



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

Voices of people with disability

Book 2



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.

Hilary

Hilary's parents are Deaf.

'I was Mum's and Dad's interpreter,' Hilary told the Royal Commission. 'English was my second language ... It's only in my later life that I have really picked up the English and understood it. I still think in Auslan.'

Hilary isn't Deaf, but said she didn't start speaking until she was five 'because [her family] used Auslan in the home'.

Hilary still interprets for her parents.

'[My mother] couldn't even get an interpreter for a solicitor's appointment yesterday through video remote interpreting. I couldn't get anybody for the whole of Australia. I had to interpret my mum's solicitor appointment.'

Hilary works as a professional Auslan interpreter in a regional city. Much of her work is with First Nations people in the legal system.

'They haven't got the support. It's really, really sad for the Deaf [in remote communities]. It's just heartbreaking, what I have heard, some of the stories. Grew up in a hearing household remotely and didn't understand. Just heartbreaking. And the access to interpreters [in remote communities] there is very difficult.'

Hilary said when Deaf First Nations people first come into contact with the legal system it can be 'life and death'.

'How many times have police pulled people over and then they're arrested because they're making all these terrible noises? It's because they're Deaf and they don't understand. Some Deaf can be very loud and can sound like they're being violent, but they're not.'

She said some end up in court without knowing why.

'Before we go in, we're talking to the lawyer and the Deaf person says, "I had no interpreter when the police were talking to me. I was put in handcuffs and walked away. I don't know what I did." ... They have no idea. I nearly cried. And have come home so many times after court just going, "My goodness. This poor person. If they had an interpreter we would know what had happened."'

Hilary said there are no Auslan court interpreters in her town who can speak First Nations languages. As a result, some people 'don't understand what's happening and how there's a law in all of this, because they grew up in remote areas'.

Hilary said she wants to learn First Nations languages, but the high demand for her services means she doesn't have time.

'I can go 21 days straight without a break ... There's not enough of us.'

Dominick

Dominick, in his mid-50s, describes himself as an 'incomplete quadriplegic'. He has paralysis in his arms and legs following an accident in his late teens. On a good day he can walk a bit, but mostly he uses an electric wheelchair.

When he returned to school after his accident, Dominick was bullied for being 'spastic' and was unfairly suspended.

He lobbied to hold the school accountable and eventually received a government apology. He dropped proceedings after that.

'Sometimes you've just got to put it in its box, lock it away and just carry on,' he told the Royal Commission. 'Or else you're a blubbering mess, you'll never get anything done, you know?'

Dominick sees that experience at school as an introduction to the discrimination that has followed.

'The common theme is that a disabled person – how dare a disabled person assert their human rights, you know ... The ableists are offended and the way they express that offence is either through verbal abuse or physical abuse.'

Dominick gained several degrees at university. He withdrew from his studies in one faculty because of the lack of support, and enrolled in another where he was welcomed. In a third, he was met with open prejudice. The faculty dean asked why he'd chosen to study there, saying, 'You're a cripple, you can't write.'

In his professional life, employers have not given Dominick jobs he is well qualified for, or promoted him when he should have been. He gave examples of unexpected office restructures that made his role redundant. He described mentors leaving and a new manager terminating his employment.

One employer did offer Dominick a permanent job, but for substantially less than he was earning in the same role on contract.

'I said, "Fred, how's this fair, mate? ... Is there any room to negotiate?" He said, "You either take it or leave it." That was his attitude towards me, after being at an organisation for nearly two years.'

One employer shortlisted Dominick for a job and invited him to an interview. Dominick hadn't indicated in his application that he has a disability. The hiring manager looked at him with 'an expression of horror'.

'Like, when I went to reach for the glass and put the glass to my lips, it was like it was horrible for her. It looked like, you know, that I was some kind of creature to be despised, an awful creature. That was the body language and expression that I got and, you know, it puts you off.'

Dominick also spoke about his disappointment with the Australian Government's RecruitAbility scheme. He said the scheme requires employers to interview candidates with disability if they meet minimum requirements and mandatory qualifications. He has only been interviewed twice, and didn't get either job.

'You know, they say they've got schemes to help people like me. It hasn't worked the last six years. I can't pay the bills, I've lost the house. You know, it's all because of ableists not wanting to hire me ... The only way I've been able to get work is through contract work as an independent contractor, right, providing my services because they feel that there's no risk to them. "We can sack him tomorrow. There's no liability."'

'All this is prejudice and hate in regards to a person living with a disability. I tried to assert my rights as an employee, I try and assert my rights as a person, but they – these ableists see me as having lesser rights than them. It's like, "How dare you challenge us?" That's the common theme.'

Iain and Sherry

'[Iain] ... was loved and his life was valued. And it has been a long time, but I still miss him very, very much, very, very much. And people with disabilities are important and they deserve to be happy and safe and cared for.'

Iain was born in the 1960s with brain damage.

'They decided that they needed to induce my baby's birth because we were both in a very critical way,' his mother Sherry told the Royal Commission. 'They told us, "Look, [Iain] has suffered severe brain damage during his birth process and he is going to be pretty severely disabled both physically and also intellectually.'

Iain developed slowly, and doctors told Sherry he would eventually need professional care.

'I said, "No, no, he'll stay with us for as long as we can," you know. And I used to worry a lot about that.'

Iain lived at home and started school 'surrounded by the most wonderful group of caring, loving, beautiful people'. Eventually, Sherry and her husband moved him into residential care.

'With much fear and trepidation, we took him out on his first day, brand-new clothes and a whole brand-new wardrobe so he didn't look like he was uncared for ... It was four individual villas with permanent staff, well-trained, some nursing staff.'

Iain continued to go to school and 'the care was just phenomenal'. 'You could walk in at any time and [Iain] was happy and laughing and you could see he was perfectly cared for.'

During deinstitutionalisation in the 1980s and 90s, Iain moved into a smaller group home.

'This was a very worrying time for us because we had heard about group homes, you know ... but we had no choice.'

Sherry found a home with wheelchair access that was 'bright and sunny' with 'fully-trained disability staff'. Iain settled in.

But then, said Sherry, the residential care system started to deteriorate.

'[Service providers] started using a lot of casual, untrained staff. A lot of them, without being negative, a lot of them were from overseas and didn't have good English, and that really worried me in terms of communication.'

One day after a weekend at home, a new support worker turned up to take Iain back to the group home.

'I said, "Have you read [Iain's] care program?" And he sort of looked at me and he said, "It's only the first day I have been in the house." And I said, "Okay ... Well, I suggest you go back and you read his plan."'

Sherry stressed to the worker that Iain, who was unable to sit unsupported, had to be supervised around water.

'We said, "Never ever, ever leave him alone."'

An hour later a manager at the group home called her. Iain had drowned. Sherry raced to the hospital.

'[Iain] was surrounded by this wonderful team of nursing staff who didn't leave us alone for one minute, who asked what his favourite song was. So we sang [it] until we could sing it no longer.'

Soon after, the doctor switched off his life support.

Mariam

Mariam is in her early 50s and lives with post-traumatic stress disorder (PTSD) caused by 'sustained childhood trauma and abuse'.

'I've always been treated and referred to as having a mental health issue,' she told the Royal Commission. 'Because my sexual abuse experience was during infancy, my problems stem from physical damage ... That is what causes me functional difficulty.'

About three decades ago, Mariam 'was being psychologically and emotionally manipulated' by her de facto partner and was under 'high-level stress'. She had a breakdown and was hospitalised.

'I had become psychotic – which is extreme disassociation caused by anxiety and fear because of complex PTSD.'

During her admission, hospital psychiatrists diagnosed her with bipolar disorder. But Mariam said 'this initial and subsequent psychiatric diagnoses' was based on information provided by her partner, who was 'put in charge' of her.

'I was sent home to be cared for by a controlling and emotionally abusive partner, who now had backing from psychiatrists that any problems we had were indeed all my fault ... It was obviously so completely wrong.'

Mariam's psychiatrist medicated her for bipolar disorder.

'Seven years of lithium carbonate therapy left me hideously fat, physically ill and cognitively impaired. I was only discovered to be on the wrong medication by accident.'

When Mariam got 'an acute infection' in her thyroid gland, doctors stopped the bipolar treatment. 'And my non-existent bipolar disorder didn't reappear.'

Not long after that, Mariam was diagnosed with borderline personality disorder. Meanwhile, she continued to live with 'abusive patterns of coercion and control'. Her partner saw her Disability Support Pension as 'disposable income', as 'his money'.

Mariam said she stayed in the violent relationship for so long because health professionals had pigeonholed her as mentally ill.

'I had been diagnosed ... I just didn't stand a chance. He was backed up by the mental health profession.'

During that time she made 'multiple suicide attempts' and abused drugs and alcohol. 'I was just trying to escape this seemingly impossible trap that I was in.'

Mariam was hospitalised again about a decade ago, ‘after quite a few months of just outright bullying’.

‘And it was there that I found the right medication and the right therapy ... [and] started the long, slow journey to freedom.’

She is now being treated by a psychologist for PTSD.

‘I do not have, and have never had, a treatment-resistant personality disorder. But I was treated as though I did for at least 10 years.’

Mariam did finally ‘get away’ from her violent partner a couple of years ago, but has struggled to get the right support.

‘I desperately need legal support that understands how vulnerable someone with complex PTSD is, and it just isn’t available.’

She wishes the justice system would live up to its promises on domestic abuse. ‘Cos all the advertising and everything is, “You can get out,” and, “You can escape this.”” But when she first turned to the police, they said her partner ‘hadn’t done anything wrong’.

Mariam wants better screening by mental health services for domestic abuse and violence.

‘Because not everyone turning up to a mental health triage is mentally ill. They’re there because they’re desperate ... Putting it in the nebulous basket of mental health is putting it in the wrong area of therapy to start with.’

‘With the right treatment, everything changed. I’m starting to feel like I can do anything that I want to do. I ride a bicycle everywhere ... I now have a learner’s permit – because I am no longer being told all the time that I’m useless and defective and blahdy-blah blah. So, life begins at 50, I’m living proof.’

Kat

'I just walk differently. It's not disability, it's a "diffability". I'm just different. Let's just call it "diffability". We're all just different.'

Kat is in her 50s and has a disease of the spine that causes muscle atrophy and pain.

'This is a life-threatening, progressive, degenerative disease,' Kat told the Royal Commission. 'If I make a wrong move, I can die – that's how dramatic it is. I'm trying to minimise every risk I can to still be physically functioning, cognitively functioning and contributing to the community.'

Kat uses a wheelchair and works in the creative industries sector.

'There was probably about two years where I was completely couch-bound, couldn't move more than maybe 10 metres if that, and so I know what it's like 100 per cent to be at the absolute mercy of everything out of your control.'

Kat is now supported by the NDIS, 'the most wonderful scheme that has changed [her] life'.

'I hadn't been able to drive for years and I got hand control. You know, like, the actual outcomes of the money that is being used is tremendous for people with disabilities.'

However, Kat said abuse is 'rife within the system'.

'When people are aware that there's, you know, a pool of money that they can tap into ... it just turns people into green-eyed monsters and their humanism goes out the window.'

Kat said service providers employ support workers who are poorly trained or have no qualifications. For example, before she had her car modified so she could drive, a service provider drove her to physiotherapy appointments. One day, the provider sent Kat a driver who broke several laws.

'He stopped on the top of the hill in the middle of the road to put his seatbelt on ... His phone was balancing dangerously on his knee for directions on a map ... And then we got to an intersection ... he went through a fricking red light. It's a very dangerous intersection ... He had earphones in the whole way.'

Kat said he stopped 'with a massive jolt', further injuring her back.

'I wasn't asking someone to bloody, fricking pluck hairs from my underarms. I was, "Can you just send me a driver?" It wasn't that hard a task, [but] if that's happening at that level, what's happening to people that have to have catheters put in every second day?'

Kat said she also had ‘terrible experiences’ with support workers who help her in her house.

‘I’m already at the fricking mercy of the world when I can’t do so many things, you know. I’m at risk of falling ... I don’t want a risk of someone coming in that might be casing the joint.’

Kat told the Royal Commission she also faces barriers when she goes out. If she arrives in a wheelchair, restaurants often say they’re full.

A disability lift at her local shopping centre ‘has never worked’.

‘It’s brand-new, but someone has turned the electricity off. It has never worked in all the years I’ve been living here because it’s going to be too much trouble if it breaks down ... There’s only probably one or two people that use it a week, let’s not bother. And that’s not okay.’

Mathias and Viola

‘Please stop overmedicating children and using security men to hold them down and block their exits and put shackles on children.’

As a young child, Mathias experienced visual and auditory hallucinations and tried to suicide. Viola, his mother, told the Royal Commission that doctors, using the Mental Health Act, admitted him to a closed hospital ward.

‘He was locked in there with teenagers,’ she said.

Security guards or nurse support staff guarded him 24/7. The hospital didn’t let him leave his room without permission and restricted all visits.

‘When I turned up one morning, his clothes were all askew, his bedding wet, and he had his medication ... dripping out of his mouth. I tried to get him out of there, but as a mother you’re absolutely powerless in that situation, once the Mental Health Act takes over.’

Doctors diagnosed Mathias with bipolar disorder.

He had to take a cocktail of antipsychotics and mood stabilisers, which made him drowsy, incoherent, moody, irritable and confused. He also developed a motor problem with his mouth and tongue, which can be a permanent side effect of antipsychotic medication.

Viola said staff regularly restrained, abused and assaulted Mathias, even though he was only little. For example, nurses would often pull him by the arm and drag him to the ground to get him to move.

During one admission, Mathias saw a teenage patient sexually assault another patient. But when Viola made a complaint it was ‘covered up’.

Over time, Mathias ‘gathered’ diagnoses – autism, Tourette syndrome, epilepsy, anxiety and psychosis. Later he would be diagnosed with schizophrenia and intracranial hypertension.

Mathias had a ‘terrible time’ at his mainstream primary school. ‘He was excluded from excursions and outings on a regular basis. He was punished for his tics.’

One time, he was punished for fainting because the principal thought he was ‘attention seeking’. Another time, during drop-off, he became distressed and took off towards the road. Viola rang the principal asking for help. ‘But they wiped their hands of it because he wasn’t on the school ground. We’re talking, a ... little boy!’

Students bullied Mathias. When Viola made a complaint about a serious assault, the counsellor told her Mathias was paranoid.

When Mathias transitioned to high school, the school thought Viola was exaggerating about the support he would need. But after calling the ambulance twice in the first week, ‘they quickly got their funding to keep him safe and supported’.

Mathias started attending an autism support class and ‘things settled down’. But he missed out on ‘mainstream learning, mainstream friendships’ and was ‘excluded from excursions and outings’.

Mathias spent his final two years in the ‘emotionally disturbed class’ with children from different years and levels. He wasn’t allowed to attend the year 12 support class and no-one supported him to do mainstream work. Viola said he didn’t learn anything during this time.

‘He was years ahead, and now he’s years behind. He says he feels stupid, he is dumb, he has no friends, and that is the damage that the education system has caused my son.’

Mathias, now 18, spends most of his day in bed or gaming.

‘If we do go out and socialise, it’s with headphones on, because he can’t cope ... I think this deterioration could have been prevented if he was treated well by the mental health system and the education system ... He could be a flourishing, happy, active, contributing member of his society, but I can’t even get him out of the front door ... Because the world is scary, people treat you badly ... That is the life script that the mental health system and education system have given him.’

Alistair

Alistair is a First Nations man in his late 30s. He lives with depression, anxiety and post-traumatic stress disorder.

When he was 14, Alistair was placed in an adolescent mental health centre at a hospital he called 'the asylum'.

'I was admitted because I had psychiatric problems ... Cos I just wasn't coping with life,' he told the Royal Commission. 'Since then I've been in and out of the mental health system a fair bit.'

Alistair started working in his mid-20s.

'I thought I'd better get to work ... And I liked old people, so I thought I'd get into aged care.'

Several years ago he started working as a peer support worker for a community organisation. His role was to help people with mental illness get into independent living.

'Straight away ... it really grabbed hold of me ... There was a spark there, and it felt like [the perfect] moment to be able to use my lived experience of mental illness to shorten the learning curve for other people.'

Alistair 'got promoted fairly quickly'. He managed a respite house 'for people transitioning from homelessness or hospital to our live-in facilities'.

But soon his ideas of the 'wonderful organisation' he'd fallen 'hook, line and sinker' for, changed.

Alistair noticed many of his peer worker colleagues 'weren't getting treated very well'.

'There was a lot of exploitation of people with disability ... We were lied to a lot ... [told we'd] be given more hours, for example ...'

'[One guy] who'd suffered from bipolar ... laid down his career as an engineer to come and help other people ... Because he only got 15 hours work a week, he ended up couch surfing ... So, I've got a guy who's working in a program to eliminate homelessness, who's homeless.'

The crunch came when Alistair tried to get a particular woman into the transitional housing program.

'She came in, she was in pretty rough shape ... She had two children with autism and she had a mental illness.'

Alistair didn't want to 'let her go back out into the world unsupported'. 'I felt like we really had to do something.'

He put the case to management. 'Instead of supporting me ... they set me up pretty badly.'

Alistair feels his manager wanted to get rid of him. 'I was starting to question him about some things ... around ethics and the right thing to do.'

The manager referred him to HR. 'Then I fell into the HR thrashing machine ... He made an accusation and they prosecuted it without ever really getting my side of the story.'

Alistair said he was 'driven away from the organisation', like many other workers.

'Whenever they came forward to advocate, you know, around the client's safety ... they would be fired.'

'[The job] gave me energy,' he said. 'And then it all got taken away. So that, that was really, really crushing.'

Alistair had a meltdown. 'Like, I drank for the first time in seven years. And then I got addicted to painkillers ... It took me about a year to – to even be able to try to go back to work.'

In one job, at a restaurant, he caught the owner 'doctoring timesheets' and stealing pay. He said the 'exploitation' was widespread.

'She'd done it with people who've got quite profound disabilities ... They've got less opportunity to earn an income than just about anybody, so to actually steal off them, that was very, very low.'

Alistair is committed to setting up his own social enterprise. 'I have no tolerance left for shenanigans ... the dodgy stuff.'

He said speaking up for social justice 'keeps getting [him] into trouble'. But he'll continue to do so.

Tala

Tala is in her 50s. She told the Royal Commission that until 2010, she had been ‘condemned’ to live with ‘unrecognised autism’.

‘Autism wasn’t recognised. People like me were named under conditions. They didn’t understand our behaviours. I had a learning disability, ADHD [attention deficit hyperactivity disorder], dyslexia ... I did things differently to others. We didn’t have the proper care and protection ... We were put in mental hospitals.’

This was Tala’s experience for 25 years.

‘At school I was non-verbal until I was six. I was scared of the other kids. They were strange to me, and I had no idea ... The teacher couldn’t get me to talk. I had to go the toilet, but I couldn’t tell her ... I then wet the floor, and the other kids laughed at me.’

Through high school, Tala ‘wasn’t getting any help’ because she was in ‘normal classes’.

When she left, she was ‘completely lost in the outside world’.

‘It was terrible. It was very traumatic for me.’

She started doing seasonal work on a farm, but was hit by a car and acquired a brain injury.

After that, Tala went with her family to live overseas for a while. Tala became pregnant, but her baby boy died.

‘I got back to Australia and I was a mess. I had undiagnosed autism, and now PTSD [post-traumatic stress disorder] on top of that.’

Within weeks, she was admitted to a mental health facility, ‘really stressed out and repeating [herself] and talking loud’.

