trying to inject him with, the nurse refused to say.

'He didn't want to tell me what was going on. He was just basically saying, "The doctors told me to give you this. You're either going to take it or I'm going to get security to come in and give it to you." And he just wouldn't listen and wouldn't explain to me what treatment I was being given. And basically, without explaining what was going on, he then went off, got six or seven security guards to come in and pin me down and I was then shackled to a bed and forcibly given this medication.'

Howie discharged himself from the hospital and was then admitted to one for veterans, where he had a much better experience.

'I was actually informed of what was going on with my medical treatment,' he said.

He told the Royal Commission that while in hospital he was 'petrified' he would be given electroconvulsive shock therapy, which can be administered without the patient's consent. Consent is an issue for people with disability, he said.

'The legal paradigm that surrounds all of this is such that the law does not treat individuals with mental health impairments or disabilities with the same level of respect and dignity that other areas of the law treat everybody else with. They just assume, "Yep, we're going to do stuff to you."'

Howie has had recent involvement with the court system, and encountered similar discrimination there.

‘The fact that I have mental health disabilities has been weaponised against me.’

He has also experienced it in the education sector, where he sought adjustments to allow him to participate in a program of study.

‘It seems to be a constant struggle – especially in the tertiary sector – to obtain reasonable adjustments if you are a person with disabilities. The onus always seems to be on you as the individual with disabilities requesting the reasonable adjustment to prove why you need the adjustment, rather than the institution accepting that they need to make their material and their courses more accessible.’

Howie explained that the main adjustment he wanted was to be allowed to attend lectures and workshops remotely.

Eventually, the university agreed. But the process didn’t work. Transmission of three-hour classes cut out after an hour.

‘It was literally an IT issue that could have been resolved by whomever doing it – and they just didn’t do it.’

Tammie

‘When you have three or more people with disabilities within your family, I mean, this lovely idea of the NDIS as an individual-with-a-holistic approach, it’s bullshit.’

Tammie lives in a regional area and has several children with a number of disabilities between them.

‘I’ve almost had two breakdowns trying to get support,’ Tammie told the Royal Commission. ‘That’s also partially due to a support organisation that was so badly run they almost put me into another breakdown as well as not having the funding.’

Tammie’s eldest child is blind and now studying at university. A teenage daughter has an intellectual disability and ‘a beautiful heart’. One son in primary school is autistic, has severe dyslexia and loves audiobooks. Her youngest child has epilepsy and cerebral palsy.

The NDIS supports her children, but Tammie said NDIS planners struggle to understand the family’s complex problems.

‘I lost all faith in [planners] to be able to recognise the complexity of my [youngest child’s] needs and it really screamed to me that there needs to be almost levels of training in regards to planners.’

Tammie said the planners assigned to her youngest child ‘don’t understand the diagnosis even though it’s clearly written up’. During a recent review the planner admitted she had only an hour ‘to skim through the notes’.

‘We spent thousands getting consistent [reports] and getting prepared and getting the details that she didn’t even read.’

Tammie’s older children share an NDIS planner between them.

‘We’ve been placed with a different planner every single time we’ve had to go for a plan.’

At one point a planner told her she wasn’t eligible for the extra support she asked for because it fell under ‘normal parental responsibility’.

‘[A normal parent is] not trying to coordinate specialists in neurology, neurosurgery, genetics ... rehabilitation. You’re not doing orthotics and check-ups with cerebral palsy, orthopaedic surgeon every six months ... You’re not having to constantly monitor her for epilepsy seizures ... You’re not having to put a nasal gastric tube down your child’s nose.’

Tammie said she developed post-traumatic stress disorder from interactions with the NDIA.

‘Right from the beginning, you call up customer service and you can get a different answer to the same question from three different phone calls. Where’s the training and consistency? That’s a systemic problem, but it creates a lot of background trauma when you’ve got people who are already struggling with so much, desperately trying to get help.’

Tammie said when she asked for a complex support coordinator to deal with the family’s complex issues, the NDIA told her she’s not eligible because her children aren’t ‘at risk’.

‘My recommendation would be to create a team within the NDIA to actually support families with complex disabilities or complex families with multiple disabilities.’

Chas and Jacquie

Chas, early 40s, has cerebral palsy, intellectually disability, vision impairment, depression and anxiety. He has represented Australia in elite sport, winning gold for Australia.

In his late 20s, Chas wanted to be more independent and move out of the family home.

'I wanted him in an environment where they understood his disabilities,' his mum Jacquie told the Royal Commission, 'where he was going to get the right support and where he had some company.'

Chas moved into a group home with numerous residents of mixed age and disability.

He was living a full life and volunteering several days a week at this time. He was used to being independent and having choice.

But staff at the home took away a lot of Chas's choice and control.

He liked to come in the side door but staff refused to let him. They would tell him he couldn't have vanilla ice-cream because they only bought Neapolitan. They made him eat soup even though he found it difficult to eat without spilling it everywhere.

'That was enough to give him a meltdown, literally.'

Jacquie said staff assumed Chas's capacity was greater than it is.

'He is visually impaired and in a wheelchair. And he had to clean his own room, he had to clean his own toilet and he does have difficulty with toileting sometimes. You might have to help him.'

Chas's room became a mess and his personal hygiene deteriorated.

'They wouldn't help him with his shaving, they wouldn't even cut his fingernails.'

His sheets and clothes became filthy and would go missing. His room became a mess and he couldn't find anything.

'He would be having a meltdown because he was going to be late for work ... But they didn't really take on board that he was going to his job.'

Chas became more and more frustrated.

Staff started ringing Jacquie every day to complain about Chas's behaviour.

One of the residents picked up on the way staff spoke to Chas and started to goad and bully him because he was an easy target.

‘All of it culminated in my son unravelling, my health declining, our family suffering because I was really quite unwell.’

The residents ganged up on Chas and told him they didn’t want him to live there.

Chas was traumatised.

‘This is a man who in the right environment won a gold medal. If he was treated with respect and his needs were understood, he could rise to the occasion.’

Soon after, Chas was on a train. He became distressed when a group of athletes got on, and tried to get off. The driver intervened and Chas lashed out.

Police charged Chas with assault. He was set to appear at the Magistrates Court until an advocate intervened.

‘It took him getting into trouble with the police for anybody to actually listen.’

The court provided a justice worker, a psychologist, behaviour management specialist and organised a psychiatric assessment.

‘[The assessment] clearly demonstrated [Chas] has no ability to regulate his own emotions and the level of supports he requires. This has assisted to get support workers to understand his level of need.’

Chas now lives in a one-bedroom unit. Support workers come in to do his washing, make him meals and help him shower.

‘He likes his workers at the moment, but I would have to say he just had to fit into their timetable ... It is about the person fitting into their environment rather than them fitting into the person’s needs.’

Chico

Chico, late teens, is autistic.

He attended a mainstream primary school but spent all of his time in the special education unit.

‘It felt like we got treated different compared to the other mainstream kids. Like, in a bad way.’

Chico told the Royal Commission most of the kids in the unit had ‘really bad anger issues’ and he didn’t want to be there.

‘It was just more that I couldn’t really learn properly and stuff like that. My anxiety just didn’t help me with that.’

If a kid ‘got out of control’, staff locked them in a storage room, ‘for however it took to calm down’.

In year six, a ‘very violent’ substitute teacher started.

One day a kid started kicking and messing with the shelves.

The teacher swore and threw a whiteboard marker at him with such force the pen shattered.

‘Everybody just went completely silent and didn’t really want to talk or anything like that, because everybody was just afraid. He seemed really, really out of control.’

Chico and his friend often tried ‘to get away from the violence’ and would roam the school.

The teacher got mad at them and locked Chico in the room for more than two hours

‘I have nosebleeds whenever I get overheated or really anxious or stressed.’

When Chico’s nose started to bleed, ‘all they did was just bring in tissues’.

The teacher would physically restrain kids.

‘I came home one day with, like, a bruise on my eye and all over my back.’

Chico’s friend hated being locked in the room. One afternoon his friend was feeling ‘uncomfortable and angry’.

‘The teachers were about to go lock him in that room because he was getting out of control. There were four, five teachers all blocking him into a corner. He was just trying to stop himself from being locked in that room.’

Chico told the teachers to leave his friend alone.

'I had two grown adults sit on top of me because they thought I was going to do something wrong. I feared for my life because one of them was sitting directly on my chest and the other one was sitting on my legs ... I was telling her and begging her to get off me because I was wheezing. I couldn't breathe properly.'

The teachers broke capillaries in Chico's neck, behind his ears and on his face. His shirt was covered with blood.

Chico's mum pulled him out of school and homeschooled him until the end of primary school. She took the education department to court but ended up withdrawing the matter.

'They actually told her if she loses the court case she's going to have to pay all the bills of all the lawyers for the education department, and that's going to cost her and set her back tons of money.'

Chico received counselling but didn't want to return to school.

'Anything that was learning-related I really struggled with. Ever since that happened at that school ... I just couldn't learn anymore. I was struggling to do anything at school.'

Chico attended several different high schools but 'they didn't really do anything to help' him.

The last school was much better at helping kids regulate their emotions.

'They used to calm them down and give them their time to calm down. They would make sure everything was okay. They didn't restrain kids or anything like that. They simply just kept them away from hurting other kids.'

Chico left school as soon as he finished year 10. He loves computers and has tried to study at TAFE, but going to campus reminds him of school.

'It just gives me really bad anxiety and stress knowing that I have to go there.'

Chico spends most of his time gaming at home.

'Since I wasn't really having a good time at school, I didn't really make many friends. The reason I stay home all day is because I have no friends.'

Monika

Monika has multiple chemical sensitivity (MCS), also known as chemical intolerance (CI) and chemical hypersensitivity.

‘So almost anything you can think of that is man-made, people are wearing, using, washing their hair with, washing their clothes with – all of those things are like kryptonite to my body, so I can’t go anywhere near them.’

She experienced the first symptoms in her early 30s, when she had a strong response to a work colleague’s perfume. A decade later, her sensitivities have become so extreme she is hardly able to leave the house.

When Monika first became aware of her disability, she was working in a government office. She approached her manager to ask for some measures to be put in place so her sensitivities weren’t triggered.

‘I don’t know if you know spearfishing, and it’s like – that’s what it felt like. It felt like someone put a spearfishing prod right into my brain, like it was just so painful and I couldn’t concentrate so it was really, really impacting.’

She hoped a solution could be found that would allow her to ‘work and feel healthy and just get [her] job done without being in dramatic pain all the time’.

But what eventuated was years of workplace bullying.

The colleague didn’t want to accommodate Monika’s needs. Over time the Occupational Health and Safety team became uncooperative too, and refused to acknowledge Monika’s disability unless she got an official diagnosis from her GP.

‘It’s becoming more known now, my disability. But back then people just acted like there was just some problem with me, not that I was actually experiencing a disability and the symptoms of it.’

In the mid-2010s, Monika accepted a secondment to another role. All went well in this workplace, where her manager made adjustments for her. Monika’s GP formally diagnosed her with MCS and a specialist confirmed it. The specialist also told Monika that the condition is a disability that is covered by the Disability Discrimination Act.

Returning to her previous workplace, Monika let her managers know that she now had a diagnosis of a formally recognised disability.

‘They refused to develop a ... policy and unfortunately, which I’ve found a lot, ... is that when people find out that I have this disability, there are people who will go out of their way to bring things to me that make me sick.’

‘Like, literally coming out of their way to let me know that they haven’t accommodated my disability.’

It was ‘really challenging’, Monika said. ‘I noticed a very quick decline in my health.’

Monika continued to press for adjustments and her managers continued to resist. At one meeting, a manager said to her ‘Why don’t you go work somewhere else?’

‘It was a really horrible thing for her to say,’ Monika told the Royal Commission.

Monika devised a work-from-home plan hoping to circumvent issues that way. She received permission to do so for a few hours a day, an arrangement that wasn’t practical.

‘I never received a reason as to why I was unable to work from home – just, “We don’t do that.” There was never any sound, like, rationale behind it as opposed to “No”. That was it. That’s all I ever got.’

The relationship between Monika and her managers deteriorated, as did Monika’s health. She took long periods of unpaid leave. Her role was filled by someone else, her records were lost and many of her workplace rights were contravened.

Monika filed a complaint with a human rights commission which was resolved by conciliation. Monika feels she capitulated, which she regrets.

She has left her role and recently set up her own business. It’s ‘slow at the minute’, but she’s positive about reaching the ‘end of a big long chapter’.

‘It’s all blue skies from here after today.’

Ares

Ares is a transgender man in his late 20s. He is autistic and has bipolar disorder and complex post-traumatic stress disorder (C-PTSD). He was diagnosed as 'bipolar with psychosis' a number of years ago, but is still struggling to get adequate supports.

Ares blames this on NDIS local area coordinators (LACs), starting with his first.

'She formed the opinion right when she first started working with me that, like, I was overfunded,' he told the Royal Commission. 'I was, like, not as impaired as I seemed to be because I communicate really well over written medium.'

The coordinator told him, 'You don't meet the criteria. You can participate in planning meetings by yourself.' She asked him why he couldn't use informal supports.

'And I was like, "Because I can't use my parents for support. And I don't feel like I have to have my friends needing to be my support workers. Like, I want different support."'

His support worker and recovery coach were advocating for him to be moved into the complex stream. But Ares said the coordinator repeatedly refused to facilitate this. The coordinator failed to include his more recent diagnoses of autism level 3 and C-PTSD in the plan, so he got no support for those. Ares said she questioned him inappropriately about his trauma.

'And, so, I made a complaint about her because ... I didn't have to tell her.'

The NDIS allocated Ares a new LAC from a community organisation, but they refused to include behaviour therapy needs in his plan despite a report from his psychologist.

'[They] said that I didn't need like positive behaviour support at all ... Like my behaviours of concern are – well, like, when I cut myself, it's not that bad ... The third-degree burns, and, like, I do drug use, unsafe sexual behaviour, suicide attempts ... How is this not necessary? So I missed out on \$25,000 worth of funding and then finally found a place that worked. And it was so expensive, you know, that I'm almost out of funding.'

During a review process, the LAC has been pushing for Ares to be agency-managed instead of plan-managed.

The LGBTQI+ agency Ares uses for several support workers is not a registered provider. He fears he will lose them if he is agency-managed and face more discrimination, sexual harassment and abuse.

'It's actually triggering me, like having to think about going back to agency providers who have no training in how to, like, support someone like me ... The amount of discrimination that I face, and the kind of things that people have said towards me and done to me ... It's actually just added onto, like, my existing complex trauma.'

The best outcome Ares hopes for is that he moves up to a complex support needs plan.

'So that I'm directly with an NDIS planner. I won't be with any LACs anymore.'

Syd and Lyndal

Syd, early 40s, has cerebral palsy and uses a wheelchair.

When he was young, his mum was pressured into placing him in an institution.

‘Mum had a nervous breakdown losing her baby,’ his sister Lyndal told the Royal Commission.

Fifteen years later, the institution closed down and Syd moved into a group home.

‘At first we were so excited and happy, but then he started losing a lot of weight.’

Lyndal discovered one resident was on a low-fat diet and it was cheaper to feed all the residents the same food.

Syd lost 10 kilograms in six months and became dangerously underweight.

In the following years, Syd experienced hundreds of incidents of violence, abuse and neglect.

‘If you’re a person in a wheelchair, you could be sharing a house with a person who has high behaviours where they hit, bite, punch, smash things. And [Syd], he cannot move himself ... He’s 100 per cent vulnerable.’

One resident didn’t like people in wheelchairs and targeted Syd.

‘He had a history of headbutting and biting people. And that’s exactly what happened ... He’d bite so hard he would pull [Syd] out of his moulded wheelchair seat.’

Lyndal asked staff to separate the men to stop the abuse.

The man’s mother called Syd ‘a bad boy for making the door shut on her son’.

Every time she was in the house she would abuse and belittle Syd.

‘He was so anxious about this gentleman and his family that he just didn’t want to leave his room.’

Lyndal fought for him to see a counsellor.

‘He can understand and he can talk, he needed to go through what was going on.’

Over the years, Syd has fallen out of chairs and his bed and broken his nose and hips. Staff have pushed him into doors and broken his leg.

One time, Syd had a gangrenous testicle no-one noticed during showering. He became violently ill and ended up losing the testicle.

Another time, staff gave him medication and immediately put him to bed. A different staff member heard him groaning and gurgling.

‘She saved his life. He was choking.’

When Syd made a complaint, staff would be nasty to him and he ‘had to live in retribution and cop it.’

Lyndal would complain and management would become defensive instead of fixing the problem.

About two years ago, the provider decided to move Syd to another house.

‘He went from this small room, which was about three metres by three metres, into this bedroom that is now five metres by five metres. And he’s got a little garden area. It’s a beautiful place.’

But Syd lost all choice and control. Staff told him when to get up, shower and have meals.

‘They came from day programs straight into a shower. Had their dinner by five o’clock. In bed by 5.30. The staff would sit down and relax ... It was like an institution again.’

Syd was so unhappy, Lyndal and her sister helped him and the other residents make a complaint.

Syd ‘copped it a lot’ after this. Staff called him names and ‘badmouthed his family’.

Staff sometimes forgot to give Syd his medication, and sometimes gave him someone else’s. He missed iron infusions. They fed him mouldy food. They didn’t follow mealtime protocols and there were a number of choking incidents. One time Syd was badly injured and needed medical attention. Staff left him in bed for hours, in clothes he had urinated and vomited on.

Yet Syd didn’t want to move. So Lyndal and her sister pushed to have staff removed.

‘That would take up to three-to-four months, where [Syd] still had to stay with them after we put in a formal complaint.’

Several staff members have left and things are a little better.

Syd would like to live on his own with staff who focus on him and his needs.

‘What are his options? We don’t feel there are options,’ said Lyndal. ‘We feel this is it.’

Ernesto and Armani

All of Armani's children have vision impairment, but Ernesto's is the worst. He is 'legally blind in one of his eyes' due to a developmental disorder, Armani told the Royal Commission.

Ernesto is in his teens and has an NDIS plan. Several years ago an occupational therapist visited the family in their public housing and 'recommended some modifications to the home to suit his needs long term'. Armani lodged the report with the housing department.

One of the managers in the housing department 'was making life difficult'.

'She wasn't approving things. She was questioning everything, back and forth with the OT. Tried to change [the OT's] recommendations. She had to amend her report six times until I put my foot down and I said, "Enough is enough."'

For more than three years, authorities have been 'digging in' asking for more proof of Ernesto's disability housing needs. Armani said more than half of Ernesto's funding for therapeutic supports was 'wasted on tit for tat not agreeing at anything'.

'Poor [Ernesto], he end up with no therapy for maybe a year and a half, just to sort department of housing issue. And still until today's date it hasn't been resolved.'

After lengthy delays, work began on the house. When it did, a builder found that the roof was unstable.

'As soon as he went up he said, "Holy crap. I'm not going in. The roof is not safe. It hasn't been replaced. It will collapse."'

Armani learnt that the house had been uninhabitable while the family had been living there. The engineer's report advised 'immediate evacuation'.

Nonetheless, the department's requests for more specialist assessments continued. Each time, therapists were billing her from Ernesto's budget. Armani feels the NDIS and public housing authorities have exploited her son.

'You cannot neglect and put people at risk. With the department of housing, anyone with a disability they think that they could do whatever they want. They look at you that you're disabled, you cannot stand up for yourself.'

The government finally agreed to provide the family with a purpose-built home. But Armani says officials have been dragging their feet for months and 'are not taking this matter seriously'.

Last week, she met with her local member of parliament who promised to 'escalate it to the minister'.

'I told her to stop wasting my son's budget. The department is abusing a child with a disability, using his funds. There is major negligence in this situation.'

Bria and Odette

‘She was totally mistreated at school. She was mistreated in the way she was labelled. She was neglected. And I think there was a lot of victim-blaming. Blaming her and blaming us as parents. It is still happening.’

Odette’s daughter, Bria, is autistic and has attention deficit hyperactivity disorder (ADHD) and ‘extreme anxiety’.

Odette told the Royal Commission that problems with Bria’s schooling began at her early learning centre.

‘The director called me into her office and was quite angry and frustrated. And she had a list of complaints ... Her first complaint was that [Bria] was too active, which I thought was part of a two-year-old’s job description.’

The teacher also said that Bria had ‘no empathy’ and ‘acted via stealth’.

‘Which I think is disgusting. But they complained that she would slip away ... and let herself into the building and go into rooms that she wasn’t allowed to be in. She would then run around and lock all the doors so the staff couldn’t get in.’

At preschool, ‘things didn’t improve’. Again, the principal and teachers called out Bria’s behaviour.

‘And it seems that her four years there were spent with her hiding under desks in the classroom, in the reading corner, running away ... Or she was in the principal’s office. And she was labelled as a naughty child and a badly-behaved child ... Now to me, that’s a problem on their end.’

Bria switched schools for year 3 after being formally diagnosed with ADHD. The ‘flags immediately went up’, Odette said, when staff contacted her, concerned about ‘a number of issues’.

The school psychologist did an assessment of Bria.

‘It was like a whole lot of hand grenades going off through this report, because she was complaining about her behaviour again, saying that she “was really difficult” ... I was really upset and distressed and very angry, because I felt from a school psychologist it was a series of attacks on [Bria].’

Soon after, Bria ‘got the diagnosis for level 2 autism’, and also dyscalculia and dysgraphia.

‘The childcare centre and primary school didn’t pick up that the reason she couldn’t hand write or whatever is she’s got a problem.’

Bria is now in year 6.

‘And her teachers are great but we know she struggles.’

Odette said the fight will never be up to ensure Bria gets ‘the most basic support’.

‘I know that my child, who is disadvantaged because of her disabilities, I’m putting her into a broken system that is not going to be able to support her, and I’m gonna have to pick up the slack.’

Promises of an ‘inclusive learning department’, including a sensory room with support from a dedicated teacher, have already been whittled away.

‘I feel like I’m looking down the barrel of the next six years of having to fight.’

Kerry-Ann, Shireen and Wilfred

Kerry-Ann is autistic. She is in her 20s and lives in support accommodation with the help of the NDIS and support workers.

‘She loves music, she loves to go for a drive, she loves to just go to the beaches,’ her dad Wilfred told the Royal Commission. ‘She’s just happy doing the simple things in life like that ... We look out for her as much as we can.’

‘She can be very loving, but she had times where she’d just have meltdowns,’ said her mum Shireen. ‘We’ve had a lot of troubles with service providers who just relinquish care at very short notice.’

Wilfred said it was difficult to find suitable, trained support workers. For example, one support worker tipped Kerry-Ann out of bed one morning and ‘frogmarched her to the backyard and sat her on the grass for 20 minutes in the nude’.

Another time, when Kerry-Ann spilt boiling water on herself, her support workers didn’t report it.

‘She ended up going to hospital, but it was 10 or 12 hours before we were even told about it. And in that time she really didn’t have any medical treatment.’

Wilfred and Shireen complained to the NDIA, which recommended the service provider give its workers more training.

‘Shortly after [reporting the incident] we were dumped,’ said Shireen. ‘Service was ceased straight away.’

‘They put it back to high turnover of staff and things like that because [Kerry-Ann] can be so difficult to manage,’ said Wilfred. ‘We have expectations as carers ... and they don’t like that.’

After the service provider dumped Kerry-Ann, Wilfred took several weeks off work to care for her.

‘The last straw was when he had her 17 days in a row on his own,’ said Shireen.

Exhausted and with ‘nil carers or a suitable service provider’, they admitted Kerry-Ann to hospital.

‘There isn’t enough crisis accommodation ... She was only in hospital because of service provision breakdown.’

The hospital kept Kerry-Ann in a general ward where the nurses complained that they were ‘not trained to deal with somebody like her’. They restrained and medicated her.

‘We had to get an advocate because they wouldn’t allow [Kerry-Ann] to go outside for fresh air ... They were actually tying her to the bed ... But initially they weren’t up-front about this.’

Wilfred and Shireen tried to find Kerry-Ann suitable accommodation but weren't acting fast enough for the hospital, which applied for guardianship.

'They wanted to move [Kerry-Ann] out of there into several [unsuitable] group homes,' said Shireen. 'It was to move us out of the way.'

'We were just astounded that they tried to take her guardianship off us,' said Wilfred, 'because every decision we made for [Kerry-Ann] is thought out and just and for the better of [Kerry-Ann].'

The hospital dropped its application and after several months Wilfred and Shireen found a suitable provider 'happy to take [Kerry-Ann] on outside of the hospital ... and build a team'.

'She was very much a busy young lady. She had something on every day other than Friday. So obviously the hospital situation didn't help that,' said Shireen. 'So we've had to work really hard to get all of that back to where it was.'

Hadleigh and Tarana

Hadleigh died this year, having lived with 'severe intellectual disability' for five decades.

Her sister, Tarana, told the Royal Commission Hadleigh had the cognitive capacity of a two-year-old but was never diagnosed.

'We're talking about a person that could do nothing for herself. She couldn't feed herself, wash herself, get up from the chair, do anything. So totally dependent on somebody being there for any of her actions to happen.'

As a child, Hadleigh's parents didn't want her to go into a nursing home or an institution.

'So they kept her home. She always lived with family members,' Tarana said.

Disability services organised day care for her five days a week.

'And it was basically a child-minding centre. That's all really they were back then.'

Hadleigh had a lot of accidents at the centre.

'And finally, about four years ago, she came to me full-time,' Tarana said. 'And then that's when the struggle sort of hit.'

By that stage, Hadleigh's condition was getting worse. Doctors thought she may have Rett syndrome, which causes a progressive loss of motor skills and language.

'She'd always been regressing down. Specialists and everyone said her condition will never improve. It will always deteriorate ... And it did.'

Tarana helped get Hadleigh her first NDIS plan, which fell way short of her needs. The NDIS cut her existing funding for therapies and respite hours, despite 'medical evidence she needed 24-hour care'.

This meant Tarana had to look after her through the night and Hadleigh could never get out of the house.

'I wanted her to have one-on-one [support] because my belief is that's what she should have had. More hours for a carer basically, to take her to what she would like to do, like to go swimming ... to a music group, to go out.'

'The NDIS talk about having a normal life. I hate that word because everyone's normal is so different. Well to me, a normal life is that my sister doesn't have to spend 24 hours with me.'

NDIS planners never met with Hadleigh in person.

‘They have people there that, I believe, have no idea about disability. You’re relying on somebody on the other end of that phone who is magical because, basically, their perception comes ... by forming an image in their own mind ... In the three years she was in the NDIS, we had six plans. So that shows you how wrong they got it every time.’

Tarana fought for a review of Hadleigh’s plan, which helped her get a better day program and support workers.

‘It wasn’t near what she needed, but the group of people that we got in the end to be her carers were fantastic. They loved her and she loved them. It’s just what it took with the NDIS to be able to get [Hadleigh] to have an actual life.’

For the last year of her life, Hadleigh was able to go on day trips with support workers.

‘Her favourite thing in the world was going out in the car ... Any time that she could get out and not be stuck in four walls, then she was the happiest she could be ... So that’s what sort of we got to in the end.’

Piers and Danelle

Piers is a First Nations teenager with psychosis, attention deficit hyperactivity disorder, borderline personality disorder, dyslexia and learning difficulties.

'I've been dealing with people with disability since, God, all my life,' his mum Danelle told the Royal Commission. Danelle's brother and former partner both have disability and both spent time in prison.

'[Prison] doesn't help them at all. It just makes things worse. I'm trying to break that cycle.'

Danelle said the NDIA rejected her applications to support Piers.

'I applied twice, but they've been knocked back so, yeah, I just didn't bother anymore.'

Danelle said Piers sometimes comes home with black eyes and other injuries because, without treatment for his psychosis, his behaviour is confronting.

'He hears and sees things that aren't there so when he's walking around in the streets he would sort of nearly attack or abuse someone that was near him because he thought that it was coming from them when it wasn't.'

Police have arrested Piers several times in the past few years. Recently, Danelle saw several police officers throw him to the ground.

'I actually jumped in between them to stop them because I said, "He suffers from this. You can't approach him this way, like, he will get more aggressive" ... and they actually said to me, "Aren't you afraid of him?" [I said] "He's my child, like why would I be afraid of him ... He's aggressive because you're surrounding him and he feels he's being enclosed. Just walk away." They don't understand. They really, really don't.'

Piers recently spent a short time in a youth detention centre 'which with his psychosis is really bad'.

'They're not trained in helping people with disabilities or mental illness or anything. Like instead of putting these kids and adults in prisons they should be making hospitals.'

Danelle's former partner, who had schizophrenia and depression, was recently released from prison. Not long after, he killed himself.

'There's so many adults and so many young with disabilities that come out [of prison], that die,' Danelle told the Royal Commission.

Danelle's brother, who has brain damage, is still in prison awaiting trial.

'They're saying that he's putting it on. I don't understand how someone that's been diagnosed with ... brain damage from the day he was born is putting on something. It's so wrong. Like it doesn't make sense.'

Danelle fears Piers will also end up in prison because of his disability. She never used to make her and her son's First Nations heritage known to authorities – she feared it might make things worse for him.

'My dad always told us not to tell our background [because] ... people look down on you.'

Danelle struggled for years to get Piers appointments with specialists.

'So I've only just started saying [we are First Nations] the last couple of years because I've actually needed help, more help with my children.'

Piers now sees a psychologist who specialises in psychosis. Danelle hopes they can keep Piers out of prison.

'Something really does need to change with the judicial system and disabilities.'

Benoit and Aria

Benoit is in his early 20s and has cerebral palsy. He is autistic and has 'significant intellectual impairment and multiple medical conditions including epilepsy', his mother Aria told the Royal Commission.

'He has the developmental age of a toddler and cannot do a single thing for himself. He is non-verbal. He has no way of communicating. He has mobility problems, he's incontinent, he's got a vision impairment.'

With the NDIS rollout, Benoit's parents thought his disability services funding 'would simply roll over and nothing would change'. But it had 'a huge impact on his supports'.

'We had agencies and NGOs who were supporting our son ... suddenly cancelling because there was no funding. Lots of things just fell apart very, very quickly.'

The government was looking at transitioning Benoit into independent living with supports from the age of 16.

'Because the home situation and his challenging behaviours and the no sleeping, and just the level of support he needed was way more than I could provide for him 24/7. By the time he was 18, he would be able to be living independent and we could all have a far better quality of life. But the NDIS did not want to follow that process.'

Aria spoke to an NDIS planner whose response was 'disgraceful'.

'She said to me that I basically was wanting to abandon my son and had no interest in caring for him. Whereas we are doing everything we possibly can to support him and make his life better.'

NDIS planners kept 'demanding' report after report, but then ignored them.

'The NDIA were very, very determined to not pay for the supports that [Benoit] required. Every therapist's report, every behaviour specialist's report who'd known him for many years, they didn't wanna listen to any of it,' Aria said.

The NDIS kept promising it wasn't going to cut Benoit's funding. But a new planner then halved his plan without ever meeting Benoit or his parents, and he ended up 'completely out of funding'.

'It was a nightmare. We didn't have funding to do short-term accommodation, so the only option we had was to have him stay at our home with carers for short periods of time.'

Aria said NDIS planners are unqualified and 'can't even wrap their head around one disability', let alone 'such a complex young man'. They were ringing Benoit's therapists 'abusing them for writing a report'.

'I am horrified that someone who's had no training in disability whatsoever thinks they know better than professionals and can just make their own mind up. The allied health professional doesn't make it up. Why are they being constantly questioned over their professionalism? That's then detrimental to the person with a disability.'

The case 'kept going around in circles' and Benoit's parents ended up in the tribunal process, 'fighting it out for funding'. He had 10 NDIS plans in six years.

'And we've been just labelled as these people who just want to demand everything. We will only argue and fight for what it is that his basic needs ... We're not asking for the whole wide world.'

Today, Benoit's funding is 'not ideal' but 'his day-to-day care needs are met'.

'He's very well cared for. We're very happy with the team of people who are looking after him.'

Aria hopes the review system will improve.

'His needs and his level of support are not changing so much that every six months we need another report. We want to make a difference, not just for him, but for people who access the NDIS and just have a horrendous time trying to ensure that their family member is cared for.'

Nik and Betsy

‘No-one with disability is less. You find what they’re good at, they excel.’

Betsy is the mother of Nik, a First Nations teenager who’s autistic and has attention deficit hyperactivity disorder (ADHD).

‘I actually knew something was wrong with him from the day he was born because I actually never heard him cry,’ Betsy told the Royal Commission. ‘So my poor little baby, I used to have to set alarms for him just so I could remember to feed him because he wouldn’t make a whimper.’

Betsy struggles to get Nik support.

‘Every time I was trying to get help ... they would tell me that he’s not severe enough. Like, I don’t understand how a child that can’t dress themselves and talk at seven years old how that’s not classed as severe.’

Betsy said Nik wasn’t initially eligible for support at primary school, because his IQ was just outside the qualifying score.

‘You get a score of 70, you get funding. You get a score of 71, you get nothing ... So his score in grade 3 was 71. So the next time he got scored I told him to get a couple wrong, which is horrible. One score over shouldn’t matter for him to be able to get an aide in the class with him and to be able to have that speech therapy.’

Once Nik had the extra support, he started speaking. Betsy tried to transfer him to a special school, but he didn’t want to go.

‘I know I’m different,’ he told his mum. ‘I don’t need to go to a school where everyone knows that I’m different.’

So he attends a mainstream school which, Betsy said, is ‘very hard’ for him because he ‘already feels like a social outcast’.

Nik ‘excelled’ at primary school and was catching up academically with his peers in his first year in high school.

‘The principal there, amazing,’ Betsy said. ‘He had compassion for the kids that came in, helped them a lot. When it came to needing financial help with aides or, you know, extra one-on-one in class, he made sure that all happened.’

But when a new principal arrived, Nik went backwards.

‘All [the new principal’s] worried about is spending money on art classes and getting his high [academic] scores.’

The NDIS doesn't support Nik.

'He's been rejected through NDIS nine times now, so I haven't even bothered with that no more.'

Betsy told the Royal Commission that Nik was accepted at one stage, but because her doctor went on holiday and she couldn't return a form on time, the NDIS stopped his funding.

'I never tried again after that. It's too stressful, too, too stressful. So now I just work two jobs ... I have to work two jobs so he can function properly.'

Betsy works a day shift job and then a night shift to pay for Nik's supports.

'So I have like two hours, three hours sleep every night ... I had everything when I was younger so I need to make sure that [Nik has] the best possible start, middle and end. So everything that I go through for [Nik] when it comes to like doctors and everything, it's all private. I don't go public. So I pay those.'

Betsy said it's better than waiting 'months or years' to see a specialist in the public system.

'Like one of my friends, her child should have been diagnosed with ADHD when he was five years old or even younger. When he wasn't, I told her to go to my doctor even though it was so much money, and he got diagnosed straight away with it. They just classed him as a naughty child before that.'

Lacey and Hannah

‘One hour of incompetency was a whole year of repair.’

Lacey is in her 60s and has multiple sclerosis. Her sister, Hannah, has been her primary carer and ‘full-time advocate’ for more than two decades.

Hannah told the Royal Commission her biggest problem is getting qualified support workers for Lacey. She said disability service providers are careless about ‘who they employ and who they deploy’.

‘They rarely interview anymore. They definitely don’t tick off whether they’re capable of doing the job that they’re supposed to do. So even with people with high needs like my sister who has bowel care, an SPC (suprapubic) catheter, you may get people that come on board that have never seen a catheter ... They have no experience. In a home setting, for some reason, we find that allowable and it causes a lot of injuries and abuse.’

Hannah said that ‘mismanagement’ by support workers led to life-threatening injuries for Lacey.

‘She had numerous falls. She had a broken leg, she had choking that needed surgical removal of food. There were multiple hospitalisations and neglect from having untrained people come to our homes.’

On one occasion someone ‘walked in that’s supposed to have experience of bowel care’. Misuse of Lacey’s catheter caused chronic urinary tract infections and a perforated bowel. Lacey ‘nearly bled to death’. She will need to take antibiotics for the rest of her life.

When Hannah tries to hold providers to account they just say, ‘You prove that we did it.’

‘Even if they injure that person, they just walk away,’ Hannah said. ‘Then the person doing the rosters will have no idea. You definitely won’t get incident reports. So you often get the same person who dropped her, who perforated her bowel, who didn’t know what a night bag is arrive the next day, with no further training.’

Because of this, a lot of the training ‘is pushed back to the family or the carers’.

Even so, the neglect continues. Lacey is on a ‘big package’ and needs about 14 hours of in-home nursing care. She has two providers.

‘We could never get enough care from one agency so I use a lot of online people also. We just moved from a very small company to a bigger company to see whether we can get more staff and more qualified staff. We’ve already had maybe six or seven staff turnover ... Half the time, they don’t know much. She’s on a power wheelchair. I’d say 99% of the people that come to us do not know how to use it, so her independence is minimal. She goes from her bed to her chair unless I’m here.’

Sometimes staff simply don't show up.

'There's no responsibility of filling shifts anymore. So if a person doesn't turn up, who knows?'

Hannah says people with disability have become 'cash cows' for the providers.

'These agencies know – it doesn't matter who we send out, as long as someone turns up we're going to get paid. And that's what NDIS has granted them, so you just get anybody thrown at you.'

The poor quality of care has taken its toll. Lacey is 'on the decline down'.

'The anxiety that it creates within the person with disability is just beyond what people understand. They don't want you to leave, they depend on you totally, they're scared to have a new person walk in the door.'

Santiago and Neva

‘The education system is not set up for intelligent children with ASD or intelligent children with behavioural issues.’

Neva is the mother of two autistic teenage boys. Santiago has level 3 autism spectrum disorder [ASD] and oppositional defiance disorder.

‘He was diagnosed when he was around three and so we immediately commenced behaviour support, occupational therapy, speech therapy,’ Neva told the Royal Commission.

After some early intervention, the family hired ‘psychology trained support workers’ to help.

‘They would not follow the support plans or didn’t have the skills to implement them. We saw an escalation in behaviour.’

When Santiago started primary school, he had a support worker to ‘try and keep him at school’.

‘But the school then wouldn’t let him integrate when he got elevated,’ Neva said. ‘When he was violent, they locked him into an area of the playground ... We were essentially just presented with that as a management strategy.’

The school suspended Santiago.

‘He’s been through four schools now. His education has been quite disrupted since because of this very partial attendance.’

Santiago’s recent transition to high school ‘has been very difficult’.

‘When we asked the school how they were going to manage his behaviours if he escalated they couldn’t answer that. There was no proactive planning or consideration.’

Neva said that when Santiago became violent, ‘three teachers restrained him for 10 to 15 minutes ... until he calmed down’.

‘That triggered significant behavioural changes in him.’

Santiago’s behaviours got worse. A psychologist report warned there was ‘a significant risk of harm to both students and his brother’.

‘His brother has been bitten on a regular basis, hit ... We were being assaulted, verbal and physical assaults. He was injuring himself.’

Things with Santiago ‘hit D-Day’. He was ‘ripping the walls off’ to locked areas of the house, and was ‘really struggling, not learning and totally disengaged’.

The family was employing full-time support workers because the NDIA wouldn't help. Santiago went into short-term respite while his plan was reviewed.

'They told us that he wasn't eligible for voluntary out-of-home care and that respite funding would cease.'

The NDIA told Neva it was 'not a crisis agency' and to call child protection services.

'That's very confronting. The whole process took us through to a decision a parent should never have to make, that we would relinquish our child if push came to shove.'

Her only other choice was to take him home 'against medical advice' and put her family in danger.

'The child protection system I think is very rigid in that sense. It provides no protection for [Santiago] at all short of going down a legal pathway, a criminal pathway which is definitely not what we want.'

In the end, the department placed Santiago in temporary 'voluntary out-of-home-care'. Neva still fears he will end up under state guardianship. She's trying to get him complex support needs with the NDIS. All she wants is for him to have 'appropriate supports' so he can realise his potential.

'To have him educated to his demonstrated intelligence, the HSC regular outcomes. He's a smart kid.'

Recently Santiago was accepted into the local high school and now has a learning support team. His behaviours are improving.

'It's still far from perfect ... It would have been better to do it before he was so traumatised. But it has allowed us to step back from fighting the fires and go back to being a parent ... and support him on that journey.'

Kaite and Victra

Kaite, late 50s, was born with an intellectual disability. Her older sister Victra said Kaite has the cognitive age of a six or seven-year-old.

'In those days, when she was born, she was classed as moderately retarded. That was just the classification they used in those days. They didn't really drill down into syndromes and whatever. So she also had congenital physical disabilities, but these were never labelled because genetics as we know it was never explored in those days,' Victra said.

Kaite lives alone in her own home in a small regional town. Before that she lived in a group home for many years. She moved when the NDIS was introduced and it seemed that she would have a better quality of life living independently.

'We would never have taken her from her group home where she was at least supported and, in some ways, protected, had we realised that the NDIS would fail her so dramatically.'

Kaite receives NDIS funding for her intellectual disability but not for her physical issues, which the NDIS deems 'medical'. The funding is for capacity building. But most of it goes on the support Kaite needs to manage her physical conditions, for which she needs to see her GP every week.

'Someone without capacity and without the physical wherewithal and without the taxi service – the taxis won't take her – she can't physically get herself to a doctor. She can't really understand the doctor's instructions ... So the service [provider] actually has to redirect the funding that should have been used for capacity building and goal setting and achieving her goals and all these lofty ideals that they trot out, in taking her to the doctor.'

Victra said Kaite is 'severely underfunded, even for her intellectual capacity'. She has asked for a range of supports for Kaite that the NDIS planner won't even consider.

'The last plan review that we had, we were no further than 10 or 12 minutes into it when she said, "No, I'm rejecting your plan. You can apply for a review if you like." You know, "The reports aren't sufficient. I suggest you get another OT, a different OT, to write a different report."'

Victra has organised OT reports from every OT in the area and one visiting OT.

'They keep rejecting all the reports we give,' she said.

Victra asked for a support worker to help Kaite develop an eating plan and prepare healthy meals, and the answer again was no.

'NDIS says, "That's not value for money. Get her to order in Lite n Easy or something." So, don't teach her anything, don't give her skills, don't, you know, inform her about her health situation, how it can be enhanced with food. No, just order in some meals. That was their thing ... "It's not value for money to have a person there."

Kaite has been sexually assaulted several times in her home. In each case her assailant was someone she'd met through their shared disability services provider.

'The police virtually told us that there's no point really taking it to court because [the perpetrator] lacked the capacity for understanding right from wrong and nothing would be done,' Victra said.

She said better funding from the NDIS would have made a difference.

'I really believe that had [Kaite] been funded and supported, even in behavioural therapy, assertiveness training, all that kind of thing, personal safety – all of the things that she could have had capacity building in if she'd been granted sufficient hours to have that done, perhaps she could have fought back a little bit, perhaps she could have kept the door closed. You know, perhaps things could have been different.'

Victra has now organised expensive genetic testing for Kaite. She is hoping this will confirm Kaite's physical disabilities and provide evidence the NDIS will accept.

'If we can come up with a syndrome – it seems to be that if you have a label, that will unlock some funding for you.'

Celia

Celia told the Royal Commission she has been 'in the system' since she was 12 years old and has 'very little trust' in it.

She was diagnosed with schizophrenia, but she doesn't understand why. She did not understand why she needed to be injected with antipsychotics, or why, now, she no longer does.

'I've never had a proper answer when I've seen psychiatrists about it!' she said.

In the facilities she has been in, Celia has experienced neglect.

'I've been obviously ignored by workers as if to say you don't exist!'

Celia says she has been bullied by mental health workers, to the point of being concerned for her safety.

'I didn't know who to speak with about it or if they'd do anything about it, and by the time I thought I could say something they said it was too late to complain, it was like bcoz I had no proof except my word over his it was pointless to say anything.'

She has also encountered inappropriate sexual behaviour from a female worker.

'Like she was baiting me ... her behaviour was flirty but awkward at the same time ... she would pull her shirt down in a strange way looking directly at me and she had a bruise like she wanted me to look at her!'

Celia did try to tell someone about her experiences, but they directed her to an online complaint form. Celia says using this kind of form is difficult for some people and, in the end, she didn't think there was any point.

'It's legitimacy is an issue,' she says. 'Complaining without proof has been pointless for me.'

Celia thinks that mental health workers 'should be watched like hawks ... to protect the clients from bad workers and to protect good workers from bad workers screwing with them'.

Celia has had help from some people she liked. She had been seeing a psychologist she thought was good, but the location was too far and required public transport, which is difficult for Celia when she is in an emotional state after a session.

Celia has also liked some of the volunteer workers and student nurses, but she wonders if they are good because 'they are not jaded or exhausted from the job yet'.

'I wanna see mental health, disability and old age homes never have fearful clients like myself and others! I don't want to see deaths that didn't have to happen in news articles! I wanna know that I'm safe in these places.'

Kostas, Lydia, Marko and Angie

Angie is mum to two children with attention deficit hyperactivity disorder (ADHD). She told the Royal Commission there is not enough support or understanding of the condition.

‘There needs to be more acceptance that this is not a child who eats too much sugar, he will grow out of it or he is just bad. It is a neurological disorder that is lifelong ... this is a vulnerable group that is more likely to end up in prison, substance abusers, dead or with broken relationships.’

The symptoms of ADHD for the two children – Kostas and Lydia – are quite different. The impact on Kostas, who is also autistic, and on his family is severe.

‘He does not realise the impact of his lack of impulse control. He hardly eats and he is always on the go ... Our lives from the day he was born have revolved around him ... his needs always have to come first and he does not care about the collateral damage he does when he does his behaviours. It is so hard for all of us and him.’

Lydia’s symptoms are milder and more manageable but she still needs support, particularly as she moves into adolescence. Lydia’s parents can’t afford to take her to an occupational therapist, but the NDIA won’t help because it doesn’t recognise ADHD as a disability.

‘Families need assistance to NDIS and more Medicare rebated appointments; 10 is not enough and we as families cannot afford it ... no support and not enough psychology hours are affecting our vulnerable children.’

Angie also has a son called Marko, who has level 3 autism. He cannot toilet himself, feed himself properly or participate in social situations, but he does not qualify for an aide at school because his language skills have been measured at 1.7 deviations from the mean, rather than 2 deviations. ‘It should be a sliding scale,’ says Angie, ‘not a cut off’.

‘He needs support and the teacher struggles to give him the attention he needs. They have to use another child’s full-time aide to assist him, when they can. He is only going to fall further behind. He needs an aide now to improve his chances of settling into school. We have been told the system is such that when [Marko] fails they will help him. But with autism the regression can take so much longer to come back.’

Kara and Ronin

Ronin told the Royal Commission its challenge is ‘to make the little stuff big stuff’.

The ‘little stuff’ is the systemic unfairness and neglect his daughter Kara and his family experience almost daily. It’s ‘not criminal’ and rarely ‘leads to a public outcry’ but, he says, it’s just as damaging.

Kara is in a special unit in a mainstream high school. She has ‘a global development delay ... walks with difficulty and requires a wheelchair’. She is incontinent and wears nappies.

Not long ago Kara broke her hip. When her orthopaedic surgeon said she could return to school, her parents thought it would be straightforward.

But it wasn’t. The school required a ‘return to school contract’ and a certain type of medical certificate.

One of the clauses in the contract ‘entitled the school to revoke her access should the school elevator be out of operation as she was wheelchair-bound after the break’.

The school was also concerned ‘the presence of a wheelchair on the school grounds was a risk to other children – who could hurt themselves if they ran into the chair’.

These arbitrary decisions meant Kara was denied access to school at times and her parents – both medical professionals – missed countless days of work.

During COVID-19 the school again cited health concerns to deny Kara access to school. Staff in the special unit decided they would no longer be able to change Kara’s nappies. Kara was forced to stay home for months longer than her peers.

The school has a policy of not allowing non-school staff – including allied health professionals – onto its grounds. This affects Kara and her family in many ways.

During the COVID pandemic, it fell to Kara’s parents – despite being essential workers – to juggle work and Kara’s care.

Kara’s NDIS package includes speech and occupational therapy which improve Kara’s communication and behaviour and ‘make her happier and easier to care for’. Ronin says it is also an opportunity for regular ‘individualised professional support at zero cost to the school’ and could be an opportunity for teachers to collaborate with specialist experts.

The school cites the risk and disruption to students as the reason they exclude these specialists. But Ronin believes it is ‘a deep insecurity of the staff in the school’. He says they do not want ‘to be shown up for any ignorance, prefer to deprive the children and themselves of opportunities to learn from professionals’.

Because of this policy, Kara has to attend therapy at the end of a long day at school and her parents have to take time off work.

This policy has resulted in detentions and suspensions for Kara. For example one time she was suspended for pulling another child's hair. Kara didn't connect her suspension with the hair pulling, but when Ronin informed Kara's therapists the behaviour was immediately addressed and modified.

Ronin is also concerned the school pushes ahead with the unit curriculum with no consideration for Kara's abilities. For example Kara can't swim, but she has a life-saving certificate as per the curriculum.

Ronin has complained to the department to no avail.

'Telephoning or writing to the [education department] about problems is ... pointless as [they are] an expert at ensuring nobody ... is available,' he said.

Many teachers have told Ronin they too are frustrated by the system but feel powerless to intervene.

'The problems we have described are endemic and begin with our daughter's special needs unit that believes the unit is a "mainstream service" that must follow a curriculum, and cannot allow specialists on the premises as these would disrupt the class. They continue with principals who acknowledge that special needs is not "really their thing" and defer to the special needs unit head. It then continues with the [department] itself where the likes of the [senior managers] cannot respond to little stuff.'

Archer and Laila

‘I believe so strongly that education is the key for all of us and that no-one has the right to facilitate under-achievement.’

Archer’s academic progress in primary school was good ‘because he was pushed to work hard to meet his potential’. But in high school, his mum Laila told the Royal Commission, he had to fight for his right to an education. She said that because Archer has Down syndrome, teaching staff constantly assessed his potential as ‘not up to much’.

In primary school Archer was in a special education unit, but he was always included. ‘He was considered just one of the students who needed a little extra help,’ Laila said. Archer was good at sport. He enjoyed it and participated in all sport activities.

When Archer began high school, the students in the special education unit were mainly segregated. They only spent time with the other students during assembly and in the 20-minute pastoral care period.

There was little academic work done in the unit. Laila said there was ‘a lot of colouring in’ but the main work was delivered by two external teachers who only attended the unit for a two-hour period one day a week.

Archer was no longer allowed to participate in sport with the rest of his peers – his ability was never assessed.

At the end of the year a group of parents spoke to the principal and demanded change.

The school attempted to integrate the students to a greater extent. Archer was able to participate in sport and in more classes with his peers. Laila said most of the teachers ‘tried their best to ... ensure some level of education’. It was the special education teacher who was the most resistant. But eventually, after two years, she replaced the ‘glorified baby-sitting’ with ‘a more meaningful academic program’.

Then, at the end of year 11, parents were abruptly informed with no consultation that the special education unit would cease to operate. Going into year 12 all students would be fully integrated.

‘The timing of the notification was obviously designed to pretty much cut off any avenue for review,’ Laila said.

Many students moved schools, but Archer stayed. It was his final year and it would have been too difficult for him to move away from his friends. Laila was fully aware most of the teachers’ focus would be on the students with greater academic potential, but she wanted him ‘to experience graduation and the formal with these students’.

Laila believes Archer's secondary education was a wasted opportunity. She believes the teachers had good intentions, but they received no training or additional support and often were not included in decision-making.

During the five years of high school Archer's academic progress slowed dramatically. Laila expected the gap between Archer and his age peers would widen over this period, but she believes more should have been done. 'Taking away the unit completely undermined the ability to continue with the numeracy and literacy program of education' which was vital for Archer.

'I would hope that a time comes when we look at how best to provide an education which encourages all students ... To do this we need to be more open to the notion that people with a disability have potential which may not be the same as others but, in achieving their potential they will be happier, more productive and more able to give back to the community.'

Tyler

‘I think there really needs to be a recognition that disabled people are different to non-disabled people, but we aren’t inherently worse, we just live in the world differently.’

Tyler is a 21-year-old who identifies as non-binary and who has disabilities that include dyslexia, depression, anxiety and an undiagnosed chronic pain condition. Tyler wrote to the Royal Commission about their experiences in education and employment.

Tyler started their education in a primary school that was ‘very supportive’, but high school was a different story.

‘I found it hard to adjust to the demands ... and was offered little-to-no extra support,’ Tyler said.

In year 10, Tyler applied for special provisions for dyslexia to help them with their year 10 certificate.

‘However the school refused to let me do it, because they felt I was “too smart” for special provisions.’

It was around this time Tyler ‘first started realising [he] was LGBTQI (but in very strong denial)’ and started experiencing symptoms of depression.

‘There was little to no education surrounding depressions, so I thought I was just sad for no reason.’

Tyler started self-harming.

‘No teachers or anyone like that said anything.’

When Tyler got to university, they considered applying for special provisions with the accessibility department, but the bureaucracy surrounding it was ‘too demanding’.

‘I was no longer seeing a regular doctor and so I didn’t really have anyone that I could go to to get “proof” of my disability that was still current, and I couldn’t afford to get a re-diagnosis.’

Tyler said they were able to get by at university and passed all their subjects, but said, ‘I know I would’ve been significantly more successful if I had access to [health supports].’

‘When I was in my fourth year of university I had my first flare up of chronic pain. I missed enough classes that I failed the subject, and was advised by the lecturer that it would be better if I pulled out of the subject and just got a “fail-withdrawn after census date” instead of a straight up fail.’

Tyler would like to see change in the way education and employment systems handle mental health. Both systems, Tyler says, provide additional stress and shame instead of understanding and options.

‘In the workplace, I’m not open about my disabilities. I find it something I’m way too uncomfortable to bring up, as I am worried people will treat me differently, they will use it as a way to prevent me from moving up in the workplace, and they will punish me for my symptoms (particularly fatigue and lack of motivation) ...

‘We need specific support that is different to everyone else in order to achieve our best, because while we can still do well without that support in life, we can do even better with it.

‘The world isn’t set up for us. But with compassion and support that we deserve, it can take a step in the right direction.’

Fiona and Rex

‘I accept my husband, Rex, will die from complications of [his disease] and he has a Health Directive, but I will not accept him dying from neglect.’

Rex’s wife, Fiona, wrote to the Royal Commission about the neglect Rex has experienced at his supported independent living house.

Rex is an older man with an inherited degenerative disease. He needs assistance and supervision in his daily life. Rex moved into the house when he got his NDIS package.

‘I have had numerous issues with the house manager ... and this company,’ Fiona said, ‘and I am puzzled as to how they can operate with no apparent regulatory party ensuring they [are] meeting the required qualifications and following what is expected.’

First, Fiona noticed there was no fire safety protocol in place at the house. She mentioned this to the manager but no action was taken. It took an intervention from a disability advocacy group for management to establish the protocol more than a year later.

Rex began having problems with his bowels and Fiona engaged a nursing service to help out. The visiting nurse asked the house manager to have staff complete some bowel and bladder charting for Rex. She emailed the charts to the manager. But when the nurse returned a week later the charts could not be found and she had to rely on the recollections of staff.

A few days later Rex had to be taken to hospital with a compacted bowel, pneumonia and sepsis. These were life-threatening conditions, but Rex pulled through.

‘At no stage whilst Rex was admitted to hospital did the manager contact the hospital,’ Fiona said.

The house manager was told that improved documentation needed to be in place before Rex could safely be discharged back to the residence. These included bowel, bladder, diet, fluid and sleep pattern charts for the staff to fill out as required. The manager passed on a bowel chart to the staff, but none of the others.

It took another intervention, this time from the NDIS Quality and Safeguards Commission, for all the charts to be put in place.

‘I have found it very frustrating and time consuming to find the right place to take my concerns. I know, when you have a loved one in care, even though you have help, it consumes your life ... It seems wrong that service providers are profiting whilst ... their clients’ lives are at risk.’

Francine

‘I felt like something was wrong with me, I was lesser than, broken and in need of being “fixed”.’

Francine went to a private religious school for years 11 and 12 in the 1980s. She told the Royal Commission she made this choice because she believed it would give her ‘the best opportunity possible to receive a good tertiary entrance score’.

Francine’s physical disability meant that she used a wheelchair most of the time. However as the school wasn’t fully accessible, she took her crutches to access the upstairs classrooms.

Francine said that ‘well-meaning teachers’ chose to focus on developing her physical capacity – which they had no qualifications in – at the expense of her education.

‘Seeing my wheelchair as negative, teaching staff ... would encourage me to walk around the large school campus with my Canadian crutches instead of using my wheelchair.’

Keen to ‘fit into the school community’, Francine complied.

‘This resulted in me being ... late for every class and then having to pack up my things ten minutes before class finished so I could start the difficult journey to my next class.’

Francine became exhausted with the additional mental concentration and physical demands she had to put her body through every day to please the teachers and not be thought ‘lazy’.

It also dramatically affected her ability to move with speed between classes. She was often late and by the end of the day felt exhausted, ‘unable to focus on homework, assignments and study’.

‘As a child I thought my lack of academic performance ... was my fault because I wasn’t smart enough or because I was lazy – teachers thought this too even though they were the ones enforcing this intense physical regime.’

Meanwhile, without the consent of her parents, the school took it upon itself to ‘pray for [Francine’s] healing’. Teachers would make her walk with her crutches around the large school campus.

‘They wanted to see the “work of God” through me,’ Francine said.

‘Praying for me involved teachers, school staff and students putting their hands on my body and pushing me backwards onto the floor. One teacher in particular reinforced my developing negative self-worth by telling me that I wasn’t healed because I didn’t have enough “faith in God”.’

Francine looks back on her time at that school as emotionally detrimental.

'Due to their preconceptions of disability and lack of any cultural awareness of disability, they chose to focus on my disability as a negative thing that needs to be healed.'

Francine would like changes made to the Australian education system to ensure the rights of the child are central and 'kids with disability [can] grow up to feel proud of who they are as people with disability, not ashamed'.

Jasper and Patton

Jasper is a support worker. He wrote to the Royal Commission about endemic failures of care and support at the centre he works at, and how these failures impact the clients and staff.

Jasper said the centre regularly undercuts support workers' wages, fails to fulfil contractual pay rates and often puts the health of residents at risk.

Jasper told us about one client, Patton, who lived in a house with three other residents.

One of Patton's behaviours was to play with his faeces and track them around the house – on light switches, door handles, whatever he touched. Jasper said this regularly made staff and the other residents ill.

'House staff did everything they could to try and work with Patton to no longer do such things but nothing changed,' Jasper said.

The three residents were 'not able to advocate for themselves or accurately describe their living conditions to their families' and Jasper said management made no attempt to remove Patton from an environment where his habits were making others ill.

'Instead it was regularly covered up so the families of his housemates would not see.'

Jasper says his employer is 'not a company who look out for their workers and cannot be trusted to do the right thing'.

'Decisions are frequently made that are easy, even if it leads to [resident] neglect or damaging staff's lives ... I suspect there is so much about this company that is wrong [that] people need to either lose their jobs or the company lose their licence.'

Katya and Galina

‘The impact of a psychosocial disability diagnosis can have the same amount of impact on a person as a physical disability – I wish people would understand this, and accept that these people need as much care.’

Katya has a psychosocial disability. She finds it hard to do the basic activities of daily life, such as showering, remembering to take her medication and preparing meals. She is frequently hospitalised. Recently her partner died, leaving her a sole parent of several children.

Her sister, Galina, told the Royal Commission, ‘People with psychosocial disabilities have a harder time proving their disabilities and impact on function to the NDIA.’

At a recent NDIS meeting, the planner told Katya she would be ‘better off with a physical disability’ and that she should ‘just take medication’.

Katya made a complaint to the NDIA, which then approved a plan that funded 24/7 care support at home, psychology and equipment.

However six months later, Galina said, the NDIS planner cut the plan by almost 75%. They said the initial plan was made to support Katya during the grieving period for her partner, ‘as though grieving has a strict timeframe’.

Galina said Katya’s health declined along with the reduction of supports and soon after she was admitted to hospital with high blood pressure. Galina believes the NDIS process caused this stress.

‘The NDIS plan review process is a nightmare. Every six to 12 months we are forced to PROVE to the NDIA that my sister is impaired, with various specialist reports, and even when we provide this evidence, our requests are frequently rejected with NO reasons provided.’

Vaughn

‘The hospital system does not display any compassion towards people with disability.’

Vaughn is a pensioner with multiple disabilities. These impact his gross motor skills such as movement and speech, and fine motor skills such as writing and texting.

Some years ago Vaughn was admitted to hospital with blood in his urine. He told the Royal Commission he was discharged with ‘minimal notice’. Vaughn asked to see his file, but the hospital would not let him. The urology nurse yelled at Vaughn in front of staff and patients, an experience he describes as ‘very humiliating’.

When Vaughn recently presented at a hospital, staff determined that he was drunk because of his slurred speech and lack of coordination. They forced him to undergo an alcohol withdrawal program.

While at the hospital, Vaughn was accused of abusing a nurse, ‘throwing tablets in her face’. Vaughn said he didn’t do this, but was forced to sign an agreement to not throw anything at nurses. He said he signed the agreement because the hospital threatened to withdraw treatment if he refused.

Another time, Vaughn fell out of his wheelchair and cut his head and an ambulance came. ‘They shone lights on [me] and left,’ Vaughn said. The ambulance returned with the police, assuming he was intoxicated.

Vaughn’s experiences with health and medical agencies has a recurring theme. Medical and emergency staff presume he is an alcoholic when treating him rather than investigating or enquiring, due solely to his speech patterns.

Ute

Ute is in her early 40s. She is from a culturally and linguistically diverse background and has a mental health condition.

She told the Royal Commission that, while hospitalised, staff performed medical procedures on her without her consent.

'I remember being put into a room, with these circle suction things placed on the sides of my head with wires attached to them. They did not disclose to me what they were doing or why I was in this room. I'm concerned I've had [electroconvulsive therapy] against my wishes,' she said.

She also told us she saw hospital staff withholding patients' medication as a form of control.

'I remember on one occasion ... a patient was yelling in distress for his medication. He was yelling, "I want my medication; I want my medication."'

She said these incidents and others were reported to hospital management, without resolution.

Ute would like Australia to realise that some people with mental illness can be highly intelligent.

'We need to nurture their talents and gifts, not sweep who they are under the carpet.'

Noelle

Noelle identifies as a transgender woman. She has a mental health condition and post-traumatic stress disorder. She told the Royal Commission she has been denied parental rights because she has a disability.

A few years ago, Noelle and her wife had a baby girl. Shortly after the birth they were called in to see the midwife, who asked if either of them had a cognitive impairment. Noelle responded that she had a report stating she did.

The midwife said that in that case there was no option but to get the department of health involved.

‘They provided no help to myself or my partner they just said you can’t be parents you failed assessment. I asked about education courses [and] they said you have a disability and it would be no use teaching you.’

Noelle and her partner are still trying to get their daughter back.

Noelle hopes that in the future government bodies can be trusted and will help parents with disability.

Sharon

Sharon is a support worker in a group home. She told the Royal Commission she is concerned about the financial exploitation of people with disability she sees every day.

Sharon supports four men, aged in their 30s and 40s, who have cognitive disability. She says their level of disability might mean they 'would not understand how they are being treated'.

Sharon says the group home has directed support workers to spend no more than \$64 on each resident each week. This is supposed to provide three meals each day 'plus snacks for morning and afternoon tea'.

Sharon told her team leader it is impossible to provide that many nutritious meals for such a low budget, but nothing has changed.

Sharon hopes that by making her submission, she is taking steps 'to protect these people that are unable to protect themselves'.

Ines

Ines has twin adult sons. One has an acquired brain injury and the other has anxiety and depression. Ines told the Royal Commission that both her sons, and she as their parent, have experienced police harassment, bullying and intimidation.

On many occasions, Ines said, the police threatened to charge her if her sons refused to admit to certain behaviour and actions.

In one instance, the police threatened to put out a warrant for the boys' arrest because Ines was unsure of their whereabouts – she was at work at the time.

Another time, police arrested Ines, fingerprinted her and took mugshots because her sons refused to admit to stealing. Ines was falsely charged with receipt of stolen goods. An investigating officer threatened one of Ines's sons that his mother would get a criminal record – which would put her job in jeopardy – unless he admitted to a crime he did not commit.

Ines's experience of the police and courts is that there is 'a definite lack of understanding and knowledge of people who have a disability – particularly in regards to communication, compassion, empathy'.

She thinks there needs to be a better support service for people with disability during interviews with police and in the court environment.

'This intimidating environment makes people with disability nervous and impedes their understanding of questions they are being asked.'

Ines attended with her son during legal proceedings but says she was not allowed to assist her son verbally when he felt overwhelmed with the questions.

She would like to see all people working in the justice system 'be better trained in the disability sector to give them a better understanding of how people with disability live, and also the social barriers that they face on a day to day basis'.

Logan

‘We shouldn’t have to fit into this ableist box to succeed.’

Logan lives with a sensory processing disorder and chronic pain disorder.

Logan shared with the Royal Commission their experience of ‘restrictive and condescending experiences’ at the private girl’s high school they attended a few years ago.

‘Sometimes if I had a particularly loud or explosive panic attack or meltdown I would be made to sit with teachers or nurses I was not comfortable with. I was also moved away from spaces I felt safe (such as between lockers) and into spaces that made me feel worse, like the sick bay or an office.’

Teachers and students failed to listen to Logan when they tried to plan for panic attacks or meltdowns. They made decisions based on their perception of Logan’s needs rather than what Logan actually needed.

‘I felt neglected and invalidated. I felt like I had no voice or space because of things I could not control ... they still disregarded my feelings of safety and made me feel like I was incapable of making decisions for myself.’

Logan is now at university and in the workforce, but said their experience at school has made them ‘incredibly anxious’ about disclosing their disabilities.

‘I’m afraid people will become invalidating if I say anything and [I] avoid a lot of in-person meetings to make sure no-one ‘finds out’.’

Logan would like to see schools become a ‘more adaptable space that can work with students to actually thrive, working with their differences ... rather than making them adapt to a rigid school system’.

Gloria

'I have had many negative experiences throughout my life as a result of my mental health, in particular ADHD,' Gloria told the Royal Commission.

Recently, Gloria was admitted to a hospital emergency department.

'I was treated like someone who was "sleeping something off", left on a bed for many hours asleep with no spoken interaction with staff. When I woke many hours later I tried to leave and was cornered by many medical staff in front of a locked door. I responded poorly [because] I was frightened and upset ... If staff had treated me (spoken to me) they would've found out about my mental health conditions and that I'd lost my medication while away on holidays.'

One of the doctors accused Gloria of throwing an object at her and she is being charged with common assault and property damage. Gloria denies the charge.

'I'm now fighting this at my own personal cost,' she says.

Gloria has faced other challenges due to her 'untreated ADHD'. She has been charged with many driving offences, and had charges relating to overpayment of Centrelink benefits.

'This has caused me significant emotional trauma and resulted in a 12-month Intensive Corrections Order which I successfully completed,' Gloria told us. 'This has had a lasting impact on my life and will continue to do so ... I don't trust those in positions of authority (police and medical) as a result of my experiences, particularly recently.'

Gloria is a recovering alcoholic.

'I self-medicated for 10+ years, attempting to calm my chaotic, busy and anxious mind. I failed at many jobs despite my best efforts.'

Gloria is now sober, but says, 'these mental health conditions have taken so much' from her.

'People with ADHD and mental health conditions need to be recognised for our struggles. We need to be supported ... Just because someone looks "normal" or "ok" don't assume that their negative behaviour is just poor/bad behaviour. We aren't "drunk" or "high".'

'Be better,' Gloria says, 'investigate things further. Especially if you are in positions of power and/or authority.'

Gloria's hope is that 'we treat each other with kindness, compassion and understanding' and that 'struggle is supported'.

Raymond

Raymond told the Royal Commission he is concerned that the tragic case of Ann Marie Smith – a South Australian woman with cerebral palsy who, neglected by support workers, died alone in her own home – potentially mirrors his own.

He explained that in some of the news footage, the reporter asked why the NDIS approved local area coordinator hadn't picked up on Ann Marie's neglect.

'The thing I wanted to share is that my local area coordinator has never contacted me to ask questions about how I am doing, the only contact I have is when my new NDIS plan needs to be reviewed.'

Raymond said he has called 'on several occasions' when he had questions or needed assistance, but his calls have never been returned.

Raymond would like to choose which company he uses as his local area coordinators, but in the regional town he lives in, there is only one company the NDIA allows to do this. 'So I do not have any choice,' he said.

Raymond is also struggling with employment and does not understand why, as 'a multiple amputee', he is not classed as having a permanent disability.

'They reject my disability claim, and put me on jobseeker (Newstart) and expect me to compete with able-bodied people for work, I am at a disadvantage from the beginning.'

Meanwhile Raymond is finding his NDIS funding inadequate, and he cannot afford to have as many sessions with his exercise physiologist as he needs. He has been told he can pay for the extra sessions himself but, having to 'live on \$40 a day', this is not an option for him.

'All Government departments need to have the training on what it means to be disabled, and the limitations we face, so they understand our needs instead of first thinking about the amount of money they can save by not funding us properly.'

Ari

Ari has been employed as a disability support worker for more than eight years. He told the Royal Commission that three of the organisations he has worked for in this time have been neglecting and abusing their young clients in a variety of ways, including using restrictive practices, limiting access to food and ‘using the kids as cash cows’.

‘I have seen one young guy 14 years of age allowed to play Xbox Live online ... all while he sits on a urine-soaked couch all day. I have witnessed companies feeding kids in care junk food as a way of shutting them up and not cooking proper meals and I have seen an over use of computer games.’

Ari says he has seen children ultimately become violent offenders as a result of the mistreatment and neglect they have experienced in residential facilities.

‘There is a growing number of kids becoming violent and being swapped from provider to provider ... The kids gradually get more violent and bigger and stronger and nothing is done ... I have seen clients get stronger and stronger medication doses and break things, smash cars, windows, TVs, and no action [is taken].

‘They replace these items over and over and say “all good”. There is no system in place to actually help these kids and support ... it’s just a patch up job ...’

Ari believes the system is ‘broken’ and that big companies ‘target’ child cases to ‘get millions in payments’ – ‘They do it not for the child but for the money.’

‘There are organisations that buy a house, call themselves a respite place and break all the rules ... There are companies hiring staff with no police checks and they are working with no checks.’

Ari says we need a plan to help fix this problem, ‘not pay out millions to hide the fact these kids are broken and should be getting help’.

‘To be honest the system is broken really bad to the extent it’s now an industry that has a high turnover and ... if a staff member wants to complain, as most are casual you lose those hours and they replace you with someone that won’t have a voice.’

Kiefer and Lilly

Kiefer and his sister Lilly lived in different states. Kiefer didn't like the phone and didn't have a mobile phone or computer, so communication was infrequent.

Kiefer, in his 50s, lived with schizophrenia and other disabilities. He managed his schizophrenia with a regular injection from his GP. There were a number of people and organisations he interacted with on a regular basis.

'I reassured myself that he had a cleaner and a registered nurse going into his home, as well as a support coordinator who organised the services he required,' Lily told the Royal Commission. 'I made the assumption that someone would ring me if something was amiss.'

Every year, Lilly sent Kiefer a birthday present. One year, when she didn't hear from him, she became concerned.

'Every year without fail he rang me to thank me for the present,' she explained.

After ringing him repeatedly, she asked the local police to do a welfare check.

'That night at 10 pm [my local] police knocked on my door and told me that [Kiefer] was dead. The most shocking part was that he had been dead for months.'

Kiefer's body was so badly decomposed that a full autopsy was not possible.

Lilly couldn't comprehend how this had happened. Kiefer had received services from a community organisation for 35 years.

'This was a comprehensive, multidisciplinary service that provided regular check-ins and support through a psychiatrist, social workers, qualified staff and, most importantly, case management. Whenever I had concerns about [Kiefer] throughout this period, I was able to easily make contact with a social worker and these issues were followed up.'

When Lilly started to investigate Kiefer's death she discovered this service closed a few years before Kiefer died.

Kiefer had been transferred to another mental health service, but this service discharged him. When Lilly accessed the discharge notes through freedom of information, she discovered Kiefer had been encouraged to discharge himself. Staff told him he seemed well.

The service referred him to a medical practice with mental health services, but the information they gave him was out of date and the practice had closed.

Additionally, Kiefer's only friend had died and no-one told him.

Kiefer was alone. He died not long after being discharged from the mental health service.

‘I believe it was the discharge from mental health services that is the key factor that led to [Kiefer]’s death. [He] should never have been discharged as he was extremely isolated and experienced psychosis, at times living in his backyard.’

Lilly also questioned why Kiefer’s regular GP didn’t intervene. The clinic made no inquiries when he didn’t appear for his weekly injection.

Nor can she understand why his NDIS support coordinator didn’t raise the alarm. Around the time of his death Kiefer failed to attend a review meeting, causing his NDIS payment to be stopped.

‘There appeared to be no effort made to find out why [Kiefer] did not attend this meeting ... It appears that my brother died shortly after his NDIS funding was discontinued.’

The coordinator told Lilly they had trouble contacting Kiefer because his phone had been disconnected. But Lilly contacted the telco who told her the phone was connected.

‘I believe that [Kiefer]’s schizophrenia made him invisible and the neglect he experienced was normalised, rationalised and condoned by those whose task it was to care for him.’

Lilly believes the neglect Kiefer experienced continued after his death. She says the police failed to investigate her brother’s death properly, reducing it to a ‘level of insignificance’.

While dealing with the coroner, Lilly was asked to use the case number, not his name. ‘This process is dehumanising,’ she said. And not knowing how Kiefer died ‘is unacceptable’.

Luna

Luna used to be a fashion and textiles teacher. She has a hearing disability and uses hearing aids, but still had difficulty hearing students and staff.

Luna felt that teaching staff at her school didn't understand the nature of her disability or 'how to relate to a person with a hearing disability'. They seemed to think she was 'deliberately being difficult or obstructive'. They became impatient and treated her 'with contempt'. Luna told the Royal Commission she experienced 'bullying, isolation, intimidation, marginalisation, unfounded disciplinary action, baseless accusations and lack of support' during the several years she spent teaching at the school.

There were many examples of this. If there was a meeting, staff would signal to each other before leaving the staffroom to walk to the meetings together. Luna missed the signals and often missed the meetings. One time she called out to them to wait so she could walk with them. They ignored her and kept walking.

Another time, while she was preparing materials for a class, she noticed a number of teachers from her faculty go into another room. It turned out they were attending the demonstration of the 'new, long awaited, very expensive 3D printer'. She felt angry and excluded and asked if they forgot to let her know about the demonstration. The faculty head was dismissive, saying it wasn't important.

On a few occasions during faculty meetings, some staff made 'hurtful comments and behaviour' directed at Luna. The faculty head ignored it and 'showed no support or consideration' for her.

Management and other teachers repeatedly ignored Luna's requests for accommodations or assistance.

At one stage Luna asked for assistance in dealing with ongoing behaviour and learning issues in one of her classes. Initially there was no response. Then one day, without warning, the head of the senior school came to her class to talk to the students. He asked Luna to leave so the students would be able to 'speak freely'.

'I felt seriously disadvantaged by this, it undermined me, excluded from dialogue and did not allow me to contribute. This was the only time anyone came to speak to students about their behaviour towards me and I was prevented from being included. I received no feedback. I did not see this as supporting me, I felt intimidated and left in the dark.'

About four years into her time at the school, the faculty head changed Luna's timetable and working conditions with no consultation or warning. It turned out they had offered a less senior teacher her choice of Luna's classes. This resulted in Luna being taken off the class she had been instrumental in 'designing, implementing, trialling, adjusting' for the state's Certificate of Education. It also meant she now had a larger class of younger and 'exceedingly noisy' students, a much less manageable situation for a teacher with a hearing disability.

At the same time, the faculty head asked Luna to assist the incoming teacher with delivery of the class. 'This made me feel I was in fact training my replacement,' she said.

'I felt insulted and undervalued ... I really felt like I didn't matter. I also felt they wanted to get rid of me.'

Around the same time, the school had a series of student suicides. Staff were put on 'suicide watch'. Luna had had her own experience with suicide and felt 'traumatised'. She wrote to the principal about how she felt about being on suicide watch. She never received a response.

Luna was feeling desperate. She went to the state association for the Deaf for help. They provided an advocate who assessed her 'as being in need of immediate intervention in the workplace'. But this never happened.

'I experienced despair. I was severely depressed. I was shut down. My health deteriorated significantly and I could no longer cope, which forced me to leave work. I have not worked again. The lack of support from my employer and the result of the discrimination robbed me of the ability to earn a living.'

Trent and Rebecca

At his school, only eight year 12 students chose to sit exams to determine university entry. Trent was one of them.

But in his midyear exams, something went wrong.

'[Trent] re-wrote questions, wrote questions back to front and as if in a mirror, drew pictures and wrote the phonetic alphabet,' his mother Rebecca told the Royal Commission.

He did this in every exam. The school became aware of it after the second exam, but didn't tell his parents and let him continue. The school later said they had planned to 'deal with it after the long weekend'.

But they didn't deal with it. Before school resumed after the break, Trent took his own life.

Rebecca said she had informed the school about Trent's mental health diagnosis a year earlier. She sent follow-up emails, but never received a response. After the third email, she had contacted the school psychologist directly.

'She told us that she would discuss [Trent] at the next staff meeting she would have with senior staff,' Rebecca said.

But Rebecca never heard from the psychologist again.

'Knowing what we know now we should have chased her up,' she said.

But Rebecca had assumed the school was supporting Trent. She only discovered later that none of his teachers had been informed of his mental illness.

After his death, Rebecca asked a manager from the hospital to ring the school on her behalf to make sure they were looking after Trent's friends. If any of the kids wished to 'say goodbye to their friend', the manager relayed, they were welcome to come to the hospital.

But the school only informed one student, who was told to keep off social media and not tell any of Trent's friends. Hours later, in the middle of a class, Trent's best friend learnt his friend had died.

'[He had] to excuse himself to go and ring his parents.'

Rebecca says 'dealing with the school' since her son's death has 'been awful'. Individual teachers have been deceitful, disrespectful, unprofessional and have breached countless guidelines and procedures.

The school never publicly acknowledged Trent's death. It refused to share details of Trent's funeral, telling the family it was 'against department of education guidelines'. The school discouraged students from talking about Trent's death because it would upset people. Students had to push to have their friend and classmate acknowledged at graduation and in the yearbook.

The family petitioned the state coroner for an inquest into Trent's death, and were refused. They complained to the education minister, but were told the school 'could not have foreseen' Trent's death.

Rebecca found this 'an outrageous thing to say' given the school knew Trent 'was suffering with anxiety and depression and had evidence of his clear mental distress in what he had written in his exams'.

Rebecca wants the school to be held accountable. She wants all teachers to undertake mandatory and comprehensive mental health training, and she wants the education department to 'protect our children rather than protecting the schools'.

More than anything, she doesn't want this to happen to another child.

Luke and Naila

‘My son’s tired. So am I. Childhood is meant to be fun, along with lots of learning. My son is capable of this – but little has been done to modify anything to his needs.’

Naila’s son Luke has attention deficit hyperactivity disorder (ADHD). Naila also has ADHD and, as someone who wasn’t diagnosed until later in life, she knows the importance of early intervention.

‘I was without support at school, and whilst smart I did not have the ability to organise my work. This led to me dropping out of ... a law degree as I could just not manage to coordinate things.’

Naila told the Royal Commission people were always telling her to ‘try a bit harder’. ‘[This was] so damaging to my self-worth and self-esteem,’ she said.

Naila finds that people are often judgemental about ADHD, ‘scoffing it’s made up or an excuse to get access to various medications’. So she rarely tells people she has it, for fear of judgement or having to explain herself.

Luke is seven. ‘He’s engaged, interested in many things’ but has anxiety and ‘his working memory speed is slow’.

The school he attends offers very little support.

‘His teacher was surprised with his diagnosis saying, “I didn’t realise ADHD presented like that.”’

That’s because Luke is quiet at school, ‘bottling it up until he gets home’.

Because of this Naila fears he falls through the cracks and she has little confidence the school is making any adjustments to suit his needs.

‘The school developed a very poor [Independent Education Plan] without informing me. It’s not been updated since and I’ve asked numerous times over the last 12 months.’

Outside school Luke has a reading tutor who uses a multisensorial approach, and sees an occupational therapist (OT) to address motor development issues.

Naila has to pay for all Luke’s support herself because there is no support from the NDIS for people with ADHD. Naila would also benefit from more support.

‘Strategies that would help my life immensely would be an ADHD coach, an OT, some support at home. I’d be able to work and contribute more if I had these. I’ve sometimes self-funded these but it becomes expensive and I can’t always afford it.’

Because Luke receives limited support at school he often cries and tells Naila he doesn't want to attend.

'He started saying things like, "I am dumb or I am not good at that." It was heartbreaking.'

Naila says that unless children, families and educators are given adequate support there will continue 'to be a stigma attached to ADHD'.

'People will not reach their potential and end up with mental health problems such as anxiety and depression.'

Naila hopes in future the education system will be 'more inclusive and dynamic' and support all learners.

'The long-term impacts of no support across a life span is pretty awful.'

Ruben and Joan

Ruben was a ward of the state when he came into Joan's care at the age of six. He had been abused and neglected as a baby. He has a mild intellectual disability and is autistic.

When Ruben started at the local public school, staff knew about his diagnosis, his traumatic history and challenging behaviours. Yet, Joan said, they showed him little understanding or compassion.

The bullying began straight away. Time and time again, he would get in trouble for reacting to the horrible things other kids would say or do to him. Teachers blamed Ruben for the bullying behaviours of the other children. One teacher complained that 'the other students had become more challenging since [Ruben] arrived'.

Joan enrolled Ruben in a support class for the first time when he started at high school because she was worried he would not be given enough support in the mainstream class and she was concerned about the bullying.

This was an 'exceptionally difficult' year for Ruben. He had limited contact with the few friends he had in the mainstream class, and the behaviour of some students in the support class was 'very challenging'. He was being threatened and physically assaulted.

By year 9 Ruben was 'miserable and afraid almost every day'. Joan decided to transfer him to a different public school for a 'fresh start'.

At the new school, little changed. Joan said Ruben received little to no encouragement, even though from time to time she would hear isolated reports that he was doing well. It seemed, on the whole, teachers were inclined to think poorly of Ruben and were 'unkind' to him.

There was a particular incident at Ruben's final cricket match in year 9. Joan's sister, May, was watching from the bleachers. When Joan joined May later she found her in 'a distressed state', angry and crying. Two people sitting behind May, not knowing she was Ruben's aunt, had been making fun of him the whole time, ridiculing the way he was playing, his poor eyesight – May couldn't even bare to tell Joan the worst of the insults. It turned out these two people were teacher aides from Ruben's support unit.

Throughout year 10, Ruben's behaviour deteriorated. He was often 'angry, hyperactive and fearful'. He was given formal cautions and suspensions, and was sometimes placed in isolation.

There was one kid in the support unit who caused particular problems for Ruben, a boy named Brady. One day Ruben told Joan that Brady had been boasting that 'he was going to have sex with [one of the girls in the special unit] tomorrow'. Joan immediately notified the head of the unit so they could protect the girl.

By year 12, Ruben was 'miserable' all the time. Finally, towards the end of the year, Ruben told Joan that Brady had been sexually harassing him for a long time.

When Ruben needed to leave the class to use the toilet, Brady would sneak out and assault him.

The deputy principal told Joan that, even though he believed Ruben, the school wouldn't pursue consequences for Brady as he had denied any wrongdoing.

Joan withdrew Ruben from the school until they could work out a plan to keep him safe, which took a couple of weeks.

'Ruben was very upset at home,' Joan said. 'I attempted to work through these issues with him. He identified the problem as being afraid he would be punished if he used force. He was also angry with Brady and angry with the school for not doing anything ...'

'Ruben said his whole life was like "prison torture". He talked about his bad dreams where he had been forced to do terrible things.'

The year after Ruben graduated from high school, Joan received a call from a detective from the child abuse squad. He asked if Ruben would be prepared to give a statement about what happened to him at school. Brady had been charged with assaulting other students and the detective wondered if Ruben would like to join the case and have Brady charged. Ruben made a statement and agreed to have Brady charged.

A few years on, one case has already been aborted. Joan says Ruben has never wavered in his resolve to have Brady charged.

'He says he understands that there is no guarantee of a guilty verdict but he believes he needs to tell his story in court.'

Meanwhile, Ruben is doing well. He has almost completed his TAFE course, which he loves.

'He has an excellent teacher and support teacher,' Joan says. 'He has some supportive friends around him at last'.

Ruben has a driver's licence and Joan is 'hopeful' he will find stable employment.

Nonetheless, Joan says, 'flashbacks and nightmares recur fairly often'.

**'I'm stuck here in the prison cell in my mind,' Ruben told his mum.
'I don't have the key. I'm free of school but in my mind I'm still trapped in my cell.'**

Mariah

Mariah is a paid support worker. She told the Royal Commission she is concerned the company she works for is not properly providing for the residents in its group homes in order to save money.

'We are expected to feed the people in a group home for \$65 per week ... We do three meals a day for them and three snack meals a day and if they go to any day placement they still require us to pack their food for that day.

'We also buy other household needs out of that [\$65] like toilet paper ... so that amount is not just for food alone.'