A junior doctor diagnosed Tala with ‘hypomania’ and put her on antipsychotic drugs, even though her mother insisted the behaviour was ‘nothing different to normal’.

‘She knew my autism ... He didn’t recognise this.’

For two decades, Tala was in and out of ‘psychiatric wards’. During that time, she said, mental health professionals ‘punished’ her for her disability.

‘They would lock you up, medicate you involuntarily.’ Nurses were ‘cruel’ and would ‘attack’ Tala. ‘Shining lights on me and injecting me when they didn’t think my behaviour was good enough. I kept getting more and more medication.’ She was ‘sat on and injected, held down by force and hurt’.

Tala said at times staff put her in a 'cell' and left for up to 36 hours 'with no food, no water, urinating in the corner'. The 'time-out rooms' were nothing like 'the sensory rooms with squishy balls and teddies, and blue lights' used today. 'They were cold, hard rooms made for adult criminals.'

Tala felt she was being detained 'for no reason'.

'[With] little lighting, no windows, locked doors, imprisoned, afraid, terrified and trapped. Thinking over and over, "What did I do wrong?"'

The years of 'inhumanity and degradation' stole her dignity.

'I felt like I was worth absolutely nothing, lower than a worm in the earth by the way I was treated. It was extremely and absolutely terrible.'

The drugs took their toll too. They made her 'brain injury worse' and 'masked' her autism.

'The drugs were to control our behaviours. They thought it was a mental problem or deliberate bad behaviour, rather than being understood as sensory meltdowns or childlike behaviours.'

Recently, Tala was discharged. Doctors found 'no evidence of psychotic and mood symptoms' and ended the antipsychotic injections.

She is currently in a rehabilitation centre struggling with the 'full choice and control of being thrown into the outside world' after the 'overcontrolling mental health services'.

Tala has a dream – to create special 'sensory free areas' in health centres and hospitals, 'where it's quiet and doctors understand people with disability'.

'We need to learn to live in the outside world, and they need to compromise and live with us.'

Hunter, Emerson and Lauryn

Hunter is in his late 20s and has a rare developmental disorder that causes ‘a lot of autistic tendencies’. He is ‘very sound sensitive’ and has ‘problems expressing himself’, his mother Lauryn told the Royal Commission.

‘As soon as he starts to get overloaded with too much noise going on around him, he gets very stressed out. That’s often when behaviours will start ... self-injurious behaviours too, cos he’s not coping with the environment around him.’

About a decade ago, Hunter’s parents got him into special accommodation that was ‘designed around his needs’.

‘We did have an input into what should be in this group home,’ said his father Emerson. The idea behind it was ‘to keep people with disabilities in the environment close to their families’.

Soon the home came under new management.

‘It was a very inexperienced mob of people looking after the house with very little knowledge in the disability area,’ Emerson said. ‘And they were looking after three very high-needs, challenging clients.’

He said staff regularly abused Hunter.

‘We’re talking about locking him in the car on a hot day. Using medication as a restraint, even against guardianship orders, which is illegal. They were neglectful with his hygiene, he was exposed to domestic violence and verbal abuse daily.’

Once, Emerson found Hunter locked out as other residents ate. ‘Everybody else was inside the common area ... He had no water, no nothing.’

On another occasion, support workers left Hunter alone at the hospital wearing ‘no shoes or socks’. ‘The hospital staff didn’t have any idea what medications [he] was on.’ According to the discharge report, ‘On numerous phone calls, the service provider manager refused to pick Hunter up.’

When Emerson complained about the lack of experienced staff, the provider replied, ‘Well, it’s agency staff, we don’t have to train agency staff.’

‘The amount of money those providers were getting, they should’ve had their own trained staff. Because my son’s got a behaviour support plan that needs to be followed.’

But staff ‘knew nothing about this plan’ – the company had its own ‘management strategies’ for Hunter, Emerson said.

'That was keep him locked out, and don't talk to him unless you have to. So, three times a day, agency staff would go out to him and say, "Here's your medication. There's your breakfast. And go back in the house," and they'd lock the house.'

'In the end, our son was pulling his hair out and really self-injuring himself, because he was miserable.'

After he'd been at the home about 18 months, the agency asked his parents to sign an agreement saying Hunter would be evicted if he displayed 'any bad behaviours'.

'That's part of [his] disability,' said Emerson. 'And they said, "It's just a standard contract. Nothing will come of it."'

But they evicted Hunter within a month, claiming his NDIS funding was 'inadequate' to give him the level of care required. Emerson and Lauryn tried several avenues of complaint, but no action was taken.

Hunter is now in a respite house. 'They're really good,' Emerson said. 'They're following his behaviour support plan and the staff are well-trained. It's familiar staff. He functions much better with a routine.'

Fernando and Catalina

Fernando is a middle-aged man with an acquired brain injury that impacts his ability to communicate. He was recently diagnosed with osteoporosis.

Fernando has been an inpatient at the same private hospital twice in recent years.

Catalina told the Royal Commission that Fernando's first hospital stay, for hip surgery, was not a good experience. While some nurses were 'good with' Fernando, others made disparaging remarks. '[They] didn't seem to see why he should be in there with "normal" people.'

Staff didn't understand Fernando's communication problems. The family had explained his difficulty responding to questions such as 'are you in pain?', but it seemed to make no difference. Staff left pain medication on his bedside table but, unable to self-administer it, Fernando went without appropriate pain management. During one visit, Catalina noticed his lip quivering from pain.

Staff told Catalina that Fernando was being difficult, but he simply couldn't understand what they wanted him to do. For example one time a nurse instructed him to 'pee in the bottle'. Catalina explained that Fernando didn't understand, but the nurse kept repeating the request.

'[Families] are trying to make it easier,' Catalina said, '... but it just feels like we're blocked.'

Catalina believes nurses should be trained in how to interact with patients with intellectual disability.

She also says it should be policy for the hospital to hold a family meeting soon after a patient with intellectual disability is admitted, so staff can understand how to 'make their hospital stay far more successful'.

Catalina believes there is a 'big disconnect' between health care and the NDIS. Fernando's doctors did not understand that his NDIS plan covered his intellectual disability, not his injury. It does not include physio. Once he reached a 'baseline', the hospital seemed keen to push him out, assuming he would get physio at home.

Catalina noted that there 'wasn't much flexibility' between the hospital and the NDIA in providing additional inpatient support for Fernando. Fernando's support coordinator secured longer shifts for support workers, but his package did not provide for overnight care and the hospital resisted having a night nurse.

Catalina told the Royal Commission her family has fought hard for Fernando to live independently 'because group facilities really don't work for' him.

Fernando had been living happily in a housing commission home for around 15 years, with a few hours of funded support each day. However his recent injuries and risk of falling put his independence under threat. He needs 24-hour care and the family is seeking a review of his NDIS plan to fund this.

‘My biggest hope is that he can keep his independence with the support of support workers, and live in his little red house and live his life the best way he can.’

Lisa and Rowen

Lisa had high support needs, drug-resistant epilepsy and ‘an unknown neurological disorder’. She was a young girl when she died a few years ago.

‘[Lisa] was quite normal up until about six months of age, and then we noticed she was starting to develop some problems,’ her father, Rowen, told the Royal Commission.

Lisa’s parents took her to hospital several times over the following months. Every time, health workers put her symptoms down to a common chest infection.

By the fourth visit ‘she was one year old, and she was quite ill’. This time, Rowen insisted that something was wrong. ‘So, they did a chest X-ray and they found she had pneumonia ... She was admitted to the hospital.’

A few months later, Lisa started having seizures. ‘She used to have anywhere from 100 to 200 seizures a day.’

Rowen said that one time in the emergency department, medical staff ‘overdosed’ Lisa with a sedative. She stopped breathing and was put on a respirator. Rowen had told the emergency doctor that the seizures had stopped. ‘But he wouldn’t listen to us ... It happened because doctors don’t listen to parents.’

By this stage, Lisa was ‘very, very ill’.

‘(But) she wasn’t getting enough support through the hospital ... We couldn’t get oxygen or anything for her.’

Doctors were giving Lisa numerous medications that were having ‘terrible side effects’.

‘So that’s when we decided to try medicinal cannabis ... even though it was illegal,’ Rowen said.

‘That whole year, [Lisa] never had to go to hospital once for seizures ... That was [her] only medication.’

Later, the hospital refused to allow Lisa to have the cannabis. They gave her ‘rescue medications’ instead.

‘Every time they gave them to her it would cause respiratory failure,’ Rowen said. ‘Her seizures just kept getting worse and worse ... They exhausted every known medication.’

Rowen felt it was time to ‘draw a line in the sand’ and told doctors to put a stop to all medications.

The hospital responded that if he followed that course, the next time Lisa was brought in they ‘would recommend a large dose of morphine’.

Rowen described this as 'euthanasia'. 'With disabled children and disabled adults in the hospital system ... you can't hold somebody accountable for it.'

On her last hospital admission, Lisa 'died suddenly of a cardiac arrest' after doctors gave her an anti-seizure drug. 'That product is known to cause palpitations of the heart and breathing issues,' said Rowen.

Rowen is still seeking a coroner's inquest.

'I think they're scared if there is an inquest into [Lisa's] death it'll open a can of worms ... the way they treat disabled children.'

Three months after she died, the hospital diagnosed Lisa with Rett syndrome.

'We'd been pushing for a diagnosis for years,' said Rowen. He was told the tests were not done earlier 'because of the cost'.

Sheila

‘You could say I’m a product of society. I was born normal, and if I am a bit violent now, well, it was the white family, the beatings, the child sex abuse and everything else.’

Sheila is a First Nations woman in her 50s, who lives with mental health conditions associated with the abuse she experienced as a child.

A ‘white family’ adopted her and her twin brother because their ‘real mother didn’t want [them]’, she told the Royal Commission.

Sheila said her ‘white father’ sexually abused her and ‘bashed [her] with a hammer’. She left the household when she was in her mid-teens.

‘And I haven’t looked back since. But they still cause me grief in other ways. Because I left that family feeling like dirt, like I was “nothing and nobody”, because that’s what my white mother always used to tell me.’

Sheila felt her adoptive mother probably ‘turned on’ her because of the sexual abuse.

She said ‘Aboriginal children should be raised and cared for by Indigenous people ... elders of the community’, not by ‘white people’.

The trauma had a domino effect. Over the years, Sheila has ended up before the courts, in jail, in mental health facilities and violent relationships. ‘Because there’s a vicious cycle,’ she said.

In her 30s, there were ‘a few warrants out’ for her arrest. That’s when child protection services started ‘knocking at the door’.

Once they accused Sheila of abusing her three-month-old daughter. A hospital doctor ‘checked her all over for bruises’, but found nothing wrong.

However a child safety officer later came to Sheila’s home, ‘grabbed the baby off [her] hip’ and took her away on a ‘new allegation’. ‘They didn’t reveal what allegation,’ Sheila said.

Once Sheila spent 10 days in prison for not paying fines. On her release, two social workers came to her house to ‘take her three babies’ away.

They asked Sheila to sign a document. ‘I didn’t know my rights. I told them, “No, I’m not signing nothing.”’ Sheila wanted to ‘take it back to court’, but the social workers said she ‘had no hope in hell ... It had been dealt with’.

‘And they just blankly refused me the privilege of being able to fight for my kids ... I lost custody of them.’

Sheila tried 'to retrieve' her children many times over the years, without success.

So, she 'went out and hurt people' and kept 'racking up charges'.

'When [they] took my kids, they took my heart and my soul, my spirit.'

'20 something years later', Sheila discovered she had been 'legally their mother' all that time.

She wants to sue child services for forcing her to give up her children without allowing her to seek legal advice. 'They broke the law there,' she said.

Sheila recently spent two years in a mental health ward.

'I let myself go. I used to have beautiful long black curly hair ... I lost a lot of my own self-respect.'

Now, she has a dream to open a café serving up traditional tribal foods.

'And I want to buy a big property where I can farm the bush foods that we need for these meals.'

Sheila would like young First Nations people before the courts to come there, 'instead of being convicted', and 'learn about their culture, their heritage'.

Terra and Fenella

Terra is a primary school student. She is autistic.

Her mother Fenella told the Royal Commission, '[Terra] was a really happy-go-lucky kid, enjoyed going to school, looked forward to going to school.'

A couple of years ago she noticed Terra's behaviour 'had really significantly changed'.

'She was doing things she hadn't done for many years, like smearing poo, weeing on the floor, self-injury.'

Terra was 'in complete distress' when dropped off at school.

'She would get to the gates and she would hold on for dear life. She wouldn't want to enter. She would vomit at the gate. She would start banging her face on the metal bars.'

Terra's parents spoke with a psychologist. They 'felt that it was something to do with school because she wasn't doing this at home'. They discussed strategies with Terra's teacher, who 'refused' to cooperate.

'They kept sending her home saying, "She's too disruptive. She doesn't want to be here." ... The school flat out refused any offer of help from us.'

One day Terra came home 'extremely distressed'.

'She was biting her arms, hitting her face, banging it into the wall, kicking holes in things ... She went a whole night with no sleep just doing stuff like that.'

Fenella went to the school to try and identify what 'triggered' this behaviour. The head teacher said she had no idea, but Terra needed to be punished for 'poor behaviour'.

'That was a bit of a red flag,' said Fenella. 'Because what she deemed as poor behaviour was in fact a way of [Terra] communicating something was seriously wrong at that point in time.'

Fenella and the psychologist developed a 'protocol'. Terra 'was not to be belittled by the teachers' or yelled at.

'You don't mock people, you don't belittle them, you don't yell at them, especially if you're a teacher supporting a child with a complex disability!'

But then Terra started coming home 'with big bruises [like] eggs on her head, marks on her chest, scratches on her knees'.

Teachers said she ‘had done them herself’, but Fenella learnt another child ‘had hit [Terra] in the head constantly with a rock’.

She again met with teachers.

‘That’s when it all started to fall apart,’ Fenella said. ‘Because they kept saying, “Well, you know, see, the problem is [Terra]. She’s just naughty. You need to discipline her, give her some rules.”’ Fenella told them, ‘She’s clearly needing more support.’

The meeting turned into ‘a slagging match’ and Fenella walked out.

Fenella found out that Terra was retaliating when ‘bigger male students’ bullied her, and that teachers were responding with ‘really punitive approaches’.

Another student let on that Terra ‘was being physically dragged around the classroom’. When she was seated ‘her legs would be kicked out from underneath her’, and teachers would ‘shove her to the ground’.

Fenella accompanied Terra to school. Terra was ‘shaking, trembling’ as they approached the teacher and teacher’s aide. ‘And she just started screaming and crying, and I took her home.’

Fenella said Terra’s ‘reaction was so enormous’ she could no longer ignore it.

The education department said there was insufficient evidence to pursue Fenella’s allegations of abuse.

‘They literally said ... that because of [Terra’s] disability they wouldn’t believe her.’

Fenella finds it ‘heartbreaking’ that the teachers ‘will never be held accountable’.

A couple of years ago, Terra started at a new school. On Fenella’s urging it opened a special education unit for children with disability, which regularly consults with parents.

‘[Terra] has found a good, loving, safe place, and her teacher is amazing now ... I feel supported. She feels supported.’

Summer and Collin

Summer and Collin grew up living with their mum in public housing in Victoria.

‘Unfortunately, our mother was a drug addict and an alcoholic, so, we ended up in [orphanages] for about two and a half years.’ Collin told the Royal Commission. ‘It wasn’t up until [Summer] went to primary school that it was discovered that she had slower learning capabilities. So she was transferred to a special school.’

Collin knew Summer had ‘much more capability than what she was being offered’ at school, so he ‘coached’ her a lot.

‘It was me that taught my sister how to ride her bike ... I spent a year teaching [her] how to walk to school, which was roughly a 15-minute walk.’

One day, two boys raped Summer on her way home.

The police wouldn’t press charges, because Summer ‘couldn’t give evidence, due to her intellectual ... limitations’.

When she was in her 20s, Summer moved into supported independent living.

A year later, when their mother died, Collin became Summer’s carer, though he now lived in another state.

‘I could not let my sister be abandoned.’

About 15 years ago, the housing provider rang Collin. Summer had suddenly become ‘aggressive’ and was ‘slapping and kicking people and staff’.

‘She has always been a very docile, happy, smiley person,’ Collin said.

Support workers took her to a psychiatrist who diagnosed her as schizophrenic.

‘[That’s] very common for people with disabilities,’ Collin said. ‘[Summer] talks to herself a lot ... It’s not that she’s hearing voices, she’s just trying to sort of cognitively compute. And so that was misinterpreted as schizophrenia.’

In 2013, Collin was diagnosed with complex post-traumatic stress disorder (PTSD).

‘I had a great suspicion that my sister had the same.’

Summer’s new psychiatrist confirmed she had PTSD. For over a decade, she’d been ‘on the wrong medication,’ Collin said.

The residence ‘refused any accountability’ for the misdiagnosis.

Several years later, staff called Collin to say his sister 'had potentially been sexually compromised'.

'She'd been shaved way too close down in her pubic areas, like, really way, way too close by a male,' Collin said.

'I literally fell to the ground, howling, because it took me right back to when she was raped.'

A support worker was 'terminated immediately' and the police 'brought in'. Collin 'chose not to go further' because he didn't want to trigger Summer's 'rape thing'. But he was concerned that she was the 'only female in the house'.

He asked management to put cameras in public areas, 'to get further protection for [my] sister', but 'yet again [it] refused to take accountability'.

Collin said he 'put all the pieces together' about the 'two episodes' involving Summer in previous years.

'I deeply believe that something happened awful to her when she got angry.'

He asked the service provider to disclose more details of the incidents, but it refused. 'It kept on claiming privacy, privacy.'

Collin moved back nearer his sister to 'take an eagle eye over' her – but then COVID ripped them apart.

He is now trying to get her into a new home.

He said Summer, now in her 40s, 'has been completely dumbed down' from being 'institutionalised'. He is heartbroken about all her 'missed opportunities'.

Recently, she facetimes him on the iPad he bought her. 'It had been 20-something years that I got a call from my sister. It was a true delight,' Collin said.

When he visits, he takes her out, 'just to have a one-on-one with her, to get her nails done or something like that'.

'[Once] she turned to me when we were on the train, and she says, like, "We're so lucky."
... I literally bawled.'

Aidan and Ellen

'The parents of children with disability have the same aspirations for their children as every parent. School is about maximising their potential ... every child has a right to [that].'

Ellen is mum and 'full-time carer and advocate' to Aidan, who is in his early 20s. He is autistic, has cerebral palsy and intellectual disability, and is non-verbal.

'Aidan's main disability, I suppose, is his communication, lack of,' she told the Royal Commission. '[As if he] walks around with a tape over his mouth every day. He just cannot communicate, and ... he's very vulnerable.'

Ellen said she had been 'fighting battles' for Aidan to get a 'proper education' all his life.

Prior to him starting school, Ellen worked extensively with Aidan to improve his listening. They practiced for six months. 'After this, my son had 500 words – he was actually talking, he had a voice.'

But when Aidan started kindergarten, Ellen became worried. 'His behaviour was getting a little bit worse. He was more clingy. He didn't want to go.'

One day she went to pick him up early.

'And I hear, like, screaming coming out from the kinder ... So, I went in, and there she was with a water bottle spraying him like this in his face ... I was livid.'

When Ellen asked the teacher what she was doing, she said, 'We've tried to tell the kids that they have to lie down and take a nap.'

Ellen found another kindy, but the teacher recommended Aidan go to a special school.

Ellen tried another 'really good' school, but they also refused him, saying Aidan had 'a zero IQ'.

'That's like someone telling me someone's brain dead but they're still walking around. It doesn't make sense to me. And it's all because [Aidan] cannot talk.'

Ellen approached a special development school, but 'didn't feel comfortable'. There was a room with a mattress that teachers said was for kids with 'bad behaviour'. Ellen said it was 'like a jail cell'.

'What about behaviour therapies?' Ellen asked the school. 'My son can't talk. He can't do anything. You throw him in a room like this? ... This is the best that you can do?'

Ellen sent Aidan to a school for autistic students. But more than two years later he 'wasn't progressing'. And the school had failed to provide the individual learning plan it had promised.

Then Aiden 'started to wee himself, soil himself at school'. Ellen suspected 'neglect and abuse' were behind it.

Ellen approached the school but said she was stonewalled. 'The principal wasn't getting back to me ... No-one was communicating with me.'

Ellen enrolled Aidan into a new school for year 7. She said it was 'really great' and Aiden 'loved going there', but the school still placed limits on his participation.

'He was not allowed to go to year 12 camp. He couldn't do work experience, again because he needed someone to go with him because of his communication.'

Ellen 'fought and fought' each time.

'And I did win ... He did go and do work experience. And if I didn't push, well, he would have missed out ... This is [about] life skills, you know.'

Graeme

Graeme is in his 30s and has Asperger's syndrome. He also lives with post-traumatic stress disorder (PTSD), attention deficit hyperactivity disorder and seizures.

After TAFE, Graeme 'started a career in computers'.

He learnt on-the-job, 'working through the ranks of mining companies and construction companies'. 'I don't have technical challenges. I have trouble understanding people,' he said.

About three years ago, Graeme started working at a software firm in a senior role.

The business, 'renowned worldwide', fired him within a few months. Graeme told the Royal Commission the company had treated him in a manner that 'goes well beyond exploitation and neglect'.

'[The company] attracts very complicated and complex minds. Often people who identify as Aspergic like myself.'

Despite that, it made no 'workplace modifications' for his disability. 'There was simply no care, no thought.'

Just after joining the firm, Graeme attended a team lunch.

'People would go, and they would spruik their merits, what projects they were working on, how much money they were responsible for making the company.'

Instead, Graeme talked of his disability, his 'bumpy childhood' and the way he would 'tail-spin' or 'get fixated'.

After this, he said, he experienced 'alienation' by his colleagues. '[My manager] ... it seemed he was running away from me.'

But he said that when it became clear he 'wasn't going to burn out the way other people had', his employer exploited him.

The company sent Graeme interstate on a big project, with an 'unreasonable' amount of work. 'There was a point there where I had worked 24 hours straight.'

Graeme asked for help but 'the workload just continued'.

'This resulted in me burning out. I think I had maybe two and a half hours sleep over a span of four days ... And I just remember shutting down and having a neurological seizure.'

Graeme thought he would be able to go home and recover. 'I couldn't form sentences. I couldn't eat properly. I couldn't walk in a straight line.' But he was 'just put into a taxi, told to go on a flight'.

Graeme said HR's only concern was whether he had run out of medication, not the workload they had given him.

'And I could see at this point that it wasn't going to be help that I was going to get. It was – it was a termination that was coming.'

After he lost his job, Graeme developed complex PTSD and thought about suicide. He became homeless.

Graeme's complaint to the ombudsman was dismissed.

'[The company said] I was the one who wanted to stay there and do all of this work ... I was being unsafe.'

Graeme would like to work as 'a good Samaritan' for people with disability.

He feels 'legislative reform' is needed in the workplace.

'The reality is, that people with disability are being abused by the corporate agenda.'

Today Graeme has NDIS support and stable accommodation.

Terrence, Graysen and Zariah

Terrence is autistic and is in primary school.

His parents, Graysen and Zariah, told the Royal Commission they didn't want Terrence to be segregated, so they tried to enrol him in a mainstream school.

'We went to our local Catholic school, because we were parishioners there at the church,' said Graysen. 'We said, "We want to enrol our boys. One's got autism, and the other one doesn't have disability." And [they] said they don't have the funding or the personnel to have him there.'

Zariah said it was important to the family that both boys went to the same school.

'It was so hard to get [Terrence] in. And with [the other son] I could do it blindfolded, I could enrol him. That was the first time we felt discrimination.'

Seven Catholic schools rejected Terrence's application.

'And I'm thinking, I'm Catholic, it's okay, they'll accept me,' said Zariah. 'I'm, you know, a regular churchgoer, I go to the church ... I'll have no problem. They live by Catholic values. It's just a brand, I realised.'

Seven public schools also rejected Terrence, including the one in their catchment area.

'That's meant to be the safety net,' said Graysen. 'If you're having a heart attack and you go to your public hospital and they say we can't take you, where do you go?'

Graysen said a Catholic school in another parish reluctantly accepted Terrence.

'Essentially, they didn't want him there. They didn't want us there, but they especially didn't want [Terrence] there. And they were showing us, "This is the way it's going to be. And your kid's got a disability, this is the way we're going to treat him."'

Terrence's kindergarten teacher showed Graysen and Zariah where Terrence would be sitting in class.

'His desk was placed away from the class. Facing the wall, and behind the teacher's desk ... So, straight away his peers started to notice that he's different.'

One day, another boy threw a toy at Terrence, damaging his cornea.

'We had four different stories ... And essentially [the school] just wouldn't tell us what happened.'

One day a couple of years later, Zariah noticed that Terrence's penis was 'quite red and raw'. Terrence told her a group of boys had touched and hurt him. Zariah and Graysen met the school principal.

'It was an awful, awful experience,' said Graysen. 'All we wanted to know was the truth of what happened to Terrence. And all they wanted to do was just to deny that anything had happened.'

Graysen said at one point he and Zariah raised their voices and the principal terminated the meeting. A few weeks later, the principal handed him an envelope.

'And when I opened it up, it was essentially she had expelled us from the school. Our whole family ... So, basically, we had a son that had been indecently assaulted, sexually abused. We were expelled, we had four kids at home.'

The school later permitted the family to return to the school.

Not long after, Terrence came home upset and told his parents a teacher shouted at him for touching his computer and sent him to the office. The principal and assistant told Terrence, 'We have to go clean your ears, because you don't listen.'

'Terrence tells us they took him to the toilets and they flushed his head in the toilet ... And then they locked him in a storeroom.'

Zariah and Graysen are making a complaint to the police.

Valentin and Brooklyn

Valentin is autistic and has attention deficit hyperactive disorder (ADHD) and developmental delay.

‘He still eats with his hands and he’s still in night nappies,’ his mother, Brooklyn, told the Royal Commission. He ‘can’t tie his shoelaces’, but has a high IQ, ‘of 120, 130-ish’. ‘He loves chess, he loves maths, he loves robotics. He loves Elon Musk, he loves Tesla.’

Valentin was diagnosed with ADHD when he was about four.

Brooklyn said she ‘really had to fight’ to get support for his transition from preschool to a state primary school. Government agencies asked for ‘evidence, evidence, evidence’, even though it had been clear since preschool that he wasn’t coping and needed extra support.

The school and education department constantly told Brooklyn ‘not to worry’. She found the ‘she’ll be right’ attitude ‘highly offensive’. ‘Special needs children need scaffolding and support to really succeed.’

Valentin ended up with limited academic support, but Brooklyn wanted him to have supervision and support in the playground too. ‘I knew that his social skills were really lacking.’ She told the school she was ‘really worried that [Valentin was] going to hurt someone in the playground.’

Teachers told her, ‘That wouldn’t happen.’

But when Valentin bit a child, the school suspended him.

‘He was on NDIS for growth and development delay. He had ADHD. He was suspended. And the school and the system were telling me he was naughty and had to be dealt with punitively ... His disability was never taken into account.’

Brooklyn had to take time off work to care for Valentin and wanted more NDIS support.

She told the Royal Commission an autistic friend ‘coached’ her in how to ‘play the funding game’.

‘We called it “NDIS bingo”. There are buzz words that you have to hit in order to get funding and, if you don’t, if you just go in there and break down, you don’t get the funding ... The thing that gets funding to some limited degree is chair throwing and autism.’

To get NDIS funding, Brooklyn said, they ‘needed a label’. She took Valentin to a psychologist for an assessment.

'He came out as ASD [Autism Spectrum Disorder] level 3 – I was in absolute shock ... disbelief that he had autism. The system kind of forced me into that discovery.'

She felt like she'd 'won the funding lottery'. 'I'd got the ASD – I'd got the label so we could get the funding.'

But she found the application process 'very harrowing'.

'What you've got is a child that needs help ... they're struggling. But funding bodies say "That's not enough." You have to paint the worst picture on the worst day, and it's a very deficits-based approach.'

Today, both of Valentine's parents work part time so they can look after him.

'We've actually made a decision to work less to support and advocate for him, which is not a decision that every family can make,' Brooklyn said.

'A good day is when we leave the house, and he is wearing two left shoes, but he goes to chess club and wins chess against a 10-year-old child who's been practising day and night for three years.'

Jonathon and Daryl

Jonathon is a young man in his early 20s. He is autistic and has schizophrenia. He lives at home with his parents and has a part-time carer.

When Jonathon left school, he worked three days a week in supported employment. He had been there about a year when there was an 'incident'. Daryl, his dad, told the Royal Commission people were alarmed when Jonathon, appearing upset, suddenly left the tearoom with some plastic cutlery.

'Everyone thought he was gonna hurt someone. In fact, he said he would not hurt anyone but himself. But he wouldn't do that anyway.'

Staff asked Jonathon's carer to 'come and get him and take him to hospital'.

Daryl feels the employer should have notified him immediately and called an ambulance.

'[At the hospital] we worked out that the meds had been changed. So, I then arranged for him to see a psychiatrist.'

The psychiatrist gave Jonathon the go-ahead to go back to work. Despite that, the employer laid him off indefinitely.

'He ended up being off work for quite a long time before they would agree to take him back. That's when our friend COVID came into play.'

The employer retained most staff but stood down all the supported workers.

'They used up their annual leave, so they still got paid ... a pittance,' Daryl said.

'Here's a company, that is making more money off the back of a disabled person than they are off general staff. I mean, you can't tell me that's good.'

Meanwhile, Daryl found out that some of the employer's support staff had been bullying Jonathon and other supported workers. When he returned to work, 'the bullying continued'.

One day on the bus, Jonathon stood up to one of the bullies who was upsetting another worker. The bully hit Jonathon, who returned the punch.

'So, because of that, he was put off straight away.'

Daryl met with 'the big boss' to talk it over.

'You knew when you walked in the room, they had made up their mind ... And a couple of days later, we get a letter saying he's terminated.'

Daryl said the employer refused to take any responsibility.

'It wasn't their fault ... anything that happened on those buses.'

He got the same 'closed book' reaction when he complained about the supervisors, some of who made 'really rude remarks about disabled people'.

Daryl said Jonathon 'was out of work for a while' but is now working with a community support group.

'He mows one day a week ... And his money's a lot better.'

Jonathon earns \$16 an hour instead of \$3.50 at his previous employer.

With his current medications, he 'is his normal self and he's really good'.

Daryl feels people with disability should have better job opportunities.

'They get all the mundane jobs.'

Terence

Terence is a First Nations man in his 50s. He has epilepsy, an acquired brain injury and mental health issues.

He told the Royal Commission that 'racial' attitudes towards him as a child marked him for life.

'In my younger days, when I used to go to school and stuff like that, there was racial [discrimination] back then.'

In his late teens, Terence said, he was 'bashed and tortured by the police walking from one pub to another'. He now lives with anxiety and paranoia.

'I can't be around a lot of people ... I suppose it's just because of what's been happened in the past.'

About 10 years ago Terence had a brain aneurysm and began receiving the Disability Support Pension (DSP).

A few years after that, he was sentenced to prison.

'I got the blame for starting a riot. So, I was the one who got charged ... It was hurtful. I got in trouble for it, you know.'

He said he received almost no support for his disability while he was in prison.

'The only consideration they gave me was a bottom bunk ... because of my epilepsy.'

Terence said authorities should have provided counselling services.

'But it didn't happen. Which makes it harder for people like me ... They should realise that we need their help, and really not neglect us.'

He felt he'd been left on his own, other than the occasional visit from the Aboriginal liaison officer.

'That was the only person I could trust, like, to speak to. So, it was hard in there.'

Terence has four children, but his family rarely visited. 'I don't think my old man and my son liked coming in there,' he said.

'It's hard for a lot of people in there to see family ... You've got no-one in there. Every prison is like that. It's terrible.'

Terence said health care in prison was negligent. Medical staff constantly changed the drugs to treat his depression without informing him.

‘I don’t know why, but they swap their pills [around] ... and they muck it up for people.’

When he was released after about four years in prison, it took Terence a while to get back on the DSP.

‘They reckoned that I wasn’t sick enough.’

He was put on JobSeeker and struggled to pay for board and food.

A lawyer is now helping him apply for NDIS funding based on his psychosocial disability.

‘Just to help me in any way I need ... In the home and out in the community.’

Terence feels his visits to psychiatrists are helping.

‘I used to chuck a real lot of fits ... I’ve calmed down a fair bit since.’

But sometimes he has to lock himself in his room to get away ‘and stop thinking the worst’.

‘It’s terrible, you know, anxiety and depression. It just gets too much. But I’m getting along with it.’

Marty and Susie

‘It really is the little, little tiny children who are at risk here ... And it could have been prevented.’

Susie is the foster mother of First Nations teenager Marty, who has fetal alcohol spectrum disorder (FASD).

Susie, who lives in a regional town, told the Royal Commission that she knew there was ‘something not quite right going on’ when Marty was around four.

‘I was really starting to ask for a diagnosis, but he got diagnosed with other things like autism and I just kept saying, “No, no, no, he really didn’t fit a diagnosis of autism.”’

Susie said for several years she asked the families department for a new diagnosis, which was only available in another state. ‘They weren’t keen on sending us off interstate.’

Marty was nine when Susie took him interstate and a doctor diagnosed FASD.

‘It shouldn’t have taken that long to get the diagnosis ... Had he been diagnosed at the young age of four or five, strategies could have got put into place to prevent those other [behaviours] from developing.’

Marty became increasingly aggressive and anxious. Susie said she still struggles to get support for Marty at school, where there is a ‘lack of understanding’ of FASD.

‘My foster boy, he’s gone to school for years now and there’s been no change. All my going in and driving them crazy and providing them information, telling them where to go to get the training ... doesn’t seem to have made any impact in the education system.’

Susie told the Royal Commission that some First Nations organisations are downplaying the ‘huge impact’ of FASD because of the stigma attached to it. In one remote community, a woman whose child was diagnosed with FASD was punished by the community.

‘Because of that, [one organisation] wanted to slow down the process of the diagnosing system ... They weren’t giving out the actual figures of the [number of] diagnoses ... But tampering with the statistics ... isn’t going to help that little kid at the end of the day to get to a successful life,’ Susie said. ‘[The mother is] not going to get the support.’

Susie said FASD will remain an underdiagnosed cause of disability in Australia if ‘no-one wants to talk about it’.

‘I can advocate and support my boy as best I can for his generation now, but if nothing changes and we stick on this circle, [this] spinning wheel and never get off, then the next generation is [affected]. I hate to even think about it, because it’s just going to get worse.’

Corinna and Giulia

Corinna had cerebral palsy and an intellectual disability. She died in her teens in a respite centre several years ago.

Corinna 'was very unique' and had a 'cheeky sense to her', her mother Giulia told the Royal Commission. 'Everyone that knew her always thought she was a bundle of fresh air.'

Giulia said Corinna was always 'in and out of hospitals'. 'Corinna's care needs were always quite extreme ... She had oral and eating health care plans. She always had issues swallowing ... She used to aspirate.'

When Corinna was about nine, Giulia started looking at 'different respite options'. Giulia was happy with the disability support provider at the time. 'They knew about [Corinna] for a long time before we sort of started the overnight care.'

The month before Corinna died, the NDIA approved a plan covering all her needs, including out-of-home care. She moved to an NDIS provider.

Under the new provider, Giulia noticed 'supports had been changed considerably' and 'communication was lax'.

Corinna had a feeding tube due to her problems swallowing. Giulia met with the house manager and staff to explain the issue. She had made a special garment that prevented Corinna from removing her feeding tube – 'She would pull that out constantly and pop it in her mouth.' She also always insisted on the need for 'one-on-one' supervision for Corinna because of 'the risk of everything going in her mouth'.

'And I mean everything – toys, food, dirt, balloons ... She thought it was a bit of a game.'

About a fortnight later, the respite centre called Giulia and asked her to come urgently. She knew only that she had 'to get down there quick'.

'No-one had said anything to me ... I rang the house multiple times. No-one would answer, so my panic was the raw extreme.'

Giulia arrived to find two ambulances in front of the house and a police officer waiting for her. She walked into the house to find paramedics performing CPR on her daughter on the kitchen floor.

As paramedics worked, a support worker told Giulia that Corinna had 'swallowed something'.

After about 20 minutes, paramedics 'pronounced her deceased'.

'I honestly thought that she would make it ... but she was gone.'

Giulia said the ‘sheer lack of acknowledgment’ from the service provider that it had ‘done anything wrong’ was ‘the most horrendous experience’.

‘[On top of] losing her, it was the whole not recognising or believing, saying that I hadn’t told them of her complex care needs ... They denied knowing about the risks of putting anything in her mouth. They denied that every time she was to come out of her wheelchair she had to be watched.’

Two years later, a coronial inquest found Corrina’s death was preventable and resulted from inadequate care and supervision, with not enough support workers on duty.

‘They had just given [Corrina] a shower,’ Giulia said. ‘She was left in a room at the other side of the house out of eye contact, earshot – nothing.’

Giulia said the provider had not ‘followed through’ the coroner’s recommendations, making the inquest ‘a waste of time and money and with no real outcome’.

Neda and Baila

Neda is in her mid-50s and has an acquired brain injury. She is non-verbal and entirely dependent on others for her care.

Neda's younger sister, Baila, told the Royal Commission that Neda lived in the same government facility for 23 years. In the early 2010s, new management implemented a series of changes.

These included reduced access to the outdoors, changes in staff, reduced therapy services and residents being showered every two days rather than daily.

There was no consultation with families. 'So it was quite an abrupt and difficult time for ... my sister and other residents within that facility,' Baila said.

Baila and some others wrote letters and spoke to officials at all levels of the government health bureaucracy, seeking to have the changes reversed. After five months there was still no outcome. 'So we went to the external body and said, "There's a problem here, and we need it addressed."'

An independent review found that management had deprived residents of their human rights and identified several areas of neglect. It required the facility to address these problems.

As this work began, the district health board informed families that it intended to reduce the services. 'The distress that was caused by the uncertainty and the decline in services all at the same time was quite traumatic,' Baila said.

Eventually just over half the residents of the facility were relocated to a new purpose-built facility run by a charity. Baila was optimistic it would be a beautiful home for Neda, but was soon disappointed.

'They were very person-centred and very family orientated, until we got there and it's like you can't do this, you can't do that – and it became a system very, very quickly.'

There have been numerous issues with Neda's care, and Baila has found the staff unsympathetic and unhelpful when she's expressed concern. Some mistakes have been potentially life-threatening, such as forgetting to keep Neda's bed raised and not properly pureeing her food. One time Baila found chicken bones in Neda's pureed meal.

'I went to the manager and said, "Can you tell me what this is?" and his response was, "I don't know. I'm a vegetarian." As you can imagine, that's quite distressing when [Neda]'s not verbal, and you're depending on staff feeding her.'