Mariah has raised this issue with management at different levels, but they have all insisted that this budget must be adhered to.

Mariah's hope for the future is 'for the government to have more control in private companies and to have independent people checking up on things often'.

She says these independent inspectors should talk to the people who work in the home rather than managers who, she believes, will invariably hide the truth.

Della

Della has cerebral palsy. She told the Royal Commission she worries that providers are using COVID-19 as ‘an opportunity to take away choice and control from their clients’.

Prior to COVID-19, Della lived alone in her parents’ house with 24/7 support from 14 support workers. This allowed her to ‘contribute to society by being able to work’. She enjoyed her independence.

But when COVID-19 began, Della realised the number of people coming in and out of her house was no longer safe. She decided to give up her night support workers.

Around the same time her major provider said they were limiting the number of support workers because of the pandemic. Della wasn’t going into work and there were limited opportunities to go out into the community, so she negotiated ‘three days per week of supports, leaving four days without anything’.

Some months down the track, Della’s employer asked her to return to work. Before the pandemic a support worker used to transport Della to her workplace, help her into the building and set her up at her desk. To attend work, she needed the provider to increase their support.

The provider agreed to do this but told Della she would need to sit in the back of the car. This wasn’t possible because the space was too small. Instead they agreed Della would take a taxi and the support worker would follow her and set her up for work.

However, Della realised she could not socially distance from the taxi driver. He needed to strap her into the car and she ‘could not control who the driver was around’. She also couldn’t understand why a support worker could get close enough to shower her yet that same support worker couldn’t drive her into work.

‘I really felt that the provider was prioritising staff welfare over my welfare.’

But Della didn’t want to fight with the provider because her priority was getting to work.

‘I value my job. It has taken me a long time to get my job, I am happy with where I work and who I work for. I was not going to let my service provider put that at risk.’

Instead she used an online service provider.

But after a few weeks it became difficult to find suitable staff and Della had to go back to her regular provider, who eventually increased support to cover her work hours.

Then Della received an email from the provider claiming ‘that they would like to improve services’ by changing her hours.

Della said the new hours 'did not consider my lifestyle'. In her opinion the provider changed her hours and supports to suit itself with little regard to her.

Della is concerned providers 'are more interested in protecting the parts of the business that bring them in more money instead of providing individual client centred care'.

Della says she was one of the lucky ones who continued to receive some care during the crisis. She believes this is only because she spoke up and had family to support her.

'[The providers have been] able to dictate my quality of life, which would have been very poor if I didn't speak up and assert my right to services that should always be essential.'

Darla

Darla is a paid support person. She told the Royal Commission that improving training and working conditions for support staff would lead to fewer cases of abuse and neglect of people with disability in a support context.

‘What I find is that there is a severe lack of training for disability support workers in all aspects, but mostly on how to handle stress in the workplace when residents behaviours are pushing support workers too far.’

Darla has observed that there is often conflict or ‘clunky communication’ between staff, doctors and family when it comes to making a decision about medications, particularly medications for controlling a client’s behaviours.

‘Too many times,’ Darla says, ‘management of an organisation have stepped in or tried to step in and a patient has ended up incorrectly medicated ... management of an organisation are not medical experts.’

Darla thinks there should be someone who oversees these issues and then cannot be overridden – ‘a “buck stops here” board of medical specialists/advisers’.

Ultimately, Darla hopes ‘that vulnerable people get a chance at a life that is their kind of normal and have access to all the supports that they need including medications that are suited to them to give them the quality of life they deserve and support their emotional welfare’.

Leena and Monique

‘While in their care, she was exposed to, indecently assaulted and sexually assaulted twice, by a student who was known by school and Departmental Executive, to put others at risk.’

Leena has an intellectual disability and in the mid-2010s attended a learning support unit at the local high school. Monique, her mother, thought Leena would be safe there. She told the Royal Commission she had been wrong.

Halfway through year 8 Leena was indecently assaulted by two boys in class. Joseph and Quaid were sitting either side of Leena watching pornography on a computer, touching Leena inappropriately and making her touch them.

It was not the teacher or the aide, but another student who intervened, removing Leena from the situation by taking her to the assistant principal’s office.

The assistant principal advised Monique to report the incident to the police, saying ‘they’d been after [Joseph] for some time’. Joseph had a history of this behaviour and had sexually assaulted another girl in Leena’s class.

Leena reported the incident to the police and the boys were suspended.

It was only at this point that the truth started to unfold – Joseph had been sexually assaulting Leena since year 7.

Joseph ‘befriended’ Leena when she first started at the school. One day when she was looking for a friend in the playground Joseph exposed his penis to her. He told her ‘if she touched it he would tell her where her friend was’.

Leena reported the incident to a staff member. Monique remembered being called to pick Leena up from school and finding her ‘inconsolable, hiding behind furniture, unable to verbalise the cause of her distress’. Staff knew what had caused this distress, but no-one told Monique. She wouldn’t find out what had happened until more than a year later.

Not long after this incident Joseph took Leena to a highly visible area within the gated grounds of the support unit.

‘He hit her on the head, pushed her down, pulled her pants down and raped her. When he was finished he called her a whore and told her he would kill her if she told anyone,’ Monique told us.

Leena didn’t tell anyone, but Joseph told some of the boys what he had done. Some of the boys told their parents and at least one parent told the school.

Again, the school failed to notify Leena’s parents. They remained in the dark.

Joseph escalated his behaviour. He took her off the school grounds to a block of toilets at a nearby park. He removed her clothes and raped her. Monique only found out about this following her report to the police about the incident in the classroom in year 8.

Monique feels devastated Leena wasn't able to tell her about these incidents at the time. She suspects she didn't have the language or words.

Joseph was found guilty of multiple counts of indecent exposure and sexual assault and remains incarcerated.

While he didn't return to the school after the suspension, Quaid did.

Seeing Quaid at school increased Leena's anxiety and distress. The school suggested she restrict her movements at lunch and not use the playground because Quaid needed 'to run around'.

When Monique complained, they set up a girl's area outside the gates. But this area was unsupervised and Quaid was allowed to play soccer nearby.

During a mandatory safety awareness program given to the students in the unit, Leena told a teacher she felt unsafe with Quaid in the class. She was told 'to be strong and pretend he's not there'.

Then, without informing Monique, the school brought Leena and Quaid together in the playground. A teacher rang Monique with 'the good news' Leena had 'made the adult decision to forgive [Quaid] so they can move on and be friends'.

Monique and her husband were outraged. Leena did not want to be Quaid's friend. Leena's counsellor was also concerned about this intervention and the damage the school continued to inflict on Leena.

Monique removed Leena from the school.

Determined to ensure what happened to Leena would not happen to anyone else, Monique pressed the department and school for a full review. Ultimately she had to involve her local member of parliament to make it happen.

'I hold the Department of Education responsible for the assaults on my daughter. I hold them responsible for their lack of sense and sensitivity in their treatment of her as a victim and the ongoing trauma this has caused her.'

Vito

When Vito was about six months old, doctors told his parents he was a ‘rubella child’ and had multiple disabilities, including deafness, blindness and cognitive impairment. The doctors told them to put Vito into an institution.

Vito told the Royal Commission he imagines his parents, who were migrants with little English, would have been scared. But they pushed backed against the experts and kept Vito at home.

It turned out the doctors were wrong. Vito is legally blind but can hear and isn’t cognitively impaired.

Vito attended a boarding school for blind children, where the academic expectations were low.

‘My parents were told by the then principal that I would probably go to technical secondary school and then possibly end up making baskets and brooms as a career.’

Around this time school policy was changing and mainstream schools were becoming more inclusive. Vito attended a mainstream school one day a week, where one of the teachers saw his work and suggested he switch to a mainstream high school.

The boarding school fast-tracked Vito’s education so he could begin school with his peers.

Vito did well at school. His year 12 coordinator told him he would have achieved better grades if he had access to the information in a timely manner and in a format he could read.

At university Vito studied accountancy. Most lecturers allowed him to record lectures but some refused. Only the core textbooks were available in audio versions.

‘If I lacked comprehension in a particular area of my study there was no possibility of me being able to access additional reading material to assist me develop the knowledge in that area.’

Unexpectedly, Vito was contacted by a retired accountant who had been employed by a disability support organisation to read the textbooks for him.

He told Vito he felt uncomfortable reading accounting material for him because there was ‘no way’ a blind or vision impaired person could be an accountant. Vito tried to explain how he adapts to situations and the equipment he uses, but the retired accountant was not convinced.

‘He could not even comprehend that I could make such a decision myself. I knew the challenges that were ahead of me in my future career with that kind of bias.’

Vito feels he could have graduated with honours if he’d received reasonable adjustments.

He found an employment agency who assisted people with a disability and got a job as an accountant in the public service. He considers programs to hire people with a disability were better and more effective at that time than they are today.

Access to information in the workplace continues to be difficult. Often the IT system isn't compatible with Vito's assistive technology and he is left to figure it out. When he attends meetings where there are visual presentations he is rarely given access to the material in an accessible format beforehand. Touch screen technology is designed for people with good sight.

Vito said that when he had been passed over for promotion early in his career, he hadn't felt it was because of discrimination. But as he progressed, he believed this was the case.

In the 13 years in his current role, he has seen several other staff progress from levels below him, to levels above.

'If you have a disability, the barriers you face and in my case the neglect I have faced over the years – the ability to access information in a manner and format that I can read, accessible training, and the neglect in obtaining the IT infrastructure in order to efficiently do my job – are not recognised in selection panels.'

Victor now chairs an employee network within his organisation. He is determined to make systemic workplace change.

'There needs to be a culture of access and inclusion across the whole Australian society. It needs to be second nature to everyone not just the disability sector. Access and inclusion need to be considered a "top priority" and not just a "nice to have".'

Quenton and Wallace

Quenton, now in his 20s, was born with a chromosomal deletion syndrome, which caused severe intellectual and physical disabilities.

After Quenton's mother died, his father Wallace struggled. He ended up putting Quenton into voluntary placement care.

'A voluntary placement does not have any court orders. It is used to provide support for a family to ensure that, in this instance [Quenton], is receiving good supports,' said Wallace.

Wallace remained in constant contact during the decade in which Quenton was in care. He always intended to reunite with his son.

When Quenton transferred to the NDIS about five years ago, his former service provider ended the voluntary placement agreement. The NDIS appointed a new service provider to find a new voluntary support worker.

That's when the financial abuse started, Wallace told the Royal Commission.

'The commencement of NDIS has allowed for the abuse of my son, by his carer, to go ahead with no responsibility taken by [the state health department] or NDIS.'

The flow of information to Wallace stopped.

'The carer was abusing the power of plan nominee to prevent family inclusion and to prevent Quenton's doctor providing current medical information to myself as Quenton's father.'

Wallace said the new voluntary support worker kept all Quenton's pension, but failed to use it all for Quenton's benefit.

'The management of the placement for my son went unmonitored and when I thought I was following process to have my son returned to my care, I was denied access and information.'

Wallace successfully applied for guardianship of his son. The day he took him out of the voluntary support worker's home, Wallace said they kept some of Quenton's property, claiming it as their own.

'[The] past 2 years' events ... have resulted in a struggle which caused trauma to our family and placed my son at risk,' said Wallace.

He said safeguards for voluntary placement no longer seemed to exist after the introduction of the NDIS.

'I am now able to advocate for my son, but my concern for others is very real.'

Carlos and Bella

Carlos is 'gifted' but also has attention deficit hyperactivity disorder (ADHD), a 'lifelong disability'.

His mother Bella told the Royal Commission that knowledge about ADHD at Carlos's school is 'outdated and full of bias and stigma'.

Bella struggles to engage his teachers. She has provided the latest scientific-based research to the school but she's unsure if it's even being passed on to the teaching team.

She says that students with ADHD 'thrive on challenge and can be easily motivated by interest'. But Carlos is 'stuck in a class where the teacher thinks he doesn't get maths so is only taught how to pass the test'. She sits at the front of the class and spoon-feeds the students. She won't let Carlos ask questions during the class.

'My child has ADHD – asking him to wait until the end will mean that he's forgotten what question he wanted to ask!'

Bella has suggested Carlos attend more advanced classes, but he is prevented from doing so because he performs poorly on tests.

He performs poorly because during testing he can become distracted and lose concentration. Bella says the five-minute rest break allowed for national tests is not suitable for all students with cognitive disabilities.

'No two ADHDers are the same ... Accommodations should be tailored to suit each individual ...

'The government could help this situation by promoting and reframing the way ADHD is perceived,' she says. Students with ADHD are seen as having 'behavioural difficulties'. They are often treated as if 'they are doing it on purpose' and then suspended from school.

Instead, Bella says, ADHD behaviours should be understood as 'symptoms of a neurodevelopmental disorder – something that they have no control over'.

'ADHD currently is one in 20 primary aged students, therefore, on average there will be at least one ADHDer in each class. It is imperative that every teacher is given up-to-date training on how to cater correctly for them.'

Kamila

When Kamila was 18 she was diagnosed with bipolar disorder.

She already had a short temper, she told the Royal Commission, but after the diagnosis her GP put her on medication that made her 'an extremely angry and aggressive person'.

Kamila told her GP her concerns about the medication but was advised to keep taking it.

'One night, after a minor family fight, I was so angry that I was screaming and throwing objects at the floor, I just could not calm down,' she said.

Kamila kicked a tiled wall with her bare foot. The next day her toe 'was black and blue' and painful.

Kamila couldn't get in to see her GP, so she went to a clinic and was referred for an x-ray.

'It turns out I broke it, but I was so angry the night before that I didn't feel the pain.'

When Kamila told her GP what had happened she said, 'Well it serves you right.'

Kamila was very upset and 'nearly burst into tears right there'.

'I only kicked that wall because I thought it better to hurt myself than somebody else.'

Kamila stopped taking the drug because she didn't want to hurt anybody.

'I was worried that I wouldn't be able to stop myself from doing that one day.'

But when she stopped the medication she 'got terrible withdrawals, and ended up being more suicidal than usual'.

Kamila didn't want to go back to the GP and went to the hospital. The hospital didn't take her seriously and after they made her say she wouldn't hurt herself, sent her home. So she returned to the GP who again told her it was her fault for going off the medication.

Kamila felt ashamed. She stopped seeing the GP and has avoided the hospital ever since.

Some years later she was diagnosed with borderline personality disorder (BPD).

Kamila says there is a 'huge stigma associated with BPD'. She would like people with BPD to be seen as people, 'not bratty, manipulative, hard to treat, attention seeking [and a] waste of resources'.

'We are not monsters, just people trying our best like everyone else.'

Landen

A year after Landen started his PhD his supervisor retired. The new supervisor seemed uninterested in Landen's project and Landen became depressed.

Landen told the Royal Commission he'd been diagnosed with depression and anxiety 10 years beforehand and used medication to manage his symptoms.

'I knew that I could not increase the medication dosage any higher, or I would be sleepy all the time. So I moved my next appointment with my psychiatrist forward.'

While waiting for his appointment, Landen spoke to a university counsellor. Initially he thought she wasn't listening to him and was surprised when she suggested taking him to hospital for an assessment. He thought it would be easier to go with her than disagree.

When they arrived at the hospital the counsellor told the nurse she was worried about Landen's 'presentation'. They were told to wait. Landen said, 'She did not talk to me at all during this time.'

After three hours he was seen by an emergency department doctor who asked him to wait for a psychiatric assessment. At that point the counsellor left.

Some hours later, eager to return to university, Landen explained to the nurse he wasn't feeling suicidal and asked to leave. He reassured her he had an appointment with his private psychiatrist. The nurse told him they couldn't legally detain him.

Back at university, Landen received a call from the emergency department doctor warning him to come back immediately or she'd call the police. He found the call inappropriate and insensitive and was glad he wasn't feeling suicidal.

'I was not on a treatment order yet, so I don't think that this was legal – but I didn't know that at the time.'

Landen returned to hospital and after waiting for around eight hours someone finally assessed him.

He was asked a series of questions he thought were ridiculous, such as, 'do you hear voices of people not in the room?' He asked the doctor if they'd heard of telephones.

He was also asked if he had ever considered harming himself and told them he had in the past.

'I do not recall actually being asked if I felt in any way suicidal.'

Landen accepts he may have been too literal with his answers but was taken aback when the doctor informed him he was going to be detained based on his responses. A security guard was asked to watch him.

The next morning Landen was transferred to a mental health hospital. But when he arrived he learnt his treatment order had not been verified by a psychiatrist because no psychiatrist was on duty at the first hospital. It was not until mid-afternoon, more than 24 hours later, a 'real' psychiatrist saw Landen.

The psychiatrist agreed Landen wasn't suicidal and revoked the treatment order. But they insisted Landen remain in hospital while they changed his medication.

Landen protested, concerned about an unfamiliar doctor making changes to his medication.

'I have no idea why they considered that my own GP, psychiatrist and psychologist were not up to the task of treating me.'

The new medication had adverse consequences. Landen started having suicide ideation which worsened when they tried to bring him off the drug too quickly.

During this time Landen's parents had been away. As soon as they returned they spoke to the psychiatrist and took Landen home.

The drug withdrawal symptoms continued for some time and his psychiatrist told him he should never have been given the different drug.

Landen said he has experienced this type of neglect for most of his life, but 'not from people who are supposed to be trained healthcare professionals'.

'Hospitals should have properly qualified staff available at all times to correctly assess someone. Simply trying to give people medication (especially when they are already on medication) is not proper treatment. And if the patient happens to have a psychologist, psychiatrist or even a regular GP, then those people should be contacted immediately for advice or even called in to assist with treatment.'

Harper and Melissa

‘Each individual has their own unique way of making it in this world, we all need support in different ways so let’s help each other out as individually needed and not assume there is one set way for the masses.’

Harper is autistic and, his mum Melissa says, ‘highly intelligent beyond his current grade’. He does, however, need ‘strong support from the school ... for him to be able to participate in his education’.

Melissa feels it was a lack of this support that saw Harper suspended twice within his first two years of schooling. In kindergarten he was suspended for running away, and in year 1 he was suspended for violent behaviour.

Melissa told the Royal Commission both incidents were the result of ‘expected triggers that were known to the school and not adequately managed’.

Prior to the transition to year 1, Melissa organised a team of medical professionals that included a paediatrician, occupational therapist, psychologist and speech therapist to document support strategies for Harper.

The strategies included exposure to the new classroom and teacher during the final term of kindergarten and placing his supports – for example his blanket and tent – in the new classroom. The psychologist, occupational therapist and Melissa all offered to come to the school to support the transition ‘at no expense to the school’.

The school did not respond to this offer. The kindergarten teacher produced a document for the year 1 teacher, who then briefly observed Harper. This was the only transition.

Unsurprisingly, Harper was triggered by his new teacher. He lashed out and was suspended.

When Melissa spoke to Harper about the suspension he saw it as a positive – ‘he gets to spend more time with me.’ She worries about ‘a young child’s thinking that [sees them] repeat behaviour to have increased time off school with a parent’.

Harper’s parents were unsuccessful in appealing the suspension. They have escalated their complaint to the department and the education minister and are waiting for a response.

Melissa would like transition plans from one year to the next to be mandatory. She would also like all teachers to be comprehensively trained in working with neurodiverse children.

‘I hope in the future all education facilities and staff embrace and support neurodiversity and disabilities, which flows on to a more compassionate, inclusive and productive society as a whole ...’

Tarni

When Tarni first met with her advocate more than two years ago, her two priorities were accessing more of her own funds and going home to country.

Tarni is an Aboriginal woman. She comes from a remote community where people identify strongly with their ancestral countries and their languages, stories, songs, dances and histories. However because there are no relevant disability or health services there, she has no alternative but to live in supported accommodation in the nearest city – an eight-hour drive away – estranged from her country and family.

Tarni is in her late 40s and has an acquired brain injury, chronic liver disease and other health issues. She is on the Disability Support Pension and a public trustee manages her financial matters.

At the time Tarni met with her advocate, her weekly funds allowance was so low that she was living below the poverty line and could not afford to engage with the community in even the simplest ways, like going out for a cup of coffee. Her quality of life was suffering, yet there were funds available.

As a result of Tarni's acquired brain injury, a successful claim had been made against her superannuation fund for total and permanent disability (TPD). These funds were rolled over to her superannuation fund and could be drawn down at any time. So her funds included the Disability Support Pension, superannuation and TPD.

Yet, when her advocate went to the public trustee about this issue, they were met with 'complete resistance and lengthy delays'.

The public trustee argued that Tarni's superannuation funds should be maintained for her retirement. Her advocate argued that this is 'inherently discriminatory when it comes to Aboriginal people as their life expectancy is shorter than the rest of Australian society'. It is unlikely, they said, given Tarni's disability and serious health conditions, that she would even reach the superannuation preservation age of 60.

The advocate argued that it was also the public trustee's duty to take into consideration the 'maintaining of an adult's cultural and linguistic environment'.

The advocate said that in their experience, the public trustee 'prefers to maintain funds at all costs and there is a culture within the public trustee office which promotes this value above others'.

It took more than three months and an internal complaint by the advocate for the matter to be resolved.

Meanwhile, Tarni's need to go home was intense. Every time the advocate met with her the words 'I want to go home' were 'recurring and urgent'. At one stage, she was in danger of self-harm – she felt 'like the only way she was going to get there was "in a box"'.

In support of Tarni's application to the public trustee for funds to go home, her doctor wrote:

'Tarni has ... significant medical comorbidities that will limit her quality of life and long-term prognosis. She has recently been seen by ... a general physician who strongly agrees that getting Tarni back to country is an urgent priority ...'

It took almost two years of back and forth between the public trustee, Tarni's guardian and the NDIS – of obfuscation, negotiation, gathering information and reports and trying to find appropriate supports – before the public trustee finally allowed Tarni to access her TPD funds to go home to country for a holiday.

Her tickets were booked, she was ready to go, it was finally happening. Then the COVID-19 pandemic hit.

Only a couple of weeks before Tarni was due to fly home, her community was placed under a restricted access direction. Her trip was cancelled.

The advocate said that due to 'the public trustee's continued resistance ... and a veil of non-disclosure of information and lengthy, unreasonable delays by various government departments', they are fearful now that Tarni's words of only going home 'in a box' might come true.

Lawson and Irina

Lawson has a rare genetic syndrome, attention deficit hyperactivity disorder, autism and anxiety disorder. He also has profound information processing issues and communication and social difficulties.

Irina told the Royal Commission that Lawson had been well supported in primary school and progressed academically, but his experience of high school has been poor.

Lawson has a substantial funding package (\$45,000 per year) to support his inclusion and education, yet the school has 'consistently allocated one education assistant to nine students'.

Irina believes the school is exploiting Lawson and using his funds to support other students.

She has made many complaints and attended 'countless meetings', but the school says it is not required to use the funds for Lawson.

'I was told they could spend the funding how they saw fit.' Irina said. 'The principal even wrote that the gardens are expensive and [Lawson] should contribute to those!'

Irina felt powerless.

'Another parent with the same concerns was told she could try another school.'

Irina's says Lawson's education hasn't really progressed in high school.

'I have not received an IEP [Individual Education Plan] for [Lawson] for years. He has never been in the school magazine in six years – the school exploits their funding and shuts [students with disability] away.'

The school also failed to act when Lawson was bullied, by a teacher and a student, over a number of years.

Irina said as a result of his school experience Lawson is 'a sad, scared young man'.

'We didn't have any notion how difficult high school would be. We thought everyone would be on our son's side to give him the education [he was funded for]. We were so wrong.'

Irina hopes in future the education system will be transparent and the community is allowed to see a return on their investment in students like Lawson.

Omar

Omar is in his early 50s. He has cancer and is paraplegic. Omar wrote to the Royal Commission to share his 'horrendous experiences' at the hands of the 'care industry'.

Omar believes the biggest issue is that companies employ people 'who are unemployable elsewhere with little or no skill sets at all'.

'They get NO training at all and are sent out to people like me to administer medical ... They can't look after themselves let alone look after a patient with serious medical issues.'

Omar told us about one of his recent support workers.

'She knew absolutely nothing [not] even the basics: couldn't use washing machine, didn't know any medical procedures ... in short I had to teach her absolutely everything about everything.'

After working with Omar for about a year, the support worker quit.

'The company only ever gave her a total of only six hours work per week – the poor girl eventually waking up to being used – she left [and] found a full-time job in aged care.'

Omar believes disability support organisations should be closely monitored to make sure they fulfil their contractual obligations. He says that because of the way they hire staff, they have no 'regular manpower'. The casual staff regularly either don't turn up or are late, and there is no-one to cover the shift when this happens.

Omar moved to a new disability support organisation and the situation was the same. They sent a man who had 'no skill sets'.

'He didn't do personal care, didn't do domestics, didn't cook. He said he could drive. We went out [on] a 10 km drive – his driving left me traumatised.'

'These are not carers – this company has diminished any chance of me having any type of quality of life – nothing but continual drama.'

'But I fear for the care of others more disabled than me ... how can these untrained people be allowed to continue carrying out medical procedures?'

Omar tells us he has made 'dozens' of complaints, but they have 'fallen on deaf ears'.

Kieran and Ernie

Ernie doesn't want his son, Kieran, enrolled in school. He says Kieran doesn't need maths and science, but 'the best possible life' his parents can give him. He feels the education department is standing in the way of this.

Kieran has a rare genetic disorder which results in global development delay, vision impairment and low muscle tone. He has epileptic fits, incontinence, gastric reflux, requires a feeding tube and has no independent mobility or ability to communicate.

Ernie says that only 50 per cent of children with this disorder live longer than 10 years and very few people reach the age of 20.

When Kieran turned 12, Ernie applied for an exemption from school. 'I needed to make sure I had every aspect of [Kieran]'s health covered and the exemption would help me do this,' he said.

Also Ernie's trust in the principal and school had eroded over the years.

Four weeks after submitting the application to the director of education he was informed the exemption had been refused.

'I was extremely disappointed but did not take it any further because I felt that it would require a battle that was doomed anyway.'

Ernie registered Kieran for homeschooling, and was shocked to discover the lack of support provided to parents who homeschool.

He also discovered the curriculum failed to address the needs of many children with cognitive and physical disabilities. He says the curriculum expects parents to work towards unachievable outcomes.

'It's like asking someone with no legs to keep trying to walk – it's cruel to kids and to parents.'

Ernie decided to reapply for Kieran to be exempt from school. This time he applied directly to the education minister.

But the minister sent the application to the same director of education who had refused the first time. Ernie was never contacted and the application was again refused, the medical evidence dismissed.

'She just sent me a letter saying it was declined, making reference to declining the application last year in such a way that it read like, "I told you last year, why are you bothering me again."'

Ernie found it unbelievable there was no reference to what was best for Kieran.

Ernie has since been told to reapply for an exemption, this time to the executive director. But when he followed up on his application he was told it will take three months.

‘The education department are acting like they know what is better for my son than me or his doctors ... The law should recognise medical practitioners over bureaucrats ... This is an absolute abuse of power.’

‘I’m tired. I want to stop writing letters and emails and complaining about things that should be just common sense.’

Despite his medical conditions, Ernie describes Kieran as ‘a happy boy ... oblivious to the challenges these issues bring to his life as he has never known life to be any other way’.

Ernie says it is the barriers he and his wife encounter in trying to give Kieran ‘the best life possible’ that impact him the most. They can be ‘so overwhelmingly exhausting’ and directly affect their ability to focus solely on Kieran’s needs.

‘People that don’t live this life are making all the decisions for people that do.’

Matthew

‘I don’t have any friends. I hardly ever go out. I have a support worker who occasionally will take me to appointments, and that’s all.’

Matthew is in his 60s and lives alone in a one-bedroom apartment in the city. He has no family and told the Royal Commission he ‘feels very isolated’.

When Matthew was a child he was abused and exposed to abuse.

‘My father was physically abusing me and my mother. He was also threatening to kill my mother.’

This abuse has had lifelong consequences for Matthew.

‘It left me with a lot of emotional scars including post-traumatic stress disorder and other psychiatric disorders.’

He also has several health issues.

Matthew said he is scared to go out on his own because of his phobias. When he’s triggered his anxiety increases and he wets himself. Because of this he avoids social gatherings and stays in his house and becomes more isolated.

Matthew asked the NDIA to increase his funding to provide more social support so he could exercise and maybe go to the cinema. He also asked for technology or training programs that would improve his communication skills.

‘I feel embarrassed even saying this, but I could benefit by improving my language/spelling skills.’

However the NDIA refused. Matthew said he is being discriminated against because his disability is psychosocial and the agency refuses to accept the permanency or longevity of his disability.

‘How can they not consider my doctor’s recommendations?’ he asks. He says the abuse he received from his father ‘will never go away’.

‘I feel interrogated by NDIA. They are trying to find gaps and refuse me further supports and programs that could increase my social participation and help me improve my mental health.’

Matthew has been appealing the decision for a year and said the protracted process is causing him further trauma. His health and mental health are deteriorating.

‘NDIA staff should also be trained to develop more active listening, empathy, and communication skills when it comes to dealing with people who suffer from complex mental health issues ... so they avoid re-traumatising them.’

Matthew said being funded to attend programs and activities would open new opportunities for him to work and study as well as make friends.

‘The NDIS should take the needs of socially isolated people into greater consideration and ensure they have enough funding on their NDIS package to access the necessary services and supports so they can improve their health and wellbeing.’

Vance

A few years ago Vance was riding his bike to work when he was hit by a car. The accident left him with quadriplegia and needing 'high-level care' for several hours a day.

Despite limitations on his mobility and activities, he has been able to continue working full time due to 'substantial modifications' made to his work duties and the workplace.

Vance works as a medical professional, but he told the Royal Commission it was his accident that taught him a 'great deal about living with a disability'.

One of the things he learnt 'is the seemingly inflated cost of many of the physical and mechanical supports disabled people need'.

Vance suspects the costs are 'artificially inflated for disabled people' because the 'funders for many of the services are government and insurance agencies'.

He believes this is exploitation.

For example his 'physiotherapy sessions are \$232 for a 90-minute session with transport time on top of this. Occupational therapy is \$180 for an hour'.

In comparison, when his own patients privately access the services outside of NDIS or disability insurance providers, the cost 'appears to be much less'.

He found similar cost discrepancy when building his new home. The various disability services were helpful, but they charged 'large amounts for the services, sometimes for slow, poor quality work'.

Another concern is the cost of equipment, which seems to be 'disproportionately expensive'. A 'thin piece of material with some Velcro that is wrapped around [Vance] as a seatbelt' costs \$120. 'An exercise bike with functional electoral simulation is \$40,000 ... [and a] ramp to enter my workplace is \$3000,' Vance told us.

While he appreciates prices are higher when equipment is manufactured in small quantities, Vance believes the disproportionate price difference is wrong.

He said he has seen similar price gouging in his medical work where prices are higher if the government is paying for the service.

He would like more scrutiny and justification of the price of services and items paid for by government as opposed to privately.

Chris

Chris has a range of medical issues and disabilities that cause him significant pain and limit his vision and mobility. He lives in community housing and recently had an altercation with his neighbour, which resulted in him being arrested and spending a night in police custody.

Chris told the Royal Commission there were no witnesses to the altercation between him and his neighbour. He had gone around to the neighbour's house to try to 'clear the air', but the neighbour responded with anger. Nobody was seriously hurt, but the neighbour threatened to kill Chris.

Shocked and scared, Chris started to 'binge drink' because he 'wasn't thinking straight with the adrenaline and hypertension'. The next thing he knew, the police were there. The neighbour had accused Chris of assaulting him and the police were arresting him.

The police handcuffed Chris. He blacked out as he was being dragged out of his house, and awoke to find himself lying on the ground in a pitch-black room. He was in 'searing pain', his hand was broken and his shirt was soaked in urine.

He didn't know whose urine it was as his own pants were dry.

'At first it took me a minute or two to get my bearings,' Chris said, 'and I honestly thought I was in a horror movie situation.'

Eventually a police officer took Chris to 'a regular cell'. He left the urine-soaked shirt behind and spent the rest of the time in just his shorts.

In the new cell, Chris called for medical attention for his hand and his medications for blood pressure and diabetes, which were overdue. The police denied both requests.

Eventually, after banging on the cell glass for a while, a duty nurse came to see Chris. He was explaining his medications to the nurse when the officer interrupted, offering him a coffee.

Chris responded, 'you really wanna give me coffee, a stimulant when I am hypertensive and without my medication, are you trying to kill me?' The nurse and officer left the room at that point.

'Shortly after this,' Chris said, 'I started getting taunts over the intercom saying "you wanna coffee, you wanna coffee" ... and I could hear others giggling in the background.'

'Then the taunts got even more bizarre as they added "black lives matter", in a sinister and sadistic tone. The next day I learnt my friends had come to check on me and they are Aboriginal.'

Still having received no medical treatment or his medication, Chris was taken back to an isolation cell and spent the rest of the night in just his shorts on the ground with no blanket.

'The cell has night vision cameras so the guards would have clearly seen my distress as my body shook and began to cramp up from the cold,' Chris said.

Chris was released mid-afternoon the following day, in just his shorts, with a bag holding his possessions, including the medication they had withheld.

'I could not walk further than a few metres given my disabilities and the damage done in custody without my walking stick, I could not get a taxi with no shirt and stinking of urine, so I had to sit outside the police station for an hour waiting for my friend.'

The following morning, in distress and pain, Chris went to the hospital. He was found to have tachycardia – a very fast heart rate – and a complete fracture in his hand.

Chris is furious about the way the police treated him and that while he was 'being tortured', his attacker was 'nice and cosy at home'.

Manuel

Manuel has cerebral palsy and uses crutches and a wheelchair to move around. He also has anxiety.

In the 1970s Manuel attended a special school for children with disability.

He told the Royal Commission that soon after he started, a nurse abused him.

He recalled going to the toilet and the nurse following him.

‘She tried to grab my private parts and I tried to shield myself. She pushed me with great force and I fell backward and hit my head on the concrete floor. She held my head down as I screamed for help.’

Manuel said he lost consciousness and his next memory was being in the sickbay. Someone was stitching a wound on the back of his head.

‘I reported the incident to people there but no-one believed me.’

This was not the first time the nurse had abused Manuel.

She targeted him during lunchtimes when there were no other adults around. She would throw banana peels at him and tease him, in front of the other children, about his migrant background.

Manuel said he told his parents but they ‘did not speak English very well and did not want to antagonise the authorities’. He believes they were afraid the authorities might take him away from them.

When he was about nine the other children told him the only career pathway for him after the special school ‘was a sheltered workshop’.

But Manuel wanted to go to university.

‘Eventually I stood up for myself and ... pushed the authorities at [the special school] to let me go to a normal school.’

Some of the teachers supported Manuel, but he still had to face a panel who asked him why he wanted to leave.

His request was successful and he was allowed to transfer to the public school.

Eventually Manuel went to university and completed a master’s degree in education.

Manuel would like all education to be inclusive.

‘People with disabilities should not be segregated into special schools or institutions.’

Solomon and Troy

‘My son is traumatised, his siblings have suffered, his mother and I are traumatised. I am being treated for PTSD and depression as a result. I am exhausted and can hardly fight anymore.’

Troy wrote to the Royal Commission about the treatment of his son Solomon, a First Nations man, in supported independent living.

Solomon lived with his parents until he was 20. A series of family tragedies occurred placing an enormous burden on Troy and his wife, who were also supporting their four other children through trauma and loss. They had to relinquish care of Solomon.

‘Our whole life revolved around Solomon and his needs. The litany of checks and balances of government regulations [meant] that if his siblings worked to full capacity we would lose our housing subsidy.

‘It was a hopeless cycle. Basically we had to move him out to allow my kids to have a working life.’

Solomon moved in to group accommodation, but there have been problems with the provider.

‘My son, I reckon, has less rights than a criminal. The NDIS has resulted in a lower standard of conduct by providers and more trauma for my son and me. It is totally disgusting.’

The organisation refused to apply reasonable adjustments to safeguard Solomon, such as putting child locks on doors when travelling in the car, or locking the front door of the house. ‘They simply said [they] would not do it,’ Troy said.

Staff failed to monitor or intercede in Solomon’s excessive eating, which saw his health decline and his weight balloon.

The organisation also demanded payment for damage to property they should never have allowed Solomon near.

Troy said Solomon is now expected to pay for \$20,000 in damages, which is 75 per cent of his pension. This is despite the organisation getting around \$460,000 a year to look after him.

‘Under the old ADHC [Ageing, Disability and Home Care] model he would have never have to pay for this. As a result of the NDIS disabled people have less rights than they once had.’

Troy has shared his concerns with his local member of parliament and other agencies, but he believes ‘no-one can do anything because the laws are flawed’.

Troy would like to see changes to legislation implemented so ‘the NDIS should result in more rights [for] the disabled. Not less.’

Rayne and Milani

‘I do have serious concerns about this patient’s welfare, safety and her health.’

Shortly after Milani started working in the acquired brain injury unit she witnessed two male staff members ‘slap, hit and punch’ one of the patients, Rayne. Milani told the Royal Commission the staff were abusing Rayne because she didn’t want to eat her dinner.

Rayne has an acquired brain injury and has difficulty eating and swallowing, is non-verbal and has a physical disability.

Milani told Rayne’s husband about the abuse but he didn’t seem concerned.

She described Rayne’s husband as ‘an evil man’ who she’s scared to be left alone in the room with when she’s treating Rayne. And he left Rayne ‘neglected when he visited her’.

The second time Milani witnessed the abuse she reported it to the unit nursing manager. She told Milani she would deal with it but nothing happened.

Milani witnessed the abuse a third time and wondered if Rayne’s husband was exacting ‘some kind of revenge’ by allowing staff to ‘hit his wife and mistreat her’.

As soon as the staff members left Rayne’s room, Milani went to check on her and photographed the ‘swelling and damage to her head’.

Now Milani has evidence, she will report the abuse to police.

‘Someone needs to save and help this poor woman from ongoing abuse.’

Yakov

‘Unfortunately, news of negative experiences travels quickly in emerging CALD communities.’

Yakov told the Royal Commission he has been denied access to the NDIS four times. A middle-aged man from a culturally and linguistically diverse background, he has post-traumatic stress disorder and chronic pain resulting from military service as a young man, and other health conditions.

About four years ago, having attended a job capacity assessment and disability medical assessment and providing medical, psychologist and dietitian reports, Yakov’s application for the Disability Support Pension was approved.

Due to the comorbidity of his conditions and the impact it has on his ability to perform daily personal activities, he applied for the NDIS. But the application was rejected.

Yakov said that during the application process he was asked about his cultural background and religion.

‘What difference does it make where I come from?’ he asks. ‘We all belong to the human race.’

He feels certain that his cultural background is the reason his application was rejected.

This rejection was shocking to Yakov and triggered previous trauma. He experienced episodes of depression and anxiety, with a detrimental effect on his overall wellbeing.

‘I could not believe that I was rejected by the NDIS even though I cannot look after myself, I am struggling, really struggling. All I want is to be able to live life independently.’

Yakov does not want to burden his family by asking them to help him. He is currently undergoing a review process to receive funding for personal care and a mobility aid with the support of an advocate. He is still hopeful that the NDIS will ‘hear’ him and provide him with funding to help him ‘live an ordinary life’.

Yakov recently attended a group program run by ‘a well-known provider’. But he felt excluded by the lack of cultural awareness and culturally appropriate activities. ‘There was no-one there that looked like me, there was no-one from my community,’ he said. He did not return.

Yakov pointed out that ‘the uptake of NDIS amongst the CALD community is much lower than the mainstream community’ and he believes this is due to ‘negative encounters many in the CALD community experience’. He would like to see the NDIS offer ‘specific support’ to connect with CALD communities in a culturally appropriate way’.

He also says there should be a simplified application process for the NDIS that would benefit all participants.

Kyra

Kyra has an acquired brain injury and has been diagnosed with post-traumatic stress disorder and depression. She also lives with chronic pain and fibromyalgia.

‘This has impacted me in many ways – I live below the poverty line on the Disability Support Pension (DSP) and I cannot work full time,’ she told the Royal Commission.

Nonetheless, Kyra was managing quite well because of hydrotherapy, and support and art programs provided by her local community mental health service.

But when COVID-19 arrived, the community health service stopped all programs and face-to-face visits.

Worse still, while under stage 3 restrictions, Kyra received an email informing her she had been ‘exited’ from the service.

‘This came as a shock. I did not request this. I was not prepared for this. It has caused me quite a lot of mental distress, including a return of self-harming and suicidal thoughts ... I do not believe that any one should be exited by their mental health service, unless they request this. People should definitely not be exited during a State of Emergency.’

Kyra says the ‘language of “exiting”’ is problematic.

‘It is not uncommon that people who receive such a letter are already thinking about exiting their life, and such a letter only exacerbates such feelings.’

She also thinks her exit letter should have at least had a referral to another service.

‘I was in crisis and they assumed that I was not.’

Kyra wants to access her medical records from the service, but past experience has made her reluctant to ask.

When she was previously threatened with being exited she requested her files on multiple occasions. She was told yes, but she never received the information.

Ultimately she stopped asking because of ‘fear of retribution’.

One of Kyra’s friends was recently told she will be exited shortly. ‘She also lives with mental illness and physical disability’ and is ‘struggling like so many to just survive lockdown’.

Kyra says she is disgusted about the situation and she is concerned for others.

‘Exiting often leads to worse mental health, which from my own experience, can lead to loss of housing, work, support and family and generally awful things.’

Korbin

'I am on the autism spectrum. I'm totally alone. I haven't seen my family in over 10 years and haven't talked to them for over a year before the pandemic.'

Korbin told the Royal Commission his family have disowned him because he is autistic.

'[They] have not acknowledged my autistic traits and provided any semblance of caring.'

He asked an autism advocacy group to confirm to his family he is autistic, but it didn't make a difference.

Prior to COVID-19 Korbin was living in an apartment and had successfully applied for an NDIS package. But he had to leave his apartment because it gave him respiratory illnesses and allergies. He moved into his van thinking it was temporary.

Then COVID-19 arrived. He didn't want to be homeless, so he reached out to the NDIS.

Because there were no homeless services included in his package the support coordinator couldn't help him.

'She decided that I needed to do what's called an "unscheduled review".'

But six months later this still had not been done, meaning Korbin couldn't access any NDIS provided services.

Korbin said he became homeless as a result of COVID-19.

'I rang the homeless hotline and the state government put me in a motel.'

When that accommodation ended Korbin found a room in another motel as a private rental. He also had some support from a church community service agency.

'But the NDIS were completely useless,' he said.

An NDIS local area coordinator met with Korbin and 'passed [him] on to someone else' who was part of a complex needs unit and 'was supposed to be able to "make decisions"'. This person was meant to complete the unscheduled review.

But the person never contacted Korbin and he found out down the track it had been cancelled. He was never given any information about this.

Korbin has been able to work as an Uber driver but needs support to continue. He says it's good work for some people with disabilities if they have support.

Korbin has 'overcome many problems and challenges along the way and earned some money', but says he still needs support.

'I am truly alone in the world.'

Myla

‘It is difficult to find an appropriate NDIS service provider if you live in a small rural town.’

Myla has a rare form of dwarfism and lives in a remote, rural area. When she transitioned to the NDIS, her provider ‘was based in a small city around 50 km away’. The assistance she received initially ‘was sufficient and working reasonably well’ and her case manager was supportive.

However the case manager was soon replaced. She told the Royal Commission, ‘From this point I felt [the provider] was no longer understanding or caring for my specific needs.’

Myla explained she is supported to go shopping in her plan but the support worker ‘appears disinterested and unmotivated’. She just stands there and watches while Myla packs the shopping.

She suspects the reason the workers behave as if Myla is a burden and ‘a lower priority than their other clients’ is because of where she lives. She said it takes a half day out of their schedule to support her to shop because of the travel time. Workers are often late which affects her other appointments.

Myla was also shocked when she discovered a new support worker the provider sent to her home had ‘failed the police check’. This was the explanation the provider gave Myla when the worker didn’t show up the following week. She felt anxious she had ‘let a person into my home under the impression that they were a vetted and safe employee’.

This situation left Myla so fearful she suspended her agreement with the provider. But finding a replacement is difficult because of where she lives. COVID-19 is making ‘finding a provider even more difficult’.

‘I believe the NDIS could be a very good scheme if appropriate services were funded to cover all areas. However, it feels like this is not in place where I live, leaving me with difficulty finding the right provider to meet my needs.’

Daisy and Palin

‘He moves her arms and legs forcefully while getting dressed and undressed like he will break her bone. I’ve tried to calm him down and remind him that he can’t do like that. He says, “It’s not rough enough.”’

Palin is a support worker who wrote to the Royal Commission about the husband and primary carer of one of his clients, Daisy.

Daisy has multiple sclerosis and dementia, and Palin has been working with her at least once a week for more than a year. He’s worried about the care Daisy receives the rest of the time from both her husband and the service provider.

Palin said Daisy’s husband is ‘very rough and aggressive’ with her. For example, she needs a hoist to get on her bed and into the shower chair and wheelchair. Palin said her husband swings her so aggressively that she bumps into things and gets bruises.

When Palin told Daisy’s husband that she had broken skin, rashes or blisters, he told him ‘not to worry until it’s infected’.

Palin is also concerned about the quality of service from the service provider. Daisy spends most of her time in one position, which means she gets pressure sores. These need proper cleaning, padding and ointments. But some support workers don’t do this often enough. If Daisy has had bowel movements during the day, they just put a clean continence aid on without cleaning.

‘I just came out of her house, when I got in her room it was smelling very bad and I could tell why,’ Palin told us.

Palin said he has reported this to the service provider a number of times to no avail. He has also raised the issue with Daisy’s husband, who said he ‘couldn’t care less’ about Daisy’s wellbeing.

‘He yells at her and says it’s her fault for being in the wheelchair, it’s her fault that the nappies are not put on properly and the bedsheets are soiled, which gives extra work to him.’

Palin would like to see aged care and disability care workers do emotional intelligence tests before they are appointed, especially those working in home care.

‘I hope all the people regardless of their physical or mental conditions receive the treatment they deserve.’

Vica

‘Funny how lots of people can work from home when it suits but total inflexibility and exclusions apply to the person with a disability when they are trying to enter the workforce.’

Vica uses a wheelchair and recently applied for a position as a local area coordinator for an NDIS provider.

She said she applied for the position not just to utilise her ‘highly appropriate skills and experience’ but because the selection criteria specifically stated ‘lived experience’ of disability.

After Vica applied she received a phone call and was asked where she wanted to work. She told them her preference was to work in the main town in the region.

They told her the position was based in a smaller town, a one-hour commute from the main town. They refused to negotiate and told her if she didn’t want to work where the position was based she should withdraw her application.

‘This in itself shows total lack of understanding of how a person might manage their disability,’ Vica said

Vica decided to visit the office and found it was unsuitable for a wheelchair user.

Entry to the office was via a small elevator, which is confining and can be frightening for a wheelchair user. The buzzer in the reception area was inaccessible to a person in a wheelchair, and carpeted areas throughout the office would have made self-propelling a wheelchair extremely difficult. She wouldn’t have been able to work there.

When Vica pointed out the issues, the provider told her they have a three-year contract and would not be moving or modifying the office in that time.

Vica complained to the relevant minister and received ‘a spurious inaccurate reply’.

‘How on earth is the person with a disability going to increase their representation in the workforce when these inflexible, non-negotiable, archaic recruitment practices remain?’

‘Inclusion doesn’t just mean rhetoric in fancy documents.’

Zeke and Helena

Zeke is a teenager with autism. Helena, his mum, wrote to the Royal Commission about the neglect and abuse he has experienced at school, leaving him with diagnosed anxiety and post-traumatic stress disorder.

It began when Zeke was in year 5 at the local primary school. Helena found out that Zeke was frequently made to sit in an office for hours on end, 'doing nothing'.

Then there was an incident where a teacher attacked Zeke with a chair. The teacher told the young boy she would get her husband – a policeman – onto him. Zeke was so terrified 'he walked home over 2 highways, scared [of] coming the quickest way home'.

When Zeke started at high school, all the parents with kids entering the special class 'were sat down with police youth officer and pressured into signing papers giving permission for teachers to restrain kids'. Helena refused to sign.

The following week, Helena said, the main teacher 'king-hit my son, bent his wrists back, stomped on his bag'. Zeke has been in counselling since this happened, about five years ago.

'He only just got use of his wrists back.'

The abuse was reported to the police, but they said Zeke would not be a good witness because of his disability. Meanwhile the abusive teacher was still working at the school, so Helena began homeschooling Zeke.

Recently, says Helena, she was 'lured' back into sending Zeke to mainstream schooling. But the school 'taunted' Zeke, 'trying to trigger his autism [to] get funding'.

This 'taunting' led to Zeke having an episode, which resulted in the police tasering him, handcuffing him for hours and taking him to hospital for mental assessment.

Helena says Zeke now has extreme anxiety as a result of this abuse. Even as a teenager he continues to wet the bed and 'won't sleep cause once he does he relives the abuse'. He has put on weight, won't leave the room and is missing out on an education, 'all because no-one will accept he is a victim'.

North, Keegan and Tilly

Tilly is a support worker in several group homes. She is concerned about two of her clients – North and Keegan – who she believes are being financially abused by their families.

North's debit card is kept by a member of his family. Tilly says this person makes 'regular transactions including food, alcohol and personal items for themselves'. North has no access to his own money and isn't aware of the transactions made by the family member. Tilly is concerned because this 'appears to be happening for a very long time'.

In Keegan's case, Tilly told the Royal Commission, 'the family member had spent board and lodging costs [required] to pay the organisation'. This 'resulted in considerable debt' which Keegan 'has to slowly pay back to the organisation'. Tilly suspects the organisation is not telling Keegan 'the full extent of the financial abuse' because it wants to 'try and maintain the connection with family'.

Tilly has spoken with the organisation about her concerns a number of times, but it has not reported the matter to the bank or any other authority. Management told her they are 'trying to work directly with the family to resolve the issues' and 'reporting is the last resort for them'.

This 'sits uncomfortably' with Tilly. She believes people with disability 'should have full access and participation to decision-making pertaining to their finances'.

Robbie

Robbie, aged 10, is autistic. He is lonely, distressed and isolated.

'My son is not allowed on excursions, school camps, school awards, and was not included in the school yearbook,' Robbie's mum told the Royal Commission.

Robbie attends a large mainstream public primary school and he's the only 'non-mainstream' student.

At school, Robbie is separated from other students by a cubicle partition in the corner of an activity area used by students from other classes.

'The children and parents call him "the boy in the box",' his mum said.

A couple of years ago, the school suspended Robbie several times and then excluded him for an entire term. He hasn't been in a classroom with other children since. Now, in the reduced hours he attends school, he has a one-on-one teacher inside 'the box'.

Robbie is very unhappy about his school experience and is refusing to attend. His mum said he hates not being in a classroom with other children. He feels they've forgotten him and moved on. They have nothing in common with him, as they are all in classes and he isn't. He feels a terrible separation as the only 'non-mainstream' child at the entire school and is very distressed to be known as 'the boy in the box'.

'Schools are needed for children such as my son. Deemed too high needs for "mainstream", yet he is the lone "non-mainstream" child in his entire school, and not eligible for any other schooling. IQ over 70 means he is prohibited from attending a special unit.'

She said in country areas 'these children end up in the scrap heap with no education ... even the basics'.

She would like to see a school in every region to cater for every 'non-mainstream' child with an IQ over 70, so they can attend full time like mainstream children are allowed to.

'To not be segregated apart from other children in schools. To be included in activities. To not be excluded. To receive support from school staff in relation to their disability and gain an education just like mainstream children have. To be allowed on school camp, excursions, awards and the school yearbook.'

Grady

Grady is in his 50s and lives in community housing. He has a range of disabilities including physical and psychosocial disabilities.

Grady told the Royal Commission that during the pandemic he considered himself at increased risk of COVID-19 because of his disabilities and illnesses.

‘I followed the advice of the authorities and self-isolated,’ he said.

He didn’t know how long he would need to be in isolation, so he ‘purchased additional food and medication’. But this left him unable to pay his rent.

Soon after falling behind in the rent he received a letter from his community housing provider that he ‘had breached the Residential Tenancy Agreement’.

Grady said he was shocked and disappointed by this letter. He expected the community housing provider to behave with more consideration during the pandemic.

‘[The provider] ignored the commitment by government, and even its own policies to protect the accommodation of vulnerable people during this period of high risk.’

The threat of homelessness exacerbated Grady’s anxiety and his heart condition, ‘requiring additional medication and visits to [the] doctor’.

His doctor was very supportive and Grady contacted a disability advocate and Legal Aid.

‘With representation, I was able to avoid eviction.’

In Grady’s opinion ‘the community housing provider breached their duty of care’ and put his physical and mental health at risk of harm. Unfortunately Grady’s problems with the housing provider have continued.

‘I feel that they continue to ignore their duty of care to me by not meeting their responsibilities to keep me safe, comfortable and provide me with well-managed and maintained housing as required by law.’

Grady’s advocate continues to help him deal with the housing provider. In his opinion external measures are needed ‘to keep an eye on the behaviour of this community housing provider’.

Erin

Erin is a disability support worker. She told the Royal Commission that when she started with her current organisation more than two years ago, she witnessed other staff mistreat and abuse clients.

Erin used the organisation's complaints and incidents procedure to address the issues. After some months – during which time the behaviours continued – the staff members who perpetrated the abuse were made redundant.

But the problem has not really been addressed, Erin said, and the two staff members in question are now working for another disability support service in the same town.

'I have great fears that these people may not have changed their behaviour. One of these staff members is now doing community access with a customer I support and they come to the residence where customers they previously mistreated live ... I have to be careful as I live in a small regional town where everyone knows each other, so I have been too scared to address this in any other way than to inform the Commission.'

She noted that her customer, who goes on community access outings with one of these people, often returns in an agitated state. 'I am concerned what is being said and how she is treated whilst out with this staff member,' Erin said.

Erin told us she thinks disability support organisations should check with previous employers if there have been complaints or incidents implicating a staff member they are considering for a job.

'We need people to not be scared of standing up for themselves and saying if they feel mistreated or for others to not be scared to speak up for those who cannot do so ... I hope that all forms of abuse and violence towards anyone anywhere will be exposed and offenders made accountable and that our society moves towards being more fair and just.'

Yusef and Tori

Yusef is autistic. About 10 years ago he started attending a special school for children with autism. His mother Tori told the Royal Commission the school's model fails its students.

Tori said that Yusef would often come home from school with bruising and bite marks.

'I became increasingly concerned that he was being seriously injured both physically and mentally. On a number of occasions when I noticed marks on [Yusef], I called another parent of a child in the same class ... Her child would tell her the same as my child told me, that another specific child had inflicted the injury in a malice way.'

Tori approached the school with this information, but said the staff 'became extremely defensive' and denied any violence. They implied that Tori was 'a liar and manipulator'.

Tori said that in the two years Yusef attended the school, he 'received very little integration or inclusion in the mainstream school, despite the plan for him to transition to the mainstream school into year 1'.

For example, once a week Yusef and another student would go to the mainstream school. But they sat in a separate classroom, with a teacher and an aide, watching movies and the teacher's wedding videos.

There was no meaningful integration or education. Any 'inclusion' in mainstream activities was always as a segregated group with the other children with autism.

'The [school's] model is to keep the children segregated and isolated and promote themselves as the leaders in autism. Further ... while my son was at [the special school] he was provided with government funding in excess of \$40K per year, but when he transitioned to mainstream schooling he was only provided with about \$12K per year.'

Tori managed to find a primary school 'whose staff and ideology aligned with our own'.

'[Yusef] had a wonderful primary school experience at [this mainstream school]. Why, when they gave Yusef more than [the special school] ever could, are they disadvantaged in the funding model?'

Cai

Cai is from South East Asia. She came to Australia with her husband and young son in the mid-2000s. She has a psychosocial disability.

Cai told the Royal Commission the relationship between her and her husband was volatile from the beginning and that he was often violent and abusive towards her.

She contacted the police on many occasions but she was always met with indifference. 'The police think I am crazy,' she said, 'so they do nothing.'

Socially isolated and living in a community with different cultural norms and no connection to formal support networks, Cai endured this abuse for many years.

Cai recalled one instance when she feared for her life. She called the police to protect her and they issued an Apprehended Violence Order (AVO) against her husband. But Cai said the AVO did not stop her husband coming to her home to terrorise her.

During this time, her husband also tried to isolate Cai from her close-knit cultural community. He would come to her place at night, screaming outside her house – hoping to also wake up the neighbours. He would scream insults and claims of infidelity for all to hear.

Cai's isolation was exacerbated by her low-level English literacy skills. Her husband prevented her from enrolling in English classes. He also refused to let her drive.

After years of abuse, Cai's mental health deteriorated. She felt like her life was falling apart and feared for her life.

Finally, sick of the 'humiliating and demeaning' abuse, she sought help from an advocate to get a divorce. It was time to start living life on her own terms.

But Cai's husband had other ideas. He began stalking her, arriving at her home unannounced, entering without permission and refusing to leave.

One terrible night, Cai felt pushed to her limit. When her ex-husband barged into her home and threatened her life, she tried to defend herself and reacted with violence.

Cai told us this cost her her children, who were taken into care. She has now been granted visitation rights on a fortnightly basis and is working hard to get them back.

'I love my kids.'

Cai understands the priority is to make her home safe so her children can return. Her children have a caseworker to support their needs, but Cai feels she too would greatly benefit from a dedicated caseworker to help her develop the skills she needs to have her children living safely back in her home.

She believes that with a dedicated caseworker who would focus on her strengths, support her to learn English, learn to drive and achieve other goals, she could gain confidence to make other changes in her life.

‘It is just as important for the parents to be supported to develop skills when it comes to keeping families together,’ Cai told us.

Cai also said culturally competent programs should be developed for different community groups to improve mental health literacy. She feels there is negative stereotyping in some communities that stops family members seeking support for the person experiencing mental health issues.

And if a person is socially and geographically isolated from family, as Cai has been, there is no support at all.

Cai also thinks victims of family violence should have support people – such as mental health workers or disability advocates – with them when attending interviews with police or child protection staff. She wants police to make referrals to appropriate specialist agencies that are able to provide intervention and other services to help victims and their family members.

Landon and Paloma

Landon is in his 30s. His mum, Paloma, says he ‘experiences behaviour issues and suicide issues’.

Paloma told the Royal Commission that Landon’s health has declined over the years because health professionals have forced excessive medications on him. Some have created psychosis, others malnutrition.

‘He was medicated with antipsychotics and labelled [with] schizoaffective disorder. From there his mental health also became physical health issues.’

Paloma says the prescribing doctors acknowledged this. But even though Paloma reported the issues to the hospital mental health unit, ‘they continued to increase this medication and placed numerous Community Treatment Orders on [Landon], forcing him into psychotic states 15 years later [due to] the continued abuse of medication’.

Recently, Paloma managed to get the amount of medication Landon is prescribed reduced and for a while he seemed to improve, ‘with less voices, less confusion and less weight gain’.

However, it didn’t last. The hospital readmitted Landon to hospital and resumed medication at high doses.

‘[This] has again bought on psychotic voices and confusion and weight gain, and I am unable to get him proper help due to the serious effects of these medications ... I find this is an abusive treatment and violating his abilities [leading] to an unhealthy mental and physical state.’

Paloma has reported her concerns ‘to many authorities’ – state, federal and private – but says none has intervened or offered assistance.

‘I need this hospital and support system to leave him alone, take him off their system, so we can seek help through another source as we have done in the past.’

Paloma would like health professionals to give more consideration to available treatment options for people with psychosocial disability and stop automatic prescribing of multiple, sometimes uncomplimentary, medications. She would like doctors to stop disregarding people’s wishes for their own treatment and ‘stop the abuse of these dangerous medications’.

Thomas and Hope

Hope told the Royal Commission her son, Thomas, is a victim of domestic violence and 'is not safe in his own home'.

Thomas has been attacked in his own bedroom, assaulted numerous times and king-hit on at least two occasions. His attacker is Vince, a co-resident in supported accommodation. Hope believes Thomas isn't his only victim.

Thomas is in his mid-20s and is the youngest resident in his house. He is non-verbal and is completely dependent on others to care for him and keep him safe from harm.

As with most young people, says Hope, Thomas had been looking forward to leaving home to gain some autonomy for himself. He settled in happily, appearing 'proud of his place in his new home'. Staff managed his anxiety levels well and his behaviours were improving.

The first attack happened a week after Thomas moved in to his new home. At the time Hope thought Vince may have been jealous of the 'new boy' and wasn't too concerned as Thomas seemed to recover quickly. But the assaults continued.

During one of these assaults Vince ran into Thomas's bedroom and king-hit him. Thomas was hospitalised and the incident was reported to the police. But the police advised they were unable to do anything because Vince would not understand the consequences of his actions.

Hope believes this violates Thomas's human right to live free from fear of being physically assaulted.

Hope would like Vince to be relocated but management says this would make Vince homeless. When she tries to understand why this would be the case, they say they can't fully brief her on the situation because of privacy and confidentiality concerns.

Instead, management rosters additional staff to work when they anticipate Thomas is most at risk from Vince, and Vince is isolated at the back of the house. Thomas can no longer freely move around his home.

The situation became even more distressing when Thomas recently experienced his first seizure. The hospital neurologist believed it was the result of 'tiredness, stress and anxiety'. Hope is certain this stress and anxiety is about Vince.

The situation remains unresolved and Hope has written to the ombudsman, state and federal ministers and peak organisations in her quest to keep Thomas safe.

'As a parent of a disabled child, we live with a constant fear of how he's being treated by others. We have to trust our community and its leaders that [Thomas] will be treated with the respect and dignity he is entitled to, and that this basic human right is not ignored because of his disability. The lack of an adequate response from [the home] has been absolutely heartbreaking and demoralising. The fact that [Thomas] is not safe, even in his own bedroom, is horrifying.'

Heather

Heather has a psychosocial disability. In the mid-2010s she spent almost a year as an involuntary treatment patient in an eating disorders clinic. She told the Royal Commission medical staff treated her ‘without dignity or respect’ and she believes the abuse and neglect was systemic.

One time when she was in intensive care, a nurse refused to speak to her other than to say that her bed ‘would be better used by someone with “real health issues”’.

When Heather was transferred to the clinic she felt intimidated by the number of people present during her first treatment meeting. She was confused and unsure what it meant to be an involuntary treatment patient. The head doctor asked if she realised she was unwell. Heather said she wasn’t sure. Then in front of more than 10 medical professionals, the doctor yelled, ‘You look disgusting. Haven’t you looked in a mirror? You look like a prisoner of war.’

At the clinic there was ‘a predatory male night shift nurse’ who would routinely come into her room and give her ‘bear hugs’ before she went to sleep. The nurse would lean over her and hug her for minutes at a time. She was on her back, her arms pinned under the blankets as he pressed against her.

The eating disorder patients spent their day all together in a small lounge room. One time, the senior nurse stormed in and proceeded to shout at them telling each patient what she thought of them. She told one girl, ‘you need to stop throwing up all the time’ and another ‘and you need to stop exercising in your room’. She eventually got to Heather and told her she ‘was the rudest girl she had ever met in her life’. She finished her spray saying Heather needed to pull herself together and that she was ‘a nasty, mean and horrible person’. Then she slammed the door and stormed off.

It was difficult for everyone to have details of their illnesses shared around.

Not long after this one of the inpatients died. Heather says they were all quite close ‘given [they] had to spend so long together confined to a single room’. But the clinic didn’t offer any counselling. Instead the nurses used the patient’s death as a cautionary tale, telling them if they ‘didn’t decide to get better’ it would happen to them.

Heather acknowledges the clinic played an important role in her recovery, but she believes the practice of re-feeding was problematic. Staff fed patients through a tube against their will and were ‘not given ANY mental health support during their treatment’.

‘As a patient who was there for two four-month stays, I was returned to a healthy weight, but had no psychological help during this time. It was very difficult to be force fed back to a healthy weight but have no treatment for what was going on ... inside. Especially in the context of being confined to a bed and unable to go outside or go to the toilet by myself. The terrible treatment of patients by staff made the entire process much more difficult.’

Heather says anorexia nervosa has the highest death rate of all psychosocial illnesses and is a disability. She would like nurses better trained 'and have compulsory ongoing training' when they are working with patients with a disability. She also believes mental health professionals should be employed at all eating disorder clinics.

'Just because people may have disabilities it doesn't make them any less human or deserving of kindness, dignity and respect.'

Alex

‘Change the goal of the DSP from forcing disabled people to work to survive, to actually letting us exist. Cut it out with the punishments, the “mutual obligations” bullshit, the tightening criteria noose.’

Alex is autistic and has attention deficit hyperactive disorder, obsessive-compulsive disorder and genetic issues.

‘My mental and physical functions are deeply diminished, both in ability and how much energy I have to use those abilities,’ he said.

Alex told the Royal Commission they would like to be left to get on with their life.

‘I don’t need a maid, a “care plan”, or a monthly review to see if I’m still autistic.’

Alex believes there needs to be a complete review of the Disability Support Pension (DSP) and how it is administered. They say the biggest obstacle to improving their wellbeing is government policy.

The DSP does not allow Alex to meet their basic needs without working, and often they can’t work, Alex said. And all the training courses don’t help.

‘There’s no coping strategy or financial literacy class that turns \$5 into \$10, no amount of elbow grease and “putting my head down” that will remove my lifelong conditions ... When a condition is permanent it means permanent. It doesn’t mean check every fortnight to see if it’s magically wandered away.’

It also doesn’t go away if you ‘marry someone successful’, Alex said. Their partner’s success means their DSP is cut back.

‘I become entirely reliant on my partner’s income.’

Alex told the Royal Commission this creates a ‘breeding ground for abuse’. Their partner ‘feels stressed, agitated and over time resentful because they have to support this person that’s not bringing any money in’.

Alex described the impact of needing to ask their partner for money.

‘Self-esteem plummets – how do you be kind to yourself, convince yourself that you’re not dead weight when every financial move reminds you that you are?’

Alex would like the DSP to be permanent and ‘all the arbitrary and disingenuous obstacles ... added year after year’ removed. They would also like to see the amount ‘mirror a livable income’.

Alex believes the only way things will change is ‘if the government acknowledges ... that poverty is not caused by a fault of character’.

Liana

‘We ALL have something to offer – and sometimes our real strength lies in our perceived weakness ... and NONE of us is immune to the challenge of disability at some stage in our lives.’

Liana is blind. She lives independently with her guide dog, Yuki.

Liana told the Royal Commission she experienced significant workplace discrimination and abuse in her last job, in the public sector. She has not been able to work for three years and it has taken her this long ‘to feel safe enough to speak out’.

It began when she was moved to a new section and a new manager, with no consultation. Liana said the move was ‘entirely unrelated to [her] professional skills, involved no such consideration’.

The new section was ‘on the top level, accessible only by steep stairs’ which Liana and Yuki found difficult to navigate.

The new manager was unable to provide Liana with meaningful work. For example, she instructed Liana to copy the organisation’s draft strategic plan from yellow post-it notes stuck on the walls of the manager’s office. Having only ‘2 per cent sight’, this took her several weeks. ‘Senior staff were aware of this and commented on its inappropriateness but did nothing,’ Liana said.

The manager repeatedly mistreated Yuki, adding to Liana’s distress. The new office building was infested with possums and on one occasion the manager encouraged Yuki to eat possum poo. When Yuki vomited, the manager made Liana clean it up. The manager would complain when Liana took Yuki to the park for a toilet break twice a day.

One day, Liana and Yuki were almost hit by a car on the way to work. Traumatized, Liana rang the only staff member whose number she could remember to tell her she would not be in. Liana said that the next day ‘instead of empathy, I was rebuked ... for not contacting my manager directly’. Once the manager finished berating her, she added ‘she hadn’t even noticed [Liana] had been absent from work’.

Liana complained to HR and suggested options within the department that would be a better skill and safety fit, but was told it was ‘too difficult’ to move her.

Eventually ‘with failing sight and associated health conditions’ exacerbated by the ‘callous and negligent treatment,’ Liana took leave. She said her confidence and reputation were ‘destroyed by one manager’.

Liana would like the department and the manager to be exposed and held accountable for ‘unsafe, cruel workplaces’

Zillah

Zillah, early 40s, is autistic and has schizoaffective disorder.

'I've also had eating disorders – anorexia, bulimia, but they all relate back to what happened in my childhood and teens, which is trauma,' she told the Royal Commission.

At 16, Zillah was living on the streets.

'So much abuse – psychological, mental and sexual abuse I experienced in my teens – I thought was normal. And when I ended up in the psychiatric ward the first time, none of that was spoken about. They just saw me going blah, and they diagnosed me with schizophrenia without questioning the last 20 years.'

Since then, Zillah has been in and out of psychiatric wards and mental health units.

'The psychiatric wards – they're violent, and they're using violence against people who have been traumatised by violence.'

A few years ago, Zillah's support dog died.

'My dog was my only link to love and support ... So when he died my whole world collapsed.'

Zillah's mental health deteriorated and a friend took her to emergency.

'I remember being taken to a small room off the triage – like an interview room or something – and told to wait there ... I don't know how long I was in there for. It was a long time. No-one came to talk to me or anything.'

Eventually a nurse told Zillah she was going to be admitted to the psychiatric unit.

Terrified, all Zillah wanted to do was escape. She 'made a run for it' and was thrown to the floor by a security guard.

'At this point, I was having a sensory overload episode – of touch, the noise of the emergency department, the movement of people, the smells, everything. I started to fight back and scream.'

Three additional security guards jumped on her and held her down.

'That added to my sensory overload ... And I wanted to get these men off me because it reminded me also of sexual abuse that happened in my teens.'

Zillah struggled to breathe and screamed at them to get off her chest.

The last thing she remembered before she lost consciousness was being trolleyed out of emergency. At some point between the emergency and the psychiatric unit she wet herself.

Zillah woke up in solitary confinement.

'I'd not been in solitary confinement for a long time, so it was an absolutely shock.'

There was a plastic mattress on the floor and a drainpipe in the middle. She could hear male patients screaming outside her door.

'I was absolutely petrified. Still no-one had talked to me or anything.'

Zillah doesn't know how much time passed while she was in that room. At some point somebody came in and told her 'she could go now'.

They led her back to the general ward where they left her, still in her soiled clothes.

Zillah made a complaint, but it went nowhere.

A private psychologist is helping Zillah deal with her complex trauma.

'There was only one trajectory for me in the public mental health system, and that was death.'

Zillah believes public psychiatric units need to change.

At the moment, people using drugs, people with depression, people with psychosis, people from different cultural backgrounds, '30 divergent strangers' are all 'thrown in the same space to live together'.

'I find that highly inappropriate, especially people with complex trauma who are terrified of other people,' she said. 'I feel that we need to have separate spaces ... because they're very, very, very different realities.'

'They need access to open fresh air, trees, nature, arts, activities that give people a feeling of healing and storytelling. We need to have spiritual spaces where people can talk to God or whatever their belief is.'

Rajan

‘Autistic people very much receive atrocious treatment at the hands of police. We are profiled massively.’

Rajan is a hospitality worker in his 20s. He identifies as non-binary but uses male pronouns. He is autistic and has attention deficit hyperactivity disorder (ADHD). A couple of years ago, a police officer arrested him while he was out shopping.

‘And I was carrying a pouch of Xanax ... I panicked and yeah, so withheld it,’ Rajan told the Royal Commission. ‘He like tackled me, pinned me to the ground ... then threw me in the back of the paddy wagon.’

Rajan feels police ‘prey’ on and ‘exploit’ people with disability.

‘I was not under the influence of anything and that was the grounds for the stop and search.’

He said police lied to him about his rights before charging him with drug trafficking.

‘The evidence was taken wrongfully ... I was under duress.’

Legal Aid promised to provide ‘the same support and resources as a paid lawyer’.

‘That was absolutely a lie. The system is set up to see neurodivergent people thrown under the bus. The first meeting with the Legal Aid barrister, he basically said, yeah, you’re guaranteed to go to prison.’

The barrister didn’t turn up to the initial hearing.

‘Like the whole thing was just a joke. The lack of proper communication made the situation so much worse,’ Rajan said.

‘The law firm, I don’t think they had any intention to help me. Their intention was to let me be chewed up by the system. There’s one system for the rich and one system for the poor. Most people with disabilities are more inclined to be poor.’

At court, the police officer acknowledged Rajan’s disability but still felt the charge ‘was justified’.

‘He admitted that he didn’t have an awareness or understanding of autism or ADHD or the symptoms, but that he could tell I was in a compromised mental state.’

‘[The officer] claimed he didn’t have his police camera on because it hadn’t been charged,’ Rajan said. ‘Obviously the system favours the police and lets them get away with an awful lot, especially when it comes to autistic people.’

Rajan didn't go to prison.

'But I still have a criminal record,' he said.

He blames 'disability discrimination by the court system', which is not 'inclusive or considerate of peoples' needs'.

'It is essentially designed to punish you and to make your life hard.'

Recently, Rajan forgot his transport card. He got off the train and let an officer know.

'I got all my belongings searched and, like, pat down and everything. Obviously for my ADHD I take dexamphetamine ... He believed, like, that I was under the influence of substances ... 100 per cent, the police officers profile and make assumptions. That basically gives them free rein to do what they like without any respect for our rights because we don't present normally.'

Rajan plans to do 'a lot more disability advocacy', particularly in the hospitality industry.

'RSA [responsible service of alcohol] laws are just a free licence to discriminate. I don't know a single disabled person who hasn't faced some sort of discrimination ... refused entry into a venue because they assume you're drunk.'

He also wants to open a bar that is 'run by and for autistic people'.

'To create opportunities for young autistic people ... To get those skills and that training from someone that has gone through the hardship of being discriminated against, like, left, right and centre.'

Nicolo

Nicolo, late 40s, has paraplegia as the result of an accident a few years ago.

Prior to the accident, Nicolo worked outdoors and was building himself a home. Following the accident, he needed to find a new job and modify the house he was in the process of building.

Nicolo was offered a job in sales and was really excited.

The building did not have an accessible bathroom so Nicolo secured funding to install one at no cost to the business or the owner of the property.

A week later, Nicolo received an email rescinding the job offer. The owner of the building didn't want any structural modifications made to the building.

'It's definitely discrimination. Every workplace should have a disability access bathroom for either an employee or a member of the public.'

Nicolo started to engage with the NDIS to see if they could assist with the cost of modifying the home he was building. He needed to widen some hallways and install sliding doors.

But he found the cost of getting occupational therapists and engineers to write reports and an NDIS approved drafts person to redo the plans, added significant costs to the build and chewed up the funding.

It also meant a delay of 12-18 months to finish the home.

'The paperwork and the amount of hoops you have to jump through to get some sort of assistance with a few extra things, to me, it just was not worth it ... We've been living in a shed long enough.'

Nicolo also told the Royal Commission about a particular incident that took place soon after his accident.

'It was fairly short and fast recovery,' he told the Royal Commission, and he was keen to 'venture out a bit' in his wheelchair.

Nicolo booked an accessible ticket to attend a concert with his son.

He arrived at the venue and discovered his accessible ticket was halfway down the grandstand.

'In no way was that seat accessible for anyone in a wheelchair, unless you're able to stand up and go down steps.'

The usher 'had a bit of a chuckle' and told Nicolo he needed to contact the ticketing agent. But there was no ticketing agent on site. Nicolo spoke to 'two or three chains of command'. They all suggested he leave and speak to someone during office hours.

'My words were, "I'm in here now. I've paid my money and I'm not going to go outside, because this is something that is a once in a lifetime opportunity."'

They advised him to wait in the disabled area in case there was a no-show.

'Fortunately for me, someone wasn't able to attend and I was able to stay in there with my son.'

Nicolo has limited feeling below the waist, and although he monitors what he eats and drinks, has the occasional toileting accident. During the concert he needed to go to the bathroom to clean himself up.

'Unfortunately, a bit of a mess to sort out, but it's a lockable accessible room. Massive. It was great.'

But while he was in there, a woman jimmied the lock on the door.

'I'm halfway through doing my business and cleaning up, and the door gets swung wide open. It's right next to the bar area so there's a heap of people able to see.'

Later on, Nicolo needed to go to the bathroom again, but able-bodied people were using them. Nicolo was desperate – he has a limited time to get to the bathroom before he has an accident.

A man saw his distress and knocked on the toilet door to kick out a couple he had seen go in. They were in their having sex.

There was a heated exchange.

'One thing that struck in my mind was the young lady coming over to me and leaning right over and looking at me in the eye and saying, "Look, listen, let's not ruin a good night."'

Faune and Kirsteen

Faune is in her last years of high school. She was diagnosed with autism when she was six. She is intellectually gifted, but this has gone largely unrecognised in the many schools she has attended.

Kirsteen, her mum, told the Royal Commission that Faune's experience across different school systems reflects the lack of equitable access to education that people with disability face.

'I know every single parent who has a child in education with disability is facing exactly the same journey and it's ruining – ruining us ... It's so soul destroying. I have never felt this destroyed as I have in the last couple of years.'

For her first years of education, Faune had a teacher who had just completed autism training.

'So she actually made her classroom autism friendly, which was brilliant,' Kirsteen recalled. 'She kept the room very calm, the lighting very calm, and things went quite well there.'

The school didn't progress beyond the early years, so Faune moved to a small public school. It did not go so well.

'I got called constantly almost every day to come and get [Faune] because she was hiding under tables and crying. They would say she wouldn't communicate with the teachers, but she actually wasn't able to communicate with the teachers ... There was no assistance offered from any professionals, allied health, nothing.'

Kirsteen enrolled Faune at a private school next. The principal told her Faune would be welcome, but it wasn't long before 'it all fell over'.

'They wouldn't do any reasonable adjustments. Their idea was that they would welcome [Faune] with her disability as long as she fitted into how they already operated their school.'

The situation deteriorated as Faune became a target of bullying.

On the advice of a psychologist, Faune withdrew from the school and Kirsteen homeschooled her.

This happened again during high school. Several times, homeschooling and distance education became necessary interludes to the bullying by students and lack of understanding and care from teachers.

At one school, teaching staff excluded Faune from activities.

'We had problems with her attempting swimming, sporting events, cultural programs, everything. They would either block her and say she needed to stay back on campus, or they'd take her with a really clear plan that I had helped develop with them and then totally ignore the plan,' Kirsteen said.

At another school there was an inclusion unit and a 'really good learning plan', but Faune's teachers 'just flatly refused' to make reasonable adjustments to her work or 'to change anything they were doing, any of their processes at all'.

During one period, Faune became 'really distressed and unregulated all the time'.

'She started pulling her hair out, ripping her nails down to the bed til they would bleed. And other things were starting to happen. She was in a really bad way.'

To prepare for her last years of school, Faune enrolled in a TAFE college. She thought she was on track to study for her higher school certificate, but the head of her unit had enrolled her in a different program for people with disability.

This led the principal to think Faune needed to be in a 'special class for people like her'.

'He was allowed to say that about me because I'm disabled so I don't matter,' Faune said. '[That] I'm not smart, I'm not going to benefit society in any way. So just shove her over there and let her put labels on jars.'

Faune is not sure if she'll give school another try.

'I just feel like it's – that the teachers don't want to teach me ... It's almost like they're setting me up to fail ... And I think that at this point – like, why go and try and get an education from people who I believe just don't like me? There's no point.'

Edwin

Edwin was diagnosed with schizophrenia in his 20s while he was at university. He disagrees with the diagnosis and believes his mental health problems are related to infections.

‘My entire body was infected inside and out and ... I started getting pain that I couldn’t handle. Like, I was totally disabled.’

Edwin said doctors don’t listen to him.

‘There is no-one who sits down, listens to me and helps me to recover in 30 years. Not one person. They treat me like a mentally ill fool.’

About a decade ago, Edwin was hospitalised for a few weeks.

‘And in that period in that psych ward they drugged me ... to such an extent that I came out totally delusional.’

He feels the mental health system has experimented on him while ‘manufacturing [his] mental illness’.

‘They basically created my situation then they victim blamed me ... They were drugging me with substances. When you take it, you become aggressive and ... you act out – out of control. They’ve injected substances into me and drug me to shut me up. And there’s nothing I can do about it coz I’m stuck in the system.’

Recently, with a legal advocate, Edwin managed to put a stop to some of his treatments. He now feels ‘free from all of this oppression’.

Wanda, Brook and Stacy

‘It takes one individual to set a student up for success ... but it also takes one person in a position of leadership or one bad teacher to ruin those educational opportunities.’

Stacy and her three children are autistic.

‘My son started primary school knowing he was autistic. [Brook] was diagnosed at 10 and [Wanda] was diagnosed at eight.’

Stacy’s daughter Brook, who’s now at university, supported her mother at the Royal Commission.

‘We have a really wide range of experiences with the education system,’ said Brook. ‘It’s particularly important to us to acknowledge that there’s a lot of trauma that comes into this, not only as a student that went through these experiences, but also from the parent’s perspective as well.’

Stacy described her children’s primary school experiences as ‘constant challenge after discrimination after challenge after bad experience’.

For example, in Brook’s final year at primary school, the students voted her into a leadership position. The teacher, however, wouldn’t allow it.

‘[Brook] was [also] supposed to be getting the academic achievement award of the year and she had it taken off her,’ Stacy said.

When Brook started high school, Stacy found only one private school ‘that would offer her support because of her autism’.

Initially the school was very supportive.

‘It was really positive,’ said Brook. ‘But then the vice principal retired.’

Brook said the retiring vice principal was ‘really interested in ... putting the students first’. The new vice principal was ‘far more concerned with policy’.

‘The policy’s very strict ... You can only conform within the specific written legislation. And so all of those accessibility features and modifications we’d come to experience and appreciate were going.’

Brook and her brother graduated not long after these changes, but Wanda still attends.

Brook says there are times when the school makes Wanda sit outside her classroom ‘almost feeling like she’s being punished’. The school won’t let her therapists attend unless they walk ‘a hundred metres behind’.

'And [Wanda] wasn't allowed to talk to her [therapist] if there were teachers around ... Even now, for the therapist to go into the school she's not allowed to go to the toilet!'

Brook said inflexible school policies make it too hard to appropriately support Wanda. She has 'gone backwards' and is 'losing her voice in the academic field'.

'We don't know if she will actually finish out her high school years there because it's getting so difficult ... It's been a really sad journey, honestly.'

'I think we've forgotten the goals and the individualised participation verses policies and procedures,' said Stacy.

Patrica

Patrica has had complex post-traumatic stress disorder (C-PTSD) since she was a young teenager, the result of sexual abuse she experienced as a child.

Patrica said she has received mental health support for her C-PTSD since it was first diagnosed.

‘All my life, I’ve worked on it and got a lot of support for the trauma ... And I was doing pretty well, and always getting supports, seeing psychologists and doing different support groups.’

She is now about 40 and recently had her second child. The baby was removed from her care just hours after the birth and, following a court determination, is now in the care of the father, Rolf.

Throughout her pregnancy Patrica was seeing a psychiatrist, a counsellor and a person she thought was a psychologist, who turned out to be a social worker.

Patrica had not spent much time with Rolf when she became pregnant. During the pregnancy he was living in another state and she saw him only occasionally. She said he was addicted to drugs and when they were together he could be abusive. He was also fearful of COVID-19 and its possible impact on the baby, and made Patrica afraid too.

About halfway through the pregnancy, a close family member died and Patrica’s mental health began to deteriorate. There were numerous pressures, including medical issues that also affected her mental health. She took confronting photos of herself and sent them to Rolf.

‘He didn’t take it seriously, he knew that I was just being dramatic,’ she said.

Patrica also told the mental health professionals in her life how she was feeling.

‘Obviously I was trying to look at better ways to handle my emotions and my feelings, and act in better ways.’

Without telling Patrica, the social worker reported her to child protection services.

‘In my hospital notes, it shows they were planning to take the baby behind my back.’

Patrica believes she was discriminated against because of her psychosocial disability.

‘They just completely were biased towards the father after the removal of the baby. Everything in the court reports was very prejudiced against me. And they said things like my mental health had never been treated and it was always unstable ... And they never even sat down with me to talk about the work I’d done on my mental health.’

A court-ordered psychologist’s report confirmed Patrica’s diagnosis of C-PTSD, and didn’t identify any other mental health issue.

'The psychologist's report said that with the right treatment, my post-traumatic stress could be treated within a year,' Patrica said.

Yet the court considered her disability to be a greater risk than the father's drug addiction and, once he produced a clean drug test, gave the baby back to him.

Patrica said that pregnancy can be a 'quite challenging' time even in normal circumstances.

'Any mum during pregnancy probably has, you know, a quite high vulnerability to suffering mental health because of the fears that a pregnancy can bring up. Let alone a pregnancy where there's health problems, two family deaths, domestic violence and isolation. They just need to take it into account that, you know, mothers don't need to lose their babies because of it. That they needed to be offered more support.'

Patrica felt better immediately after the baby was born.

'I just felt that it was finally over – like I can just relax and enjoy being a mum. And I was so happy, and I was so relieved ... And they didn't give me a chance. They never gave me one chance. And now the baby's interstate ... and it's been so heartbreaking. Sometimes I feel like I could die from a heart attack, from just the pain of losing my baby.'

Rikki

Rikki is a First Nations man in his 20s. He experiences anxiety and depression and has an undiagnosed mental illness. He is currently in prison.

‘My whole life I’ve had a lot going on in my mind,’ Rikki told the Royal Commission. ‘My mother is bipolar, schizophrenic. And also she did use drugs and drink a lot while she was pregnant with me.’