Baila has also raised concerns about poor care and hygiene practices. When she asked for Neda's room to be tidied one day, a staff member told her the mess didn't bother Neda, only her. 'And I thought, who are you to say that about my sister, who is non-verbal? How can you tell if that disturbs her or not? How can you even think that this is okay?'

Baila said she feels ostracised by staff because of her advocacy for Neda. She worries about how they treat Neda in her absence. She had asked a health regulatory agency to allow her to install a camera in her sister's room, where most of the problems with her care occur. They refused this for privacy reasons.

She hopes the Royal Commission will recommend the installation of cameras in residents' bedrooms. 'You put a camera in you'll rectify everything, almost instantly and, if it doesn't, I can tell who it is and why it's happening ... So, if I can advocate for anything to the Royal Commission, that would be for cameras in rooms with people who have no voice.'

Andre and Amalia

‘I would [be] asked ... “Oh, Tell me about your family history? You know, drug and alcohol? Family violence?” ... But other medical doctors that I go to, if I don’t say I’m Aboriginal, none of that stuff comes up.’

Amalia is a First Nations woman in her 50s. Amalia’s son, Andre, is in primary school. He was recently diagnosed with autism. Prior to that, he had been misdiagnosed with schizophrenia.

Amalia knew Andre was ‘a bit’ different when he developed an aversion to noise as a toddler.

‘He would run, and what he was running from was the noise. He’s a runner, and he did that at school. But, look, he’s a bright kid. He’s a really bright kid. And that was the problem because people saw that he was bright ... That’s where I guess the confusion happens when you’re talking about autism.’

When Andre went to preschool, teachers urged Amalia to get a diagnosis for his behaviour. She went to a First Nations health service, where a paediatrician linked Andre’s behaviour to anxiety. They diagnosed schizophrenia.

‘Being a young doctor ... he would have been worded up. He would have been told ... what to look out for in Aboriginal people, and that would have been all the normal stuff – mental health, family violence is a big one, you know, diabetes.’

Doctors gave Andre antipsychotic medication, but his behaviour didn’t improve. When he became violent and the school suspended him, the child protection department contacted Amalia.

‘They chose to listen to [the First Nations health service], the doctors more than the schools. Because – I don’t know why, to be quite honest.’

Amalia said the school believed Andre wasn’t getting the support he needed from the health service and tried to advocate for him.

‘That’s one of the things that, you know, I really regret – that I should’ve listened to the schools a lot sooner ... He missed out on those crucial years of schooling and everything else that attaches.’

A couple of years ago, doctors diagnosed Andre with autism and ended his antipsychotic medication.

‘I feel like I’ve got [Andre] back now. He’s not so drowsy anymore.’

He now attends a school for autistic children.

'I can't even speak highly enough of it,' Amalia said. 'It is just really good. I've noticed that academically he's progressed a lot ... He doesn't feel like he is different anymore. He feels like he is part of a group and he accepts them.'

Andre is supported by the NDIS. Amalia recently applied for funding for hearing technology to overcome his aversion to noise, but said the NDIA rejected the application because Andre isn't deaf.

'They're listening devices, but they don't block out the whole sound ... I think what [the NDIA] do is, they just look for a way not to fund something, rather than look for a way to help people with disabilities.'

Freia

‘When a patient is given the wrong medication and has an allergic reaction to it which induces psychosis, it should be acknowledged as a cause and not be labelled as schizophrenia.’

Freia is in her late 40s and lives with mental health issues. She worked as a teacher until she was diagnosed with a ‘schizoaffective disorder’ about a decade ago.

‘Basically, I’m not even sure what classification I fit into with disabilities,’ she told the Royal Commission. ‘There’s a chance that maybe I have undiagnosed autism or Asperger’s syndrome.’

Freia said she had been admitted to hospital several times since 2009 after seeking assistance for her mental health. Every time she felt she was overmedicated.

‘[Doctors] keep me in hospital and put me on the drugs and then tell me I have to stay on the drugs.’

Around 10 years ago, Freia took herself to the emergency department after she had an allergic reaction to a drug a doctor had prescribed. The drug ‘kept [her] awake for 72 hours’.

‘And I basically went into, like, a psychosis, and my heartbeat was 165 beats per minute for three days.’

Freia said she was then put on medication used to treat schizophrenia, which ‘sent her “loopy”’.

On discharge, Freia was ‘drugged up so much’ that the side effects were debilitating.

‘The drugs they put me on ... made me really fat. And, so, I went from being a lovely teacher who was fit, healthy, to incapacitated for a whole year, where I couldn’t work and I had to use up all long service leave.’

The high dosages of the medication made her lose control of her bladder.

‘I would wet my pants about 16 times a day and – which made it very difficult – and ... I started lactating.’

Freia said she had just been starting to get back on her feet after experiencing domestic violence about four years earlier.

‘I was sexually assaulted in my own home by the father of my child ... Well, basically, I had been in a domestic violent relationship for a long time.’

She said she had ‘got through the trauma’, but then the treatment for schizophrenia knocked her down again.

'My perpetrator doesn't get any slap on the wrist or anything and I end up ... labelled ... and I still have that label today.'

Freia said she came off the medication about four months ago.

'When that happened, I started to [have a] clearer mind and started enjoying life more, because I've been drugged ... for seven years.'

An 'expert psychiatrist who specialised in trauma' said there was 'no way' Freia was schizophrenic.

'The psychosis I had was due to that medication I was given by my doctor.'

Freia would like to see the 'whole system, especially the medical system', take 'a holistic approach to a person'.

She described the way medical professionals treated her as 'the lithium cycle' which, she says, often happens after a woman is raped.

'The doctors just see a traumatised girl or woman. And they're put on drugs and a common one is lithium, and it just turns them into zombies. They've tried to put me on lithium several times.'

Freia would like to teach again but doesn't like her chances of finding work.

'Living through this ... it's impeded my chances of full-time employment having this schizoaffective thing labelled on my teacher register.'

Irena

Irena is a First Nations woman in her late 40s. She was institutionalised in her early teens and lives with complex trauma arising from her time in a psychiatric hospital.

'I was bullied at high school. My teacher ripped my assignments up and said that I'm not going to amount to nothing,' Irena told the Royal Commission. 'She put me down because I was never any good at spelling and all of that. I couldn't do assignments.'

She told her mother about the bullying. 'Mum thought I was a bit womba [crazy] ... I wasn't. I was stressed out.'

After that, a doctor had Irena institutionalised. Irena said her mother would never have accepted it if she'd fully understood her situation at school.

'I wouldn't tell her any of my problems because I didn't want to stress my mum out.' Her mother had cervical cancer. 'She was dying.'

Irena said the abuse started the day after she arrived at the institution. 'One of the patients threw hot water on me, and my skin was peeling off my chest.' Staff refused to help her.

'I feared for my life because I've seen girls and they were getting raped in the institution I was in.' Irena was in the 'juvenile unit' but was moved to the adult section. 'I think because I knew too much and I witnessed those things.'

Irena told the Royal Commission that one day a male nurse tried to rape her. 'My mum came up to visit me ... She said, "I want my daughter to be out of here today."'

With a solicitor's help, Irena moved to a different ward. Here, she said, she witnessed nurses murdering a patient. 'I pretended to be asleep. I got up and could see them through the curtain.' Irena said after pulling the curtains, the nurses 'put all these tablets down [the woman's] throat' and 'suffocated her with the pillow'.

The 'old white lady' was Irena's 'very best friend'. 'She was like a mum to me.'

When Irena told supervisors about it they placed her in seclusion. She didn't see her mother for several months and was put on high levels of medication.

'They sedated me. They were taking blood out of me every day. My body was getting weaker and weaker. I felt like I was going to collapse and die ... It was terrifying.'

Psychiatrists diagnosed Irena as schizophrenic. She was released after about 10 months, but kept getting sent back.

'I'd be kicked out and that. I started wandering on the streets, like, you know, homeless. And the police used to pick me up, because I was under this Mental Health Act, and take me back.'

She said for more than three decades, mental health professionals have treated her in 'an inappropriate way'.

'They've been pumping me with medication ... I'm trying to get off it. There's nothing wrong with me whatsoever ... I don't know what the hell they're trying to do.'

Irena is finally 'going to therapists', and wants to see more counselling for First Nations people in mental health hospitals.

'There was male Aboriginal counsellors, but there should be more ladies ... For some reason they just set us Aboriginals up for failure ... I want programs, you know, drug and alcohol and suicide preventions.'

She'd like to get involved with counselling and supporting people when they come out of institutions.

Bryce

‘I think that it’s pretty easy for service providers to neglect and abuse people with disabilities, if there isn’t a solid complaint process.’

Bryce is a First Nations man in his 50s who lives with early onset dementia, post-traumatic stress disorder (PTSD) and depression.

Bryce lives in social housing in New South Wales. He receives NDIS funding, but feels isolated in his community because there is ‘not much in the way of personal support’.

‘Sometimes I just get a bit lonely ... because I live on my own and – I, sort of, feel very limited about what I can do and where I can go,’ he told the Royal Commission.

Bryce says he sees a support worker three times a week, but that ‘leaves a few gaps’.

‘Maybe I would benefit from living with somebody else or having more care.’

Bryce found the process of applying for NDIS support ‘tricky to navigate’.

‘It was very confusing, like to find somebody to help me, then to try and understand ... this big cake that was cut up into pieces, and they say this much is for your core support and this much is for this and that.’

Bryce had no local area coordinator and struggled on his own to find an honest service provider.

‘It’s like a lucky dip, you know. When you’re looking for somebody, you don’t know if they’re going to be honest or reliable ... So, you just have to, you know, try it out. But then if it goes wrong it’s difficult to end it and find somebody else.’

His first disability service provider was ‘run by a family’ and unreliable.

Support workers ‘wouldn’t turn up’ or would ask him to travel long distances to receive services.

The provider also overcharged him for cleaning and other services.

One day, Bryce was in his support worker’s car. The support worker started to ‘mock’ the way another person spoke ‘because of her disability’.

Bryce complained to the NDIS Quality and Safeguards Commission, which ‘didn’t do much’.

When the manager learnt of the complaint he was angry and ‘kept harassing’ Bryce to drop it.

The provider then left him 'stranded' without care, and Bryce went without proper food for weeks.

He informed the provider he no longer wanted their services. The company took no notice and continued to charge him for services he did not receive.

'I kept telling them that ... I didn't want to be with them anymore – and they kept ignoring my requests and so I felt a bit stuck.'

The manager told Bryce he had 'shredded' all the paperwork. He then produced fraudulent documents, including a service agreement for Bryce with a forged signature. As a result his funding was exhausted months before it should have been.

The NDIS fraud division investigated the case. 'They said it was resolved,' Bryce said.

A friend helped him find a new provider. 'I was scared. I was saying, what if they end up being, you know, no good.' So far, he has found 'they run the show pretty well'.

Bryce said the whole experience had left him 'a little bit more vulnerable'.

'But, I think, if anything good came out of it, I've learnt more about my rights, because – it's like one of those terrible things ... You're not aware of it until it happens.'

Dariel

Dariel is in his early 50s and has an acquired brain injury from a workplace accident about 15 years ago. He and his wife, Julie, had two young children at the time of his accident.

‘When I had my accident, I had to learn to walk and talk again,’ Dariel told the Royal Commission. ‘I had trouble with some parts of my conversation because I would say things in reverse – the opposite to what I wanted to say.’

A few years ago, Dariel received more than \$1 million in compensation. The public trustee was appointed to manage those funds, ‘for three years ... not for a lifetime’.

Dariel wanted ‘proof’ of how the trustee was going to invest the money – ‘where it was going, who was going to run it, what was going to happen with it’. But the trustee refused to give him any information. ‘They can do whatever they want, and they basically told us that.’

Just before he got the payout, the couple had sold their house to fund his treatment costs. The administrators purchased a home for the family to live in using most of Dariel’s funds.

The house is falling apart but the trustee ignores his requests for help.

‘Every time it rains, water pours in to the roof ... My son was getting waterboarded in the bed. That’s how bad it was, and it still is. There’s water running down our walls. The electricity is bugged. They refuse to fix it.’

Dariel has had to fix the plumbing himself and has spent thousands of dollars in repairs. He said the trustee was charging him almost double the usual rates.

‘I mean, they’re robbing me. They’re doing this to hundreds of people ... And they’re getting away with it.’

The office never replies to Dariel’s calls or emails, and won’t meet with him. ‘They’re evasive and don’t answer questions,’ Julie said.

Dariel feels they are discriminating against him.

‘When I started making complaints – things got worse. I stopped getting stuff ... They say, “Oh [him], he’s had a head injury ... He’s difficult to deal with.”’

The trustee won’t let the couple buy another house. Nor will it cover the cost of Dariel’s medical treatment – claiming that’s the job of the NDIS. ‘I’m missing out on medication that costs \$300 bucks a month ... because they won’t pay for it.’

The situation has made Dariel's 'stroke-like seizures' worse. 'I was having a seizure every couple of years. Now I'm having four or five a month, every time I have constant contact with them.' At one stage, he had up to four seizures a week and 'was pretty ill'.

Dariel says his dispute with the trustee has 'stripped him of all [his] dignity' and damaged his relationship with his kids because he's 'so wound up all the time'.

'I tried to take my life because of it ... It's supposed to help people. They're supposed to be public servants. They don't give me nothing. They don't do nothing for me.'

Now he 'wants his life back'. He would love to work again. 'But no-one will hire me because of the tablets I take. You can't have people walking around on morphine tablets on your worksite.'

'[He] can't retain new skills,' Julie said. She wants him to get out 'and do some volunteer work' or an activity like sailing. 'He doesn't like going out in public, but I'm trying to encourage that just so he doesn't sit at home.'

Dariel is glad his speech is improving. He believes he can manage his own money and would like to administer his own affairs.

Capri, Colby, Cain and Brylee

Brylee and Cain are the parents of Capri and Colby, who are both autistic. The family lives in a regional town.

‘Capri ... can’t sit still, loves horses. She’s very good at sport, so she loves surfing and swimming and anything that keeps her active,’ Brylee told the Royal Commission. ‘And then Colby ... likes to just spend time on his own.’

After failing to find appropriate supports at the local Catholic primary school, Brylee and Cain enrolled their children at the public school.

Brylee said that when they suggested the school apply for funding for additional support, it became apparent the teachers ‘didn’t think [Capri] had autism’.

‘They thought she was just young for her age, and they recommended that we just repeat her kindergarten year. So, they completely dismissed her diagnosis.’

Brylee and Cain approached the education department directly to fund a teacher aide for Capri.

‘The principal had this real ideological sort of opposition to having teacher aides,’ said Cain. ‘She thought we should use the money to have more teaching time.’

The principal also wouldn’t let Capri’s speech therapist come to the school, so Capri had to leave school for appointments. ‘Then we got raked over the coals because our children were missing too much school.’

When Colby started kindergarten, he was given a support worker to help him transition to kindergarten.

‘The principal was really, really rude to our support worker. She pulled her into the office while she was supposed to be with [Colby] and ... basically treated her like, “You don’t need to be here. You’re not even worth looking after this person.” And while she was called into the office, [Colby ran away].’

Brylee and Cain said the school failed to adequately implement their children’s individual learning plans. After they complained, they discovered the president of the school’s parent committee had contacted other parents suggesting the family was causing the principal stress.

Cain said that one day the school banned Brylee from contacting the school ‘by any means at any time’. ‘[She] wasn’t allowed to ring, she wasn’t allowed to send an email, wasn’t allowed to talk to anyone in person or to have communication with anyone.’

‘Apparently, I’ve behaved inappropriately,’ said Brylee. ‘But they’ve never explained that and haven’t given me the right to reply, and then just imposed restrictions on us.’

On the first day of the ban, Brylee forgot to give the children their medication.

‘[Cain’s] at work ... I have to call him to be able to ... find out what time can I meet someone at the gate, because I’m not allowed to contact the school.’

Brylee said she felt ‘sorry for the staff’ because the education department hadn’t helped the teachers ‘in understanding what their responsibilities were for children with a disability’.

Cain said the school now has a new principal who is ‘much better’.

‘It’s entirely down to an understanding of the problem, a willingness to spend time and work through and compromise, and a willingness to actually listen to us and say, “What do you think?”’

Alfred

‘Solitary confinement for me is like a dull ache in your head. It just sits there. There is no escaping it ... It just eats away at you, it destroys you.’

Alfred is a First Nations man with mental illness. He is in his 50s and has spent more than three decades in prison.

‘I’ve spent my entire life pretty much behind bars,’ he told the Royal Commission. ‘Since the age of 11, I’ve spent 18 months out of institutions.’

Alfred said being abused as a child played a hand in the ‘shocking behaviour’ and crimes that saw him end up in jail.

‘I was abused very young, from about the age of nine. And, you know, I often wonder if that abuse hadn’t happened, would I have fallen down that same path? I went on to abuse other people sexually, and it has literally consumed my life.’

Alfred is currently in a maximum-security prison and has spent more than six years in solitary confinement.

‘I cannot, express in words the stress, the trauma that is suffered as a result of being in solitary confinement for long ... These environments are hard enough as it is, without having a mental illness. You just want to shut down. You want to sleep all the time. You become dehumanised.’

Solitary confinement exacerbates inmates’ mental health problems.

‘For guys that can’t actually control their stress and their depression and their emotions, they act out. They cut themselves. They kick doors. They scream. They self-harm ... These sorts of behaviours are treated as behavioural issues. They’re not treated as mental illnesses.’

Alfred said ‘there is no rehabilitation’ for prisoners with mental health problems.

‘I’ve never gotten diagnosed ... There are counsellors that are hired to come into these environments. But you can’t torture someone psychologically, emotionally and mentally and then offer them five minutes of counselling and expect that to sort of fill the gap.’

Because of the isolation and lack of mental health supports, he feels that prison has compounded his trauma.

‘It’s an isolated environment ... It’s very rare that we get to speak with people. So that exacerbates any kind of mental illness. It is torture to have to endure these environments for long periods of time – there’s no stimulation. You are hanging on to maintain your sanity.’

Sometimes, it's pushed him towards the edge.

'I am not suicidal ... but there are times when I sort of wish that there was an end to this existence. It has been that depressing, that stressful. And there's just no end in sight. I mean, it's that lack of any kind of end.'

Alfred said he'd also 'been subjected to physical and sexual violence within the prison system'.

'It's a closed system. There's no – there's no external eyes on this place.'

He believes he will die in prison, and the lack of rehabilitation is partly to blame.

'The crimes that I've committed, there's no excuse for them ... But there are factors that have contributed to my behaviour. And you know, prison has destroyed me as a human being. I don't know if I could ever come back from what I've experienced.'

His saving grace had been education.

'I have been lucky. I've found study. I studied and I've educated myself in prison. But for other prisoners who don't have that, who don't have that escape ... They're dead behind the eyes.'



Artwork by Alyson Booth

Bronson

‘They said, “What do you want?” I said, “I want a fair go.”’

Bronson is in his 70s and has cerebral palsy. For nearly 50 years he worked on the railways, where he was ‘put in a box and judged for [his] disability’.

‘I was overlooked for work positions that I was qualified for,’ Bronson told the Royal Commission. ‘I was unsupported by my managers, work colleagues and union representatives.’

When Bronson was at school, he won a scholarship and played a lot of sport.

‘I played hockey for the school. I was in the Army Cadets. I used to do cycling through an amateur cycling club. And I used to go out on a Sunday to the rifle range.’

When he left school in the 1960s, Bronson worked at the town’s railway shunting yard, doing a range of physical and administrative jobs.

‘Not one word was said anything about my disability.’

That changed several years later when he transferred to the city. Bronson sat a stationmaster’s exam and passed.

‘I started to apply for vacant positions. And it would come out as being cancelled. No suitable applicants. And the same position [re-advertised] again.’

Despite his experience and qualifications, Bronson ‘never went out as stationmaster’.

‘I was still stuck at the same level.’

When he asked why he wasn’t being interviewed, one manager suggested he see the government medical officer for an assessment. A senior staff member called him a ‘half cripple’.

One day, a station manager blamed Bronson when money vanished from a cash drawer.

‘The report noted that as I was a “semi-invalid”, I made “many mistakes”. The report failed to mention that other staff members and [the stationmaster] himself operated from the same cash drawer.’

In the 1990s, a colleague who regularly bullied Bronson accused him of ‘not carrying out [his] duties’.

‘No-one would speak to me during my shifts ... I was not allowed a meal break or a toilet break, despite others being granted these privileges.’

When Bronson failed to get jobs that encouraged ‘Indigenous persons and staff with disabilities’ to apply, he was told he ‘wasn’t the best applicant’.

‘I felt overlooked and discriminated against.’

When Bronson’s bully was promoted, they offered Bronson a job ‘re-papering portable ticket machines’.

‘This meant a substantial reduction of pay for me.’

One day, Bronson was working at a suburban station when it was robbed. After a series of traumatic incidents and injuries, for which he was given no reasonable adjustments, he was told to take an unsuitable job or retire. He left.

‘Despite my many years of dedicated services, my watch was in a dirty recycled envelope, minus the case. This, again, really showed their contempt for me.’

Bronson said he didn’t want to stop working, so he applied for a job at a pizza chain.

‘I said, “Am I too old?” “No,” she said. “We’ll give you the traineeship.” ... Over that time, I made advancement and I never looked back. At all times I was treated with dignity, fairness and equality and was valued as a worker and a person.’

Bronson is now a supervisor at the pizza company.

‘When they looked at me they did not see my disability. They saw my potential.’

Josey and Simonetta

Josey is in her 40s and has intellectual disability. When she was in her early 20s, she moved into transitional housing for 16 weeks. The idea was for her to learn life skills she would need to live independently.

Driving back home, Simonetta 'sent up a prayer' for her daughter. 'Because up until that time, she tended to slip through the cracks of whatever was available to her, through her schooling, through her trying to find work period of her life.'

When Josey entered the program, she was already 'very competent' at cooking, cleaning and shopping, but she 'needed help with her money'.

On finishing the program, management decided she was ready to move to shared housing with another young woman.

Simonetta found them a place a short drive from her home. But within days, Josey left because the housemate was going to the swimming centre around the corner and 'bringing home fellows from there'.

'So, that was her first experience of a group home,' Simonetta said.

At the next residence, run by a church provider, there were 'rats from overflowing rubbish, food and food scraps littering common rooms'.

The organisation moved her to another home they managed.

'And I objected to her being moved there or anywhere else as I felt she was not receiving enough responsible supervision,' Simonetta said.

Josey's bedroom 'quickly became a potential death trap' because of her 'hoarding tendencies'. 'The floor space was virtually ankle-deep with litter, clothes and belongings.'

The room had just one small window, high up, and the sliding door out to the passage was difficult to open. 'In case of a fire occurring, I doubt she would have made it out of the room unscathed, if she made it out at all,' said Simonetta.

Simonetta met with the organisation's manager to voice her concerns. There was 'a lot of head nodding' and 'talk about looking into issues', but 'no action was taken'.

Management kept telling her that Josey is 'an adult', and 'she can make her own decisions'.

'But she wasn't making good decisions, and there didn't seem to be enough interaction with supposedly trained people to help her with her problems ... with money, to start with.'

Meanwhile, the 'unsuitable person' Josey first shared a house with had 'come back into the picture'.

'And she was introducing [her] to males that she had friendships with from her secondary school. The resulting two relationships [Josey] had were sexually, physically, financially and mentally abusive.'

Simonetta said staff knew about the ongoing abuse but 'never alerted' her or did anything about it.

'I learnt later that at least one other male had access to the house and had sexually abused [Josey].'

By the time she found out, police said it was 'too difficult to follow up'.

Josey returned home to live with her mother. Simonetta says her daughter developed anorexia and depression because of her experiences in group homes.

Jo

Jo is in her late 40s and lives with depression and a degenerative nerve disease.

She grew up in a poor family in a rural area – the youngest of six children. She used a wheelchair for mobility.

‘And at the time, there was never a big fuss made about my disability. You know, like those mums and dads that get in there and push their disabled kids, “You go, girl!” I wished I’d had a mum like that.’

At primary school in the 1980s, Jo had to pull herself ‘up and down the stairs’ several times a day.

‘The school had no lifts and no ramps ... and I had to struggle up three flights of stairs to get to class. No allowance was made by the school for my condition.’

After Jo had ‘major back surgery’ for scoliosis in late primary school, her mother pulled her out of school.

‘She didn’t want to send me to high school, because kids could get rough. And I must admit, you get pushed and shoved or called names back then. And I had a few busters and things, and skin off the knees and things like that.’

Her mother organised distance education, but she ‘was not qualified to teach’, Jo said.

‘Because of this my secondary education suffered, and by the time I finished grade 9, I was too far behind to go onto higher grades. So, I just went straight onto the disability pension ... There was nothing else I could do apart from domestic work at home.’

In the early 2000s, Jo and one of her brothers moved interstate ‘for a better life’.

‘I went to a lot of effort trying to get employment, either paid or voluntary.’

She did some ‘successful volunteer work’ in animal welfare and tourism.

‘And I found that really good ... a little bit social, and I like that. But they didn’t give me any training.’

Jo experienced discrimination at work.

One manager asked her if she really needed ‘that wheelie-walker’.

'With my condition, if you took the walker off me, you'd think, "Is that person drunk?" ... I really can't get around without the walker.'

A few years ago, Jo went for a 'regular check-up with the orthopaedic surgeon'.

Following ankle reconstructions years before, the specialist said one of her feet was 'slightly out of whack'. He wanted to 'realign' it by putting it in a cast.

This led to a serious bone infection and, recently, Jo had to have a toe amputated. She feels her lack of employment impacted on the quality of health care she received.

Today, she is still recovering from the surgery, and lives with her carer.

Her quest for 'paid employment' still troubles her. 'I really notice that missing, especially now at this time in my life.'

Jo dreams of taking up horse riding again. Once, she took part in a riding activity for people with disability.

'I didn't come off that natural high 'til I got off the horse. And I'd be still going for a bit after that ... The feel of the sun shining on you, and the light breeze in your face, and playing with its mane as you're walking ... Everything else, the worries on my mind just went to the side.'

Julien and Chiara

Julien is a teenager with sensory processing disorder and attention hyperactivity deficit disorder. He is 'very sensitive to sound'.

'He's a very creative boy,' his mother Chiara told the Royal Commission. 'He's always got a pen in his hand, just to draw and write things.'

She said Julien's first school was 'really inclusive' and 'looked after all sorts of children's needs'.

Julien was 'prodigious' and won lots of awards. He had no special supports.

'He was in the mainstream. He had an extraordinary teacher for the last two years ... They were big classrooms with a small group on the side so they had time for integration.'

Julien's transition to high school didn't go well. He's currently in year 10. The school is large and loud.

'All of a sudden, you have seven different teachers ... There's always people talking and in between classes it's like a big huge river – rapids.' In the corridors, the 'volume's up' and 'the adrenalin's up'. Julien finds it 'too stressful'.

Recently he asked if he could be in a class with his friends. His teachers said no.

'He's asking for what he needs, but they're not giving him what he needs ... They're just saying no, always. I don't think he understands why.'

Chiara, who's a teacher, said Julien is getting no support. 'I really think he has got huge gaps ... He really struggles with maths.'

She wanted him to be assessed, but his teacher said 'No, don't worry.'

Julien chose to be put in the integrated class. 'But the teacher ended up giving him year 10 box plot stuff, which is just way over his head.' He comes home frustrated because he doesn't understand anything.

'He says, "I just copy the stuff off the board" ... But, in primary school, the teacher would get to know that and learn how to manage that. That is what worked. The relationship.'

That and the fact that 'the environment was much quieter'.

'I don't think he has written anything since then,' Chiara said.

Chiara feels Julien's current teachers are 'bluffing' his grades and have set 'low expectations' for him.

She said there's 'a big divide' at the school.

He is often excluded from extracurricular programs which he feels are reserved for students who 'are special'. On holiday programs 'they've sat him in a room by himself', Chiara said.

In the last weeks she's seen cause for hope. There's a new person 'with a background in disability education' in charge of student support. 'Somebody who has an understanding and who doesn't look at children's behaviour as bad.'

But she fears it's 'too late'. Julien no longer wants to go to school. He 'hates it'.

Dillon and Shelly

Shelly's brother Dillon was born with cerebral palsy about 70 years ago.

'Mum would always set him up with a book and do her housework around turning the page,' Shelly told the Royal Commission. 'At that stage he used a headpiece that he would paint and type [with] and that's how he did his courses.'

In the 1960s, Dillon went to a special school run by a charity.

'He did the same curriculum that I did, but he had physio, OT [occupation therapy], speech therapy, five days a week ... He got straight sevens in his senior certificate which is quite high and probably, if he was born now, with what you can do digitally, he probably would have been a scientist or something like that.'

Dillon had an IQ over 130 and 'administered all his own affairs'. In the 1980s, he insisted on moving out of home and into supported care.

'[It] was like an over 50s retirement village now. So, it had a swimming pool, a rec officer, a bar that was open seven days a week, a chef that prepared the meals, and they all came together for the meals.'

Things changed in the 1990s when his service provider began employing staff with less training.

About 15 years ago, Dillon had a seizure, but the staff didn't call a doctor. The next day they told Shelly it was 'just a cerebral palsy thing'.

Shelly insisted he go to the hospital, where a scan revealed a benign brain tumour. A doctor referred Dillon to a neurosurgeon and sent him back to the service provider.

'I kept asking [the service provider], "Have you heard from the [hospital] yet?" "No, no, no." Then, "No, haven't heard. Haven't heard." So, I go to [Dillon's] bag several months later and here's: "This is your neurosurgery appointment. We haven't heard from you. This is your final notice. We have cancelled the appointment."'

It took nearly a year to get another appointment, where another scan revealed serious damage to Dillon's spine, possibly caused by the headpiece he used to paint and type.

'The [hospital] registrar said, "You know ... it doesn't change anything. He was a spastic quadriplegic anyway, so we're not going to do anything."'

Shelly didn't make a complaint at the time. But she did find a neurosurgeon who performed emergency surgery to repair the damage.

'With all of this you have to pick your battles because of fear of retribution. That's always there and you've got to go, "Am I taking this on today or will I politely send a letter in a few weeks time?" That's the hard thing.'

Shelly said the quality of support workers caring for Dillon continued to deteriorate over the years.

'Their level of complacency and their mercenary approach to things just does my head in ... Some of them had no idea about basic nutrition or hygiene.'

For example, one day Shelly noticed Dillon's urine bag had spilled and he was saturated. She asked a support worker to put him into the shower.

'This [worker] is holding this small little bowl of food, and she said, "No, no. I'm going to feed him his dinner first, and then he can have a shower." And I said, "I'm sorry. I'm not sure if you heard me. He is saturated in urine." She said, "That's okay. He can eat his dinner first." And she was the one that was leading by example.'

Shelly became concerned Dillon was becoming dehydrated because his support workers weren't giving him enough water.

'It got to the point where we had to get his GP to write "water" on his medication sheet.'

One day, Dillon was admitted to hospital with a severely impacted bowel. 'He had it aspirated because he was just concrete and there was just no way of moving it.'

'He spent the next three weeks fighting for his life,' Shelly told the Royal Commission. 'And he had all his faculties before he died.'

Vaughan and Suzy

'If this situation with the mental health system doesn't improve ... people like me and people like [Vaughan] are going to be really reluctant to go to the services because you end up coming out worse than when you went in.'

Suzy is the sister and legal guardian of Vaughan, who's in his 50s and has an intellectual disability.

'At the age of about 19 he had a psychotic episode and was diagnosed with schizophrenia,' Suzy told the Royal Commission. '[Vaughan's] life was pretty settled for a long time. He had his disabilities, but he had a day job, he had friends, he lived independently in a unit [in a regional town] close to his mother.'

About a decade ago, a hospital gave Vaughan incorrect medication that caused kidney failure and brain damage.

'Frontal lobe, catastrophic. It occurred in the, as far as we can tell, [local hospital] mental health unit.'

Suzy said the hospital told the family nothing about what happened.

'He ... spent the next 14 months in and out of hospital. When he was eventually discharged he had to learn how to walk, eat, talk. His life was completely turned upside down.'

Suzy applied for guardianship and moved him to live near her.

'He went very, very well ... largely due to his own incredible efforts [and] really good clinical staff. [His psychiatrist] was very instrumental in getting the meds right.'

Suzy said Vaughan's brain injury increased his sensitivity to medication. Whenever he was admitted to mental health units, staff overmedicated him.

One day, Suzy found Vaughan unconscious in a mental health unit.

'He had been given eight different [drug doses] in a five-hour period by a registered nurse ... I was incredibly shocked. She basically kept on giving him [medication] until he passed out.'

Suzy said the nurse explained that she had given him each subsequent tablet because the previous one 'didn't work'.

'It seems to me that mental health units, and particularly mental health nurses, are ill-equipped, ill-trained to deal with behavioural issues ... and everything is medicated. Not all of them. Some of them are quite good, but generally the first line of response is to medicate.'

Vaughan is supported by the NDIS and lives independently with support from a service provider. A few years ago, a support worker doubled his medication.

‘He had been given the dose for the evening meds as well as the morning meds within about a two-hour period. It took a while to actually get that out of the particular worker.’

The impact was devastating.

‘Within two days, his deterioration was obvious. He was back to where he was years before. He hadn’t slept. He was walking backwards. His cognition, orientation, everything was like going back years. It was like all the work that had been done had been undone.’

Vaughan spent six months in hospital. After he was discharged, he needed increased care.

When Suzy complained about the incident, Vaughan’s service provider insisted she give them all the evidence she had against them to send to the NDIS Quality and Safeguards Commission, which would investigate. Suzy said the commission wouldn’t accept the information directly from her.

‘The commission said ... “You can’t provide it directly to us because we consider you a third party.” And it was like, well, I’m his guardian. I’m the one who put in incident reports. It got very confusing. And it was almost bordering on harassment from the provider demanding confidential health records.’

After more than six months trying to get an outcome from NDIS Quality and Safeguard Commission, Suzy said she ‘gave up’.

‘What’s the point of having this body if they don’t actually do anything when it’s this serious? ... It seems to me that quite often the commission was more concerned about the provider and liaising much more with the provider than they were with me and my capacity as a guardian.’

Clinton and Dustin

Clinton is in his late teens. He is autistic and has an intellectual disability, obsessive-compulsive disorder and post-traumatic stress disorder.

‘If you look at him now, he’s a young man who sometimes asks you to stop and let him process information,’ his dad Dustin told the Royal Commission. ‘He’ll take time to understand what you’re trying to say.’

Dustin brought his family to Australia more than a decade ago.

‘When we arrived here, my goal was to ensure the children had an adequate, or a very good, education.’

Dustin enrolled Clinton in a Catholic primary school.

‘Usually [Clinton] would be behind everyone and everything. But in year 6 his teacher was saying, “I’m so proud of [Clinton].” He really started to make real progress. He would start answering the questions. He would get in, engage with the class. Everything was going smoothly.’

After Dustin shared Clinton’s medical history with the school, he noticed the principal targeting Clinton.

‘So, she was exploiting it by saying things like, “[Clinton’s] exhibiting sexualised behaviour.” ... He has never exhibited sexualised behaviour.’

One day, the principal came to Clinton’s class and asked him repeatedly if he was anxious.

‘The other children started laughing. [The principal] kept asking me the question and I was frightened and embarrassed in front of my classmates,’ Clinton told the Royal Commission.

He left the classroom chased by the principal. In the playground, crying, he ‘threw a bin over’.

The principal locked down the primary school.

Clinton had been enrolled in the nearby Catholic high school, but after the incident, the high school principal told Dustin there was no funding to support his son’s enrolment.

‘They didn’t want him going to the high school and that was the end of the matter,’ Dustin said. ‘Basically, “You’re not going to high school.” ... We were shocked by that. We didn’t know what to do. We weren’t prepared for it.’

Dustin took the case to an anti-discrimination agency.

'It's a mediation service ... The problem is, there's no balance of power when we go into a mediation, right? We're hoping that they will listen to us. We're hoping that they will hear what we're saying, that we have the best intentions for our son, for his education, for his life.'

Dustin said one of the Catholic school's representatives called Clinton 'nothing but a vagrant', and the mediation stopped.

'A large proportion of people with disability have a huge contribution to make to our society. And, you know, they are entitled under international law to reasonable adjustments and accommodations ... It's called a right. It's not open for negotiation at all.'

Dustin said Clinton's mental health deteriorated after the incident.

'It could've been far, far more positive for Clinton at this age than him ending up ... nearly killing himself, all because of what happened all those years ago.'

Briana

‘I still have nightmares about this. Nobody should have nightmares about their employer.’

Briana is in her late 40s and has multiple sclerosis (MS). She also lives with psychosis and depression.

Briana was diagnosed with MS in the early 2000s. At the time she was working in a management role for a state government department.

For years she carried the ‘terrible burden’ of an ‘invisible illness’, she told the Royal Commission.

‘I wanted to tell my colleagues ... Because I was going through such an experience and I wanted to let them know what was going on for me.’

Her workmates were supportive and said they would do whatever they could to help. ‘Until we got this new manager,’ Briana said.

Briana asked her new boss for a workstation assessment, noting any ‘reasonable and necessary modifications’ for her illness. The manager refused.

‘And we had a screaming match about it, and it was only when I screamed back at her that she finally relented and said, “Okay, fine, I’ll do it.”’

But the abuse escalated. Briana said her manager targeted her because of her disability.

‘She ended up putting me on performance management, which is code in the industry for managing you out of the job.’

The manager increased Briana’s workload.

‘What I was expected to do she couldn’t fit on an A4 piece of paper ... There were so many tasks I was expected to complete ... And I said, “But that’s not making any workplace adjustments for me.”’

Briana, already exhausted from managing MS, worked up to 11-hour days to ‘try and complete these unreasonable work tasks’.

‘The fatigue is worse at the end of the day ... It got to the stage where ... I’d fall asleep at my desk. It was pretty bad.’

At one point, the manager tried to force her to ‘write off’ 140 hours of overtime.

The employer offered Brianna 'an alternate position in admin' with a \$15,000 cut to her salary which, she said, she 'can't survive on'. So she left.

Brianna felt the employer had 'bullied [her] out of the workforce'. She ended up in a psychiatric ward.

'They had me convinced that I'd quit because I was mentally unwell by the time I left ... It actually brought out psychosis ... I had to have so much psychological counselling over what that job did to me.'

It took Briana five years to recover from the 'horrific experience'.

'It made me physically unwell, emotionally unwell, mentally unwell. I was so broken after what had happened.'

Currently Briana volunteers for a community organisation. She can only work a few hours because her tiredness is 'so bad'.

She said if her former employer been more supportive, she'd probably still be working there on reduced hours. Instead, they 'destroyed [her] career'.

Kalon and Asha

Asha and her son Kalon, who's in primary school, have attention deficit hyperactivity disorder (ADHD).

Asha was diagnosed a couple of years ago.