Rikki said he started drinking alcohol when he was 11.

‘Twelve years old, cannabis and 15 years old, methamphetamines. All from hanging around the wrong crowd. And also stupidity.’

Rikki entered a detention centre when he was 14. When he was first arrested, the police strip-searched him. ‘Something bad’ also happened in the lockup, but he ‘can’t bring [himself] to talk about it’.

‘It was a bit like a trauma event. As kids we didn’t know how to handle it. It took us out of our comfort zone. Then when we got back to our communities we just couldn’t cope.’

The detention centre made Rikki more violent.

‘A lot of fights would happen. Different kids would deal with their emotion in different ways. Some would get angry, some depressed and others alienated. I was a bit of all ... If I had a good experience at [the detention centre] it could have been different in the way my life went.’

Rikki said that because of the way police treated him, after he was released he considered the police ‘the enemy’.

‘I’ve had police, like, pretty much nearly try to snap my arm, smash my head into the ground ... Pretty much every time I’ve been arrested I’ve been, like, injured in some way from police.’

When he was first sent to an adult prison, Rikki was still under the influence of drugs and argued with a guard.

‘They called me up to the ... office. There was about six of them in there and as soon as I walked in one of them grabbed me by the throat, pushed me up against the wall and they kept saying, “You’re not in [juvenile detention] now. This is the big boys’ house.”’

After that, Rikki spent a lot of time in isolation. When he’s not in prison he doesn’t get much support ‘for mental health and everything else’.

‘A lot of the younger generation, they get treated the same as the generation before were treated and the generation before that got treated, and it’s like a never-ending cycle,’ he told the Royal Commission. ‘Sort of getting depressed just talking about this stuff.’

Rikki said although he's back in prison, he's less angry and just wants to go home to get help.

'These days I am trying to let go of anger, but the more I let go of the anger it turns into depression. I don't get angry anymore. I get depressed.'

Rikki said he makes no excuses for his past behaviour, but police and prison guards also need to change their behaviour.

'You ask them why they work here [and] they say, "To make change." But there is no change ... I believe that there should be stuff that helps us rather than us being depressed to the point where we want to take our own life, which a lot of brothers do.'

Tay

Tay, mid-20s, has physical disability, Ehlers-Danlos syndrome and a blood circulation disorder.

A few years ago, Tay enrolled in a course at TAFE.

Tay told the Royal Commission that their teacher set up a message group excluding them. The teacher would post changes to class times and organise class lunches without telling Tay.

When Tay damaged their back, the disability officer assisted Tay access assistive equipment, including a specific chair.

But the teacher encouraged other students to sit in Tay's chair, telling Tay 'to get over it' if Tay complained.

'She just thought it was funny. And then she'd say to me, "Oh, you're so weird, aren't you? You're not a people-person, are you?" or just laugh at things I would do or say.'

The teacher told Tay they did not fit in the class.

'All this made me get really anxious.'

The disability officer organised an app for Tay to use in class to help with their anxiety.

'Everyone was just really mad that I got to go on my phone and no-one else could. They all just started complaining saying there shouldn't be a rule just for me and it wasn't fair.'

The class requested a meeting with the department head to 'air their grievances', scheduling the meeting on a day the disability officer didn't work.

Tay had no support.

'[Everyone] all just saying they don't like me and it's unfair and I don't fit in. It was an hour-long meeting.'

Tay decided to stop talking in class and relinquished their accommodations.

'It was kind of okay after that because I wasn't saying anything, and then they weren't bullying me anymore. They were just ignoring me.'

Tay was one of a handful of people who completed the course, and went on to enrol in a related course at a different TAFE campus. In the prerequisite interview, Tay let the teacher know they had a disability.

‘She said, “Oh, the class is difficult. You’re not going to be able to keep up,” even though I hadn’t even told her what my disability was.’

Tay made a complaint to the state equal opportunity authority.

When the TAFE found out about the complaint, they agreed Tay could enrol in their chosen course.

The teacher tried to move Tay to a disability course.

Tay discovered the course didn’t teach anything and was more like ‘day care for disabled people’. Most people had intellectual disability and had done the same course six times.

‘The people in those courses don’t have anything in common apart from being disabled ... Let them do something they’re interested in.’

Tay insisted on doing the course they had enrolled in.

On the first day the teacher told Tay she wouldn’t provide reasonable adjustments.

‘She was just really cruel to me. She just didn’t like me. She would walk up to a group of people chatting with me and she’d be like, “[Tay] you’re the worst in the class. You’re the slowest in the class.”’

When Tay required time off because of their health, the teacher gave them additional work on top of the work they had missed.

‘If I did anything slightly wrong she would just yell at me.’

After six weeks, Tay left the class.

The disability officer helped Tay apply for the Disability Support Pension and NDIS support.

Tay appreciates the support, but would like a career.

‘I’m an adult and I’m on a pension.’

Ashleigh and Courtney

Ashleigh, early 60s, has cerebral palsy and lives in a group home.

Her sister Courtney is her guardian.

In the mid-2010s, Courtney was living in a different city but was in regular contact with Ashleigh.

One day the provider emailed her saying Ashleigh had had 'a bump on the nose'.

That night, she received a phone call from a doctor who urgently needed her consent to operate on Ashleigh.

'She was in a critical condition ... If they didn't operate she would die,' Courtney told the Royal Commission.

A staff member had not put the rails on Ashleigh's bed.

'My sister rolled out of the bed, straight down. She can't protect herself. She can't put her hands out to protect herself. And she fell down, face-down, on concrete.'

Courtney demanded an investigation into what happened.

The provider tried 'to get on the front foot' and made an application to the administrative tribunal to remove Courtney as Ashleigh's guardian.

They told the tribunal Courtney had mistreated Ashleigh when she was in hospital.

An investigator discovered a manager had visited Ashleigh in hospital with a tape recorder and tried to get her to make false allegations against Courtney.

'In her report, [the investigator] said, "The only abuse that has ever occurred here, in my opinion, is with this woman trying to coerce [Ashleigh] into making these statements.'

The tribunal found the allegations against Courtney had no basis. Ashleigh left the group home and lived with Courtney for a while.

While recovering from an injury, Courtney began to worry about what would happen to Ashleigh if she died. She spoke to Ashleigh about having a 'trial period' in a group home run by a different provider.

The trial was abysmal because the home wasn't adequately staffed and the co-tenants were not compatible.

But the provider refused to let Ashleigh leave.

‘My sister has to make that decision. And my sister had no idea that she was being put in there permanently, and I gave absolutely no indication to anybody that she was going there permanently. This was a trial situation.’

The provider made a claim to the administrative tribunal to remove Courtney as guardian, saying she inappropriately removed Ashleigh from the group home.

The tribunal dismissed the claim, but only after Courtney spent a considerable amount of time and energy on the proceedings.

Courtney believes the claim was motivated entirely by the organisation’s desire to retain Ashleigh’s NDIS funding.

Ashleigh moved back in with Courtney.

Initially they were able to find good, reliable support workers, but over time it became more difficult.

When Courtney became unwell, Ashleigh had to move to another group home.

The home turned out ‘to be just another institution, and a very dubious institution’.

Staff refused to help Ashleigh use the toilet.

‘If she’s with one-to-one, they come to understand when she needs to go and they can just put her on the toilet. And it’s just not a fuss,’ Courtney said. ‘But they just wanted to put her in pads 24/7. She had to defecate on the cushion most of the day.’

When Courtney complained, staff agreed to ‘three rostered times’ Ashleigh could go to the toilet each day.

‘This is abuse ... not having the right to go to the toilet when you actually need to go.’

The provider has made an application to remove Courtney as guardian. The grounds for this application are ‘ridiculous’. They allege Ashleigh isn’t allowed ‘treat food’, doesn’t have enough towels and sometimes wears Courtney’s clothes.

‘It’s become like a witch-hunt ... It’s just been a really, really difficult, awful process ... My sister is 60 years old and she continues to be forced to live in these kinds of institutional arrangements.’

Ravi and Josefine

Ravi, early 20s, is autistic and has complex post-traumatic stress disorder. He is non-verbal.

Ravi's parents separated many years ago and Ravi spent equal time living with each. A few years ago when Ravi was about to leave school, his mother Josefine tried to make a plan with his father about Ravi's future. When they could not agree, the court appointed a public guardian for Ravi.

Josefine told the Royal Commission that the guardian, Mr McDonald, was a lawyer who seemed to have little interest in Ravi or knowledge of people with disability.

When Ravi's stepmother left his father because of his violence towards her, Mr McDonald refused to investigate whether Ravi was safe with his father. Josefine urged him to, but he wouldn't.

'There was this underlying current from him that [Ravi's stepmother] and I colluded in some way and we were like – had a vendetta against [Ravi's father] or something. So he never ever investigated anything.'

Mr McDonald's hands-off attitude continued even when Josefine provided evidence about her former husband's violence. Ravi's stepmother said she had seen Ravi's father neglect and abuse him, and a therapist said Ravi showed signs of trauma from abuse. When one of Ravi's support workers visited the father's home to collect Ravi, she found the place in disarray and he was 'very aggressive' with her.

'She was too frightened to go back,' Josefine said.

Some months after Ravi left school, his father declared he could no longer care for him.

'From that, [he] has never tried to make any contact with [Ravi] whatsoever,' Josefine said.

As guardian, Mr McDonald took over Josefine's role as Ravi's NDIS plan nominee. Josefine said Mr McDonald 'ran [Ravi's] NDIS funding into the ground', then went on leave for four weeks without arranging any care.

Though he was not responsible for Ravi's accommodation, Mr McDonald then proposed Ravi be placed in segregated accommodation. Josefine refused.

Eventually, the guardianship became the subject of a tribunal hearing.

The tribunal appointed a new guardian for Ravi, who investigated the alleged abuse of Ravi by his father and found it definitely occurred. He revoked the guardianship, telling Josefine there was no need for it as the father was no longer part of Ravi's life and she was 'more than capable' of managing Ravi's affairs.

'So I had to put up with all that for nothing,' said Josefine. 'It was a stressful, stressful time and [Ravi's father] got away with everything. He wasn't reported, nothing happened to him, and he just dropped [Ravi] and he hasn't seen him since.'

Josefine is more concerned about the failures of the guardianship office.

'I was extremely disappointed because I thought at the beginning when a guardian was appointed, great, there'll be less pressure for me. But ... the fact is that I was just left hung to dry to solve everything myself for [Ravi],' she said.

'There are no policies and procedures ... dealing with non-verbal people. That's ridiculous ... [Public guardians] need to have policies and procedures around dealing with non-verbal clients. And if they can't do, they're a failure as an organisation dealing with people with disabilities as far as I'm concerned.'

Sandro

‘The problem with this schooling stuff, they force this stuff in front of you as if you’re a robot. You’ve got to be the same as everyone else. No-one’s the same in this world ... The school should be guiding someone to what they really want to do.’

Sandro, early 20s, is autistic, short-statured and has intellectual disability.

He told the Royal Commission he ‘wasn’t treated right’ in primary school. Students would pick on him and he’d react. The principal would remove Sandro and lock him in a room.

‘He’d be quite aggressive about it. Scream at me and threaten.’

Sandro said the school gave him a computer but no-one helped him learn.

The principal suspended him multiple times and expelled him in year 6.

In high school, Sandro had to stay in the special unit.

‘I couldn’t go in and do certain things because apparently I’m too violent, dangerous.’

Sandro was good at fixing things and wanted to do a mechanics course with the mainstream kids.

‘The main part of the school won’t accept me ... I was classed as a bad person ... Making out I’m a threat, I’m too dangerous to do that ... I was fighting this battle trying to get this program and they wouldn’t accept me ... classing me as a halfwit.’

Sandro left school at the end of year 10.

‘I don’t want to be going to school wasting my time hearing a bunch of rubbish ... I want to do a course that I can leave school, I can get into an apprenticeship, get money and then set myself up.’

Sandro joined a program for at-risk youth and did a mechanics course. It was good. But it wasn’t an apprenticeship and he couldn’t get a job.

Centrelink initially refused to give Sandro the Disability Support Pension. He had a meltdown in the office and they approved it immediately.

The NDIA approved funding and Sandro moved into supported independent living (SIL) accommodation.

He was living with people of mixed ages and disability and he didn’t feel comfortable. One man was in his late 60s and had just been released from prison. Another man would open the door when Sandro was having a shower.

Residents would smoke in the house. Sandro is pretty sure some were using drugs because he found used syringes.

People didn't clean up after themselves and the place was dirty. There were cockroaches and mould in the bathroom and blood on the bathroom windows.

Sandro wanted staff to support him to go out each day, but they could only leave the house if another resident came too.

'They refused to take me out ... giving excuses for the other guy, they can't take me out because that guy's asleep,' he said.

'One day I lost it because of the whole situation.'

Police arrived and charged Sandro with assaulting a police officer and property damage.

He said they treated him badly and didn't provide a support person.

Sandro's NDIS support coordinator contacted an advocate who helped him prepare for court, but the advocate wasn't allowed to come into the court room. Zac found it hard to understand what was going on and said the matter was referred to the 'intellectual disability court'.

Sandro's case kept being adjourned. He ended up receiving a six-month community-based order.

Sandro moved to a different SIL home.

One of the residents told Sandro he'd like to see him naked.

'Starts talking about sex and inappropriate stuff ... It makes you feel uncomfortable.'

Sandro would like to live on his own.

'I just want my own house ... coz people get me on edge. I get anxiety, I isolate. I just want to focus on me ... Not too big, just something that has the space for me really. As long as the house is livable, it's a home.'

Bosco and Michele

Bosco, early 20s, has intellectual disability, behavioural and sensory disorders and ongoing health issues.

‘His behavioural disorders cause a lot of aggression,’ his mum Michele told the Royal Commission. ‘His sensory disorders cause aggression as well, so he doesn’t cope living with other people, not even his own family.’

Until recently, Bosco couldn’t leave the house because his anxiety was so high.

Michele struggled to find and retain in-home therapists.

‘The supports didn’t really work in the home because of the environment.’

Bosco’s siblings became so frightened of him they would lock themselves in their rooms.

‘We were always worried that just them moving through the house or being too noisy would set him off,’ Michele said.

‘He doesn’t want to hurt us. He doesn’t mean to, but his impulse controls are not there. When he’s distressed, it’s the only way he can communicate. After he would hurt us, after he’d hurt himself, he would break down and cry and say sorry and just keep hugging us.’

Medication didn’t help.

‘We’ve tried so many medications, and there’s only so much medication you can do. His environment plays a big factor in his behaviours.’

Bosco was frequently admitted to hospital because of his behaviours.

During his last admission, child protection and police became involved. They threatened to remove his siblings if Bosco remained living in the family home.

Bosco had to stay in hospital for several months while Michele tried to find somewhere for him to live. During that time, he was able to stay in his own room and he became calmer with no-one around.

‘That’s when it all started to become quite clear that he could not handle the busy environment of living with other people. When he is in an environment which is only him and one other person supporting him, he can thrive.’

Bosco left hospital and moved to supported independent living (SIL) accommodation by himself.

Michele notified the NDIA of change of circumstances and asked to use some of Bosco's core funding on accommodation. The NDIA agreed, indicating they would approve one-on-one SIL funding when they reviewed his plan.

But this didn't happen.

The NDIA approved one-on-three funding, telling Michelle she didn't provide enough evidence to justify one-on-one support.

'The planners and the people that make the decisions for my son and what funding he's entitled to, they're not trained, they're not taking on the recommendation from the professionals,' Michele said.

'I wish they could just come and spend the day with my son and see how complex he is. Try to have a conversation with him and see the reaction. And then tell me that they would be willing to put other participants with him and put other participants at risk.'

Michele asked for an internal review. She uploaded almost 40 documents from medical practitioners and police, including photos of her and the children's injuries.

The review panel upheld the original decision. Michele discovered the panel never saw the additional information.

She had to again apply for change of circumstances funding. Michele believes she shouldn't have to go to the administrative tribunal to get the support Bosco needs.

'We don't want him to have to be in one-on-one forever. It's just something that is required for at least a few years so he can learn functional communication, learn how to reduce his behaviours a bit better and meet some therapy goals. Unless he's able to meet his therapy goals, he won't be able to live with other people.'

Since Bosco's been living in SIL accommodation with one-on-one support, he's engaging with therapists and making progress.

His siblings are no longer scared of him.

'He now comes home for dinner three nights a week and he goes grocery shopping. Finally got his dentist appointments and doctors appointments, which we haven't been able to get him to do for four years.'

Dermott

‘Being out in the community is really, I think, key to developing a really strong relationship. Not only the people you’re dealing with day to day, but also the community knows that you exist and you have something to contribute.’

Dermott is in his 60s and deafblind.

‘I’ve always had hearing impairment since I was born and vision [impairment] probably since about 10 onwards,’ Dermott told the Royal Commission. ‘It accelerated to the extent that I did have difficulty at university with my studies in terms of vision, which makes it much harder to read material. But I got through that okay.’

Dermott said he was lucky to have been active in the community as his sight and hearing failed and ‘people became aware over time’ of his disability.

‘[The reason] I’ve had a reasonably fortunate life is the fact that I was in the community and therefore was able to develop relationships.’

For example, one of Dermott’s colleagues at university helped him get a good job.

‘I got a good reference from him [and] a person who looked at my application went, “Oh yeah. Maybe we could find a place for this guy.”’

Dermott worked for about 15 years, until he couldn’t anymore.

Dermott now uses a guide dog, but struggles to maintain community contact because of discrimination and poor support.

For example, taxis sometimes refuse to pick him up.

‘Some of them will just not even stop. They will just see you and drive on past.’

He also struggles to find interpreters who are fluent in the ‘whole range of different ways’ deafblind people communicate. In his regional city there are only one or two interpreters who can do that.

‘If I’m requiring an interpreter that’s competent ... I may need to book that interpreter a month ahead to be sure that they will be available, because if you leave it until the day before they’re not available.’

Dermott said many support workers also don’t know how to help deafblind people.

'They don't understand, for example, that it's their role to support you, not to actually take the initiative ... I've even heard stories of people deciding, "Oh well no, we won't go there, we'll go to such and such a place because it's easy to park there." ... So sometimes initiative is taken away.'

Dermott tries to help other deafblind people maintain contact with their community.

'[Deafblind] people who have been institutionalised ... learn that there's no point trying to get any interaction back, and over time they actually lose their skills and abilities ... Once you lose your confidence you're vulnerable and you'll just be pushed around.'

Matilde, Elio and Lindsay

‘The trauma our children are experiencing and the way that trauma is manifesting is heartbreaking ... Every day I hear a story and I think, “That’s the worst I’ve ever heard.” And the next day, the story is worse.’

Lindsay worked as teacher and assistant principal for many years.

When her grandson was a toddler he had some behaviours that were ‘red flags’.

His preschool refused to have a field officer observe him in class. They said her grandson wasn’t autistic. ‘What is happening here is a child from a broken home,’ they said.

In year 1 he had a good teacher, but year 2 was a disaster.

‘He was the young boy who was climbing up trees ... He got caught under the fence trying to escape school, digging his way out. He was hitting in frustration.’

Lindsay approached the principal and started advocating for her grandson.

‘We built a team around my grandson. He’s now in year 7 and is doing extremely well ...’

Lindsay changed careers and became a disability education consultant.

She told the Royal Commission about Matilde and Elio – two young autistic people she has worked with recently.

In year 5 students started bullying Matilde, posting photos with derogatory comments on social media.

‘They would say things to her like, “I wish you would get COVID and die. Why don’t you go and kill yourself?”’

Students would taunt her and tell others not to play with her.

Matilde’s parents made complaints, but the principal said it was ‘an out-of-school issue’. Lindsay met the principal but he was defensive, deflective and refused to act.

The bullying continued.

Matilde self-harmed and was admitted to hospital.

The education department became involved and forced the school to develop a support plan for Matilde. The principal was absent from all the meetings.

Matilde stopped using social media, but the students continued to make nasty comments online.

One day Matilde came home from school, managed to climb up and get her medication from a cabinet, and took an overdose.

'You promised me I would be helped,' she cried, throwing the empty box at her mother.

Matilde required medical treatment.

She changed schools and, for a while, was happy.

But when Matilde started high school the bullies were there and they started bullying her again. Eventually she refused to go to school.

'She is now in a flexible learning centre. She's very angry. She's very anxious. She's traumatised ... The learning gap between her and her peers is growing.'

Elio's year 6 teacher was 'quite aggressive in her language'.

Some students in his class thought she was unfair to Elio. They covertly recorded her talking about him, ridiculing him and calling him terrible names.

Despite not being involved in making the recording, the principal told Elio he had broken the law. He threatened to ring police to take him to juvenile detention.

Elio started having night terrors and couldn't sleep alone. He became terrified of the police.

Lindsay and Elio's parents reached out to police and told them what had happened.

The police were terrific. They invited him to the station and they all said hello. They explained he hadn't broken the law and they weren't going to take him away. They showed him around the station and let him sit in the car and put the siren on.

'He is no longer terrified of police but he still won't sleep alone ... He's absolutely traumatised. The mum's traumatised.'

Meanwhile, the school placed Elio on an internal suspension. He couldn't participate in interschool sports, which he loved and was good at, and couldn't attend the end-of-year excursion and graduation.

Lindsay involved the department of education and the school lifted the suspension.

'Consequence to the teacher? Nothing,' said Lindsay. 'It was all on our young person.'

Keely and Freda

Freda is in her 70s and is mum to Keely, who has Down syndrome.

‘She ... functioned fairly well until the age of about 19 and then suddenly ... she lost of a lot of skills and really went downhill,’ Freda told the Royal Commission.

Doctors diagnosed Keely with dementia.

‘It’s just been one horror story. But to set the scene prior to the NDIS when [Keely] really had become very difficult living at home with me – I couldn’t look after her anymore.’

Keely entered a group home, which Freda described as ‘a disaster’.

‘It was a staff ratio of one-to-four ... The other three ladies were functioning an awful lot better than [Keely] so their families wanted to gear the funding towards what suited the three of them. We were always the odd one out.’

When Keely became aggressive and wouldn’t let staff wash her or brush her teeth, Freda and her husband tried to get her out of the group home.

‘Along comes the ray of hope, the NDIS. This is the first ray of hope of actually being able to get her out of that group situation.’

The NDIS planner, however, was ‘hostile’ and insisted Keely didn’t need one-to-one support. Freda said the NDIS funded tens of thousands of dollars on reports that supported one-to-one care, but they ‘seemed to make no difference’.

‘It was just so evident that there was no way [Keely] could live with anyone ... She would be screaming. It was just dreadful.’

Freda took the reports to the Administrative Appeals Tribunal (AAT).

‘[The] NDIS ... put up a corporate lawyer against you. The man was absolutely implacable ... Wanted an update report and the AAT member said to him, “They’re hardly out of date.” Nevertheless, “We want updates. We want more information.” ... I hate to think how much money was spent on this lawyer alone. Far more than would have been needed in [Keely’s] plan.’

Freda said Keely in the meantime ‘wasn’t safe’ in the group home, and while the NDIS fought to keep her there, Freda and her husband ‘spent their last dollar’ buying a cottage and moving her out.

'Because we're in our 70s absolutely no-one would give us a loan ... I'd done some fundraising within the family and a couple of business people I know ... and it's turned out to be the best thing we ever did.'

They built a garden so Keely 'could walk on a path and enjoy the fragrances and the birds', keeping her mobile and out of a wheelchair.

Recently Freda found a psychiatrist who re-diagnosed Keely's dementia as Down syndrome regression disorder and changed her medication so she's 'more calm'.

'I've had 40 years of this,' Freda told the Royal Commission. 'You have no friends left. They drop by the wayside long ago ... peers are all off holidaying or enjoying long lunches. I haven't been able to do that. I'm so tired of pushing myself to breaking point by evening, every evening.'

Freda recently had heart surgery and said more than two years of fighting the NDIS has 'just about run [her] into the ground'.

'I'm saying to myself, "How much more does this government want from me?" We have put our last dollar into trying to be independent and not use government resources. We've housed our family member with great difficulty ... I just find that at the moment I've got nothing left.'

Yanni and Carmina

Yanni is a young autistic man in his early 20s who also has attention deficit hyperactivity disorder (ADHD) and post-traumatic stress disorder.

‘He had undiagnosed autism until he was about six and probably nine or 10 for the ADHD,’ his mother Carmina told the Royal Commission. ‘He had a rocky childhood with an abusive dad. He had a trauma background ... He tends to explode. That’s the way his autism shows up.’

Back then, it was ‘perfectly legal to use restraints’ at school.

‘And that’s what they did. If he got to the point he was getting niggly, about to blow, they’d get an adult on every corner and drag him through the school, kicking and screaming, lock him in a courtyard ... [Then] they would call the police and have him dragged off by police.’

The mistreatment at school made Yanni ‘hypervigilant about the world’. His behaviours worsened.

‘Dehydration, heat and not eating are his three main triggers.’

A couple of years ago, Yanni was having a meltdown at home and had become violent. Carmina was not at home, but her daughter was.

‘When he escalated, the police were called.’

Scared because of his past negative interactions with police, Yanni barricaded himself in his room. When Carmina arrived, police were shouting at him, ignoring his sensitivity to noise. Yanni wanted police to leave so he could drink his milk.

‘Even after he’d gone in his room and was cowering in his room, begging them to leave, they refused.’

Police told her there were two options. Either to give him ‘a light sedative’ and take him to hospital to be assessed, or charge him for the damage to the walls. Carmina wanted to help de-escalate his behaviour by rehydrating him.

‘But they we’re going to take him one way or the other.’

Carmina said police pinned Yanni to the ground and injected him with ketamine. He became increasingly distressed and said he couldn’t breathe. When he asked whether they were giving him a lethal injection, one officer replied, ‘No, that comes later.’

Carmina said this incident ‘pushed him into post-traumatic stress disorder’.

'If he hears a siren, if he sees a policeman anywhere, you know, sees a cop car, he loses it.'

A similar incident happened recently when Yanni 'was not mentally well at all'.

'Police came to the house. When he is in the midst of a trauma reaction, the stuff that comes out of his mouth is disgusting ... He hates those words, but he can't stop it ... He locked the doors on them, so they decided to bash the door down. They ambushed him. They screamed and yelled, "Get on the ground. Get on the fucking ground" ... And they put him in handcuffs.'

Again police refused to back off when Yanni 'was in a crisis'. One police officer said he had autism training but, Carmina said, he was 'on a power trip ... not listening to what needed to be done'.

Yanni had 'a great life planned ahead of him' after studying programming.

'Only thing he ever wanted to do. Did well at it, graduated, and that's when all this stuff started happening. And since then he has become an absolute shell of who he was.'

Jeanine and Frazer

‘Bad apples aren’t being weeded out of the system. They’re just disappearing into the system.’

Jeanine and Frazer run a service to match people with disability with support workers.

‘All of our work is inspired by [our brother] and his life and the challenges that he faced as a person with cerebral palsy,’ Jeanine told the Royal Commission.

Jeanine and Frazer’s company is registered with the NDIS.

‘We are very proud of the audit processes that we go through ... to maintain our registration status,’ said Jeanine.

The problem, said Frazer, is that many service providers aren’t NDIS registered and never get audited.

‘People are saying, “Why do we have to register? Why would we bother with an audit and paying all this money and doing all of this costly complex work when we can just operate as unregistered?”’

Frazer said the NDIS was supposed to be a ‘consistent, connected, joined-up national system’, but it no longer is.

‘We’ve got a highly fragmented approach to quality and safeguarding within the disability sector.’

Jeanine said the number of unregistered service providers is going ‘through the roof’.

‘In 2015 ... there were 2000–3000 providers. Now there’s 120,000–130,000 providers and a lot of those are the independent, small business, sole traders ... with only the oversight of a code of conduct that is unenforced.’

Jeanine said 90 per cent of those providers aren’t registered with the NDIS and the number of people being ‘extorted or abused or neglected or not knowing their rights was sort of inevitable’.

‘It’s absolutely possible today for a person to go and get an [Australian business number] ABN and become a support worker the next day with no, you know, criminal checks ... and to me that’s deeply concerning.’

Frazer said, for example, he knew of an unregistered support worker who recently demanded an extra \$10 an hour from an NDIS participant.

'The participant said, "I can't pay you \$10 extra every hour," and the support worker said, "I'm gonna withhold care until you pay me more money." So effectively individual workers who are not bound by much oversight or supervision are extorting participants for extra money per hour. There are literally hundreds, hundreds of these stories.'

He said it originally made sense that allied health professionals such as physiotherapists don't need to register with the NDIS if they already have an industry qualification.

'Again if I need to buy continence aids I don't want to have to wait for some slow specialist provider to provide those if I can go and buy them at Coles.'

The problem is that, in practice, many other types of service providers 'have just opted out' to avoid scrutiny and the cost of compliance.

'What's been added by the NDIS into the mix is significant amount of money ... If you're a, you know, a con artist and a fraudster and you're looking for vulnerable people with a lot of money ... that's an absolute flashing beacon.'

The system is 'so unregulated', said Frazer, that abusive support workers 'continue to move through the system with no oversight'.

Jeanine said while people are entitled to choose their service providers, there should be 'some regulatory framework', such as there is in the car and food industries, to keep people safe.

'We need one system for everybody, small and large, and at the moment we have two systems,' Jeanine told the Royal Commission. 'We have those organisations who opt in to following the rules and those who then decide they're not going to.'

'The underlying attitudes to people with disabilities is a massive systemic issue, but if we don't have a sensible, consistent framework to protect people we're going to have the very worst kind of people coming into our sector. And I think it's already begun.'

Millie and Gemma

Millie is autistic and in her teens. She also has attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD).

Gemma, her mother, realised when Millie started prep that ‘there was definitely something going on’, but she wasn’t diagnosed for another six years. Teachers kept telling her ‘that too many children were being diagnosed with autism and she was perfectly fine’.

‘There wasn’t seemingly too many issues at school. The issues were where she would hop in the car after school and she would be throwing drink bottles at me. Huge big meltdowns ... Then be able to get really wonderful marks in class but be terribly behaved for me at home.’

Millie was clearly ‘really upset about many things after school about what had happened during the day’. Gemma was constantly going to the school with her concerns ‘and it would often be dismissed’.

‘I just felt like I was this squeaky wheel and no-one wanted to help. I pulled her out of school in grade 1 and we homeschooled her for about nearly two years.’

When Millie returned to school, it was ‘very obvious in all of her report cards’ that she had ‘social emotional issues, not academic’. But teachers continued to say there was nothing wrong with her.

‘The dismissiveness really stopped me from getting that early intervention. Looking back now, it breaks my heart because of where we ended up.’

Gemma sent Millie to another school for grade 5. Soon after, she received ‘a very comprehensive diagnosis’ at a private clinic – yet to be verified by a paediatrician.

‘She had ADHD, ODD ... every acronym that you can think of ... So we gave the paperwork to the school but they refused to acknowledge it or make any adjustments that I was requesting.’

Without any supports, Millie was self-harming and had very ‘low self-worth’. Again, Gemma pulled her out of school and put her into distance education.

‘She was hanging off the side of my car. Huge meltdown. Punching windows. Screaming ... It was just out of control by that stage and I still was on the phone to occupational therapists just begging for appointments.’

Gemma thought Millie’s high school was going to be a ‘golden ticket’.

‘They had all of these beautiful inclusive things that we could access and I thought, oh my goodness, she might come home and feel like she’s been nurtured.’

But the school never gave Millie access to the inclusive learning centre, and suspended her for her behaviours. They didn't have 'the understanding or the resources' to support her, Gemma said.

Meanwhile she was trying to get Millie NDIS supports. Local area coordinators kept telling her she 'can't access mental health because she has autism'.

'Without them looking at my evidence ... They would just blow me off.'

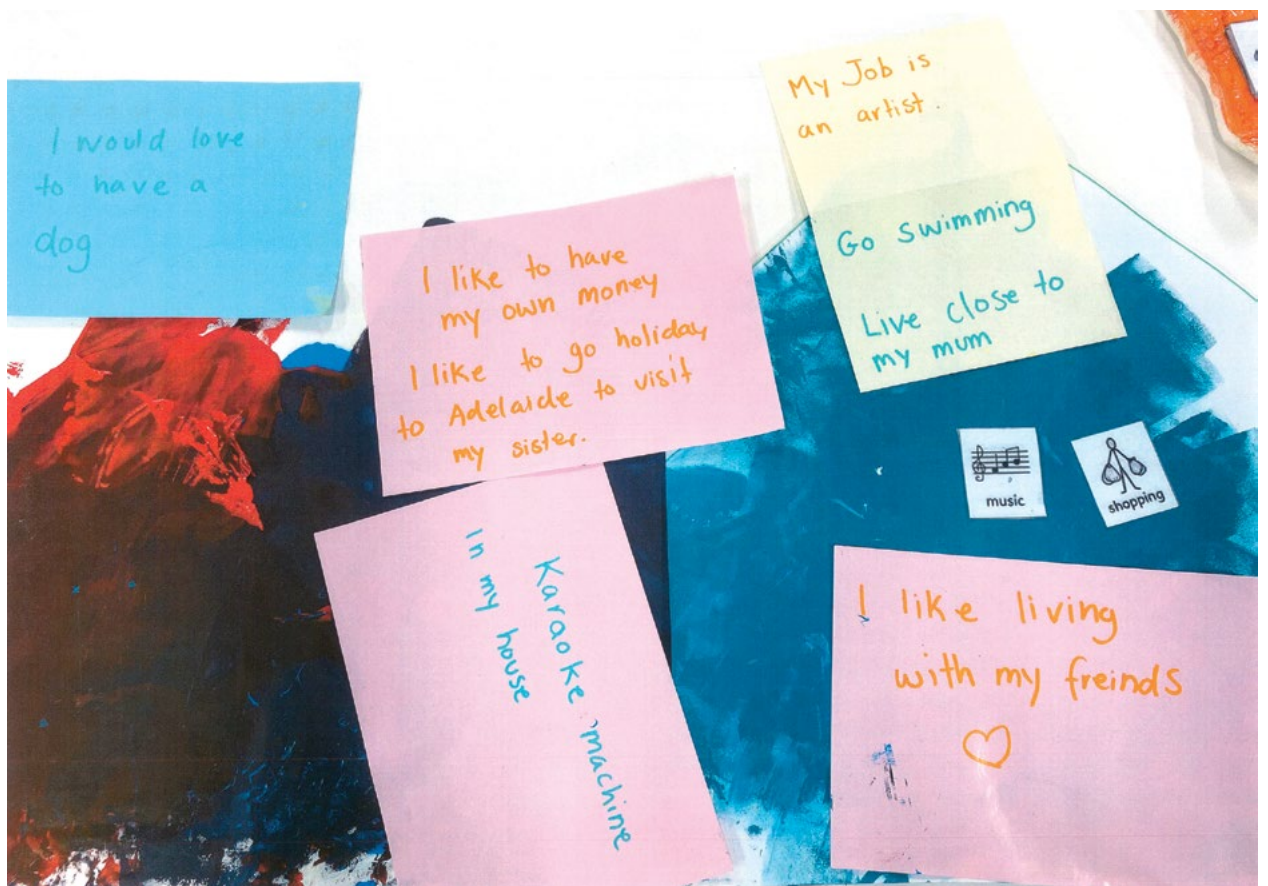
Millie's mental health went downhill. She was becoming increasingly violent and was having suicidal ideation.

'And mental health would say we can't help you, she has autism. Go back to the doctor. It was just this constant cycle. Like I was just never getting the help for [Millie] that she desperately needed.'

In the early 2020s, after an overdose and several hospitalisations, Millie 'finally' got NDIS funding and mental health supports.

She is at a new school which focuses 'on engaging the children' instead of imposing rigid rules.

'[Millie] is a very exuberant personality. She likes to push boundaries and it seems like they don't really worry too much about those things. She's doing well at the moment ... especially academically. I think if she's supported well enough she can absolutely be the vet she wants to be.'



Artwork by Jim Simpson

Jory and Hagar

Jory is in primary school. He is autistic and non-verbal and communicates with a computer tablet.

‘With COVID his anxiety levels went through the roof and it’s come out in his behaviour,’ his mum Hagar told the Royal Commission. ‘His behaviour has turned, I guess, violent ... and most of it’s directed at me for whatever reason.’

One day when Jory was damaging furniture and hurting himself, Hagar called the police to help her control him. They handcuffed him.

‘I don’t think it helped and actually one of the support workers even said to the guy who’d been struggling with [Jory], “Hey mate, he’s a child ... Like why are you handcuffing him?”’

Hagar had Jory admitted to a hospital psychiatric unit.

‘[The staff] decided that he doesn’t understand what’s going on. I said to them, “No, he understands, [but] he needs a communication partner.”’

Jory’s communication partner uses a communication technique that psychiatric unit staff consider unscientific and they wouldn’t let that person come in to help him.

‘They feel that is controversial, the facilitated communication. But that’s my choice and that’s my son’s choice ... The school that he goes to has accepted it very well.’

The hospital discharged Jory.

‘[The hospital] told me that they can’t help and not to bring him again. They also called child protection on us.’

Hagar said the hospital also wrote to the NDIA accusing Jory’s communication partner of being ‘not just ineffective, but dangerous’.

‘I just feel like I’m in an abusive relationship ... I think [the NDIA is] also looking at options of how they don’t need to fund people. So I think that the report from the [hospital] suited their narrative that, you know, here’s something we don’t have to fund.’

The NDIA told Hagar that if she continued to use the communication technique they’d stop her managing Jory’s funding.

‘That’s terrible, like you’ve got some supports in place that he’s very close to and feels very comfortable with, and [taking some away] would actually destroy him.’

She said the NDIA wasn’t letting her and Jory ‘choose what works’.

‘Some people find a therapy dog really helpful. Well, [Jory] doesn’t. For [Jory] I wouldn’t even think of it. He doesn’t particularly like dogs. So you can’t group everybody [together].’

When Jory’s behaviour deteriorated during COVID-19, Hagar asked the NDIA for more support.

‘[They’re] telling me that I should be looking after him. I feel like saying, “If you came I would like you to look after him. He doesn’t let me anywhere near him at the moment. That’s why I’ve got people to help me.”’

The NDIA kept asking her for reports ‘over and over again’ from specialists such as Jory’s psychologist, who were ‘sick of it’.

‘I felt like I had to justify every decision I made ... I’m his parent, this is my role, I need to look after him and ... I need to just be given credit rather than be demonised as someone that is causing trouble.’

Timmy and Flora

Timmy is in his 30s and needs 'one-on-one support round the clock', his mother Flora told the Royal Commission. He is autistic and has schizoaffective disorder.

'Mainly there's an impact with his emotional regulation and impulse control, learning and executive functioning. This complex interplay of my son's intellectual disabilities, autism symptoms as well as a mental illness, makes it very difficult to manage his emotions within the home and in public.'

Finding staff trained 'to communicate effectively' with him 'has always been a problem'. 'Family have always supported him,' Flora said.

Timmy lives in a unit attached to a group home.

'The accommodation is not appropriate. They can't source support workers, so there are gaps in his care. For nine hours every 24-hour period he's not supported. That places my son in a vulnerable situation because he self-harms a lot.'

For Flora, a big part of the problem is the NDIS.

'Family were approved originally to be paid formal supports by the NDIA in order to seek and source the appropriate staff. The NDIA very abruptly ceased that without even letting us know. My son was left unsupported, unfunded for over a month.'

When Timmy's plan was reviewed a couple of years ago, Flora insisted on the family being involved.

'I believe families should be acknowledged and paid if they are the best support staff that can support the family member. I truly believe that has to change.'

She and her other son are both 'qualified workers in disability and mental health sectors'.

'The NDIS didn't take that into account. We asked for a 12-month period of transition so family could be paid until the appropriate support workers were found. We asked for the plan to be plan-managed as opposed to NDIS-managed, as the plan was incredibly rigid to the point where we could not access the funds ... We asked for increased transport funds, increased support coordination funds. Everything was rejected ... Which meant that only service providers that were registered with the NDIA could support him and only two service providers were named.'

The family took the case to the Administrative Appeals Tribunal.

'We fast-tracked it on the basis that it was life-threatening. [Timmy] was experiencing neglect because of poor supports, he was not receiving his medical care. And we had a report from his GP stating that.'

The NDIA rejected evidence from Timmy's psychiatrist, occupational therapist and behaviour support practitioner 'stating the importance of him receiving family-supported care'.

Flora said the whole process was traumatising.

'We were condemned before we even started. They did not look at my son and his situation and how we can fix it. It was more about targeting the family. It was incredibly unjust.'

Timmy's new plan nominated five providers.

'So again, it's reducing the pool of workers for us. There is no choice and control in our situation. They have dictated to us their terms.'

Flora feels the NDIS should be plan-managed 'across the board'.

'Until today we still have this problem, we cannot find support staff. If we don't have the right workers who can understand the complexity of my son's disabilities, that is placing my son's life at risk.'

Emma-Jane and Catherine

‘[Emma-Jane] has an intellectual disability. For somebody to actually prey upon her, it’s so bad. It’s so disgusting.’

Catherine is the support coordinator for Emma-Jane who is in her mid-30s and lives independently with in-home supports.

Jackie had been Emma-Jane’s support worker for several years. She worked for a service provider that managed Emma-Jane’s NDIS plan. Catherine told the Royal Commission that a couple of years ago, Jackie ‘pretty much kidnapped’ Emma-Jane. She left the company and ‘poached’ Emma-Jane as a client.

After moving into Emma-Jane’s home, Jackie started claiming NDIS payments as her support worker and plan nominee, making decisions on her behalf. She then took Emma-Jane to live at a friend’s apartment, ‘disconnecting her from her whole family’.

During that time, Emma-Jane was raped while Jackie ‘was out shopping’, Catherine said.

‘[Jackie] had billed for [the time], but she wasn’t there.’

Emma-Jane’s family lost contact with her during this time, and Catherine had to go on ‘a bit of a mission’ to find her.

Catherine found out that Jackie had moved Emma-Jane from one service provider to another and ‘was utilising her and her NDIS plan to gain employment’. She was ‘using it as leverage’.

Jackie asked the latest provider to find accommodation for Emma-Jane, ‘and within days ... was living there’.

‘The company tried to move her out ... and she just refused to allow them entry into the property ... They pretty much lost all access to that house and [Emma-Jane] from that point.’

Emma-Jane’s mother contacted Catherine, desperate.

‘Like the stories she’s telling me are horrific ... [Emma-Jane] is being locked inside the house every evening when the carer goes to another client. She takes all the keys.’

‘I can’t get out,’ Emma-Jane told Catherine in a video chat. ‘The shutters are down and she takes the handles off the winder.’

Jackie had also taken control of Emma-Jane’s mobile phone and social media.

‘They were all being vetted. She had no contact with the outside world.’

Catherine said Jackie ‘siphoned off’ more than \$90,000 from Emma-Jane’s NDIS funding while living with her. One of Jackie’s friends was ‘also trying to be a provider’, though completely ‘unqualified’.

‘When I tried to report this to the NDIA Safeguards Commission I was told that the clients had to report this matter themselves ... I was horrified.’

Catherine eventually helped Emma-Jane escape while Jackie was on a night shift. She had Emma-Jane placed in emergency accommodation.

‘All her funds had been exhausted and I needed to keep her safe ... She was absolutely, like, scared out of her wits of the carer, who would be calling her phone.’

Catherine believes there needs to be much better screening of NDIS providers, particularly unregistered ones.

‘It should have been picked up or flagged when the plan nominee was also claiming funding ... That’s against the law.’

Catherine is still trying to help Emma-Jane get back on her feet.

‘There’s so much abuse there that it’s really difficult to even comprehend how this young girl actually still believes in the human race today.’

Zena and Tilda

‘A funded provider should not be permitted to put in an application for guardianship to a tribunal. They have, which is irrefutable, a financial vested interest in the outcome.’

Zena is autistic and has intellectual disability. She lived with her foster parents until a couple of years ago. ‘They raised her for 20 years, you know, since she was about the age of 14,’ her foster sister Tilda told the Royal Commission.

Throughout that time, Zena attended a day program run by a mental health and disability service.

‘They have been involved for a very long time. When my parents wanted to change day programs, they actually threatened them ... That’s what happens when people kind of control the situation.’

Prior to the rollout of the NDIS, Zena’s decisions were ‘made informally by the family’.

‘[When the] NDIS came in ... within months she had her first guardianship order placed on her at the initiation of providers.’

Tilda believes the catalyst was the family requesting that Zena’s NDIS plan switch from agency-managed to plan-managed. This would have allowed her to do activities offered by different providers.

‘We wanted to give her the most choice and control, whatever she wanted to experience ... to engage with community and mainstream-type services that weren’t registered with the NDIS.’

Within 24 hours, a second provider who coordinated Zena’s supports applied for a guardianship order on her, Tilda said.

‘[It stated] that her foster family was going to kidnap her and she was at great risk of harm. They did it in secret. They didn’t tell any of us.’

Tilda believes the two providers colluded to take control of Zena’s personal decision-making for financial gain.

The tribunal ‘put the order on’ even though neither of the providers were able to ‘back up any of their allegations’.

‘And then it’s just got worse from there.’

Tilda said the guardian moved Zena into a ‘completely inappropriate’ group home run by her long-time service provider without consulting the family. Within months she was hospitalised ‘at critical levels’.

‘So it took them less than six months to pack the weight on her and she ended up with a diagnosis of type 2 diabetes.’

A tribunal recently revoked Zena’s guardianship, but within a couple of months the provider reapplied.

‘As soon as they thought they were going to lose a client and lose funding, they slapped another order on her to stop that happening.’

The provider claimed that the family was ‘exploiting, coercing and abusing’ Zena and was responsible for her ‘current critical health’. Tilda said the tribunal took this ‘hearsay’ into its decision-making.

‘It was very clear to us that the tribunal didn’t consider any of the evidence we submitted that actually stated the facts and refuted the outrageous allegations from the provider and from the public guardian. They were very clearly biased.’

Zena indicated to the tribunal that she wanted Tilda to be her guardian ‘if she needed one’.

‘They haven’t taken any notice of this either. In the hearing, she didn’t really get to speak very much at all.’

Tilda fears Zena’s health will deteriorate now the public guardian has been appointed for another two years.

‘[Zena’s] human rights have been decimated, her entire family have been traumatised, and she is going to be facing more trauma. We only have her best interest at heart. We lost.’

Tilda says Zena has lost control ‘over every function of [her] life, including health, medical services and access to her family’.

‘We will have to ask permission if we want to speak to her, whether or not we can take her out to coffee. It is beyond devastating, and she won’t understand.’

Jai

Jai is in his 60s. He has vision and hearing impairment and epilepsy. When he goes out Jai uses a guide dog to help him see, and is accompanied by a support worker in case he has a seizure.

‘I have sudden blackouts, seizures, and I don’t know where I am,’ Jai told the Royal Commission. ‘So when I come to I just don’t know where I am. I’m bewildered, lost.’

The NDIS supports Jai, but recently it cut funding for his guide dog.

‘They’ve relabelled [the dog] as an assistance dog, not a guide dog. I’ve had to battle to fight or to get the money back for [the dog] because everything I’ve been doing I’ve been paying out of my own pocket. And it’s very hard on a disability pension.’

Jai said when he complained, an NDIA representative suggested he get a job.

‘I tried to explain to her that, look, no-one will employ a person who has seizures and is out of action for two to three weeks. I’ve been trying for years to get a job.’

Jai said some of his funding plans appear to have been ‘cut and pasted’ from other people.

‘There’s been such a rush job been done on some of these plans ... I’ve had someone else’s plan put into mine where I needed showering and toileting.’

Jai said his funding’s often not enough for his needs, but feels NDIA staff demean and patronise him when he asks for a review.

‘People on the NDIS are treated more like numbers.’

Keir and Sally-Anne

Keir is in his late teens. He has intellectual disability and attention deficit hyperactivity disorder, and recently moved into supported accommodation.

‘He thought he was going to live with mum and dad, that’s me and my husband, forever,’ Sally-Anne told the Royal Commission. ‘But he didn’t understand, you know, we’re both [over 70].’

One day, a support worker phoned Sally-Anne to tell her Keir’s ‘girlfriend had arrived’.

‘He will take anybody in. He’s so, so vulnerable ... and the next night she took him to a motel and he stayed with her in this motel for quite a while.’

The service provider told Sally-Anne that Keir couldn’t live in the house anymore.

‘He’s got a disability and I thought they should have been a little bit lenient ... So where do we move him to? We had nowhere. There weren’t many options.’

The service provider offered him another house more than an hour away.

‘It was not a good place for [Keir] at all ... He had another homeless girl who was coming and sneaking in through the window of a night. They had drugs coming in ... The house was an absolute pigsty.’

Sally-Anne said the support workers let homeless people stay in Keir’s house, telling her they ‘had a duty of care’ to help them.

‘My husband says it’s a tin-pot show ... We were concerned what was happening to [Keir], but we kept on saying to ourselves, “What about other kids who have come out of the system like [Keir] and gone into [this service provider]?”’

Sally-Anne said that at one point Keir had little food because the support workers lost his credit card. They also mismanaged his medication.

‘He was given his night-time medication of a morning, which was sleeping medication.’

Eventually, Sally-Anne brought him home and found a new service provider.

‘He’s in a house by himself now and it’s only got two bedrooms and ... it’s much better, much better.’

Eliot

Eliot is in his 20s. Doctors diagnosed him with Asperger's syndrome just before he started primary school.

'I hadn't expected school to be so confrontational and adversarial,' Eliot told the Royal Commission.

When Eliot started high school 'the bullying happened pretty much immediately' and teachers regularly punished him for retaliating.

'The teachers heard the shouting and everything, came over and of course I was the one who ... seemed to be the instigator.'

Eliot said he struggled to find a school counsellor to talk to.

'It was very, very difficult to get an appointment with them. And they were spread across three or so schools ... and particularly if I was having a really bad day and I really needed to talk to someone with that kind of specialty training, I never really got that opportunity.'

Things weren't much better when Eliot went to university.

'I did tell them on the first day like, "Look I am autistic. It does take me a little bit longer to get these kinds of things. Is it possible to simplify it?" Their initial response was like, "You're autistic? What are you doing here? Why are you doing this?"'

Eliot studies health and in his first year at university was placed in a high-needs aged care home. He was required to apply skills in which he hadn't yet been trained, and 'basically had a meltdown'.

'It was all completely different to what I've been trained for and what I'm told. And so the outcome of that meltdown was essentially I got taken off the placement.'

His university supervisor asked him to explain why he 'shouldn't be expelled'.

Eliot said that after several meetings the university agreed to change its policy on disability and to provide more structure for students on work experience. Eliot completed his next placement and has 'passed everything else so far'.

'If I can help future generations in not having to go through that I reckon that's a pretty good thing,' Eliot told the Royal Commission.

Kamran

Kamran is in his 30s. He has a degenerative eye disease and uses a cane. He arrived in Australia nearly a decade ago and claimed asylum.

'I have a political profile with the government [of the country of origin] and this government ... it has an agenda,' Kamran told the Royal Commission. 'It's not safe for anyone. It's treats harshly anyone that disagrees.'

Doctors discovered Kamran's eye disease a few years after he arrived, while he was still in detention. A few years ago the government released him on a bridging visa that's now expired. It rejected his application for a visa to remain in Australia, which means Kamran can't get adequate support for his disability.

'I was working, like, two years ago. I was working very hard, but no-one [is now] giving me job with my vision. My vision is really bad ... I'm going to be blind soon and I have no support. I have nothing.'

Kamran isn't eligible for Medicare and relies on a charity to help him pay to see the doctor. He gets a Centrelink payment, but has been told that's about to stop.

'They cannot deport me, but they can make it hard for me. If I [don't] return back to my country they make it hard for me. So they stop my payment, they stop everything ... even NDIS and agencies [are] like that, because I don't have visa they don't help.'

Kamran said he's also being told to leave his subsidised room.

'If I rent a one-bedroom [flat] I should pay rent at least per week \$150 or \$200. And if they stop my payment, I can't pay my rent. So I'm going to be homeless or I will be on the street or somewhere because I have no-one here in Australia to be honest.'

Kamran said he doesn't require 'a whole lot', but needs at least some support because he can barely see.

'They're giving me so much stress and they put me under pressure right now and I'm really depressed now.'

Freddy and Kayla

Freddy is almost 20 and has an ‘extremely rare’ brain disorder that causes intellectual and physical disability and psychosocial impairment.

Freddy is on the NDIS and has complex needs. He is incontinent and has no ability to care for himself. Kayla says he’s had ‘some pretty rough handling’ from some support workers.

‘One day I went [to his home] and he’s sitting in a pool of urine, cowed on the couch. He had two nappies just tied to him. The worker was leaning against the wall with his arms crossed. And I just sat down and said “Do you want to come home with mum.”’

A few years ago, Freddy returned to Kayla’s care after living with his father. She lives in a regional area and found it hard to get ‘reliable supports’ through the NDIS.

‘Support workers basically don’t want to travel out here ... And I had no support.’

Kayla turned to child protection for help.

‘So they took him. They said we’ll give you some rest and we’ll get you some supports built up and we’ll get you a new plan and we’ll get this all sorted and [Freddy] can live with you.’

The department put Freddy in accommodation with a support worker from a disability services provider part of the week.

‘These people ... They put him in motel rooms with broken doors and smashed fittings in showers. I’d go there, there would be, you know, plates of food dried, not covered and I’d say, “What, is that what you’re feeding my son? What happened to all the veggies from the garden I’ve bought in?”’

Kayla said the agency staff were poorly trained and ‘didn’t speak English’.

Once, Freddy had a seizure while he was out with a support worker. A stranger rang her and said, ‘If that’s your son, he’s lying under a car in a carpark ... The carer is not coping.’

A couple of years ago the NDIS ‘kicked in’ with all of Freddy’s funding, including specialist disability accommodation ‘to share with one other’.

He is still waiting on the housing and ‘two workers at all times’ outlined in his plan.

‘We’ve got a provider but he’s in a private rental now at great risk to himself and others. He put his head through a window last week, picked up the glass and smashed it on his head.’

Freddy is currently on his sixth NDIS plan.

‘That lasts eight weeks. So we have no security ... He just needs help to find what’s best for him because I haven’t been able to. I’m still fighting. There’s nowhere to go.’

Josue, Maxie and Emiliano

Josue, in his mid-20s, is autistic and has dyspraxia. He receives NDIS funding that allows him to live in specialist disability accommodation (SDA).

His brother Maxie, who has the same conditions, also gets SDA funding from the NDIS.

Their father Emiliano applied for the brothers' funding at the same time, but it has taken several years longer for Josue's to be approved.

Emiliano explained that eligibility for SDA funding depends on a report from an occupational therapist (OT), who assesses the level of support that is needed. The OT reports for the two young men differed slightly, allowing Maxie to be approved but not Josue. Emiliano applied for Josue the following year and was turned down again. He then requested a review of the decision.

'So that was put forward ... earlier on this year, only to come back with once again an answer of no,' said Emiliano.

He decided to appeal the decision in the Administrative Appeals Tribunal.

'Right from the word go, I was determined to go through to the end.'

Emiliano has numerous concerns about the process that followed. Chief among these, the NDIA failed to tell him it had reviewed its own decision and overturned it.

'Positive result – I knew nothing about it.'

This information didn't emerge until several months later when the appeal was underway.

'It's incompetence or manipulation. It's one of those two things,' Emiliano told the Royal Commission.

In preparation for the appeal, Emiliano had filed several Freedom of Information (FOI) requests. The documents he received from the NDIA showed forms incompletely filled out and outdated information copied from one place to another.

'So therefore, I call that incompetence,' he said.

But he suspects something more.

'You know, they'll say they're there to help. But then, the reality is, "I'm going to force you to go through this arduous process right till the end, right till [the appeals tribunal] so that if you want to get justice, I'm going to make it as hard as possible for you.'"

Emiliano had to make the FOI requests because it was the only way to access the information he needed.

‘The plan review rejection letters from SDA, specialist disability, are not sent to participants. They’re not. So they never know what’s actually happened without lodging a Freedom of Information request. And how many lay people would have the wherewithal to – to even know what to do or even know that there’s such a process in place?’

The case was ultimately dropped, but Emiliano ‘tried to force the issue of getting that information’. The NIDA still did not want to hand it over.

‘Why can’t I still have the information that’s really important to me for the future, having gone through all this pain?’ Emiliano asks.

Emiliano said the resolution process seems designed to ‘batter’ the ‘opponent’.

‘They’ve designed it to make it as hard as possible so people give up. Now fortunately, with myself, I’m never going to give up ... But what about the others? That’s who I’m here to represent. It’s the other people that are not so fortunate.’

Zaire and Navita

Zaire, mid-20s, has a rare chromosome disorder causing intellectual disability and epilepsy.

For the past 10 years he has lived in group homes.

‘I can’t tell you how much it pains me,’ Zaire’s mum Navita told the Royal Commission, ‘to have to entrust the care of my son, who can’t speak, to people I don’t know.’

Zaire frequently plays with his penis.

‘He doesn’t masturbate, it’s just like a toddler, he’s got his hand down his pants a lot.’

Some years ago, Zaire was living in a home with three other young males who had high support needs.

Zaire walked into the lounge room, ‘flipped his penis out’ and started playing with it. A male support worker told him to put his penis back in his pants.

‘But Zaire doesn’t follow directions. He doesn’t really know how to follow directions very well.’

Zaire continued to play with his penis and the support worker started yelling at him.

‘Then he started to kick him and he kicked him and kicked him in the genitals until [Zaire] cried and left the room.’

A female support worker immediately reported the incident.

The provider ‘did all the right things’ and ultimately terminated the support worker’s employment.

Navita went to police who told her there was nothing they could do because Zaire couldn’t testify.

Navita didn’t push it any further, even though there was a witness.

‘I wanted [the support worker] to be rehabilitated rather than to be punished.’

Some years later, Navita discovered he was working for another disability provider.

She believes there needs to be mandatory checks for people working with vulnerable people.

‘He would have immediately been put on that list and not be able to wipe his CV clean and go and get a job with [another provider].’

A couple of years ago, Navita was in Zaire’s room getting some things. The support worker didn’t realise she was still in the house.

Zaire walked into the living room with his hands in his pants, playing with his penis.

A male support worker yelled at him 'in the most angry voice', telling him to get his 'fuckin hands out of his pants'.

Navita told him to stop abusing Zaire. He apologised, saying he was having a bad day.

When Navita got home she became concerned about what else must happen when she's not there.

She decided to contact the support worker directly to pursue her own 'informal restorative justice process'.

She told him how she felt hearing him abuse Zaire and wanted to make sure it didn't happen again.

'If you feel like you're having a crappy day, don't go to work because it's not fair for people like [Zaire]. They can't fight back, they can't talk back and it's really not fair.'

The provider initiated a disciplinary process, which they believed worked much more effectively because Navita had spoken to the support worker about how she felt.

'We need a process that can support us and support the workers to come together and resolve it differently and to get behaviour change in people.'

Mylan and Lya

Mylan, early primary school, is autistic and has attention deficit hyperactivity disorder. He lives in regional Australia.

‘The process of getting my son some support through the NDIS, getting an occupational therapist and a speech therapist, was quite a long process,’ his mum Lya told the Royal Commission. ‘It’s not easy to do when you’re so remote.’

A few months before Mylan was due to start school, he received his formal diagnosis.

Lya immediately contacted the principal and gave him the assessments.

‘His basic response was, “Aspie kids are cool. I’ve dealt with many over the years.”’

Slightly concerned by his comment, Lya provided additional sensory materials and resources. She followed-up with detailed transition documents prepared by the kindergarten teacher and Mylan’s therapists.

‘I felt that they treated me as if I was just an overactive parent and it was just dismissed.’

On the first day, Lya discovered the teacher and teacher aide hadn’t read any of the transition documents.

‘It just went very bad very quickly.’

Mylan started having meltdowns and running away.

‘It was sensory overload. He wasn’t coping ... There’s plenty of preparation that they could have done but they neglected to do that.’

At the end of week two, the school moved Mylan to a storeroom, away from the teacher and his peers.

‘That’s where he stayed for two terms,’ Lya said.

‘They just didn’t know how to support him and it was easier for them to alienate him and segregate him rather than be proactive and get some resources and get some assistance.’

The storeroom wasn’t heated and Mylan had to wear several jumpers and a jacket to stay warm.

In the playground, older students started bullying him. They called him names, teased him and would jump out and frighten him. When he reacted, they would take his photo, photoshop it and pass it around.

'It's just mindboggling how it can even happen in this day and age.'

The school started documenting Mylan's behaviours and 'tried to pin him as a badly-behaved child'.

Mylan was traumatised and couldn't cope.

His speech therapist and occupational therapist intervened. They worked with the teacher and provided games and resources to help Mylan integrate with his peers. The teacher acknowledged the resources were useful, but rarely used them.

In term 4 a new teacher started and moved Mylan back to the classroom.

'She's been brilliant in making really good adjustments and seeking further outside information.'

She stayed on as his teacher the following year, and 'a brilliant' new teacher aide started.

'He's a very intelligent boy and that just reflects the importance of having those people there who can support and who can make adjustments. A child with disability can actually be within a mainstream school, not a specialised school. He's doing really well, which I'm happy about.'

Zoya

Zoya, early 50s, has physical disability and vision impairment.

For the past 10 years she has only been able to work from home. She has 30 years of experience and multiple degrees, but finds it difficult to secure ongoing roles.

‘Labour hire companies get very excited about my CV,’ Zoya told the Royal Commission. ‘They pass it around. They show everybody my CV, and they’re like, “You’re going to be perfect for this job.” I don’t hear anything more because I do also share information about my workplace adjustments.’

Zoya now only shares information about workplace adjustments if she is shortlisted.

This strategy has been successful – she has been invited to interviews and shortlisted to the referee stage.

But even if she is the preferred candidate, as soon as she mentions the workplace adjustments she needs, she faces barriers.

Often, hiring managers tell Zoya the workplace adjustments are not a problem, but ‘you can tell for them it is not ideal’.

The barriers are systemic and hiring managers do not have the authority to address these barriers on their own.

Zoya said the public sector is the worst because of inflexible work-from-home policies.

About 18 months ago she was shortlisted for a federal government position.

Zoya told the hiring manager about her workplace adjustments at the start of the interview. The hiring manager said she may not be eligible for the position.

‘I even saw tears in the eyes of the hiring manager ... because she didn’t want to say I wouldn’t be eligible, but she didn’t know because there are policy considerations.’

The hiring manager then asked, ‘Should we start the interview now?’ Zoya said it was difficult to proceed without knowing if she was eligible.

‘I spent eight months applying for roles where the approval of my eligibility was with the secretary or equivalent. That is a lot to put on an applicant.’

Zoya wasn’t successful. She asked for feedback but never received it.

A few months later she applied for a role in the state public sector. The hiring manager was very supportive throughout the recruitment process.

Zoya disclosed her reasonable adjustments after she was shortlisted with one other person to referee stage.

The other person was selected because they had more experience in an ongoing role.

The hiring manager told Zoya even if she had been selected there would have been policy restrictions around eligibility because of her request to work from home.

The hiring manager is using Zoya's experience as a case study to explore a potential change in policy.

'People mean really well and I want to have those conversations with those people. I'm not putting in a complaint, but to see whether there's any pathways and any solutions that we can work together to find those adjustments.'

Some years ago, Zoya did make a complaint to the Australian Human Rights Commission.

'The Commission was lovely ... but the workplace proceeded to try and discredit me, and the way that they tried to discredit me was listing all the reasons why, with my disability, I wouldn't be able to continue with the role ... Lots of assumptions. Didn't mention any reasonable adjustments. It nearly broke me. And these rejections, they do break me every time.'

Lee-Anne and Selah

Lee-Anne, now 10, was diagnosed with autism as a three-year-old.

Her mum Selah said that as a little girl Lee-Anne was ‘bubbly and just full of life’, unafraid of anything.

‘She was just happy – like, really happy ... She enjoyed life just so much.’

Her parents could tell she was ‘really clever’.

‘She had the quest for knowledge ... and she just wanted to know more and more, so she was very, very interested in learning,’ said Selah.

In preschool, Lee-Anne spent three days a week in a mainstream classroom and two in a special class. At the end of the year, the report from the mainstream class said she was doing well. She could count to 20 and was working towards 25. Selah was concerned.

‘I knew [Lee-Anne] at two years could count past a hundred, so ...’

Hoping for a more engaging learning environment, Selah enrolled Lee-Anne at a different school, one with a special learning program (SLP). Staff promised Selah that Lee-Anne would be in a mainstream classroom most of the time and, if at times she couldn’t cope, could learn in a ‘home room’ with other autistic kids.

The school promised, but didn’t deliver.

‘They said it was fully inclusive, it was supported, it was emotional support. Yeah, and it wasn’t.’

At a parent-teacher night, Selah asked Lee-Anne to show her the main classroom. She discovered Lee-Anne had no desk or place to sit, none of her work was displayed and she didn’t know any of the other children. Staff told her Lee-Anne couldn’t cope in the classroom so had been spending all her time in the home room.

By year 3, Lee-Anne had hit ‘rock bottom’.

‘This is a kid that came from an early intervention – she had her independence, like packing her bag, putting her homework in her bag, going to library, getting a library book, going to assembly,’ Selah said. ‘[At school] they taught her helplessness.’

““Oh no, she can’t get through an assembly.” “No, she’s not capable of getting a library book out.” “She doesn’t want to do sport.” Like, it was all these things that [Lee-Anne] couldn’t do – not, “Oh, she’s finding that difficult – we’re going to support her through this by doing this, this and this.” ... All her independence went, all her spark went. She was no longer a happy child.’

One day the coordinator of the SLP complained to Selah about Lee-Anne’s ‘disgusting’ behaviour. Selah asked for details and the coordinator showed her videos of Lee-Anne in the home room.

Selah was shocked by what she saw. The educational aides were escalating Lee-Anne’s behaviour, handling her roughly when she became distressed, evicting her from the classroom and showing no kindness or softness towards her.

‘I just thought, “They don’t care about my child. I don’t think they even like her.”’

Selah organised for Lee-Anne’s psychologist to observe the class. The psychologist thought Lee-Anne was being mentally abused.

‘Every behaviour that she exhibits is her surviving, is her, like, just trying to cope with what she’s going through,’ she told Selah.

Selah asked the school to modify its approach with Lee-Anne, but the SLP coordinator refused.

Selah made a formal complaint to the education department. Investigators never interviewed Selah or asked to see the videos they knew she had. Nearly two years later, the department told her they did not find evidence to support her complaint.

Lee-Anne is at a different school now, mostly doing well in a mainstream class with a teacher she likes and respects.

‘There’s a lot of deficits she has because of what she’s been through ... Not because of her autism, but because of the way she was treated.’

Zacharie

‘A lot of changes need to be made in this industry because there’s a lot of things that aren’t right.’

Zacharie, early 30s, is autistic. He has Tourette syndrome, attention deficit hyperactivity disorder and intellectual disability.

As a teenager, he occasionally stayed in respite accommodation. One weekend, a male staff member sexually assaulted him.

Zacharie didn’t tell anyone.

His mum, Jackie, noticed changes in his behaviour, particularly before and after staying at the respite centre. She thought he was just being naughty.

Sometime later, Zacharie told his mum what happened. He told the Royal Commission his mum helped him report the assaults to police.

‘Nothing much happened,’ Jackie said, ‘because it was too far down the track, after the fact. There was no actual physical evidence. So he didn’t get charged.’

The provider sacked the staff member but he continued to work in the industry.

A few years later, Zacharie moved into supported accommodation. He said most providers and staff are ‘an absolute disgrace’.

For the last few years he has been living by himself in a community residential unit (CRU) attached to a group home.

‘I’ve gone through a lot of harassment and bullying since I’ve been in CRUs. And most has been harassment and bullying by staff members.’

Jackie believes staff target Zacharie because he’s ‘a great advocate for all the other residents who are non-verbal and high needs’.

‘If [he] sees something not right, he’ll report it immediately.’

Not long ago, Zacharie saw a staff member use unnecessary force with one of the residents. He immediately reported it and the staff member was dismissed.

But the harassment and bullying escalated.

‘I’ve had staff that make false allegations against me to try and get me arrested for bullshit,’ Zacharie said.

Jackie said staff antagonise Zacharie 'to the point where they escalate behaviours of concern'.

'Then they call the police. They've very good at doing that.'

She believes staff are not properly trained and don't understand how to work with people with complex disability.

'There's no consistency ... The other house handed over a very large document for his behaviour support plan. I guarantee not one of the staff read it. They didn't do anything that we suggested that they should do to avoid behaviours and to have a harmonious-type house.'

Jackie is concerned staff are not giving Zacharie his medication.

He is supposed to have 20 hours of community access support, but staff refuse to be proactive and leave him 'to meander around'.

Recently, staff started spiking his food with chilli. When he complained they stopped making his meals.

After another complaint, they told him he could eat what everyone else is eating – most of the other residents eat soft or pureed food.

Lately, the provider has been trying to get him to move out of the unit and into the house because of a funding cut.

Zacharie doesn't want to leave his unit and his mum says she 'will not agree for him to go into those sorts of homes again'.

Lud

Lud has ankylosing spondylitis (AS), a type of inflammatory arthritis that affects the spine. He is autistic and has attention deficit hyperactivity disorder.

Lud is in his early 50s. He was diagnosed with AS about 15 years ago, soon after he started work in the call centre of a large company. His employers were not sympathetic when he asked for time off to attend specialist appointments and for modifications to his work environment.

Lud said their response to such requests was a 'defensive, reactive posture'.

'As soon as I put my hand up, I've been dragged into formal meetings and ... issued warnings for things. But it was just me trying to put my hand up and say, "Look, I need some help here."'

Lud believes his employers could have seen meeting his needs in the workplace as an opportunity.

'Where we can actually accommodate someone and get it right, and set a really good example – but they don't see it that way.'

Lud's role at the company eventually became 'untenable' and he resigned.

The workplaces he has been in since have also largely failed to understand or accommodate his needs.

At one job, he asked to work fewer hours. His managers said they needed him to work full-time.

'I said, "Thanks, no more, I can't handle that. It's too – physically too much. It's too tiring, too exhausting on me." Because one of the big side effects of ankylosing spondylitis is severe physical and mental fatigue. And when you get to that point where the fatigue kicks in, you have no productivity at all. It just can't happen, it just doesn't work.'

At another, the HR team lost a letter from Lud's medical specialist so his employers never saw it and didn't realise he had a disability. His manager found out for the first time when Lud asked for time off for a medical procedure.

'He basically said to me, "Last time we had someone with ankylosing spondylitis, it was a bit of a disaster. And had we have known, we would have made a different decision."'

When the employer tried to curtail his contract, Lud complained to the human rights commission. It found in his favour. The company's occupational therapist drew up a plan for Lud but left her job before it was implemented. Lud left too shortly after.

Lud got his next job with the help of a disability employment service, again working in a call centre for a large company.

'The moment I got there it was a case of, "Oh, you've got ankylosing spondylitis. What's that? What do we do?" And it was just so vague, their responses were just so vague. I couldn't get specific answers to questions. They would just look at me, shrug their shoulders and say, "I don't know."'

After several months off to recover from major surgery, Lud received an email from his team manager.

'He basically threatened my employment.'

Lud complained and there were meetings with HR and the disability employment service.

'HR came back and said ... they had counselled him on this conduct, that it wasn't – not appropriate. And, you know, moving forward it wasn't to happen again kind of thing.'

This was only a temporary fix, however, and over time Lud's experience in the workplace deteriorated. He was harassed and bullied.

Eventually, Lud resigned.

'I just didn't feel safe there anymore.'

Lud believes many of the problems he encountered arose because of a lack of training.

'They just didn't know anything about discrimination, how it works and how it's supposed to be resolved,' he said. 'This is supposed to be employment basics 101, is discrimination training, and it's not there.'

Wes

Wes is in his 60s. He has an acquired brain injury and uses a wheelchair. He also lives with mental health issues.

'I was hit by a semitrailer and that's why I ended up partial or incomplete paralysis,' he told the Royal Commission. 'Which brings you on a hell of a ride. I went to hospital and I was there for six months.'

Before the accident, Wes was 'mistreated and misdiagnosed as [having] a mental illness'.

'I'm a little bit on the autism side. So I still had a disability and I was working with other people with disability, from Down syndrome through to everything. Poor people straight out of the psych ward.'

Previously, Wes was on a home care package and waited two years to access the NDIS. He had a lot of trouble navigating the process.

'They just said, like, 'Here's all the paperwork. Whamo, good luck with that.'" I can honestly say, from the bottom of my heart, this is the worst experience of my life.'

Today he lives at home with 24/7 care but said the battle is not over, particularly getting equipment 'to make life easier'.

'We've still been trying to get the stuff that they approved ... but either it couldn't be supplied or, you know. Like, there's 100 reasons they've got, none of which make any sense.'

Wes has been waiting for more than a year for upgrades to his wheelchair.

'I've been stuck a few times ... I need new tyres and some other things fixing.'

He says the companies have 'a monopoly'.

'I know someone that paid for a wheelchair that should've been 12 grand. \$28,000 on the NDIS. It rips my heart out.'

Wes had trouble with two support workers 'stealing' from him.

'They ended up invoicing under their own name. They weren't going through the provider ... Because all you need's a name here to be a carer in Australia ... My plan manager shut the door on them.'

Wes tried to get the NDIS Quality and Safeguards Commission to look into it.

'And those are like, "I don't know what they've done wrong." And I've just gone like, "Well mate, we got a problem. That's what I need to relay to ya." ... Would you not call it the rort system? It's an absolute diabolical mess.'

Wes said the 'training of carers' is a problem. He finds his support workers put him 'at risk' with the busy places they take him too. He'd much rather be doing outdoor activities like he used to.

'There's so many things I had to stop being involved with since the truck hit me. Trying to work at my rehab. They said, "You'll only need to live like that a year or two." It's been 15.'

Jed

Jed is autistic and lives in a regional area.

‘I became very involved with the disability sector because I’ve got a son with autism,’ Jed told the Royal Commission. ‘So I became more interested in how disability is reflected between government departments and people with a disability.’

After graduating from university, Jed started a postgraduate degree looking at autism in society. He said the university didn’t provide much support.

‘Even though I was, from day one, registered ... as a regional person with disability, no-one approached me about what my needs were or approached me about different alternatives and study format. It was just I was on my own.’

Jed said the university didn’t seem to have adequate disability policies and procedures in place when he enrolled.

‘I was given the line [that] it’s up to me as a person with disability to tell them how they can best support me.’

Jed struggled to find supervisors with any background in disability. He felt he was writing his thesis to educate his supervisor, who didn’t seem to understand autism. The university told him his slow progress was his fault and that he wasn’t a very good student.

When he finished his thesis, the university gave him a large amount of administration that he struggled to navigate.

‘Probably my expectations may be too high. But it should be, “Okay, well this person’s flagged with a disability. Maybe we should sort of give them a hand to help them jump through the last hoop.”’

Jed’s PhD examiners, ‘internationally renowned in the disability sector’, praised his thesis and approved it with no amendments.

He now works in the disability sector.

‘Beforehand I was just a bloke with good ideas. “Oh you’re this person with autism.” But now I’m a doctor. “Oh you’re a doctor.” So people seem to be listening to me now.’

Vivien

Vivien is in her 50s. She has cognitive disability and complex post-traumatic stress disorder. She had a stutter as a child, but it was resolved after treatment.

'I went in [to a shop recently] and I spoke to the lady and the lady looked at me like I had six heads and I'd spoken in another language,' Vivien told the Royal Commission. 'My stutter had come back ... And obviously it was quite noticeable because she'd obviously just not accepted what I had said or not understood what I had said.'

Vivien had had a stroke.

Now, Vivien says, she's afraid to go out because of the way people react to her stutter.

'People would avoid serving me because they thought that I was actually drunk ... Talking on the phone even became an unpleasant experience, and so the stutter that I had became worse.'

Vivien self-manages her NDIS support plan, but struggled after her stroke to apply for a new plan. Vivien said an NDIS representative recommended a support coordinator who wasn't registered with the NDIS and seemed 'obsessed with money'.

'I remember wanting to know about the invoicing and know exactly, you know, what he was doing for me, how he was being paid. And he made it out to be too hard, you know, that he couldn't do that.'

When she was given her new plan he 'worked it out pretty damn quick' that his funding was being cut.

'So immediately there, "Oh we need to appeal this."'

'He found an [occupational therapist] OT that was a friend of his and she came and did a shocking, shocking assessment of me. And there were lies in that assessment and his explanation to me over that was that's how they do it – you have to say ... that it's really bad because that's how you get more money.'

Vivien said the OT, for example, reported that she was incontinent.

'That sticks with me until today in my plan, that I'm incontinent. I am not incontinent.'

Vivien said her support coordinator was also supposed to find her a physiotherapist to help her recover from the stroke, but he never did.

‘He took away my choice and control. He just took away anything like my respect that I had built up, my self-respect. He took it all away.’

She sacked him and complained to the NDIS.

‘Someone was going to call me, and that went on for three weeks and no-one contacted me.’

Vivien said that when she eventually did hear from the NDIS, an officer advised her to ‘stay away’ from unregistered providers.

‘In saying that, then why have a gate open for unregistered people? Why even allow unregistered people in?’

Vivien said her new coordinator is ‘brilliant and registered’.

Leila

Leila is autistic and has a hearing impairment.

School was tough, she told the Royal Commission, as ‘they didn’t really understand what autism spectrum disorder was’.

The private school had a deaf integration unit, which Leila attended for all her schooling.

‘They help you with your homework. I’m willing to do some classes at lunch time ... But there was a teacher who didn’t want me to learn, because I was too slow or whatever. It was just a small class ... and I think that she should know ... children learn at different paces.’

Other students bullied Leila.

‘One thing is that I found a discrimination with racism ... and disability.’

She ‘didn’t particularly do as well in school’, she said, because she was ‘traumatised’ after another student sexually assaulted her.

‘And [the school] did not support me in any way shape or form,’ she said. ‘The principal ... she didn’t really make an effort at all. There wasn’t like anyone that was there to support me and the teachers were just annoyed about it and they didn’t really understand.’

Leila turned to a school counsellor for help, but said even they took ‘no action’.

‘They didn’t try to decipher what I was trying to say ... Or make an effort to help me understand what happened to me.’

For the next couple of years, Leila had to study with the person who had assaulted her.

‘Then the student was expelled from school ... They could have stopped her earlier from doing these things. Instead of having these behaviours and repeating it and stuff like that, you know.’

Leila went on to TAFE and university and graduated. Now in her 30s, she struggles to find permanent work.

‘I do technology roles ... I think the majority of the employers that I’ve had aren’t properly trained in neurodiversity or hearing impairment and, you know, just giving reasonable accommodation.’

In one office, she thought her employer had taken her needs on board, but they never gave her any supports.

‘So you do have to go it alone quite a lot. That’s not satisfactory from my side. I felt kind of exploited.’

Leila had to leave after a couple of years because 'it was just difficult to keep up'.

Leila thinks the lack of 'diversity and inclusion' at school have led her to miss out in the workplace too.

She lives with her parents as she can't afford to live independently on the Disability Support Pension.

'When I'm not doing full-time work ... I do stuff on not-for-profit organisations, just – yeah, just helping out.'

Kelsea

Kelsea is in her 50s and has post-traumatic stress disorder (PTSD) and a stutter.

'I had an accident [several] years ago and now I've got a permanent disability in my upper limbs,' Kelsea told the Royal Commission.

Kelsea used to teach music and was a keen gardener, but the accident 'really put a stop [and] really changed [her] life around'.

The NDIS supports Kelsea.

'I can't overstate how grateful I am because, yeah, without the help from NDIS I would be lost.'

Some parts of the NDIS, however, are 'problematic'.

'I feel that anyone can walk in and put an ad up and call themselves a support coordinator. They don't need to do any course or any training and they've got no-one that they're accountable to ... I think it's a sitting duck for people who [are] looking for chances to exploit things.'

Kelsea's first support coordinator offered to help her prune her trees.

'She was very keen on these tree people and said ... "Just trust them. They definitely want to do the right thing. They've got your back." She was very keen on me not to get any more quotes.'

The company ignored Kelsea's detailed instructions, cut down her trees and removed a section of garden.

Kelsea feels she's being exploited.

'I was having complex trauma and maybe my speech might mark me up as a good target.'

Kelsea lost trust in her support coordinator and found another one. This person would send her invoices, but 'wouldn't explain what any invoices were for'.

When Kelsea asked for itemised invoices, the coordinator said it would cost 'too much money for her to spend the time to extract all of the breakdown of the info'.

One time, Kelsea said, an occupational therapist 'tricked' her into getting assistive technology she didn't need. When she told the NDIA, they suggested she advertise it 'on Facebook groups and sell it there'.

'But it just feels that's a bit dodgy.'

Kelsea said other aspects of her NDIS funding felt 'strange', but she wasn't allowed to see her NDIS plan. Instead, she had to apply for it under the Freedom of Information Act.

'I accessed my NDIS plan and I've realised why my plan was quite strange ... [It was] because it's based on someone else's disabilities that had nothing to do with me.'

Kelsea said she's 'super nervous' about asking for a review because 'in the peer groups there's a common theme of people's plans being slashed'.

'And I don't like arguments or fights or confrontations ... It physically causes stuff to go on in my body.'

Wolfie and Marianne

Wolfie, in his mid-20s, is autistic and has intellectual disability.

Wolfie lives at home with his parents and works two days a week in supported employment, which he enjoys.

His mother, Marianne, says that while the wage is low – just \$6 an hour – she doesn't want to see supported employment abolished.

'If [Wolfie] didn't have this option, he would technically be unemployable. He needs that hands-on, he needs that guidance, he needs that structure that a normal workplace would not be able to provide him,' she said.

'Tonight he'll get home and he will prompt me to say, "What happened at [work]?" And I'll go, "Oh, what did you do at work today?" "Did the dustbins," [he'll say]. And you can see he is proud of what he's doing.'

Wolfie receives NDIS support, but Marianne has had to go to court to access his full entitlements after plan reviews resulted in reduced funding.

At the moment she is in dispute with the NDIA over housing for Wolfie. He has a friend he wants to live with, and the families of both young men have put together a detailed proposal for the NDIA about how this could work. The NDIA wants to make significant changes to the proposal, which would mean it no longer meets Wolfie's needs.

'All these people who are making these decisions at the NDIS haven't met [Wolfie]. Especially since COVID, because we don't do any plan meetings face to face anymore. None of them know [Wolfie].'

She is frustrated by their lack of understanding, their inefficiency and the difficulty of accessing information from them. Several times they have lost important paperwork they requested. As well, she said, 'they make up stuff'.

She recalled being at a case conference and asking the NDIS lawyer how certain calculations were done.

'The lawyer sat there and said to me, "Well, we spoke to the SIL [supported independent living] provider, and ..." And I said, "Stop there. We don't have a SIL provider. So how did you work out the funding?" And they said, "Well ..." And I said, "Well, I'll tell you. I've done a Freedom of Information request and I've got a copy of the timetable that you guys made up out of I don't know where – with no information from me – because it's totally incorrect. And your calculation's been made on totally false information.'"

Marianne said the NDIS used to be different.

‘I’ve seen the change. I’ve dealt with it from day dot. And in the beginning, it was very – very inclusive. It was about having a conversation. It was about – the planner would sit there with [Wolfie] and me and get to know [Wolfie], and have a conversation about what he wanted to do through life.’

These days, she feels her dealings with the agency might give her a heart attack.

‘They just are so untrustworthy. They make it up as they go along, they don’t care,’ she said.

‘I mean, it’s not a matter of not knowing the rules of the game. I don’t know which game I’m playing half the time. Do I need a bat? Or is this a game where I need to shoot a ball in a basket? And then this week I’m shooting between the two posts ... It’s constantly moving and changing, and there’s no sense of solid ground to be able to be confident that in – you know, that [Wolfie] will be supported to have the life he has the right to have. And that’s with me fighting tooth and nail. What’s it going to be like when I’m not here to do that?’

Cee and Karyn

Cee, late teens, started to self-harm and have suicide ideation at 13.

She was diagnosed as autistic with borderline personality disorder, attention deficit hyperactivity disorder, depression and anxiety.

Cee would 'slice herself' in front of her family.

'Our whole life was controlled by lockboxes for everything – medications, knives,' her mum Karyn told the Royal Commission. 'It was hell.'

Karyn spoke of the difficulty finding supported independent living (SIL) respite.

'It doesn't exist for a girl under the age of 18 in our area. In fact, as a girl over the age of 18, it has been quite difficult.'

Eventually, through a new provider, Karyn found SIL accommodation for Cee with one-on-one support.

Cee loved it because it was in a rural area with farm animals. But the support worker would forget to give Cee her medication and let her stay up until 2 am.

After a short time, Cee moved to a brand-new five-bedroom house.

She was their first female client, and for a time their only person in the house. All the support workers were male.

One night, Cee woke up with a man standing over her.

'There was just no justification for it. None of these houses have locks on the doors, which I don't disagree with. But I do disagree with them behaving like there's not a lock on the door.'

Cee asked for female staff but the provider refused.

She refused to take her medication, and staff believed they were powerless to act.

'We know the medication wasn't administered accurately because of how it was dispensed,' Karyn said.

Cee's behaviour became more and more erratic.