'The stigma was horrendous,' she told the Royal Commission. 'When you call around psychiatrist practices and you have a receptionist saying ... "The doctor is not seeing anyone with ADHD." It's like, okay, I didn't know they picked and chose their patients, but okay ... It's just such a shaming experience.'

Kalon, who's now in year 4, was diagnosed several years ago. But he still struggles at school.

'I've been battling since prep,' said Asha. 'I'm into my fifth year now of trying to get [the school] to understand ADHD. I've provided resources. We've had countless meetings. Overwhelmingly, what happens every meeting is I feel that they've already made decisions around what's happening.'

Asha said teachers' lack of understanding of ADHD leads to 'unintentional psychological abuse' of children.

'The culture is, "We know what we're doing and what this child needs and the parent's a bit too soft and forgiving of their child, so we're just trying to get the parent onboard into our way."

For example, teachers often blame Kalon for 'making bad choices' when he doesn't complete his work or becomes frustrated.

'There's a judgement behind it that the child is making a choice ... Every time they see a behavioural incident, I can trace it back to, "You gave him this task and it was beyond his working memory capacity."

One day, Kalon's teacher called the principal to the classroom 'because [Kalon] couldn't do the work'.

Asha said Kalon was terrified of the principal and tried to run away.

'She blocked the doorway, so he's trapped in this classroom with everyone watching him having this full panic. And then he jumped over a desk ... and she then chased him around the carpark.'

Kalon was blamed for his behaviour, even though the principal 'blocked the doorway of a child in flight mode'.

Asha said teachers needed better training to not only help kids with ADHD, but prevent psychological damage.

‘It’s the child that’s scapegoated and ... it’s really just very unintentional bullying to a terrible, terrible level.’

Asha said many principals were sceptical.

‘There’s a nonevidence-based debate going on about whether ADHD exists or not. Part of it is inflamed by statistics coming out of the United States saying it’s been over-diagnosed ... but that’s a really different situation to Australia.’

ADHD can be expensive to treat. Asha recently applied to the NDIS for support.

‘The bar is too high, in terms of dysfunction and impairment, to get the funding. And all those that are above the bar, the ones that I know, [also have] autism.’

Asha said although ADHD is effectively treated with medication, people with ADHD can benefit from ongoing therapy.

‘It won’t change the ADHD symptoms. But it will change those secondary outcomes, the anxiety, depression, all those co-occurring things that happen to every adult with ADHD. It will lessen the chance of suicide, lessen the chance of substance abuse, so it’s a long game in equipping the child with everything they need to cope, and buffering their self-esteem.’

Al

Al is in his 40s and has borderline personality disorder and dissociative identity disorder. He lives with osteoarthritis, post-traumatic stress disorder and an autoimmune disorder. He uses a wheelchair.

'I'm a law graduate. I'm one of those spectrum disabled people who speaks up,' Al told the Royal Commission. 'I'm not the quiet type.'

Al left home when he was still in school, in the 1990s.

'I was homeless and, eventually, I meet the missionaries. Like, they come across as really friendly, really approachable, sincere. Well, to my big shock ... things went pear-shaped when I ran into a guy named [Dave].'

Dave was a church leader visiting from America.

'When you are called as a leader, they believe they are called by God and they can never do anything wrong.'

Al said he felt unsafe around Dave, who told dirty jokes. One night, Dave raped him.

'I missed church for about a month and my friends were wondering where I went.'

Al asked one of his friends why he hadn't warned him about Dave's known predatory behaviour.

'I said to him, "I'm a disabled person and I was disabled when you first met me." ... He basically said, "Oh, God commands you to forgive." Basically, I was told that I have to forgive his mistake and his sin because I'm not perfect either.'

Al told the bishop.

'The bishop was good friends with [Dave]. He said that I was flirtatious. I was at fault. Like maybe I should start wearing appropriate clothing [and] stop flashing my skin in front of him ... So, they didn't deny it, but they just victim-blamed.'

Dave returned to America. The bishop told Al to undergo electroconvulsive shock therapy.

'The bishop basically thought I was a homosexual ... He said, "It will also cure your other ailments as well, your other disabilities."'

Al left the church.

Years later when Al applied for NDIS support, his NDIS planner asked him about the rape.

'She was given all the information by my clinical psychologist of 20 years and my doctor ... She joked, "How big was his penis?" ... Asking questions like, "How many times were you sodomised?" And [it's] those kind of questions that pushed me over the edge.'

Although Al was facing homelessness at the time, he said the planner ignored multiple doctors' reports and withheld his application for accommodation for nine months.

'Basically, "You're a big boy, you can handle it." I needed special disability accommodation because I've got osteoarthritis, osteoporosis. I've got Hashimoto. I'm a cancer survivor.'

Al said the NDIS only supports his borderline personality disorder. He recently struggled to find a suitable apartment and in desperation rented one on a second floor.

'It doesn't have a lift. It does not even have much space to accommodate my wheelchair ... I actually have to crawl up the stairs, like every time I come home.'

Al can't access the shower. He uses his Disability Support Pension to pay someone to wash him. His NDIS planner told him to complain to the Administrative Appeals Tribunal (AAT) if he had a problem.

'It's like every time now they intentionally cut your funding, reject you for everything, they will basically say, "Just take it to the AAT."'

Al said the last time he appealed a decision, the AAT attacked him, his support worker and his clinical psychologist.

'The NDIS was meant to be designed to help the vulnerable people, but it seems to be more of the strongest survive and basically disabled people are then left in the lurch.'

Reid

Reid is a Paralympian. He has physical disability and uses a wheelchair.

As a child he used 'crutches and callipers for mobility'. His years at high school were 'horrific'.

'I was up against constant bullying and segregation including acts of physical and psychological violence,' Reid told the Royal Commission. 'Somehow I managed to see [it] out ... under conditions that no-one should ever have to experience.'

The school showed 'zero support, and disinterest'.

'The principal pointed out to me that what I was experiencing was "normal schoolyard teasing".'

The school excluded Reid from lessons and activities.

'Because I couldn't stand for long periods. I was relegated to the library [during school assemblies], and again by myself during sport and periods, which I was not allowed to participate in,' he said.

'These acts of bullying, violence and what I term to be terrorism towards people with disability, basically prepared me for what I should expect in all facets of my life ... They were specifically targeted and designed to instil fear, intimidation and control over me because I have a disability and, therefore, am an easy target.'

After he left school, Reid was diagnosed with post-traumatic stress disorder (PTSD). 'Even the uniform continued to evoke a PTSD reaction.'

Despite this, Reid went on to become a competitive athlete, participating in Paralympics, Commonwealth Games and world championship events.

But even when he got involved in community sport, running activities for people with disability, people 'undermined', 'heckled' and 'did not respect' him.

'[This] continued on throughout all aspects of my life in various forms ... Each time ... reopening my old wounds from high school ... I have never been able to trust anyone since nor establish a meaningful relationship of any kind, including an intimate relationship.'

Reid feels isolated.

'I find people are not wanting to or interested in making friends with me, let alone developing any stronger kind of relationship with me or other persons with a disability.'

Participating in sport let him rise above that. '[It] was the best and most rewarding part of my life,' Reid said.

'In the Paralympic village you are in a world for two weeks where you are a person first and your disability is second. Accessibility is 100 per cent ... [Everyone] treated each other with the utmost respect and equality, and for me that has been an absolute breath of fresh air.'

Tru and Jaylee

‘There are children who need specialised schooling. There are children who are never going to fit, and their parents know.’

Tru is a First Nations autistic man in his late teens.

Jaylee, his mum, said Tru was diagnosed with global development delay when he was 18 months old. ‘I had a doctor tell me that my son was abnormal, looked abnormal and was probably never going to be normal,’ she told the Royal Commission.

But when he started school, following ‘wonderful early intervention’, teachers assessed Tru’s intellectual disability as ‘borderline’. As a result the school placed him in a class with no supports.

‘I knew he was never going to fit in a mainstream school,’ Jaylee said. ‘When you get touched with autism and have sensory issues, sometimes it can feel like pins and needles and people pricking you.’ If children were playing, and they touched him, Tru would react aggressively because it ‘was causing him physical pain’.

In kindergarten, Tru ‘pushed somebody and bit somebody’. The school suspended him.

Jaylee pressured the education department ‘really hard’ to reassess Tru, and he was diagnosed with autism. That bought ‘some help’, but Tru’s classmates and their parents bullied him because of his disability.

When Jaylee dropped her son off at school, it felt like ‘dropping a lamb to the slaughter’.

‘We live in a rural area ... It’s full of some red neck-y people who don’t see the value in people with disabilities ... I call it the car park mafia, where all the mums sit around in the car park and they judge everybody who comes in based on their child.’

But the school had an ‘extraordinary principal’ who ‘stood up to everybody’.

In grade 7, Tru moved from ‘a school of 40 to a school of 1200 children’.

‘So, the noise – just everything about it,’ Jaylee said. Teachers ‘created a quiet place’ for Tru, but other kids came in and ‘bullied and harassed’ him.

‘They knew what his triggers were and how to upset him. So, they would tell him to do stupid things. They would make him cry. They would call him a retard ... Then they would record him on Snapchat and video him and then share that to their stories and to their friends.’

Jaylee pushed hard 'to get him out of that school' and get him 'the right help'.

She secured him a spot at a behavioural school in the middle of grade 8.

The school was on a farm and was all about teaching children 'life skills'.

'They did all of the stuff that kids love. They rode tractors, they mowed lawns, they had animals to look after, they were allowed to choose their activities.'

Tru stayed there until year 12.

'That was where he finally found somewhere safe ... it was about his needs.'

Geoffrey

Geoffrey, a retired teacher, injured his spine in an accident 40 years ago and sustained physical disability.

‘Right from the word go [the education department] didn’t want me to continue teaching as a primary teacher, because they couldn’t see how I could do that,’ Geoffrey told the Royal Commission. ‘And so, I had all these fights.’

Geoffrey refused to resign and was eventually promoted to principal. His primary schools became ‘magnets’ for children with disability.

‘Some of my colleagues refused to take kids with disabilities. And they would say, “Oh, go to [Geoffrey] because he accepts kids with special needs in his school.” So, the discrimination was quite blatant.’

Geoffrey said his mainstream primary school had ‘about 20 per cent of the kids having special needs’.

‘We are neglecting our kids with disabilities as an education system. And I think, to quote one of my colleagues at the moment with regard to kids with disability, “We do what we can with what we get.”’

For example, Geoffrey used the department’s languages other than English (LOTE) program to introduce Auslan as a LOTE class for all students.

‘As soon as I moved out of that school, the department took it away because it wasn’t an official LOTE.’

Geoffrey introduced a practice of assessing each child in the school to determine their needs and created classrooms ‘around having equitable needs, learning needs’.

‘And so, some classes might have had 20 kids, some might have had 15, and it was quite a good process ... particularly with our kids with ASD [autism spectrum disorder]. And I had some brilliant teachers who would create a classroom environment in a way that optimised outcomes for these kids.’

Geoffrey said that when the education department introduced the national assessment program NAPLAN, the school was forced to rearrange classrooms for tests without considering the student’s disability.

‘One particular kiddie came into the classroom and was sat in their desk, which had been moved and separated and outside their comfort zone. And his response to the NAPLAN test was to eat it ... NAPLAN is an abomination before God with regard to kids with special needs.’

Geoffrey said at his last school, before he retired, a student without disability brought her father to a Christmas concert.

‘And he came up to me and he said, “My child’s been coming to your school for years, and speaks about you often as a principal. But never once did she mention you [have disability].” And it’s that childlike view of the world that we are missing.’

Warwick

‘Within myself I feel dirty. I know what happened to me is not my fault, but I feel dirty.’

Warwick, now in his early 80s, had polio as a child. As a baby he was placed in a home for children with disability, where he lived until his early teens.

‘I was taken down, so my granny tells me, in the iron lung. I was flown down there as a little bloke ... I might have been about one, I suppose,’ Warwick told the Royal Commission. ‘I called her grandma, she looked after me. I never had any parents.’

Warwick did his primary schooling at the home. There were more than 100 residents there, boys and girls.

‘I used to wear a calliper and I got very embarrassed because everywhere I went, people looked, in those days, calling me “hoppy” and all that sort of thing.’

Warwick stayed in the junior boys’ dormitory.

‘Underneath, was an air-raid shelter ... I used to go and play with my little mates down there.’

One of the religious sisters at the home warned them against it. She said, ‘Don’t go down there! The senior boys go down there and everything else. Stay out of there.’

But Warwick didn’t listen.

‘So, that’s when we run into a bit of trouble.’

Warwick said senior boys sexually abused him in the bomb shelter.

‘They would play with your you-know-where. I was at that age – nine and 10 – you didn’t know any different ... We would try and keep away, but you’d get caught every now and then.’

Once Warwick ‘got caught’ in the linen room, ‘right opposite the boys’ dormitory.’ After that, he was always ‘wary’.

‘I’d run past there ... [to get] to school.’

He told one of the nurses and religious sisters about the sexual abuse, but ‘nothing seemed to happen’.

The nurses also abused Warwick. A couple of them used to tie him up all night.

'They were hell to me – me and another little bloke ... They are the worst people in the world. When they were on shift they used to come in and tie us down.'

Warwick 'lay there all night' in terror.

'I used to wake up with a rash from the urine.'

Warwick said the abuse marked him for life and made him fearful of participating in many activities.

'I missed a lot of things out, like sport and everything.'

The trauma left him terrified of public toilets.

'All my life, I have to do my business at home before I go out.'

Warwick has only just told his wife about the sexual abuse.

'I never told her because you – you feel ashamed or you feel dirty or something.'

He still doesn't want to tell his kids.

Cliff and Loretta

‘I cannot see [Cliff] having a life outside and I worry that he will do like others of my kids [who] have died. And that’s suicide.’

Loretta is a First Nations woman who advocates for Cliff, a First Nations man in his 30s. Cliff was born with fetal alcohol spectrum disorder (FASD), intellectual impairment and developmental delay.

‘He was abandoned in the community hospital by his mother and one of the domestic staff adopted him,’ Loretta told the Royal Commission. ‘She had breast cancer [and] died when he was about eight or nine. His father also hanged himself.’

Loretta met Cliff when he was 14.

‘He couldn’t read and write. The youth detention centre said, could I take him? And so I said yes, I would. There was never any financial arrangement made, but I didn’t ask for it.’

Loretta said doctors diagnosed Cliff’s FASD ‘too late’, when he was 15.

‘As soon as he could walk, his little legs would just take him anywhere and he would say, “No, I’ve got to go,” but I found this with a few children. They’d just take off.’

One day, Cliff went for a short walk before a State of Origin rugby league game.

‘[He] assured me he’d be back in five minutes, but he was gone. I found him in the [police] watch house four days later. And when I said, “You missed out on the State of Origin,” he was so upset ... His little legs and his head just weren’t working in tandem. And so over the years he’d faced some terrible times inside.’

When Cliff wanders away and becomes hungry, he sometimes steals food. Since turning 17, he’s spent much of his time in jail. When he’s released on community-based orders, he’ll often vanish again.

‘He was never able to keep probation program despite having wonderful people to look after him because he would disappear. You know, when they came to pick him up he’d be gone. He either went and got a job, then the same thing happened, [or] they’d call to take him to do some really exciting project in the day and he wouldn’t be there.’

When he’s in prison, Cliff can’t follow instructions and doesn’t understand why he’s being punished.

'His privileges [are] taken away and that included his television, except he couldn't read and write and I said to him, "What did you do, dear?" And he said, "I did push-ups on the floor."'

Loretta said Cliff is currently in prison and 'part of that big cohort' of young people with FASD who 'cannot manage their freedom because they're so institutionalised'.

'We will have many recidivists who should have had meaningful interventions when they were young. Nobody could see them when they went to youth detention [and] he should have at least been taught to read and write.'

Loretta said children with FASD, such as Cliff, are overrepresented in the justice system.

'I'm very fearful now of what his situation is and which will pertain also to the other ones I call my kids ... a cohort of children ... affected by alcohol exposure before birth.'

DJ and Emely

DJ has just started primary school. He is autistic and has attention deficit hyperactivity disorder (ADHD) and oppositional defiance disorder.

‘DJ loves water. He’s a swimmer and a surfer. He’s ridiculously smart,’ Emely told the Royal Commission. ‘It’s just, we need the help and the support from the system. To get through it.’

Emely, a single mum, said she had a ‘gut feeling’ DJ had a disorder when he was a toddler, but it took several years to get doctors to diagnose him.

‘[The] waitlist to see a specialist was anywhere between nine months and a year, and when we finally got in ... they wouldn’t diagnose for us. They said we had to go somewhere private, and then that was at least \$3000.’

When DJ started school, Emely couldn’t find a private school willing to take him, so she enrolled him in the local public school.

‘They used to keep him away from everyone ... At lunchtime and recess he’d have to go and sit by himself in the office or in the yard.’

In his first year, the school suspended DJ seven times. DJ didn’t understand why he was suspended.

When she picked him up from school, Emely noticed DJ looked ‘like a zombie’. She and DJ’s doctor had arranged for one teacher to give DJ his regular ADHD medication. She discovered another staff member was medicating him.

‘She was giving it to him whenever he wanted, pretty much ... If he just said, “No, I’m not doing it,” she would go get him a tablet or, if he wouldn’t sit in his seat, she’ll go get him a tablet.’

Emely said the education department investigated, but took no action.

‘I did go a little bit nuts on it, because I was even thinking about calling the police, but I was talked down from it.’

She said the school also kept a book about ‘how crap [DJ] was’ and ‘read it to him every day’.

‘Pretty much, “This is what’s wrong with you. You kick people, so you have no friends.” That’s what it was in the book. “You have no friends, because you can’t keep your hands and feet to yourself.” Turn the page. “You don’t play at lunchtime because you don’t know how to play with your friends.”’

Emely said the school doesn't give him a chance. For example, it refused to let DJ attend his class photo.

'We said, "Yes, we understand he's suspended, but can he just come in for the class photo?" Like, let him be part of something. They don't let him do anything. Like, he doesn't feel a part of the community of the school because he's not allowed to do anything in the school.'

DJ now attends a special school several days a week.

'They get him. And [kids like DJ] just want to be trusted. They want to be acknowledged, these kids, you know what I mean? And that's how they treat them. "Yes, you had a moment. Tomorrow's a new day." Whereas at [the old school] it was like, "No, you're the bad kid now."

Emely said DJ vomits on the mornings he has to go to his old school.

'So, he gets to the gate and he sees everyone. He runs. He bolts, because he doesn't want to walk into the school. It's like they've just offloaded him.'

Lorraine

‘They have created a culture where working illegally and immorally you get away with it. And they have been getting away with it for so long.’

Lorraine has been working for the same disability service provider for more than a decade.

‘Every single site I’ve been at ... there has been something [wrong], to the point of someone going to jail or just morally not right,’ Lorraine told the Royal Commission. ‘And all the long-time staff members that I know, it’s [also] every site they have been at.’

Lorraine said at her first job, her manager verbally abused staff ‘to the point that they were in tears each day’.

‘She started doing it to customers ... [She told] one of my customers ... “You’re stupid. You don’t understand what I’m saying, do you.” I think it was that same day she grabbed another customer, who isn’t very good on his feet ... and as a result he fell down.’

Lorraine told a senior staff member, who told the manager to leave ‘or be fired’.

‘She obviously left and got a job with [another service provider] within the month, so it didn’t achieve anything, really.’

Lorraine said many of the people at the same facility were funded for one-on-one support, but the service provider rostered one support worker for every five people.

‘We asked if we could get agency [help] because we weren’t coping and the customers weren’t receiving an appropriate level of care, and they wouldn’t allow it.’

Lorraine moved to another facility where she discovered a male support worker showering a female resident who’d been abused in the past.

‘We were putting in reports and asking for this not to happen on a daily basis. He was there that often. And then he got to a point where he was inappropriate towards myself and my friend ... We asked to not work with him.’

Lorraine said the man was eventually convicted of assaulting a resident.

Lorraine described other incidents of abuse at other sites operated by the service provider.

‘I did put in the incident reports, but ... I can’t access them anymore.’

When one of her relatives was about to be placed in a group home, Lorraine ‘begged’ his parents not to use the service provider she worked for.

'They didn't listen, but, like, they didn't really have many options.'

Lorraine said one day a support worker injured her relative by cleaning him with a high-pressure hose. 'There was no incident report.' When his parents told staff to call a doctor, they 'left it to another day'.

Lorraine still works for the service provider, which employs mainly part-time staff 'even though there are people begging for full-time work'.

'I work three jobs to meet my full-time hours ... They're just not staffing correctly.'

Danika and Raegan

‘She had areas she excelled in ... but they played to her deficits on every occasion and they discounted the things that she was good at because she came with a label of having a disability.’

Raegan’s teenage daughter Danika is autistic and has attention deficit hyperactivity disorder, obsessive-compulsive disorder, post-traumatic stress disorder and anxiety.

‘It was picked up in kindy that she was a bit different,’ Raegan told the Royal Commission. ‘And after a year we were told, “There’s something wrong, we don’t know what it is and we don’t know where you can go for help.”’

Danika was diagnosed with autism at the end of her first year in school. She was integrated into a year-2 class with her own teacher’s aide.

‘She was funded for 45 minutes a day, but that was the only teacher aide time that class got and it very often didn’t go to her.’

At the end of year 2, Danika’s behaviour deteriorated. Raegan and her husband discovered Danika’s teacher punished her for fidgeting.

‘[Danika’s father] went in to drop her off one day and ... he heard one kid say, “Oh, Miss, [Danika’s] not on her cross.” And he looked around and he’s pointing to this sort of masking tape cross in the middle of the concrete floor.’

Classmates then began bullying her.

‘[One] kid was taunting her or hitting her and [Danika] had held her up against the wall to make her stop. But [Danika] was the one punished for it and we were told that the aggression was due to autism, even though she had absolutely no history of aggression.’

Raegan said children taunted Danika to get a reaction. On one occasion three girls were accusing Danika and she was highly distressed.

‘She could hardly talk, snot running down her face ... And she was being held up because she could hardly walk and the teacher ... And the teacher just said, “Now you have to apologise, [Danika].” She was forced to apologise to these three girls.’

Danika’s paediatrician diagnosed her with trauma and told her parents they needed ‘to get her out’.

They enrolled Danika in a new school.

'It took her about two years to recover, and during that time she settled right down in a supported schooling environment and was excelling. And by the time she had left in grade 6 ... she was [a] champion swimmer of her school. She was ... in the school musical.'

Danika received a creative scholarship to a private high school where, after a few weeks, she 'stopped sleeping and she stopped eating and she changed'.

'And we thought, oh, teenage years. [But] she started harming herself.'

Raegan said she discovered classmates were again bullying and excluding Danika. When Raegan and her husband complained, the school told them that Danika's behaviour was a symptom of autism and not of bullying.

"'Oh, she's far too sensitive, she's misinterpreting the situation" ... It's like my daughter's a walking stereotype.'

Raegan said Danika's teachers put no effort 'into trying to make sure she's included in class'. In consultation with her paediatrician, they took Danika out of school.

'She's not the same child anymore because she can't see a future for herself. And I have to say we're struggling with that as well.'

Callista

Callista is the principal of a regional primary school in which 15 per cent of the 300 students have a disability.

‘I not only have a refugee community, but also a dozen languages spoken at my school as well as 20 nationalities,’ Callista told the Royal Commission. ‘Navigating that is difficult.’

Callista said there aren’t enough support services in the town to help all her students.

‘Last year the [town’s] paediatrician actually closed their books on any new patients. They did that because they were overwhelmed with the number of students or children who were requiring support.’

Callista said of the 15 per cent of her students with disability, a third are still waiting for a diagnosis.

‘Particularly if parents can’t pay privately, which my families and, I would think, regional and remote Australia can’t ... the minimal wait is three months, and the maximum is two years to try and get into a paediatrician.’

For example, Callista said one of her students starting kindergarten is non-verbal and still in nappies, but hasn’t received a diagnosis.

‘For whatever reason that parent just couldn’t get to a paediatrician appointment or engage in early intervention services.’

Callista said the school employs a speech pathologist to try to assess what the child needs, but there are often language barriers with refugee and CALD families.

‘Coming to a new country under quite challenging circumstances is difficult within itself ... Then you realise perhaps there is something more going on for their child.’

Callista said while the school waits for a diagnosis and the special funding that comes with it, the child often needs one-on-one support, which drains the school’s budget and creates a ‘real moral dilemma’.

‘I am spending \$30,000 on one child, where that \$30,000 could be spent on academic program intervention. It could even be spent on students with academic needs or emotional support needs. That is where the dilemma comes.’

After the child’s diagnosed, the school fills in a form for funding that ‘doesn’t really take into consideration the child’.

'If they have a physical disability, so if they are in a wheelchair ... they attract more funding. If there is a safety issue, they also attract more funding ... Students that [have] quite severe autism or have a cognitive and emotional disability, that is where the funding is lacking because it is not visible.'

Callista said she also struggles to find staff to teach them.

'There is a huge shortage of teachers with a background of disabilities or even wanting to go into that field.'

Refugee families in her town also struggle for resources outside school.

'I have got colleagues that are navigating that for their child and they are educated people and they are finding it challenging. For a lot of our community, literacy is a big issue, so limited or illiterate parents are navigating the field of that.'

For example, Callista said the father of one of her students with disability is illiterate.

'For him, the whole NDIS early intervention is just so overwhelming that unfortunately he has just closed the door on it. His eldest child is not able to get that service provision. What his pathway in life will be will perhaps be hindered by that.'

Beckham and Aubree

Beckham, a teenager, is autistic, has developmental delay and is non-verbal. His mum, Aubree, is a single parent caring for two children with disability and her elderly mother.

Beckham used to occasionally attend a respite facility overnight.

One morning, after a night at the facility, another resident bit Beckham.

Staff quickly contacted Aubree saying they had applied ice and water and Beckham 'seemed happy enough'. They did not give her the impression the bite was serious.

When Aubree arrived to collect Beckham a few hours later, she was 'horrified to see how serious' the bite was. It was 'like two deep, deep cuts' and the arm was red around the site. Somebody told Aubree a nurse had been called to attend, but Aubree is 'sceptical'.

Aubree took Beckham to the doctor, who couldn't understand why staff hadn't covered the bite or applied antiseptic to it.

The facility finally provided an incident report six months later. It showed that staff had left the resident alone in the same room as Beckham despite knowing the resident had bitten a staff member shortly beforehand.

Aubree complained to the NDIS Quality and Safeguards Commission about the incident. She felt the case manager 'didn't have a very compassionate manner'.

'I didn't feel that he would be advocating for me ... I ... didn't get a very good feeling.'

Having heard nothing from the case manager for some months, Aubree phoned the commission and requested they assign another case manager. But the second case manager 'didn't seem

to grasp things very well'. The NDIS Commission finally emailed Aubree, 'basically wrapping it up, summarising everything'.

'[They said] they've done all they can do and that if I'm not happy ... I can go through the ombudsman.'

But Aubree said that the ombudsman has seemed unwilling to take up the matter.

Aubree believes the respite provider was negligent and incompetent. 'And ... there's no consequence ... It's like, "Well, we will do it better next time."'

'What is the purpose of having the Quality and Safeguards Commission when I feel all the things that I raised, there was always an excuse? It was like they were protecting them.'

Aubree has lost trust in the system and no longer uses respite services.

Martyn and Kristin

‘We were literally fighting every single day. Every week. Every term. Every year. It was very frustrating.’

Kristin is the mother of Martyn, who has a chromosomal abnormality, intellectual disability, autism and a range of health conditions. Martyn recently graduated from high school.

‘All the kids accepted him. There was never any bullying. Nobody spoke badly about [Martyn]. They loved him. They loved him to bits,’ Kristin told the Royal Commission. ‘The whole bullying thing came from the teachers and the principal. That’s where the issues were.’

Martyn started kindergarten in a non-government school.

‘They just believed that [Martyn] should never have been at that school ... There was a message where the teacher said, “You know, he should be going to a school down the road.”’

Kristin kept Martyn at the school, but it refused to give him an individual learning plan.

‘I mean, we were only asking for [the learning plan] which [Martyn] was entitled to. And we were called into that meeting and [the principal] said, “You know, stop telling us what to do. You can’t tell teachers what to do.”’

In year 5, Martyn’s teacher wouldn’t let him socialise with other students at the school.

‘If he showed any kind of way of trying to make a friend or whatever, she took that away. Like, literally every time. She would make sure that child sat on the opposite side of the room. He wasn’t allowed to talk to them.’

Kristin said that when Martyn moved to high school in the same system, his school records were ‘literally thrown away’.

‘So, they knew nothing about what [Martyn] was like, what he needed during the day. All that made it very difficult for [him].’

Martyn has irritable bowel syndrome. One of the senior staff members told Kristin that Martyn’s syndrome is contagious and he shouldn’t be there.

‘We kept saying that it wasn’t contagious, no-one’s going to catch it ... And he said, “It’s not negotiable.” Like, basically he cannot go to school. And we just felt like, yeah, there was not much else we could do, but to hopefully find another school that would be more supportive.’

Kristin enrolled Martyn in a government high school.

‘Unfortunately, it wasn’t much better.’

The high school promised to be inclusive, but wouldn't allow Martyn to do work experience.

'They actually made him stay in school and do gardening. So, he never got that opportunity to go out and work with other people outside of the school.'

One teacher made Martyn sit in the classroom on a tarpaulin inside a makeshift tent.

'He wasn't able to communicate that he needed to go to the toilet, so then he just soiled himself. And they thought that was a really good idea ... Just him in the corner against a wall, so that when he was looking, it was at the wall. So they could not see him.'

Kristin told the Royal Commission governments should apply a national standard to all schools, to make them 'inclusive to all children' regardless of their disability.

'At least have some kind of basic standard so that all of the children in the playground, and the children with disabilities, they are not just standing there, they are not just sitting there. They are engaged, they are encouraged to engage with other children, play on the equipment. Just because they can't do it, doesn't mean that they aren't allowed to do it. And the same [in] the classroom.'

Giuliana

Giuliana has quadriplegia and is terminally ill with a bone infection.

'I led a very active life of working with my dad on a farm, helping my mum in various difficult jobs, had my own horse, played sports, knew the whole neighbourhood,' Giuliana told the Royal Commission.

When she was a teenager she had an accident and became quadriplegic. Giuliana continued to live an active life and be physically and financially independent.

'I've always been very mentally strong and mindful, and got other strengths. And that's held me in good stead. It helped me get through the life that I've led since I've been in the chair.'

Giuliana gave up work 15 years ago when her health deteriorated.

'And when you've been totally in control of your life as a person, and then a person with a disability, it is even harder to have someone tell you what you can do and what you can't do.'

The first disability support service she hired tried to tell her what she could and could not do in her own home.

'I wasn't asking them to paint the roof or, you know, clean the gutters ... but I did expect them to assist me with my personal care for myself. And also look after my home and my yard, because that's part of my environment that keeps me in the community.'

Giuliana said the service provider ended her contract when she was in hospital with septicaemia. She found a new service provider that allowed her to manage her own funds.

'We had the power ... We were given that respect to know what we were doing with our life.'

When Giuliana became ill a few years ago and asked the provider to take over more responsibility, they 'decided to drop [her] services'.

'They told me their book was full ... I was in a vulnerable position, mentally stressed ... And I was just shocked, absolutely shocked.'

As the NDIS was being rolled out, Giuliana found a new service provider.

'Unfortunately, the NDIS is seen as a money tree out the back ... Even though it's our funding that's been given to us, and we employ the agency, as far as many of the home carers and the agencies are concerned, the staff work for them, not for us.'

Giuliana said one support worker was abusive.

‘She would ... physically yank my leg until it hurts, you know what I mean? Like really pulled it so it jarred my pelvis and my hip ... And she yelled at me, “Why don’t you take painkillers like the rest of my clients?”’

Giuliana said she often has to train the support workers.

‘It’s the client is the one that’s training them ... I’m not saying this just from my point of view. I’ve talked to many people with a disability and it’s like hearing an echo when you talk to them because it’s always the same complaints over and over again.’

Giuliana said that, over the years, untrained staff broke her legs three times helping her out of bed. Because more staff are now poorly trained, her friends with disability are scared a worker will accidentally hurt them.

‘So, they just stay in bed, they won’t get up and shower at all, you know. And I was the same for a while, scared of getting my legs broken again. So, we go weeks and weeks without a shower, and just having a bed wash, because I didn’t want to get hurt. And that’s not right.’

Wally

Wally is a First Nations man in his 60s with cerebral palsy.

Wally told the Royal Commission that in the 1960s, a government medical officer and the director of Native Affairs 'sat down, deliberated [his] issue and decided there and then [his] future'.

'From then on, from what I call a stroke of a pen, my life changed completely.'

The government made him a ward of the state. Wally only discovered years later – when he asked for his medical records – why he was 'medically removed' from his parents and placed in an institution.

The government first sent Wally to a hospital to be assessed. Doctor's observed him with other children.

'I didn't react because I didn't know who the children were ... [They] came up with the conclusion that I was mentally retarded. I've got this on my file that I got some sort of mental retardation. I don't have mental retardation.'

Wally was then put into an institution with other children with disability.

'One of the kids pulled me aside and said, "You're different." And I said to him, "How is that? You know, we're all the same here. You're in a wheelchair, I'm in a wheelchair, that kid over there is in a wheelchair." ... And then he said to me, "You're black." I did not understand that word or where he was coming from.'

Wally was allowed home to see his family on holidays.

'My family had to ask for permission to travel out of their community and to wait all day for a travel pass back to [the community]. And it gets me, you know.'

Wally said the nuns who ran the institution abused him if they thought he misbehaved.

'You were given the belt by the nuns and put in isolation rooms if you had played up. For example, isolation would be like, you're in a wheelchair. You can't stand or anything so you'd be put in a room where the door handle is beyond your reach ... It became the norm and I got used to it.'

When he was older, the government wasn't sure how to support him.

'They thought because I had a disability I'd be better off talking to a disability liaison officer. But because I'm Aboriginal, [they also said], "You should be talking to an Aboriginal liaison officer." And that's when I said to myself, "Hey, what's going on here? ... Hang on, you're an Aboriginal person.'"

Wally said he is continuing to find out where he's from and who he is.

'Despite my special needs, I still have that inherited right. My family before them and their families before them, all Aboriginal ... There were thousands upon thousands of children like myself, who were medically removed. And we've got the scars and we've got the memories and we're trying to heal.'

Anders and Blair

Anders is in his 60s and has intellectual disability. He lives in his own unit in supported accommodation in a regional town. Blair is his sister and legal guardian.

'He is very verbal ... and recently he's just had pneumonia, so I phone to make sure he's okay and getting up, getting moving, that sort of thing,' Blair told the Royal Commission. 'Because I've learned from hard experience I cannot trust, unfortunately, the [support service] staff who are paid to take care of him.'

Anders's parents cared for him until they became ill about a decade ago.

'He ... was very happy at home and very well cared for. But, sadly, things changed dramatically when he moved into the [service provider's] residence.'

Blair said that Anders needs one-on-one care, but '80 per cent of the time he's on his own'.

'Sometimes ... [Anders] is just lying there in urine and faeces, hasn't had breakfast, hasn't showered or anything ... He'd be so distressed, because no-one had checked on him. You know, they'd just dump the food there and cold fried eggs and, disgusting.'

One day, Blair arrived and couldn't find any support workers. After an hour, she found the staff in part of the property 'smoking and just talking'. 'It's like a social club,' she said.

Another day, Blair arrived to find Anders lying in a hallway with a broken leg.

'The person who was supposed to be there, just one-on-one with [Anders], taking care of him, had left all the windows open, all the rain had blown in. The hallway never met safety standards as it was, the gradient was far too steep. [Anders] slipped.'

One time, she found Anders shaking.

'[Their] response was, "Oh, but your brother always shakes. There is nothing wrong with your brother."'

Blair insisted he see a doctor.

'That was when he was diagnosed with the very, very severe heart infection and he spent almost three months in hospital on an IV drip.'

Several years ago, Anders complained of chest pains and Blair took him to hospital. Anders told the doctor the support workers didn't believe he had chest pains.

‘[Anders] was just left lying on his bed. And this has been a pattern many, many, many times – just the failure of ... staff to respond by getting the ambulance and, you know, leaving [Anders] with severe infected toenails.’

Blair said one of the support workers tormented Anders by telling him he was being sent to another town.

‘He was just living in terror.’

When she confronted the support worker, he told her, ‘Oh, it was a joke.’

‘I just, I want to make a change,’ Blair told the Royal Commission. ‘And I know if this is happening to [Anders], it’s also happening to a lot of other people.’

Finnegan

‘We are a very valuable employee when we’re allowed to do what we’re good at. The trouble with Asperger’s, it’s very easy to push us over the edge.’

Finnegan is autistic, has dyslexia and lives with anxiety and psychosocial disability. He has a PhD in information science.

‘I’m hyper-professional, I am hyper-intelligent ... If you give me technical problems to solve, I’m very good. But, if you put me in an emotionally distressing state, my conduct degrades to that of a primary school student,’ he told the Royal Commission.

About a decade ago, he started working for a technology company ‘on high-pressure projects’ and was ‘performing above expectation’.

‘My work was of such a standard that I was receiving annual performances bonus of \$30,000-plus ... So, it wasn’t that I was a problem employee.’

After about five years, the company approached Finnegan about a new role.

It was then he first disclosed that he had autism.

Prior to him accepting the role, he asked his immediate supervisor to learn the necessary skills for dealing with his disability. This was important given his history of ‘Asperger’s meltdown states’, which led to ‘extreme emotional displays’.

‘When you have a neurological seizure ... in Asperger’s, it hits your emotional centres,’ he explained.

Finnegan said his manager needed to know how to avoid putting him in a situation that would trigger this, and understand ‘how to deal with it’ if he was triggered.

‘I sat down with the manager and said, “If I get into a broken state, it will be a spectacularly fiery train wreck because I become overemotional.”’

After speaking with HR, the manager assured Finnegan she would get the training. But afterwards, he said, she bullied and ostracised him.

First, the manager moved him ‘to a very inappropriate place’ away from his colleagues. ‘You remind me of my former lover, and I don’t want to lose my third job over an extramarital affair,’ was the reason she gave.

‘I had no work for six months. I sat in a remote isolated location, I had nothing to do.’

His manager also told him about her personal problems, which were emotionally triggering for him.

‘After about six months of this, I had a breakdown ... I eventually ended up curling up in a ball and crying at my manager’s feet that I couldn’t cope.’

Finnegan said that even though his manager was concerned about his ‘suicide risk’, she kept on causing him ‘pain and distress’. He believes she sadistically assigned him tasks he found difficult, like taking notes.

‘Because I have a disability with written language, I used a disability support aid to take notes in meetings, and that was my mobile ... recording the meeting from beginning to end.’

Finnegan made a complaint to HR about his manager’s conduct. ‘And at that point, the company internally decided to get rid of me,’ he said.