'She deteriorates really quickly and becomes worse and worse. She's not eating, she's not medicated. She went through complete withdrawal and resulted in the health problems,' Karyn said. 'She started eating paper again. It was a lot of cries for help. There was cuts on her arms.'

Cee was admitted to hospital.

Following discharge, she moved to a house almost two hours away.

During COVID 19, Karyn wasn't able to visit.

She had to organise the internet and a phone for Cee, even though the provider was charging for internet and phone services.

Staff made half-hearted attempts to administer medication and didn't keep any medication records.

They refused to pick up Cee's medication from the chemist – Karyn had to beg the pharmacist to drop it off.

On overnight shifts, staff would go to sleep and leave Cee's medication in a lockbox.

'If she woke them up they would yell at her.'

Cee started going to the toilet in the backyard because her toilet was filthy and no-one would help her clean it. Instead they left a bucket of bleach for her to use, despite knowing she was suicidal.

'There were faeces all through her ensuite, right next to her bedroom.'

Staff allowed Cee to have a pocket knife, which she used to self-harm.

'She was left alone in a [hospital] waiting room with all of her mental health issues. She's severely depressed, she's suicidal. The police have had to come.'

Karyn made a complaint to police about the provider. They agreed there was neglect but said they couldn't act because they didn't have jurisdiction. Police suggested she contact the NDIS Quality and Safeguards Commission.

Karyn discovered the provider had no previous experience in disability.

'The NDIS is a goldmine for them,' she said.

Cee moved to a house about 30 minutes away from Karyn.

Things are a little better and staff are able to get her to take her medication.

'She's ended up in an okay place.'

Clarke and Althea

Althea is a single mother with chronic fatigue syndrome. Her son Clarke, who's in preschool, is autistic, has attention deficit hyperactivity disorder (ADHD) and global developmental delay.

'He can't go outside,' Althea told the Royal Commission. 'He's still having issues with even leaving the house because of the wind, the sound, the noise, the smell.'

Althea said a paediatrician initially diagnosed Clarke with global developmental delay and ADHD, but he became violent as a toddler. No treatment worked.

'He was volcanic. I was too scared to walk around my house. To open my mouth. To look at him for fear of him lashing out bruising me and giving me fat and blood lips. It was flight of flight for me as a mum. He was my three-year-old son.'

When she sent Clarke to childcare, he lashed out at other children and she had to keep him home.

The NDIS supports Clarke, but Althea said the funding's not enough to help her control his behaviour. Althea asked the NDIS to review his funding and took her case to the Administrative Appeals Tribunal (AAT) supported by doctors' reports and an additional diagnosis of autism.

'They were asking why, you know, where's the evidence? When they had the evidence the whole time ... They just didn't, obviously, add it to his file or recognise it or read it. Like if they had have read it they wouldn't have asked the same questions over and over.'

Althea said she developed post-traumatic stress disorder dealing with Clarke's increasingly violent behaviour, the lack of support from the NDIA and the arduous appeals process.

During the appeal, the NDIA cut Clarke's support hours.

'And then that affects him, his behaviours, his eating, his speech, everything to do with the autism that affects him because they've cut the hours back.'

Althea said child protection began investigating Clarke's deteriorating behaviour and she was 'in a constant state of panic'.

'[Child protection] were also pushing for him to go to childcare, fully aware of his diagnosis.'

Althea said the AAT, however, 'kept referring to him being a normal child'.

'I realised after the fact, after the tribunal had finished, that they haven't read the evidence. They have not read the evidence. If [they had] they would not have kept asking me and saying these, like, intimidating things.'

Althea said that, during a phone conversation with the NDIA, she discovered they had failed to put Clarke's autism diagnosis on his file.

'I found out the global developmental delay was the only thing [on his file]. I said, "No, look." I went through the documents in my phone still ... [The NDIA staff member] added it to his file on the phone the same day.'

Althea said she's 'still waiting for the review to happen'. In the meantime, she's homeschooling Clarke because he's too anxious to leave home.

'I'm worried that ... we're not going to get the kind of help we need ... in a situation that we're going to have to live in, with the homeschooling and the education.'

Manfredo and Lola

Manfredo is in his 30s. He is autistic and has intellectual disability and epilepsy.

'He has congenital brain damage. He's functioning at a level of, if you want to put it bluntly, a three-year-old child with severe disabilities,' his sister Lola told the Royal Commission.

Things were a 'struggle for him right from the start,' said Lola. 'We were a great believer in the integration system. We didn't want him to go to a school for just disability. When he started school, the principal didn't want him there, he did everything in his power ... but we won the day.'

The principal told Lola, who was several years ahead, that she would have to look after Manfredo 'every recess and every playtime'.

When Manfredo soiled himself, they called her to come and change him.

'Because they wouldn't do it. One time I wasn't at school and mum got the call. She had to take him to hospital because he'd had third degree burns.'

During a parent-teacher meeting, Lola said the principal 'produced a grubby looking exercise book'.

'And he announced that this was for the purpose of recording everything [Manfredo] did wrong, and I was amazed.'

Manfredo came home from school one day indicating his chest was sore.

'There were marks ... It turned out that [a staff member was] you know, squeezing and pinching, twisting his nipples.'

Lola made a complaint and the school sacked the staff member.

Manfredo went on to a special school that did 'some individualised teaching with him' when he 'couldn't cope' in class.

'And that really helped him. They taught him to write his own name.'

But he really 'didn't improve', Lola said, because his paediatrician 'flatly refused to diagnose him with autism until he was 18'.

'He just learnt bad things ... terrible language and behaviour.'

The 'first good thing for him', was attending a day training centre a few years ago.

'The manager treated him like a human being. He concentrated on the abilities and [Manfredo] did wonders. He had good support from the carers.'

With NDIS support, Manfredo currently lives in a flat by himself 'with a great team of carers who look after him'. But the NDIA has warned his next plan will be 'stepped back' because Manfredo should 'improve his capacity'.

'They refuse to accept that his health condition can't be improved. He's losing his skills,' Lola said.

'In a lot of cases, they don't even read the reports. Something that gets to me, none of these people from NDIS have ever met him ... ever wanted to see him. It's Franz Kafka, that's what it is.'

Haifa and Adira

Haifa, late teens, is short-statured, autistic, has attention deficit hyperactivity disorder and intellectual disability.

Her first primary school was a special school and she did very well.

A few years later, her family moved and she attended a public school with a special unit.

‘The special needs teacher couldn’t gel with [Haifa],’ her mum Adira told the Royal Commission.

Haifa’s behaviour deteriorated and the teacher would ‘lock her up’.

The school tried to suspend Haifa, but Adira refused to let them. She told the school and education department she would continue to drop Adira at school because she had to work and Haifa had a right to an education.

The department found Haifa a place in a special school. She studied a range of subjects, played sport and participated in after-school activities with an NDIS provider.

‘She had a busy lifestyle,’ Adira said. ‘She had everything going for her. She was very good.’

One day, at an after-school activity, a man in his 20s touched Haifa inappropriately several times.

Haifa wasn’t yet a teenager and Adira hadn’t realised some of the participants were adults.

Haifa told the supervisor what was happening.

‘They say, “No, I think you’re imagining it.” They don’t want to accept it.’

Later, Haifa told a support worker who reported the incident.

‘Once you report it, then it becomes a chaos ... Police get involved ... Child protection unit gets involved.’

Adira said the provider refused to accept responsibility, which ‘was so wrong’.

Haifa became very distressed and refused to leave the house.

‘She is traumatised. And because of her trauma and because of the autism triggers ... she is a mess.’

Some time later, Haifa went to stay with her father for the holidays.

Her father refused to let her return home, and coerced her into telling authorities that Adira was abusing her.

Haifa managed to run away and told police she wanted to come home. She later told Adira that her dad had been locking her in the bathroom and leaving her there on her own.

‘She was a totally different person when I got her here. She was traumatised. She was self-harming ... She was breaking things in my house, she was cutting herself.’

Adira took Haifa to hospital where they sedated her and sent her home.

‘I had no psychiatrist – a big wait list. No therapist – a big wait list. I’m going round and round in circles.’

Haifa’s former school found a place in a suitable high school. But her behaviour deteriorated and she became more and more aggressive.

‘I sent her to hospital. They sedate her and send her back because she becomes physical. She hits the teachers, she hits me,’ said Adira.

One time, Haifa and Adira were seriously injured.

Police and child protection became involved and removed Haifa from Adira’s care.

Child protection struggled to find suitable respite accommodation because Haifa didn’t have sufficient NDIS funding.

‘I actually offered that she stays at my home and I’ll move out and they said, “No, we’ve got to move the child out under the legislation.”’

Eventually child protection returned Haifa to Adira.

‘I’ve got a behaviour therapist, I’ve got a behaviour practitioner, I’ve got a psychologist, I’ve got a speech therapist. These people are in [Haifa]’s life very much. We’ve worked very hard.’

But it is difficult to find support workers and every couple of weeks Haifa returns to hospital.

Hospital staff ‘don’t want’ Haifa. They disregard her disability and trauma and instead restrain and medicate her and then send her home.

‘There is no place for people with disability to go to for a few days if they feel very, very anxious,’ Adira said.

‘Every time she is discharged, she breaks things ... All the people that work with her, they’re exhausted. They go. She needs consistency.’

Roisin

Roisin is in her 40s and has complex post-traumatic stress disorder and spinal stenosis, which limits how far she can walk and how long she can stand.

'I was recently also diagnosed as autistic,' Roisin told the Royal Commission. 'I had been misdiagnosed with borderline personality disorder prior to my [autism] diagnosis which is quite common for women ... The lack of diagnosis has been incredibly damaging for me.'

Roisin is academically gifted, but other kids bullied her at school for her autism-related behaviours. Her family didn't support her and in her teens she began to self-harm and drink.

Since being diagnosed with autism, Roisin said she's 'actually understanding' herself for the first time in her life.

'Which is wonderful, but for [more than 40] years a lot of opportunities sort of passed me by.'

Roisin's children, in their teens and 20s, are also autistic. Both were well supported in primary school, but when they reached high school the education department denied them support because their IQ is too high.

'[The system] is not built to be delivered to kids that have communication issues,' Roisin said.

The school refused to let her children's therapists help them in class.

'We did provide [the school] with a bunch of reports and recommendations about how to support [them]. It turned out after the first year that we found out that none of the teachers have read them ... The level of care factor was very, very low. I think my son had a lot of potential which was missed, which was unfortunate. His confidence decreased over the years.'

Roisin said the poor quality of some service providers caused further damage.

'We've had speech therapists who might attend and meet my children who, due to their own trauma, have difficulty engaging and building a rapport with service providers. And they build relationships with my children and they leave after the second session.'

Roisin said her eldest son now refuses to see speech therapists.

The lack of appropriate support provided to her son at school or from service providers has made his anxiety and depression worse.

'He was unable to leave his room for about seven weeks at one stage. He was unable to communicate more than a sentence at a time for about three months.'

In his final years, the school told her to enrol him in distance education.

‘They didn’t want my son at the school.’

Roisin instead enrolled him in a vocational college, and he’s now studying at university.

‘My son’s quite amazing when it comes to his resilience. He’s a very special person.’

Since her own autism diagnosis, and with NDIS support, Roisin is also studying at university.

‘I’m doing a dual degree which I think is just, you know, rewarding. It has come from the last few years – having the NDIS plan, having more consistent support. So things around the house, I can’t organise my life to save it. Having assistance around the house really [helps] my ability to cope with other things.’

Irvin

Irvin is a First Nations man in his 50s. He was diagnosed with schizophrenia in his 20s and placed under a guardianship order. A few years ago he incurred a spinal injury and has been using a wheelchair since.

‘I was put on public guardian for, like, drug-induced schizophrenic psychosis,’ he told the Royal Commission. ‘When I started being a drug addict, it just sort of spiralled. I tried to get help. I went to a psychiatrist and I cried out for help, and he treated me like dirt. Just didn’t care about me.’

The psychiatrist put Irvin in a psychiatric ward under an involuntary treatment order.

‘They used that to sedate the Indigenous males. Like I’ve had a couple of friends that have died ... Midazolam’s a potentially lethal injection.’

About a decade ago, Irvin spent several years in prison.

‘I got out of jail expecting like ... I thought I had the guardianship in place to find me somewhere, a room. I rang up the guardianship, they said ... “You’re not under the guardianship anymore.” Public trustee paid a psychiatrist that never seen me, out of my funding, to do a report on me to remove the appointment of the guardian ... So it left public trustee in total control.’

Irvin wants the financial management order overturned.

‘Like I did need the public trustee in the beginning, but I don’t need them now. I can full control my life. I’m not a drug addict no more.’

But he can’t get the legal representation or health care required to free himself from the system.

‘No solicitor wants to know about, as soon as I mention public trustee ... And I haven’t got money to pay someone that’s willing to fight ... I’ve got the forms, but I’ve got no doctor to fill out the forms. One, like ... he said he can’t do that. He said I need a capacity assessment from a neuropsychologist, but I’m having trouble even seeing that doctor again.’

Irvin said the public trustee is robbing him of his life savings.

‘They steal money and they don’t care, they treat it like it’s their money ... They took all my super funds ... just disappeared. I’m entitled to that money ... It’s for my retirement.’

Irvin has been to the ombudsman ‘hundreds of times’ to complain, but can’t get help. One staff member told him not to ring the office ever again.

Meanwhile, Irvin said NDIS service providers are exploiting him financially – either overcharging or charging for services not provided.

‘Like, one of my support coordinators was doing things for me that I didn’t ask her, I told her not to ... to use my funding up.’

Recently, Irvin received invoices for a psychologist he’d never seen. When he questioned it, he said the provider ‘bullied’ him.

‘These NDIS providers, they just care about the money ... I just believe that they didn’t do the services they were doing. But the NDIS informed me that they’re going to take off my rights to approve the invoices because I said they’re corrupt.’

On another occasion, a provider billed him \$2,000 for 20 hours work to fix his wheelchair.

‘He come out, looked at my chair and stayed ... not even an hour.’

The NDIS paid the invoice.

‘That’s the NDIA. They regulate who’ll be a provider, who doesn’t ... And they only talk to me when it suits them, but if you’ve got a complaint against them, they try to shut you up, like, don’t want you to make a noise.’

Joni, Kale and Lizzie

Joni is in her 30s and has a cognitive learning disability.

'People take her the wrong way sometimes because she talks loud,' her mum Lizzie told the Royal Commission.

Joni's partner also has a learning disability. Several years ago, Joni fell pregnant.

'We were really, really excited.'

Joni had a son, Kale, but after the birth Joni needed an operation. She'd never had anaesthetic before and it made her violently sick.

'The nurse was really rude and she documented on the piece of paper that [Joni] wasn't bonding with [Kale]. But she just come out of anaesthetic and she wasn't, you know, with it,' Lizzie said.

Several weeks later Joni was home and 'looking after [Kale] perfectly fine' when she became ill again. She told a hospital social worker at the time that the pain was so severe she felt 'like burning the house down'. Doctors diagnosed postpartum sepsis, gave her antibiotics and 'put her in the mental health ward instead of being in a normal ward'.

'There are all these mental doctors around her trying to prescribe her all these tablets. And she, you know, was just about to die from this. She had the strongest antibiotic going through her.'

While Joni was in hospital, child protection officers took Kale away.

'I said, "Well I'm [Kale's] grandmother and [Joni's] mum and I work with children. I'm from a big family. I've brought my two children up on my own." And they said, "No, it's in our hands now."'

Later when Joni asked for Kale, a child protection officer told her she couldn't see him.

'[Joni] ran outside the building and down the street and I ran out after her to see if she was okay, because it's a hell of a shock.'

Child protection insisted Joni have a psychological assessment, which Lizzie said showed she's 'only got a cognitive learning disability'.

However, a judge ordered Kale remain in foster care for two years. Joni did a parenting course to try to get her baby back. When Lizzie said she'd care for Kale, child protection officers described her as 'toxic, malicious, vexatious'.

'They even wrote it down ... I just thought, "Oh God I can't believe it." And [Joni] said, "No, mum's not toxic, she helps everybody" ... I just think it's unbelievable.'

Lizzie said during another court hearing, a judge ordered that Kale be kept in care until he's 18.

'It just went over the phone because the pandemic was on. They said we couldn't come to court and it was a 10-minute phone call to say, well, the judge said, "I don't think either parent is capable."

Kale's still in foster care and Lizzie's worried about his mental health.

'It's [an] error of law what they've said about [Joni]. She hasn't got a severe impairment, ... She's got a cognitive learning disability and not severe impairment,' Lizzie told the Royal Commission.

'Even her partner, he's done nothing wrong either. Like they've taken this child for 18 years to these people and we're really worried. And no matter what we say to child safety they just disregard it.'

Joni is allowed to visit Kale, but a child protection officer told her not to call her son 'darling'.

'She can't mention the word "home" ... [Joni] doesn't know where to turn and she's just been so quiet and she just takes everything in and just keeps coping it and coping it.'

Sofia

‘I was saying to them, “Mental illness is an invisible disability.” They can’t understand that my brain is broken. I would have thought that a government institution would be leading, but it’s so far behind.’

Sofia is in her 50s and has lived with ‘very severe mental illness’ since she was 13.

‘I’ve had multiple diagnosis,’ she told the Royal Commission. ‘I have borderline personality disorder. I think about suicide every day.’

A couple of years ago, Sofia had her ‘worst year’ as COVID restrictions made accessing support services and housing difficult.

‘My mental health was just deteriorating really badly. I was having panic attacks ... I became manic for the first time in four years. I was hospitalised a couple of times because I was in such bad shape.’

Sofia had been doing housesits but ended up homeless.

‘And sleeping in my car. I slept in sheds.’

She couldn’t afford her antidepressants was often ‘a total mess’ after going without sleep for days.

At the time, she was studying a TAFE course online and asked TAFE to put strategies in place to help her.

TAFE had ‘no empathy at all’, Sofia said. She was ‘immediately shut down’.

‘There is a broad scope of reasonable adjustments that they could have implemented that would have made it very easy on them then very easy on me.’

Sofia turned to her course manager who ‘flat-out refused to talk’ to her. She kept knocking back requested changes to Sofia’s study plan.

‘She just tried to bully me ... She just didn’t understand maybe how mentally ill or how bad I could get ... She was just sort of throwing it back in my face and telling me that the lecturers knew what they were doing.’

Sofia said TAFE administration had no awareness about people with psychosocial disability facing homelessness. They kept pressuring her to buy things she couldn’t afford and were hostile to her.

'They just hated me from the word go ... They like isolated me ... They talked about mental illness in a really, you know, ignorant way.'

Sofia had to give up her studies because of the stress.

Around the same time, she was working as a trainer for a mental health organisation – 'teaching people with barriers to employment how to find work and stuff.'

She began to have suicidal thoughts at work.

'And one day, I showed up and I told one of my co-workers that.'

The next day, management called her.

'And they gave me a workplace appraisal that I failed, because I was suicidal.'

On another occasion, when she asked for help, her boss 'shamed her further' by calling the police.

Sofia resigned and is now unemployed.

'The amount of discrimination that goes on within workplaces is obscene ... I've developed social anxiety. I can't go to a shop now. I'm very isolated ... I'm still homeless.'

Sofia is now on a disability pension and is seeing a psychiatrist once a week as she awaits the outcome of her NDIS application. She hopes this will enable her to complete her qualification.

'For the most part, I can ... I can maintain my recovery ... for my illness. But trying to improve myself through studying ... If I want to try again, it's going to be really hard and I'm going to have to really be in touch with my mental health network, you know, my support services.'

Clara

‘There was some pretty horrific stuff happening in there. It was very much a culture of nobody speaks up.’

Clara is a support worker for people who are deafblind. About three years ago, she was regularly visiting an institution for people with intellectual disability.

‘I was going in with a young deafblind man as the peer to meet deafblind people in there and get to know them,’ she told the Royal Commission. ‘What we saw in there was horrendous. We witnessed what was a preventable death of a deafblind man ... He was very unwell. He was displaying quite distressing behaviours that day. Staff were incredibly rough with him when we took him back to his unit.’

Clara alerted management. So did a community access worker who visited in the afternoon but found him too unwell to take out.

‘He died that night. There was no medical intervention. Nobody called anyone ... There was never an answer to any of the emails or any of the concerns that we raised.’

Staff had always neglected the man, Clara said, leaving him in his unit ‘for hours and hours on his own’. They showed the same ‘lack of dignity, lack of respect’ to all other deafblind residents.

‘Nobody touched them. Nobody came near them. They didn’t have access to anything to drink. It was common to see them make their way to a bathroom and drink out of the tap. No toilet paper was provided. The dehumanisation of that place was incredible.’

Clara said staff ‘straightjacketed’ another deafblind woman and put her arms in restraints, ‘so that she couldn’t bend her arms and poke herself in the eye’.

‘It was considered a behaviour that she had ... Those behaviours are communication.’

When the institution closed, the government promised jobs to its staff.

‘And so those practices and those attitudes and that culture has just moved with them into group homes ... with the same things happening, and we’re still witnessing that.’

Clara said deafblind people were moved into ‘multiple homes’ all over the place. That made it ‘really difficult resource-wise to support them in any appropriate way’. They needed to be housed together ‘where there is at least an opportunity to have a communication-rich environment, and to have staff that know how to work with deafblind people’.

Clara is involved in training support staff for a peer-led disability organisation.

‘We talk about people being engaged in meaningful activities in their home life. You know, like, unpacking the dishwasher and putting their own clothes away. And we get responses like, ‘No, they have unhygienic toilet practices and they can’t be touching dishes of other people. And you know, it’s bullshit.’

One woman has been in a home for 18 months.

‘Every area of her life has declined. Her mobility has declined. She’s mostly in a wheelchair now. They stopped organising community access for her to engage with the community.’

Some deaf support workers refused to work there, Clara said, ‘because of the way they were treated and discriminated against.’ She complained to the NDIS Quality and Safeguards Commission.

‘It’s a toothless tiger that holds no power to do anything.’

One of the problems, Clara says, is that ‘deafblind is not a disability in the system’.

‘When you have to choose whether your vision or your hearing is the worst disability, it’s stupid.’

Clara has been an NDIS local area coordinator and finds ‘there’s a lack of understanding among planners and LACs around deafblindness’.

Deafblind people face huge discrimination when it comes to access, she said.

‘There needs to be a service for deafblind people ... If you can make it accessible for deafblind people, you’ve pretty well covered every disability, because that’s probably one of the most marginalised groups.’

Timothy and Dalia

‘That house should have been shut down immediately. Those people should have been taken out, replaced with agency staff. That is what the protocol asks for. It was never done.’

Timothy had Down syndrome and was non-verbal. His mother, Dalia, moved him into a disability group home when he was about 10 as she thought he would be better supported.

At 10, Timothy was ‘fit and healthy and a great kid going to school’, Dalia told the Royal Commission. ‘By the time I got him back [from the group home], he couldn’t walk, couldn’t see, couldn’t feed.’

Dalia said Timothy was ‘abused mercilessly’ at the home.

One support worker gave him ‘a nice black eye’ and ‘continually assaulted’ him. He was beaten and ended up with a head injury.

‘[The support worker had] been reported multiple times by other houses for abusing clients. They didn’t sack him, they moved him. He beat [Timothy] relentlessly, but everybody around there watched it happen.’

When Dalia reported the abuse to police, they ‘laughed at and ridiculed’ her.

‘People think because they are disabled, intellectually, that these children don’t exist. They don’t have feelings.’

By his early teens, Timothy weighed 32 kilograms and experienced difficulty walking.

‘They kept telling me he wouldn’t eat. Then I find out he has been fed his own faeces. They were eating all the food, the staff.’

A new house manager, Sarah, realised ‘within a day’ that there was ‘abuse in the house’.

Sarah noted bruising on Timothy’s body and learned that the provider had taken him to hospital emergencies more than 20 times without informing Dalia. She asked staff and her superiors why they hadn’t reported the incidents.

‘Everyone was very much tight-lipped.’

‘[Sarah] was stood down and defamed,’ Dalia said.

Timothy, with ‘marks all over his back and his body’, returned to live with his family.

‘Razor blade marks, burn marks ... everywhere. It took him nearly two years to feel safe enough at home and not have flashbacks.’

But Timothy’s health had deteriorated, and he was often ‘writhing in pain’.

‘To the point where he was having fits. He couldn’t hold his bowel any more. And the screaming, the screaming, the screaming ... He didn’t get up. He didn’t walk anymore, he didn’t smile anymore.’

Dalia couldn’t get supports.

‘I didn’t get carers, I couldn’t get a package. They made it really hard ... I couldn’t get him in hospitals, no-one would touch him ... Community services wanted to push him back into that agency and back into their funding.’

Dalia ‘kept him alive’ for about five more years, and Timothy passed away in his early 20s.

There was no coroner’s inquest. Dalia said the group home ‘vaporised’ all of Timothy’s records.

‘My son is dead because of these people. I need accountability and I need to know he didn’t die in vain. I want my son to be something that happened that caused great change for all people with disabilities.’

Abigail

‘At times I’ve got quite angry because I’ve lost 20 years of my life, of earning potential, the chance to have children. I’ve lost that bit by bit because I was just left to rot. I was labelled and I was drugged.’

Abigail is in her 50s. About 20 years ago, she was told she has bipolar disorder.

‘When I first approached the mental health system I was in a difficult situation and I was asking for help on how to manage that. Instead I got drugs and a label,’ she told the Royal Commission.

Over the next two decades, psychiatrists changed and increased her medications.

‘No-one ever explained why I was having so much medication. I’ve never had a manic attack. I’ve not been consistently under the care of a psych professional. When I’ve been assessed, it’s been at times of crisis and they’ve assumed that my emotional state ... was my normal headspace.’

Things ‘came to a bit of a head’ about five years ago when Abigail was ‘repeatedly given a different label’ for mental illness.

‘I mean people would meet me and give me snap diagnoses. Nobody ever attempted to explain what any of these diagnoses means, it was “cluster this, cluster that”, “acronym this, acronym that”.’

That same year, Abigail ‘was beaten up by a housemate’.

‘The police didn’t take it seriously ... I was made homeless.’

She went to a hospital ‘to ask for help with the depression’. Mental health professionals talked to her family, not her, before admitting her to a psychiatric ward.

‘That was a massive breach of my privacy. They should have at the very minimum had a conversation with me, asked my consent ... When I complained about that situation, I was brushed off and I was ignored. I felt totally disempowered, I felt not listened to.’

Later in the year, Abigail was living with her cousin whose husband ‘was getting quite aggressive’. She rang police. When they turned up six hours later, they took her to hospital emergencies and she ended up on a mental health ward again.

Abigail felt ‘invalidated by the police and the health system’. She ‘got knocked back every time’ she sought help. Her interactions with the police ‘have been quite problematic’.

‘They just turn up out of the blue ... saying that someone had called them, saying I’m suicidal,’ she said.

'I've had cops bashing on my doors, front and back, screaming at me that they're going to take me to hospital. It's terrifying, absolutely terrifying.'

A couple of years ago, Abigail reported that a neighbour assaulted her.

'The police insisted that I'd assaulted him ... I was so distressed, I couldn't talk, I couldn't get a lawyer ... When I did speak to Legal Aid she refused to read what I had to say, so I was convicted.'

Abigail believes 'police deliberately provoked' her. They 'target' her because of the 'mental health stigma'.

'It's really hard when you're told you have a mental disorder. You can't trust your own brain. And you're trying to assess your own behaviour and you don't have anyone you can trust to talk it over with.'

About three years ago, Abigail took herself off medication. Then she started seeing a new counsellor who's helping her 'with strategies to manage difficult situations'.

'And it's been incredibly useful, very effective. She's the first person in the psych industry who's never given me a label. I've been waiting 20 years for someone with this kind of skill and listening capacity. It's kind of bizarre.'

Steven

‘Medication cannot mitigate an environment that denies you the basic human needs.’

Steven is in his late 30s and has attention deficit hyperactivity disorder (ADHD) and post-traumatic stress disorder (PTSD). He battled ‘chronic feelings of emptiness’ for years as doctors diagnosed him with other things.

‘It was just really difficult to maintain emotional stability. I didn’t know what was going on,’ he told the Royal Commission.

Steven managed ‘to get [himself] through university and became a health professional.

He became involved with, and married, an abusive woman. The psychological abuse triggered the trauma Steven held from a violent childhood.

‘I started taking home the discarded portions of opiates from work ... just to help me get through.’

About decade ago, Steven was diagnosed with PTSD.

‘That’s when she started hitting me ... gaslighting me, saying like, you know, “You’re a psychopath.” I just lost a sense of reality ... losing my mind sort of thing.’

Steven turned to his employer.

‘I showed them the ... marks in my arms ... The abuse got to the point where ... it was just far too much.’

He also ‘confessed’ to them about the opiates. Instead of offering him support, he got ‘a flat-out termination’.

‘Like they didn’t want me there anymore. They were convinced that I had like a personality disorder or something ... This is all unfounded and it turned out to be, like, undiagnosed ADHD stuff.’

Steven said the way his employer treated him contradicted workplace policy.

‘That anyone who was experiencing family violence ... would be supported ... That it would be a health issue. They took away my registration ... It was torture.’

Steven reported the domestic violence to police.

‘They didn’t believe a word I said, because of, um, the mental illness. He had already made up his mind before I even said anything that, um, I was the perpetrator ... So he coerced my statement.’

Steven made complaints to an anticorruption commission.

‘No-one listened to me. That was really distressing because you know, it didn’t matter what I said.’

About four years ago, things were ‘settling down’.

‘I got through my PTSD. Started to go back to work. I got my registration. So that was the second chance at life, alright? So that was great. It had been five years and I’d never touched a drug or anything.’

But Steven ‘got knocked back for so many jobs it was not funny’.

Two years ago, he got the ‘life changing’ ADHD diagnosis.

‘Everything just started to make sense. Took the medication ... literally all the tension in my body just went. It was just like, ah. For the first time in my life I don’t feel empty, I feel complete.’

But he still can’t get work. At one interview, an employer saw that he sees a psychiatrist.

‘The second they saw that they reneged on giving me a contract that they promised.’

Steven said the ‘miracle of being diagnosed with ADHD and the potentials that opened up’ have been ‘completely nullified’ by discrimination over his psychosocial disability.

‘I’ve got this new brain that can actually learn stuff, but now I’ve got an environment of people who keep saying, “No, you can’t do that,” or “You’re weird, so we don’t want you.”’

Steven’s health is deteriorating and he’s having suicidal thoughts.

‘I’ve been bullied at every stage of my life ... My career was taken away from me and I did nothing wrong,’ he said. ‘I’ve been excluded from society.’

Ariane

Ariane, in her early 70s, has limited mobility because of damage to her spine, hips, legs and feet. She has a very low tolerance for medication, and is likely to react negatively to any she takes.

Several years ago Ariane had knee surgery in the regional hospital near her home. Afterwards, she wasn't able to perform the tests she needed to complete before she could be discharged.

'Because of my pre-existing illnesses, physically, I wasn't able to do what they wanted me to do. I tried to explain. They wouldn't listen to me.'

The physiotherapist attempted several times to push Ariane through the tests, which was 'really painful'.

When Ariane couldn't pass the tests, she asked the physio for additional rehab support. 'No, we don't have time for that,' she was told.

Then, without her knowledge or consent, nurses administered opiates to her. She had told the medical team about her sensitivity to such drugs, but they ignored her. The drugs caused hallucinations and other side effects.

'I kept getting sicker and sicker and they're giving me these anti-nausea tablets which are not working ... Apart from that, they upped the medication without me knowing. Until they overdosed me.'

Shortly afterwards, Ariane was transferred to another hospital for post-surgery recovery. But she was sent with incorrect medical records that didn't note her low tolerance to medications. At the second hospital she was again given drugs that made her sick. As she recovered, nurses in the hospital treated her abusively.

Ariane was still unwell when she left the hospital.

'My doctor rang the hospital and he said "Why was she allowed out?" And they said, "She discharged herself." I hadn't and I can prove it.'

Ariane made a formal complaint, but she says it was not upheld because the hospitals falsified her medical records and lied to conceal their negligence. She has tried to pursue the matter further, but without success.

Ariane believes her experiences in the two hospitals has left her with post-traumatic stress disorder.

'I still wake up and I'm scared ... in case I'm still there with the nurses there. So I know it's still with me,' she told the Royal Commission. 'It's very hard when you have to trust in a system and they, yeah, you're at their mercy.'

She is critical of a complaints process that leaves people with disability 'absolutely dead ended'.

'We have nowhere to turn at all,' she said.

Lazlo and Philomena

Lazlo, early 30s, has intellectual disability.

He works at a disability employment enterprise.

His mum, Philomena, is ageing.

She told the Royal Commission she is worried about what will happen to Lazlo when she can no longer care for him.

A few years ago, Philomena started looking at disability accommodation options close to Lazlo's work.

There was limited choice and the houses were disappointing. Most didn't feel like a home and provided limited opportunities for residents to participate in the community.

'The places I did look through didn't offer an environment where I felt he would be happy living out his years.'

By chance, Philomena heard about a house, recently completed, providing 24/7 care. A group of parents had lobbied governments and councils and raised the funds to make it happen.

For 'a modest outlay', Lazlo was able to secure a place.

He lives with a group of young men and women of similar ages he calls his other family.

'The first thing you notice is the warm, family environment and the genuine care and concern the residents have for one another.'

There are multiple living areas, a large gym, outdoor gazebo, vegetable gardens and hens.

Lazlo can join in activities or spend time alone. He is able to walk by himself around the grounds.

'[Lazlo] has grown since being in the house, displaying more independence and an improvement in general life skills,' Philomena said.

He prepares simple meals and takes more responsibility for his own care.

He takes his turn to help with the chores such as drying dishes, unstacking the dishwasher, taking rubbish out and feeding the hens.

Lazlo spends more time in the community than he did at home. He plays basketball, does trampolining, goes bowling and to the gym.

The residents visit farms, the beach, go on picnics and go to the football.

Parents are involved in different ways. They mow lawns, fundraise and maintain the house and property.

Philomena says the home is a 'model of excellence in disability housing' and should be replicated across Australia.

'Those living with disability and waiting for housing [should] experience the same care and social connections [these] residents do.'

Philomena feels blessed she has seen Lazlo happily settle into his new home with his new friends.

Zelda

'I have been ripped off by quite a few different people, and I just get sick and tired of being the one they pick on.'

Zelda has epilepsy.

She told the Royal Commission that she doesn't think as quickly as other people do.

For many years, Zelda lived with a person who was scamming and financially exploiting her.

The woman would take Zelda away for a holiday and buy her treats, telling her there was no need to pay her back.

The woman would later demand money and tell Zelda she owed her.

'Just because they've done good things doesn't mean they can always ask for money, because I don't get all that much money. There needs to be some kind of agreement, but there was no agreement.'

The woman was educated and good with words.

'It took me a while to realise that she was ripping me off ... It was her mind over mine, and her mind always won.'

Zelda said the woman's behaviour made her feel depressed and a failure. She spent a lot of time lying in bed wanting to give up.

'It was hard for me to realise that I was better off without this person. I didn't want to end up living by myself. I really didn't. That's what made me stay with this person for so long. But I just came to the point where I had enough.'

Living by herself was lonely.

Zelda started to go online for company, and found herself being scammed.

'You can't always pick a scammer. It's like trying to predict the future, you just can't.'

COVID-19 lockdowns made things worse.

Then one day, Zelda found a scammers survivor group.

'Just an outlet and a little bit of company, through people that have been scammed like myself, and help me realise that I'm not the only one.'

She believes people with disability are particularly vulnerable and need more help to avoid scams.

The group has helped Zelda recognise scammers.

'I try not to type in too much information either on my mobile or whatever. Especially when they are wanting your personal information and stuff like that. And they say things will have to cost an extra amount of money, I just totally avoid that.'

Zelda now takes her time to think about what people are asking her to do.

'I just make doubly sure I don't get ripped off. It may seem as though I'm getting about slow, but I just like to think for myself, rather than just rushing into things like a bull in a china shop.'

If someone phones or messages Zelda and she thinks it a scam, she can contact the scammers group and ask their advice.

'It's about time for me to stand up for myself, because nobody else is here standing up for me.'

Talulla

Talulla, mid-40s, has intellectual disability.

In her 20s, she wanted to be more independent and find a place of her own.

'I like living with other people. I feel safer. Being alone would not do me any good.'

Talulla's mum helped her find a community group home.

'But it didn't work out,' Talulla told the Royal Commission. She didn't have much in common with the other residents and everyone had different support needs.

After some time, Talulla had had enough.

'So I stood up to my mum and said, "I want to move on."'

Talulla moved to a purpose-built home with three older residents. They have become good friends and do a lot of things together.

'The carers are good. And they take us away sometimes, and it's good fun.'

Once a week, Talulla attends a self-advocacy course to help her 'stick up for [her] rights' at home and at work.

She has become a disability ambassador and advocates for herself and the other residents.

'That means I make sure that the carers are doing the right thing. I'm making sure they don't abuse us or hurt us or anything like that.'

One of the things Talulla has learnt is to calmly tell support workers they need to knock before they enter her or the other residents' rooms.

She makes sure 'that people are listened to'.

Talulla also advocates in her workplace.

'If you don't get paid, I'll be talking to them.'

Talulla is concerned advocacy isn't very well funded in the state she lives.

'We need money for our self-advocacy course.'

Currently, Talulla is involved in advocating for more timely access to mobility aids and for public transport to be more accessible.

'Some people always wait for a very long time to get a wheelchair ... We need help to get that organised. We don't want them falling over.'

She is also advocating for people to be able to leave the homes they are in if there are problems.

‘They tell me that some of the staff are a little bit rude and arrogant. And then I’ll say to them, “Well that’s not fair.” I mean, people should respect the client, instead of being rude to them.’

Talulla is happy. Being able to advocate makes her feel safer.

‘We need that voice.’

Salina

Salina, in her mid-40s, has a neuropathic disorder that causes episodes of intense pain. She needs support to complete many daily tasks, including showering.

Salina was diagnosed several years ago, and her then-partner became her main carer. Salina said he took advantage of her disability to sexually abuse her. He would help her to shower and ‘force himself’ on her every time.

‘It got to the point where I stopped having showers deliberately so that I wouldn’t be in that position.’

When Salina started receiving the NDIS she was able to pay for assistance with her daily needs. To get away from her partner, she moved interstate. Once there she used Crime Stoppers online to report his sexual assaults. But the next steps in getting police to respond are proving difficult.

Salina called police both in the state where she had lived and in the one she had moved to. In the state she’d moved from, police told her she had to make her complaint in person.

‘They said that they can’t take a statement without being able to see me face to face. That was all I was told. And I’ve tried many, many times,’ she told the Royal Commission.

‘They said they can’t do anything because I’m over here, that over here has to take a statement. The police here say that because it’s historic that they won’t come out to the premises to take my statement to report these things ... I get sent back to, “You’ll have to come in to one of our offices.”’

Salina’s condition makes this almost impossible.

‘I have a lot of trouble getting into a vehicle, so getting down to a police station is quite an onerous task for me,’ she explained. ‘I can’t even sit in a chair for long enough for them to take my statement now if I’m totally honest ... If I manage to get there I’m not going to be able to tell them very much without needing to lie down and have some exceptional painkillers.’

Salina feels ‘like a ping pong [ball] that’s gone across a ping pong table a hundred times’. She doesn’t think her situation is unique.

‘I feel that a lot of disabled people aren’t going to be able to report when the incidents are occurring because you’re reliant on this person for your basic daily needs – food, clothing, being able to dress yourself. And that when we do get to a place where we are able to report these things without fear of repercussions from that person, we’re still not able to.’

Salina thinks police should offer online meetings as an option for people like her.

‘Since COVID a lot of medical things have become much more available to people like me because we can do a video or telehealth,’ she said. ‘There needs to be a little bit more in that sort of arena with reporting to police too.’

She would also like police services to create a new role of ‘disabled persons liaison officers’. These officers would be trained to meet the needs of people with disability within the context of the police system.

‘If a person like myself can’t attend a police station to make the formal report ... especially across state borders, and there’s an officer that’s dedicated to attending the premises and actually speaking with a disabled person ... there’s more opportunity for the disabled to be able to report these things that go on.’

Elyna

Elyna came to Australia in the early 2000s.

She had a stroke about five years ago during a medical procedure. She woke up in recovery and was blind.

'After the initial shock', Elyna became severely depressed and told nursing staff she wanted to harm herself.

'It has taken a very long toll on me,' she told the Royal Commission.

After several months in rehab, Elyna went home. She had no support other than her family.

'I didn't know what I had to do. I didn't know where I had to go ... I didn't even know how to use my phone to make phone calls.'

Elyna was 'anxious and nervous' and found it difficult to leave the house.

'Taking me shopping was hard. I would cry in the shopping aisle.'

She couldn't orient herself and kept walking into everything.

'Everything I would touch would feel horrible to me.'

After a couple of weeks, Elyna received a call from the NDIS asking if she would like to register. Encouraged, she completed the application forms.

But Elyna discovered she wasn't eligible because she wasn't an Australian citizen. She thought that two decades of her and her husband working, paying taxes and contributing to the community would count for something.

Elyna couldn't afford support workers. With her husband needing to work, it fell to her young children to support her.

They had to do all of the chores around the house and learn to give Elyna her medication, some of which was intravenous.

One of the children, who was in secondary school, had to take time off school to take Elyna to her medical appointments.

They had to use public transport to get everywhere.

Someone told Elyna the children could apply for carer's support but they 'struggled to find the right paperwork'.

Elyna's eldest daughter said the family became isolated.

'When mum lost her sight, it's like we lost sight of the community too. There was not one person there that would help us.'

Eventually someone referred Elyna to Vision Australia.

For a fee, she was able to access occupational therapy, mobility support and day programs.

She learnt to use a white cane, made friends and became more confident.

The family moved cities to be closer to a supportive health service.

The health coordinator recommended some less expensive changes she could make to her home to make it safer. They also helped her access technology to help her manage her diabetes.

Elyna also connected with a psychologist.

Friends donated money to help her buy assistive technology and some other items she needed.

Despite Elyna's positive experiences, she said the financial, emotional and support cost to her and her family has been huge.

Her daughter told the Royal Commission, 'It was really hard trying to be strong those other three years.'

Elyna said it would have been a much easier journey with the NDIS.

Isha and Carra

Isha is in her teens and has epileptic encephalopathy, which involves speech problems, intellectual delay and seizures.

After Isha left school, her mum Carra applied for NDIS support.

'I'm not used to asking for help. I'm used to having to do everything myself. So I kept trying to do everything myself. Everyone kept telling me I had to do everything myself so I believed them. And it was true. I did have to do everything myself even when the NDIS came in.'

Carra said she's shocked how difficult it is to apply for an NDIS plan.

'Unbelievably hard. And when you ask for help you're just minimised. You know, they haggle with you. It's like, well, haggling is just an indication that they don't believe that what you're asking for is actually a necessity. They're letting you know that they think you're just trying to get what you can for fun or something.'

For example, Carra asked for a support worker at night because taking care of Isha 'with all her seizures and her disability' is emotionally and physically exhausting.

'I've had someone from the NDIS say ... to me, "My 16-year-old wakes me up at night too." And presumably she's read all the reports that I've given in. Presumably ... she knows that she's not a typical 16-year-old that wakes you up at night. That she's having between three and seven seizures a night and you're having to bring her out of the seizures, give her emergency medication, give her oxygen.'

Recently the NDIS defunded all Isha's activities.

'[They] said she can just go to the local swimming pool and swim with the other kids. That's literally what they said in the plan. Oh well, she can't do that. She obviously can't do that if they read any of the reports. It's so frustrating.'

Carra asked the Administrative Appeals Tribunal to review Isha's plan.

'That's been horrible. Like they just keep asking for more reports ... The lawyer for the NDIS would say, "Oh well my client wants these questions answered." And I would say, "But those questions are answered in this report, that report, the other report and another report that you've got." And he'd say, "Oh could you highlight those answers for us and send that in?" It's like, well, isn't that your job to read the reports that answer your questions? You asked for the reports!'

Carra said the NDIS should be talking with the health and education departments 'so that a parent doesn't have to say the same thing over and over ... and so there's an understanding between departments of what these child's needs are, what these parents' needs are and what the plan is.'

'You know there needs to be a plan, not just blaming.'

Gilles

Gilles, early 30s, is autistic and has intellectual disability.

He came to Australia in early primary school.

Gilles told the Royal Commission that schools in his country of birth would 'identify any potential issues that might arise' early on. A teacher or teacher aide would take him outside as soon as the classroom became too noisy and he became unsettled.

At school in Australia, Gilles would become more and more unsettled and teachers didn't know what was going on or how to support him.

'Aggressive coping behaviours were reflective of the difficulties I was having trying to fit in.'

The school suspended Gilles a number of times.

'Then another incident or issue occurred, and it was a 20-days-long suspension.'

Gilles was finally assessed and diagnosed as autistic.

The education department moved him to a different school and employed a teacher aide to support him. But the teacher aide was only funded for three days a week.

'It meant that I was only able to be at school part time ... That was a problem I commonly faced.'

Gilles's parents made an anti-discrimination complaint, to no avail.

'They are not making the adjustments for the person with the disability to have the full potential that a student without a disability would find.'

Over the next few years Gilles moved schools several times, usually because he was excluded.

'I had a lot of problems ... particularly the triggers with the noise and distraction.'

Teachers didn't know how to support him and his behaviour started to escalate.

An incident happened on a very hot day.

'I was still quite hot from the lunch break ... I was not settled and the teacher was trying to push to start the class. When she started to discipline me, that's when it started to go really bad where I sort of was throwing things around the classroom and I got very angry at the teacher. Eventually I was moved out, locked outside.'

Gilles was excluded.

At the next school Gilles, aged 10, was placed with students who were on lifelong suspensions. His parents appealed and the department moved him to another school.

There, Gilles said, incidents escalated because teachers didn't follow his behaviour support plan.

'They had the specific calm down techniques that they were supposed to apply, but then what happened was the teacher aide lost her composure and got angry.'

The suspensions, exclusions and school transfers continued in the early years of high school.

In his final years at school, Gilles was finally given more support.

'I managed to eventually work out the education program where I was doing two subjects plus extra work.'

He completed high school, attained good grades and was able to enrol in a TAFE program.

Shayne

‘It was really a terrible workplace, I was never involved. Others could take time away from the machinery, but I was forced just to work hard.’

Shayne is Deaf and in his 60s. He worked in a factory for two decades and it was a ‘terrible experience’, he told the Royal Commission.

‘It would be 22 years of horrendous talking down to from the people around me in my workplace. I was never offered shift work ... And then if I was to leave a few minutes earlier or something or other, I would get a talking to. But the other staff who came and went as they pleased never got a talking to, so I felt like I was being singled out.’

For all those years as a ‘really hard worker’, Shayne felt he had ‘absolutely no-one’ to turn to for support.

‘I was just ignored. I was a fast worker ... I was doing all the right things, but I constantly felt like, you know, that my colleagues would ignore me if I needed some help or some assistance ... They’d go, “Oh we haven’t got time for this, you’re gonna have to work it out for yourself.”’

Shayne said his boss was ‘absolutely horrible’ to him. He refused to make any adjustments to help him and held him back.

‘He just was not fair in the workplace. He was very abrupt, very rude ... When there was some training being offered, that, you know, others were getting a qualification for, I wasn’t given that opportunity. I was just told to work at my station.’

Shayne felt excluded because the company wouldn’t provide an Auslan interpreter even during important meetings.

‘I said, “Look you must. I think you’ll find that there are laws saying that you should be providing an interpreter for me.” But they insisted that they didn’t have to and that they wouldn’t.’

His employer never gave Shayne a promised pay rise.

‘I think that my income was not right, and I didn’t understand a lot of that ... I eventually raised it with my boss, and then all of a sudden they lost my paperwork.’

With legal help, Shayne got a few thousand dollars as a ‘lump sum that was to go somewhere to compensate for that’.

Noemie

‘The Australian system has severely let me and my family down.’

Noemie is autistic.

About 10 years ago, she moved to Australia with her children and her then husband who was her registered carer.

Sometime later, she became aware that her husband was emotionally, sexually and financially abusing her.

Noemie tried to report the abuse to police but they didn’t believe her.

Her ex-husband immediately started Family Court proceedings.

‘On the same day, my ex-husband cut off all my finances, cleared out the bank account, left me without any money, no means of support and served me with these papers and then phoned the police on me.’

Without access to money, Noemie tried to find a publicly funded disability lawyer and advocate. She discovered there were no specialist disability lawyers in Australia and only a few advocates.

‘Before I moved over here, I had an immense amount of support. I didn’t have any worries or anything. I could access a disability lawyer, I could access an advocate. The services were absolutely immense.’

In court without a lawyer, Noemie explained to the judge that her husband had contravened the Family Court rules by serving documents on a person with disability without a support person present.

The judge seemed surprised and said, ‘You don’t look as if you have a disability.’

The judge dismissed the complaint and ordered Noemie to leave the family home.

With nowhere to go, she returned home. When her ex-husband discovered she was there he called police.

Noemie was on a skype call with a family member when police arrived. She tried to explain she had a disability but they ignored her.

The family member watched ‘these brutal police officers dragging [her] across the floor’ and throwing her out of her home.

Noemie applied for the Disability Support Pension but wasn’t eligible because her visa had been approved on the basis her husband would support her.

She borrowed some money and engaged a lawyer.

The lawyer told her not to mention her disability because it would go against her and she would lose custody of her children.

Noemie naively didn't believe the lawyer. In her home country, parents with a disability are valued, respected and supported.

Child protection and human services became involved.

'To come over here and be told by child protection and human services, "Oh, you've got a disability. Oh, well you're not competent enough to look after your children." It was a shock.'

Noemie lost access to her children.

She tried to take legal action but discovered the Disability Discrimination Act is routinely disregarded and has no teeth.

'There has to be consequences for not complying with the Act,' she says.

Noemie believes Australia is getting better but it still has a long way to go in protecting the human rights of people with disability.

'I also have faith that my children will eventually come out of the darkness and into the light and we can be reunited.'

Kyro and Lindelle

Kyro was born prematurely after his mother Lindelle was in an accident. He is now in his final years of primary school, dealing with a 'whole picture of issues', Lindelle said.

'He has language delays, he has got developmental coordination disorder, he has got a specific learning disorder in reading and writing. He suffers a lot of anxiety.'

Lindelle told the Royal Commission that Kyro works hard and is a good student, but the education system has failed him.

'He is a very clever boy, so he is actually what you would say is gifted, like, he is in the high IQ range. But because of his disabilities, he is not able to perform and demonstrate, you know, that IQ type.'

Lindelle was concerned about the lack of resources in the public education system, but several schools in the private system turned Kyro away.

'One school actually refunded our money and said, "We can't cater to him because of his problems." ... So he has that discrimination against him from schools because of his disabilities.'

Kyro does now attend a private school, but Lindelle said he suffers from the teachers' lack of understanding.

'Like, particularly the developmental coordination disorder ... That impacts on his writing, he can't write, I suppose, climb and jump and catch and a lot of those sorts of things. So in the classroom he is disadvantaged because of those struggles.'

Lindelle has worked in classrooms herself and appreciates how difficult it can be for teachers. She believes teachers need to be better trained for the range of needs they'll encounter in their students.

'There's all those sorts of types of conditions which are every day and, you know, in all settings ... [Teachers] are not taught how to differentiate, how to, you know, cater for those children,' she said.

'And out of 20 children, you have got so many children with different learning needs and stories, and some teachers just label them – that's a naughty child, or that's a child that ... they are dumb or something.'

Lindelle said that when Kyro was six he came home and told her that the teachers at his school thought he was dumb and stupid.

'I am not dumb and I am not stupid,' he told his mum. 'I know how to do things, but they just think that way. So because they think like that, I am just going to be like that.'

Lindelle has found teaching staff are often unsympathetic to her efforts to help Kyro. They think she's 'a pain', and 'just wanting things to be [her] way'. If she raises an issue, 'they just sort of roll their eyes'.

She has also experienced painful judgements about her parenting.

'So with, say, [Kyro]'s anxiety, they were saying that I must be an anxious person so therefore I'm, I suppose, filtering my anxiety on to him and therefore his anxiety is sort of – you know, I am creating anxiety in him.'

She believes schools need to do better.

'A lot of schools, "Oh yes, we do this, yes, we do that," but they don't ... You know, they make these little individual learning plans, which all look pretty on paper and it all looks good, but it is not implemented. And that's where the downfall is,' she said.

'The education system itself, I think, really needs rejigging for children, or anyone really, with disabilities. I think it's not – it is still very much in the 1950s, you know. It is not catering for the kids.'

Janis

Janis has physical disability. A few years ago, she started relying on her wheelchair more frequently. She applied to the NDIA for funding to modify her home.

After almost three years, the modifications are still not complete.

Initially the NDIA refused to fund Janis's application because they felt the occupational therapist's plan wasn't 'value for money'.

'All they've seen is I'm in a wheelchair. They got no idea why I'm in a wheelchair. They've read nothing.'

Janis contacted them and ended up having to describe her 'physical makeup'.

'I'm so sick of describing me ... She was already advising me on the way to fix my kitchen and she didn't even know I had no arms. How is it possible these are the people that are making the decisions about my needs?'

After more haggling about ramps and automatic doors, the NDIA eventually approved funding.

Janis then had to find NDIS approved contractors, which has been almost impossible because of where she lives.

It has become increasingly difficult to live in her home.

Janis has to go to the toilet in a bucket and is unable to use the shower. She can't access the running water in her kitchen.

Recently, the NDIA moved her to an accessible motel room until the modifications are complete.

She is able to use the shower and toilet but it continues to be extremely difficult to find regular support workers, living where she does.

'There's at least a dozen girls in this town who have seen my body. And I've had enough. I'm over it. I want some personal time. I'm having so many people in the shower with me I had to cut down my showers.'

Janis has managed to find one support worker who can come once a week, every week. So now she only showers once a week.

'I'm looking pretty shitty, and I'm feeling pretty shitty and emotional.'

Janis said her service provider has started cancelling services with almost no notice.

'They rang me up and just said, "We can't service you tonight." I've literally gone, "So, I'm not eating?"'

Another time a support worker brought her grandchildren to Janis's house during her shift. The children stood watching Janis, amazed at the way she eats because of her disability.

'Do you think I needed that in my lounge room at the end of the day?'

Janis made a complaint to the provider to no avail.

'I am probably one of their most pedantic people with my pride and my dignity and my wanting to be private. I don't know why they don't treat it seriously.'

Janis's provider has asked her to train support workers in exchange for food vouchers.

She would like them to employ her, pay her a wage and train the support workers properly.

'It's just an ongoing battle. And I just don't think it will change.'

Janis hopes the modifications will be finished soon and she can move back home.

'I'm tough. I've been handling it. But it's getting a bit much. I'm a lot weaker. I'm a lot more impatient. I certainly swear more than I ever swore.'

Kel

Kel, in her early 40s, has bipolar disorder, borderline personality disorder and post-traumatic stress disorder. Around five years ago she separated from her partner and in the property settlement ended up with a large sum of money.

Because of her psychosocial disability, and because her mental health was 'quite bad at the time', she appointed a couple she knew as her powers of attorney.

'They were trustworthy – so I thought.'

Over the next few months, the couple spent all the money. Kel had no idea. She was receiving a Disability Support Pension and they accessed that money as well.

'I ended up homeless ... I had quite a few hospitalisations during this time for my mental health, in the private hospital, and they told me they didn't want me going to private hospitals anymore. They'd tell me that they'd cancelled, or let my health insurance lapse. There were days where I was left without food.'

The couple refused to give Kel any details about how they were managing her finances, so eventually she went to the bank to find out.

'That's when I discovered that I had no money, that it had all been stolen,' she said.

'They apologised when I confronted them. They took me into their home and they convinced me at that time that I had been healed by God ... of my mental illness and to come off of my medication.'

Off her meds, in a psychotic state and isolated from family and friends, it took several months for Kel to recognise she was in an abusive situation. When she did, she went to the police and asked for the powers of attorney to be reversed. They refused. It wasn't till she went again with her mother that police agreed to take her statement.

Kel's police statement became the basis for legal actions that followed. Kel contacted 'every community legal centre [she] could find' looking for support, but was rejected time after time.

'I didn't fit into any of the support categories. I couldn't get support through any of the disability organisations because I didn't have an intellectual disability. I couldn't get support through family violence services too easily because it wasn't the same sort of family violence. So there was a huge gap that I was falling in, left, right and centre.'

Finally, a legal clinic put in her touch with a law firm which took on her case pro bono. With their support she got nearly all her money back. She is grateful for that outcome but notes the money is, in a way, 'the least' of what happened to her.

'It's all the other abuse that was associated with the money. Like, I don't have nightmares about losing money but I have nightmares about their treatment of me. I have nightmares about being left without food for days, and I have nightmares about being homeless, you know.'

Kel said her experience wasn't caused by a lack of skills or capacity. Mostly, she said, she is 'great' at managing her finances.

'This is something that'll only come up, you know, a certain percentage of the time, but at that certain percentage of the time education isn't going be able to manage it because I'm kind of crazy at that moment and I can't consequentially think ... This is more a situation where the capacity is there but there are times when I don't have capacity because of the nature of my disability.'

She believes having an advocate would have made a difference, and she would like to see this kind of support offered through a system of disability 'hubs', similar to those established for people experiencing family violence.

'I had to be my own advocate at a time when I was really sick ... And just, you know, having somewhere where you can access that bit of extra support so someone's walking alongside you would've been amazing.'

Calder and Mirren

In kindy, Calder started having 'big behaviours', his mum Mirren told the Royal Commission. 'I wasn't really sure what was happening to him at the time.'

The education department sent someone to assess him.

'The person came in for about an hour, spent about an hour there, observed him and went away and that was the end of it.'

Calder started primary school but 'his behaviours continued to regress'.

He would defecate in the playground and abscond any chance he would get.

The teacher started separating him from the class and isolating him.

Mirren demanded to know what was going on.

The education department referred him for specialist assessments.

'Any time you go for an assessment, it's sort of treated as though it's the family's fault. It's like, "Oh another Aboriginal family that is dysfunctional and therefore there must be faults within that family."'

Calder was diagnosed as autistic. Sometime later, he was also diagnosed with attention deficit hyperactivity disorder, oppositional defiant disorder and hypoxic brain injury.

The education department transferred him to a school for autistic students, which was some distance from home and Mirren's work.

He had to catch the school bus and he would be on the bus for hours each day. Calder couldn't cope being on the bus for so long.

'He was weeing himself on the bus. They weren't allowed to eat on the bus. It ended up that his behaviours escalated to the point where he was attacking the chaperones on the bus.'

No-one told Mirren what was going on until the bus driver banned Calder.

She contacted the education department, asking for an explanation.

'This particular incident resulted in about 13 people attending a meeting, it was so ridiculous.'

The school showed Mirren several letters from other parents 'wanting him off the bus'.

The letters weren't dated and Mirren had never seen them before.

'You feel ambushed,' she said.

Mirren discovered staff at the bus company weren't trained to deal with children with disability.

She also discovered the reason Calder 'had gone off' at the chaperone was because they were making racist jokes.

Mirren believes Calder's experiences at school also contributed to his behaviours.

His classroom was completely segregated from the rest of the school.

'The kids were not allowed to join in the school production play because they were considered too high risk to be able to understand the thing. They were not allowed to go on excursions. The only class materials they had was stuff that was printed off online, and there was no opportunity for anything else.'

A padded room was attached to the classroom.

'When the kids would start harming themselves or ramming their heads or biting and banging, they will place the child in that room.'

Calder spent a considerable amount of time in the padded room.

'He would come home with clear finger marks dug into his shoulders and back and other unexplained bruises.'

Calder told his mum that staff would grab him and restrain him. Mirren made a complaint but 'got absolutely nowhere'.

Over the years Mirren has tried to find services to help Calder, now late teens.

'The way that you're made to feel through the process of trying to get services is disgusting. And once you do get into the service, if it's not suitable, your kids end up getting restrained or they end up getting kicked out of the program.'

Mirren said the services aren't culturally safe.

'There's none of our mob that are staff ... There's no consultation or engagement within the programs ... There's no consultation with local community about what they're trying to achieve.'

Kinney and Calan

‘All kids could do something productive and useful in their adult life if they’re able to communicate.’

Calan’s sons are autistic and have global development delay. They are non-verbal and use augmentative and alternative communication.

‘They’ve basically just got a tablet computer that they carry around with them. They can point to symbols. And when they point to the symbols, it populates the message bar up the top. And then once they finish their message, they sort of press go and it speaks for them.’

Calan told the Royal Commission that the education system is failing to support the boys to use their communication devices.

‘I’d pretty much describe our schooling experience as just poor-quality childcare.’

One son, Kinney, has attended special schools and special units in mainstream schools.

His classroom is always ‘a little barricaded corner of the school’. He has no opportunity to mingle and talk to his peers.

‘I don’t think that segregation is the way to go,’ Calan said. ‘Because it’s just so isolating. The boys need some peer models of kids being kids and kid things to talk about.’

Because Kinney doesn’t have any behaviours of concern, he spends most of his time ‘at the back of the class amusing himself’.

No-one expects Kinney to communicate, so it’s not a priority.

‘That’s the disappointing thing. It’s really hindered the boy’s opportunity for education.’

This year, not one of the adults in Kinney’s classroom ‘has taken any time’ to learn his communication system.

‘Surely if you’ve got a class of kids who use communication aides, then it’s a prerequisite that if somebody comes in to support those kids, they learn about how to use communication aides.’

When Kinney’s device is used, it is for the teacher to talk to him, for example, ‘It’s time to pack up’ or ‘It’s time for lunch.’

‘They need somebody throughout the day actually modelling communication that’s meaningful and valuable to them ... they never get any modelling of what their message could be in that situation,’ Calan said.

Calan is expected to drop Kinney off at the gates each day and never has an opportunity to talk to the teacher.

He wants to know what Kinney is learning each day. He wants the teacher to tell him that they couldn't find certain words in Kinney's device and ask him to add the words. Then he would know school was working and Kinney was learning.

The school also refuses to support Kinney learn toileting skills. Staff check Kinney's nappy twice a day. During the holidays, Calan was able to teach Kinney to ask to go to the toilet. Calan asked the school to follow through, but they haven't.

'We've lost that progress.'

Calan recently made a complaint to the Australian Human Rights Commission.

'It's pretty much a waste of time ... It's really only a mediation service.'

The education department agreed to 'try and do better', but they refused to agree to anything that was outcomes-based and could be measured.

Calan says the next step is the Federal Court, but it will take time and money and soon Kinney will be in high school.

'I can't see how school is helping to deliver any quality of life outcomes at the moment. And at some point, school's going to finish and we're just going to be left to do everything ourselves. Communication, it's just not a priority. And that's what it comes down to.'

Damo and Orette

Damo, late 20s, is autistic and lives with his parents.

Damo has had NDIS support for about five years. His first plan funded a work readiness course, transport there and back, support workers, occupational therapy and psychotherapy. Damo's mother Orette said that with this level of care Damo made steady progress and his life skills improved.

In Damo's second plan his funding was reduced by a third, without explanation.

His third plan was reduced further.

The family went to the Administrative Appeals Tribunal, and the NDIA capitulated on several points as the process got underway.

Around this time Damo was diagnosed with further health issues. He wasn't well enough to use the additional funding he was asking for, so the family ended up 'pulling the pin' on their appeal.

Orette said that the government disability support service in place before the NDIS had much to recommend it.

'They recognised that the integrity of the family was important. If we weren't together and sane enough to look after [Damo], then that burden was going to fall on the government. So they made sure that we had the help that we needed.'

Also, under that previous system the family worked with a case manager. Orette said she was 'fantastic'.

'She knew [Damo]. She got to know him over the years but she also knew the system and she knew the industry. So she was able to say, "Have you heard about this or did you know about this program or there is this thing coming up."'

There was less funding but they were able to spend it more effectively.

'Now we get a lot of funds from the NDIS, but there is actually no professional guidance on the best way of using it, and I think that is criminal. I don't want to be responsible for all the money and not using it in the best way to help [Damo]. And it is a full-time job to try and find all that.'

Orette said that 'every interaction with the NDIS has been a fight', right from his first plan.

'They gave us a very generous amount of money ... and we were really, really happy with it. However, they put it in the wrong boxes and we couldn't use it. So [Damo] would have had the equivalent of 300 hours of therapy and very little community access.'

Orette assumed this would be simple to correct, but it wasn't. It took months, as have all the other issues that followed.

At Damo's most recent review, she explained to the NDIS planners that every item in Damo's plan was critical.

'I must admit, I was a bit surprised when they came back and didn't even give him half of what he had spent the previous year. But that is my expectation of the NDIS. I have a very low bar and they tend to meet that every single time,' she said.

'You sit there with a person, you tell them everything you need, but really their hidden agenda is what can we deny, what can we get away with, what is the least amount of money we can spend on this person.'

Orette has been advised to seek out cheaper services for Damo and to get family and friends to help provide them. The NDIA questions or dismisses reports from medical specialists, as if they are thought to be 'in collusion to get money from the government'.

'Really, this is not the way we would choose to get money from the government. If it was possible to have [Damo] not needing any help at all, that is what we would really rather have. But, you know, life hasn't dealt him that card.'

Kevan and Ainslee

Kevan is a First Nations teenager. He is autistic and has attention deficit hyperactivity disorder (ADHD) and anxiety.

‘He’s a lovely person,’ his mum Ainslee told the Royal Commission. ‘He’s got such a heart of gold you could do anything to him and he would still try and help you to maintain that friendship.’

Kevan did well in primary school where he had a one-on-one support teacher.

‘When he hit the high school mark and went into year 7, that’s when it all just basically disappeared.’

Ainslee said that before he started high school she met his teachers to explain what he needed.

‘They had this great plan, but they never ever followed through with it. They just basically threw him in a classroom and left him to his own devices.’

Kevan was never violent, but was often suspended.

‘He was not an abusive child, but he was one of those children that couldn’t sit still, would get extreme anxiety. He would get so upset and he’d have to run out of the classroom.’

One teacher told her the staff didn’t have time to support him.

‘She said, “We haven’t got time for children’s behaviour. We haven’t got time for children on the spectrum. We don’t have any time for that.”’

One day, Ainslee discovered that Kevan regularly hid during class.

‘They didn’t tell me for over six months that he was actually hiding under a table every time he went in the class. Now don’t you think, as a mother, I should’ve been informed about that?’

Kevan tried working at a retail store several years ago, but was bullied.

‘He’s very scared. He’s scared to make friends because of being bullied and he still gets bullied to this day.’

Ainslee said that when the NDIS started funding Kevan, no-one helped her access it or told her what the funding was for.

‘His NDIS sat there ... didn’t get used because I didn’t know how to use it ... Every time I tried to ring up to find out, “Can I do this? Can I do that?” “Nope you can’t use it for this. Nope you can’t use it for that.” Well what have I got it for? ... Like I didn’t even know there was hours at this stage.’

Before the NDIS, the state funded a support worker for Kevan several hours a day. When the NDIA reviewed his plan and found he wasn't using most of it, it cut funding to two hours a week. Ainslee appealed and the NDIA appointed a new support coordinator and reinstated his supports.

'Him having a set routine so many days a week for at least four hours a day to five hours a day, that achieves a lot and gives him purpose. It gives him strength. It allows him to start learning things. It allows him to build up courage. It gives me a break from it all.'

Ainslee now worries what will happen if the NDIS cuts Kevan's support again.

'With autistic children and ADHD they've got to have this ongoing structure ... If the funding goes down then he loses that stability. And that is my main concern.'

Cornelia and Nance

Cornelia is autistic and in high school.

‘All ... our children have specific learning disabilities and I have imputed dyslexia as well,’ Cornelia’s mum Nance told the Royal Commission. ‘Her older siblings have actually all finished school now, all doing degrees and PhDs and masters. So we have quite a long-standing experience of the education system.’

Nance said Cornelia has a high IQ but still needs support at school, particularly for her dyslexia. Nance and her husband, both medical professionals, chose a primary school that promised to be supportive.

‘We tried to bring in additional supports through technology and use of software programs, but none of those seemed to be taken up by the school. They kept giving her activity books which were two or three years below her.’

Nance said Cornelia felt humiliated in front of her friends and began to self-harm. Nance consulted experts and offered to pay for assistive technology such as speech-to-text software, but would ‘just get brick wall after brick wall after brick wall until ... [Cornelia] asked to finally leave the school’.

The next school also told Nance it would support Cornelia using assistive technology.

‘They did exactly what she’d had before. Give her written information, large amounts of it, expecting her to be able to read it. Then when she can’t, assuming that that lack of being able to access written print seems to constantly be considered a reflection of her intellectual capacity.’

The school gave Cornelia books that had exercises beneath her ability, such as join the dots. Cornelia was embarrassed to attend the class and began to fall behind her peers. When Nance complained, the teachers became defensive.

‘We’re now getting more and more antagonistic ... so the teachers are then not emailing things.’

Instead of giving her access to assistive technology, the school decided Cornelia ‘didn’t need’ the same laptop that the other kids used.

‘There’s like a whole philosophy that says it’s okay if I just put a big neon sign over you that says you’re different and you’re not good enough, you don’t fit.’

Cornelia’s high school also refused to make reasonable adjustments or allow her to use assistive technology.

Nance said the high school boasted about being inclusive, but segregated children with disability.

'It came to the point where [Cornelia] was in year 7 doing hands-on-head Simon Says. And we said to her, "What were you doing that for?" She says, "Well because that's what they want us to do." So she was embarrassed to be in that class.'

Nance said the school received tens of thousands of dollars to support Cornelia, but never explained what it spent that money on. Nance and her husband still struggle to negotiate with the school about reasonable adjustments for their daughter.

'How do ... parents [who] don't have literacy skills to be able to read all those documents [cope]? ... We have several [degrees] ... but even this has sent us both bonkers. Our family is sick of it. We're sick of it.'

Trev and Alecia

‘You have to take everyone as an individual. Label is not important.’

Alecia’s son, Trev, is in his 20s and autistic.

‘He never saw himself as being a child on autistic spectrum,’ Alecia told the Royal Commission. ‘Maybe because I didn’t talk about autism ... I didn’t know where to start, where to finish, what’s going to happen.’

Alecia was born overseas and migrated to Australia. She said when Trev was a toddler she waited years to see a speech pathologist in the Australian public health system and eventually paid for private health care.

She enrolled him in a private school.

‘I did want strong science subjects ... but first of all I started with the research regarding the schooling system, so that was my choice.’

In his first year, Trev had a passionate teacher and ‘didn’t experience issues with the school’. Things changed the next year when another teacher enforced a strict routine making it ‘difficult for [Trev] to comply’.

When Alecia asked if Trev could change classes, the teacher told Alecia, ‘This is not a place for [Trev],’ and that she’d already spoken to an autistic school which would be ‘more appropriate’.

‘For the first time in my life I was speechless. I admonished her for attempting to set out the pathways for my son without consulting me.’

Alecia said Trev’s school then ‘decided to really somehow create a situation’ so that other parents would intimidate her into taking Trev out of the school.

One day, after Trev retaliated to being bullied and hit another kid, a group of parents met Alecia at the school.

‘All stood staring ... I walked in, like a red carpet of shame.’

Alecia pulled Trev out of the school. A year later she decided to make a complaint to the state human rights commission.

‘I didn’t know the rules. I believed in human rights forever. It doesn’t matter if the case happened 10 years or 20 years ago ... but what was the response of the Human Rights Commission? That ... this was an administration issue and is out of date so they can’t assist me.’

Alecia enrolled Trev in a local primary school followed by a private high school. He is now completing an honours degree at uni.

‘Imagine if I had followed [the school’s] advice and couldn’t advocate for him.’

Trev is now dealing with discrimination in the job market. Alecia said that recently, when Trev applied for a particular job through a recruiter, he mentioned he had previously looked for work through a disability employment service.

The recruiter then told Trev he should look for ‘more appropriate’ work and didn’t submit his application for the job, despite his qualifications.

‘All of a sudden they redirected him to the disability part of the business.’

Alecia says the system is working against Trev.

Tameka

'I was begging and begging and begging them to get off the medication. They just said, "You've got schizophrenia. You need to take this."'

Tameka is in her late 20s and was diagnosed with schizophrenia a decade ago.

Prior to her diagnosis, Tameka was in the creative industries. All that stopped when psychiatrists placed her under an involuntary treatment order.

'I just wanted to work ... Then they put me on all these medications. I didn't want to take it. And I started getting all these adverse reactions. I was just sitting in my bed all day, like, not moving, or I just was looking, like, at the wall and I couldn't fold my clothes. I couldn't do anything.'

On her release, Tameka lived in a 'mental health rehab place'. Doctors never helped her deal with the 'horrible' side effects of the treatment, which led to 'suicide attempts'.

'I kept trying to negotiate with them to come off the medication ... I kept telling people, like, "I can't think." There was no way to come off of it. They wouldn't listen to me.'

Tameka said that a couple of years ago she had 'the worst' mental health review of her life. Psychiatrists told her that all of her 'dreams and aspirations' were irrational and placed her under a guardianship order.

'And I just broke down and I was crying my eyes out. I didn't let that stop me. That was their perspective on me, that I was delusional about my life, but it really affected me.'

After that, Tameka was admitted 'plenty of times' to a mental health inpatient facility.

'So that was that. For about two years I was going in and out of psych wards. Every single time it's been involuntarily.'

During this time, doctors started her on a new antipsychotic treatment.

'They decided to give me injections in my butt cheeks. And this medication ... it numbs my brain.'

Tameka said the public trustee has abused her while managing her finances.

'At one stage, they were only giving me \$30 a week into my account along with food vouchers ... So they would always be in control ... I never really had a say of where I was living.'

Meanwhile, the negative fallout of her 'zombifying medication' continued.

'So I absconded. I just didn't have a choice, because the mental health workers, my GP, they were so in control of my life. They would enter my house without, like, asking me. I had no privacy. They would pick me up for my injections and I didn't want it, and I knew I didn't need it.'

After six months in a psychiatric facility, Tameka recently took herself off the injections. The injections have left scars and she has had to have surgery for an abscess they caused.

'But now I can sleep. I'm on tablets just weaning myself off. Definitely, I feel way better. I've pretty much gone through everything.'

Mabel and Paisleigh

Mabel is a First Nations woman in her 30s who has a genetic disorder that causes 'difficulty walking, talking and swallowing'. She is non-verbal and has multiple secondary illnesses. Her Aboriginal disability support worker, Paisleigh, helps her with most daily tasks.

Paisleigh told the Royal Commission that when Mabel's condition started to deteriorate a few years ago, living independently 'was no longer a safe or possible option' for her.

Mabel moved into a supported independent living residence where she was supposed to get eight to 10 hours of support a day. Instead, Paisleigh said, support workers were turning up only briefly three times a day to administer medication.

'The support worker would also assist her with showering every second day ... And then someone would come every now and again to do a bit of cleaning and cooking.'

For more than six years, the disability service provider charged for the hours set out in the service agreement. On top of client neglect was 'financial abuse', Paisleigh said.

'What they were claiming and what they were providing were two different things.'

Mabel's funding included passive overnight care.

'This meant that at the very least a support worker would be sleeping over at her accommodation at her request.'

That never happened.

'Support workers would begin a shift at her house, but then sleep next door at the home of another client.'

During this time, Mabel became depressed and 'experienced thoughts of self-harm'.

'This led to her attempting to slash her wrists. When she requested medical treatment for the cuts on her wrists, the service provider refused to arrange this for her. One support worker told her, "You did this to yourself."

Paisleigh said the lack of support made Mabel 'feel helpless'.

When Mabel vented her frustration to staff, two support workers called her 'a fucking selfish bitch and a slut' and threatened her with assault.

'They were constantly speaking to her in unpleasant manner. In another instance, she was called "a dumb selfish bitch" ... When [Mabel] reported this verbal abuse to her support coordinator, the response she received was, "They are trying to do their jobs."

Paisleigh said the exploitation continued when Mabel moved interstate, and she ended up homeless and self-harming.

‘So as a provider, a non-verbal disabled Aboriginal woman was left alone without support in a town where she knew almost no-one. They had a duty of care.’

The provider also ‘quarantined her funding’, so it was ‘inaccessible to any other support provider’. Paisleigh said they were claiming ‘hundreds of thousands of dollars’.

‘And this was after they ceased providing the services. They were billing for services she was no longer receiving.’

Callam

‘Things are meant to be getting better with ... the NDIS. The NDIS thought that the market would catch up. It would be driven by a free market. But it’s not. It’s getting worse.’

Callam is in his 50s and has physical disability. He runs a service provider.

‘It used to be a profession for a lot of my home care workers. You know they did it for 10, 20, 30 years. Now the majority of people that want to work in this sector, it’s just a passing job they’re doing while they’re at uni or they can’t get another job or whatever reason they join the profession. And I don’t think it’s the right reason.’

Callam said the quality of disability health care also declined after the introduction of the NDIS. After the accident that caused his disability three decades ago, he was out of hospital and back home within 11 months.

‘Before the NDIS they had it down to four-and-a-half, five months. That’s from a newly acquired high level spinal cord injury to home, right? So you ... don’t become institutionalised. It was brilliant. I don’t know what the outcome is now, but I know it’s up around about a year again. It’s not good enough.’

When Callam fell ill recently an ambulance took him to the closest hospital, which doesn’t have a specialist spinal unit.

‘They couldn’t look after me ... They worked out that there was something wrong with me, but they didn’t know what.’

The next morning a doctor told Callam to take a taxi to the spinal unit at another hospital.

Callam said a friend with quadriplegia died from a twisted bowel because an ambulance took him to the same local hospital where the doctors ‘didn’t know what to do with him’.

‘We call it the quad killer. They kill quadriplegics. We’ve been told, “Don’t go there, you won’t come out.” You know, they don’t understand autonomic dysreflexia, they don’t understand a twisted bowel, they just don’t get it.’

Callam said most medical professionals ‘don’t have an understanding of disability’ and need more training.

‘I’ve been up to my GP practice on three occasions to educate them about autism, about spinal cord injury,’ Callam told the Royal Commission. ‘They’ll tell you outright, “We don’t really deal with disability. It’s more of a specialist area.”’

‘GPs aren’t trained in disability, hospital staff aren’t trained in disability. My biggest fear is winding up in hospital without one of my support workers ... Health needs to start talking to the NDIS and we need to train health professionals in how we look after people with disability.’

Callam said it’s also increasingly difficult to access good allied health professionals because it costs too much for them to register with the NDIS.

‘People are exiting in droves and the main reason is because of the compliance. So an [occupation therapist] OT ... was given a quote of \$14,000 to have their audit done so that they could be registered. They’re a sole trader. They’re not going to spend 14 grand.’

He said it’s one reason why people with disability in rural areas struggle to get help. Two of Callam’s friends who live outside the city, one with paraplegia and another with a daughter who’s autistic, control big support plans.

‘Lots of funding [for] behavioural support, speech therapy, occupational therapy, but when there’s no speech therapist, there’s no occupational therapist, there’s no behavioural specialist down there, what’s the point?’

Dan and Annika

Dan is a First Nations boy in his early teens. He has Tourette syndrome and obsessive-compulsive disorder and is currently being assessed for schizophrenia.

His mum, Annika, told the Royal Commission that he was ‘carted away in the divvy van’ to youth detention several times last year due to a lack of mental health supports.

‘He’s not a normal naughty boy ... He is naughty because he’s mentally sick. He sees things and he hears things that aren’t there ... So my son’s mental health has actually caused him to go through the justice system.’

Dan ‘dreaded’ the children’s psychiatric unit, ‘where you have restraints ... all these interventions ... substandard to other cultures’.

Annika said Dan was abused in this unit about a year ago.

‘An incident occurred where four security guards ended up on top of him to restrain him. When he came home I took photographs of all the bruises. The security guard had kicked him in the balls and made him sick.’

The hospital discharged Dan after this incident. Annika said it has since refused him treatment several times.

‘This to me is plain racism. I don’t know how many times he’s been taken up to the emergency department to be told to go home and stop being naughty. One mental health nurse told me we’d be best to put him through a therapeutic treatment going through the justice system. I was disgusted. He’s not being treated because he’s Aboriginal.’

After this, ‘things got worse’ for Dan.

‘My poor son was in [a] boys detention centre here, I think five times after that,’ Annika said.

‘He’s genuinely sick and he shouldn’t even be in those detention centres. I blame the [hospital] for not treating him properly, and he’s deteriorated over time.’

Annika feels the health system has neglected Dan, like other ‘young Aboriginal men ending up in custody’.

Annika said that after Dan’s last release from prison, the NDIS started removing supports.

‘When child protection services got on board, they were there to help us with horrible mental health issues he’s had ... It really put a lot of resources in him for us to utilise. But now there’s an ongoing issue with the NDIS.’

Annika was trying to self-manage Dan's complex needs package. The local area coordinator didn't top it up, so she 'had no money to pay his support workers'.

Dan's behaviour and occupational therapists say he needs two full-time support workers, but the NDIS disagrees. But Annika says that's been the only thing keeping him out of detention centres over the past few months.

'This is the longest he's been out. And that's because we've got the two care workers throughout the day to help us with his behaviours. This is the reason why NDIS are not happy with us ... It's straining their budget. But what can we do? I don't want him being a statistic. That's why I'm working so hard. I won't rest until he's actually at peace with his mental health.'

Joesy

Joesy, early 50s, is blind.

She told the Royal Commission that as a student, at various times in her life, she has felt invisible and 'profoundly isolated'.

'Legally blind and visually impaired students were not treated as students, let alone people, and were not treated with dignity.'

At school, Joesy used braille and audio to access information. One school refused to provide any materials in these formats.

'Trying to gain access to handouts and braille textbooks was extremely difficult or virtually impossible.'

Another school refused to make any adjustments for Joesy so she could study a language orally without having to write it.

Schools never gave Joesy her report cards in a format she could access.

'I also would have liked to have seen my file in braille ... because I am a real person and not a fictional character in a book.'

In her final year of high school, teachers never included her in employment programs. She didn't get to complete work experience, practise being interviewed or learn how to write a CV.

Joesy was 'bitterly disappointed' the school didn't give her a reference.

'I attended all the swimming and running sports carnivals, concerts and workshops that the school conducted. I was hardly ever absent.'

Following school Joesy went to TAFE, but only lasted half a day.

The coordinator didn't realise Joesy was blind when she accepted her into the course. She told Joesy that she couldn't continue because she wouldn't be able to complete the first aid part of the course.

'I had to go home by taxi all alone and distraught. I did not receive any emotional counselling from the TAFE.'

Joesy decided to prove the coordinator wrong and successfully completed the course at a different institution.

At university, Joesy had to stop using her braille machine because students complained it was too noisy.

Joesy returned to study at TAFE a few years ago. This time, she is involved in a student telelink group.

Telelink is a service that connects people for facilitated group sessions by phone or video conferencing. Blind and visually impaired students meet once a month to discuss issues such as the NDIS, support dogs, access to course materials, advocacy and technology.

Joesy likes using the telelink service because she can hear a person's voice.

'The telelink service I am involved with means that I am at home and can converse with other legally blind and visually impaired adults all around Australia. I am also in a safe environment and do not have to catch a taxi home in the dark at night.'

Joesy says a peer telelink program would have made an enormous difference to her when she was in high school.

'That is why I would like very much to see a telelink group ... for students who are currently studying at secondary school.'

Students could discuss issues relating to school and exams.

'No student should have to put on a brave front. It is perfectly all right to say, "I failed an exam" or "Well I could have done better" or "I passed with flying colours."'

Students could also talk about relationships – romantic and platonic – and discuss strategies for building friendships and dealing with bullying. They could also share tips about new technology and discuss better ways to communicate.

'Peer support is so very imperative. I cannot tell you how imperative this is particularly when adolescents are vulnerable.'

Joesy says it is vital for legally blind and visually impaired adolescents and adults to have a voice 'to discuss inclusion and integration within our community, which would help to conquer barriers to education'.

Darrin and Carine

Darrin is in his 20s and has spina bifida.

‘He would like to be happy and friendly and outgoing, but he has so much anxiety around things that have happened to him happening again that he really struggles to do that,’ his mum Carine told the Royal Commission. ‘He wanted to live as independently as possible.’

A few years ago, Carine helped Darrin move out of home into supported disability accommodation (SDA), even though it was in another region.

‘We thought we’d hit the jackpot. He got into a [service provider] property which, as a building, is absolutely amazing.’

But after 18 months in the home, Darrin weighed less than 40 kilograms.

‘I can’t tell you how bad I feel,’ Darrin told his mum over the phone. ‘I’m just going to send you this photo.’

When she saw the photo, Carine immediately organised for him to be flown home.

‘I nearly burst into tears at the airport. I thought if he’d been in there another week he’d be dead. He was so thin. He was so grey. He looked like he’d aged 30 years. He looked like he was about 60 years old.’

Carine said when she asked the service provider for his food diary ‘there was just day after day after day of nothing entered into it’.

‘And then there’d be, like, “Offered him food.” Did he eat it? What was it? We don’t know.’

Darrin needs one-to-one care 24 hours a day and is supported by the NDIS. But after Carine moved him to another SDA home, the NDIA cut his funding by about half.

‘I rang and I said, “What do you want me to do?” Because they wanted him to have seven hours of support a day, no overnight, and for him to be in the house on his own the rest of the time. And I said, “Well, if you do that he’s going to die because he can’t do his own catheter, he can’t prepare his own meals, he can’t get them out of the fridge, he can’t open the door.”’

The NDIA then suggested he move to another house ‘so that he could have one-to-three’ care.

Carine struggled to find someone at the NDIA she could talk to.

‘I was ringing every single day. “Can you please make contact with me?” ... And this went on for three or four months. Not once did I get a phone call back.’

Carine and her husband eventually gave up trying to find a suitable home for Darrin and set up their own service provider.

'We decided when all of this happened that we needed more oversight and more control over where he went and who had access to him. And so we set a disability share-house and then we put him in it.'

Darrin's since had his original funding reinstated.

'It's taken us two years to get good support around him ... He's safe now. He's happy now. He's putting on weight, which is great.'

Roddy and Carol-Ann

'The system and the NDIS Act is built in such a way that if you can't see an illness, the illness is frankly not there [and] you are made to feel blamed as a parent and guilty as a parent that you're not doing enough.'

Carol-Ann lives in a regional city. Her son Roddy is autistic and has attention deficit hyperactivity disorder (ADHD).

'He enjoys computer games. He has an extremely dry sense of humour and personality,' Carol-Ann told the Royal Commission. 'He's very smart. Very, very intelligent.'

Carol-Ann said Roddy was 'always an incredibly difficult baby'.

'From the get-go I advocated for [Roddy] to get the supports ... Unfortunately, the services are simply not available here to actually get the allied health professionals, the medical professionals, the psychologists, the psychiatrists, all of those people to chronologically assess [Roddy] to get a diagnosis.'

Roddy's paediatrician diagnosed Roddy with ADHD, but refused to diagnose autism, despite his behaviour.

'I would write her emails to say that he's run out on the road. That he was threatening self-harm. And she would tell me that he simply, from her observations, has ADHD.'

An NDIS early intervention scheme funded medical reports for Roddy, but until a doctor diagnosed him he wasn't eligible for support at school or home. Roddy's mainstream school kept sending him home.

'He's smashing up the place. He smashed up a car. He's melting down. He's in a classroom taking plaster off the walls. He's screaming, beside himself with anxiety ... It's scary for the people who don't know what a meltdown looks like.'

Carol-Ann and her husband separated and she changed jobs, which 'had a massive impact' on her mental health. A local school specialising in autistic kids wouldn't take him until he had an autism diagnosis.

One day, when Roddy threatened to kill himself rather than return to school, Carol-Ann took him to the hospital emergency department. A doctor told her the problem was 'parenting dysfunction' and tried to discharge Roddy.

'I kind of felt that at every juncture ... we were made to feel like we were bad parents.'

Carol-Ann refused to leave and after several hours, during which Roddy 'smashed the entire room', the doctors could 'no longer deny his behaviour'. A new paediatrician diagnosed autism.

But Carol-Ann still struggled to get appropriate support from the NDIS.

‘I was told that I need to assume parental responsibility and that if we have a crisis I should call the police.’

Roddy’s funding ‘didn’t even cover the OT [occupation therapist]’, so Carol-Ann went to the Administrative Appeals Tribunal.

‘I found it difficult to keep my head above water ... At the end of the day, even I found it incredibly challenging, and I know how to read the law. It is a complete and inherent systemic neglect for all those other children that have a disability in Australia when faced with this issue.’

The NDIA eventually approved a plan that gives Roddy access to therapy and respite, but Carol-Ann said it’s ‘too little too late’.

‘We needed the support two years ago.’

Roddy now lives mainly with his father because Roddy ‘would meltdown with me and he would punch me’.

‘It’s damaged my life ... I no longer have care of my child because the [early] intervention was lacking despite our continued advocacy for him 24 to 36 months prior ... My life has been damaged, irreparably damaged, because I’m never going to get this time back with my child.’

Natalia

Natalia's in her 50s and lives with depression and chronic fatigue syndrome.

About five years ago Natalia moved into a group home for people with mild intellectual disability. She saw it as 'a really good fit', particularly with a 'live-in housekeeper' to prepare meals. She also liked the idea of sharing with nine other residents.

'Sort of close enough and a community-based thing. I thought it would be fantastic.'

But the housekeeper was a bully and would humiliate the residents.

'She would yell at you ... It was insane. She had to have a go at a couple of residents at a time and I became one of those. She'd be running me down to other residents. She discussed private issues,' Natalia told the Royal Commission.

And the food was 'just so bad'.

'The old vegetables from like the day before that didn't get eaten were put in a pot of water, boiled again ... packet of cup-a-soup added and it was served ... as their meal. It was just horrific. And I saw an old gentleman in tears trying to force down food.'

Natalia and her housemates would 'get punished for weeks' if they dared say a thing.

'These are fragile, old and disabled people. She'd say, "Right, you don't get no more bickies," as if they're five-year-olds who have been naughty ... It was a schoolyard mentality. She divided the table into those she liked ... and those she didn't like. She served the ones she liked and then walked out.'

The housekeeper didn't clean the communal areas and was 'taking residents' groceries'. She treated the house as her own. Her family and friends would just 'waltz into the residents' area and help themselves to [the residents'] food'.

'She would have parties with half-a-dozen girlfriends. You'd go down and make a cup of tea and you felt like you were walking in on someone else's loungeroom, you know, someone else's party.'

Natalia and others complained to a committee appointed by the provider to consult with residents.

'Instead of them saying, "I can see we have a serious problem here," it completely supported her.'

At a meeting, committee members said, 'This is not a hotel. Why aren't you bucking in and cleaning it yourselves? Leave if you don't like it.'

The housekeeper 'intensified her bullying'. She 'kicked residents out of the communal lounge room' if they 'cramped her style'.

'Now if we, as adults, want to have a drink, we had to ask her,' Natalia said.

At an 'abusive horrible meeting', residents again protested. Natalia was 'yelled over, called stupid and told to shut up'.

Natalia engaged an advocate and, with their help, the housekeeper 'finally left'.

But her replacement also took 'ownership of the house' and locked the kitchen on residents. Committee members all threatened 'to quit' and leave them without a housekeeper or money for food when asked to step in.

'We're supposed to be part of decision-making about things that go on in the house,' Natalia said. 'You know, regular check-in with the residents, "Is the work being done? Is the food decent?" "What's to be spent on meals?" The model is just not followed. You get to treat people any way you want and no-one will do a damn thing. Nepotism is absolutely rife in the system here.'

Lottie

'I don't understand how multiple people can get away with sexual abuse. Abuse in homes. Abuse everywhere.'

Lottie is a young First Nations woman who lives with borderline personal disorder and fetal alcohol spectrum disorder.

Lottie told the Royal Commission she was physically and sexually abused 'from three to 14' while in foster care. Lottie feared if she spoke out to the department for child protection (DCP) or police, she 'would cop more abuse'.

At the time, Lottie was unaware of her disability.

'I had the diagnosis when I was born but my foster carer didn't tell me.'

Lottie described one of her foster carers as 'a white supremacist' who denied her 'any association' with Aboriginal culture and her family.

'She didn't even want me to go to my mum's funeral.'

When Lottie eventually told the DCP about the abuse, she said they 'didn't really care'.

'Everyone would say that I was a liar, a manipulator.'

Lottie blamed herself and her mental health 'started declining'.

'That's all I knew my whole life was that I was jinxed and I deserved to be sexually abused. I started going into hospital more but DCP wasn't really worried about that. I was in and out of drug rehab. I knew something was wrong. I started lashing out ... I developed an eating disorder. Any time a man would come near me I would scream and shout and run away.'

In her teens, she 'eventually started fighting back'.

'The police started coming coz the neighbours were telling them what was going on. They did investigate ... No-one got charged for anything ... I don't understand why. I left that foster carer when I was 16 and DCP took me back. And then they finally realised, okay, she was acting up because she was being abused in care.'

The DCP took Lottie to a psychiatrist who diagnosed her with borderline personality disorder.

'I was finally taken on board by the NDIS.'

For the last couple of years, Lottie has been 'bouncing in and out of group homes'.

At one home, a staff member gave residents alcohol 'and it ended up escalating'. A resident assaulted Lottie.

'I'm still recovering from a fractured rib. She would kick me, hit me, pull my hair, try and strangle me. Try and strangle other staff members. And every time I went to hospital, went to the police, they're like, "Oh, it's just your disability. Like it's just playing with your mind." ... I feel like everything's my fault.'

Lottie is studying at TAFE and 'trying to heal'. After about 20 homes, she's 'actually in a safe place'.

'With the support I am growing and learning.'

Lottie said authorities should have 'stepped in' to protect her much earlier. She recommends regular house checks of children in care, even those under long-term guardianship.

She would also like to see more Indigenous and mental health supports in child protection services.

'If a child discloses any abuse to them, please investigate ... Because that can save someone's life. They need that support from DCP ... I should have got the love and care.'

Jaye

'If we have really created a world in which undiagnosed women start sex working in order to afford getting medical diagnoses, this is the most terrible system.'

Doctors recently diagnosed Jaye, a sex worker in their 20s, as autistic. Jaye, who identifies as genderqueer, came to Australia several years ago.

'I always felt a bit odd at home. Never fitted in. Didn't know why. Oh well, autism, but I didn't know this [at the time],' Jaye told the Royal Commission. They said they experienced sexual abuse and 'other violence' during his childhood.

Jaye stayed in Australia on a student visa and started working part-time in the hospitality industry.

'And the few job offers I got was cash in hand \$16 an hour ... I never wanted to work illegally. You know at the time the student visa had restrictions of 40 hours per fortnight. That's not much to survive in Australia.'

Jaye at first dated men who paid for a meal and had a 'warm bed for the night'.

'You know, just something nicer than the hostel where the heater didn't work. And I didn't realise at the time that this is already a form of sex work.'

Jaye was sometimes assaulted, but didn't always recognise it as abuse.

'I was definitely taken advantage of due to undiagnosed disability. Men definitely picked me as naïve ... I didn't have many friends growing up. I thought this [abuse] was normal.'

Jaye also has anxiety, depression and a history of 'meltdowns'. They occasionally ended up in hospital.

'Nobody could diagnose me. The only thing I kept hearing is, "It could be borderline or bipolar [disorders]." And borderline is something that like half of my brothel was diagnosed with because apparently that's the one diagnosis they keep giving to sex workers.'

Jaye said 'around one in two' sex workers identify as a person with disability.

'There are wheelchair users. People with cerebral palsy. People with intellectual disabilities. So many autistic and [attention deficit hyperactivity disorder] ADHD late-diagnosed people.'

Many also have undiagnosed disability.

‘A lot of us start pursuing sex work because it’s the only way we could survive with so many undiagnosed disabilities ... I’m starting to have the feeling that maybe the world has, you know, stopped diagnosing women.’

Jaye said sex workers they know ‘keep getting rejected’ by disability support services because of their sex work, ‘even though a disability is the reason why [they] are working’.

‘The money is good. You’re able to definitely survive on 40 hours per fortnight and even pay for like going to different psychologists and psychiatrists.’

Jaye said although sex work is decriminalised, police still treat sex workers as perpetrators of crimes, not victims.

‘Every single time when I went into the police station and said, “This guy has assaulted me. This guy has threatened me,” they first were like, “We have to figure out what we should charge you with.”’

Jaye told the Royal Commission that they would like other job choices, but options for people with disability are limited.

‘I think it’s honestly about choices. I would love to have employment which is disability friendly and which makes enough so that I can work, you know, just cover basic needs, food, rent et cetera.’

Alina

‘Due to the misdiagnosis, I’ve got a lifelong physical disability. I missed out on many formative experiences during my adolescence. I lost all my friends and was separated from my mum at the most terrifying time of my life.’

Alina is in her 30s. She has a brain injury and post-traumatic stress disorder from time spent in a psychiatric ward as a teenager.

At high school, doctors misdiagnosed a genetic condition with anxiety, Alina told the Royal Commission. ‘So I was prescribed antidepressants which gave me severe side effects including self-harming and suicidal behaviour.’

After being admitted to a children’s hospital for treatment, Alina’s suicidal behaviour ‘increased in severity as the medication was increased’. It was a ‘known potential side effect’. Her mother wanted Alina off the drugs but doctors refused.

‘So mum withdrew consent for the treatment and requested for me to be transferred to a different hospital.’

Doctors responded by applying for Alina to become a ward of the state.

And so, Alina said, the ‘punitive, negligent and traumatising’ treatment continued. The mental health team put her in isolation and used restrictive practices on her.

‘I was detained for weeks on end in a small locked area ... The hospital didn’t let me see my mum or have visitors for extended periods ... I went without human touch for many months at a time.’

Alina said medical staff treated her like ‘a specimen’ and ‘punished’ her when she self-harmed.

‘If I had difficulty eating, I would be forcibly, roughly and painfully restrained by multiple staff members who would force a nasogastric tube up my nose to feed me. They told me they were using the largest tube possible because I deserved to feel discomfort because of my bad behaviour.’

Alina was not allowed outside or even to talk to other patients. She felt ‘like a criminal’.

Workers often ‘crash-tackled’ her to the ground when she tried to escape.

‘And I’d be left with lots of bruises. I think the practices amounted to inhumane treatment in many circumstances.’

The hospital never gave Alina ‘access to a lawyer or an understanding of what was going on or when it would end’.

‘I think my story illustrates a number of systemic issues relating to the inappropriate use of child protection proceedings in the context of medical treatment. This practice disproportionately affects children with disabilities and their families, and denies them the right to family life.’

Alina said that during her time on the ward, doctors ‘disregarded genetic tests’ showing that the drugs were harmful to her.

After a couple of years, a mental health review tribunal overturned the treatment order.

‘And that’s what eventually led to my being discharged and allowed me to stop taking medication. And within two months my symptoms had disappeared.’

Alina returned to school and has never had ‘any similar kind of mental health episodes’ since.

‘This confirms that the illness was caused by the medical system.’

Today she’s on a ‘simple treatment’ and has NDIS supports.

‘I had to learn to walk and talk, and the brain injury still affects me every day. I need substantial daily support for physical activities.’

Alina believes none of this would have happened if doctors had ‘taken the time to do a simple blood test.’

She won a case of damages against the hospital and has ‘done very well’ in her profession despite battling discrimination.

‘As soon as I disclosed my disability, they’d simply withdraw the job offer, decided I wasn’t fit. I’ve lost significant income and missed out on many career opportunities, but I’m proud of what I’ve overcome.’

Santos

‘This whole environment of community housing, it’s as if it’s just real estate, like proper real estate ... No compassion, no love, no nothing. You know, so that’s how they treat us. We’re treated like dirt.’

Santos was badly abused as a child and teenager, and has post-traumatic stress disorder. He is in his early 40s and for the past decade or so has lived in community housing for people with disability. It is managed by a not-for-profit provider and Santos is deeply unhappy with the standard of the housing and the way it is managed.

Santos listed several issues that concern him.

‘The first point is negligence,’ he said. ‘Second point is maintenance. Third point is attitude.’

Matters are not dealt with in a timely way and it is not clear who he can turn to for help.

Santos said that for several years he had to ‘beseech’ managers to get plumbing repaired, but they ‘literally just ignored it’.

Problems with mould have also gone unaddressed for nearly half a decade. ‘So it’s spreading like wildfire,’ Santos said. ‘They don’t care.’

He feels that managers and people working at the site look down on the residents.

‘Oh, man, they hate us. They hate us so much. We’re just seen as rats. Like we’re just seen as problems. We’re just seen as battery hens. We’re seen as, “Give us your money and just shut up.” That’s the attitude. Like I’ve heard behind closed doors like when they’re at my front door, [I’ve] overheard them through the door say, “They’re all just dole bludgers, pieces of shit, ignore them.”’

Santos would like to see closer regulation of community housing, to ensure standards are maintained – ‘Maybe have a government party that oversees community housing henceforth.’

Santos has the option of moving to different housing with another provider, but he has support workers he likes and doesn’t want to move away from them.

He goes for walks with one of his support workers, and finds it helps his state of mind. He prefers exercise to medication.

‘Like I’d rather live in reality and find a way out than live in denial and numbness and never get out of it,’ he said.

Every day is like a rollercoaster. I go out and feel hope, come home, dread. Go out, feel hope. Come home, dread. Repeat that for years. It’s hell.’

Jaxen

Jaxen, in his early 60s, has a progressive neurological disability and problems with his spine that cause chronic pain and make it difficult to move and walk. For a long time he lived in social housing with his father, but when his father died several years ago the housing providers tried to get him to move out.

Jaxen had asked to be re-housed in accommodation that didn't have steps and would be easier for him to access. The providers agreed, but when a suitable property became available they allocated it to someone else.

Then they asked Jaxen to undergo a medical examination to assess whether he was able to live alone. Jaxen believes they hoped the assessment would find he couldn't, providing an excuse to get him to leave. Instead, it found he was capable of living independently.

It took more than a year, but finally the providers found a place for Jaxen to move to. The relocation was a big job as Jaxen had not only his own but his father's and another family member's possessions to deal with.

'So I had to sort through that and it was every, oh my God, it went on, I think it took 10 weeks for me to move out.'

Jaxen thought that was okay, because when he signed the lease the housing provider representative told him he could take his time.

'I actually said, how long have I got to move, and her words were ... "as long as it takes".'

She told Jaxen that until he was re-settled he would pay \$10 a week rent for the new place and the existing rent on the old place. 'I thought that was reasonable,' said Jaxen.

Instead, the providers started charging Jaxen full market rent on the new property just two weeks after he signed the lease. The letter informing him of the changed financial arrangement was sent to his new address, not to the one where he was living. It was sent several weeks after the providers started charging the increased amount, so Jaxen was already in arrears when he received it. Essential repairs on the new property to make it livable had not yet been carried out.

Jaxen paid no attention for a while.

'I didn't understand what they were trying to do. I was going on the verbal contract agreement of what was said at the lease signing ... If you say something, I've got to take your word for it.'

As the weeks went by he accrued a debt of thousands of dollars. The housing providers sent another letter. It said they were pursuing the debt through a tribunal process.

At the hearing, the woman who'd made the arrangement with Jaxen about the lease wasn't there. Jaxen successfully argued the hearing shouldn't proceed without her.

At the rescheduled hearing, no-one from the housing provider turned up and the case was dropped. Jaxen is now living in his new home.

He is still angry with the housing providers, who he believes discriminated against him because of his disability, treating him like a 'piece of crap'.

'I'd like a copy of their policies because what they give you, they say in their – "We're very accommodating for disability," well, I'd strike that one out, you know what I mean? ... They just treat you with contempt. That's about it.'

Aisling

Aisling, 30s, lives with intermittent deafblindness.

'Things in my world would fuzz, move, disappear, have patterns,' Aisling told the Royal Commission. 'There was no name for it when I was a kid, so education was extremely difficult.'

Aisling couldn't keep up with the class and did practically no work. Students bullied her and teachers called her 'dumb'.

'If you think I'm dumb, you're not actually going to teach me. You're not going to teach me any more than what you think I'm capable of, which is a problem in itself.'

Except for a reader and writer at exam time, no-one supported her.

'I constantly failed.'

At 17, Aisling had a reading age of a 12-year-old, but the school thought that was enough for her to get a job.

Aisling went to university but said it was a nightmare. She couldn't access support during the semester, only at exam time.

When Aisling asked for more support her teacher told her she could go to another campus. But Aisling couldn't drive and had no way to get there.

'It's this constant thing with education, having to educate people but then really not being heard.'

Aisling is currently studying at TAFE and is still not well supported.

'Even getting into that TAFE building there's practically no walking spaces safe anymore. There's more and more shared spaces. It doesn't feel like a shared space because you're forever having to negotiate with people who don't even look for your cane at all. They don't look for the cane, they don't look for the wheelchair, they don't look for anything like that.'

Aisling says the NDIS is a constant battle. Staff don't understand deafblindness and don't understand her needs. She has to continually negotiate the technology and supports she needs.

'I find it insulting because I have to explain myself all the time.'

Aisling also finds Centrelink difficult to navigate.

She requested assistance to fill out a form, but she never received it and staff made excuses about why they couldn't help her.

Aisling has only ever been able to secure low paid jobs because she doesn't have the support she needs.

'One of the biggest gaps for people with disabilities is that no-one is really thinking about you when you leave school. I can't have a reader and a writer at a job. No-one will hire me if I need a reader and writer at a job.'

Aisling has tried to volunteer but it is 'practically impossible' because she doesn't drive and IT systems are not accessible.

'I'm not really made for this world pretty much. It's frustrating too because I'm not a person who sits in the corner and does nothing ... But it's quite difficult. I don't fit in anywhere.'

Seraphina

Seraphina, in her early 50s, was diagnosed with multiple sclerosis (MS) about 20 years ago. About six years ago, she was diagnosed with cancer and hospitalised for surgery.

While in hospital her relationship with her family broke down and she was left with no support. She saw a social worker, but all he did was organise an Aged Care Assessment Team assessment, to enable her to move from hospital to an aged care facility.

He did not tell her about the NDIS or put her in touch with any support services, such as the MS Society.

'I think he got himself into a situation that – he had never had to deal with a disabled person,' said Seraphina. 'There was nowhere for me to gain information on what my rights were, where to go. I was literally stuck in a hospital with nothing and no-one to support me or anything.'

Seraphina said her experience in hospital left her traumatised and 'devastated' by the fear she might have to return there.

'I'm petrified that I just won't get out of the system again. And I'm like I know I have everything in place, that there should be no reason anyone can stop me. But ... I have that word or that disability stigma in front of me.'

She said the hospital did not understand the needs of people with disability. Instead, staff viewed her as a 'problem patient'.

'There's a 90 per cent chance they don't even realise that I'm disabled because they've just come onto shift so they don't know and then because I'm uncomfortable and I'm saying can you please ... – "Oh, we've got other priorities." It's like, well, I'm a priority. I can't sit myself up, like, I can't eat in bed. You need to seat me in a chair. I will choke if I'm lying in bed ... There's no form that I can fill in saying these are my needs, I need to be sitting up to eat, I need to be this, I need to be that,' Seraphina said.

'Even having my own wheelchair there, you know, that's a nightmare because hospital staff think they can come in and it's just a wheelchair, they can take it ... The minute I have to go into hospital it's like everything – I want my names on the arms, I want my name everywhere. Because physios and that, they just walk in and they're like "Oh here's a wheelchair" and it's like, "Ah, no, that's my wheelchair. My personal property, like, you can't take it."

She also felt discriminated against. A patient in similar circumstances to her but without disability was offered help to find somewhere to live. Seraphina's only option was an aged care home.

'I believe it was just the fact that I had MS and I would never be able to be fully independent.'

She had to argue for help to return to her previous level of strength and fitness.

‘I have to justify why I’m entitled to rehabilitation so that okay, no, I’m never going to get up and walk but I still need to be able to stand to transfer out of my wheelchair and into bed ... They’re just like “It doesn’t matter, we’ll just hoist you on the bed.” It’s like, but I have to learn how to do these things again ... Why am I not ... allowed to get back to my baseline?’

Seraphina thinks a new role of disability liaison officer would help hospitals improve their treatment of people with disability.

‘I wouldn’t be scared to go to hospital if I knew someone was going to be there and I knew I could say to that person okay, this is what I need, this is what I don’t and, hopefully, they understand what I’m talking about.’

Hassan

Hassan is in his 30s and is autistic.

'I was told by my mother that I was a difficult child, that my brother and sister were not like me,' Hassan told the Royal Commission. 'Reflecting back I was exhibiting autistic behaviours and ... you know, I was physically punished for it.'

Psychologists diagnosed Hassan's autism a couple of years ago, after a domestic violence incidence during which his wife tried to take his daughter from his arms.

'I stupidly pushed her and she called the police. Police came, I was arrested and charged ... I am remorseful. I accept that my behaviour and reaction on that day was not right.'

Hassan said although his wife had 'punched and slapped' him and is verbally abusive, he didn't realise her behaviour might also be considered domestic violence until he started a compulsory program for male perpetrators.

'When you start questioning or start explaining your experience [during the program], you were either forced or guilt tripped to accept this mantra ... that all men are the only perpetrators of family violence ... The program also took the position that no matter how hard, disability is not the cause of violence.'

After being charged, Hassan couldn't return home and moved in with his mother, who didn't believe his 'western diagnosis' of autism.

'She doesn't want to recognise my autistic traits and she tells me that I need to be a better person.'

Hassan and his wife divorced. He said a report written for the court stated he would 'never make a good parent because of [his] autism'.

'To me this is ... discriminatory, but I don't have a way to lodge a complaint.'

Hassan said the 'one-size-fits-all' approach to domestic violence doesn't help autistic men learn how to control their behaviour.

'Instead of understanding the context of our offending and providing someone with no criminal history and of low risk ways to work on their behaviour, I felt that I was categorised into the same category of those that committed appalling violence.'

Genna

'We shouldn't have to be suicidal before someone says maybe there's something wrong. We shouldn't have to be broken before we can find out that we're just atypical.'

Genna is in her 50s and has complex post-traumatic stress disorder. Doctors recently diagnosed her with autism.

'I'm just now trying to put myself back together as an autistic adult rather than the broken person who ended up in hospital because she can't cope,' Genna told the Royal Commission.

Genna recently spent six weeks in hospital where tests showed she was 'fairly significantly on the autism spectrum'. But doctors told her they couldn't officially diagnose autism.

'Instead of giving me an autism diagnosis, they gave me a borderline personality disorder diagnosis because that was what they had available to them. And that seems ridiculous.'

Because she had no official autism diagnosis, doctors wouldn't treat her as being autistic. Instead, she paid \$2800 for a diagnosis from a clinical psychologist after she was discharged.

'When you are given a cornucopia of mental health diagnoses you feel broken. You feel like garbage because your world is falling apart. But when you are given the opportunity to see yourself through a lens of autism – I'm not broken, I'm just different and that's okay – you can readjust your self-image.'

Genna said some doctors still don't take women's mental health seriously, which is why so many women are misdiagnosed and inappropriately treated.

'I have had doctors say to me, "If you just stopped being fat all your symptoms would go away."'

Genna fears many adult women with undiagnosed autism 'have missed the opportunity of having a respected neurodivergent position within society'.

'They're just written off as quirky, they're written off as being the odd one out, when they could have a much more self-invested and dignified life,' she said.

'When you've gone half a lifetime being completely misunderstood, putting yourself in dangerous situations because you don't understand the social set-up, being misinterpreted, being frustrated, being unable to handle tertiary education ... that made me a less productive person.'

Topaz

Topaz, in her early 40s, is Deaf.

Topaz has two children. She ended her relationship with their father because of his violence and abuse. After the couple separated they split the care of the children, an arrangement that worked amicably for years.

'The kids were happy and we had a good life,' she told the Royal Commission.

The situation changed when Topaz started a new relationship and her ex-partner claimed full custody of the children.

'I was very shocked. I didn't understand what was happening,' she said. 'I couldn't understand why this would happen, because we had this shared arrangement. It was a very confusing time. I was very confused by how this started.'

Throughout the events that followed, Topaz experienced discrimination because of her deafness.

'I've gone through a lot the past few years, and I've suffered a lot of abuse at the hands of the system,' she said.

In seeking to deny Topaz access to the children, her ex-partner made up stories about her and reported her to child protection. She had to submit to an assessment process where a child protection supervisor observed her interactions with her children. The supervisor had no knowledge of Auslan.

'And they were so incredibly impatient with me. They accused me of being violent and aggressive because I was using my voice loudly and I was gesturing and using signs with the kids ... They would make comments like "Why are you talking like that? Why are you using your hands like that?" And I would try to explain to her, "I'm not being rude, I'm just Deaf. This is how I communicate." And she would comment on why I'm always frowning and – you know, that's a grammatical feature of Auslan. It's a thing we do when we're asking a question.'

The custody claim was eventually heard in the Family Court, where her ex-partner claimed she was not a good mum and that because of her deafness she couldn't look after the children.

'He made me feel very small. He belittled me,' Topaz said. 'My ex didn't understand what it was like to be in a Deaf family in terms of a cultural perspective and didn't understand that children of Deaf adults have their own culture and are a bit different.'

Child protection didn't understand either.

'They didn't understand the dynamic of having Deaf parents. They were discriminatory. I was heartbroken by some of the things they claimed, because they also thought ... I couldn't parent because I was Deaf,' she said.

‘And the Family Court system didn’t look very favourably on me and was believing what was said by my ex.’

Communication issues made everything harder. Topaz had to provide her own Auslan interpreter, and no concessions were made to the difficulty of the interpreter’s task. People spoke quickly and over the top of one another. Her ex-partner’s lawyer made fun of the interpreter’s signs.

‘I ended up walking out of there in disgust at how I was treated. And there was nothing I could do about it. It’s not right, that there’s nothing – you know, I was trying to do something very serious in court that day. It had a huge impact on my family, on my children. And everyone there thought I was a joke and treated me like I was a joke.’

The magistrate found against Topaz, who had to relinquish custody of the children to her ex-partner. She believes this outcome was deeply unfair. She says people with disability get ‘picked on’.

‘Sometimes it might only be minor disability like blindness or deafness. Family law uses that as a weapon against people ... [It’s] used as a reason for separating parents from children,’ she told the Royal Commission.

‘I think changes need to happen in family law ... I think our child protection services definitely need some serious overhaul.’

Coby and Baillie

Coby is in high school and has a genetic condition that causes developmental delays.

‘He’s curious, delightful,’ his mum Baillie told the Royal Commission. ‘His really good memory is for all the facts and figures to do with AFL, like, absolutely obsessed.’

Baillie wanted Coby to have an inclusive education at a private school, but struggled to find a school that would take him.

She eventually enrolled him in an independent primary school that focused on creativity.

‘You weren’t allowed to do sport at the school. And then he taught himself to read through reading, at the time, rugby magazines.’

Baillie said his teacher believed Coby was ‘reading too early’.

‘Then she’s like, “You can’t bring in your rugby magazines, I don’t believe in sport.”’

The teacher made Coby sit outside the classroom during some lessons because she thought they would be ‘too hard for him’.

‘I felt like that became, like, bullying by the teacher and then obviously the kids pick up on that.’

The school also rejected an occupational therapist’s lists of recommendations to help Coby at school.

Baillie and her husband withdrew Coby from the school and tried to find another.

‘As soon as you give them a diagnosis they’re like, “You know I think you should try somewhere else. We can’t cater to you, we don’t have supports.”’

To enrol Coby in a high school that would accept him, Baillie and her husband moved to another state.

‘I feel like we should have choice, a choice in a value of a place to go to. Like, you choose where you want to live or work or be in life, and it would be nice to have a choice for my child to be among people that I agree with their values, or whatever I choose for my child.’

Baillie said although she wanted Coby to go to a private school, the public school system in the new state was more inclusive.

‘The kids are very sporty and they’re just more easy going and it’s just a different culture, I guess, so that’s good for my son ... The support staff there and the head of assisted learning are incredible, so I just want to give a shout out to them.’

Joanie and Beryll

Joanie had had epilepsy and cognitive impairment since she was a young child. Now middle-aged, she recently had her cognitive abilities medically and legally assessed for the first time. The assessments found Joanie's impairment is mild.

Joanie's older sister Beryll wasn't surprised. Joanie has a processing delay so is slow to speak and respond. Because of this, Beryll said, people underestimate her.

'That processing delay might lead people to believe – if they don't give her the time to process, they might believe that, you know, there's no-one home, the light's not on. But in fact the light is well and truly on.'

'She's able to articulate her wishes and hopes for the future, her dreams – if people are prepared to listen to her.'

Joanie has always lived in the home where she grew up, with her mother. For the past 10 years or so, one of her brothers has lived there too and has been her main carer. When their mother went into aged care several years ago. Joanie's brother and another sibling became very controlling of Joanie, imposing a series of restrictive practices on her and isolating her from family and friends.

'The United Nations Convention of the Rights of Persons with Disability says that a person with a disability should have the right to autonomy and to have some control over their own decisions, but every single decision was taken out of her hands,' said Beryl.

'She was never consulted. Her opinion was never sought. Things were never discussed with her. The outcome of [their] decisions were never communicated with her ... I can't comprehend that people would treat another person like that.'

Matters came to a head when Joanie contacted Beryll and asked her to intervene. Beryll organised the cognitive assessments. This formal recognition of Joanie's capabilities meant she was then able to appoint Beryll as her Enduring Power of Attorney (EPOA).

Beryll said being appointed EPOA is 'very big'.

'It's an important key. It opens a lot of doors and yes, I found out a lot of things.'

As EPOA, Beryll now has access to Joanie's financial affairs. Examining these over the years her siblings managed them, she found they had been financially exploiting her, using her account for their own purposes and illicitly withdrawing her money.

'When we first discovered that that had happened, every time I described it I just burst into tears because I thought how can they have done this? ... They don't know the difference between right and wrong,' Beryll said. 'She was a cash cow and it was as simple as that as far as we can see.'

She told the Royal Commission the family is now 'totally fractured', following a 'massive dispute' over Joanie's capacity to appoint her as her EPOA.

This dispute is soon to be the subject of a hearing in the state administrative appeals tribunal. Beryll and Joanie's siblings are arguing the cognitive ability assessments are fraudulent, and that Beryll's EPOA should be set aside. Beryll is arguing that it shouldn't be, but if it is, she should be appointed as Joanie's guardian.

Joanie has had to move out of the family home, which Beryll described as 'traumatic' but also the 'best thing'.

'She's been liberated from the environment where she was previously and she's now having the happiest life ... So lots of positive things have come out of, you know, what might sound like quite a shocking situation.'

She hopes in that sharing Joanie's story, 'future [Joanies] don't have to go through the same thing, or that there are more safeguards in place – that findings are made that make it easier for people in those kinds of situations to be identified and yes, saved from what [Joanie] and our family have been through.'

Lilardia, Miro and Karri

Lilardia is autistic, has fetal alcohol spectrum disorder, attention deficit hyperactivity disorder and intellectual disability. Miro also has fetal alcohol spectrum disorder and intellectual disability.

Karri is their kinship carer.

Lilardia was removed from her mother as a baby and placed in foster care. She lived in more than 10 foster homes in two years before coming to live with Karri, who had struggled to find her.

'This could have been avoided if they looked and done their research into the family tree of who's family and who's not,' Karri told the Royal Commission.

'If there's capable family members to look after these children, they are to be placed with family first before foster family.'

Karri discovered that while in foster care Lilardia had been sexually assaulted as punishment for wetting the bed. She became terrified of wetting the bed.

Lilardia's foster carers had let her eat as much as she wanted. She became so overweight she could not stand up and had to roll over on all fours to try and get up.

Lilardia continues to have a serious sugar addiction and will binge eat if left unchecked.

Other children bullied her and told her no-one loved her because she had been moved around so much.

'She's terrified ... about being removed again from us. When she first come to us we had to go and lock our front gate with a padlock. And she had to witness us lock the gate, witness us lock the front door, lock the screen door, everything, so they couldn't come and get her.'

Although Lilardia has lived with Karri for several years, Karri has no say over what happens to her because she is not her legal guardian.

Karri couldn't get access to Lilardia's NDIS information and wasn't invited to a recent plan review meeting.

She kicked up a fuss telling them, 'Do you know what happens in her daily life? No, you don't, because you only just sit up here. I'm the one that's on the frontline with her every day with her issues ... her disability.'

Child protection have agreed to include Karri in future meetings.

When Miro's mum became unwell, he asked child protection to intervene and place him into care.

'It's just really sad that he got passed around everywhere first, before he was placed with me,' Karri said.

Miro attends a special high school but doesn't like it and isn't engaged.

'He's got really bad memory – he can't remember what day of the week it is. So I have to do visuals for him.'

Before he came to Karri he couldn't read or write. She has been teaching him and he is improving.

Karri has helped Miro access the NDIS.

'We've got all the supports around him properly. He's got a good support coordinator. He has people come and pick him up two days a week to do activities. He is learning how to cook, learning how to be able to budget his money.'

Karri has been supporting Miro's mum and organised for her to see a specialist.

'Because if we can get a diagnosis, we can get her on the disability pension and get her into the right services and right supports around her. She's got a lot of trauma from her own childhood.'

Miro's mum has recently been diagnosed with schizophrenia.

Karri hopes with the right supports Miro might be able to live with his mum.

Karri wants more support and greater respect for kinship carers.

She has no respite and feels 'worn out' by the system.

'I'm just a bit frustrated, but I'll get there eventually ... You need to listen to us carers that have them. Us kinship carers, we've got lots of knowledge of what these children go through.'

Kash and Ariel

Kash, almost a teenager, is autistic and has complex and aggressive behaviours.

His mum, Ariel, struggled to find a behaviour management therapist. When she eventually found a male therapist, he insisted on treating Kash in the family home.

The first time Ariel saw the therapist she felt uncomfortable.

‘He was looking me up and down,’ she told the Royal Commission. ‘And he made comments like, he liked the smell of my perfume.’

But he seemed very good with Kash and Ariel was desperate for help.

The therapist wanted to see Kash every week, which was difficult because Ariel had to pull Kash out of school. She also found it hard to manage her other children around the appointments.

At the start of each session, the therapist would instruct Ariel to incite Kash to have a meltdown. He would then restrain Kash and tell Ariel to leave the room.

‘I thought that was normal but I found out when [Kash] had a new behavioural therapist, it’s not.’

Kash’s younger sister is also autistic.

She started to exhibit sexualised behaviours, touching herself in front of other people and asking strangers to touch her.

Worried, Ariel spoke to Kash’s therapist.

He questioned Ariel at length, getting her to reveal intimate details about her past.

‘He wanted to know everything about my personal life, just everything. He was trying to get inside my head. I felt so small and vulnerable.’

Ariel told the therapist about her teenage sexual abuse.

‘Ever since I told him that, he exploited it to the other therapists about my past and how it affects my parenting.’

The therapist started making sexually inappropriate suggestions.

‘There was a shortage of therapists here. He wanted me to do things with him and I feel like I couldn’t say no because he had a very good way with words. And he had that influence.’

He told Ariel she had a split personality disorder and needed help.

Meanwhile, Kash's behaviour was deteriorating.

'[His therapist] wasn't providing the help we needed, he was undermining the other therapists. He wanted me to change everything to his people who worked under him and he was trying to bully me.'

Ariel spoke to an advocate who helped her organise a meeting at the school.

'[The therapist] humiliated me in front of all the teachers about my parenting, how I need to see a psychiatrist and how I affect my kids.'

After the meeting, Ariel told the therapist she didn't want to use his services anymore.

'He just went right off. Stood up. I was nearly going to faint. I was in tears and really pale. He was quite aggressive. He was yelling.'

Ariel made a complaint to police and the NDIS Quality and Safeguard Commission. She's not sure of the outcome.

Kash is now seeing someone through telehealth because there are no behaviour management therapists available to see him in person.

Ariel said she really needed someone to help Kash, but in the end the therapist made it worse.

Leith and Glynis

Leith, in his 30s, is autistic and has intellectual disability.

‘He had quite complex and challenging behaviour issues [as a child],’ his mum Glynis told the Royal Commission. ‘Lots of screaming, spitting and no language et cetera. So quite, you know, a challenging thing to organise.’

Glynis’s family didn’t believe Leith was autistic.

‘As a young mother I think the hardest thing was that ... they were not supportive of me and didn’t actually believe that my son had a disability and weren’t willing to help because they found him too hard.’

A mainstream primary school expelled Leith because of his behaviour.

‘Other parents watched the principal dragging him physically down the stairs and telling him what a horrible child he was. All the while my child was screaming.’

The other parents told Glynis they didn’t want Leith at the school.

‘They felt that he was disrupting their child’s educational experience. So I would often be abused by other parents and asked why don’t I take him somewhere else.’

Glynis said despite Leith’s intellectual disability he was ‘quite intelligent’ and was learning at the school with the help of speech therapy. But because the principal didn’t want him there, the education department suggested a special school, which Glynis feared ‘was not going to meet his needs’.

‘But he ends up there anyway ... I worked really hard to get him into services, to get him into therapy. I did everything I could because I wanted him to have the best life.’

Glynis had more children and Leith’s behaviour deteriorated. He only slept a couple of hours a night and one time tried to hide one of the babies.

‘I’m sitting at three o’clock in the morning with a baby in each arm and trying to stop, you know, control his behaviours and manage everything.’

Exhausted and with no family support, Glynis asked the child protection department for help.

‘The only way I could get a foster care arrangement, which I was hoping for two to three months, was to ... effectively sign a form to say that I was abandoning my child.’

Leith’s behaviour improved with his foster family, where he was better supported.

'I think it was the environment. Smaller community, less going on. The school was accepting of him. And [Leith] ultimately ended up staying with those foster parents.'

'The big issue there for me was that if I had been provided with support I could have kept him with me ... [What] has affected me personally and obviously [Leith] quite deeply, is that I had to officially abandon my child to get support. And it's something I'll never recover from.'

Candy

Candy is in her 40s and is autistic.

'I've had 16 or 17 different diagnoses throughout the years,' Candy told the Royal Commission. 'Now I personally think it's okay to give these diagnoses, but there was no support put in there to my parents [and] they didn't know what to do with it.'

Candy said her parents neglected and abused her at home, and students and teachers bullied her at school.

'When I was 11 years old and things weren't great at home, I was sent to a youth group. And one of the people who I actually attended school with had taken me into a toilet and sexually assaulted me.'

Her mother threw her out of home and Candy became homeless until a charity found her and child protection put her in a foster home.

'They were expecting me just to go to school and everything would be fine. But it wasn't fine because I'd just had a significant trauma and a disability and been thrown out of my family home.'

Candy said she moved 'from place to place to place' before the child protection department put her in a boarding house with 'mainly older men who had drug and alcohol and mental health issues'.

'Which wasn't really a suitable place to be putting a 17-year-old who's, you know, had a history of complex needs and disability ... That's where I fell pregnant with my first child.'

Candy said the department promised to give her a place to live and to support her and the baby, but 'this didn't happen'.

'They cut the cord, the police and child protection were at the birth, and then ... the police came with their little blue piece of paper ... I think they thought that it wasn't possible for me to parent my children.'

Candy said she had three children in an abusive relationship and child protection removed them all.

'I never saw them again.'

Candy left the relationship, but several years ago a man assaulted her and she became pregnant again.

'The doctor actually had said to me, "Look because you've got a disability and because there's no father involved, I think you should terminate the pregnancy.'"

Candy said she was determined to keep this baby and asked a hospital support team to help her stop child protection taking it away.

'I saw a psychiatrist. My past diagnosis was borderline personality disorder and she said that she couldn't see any symptoms of borderline personality disorder.'

Instead, Candy was diagnosed with autism.

'I gave birth in the morning and then [child protection] always turn up in the afternoon, you know, with their little check book. But all the professionals had all come together and they were all on my side,' Candy told the Royal Commission.

'I've successfully been parenting my child, what, for the last two and a half years now ... Some people think that it's not possible for someone with a disability to parent their child, which is completely incorrect. And I've proven it because I've done it.'

Antonia

Antonia is a First Nations woman in her 60s. She has bipolar disorder and a spinal injury. She works in academia.

'I was in juvenile justice when I was a kid, not because I did anything wrong but because I was being abused,' Antonia told the Royal Commission. 'I'd been diagnosed with bipolar as a young person but, you know, managed to overcome it.'

A few years ago Antonia fell, injuring her back.

'It also happened at the beginning of COVID so it was the worst possible time to have something happen like that.'

During her admission to hospital some staff thought she was pretending to be in pain.

'It was said in my presence and when people thought I wasn't listening, things like, "Oh you know what these people are like. She just is after, you know, opioids ... They bung it on."'

Antonia said she didn't get the treatment she needed and was discharged 'in so much pain' and 'in tears all the time'.

'I had to go to work and say, "I've got to go to the hospital again." And they did more scans and then they went, "Oh yes, you have fractures in your back."'

During later operations, Antonia had an adverse reaction to medication.

'The registrar ... came in – this is a perfect example – he said to me, "So [Antonia] do you work?" and I said, "Yeah," and he said, "Oh what do you do?" Really patronising tone, you know? "What do you do?" And I said, "I work at the university here," and he goes, "Oh? So what, do you do cleaning or admin?" Not that there's anything wrong with that either, but I said to him, "No, I'm an [academic]."'

Antonia had a long career in health care but said that, as a patient, staff treated her as if she was stupid.

'It's been quite shocking and demoralising and almost like betrayal. And disheartening to think that that's been my whole career and then that this is the way people who, if they had been my students, I would fail.'

Antonia said she fell again in hospital and again had an adverse reaction to the same medication. She asked a nurse to have a specialist review the medication. She was told to 'calm down'.

'Next thing I know I'm in intensive care with multi-organ failure ... I feel so lucky I survived that.'

Antonia said she asked for an Aboriginal Liaison Officer, but never received one.

Antonia now uses a wheelchair and is supported by the NDIS, but feels isolated because of the way people treat her when she goes out.

'They don't talk to you. They talk to the person who's pushing the wheelchair and you go, "Hello, I'm here."'

One time Antonia was in a shoe shop and the sales assistant asked why she needed shoes.

'I'm like, "I'm in a wheelchair. I still have feet."'

Griff and Krystie

Griff has quadriplegia as the result of a motorbike accident about a decade ago.

'If my brother didn't have a supportive and relatively confident family to speak up and advocate and speak out about so many different things, we'd hate to think where he would be,' his sister Krystie told the Royal Commission.

Three months after the crash, the hospital sent Griff to a rehabilitation centre where staff neglected him.

'Pressure sores that got so bad ... you could see his, like, the bones of his thigh.'

Staff didn't help him eat or take his medication.

'Obviously being a complete quadriplegic he had no hand function or ability, particularly at that early stage ... [He began] to deteriorate in lots of different ways both physically and mentally, which really delayed his rehabilitation.'

Krystie said Griff's family ended up feeding him and making sure he took his medication and cleaned his teeth. They relied on security staff to help him get in and out of bed.

'Most people were too scared to speak out to the head of the facility and so, yeah, what we ended up doing was just trying to manage it as best we could as a family.'

Griff remained in rehabilitation for more than a year because there was no funding to help him find supported accommodation.

'My parents sold up a heap of their assets and bought another place and had it modified as much as was able to ensure that he could have the facilities there to be able to shower and toilet.'

The NDIS now supports Griff, but Krystie said he still struggles to find good service providers.

'The NDIS has allowed him the flexibility to be able to try some different providers, but you know, it's sort of out of the frying pan into the fire ... He's had so much trouble.'

Krystie said this stems from the 'quality of support workers'.

'I think that it's such a transient workforce and there's a lack of oversight ... And don't get me wrong, he's got a couple of great support workers who have been with him for a number of years. But for many there's not any commitment to it being necessarily a career.'

Krystie said the NDIS is a 'blessing' that has improved Griff's independence, but not the quality of support workers. For example, Griff has to adjust his life to fit around his support workers' shifts. If he's not home every night by 9.30 there's no-one to help him get into bed.

'They just say they can't do the shift ... Or the other thing is quite often he has been left not picked up by [taxis] ... Quite often he will say no to going to the football game because he's just like, "I just won't be able to get a taxi home."

Krystie said Griff spends much of his time trying to coordinate people just to get him in and out of bed each day.

'He doesn't want to complain because he doesn't want it to be worse than what it is ... He just doesn't have the confidence that it's going to change anything. Or he is fearful that he will lose the good support workers that he has.'

Aviva

Aviva, early 20s, is Deaf.

Not long ago, she went to her local public hospital to give birth.

‘I was scared. I was a first-time mum.’

Aviva told staff she needed an interpreter so she could understand what was going on. Staff said they didn’t know how to book an interpreter.

‘When hearing people don’t understand how important interpreters are to help us communicate with everyone, it’s just frustrating,’ Aviva said.

Aviva spent most of her labour without an interpreter.

‘I didn’t get access the way I should have when I was in labour,’ she told the Royal Commission.

Soon after delivery, someone contacted child protection, questioning Aviva’s ability to look after her child.

Child protection officers came to the hospital and removed the baby from Aviva.

‘They said it was because I couldn’t hear my baby, and so I couldn’t possibly look after him. I said, “I’ve got a flashing light that flashes when the baby alarm goes off. The light flashes. So I will know when my baby cries because I don’t need to hear him.”’

Aviva had to prove to child protection she could look after her baby.

After two months, they admitted the report was false and returned the baby.

Three months later, child protection removed the baby again without any warning.

Aviva asked the officers for an interpreter but they told her to use her NDIS funding and get an interpreter herself.

She told them that’s not how the NDIS works. She needs to book interpreters in advance.

Officers pressured Aviva to sign paperwork.

‘I didn’t have an interpreter there, so I didn’t understand what they were getting me to sign,’ she said.

'Later, I realised that it was official paperwork, but I didn't understand what any of it meant until much later.'

Child protection allowed Aviva to see her son once a week but never booked an interpreter.

'I felt like I was being threatened and discriminated against, and that I just had to continue putting up with it because I wanted contact with my son.'

Legal Aid helped Aviva find an interpreting service and a support worker. They also helped her go to court to get her baby back.

'I told the judge how I was feeling and how people were threatening me because I was Deaf. And how people were discriminating against me because I was Deaf. How people were refusing to book an interpreter. So the judge realised, and gave me my son back.'

Tracyann and Moya

Tracyann is in her 60s and has cerebral palsy and quadriplegia. She's uses a wheelchair and is non-verbal.

'[Tracyann] can't speak with her mouth so she speaks with her eyes,' her sister Moya told the Royal Commission. 'She's got a fantastic brain. Just can't get it out.'

Until a few years ago, Tracyann lived with her aunt and uncle and Moya would 'go there to help assist to bath her, shower her, feed her, dress her'. With her aunt and uncle ageing, they could no longer care for Tracyann and placed her in a group home.

One day not long after she'd moved in, Moya visited and saw that Tracyann was upset.

'She kept looking down, which is an indication she wants the toilet so that was the first thing that come to my mind. I said, "Do you need the toilet?" "No." She can say "No". And anyway, long story cut short, I felt through her tracksuit pants and she had a nappy on. She doesn't wear nappies.'

Moya said Tracyann began to lose weight because staff didn't adequately communicate with her about what she liked to eat. During the COVID-19 pandemic, when the home was understaffed, Moya often visited to help feed and shower her.

'One time I went in and I could hear her crying, she was in the bathroom and ... they're standing there hosing her like they're watering the garden.'

Moya said support staff had strapped Tracyann to a chair with her legs apart.

'I unclipped her, I picked her up and I've carried her to her bedroom. You know, it's heart-wrenching.'

Moya complained to the service provider but didn't get a response.

Another time when Moya visited, Tracyann wouldn't stop crying. So she took her home for the weekend. That night when Moya went to change her she noticed her slacks were wet.

'I've put her on the bed. I'm not lying, I've got photographs of it ... She had a hole in her coccyx back to her bone. It was weeping, all infection coming out of it.'

Moya spent five weeks, guided by her doctor, treating the infection. She complained to the NDIS, which appeared to communicate only with the service provider. It was only when another family filmed a support worker abusing a resident that staff were 'stood down'.

'There was a bit more done for [the other resident] because they had evidence where I didn't, I only had word-of-mouth and photos, you know.'

Moya didn't take Tracyann back to the group home and eventually found another.

'She's happy at the moment. And if anything's wrong she lets me know because at the moment I go out there twice a week ... But she's a lot better off where she is now, thank God.'

Orlagh

Orlagh, early-20s, is autistic, deafblind and has Tourette syndrome.

She told the Royal Commission she attended about 10 schools and all of her experiences were negative.

Students bullied her relentlessly in primary school, calling her weird because she wore thick glasses and acted differently.

‘No matter how much I went to the teachers, I was always blamed for it ... I was always in the wrong, no matter what I did.’

One teacher forced Orlagh to sit with the students who were bullying her and ‘make friends’. They continued to bully and embarrass her and the teacher did nothing.

One time, Orlagh put her hand on a spider and it bit her. She got into trouble for touching the spider, even though she couldn’t see it.

The bullying and name calling continued in high school.

Orlagh’s vision was deteriorating and she couldn’t see the board. She asked to move to the front but most teachers refused, citing the seating plan.

Even at the front, Orlagh struggled to read the board because of the glare and small writing. One teacher told Orlagh to go home if she couldn’t read the board.

Orlagh stood up for herself, telling the teacher it was her job to make the lesson accessible.

‘As soon as I spoke up ... and I voiced what was happening to me, I was immediately left out and I was discriminated against.’

One time, Orlagh had to pick up some paperwork after school.

The deputy principal told her to get off the school grounds or she would call police.

When Orlagh explained why she was there, the deputy escorted her to the office and off the grounds.

Orlagh said every school she attended had multiple sets of stairs, no lifts and almost no ramps.

‘They have no identification on poles and things. There were multiple times when I walked into poles because I hadn’t seen them. And I was told to “Just look out for them.” And I’m like, “I’ll give that a go, but I can’t see.”’

Teachers started to convince Orlagh's parents that she was the problem.

'It got to a point where I believed that I was actually the problem, and I stopped speaking altogether. I no longer talked in class. I didn't have any friends to talk to. Any opportunity I could, I would take the day off school, or I'd not go to a certain class and I'd sit in the bathroom.'

Following school, Orlagh attended TAFE.

One morning she woke up and couldn't see anything – she was blind.

Orlagh contacted the vision department and they put in place all the adjustments she needed.

'The students were absolutely amazing to me, helping me out. But the teachers bullied me constantly.'

One teacher refused to implement the adjustments because she didn't believe Orlagh needed them.

Instead, she would take Orlagh out of class and make her blow the materials up to an A3 size on the printer, which Orlagh still couldn't see.

'I wasn't learning anything, because I couldn't do my work.'

In the breaks, Orlagh's friends started reading everything to her and helping her with her work.

She made a complaint to the vision department and they gave her a reader writer. But the teacher didn't like the reader writer being in the class and would yell at them both to be quiet.

'She was actively belittling me in class and making fun of me.'

Orlagh made a complaint to the department head but nothing happened.

With the help of the vision department and her friends, Orlagh completed the course and did very well.

The department accused her of cheating because she had the reader writer.

'That was the first time I actively saw myself as disabled. From then on, I knew that I was not in a world that was accessible. And I knew that I'd have to learn to advocate for myself.'

Orlagh moved to a different TAFE campus and completed the course.

Orson and Enya

Orson is autistic and has intellectual disability.

His mum, Enya, said he really loved primary school.

'We had a wonderful principal who was very proactive in making sure students were included in everything,' she told the Royal Commission.

'Everything was pretty much person-centred for each child or student. They had their own individual learning plans. The teachers spent time understanding the students ... Teachers asked us, "What are the triggers? What are the things that are helpful? What are your child's strengths?"'

Orson is a visual learner and teachers included lots of visual aids to help him engage.

At the beginning of year 6, he started preparing to transition to high school. He was very excited.

'They made a social story about all the different rooms they had in the high school. He was particularly drawn to the new music rooms and computer rooms.'

Orson was supposed to have several in-person transition sessions but, because of COVID-19, only had one.

On the first day everything seemed fine, except Orson's autism classroom was upstairs. Orson is very active and needs a lot of movement breaks, which his primary school had encouraged. But upstairs, he had no access to a safe playground space.

In the first week, Orson found scissors and cut his hair.

'From then on, things went downhill.'

In week two, the school told Enya that Orson wasn't coping. They asked her to fill in a questionnaire about his triggers and dislikes. She'd already provided the information but did it again.

The next day, Enya asked to meet about getting some assisted transport. There were several people at the meeting, including the counsellor.

'One of the things she first said was, "I don't think your son's in the right setting," and I thought to myself, "Had I known that this was what the meeting's about, I would have asked for my husband to come with me or a support person.'"

They told her Orson had been absconding looking for the music room. This made perfect sense to Enya because they'd spoken so much about the music room during transition.

The school said the music room was only for mainstream students.

The meeting continued with school staff listing all the things they thought Orson was doing wrong.

'He's not safe. He's doing headstands in classrooms. He's climbing furniture. And, I thought to myself, "This is not my son. They never said anything like this to me when he was in primary school."'

The school suggested Orson move to a special school.

'According to them, my son didn't belong to their school. He belongs to an even more specialised setting for students who needed to be away from mainstream schools.'

Enya felt another transition would be too difficult for Orson.

She asked if he could have the adjustments they'd requested – movement breaks, a buddy and a quiet space – but the school declined.

Eventually they agreed to let him have movement breaks if he wore a high-vis vest. But the school never followed through on this.

In primary school, Orson would point to a toilet sign if he needed to go to the toilet next door.

In high school, there was no sign, the toilet was down the hall and locked and they didn't want him to go on his own.

'At times he actually went to the toilet in the classroom because that was all too much.'

Teachers started treating Orson as a naughty boy, and he felt he was always in trouble.

The class teacher refused to complete Orson's independent learning plan until they addressed his behaviours.

'And I'm thinking, "No. You need to have the strategies in place and a goal set, so that he can learn, so that he's not bored to tears, so he's not displaying these behaviours."'

At the end of term 2, Enya pulled Orson out of school.

He now attends distance education from home. He is happier, but it is challenging for Enya and the family.

Honora and Edda

Honora, late teens, has intellectual disability and sensory disorder.

As a child she bounced from foster home to foster home.

‘She came to me at eight-years-old,’ Edda told the Royal Commission. ‘She had never fed herself, she was not toilet-trained. She didn’t speak, she screamed and lashed out a lot. She was a very angry little eight-year-old.’

Edda and her family worked hard to help Honora feel safe. She began to speak, developed skills and became independent.

‘We love her, have loved her to bits.’

About three years ago, Edda needed to visit family so she took Honora to a respite centre.

A couple of days later, Edda received a call from the respite manager. Honora had made allegations of inappropriate behaviour from one of the male participants. Edda was given the impression it ‘was something very minor’ and the manager told her the participant involved would be removed the next day.

Edda advised the manager to report the allegations to police.

A few days later, police rang Edda and asked her what she wanted them to do. She suggested they speak to Honora because she is very verbal, has a good memory for detail and would be able to provide an accurate account of what happened.

But police didn’t speak to Honora.

A short time later Edda arrived home and picked Honora up from respite.

‘Everything that happened to her came out of her mouth. It was a terrible, terrible story.’

About an hour after Edda dropped Honora off, the respite centre had agreed to accommodate a man in his 40s with a history of prior sexual assaults.

Later that night, in full view of the other participants, he sexually assaulted Honora and physically restrained her. Honora called out to staff who were in a locked staff room. She managed to get away and banged on the staffroom door.

Staff accused her of lying and sent her to her room.

‘She had a big meltdown, throwing things and screaming.’

The next day, the man sexually assaulted Honora again.

‘She wasn’t believed, she was told off. She was just berated for making up stories,’ Edda said.

Staff told Honora to go and have a shower.

While she was in the shower the man sexually assaulted Honora again.

The man sexually assaulted Honora five times during that weekend.

Edda supported Honora to make a formal complaint to police and the NDIS Quality and Safeguards Commission.

But police never formally interviewed Honora or talked to the man.

‘They had lots of information but there was really nothing they could do.’

Edda discovered the respite centre had received a substantial amount of money to accommodate the man at short notice.

‘The least they could do was provide an extra staff member to make sure he was supervised – even though it should never have happened,’ Edda said.

‘They took no steps to protect her, even after her third disclosure.’

The respite centre never took responsibility for what happened and never apologised to Honora.

Child protection said they would launch a civil action against the centre on Honora’s behalf, but never did.

Micaela and Calista

Micaela has complex trauma and bipolar disorder.

Highly educated, she became unwell for the first time in her 20s.

She was placed in a locked psychiatric ward with drug users and people with violent behaviours. One young patient was so terrified she clung to Micaela at night and couldn't sleep on her own.

'She was like a frightened animal,' Micaela told the Royal Commission. 'She was completely disoriented.'

When Micaela's mum Calista visited, she 'found it quite horrific'.

Calista brought Micaela home and helped her get counselling, as there was 'quite a bit of trauma'.

Micaela was very depressed and didn't feel she would ever be able to work. She unsuccessfully applied for the Disability Support Pension and eventually got a job through a Centrelink program.

Shortly after, Micaela began a relationship with her boss.

'She was very vulnerable,' Calista told the Royal Commission.

'She started experiencing domestic violence ... a lot of it was unrecognised psychological violence ... And perpetrators know what they can get away with.'

Her partner and boss started receiving a carer payment. Micaela felt trapped in the relationship. She was in and out of mental health units, rarely seeing the same doctor twice.

'There's no official means for recognising family violence or abuse,' she said. 'Particularly when it is psychological and particularly when it involves a person with known mental health concerns.'

One time, Michaela was hospitalised after her partner seriously assaulted her. At the hospital, he 'spun his story' and medical staff ended up sedating Micaela.

'He got to watch me being restrained and injected,' Micaela said. 'If mental health was taken out, I think services would have been more sensitive.'

Micaela was involuntarily admitted to a locked mental health unit.

'Which was very much like a dungeon,' Calista said. 'It was down in the basement. It was horrific. People didn't see the light of day for weeks.'

Calista said Micaela's partner was 'hoodwinking' hospital staff.

'There wasn't enough awareness of domestic violence and trauma to see what was happening.'

Shortly after, Micaela had a child and decided to leave the relationship.

She tried to get a restraining order but police told her the incident was 'too far back'.

Her now ex-partner ended up taking the child.

Micaela begged police for help, but they told her they couldn't do anything because 'she was unwell'.

Calista warned police Micaela was at risk of suicide if she was separated from her child.

'And they said, "She won't suicide. She's too selfish."'

Micaela became severely depressed and was hospitalised. The hospital staff asked the father to allow her to breastfeed the child, but he refused.

The court eventually ordered him to return the child.

Some months later, Micaela went to court to finalise child custody arrangements.

Micaela's lawyers told her not to tell the judge she had a disability – 'that would be a negative'.

'[The judge] trivialised domestic violence with the perpetrator in the room,' Calista said. 'That's been a way for him to continue the psychological abuse because he's done it through the court system.'

Micaela found it very hard to function in the Family Court environment, 'often to her detriment'.

'She was often forced to make quick decisions. I remember the final parenting order where there was all this buzz. And I could see she wasn't processing stuff. Someone with a disability due to a mental health condition should not be put under that sort of pressure.'

Micaela ended up sharing custody.

'She's still in that situation where she's negotiating with him.'

Micaela is now seeing a private psychiatrist and is more stable.

'We definitely had a better scenario hooking up with the private psychiatrist than we did with community mental health,' Calista said. 'If you could take that private psychiatrist somehow into the public system when you go, that would be a better scenario. Patients need to have their experiences validated.'

Blossom and Keira

Blossom is in her early 20s and has Down syndrome. She loves horse riding and going to the gym.

Blossom began her education in a 'full mainstream school', her mother Keira told the Royal Commission.

'She was quite a handful, but they bent over backwards trying to follow the behaviour support plan. They made up visuals. They educated the kids and the parents and got the kids working with her.'

However in year 4 Blossom's behaviours deteriorated.

'I think because it was just getting too beyond her,' Keira said.

Keira switched Blossom to a school with a support unit.

'That was hard for me because I just liked sort of inclusion and everything.'

The school assured Keira it was inclusive, but it wasn't. The unit was isolated from the rest of the school and had lots of 'locked up zones'.

'It had a great big fence and locked gates around it. And the doors of the classrooms were all under lock and key. The kids weren't allowed to be a part of that whole main school thing. The attitude was so different in the kids alone. Like, they would laugh at her.'

Blossom was suspended 'after the first couple of days' and had to take a week off school.

'For something really minor ... It wasn't for biting or pulling hair or anything. I think it was her trying to abscond. And I just sort of was, "Oh, you've got to be kidding."

Blossom told the Royal Commission she often felt 'upset' and 'stressed out' in class because of the lack of support.

'They did not help me,' she said.

Teachers locked her in a small area outside the classroom for a day to punish her.

'That was my area ... I was pulling people's hair. I bite because I am a bit stressed.'

Keira described this area as 'a concrete slab' hemmed in by a brick wall and high fencing.

'[Blossom] looked like a lion in a cage. Just pacing up and down, up and down and trying to work out why there was no teachers. It wasn't playtime. They were all in the classroom.'

Blossom said teachers were cruel to her. They pulled her arms behind her back and 'shoved' her.

'Year 7 was really traumatic,' Keira said. 'There was a hell of a lot of manhandling. [Blossom] had violent outbursts.'

The way teachers 'grabbed and enclosed her' gave Blossom the 'feeling she has no control'.

During this period, Blossom's speech and learning 'just went', and her mum pulled her out of school.

Keira said that once removed from the school environment, Blossom 'blossomed'.

She's really great now, she just thrived.'

Blossom now attends a beauty course at TAFE and wants to go to college next.

'I want to do that, so you have ... you have a life,' she said.

She would like to live independently and have 'a nice person' in her life.

Zahra

Zahra is in her 60s and is on a Disability Support Pension. She told the Royal Commission her anxiety and depression are 'a hangover' from the abuse and neglect she experienced as a child with vision impairment.

Zahra said that at school she and her vision impaired friends were abused and ostracised.

'The nuns belted the crap out of me ... They were bullies, they were nasty, they picked on all these kids with disabilities. The teachers boxed and tied you, threw you overboard. We were judged ... and given very, very low expectations.'

Zahra said her 'mental health issues' stem from similar mistreatment at home. Her adoptive mother never took her to an eye specialist.

'Dependence was encouraged. The more she could present me as her blind child that she had to do everything for, the more she sort of spring-boarded her life off me.'

Zahra's adoptive mother told her she 'was ugly' and 'a horrible child'.

'Appearance was very important to her. I wasn't supposed to look blind, but everybody was supposed to remember I was. I was made to feel very uncomfortable most of my life.'

When Zahra went to an eye specialist to get glasses in her teens, her parents told her 'it was a waste of time'.

Zahra said health professionals also treated her cruelly.

'One doctor told me people like me should never have kids, think what I'd do to them.'

Zahra later worked in a bank and 'fought' her way up from the switchboard to financial services.

'There was a lot of negativity, discrimination and judgement against what we could and couldn't do, and mostly it was what we couldn't do according to them.'

Her employer treated her as 'a charity case' who was 'taking up the place of somebody who really needs a job'.

'They were forever trying to get rid of you and the wages were so low it wasn't funny. And then if you complained, it was like, "Blind people can't do that." We were supposed to be grateful that we were given a job and just sit there. All of us ended up leaving because we were just bored to death.'

Zahra still struggles to get the right health care. One eye specialist recently made her feel like

she was 'a waste of time'. She has had many GPs 'who don't understand disability'.

Zahra is trying to get a support worker through the NDIS, which she described as 'a minefield'. She wants to self-manage her plan.

Her greatest fear is having her hard-earned independence 'taken away' and 'going backwards instead of forwards'.

'There's so much stereotyping and assumption that we can't do things ... I consider myself as having a mild disability. I still want to be able to go out and get on public transport and walk by myself and things like that.'

Gladys

‘There were things outside my control, which I didn’t understand and had no ability to influence. I felt completely sort of invisible to anything that might have a moral compass.’

Gladys is in her 70s. She lives with bipolar disorder, post-traumatic stress disorder (PTSD) and physical disability.

‘I’ve gone through a bit of a slew of different sorts of disorders,’ she told the Royal Commission. ‘I also have ... narcolepsy with cataplexy. I go into REM sleep whilst I’m actually walking or something, so I fall and often injure myself, sometimes seriously.’

A few years ago, Gladys was ‘very deeply depressed’.

‘I was in a stage of the bipolar cycle where I hadn’t gone to sleep for five days and I was starting to be affected in my ability to walk and those sorts of things.’

When her usual private hospital was full, Gladys’s GP had her ‘admitted voluntarily’ to a public hospital.

When she arrived, medical staff took her clothes and possessions and placed her in a room alone for hours. They also confiscated her prescription medication and gave her a different one instead.

‘Over the next few days I became increasingly sick, which apparently is what happens if you don’t wean off these antidepressant pills.’

The stress triggered a cataplexy episode.

‘I’m on the floor. I can’t move. And they say, “She’s had a heart attack” ... Somebody then says, “She’s faking it.” So they do something called a sternal rub ... running something very heavy down your sternum ... It bruised my chest. And I could feel the intense pain, but I couldn’t scream or speak or do anything.’

Gladys said if staff had read her medical history, none of this would have happened. She feels the hospital neglected her complex health needs because of her mental health issues.

Two days later, they admitted her to a mental health ward.

‘I was sectioned ... I was made an involuntary patient. I wasn’t allowed to leave the hospital.’

During this time, staff denied her access to belongings and the right to call family members.

‘They had my mobile phone, they had everything.’

Gladys said that by law she was free to leave within 24 hours of admission as an involuntary patient. 'Because I hadn't been certified twice ... and that period had lapsed.'

But when she went to walk out the door, two uniformed men tackled her to the ground.

Gladys said she was 'forced' to stay in the psychiatric unit for another 10 days. During this time, if she needed something – 'water ... pretty much anything' – she had to go to the nurses station to request it.

'I would stand there for half an hour, three quarters of an hour ... nobody would come and speak to me. And I wondered if perhaps I've actually already died and I wasn't really there,' Gladys said.

'It was almost a denial of my existing as a person. You know, taking up volume. Being real. I felt dematerialised in some sort of weird way.'

That feeling continues 'to revisit' Gladys, who was traumatised by the mistreatment at the hospital.

'I've had PTSD treatment and I take medication for PTSD and, you know, to make me sleep. And of course, I still don't sleep.'

Gregor and Bess

Gregor, a teenager, is autistic and has attention deficit hyperactivity disorder and post-traumatic stress disorder.

His mother Bess lives in regional Australia. When she spoke to the Royal Commission, she was selling her house to move to a city 'where there's medical help'. She said Gregor's psychiatrist was on holiday leaving Gregor without a refill prescription for his medication. There's no other psychiatrist available in the area.

'He's fairly unsupported. Other than all of those dramas, 99 per cent of the time he is calm, fantastic, engaged and a thoroughbred of a human ... but if he has a violent psychotic attack I might not be safe.'

Bess is separated from Gregor's father. When Gregor was in primary school, she worked part-time in their regional town. His school complained he was disruptive and 'didn't have the funding' to support him.

'I kind of go, "Look he seems to be fine everywhere in the world but with what's going on at your school."'

The school told her to quit her job so she could take him home 'whenever they had an issue'.

'I have the letter from [the school] to Centrelink telling Centrelink that I needed to go on the carer's pension because of my son.'

Bess said she did her best to support both the school and her son.

'It seemed to be the avalanche just started to crash on me from then ... There's not enough support for the primary caregiver.'

Bess said she became 'chained to that school' and even had trouble getting dental appointments because the dentist was in another town and she 'needed to be five minutes away [from the school] at all times'.

One day a teacher told Gregor to leave class. In his frustration, he indirectly caused minor property damage. When one of the school staff couldn't reach Bess on her mobile, they called the police.

'He's not interacted with property or person. He's been standing quietly in the principal's office.'

When the police officer arrived, Gregor walked away and the officer followed and 'wrestled' him.

‘You’ve got a very small boy being held in a kind of, they call it a basket hold, where you’re off the ground, you can’t breathe ... That hold goes for about five or six minutes.’

The school wouldn’t let Gregor return.

‘That has set up the most disastrous ongoing nightmare and we already had support issues and now we’ve just got an ongoing nightmare with authority.’

Bess said Gregor was well behaved outside school before that incident and wanted to be police officer.

‘[After the incident] the first thing he said to me was, “I don’t want to be a policeman anymore.”’

Bess has custody of Gregor, but after the incident child protection became involved. Because there was no other school he could attend in the area, he moved away to live with his father.

‘I lost my son. Now, unfortunately ... [his father] was in complete denial there was ever any issues with his son on any level [and] as soon as he hit high school basically he was expelled very quickly.’

Bess said Gregor had no supports at high school and eventually his father ‘threw him out’.

‘He’d go up against police there and get thrown in paddy wagons because he’d react to them ... The police officer just touched him and that was enough to set off the most insane violent reaction.’

Bess recently brought Gregor back to live with her in the regional town, where she still struggles to get support.

‘I’m back on the carer’s pension ... I just wish someone had actually supported me when he was nine and 10 so I’m not in this situation now, instead of having him taken off me and it being worse, been made worse and worse and worse.’

Liesl and Terry

Liesl is in her 20s and has an intellectual disability that affects her speech, motor skills and memory. Terry is her father and primary carer.

‘She’s been labelled with global dyspraxia,’ Terry told the Royal Commission. ‘Basically, it’s like a permanent head injury but it’s from birth. It impacts on her daily functioning and capacity for everyday life including work.’

Liesl is on a Disability Support Pension and has worked at a supermarket through the supported wage system for eight years. She is paid based on her productivity.

‘But there’s a limit on how much they can reduce her pay ... And it never affects her pension,’ Terry explained.

Terry says the system has its shortfalls. As her nominated advocate, he has ‘to prove’ that Liesl is disabled every four years.

‘There’s like this ongoing rollercoaster.’

A few years ago, there was a change in policy and Centrelink wrote to Terry saying it wanted Liesl to ‘start reporting her income every two weeks’.

‘It also stated if I didn’t contact them, they would stop her disability pension.’

Terry made contact.

‘I flagged to the lady that [Liesl] doesn’t have the capacity to do that. You know, she wouldn’t even know how much she gets paid ... She would have no understanding.’

Terry said Centrelink refused to recognise that Liesl could not meet the new reporting requirements. It insisted that she had ‘a mutual obligation because of her pension payment’.

Terry pointed out that Liesl had been exempt from that for years.

‘[The Centrelink officer] said, well it had all been done wrong ... this whole time.’

Terry reluctantly ‘agreed to go along with it’ so Liesl wouldn’t lose her pension, which would be ‘catastrophic’. She ‘would no longer be able to purchase food or cover the costs of her accommodation’.

Terry has been trying ever since to get the agency to tweak the ‘absurd’ rules that discriminate against Liesl and ‘a plethora of people who are disabled’.

He feels the current policy is a disincentive for people with intellectual disability to work.

'It gets too hard to actually do that, because it creates more work for the carer or the parent.'

Terry says this barrier to work is threatening Liesl's livelihood and happiness.

'This is the whole idea of getting her a job – because it's integral to her capacity to enjoy working, like she's doing what everybody else does.'



Artwork by Maree Fairbanks

Storme

Storme has used a wheelchair since an accident about 15 years ago.

'From that day onwards, I think I was failed because I was in a wheelchair,' she told the Royal Commission.

After three years of rehabilitation, Storme was 'getting sicker and sicker and sicker' and had to be hospitalised again.

'They were telling me I was getting sick because of urinary tract infections. I had never had a UTI before my injury,' Storme said.

For a couple of years, Storme was 'in and out of hospital being pumped full of the most toxic antibiotics'. Her GP also started to doubt the hospital's diagnosis.

'It was two and a half years from the point of getting sick for them to pay attention.'

Finally, doctors found what they thought was a small cyst on Storme's ovary.

She feels that the hospital and doctors were careless and made 'smash judgements' about her because of her brain injury. Storme said that after further tests, a physician came out to the recovery room and announced the results to the world.

'From 40 metres away he yelled out, "Your cyst, it's this big. It's the size of an orange!" And I was just disgusted and so upset in how he projected that to me. Like, telling me bad news that's gotten even worse ... And he also had a laugh on it. It was a joke to him ... I was just mortified.'

Storme was 'shafted' to another hospital where medical staff told her she was 'too old for it to be cancer'.

A month later she was operated on, but not by the surgeon she'd been seeing. 'Unbeknownst to me, it was his registrar,' Storme said.

A standard biopsy turned into a major procedure when doctors discovered Storme had ovarian cancer. Storme said the surgery was done with 'uninformed consent'.

'They just threw the paper under my nose ... didn't explain anything. They didn't even ask me if I wanted them to save my eggs before that.'

Storme was traumatised by the experience.

'I will never ever let a man be with me because they totally destroyed my body ... I woke up in excruciating pain, worst pain I've ever felt.'

Ahead of a follow-up, she asked her GP to ensure that 'a female doctor do the internal'. But the same doctor performed the examination.

'It felt like they raped me all over again. Like, it was just disgusting.'

Storme has had problems with her NDIS plan, which she said is 'ridiculously' underfunded. Her long-time service provider 'was asking for exorbitant amounts of money' for things she'd 'never even asked for'.

'She walked away from me and left me with no money and no plan ... I'm trying to hold her accountable.'

The NDIS realised Storme had been 'in some kind of situation' and 'put the money back'. But it gave her a new support coordinator with 'no qualifications whatsoever'. Now, she's pinning her hopes on a new support team and a big injection of funds for therapy and equipment.

'This is the first year I have received equipment out of five years.'

Myrtle

Myrtle is in her 50s and has bipolar disorder and physical disability. About 15 years ago, after she was diagnosed with a chronic illness, her psychologist helped her apply to the housing department for accommodation.

'I was finally given a home,' Myrtle told the Royal Commission. It was in 'a beautiful magic' place, but she 'felt very isolated'.

Myrtle said one of her neighbours had schizophrenia, and one day he attacked her.

'He ran at me, jumped on top of me and squashed me, ripped my t-shirt up. And I got rushed to hospital and there wasn't much help there, sent back home. Then I told housing, and I said, "You know, I'm pretty scared."'

The housing department did nothing, and the violence from her neighbours escalated. A new neighbour arrived, who was just out of prison.

'He was pretty dangerous ... I was going through lots of violence from the day he moved in,' Myrtle said.

Once he 'pulled out a sawn-off shotgun' on Myrtle's front lawn.

'He was firing off anytime he felt like in the neighbourhood ... When I said, "I don't want to know you," then he jumped on my car and smashed it all up, the windscreen. Every time I replaced it, he'd write them off and stand over me and hurt me and stuff.'

Myrtle got a restraining order on the neighbour but feels that police 'turned on' her as a woman with psychosocial disability.

'My name was blackened. And then I realised ... there's just no help.'

Housing eventually moved Myrtle to the city. A 'lovely lady' accompanied her to the new home.

'I remember having tears in my eyes saying to her, "Is this mine? Is this truly where I get to live the rest of my life?" ... The very first day that I moved in, when I put the furniture truck in the driveway, a neighbour came out and said, "Move your truck," the word b-i-t-c-h, "because I own this driveway." So, I fell into a heap.'

The situation with this neighbour deteriorated. He constantly abused her for using the driveway, even though it was the only way she could access her property.

Myrtle said that instead of protecting her, the housing department 'dragged' her through it.

'They used that as a strike tactic to strike my lease to try and evict me pretty much straight away.'

One day, they called her into their office because she hadn't filled in a pet form for her dog in the tenancy agreement. She said that became a pretext for her to be 'struck out on' again.

Myrtle's father died just before Christmas.

'I had been going through all that trauma, all that domestic violence, and I just felt like no-one cares. And then when I got home from dad's funeral, there is a notice to vacate stuck on the backdoor and I had to pack up. Six months later I'm evicted ... They said it was because they just weren't renewing the lease. I couldn't find out why or anything.'

The department issued the eviction notice after the appeal period had lapsed, so Myrtle had no say in the matter. She said the department did not consider her disability when they made her homeless.

With the help of an advocate, Myrtle turned to the ombudsman who found the department was in the wrong.

Myrtle is still on the waitlist for housing despite being classified as a high priority, and currently lives with her mother.

'My health just deteriorated for all these years of abuse from the housing department. They ripped me to pieces. I've missed seven years, I've lost everything I owned. I don't own anything other than what I'm wearing.'

Kiralee and Isolde

‘I’m not asking for anything apart from just kindness and inclusion. Obviously our society has just shut down on disabilities. You’re negated and devalued and denied on a systematic level, because you’re not convenient.’

Isolde is the mother of Kiralee who is in her 20s. Kiralee is autistic and has psychosocial disability and associated disorders.

Isolde feels the education and health systems have left Kiralee with ‘no practical support whatsoever for her complex needs’.

‘They’re not supportive and if they are, it’s only token,’ she told the Royal Commission.

Isolde said ‘support structures were non-existent’ at Kiralee’s primary school.

Isolde paid ‘hundreds of dollars’ to see specialists and went ‘to meeting after meeting’.

‘You jump through all these hoops and none of those actually offer anything. You come away feeling like you’re the fault and basically there’s no help.’

When Kiralee reached her teens, Isolde moved her away from the ‘faceless city environment’ to a regional area.

‘I visited several disability schools. Tried to maximise her opportunities for a good outcome. I spoke with the education department months before we arrived here. I had no meaningful response from them at all.’

Isolde settled for the local school.

‘But they didn’t have a special needs class, which is really what worked best for her.’

Kiralee ended up ‘isolated and abandoned’. Isolde said the principal refused ‘basic interaction or supportive skills’ for her and excluded her from learning and social activities.

‘She was put into classes which weren’t relevant, which shut her down. The teachers themselves were probably trying to do their best. Didn’t have the right supports.’

When Isolde tried to raise this with the school, ‘they would ambush and stonewall, even lie’.

‘They were just covering, you know, the complete abandonment and undermining of good outcomes for my child and obviously that’s systematic within the school system.’

Isolde feels the principal was ‘acting on deliberate political strategies’ to not fund ‘innovative programs for autism that make a difference’.

'I was just really shocked at the degree of sabotage. If [Kiralee had] gone to a class where she could navigate her social as well as her educational opportunities, she would be in a much better frame of mind than she is now. In the end, she refused to go to school.'

Kiralee left school in year 9. This led to 'chronic social disconnection' and an eating disorder. Her mental health issues deteriorated and she started having seizures from malnutrition. Isolde said medical professionals did 'nothing constructive to assist'.

'When we go to the hospital, no-one does or says anything. She's starving herself ... All they want to do is give you some pills, which is fine, but it's not going to stop her nutritional deficiency from getting worse and worse.'

Isolde was 'just horrified at their lack of addressing the critical needs'.

'It's abuse to not deal constructively with the primary issues. It's like watching her die every day.'

Isolde said Kiralee was recently 'chucked out of a mental health facility' where she had just been 'starting to engage and to respond'.

Isolde wrote to the medical complaints board but found the complaints mechanism was 'toothless'. There's no way of holding people 'legally accountable'.

'So now I have this child who is in a very depleted situation. For the last eight year she's been in her room hardly engaging ... She's completely dependent on me. The whole thing has been completely annihilating.'

River and Murielle

‘Our issue was, where’s everyone’s duty of care?’

River is autistic and has intellectual disability. She is in her late 40s and is non-verbal.

Her sister, Murielle told the Royal Commission her parents ‘looked after [River] with no help’ until a couple of years ago when her mother fell ill. Murielle and her sister organised supports for River at the family home. This was their ‘initiation into the NDIS system’.

Murielle and her sister expected to be made River’s guardians because they ‘were tending to all her needs’.

‘And we felt like we were her lifeline as far as family went,’ Murielle said.

But the public trustee and guardian were appointed instead.

‘[They] were not really clear and transparent about information.’

From that point on, Murielle said, the service provider was ‘causing trouble in the house’. The support coordinator was ‘very antagonistic and rude and unsupportive’ and the support workers were ‘a nightmare.’ River ‘was not properly showered’, she was ‘smelling of urine and excrement’ and her ‘pubic hair was covered in faeces’.

‘Not only were they not looking after her hygiene, which resulted in health issues and two hospitalisations, but they were also wrapping her up in sheets, blankets, scarves, in order to stop her self-harm. There was obviously a restrictive practice that was going on as well.’

Workers neglected River’s meals and mostly bought her takeaways. They didn’t get her proper medical or dental care.

‘There was enough money to have her teeth looked after, enough money to buy fridges full of food.’

The two sisters ‘supplied over \$200 worth of groceries’ when they visited but ‘were forbidden’ to look in the fridge or cupboards.

‘We weren’t allowed to look at anything. We were treated like lepers.’

Murielle said the negligence ‘was across the board’.

‘No-one was caring enough to check in to say “Hey, is [River] getting everything she needs?” So where’s the public trustee’s role in knowing whether she’s having grocery money spent? ... That she’s not having dental care. There’s just been a big misappropriation of funds for her.’

Murielle said a trust fund from her parents' estate set aside for River 'went missing'.

'Apparently the public trustee got their hands on it.'

Murielle voiced her concerns about River's health to the guardian.

'We asked them if we could provide meals because we were worried about constipation. They said no. They promised that they were feeding her.'

But a fortnight later, the office informed Murielle that River was 'severely underweight'. She believes they'd been 'covering that up' for weeks.

'I was calling every night ... The support workers would sit her on the couch with a weighted blanket covering her up to here so we could never see her body and face.'

In 10 months, River's weight plummeted from 60 kilos to below 45.

'They were responsible for her condition ... She starved.'

Murielle found River an advocate.

'She was like an angel sent to us, because up until then no-one cared.'

River is now with another service provider and back to her normal weight.

'Her self-harming has reduced. She's a lot happier in herself.'

Murielle wants to see 'tougher laws and fines around service providers and offices of the public guardian' to hold them to account. And NDIS participants 'should immediately be offered an advocate ... so that everyone's got someone to go to for support'.

Marilyse

Marilyse is in her 60s and has schizophrenia.

She told the Royal Commission that a few years ago she went to a hospital emergency department during 'a mental breakdown'.

She was waiting for hours and 'never saw a doctor'. In the early hours of morning, she finally got to speak to a nurse.

'She said you have to leave, you have to go somewhere else ... So I had to walk home,' Marilynse said.

Back home, Marilynse's condition worsened and she rang the ambulance service.

'They told me not to ring ... unless it was a matter of life and death. So I was kind of treated like a subhuman.'

A neighbour ended up calling the police, who had her admitted to an acute mental health unit at the same hospital where she had tried to get help earlier.

A few days later, she was transferred to a mental health rehabilitation centre.

'The very first night I was there, I was collected by two nurses, a male nurse and a female nurse ... They told me to take my clothes off and get up on the bed and then ... um, I had to open my legs.'

Nobody explained the reason for the examination and Marilynse described it as an assault.

'That's what it felt like to me. I closed my eyes really tight ... It's not like they were doing an internal. It was just an external thing.'

When her NDIS service provider was informed of the incident, they organised an advocate for Marilynse. Cheryl, the advocate, had to 'battle' with the director of nursing before she could visit Marilynse.

'She told me that there was no need for me ... and I wasn't allowed on site,' Cheryl told the Royal Commission.

Cheryl said this breached Marilynse's rights under the Mental Health Act.

'Everyone has the right to advocacy.'

When Cheryl was eventually allowed to visit, staff 'fobbed [her] off' whenever she tried to raise an issue.

While Marilyse was in the rehab unit, she was placed under the public trustee.

Cheryl believes that during this period the housing department 'coerced' Marilyse into giving up her flat.

'They said that she willingly gave up the unit, but she wasn't in a mental state to fully understand what she was signing.'

From the rehab unit, Marilyse was sent to another mental health facility.

Marilyse said the medical staff there intimidated her. Once, she was on the phone with the NDIS about her package when a nurse walked in.

'She wanted to know all the whys and wheres. She said that it wasn't my money, it pays their bills ... We had an argument.'

The nurse told Marilyse's psychiatrist, who 'threatened' her with a needle.

'I just stopped talking ... It just is the way these medical professionals treat some people.'

Marilyse is still on the public housing waiting list and under the public trustee. Whenever she wants something she has to 'beg them for money'.

She recently tried to have the financial management order revoked but was unsuccessful.

'They used my history to say that, no, we still don't think you're mentally capable of looking after your money.'

She says the trustee relies on psychiatric evaluations which don't reflect the reality of her 'moving forward'.

'They're not taking note of that, it's all historical ... I'm basically quite independent.'

Alison

‘I feel I can be easily taken advantage of when I’m unwell,’ said Alison, who has a schizoaffective disorder.

Alison became a patient in a psychiatric hospital in the late 1990s. She told the Royal Commission that over a five-month period, a male nurse had sex with her four times.

Alison feels vulnerable and is concerned for herself and others with mental illness interacting with psychiatric services, hospitals and counsellors.

‘Sex with a mentally ill person in a psychiatric hospital is abuse as the person involved cannot give informed consent.’

Alison would like to see higher penalties for abusers and more support for the person with mental illness, ‘so they feel they will be believed when reporting sexual abuse by nursing staff’.

Yasmeen

Yasmeen is in her late 60s and has an acquired brain injury that, together with severe photosensitivity, impacts her daily life, her ability to look after herself and carry out household duties.

Yasmeen told the Royal Commission she was abused and neglected by support workers she was dependent on for more than nine months in the early 2020s.

‘I have been abused and neglected ... and held captive to keep me isolated from everybody ... I was told that I was not able to report on anything because they were all I had ... They would also try and prevent me from having friends.’

Yasmeen said these support workers would refuse to provide support to her during particular hours simply because the times weren’t convenient for them.

They also lied about the hours they were providing to Yasmeen, claiming they had worked overtime, weekends and times during the week when they hadn’t.

Eventually Yasmeen was able to contact the manager of the support agency, who came to see her at her home. The manager agreed that the state of her house was unacceptable and dismissed the workers.

‘This has made me feel supported however I am still traumatised by the abuse and am receiving lots of counselling,’ Yasmeen said.

‘I have called the quality safeguards commission who told me that I cannot put a direct complaint against these workers because they were employed under an agency.’

Yasmeen is concerned that ‘these workers will keep going to other agencies and taking advantage of vulnerable people’.

Yasmeen would like there to be ‘better processes to deal with people like this’.

‘I hope that the workers who are employed as support workers have more qualifications and safety checks. Someone should be checking in more on people.’

Mikayla

‘My entire experience ... has been, and continues to be, completely dehumanising.’

Mikayla is in her early 60s. She has mental health conditions that include dissociative identity disorder, depression and complex post-traumatic stress disorder (PTSD).

Mikayla experienced neglect when she ended up in the emergency department of a regional hospital where, ‘instead of being treated as mentally ill,’ she was treated ‘as a queue-jumping attention seeker’.

The incident and ongoing neglect began a few years ago when Mikayla was admitted to the local hospital after a ‘partial overdose’. The nurse gave her ‘a sarcastic lecture’. ‘She didn’t even listen to me,’ Mikayla said.

Mikayla was sent home, where she then overdosed. A local health care service called an ambulance, but when she reached the hospital the emergency doctor accused Mikayla of queue jumping.

‘It took me five hours to receive any treatment. As a result I have liver damage and an optic nerve stroke and PTSD.

‘I also had to stop going to university because my PTSD was triggered and my brain did not store and retrieve information in the same way.’

When Mikayla lodged an official complaint with the hospital, they responded that ‘it was all in her head’. She then lodged a complaint with the relevant complaints commission. Mikayla said her complaint wasn’t investigated properly, and the commission misplaced important documentation proving Mikayla had acquired liver damage. As a result, ‘it has been a case of he said she said ... a complete waste of time’.

Mikayla told the Royal Commission that there is a ‘stereotyping’ of people with psychosocial disability as ‘mentally incapable’, and an assumption that the disability will be ‘physically displayed in posture or speech’. When people with mental health issues don’t present this way, they are often treated as ‘malicious and destructive’.

Mikayla recommends that an advocate with lived experience of suicide be present at all emergency departments to ensure the hospital and associated mental health care units are following their policies and procedures, so that vulnerable people are ‘not left alone or left feeling dehumanised or devalued’.

Clementine and Demi

‘I hope that people with disabilities are treated with genuine care and not subjected to suffering at the hands of people who are supposed to help them, in medical settings especially.’

Demi’s grandmother, Clementine, had a stroke many years ago which left her completely paralysed. Since then she has spent time in both respite accommodation centres and hospitals, where she has fallen from her bed several times. Demi is concerned because Clementine cannot use her hands, arms or legs to mitigate the impact, so each fall is ‘a life-threatening risk if she were to hit her head or land awkwardly’.

When Clementine has gone into the respite centres and hospitals, her husband has asked them to erect guard rails at each side of the bed to prevent Clementine falling, but they usually refuse, neglecting her safety.

‘Most recently,’ Clementine said in her submission, ‘my grandmother got back from a hospital stay with new bruising to her shoulder and hip – noticed by my grandfather but not mentioned by any staff.’

Demi’s grandfather believed Clementine had had yet another fall as a result of ‘negligence’ by hospital staff. She had to go back to hospital for them to find out if the fall had caused her hip to be dislocated.

‘I find it deplorable that my grandmother could dangerously fall so often in medical settings due to the staff’s inability to properly care for or about her. She does not express pain vocally often and it breaks my heart that she has experienced and is still experiencing such pain at the hand of ineptitude in our disability care systems in this country.’

Axton

Axton is in his 50s and was diagnosed a few years ago with autism. Prior to that, he had been misdiagnosed with bipolar disorder, which had serious impacts on his health and safety for many years.

It was a registrar GP in his rural home town who diagnosed Axton with bipolar disorder. He prescribed a regime of mood stabilisers and antipsychotics that made Axton 'sluggish and compliant'.

Still taking the prescription medicines and unable to find any work, Axton moved to the city, where he began living in a backpacker hostel.

Axton was checking in at the local community bulk billing practice – the GPs changed frequently – and they accepted the diagnosis and kept renewing the medication.

'There was no monitoring of the powerful drugs I was on,' Axton told us. 'A single visit to a psychiatrist confirmed diagnosis and I was to continue taking the powerful medication.'

'Lacking any driving force', Axton remained living in the backpacker hostel and stopped looking for work. 'I became friends with the marijuana smokers in the hostel,' Axton told us, and he became a 'virtual smoker' of marijuana, in addition to the powerful medications he was taking.

'I had no supports outside the people living in the backpacker hostel. My family ... did not visit me or care for me. I was on powerful medication and vulnerable to a cohort of drug users ... I had trouble feeding myself and difficulty leaving the hostel to manage errands. I gained a lot of weight.'

Axton continued in this condition for a year or so, and then 'went cold turkey' in an effort to 'break out of the zombie like existence'.

Axton said he found help when he 'stumbled across' a yoga ashram.

'The yogic lifestyle of the ashram was very beneficial and I noticed huge improvements in my health and well-being.'

He believes it provided an 'ideal environment for an autistic person to flourish' and that its methods should be 'studied and replicated throughout the world'.

Elsie and Celeste

Elsie has an intellectual disability. She left school a few years ago, but still experiences trauma from what happened to her there. Her mother, Celeste, told the Royal Commission Elsie's story.

It happened on an educational support transport bus when Elsie was in her early teens. A 16-year-old boy, who also has a disability, digitally raped her.

The next day Elsie told the school she had been raped. The boy admitted what he had done, yet the principal told Elsie she had to stop saying she'd been raped, and sent a letter of suspension home to Celeste.

Following that, the principal isolated Elsie from the rest of the school for a whole term, despite a psychologist from a disability service provider advising against this.

Both the psychologist and Elsie's NDIS local area coordinator lodged internal complaints. Still, Elsie was not allowed to sit with the other students during breaks for a whole term – she was made to sit with the educational assistant instead. Meanwhile, the boy was allowed to spend his breaks playing basketball with his mates.

'I feel this sent a message to my daughter and the other girls (all with disability) that if you report a sexual assault you will be punished,' Celeste said.

On advice from Elsie's local area coordinator, Celeste reported the incident to the relevant government department. However the department said that because the incident happened in the community they could do nothing, and handed it to police.

The police response was that because both children had a disability it was too hard for them to establish a crime, so they would not investigate.

The school did not offer Elsie any counselling, but sent her for more protective behaviour training.

'I would like the disability sector to stop thinking protective behaviour training is the answer every time a kid with disability gets hurt,' Celeste said.

Now, years later, Elsie is still deeply impacted by these events.

'My daughter will now let only me and one support worker touch her or enter her bedroom. This is making it difficult for her to access the support she needs. She now has suicidal ideation and [self-harms].'

Celeste thinks police should have more training around disability, and she would 'like crisis services to treat people with disability with the same care and respect they offer to other citizens'.

‘Stop shoving people with disability into the back room of society,’ she said.

‘I feel so many systems let her down here. I feel if she didn’t have a disability she would not have been treated this way. I feel very sad for her and feel I let her down.’

Pierre and Fatima

Fatima told the Royal Commission she is furious about the way her eight-year-old son, Pierre, was treated by teachers after another student bullied and choked him.

Pierre, who is autistic and has attention deficit hyperactivity disorder, had a meltdown as a result of the student's actions.

Two male teachers responded to Pierre's meltdown by physically restraining him. He didn't want to go with them to the office, so they 'grabbed him and carried him 150 metres and locked him in a room'. While locked in the room one of the teachers, who is a child safe officer, screamed at Pierre.

'They had a thousand choices in empathising with my son's stress with being strangled, allowing him to remove himself and self-regulate. Instead they allowed their arrogance to get in the way and look at him as though he was non-compliant, making a scene and assaulted him.'

Fatima talked to the school, the parish priest and the local diocese about what happened, but 'nothing was done'.

Fatima reported the incident to the relevant commission for children and young people as reportable conduct. The commission allowed the school to conduct an internal investigation. 'Obviously,' said Fatima, 'the school came back with findings that suited their own agenda.'

'I took it as far as I could and yet no-one will acknowledge that they could have handled the situation better.'

Pierre has now moved schools but still 'has major issues trusting people'. Fatima believes 'child safe' organisations 'aren't worth the paper they print their signs on'.

Fatima wants to see schools better understand and support children who are neurodiverse.

**'These children are being trained to believe they are bad,' she says.
'They are not, they need care and support.'**

She also believes there should be an organisation 'with powers to hold schools accountable to the trauma they cause'.

'The school has no incentive to do better for children who need support ... They take plenty of disability funding yet are not accountable on how it is spent and I rarely see it put into areas to support the children that attract the funding.'

Dash and Anika

‘My intelligent, creative son has now lost over a year of schooling. I don’t know what to do anymore.’

Dash is autistic and has a disability that affects his ability to walk and run. In year 3 he started to resist going to school.

His mum Anika was surprised. She told the Royal Commission that when Dash started primary school ‘he made friends and achieved very well academically’.

Anika contacted Dash’s teacher, who was new and inexperienced. The teacher didn’t understand autism and underestimated Dash’s academic ability. The teacher believed that if a child is autistic they also have intellectual disability. The teacher disregarded Dash’s need for routine and structure in the classroom.

The teacher also dismissed Dash’s physical disability. ‘He was not offered realistic alternatives to participating in sport,’ Anika said.

As the year progressed, Dash became more and more anxious and distressed about attending school.

Anika contacted the education department and requested Dash be placed in a class that catered for autistic students.

Instead, they offered Dash a place in a multi-categorical class at another primary school some distance away from where they lived.

Anika accepted this offer because she was desperate for Dash to return to school.

‘However, despite assurances from our new school that they understand autism and school refusal, my son’s school attendance has not improved,’ she said. ‘Our new school is even less supportive than our old school. I feel judged and that the school blames me for my son’s school-based anxiety.’

Dash’s school refusal means Anika is unable to work outside the home and she recently had to turn down a position. ‘I am highly educated and I would very much like to return to the workforce and contribute to society,’ Anika said.

‘I feel isolated and overwhelmed. I continually worry for my son’s future and I am deeply concerned that he may never go back to school.’

Caitlin

'I was a lost person in there.' Caitlin is speaking of her experience in a mental health unit. 'I don't want this happening to other people.'

Caitlin told the Royal Commission that before getting myalgic encephalomyelitis (ME) about 10 years ago, she had been 'living a full life'. She had a career, she travelled and had a social life. But the disease saw Caitlin become first confined to her home, then to her bed, and she spiralled into poverty. Her partner had left her and she was becoming homeless.

It got to the point that Caitlin didn't want to live anymore.

'It was not a good life now. I made peace with my life. I made a conscious, well thought out decision, my decision, my life.'

Caitlin took what she believed would be an overdose of sleeping pills.

'I then remember waking up and I was being walked somewhere in the dark. I remember coming to in hospital grounds and a man was walking with me ... He wouldn't talk to me and wouldn't tell me where we were going ... I was put in a room that had no windows, the door was locked ... I could see the shadow of a man ...'

Caitlin had 'woken up in hell'.

'I was sitting in a dressing gown, no idea where I was. I was told to sit down. I asked where I was and why I was locked in. There was a TV on the wall, the room was very bare. I get claustrophobia ...'

Caitlin wanted to leave, but when she tried she was 'held down by four or five big, brutish security guys'.

'I'm a 5 foot 1 woman who hadn't walked in months, why did I need to be held down? This was brutal and violent on every level.'

Still pinned down, Caitlin saw that they had a big needle. They wouldn't tell her what was in it or listen when she tried to explain that ME could 'interact badly' with certain drugs.

'Another time I was pinned down by five to six people ... They yanked my dressing gown up over my head which was very violent. My underwear and pyjama pants were pulled down to my ankles ... My bum was off the bed and my bum and genitals were showing, my knees and legs were on the floor. Then I was injected in the bum. They enjoyed it, it seems like this kind of treatment of people was normal'

Caitlin thinks these injections were chemical restraints, as she has no recollection of what happened after either of them or for how long she was out.

When she woke, Caitlin talked with office staff and tried to call her family and her doctor to get her discharged. She waited three days to be seen by a psychologist and get out.

When Caitlin told her doctor about the abuse she experienced in the unit, he said he was 'sorry it had happened', but did nothing.

'We need this to be out in the open,' Caitlin said. 'These people working in these places have a sickening hold over others ... I felt there was zero care of me. The violent abuse of me as a human being that I experienced occurred for no reason whatsoever.'

'There is no basis for violence or deprivation of liberty.'

Odin and Yanis

Yanis told the Royal Commission she is concerned about the limited support her brother Odin and other residents receive in their group home.

Odin has epilepsy, asthma, a spinal disorder and intellectual disability.

Support staff at the group home are rostered from 6:30–9:30 am and 3–10 pm on weekdays and all day on weekends. ‘There are no changes to this routine to allow for public holidays or any other event that requires supervision, for example, a release from hospital or COVID lockdowns,’ Yanis said.

Yanis supports Odin on these occasions because she’s worried if something happens at the home Odin won’t be able to contact her.

Residents can use the phone when a support worker is on duty but it is locked in the office the rest of the time. An emergency alarm is linked to emergency services, but Yanis is worried about non-emergency situations.

During the recent COVID-19 lockdowns, Odin and another resident were left unattended during the day.

When Yanis discovered this she decided to bring Odin home for two days a week. But she was concerned about the other days and felt frustrated she was ‘shouldering the responsibility of the organisation’.

Then Odin was assaulted, and she increased her care again – to three days a week.

‘The assault occurred over the other resident hogging the phone – a situation that was an ongoing contentious issue. [Odin] took the phone from him, so the other resident assaulted him.’

Yanis said support staff were aware the phone created tension and should have been supervising the residents.

Odin was taken to hospital and needed stitches in his face.

Initially Yanis was told that Odin threw the first punch. ‘[But Odin] is too unstable on his feet to be able to punch anyone,’ Yanis said.

Then they told Yanis the assault was just ‘unlucky’.

‘I see the situation differently. [Odin] was asked if he wanted to press charges against the other resident, but he said no. He doesn’t understand the full implication of the assault, nor the “duty of care” required of the organisation.’

Yanis asked for 'the procedures and guidelines governing the organisation' and was met with, 'I don't know what you mean.'

When she asked for all the information relating to Odin she was told she could have it 'if [Odin] agrees'.

'This appears to be a new strategy to keep me uninformed and in the dark.'

Yanis believes the support worker who was on duty failed in her duty of care and should be dismissed and have her accreditation revoked.

Yanis would like overnight supervision introduced and public holidays to be treated the same as a Saturday or Sunday with all-day supervision. If a resident is sick and needs to stay home, the organisation should provide appropriate care. And residents need to be able to use the phone whenever they want.

'I hope in the future we engage only carers who have "heart". I have come across some very lovely, supportive people during this crisis, but wouldn't it be lovely if all people in the caring industry were like them.'

Tobias

Tobias is a disability support worker and a whistleblower.

When he would start his shift at the group home where he worked, Tobias often noticed bruises on one of the clients.

Tobias told the Royal Commission that when he reported the bruising and his suspicion of abuse to management, they reduced the number of shifts they gave him. The same thing happened to other workers who reported the bruises.

Those suspected of the abuse were given more shifts. They also began to threaten Tobias.

Tobias said that one of the managers had a 'conflict of interest' with one of the staff who was suspected of abusing the client. This manager began to make visits to the house when Tobias was on his shift and then began to make false allegations about Tobias.

Meanwhile, in team meetings, the staff who were suspected of abuse would 'talk about practicing judo on the person in care' and how they would alter the approved restraints to make it easier to restrain the client.

Tobias provided texts, pictures and audio to the HR department. In addition to Tobias's evidence, many of the body mapping reports outlined bruising of the client on a weekly basis. But the HR department said there was insufficient evidence to support the claim of abuse.

At a team meeting the public guardian of the client acknowledged that she was aware of the abuse but that the client 'needs to be put in their place to behave'.

Tobias recorded audio of the public guardian saying this in front of support workers and management, and shared this with the HR department.

He also shared his information and concerns with managers and the regional director of the organisation. There was an internal investigation, but no abuse or neglect was found to have occurred.

Tobias believes he has sufficient evidence to show that the client was being abused by support workers and that management failed to protect people in its care and whistleblowers.

'Reports of abuse need to be taken more seriously by management and HR,' Tobias said. 'It's frustrating that these claims can be ignored and whistleblowers are penalised for reporting concerns.'

'I would hope that people with a disability have more of a voice so they are able to feel safe in their own homes.'

Skyla and Pip

‘When your family has been persistently let down, punished and belittled for having a child with complex needs, you lose faith in society and social inclusion ...’

Pip is mum to 13-year-old Skyla, who is autistic. She told the Royal Commission that Skyla has been subjected to neglect and discrimination by teaching staff, management and the governing body of the private religious school she attended.

It began when Skyla was in grade 2 and a new principal started at the school. The school requested that Pip attend a meeting with the principal and the disability inclusion teacher. Pip attended, only to have the new principal tell her that Skyla needed to ‘go straight to [the special school] where she belonged’.

Pip wrote a letter of complaint to the local governing body of the school, which resulted in ‘a small apology’ by the principal some days later and, for a short time, things ‘settled’.

Then in grade 4, the school informed Skyla’s parents that she could not attend the school camp unless one of her parents went with her. Pip argued that this was unreasonable. Skyla had good communication and could dress and toilet herself. School staff would only need to assist in administering her medication.

Skyla was ready to go to camp, but the day before the principal ‘removed her’, saying she would drive Skyla to the camp for the day but she was not allowed to stay overnight. Pip fought back. She insisted that Skyla would attend the whole camp, and provided a support to go with her.

The following year, in grade 5, the school again tried to block Skyla from the camp. This time Pip had to take five days off work to attend the camp with her.

‘Grade 6,’ Pip told us, ‘was a whole new level’. The school cancelled Skyla’s enrolment interview saying that they would talk to her parents about her enrolment in due course. Skyla had been excited about the interview and was disappointed when it was cancelled. Pip was ‘appalled’ and wrote to the school.

‘I was sent a reply from the deputy principal that my husband and I needed to have a long sensible think about her enrolment at the high school and what did we want to get out of keeping her there. Her grade 6 teacher made our lives hell for the entire year ...’

‘Year 7 was an absolute disaster,’ Pip said, with the school continuing to exclude and isolate Skyla.

Then there was the school swimming carnival.

‘She was excluded from [the racing] and given a job of collecting caps of swimmers as they got out of the pool. She won her race at the primary carnival the year before, so when I arrived and saw her sitting on a chair by herself 50 metres from the rest of the students I was in shock. It was raining and she was continuing to collect caps in the rain.’

‘Her age group went up for their races and no-one took her up to race, so I went over and got her ready and walked her down and put her in a race. What parent should have to put their own child in a race? A child that was so excited about the carnival and then was excluded from it. She asked me to go home after the race. It was one of the saddest days of my life.’

With the COVID lockdown, Skyla’s workbooks were sent home. This was when her parents realised the full extent of her educational neglect.

‘I was in absolute shock that there was no work in any of her books. She did five subjects and I think one teacher had attempted to adjust the curriculum to Skyla’s level, the rest was colouring in and cutting and pasting. I was absolutely disgusted.’

‘We asked the principal if his teachers needed more help with putting together work for Skyla to do at her level ... The principal basically said to us we’ve done our best and if you’re not happy ...’

So Skyla’s parents removed her from the school and she now attends a special school.

Pip says they made many complaints to the governing body of the religious school, but ‘nothing was ever dealt with’.

‘They didn’t want her there. She was of no benefit to them.’

Jonas

‘There was no direct support or anyone that I came across who was on the side of the child.’

Jonas told the Royal Commission that as a child he experienced abuse and neglect at home, school and in the health system. Now in his early 50s, he says those experiences still haunt him today.

Jonas has a congenital disorder. It affects his physical appearance, mobility, sight, hearing and speech.

‘Home was an unsafe place,’ Jonas said. He described his father as ‘a violent alcoholic’ and said his family were very poor, ‘constantly on the run from my father’s mental health issues and violence’. Jonas remembers spending a lot of his childhood hiding under the house.

In year 5 he moved to a large state school – it proved to be as unsafe as home.

‘My disability and my physical differences were glaringly obvious and from the moment that transfer took place I was bullied and beaten on a near daily basis.’

The abuse escalated each year until the end of high school.

‘My childhood and adolescence were spent living in fear and this fear often meant that I would avoid attending school by hiding or by outright refusing to go.’

By his mid-teens Jonas was underdeveloped for his age. Doctors gave him steroids to help him grow. During this time he became increasingly agitated and violent, smashing windows and doors.

‘I was unable to control my temper and I lived in a very hyper-agitated state of mind.’

Towards the end of his teens a group of boys his own age held Jonas down and raped him.

Over the course of his life Jonas has had dozens of medical procedures.

‘I was constantly ridiculed by specialist doctors who treated me with a lot of disregard.’ Jonas was paraded in his underwear at medical conferences.

‘They poked and prodded me, talked about me, talked above me but never talked to me. They added to my sense of personal shame and self-hatred.’

Later Jonas learned many of the surgeries he had were completely unnecessary and have only added to the physical challenges he lives with.

As soon as Jonas turned 18 he stopped taking steroids. He left the city he was living in and eventually went to university.

He said he feels much stronger today but realises he was never given a chance to participate in his own life.

He hopes in future children with disability are encouraged and allowed to be part of their local communities.

Jonas wants people with disability celebrated and welcomed for their difference, free of ridicule and scorn.

Ben, Cam and Daniela

Daniela describes herself as ‘lucky to have three amazing sons’ who are intelligent, funny, loyal and incredibly loved.

Two of her boys, Ben and Cam, are autistic and have attention deficit hyperactivity disorder. They are both in primary school. Daniela said Cam is ‘absolutely thriving’ at his school and Ben is doing well at his.

However this wasn’t the case at their previous school. Daniela told the Royal Commission that Ben and Cam continue to experience trauma and often talk about what happened to them.

Ben and Cam attended a small local private school.

‘Looking back there were a number of incidents which were “red flags” for what was to come,’ Daniela said.

On one occasion Cam was distressed and becoming dysregulated. He went into his sensory tent but continued to make noise. The teacher opened the flap of the tent, put her face in the gap and told him to do his schoolwork. Cam yelled at her to leave and told her to stop touching the tent. The teacher refused and continued to tell Cam to do his work. Cam punched her in the face.

The school suspended him.

‘I still feel shocked that my son could be suspended from within a sensory tent – this should not be possible.’

One day Ben was constantly flicking a light switch and couldn’t stop. After yelling at him the teacher grabbed his arm. Ben hit the teacher and ran away. He was suspended and counselled on how to make better choices next time. Daniela said counselling should include the teacher and focus on building the skills of everyone involved.

On another occasion Ben was in trouble and ran. The principal chased him, cornered him in a courtyard and locked the door. The principal told Ben he could come back inside when he calmed down. Ben picked up a tree branch. The principal told him not to bother – the windows were smash proof. Ben proceeded to smash the windows.

‘At the time my husband and I bent over backwards apologising and expressing our horror at what he had done. Looking back, I am far more horrified that my frightened seven-year-old was locked in a courtyard by the school principal.’

Daniela said the school didn’t seem to understand autism. One time the principal told her Cam’s lack of eye contact was ‘evidence of a lack of remorse for misbehaviour and that he was avoiding taking responsibility’.

The principal also blamed Daniela and asked multiple questions about how she disciplined the boys at home. He told her husband the boys were much better behaved when she was out of town for work.

After the school had suspended the boys numerous times and restricted their attendance, Daniela decided to appeal a decision. She said the school was ignoring the behaviour response plans when they chased, grabbed, yelled at and whistled at the boys.

What followed was a sustained campaign to get the boys to leave the school. Daniela said she was targeted for advocating strongly for her boys. A child safety officer became involved and conducted a risk assessment on Daniela and the boys.

‘It was one of the most difficult things I had ever read. It seemed to focus on me more so than my children. It portrayed me as a hostile and aggressive parent who made baseless claims and criticisms. There were multiple unsubstantiated accusations in this document.’

Daniela and her husband felt they had no choice but to move town.

‘I wake often in the night, feeling frustration at the injustice of it all. I feel as though we were run out of town and that the “bad guys” won,’ Daniela said.

‘Things have drastically improved for us since we left and my children are happier and safer in their new school environments, despite this we all have ongoing trauma related to the way in which we were treated at our former school.’

Jude and Eva

A couple of years ago – he had recently started primary school – a teacher dragged Jude across the playground. No-one told his parents.

His mum Eva told the Royal Commission that when Jude woke up crying that night, she ‘did not know why’. For the next few nights Jude ‘had nightmares and could not sleep’.

Jude has attention deficit hyperactivity disorder, anxiety and a physical disability that makes writing difficult and slow.

When the school told Eva about the incident two days later, she immediately reported it to police. She didn’t have many details about what happened and police referred her back to the school.

Eva spoke to Jude further, Jude’s psychologist, some teachers and parents. It became clear there was a culture of physical abuse at the school – most of it targeting children with disability. Several teachers regularly dragged, hit and ‘manhandled’ children.

Eva made a formal complaint to the education department. Her complaint listed the allegations of physical abuse adults had directly witnessed. She didn’t include hearsay incidents or the multiple incidents of emotional abuse.

Initially the department told Eva they wouldn’t be able to investigate all of the incidents because two of the teachers had immediately taken sick leave.

The department also told Eva not to talk about the complaint while it was being investigated because of ‘procedural fairness’.

It took five months for Eva to see the report. There were several errors and only two of the allegations were supported. The most serious allegations had not been sent to the principal for a response and had not been investigated.

‘No-one took our complaint seriously, but we were still constantly warned to remain silent and not to discuss anything with anyone. The focus seemed to be on avoiding bad publicity rather than actually fixing a problem.’

Eva spoke to the school’s relatively new principal, who was also shocked. She contacted the department again and they began another investigation. Six months later they wrote to Eva advising her there was insufficient evidence to support the allegations.

Eva was incredulous. She was fairly certain the department never contacted the parents and teachers who witnessed the incidents. She was also aware the teachers never returned from sick leave.

‘We are not especially confident that there was much of an investigation. It felt like they were going through the motions to try and avoid legal action rather than any concern about the children’s welfare.’

Eva remains disturbed by the education department’s response, but she said the school principal has been really great.

‘Given that we brought an ... investigation onto his school, I have mostly not felt like he resented this or us.’

He was open, initiated training programs and introduced new policies – classroom doors must now remain open. While there have been some difficulties, Eva said his priority is the children’s wellbeing.

‘I am concerned that so much of what makes a school a reasonable place for students with disabilities is up to the principal – like they can choose whether or not to be welcoming, and there are no repercussions if they are not.’

Casey and Paige

‘Our child was excluded from his education not only by the school’s lack of expertise and poor knowledge of neurodiversity and disability but also by their uncaring and judgemental attitudes.’

Casey’s first few years of primary school were unremarkable, his mother Paige told the Royal Commission.

But then in year 3 Casey developed anxiety and refused to complete his work.

‘We were told this was a discipline problem and that we needed to be stricter as parents. We were repeatedly told he was perfectly capable of completing his work but was choosing not to participate.’

Casey became so distressed at school drop-off that Paige pleaded for help. The school told her there was nothing they could do.

Paige consulted a private psychologist and paediatrician who diagnosed Casey with autism spectrum disorder (ASD). Paige informed the school and requested learning support. Again the school refused to help, this time, because Casey didn’t have funding.

Casey’s anxiety markedly increased on the days he had music. His class had been assigned performance roles in the school musical. Paige asked if he could be given a backstage or supporting role but the music teacher refused. Eventually Casey stopped going to school on the day he had music. Paige asked for more support – instead the school excluded him from music altogether. He stayed with the class teacher when the rest of the class went to music.

Midway through the following year Casey’s teacher opened the connecting door between classrooms to start team teaching. Casey found this confusing and overwhelming and didn’t respond well to the other teacher. One day he made a rude comment and, when the other teacher told him to go to the principal’s office, he refused. Paige arrived at the school and found Casey ‘completely shut down and in a state of high distress’. The teacher and principal refused to acknowledge Casey’s behaviour stemmed from his autism and suspended him for refusing to comply with directions.

‘We came to feel that our much loved and cherished child was an unwanted problem at his local school. We came to feel that they wished our child (and us) would just be quiet and go away.’

At the end of the semester Casey’s report stated he was unable to be assessed because he hadn’t completed enough work. When Paige complained to the school leadership they said, ‘It’s not our fault he won’t do any of the work.’

In desperation Paige employed a disability advocate who assessed Casey's independent learning plan as 'woefully inadequate'. Paige discovered the school had an obligation to provide accommodations for Casey's disability regardless of funding.

Paige also discovered the school leadership hadn't shared Casey's autism diagnosis with his teachers or relevant support staff.

'The school stated this was to "protect his privacy" but ... the implication was that an ASD diagnosis is shameful and should be hidden.'

Because of the advocate's interventions Casey was able to successfully attend school camp for the first time. He was given appropriate support and 'was so happy to be able to attend with his friends'.

However the support stopped when he returned to school.

Casey began self-harming.

The school finally referred Casey to an independent student support service. His hours were reduced and a support plan was put in place with his teacher. But his teacher kept forgetting to follow the plan.

'The ongoing stress and distress this "forgetting" caused ... is indescribable.'

Casey is now a teenager and has been diagnosed with a learning disorder in addition to ASD.

'Despite being told repeatedly ... that he was behaving badly and choosing not to participate, and ... that we had poor parenting capacity because we couldn't get him to attend school, we now understand that he was not able to meet the schools expectations because of lack of recognition and support for his disabilities.'

Hashem

‘Disability seems to them like a great luck in life and they are convinced that disabled people are scoundrels. I experience constant abuse at disability parking spaces. But if I open my mouth and they hear my accent, the bogans simply go ballistic ... I hear racist slur constantly.’

Hashem is in his late 50s. He lives with psychogenic chronic pain, chronic fatigue, anxiety and depression. For almost a decade, Hashem told the Royal Commission, he has experienced violence and abuse by three individuals in his community. He has also experienced systemic abuse and neglect by the institutions and organisations he has gone to for protection and justice.

On a daily basis, the three individuals have humiliated and harassed Hashem in his neighbourhood and in his own home. They have assaulted him verbally and physically in public places, spread defamatory rumours about him, stolen from him, trespassed and urinated on his property, thrown bottles and rocks at his house, and broken glass windows and doors. They have cut the brake hose on his car several times and made countless death threats.

Hashem has gone to the police many times, to no avail. In fact, he says, the police are ‘not only useless and unhelpful but outright dangerous’.

‘First,’ Hashem said, ‘police disclosed my disability and vulnerabilities to perpetrators. That made the attacks more targeted and sophisticated’.

‘Second, police blatantly refused ... to take any action against perpetrators thus convincing them in their impunity.’

Initially, the police would tell Hashem they could not do anything about the abuse because they did not have any evidence. But they would also make fun of Hashem, telling him to ‘harden up’ and calling him a ‘nutter’.

‘Stigma of the “nutter” is present everywhere. You can see straight away that people who are paid to help you using their position to have fun of you, provoke you ...’

One police officer suggested that Hashem install security cameras. He took this advice and over time he took to the police countless video and audio recordings of abuse, death threats, trespassing and property damage.

It became clear to Hashem that the police were still ignoring his complaints. One police officer told Hashem they could only take action against the perpetrators if he had an intervention order against them. However, the police told him he couldn’t get an intervention order as ‘it is not for those who lost their marbles’.

‘So I had to obtain this order at my financial expense and at the expense of great stress, pain and suffering,’ said Hashem.

The perpetrators continued to abuse Hashem and he made more than 30 complaints about breaches of the intervention order. Still the police were reluctant to do anything.

Then the police began what Hashem described as ‘a phase of active abuse’.

‘One day I was stopped by police twice, having travelled only 75 metres from home. The result of the second stop (after 2 hours of harassment) was the defect notice for no valid reason.’

Then there was another incident of abuse from one of the known perpetrators, who used a metal pipe to smash Hashem’s windscreen. The police response was to issue a new defect notice for the car.

‘Then after half an hour they changed their mind and added fraudulent infringement notice for alleged parking in the hydrant zone.’

Hashem said, ‘I have seen in the court many disabled people who were charged with “false complaints” against abusers.’

Hashem would like to see greater penalties implemented for abuse against people with disability, removal of the police ‘monopoly’ on commencing criminal proceedings, and compulsory pro bono work for all law practices to assist clients with disability.

Ella and Cassie

Ella is in year 1. She has attention deficit hyperactivity disorder (ADHD) and anxiety. Ella is quite advanced in her reading ability. Her mum, Cassie, told the Royal Commission she is frustrated that the school won't do anything to build on Ella's strengths.

Cassie tells us Ella is reading at a year-3 level. Cassie brought this to the teacher's attention, but the teacher responded that she was going to leave Ella at her present level and Cassie was free to give her more challenging work at home if she wanted.

Cassie believes this response is about Ella having ADHD.

'Our daughter has been singled out by her teacher, her teacher sees her ADHD as attention seeking.'

This attitude extends to the school psychologist, who reported that Ella is 'manipulative, stubborn and an attention seeker'. But Cassie says the school hasn't given Ella any support for her anxiety or ADHD and 'she gets bored in the classroom because she's not being stimulated academically'.

'She has been traumatised with the way staff have handled her, her mental state has been affected, but the school is trying to convince us that she's been supported which we know she hasn't been. Our daughter hates my husband and I dropping her off at school in the mornings ... and when her anxiety gets so bad she runs off.'

Cassie would like to see schools provide better support to children with ADHD, and to their parents.

Sonsia

Sonsia's son has 'severe combined attention deficit hyperactivity disorder [ADHD]'. He has difficulty finishing tasks, including basic tasks such as eating, dressing and bathing. He can be 'emotional, short-tempered and violent'.

Sonsia told the Royal Commission that people with ADHD are at high risk of neglect and exploitation in the health care system.

When Sonsia took her son to a 'large psychology practice' to assess whether he had ADHD, the psychologist asked her if she 'had considered ASD [autism spectrum disorder]'.

'We were informed that ASD was a 'better' diagnosis because it was funded in the NDIS,' she said.

'The system for diagnosis has become a profitable business and as a parent you need to be switched on and aware that there are professionals who will attempt to exploit your vulnerability for a profit.'

The psychologist was not the only healthcare professional to suggest 'it would be better to have the diagnosis "shifted" to access assistance'.

'Without recognition of ADHD as a disability, there is simply no money or incentive for treatment services. This situation lays the ground for exploitation.'

Sonsia points out that it can be tempting for parents to embrace misdiagnosis to gain better supports and funding, but this can result in 'lifelong negative consequences' for the misdiagnosed child, who misses out on early intervention appropriate to their disability.

Sonsia is concerned that the lack of support and recognition for ADHD is setting children up for failure.

'Our son entered kindergarten with joy and excitement, he loved school and loved to learn, he was a keen participant ... He ended the kindergarten year having not progressed at all in his reading and wasn't able to write adequately.'

'It made us aware that teacher training was lacking in this area, we understand that special needs is not a compulsory subject for teachers, yet every classroom I have come across ... has a least one child with special needs in that classroom.'

'These are vulnerable kids and teachers need the training and support to understand how to teach them without damaging them.'

Anna and Penny

Anna was a proud mum, wife and First Nations woman. She was funny, cheeky, compassionate and intelligent. She loved to write.

Anna lived with psychosocial disability and became quadriplegic in middle age, but she had dreams for the rest of her life. She dreamed of moving into an apartment with her husband, of having a little garden and of getting a chocolate Labrador support dog. She dreamed of one day seeing her daughter give birth, of becoming a grandmother.

But Anna died in a hospital a few years ago, in her early 50s.

Anna's daughter, Penny, told the Royal Commission she believes her mother's death was preventable. She says her life was cut short because of systematic ableism within the health care system, the group home environment and Australian society.

During her initial hospitalisation five years ago, Anna began the stressful and lengthy NDIS application process. Once she finally had a support package, she couldn't use it. Public hospitals would not allow private NDIS providers such as physiotherapists or dieticians onto their premises, so Anna missed out on critical care that could have helped her regain mobility. Penny says this happens frequently in rural communities and is a common experience for First Nations people.

Eventually, as Anna's condition stabilised, she no longer required acute hospital care. It was time to find somewhere to live. However the NDIS would not provide Anna with funding for specialist disability accommodation (SDA) until she could provide evidence she had been accepted into an SDA. But no SDA would secure Anna a place until she could prove she had funding. Anna was trapped in hospital for months feeling desperate and suicidal.

Anna was now only in a hospital because there was nowhere else for her to go. Penny said staff began to view her as a burden, and would leave her alone behind closed doors so they did not have to hear her cry. Often they left her sitting in an old wheelchair in extreme pain. She would cry out for hours, waiting to be lifted back into bed.

Staff sought to manage 'problem behaviours' – such as crying in pain – through behaviour management plans, prepared without consultation or consent. One of the strategies was to take away Anna's phone – her only lifeline to the outside world.

It was hard for Penny to see the hospital environment as anything other than prison for her mum.

'They were places where [she] was confined and deprived of dignity and her liberty. They were places where physical, sexual and emotional abuse occurred ... They resembled asylums.'

Eventually Anna was able to leave the hospital and move to a group home. She didn't want to live in a group home, but the alternatives were stark: hospital or homelessness.

The group home was understaffed and workers routinely neglected Anna. They often left her in bed until midday, with no breakfast. She had bruised and bloodied toes because busy support workers didn't take enough care with her wheelchair and would push her into walls and doors, causing great pain. Ultimately, the group home was similar to hospital – it felt like a prison.

'She did not have independence or freedom,' Penny said. 'She did not feel safe or dignified.'

Meanwhile, Anna was still having to deal with the NDIS. Penny described the interactions as 'nothing short of hell'. Planning review meetings were highly invasive and distressing, with planners talking over and about Anna as though she wasn't there.

'She felt small and at the mercy of a bureaucracy that at its best did not care for her, and at its worse actively sought to make her life worse.'

Most areas of Anna's NDIS plans were left severely underfunded. Lacking critical support, she developed conditions that ultimately contributed to her death. Penny believes that in the weeks leading to Anna's death, hospital staff made judgements about her quality of life and gave her inadequate treatment because she was a woman with disability.

'Through her interactions with systems and institutions as a disabled woman, [Anna] was left feeling as if she was not human, and not deserving of the love, safety, dignity, liberty and respect everybody has a right to. The people and systems around Anna robbed her of her agency and humanity. They tried to diminish Anna's hopes and aspirations.'

Willow and May

‘For 20 years [my sister] was mistreated and over-medicated for a mental health condition she did not have, and not treated and under-treated for the psychosocial and physical health problems she did have.’

This, May told the Royal Commission, directly contributed to the early death of her sister, Willow, 10 years ago.

Willow was an adolescent at the time of her first contact with the state-funded mental health service in the early 1990s.

When Willow’s behaviour suddenly altered, with alarming symptoms, her family feared that something bad had happened to her. May said it seemed like she had experienced some kind of trauma she could not communicate to them. Scared for Willow and for what may have happened to her, they considered going to the police. But they decided to take her first to a specialist doctor for guidance.

The family told the doctor everything they knew and feared about Willow’s circumstances, answered the doctor’s questions and listened respectfully to their advice. But they were left feeling ‘judged and found to be fundamentally flawed human beings responsible for the psychotic state they said [Willow] was in’.

‘We will never know now if there was trauma or humiliation or adversity or discrimination or disappointment or something else that had happened to Willow a week before.’

Willow was admitted to hospital and diagnosed with schizophrenia. Doctors gave no explanation for this diagnosis to Willow or her parents. Later, when May accessed the admission notes to try to understand the diagnosis, she did not find anything that seemed to conclusively support it.

May explained that during that first hospitalisation, Willow often seemed anxious, perplexed, uncommunicative and would weep for no apparent reason. Willow’s medical records showed that staff suspected that she was experiencing auditory hallucination, despite Willow persistently denying it.

‘In making their diagnosis,’ says May, ‘they failed to consider adverse childhood experiences, or the context in which her symptoms emerged.’

According to Willow’s treatment sheet, she was being administered a typical antipsychotic three times a day. The daily total amounted to five or six times the maximum for an adult, even though Willow was an adolescent. At no time did hospital staff give Willow the opportunity to give informed consent about taking psychotropic medication.

When Willow was released into her mother's care five weeks after her initial hospitalisation, she was 'unrecognisable to those who knew and loved her'.

Willow did not like taking the medication. She explained to her sister that it left her feeling empty and 'unable to feel joy'. But, says May, the doctors 'were of the opinion that Willow had a lifelong degenerative condition and that her not wanting to take the medication was part of the condition'.

Shortly after, and 'despite no evidence for ... continuous use in the long-term', the hospital changed medication from oral to intramuscular injection – to ensure medication continued to be administered.

Within 18 months serious and painful side effects had emerged, such as lockjaw and swelling in Willow's hands. The medication continued to be administered.

Willow began to experience unusual movements of her mouth and tongue. Yet, in every encounter with a health professional the focus was always on ensuring medication continued to be administered.

For five years, Willow regularly attended a community mental health service for intramuscular injections of antipsychotic medication.

Later, May learned that there were no records from this service.

'That means there were no doctor's visits, no medical reviews, no monitoring of the effect and side effects of medication, only the administration of medication.'

When the Community Treatment Order expired, medical staff didn't tell Willow. May says they knew she would choose to discontinue the injections and 'it was their belief that the medication was needed'.

Willow continued to attend for the injections motivated by the fear that if she didn't the police would be sent to fetch her.

Ten years on, Willow began making unusual breath sounds, eventually diagnosed as a life-threatening condition necessitating emergency intubation on numerous occasions. Still, the psychotropic medication continued to be administered.

By her late 30s, Willow's psychological problems were compounded by grief – both her parents had died. She had significant health issues, including hypertension and cardiovascular disease. Yet, the only treatment was the continued administration of the antipsychotic medication.

A week before her death, Willow was given information necessary to decide whether or not to discharge herself from hospital. She chose to leave, against medical advice.

On this occasion, the hospital ensured it had all the documentation in place. 'It is quite fascinating how they overrode or adhered to their guidelines, policies, and procedures when it suited, and used them in a way to protect themselves and their processes rather than patient outcomes,' May observed.

Throughout Willow's ordeal, and after her death, May contacted people she thought would care and be able to help – including state and federal health ministers, the healthcare complaints commission, the clinical director at the hospital, the official visitors program, the clinical director of the community mental health service, the police, the Coroner's Court and others. But none of it produced any meaningful assistance, resolution or justice.

'My family and I were left devastated,' she said.

Aarti

‘Compassionate parents with disability have the right to also be parents, with some support, as much right as everyone else.’

Aarti, a First Nations woman, has intellectual disability and anxiety.

She lives independently and is able to care for herself and her home.

Aarti told the Royal Commission her disability doesn't have a 'huge impact on a daily basis ... besides some problem-solving ability issues and heightened anxiety in certain situations'.

A short time ago, Aarti became pregnant.

She said the hospital didn't have any concerns about her ability to care for her child. But a couple of days after her baby was born, the department of child protection removed him.

‘The department have not been compassionate, to give me the chance to show how capable I really could be as a mother.’

Aarti believes the department is discriminating against her because she has a disability.

‘Nobody has the right to hold a person's disability against them.’

Aarti is doing everything she can to get her baby back.

She now has an advocate and team of support people.

An occupational therapist helps her navigate and improve family contact visits. Her speech pathologist helps her with her problem-solving skills.

‘She helps me to see the bigger picture in a situation rather than just noticing the small details in what's happening around me.’

She also has someone who helps her budget her money.

Aarti appreciates the support but they can 'only assist with the mentioned things and can't overpower the department'.

‘The department have emotionally abused me, and traumatised me, and this needs to stop,’ she said.

‘There needs to be justice for parents like us, to come into human rights. Then these problems will be fixed. Parents need to be provided a chance, just like everyone else.’

Novalee and Lake

Novalee, in her late teens, has significant cognitive and physical disabilities. She requires full-time support and lives in a care facility.

Lake, her mother, is concerned about the quality of care Novalee receives at the home. She is meant to receive 'around the clock care' with four support workers caring for her at times, she said.

'This is the furthest thing from the truth. She is fed budget non-creative repetitive food. The same music is played on repeat 24/7 as a way to brainwash and control her emotions. My daughter deserves so much better than this.'

Novalee is legally under the care of the child services department, which Lake views as a grab for her NDIS funding. The department has treated Novalee with 'utter disrespect'.

'They have denied her request for continuing schooling and deemed it not necessary.'

Lake outlined numerous concerns with the way Novalee has been treated.

For a year, she didn't leave her room, eating and sleeping in the same space. She shared it with another teenager with unpredictable behaviours that were troubling for Novalee. For a while she was moved to another room, but Lake understands she is soon to be moved back in with the teenager. Lake has seen the teenager assault another resident and worries about Novalee's vulnerability.

As well, Novalee has had only male support workers at times, which Lake said is 'extremely inappropriate considering [Novalee] requires full assistance with going to the toilet and showering'.

She believes staff deliberately under stimulate Novalee, to avoid engaging in activities with her.

'They constantly say she is "tired" but make no effort to communicate with her. They treat Novalee as if she were in a vegetative state, but she understands everything.'

Lake explained that because of unresolved childhood trauma she has made 'poor choices in the past' that have led to the department's guardianship over Novalee now.

'I am a little older and wiser and have taken responsibility for the past and I am dealing with it so that I can be there for my daughter now and into the future,' she said.

She believes the department and the services provider are 'turning a blind eye' to Novalee's neglect.

'I will not stand by and let this happen,' she said. 'My daughter deserves the best care and most importantly love.'

Ishaan

Ishaan, mid-40s, is vision impaired.

He arrived in Australia on a temporary protection visa almost 20 years ago.

‘My early life in Australia was very isolated and lonely as a result of my vision impairment and my inability to communicate in English.’

Ishaan enrolled at TAFE to learn English but they couldn’t teach English to speakers of other languages who had vision impairment.

‘I also could not get any assistance to sit in classes and listen and learn. I was very intimidated by this whole process.’

Ishaan told the Royal Commission he felt hopeless.

‘This was a very different experience to what I hoped my life in Australia could be.’

Sometime later, he found an organisation for people with vision impairment and was able to borrow audiobooks and newspapers.

‘This is how I learnt English – slowly, and by teaching myself.’

Ishaan enrolled in a certificate 3 at TAFE.

He found it difficult to access course materials for people with vision impairment and many teachers wouldn’t let him record the classes.

He persisted, eventually finding individual teachers who helped him.

Ishaan graduated and enrolled in another course.

‘My confidence grew.’

Ishaan completed a diploma and started applying for jobs.

But every job required him to have a driving licence.

‘I grew very disappointed and went into an isolation mode. I felt all my hard work would not secure any outcome.’

A friend encouraged Ishaan to join a sports club where he met several university students.

He decided to go to university, completed a degree and got a job helping other refugees.

'Not many people with a disability from refugee, as well as culturally-linguistically different backgrounds, have employment in Australia.'

Ishaan believes this is because the systems are so difficult to navigate.

'I had to struggle to learn the language and relevant skills like computers and IT systems. I did not have any local connections or networks that could help me with my goals. I had no information about the places where people with a disability may find supports.'

Ishaan wants more support for people with disability from diverse backgrounds to achieve their goals and aspirations.

Albie

Albie is in his 50s. He is Deaf and lives with depression. He receives a Disability Support Pension and NDIS funding.

There were no resources or supports for Deaf people in Albie's small town when he was growing up. The school made no adjustments for his deafness and his education suffered.

'I had no interpreter or captioner – nothing.'

Other students bullied Albie because of the way he spoke and his poor academic performance. He left school early, with few options.

'Maybe I was 15, 16 and do all the different back-breaking jobs, low pay. Like gathering, labouring, truck driving job, farm work, all difficult.'

Albie experienced a lot of discrimination throughout his working life. He described a pattern of negative interactions, beginning with his bosses or co-workers being angry when he didn't understand something.

'When they get angry, I get angry, the next person get more angry. It will become, like, escalate – escalate bigger, bigger, bigger and bigger. And the only way to stop ... I always pulled out, back off, always back off or quit the job and find another one again.'

Albie never felt at home in what was often a rough workplace culture, and doesn't feel capable of hard physical work anymore.

'Getting tired, had enough,' he said.

So far he has not had success in finding different kinds of jobs. He finds disability employment services frustrating. The providers are not trained to work with Deaf people, he said, and do not have interpreting services. And because his deafness is not a visible disability, people think he has 'something wrong in [his] head'.

Albie has had similar difficulties with the NDIA, whose staff regularly try to contact him on the phone.

He described his situation as one where 'a problem layers one on top of another, on top of another, top of another problem'.

'My future is not looking good. I'm stuck,' he said.

Fabio and Joaquin

Fabio is in his final years of primary school. He is autistic and receives NDIS support. His father Joaquin describes him as ‘high functioning’ and a ‘masker’.

‘Like, if you just looked at him, you’d think he was just a normal child,’ he said.

Fabio’s parents separated some years ago and he lives with each of them half the time. Since their separation, Joaquin and his ex-partner no longer talk to each other or participate together in events and activities in Fabio’s life. Joaquin said Fabio is managing these changed circumstances well.

‘As much as he’s gone through a lot, he’s achieved a lot as well, which I have been very happy with.’

After several years of requests, Fabio now receives support at school, but there are still issues. Joaquin says consistency is very important to Fabio, and the school fails to provide it.

‘Teachers change, you know. So the constant evolution of, you know, in one year you get two teachers [working different days] ... So he had two teachers he had to deal with. And then halfway through one of the teachers left, so they got another teacher. So one year he’s had three teachers.’

Joaquin also feels the school uses his and his partner’s separation to avoid responsibility for Fabio. For a time Fabio was incontinent at school. When Joaquin wanted to discuss this with staff, they told him it didn’t happen when Fabio was staying with his mother.

‘And it just went around in a circle. Know what I mean? ... It happened about three times, and it was just – just a constant circle of, you know, blame-shifting. No-one taking accountability, responsibility for it,’ Joaquin said.

Joaquin has had similar experiences with the NDIS. Both he and his ex-partner are Fabio’s nominees. Organising Fabio’s plan together is difficult and there is no support to help manage the process.

‘For a separated parent, there’s no specific liaison communicator or support mechanisms in place. So it’s left to – “That’s for you two to work out,” you know ... “We’ve done our part. We’ve provided the funding.”’

As a result, it’s been difficult to implement Fabio’s plan.

‘I think there needs to be a more independent person, specialist, specifically for separated parents, where obviously there’s disagreement there ... Like, it’s not about me gaining anything from it. [Fabio]’s the one that – everything that gets stopped, affects him ... and that’s the biggest concern.’

Audie and Jaxxon

Audie, in their early 40s, has Ehlers-Danlos syndrome (EDS). Audie's children are autistic and have numerous health issues. Audie and their children were each approved for NDIS funding several years ago.

Audie told the Royal Commission the family does not get enough funding to meet each individual's needs. Their younger child Jaxxon, who also has EDS, was initially funded for allied health support only. Audie had asked for a package that included funding for interventions such as speech and occupational therapy and a support worker to accompany Jaxxon outside the home.

'When I said, "Look, he needs to get out of the house, he needs to play with his friends, he needs to go to school" – we couldn't even get him to school a lot of the time. And so, they were like, "That's parental responsibility," and that was the end of that.'

Audie said Jaxxon's package basically only 'covered the reports for the next NDIS package'.

Initially, Audie shared their NDIS funding with Jaxxon, which meant compromises to their supports as well. But one day they went along to an NDIA-organised 'tell us what you think kind of event'.

'One of the regional directors was there and I broke down in front of him.'

The director made a phone call and Jaxxon's funding was increased by nearly five times. It was a generous package that meant Jaxxon could have support at home and beyond. But it didn't last.

'We were just starting to get somewhere at the end of the two years and then our funding got done again last November and his got cut basically in half.'

Audie believes the NDIS planner's lack of understanding is partly because Jaxxon's EDS is invisible. Audie's EDS means they have to use a wheelchair, but Jaxxon can manage without.

Audie says the funding treats the family as a single entity rather than three individuals.

'There seems to be an issue that as a family we only need one [support worker] at a time. And it's like, yeah, but we're doing different things, we have three different lives ... A lot of it seemed to be, well, you know, you can share and whatnot. And it's like, that's not how our lives work.'

For example there is an expectation that the children can share a support worker when out in the community.

'I mean, yes, they're siblings,' Audie said, 'but they already live with each other. When they go out they want to, you know, go out separately and do their own thing.'

Audie wants to see people with disability treated in a way that respects their dignity.

'I've gone from having a normal life to being stuck at home and having nothing for such a long time. Now I'm finally getting out and it's hitting me very hard how badly we treat disabled people on an everyday systemic basis.'

Marika

Marika, 40, is autistic and has several children who are autistic. She is a registered nurse.

‘My autistic attention to detail and my ADHD ability to think at 3,000 miles an hour kept a lot of people alive.’

But Marika said she’s struggled to help her children overcome discrimination at school.

When her eldest son started preschool a few years ago he was well supported.

‘Look he was hard work, don’t get me wrong. ... but once we finally got the occupational therapy and the support into the school, he thrived. He really, really thrived. And so when my [other children] started primary school there was already the relationship there ... and we were very happy there.’

When her family moved to a regional primary school, the COVID-19 pandemic started and he received fewer supports. When she asked for better support the principal ‘started to get a bit nasty’.

‘[He rang] and said, “You know your kids aren’t that special [Marika]. Other people just get on with it or just accept that their kids aren’t going to get anywhere.” And I was really quite shocked.’

Marika says she felt like the primary school used COVID-19 as an excuse to not appropriately support her children.

‘I would get phone calls left on my phone saying that my boys were being very naughty, being very defiant. My [son] would come home and have four-hour meltdowns every single night. I would ring the principal and say, “Look something’s wrong. Things aren’t being met. I don’t know what’s going on. Can we please get an [occupation therapist] OT, a speech therapist in?”’

The school provided poorly trained teacher aides.

‘None of these school aides had any qualifications in anything nor was there an appetite to give them skills to deal with some of the behaviours. So I would walk onto this school ground and I could see very dysregulated children.’

One day, a member of the school staff told Marika her children should be in a special school.

‘I said, “That’s impossible ... They don’t have an intellectual disability.” And he’s like, “Well I’m sick to death of families like you.”’

Marika told the Royal Commission her family’s mental health has suffered from the lack of support.

Raylene

‘There’s a lot of people that are qualified and well-skilled in other trades that are wanting to bring those skills into disability, but are discouraged by the current culture.’

Raylene is autistic. After losing a job during the COVID-19 pandemic, she became a disability support worker.

‘It’s been the worst experience I’ve had in an industry, and I’ve been in hospitality, I used to work in factories, a lot of different jobs,’ Raylene told the Royal Commission. ‘And I’ve never come across just the disrespect from other workers in ways of racism, sexism and just ignorance.’

Raylene said although she has several degrees, an agency pays her ‘at the absolute base level’.

‘There’s a lot of people that have intrinsic interest in being in the industry and [have an appropriate] skill set. They’re the type of people that could be working in this industry full time and they’re interested in being properly qualified, but unfortunately those people are being deterred.’

She says some service providers favour unqualified staff, using unskilled casual labour ‘to avoid accountability’ for some of the things that happen in group homes.

Raylene said that in her first job a colleague screamed at her when she tried to communicate with an autistic resident. Another time, a colleague treated a resident ‘like she was an inmate ... He’d yell at her like she was a dog’.

‘She wanted a shower at the time. It was in the corner of the loungeroom where there was no air-conditioning on a hot, very hot, day ... but he was refusing her that and I just don’t think that a worker really has the right to do that.’

Raylene said the disability sector needs qualified and neurodiverse staff who have a lived experience of disability and who can better communicate with residents.

‘It’s quite easy and natural for me [as a person with disability], but that made a lot of the workers really uncomfortable and yeah, it was like I was supposed to not be myself, you know what I mean? Like act like [other staff] and try to hide a part of myself, and that’s not why I came to disability.’

Conal

‘All I’ve wanted to do is be who I am and be a good husband and a good dad and, you know, part of my community and neighbourhood.’

Conal is in his 50s and has a traumatic brain injury from a car crash about 30 years ago.

Conal said he remembers the hospital discharging him a few months after the crash because it needed his bed.

‘The neurosurgeon sent me home with my parents and really with practically no, you know, sort of preparation for my parents and my friends ... it was practically they said, “Look just don’t let him wander off.”’

Conal said no-one told him then that he had ‘what they called high executive dysfunction’.

‘My dad ... the only way he could describe it was that his son died in the car accident and that the young man who returned to the home after the accident was not his son.’

Conal was eventually given an insurance payout, but no support to manage the money.

‘My mum says I gave all the money away, but I can’t imagine who you’d give that amount of money to. It was, you know, it was quite a lot of money ... I mean I can’t work it out. It still doesn’t make any sense to me.’

Conal struggled to return to work and keep his relationships. He ended up in prison because he couldn’t control his behaviour.

‘I never would have imagined I would go to prison ... They knew that I wasn’t mentally ill, but they didn’t know what to do with me because like I wasn’t behaving the way they wanted me to behave.’

Conal told the Royal Commission he received no support in prison for his acquired brain injury and on one occasion a psychiatrist gave him antipsychotic medication.

‘They gave me horrific panic attacks. I reckon it took me 18 months to two years to recover from that forced injection.’

The NDIS now supports Conal, but he said he still finds it ‘very hard to function’.

‘Like I do my best to be my best ... but I’ve been to prison at least four times now, you know. And that’s pretty horrible, man.’

Wal

Wal, in his mid-30s, is autistic and has bipolar disorder, attention deficit hyperactivity disorder (ADHD) and complex post-traumatic stress disorder. Growing up, he experienced years of abuse from his stepfather. Looking back he wishes he'd had better medical attention at the time.

'I remember again having massive mood swings during childhood as well as the ADHD medication disagreed with me ... Picking up on the autism and bipolar at an earlier age would have helped me during my schooling years as well as growing up. Maybe I wouldn't have been abused as much,' he said.

Wal receives a Disability Support Pension and funding from the NDIS. He lives in a government housing commission unit and is grateful for the stability this has provided. However, it is not on the ground floor, so he will have to move because of a degenerative spinal condition that means eventually he will need a wheelchair.

So far, Wal's spinal condition has been diagnosed by his podiatrist, physiotherapist and exercise physiologist, but not yet by a medical specialist. Without a specialist's diagnosis, Wal cannot access support from the NDIS for his physical needs.

Wal has also had difficulty accessing support from state health services, especially for issues related to his mental health. He has sought help to manage aspects of his bipolar disorder several times, including during times of crisis. Each time state health has told him that because he has autism, which is managed by his NDIS funding, he is not eligible for support.

Wal told the Royal Commission that this has been a pattern in his efforts to access support. The NDIA tells him that intervention in relation to his bipolar disorder has to be provided by the state. State health says he needs to access it through the NDIS. State health has also refused to provide Wal with other care, such as dental treatment that he urgently needs.

Wal has made a formal complaint to the state's health regulatory commission, hoping it will make state health meet its responsibilities.

Wal has also had difficulties with his NDIS plans, made worse in some instances by state health not providing documents the NDIA has requested.

'I've been told by clinicians ... I will never get the documentation that is required for the NDIA and that there is no accountability for anyone. You can make as many complaints as you want but nobody is going to hold them accountable,' he said.

'There's just no accountability in the disability sector unfortunately. I've seen this with disability organisations like support workers, organisations like when somebody is unwell, they'll just leave saying there's no such thing as duty of care, we don't care, it's not our responsibility. Doctors, hospitals are saying there's no such thing as duty of care – you're a grown arse male, go find your own supports. Which is not a safe thing to do when people are unstable or having crises.'

Wal said that causes real problems for people like him who have no support network.

‘I don’t have a carer or guardian, I don’t need one most of the time, but I have no emergency contact if my mental capacity gets affected. I’m expected to still make my own decisions, which can leave me in financial or other strife ... Most people with disability don’t have carers or guardians. They’re purely reliant on family members and some people like myself don’t even have family members to help them out.’

Wal wants to see more accountability in the sector, including the NDIA. Its decisions don’t only affect taxpayers, he said. ‘They’re also affecting people’s lives severely and they just don’t seem to care.’

Raelene

Raelene, mid-50s, has intellectual disability and complex trauma.

In her early teens, Raelene discovered the woman she thought was her mum was her foster mother.

‘That broke me completely,’ she told the Royal Commission. ‘It ended up that I had to leave school halfway through grade nine because I was getting into too much trouble, smoking and all that sort of stuff.’

Raelene’s foster mother offered to adopt her.

‘For the next six months we went through doctors, we went to psychs, we went for blood tests, we did everything. They said, “Are you sure you want her as your mum?” and I said, “I’ve had her for ... years, she is my mum.” We went through all the rigmarole and they said I had to wait until I was 16.’

When Raelene turned 16, she did all the tests again. But her mum still couldn’t adopt her because the department had lost all her files.

They told her she would have to wait until she was 18, but then she discovered she couldn’t legally consent to adoption until she was 21.

‘I really did lose it. I went smoking, I went to nightclubs, I was just really off the track.’

Around this time, Raelene met a man who loved her. But they couldn’t be together because his parents refused ‘to let a person that had disability and mental issues into their son’s life’.

Raelene became very distressed and ‘nothing seemed any good’.

One night she was raped – she felt it was her fault.

Raelene became pregnant and her mum helped her raise the child.

‘My daughter grew up with my mum as her rock.’

When Raelene’s mum died, it was very difficult for both of them.

Raelene started seeing a man who used her as a prostitute.

‘Because of my disability, he just thought he could do it to me and get away with it. When I was with him, I just thought it was normal, that it was a normal relationship. I lent him a lot of money and the only way he paid me back would be if I had sex with him, and so I accepted.’

Raelene's daughter, who also has intellectual disability, fell in love, got married and had her own baby.

As soon as the child was born, child protection removed him.

'He was going to go into foster care, but we went to court and fought to have him in our care.'

A few years ago, Raelene had to move into a care home because she needed more and more help with personal care.

'I wasn't very happy there for the first two to three years. I never called it home. It took a long time for me to get used to everybody and all the rules and regulations. It was very structured.'

Raelene missed living with her family and started self-harming.

Raelene began seeing a counsellor and moved to a brand-new group home with two women.

It is a lovely house but there are no day programs.

'You're in the house the whole time unless you organise something.'

Raelene finds it very difficult and has been experiencing disassociation and having blackouts.

'I have harmed the ladies that I live with and I can't remember it. It's made it really difficult for the ladies to even talk to me because they're frightened if they say the wrong thing I will attack them.'

Raelene wants to live on her own.

'It would be nice to have my own place and be able to do what I want, when I want and with who I want, once again.'

Tai and Caro

Tai, in his mid-teens, is autistic and has an intellectual disability. He is non-verbal and can be very aggressive.

Tai's mother Caro told the Royal Commission that when she and her partner separated, they ended up in the Family Court over custody. The court ultimately found in Caro's favour, but the process took several years and cost her hundreds of thousands of dollars.

It cost so much that after paying all her legal fees Caro had no money left for the works on her home that would make it suitable for Tai. As a result, despite the court order, Tai is currently back living with his dad.

Caro believes the Family Court system is deeply flawed. She said it failed to act in Tai's best interests.

'In the Family Court system itself, they don't feature anybody that has any interest or understanding of disability, and it relied heavily on very expensive reports being obtained. And there's no sort of – there's no sort of advocate there for the child ... I tried to get help for him for his benefit. It wasn't available. Like, no-one, like Legal Aid or anything like that, because my child can't speak so he can't say what he wants. So, it's a system that just doesn't care for children with disabilities.'

Caro is concerned it creates an environment that discourages compromise and prolongs disputes. 'It really put the parents at each other,' she said. She wishes the hearing could have taken place in a 'much less adversarial and normal setting where there's more of a discussion about who the child is and what their particular disability is'.

'Tai was always talked about like he was just this, you know, distant little boy over there. They never saw him. Trying to describe in a court setting to a barrister what it's like to look after my son when they could have seen him, they could have seen videos of him. You're not allowed to show anything like that in the court.'

As well, the judge requested additional reports, slowing the process down and creating extra expense.

'No-one tells you in the beginning how much it's all going to cost ... The stress was almost killing me.'

Caro had to organise specialist witnesses to be in court – Tai's doctor, paediatrician and others – and provide written submissions.

‘Which when you have barristers writing this stuff, they cost, you know, \$10-15,000 just for a submission ... I’ve heard so many stories of parents that just didn’t last because they haven’t got the money.’

At a second stage of hearings, a court-appointed independent children’s lawyer represented Tai’s interests.

‘Again, it’s a case of they might be a lawyer but they have no idea when it comes to looking after a child with disability.’

With no knowledge of disability, the lawyer didn’t understand Caro’s concerns about Tai and refused to communicate them.

‘He just dismissed it and said, “I’m not putting those up to the judge.”’

Caro would like to see an independent disability advocate involved, rather than a lawyer.

‘I think they would be better equipped.’

When Caro eventually won custody, and everything she’d asked for was ‘95 per cent given’ by the judge, she assumed that she would also be awarded at least partial costs. But she wasn’t awarded any.

‘I just wish that the whole thing didn’t happen in the first place,’ she said.

Marius and Jardine

Jardine, who is autistic, is a disability support worker.

Jardine told the Royal Commission that she has felt 'very isolated' working in the disability sector, and that she 'didn't have any support'.

She says the low pay and lack of support and training endangers workers and the people they support.

'Quite often the training isn't there, particularly for high needs, because you'd be aware that most providers now are unregistered and you know technically you don't need to have any qualification, even a first aid certificate, to be put in a high-needs situation.'

Jardine said a 'revolving door' of support workers abused and neglected one of her clients, Marius.

'They're recruited because you get your six hours of government grant for recruiting them, so they employ them for the absolute minimum amount of hours and keep that door revolving ... There's no quality because the client never gets the same person.'

She said one support worker dropped Marius and broke his legs. Another caused his bladder to burst by mishandling his catheter.

Doctors admitted Marius to hospital where, Jardine said, staff abused her for advocating for him.

'You feel like the whole system is coming down upon you and that was very much how I felt with [Marius] and his end days when he had his medications removed from him.'

Jardine said at one point a doctor at the hospital tried to pressure her to change Marius's advanced care directive.

'That's as possible as me changing your will. It's not my role ... and I found that extremely distressing.'

Jardine said Marius was also given a drug 'to shut him up because he was crying for water'.

She asked doctors to discharge him so his family could better care for him.

'I was going to make sure he passed away at home with his whole team around him ... It was lovely.'

Jardine told the Royal Commission there is 'systemic incompetence' in hospitals because they don't understand disability and won't communicate with the NDIS.

'We have a hospital system, not a health care system.'

Barnaby and Ellena

‘He could die in there, Commissioner. That’s what I’m frightened of. And because of his impulsivity and he makes poor judgements and things like this, I’m scared that one morning I’m going to get a phone call to say [Barnaby] is unresponsive.’

Ellena’s son Barnaby is a First Nations man in his 40s who has an acquired brain injury (ABI) after being assaulted more than a decade ago.

‘When he got assaulted he lost everything,’ Ellena told the Royal Commission. ‘He lost his bubbly life he had and his good work, his good pay. Lost all his good friends and no-one wanted to know him.’

Barnaby also developed seizures and lost the ability to control his behaviour.

‘He suffers with, oh what is this thing? ... Impulsivity, where they just hit out straight away because he hasn’t got that thing to slow him down when people provoke him.’

Ellena said that a couple of years ago Barnaby injured a man who attacked him. Police arrested and charged Barnaby. Barnaby’s lawyer didn’t tell the court about his ABI and a magistrate remanded him in custody until a trial.

‘Poor Barnaby had no say. We didn’t have no say. So that’s what happened, he went into [prison] and he got treated so badly, you know.’

Ellena said the prison staff told him he was ‘playing doggo’.

‘They said, “You haven’t got an injury. You’re just a criminal.”’

At one point Barnaby’s cell had no water supply.

‘He couldn’t flush the toilet where he was and maggots were coming out of there. He asked the wardens to please get him a drink of water and give him his tablets. They wouldn’t give him his tablets for his seizures.’

Ellena said Barnaby spends much of his time in solitary confinement. On one occasion he was confined alone for ‘three or four weeks’.

Before being remanded, doctors were treating Barnaby for an infection. He was also in remission from cancer and the NDIS supported him for his ABI. Most of his supports stopped when he went to prison.

‘I’m concerned for [Barnaby] because he needs to get out of there and get his treatment and start using the services that are going to help him.’

Sidonie and Martie

Sidonie has an intellectual disability and the functional age of a 12-year-old. She also has complex post-traumatic stress disorder, attention deficit hyperactivity disorder and a number of issues related to anxiety.

Sidonie has lived with her foster parents, Martie and her husband, since she was a young child.

‘We love her very, very much. And she is, for all intents and purposes, our daughter, although we share that privilege with her birth family,’ Martie said.

About a year ago, Sidonie was a cheerful high school student, involved in a wide range of activities, with good friends. She attended a school with a hands-on learning support team, and with their help was achieving well academically. She had a part-time job and plans for her future.

‘[She was] loving, she was content and she was absolutely thriving on life,’ said Martie.

During lockdown, Sidonie took on a new job not far from her home. At first she worked there for just a few shifts a week, but quite soon she started spending more time there. Within a month or so, her hours increased to between 40-60 hours a week.

‘And then she started to completely disengage from us ... This was a kid who shared every moment of her day with me, you know. If she wasn’t with me, she’d send me messages. We were really close, and now she was just suddenly disengaging,’ Martie said.

Soon afterwards, Sidonie stopped going to school and moved in with the proprietor of the business, Lucy. When Martie tried to reason with Sidonie, she and Lucy reported her to the community services department for abuse.

The concocted allegations were quickly dismissed. But Lucy’s influence over Sidonie continued to grow and she soon took steps to extend her control.

‘Within the first week of [Sidonie] living with her, this woman rang the school and tried to change her next of kin emergency contact details. She told them that she was [Sidonie]’s new mum. The school, thankfully, rang me straightaway. She told [Sidonie] that she didn’t need to go to school, that it was a waste of time, that education wasn’t important.’

School staff tried to contact Sidonie, calling her and visiting the Lucy’s business.

‘[Lucy] just wouldn’t let them through to [Sidonie]. She would not let them have access to her,’ Martie said.

Lucy also convinced Sidonie to stop taking her medications and cancelled her medical appointments.

Despite Martie and her husband's formal role as Sidonie's foster parents and the government's legal responsibility for her until she turns 18, they could not get the community services department to intervene.

'They said that there was nothing they could do because she was 16 at that point. She could decide where she wanted to live.'

The situation deteriorated. Lucy applied to become Sidonie's foster parent instead of Martie and her husband, but Martie argued fiercely against this. In the end the department didn't approve the change, but Sidonie continued to live with Lucy and work unpaid in her business. Still, the department did not act.

'They just kept saying that there's nothing they can do, she's ... able to make her own decisions. And then they started throwing in things like, "We cannot protect her from making her own mistakes."'

Martie is angry about the department's lack of knowledge about disability.

'There was no recognition or support or understanding for her psychiatric issues and how they actually came together,' she said.

'I mean, I understand and support the fact that [Sidonie] has rights ... Of course she's got rights. But she's also entitled to extra protection. And people [in the department] keep hiding behind the fact that because she's 16 and 17, she's capable of making these so-called decisions, and she's not ... So they've left her in an absolutely abusive and exploitive environment.'

Dea

‘COVID made us deafblind people so depressed. It wasn’t fair. [Other communities] can go buy things, they can go places, they can go see people if they need to. And we deafblind people were just left in our houses.’

Dea is in her 60s and deafblind.

‘I didn’t learn to sign at school, [not] until after I left high school,’ Dea told the Royal Commission with the help of an interpreter. ‘[I’m] the only person in my family who’s deafblind.’

When the COVID-19 pandemic began, Dea was in another city and didn’t understand what was happening.

‘Things were being cancelled left right and centre which was really unfortunate. And I really didn’t know or understand what was going on during that time.’

Dea can’t see or hear the television without help, for example.

‘I can’t read the online, but I just saw that there was things happening, but I didn’t actually understand what was happening because I couldn’t read it properly.’

She said before COVID she ‘used to be able to go everywhere’.

‘It was wonderful. I had plenty of support workers, I had places to go, I had things to do and, wow, what an impact.’

When she got home at the start of the pandemic, her service provider told her it had cancelled many of her services.

‘And that made me quite depressed. It made me a little bit on the back foot not knowing what was going on. For example, people wouldn’t come and take me out.’

Dea said she feels forgotten because she’s deafblind.

‘I felt like I’d lost my family, I lost my friends, I felt like I lost everything ... I tried to be positive, I’m trying to be strong, I’m trying to think positive and I’m trying to not be depressed, but I was stuck at home.’

‘I feel there’s so many barriers now.’

Dea still struggles to get an interpreter. For example, she booked an interpreter two months before an important medical appointment, only to have the appointment cancelled at the last minute. When she booked another appointment, the interpreter cancelled the day before.

'There's nobody available because of being such short notice because the appointments keep getting changed.'

Dea said the same thing happened with a dental appointment.

'It's happening all the time, on and off, on and off, on and off. And sometimes I'm lucky and sometimes I'm not lucky.'

The lack of interpreters and reliable support workers means Dea is often stuck at home and endlessly rearranging appointments.

'I need to go shopping, I need to do things, I need to go and they have limited hours, that's not enough hours. So I try to move to different agencies, different support workers ... sometimes there's nobody available.'

Dea said when a worker does turn up, she's made to feel grateful.

'You're forced to work with somebody that you don't feel comfortable working with and ... I'm forced to say yes, yes, yes I'm happy thank you very much for helping ... because if I say no, that I'm not happy, then I know that my supports will be withdrawn.'

Dea said she's often given inexperienced and rude support workers who leave her alone in shops and then call her 'bossy' and 'demanding'.

'But really I'm blind, I can't see where they've gone to, they need to tell me where they're going. I booked you, you should be with me and then it's not fair if you wander off.'

Christabel

‘It seems like students with disabilities and access needs are constantly an afterthought, and not valued or wanted in higher education.’

Christabel, early-20s, is autistic and has attention deficit hyperactivity disorder and fibromyalgia.

In the weeks prior to starting university, Christabel met the disability adviser.

She shared information about her sensory and auditory processing issues, and requested accurate captioning and content warnings on all recorded lectures.

The disability adviser assured her the university would provide all the adjustments she needed.

However, by the end of week three there were no captions or content warnings.

Soon after, classes moved online because of COVID-19, making the need for captions more urgent.

Christabel told the Royal Commission she followed-up repeatedly.

‘To understand all of the content without captioning, I would have to re-watch lectures three or more times. This put me at a large disadvantage to my peers who did not need captions.’

Two weeks before the end of semester, she finally received lectures with captions.

Christabel enrolled in a winter course.

The university reassured her captioning would be available.

Two weeks later, they informed her they wouldn’t be providing captions and suggested she drop out.

Christabel threatened to make a complaint to the Australian Human Rights Commission, but the university suggested she make an internal complaint.

A staff member, who seemed empathetic, promised to follow-up on the issues she raised. But for a year, nothing happened.

‘I was forced to request a formal response. This formal response still did not answer a lot of my questions and honestly sounded to me more like the university was sick of dealing with me.’

After two years, the university provided captions for about 90 per cent of recorded lectures.

Still, Christabel said, additional content such as seminars about specific assessments and YouTube videos that are linked in lectures are not captioned.

‘I have had to expend enormous amounts of energy writing emails, continuously following-up, making complaints just to try and get my most basic adjustments met,’ she said.

‘This entire process has been so distressing, disheartening and dehumanising to me. There have been multiple points when I have considered dropping out.’

Christabel continues to be ‘extremely nervous’ about the adjustments she will need to complete her placement.

‘The university has let me down again and again, and I feel like I cannot trust them to provide the adjustments I need.’

Christabel also experiences ableism in the course materials.

One of the mandatory texts uses the phrase ‘deaf and dumb’ to describe a character, as well as positioning her as broken because of her disability.

‘This was never discussed critically in class and that book was required to be read by almost every student in my year, nationwide.’

Another class used the term ‘differently-abled’ to refer to disabled people despite ‘many disabled people saying that this is an inappropriate term’. Again, Christabel said, this was ‘never critically examined’.

‘I hope that I can finish my degree with the supports and adjustments I need, and maybe contribute to research that will make the lives of disabled people better.’

Mariana

‘There’s a link between the way disability services are regulated in Australia and how the current methods are allowing violence, abuse and neglect to remain in plain sight, unreported and undetected.’

Mariana has worked for disability service organisations ‘as a consultant and a practitioner’ for two decades. For the past 10 years she’s focused on quality control in the disability sector, she told the Royal Commission.

‘The current system doesn’t monitor service quality adequately. Much of my findings were that people performing regulation in Australia would focus predominantly on paperwork. Very little time goes towards observing the lived experience of people with disabilities ... So, you know, people with disabilities at the moment really have very little scope to sort of say, “I’m not okay.” ... There are so many layers of restriction imposed on people with disability.’

Through her research, Mariana spoke to hundreds of staff and leaders in disability organisations to try to understand the shortfalls.

The regulatory body is ‘not allowed to consult’ with disability service workers.

‘Staff attitudes and knowledge and perceptions, you know, they’re one of our biggest indicators of whether or not good or poor service provision has been applied. So it’s a very odd system. People don’t feel safe to raise things necessarily with auditors because it’s very much a compliance or noncompliance culture.’

Mariana has encountered a lot of staff with ‘minimal training’. They have no understanding of ‘communicating trauma or issues through nonverbal communication’, she said.

‘That means that people are not reporting violence, abuse and neglect, they’re unable to recognise it at all levels from the board down. It’s re-labelled as incidents ... challenging behaviour, or property damage or whatever. We need observation methods from specialists who really understand disability.’

Mariana wants to see regulatory reform to make the system ‘more responsive’. Currently, she said, there’s ‘a lot of waste’ and money spent on process that ‘doesn’t improve anything’.

‘Essentially there’s a lot of regulatory ritualism going on. There’s a lot of tick-box compliance ... We don’t learn from it, from a wider sector benchmarking perspective. If we can just try to, in Australia, see regulation as not just a benign big stick but a way to educate and inform whilst critiquing practice for knowledgeable individuals, I think that we could actually do really great things.’

Zaylee

Zaylee, a First Nations woman, is hearing impaired.

Following school, Zaylee started a healthcare degree.

**‘I’ve always wanted to be in health,’ she told the Royal Commission.
‘I thought ... I can be there to help my family when they need it.’**

Her lecturers warned Zaylee it would be ‘a daunting task’ but they were ready to support her. They gave her a digital electronic stethoscope to use.

Zaylee passed her first year, including a placement.

At the start of second year, Zaylee transferred to another university. She asked the new university for support and they directed her to disability services.

They provided a notetaker, but Zaylee and the notetaker ‘didn’t click very well’.

She ended up doing most of her studies online using assistive technology and struggled to pass the practical subject.

Zaylee quit her part-time job and worked in an aged care facility to gain experience. She eventually completed the practical subject and the university offered her a hospital placement.

Zaylee was anxious and asked her lecturer for more support during the placement. They told her someone would be supervising her and she would be fine.

Zaylee asked if she could have written handovers about each patient instead of verbal handovers, but her lecturer told her she wasn’t sure.

‘My first week was chaotic. I was very nervous. I forgot things ... I had anxiety. It was my first placement in such a long time.’

Zaylee could hear buzzers going off but struggled to understand what people were saying to her.

‘I never put a patient at risk. I made sure that they were safe. I made sure that I did what I was trained to do, even if it took me a while.’

After a few days Zaylee’s lecturer contacted her telling her she was ‘officially off placement’ because her ‘hearing impairment was too severe’. She told Zaylee to think about other options.

'I never expected her to tell me that the program was not suitable for me ... You don't just tell someone who's been spending the last [few] years studying ... that they can't continue their degree because they're too deaf.'

Zaylee was very upset.

'I think the hardest thing for me was to tell my family,' she said. 'I had a dream. I was dedicated to finishing my degree.'

Zaylee met staff members from the university and hospital. The hospital was willing to work through the issues, but the university wasn't.

Zaylee asked to do her placement with an Auslan interpreter. The university refused because the interpreter would need a first aid certificate and 'it was too difficult'.

They also refused to allow her to do her placement in a quieter ward.

'Maybe I'll never be able to work in an emergency ward because there's so many things going on, but I could've done my placement in a quieter ward ... in a constant care ward or a palliative care ward.'

Zaylee became severely depressed.

'I lost the one thing I was working on.'

She lost her confidence and felt she had let everyone down. Zaylee had to move back home.

After some time, Zaylee completed a certificate 4 and is now working in a First Nations health clinic.

'Every day is still a bit of a struggle because of what happened to me ... what [the university] did and how it went about it,' she said.

'Now I have to double-check my work ... I have to write down every little thing, even if it's something small ... And all because I got told that my hearing impairment was too severe.'

Harvey

Harvey, in his 60s, is from a culturally and linguistically diverse background and has schizophrenia. He's been on a Disability Support Pension since the mid-1990s.

In the early 2000s, Harvey spent a few years in prison on drug offences. He tried unsuccessfully to appeal the conviction. He told the Royal Commission the court proceedings were unfair.

'They called me a liar and they forgot to assess properly. My lawyer ... he bug up all the system and represent me to convict me.'

Harvey said prisoners bashed him up as soon as he arrived at the prison.

'They tried to kill me. And I asked protection and they send me to the most secure, secure, secure ... highest security unit.'

Harvey was in a lot of pain, but said he wasn't given any medical care.

'With the disability, or for my accidents which I had in my past ... I have aches, head, body, everywhere ... I wasn't respected, and not even painkillers they give me. What they did, they torture me. They doesn't want to give me my, um, painkiller. They doesn't want me to talk. They put me in a cell with, ah, [someone] next door yelling me, "I kill you now" ... They torture me with that sound.'

Harvey eventually got painkillers when his doctor visited the prison and spoke with officers. But he still didn't receive treatment or supports for his mental health.

'How we talk mental health when they daily basics was torture?' he asks.

Harvey said he had to focus on 'how to survive', as inmates and officials abused him 'hundreds of times'.

'The guards they want to kill you. And they bash you up. They torture you.'

Once 'a big, big, big guy' caught him.

'Put me in the storeroom, where is the broom and rubbish bag. Put you there and put a plastic bag on your neck, pick you up, and then they said you can take that off or leave it there. And then he said, "You hang up yourself."

Harvey said other prisoners died from this kind of treatment.

'Two guys jump in your room, they close the door, um, the video security is off, ah, in five minutes you are off and then they run and, ah, go and play soccer, and they kill you ... and they said it's, um, death in custody.'

Harvey said that one time security officers raped and bashed him.

‘They put something that put me to sleep and they have sexual [relations] with me. I wake up in the morning with such a big pain on the leg for how much they push me in the wall.’

Harvey’s advocate told the Royal Commission prison is not the right place for someone with schizophrenia.

‘His mental health has been really bad since. He’s had psychosis, anxiety, panic attacks, really serious pain and a lot of depression as a result of what happened to him.’

Lang and Barb

‘Our sense is that it’s due to his disability that he’s been denied services.’

Barb’s uncle, Lang, is in his 50s and has bipolar disorder and schizoaffective disorder.

‘He likes going to the movies, he likes going bowling. He comes over for lunch and things like that,’ Barb told the Royal Commission. ‘[Lang’s] someone that’s had bipolar all of his life. He’s always taken medication as prescribed.’

Lang’s been taking lithium to control bipolar disorder for so long it’s damaging his kidneys. Barb said if Lang doesn’t take lithium, he becomes manic and catatonic.

‘Lithium is the only lifeline for [Lang] that works to bring him back from his condition ... He’s always said he wants his mind more than his body and so we’ve always advocated for his lithium.’

A few years ago doctors admitted Lang to a hospital medical ward to treat an infection.

‘He was removed from his psychotropic medication, which generally happens every time he goes into hospital ... because once they get him there they say, “Oh his kidneys are really bad.”’

Within a couple of weeks Lang was ‘basically lying in bed, not moving, only eye contact, no verbalising’.

‘The feedback we were getting was, “No he’s got a physical health condition. We don’t believe there’s a mental health component to this.” And we were like, “... he clearly does have a mental health condition. He’s had bipolar since he’s 19.”’

Barb said Lang remained catatonic in the hospital medical ward and lost a lot of weight.

‘He spent a good nine months lying in bed, with us trying to argue to get him treatment. He became completely deconditioned. So he walked into the hospital semi-independent and since then he’s never been able to walk again.’

While his condition deteriorated, hospital staff urged Barb to consider palliative care.

‘[Lang] does require a lot of resources when he’s unwell. He generally needs in-hospital one-to-one special care,’ Barb told the Royal Commission.

‘We have even been told by [one hospital] that he’s costing the system too much [and] palliative care would be the best option.’

Barb said Lang ‘always wanted active treatment’. Eventually, doctors agreed to trial lithium if the family accepted ‘the risk to his kidneys’.

‘Within two weeks, Commissioner, he started talking.’

When the hospital discharged Lang, Barb asked if he could access the rehabilitation unit to help him walk again.

‘And they said no, he doesn’t have rehab potential.’

Barb said hospitals often discharge Lang without adequate treatment.

‘What we’re having now is everyone shutting the doors on him and he’s not receiving the health care that he deserves.’

Barb said when she complains to the hospital about his treatment ‘it doesn’t seem to do any good’.

‘To be honest we’ve always been afraid to ... We’ve had times that we’ve lodged a complaint because we’ve not been heard and he’s been immediately discharged that day or the day after from hospital.’

Lang hasn’t walked since leaving hospital and uses a wheelchair.

‘We felt, due to the stigma that he’s received because of his disability, that ... has made it very difficult for him to access the right treatment ... and now his physical health has been affected.’

Rina and Janie

‘If there was any place that should accept [Rina] it was an educational setting ... And it made us feel like, if they don’t accept her, how is the rest of society going to accept her?’

Janie is the mother of Rina, who’s autistic and just started primary school.

‘I was born overseas and my parents are both non-English speaking. Public education gave me the pathway to success,’ Janie told the Royal Commission. ‘So it’s been really disheartening to see that those same accommodations were not made for [Rina] who has a disability.’

Rina is non-verbal and also has a moderate intellectual disability and attention deficit hyperactivity disorder. When she started childcare, the centre manager didn’t want her there and separated her from her peers.

‘She would discuss [Rina’s] disability in the foyer,’ Janie said. ‘[One time] she proceeded to yell across the room that [Rina] was developmentally delayed and that she should not go forward ... She just saw [Rina] as a problem as opposed to wanting to work with our family.’

When Janie tried to enrol Rina in a mainstream primary school, the vice principal refused to meet her. Once Rina was enrolled, the vice principal sent her paperwork to another school.

‘I just didn’t understand why she did that without even talking to us ... We had really tried so hard to provide everything that we needed to do to get [Rina] into our local school, which she has every legal right to go to. And we just kept getting, you know, pushback and gatekeeping.’

Janie said the vice principal eventually ‘won’ and she withdrew Rina from the school.

Janie enrolled Rina in a local private school and is now ‘on edge’ wondering if it, too, will reject her.

‘One particular teacher ... made a comment that [Rina] is a difficult child and that she was not willing to lower her expectations to accommodate [Rina’s] needs, which was really hard to hear.’

Janie is reluctant to complain.

‘It’s such a fine line where you don’t want to upset the school because you feel like, are they going to ask you to leave, you know?’

Janie said experts advise her to keep Rina in a mainstream school, but ‘it’s just really so difficult’.

‘They all say, “This is the way we should be going, this should be the future.” But it’s not reality, you know? It’s not our reality. It never was from the start,’ Janie told the Royal Commission.

Janie said although she and her husband pay full fees for the private school, Rina's only allowed to attend part time, which makes it difficult to keep working to pay the fees.

'We want children with disabilities to be in schools because, for me, I see so much value in it. [Rina] gets to be a part of her community ... and those children in the class with [Rina], they're learning so much from her just as much as she is learning from them. But there needs to be better facilitation of this so it's not so difficult and traumatising for the family.'

Tonya

Tonya is in her 40s. She is autistic and has epilepsy. She has many children, who are also autistic and have a number of other disabilities.

Tonya's family lives in a rural area. A few years ago, bushfires threatened their home.

'We've been watching the bushfires like everyone else for about a month because they had been up in the mountains there, watching them come down ... We've got lots of special needs children ... so it wasn't rocket science to us that we'd leave.'

One day the state government sent a message telling them to evacuate.

'We've practiced for a few weeks fire evacuation drills with our children. Being an autistic family it's really important that we practice everything ... So we came home and told the kids we're on a 10-minute leave.'

Tonya said one of her teenage children had an 'extreme meltdown' and started punching himself.

'He said that he punched himself because his brain couldn't actually think anymore. It was pretty horrific ... At 4 o'clock in the afternoon it was pitch black. It was like it was a night with no moon. There was just ash and I had an asthma attack in the car.'

Tonya said the relief centre in a nearby town was expecting them when they arrived.

'They knew that we had an autistic family. When we arrived the lady said, "You're not in the red zone. You don't need to be here. You shouldn't have evacuated." And I said, "But the government sent me a message to evacuate and we were told to get out."

The family was eventually allowed to stay in a busy, public part of the centre and didn't feel welcome.

'By then [the son who punched himself] was quiet. All the kids were pretty good. In fact we had not one meltdown the whole time we were at the relief centre and we didn't have any undesirable behaviour. We just felt a lot of judgement from particularly the management.'

Tonya said she overheard the manager refer to her as 'the mother with kids who have autism'.

'The feeling that we had at the time was that we felt like we were a nuisance. ... So we made a decision [that] we would use our savings, put ourselves in a motel.'

After a few days when their money ran out, they tried to stay in a bed-and-breakfast that was being opened to evacuees, but were told they weren't 'real fire evacuees' because their house hadn't yet burnt down. Tonya said she was coughing constantly from the smoke.

The family returned to the relief centre where the manager told them to leave.

'Sometimes people think, "Oh they're autistic, they'll be a problem." But ... our kids just become withdrawn and quiet. They were really well behaved. I actually can't express how impressed I was with the children's behaviour.'

Tonya said some of the children are still traumatised. One son has 'panic attacks' when he sees smoke and another 'never has been the same boy since'.

'He was very soft, gentle boy and now he's out of control.'

She said they didn't lose their home, but the family's treatment at the relief centre made a traumatic situation worse.

'We're used to [being judged] ... but when you get it from professional services, the level that we got, it's very damaging. I'll think twice before I go to a relief centre.'

George

George is a First Nations man in his 40s who lives with bipolar disorder and attention deficit disorder.

‘I was always ADD, so I had troubles at school,’ he told the Royal Commission. ‘I developed another personality when I was younger to stick up for myself, because the other person didn’t. I started to flick in and out of these two personalities. And it got harder and harder trying to work the stuff out ... coz of my childhood and the trauma and everything I carry.’

George has lived in public housing for about a decade. Over that time, his mental health has deteriorated because of neglect, bullying and harassment by a community housing provider.

The ‘trouble started’ when he moved into his first home. He had separated from his wife and had a young daughter living with him on and off.

‘And my housing provider made it as difficult as possible for me to ... be a father.’

The house had exposed electrical wires and was generally run-down.

‘I talked to the provider about this. They didn’t care.’

After three weeks, George still had no power.

‘I’d been paying a week’s electricity and still hadn’t had an inspection.’

Things ‘never got fixed’ and he was constantly ‘flooded in’ because of problems with the drains.

‘I couldn’t get out of my house. I had all these sandbags to stop the water coming in, but it was running through the lightbulbs and everything.’

The provider did nothing, even after maintenance reports.

‘I expected things to happen. They never did ... Not a thing repaired ... Then the hot water system started to leak.’

The operations manager bullied and threatened George when he raised issues.

‘She had it in for me. And she said, quote, “I’m going to get rid of him. He’s out.”’

George said his neighbours were bikers and ‘druggos’.

‘There was people that used to walk around the complex with Rambo knives.’

He said the agency completely failed in its duty of care.

'I just can't believe that an organisation like this can be funded by government ... They can bully their arses off and think they can get away with it. They play God. They pick on the unfortunate ... If people hold them accountable or whistle-blow on them, they throw them to the cleaners. They make their life as difficult as possible. And that's what they did.'

George had to live with the constant threat of eviction and ended up 'broken'.

'I've got post-traumatic stress now and everything. Like, I'm not functioning. I'm quarter of the person I used to be ... and it's all their fault.'

George has 'spent the last two years sleeping on a mattress on the floor' after more problems with his tenancy.

'The things that get to me is the unjust things. When people who are supposed to be helping me out, make my life 10 times worse. These people need to be held accountable.'

Randall and Chanelle

Chanelle's teenage son, Randall, has vision impairment and epilepsy.

'He requires support to converse with people and to sort of carry the convo along ... you know a happy boy,' Chanelle told the Royal Commission. 'Part of our household, his jobs are putting the wheelie bins out, emptying the dishwasher, making us coffee.'

Chanelle enrolled Randall in the local mainstream primary school.

'He was suspended maybe three times from memory in primary school, but that soon stopped when I said that that's kind of not on ... We had a few different principals come and go, but the head of special ed was a constant and she pretty much gets what inclusion is and what it should be.'

Chanelle said she didn't want 'something special' for Randall.

'We want the same for our child as every other child and for them to be supported to do that. So if the class is doing maths, our child is doing maths in whatever way [looks] the same as everyone else, but it's adjusted to them.'

When Randall started high school, Chanelle wanted him to continue his inclusive education and enrolled him in the local mainstream school.

Chanelle said the school's idea of inclusion was a special education block where he spent much of his time.

'That was my first indicator that we're not on the same page ... [the principal] said, "Well you think inclusion is one thing, I think it's one thing, and the department thinks it's another thing."'

Chanelle said Randall went to the classroom for only the last 10 minutes of each lesson. Teachers were instructed to separate him from his peers on school trips as part of a written 'risk assessment'.

He's also forced to use a ramp, which he doesn't need, and kept away from objects that he might throw at others – 'which he has never done'.

Chanelle said she had 'meeting after meeting' with the school asking for information about his day so she could help the teachers manage his behaviour.

When she eventually pulled him out of school she asked for his report card. It was more than 400 pages long.

'It's a rap sheet ... words like "misconduct involving object", "other conduct prejudicial to the good order and management of school", "physical misconduct", "defiant threats to adults", "disruptive" ... That's just some of them. They're the most common ones. And "motivation" is "don't know" and "parent contact" is "No."'

She said some of Randall's behaviour suggested to her that he simply needed to go to the toilet.

One day Chanelle picked Randall up from school. She found him 'sobbing uncontrollably and no-one could say why'.

'We sort of thought really long and hard about, "Can we manage this?" as a family ... So in the end [we decided] just no. Ran out of energy.'

Chanelle decided to homeschool Randall.

'I've found that if you try and do anything that looks like school, it's a shut down. He gets visibly upset ... Everyone's sort of calmed down [now] and, yeah, it's just a really nice way of life for us. We're lucky that we can do it.'

Xandro and Agnetha

There was ‘something different’ about Xandro at six weeks old, his mum Agnetha told the Royal Commission. ‘He was a baby that never wanted to be still.’

‘But because he had this incredible intelligence and he was hitting his baby milestones, [he] never got diagnosed with anything.’

Agnetha struggled to help Xandro.

In kindergarten, Xandro would become heightened and run away. Agnetha begged staff to fix the holes in the fence, but instead they sent him home.

Soon, they were regularly suspending him.

‘I was given no support as a parent and a carer of a child with an undiagnosed disability. And rather than the kindergarten reaching out and saying, “You’re struggling. What can we actually do to help?” they just reported us.’

Child services became involved.

‘They were the only ones that could see that the family was actually struggling, but not for the reasons that they were investigating.’

Child services dismissed the kindergarten’s allegations and referred Xandro for assessment.

He was diagnosed with attention deficit hyperactivity disorder (ADHD) and anxiety.

Agnetha applied to the NDIS but was knocked back because ADHD isn’t an approved disability.

At school, Xandro was overwhelmed and anxious and behaved accordingly. The school responded by sending him home.

If he wet his pants they would call Agnetha to change him.

‘I was called into school probably every second day to pick my child up by recess. He was not getting educated ... [It] made it impossible for me to ever work.’

In year 2, Xandro was formally assessed as autistic.

The school didn’t make adjustments and continued to punish him for his behaviours.

When they tried to expel him, Agnetha sent them a copy of the Disability Discrimination Act.

Soon after, the principal pressured Agnetha and Xandro’s doctors to change his medication.

Xandro began experiencing adverse side effects.

‘I had a seven-year-old who was so scared of the vivid dreams that this medication gave him that he wanted to kill himself to make the dreams stop.’

Agnetha stopped the medication and booked the next available appointment with the doctor.

When the school discovered Xandro was no longer taking the medication, they accused Agnetha of giving him a ‘medication holiday’ and reported her to child services.

The investigation was closed almost immediately, but caused significant stress for the family.

Agnetha believes the school reported her to child services because they had been unable to expel Xandro.

Shortly after, the first COVID-19 lockdown began.

The school refused to support Xandro with online learning because they had to ‘focus on educating the majority, not the minority’.

Despite this, when he didn’t submit assessments, the school again threatened to report Agnetha to child services.

‘I now know unequivocally they were reporting me to [child services] on a weekly basis.’

Agnetha discovered the school was also widely sharing personal information about her and her family.

She felt she had no choice but to remove Xandro from the school.

He briefly attended the local state school but they would only allow him to attend for about two hours a day. After a few weeks the principal suggested Xandro move to a special school.

The special school assessed him as gifted and didn’t believe they could educate him. He would have been the only child in his year without an intellectual disability.

Agnetha decided to enrol Xandro in distance education and he completes the curriculum from home.

She said a high proportion of students enrolled in distance education are autistic.

Xandro has recently done his year 5 NAPLAN, and his results have all been in the top band for his year.

‘I’m incredibly proud of how far he’s come.’

But distance education is not a long-term solution.

‘It makes things difficult financially,’ Agnetha said. ‘I still can’t work.’

Rena

Rena is a First Nations woman in her 40s who has physical disability. She uses a wheelchair and has difficulty expressing herself.

A couple of years ago Rena moved from an aged care and disability facility, where she had 24/7 care, to a group home. She told the Royal Commission she is unhappy there as staff at the home 'control everything'. They have taken away her freedom to do activities she likes.

'I want to do my own stuff. Those people stop me. More shoppings. I like doing shopping.'

The public trustee manages Rena's finances and allocates weekly funds for 'petty expenses'. But staff at the home 'hold onto it' and refuse her money to buy gifts for her sons. 'They always tell you "no money",' she said.

Her counsellor told the Royal Commission that this is denying Rena a big part of her Indigenous culture.

'You know, [her sons] are still young ... and when [Rena] can't support them, that's big feelings of shame for her ... And [the staff] have taken quite a lot of control over her life with that. But they make lots of different excuses as to why [Rena] shouldn't have her own money.'

When the counsellor visits the home, the manager complains about Rena 'over and over'.

'Obviously [Rena] got upset. She knocked on the door. She said, "She's my counsellor. She's coming here for me."'

The counsellor removed a 'dos and don'ts list' staff put in Rena's room. It included 'certain words she shouldn't use'.

'Because according to them it's not white enough,' the counsellor explained. 'And I said, "She's got freedom. It's her room at least."'

Once, she said, staff uninstalled social media apps on Rena's phone, preventing her from 'connecting with her friends and family'.

Rena has no choice over the foods she eats either.

'Instead of building her up, they've taken complete control, to the point where she is stuck. She doesn't have much choice and control over anything in her life when they're around.'

If Rena complains about anything, staff say, 'It's not your house.'

One of Rena's support workers is verbally abusive and racist, which makes Rena feel unsafe.

'She had told me I'm a black bitch and she said, "You think you're an Aboriginal" and I said, "Of course I am Aboriginal."'

Rena said workers abuse another resident as well.

'They always fight and they always shout at him ... And he can't even talk.'

When Rena wants to go on Country, staff discourage her or insist on going with her.

'It's almost like they think they're a parent or something, and they're taking control over her,' Rena's counsellor said. 'And it's so wrong.'

The counsellor believes the service provider is misusing Rena's NDIS funds. The provider applied to manage her plan and, since then, 'money has been disappearing'.

'We have no idea where it's going ... because [Rena] doesn't use a lot of money.'

Sometimes support workers ask Rena for money for their lunch and never pay it back.

The counsellor fears the neglect of Rena's health and dietary needs is impeding her chances of ever walking again.

Sigrid and Benicio

Sigrid is in her 40s and has an acquired brain injury. She is 'partially paralysed', mostly non-verbal and has 'high, complex disability needs', her brother Benicio told the Royal Commission.

'She hasn't lost her intelligence, fortunately, although she does have very short-term memory of three to five minutes still. When she gets good care, that improves. We went to a lot of rehab. Placed her into aged care near where family was ... That was the only option at the time. And then the nightmare begins.'

Sigrid experienced '15 years of severe, deliberate, orchestrated, physical, emotional and psychological abuse' at the home, Benicio said. The director of nursing was a 'sociopath' who told staff to 'starve' Sigrid, 'treat her like an animal', 'leave her in her own faeces' and 'chemically restrain her'. She also sought to 'isolate her from friends and family' and to 'foster bad behaviours' by excluding her from day programs.

'How she's still intact, I have no idea, other than her short-term memory probably saved her.'

The family 'pursued the complaints process to its fullest extent possible' for several years, but got nowhere.

Meanwhile, Benicio said, Sigrid's recovery regressed because of the 'torture and abuse'. She is no longer walking, her memory and speech deteriorated, she started engaging in aggressive behaviours and now has post-traumatic stress disorder.

Benicio spent a few years battling to get Sigrid enough supports.

'Acquired brain injury is still very poorly supported or recognised in Australia, including the medical system. We've advocated, gone to the AAT. We now have the full funding we need.'

Since Sigrid joined the NDIS, Benicio says 'systemic large provider fraud' and poorly trained staff have been the biggest problems.

'We've been through five different providers and the quality is probably similar ... NDIS is working brilliantly ... It's the providers and the other people abusing the system.'

For a couple of years recently, Sigrid was in a supported independent living facility.

'They weren't doing any behaviour management, even though they were being paid by the state government.'

Benicio said staff were 'inappropriately' restraining Sigrid instead of implementing the behaviour support plan funded by the NDIS.

'Completely contrary to our intention to rehabilitate her ... they basically wanted to keep her fully restrained 24/7. We were being obstructed, deliberately prevented from progressing her.'

When Benicio complained, the service provider 'evicted her from the premises during the COVID-19 pandemic'. It then moved her back into an aged care home without his consent.

He complained to the NDIS Quality and Safeguards Commission, which refused to intervene. Benicio suspects the commission is either 'in cahoots' with big providers, or the providers feel 'no need to comply' because they know the commission is powerless.

The provider tried twice to remove him and his mother as guardians.

'It was absolutely malicious behaviour. They presented that we weren't her guardians ... Secondly, that we were unfit and the cause of [Sigrid's] problems.'

Today Sigrid is in assisted disability accommodation run by a new provider. She's finally on the right path with support. The family hopes to use technology to assist her communication.

'We've got a very clear idea of how to rehabilitate her. We also expect her to be capable to walk. Although time has passed, we still want to give her that best chance. We think she's capable of, you know, what I call a semi-independent quality of life.'

Sofja and Tully

‘There must be accountability. Criminal charges and disciplinary action against providers who abuse, neglect and exploit a participant. My sister’s one of thousands.’

Tully is the younger sister, legal guardian and financial administrator of Sofja, who is in her 50s and has Down syndrome, schizophrenia and early onset dementia.

‘She’s encountered a lot of trauma due to disturbing events in her life,’ Tully told the Royal Commission. ‘It’s been sexual, physical, mental and financial abuse.’

Child protection services placed Sofja in an institution when she was about 10. When the family visited, staff would tell them Sofja ‘wasn’t available or was on an outing’.

‘This caused my mother much despair and heartache. There was never any communication. The government isolated her from the family.’

When the organisation relocated Sofja without informing her family, she disappeared ‘off the radar’ for years.

Tully eventually tracked her down in the mid-90s. She learned from the providers’ files that Sofja ‘had been a victim of serious incidents of rapes and sexual assaults’ at the institution.

‘The provider was very aware of these criminal offences. The evidence was actually never reported and followed through.’

Sofja’s legal advocate described the oversight as ‘alarming’. There was no police involvement or criminal charges, and the provider took no steps to protect Sofja.

‘Did they just go, oh look, she has Down syndrome, just don’t worry about it?’ asked Tully.

About a decade ago, Sofja was living in a unit on her own. Tully said the provider was giving her little spending money from her disability pension.

‘We suspected there was a lot of theft and misappropriation of her funds. You know, we’d buy her items and they’d go missing ... The carer who was taking her out for the day doing grocery shopping was helping herself to [Sofja’s] groceries.’

Sofja was in ‘significant financial deficit’ because of the fraud. Tully approached the public trustee, Sofja’s financial administrator.

Tully said the public trustee failed to act.

‘It’s been overlooked for so long and no-one has stepped in ... They left her in an abusive position ... It was a conflict of interest. They were all covering for each other.’

Tully said the abuse continued. Despite significant NDIS supports, Sofja had 'minimal service provisions' to access medical treatment, and many appointments were missed.

'This neglect has seen her health deteriorate immensely. She's non-verbal now. She's not even mobile, she's now confined to a wheelchair ... It's just horrendous.'

A couple of years ago, Tully started questioning the provider more about her sister.

'Why was she in a situation that she was in? Why did she look the way she is? Why is she not getting the care that she needed? ... And they shut me down.'

The organisation moved to place Sofja under the public guardian. Tully said service workers who wanted to give evidence of the neglect at the tribunal 'feared they were gonna lose their job'.

'They were given less hours ... Given a hard time just for coming forward.'

Tully's concerns about the provider weren't 'investigated or actioned'.

'Leaving them free to take advantage of other disabled clients ... They're not really interested in my sisters' care ... I'm glad to be on the scene, making all of her doctor's appointments, and I'm ensuring that's happening.'

Sidney

'I was crying because they cut my white cane. They cut it up.'

Sidney is in his 60s and is deafblind.

'Deafblind people communicate differently,' Sidney told the Royal Commission. 'It's always a problem because we don't have enough interpreters who can understand me and I understand them.'

The lack of interpreters means Sidney often has to travel alone and struggles to be understood.

'People regularly push me, and if I have a support person to guide me through the trains that's so much safer, so much better.'

Sidney recently had to fly to another city but couldn't find anyone to go with him.

At the airport, an airline worker took his cane away.

'She said, "You've got to be led by the arm." And the lady took my cane and I couldn't see where my cane was. They took my cane and I had to try to follow to see the seats as to where to go. I really didn't know where I was going to go.'

Sidney said they put him at the back of the plane and when the plane landed no-one helped him.

'I didn't know where to go, how to get out, what to do, and everything was just so wrong. And the exit sign is really small so you can't see the exit sign ... You can't see where to go to walk and I kept on bumping into things.'

Sidney said he injured himself on an escalator and struggled to collect his luggage.

When he returned to the airport terminal to catch his flight home, security officers took him into a room and took away his cane.

'They actually cut my cane up and the man punched me in the arm and then, yeah, I kept getting bumped into because of the way they were walking [me] through the airport,' Sidney told the Royal Commission.

'I said to them, look, I'm deafblind. I'm not a murderer. I'm deafblind. I just can't see. I'm not going to kill anybody. I'm not going to hurt anybody.'

Sidney said being deafblind is like being in solitary confinement and 'leads to paranoia' because it's so difficult to communicate and understand what's going on. Police once arrested Sidney and took him to a hospital mental health unit.

'I said I'm deafblind. They [said] I was mentally ill and I said no, I'm not ... I'm deafblind. If I'm [only] deaf it might've been a different story, but I feel like I'm in jail.'

Sidney said the hospital didn't provide an interpreter. They put him in a room alone where he 'got really angry'.

'The boss of the hospital said, "This is the right place for you and you have to have medication. It will help." I said, "I'm not mentally ill. I'm not mentally ill. I'm just deafblind."'

Dushane and Noelene

Dushane, mid-20s, is autistic and has other neurodiverse conditions and dyslexia. He is a university student living with his mother, Noelene, who is his main carer.

Dushane hopes one day to help improve the lives of autistic people. He said that in Australia, the first step is amending the Disability Discrimination Act.

'I really do believe ... that there definitely does need to be some rapid, massive changes with respect to current government policy and legislation regarding autistic and neurodiverse people such as myself.'

He said the legislation at the moment does not specifically recognise autism or neurodiversity.

'The thing is really that ... with the Disability Discrimination Act, right, at the time that was a brilliant way to sort of get the argument rolling with respect to disabilities.'

But, he said, it uses disability as a 'paintbrush' term.

'So a one-size-fits-all term. And it sort of covers up the – the intrinsic differences that go between those who have physical disabilities and those who have cognitive disabilities.'

Dushane and Noelene want the Act updated so it references autism and other neurodiverse conditions, to help identify and fight discrimination.

Noelene said that at secondary school, Dushane had no support in meeting his academic goals and his ambition to go to university was dismissed. 'School – they did nothing,' she said. The vice principal said Noelene was 'kidding' herself in thinking Dushane could fulfil his ambition. Noelene says this attitude is discriminatory, but that 'we can fight nothing in this country because there is no autistic neurodiversity legislation'.

Dushane and Noelene also want the Act to outline the rights of autistic people in relation to their carers. At school and now at university, Noelene has not been allowed to provide the support Dushane needs.

'For the most part, the standards that are emphasised at a university level, are, you know, that students are supposed to be self-learning, autonomous in that sense. And being able to get through the hoops themselves,' said Dushane. 'Now the thing is, when it comes to autism, it's much, much more difficult to do that ... As well, there are a lot of areas that the university simply can't cover with respect to providing supports.'

Dushane said the disability support team at his university did not have experience in working with autistic people.

'Especially in terms of addressing my concerns ... So for the most part I was speaking into

a void of people who really just didn't understand what my needs were.'

Dushane said there should be 'a distinct set of rights' for carers in relation to how they're 'incorporated into the education process'.

He understands the role of teachers and psychologists, but said 'a lot of the time, they're working on professional experience that really doesn't apply'.

'Because this whole thing with autism is – it's a case-by-case basis, you know? I wouldn't say, well, because ... Tom is neurotypical, so he's the same as Joe. We're two different people.'

Both Dushane and Noelene want the chance to share their understanding of autism.

'Being autistic, at the end of the day, I even have struggled accepting it when I was going through school ... Socially I couldn't coordinate and I felt really down about myself as a result,' said Dushane. 'Only because my mum's support got me through it, that I was able to become confident at that. And I want other autistics, both of us want other autistics – and their carers as well – to feel confident there is no stigma about that.'

Dayna and Jeri

‘We have a group of people, unique people in the community, that get up every day and they want to live their life, but because of the lack of services and awareness they can’t.’

Dayna is in her 70s and deafblind. She spoke to the Royal Commission with the help of her daughter, Jeri.

‘She uses tactile deafblind sign and she communicates face to face and she has no other mode of communication,’ Jeri told the Royal Commission. ‘Mum enjoys living by herself and being an independent woman, but there are some barriers that mum experiences to being a fully independent woman.’

When she goes out, Dayna relies on interpreters who have to be booked in advance.

‘I’ve got a few,’ said Dayna. ‘Off and on ... sometimes I’ve got an interpreter for like half an hour or so.’

Jeri said it means her mother usually has interpreters for regular hospital appointments, but not for sudden visits to the doctor.

‘If mum needs to see the GP I can’t recall one time that an interpreter has been available when she’s needed it.’

Jeri said Dayna’s service provider recently gave her a computer tablet to book support services, but Dayna also needs someone to read it for her.

‘So when supports are cancelled for my mum, mum is left at home alone with no way to communicate ... so mum will pace the house, check the front door several times, and then hours later she will come to the realisation that she’s not receiving supports that day.’

Jeri said her mother struggles to find support coordinators, service providers and workers who understand the deafblind community.

For example, Dayna keeps running into doorways, even though she’s lived in her home for two decades.

‘The idea that has been recommended is a rope from her chair to the doorway ... I was so angry I could not respond and I know it would not have been discussed with mum.’

When Dayna developed diabetes, a dietitian’s assessment stated that she ‘doesn’t have the capacity’ to cook meals, which Jeri said is untrue.

‘If you go to mum’s house for dinner you will get meat and veg and dessert.’

Jeri said Dayna has little choice but to employ people who don’t know how to adequately support her. Many of Dayna’s friends in the deafblind community also struggle to get appropriate help.

‘A lot of them were diagnosed, which we’re not sure how, with mental health conditions and were under medication because their behaviour [is misunderstood],’ said Jeri. ‘If we can see more awareness and training for deafblindness it would be a really positive thing for this community.’

Annick and Soraya

‘What she needed was medical treatment, not mental treatment.’

Annick was in her teens when she was placed on an adult mental health ward.

Her mother, Soraya, also ‘spent time in a psych ward’ as a child. ‘Our legacy is part of the Stolen Generation,’ Soraya told the Royal Commission.

Annick ‘lost the plot’ after traumatic events in the family.

‘My daughter had gone walkabout, which is cultural. They’d be trying to medicate her saying she was bipolar. They made her bipolar. They took away my daughter’s spirit.’

At one point, Annick was hit by a car and was ‘in a bad way’.

‘Because she was conscious, they sent her to a psychiatric ward ... She was that terrified, they took the baby off her, don’t tell the mother, and fly the baby back here. Put the baby in foster care and lock her up in the ward. Hello!’

Soraya believed Annick had a brain injury from the accident, but doctors disagreed and sent her to the adult psychiatric ward.

‘It was like a cell where she couldn’t breathe ... They wouldn’t tell me anything ... She hardly even knew who I was, she was that sedated.’

Soraya said Annick was detained with ‘some pretty dodgy people’, including known sex offenders, and was sexually abused.

‘This guy figured out that she was hanging for a cigarette, so he took her into the toilet and told her to suck his dick.’

Soraya ‘jumped up and down’ for doctors to release Annick. But they put her on a community treatment order and took out a guardianship order.

They told Soraya, ‘We don’t really think that you can make any decisions on her behalf, so we’ll make the decisions and you be her mum.’

‘For two years, they just played bat and ball with my daughter ... They had her right where they wanted her. Terrified.’

Annick kept getting ‘locked up in some psych frigging ward ... in the pretence it will keep her safe’.

‘And it would terrify the life out of her.’

Once she walked almost 80 kilometres in 40-degree heat ‘trying to get away’. Police arrived and were ‘baseball tackling’ her ‘because she was a runaway’. At another facility, staff ‘crucified and labelled’ her as an alcoholic and ‘handcuffed her to the bed’.

‘You know, there were times when my daughter was seen to be staggering. They just assume she’s drunk. We since found out that was a result of the Clozapine dose they had her on, which could have killed her.’

Soraya says that, given community treatment orders are ‘literally taking away people’s rights’, there ‘seems to be very little independent kind of oversight’ of them.

‘There’s no-one you can call on to represent your legal rights in that kind of situation. Financially, you can’t afford them.’

After more than a decade of being ‘messed up’ and ‘let down’ by the system, it turned out Annick had an acquired brain injury after all.

She’s now receiving support from the NDIS and is ‘in a place where she will do things to better herself’.

‘[But] she will not ever get back her teenage years. She won’t never get back what was taken. The damage has already been done.’

Greig and Jaimie-Lee

Greig contracted a life-threatening illness several years ago. He now lives with an acquired brain injury (ABI) and uses a wheelchair.

‘We both went from working full-time overnight to both of us not working at all and surviving and trying to keep our family going,’ his wife Jaimie-Lee told the Royal Commission. ‘You know, [with the] kids going through pretty significant trauma, lots of different things happening.’

Greig spent several months attending a hospital rehabilitation unit, where he was often neglected.

‘He would be at the hospital for five hours for treatment, but nobody would organise food or medication or drinks for him. And this is a man with quadruple amputations ... and you have to get angry and be his full-on advocate.’

The hospital gave Jaimie-Lee little support and she struggled to care for him at home. When she applied for support, the NDIA initially knocked him back.

‘They actually said, “We don’t think we’ll accept him into the system because we think it’s more of medical condition than a disability at this stage.” And I said, “Yeah, you’ve picked a fight with the wrong person.”’

After being accepted, she waited a couple of years to have a wheelchair ramp installed at home and have the bathroom modified.

‘You’ve got your bunch of health professionals who are well and truly qualified to assess and recommend the right equipment for [Greig] and ... they’re recommending things that are pretty good, but then it’s got to go to another level of bureaucracy at the NDIS to be assessed by another group of health professionals who may not necessarily have the same opinion, even though they’ve never met [Greig].’

Frustrated by the delay, the family built a ramp and raised money to modify the bathroom. The family struggled financially.

‘I’m [Greig’s] biggest informal support and NDIS recognises the informal supports are important and they rely on informal supports as cost saving measures.’

But Jaimie-Lee said being an unpaid carer means her work isn’t acknowledged or respected.

‘And that’s neither in the health sphere, not in the disability sphere and not in the welfare sphere ... We’re a family who’s been under significant trauma.’

Recently, Jaimie-Lee got a part-time job. This meant Greig lost his healthcare card.

'We're not actually much better off when you think about what the expenses are relating to work, but it's actually been good for me and for my health and wellbeing, this job ... [but] we had so many out-of-pocket expenses because he didn't have a healthcare card.'

Jaimie-Lee receives a carers allowance of a few thousand dollars a year. When she fell ill with a serious stress-related condition and told the NDIA she could no longer care for Greig, they added nearly \$200,000 to his budget to fund supported accommodation.

'So what they were saying is to replace me cost [nearly \$200,000] a year ... My own mental health and wellbeing has been sacrificed. Those things haven't been addressed ... That was, I found, particularly insulting.'

Emile and Anja

Emile is in his 20s. He has Down syndrome and is non-verbal.

‘He lights everybody up that he sees, like he’s got a smile that just expands and goes through his whole face and he just brings a lot of joy to a lot of people,’ his mum Anja told the Royal Commission. ‘He was very social before the last few years. Now we’re trying to get him to start coming out of his shell a little bit again, but a lovely guy.’

Anja is a single parent and for many years was Emile’s sole carer. When Emile was a teenager, doctors admitted Anja to hospital for a back injury.

‘Child [protection] got involved ... they wanted me to sign a form saying that I was neglecting him.’

Anja said she felt she had little choice but to relinquish care.

‘I can tell you it was the worst experience of my life. To this day I struggle to tell people that [Emile] was put in care because I feel like the worst person in the world.’

When Emile turned 18, he entered a group home. One day when Anja visited she noticed a new lock on his bedroom door.

‘I’m like, “Why’s there a lock on [Emile’s] bedroom door now?” and ... they go, “Oh well no reason, just for privacy.” And I find out afterwards another young man living in the house had gone in there and tried to strangle him. [They] never told us.’

Anja said when Emile first went into the home the staff treated him well, but when new support workers arrived Emile began to lose a lot of weight.

‘I mean they were giving him milk, regular milk, when he’s lactose intolerant.’

When she asked the provider about his diet plan they told her it was ‘happening’, but later said they’d ‘never received it’.

‘Some of the workers would say to me, “Well we’re taking away his choice if we follow the diet plan.” ... At one stage [Emile] was just getting boiled potatoes. That was it.’

Emile’s behaviour deteriorated.

‘We went with the behavioural specialist to have a meeting with one of the workers that knew [Emile] well and we walk in ... and she said, “This guy has asked to have sex with [Emile] and we don’t know whether he has or not.” ... I got [Emile] out of the house that moment. He never went back to that house.’

Anja said she learnt the other resident had sexually assaulted someone else and threatened to harm Emile. The police told her they couldn't do much without evidence.

'Do you know if they have anybody that specialises in the police force with people with disabilities?' Anja asked the Royal Commission. 'Or is it that they just don't ever want to get justice for somebody with special needs? Because that's what I'm kind of feeling. There was nowhere to go to.'

Anja said the service provider didn't report the incident to the police until after she reported it.

'[The] police said to me, "What do you want to happen?" I said, "I would like the person that did it, who has a disability, to be protected so they're not put in a position where they can do this again. I would like the people that live with this person to be protected ... and I would like the company to be accountable because they have hidden and not reported it."'

Another service provider now supports Emile.

'He's now with a good provider. It took a lot, but I was scared for his life.'

Eugenie and Patrice

‘There is literally nowhere to go when you have got a child that has a disability and mental health problems. So everyone tells us how bad the [hospital] mental health department is. With disability, it is non-existent.’

Patrice is the mother of Eugenie, a teenager who’s autistic and non-verbal.

Patrice told the Royal Commission that doctors and teachers ‘severely underestimated’ Eugenie’s intelligence when she was younger.

‘Everyone that has worked with [Eugenie] has always told me that she is a lot brighter than what anyone gives her credit for and I think, unfortunately, that fuels also the self-harm because I think it fuels a lot of frustration.’

When she was young, Eugenie developed a medical condition that caused her a lot of pain. When she began to self-harm, Patrice took her to a children’s hospital where doctors saw only ‘bad behaviour’ and misdiagnosed her with a psychiatric condition.

‘I was horrified when I first discovered that the hospital system does not understand disability.’

Doctors prescribed psychiatric medication and Eugenie’s painful medical condition remained undiagnosed for years.

‘I would be better off if [Eugenie] could yell out, “I am in excruciating pain.” Someone would act on it. But for her to go up and hit herself ... what the hospitals tend to look at is that this is behaviour.’

By the time the hospital found and treated her medical condition, Patrice said the self-harming was ‘impossible to completely stop’.

‘We have realised that too late. And now she has no quality of life at all.’

Patrice said the hospital now treats Eugenie for her injuries every few weeks and her family is struggling.

‘[Eugenie] doesn’t sleep. So my husband has three hours sleep. I’m lucky to have a husband. Look, if there wasn’t a second adult in the house I would have to relinquish her because I just can’t do it.’

Patrice said she’s also struggling to support Eugenie’s sister, who is also autistic.

‘She is just going to be traumatised, I think, because we have got someone who is screaming and crying all night ... The toll on us is massive.’

Patrice said the hospital now often won't admit Eugenie until she 'bashes herself really badly'.

'I cry before we have to go into hospital because it is so hard. It is such a fight.'

Eugenie is 'very, very strong' and needs her own room with two people to help her. Patrice and her husband often sleep on the floor beside her bed to help hospital staff cope.

Despite years of admissions, when Patrice recently admitted Eugenie to change her psychiatric medication, the hospital still treated her as if she was behaving badly.

'They are not understanding disability ... We are constantly having to prove things and it is exhausting. It is really exhausting.'

Eugenie often needs sedating to receive medical treatment, but because it's a restrictive practice some procedures just can't be done.

'If she needs blood taken there is no provisions for any sedation ... And I am sort of saying, "No, no, no. The procedure needs to be done. You want bloods, she deserves to have bloods and, you know, we need to get the answers. Make it happen." And they can't and they don't. So she just doesn't get bloods taken.'

The NDIS supports Eugenie and funds two support workers during the day, but it's difficult keeping workers and Patrice worries the NDIS will cut her funding.

'Thank you for understanding the intensity of the situation,' Patrice told the Royal Commission.

'I think sometimes it is hard to have people understand, but it is extreme and ongoing. Yeah, I can't sustain it. I have already got breast cancer last year and so, you know, it will be something else next year.'

Kalel and Jaliyah

Kalel is autistic and has obsessive-compulsive and attention deficit hyperactivity disorders. His family immigrated to Australia when he was a young child, and he is now in his early years of high school. He has attended five or six schools in Australia, as the family has relocated often for his father's work.

Kalel's mother Jaliyah said there have been good experiences and bad.

At Kalel's first school, the principal was welcoming and Kalel had a school learning support officer (SLSO). But on her visits to the school Jaliyah noticed that Kalel was usually on his own.

Jaliyah told the Royal Commission that coming from another culture, she did not quite know what to expect from Australian schools.

'I never know any – anything is standard or education law or whatever, I did not have any idea. Maybe at that time, my approach was not very professional, mostly emotional.'

Jaliyah took the advice of an allied health professional who was working with Kalel, and employed a disability advocate for him.

'Advocate try to get some support in the classroom and in the playground so my son can participate in the academic stuff,' she explained.

This helped, and with the additional resources Kalel managed well.

When the family moved interstate, the principal at their local school would not let Kalel attend for the full day because of his disability, despite his good academic record. This was difficult for Jaliyah, who needed to get a job.

'I ask for a meeting, so the school principal, assistant principal, me, my husband – we all join. The principal ... told [us] that having your son in the classroom without education assistant is not fair for other children.'

Jaliyah contacted a local disability advocate, who told her to remind the principal it was Kalel's right to attend school full-time. The advocate then emailed the school as well.

'She said "You are not abiding the Australian law and we will help the family to lodge complaint against Department of Education,"' Jaliyah recalled.

This threat was effective. The school organised an SLSO and Kalel was then able to go to school full-time.

There continued to be issues, however. The school communicated poorly with Jaliyah and didn't make simple adjustments that would have helped Kalel, such as writing his tasks down on a sheet of paper rather than making him read them off the board.

Kalel began self-harming.

The disability advocate made a formal complaint about the school on the family's behalf.

When Jaliyah's husband got a new job and the family prepared to move interstate again, the school filed a complaint about them with child protection services.

The complaint came as a shock, and Jaliyah's husband was 'very very angry, sad, frustrated'. It was assessed by the agency and quickly dismissed as a misunderstanding of something Kalel had said.

The disability advocate told Jaliyah that it was a 'tactic' on the part of the school – 'Like, every time the school get complaint by parent, parents are victimised by this.'

At Kalel's next school, things went well.

'Most of the kids were really kind to him. Class teacher was very good to him and as my son was happy, we were not worried about his academic [progress],' said Jaliyah.

The school encouraged Kalel to enter an extracurricular competition, which he won.

'He still cherishes memory and he was – he was valued and he did really well.'

Kalel is now entering puberty and new issues are emerging to do with appropriate behaviours at school. As Jaliyah tries to ensure Kalel's needs at school are met, she finds being a migrant whose first language isn't English makes everything harder.

'I can still, like, when I go and try to talk to the meeting ... I – I – I shut down very easily. They shut down me very – I could not – I cannot finish my talking,' she said. 'I feel like it was racism lots of times.'

Petronille

Petronille lives with mental illness and is an NDIS participant. Problems with her plan management provider have put her in an 'unstable situation', she told the Royal Commission, and a few months ago she 'was not in a very good place'.

'I was in a point of crisis in my mental health ... They actually put me into hospital to – I actually got evaluated and assessed.'

Petronille was 'a victim of family violence', but had a residential address.

'I asked for short-time respite stay ... and it got approved by my plan manager. Then the next day, it got disapproved by his manager because she read it as if I was needing crisis accommodation. They were trying to make out like I was homeless, which was absolutely not correct.'

Because of this Petronille's respite accommodation was not funded – 'It was approved to then not be approved.'

Instead of rectifying the problem, Petronille said the provider ignored her.

'I wasn't getting heard or listened to, and I then got verbal and got aggressive because it was just like I was talking to a brick wall.'

Petronille's support worker was on the phone advocating for her.

'She saw how I was treated ... If it wasn't for her and my dog, I would have committed suicide. Like, they're the only two things that stopped me.'

But the support worker's advocacy 'really didn't help'.

Furthermore, the provider 'disclosed personal information' without Petronille's consent.

For more than six months she's been trying unsuccessfully 'to get this resolved'.

'I've been lied to ... I'm trying to cope as well as I can without going to – do any harm to myself ... I've escalated that many complaints, that many inquiries for my planner to get in touch with me and it's like she doesn't exist,' Petronille said.

'It's so upsetting because I've been left feeling helpless, worthless, unwanted, unsupported. Like I have no-one to turn to.'

She's tried everywhere to get help including the NDIS Quality and Safeguards Commission.

'I have emailed every single one and I'm waiting for ... a response back. And I believe that ... my plan management company who is looking after my funding, or paying the invoices, needs to be held accountable for what they did to me. Like, they can't get away with this shit. This is not what the NDIS is there for. It's there for support and to serve people with mental and physical disabilities and they're not doing it. This is a real failure in the system.'

Sheree

Sheree is blind and has physical disability.

She met Jay, an advocate, while living in a hostel.

Jay told the Royal Commission that Sheree was badly neglected by hostel management. She spent most of her time in bed, which was often soaked in urine. The mattress was so old and unsupported, it almost touched the floor.

No-one helped Sheree shower or bath regularly, and she would wear the same clothes several days in a row.

Sheree's health was poor and her eyes were often infected.

Other residents abused Sheree and took advantage of her because they knew she wouldn't fight back.

Initially, Sheree didn't want to talk to Jay about the conditions in the hostel. She said she was frightened of the owner and knew he would punish her for talking to an advocate.

Jay successfully applied for funding for Sheree so she could leave the hostel. He tried to convince the owner to facilitate Sheree's move, but the owner was opposed and adamant she had to stay.

Jay believes Sheree was 'easy money'.

The hostel owner banned Jay from the hostel.

Jay contacted the public guardian and they agree to investigate Sheree's living conditions.

Several months later, the public guardian made an order for her to move to respite accommodation.

'For the first time in [almost 20] years [Sheree] was out of the hostel, and she promptly stated that she did not want to return.'

Jay arranged alternative accommodation and support, ensuring appropriate safeguards were in place.

Jay believes hostel accommodation is unsuitable for people who have disability.

'While efforts have been made to regulate the rooming accommodation industry, these have not got far enough to address the needs of people who require a level of support that hostel managers cannot provide, or are unwilling to provide. Further, exploitation of people who are vulnerable living in hostels is of major ongoing concern.'

Tiggy

‘This really horrible case of wrongdoing that the system just won’t acknowledge has been done, and I’m having to live with the consequences.’

Tiggy was diagnosed with mental illness about 15 years ago.

‘My disability is the result of the drugs I’ve been given,’ she told the Royal Commission. ‘I am an innocent person who got stuck in the system and has not been assisted to get out of it, not been listened to the whole time that I’ve been in there, have been lied to the whole time.’

Back then, Tiggy said, she was ‘functioning normally, working full-time’. Then an assault triggered trauma from ‘a childhood sexual abuse history’.

‘I went to my GP ... She didn’t believe me, gave me a pack of pills and sent me home. Didn’t explain what they were.’

Tiggy’s family took her to a psychiatric clinic after realising the medication was an antipsychotic.

‘The doctor diagnosed me wrongly with anxiety with psychotic features. Said to me, “You’re going to have a have a pill for rest of your life.” I didn’t have options. And I wasn’t assessed properly or anything there. I wasn’t allowed to speak.’

Tiggy had ‘a nominated person’ at the meeting to advocate for her.

‘[The doctor] wasn’t listening to her ... Kicked her out of the hospital. His training and personal skills were atrocious.’

The following year, Tiggy spoke to the psychiatrist about the sexual abuse, believing that she had post-traumatic stress disorder.

‘He laughed at me ... Said that the treatment was the same anyway. Kept his original diagnosis. And my life fell apart. He wanted me to stop working at that point. Didn’t explain that I could apply for DSP [Disability Support Pension], or anything like that.’

Tiggy continued to work as her health declined.

‘My whole physical self was destroyed. Like, I doubled my weight and had full-blown insomnia after being medicalised.’

In their ‘10-minute consultations’, her psychiatrist continued to deny her health issues had ‘any association’ with the drugs he was giving her.

‘My situation has been kind of severe ... I was on benzos for 10 years, withdrew from them. I had a clonazepam overdose.’

About three years ago, she complained to the medical board who 'failed to find that the original assessment was incorrectly done'.

'They said there wasn't enough evidence, so therefore he was doing everything right, which is bullshit ... Four out of five of the standards and guidelines were breached in the examples that I gave. He's supposed to provide psychological intervention first, before medicating.'

Tiggy ended up under a mental health order for more than a decade.

'I haven't been able to have children, haven't been able to have meaningful relationships ... Not being able to work, to engage as I normally would. Like, I'm now living on DSP with no income.'

Tiggy says her current psychiatrist doesn't listen to her either.

'He has a skewed view of me.'

Recently she went to a mental health tribunal 'to review whether [she has] to continue on medications or not'.

'[The psychiatrist] is twisting everything I say. Like, he's not documenting things accurately ... And saying I'm deluded when I'm not, and all of these, you know, horrible things.'

He also wants Tiggy to become an NDIS participant.

'I'm not willing to do so at the moment ... I don't think it's what I need. It's like you're signing off that you're going to have a disability for the rest of your life ... It's medication that causes what I'm now experiencing.'

Vigo

Vigo has attention deficit hyperactivity disorder (ADHD), complex trauma and mental health issues.

He told the Royal Commission that he was diagnosed as a teenager and, for most of his life, has had difficulty accessing appropriate mental health support and medication.

Vigo uses illegal drugs to self-medicate. As an adult, he has been 'in and out' of prison.

Following a recent release, Vigo 'tried desperately to see a psychiatrist and obtain some kind of medication'.

Initially he tried to see a private psychiatrist because his experiences in the public health system have been unsatisfactory.

But the wait times were so long, Vigo had no choice but to access the public health system.

He said the psychiatrist on duty didn't believe he had ADHD, telling him 'you grow out of it'.

'I begged for help and did not receive it,' he said.

Instead Vigo 'was dumped' in a drug rehabilitation program.

But it didn't help.

Vigo says these programs don't provide the help or support he needs to treat his ADHD or complex trauma.

He continued to use drugs to self-medicate, eventually ending up back in prison.

In prison, Vigo asked for mental health support and medication.

They said he needed to be reassessed because his ADHD diagnosis wasn't up-to-date.

Vigo's family member arranged for him to see a private psychiatrist and the prison approved the appointment.

But on the day, at the appointed time, the prison informed the psychiatrist they were running late and needed to reschedule to a later time.

The psychiatrist had a full schedule and cancelled Vigo's appointment.

Vigo has not been able to reschedule the appointment. A prison officer told him he would have to arrange the assessment when he got out.

‘Mental health concerns should be managed before people end up in prison. Instead, people end up in prison and are then dumped in rehab after prison or left to deal with the incompetence of our public system.’

Vigo wants to be properly supported to stay out of jail.

Win and Lenah

Win was diagnosed as autistic a few years before he started school.

He accessed services and supports and his behaviour settled.

Primary school brought new challenges, his mother Lenah told the Royal Commission, and Win struggled to cope.

The school responded by excluding, restraining and suspending him.

Lenah sought medical help and Win was further diagnosed with attention deficit hyperactivity disorder.

He accessed additional services and supports and his behaviour improved.

In the middle of primary school, one of Win's siblings died.

He began having 'more issues', Lenah said, and the school suspended him 'over and over'.

She requested an NDIS plan review so Win could access additional support.

'This review resulted in them removing all psychology funding from [Win], saying that his issues were all grief related now.'

Lenah spent the next 12 months successfully challenging the decision.

Meanwhile, she privately engaged a psychiatrist and a behaviour support specialist to help Win.

But the school refused to allow the specialists to attend the school.

'I felt the school begin to disengage and go from "helping" to part of the problem.'

The school began to see Win 'as the problem'. They believed his 'bad behaviour' could be 'punished out of him'.

'There needs to be better education for teachers around disability and grief and trauma. The belief that autism is some sort of "buffer" is prevalent, with most not understanding how autism complicates grief and trauma, and how to actually deal with children instead of yelling and traumatising them.'

One day at lunch time, another student attacked Win.

Lenah warned the school one of the children would be seriously hurt if they didn't improve their supervision and support. The school refused to address the issue and blamed it all on Win.

The school banned Win from attending class camp. Lenah offered to accompany him but they declined saying, 'He would just have to miss out.'

This was 'the final straw' and Lena removed Win from the school.

So far, he is having 'a very positive experience' at his new school.

'He has had no suspensions, he successfully attended camp with no issues.'

Lately, Win has been diagnosed with post-traumatic stress disorder because of his experiences at his previous school and the 'serious lack of protection he had there'.

The NDIS has recently reviewed Win's plan. They have halved his psychology funding despite letters from all the specialists who have been working with him.

'I am terrified for my son entering high school ... that he will continue to experience violence, exclusion and fear.'

Dusty

Dusty is in her 40s and has hydrocephalus and cerebral palsy.

‘I have poor coordination and balance,’ Dusty told the Royal Commission. ‘I have difficulty with tasks that require fine motor skills and I can fail to notice things that are in my peripheral vision or where there’s a lack of contrast.’

The NDIS supports Dusty and a service provider sends support workers to help her around the house. Dusty said one support worker ate her food while preparing meals and another hid items they’d been told to throw away around the house.

‘When I asked why she was stashing things under my laundry cupboard she said she’d intended to take them home to use herself.’

One day a support worker approached her from behind.

‘As she put her arm around me she said rhetorically, “Can I give you a hug?” I just froze. As she let go she said, “I’ve been wanting to do that for a long time.” There was no reason for her to hug me.’

When Dusty reported the incident, the provider admitted removing the worker from other clients ‘because she had been touching them’.

‘We’re surprised you put up with it for this long,’ they told Dusty.

Dusty said service providers may be reluctant to admit abuse is happening in their organisations because they’re ‘afraid of losing government funding’.

‘It’s not going to be the support workers at the bottom of the pile who really lose because they get paid peanuts. It’s going to be the bosses at the top and their pay packets are huge. And so there’s a lot of incentive to keep the organisations going no matter what.’

Dusty said assaults and pilfering might be related to low pay.

‘Because they get paid so little I suspect that’s some of the rationalisation ... She would be thinking, “Well I don’t get paid much so it’s okay for me to do this because I don’t have the money” ... or to say “Well, you know, besides the money I want some other gratification so I’m going to touch up my clients” or whatever is their gratification of choice.’

‘I think they need to be paid better. And I don’t think the recent steps to increase pay to low-paid workers is enough. I think they need to get paid properly to just completely remove that low pay as an incentive.’

Auden and Caprice

‘Airlines should be made to have hoists available at every terminal in Australia. Using aisle wheelchairs is dangerous and humiliating.’

Caprice’s partner Auden has quadriplegia.

He needs to travel by air regularly.

At check-in, six to eight staff – often not properly trained – transfer Auden from his power wheelchair ‘to a tiny aisle wheelchair’, which doesn’t have the recommended support.

Often staff use a slide board but these can be dangerous and cause injury.

Caprice says passengers should have the option to stay in their wheelchair until they reach the plane.

Once onboard, the same number of staff, sometimes using a slide board, transfer Auden from the aisle wheelchair into his seat.

On a recent flight, a staff member slipped and Auden almost fell.

‘On top of this risk for physical harm,’ Caprice told the Royal Commission, ‘it is a humiliating and demeaning experience for my partner.’

Several times, Auden’s power wheelchair has been damaged during transfers.

‘He’s been left strapped in to a tiny airline wheelchair and expected to stay bound into an aisle chair for over an hour.’

Occasionally, some flights have a hoist. One or two staff are able to transfer passengers directly from their own power wheelchair to the aircraft seat.

Caprice and Auden want every airline and airport in Australia to have a hoist.

They would also like the passenger’s wheelchair to be available at the arrival gate, instead of the baggage area, for immediate transfer.

‘These are simple solutions that would save airlines money and mean they are no longer discriminating against people with disabilities,’ Caprice said.

‘[Auden] deserves the same rights and treatments as other Australians.’

Sven and Katriona

Katriona is in her 80s and cares for her grandson, Sven, who's in his 30s and has Down syndrome.

'My grandson who drives a car has a full licence, holds down two jobs ... is a very capable person,' Katriona told the Royal Commission. 'So the discrimination and the low expectation and the bias that we've actually had throughout his life really does not equate to him.'

Katriona said the low expectations of Sven started in a mainstream primary school. A teacher told her to put him into a special education school, but she refused.

'I said ... "I would like him preferably to stay in a regular school where he would be taught amongst his peers, regular peers, so that anything he learned in the way of behaviour would be from his regular peers rather than from other children with disabilities."'

Katriona said the school continued to discriminate against him. When he left the class without permission one day to go to the toilet, the teacher called a meeting with her and the principal.

'Which I thought was ridiculous because if a regular child does that they will simply say, well, next time you leave the class tell the teacher. But, no ... the focus was on the disability.'

Katriona said Sven's high school once denied him work experience. When she asked why, she discovered the school had described him as 'severely disabled'.

'Couldn't look after himself, couldn't communicate, couldn't commute.'

When she challenged these descriptions, the school found him a placement where the employer gave him a 'really good report'.

Sven's first job out of school was in regular employment for an award wage, but after a few weeks someone in management had him reassessed.

'A regular person would be given the opportunity to work for three months before they assessed him at the job ... And after they then reduced his wages to quarter of the award.'

Sven has since used a number of Disability Employment Services to help him find a job, but they rarely offered anything suitable. Not long after Sven found a job himself, an employment service asked him to quit to take a job as a cleaner.

'He was already working [in a job he liked], why would he then stop working ... to clean toilets?'

Sven enrolled in a hospitality course and now works for an award wage outside the disability employment system.

Spencer

Spencer has mental health problems and is currently in a correctional centre.

He was abused at a boarding school when he was a child, he told the Royal Commission.

'I got sent off to a Catholic school ... One particular brother asked me to go with him up to an alter room and that's where the abuse started.'

He says the abuse and the fallout have been ignored for 40 years.

'I had a voice in my head from that incident right up until now ... I've never been diagnosed with anything cause I've never seen any psychologist or anything.'

Spencer feels that led him to commit the offences that put him in jail and left him with a psychosocial disability.

'Because I was abused when I was a minor ... Yeah, I can't stand people around me. I've got to be by myself, I can't interact with people properly ... It's basically – has destroyed my life.'

Spencer has no support services in prison. He told a counsellor about the abuse.

'And they said they can't help me.'

He recently talked to a prison psychologist, but there was no follow-up.

Currently he's doing some rehabilitation.

'But it's just bringing back everything, what's happened to me. And I don't know what I can do about it.'

The voice in his head is 'always there'. He never sleeps more than two or three hours.

'And that's why I want to get some help, to – get a break from it. I don't want to take any medication.'

Spencer says the abuse 'stole something' from him.

'If I got this sorted when I was younger ... the impact it's made on my life, I haven't had a life. I've just gone through emotions and done everything I've done, just to survive away from people as much as possible. And you can't literally live a life like that, because a human being is to be around people. Not to be isolated.'

He'd rather be around people and 'out in the community'.

‘But I – it just freaks me out too much. The feeling I have is to get away from everyone and go on a deserted island.’

Spencer decided to deal with it himself by contacting the Royal Commission.

‘I just took it as you rip a band-aid off one day.’

He’s hoping he will now get access to psychologists. But he still doesn’t know what the future looks like.

‘Honestly, I don’t see myself anywhere. That’s what it is ... I see myself in a corner, in a dark corner.’

Lockie

Lockie, late 20s, is Deaf. He has cochlear implants.

He told the Royal Commission that he loves going to the theatre, movies, concerts and musicals.

He relies on a hearing loop to access the entertainment experience.

A hearing loop provides a magnetic, wireless signal that is picked up by a cochlear implant or hearing aid when it is set to a 'T' setting. Reverb and background noise are eliminated, allowing the person to hear the entertainment as if they were up-close.

Lockie says most venues advertise hearing loops but the loops are broken, outdated or incompatible with new hearing device technology.

A short time ago, Lockie attended a performance at a large venue.

Staff assured him the loop technology worked, but it didn't.

Lockie missed the first half of the performance, going back and forth with staff to find a solution.

'I had to switch between two different hearing loops, one of which worked, but not clearly. However, the one that "worked" had a low battery that went flat before the end of the show.'

At another performance, the first two hearing loops were broken.

When Lockie asked staff for a third, they warned him most of them were broken.

'This raised concerns for me that the business is very aware that the hearing loops are broken and had not taken action to fix this or change their advertising.'

Recently, Lockie went to the box office to collect the hearing loop and staff told him they didn't have one.

When he pointed out that they advertise a hearing loop system, staff became rude.

Lockie asked to speak to a manager.

The venue offered him a free ticket to use when they installed a new hearing loop, but with 'no specific commitment to a timeline for when this will happen'.

'What use is there for a free ticket to return to see an inaccessible show or movie again when there is no commitment to fix the inaccessible equipment in the first place?' Lockie asks.

Lockie would like more accessible options for Deaf or hard of hearing people such as Auslan interpreted, captioned and audio described sessions or performances.

‘Deaf and hard of hearing patrons are not asking for handouts. They are asking for an accessible entertainment experience that they can attend, enjoy and not have to constantly battle to educate staff and test and fix broken and outdated technology.’

Gisele

Gisele is in her 30s and lives with complex post-traumatic stress disorder and physical disability. She receives the Disability Support Pension and, because she is studying, a mobility allowance.

A few months ago, Centrelink warned Gisele her mobility allowance would be cancelled unless she 'provided some updated information'.

'I did that well and truly in advance and it ended up that the mobility allowance was taken from me despite that.'

Gisele has spent hours on the phone trying to rectify the problem and feels Centrelink has 'a poor way of handling things'. They keep telling her that her case has been 'marked priority', yet she's still waiting.

'It's been months now. They know that there's an error on their end. And they have agreed that they will reinstate the payment and backdate it.'

Nobody will give her timeframe or explain the delays.

'There's no accountability ... and no apology even. And in the meantime, I'm functioning without that payment. Which is grossly unfair.'

Gisele says 'it's not an isolated experience' in her dealings with disability services.

Currently she's 'having a really difficult time' accessing the NDIS because it's 'still very much geared for physical disability'. For complex PTSD, Gisele said, 'the whole process ... is generally really unfair'. The NDIS initially ruled her out 'capacity wise'.

'Because I presented very articulate. And so a whole bunch of assumptions come with that. I've been outright denied access to the service, because I don't fit the stereotype,' Gisele said.

'The actual process itself retraumatizes people. And it's disgraceful. It shouldn't be like that. Just from the get go, like just to access the service is really difficult and really deterring.'

Now she has 'an organisation who specifically deals with the psychosocial applications' helping her.

'They're very aware of what the NDIS require. Now I'm being coached in how to have a disability. I wouldn't be able to access NDIS on my own. There's just no way that I could go through the application process.'

Gisele's efforts 'to engage with disability support services she's entitled to' have all been 'so overwhelmingly un-positive'.

‘Really difficult to access medical care, really difficult to access housing, really difficult to access even – even counselling and things like that.’

That’s led to social isolation and has been very detrimental.

‘It’s exacerbated my mental health ... affected by finances, my relationships ... Like I’ve had a nervous breakdown. I’m no longer working. My whole life has been disrupted.’

Han and Ren

Han, early 40s, is autistic and non-verbal.

He lives in supported independent living (SIL) accommodation and requires 24/7 care. He lives with other people of similar age with similar support needs.

In the past few years, Han has lived in two different SIL houses run by different providers.

His father, Ren, told the Royal Commission that he is 'quite disappointed' by the SIL providers.

There is a high turnover of support workers and the rosters constantly change. Support workers are not sufficiently trained and lack 'common sense'. Some support workers have never met a person with disability. Ren wonders if the provider simply hires people 'off the street'.

New support workers know nothing about the participants because there is no handover or buddy system or clear instructions from the provider.

'If a service provider cannot deliver the basic requirements, such as roster and workers, how do they provide the consistent support for goals of cooking, cleaning and house chores of supported independent living?'

Han and the other residents are not supported to do the activities approved in their plan.

'There is little choice and control for participants.'

When Ren makes a complaint, he is told to use the complaints process. He has made two official complaints and is still waiting to hear from the provider.

Ren and the other parents are ageing. They are very anxious about the future and worry what will happen to their sons and daughters.

'There's a conflict of interest and focus between us as parents and the providers. Our concerns are better and quality care of our loved ones, and providers to maximise their profits.'

Ren wants the government to introduce a star rating system similar to residential aged care, and include participants and plan nominees in annual audits.

At the very least, he says, this would incentivise providers to respond to complaints in a timely manner.

'We are searching for 'caring' signs not 'dollar' signs ... So that the senior citizens of our nation can have peace in our hearts.'

Huey

Huey is in his 50s and uses a wheelchair.

‘I can’t get out of my chair. I’ve got problems with my spine because I’ve had brain damage,’ Huey told the Royal Commission.

Until a few years ago he lived in public housing.

Huey said that one night a support worker sexually assaulted him. When he reported the assault to police, they told him there wasn’t enough evidence to take it to court.

‘Just because I’ve got a disability doesn’t mean I can’t tell when someone’s touched me down below, right? That’s not fair to me ... so he’s allowed to do it again, you know what I mean, to someone else.’

Huey said his support workers also neglected him.

‘Sometimes they leave me in there for six hours with dirty pullups before they change you. I’ve gone to hospital appointments with dirty pullups.’

One day he became sick and had to go to hospital. Huey can’t read or write, but while he was in hospital someone gave him some documents to sign.

‘They got me to sign paperwork. They did not read it to me and I didn’t know what I was signing for, right?’

After being released from hospital he discovered he couldn’t return to his house and the public guardian had taken over his affairs.

‘The government ... stepped in and took over and said, “Well he can’t look after himself.” And that’s why I lost my house and all.’

Huey now lives in a group home and his affairs are the subject of an administration order.

‘All I get is about \$40 a week. It’s not much money. And I found myself a part-time job ... and trustees want to take that off from me – little tiny bit of pocket money I’m earning – just want to take it off me.’

Huey said he’s tried to get the order revoked because he wants to move out of the home.

‘But they say no, I need more care, I can’t live on my own. That’s all they say, I can’t live in a home, they want me to be in one of their homes.’

Huey said he feels trapped in the house and can’t make decisions about his own life. The support workers treat the home as if it’s theirs. They once refused to let his friend visit him.

'She will not come back to that place because of what they're doing to me ... They listen into my phone calls, they even listen to when I'm talking to someone out the back of my yard or in my house. They don't give me no privacy, nothing.'

When one support worker endangered his life, she bragged that she wouldn't be fired.

'She said, "I won't get kicked out of here, I won't, no, nothing will happen to me." She was all high and mighty about it.'

Huey said staff threaten to report him to the police if he goes over their heads to complain and tell him to 'shut [his] mouth' when he asks about his finances.

'I want to get out of this place quick as I can because I can't stay there too much longer, I can't put up with it ... I get sick over what they do to me.'

Charis

Charis is in her 30s. When her husband, recently released from prison, punched her in the head, she was left with an acquired brain injury (ABI). Her two toddlers were at home at the time.

‘It was just the one punch that time,’ Charis told the Royal Commission. ‘I didn’t go to the hospital or the doctors or anything. I just got the kids safe.’

Charis explained that her husband is ‘very charming and violent all at the same time’.

‘Everyone covers up for him. And even myself.’

After the assault Charis’s speech ‘was really bad’, so she let her husband care for the kids while she recovered.

‘But within two weeks ... he wouldn’t give the kids back.’

Charis said her husband and his family told the child protection department she is mentally ill.

‘I was still learning to, like, try and find all my words ... They listened to everyone else that I was crazy ... They knew he had history of violence, but they didn’t do anything because I had ABI.’

It wasn’t until her husband began to stalk her and she had to hide in a domestic violence refuge that the department took the children from him.

A court sent her husband to jail and the child protection department let her husband’s family foster the kids.

Charis said the department never offered her support to look after her kids.

‘The only thing I could do ... was put in complaints and, like, that didn’t even work either. I think they, like, put a personal sort of judgement against me.’

Charis said the NDIS now supports her and she’s still fighting for custody of her children, who she sees occasionally.

‘They’re such beautiful young men and they’re so happy and bubbly and they just love life. They love their sisters and their mum and their dad and their family. And, yeah, they’re beautiful little boys. They’re just exactly like him, but really innocent and little.’

Anietra and Pavel

‘They should look after people in her situation who are really disabled. Because the brain is everything. She’s going to get worse with the days.’

Pavel’s friend, Anietra, has schizophrenia. She’s in her late 50s.

‘She’s been sick, you know, for a while. She has been in and out of mental hospitals a few times.’

Anietra is ‘living on medication’, Pavel told the Royal Commission. ‘The times she stops her medication, I’ve seen her get worse and worse. She’s a different person.’

But the drugs make Anietra put on a lot of weight.

‘She is very, very obese. So, it’s hard for her. And she’s all the time, like, you know, just sitting on the veranda of her house and hasn’t got energy or anything.’

Anietra is exhibiting a lot of dementia-like symptoms. She sees a psychologist, Pavel said, but has no other supports.

‘She needs a lot of help, because sometimes, you know, she puts on the heaters. Or the stove is on and she’s sitting outside. If someone asks her, she said, “No, I didn’t put it on.” ... She forgot about them.’

Anietra recently applied for the NDIS with the help of her doctor, but was knocked back.

‘And she gets emailed the refusal letter from NDIS. I got shocked because she needs help and support, at least in washing, in cooking ... Yeah, for someone to clean up the house for her, to take her out.’

Pavel says the NDIS process ‘is not fair’.

‘It’s too easy for them to reject the application but hard for them to accept it. Just straight away, deny it ... The problem, in my point of view, they didn’t, you know, maybe read all the documents. And they haven’t got specialised people to look into the documents and give the right decision to the right person.’

Pavel feels Anietra was obviously eligible for funding. Her application included reports from her doctor and psychiatrist, and ‘that should have been enough to assess her’.

Anietra has waited months after requesting a review of the decision. Meanwhile, she’s increasingly isolated and her cognitive impairment is deteriorating.

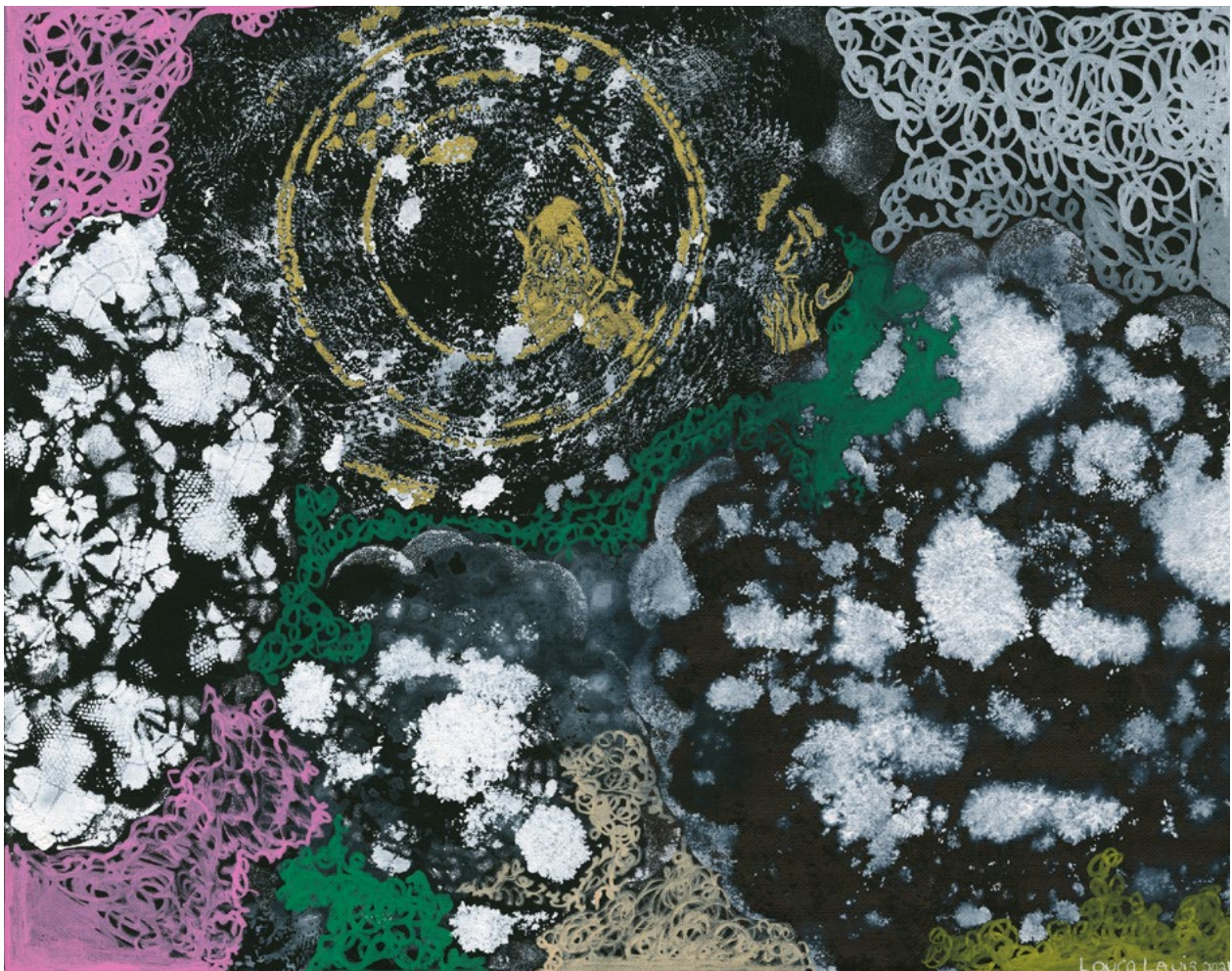
‘She can’t control herself ... She doesn’t talk to anyone. She locks herself in a room ... She’s trying to run away from people.’

Pavel's trying to get her out of her isolation.

'Because it's not easy to live by yourself. She can't get any other services ... Aged care, they're not going to take her because has to be, you know, 64 and over.'

He loves his friend and wants her to get the care she deserves.

'I feel sorry for her, to be honest. She break my heart, but I can't do anything.'



Artwork by Laura Lewis

Janey

Janey is in her 50s and has multiple chemical sensitivity (MCS).

'I react to everyday chemicals in the environment,' Janey told the Royal Commission. 'I can have exposures anytime, anyplace. I can have them shopping or at home in my own environment, which is primarily fragrance-free as best I can.'

A doctor diagnosed Janey's MCS several years ago, but it 'crept up' on her during a long career in the health system.

'At work I would have reactions to staff perfume. I would have reactions to the bleach they used in the toilets. I would have reactions to the air fresheners that they used ... and they've got a warning on the back that if you have multiple chemical sensitivity they're dangerous.'

Janey's reactions include rashes and seizures.

'I can't speak properly. I mix things up. I don't know peoples' names all of a sudden – people that I've known for years.'

Her food allergies also increased and she had to take long periods of leave. Not long after her diagnosis, she lost her job.

'My doctor had said that they needed to go fragrance-free and they decided that that wasn't a decision that they could do. Whilst I was disappointed that I was terminated, I understood because I had a very extreme condition at the time. I was very unwell and so I started losing massive amounts of weight.'

Janey said many doctors believe MCS is 'primarily a psychiatric condition'.

'I acknowledge that I have got severe anxiety. Who wouldn't have anxiety with a 25-year history of severe reactions, more so in the last [few] years to medication, foods and the list goes on.'

Janey said few doctors make allowances for people with MCS.

'When I go to the clinic I am expected to sit in a room where everybody is just wearing fragrance galore ... I've asked, "Can I wait in a separate room where I'm not exposed to so much fragrance?" And that's been denied. I've waited out in my car.'

Janey said the NDIS also denies her support.

'It's around a permanent debility of my condition. All my doctors say this is permanent ... The NDIS say, "Well, hang on a minute. You haven't exhausted all avenues." So they tell me I need to go to another doctor or I need to medicate ... I can't continually look for medications because the reactions [to medication] are just horrific time and time again.'

Janey said Australia, unlike some other countries, is yet to recognise MCS as a disability.

'People with MCS fragrance sensitivity must be able to access health and allied health care.

I shouldn't have to fight tooth and nail to get my doctor not to be wearing fragrance ... It's not just for people with MCS, it's for people with a barrage of medical conditions.'

Amryn and Cy

Amryn is autistic.

Her father Cy told the Royal Commission she is ‘the happiest person you are ever likely to meet’.

Amryn has been attending primary school for a couple of years.

She is included and well supported and participates fully in the curriculum. She has access to a quiet space whenever she needs to retreat.

Last year, Cy enrolled Amryn and her sibling in out-of-school-hours care (OSHC). He was open about Amryn’s needs and reasonable adjustments. He requested Amryn’s mum attend initial sessions to help her settle in and that Amryn have access to a quiet space.

The OSHC coordinator asked to meet the family, who arrived for what they thought would be a short informal meeting.

Amryn’s sibling joined the students outside. Amryn, ‘not her usual joyful self’ because of the unexpected change to her afternoon routine, stayed with her parents.

The coordinator described a typical afternoon in OSHC, then listed things that could result in them terminating Amryn’s enrolment.

This included taking off her shoes or needing help to toilet.

Cy explained Amryn happily wore shoes at school, and toileted independently.

The coordinator stressed that OSHC staff would not bring her from her classroom to the OSHC building. Cy had arranged for the teaching assistant to walk Amryn to the building.

A staff member at the meeting noticed Amryn was becoming unsettled and suggested they open a room for Amryn to use as a quiet space.

‘This was refused straight away by the coordinator as unreasonable.’

Amryn asked to leave and walked to the door. Cy followed her and brought her back to the table. The coordinator later interpreted this as ‘running away’ and her father ‘having to chase after her to stop her escaping’.

A few weeks later, the coordinator advised Cy they were accepting Amryn sibling’s enrolment but not Amryn. She said this was based on ‘the interview’.

‘There is no reference to an interview as part of the enrolment process in OSHC policies.’

Cy tried to contact the OSHC coordinator but she was unavailable.

'We are attempting to engage OSHC in discussions as to how we can work together to support children such as [Amryn] ... and help them to not be in breach of anti-discrimination legislation. So far, we been brushed off and told that they "didn't mean to be discriminatory", but no further consideration will be given to the matter at this stage.'

Cy is unwilling to accept the decision but is unsure how to proceed.

'We are blessed to be in a position where we have the education, abilities and resources to be able to challenge discrimination against our family. Many, many families do not and are resigned to accepting discrimination on a daily basis.'

Cedar and Trista

‘I do not want to see my boy fail. He sometimes sees prison as a life choice, because life is just too hard for him to negotiate.’

Cedar, early 20s, was born drug dependent,’ his foster mother Trista told the Royal Commission. He has attention deficit hyperactivity disorder, complex post-traumatic stress disorder and anxiety.

‘He cannot perform even simple mathematical tasks of addition and subtraction,’ she said. ‘He cannot remember key personal information such as his date of birth or phone number, and is unable to sign his full name. He cannot tell the time and has no real sense of time passing.’

Trista had also cared for Cedar’s father when he was a teenager and says children in the out-of-home care (OOHC) system don’t receive the interventions and support they need.

‘I believe that many young people raised in OOHC have significant cognitive and or mental health [issues] as a direct consequence of their birth parent’s alcohol and other drug use and generational trauma.’

Without support, Cedar struggled and his behaviours escalated. He would throw and smash things and sometimes threaten Trista. In his mid-teens, Cedar began to intimidate and frighten the other children in Trista’s care. She had no choice but to ask him to leave.

‘It was an incredibly difficult decision to make knowing full well that he was very immature and very vulnerable.’

The foster agency was unable to find alternative accommodation, so Cedar ‘couchesurfed’ with ‘mates’ he met on the street.

Trista would meet up with him and bring him food.

The foster agency referred Cedar to an 18-month program for young people leaving care who needed support to develop independent living skills.

Trista said it was a challenge trying to get him to accept the offer before he turned 18 and became ineligible.

As part of the program, Cedar lived in a flat on his own. Support workers were meant to help him develop the skills he needed to live independently.

But after a short time, the provider reduced his support because in their opinion he didn’t have high support needs.

Trista raised her concerns several times.

'Despite this and being provided with numerous assessment reports to the contrary, [the provider] never really understood the breadth of [Cedar]'s disability.'

Cedar never learned to prepare meals. He never used his oven – 'when he moved his pots and pans were all pristine'. He never used the washing machine and never changed his sheets – Trista had to buy him new sheets.

'His bathroom was foul and the kitchen sink full of detritus.'

Cedar would spend his entire weekly pay in two days. No-one supported him to pay bills and he left with unpaid debts.

At the end of the program he was evicted.

'There was no exit strategy ... [The provider] found him a shared room in a boarding house ... I said this was unacceptable.'

Trista said there were some positives – the provider engaged the NDIS and helped him get a job and stay there for a year.

Following a recent arrest, Cedar was diagnosed with intellectual disability.

The lawyer negotiated with police and they dropped the charges.

Cedar is now living in boarding house accommodation. He feels safe but refuses to use the kitchen and returns to Trista's house to shower.

'[He] finds life very difficult most of the time. He is really struggling,' Trista said. 'I feel that I have been left unsupported trying to hold him and keep him safe while he hopefully continues to grow into the amazing young man he can be.'

'I am particularly concerned for young people with disability compounded by trauma who have left, or are leaving, the care system across Australia. These young people and their carers need to be better assisted by the state and the commonwealth.'

Tye and Janna

Tye is in his 20s and has Asperger's syndrome and attention deficit hyperactivity disorder (ADHD).

His mum Janna works in education, but struggled to find Tye appropriate supports and to make sure he had an appropriate education plan 'all backed with medical evidence'.

Tye graduated in year 12 and passed several training courses.

'But then of course the next step is the workplace, and this is the barrier.'

Tye lost his first job because his employer expected him to work faster and failed to make reasonable adjustments.

'[Tye] went to them to say could he have someone to go and mediate with him to help him so he could keep his job, which of course nobody did.'

A disability employment service (DES) found him another unsuitable job, this time in a busy shop.

'It was completely against what the medical evidence showed with his documentation. He can't multitask, the overload with sensory with buzzers going off ... you've got to, you know, deal with irate customers. All of this stuff was too overwhelming.'

Tye resigned. Janna said the DES didn't appear to be serious about getting him a suitable job.

'He's got an individual plan and he refused to sign it because all they do is change the date on it, then he signs again for another year ... He refused to sign [because] they didn't meet the goals [in the previous year].'

Unable to find a job, Tye applied for a Disability Support Pension (DSP) through Centrelink.

'Somebody there said to him you have to come back every fortnight and check on the progress of your application. So he was going pretty much a whole year ... He has had Centrelink workers say to him, "You're a young man, you look normal." This is what they actually said, "You look normal just go and get a job."'

Tye learnt years later that his application was denied because of an administrative error. When he appealed, the Administrative Appeals Tribunal denied it again.

'It's straight in your face there that they were actually wrong. They wouldn't accept it so we went through that whole process with a huge expense,' Janna said.

During the process Tye developed severe depression and anxiety.

'There was two years where we nearly lost him because he was suicidal.'

Tye now receives the DSP, but still wants to work.

'He has skills and he's capable ... He cannot understand that if someone is employed to support him and people with disabilities, to meet their needs, why don't they do their job?'

Clare

Clare, in her mid-40s, is autistic. She also has complex post-traumatic stress disorder (PTSD) following 'years of trauma' and 'years of mess'.

'A lot of that is because I was an undiagnosed person with disability my whole life,' she said.

'I had multiple therapists just dump me after a couple of sessions and say, "We don't know what to do with you." Nobody recognised what was going on, you know ... so I went through all the mess and ended up pregnant with [my son] and then my whole life changed with children ... What happens when you have kids is your whole focus then becomes that little human and making sure they're safe and okay.'

Clare has several children, now in their teens. They are all autistic.

'We've got ADHD [attention deficit hyperactivity disorder] floating around and lots of PTSD,' Clare said. 'We're all this.'

Clare and each of her children receive NDIS funding.

'Handling that, learning that system, understanding that system and working it well for what the support needs are, is – is hard work.'

Helping multiple autistic children through the school system has given Clare insights she wanted to share. She told the Royal Commission that school is 'not set up at all for an autistic person'.

'It's set up for people to be going and doing this learning in a set way. It's not healthy for autistic children to be put into that environment.'

Most important is that kids are able to develop ongoing relationships with teachers and support workers.

'The only reason that my son is attending school is because he's built a relationship with his [support worker], and then he's able to go in because he wants to see her, and he's got another couple of mates there as well. And that's the only thing getting him in there right now, he doesn't go into the classroom, he sits outside in his own space.'

Such relationships are difficult to create at high school, where students work with numerous different teachers and support workers each day.

Clare went to a school meeting about her daughter and found she had been allocated four different support workers each day and was in classes with six different teachers. The arrangement was 'not going to work', she said, as the child needed 'key people' with her to keep her feeling safe.

She said this is why a lot of autistic kids 'fall through the cracks' at high school.

'Because they're having to build these bonds with somebody that they see for a very basic, brief amount of time. And the learning on top of that, it's too much and they don't cope.'

Two of Clare's kids now go to an open access college, which involves online learning and regular face-to-face meetings with peers at school. This works much better for them than a normal high school.

Clare believes the mainstream system needs to think more adventurously about how to cater to autistic students. They need more than 'a little basket of fidget toys on a desk in a corner'.

'People aren't being taught and trained in neuro-diversion friendly ways, they're being taught potentially the wrong things. They're not being taught by autistic adults what we need and what the kids need and that's huge.'

Natalya

‘Within a couple of months of ending up in the wheelchair, I just had these constant obstacles put in front of me instead of people trying to help me.’

Natalya is in her 20s and has been a wheelchair user for a couple of years. She was studying to be a nurse but things changed dramatically when an operation left her with physical and cognitive impairment, she told the Royal Commission.

‘They said that basically people in wheelchairs can’t be nurses and they asked me to leave my course. That hurt so bad. I’d been in the chair maybe a month. I didn’t even have time to process yet what I can and can’t do. I didn’t need someone else telling me that’s what I can’t do. Coz I was still really capable.’

Natalya followed her ‘really big passion in health’ into a different course.

‘But discrimination just kept occurring. I enrolled as an online student ... Then without any discussion of any sort I was forced onto campus during COVID times.’

That was ‘extremely dangerous’ for her physical and mental health, she said, and the lack of consultation ‘was just horrible’.

‘They saw no reason to have any online options for students with disabilities to participate and so I was actually pretty excluded.’

When Natalya did get to campus, the teacher talked to her with ‘a baby-like voice’ and ‘patted’ and demeaned her.

‘Like how you’d speak to someone as a toddler ... She was like, “Oh, I’m surprised you even came to class, I’m surprised you can do the work.” ... It was all focused on the fact that I had a disability ... I’m used to people putting me down but the rest was just horrible.’

In class, teachers made none of the reasonable adjustments in Natalya’s disability plan.

‘I am hearing impaired ... I couldn’t actually hear the majority of my classes.’ She ‘ended up having seizures’ in class because of the stress.

Teachers and students isolated and bullied Natalya.

‘Unfortunately, that’s a facet of society as well. No-one really talks to me, they talk to carers ... I had one teacher who encouraged the class to pick on people with disabilities to get higher grades. People who didn’t participate would actually get lower grades. And he would talk about how people with disabilities were a burden on society, how NDIS shouldn’t be existing, how the disability pension was just a waste of people’s money. And I would just sit and listen to this.’

Natalya contacted the disability unit about the 'constant belittlement'. Despite the university's pledge to provide staff with disability training, 'nothing ever went ahead'.

'I've been raising these concerns and they are treating all this as a complete joke.'

She also faced 'constant accessibility issues' on campus. The elevators were too small for her wheelchair and she had to 'crawl onto the floor, sit on the floor for the elevator ride'.

'Often, I was late for class because of this and, yeah, it was such a dehumanising process.'

The university 'didn't have a single measure in place to do with disability at all', Natalya said. She had to quit studying and has post-traumatic stress disorder 'because of everything that's happened'.

Lila and Tanith

‘The NDIS is a perfect example of government-sanctioned harm and neglect. It is legalised abuse.’

Tanith is a carer for her sister, Lila, who has schizophrenia, depression and cognitive impairment.

Tanith, who has her own health concerns, says she has ‘fought tooth and nail’ to get Lila ‘the care that she needs to be able to live independently’.

When the NDIS arrived, she ‘thought finally things could get better’.

‘But over time that hope has faded, and I’ve been thrust into a nightmare that I never could have anticipated.’

Lila’s plan was ‘not adequate’ and Tanith opted to self-manage it – ‘to have oversight on it to make sure that it was not drained by fraudulent parties’.

Tanith immediately encountered problems with payments. Her inquiries ‘still hadn’t been dealt with’ six months later.

She said the local area coordinator did nothing to help and was ‘dreadfully under skilled for the role’.

‘There was no communication ... I have never had a proper conversation with any LAC since the plan was first approved.’

‘You should be able to get their needs met without having to bash down doors.’

Then there were ‘ridiculous charges’ from service providers.

‘My sister has been overcharged for services. She’s had support workers try to siphon funding out of her account for their own benefit.’

Lila went on respite for a week.

‘The support worker tried to take extra money on a daily basis and justify certain fees and expenses.’

When Tanith spoke with the provider, she was ‘emotionally manipulative ... threatening to withdraw support’.

'In terms of the NDIS service provision, there's a blatant culture of fraud that is broadly deemed acceptable. They can get away with fleecing hundreds if not thousands of dollars off people because nobody is regulating them or overseeing them properly.'

Tanith arranged services through a new provider who 'made a lot of promises'.

But the next support worker was also 'completely disinterested in doing anything [Lila] needed' and was 'going through the drawers' stealing money.

'I don't know if she was held accountable because they didn't communicate with me after that.'

Tanith was involved in a 'months-long battle' at the Administrative Appeals Tribunal (AAT) over whether Lila 'had a rightful need for cleaning assistance'.

'I couldn't afford legal representation. NDIS staff made it look like my sister's needs were excessive or unnecessary. After an excessively stressful and abusive processes, I finally won everything that I argued for.'

Tanith sees it as 'a duplicitous and unscrupulous system' that makes disabled people 'invisible to society by denying them reasonable supports'.

'Those that I went up against in the AAT, they're complicit in the abuse of disabled people.'

Lila's plan has just been reduced again and Tanith's 'been fighting the medical system and NDIS all week'.

'They don't give you any reasons. We're trying to get her into her own house so it's thrown our plans into chaos. And it is forcing me to continue to care, when I cannot.'

Tanith feels the government is doing everything to cut supports to people with disability.

'They view them as abnormality that must be eradicated. The human rights of disabled Australians are being systemically violated. I cannot keep fighting the relentless daily strain of neglect, ableism and abuse levelled against us.'

Libbie

Aunty Libbie is a First Nations Elder and respected community member.

She has a rare neurological condition and uses a wheelchair.

Recently, the department of housing told Aunty Libbie she had to leave her home of more than 20 years and move to a different community. They want to demolish her house.

'I smile every day, but I feel like sitting out the back and crying. But that's not going to help me resolve the issue.'

Aunty Libbie told the Royal Commission that the department doesn't understand her disability and how devastating it would be for her to leave her home and community.

'I know my house, everything, and the space and the ramp are just right.'

The community looks out for Aunty Libbie and she feels safe and secure.

'I know everyone and I love my neighbours,' she said. 'Any troubles that I have here, I have my neighbours.'

Most days, Aunty Libbie scoots down to the local shops.

She visits the butcher and greengrocer or sees her doctor or psychologist.

On her way home, she stops at the grocery store.

Staff help her shop and place the groceries in a bag on the back of her wheelchair.

'When I get home, my neighbour takes it off and puts it on my lap,' Aunty Libbie said. 'If they do not, when I move to bed, the chair will flip.'

A local support worker helps her prepare and cook her meals and takes her to nearby therapies.

Aunty Libbie recently inspected the house that the department have offered her, and says it's dangerous.

'That house up there is not safe.'

The doors are not wide enough for her wheelchair and the bedroom is too small. The ramp to the front door is too long and the handrails are too wide for her to grip. The power points and light switches are either too high or too low for her to reach.

The department maintains the new house complies with Australian disability standards.

'They do not understand each disability is different,' Aunty Libbie said.

'They say I cannot refuse, or I would lose the offer.'

Aunty Libbie has engaged a legal service to help her convince the department to let her stay where is.

She is prepared to fight.

'Don't take any place if it's not suitable for you,' Aunty Libby said. 'Got to speak up and show them it is an accident waiting to happen.'

Rodger

A few years ago a court sent Rodger to prison.

'I was stupid enough to do some things,' Rodger told the Royal Commission. 'I will wear that for the rest of my life ... but to then further punish my family in the way that they were treated because of that, I found that to be completely unacceptable.'

Rodger's former partner is Deaf, but Rodger and his young child can hear.

Rodger said the prison allowed him only verbal phone calls, which effectively stopped him communicating with his child.

'I can't pick up the phone and call [their mother] ... because she is profoundly deaf.'

Rodger said when he complained prison staff labelled him a 'troublemaker'.

'If you care so much about championing the cause of the people with disability then why don't you go ... [to] where they reside within the prison?' they said to him.

Rodger jumped at the opportunity, and prison staff moved him to the area where prisoners with mainly 'cognitive disabilities, learning disorders' were segregated.

Rodger said there were 'no disability support workers at all' in the prison.

Rodger was able to help one Deaf prisoner communicate with prison officers.

'When he became aware that I was able to communicate using Auslan, every time he would see me he would want to come and have a chat and talk to me about what's going on and all that. Which I embrace because I can speak his language.'

Rodger helped another prisoner who had an intellectual disability.

'Instead of getting upset and frustrated and threatening to punch an officer or getting into a verbal altercation with another prisoner, he can come and talk to me about the best ways he can handle those sorts of things without going down that path.'

The prison eventually let Rodger advocate for prisoners with disability. Rodger said the incidents of assault and self-harming in that part of the prison fell from more than one a month to none.

'I had guys ... in tears on the day that I moved [out].'

Rodger said the prison lets outside healthcare workers in to support sick prisoners, but won't let support workers in to help prisoners with disability.

'There was only a benefit for them by prisoners being more comfortable and coming to me to explain what their issues were instead of having to go through a system that they were intimidated by.'

Rodger told the Royal Commission that better supporting prisoners with disability will prevent many of them reoffending.

'The idea with prison is to try and provide a rehabilitative environment to turn these people around. Today's prisoner is tomorrow's neighbour.'

Elinor

Elinor, in her mid-40s, has been diagnosed with schizoaffective disorder and post-traumatic stress disorder. She told the Royal Commission she disputes the diagnosis of schizoaffective disorder, for which she is being treated with psychotropic medications. She is required to take the medication under a Community Treatment Order (CTO), which her local mental health service applied for.

Elinor said that because of the misdiagnosis, she has experienced 'some difficulties in the system already'. But she can't afford to pay for another diagnosis.

'I recently went to a private psychiatrist and they were going to charge me \$550 an hour. But I believe I have autism and ADHD [attention deficit hyperactivity disorder], so I don't agree with the diagnosis that I've been under with the community treatment.'

Without medication for autism or ADHD, Elinor finds that sometimes her life 'gets really challenging'. When that happens, she checks herself into the mental health care ward at the hospital.

'Sometimes it's my family saying, "We really need you to go to into care," but it's mostly my decision.'

Elinor doesn't want to take the medications she been prescribed, which make her feel very unwell.

'I've been vomiting in the last week ... and I've been very nauseous, and I've got really bad exposure to the medication, so I'm very drowsy and I usually sleep for about three hours a day on top of sleeping 12 hours from night. And I don't feel like I'm my usual self.'

Because of the nausea and because she can't manage without afternoon naps, it's hard for Elinor to get a job. Her level of activity is much reduced.

'I used to read, but things that I used to have enjoyment with I no longer do. I don't enjoy reading. I don't enjoy walking because it makes me feel too over-tired, so I usually just do a little walk and I catch up with my mum and dad or catch up with a friend and that's all I do.'

Elinor had a job working for a local council. She told her managers she had concerns about using a particular piece of equipment because of her drowsiness. She thought it was a safety issue they should be aware of. But they asked her to send a screenshot image of the medication she was taking.

'And then they had a meeting and they just stood me down ... They said, "We don't need you to come back on Monday."'

Elinor believes she was discriminated against because of her medical history. Her employer made no effort to find other more suitable work for her.

'If you look at the law, that's unfair dismissal I'm sure,' she said.

'They said to me, "You didn't disclose it when you had your physical examination." But ... I completed the medical examination just fine and there was no question saying "Are you on any medication?" ... It just made me feel like a bad person because, you know, being on the medication, yeah, it means you can't be employable, which is not true.'

The medication affects her wellbeing, she said. She wishes she had a choice about whether or not to take it, but she has to comply with the CTO.

'If you don't comply with your medications they can put you into hospital.'

Elinor feels like no-one she sees in the mental healthcare system listens to her.

'They're very much about "We're going to do this for you, we think this will be good for you," she said.

'I feel like they treat me like a baby and ... having this community treatment order, this is another step in that process and they just want to, you know, keep me medicated ... They don't talk to me as an adult and they don't want to hear me and what I have to say.'

Cordelia and Purdey

Cordelia, in her 30s, has Down syndrome and intellectual disability.

As a young girl she attended a local private school that was accepting of children with disability.

‘They just absolutely welcomed her and she was thriving there with friends and good teachers.’

But after a few years, things changed. Cordelia’s new teacher was ‘a man who had a reputation for ogling girls and for walking in on them in the change room’.

One day, Cordelia came home from school crying.

‘I noticed that she had marks on her body. And I said, “Who did it?” And she told me the teacher’s name but she was ashamed. So, what he actually did to her was he squeezed her breasts ... He scratched her vagina and he ejaculated in her mouth. And she actually said it had happened lots of times. I was absolutely in shock and just trying to make sense of it.’

Cordelia led police to the small room where the sexual abuse took place. She told them the teacher ‘gave her a chocolate.’

There was an open box of chocolates in the room.

‘So whether it had happened with other girls or just with her, obviously that was lots of times.’

The teacher was charged, but the school ‘exonerated him’ and wrote to parents saying that ‘in the eyes of the state and in the church, he has no case to answer either to the community or his employer’.

‘Even though we moved [Cordelia] to a different school, I just felt a huge responsibility because the school was still taking in children with disabilities, more and more, and was welcoming him back on staff.’

When Purdey gave evidence to the school’s governing body, the teacher’s was finally dismissed.

‘There was still no, “We’re sorry this happened,”’ said Purdey. ‘There was never any offer of support or guidance or counselling. Their inaction is negligence.’

The ‘mental and emotional impact’ on Cordelia ‘was just devastating’.

‘From being this happy playful, engaging, funny little girl she became almost violent at times with these thoughts that were going through her head.’

Purdey wants to see ‘ongoing screening of teachers and staff in all education settings’ and ‘for schools to take seriously and investigate any reports of inappropriate staff member behaviour’.

Instead, in Cordelia's case, it's been 'isolating, blaming, victimising, stigmatising of the child'.

Today, Cordelia lives with post-traumatic stress disorder and obsessive-compulsive disorder because of the abuse.

Her abuse has been acknowledged through the national redress scheme, but never by the school.

Purdey says this acknowledgement would help Cordelia 'feel better'.

'She wants them to say, "Dear [Cordelia], we are sorry that you got hurt and damaged at our school. We are sorry that we didn't help you ... that you have been very scared, shaky, sad and worried for a very long, long time since. You are an amazing, wonderful, honest and brave young woman who told the truth. We believe you, we are very, very sorry."

Braydn and Dimity

‘It is like he is not welcomed anywhere.’

Braydn, seven, is autistic and has attention deficit hyperactivity disorder.

His mother, Dimity, told the Royal Commission she thought ‘things would be easier’ following his diagnosis, but that hasn’t been the case.

‘Even with all the medication and fortnightly sessions of OT [occupational therapy], speech and psychology, his behaviour has become escalated and violent.’

Dimity believes Braydn’s school is failing him.

‘While the school “says” all the right inclusive things I don’t feel they have the training or the expertise to deal with my son.’

The school’s strategy – to exclude Braydn from class and suspend him – isn’t working and makes things worse.

‘I feel my child is in limbo – he can’t cope with state school ... His IQ is too high for a special school.’

Dimity has investigated sending Braydn to a specialist autism school but she can’t afford the fees.

She has also considered homeschooling him but, as a single parent ‘with 100 per cent care’, she needs to work full time.

Every day is a struggle.

‘I feel that my son is losing out on his education. He is a very bright kid with things that he is interested in, but due to his outbursts and lack of ability to self-regulate he is sent to the office or home regularly.’

Dimity has to leave work almost every day to collect Braydn. She says it is not sustainable for Braydn or for her.

‘Parents of kids with disabilities need support and streamlined systems. We are dealing with so much – all the paperwork, phone calls, appointments and the child and what comes with the disability. It takes a toll.’

Dimity is trying to enrol Braydn in a ‘bush school’ part time but the ‘bureaucratic red tape’ might mean he will be unable to attend.

Dimity can't understand why the education department isn't jumping at the opportunity to help Bradyn.

'In this day and age, it is ridiculous to think the standard schooling system is adequate for neurotypical and neurodivergent kids,' Dimity said.

'My hope of the future of schooling for neurodivergent children would be choice. More options of schooling, as these kids learn in different ways and in different environments. Australia is a brilliant country. Let's be world leaders in educating and adapting school for neurodiverse children.'

Kirin

‘Employment is vital. You know you mix with the broader community, it engages people with disability in conversation and it gives us, or me, a sense of purpose. And I just don’t understand why it’s viewed as okay that people with disabilities be unemployed or underemployed in this day and age.’

Kirin is in her 40s and has cerebral palsy.

‘I have never accessed a disability service for my day-to-day needs,’ Kirin told the Royal Commission. ‘I was raised by a single dad who raised me with love and respect.’

Kirin’s father enrolled her in a mainstream primary school where one teacher expected her to meet the same goals as her classmates. But this was rare.

‘I remember ... talking with the school principal and talking about my ambition, which was to go to university, and that wasn’t really taken seriously. And I remember he was, “You don’t really need to go to university.”’

Kirin went to university and later enrolled in an honours degree, but struggled without reasonable adjustments. To get to one class, for example, she had to climb stairs.

‘I use a motorised scooter to get around. I can walk a little bit, but three flights of stairs carrying books, a laptop and all that stuff was a pain. And, I mean, I did ask the teacher at the time whether or not, you know, we could relocate it. That was shut down.’

It took Kirin so long to climb the stairs she often arrived late.

‘By week four when I came up the stairs I heard the tutor make some really disparaging remarks about me being later and later and then everyone laughing. And then I stopped going.’

When Kirin started looking for a job, she discovered it improved her chances if she disclosed her disability early in the process.

‘I found out when I went into interviews [where] I didn’t tell them ... they walked in, I was like, “Hi,” and I saw the shock on the panel’s faces.’

Kirin said when she’s applying for jobs and promotions, she’s often told she’s come second.

‘It’s not like in the Olympics where you get a silver medal. It’s, I’ve missed out. And I feel like at the moment I’m up against able-bodied people, ableism attitudes.’

Kirin said she sees those attitudes throughout the community. For example, her children walk to school and she often escorts them in her motorised wheelchair. One day, she had a baby strapped to her chest in a carrier and a woman pulled up beside her ‘almost on the footpath’.

‘She just yelled at me about how I’m an unfit mum, how can I put my children in that risk ... And then my little son ... just said to me, “Why is she yelling at you?” And you know I had to just say, “I don’t know, darling.”’

When she goes out with her husband, people often assume he’s her carer.

‘Or they like say, “He’s just a wonderful man, how amazing is he.” I’m like, yes he is amazing, but not in the way that you’re thinking, not in that patronising way that you’re thinking. That he’s so wonderful to be with someone like me. ... just because he can walk, you know, unaided, can speak in a normal community standard ... Does that mean I’m like a charity case that someone like him would want me?’

Kirin told the Royal Commission that to change attitudes, inclusion must be taught and applied at school.

‘If we don’t talk about it at school how do they talk about it in the workplace? How are adults going to talk about inclusion when they don’t really know what that means?’

Aurelia and Seshna

‘We’re the kids that don’t fit in.’

Aurelia is autistic and has attention deficit hyperactivity disorder and mental health problems. She’s decided not to go to school anymore ‘because of the way people treat’ her, she told the Royal Commission.

‘Like students and staff. I’m going to do distance ed next year, coz it’s really stressful. I’ve been bullied ever since I was in kindy ... And I thought they were my friends. Like, those were the only people who would hang out with me but then they still bullied me.’

Aurelia’s teacher was ‘really horrible’. She sent her all the time into ‘the shame corner’.

‘And I was stuck there for the whole lesson ... I dreaded class time in kindy.’

By year 1, Aurelia was ‘feeling so insecure that she hid under the teacher’s desk’, said her mother Seshna.

‘And, so, for the entire first term, the teacher just left her under there.’

At lunch times, Aurelia just tried ‘to tag along with people’ but ended up ‘wandering around the whole school just doing nothing’.

‘I’m like, “Well they don’t want me.” ... People made fun of me.’

Aurelia changed school several times.

At one of the later schools, a teacher’s aide was supposed to assist Aurelia with lessons. Instead, they grouped her with other children with learning disabilities and got them to play board games.

‘They’d just exclude me from the class ... And, so, I fell so behind in school.’

Aurelia told teachers several times that she didn’t want ‘to go and play’.

‘I wanted to join in the class. They didn’t let me ... That got me in trouble. [The teacher’s aide] would just yell at me ... So I would get no support.’

The principal at her current high school recently suspended Aurelia.

‘For basically no reason ... I’m so scared of her, coz she terrifies me.’

Seshna said the principal ‘used physical restraint’ on Aurelia. She ‘pulled her by her arm’ out of the class.

‘And that really hurt,’ Aurelia said. ‘I was so scared, and I just needed mum. She was like, “If you call her, you’re going to be in such serious trouble.” ... I was screaming and crying.’

Seshna said Aurelia’s experience of school deteriorated to the point that she ended up in hospital for weeks.

‘She developed a neurological disorder. Where all the stress and anxiety she already experiences from being a beautiful neurodiverse person was coming out in the extreme through her body ... That is why it’s been decided that she’s not returning to school.’

Aurelia would like to see children with disability welcomed at mainstream schools and ‘definitely feels that awareness is the start’. She finds special schools and support classes ‘demeaning’ and hates that her learning has been so disrupted.

‘I want to learn,’ she said. ‘It doesn’t matter what school I go to, it’s just the school environment. There’s so many dementors there ... I just feel miserable the whole time, and then as soon as I get into the car and get home, I just burst into tears. Just feels like – like, my soul’s just sucked.’

There is one reason she doesn’t want to leave.

‘I actually had friends, and I have friends at the moment. We all have some mental health issues, and – and all have anxiety. For the first time they’re actually proper friends, they understand me.’

Mika and Rhona

Mika is in her 20s and has Tourette syndrome.

‘She’s got complex [post-traumatic stress disorder] PTSD and anxiety as a result of how she’s been treated,’ her mum Rhona told the Royal Commission. ‘Tourette’s is a neurological disability ... and one would expect and hope that medical professionals, even if it wasn’t their area of expertise, would attempt to understand and would put effort into making sure somebody who has stated they have a disability feels safe.’

Doctors diagnosed Mika’s condition, which includes inappropriate language and tics, when she was in primary school. Rhona said she explained Tourette syndrome to Mika’s high school when she enrolled her.

‘They said all the right things ... and by second term she was suicidal. We had the counsellor at school decide that [Mika] didn’t have Tourette’s, she had an abusive family.’

Staff told Mika she’d ‘end up in jail’ and would ‘make nothing of her life’.

‘I ended up taking her out of the school. She was on suicide watch for six months.’

With Mika’s tics escalating, Rhona took her to a psychiatrist who told her she needed to get her daughter ‘under control’ or she’d be in trouble with the police.

‘My response to her was, “That’s why I’m reaching out to you as a specialist. What can we do?” And she ended up saying, “I don’t know anything about Tourette’s. I can’t help you.”’

Rhona said some doctors refuse to see Mika because of her outbursts of swearing. One day, Mika started swearing in a medical waiting room and someone called the police.

‘She was talking, the swear words were coming in between. She’s like, “I have Tourette’s. I can’t help it.”’

Rhona said the police startled Mika when they turned up and her behaviour became worse.

‘They put her down on the ground while she was screaming “I want my mummy. Please call my mum.” And they put handcuffs on her.’

Rhona said the police took her to a hospital mental health unit which refused to accept her because she didn’t have a mental illness.

‘The head of the mental health ward was trying to explain to the police what Tourette’s was, and the best they could come to was it was a misunderstanding.’

Rhona said Mika, despite wearing a medical bracelet, has since had several violent interactions with police.

‘You know if she has a Tourette’s attack somewhere which results in her screaming and running around I’m concerned they’re going to shoot her.’

Rhona said Mika’s condition appears to be getting worse partly due to stress.

‘She’s going through a phase of grieving at the moment ... [saying], “This is my life and what life do I have? And, you know, all my friends are getting married and having babies and doing all the things that I’ve been wanting to do. And here I am just trying to figure out life.”’

Miena

‘I look back and see I was sick, I had bipolar, I was in a manic. And I saw all the drugs that kill heaps. I’ve been the one that has cut the chain of abuse.’

Miena was sexually abused as a child and has lived with mental illness ever since. For years she was ‘suffering an anxiety disorder and post-traumatic stress disorder and not knowing and understanding’.

‘Because back in the day I wouldn’t speak about stuff that happened to me because I was too ashamed,’ she told the Royal Commission. ‘And I’m still a traumatised girl. My illness makes me suicidal and I get so overwhelmed with triggers of traumatic memories.’

Miena was in and out of psychiatric wards. She said police treated her ‘like a criminal’ when they took her to ‘the psych hospital’.

‘And it’s all scary in there, and, you know, the whole system of mental health is.’

Miena’s anxiety worsened seeing the ‘white padded rooms’ and ‘wardens giving injections’. She said mental health staff offered her no support.

‘That was terrifying because there’s other patients in the psych ward that are really psycho and scary and, yeah, it was horrific.’

Over the years, doctors prescribed her a lot of different drugs.

‘I needed antidepressants because I was just sleeping all the time and just crying and felt hopeless and helpless. And you know, there was no quality of life there at all for me ... And then I got put on Xanax, and I was never educated of the dangers of them. I just got told to take them when I felt anxious.’

Miena hid from the world, fearing she’d ‘turned into a drug addict’. She feels psychiatrists were wrong in ‘trying to medicate memories and pain’.

‘All of the prescription drugs the whole time were prescribed, so I didn’t misuse them. I didn’t doctor shop. I ended going off them cold turkey and then I got what is called benzo withdrawal syndrome. It was the worst six years of my life.’

Miena got help from a specialist.

‘He put me back on [an anxiety treatment] after two years of suffering real bad. And I’ve been stable on that for about eight years now.’

The NDIS has been a saviour, Miena said. She learnt about it at a critical time when she was having ‘a really big breakdown about everything’.

A counsellor put Miena in touch with a service provider and today she has a 'beautiful support worker'.

'And, yeah, they're helping me in so many ways. And I wouldn't be alive if that didn't happen. I wouldn't leave the house because I was petrified of what was outside the gate. Now, in the last year, I've started going out. I have created a day and I call that Friday fun day.'

Francois

‘They treat you like a criminal.’

Francois, in his 50s, is on an involuntary treatment order for schizophrenia. He told the Royal Commission he’s faced lots of abuse over three decades in the mental health system.

‘During the 90s especially. Dangerous drugs that go back to the 1920s that they used on me. And my forced injections, just criminal, using threats of violence against me. I mean, they will show up with the police at my place, and they will say, “You will either have your injection or 10 people will hold you down and give you the injection.” Things like that.’

Once, Francois said, mental health staff asked police to handcuff him while he was having his injection – ‘for some stupid reason. And of course, they’ve declined.’

In all that time, the psychiatric hospital never offered Francois the right to legal advocacy services or counselling.

He believes the earlier treatments had an adverse effect on his health.

‘I’ve been diagnosed with type 2 diabetes, which is possibly from the antipsychotic medication I’ve used. Now I need dentists because of the injections that they used on me. So that caused me some tooth decay. I just feel like I was ... one of the bad cases.’

Francois’s doctor referred him to a community health service for help.

‘And they declined to see me, for some unknown reason. They won’t tell me why. They said it would be unethical and negligent of them to tell me.’

He finds that ‘pretty poor’ and knows others who’ve had similar problems from the drugs.

‘The thing that’s getting me, I want to have dental implants but I can’t afford them on the pension. Mental health service, they should be liable for them.’

Francois tried to speak with his mental health team about the possibility of switching to other medications, but said they refused to see him.

He’s tried several other psychiatrists.

‘They all turned me down with some ridiculous excuse like, “We don’t see people with schizophrenia,” “We only see criminal cases,” “My books are closed.” Excuses like that are getting common.’

Esteban

Esteban, in his late 20s, is autistic and has severe anxiety disorder. He lives with his mother and receives NDIS funding for support workers.

Esteban is concerned that service providers are not held accountable.

He told the Royal Commission about an occasion when he and his support worker found themselves in a difficult situation, but the support worker seemed only concerned for himself.

‘He wasn’t offering any support, and I was becoming increasingly stressed ... So I told him he had to leave because it was stressing me out.’

Esteban spent the remainder of the day alone and outside until his mother, who had been out of town, was able to assist.

Following that episode, Esteban asked the service provider for access to his file. He wanted to know how it had been reported. His mother contacted the provider first of all, but the supervisor she spoke to refused to give her any information – ‘even though I’d listed her as someone authorised to operate on my behalf’.

‘They were very aggressive with that. And so when they refused to talk to Mum, Mum eventually had to put me on. And then they refused to accept the request from me unless I gave it in writing, which I have difficulty responding to emails and composing them in a prompt timeframe.’

Esteban ‘tried very hard’ to get his request dealt with over the phone.

‘But the supervisor told me that she didn’t think I was as disabled as Mum said I was and I said I was ... Even though I can’t handle emails properly, she insisted that I could.’

Esteban eventually filed a formal request for documents, and the service provider handed over copies of some correspondence between them. It was clear there must be much more in his file, so Esteban then put in a request to the NDIS Quality and Safeguards Commission to see all his records.

Through this process Esteban was given an extensive file of information, but much of it related to someone else.

‘It said stuff like [Esteban] is an alcoholic, has a gambling addiction, has been sexually threatening towards staff.’

The episode that prompted his inquiry in the first place was barely mentioned.

'There was no incident report for that at all. The file simply stated that, "[Esteban] agreed to conclude the session early," ... when I was so stressed I couldn't keep dealing with the guy.'

Esteban complained to the NDIS Quality and Safeguards Commission again. It told him that the service provider had apologised so there was no further action it could take.

'And at that point we had not received an apology, so we raised that issue. We received a call from someone at [the service provider] who offered an apology, but I asked them if they knew what the apology was for, and they said they did not know. I don't know how you can apologise for something you're not aware of. But it's not apologising for what we experienced. We raised that with the Quality and Safeguards Commission, but they told us an apology had been issued. We asked for an apology in writing, they did not deliver, and the Quality and Safeguards Commission closed our file.'

Esteban has since changed service providers, but still has concerns. The new provider charged him for multiple hours of labour it said were needed to produce his plan, but the plan was computer generated and full of errors. When he insisted the provider correct the errors, they charged him again.

Esteban reported this experience to a fraud hotline and said it was promptly dealt with.

He believes there is an issue of procedural fairness that needs to be addressed.

'Every time there was something going on, the [service providers] have the last say on everything.'

Lucan and Jonty

Lucan is in his 20s and is autistic.

‘He’s also very barmy and whacky and likes to joke and dance,’ his dad Jonty told the Royal Commission. ‘His autistic traits come out largely when he’s under stress or pressure or when ignored or neglected or whatever.’

Jonty enrolled Lucan in a mainstream school, but discovered its disability unit was ‘largely segregated’.

‘They were kept to separate playgrounds. They had separate equipment and very, very, rarely mixed with the mainstream kids.’

One day a teacher locked Lucan in a cage within the unit.

‘He was bawling his eyes out. Sitting bawling his eyes out because he couldn’t simply push his mates around on the scooter. Just simple stuff, but appalling.’

Jonty took Lucan out of the school, but couldn’t find one that offered Lucan an inclusive education. He ended up enrolling him in a special school, but discovered it was funded based on what Lucan couldn’t do.

‘How often do you need assistance with your food etc, etc? ... They used that process ... to work out how much of a deficit you had. It was all a deficit approach. There was no sense of looking for attributes and [what] you might be able to do in the future.’

When Jonty later enrolled Lucan in a mainstream high school, he had to ‘fight like hell for any integration’.

When Lucan attended a school camp, he ended up being locked in a room. His behaviour deteriorated from that point.

‘He was never the same after that camp ... Whatever happened, it’s traumatised him.’

Jonty said a psychiatrist prescribed antipsychotic medication that made things worse.

‘His behaviour just got more unreasonable and [he] couldn’t sleep, couldn’t stay still. Because he was [given medication] ... each time his behaviour would go backwards or [he’d] end up in hospital trying to get some help, they would increase it.’

The NDIS supports Lucan, but as his behaviour deteriorated Jonty struggled to find him suitable accommodation.

‘When it came to us needing accommodation he went into hospital and we camped in hospital.’

Eventually, Lucan entered a group home, where he became constipated due to poor diet. There was no fresh fruit or vegetables – everything was frozen.

Jonty said one service provider kicked Lucan out of the house for refusing to use their day service as well as their overnight care.

Frustrated with the poor service and lack of options, Jonty set up a family company. Lucan now rents a house in his own name and his family helps him control his independent living options.

‘My wife runs the menu and house, lots of the house stuff. I do the hiring and firing and staff.’

Lucan now has a permanent job.

‘He’s got real mainstream friends there who are all older than him, but he’s very much a part of the team and ... he loves it.’

Peg

Peg, in her mid-30s, has multiple mental health disorders, some caused by trauma. She also has a neurological condition she described as ‘quite physically disabling’, with symptoms that include paralysis and fainting.

Because of these and other health issues Peg has needed to seek out emergency care several times in recent years, but she said she won’t do so again.

‘For me, accessing care in emergency departments has been very traumatic and to me very abusive, and I’m actually at the point now where I – I don’t access care from emergency departments. Even if I am quite unwell, I still won’t access an emergency department.’

On several occasions she went to a hospital emergency department because of extreme abdominal pain, and each time was discharged without a diagnosis. Sometime later she experienced the pain again and returned to the hospital. This time staff carried out a series of invasive procedures including inserting a catheter. Peg screamed out as this process was underway, but the nurse ignored her.

‘At that point I sort of realised it didn’t matter what I said or did, I just had to behave,’ she recalled.

‘As a trauma survivor, I mean – you may get a lot of triggers in the pelvic area, and there was just absolutely no understanding and absolutely no room to tolerate my level of discomfort ... I think I just felt so abused in that situation, not because of what they were doing but because they just used so many tactics of gaslighting me and just dismissing my experience, dismissing my pain, dismissing my triggers.’

She described another occasion when a nurse challenged her account of her symptoms. When the nurse found out about Peg’s mental health history, she ‘started to sort of gaslight’ her, Peg said.

Another time, Peg experienced unrelenting migraines for weeks and her GP advised her to go the emergency department. The doctor she saw there asked her why she had come.

‘What are you expecting to get out of your presentation to emergency?’ he asked.

‘Like, no doctor says that to a person coming in, in an emergency,’ Peg said, ‘but for me that’s what he said. As if I had a choice ... Like I thought, “Oh, you know what? I might just go to emergency for the afternoon and waste, you know, 10 hours there.”’

Peg believes medical staff in emergency departments need better training to help support people with disability or mental health issues. Her experience in those settings has included emotional abuse, neglect and the withholding of treatment.

‘They treat you in a way where they’ve already deemed you as crazy, and they use those aspects against you or it’s a further reason why they neglect your care,’ she said.

‘They don’t have time to have deep emotional conversations because I guess most of the time their line of work is life or death, but when it comes to disabilities, mental health and chronic pain, they need to – they still need to adapt their level of care so that they’re open and I guess willing to hear people’s experiences in order to care for them properly.’

Audra

‘Why is it that hearing people have choice of over 30,000 qualified and registered psychologists and counsellors in Australia when there are around maybe 20 in the whole of Australia experienced in supporting Deaf with their mental health needs?’

Audra is Deaf. Auslan is her first language.

Last year she needed to access mental health treatment.

‘I was in a really severe stage,’ Audra told the Royal Commission ‘... after going through so much.’

Audra found it difficult to access information in Auslan about services. She contacted a government agency who gave her a list of organisations to contact.

But no-one was intensively trained in ‘deafness mental health’.

‘Where is mine?’ she asked. ‘Where is my access as a Deaf person?’

Audra says telephone counselling wasn’t suitable and the National Relay Service doesn’t operate 24/7.

‘Not all Deaf people have strong language foundation to establish English as their second language and to be able to express themselves in English via texting services.’

People need to be able to access services and information in their own language, she says.

Audra would like universities and TAFEs to introduce mandatory Deaf mental health and Deaf awareness training for all medical and allied health professionals.

‘It is imperative that Deaf people have access to support with professionals not judging them – no traces of audism and ignorance.’

Audra says professionals must understand the communication needs of all individuals.

‘It is time to stop giving hearing people all the access to mental health services.’

Yasmina and Evianna

‘On any given day we never know if she will get through seamlessly or if out of nowhere she is going to be ridiculed and teased and made fun of because of the way she was born, the way she looks ... just because someone feels it’s okay to make fun of her disability for a cheap laugh.’

Yasmina, pre-teen, has short stature.

Her mother, Evianna, told the Royal Commission the family have done their best to prepare Yasmina for people being curious and looking at her.

They have also made substantial efforts to educate their community, social groups and Yasmina’s peers about her disability.

‘Sadly however, [Yasmina] has often come home extremely upset because she has been teased for her appearance and how she looks when she walks and runs.’

Evianna says the stares and comments have taken a toll on her daughter’s wellbeing and self-esteem.

Yasmina’s passion is competitive sports.

She loves training for and competing in multi-class events, despite knowing she will come last.

Each time she competes at carnivals, children laugh at her, point at her and make rude remarks about her body and how she moves.

At a recent event, almost all the other children competing whispered or snickered about her. One boy pointed and loudly remarked, ‘Hey check that out. Look at her. Look at her body.’

Evianna was chaperoning Yasmina and told the boy to stop being so rude.

He stopped the verbal abuse but continued to point and laugh.

Evianna intervened, more firmly, warning him if he didn’t stop she would report him.

‘For her to experience this public humiliation at the hands of such a rude young boy, to then have to ... try to compose herself to [compete] – an experience she should have been so excited for – is so wrong and unfair.’

Evianna tried to remain positive but the comments hurt Yasmina and ‘tainted her day’.

‘Worse still, she was only trying to succeed at something she loves, something she has taken so long to build the courage to participate in, knowing she looks different.’

Evianna believes there needs to be zero tolerance of cruel behaviour.

'Online joking and mockery of short statured athletes is disgusting. Posting people with dwarfism on social media for entertainment and jokes should have the same consequences as posting racist jokes, offensive religious jokes, inappropriate sexual content, cruelty to animals and jokes about other disabilities.'

Evianna hopes the ridicule and abuse won't stop Yasmina living the life she is entitled to live.

'So much more public education and awareness is required for this minority group ... who just want to live their lives like any other ordinary person, not for the entertainment of others ... Shitty jokes versus a person's LIFE!'

Marguerite

Marguerite is in her 30s and has borderline personality disorder, complex post-traumatic stress disorder and cognitive impairment. Until recently she was homeless, which she puts down to poor housing services in regional New South Wales.

‘I’ve been sleeping in my car,’ she told the Royal Commission. ‘And since when I came here, I also been struggling finding an emergency accommodation. There’s nothing really here.’

Meanwhile, Marguerite can’t get proper mental health support. Even in the closest city, she said, ‘there is nothing at all’. She finds it odd that there’s no public mental health services for such ‘a big population’.

Marguerite tried a couple of specialists.

‘They just turn their back on me ... They just said, “Nope, we cannot handle your situation ... You’re so very complicated.” And they’re neglecting me with my needs ... Like, you are a medical professional. I know what are – what is your duty of care?’

Her only option is going to a capital city for care, but she hates ‘crowds and traffic’.

Marguerite is trying to get support from the NDIS.

‘I’ve been working on that since last year. It’s hard for me to do it without a case coordinator. Especially that I am struggling with my mental health.’

She is ‘overwhelmed by the paperwork’ and doesn’t understand why she’s ‘been declined’ several times.

‘It’s too complex. They got endless questions and it’s just repetitive. The list goes on. I submitted them hospital records, medical reports, specialist reports, different types of victim services counselling, physiotherapist, you name it. Medical practitioners, everything, but it’s insufficient.’

Her psychiatrist is encouraging her to try for the Disability Support Pension instead.

‘He told me, “It’s so hard for me to make a report because NDIS are very demanding.”’

Meanwhile, Marguerite feels it’s going to take ‘years and years’ to qualify for social housing. Local housing services keep questioning her eligibility, despite the evidence provided by medical professionals.

She finds her current lodgings unsafe, but the department is not giving her ‘a right to choose’ where she lives. She said that after she complained, they ‘threatened [her] with homelessness’.

‘And they told me, “Well, we are housing you and you should be grateful for that.”’

In the last year, Marguerite has 'been admitted several times' to hospital – 'Because of homelessness and I have nowhere to go.'

The lack of stability is having a 'negative impact' and heightening the risk of her 'taking impulsive, risky behaviours'.

'That's why the psychiatrist asked me to stay in hospital for I think almost two weeks, because they know that I'm going to kill myself any time.'

Marguerite is feeling increasingly isolated. She is struggling to find work due to her mental health history. Everywhere she turns, she's finding barriers.

'It's like a broken record. I'm just so tired of always trying to please everyone, just to accept me and give me a chance.'

Zeth

Zeth, late teens, has intellectual disability.

He lives alone and has no family support. '[He is] a fully independent person,' his advocate Sammy told the Royal Commission.

Zeth grew up in foster care. At 17, his foster placement ended.

Zeth moved to supported accommodation with other people with disability.

He struggled to adjust and became determined to live on his own.

Zeth accessed a rent subsidy scheme and moved to a small studio flat. But his rent subsidy ends soon, putting him at risk of being homeless.

Zeth isn't eligible for a full Disability Support Pension (DSP) until he turns 21.

Even with the rent subsidy, he struggles to cover basic and essential needs, such as food, electricity and warm clothes during the colder months. He is often behind on bills, despite his efforts to budget.

'This causes [Zeth] great stress,' Sammy said, 'as he is often concerned about making ends meet, and has no savings or safety net to fall back on.'

Zeth and Sammy believe he should be entitled to the same rate of DSP as a 21-year-old.

'This would afford him a greater sense of financial security and more opportunity to participate actively in community.'

Zeth says there is no difference between the way he is living independently and the way someone 21 years or older lives independently.

'Measures of independence, and not chronological age, [should] determine the rate of pay a young person receives on the DSP,' Sammy said.

The public trustee became Zeth's guardian when he turned 18.

'This arrangement adds further stress,' Sammy said.

Utilities often threaten to cut services because the public trustee hasn't paid the bill.

If Zeth needs additional money, he has to contact the trustee. Recently, he needed medicine.

He emailed the trustee and received an automated response. When he rang, they took 10 days to respond.

This was too late – Zeth had to ration food to afford the medicine.

Zeth wants the government to compel the public trustee to respond to requests in a more urgent manner.

He believes there should be a more personal approach.

'If a representative from the [public trustee] was to come and speak to [Zeth], to establish a relationship with him, build rapport and trust, this would greatly increase his confidence in interfacing with the organisation itself,' Sammy said.

Ki and Tobi

Ki, in his mid-30s, is cognitively impaired and has the mental age of a young child. His friend Tobi told the Royal Commission he was concerned about the care provided by Ki's support worker, Marco.

Tobi says Marco has a history of violence, including towards him. Marco has been violent in front of Ki, though not to him, and in Ki's mind this behaviour has become normalised. Now Ki has learned to be violent as well.

'[Marco] has shown [Ki] his explosive temper, right, that's caused [Ki] to go to work and do exactly the same as [Marco] did,' Tobi said. '[Ki] has gone to work at the sheltered workshop and been violent towards other people. And that's caused him to lose his job twice now.'

Tobi considered taking out a restraining order against Marco for some time and finally did so. Marco retaliated by taking one out against Tobi, which prevents him from speaking to Marco and from contacting anyone at the service provider Marco works for.

Tobi's wants to ensure Marco stops providing support to Ki.

'[Ki] would be a lovely man, but the way he is now you don't want to be around him, you know, and that's because of [Marco]. And somebody has to do something about it.'

Tobi has reported Ki's situation to an abuse hotline and to the NDIS Quality and Safeguards Commission, but can't get anyone to take his concerns seriously.

'Everyone's told me to piss off,' he said.

The NDIS told him they can't intervene for 'legal reasons'.

'The legal reasons are that [Ki] is the person who has to make the complaint.'

Tobi can't see a way to improve Ki's situation.

'Because you have to go through idiots like the national abuse hotline, right? So I can't affect how [Ki]'s life will pan out other than to remove him from [Marco], but then I have the fear that the next person they're going to allow to look after [Ki] is going to be just as bad.'

Bonita

Bonita is a First Nations woman. She is a survivor of domestic violence and has post-traumatic stress disorder (PTSD).

Bonita's been living in the same public housing flat for more than 30 years. A few years ago she ticked a box declaring she has disability.

'I ticked that box. Like I didn't previously ... I didn't want to be labelled as living with a disability.'

Bonita said after ticking the box, a public housing officer searched her home for the first time.

'He went through my house. My daughter was very sick in the first room ... I said to him, "My daughter's in that room and she's asleep and she's sick," and he went into that room ... and I feel sick because I allowed that man to be in a room with my daughter. And I'm not saying anything happened, but I'm saying it's wrong.'

Bonita fears the man will return looking for reasons to move her because she has a disability.

'So yeah ticking a box. What does it actually mean? Does it mean that then they come in twos?'

Bonita is a social worker and said a few years ago she was applying for a new job through Centrelink when a Disability Employment Service (DES) contacted her.

'Obviously they're linked to Centrelink and they saw that I live with disability. They said to me, "You're on the wrong stream," you know. "Let us support you."'

Bonita said even though she had a job in mind, the DES told her she'd lose her Centrelink benefits if she didn't sign a contract with them. The DES also insisted on seeing every payslip from the new job she lined up.

'I said, "I don't get it." I said, "I get my job and you're stealing my life." And then they said "We're going to call you every fortnight."'

Bonita said the DES kept calling her at work and she felt so intimidated she quit the job to try to escape them.

'I'm not stupid. I got another job and then off I went.'

She said the DES continued to call demanding she sign a new contract with them for the new job she'd found and asking to see her payslips. When she declined they sent someone to her home.

'They came to my place several times and a big bloke too and you're a survivor of domestic violence. They don't know, but still they should be mindful of that.'

Bonita said the DES is still threatening to send people to her house until she signs another contract.

'I get their emails. "We will not leave you alone until you call." Like, "This will be unresolved until you make contact with us." And then I get another one. "Do you want a hundred dollars?"'

Bonita said she locked her gate to stop the men coming to her door.

'I changed jobs [again] because they said to me they were going to come to my workplace,' Bonita told the Royal Commission.

'They were going to come to my workplace and they were going to talk [to my boss] and I was just like, "No you're not" ... I felt threatened ... It's still carrying on today. I don't know what I'm going to do.'

Francoise

Francoise is a transgender woman in her 30s. She has attention deficit hyperactivity disorder and dyslexia.

Francoise told the Royal Commission she was ridiculed and bullied at primary school.

‘Because of my disability, I struggled with some things. Not only was I not getting the help that I needed, which caused me to be disruptive, the teacher put me inside a cardboard box, basically, so that I couldn’t even see the blackboard ... And this box was pretty much around my whole desk and it made me the centre point of ridicule. Not only from the students but from the teacher herself. Which totally shattered my self-esteem as a young kid.’

Francoise faced more abuse at the next school.

‘The principal at the time took me into the staffroom and told me to pull my pants down, um, coz he had – he was going to whack me on the arse with a cane. Looking back on it now, I guess ... it was quite a perverted thing that he did.’

Around this time, Francoise said her stepbrother raped her ‘at knifepoint’.

‘I was always scared of him. And he was left alone with me and that’s what he did. And it was more than one occasion.’

A couple of years later, after reporting the abuse to her mother, police interviewed the boy.

‘He was lying about it for a while, and then, um, eventually told – told the truth and they let him go,’ Francoise said.

Growing up, Francoise was dealing with the sexual abuse and ‘transgender issues’.

‘Like I didn’t want to come out when I was a teenager because I was already getting bullied by other kids at school. I went off the rails as soon as I hit high school.’

Francoise feels that the lack of justice over the rape led to her ‘addiction to child exploitation material’ and current incarceration in a correctional centre.

‘In a sense it actually told me that it’s okay to abuse people. That was the message. Being told, nah, it’s all fine. It’s all good to get raped up the arse.’

She recently came out as transgender, but says she ‘isn’t receiving much counselling’ in prison.

‘I’ve also been diagnosed with autism. I’m barely even seeing my psychiatrist at the moment to check up on the medication.’

For a few years, Francoise has been 'trying to move forward in life' and start her own business.

'I'm on a disability pension on the outside, and I just can't get anywhere with that ... I get social anxiety, um, like I can't even hold a job because I'm too anxious about working. I just lose myself in my own self sometimes and I – I just – and I fail. And then I end up in here.'

All the harm, she said, 'sprung mainly from that one incident'.

'Like I wanted to be an astronaut, I wanted to be one of the first people on Mars when I was a kid. And now look, I'm in this fucking hell hole.'

Rainey and Nestia

Rainey has psychosocial disability and lives with the consequences of a spinal injury. She receives NDIS funding for a range of services, which until recently included mental health support. This was provided by Nestia, a psychologist and positive behaviour support practitioner.

Nestia has worked with Rainey regularly for several years and said she is 'a lovely young lady' with a traumatic history that has left her with significant trust issues.

It took Nestia some 40 or 50 hours to establish a rapport with Rainey, but after that their relationship functioned well and Nestia felt Rainey made good progress towards her goal of greater independence.

But Nestia has concerns about the way some of Rainey's support workers treat her.

'They engage in behaviours that they are explicitly told not to. So they are told very clearly, "Do not do this, it will cause her to escalate," and they've continued to do it.'

Nestia reported her observations to the service provider but they didn't do anything. She said the provider 'has been neglectful'.

Rainey's NDIS plan is managed by an NDIA complex needs planner. The planner recently decided that Rainey could no longer choose which allied health professionals she worked with. The decision came after Rainey asked to switch service providers.

'The NDIA's view is that she should be forced to learn to get along with the provider and that she should be forced to work with them,' Nestia said.

Rainey engages in 'frequent and furious self-harm'. Despite this the planner has not included funding for a psychologist in her plan. This means Nestia's role is no longer funded.

'So the planner made this decision ... The planner had never had any communications whatsoever with [Rainey],' Nestia said.

Nestia has provided 'so much documentation' about Rainey to help the NDIA understand her needs, but the planner has ignored it.

'The planner has basically rejected everything that I've said as the clinician. So apparently she, as a non-mental health trained professional, knows more than I do as a trained mental health professional who has worked with this person for over two years.'

The planner's changes to Rainey's plan had immediate effect. There was no thought given to transitioning Rainey or organising a proper handover. To protect Rainey from the impacts of this, Nestia has been visiting her weekly without getting paid.

She has also complained to the NDIA's Quality and Safeguarding Commission and asked for intervention to ensure Rainey has an adequate plan, including mental health support.

'They have done nothing. Very literally nothing. They don't even reply to emails.'

Nestia is very concerned for Rainey's wellbeing.

'I've got a very vulnerable young lady who has been failed throughout her life. She's now being failed by the NDIA. She's being failed by the Quality and Safeguarding Commission and she's being failed by the NDIS supports around her. And no-one will do anything to help her, even though they have the information available to them.'

She believes the NDIA and the Quality and Safeguarding Commission just want people like her to stop asking questions.

'They don't want to have to do this work. They don't want to have to answer questions that they don't know how to answer. There's a real lack of training, of quality of education within those who work within the commission and those who work within the NDIA.'

Ngarra

‘We’re struggling hard. Please listen ... We need help.’

Ngarra is a First Nations man living in regional Australia.

He has a physical disability and uses a wheelchair.

Prior to being discharged from hospital, a disability service provider gave Ngarra a wheelchair to use in his home and a scooter to use outside.

‘They give a second-hand scooter, second-hand wheelchair, not even a brand-new,’ he told the Royal Commission. ‘We need brand-new. Stop treating us this way.’

Ngarra’s house is ‘very, very old’, with steps leading onto a veranda.

The wheelchair didn’t fit through most of the doors in the house.

‘I have to go really slowly ... Otherwise, stuck.’

Ngarra couldn’t access the kitchen, laundry or his bedroom.

Ngarra applied to the NDIS for a new wheelchair, a new shower chair and home modifications.

‘You know, they promised me and promised me they’re going to make it wider. That was last year. But nothing was done.’

Someone did come and install a ramp but they didn’t consult Ngarra.

The ramp is too steep, in the wrong place and poorly designed.

Dogs drag things up the ramp and into the house and snakes can get in the house.

‘Grandchildren play around there, but we can be bitten by snake or dog.’

There is no concrete path from the ramp to the road. When it rains the ground at the bottom of the ramp turns to mud and becomes slippery.

Ngarra often can’t leave the house because he can’t get his wheelchair from the ramp to the road.

Trapped at home, his power bills are much higher than before. Some weeks he has to choose between paying for food or power.

If Ngarra doesn’t pay the power bill, the food in the fridge spoils.

‘All getting rotten because no power ... All the meat, we’ll have to throw it away for dog.’

The house has become infested with cockroaches. Ngarra wants help to clean it and fix up some of the holes.

‘Why don’t they fix all these things for us?’

‘We’re living in old houses. We’re living with the cockroach and mouse and everything. When are you going to start thinking about and giving us a good thing, cleaning houses? Who’s going to fix our house? Who’s going to paint our houses?’

Ngarra recently had a fall because his shower chair is broken.

‘I can’t have shower now. I have to go with the wheelchair and slowly sit on the floor, clean on floor of shower.’

Ngarra believes he is being treated unfairly.

‘Just because I’m an Aboriginal bloke. If I was a white man here sitting, they will do it quickly. I’m another colour.’

Ismael and Jiya

Ismael is in his middle years of primary school. He is autistic and has attention deficit hyperactivity disorder (ADHD). His mother, Jiya, is neurodivergent and also has ADHD. The disorder makes it hard for her to be organised and to manage the needs of her family. In particular, it is difficult for her to ensure Ismael's needs at school are met.

'I am always losing things and forgetting things. It doesn't matter how hard I try, I'm making careless mistakes multiple times a day. Which often means I have to do things over again ... I struggle so much to follow conversations and I'm always overwhelmed. This makes advocating for my son incredibly difficult. I feel like I'm never doing a good enough job,' she said.

Ismael suffers from extreme sensory challenges and anxiety. He struggles socially and has no friends although he 'desperately' wants them. His nervous system is in a constant state of dysregulation, and he experiences extreme fits of anger and rage multiple times a day.

Jiya told the Royal Commission that Ismael has been discriminated against since he started school.

'He has been punished, excluded and shamed more times than I can count.'

As Jiya tries to get the correct supports for her son in place, she has found the school unhelpful and unsympathetic. Executive staff would not meet with Ismael's psychologist or allow his OT to observe the class.

Jiya asked the school to put an individual education plan in place and to be consulted.

'I was handed a "final" plan and told "this is not the draft, it's the final." In the plan someone checked off that I had been consulted in making the plan... which was clearly not true.'

Jiya gave Ismael's teacher permission to call his paediatrician, but the teacher then asked the paediatrician to medicate Ismael – which Jiya had not agreed to.

Without the necessary supports, Ismael's behaviour at school became extremely dysregulated.

'I decided to keep Ismael at home until we could organise a meeting with the school to put new supports in place. This took five weeks to happen. So Ismael missed out more than half of the term.'

Jiya has depended on the skills of a neurodivergent educational consultant she hired to help manage the situation.

'She knows and understands the exact supports Ismael needs at school. If it weren't for her, I would have had to pull him out permanently.'

However, for reasons Jiya doesn't understand, the NDIA has told her Ismael's NDIS funding cannot be used to pay the consultant. She plans to appeal the decision.

Jiya wants schools to stop using 'abusive behaviourist approaches' in the way they deal with students like her son.

'I want teachers to be better supported and educated on how to support neurodivergent students ... I want schools to provide truly inclusive education.'

Kalifa

Kalifa, late teens, is from a culturally and linguistically diverse background. She is autistic and has intellectual disability and mental health conditions.

As a baby, the department of child protection removed Kalifa from her parents and placed her in foster care where, her advocate told the Royal Commission, she was abused, neglected and witnessed violence.

Following a hospital admission when she was a pre-teen, child protection moved Kalifa to a secure residential facility where, again, there were 'instances of abuse and unfair treatment'.

At 18, the department moved Kalifa to supported independent living (SIL) accommodation.

The advocate said Kalifa and her parents felt the provider disrespected her.

There were no curtains on the windows in her bedroom. Staff neglected her hygiene and personal care and she often had lice.

'The fridge for [her] food was found to have virtually nothing in it aside from pork and veal – in contravention of her halal food plan.'

There was also a 'revolving door' of female support workers.

'[This] meant consistency, something [Kalifa] really needs to achieve her NDIS goals, was lacking.'

Kalifa's family made a number of complaints.

The disability service provider agreed to relocate Kalifa to a home by herself.

Suddenly, they decided to move her to mix-gendered household where she would be the only female.

Kalifa's mother strongly objected to the move.

'Being moved to a home that includes males is in violation of [Kalifa]'s Muslim religion,' the advocate said.

The family made an official complaint. This was when they discovered Kalifa was now under the care of the public guardian.

'It is unclear as to why [Kalifa] had guardianship imposed upon her,' her advocate said. 'Her family members were not even informed about the process taking place.'

The family contacted the guardian, who was unaware of the move. They begged the guardian to stop the move and suggested several culturally appropriate SIL homes.

‘All pleas on [Kalifa]’s behalf were disregarded.’

Staff in the new home stopped supporting Kalifa to attend Friday prayers and religious celebrations.

‘Somehow family visits became a problem for guardianship authorities.’

Staff failed to keep Kalifa safe.

‘She had a particular housemate who was violent and made her so fearful she would not leave her room – not even to use the toilet. Support workers assumed she was staying in room by choice and just leave her there, and not even feed her.’

After one incident, Kalifa was hospitalised.

The local area coordinator intervened and moved her to another house managed by a different provider.

The new provider had never had a SIL client before and there was no handover.

‘They had no idea about [Kalifa] including her allergies, her likes and dislikes.’

She didn’t have sufficient medications to last a full day and no feminine hygiene products. When the family asked the guardian for some money to buy the things Kalifa needed, the guardian was unaware she had moved.

Kalifa’s advocate says the public guardian is not doing their job.

‘Why were [Kalifa]’s support people the ones who had to notify guardianship authorities and act when she was moved to a mixed-sex premises in defiance of her and her family’s cultural values – not to mention [her] personal safety – and when she was moved again?’

Kalifa says her family is ‘at the end of their tether’.

Nicoline

‘It really affected my daily life. I felt like I was in a form of pain all the time. And it made me very depressed, and I just wanted to end things.’

Nicoline was diagnosed with paranoid schizophrenia a few years ago and admitted to a psychiatric ward.

‘I was in hospital for about a year. And then they let me out into the community,’ she told the Royal Commission.

On her release, Nicoline was placed under an involuntary treatment order.

‘Which means they controlled whether I had medication or not. And the medication that I got ... had some pretty negative side effects. And every time I tried to talk to the doctors about it they wouldn’t even respond. They’d just um and ah and then not tell me what was going on. And they left me on this medication ... I really struggled for these three and a half years.’

Nicoline started having suicidal thoughts and uncontrollable restlessness, but doctors still ignored her.

‘I would have liked to have tried other medications because these side effects are only apparent in the atypical antipsychotics, and they’re pretty bad. Your suicidal risk goes way up and they can have more permanent disabling effects if you’re left on it for too long.’

Her caseworkers tried to help.

‘They all knew something was quite wrong ... They did what they could. They’re not doctors. They even asked for a reduction, like the amount of time between injections.’

Nicoline’s mental health team eventually took her off one drug, but not the monthly depot injections.

‘It didn’t take away the shaking, like my involuntary movements or you know, the irritability.’

Nicoline ‘tried to find out what was going on’ on the internet.

‘But it didn’t even have anything close to what was going on with me.’

She finally learned the truth when she ended up in a correctional centre.

‘I was able to refuse my medication after being taken off the involuntary treatment order.’

A prison psychiatrist was worried about the symptoms Nicoline described to her and gave her information on the possible fallout of her medication.

‘On the list were Parkinson’s disease and (one of its symptoms), akathisia. She’s put a note for me never to be placed on that medication again.’

Nicoline feels she has akathisia disorder as a result of medical neglect.

Most of the side effects have gone, though Nicoline still has trouble standing and sitting.

‘Even sitting for five minutes it’s painful. I just don’t feel like I’ve got the muscle strength.’

But she feels like she’s in a much better head space.

‘I’m not on any medication at the moment ... I’ve gotten much more confident. I’m focusing on educating myself while I’m in prison. I’d like to make sure that when I get out, I don’t have a hospitalisation again. Because I’m not really sure if the effects are going to come back.’

Claudio and Alphonse

Claudio has schizophrenia and is under an involuntary treatment order. Alphonse, his brother, says Claudio has been ‘screwed up in every way by mental health workers and psychiatrists’ for most of his life.

‘They’ve caused him so much damage, and nobody looks into them ... It’s criminal behaviour.’

Claudio believes doctors and mental health workers have inappropriately medicated Alphonse, and that he has been abused in their care.

‘They sedated him so much – they’ve stopped doing that now – that someone came into his room and they raped him and he couldn’t move or nothing, and my sister saw cum on his backside. And he puts poo on the walls. He never does that. I’d say that was a side effect from being raped.’

The police were ‘not allowed’ to investigate, Alphonse said, and ‘the psychiatrist at the time put it down as a delusion’.

‘That’s how disgusting and harmful it’s been.’

After that, Claudio had some good psychiatrists who prescribed an antipsychotic.

‘And that worked so good for years and he’s still on it, but then he got a new government psychiatrist. This quack comes along and puts him on the depot injection as well. And my brother’s been in hospital nine times since he’s been on this injection, and he’s been so sick. And for the few years before that, no hospital at all.’

The treating psychiatrist gave the family ‘no say on all the rotten bad side effects’.

‘He would never talk to family. No way will he. That’s their rule ... And there’s no point talking to mental health nurses. They’ll do malpractice, lies, whatever to support the psychiatrist ... support their power.’

Alphonse said Claudio was fearful of complaining about the medication.

‘He’s got to be careful not to say anything, because the person who’s really in the system has to be quiet. You can’t make your mental health workers angry,’ Alphonse said.

‘Once the quacks get into you you’ve got a mental illness, you’re screwed for the rest of your life. And you’d better not complain or you’ll really get it.’

Alphonse went to a tribunal to fight Claudio’s treatment, but said the whole hearing was skewed against the patient.

'No matter what the evidence is, it's irrelevant. They will still support the mental health worker, totally, 100 per cent. Must be billions of dollars that the government just waste in mental health matters through the system of tribunals ... They say, "Oh, that's all for the rights of people." Load of crap because, hey, family can't speak and the patient most certainly is not going to speak.'

As he advocated for Claudio, psychiatric staff tried to have Alphonse assessed for mental illness several times.

'To shut me up ... They're targeting me. I don't have mental health issues, but because of my complaint, they're trying to schedule me and put me on antipsychotics.'

After Alphonse complained to the health practitioner regulation agency, Claudio's psychiatrist walked away.

'And so another government psychiatrist came ... He listened to us. We're weaning my brother off that injection.'

While this is a positive development, Alphonse has no faith in Australia's mental health system. He said people like his brother 'feel hopeless'.

'You've got no rights to your life. And you've got no say. And that's detrimental to a person's mental health.'

Tane and Robby

Tane is in his 50s and has schizophrenia.

‘He’s highly intelligent and he knows how to play chess,’ his brother Robby told the Royal Commission. ‘He loves to go to the beach and he’s getting a bit tired of this concrete courtyard.’

Several years ago Tane lived independently, but struggled to get reliable support workers.

One day there was a fire in Tane’s flat. Police allege he lit it intentionally, even though ‘he has no previous criminal history and according to his long-term neighbours he was not responsible for the fire’.

A court ordered that Tane be admitted to a hospital mental health unit.

A couple of years later doctors transferred him to a mental health facility in another city. Robby said this was against Tane’s wishes.

‘He’s got stable housing [where he lived]. The reforms of the mental health [Acts] across Australia are saying that he’s got a human right to be in [his] community.’

Robbie said a psychiatrist told him there is ‘no recovery’ for Tane. He fears the facility will never release his bother.

‘This is a subjective space ... There’s no biological marker and, you know, are they really the sole people that should be deciding on what risk?’

Robby said psychiatrists are relying on ‘subjective criteria’ rather than objective evidence to keep Tane locked up.

‘We’re not talking about bloods, scans or x-rays like other doctors. We’re only just talking about using psychotic medications [with] adverse side effects.’

Robby said Tane is eligible for the NDIS and should be living in his community in supported independent living accommodation with 24-hour care.

‘I’ve never seen a medical opinion or anyone say that these closed wards are a great therapeutic setting for people like my brother who have experiences of paranoia. Furthermore, you’re going to put ... people with the same symptoms all together in a concrete box and incarcerate them indefinitely? What? That’s the medical model?’

After Tane was involuntarily admitted to hospital, Robby became his guardian. Despite his and Tane's objections, doctors ordered Tane to undergo electroconvulsive therapy (ECT).

'[Tane] doesn't like it.'

One day a psychiatrist rang Robby to tell him that Tane 'lost cognitive function' after a treatment, but that the ECT course would continue.

'I'm just gobsmacked. I just can't, like, he's just lifted himself off the canvas you know. So that's what I'm dealing with. So that's the space I'm in.'

Emme

Emme, mid-40s, is a proud Deaf and First Nations woman. Auslan is her main language.

Growing up, Emme wasn't allowed to sign. She used hearing aids, which didn't always work, and tried to lip-read. If people didn't face her and speak slowly she couldn't understand them.

'They forced me to be oral by depriving me of food until I said words correctly,' she told the Royal Commission.

In early primary school, the principal moved Emme to a special needs class because she was so far behind her peers. Emme couldn't communicate with the Deaf children in the class because she couldn't sign.

'I was bullied by the Deaf kids and bullied by the hearing kids.'

Emme struggled to learn in Auslan or English.

'It was so stressful and tiring to communicate ... I had to struggle every day. I didn't want to go to school.'

In high school there were no interpreters. Sometimes a teacher from the primary school interpreted for Emme.

'He was not a qualified Interpreter and had only a basic level of signed English.'

Emme said she felt 'angry and frustrated' and was vulnerable.

At 14, Emme was raped.

Her mother took her to hospital.

'Throughout the process, my mum had to interpret for me. It meant that my mum was talking to the doctor, and I had no idea what the process was in the hospital. I had to undergo a full physical examination so that the hospital and the police could obtain the forensic evidence. There was no interpreter at that time, only my mother.'

Police took Emme's statement without interpreters.

'They wrote questions down. I had no understanding of what they were asking, so I had to try to lip-read. I had to try and answer my questions that way, and through my mother as well ... I just signed the statement because my mum said, "Sign."'

In court, the teacher from Emme's primary school interpreted for her.

‘An unqualified Interpreter became my only voice.’

There was no conviction. Lawyers told her mother it was because ‘the case was very weak’.

‘I started on drugs and abusing alcohol. I actually became a problem child from that time on because of those rapes.’

Emme started living on the streets.

Once, police arrested her for being drunk and took her to the watch house.

‘The police knew I was Deaf, and that I relied on hearing aids. I asked the police, “Please can you speak slowly so I can understand what you’re saying?”’

Police told her they didn’t like her attitude and she had to stay overnight.

‘I had to remove the hearing aids, and my rings, and all personal items, and they put them in a property bag. Then they said, “Follow!” I had to follow, and we had to walk quite a long distance to the cells. I started to panic. I was ... really young ... I started to scream, and I asked for help.’

Police left Emme in a cell with no hearing aids.

She yelled and yelled. When no-one came she tried to suicide.

Police took her to hospital and released her without charge.

In her 20s, Emme started to access more Auslan and became involved in the Deaf community.

‘I work with the police a lot, and the police never think about their responsibility to provide an interpreter for a Deaf person. The police think it’s a Deaf person’s responsibility. Or the police think that writing words down on paper – to communicate with a Deaf person – is good enough. It’s not good enough.’

Emme said the courts are still poor at providing access to interpreters.

‘Adequate access to interpreters depends on where you are or where you live,’ she said. ‘Access to independent interpreters should be given to Deaf and hard of hearing people in all circumstances, and lack thereof should be made illegal.’

Jeanne, Lucienne and Taranna

Jeanne is in her late 40s and has physical and intellectual disability.

Taranna, Jeanne's new support coordinator, said Jeanne's supported independent living (SIL) service provider neglected her safety, health and complex care needs.

'While she was living there she had lots of skin degeneration, she had lots of urinary tract infections, she had blood clots, she wasn't really treated, you know, looked after really well. She then was raped by a staff member that was on duty, so there's been an awful lot of trauma.'

The NDIS has 'failed to address the trauma', Taranna said, and is 'just pushing the family away'.

'Because it's a bit of a too-hard basket, is what it seems to be. And no-one's helping.'

Meantime, the NDIS has cut several hundred thousand dollars from Jeanne's plan.

'They won't even look after her and are saying that the family should do it,' her sister Lucienne said. 'I've got all my therapists, I've got my doctors, like, we've got medical letters and we've got all this evidence. And I've gone in there 20 different times, they take my statement and then I never hear from them again. I feel very fobbed off, very discriminated against. Then we go into crisis mode because they cut all our funding and then she is at risk.'

Jeanne is 'bed-bound' and uses a peg feeder. Her doctors say she needs two-on-one support constantly. But the NDIS disagrees.

'We are so sick of hearing the NDIS say that's not value for money, to have two staff members on at night,' Taranna said. 'Obviously, that's going to place her in further harm and neglect.'

Taranna has asked for three reviews of Jeanne's plan.

'Every time a plan comes out she's reduced more and more and more, going against all the professionals' wishes.'

Taranna says Jeanne is currently dependent on her family 'to get through every day'.

'She requires two people to lift her and she also has extremely brittle bones ... So that's what we're dealing with.'

The service provider is still being funded, but 'they're not doing anything'.

'They're not delivering complex support ... There's no training of her staff.'

Lucienne believes the NDIS should never cut plans 'if there's no change in disability'.

‘Do not touch funds that you’ve already said are necessary and reasonable. Unless they can prove that the person has improved, gotten better.’

She says the system is ‘destroying families’ by putting them under so much financial strain.

‘We’re not asking for something we shouldn’t be allowed to have. She needs this stuff. We’re not asking for holidays, we’re not asking for cars, we’re not asking for stuff like that. We’re asking for stuff for her to be safe and alive and as healthy as we can get her with all her disabilities.’

Hakeem

Hakeem's family migrated to Australia when he was a young child, some 50 years ago.

When Hakeem started at the local primary school, he was an easy target. He didn't speak English well and he also stood out because of a physical disability.

Both students and teachers victimised Hakeem. Children enjoyed poking him with sticks that had been smeared with fecal matter from the toilets. They would tease him by singing songs that mocked his physical impairment. Teachers punished him physically and by segregating him from other students.

High school was just as bad. Hakeem experienced a lot of physical abuse. Looking back, he thinks teachers' attitudes towards him were typical of how 'ethnic' children were treated at the time. The violence of his teachers – at different times he was caned, hit and locked in a cupboard – made it very difficult for him to learn.

He also began fighting with other students when they picked on him for his difference. He feels he attracted abusive behaviour. He recalled being 'bashed up' on a regular basis. He was always in trouble, and always at the principal's office.

Hakeem left school as soon as he could. Having left school, he felt he did not fit in anywhere. He really needed support.

Hakeem spoke to the Royal Commission about other people he knew of who had succeeded despite their disabilities. But they had received help getting an education and other support. But when Hakeem left school he could not even write his own name. He later found out he is dyslexic.

The trauma of these early years and lack of education have affected Hakeem all his life. He has never been married and has never had a serious relationship. He does not have children. He believes women look for breadwinners, and he wouldn't qualify. He didn't even have his own bank account until well into adulthood, and has been homeless at different times.

Hakeem completed a vocational education course that qualified him to work on trucks and other vehicles. He owns a small workshop, and is thinking about selling it so he can buy a permanent home.

Different doctors and psychiatrists have diagnosed Hakeem with personality disorders, schizophrenia and post-traumatic stress disorder.

Life is difficult and Hakeem is pessimistic at times. But at other times he counts his blessings. Australia is a much safer place than the country his family emigrated from.

Koda and Romina

Koda tried to suicide shortly after he was charged with a criminal offence. His brain was starved of oxygen and he sustained an acquired brain injury (ABI).

He is totally dependent on his mother, Romina, who is his legal guardian.

Romina told the Royal Commission Koda always maintained he was innocent of the crime he was charged with. But following the ABI he has no memory of the alleged crime or the events leading up to it.

Koda's lawyer advised him he would be found guilty if he went to trial.

'[Koda] would go to prison for a very long time,' the lawyer said. 'His only chance was to plead guilty and get a light sentence for doing so.'

Romina said Koda 'was frightened on hearing this and agreed to plead guilty'.

'He was forced into a guilty charge because of a lack of memory and fear of being put away for a long time.'

At the first hearing the judge asked for more information about Koda, and delayed sentencing.

Romina sent a personal letter, an in-depth report from the head injury unit and letters from Koda's NDIS therapists and doctors.

The occupational therapist [OT] stated Koda's ABI 'had affected his short-term memory, verbal comprehension, initiation of important tasks and ability to follow through on instructions without support'.

Koda needs constant reminders to eat and drink and take care of himself.

The OT noted Koda 'experienced difficulties with keeping track of a conversation, understanding what is being said to him ... [and] tends to agree with ideas he has not fully comprehended'.

The OT made it clear the NDIS 'is not available to people who are incarcerated' and the 'stress of incarceration would hinder the rehabilitation process'.

Romina told the judge the ABI changed Koda completely. He is 'the total opposite of what he used to be like'. He is 'non-violent, never abusive'. He no longer smokes, drinks alcohol or frequents bars. He is 'quiet, lacks confidence', has low self-esteem and is introverted.

Romina said she feared Koda, being 'a person of colour' from a different cultural background, would be the victim of discrimination and abuse.

On the day of sentencing the judge said he had not received the documents and ordered a recess so he could read them. Romina said the judge was 'angry' and 'on returning he was clearly still annoyed'.

The judge sentenced Koda to almost five years in prison.

'[I] strongly believe if the judge had enough time to read the report and reflect, he would have made a different decision,' Romina said.

The judge said Koda would get the 'same care on inside as on the outside', but Romina has recently visited Koda and this is not the case.

No-one reminds him to eat or drink. No-one reminds him to eat foods that are good for brain function. No-one reminds him about his personal self-care and hygiene. No-one reminds him to get enough sleep and make sure he has enough stimulating activities to do each day.

Koda doesn't have access to occupational and speech therapy and the psychology sessions he was receiving.

Romina told us the prison is overcrowded and she wants people with disability to be 'housed in a facility that will not neglect them but help them'.

'When someone who is not a threat to society or has no indication of offending again, is sent to prison, what are their chances of returning to society a better person?'

Romina fears Koda 'will either deteriorate to the point of no return or will die in there'.

Blane

Blane is in his 40s. He is autistic and the father of an autistic teenager. About 10 years ago his partner died.

'[My partner] at this stage did have custody of [my daughter] and she was living with her boyfriend at the time.'

Blane told the Royal Commission that the child protection department took his daughter into care. When Blane applied for custody, a child protection officer said he couldn't care for his daughter because he's autistic.

'It is stated right here. "[Blane] is limited in his ability to understand [her] needs and development due to his Asperger's disability." ... [But] Albert Einstein had autism. Bill Gates has autism. Half the scientists in NASA have autism.'

Child protection also claimed his daughter would be 'at risk' in his care, even though he has no criminal history and had never been violent or used illegal drugs.

'They painted me as being incapable of looking after myself, to look after [my daughter] ... specifically on the basis that I have a disability.'

Child protection then placed his daughter with a foster family in which a family member 'tried to sexually assault' her.

Blane says the child protection system has 'an ingrained prejudice' against people with disability.

'I've noticed unfortunately that the older generations, the ones that have been in the ... system and basically all the ones making decisions, they seem to have a very much more prejudiced view of all different kinds of people.'

Blane now has a partner, having married a few years ago. Child protection still only allows him access to his daughter for one supervised hour every few weeks.

'[It] is utterly ridiculous. It makes no sense,' he said.

'I am fully of the belief that because I have autism myself [I am better] able to understand and teach [my daughter] ... One of the main things I found with my disability is that we need to focus on some form of direction ... If she gets to that she will succeed in whatever she chooses to do. I guarantee it.'

Blane doesn't want to remove his daughter from her latest foster family because they have 'been with her for so long and have established a very good relationship with her'.

'All we wish is to have more contact.'

Caitlyn

Caitlyn is Deaf. About a decade ago when she was pregnant, Caitlyn's employer retrenched her. She found another job coaching Auslan interpreters in schools.

Caitlyn said the training provided by the education department was 'really good'. The problem was when she started using it.

'This is about me being a language model for the young kids so they can develop Auslan and so when I [started work at a school] the teachers were like, "No that's not your job. We're the teachers. We run the show here."'

Caitlyn said many of the interpreters employed by the school weren't Deaf and resented her help.

'Sometimes the interpreters would really push back and go, "Well you don't have to tell me how to sign."'

When she tried to advocate for students who complained about the quality of interpreting, she was told not to talk to the interpreters.

'I said this is my job. I'm here to provide a language model for the interpreters as well as the students.'

Caitlyn said one day she was reprimanded for suggesting staff use Auslan at school and not signed English.

'[The education department] eliminated the use of signed English in schools ... they're the rules. And so when I brought this up, you know, everyone's head kind of spun.'

Caitlyn said although she was doing the job she was employed to do, the interpreters called a meeting to complain.

'Everyone else's perspectives were taken into account [at the meeting], and as the Deaf person in the room no-one would listen to me.'

Caitlyn took sick leave and a doctor later diagnosed PTSD.

'I just completely had a breakdown. I'd get in bed and I'd stay there. I couldn't do anything. I became a bit of a shell of myself.'

Caitlyn told the Royal Commission there's a disconnect between education department policy for teaching Deaf students and how some schools apply it.

'They have these huge conflicts in these regions where things are done differently.'

Brocket and Delvine

Brocket was diagnosed with a degenerative disease when he was a boy. He died in his mid-20s. His mum, Delvine, believes his disability service provider was responsible for his death.

‘We don’t know if [Brocket] could have been saved or not,’ she told the Royal Commission. But we think that if somebody had turned up, he may have still been here with us.’

Brocket loved fishing, camping and going on trips with his dad. He was very bright, his mother said.

He went to school in his electric wheelchair and participated as much as he could. Despite frequent hospitalisation, he did very well.

After completing school, Brocket wanted to live independently, like other young men his age.

An organisation building new homes for people with disability agreed to build him a fully accessible home.

It took a few years and Brockett finally moved in when he was in his early 20s.

A disability service provider supplied support workers.

In the morning, staff got Brocket out of bed, showered him and gave him breakfast. They took him shopping and to do other activities. In the afternoon, another support worker arrived to get him dinner, shower him and put him to bed.

Brocket liked to have his personal care ‘done his way’ so he felt comfortable.

He became frustrated with the high turnover of support workers.

‘A lot of carers didn’t see his point of view,’ Delvine said, and he was forever ‘training’ new people.

Brocket made a complaint to the provider but nothing changed.

Brocket decided to switch a new company, hoping a smaller provider would be able to supply a stable group of support staff.

About a year later, Brocket started to have fits.

‘He would get thrown around in his wheelchair a lot,’ Delvine said. Support workers needed to be attentive.

One afternoon, the evening support worker didn't turn up for their shift. No-one organised a replacement.

The next morning, the day support worker found Bocket dead in his wheelchair.

'He had smashed his head on the corner of a cabinet and had bled out,' Delvine said.

'We blamed [the service provider] for this not having [a] policy in place, for not getting anybody to do the shift of the person that never turned up.'

Monnie and Karinya

Monnie was diagnosed with autism as a young teenager. It didn't stop her from functioning well. She attended school, moved out of home and was able to get and keep a job.

But while working for a big company, someone sexually assaulted Monnie. No-one believed her. Her mental health broke down, leading her to be hospitalised for some months.

Afterwards she moved into her parents' house. They belonged to a strict religious community and were very controlling of Monnie. They had already reclaimed control over Monnie's affairs after she was initially placed under the guardianship of the public trustee.

Monnie later asked for a review, and this led to the guardianship being split between the public trustee and Monnie's parents, who remained in charge of Monnie's NDIS plan and medical decisions.

Monnie is in her early 30s now, and Karinya is her support worker. Karinya thinks Monnie's parents employed her because she grew up in the same religious community.

'Because I had no training. This is the first time I'd done any kind of support work. And I think they were relying on that.'

Karinya said that Monnie's parents made it clear they were in charge of Monnie.

'When I came onboard her parents very strongly portrayed to me that I was accountable to them for everything, and I was in no way to accommodate [Monnie]'s wishes if they contravened what they had told me. In any area. They were telling [Monnie] things like that she wasn't an adult, so she didn't have the rights of an adult.'

After some time working with Monnie, Karinya attended an NDIS training course. It opened her eyes to some issues in her role as Monnie's support worker.

'Doing that course made me realise that NDIS considered that I was, you know, more responsible to [Monnie] and [Monnie]'s wishes than I was to her parents. And so I started to voice that to the parents and, yeah, so they were getting increasingly unhappy with me.'

Monnie knew her parents wanted to fire Karinya.

'It's their way of controlling,' Karinya said.

But when Karinya spoke up, Monnie decided to speak up too.

'I think she'd just been biding her time for years, until she felt that she had strong support around ... [someone] that would stand up to her parents,' said Karinya.

When Monnie initiated another review of the guardianship order, her parents told her she had to move out.

Monnie now has control over her own medical decisions, and a sibling manages other aspects of her NDIS plan. She has broken off contact with her parents.

'She's been emotionally and psychologically abused since she was a kid, since she was little, yeah. And this is the freest she's ever been. Which is – you know, she's struggling with as well because now she's got freedom, she doesn't quite know what to do with it,' Karinya said.

Monnie's parents had only let her see a counsellor chosen by them, and they wouldn't let her see a behavioural psychologist at all. She has started seeing a trauma counsellor and a behavioural psychologist.

'Now she can access the help that she needs,' Karinya said.

Karinya said attending the NDIS course was 'pivotal' in what followed, and to Monnie escaping her parents' control. She hopes the Royal Commission will recommend mandatory training for support workers and carers. She also wants the matter of accountability to be clear.

'Yeah, whatever recommendations that the DRC comes up with, particularly for people who are under a guardianship, is to make sure, you know, that the carers understand who they're actually accountable to.'

Honor

Honor has attention deficit hyperactivity disorder (ADHD) and mental health issues. She wrote to the Royal Commission about the lack of understanding the education system shows towards people with disability.

‘My school knows my history not only with ADHD but also with mental health. [A] specific person neglected to read my personal records that have information in them about how to handle me when I’m in an episode.’

The assistant principal threatened Honor with police intervention for not taking off a piece of jewellery. Honor says she had been ‘distracted and hyper focused’ on doing her schoolwork.

‘A teacher should never threaten the police on a student, especially if the student is not being threatening or [is] non-violent ... the way my school also handled the situation was horrible.’

Honor hopes that in the future ‘our schools are filled with teachers who are kind and understanding, not aggressive and threatening’.



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