‘If you say executive management is a bully, they can’t sack you for that. But what they will do is they will make your working life hell.’

From then, leading up to his termination, Finnegan said HR and management discussed his ‘growing levels of distress’ in emails. One message said the organisation ‘was better off without [his] type’.

Finnegan turned to the industrial relations commission over his dismissal but was unsuccessful.

Today Finnegan receives income protection insurance and NDIS funding. He would rather still be working.

Bert and Cathryn

Bert is in his 50s. Since a workplace accident more than a decade ago, he has lived with a spinal injury, depression, post-traumatic stress disorder and anxiety.

'I picked up the last box and that was it,' Bert told the Royal Commission. 'Ruptured [a] disc in my spine like a tyre bursting on a car. I've had five mental hospital visits, two spinal surgeries, a hernia surgery, an opioid addiction ... I'm struggling.'

Bert's wife, Cathryn, gave up her business to care for him while he fights the workers compensation agency for financial support.

'It's destroyed our family,' said Cathryn. 'There's been incorrect reports put in about him. They send people to his doctor appointments that then try and bully the doctor into changing his capacity on his certificate.'

Bert said the agency's adversarial system is abusive.

'If you haven't got a solicitor, you can't talk to them. They won't talk to you. So, you've got to engage a solicitor, and he's got to negotiate and navigate it for you.'

To receive compensation, Bert needs a doctor to assess his 'whole person impairment'.

'[Bert's] solicitor was sending him to one of our doctors, and they'll give him a percentage,' said Cathryn. 'The [agency] would then counteract it and send it to one of their doctors who's supposed to be independent. But there is a pattern of them favouring who's paying for the report.'

Cathryn said the agency's doctor assessed Bert's impairment at 14 per cent, one per cent below the threshold he needs to receive compensation.

'A few months later, after we'd seen [Bert's] doctor and he gave him the 28 [per cent], they decided that they preferred their doctor's 14 per cent.'

Bert said his impairment has since been reassessed at 51 per cent.

Centrelink denied Bert the Disability Support Pension 'because he wasn't medically stable'. His disability isn't considered 'medically stable', because it might still improve or deteriorate.

'I found out this morning that the [agency] denied it and flushed me down the toilet, so I'm kind of lost at the moment.'

Bert said the agency also keeps changing his case managers.

‘I’ve had five case managers this year. Every time my file gets handed to another case manager, something goes missing, or they misinterpret it, and then I’m in trouble again, and I haven’t done anything.’

For example, Bert’s doctors prescribed cannabis oil to treat his chronic pain, but Cathryn said the case manager denied the treatment.

‘I queried, well, what medical qualifications do you have? None. They’ve got absolutely no medical qualifications to make that decision.’

Bert said the constant fighting with the agency ‘obliterated’ his life.

‘I don’t have friends that come around here anymore. Nobody wants to see me because I’m a cranky old prick because I’ve got so much anger and frustration for having to fight for 12 years. I’m punch drunk, I’m mentally fucked in the head from what they’ve done to me over this time.’

Ayden and Freyja

‘I’m telling you, teachers in primary school, if you’ve got at least 10 per cent of your cohort with ADHD, you need to understand ADHD.’

Freyja is the mother of Ayden, who’s in primary school. He is autistic and has attention deficit hyperactivity disorder (ADHD).

‘He is quite extreme in his presentation of ADHD in particular,’ Freyja told the Royal Commission.

Freyja said Ayden was demanding when he was younger, ‘whingeing and carrying on’.

‘We just thought he was a bit of an arsehole to be honest ... Every single morning, he would run up and down the hallway of our house flinging the doors open, “Wake up time!” And, like, it’s 5 o’clock in the morning. Not once a week. Every day.’

As he got older, Ayden became violent. Freyja quit her job to care for him.

‘There are so many ... families who don’t have those luxuries ... If [Ayden] was in a different family, look, I’m not joking, he would be fucking dead.’

Ayden has been admitted twice to hospital child mental health units. One time Freyja called an ambulance because he was ‘jumping off the roof wanting to kill himself.’

She says it’s hard to get help from these units because there are only 16 beds for children in the state.

‘You’ve got families knocking down the door to get into a goddamn mental health ward with their child. And you’ve got [the health department] saying, “No.” And not only “No,” but basically, “Fuck off.” Like, they are just saying, “Parenting problem, off you go.”’

Freyja is studying psychology, which has helped her advocate for Ayden at school.

‘Just persistent, persistent advocating. And parents who are working full time, they haven’t got the time to be doing this ... My son now has a space in the room that he can go to. So that’s his real estate, which is pretty extraordinary. But if he is not coping, he’ll just go into that space.’

Freyja said many of his teachers still don’t understand ADHD.

‘They’re obsessed at the moment at my school with getting my child’s hat off his head. Because if you’ve got a hat on your head in a classroom, it’s a nice sensory thing he must like. But if you dip your chin, then you’ve blocked out so much noise and sensory information. Leave the hat alone!’

Freyja said finally getting Ayden appropriate treatment has changed the lives of everyone in her family.

‘We were just in chaos, just absolute chaos. There was our whole family, his brothers, you know, just crying in the corners.’

‘Now, we understand a lot more about [Ayden] ... Everything we do now, we plan around [his] abilities. And that’s the difference in understanding disability and not understanding it.’

Freyja said Ayden has become a talented writer.

‘I just want parents to just persist. They’re good at something and it’s not going to be being a lawyer in an office ... It’ll be something else, you know? Whether it’s writing or working on a property [as a jackaroo], it’ll be something interesting. But something different.’

Raylan and Mick

Raylan is in high school and has cerebral palsy. His dad, Mick, told the Royal Commission that when he was looking for schools for Raylan, 'the local Catholic primary school was an obvious choice because [Mick and his wife] were so embedded in the local community'.

Mick said the vice principal 'seemed quite open to making adjustments' when Raylan started school.

'I think early on it had potential to be an incredible story of inclusion ... where a school embraces someone with differing abilities and makes it work.'

Students also 'embraced [Raylan] and welcomed him'.

'It became apparent that [Raylan], although he has complex disability, because he was at mainstream school from the start, he actually didn't see himself as having a disability.'

When the school later indicated it didn't have the resources to support him after all, Raylan's mother, an allied health worker, offered to help. The school asked her to train Raylan's aides.

'She [also] spent a lot of time helping modify the curriculum, working with the education consultant, working with the teachers to help in the classroom. I think, in the end, that all that effort was not really welcome.'

Mick said the school's vice principal 'made comments that perhaps there are other schools or perhaps, you know, he doesn't really belong here'.

'It felt like [Raylan's] teacher didn't get a lot of support at all from the vice principal and was really left to manage a very complex situation on her own.'

Without appropriate support, Raylan became frustrated.

'[Raylan's] nonverbal. He communicates well now with a communication device. [But at the time] he started to exhibit behaviours which, it was just his way of communicating that he was traumatised.'

When Raylan would sometimes lie on the floor to express his frustration, the school 'just left him on the floor'.

'At times I would go into the school to pick Raylan up and he'd be strapped in a wheelchair outside the vice principal's office.'

Mick said meetings to discuss Raylan's behaviour and support involved 'eight or nine from the local school plus the Catholic education office'.

One day, the school left Raylan on the floor for ‘four or five hours’.

‘[Raylan] came home ... and communicated with his device he thought the school was angry with him. I think that was it for me. I really didn’t like my son in a place where [his] distress was that great that he really didn’t feel welcome. He didn’t feel safe in the school.’

Raylan now attends a special education school, where he ‘thrives’.

‘The Catholic education system, I think it had potential. But it went quite wrong. [Raylan’s] behaviours were not repeated [at the new school] ... He really loves school now, is fully engaged and really contributing.’

Chad

Chad is in his 20s. He is autistic and has attention deficit hyperactivity disorder.

'I've got a lot of people that support me for who I am and for, you know, for having a disability and that's what you need in life,' Chad told the Royal Commission. 'You need people that will be there for you no matter what.'

Several years ago Chad was living with his stepmother, who was 'going through a bit of a separation' from his father.

About that time, Chad's father was injured in an accident and 'couldn't really work'. He took some money out of Chad's account.

'I think he was in desperation at the time ... He's paid that all back.'

Chad's stepmother told him she would be his power of attorney.

'I felt very uncomfortable with it, but she is a very passive-aggressive person. Like, she doesn't physically [abuse], but she can be really verbally abusive ... She does not pay things back. She doesn't like to admit she's wrong. And it is hard to have a person like that in your life.'

Chad said that when he was living with his stepmother he felt like a 'prisoner in [his] own house'.

'That's how I felt ... This is probably the reason why I have anxiety and depression, because that was a lot to do with her ... I felt like I couldn't do anything. I couldn't go out. My friends, I didn't even see.'

Chad said after he stopped living with his stepmother, his father discovered 'a lot of money' missing from Chad's account.

'She was taking money out of my account without my acknowledgment ... It got taken out and it's completely just disappeared to another account that I don't even know about.'

Chad said his bank couldn't tell him where more than \$20,000 from his account went.

'[The bank] could have just said to her, "I think we need your son present whether he has a disability or not." Yes, she has a power of attorney, but that doesn't give her the reasonable right to ... do something behind my back without me acknowledging it.'

Chad manages his own account now and lives independently in a group home.

'I can just go, okay, I'm going out for a while or for the night or something like that, and I won't worry about them going, "No, you can't go out." My life has just turned around dramatically ever since I got out of that environment.'

Suzi and Trisha

Suzi is in primary school and has Prader-Willi syndrome (PWS), a genetic disorder.

‘The people that meet [Suzi] ... she just impresses upon them with her vitality and her vibrance and her kindness and her sort of love of the world,’ Trisha, her mum, told the Royal Commission. ‘She’s such a bubbly little child and she has a lot to teach us about resilience and about, you know, working hard and persevering.’

PWS is complex, and people with the disorder can have trouble regulating their body temperature and showing pain. Trisha said doctors sometimes struggle to tell if Suzi is sick.

‘It can be hard to determine what’s going on and I understand that. I am the first person to help a doctor walk through those things ... But her needs and her mental condition have been let go, ignored and let develop into serious, very serious illnesses that would never have been allowed to happen if she did not have Prader-Willi syndrome.’

Several years ago, Suzi lost her speech, had trouble walking and developed seizures. Trisha took her to hospital where the doctors ‘refused to believe there was anything major wrong’.

‘There’s a whole bunch of things that they just don’t believe because they don’t want to believe. And so, you know, when I kept presenting they said, “We don’t really believe that ... She’s not really sick” ... I was literally begging.’

Even when a neurologist suggested more tests, the hospital discharged Suzi.

She was eventually diagnosed with autoimmune encephalitis from an allergy.

When Trisha returned to the hospital to ‘have a chat with them about how do we learn from this’, the doctors wouldn’t listen.

‘They said I didn’t have enough trust in them. It was my fault because my trust wasn’t good enough.’

Trisha and her family later moved to another state, where she said doctors ‘always listen to you’ and parents can ask for clinical reviews if their children aren’t improving.

‘I just want somebody to understand that you can’t say to a parent that they’ve just got it wrong all the time. Because in fact this little girl really needed you to listen and to try and solve it for her, because I can’t solve it. I’m not a doctor. All I can tell you is what’s going on with her.’

Terrance, Kinslee and Kenneth

Terrance has intellectual disability, developmental delays and behaviours associated with autism. He is in his early 20s but his parents, Kinslee and Kenneth, told the Royal Commission he looks much younger and has the mental capacity of a nine-year-old.

Several years ago, Kinslee and Kenneth learnt that Terrance was being sexually abused at his public high school, which he attended as a student in a special unit.

The perpetrator was Terrance's friend, Ben, who also has intellectual disability. Other students – who were later expelled – had filmed the assaults and shared them on devices.

Kinslee and Kenneth met with the school principal and agreed on a set of protocols that made them feel safe about Terrance returning to the school. There would be better supervision, close monitoring at lunchtimes and Terrance and Ben would not be left alone together.

But the school didn't follow these protocols. Sometime later, Kinslee and Kenneth found Terrance had been accessing internet sex sites that Ben had guided him too.

When they dug deeper, they discovered Ben had continued to sexually assault Terrance in the school toilets. Ben had captured some of these assaults on his phone.

Kinslee and Kenneth reported the assaults to a specialist police unit. They found the police helpful and supportive, but the investigation hit a dead end. Despite his mental capacity, Terrance was legally an adult. Ben wasn't.

The school's response was not supportive.

Initially the principal suggested Terrance was lying. Then the school proposed Terrance return to school and meet with a counsellor. The school made no mention of changing the way it did things, and suggested his parents could homeschool Terrance for the remainder of the year. 'Impossible!' Kinslee exclaimed.

'It actually angered me. Their response angered me because it was basically just sweeping it under the carpet,' Kenneth said.

'And no apology along with it. Nothing to say we're so sorry this has happened to you,' said Kinslee.

They decided not to send Terrance back to the school. The school still hasn't apologised.

'I feel like we've been cut from the school and that's just been no communication, no contact from all the teachers that we've been there for seven years with,' Kinslee said.

Terrance's parents feel let down by the school's lack of accountability and interest in implementing real change.

They believe banning personal devices during school hours would be a good step. Improved supervision would be another. They would like to see schools establish policies and processes that they adhere to, and provide ongoing training for teachers. They want schools to ensure procedures that keep students safe – 'every student, regardless of whether they're abled or disabled' – are properly in place.

Kinslee and Kenneth say Ben's actions and the school's neglect have contributed to their son's heightened sexual awareness and loss of innocence. Not so long ago, Terrance's favourite viewing was Frozen. Now, Kenneth said, he is a 20-year-old child whose 'default is sex sites and chat sites'.

'What's happened here is that our vision for his independence and for his future has taken a backwards step because we feel that we're always going to have to supervise him now. And that is what really hurts. That's with us, because we're now too scared to leave him be who he is as a person.'

Eden and Charleigh

‘Mum, on her deathbed, and Dad, on his deathbed, asked me to make sure that everything was done to take care of [Eden]. And we were doing our best but we were held back by people in the system.’

Eden, mid-50s, had intellectual and physical disability and epilepsy. She lived in a group home.

Charleigh, Eden’s sister, told the Royal Commission there were just ‘so many let-downs ... and failings’ in Eden’s care.

About 10 days before Eden died, a staff member saw her have a five-second seizure while she was putting on her pyjamas. Later, she saw Eden crying and rubbing her arm. She had two big blue bruises on her elbow and shoulder.

The next day a different staff member took Eden to the GP. He wanted X-rays taken and referred her to hospital. She was at the hospital for nine hours before she was discharged back to the group home. She had a shattered arm socket and was put in a sling. Staff didn’t notify Eden’s family.

Over the next few days staff continued to move Eden in and out of bed using the hoist, and in and out of taxis without any pain proper relief.

‘You’re going to go through the roof with your pain levels,’ Charleigh said. ‘It’s going to feel like it just happened every time you move it. So, for her to be given a couple of Panadeine Fortes as her pain medication, I don’t think that that would have even touched it.’

A day later, a skin integrity check showed two red marks on Eden’s wrist and neck.

The following week a staff member called Charleigh, telling her Eden was ‘in a bad way’ and she was considering calling an ambulance. ‘You should have already called it,’ Charleigh told her.

Charleigh was at the hospital when Eden arrived.

A doctor told her to be ‘wise and kind in the decision-making process’. Charleigh said she’s still ‘haunted by these words’. Eden was in a palliative state – dehydrated, malnourished and having constant seizures.

Charleigh found the hospital’s attitude baffling. She told them to treat her sister, operate if necessary and give her pain relief.

When the hospital said they wouldn’t operate, she demanded they transfer Eden to a different hospital.

The palliative team at the second hospital confirmed she was in palliative state. She was not eating or drinking and was experiencing delirium.

‘Then we find out that there can be an operation to relieve her of her pain, a nerve block, a week later.’

The operation was successful and Charleigh couldn’t understand why it wasn’t offered sooner.

Two days later, the hospital rang Charleigh and told her and the family to come to the hospital. When they arrived, a doctor told them Eden had died.

The hospital called the police, who then questioned the family over Eden’s body. The room was treated as a crime scene.

An autopsy showed Eden died from pneumonia caused from her broken arm and high levels of an anaesthetic which can bring on seizures and cause death. Charleigh was not sure why Eden was still receiving this drug given the operation was successful. The same red marks were recorded in the autopsy in addition to bruising on her right hip.

Charleigh suspects that Eden’s injuries were caused by a seizure and a fall at home, which were covered up by the provider. She also believes if staff had rung an ambulance when Eden sustained the injuries, she would have survived.

‘There needs to be more accountability.’

Indira

Indira is in her 40s and mum to six children. She is autistic and lives with mental health issues.

'My father attempted drowning me in the bath when I was three years of age,' she told the Royal Commission. 'The origins and the grassroots of what's happening to me today began then.'

When Indira's mother left her abusive husband, she and her siblings were left in the care of her paternal grandparents. Indira said they abused her so she would 'stay silent'.

'So that I wouldn't bring shame upon the family. As a young girl who had autism, already largely non-verbal at that time, living with non-English speaking grandparents was a great adversity against me.'

At school, Indira fell through the cracks because educational supports 'were centred around little boys'. As a teenager, she was labelled 'oppositional, delinquent and defiant'.

Indira was diagnosed with Asperger's as an adult but said she was not provided with any disability support. She spent years being 'disbelieved and victimised by systems' when seeking medical assistance.

'I was locked in a psychiatric institution because I had an untreated disability, and I was forced to take medication that made me very, very sick. It actually made me suicidal.'

Indira struggled to get disability funding and felt there 'was nowhere to get help'. It was a 'dehumanising feeling' to be told she 'wasn't disabled enough to need supports'.

'These gaps allow government services to make up their own minds and rules on what autism spectrum is and to refuse, deny and withhold supports.'

Indira feels discriminated against by employers.

'I have an extensive education behind me. No-one will give me a chance in employing me because of my disability.'

Today she receives NDIS funding 'on the grounds of very substantial support needs'.

'I have all the support I need now, but it happened a little too late.'

Jaycee

Jaycee is in her early 60s and lives in Queensland with post-traumatic stress disorder (PTSD) and narcolepsy.

She sustained injuries in the late 70s and has been in a wheelchair since.

Jaycee is on a pension and has NDIS funding for support at home for cleaning, cooking and shopping. 'I also have an assistance dog who goes everywhere with me, and if I fall asleep, she knocks my hand off the [wheelchair] controls so I don't crash into anything,' she told the Royal Commission.

About a decade ago, Jaycee was in hospital for an extended period because of a brain infection. When she was there, a doctor wouldn't let her use her wheelchair.

'At that stage I was still able to stand, but I couldn't take a step forward. So he decided if I could stand, I could walk ... I hadn't been walking for 12 years.'

Jaycee had to 'crawl on the floor', then drag herself up 'to stand somewhere to get attention'.

'I'd fall a lot, so I was black and blue and God knows what else. I had cuts in my arms and knees and stomach, but that didn't seem to worry them too much.'

She said the doctor was 'pretty stubborn' and 'seemed to think he knew what he was doing'.

'He then decided that I didn't need my catheter anymore ... And he tried to take that off me, but I wouldn't let him anywhere near that 'cos I knew I needed it.'

The doctor didn't listen to Jaycee. 'I don't know whether it was because I was disabled, or whatever, that he never gave me a chance to speak, or talk.' She asked to be moved to another hospital.

'And he said, "Oh, no, we can only send you to a nursing home, or you can stay here." ... This went on for nearly three months. They wouldn't give me my chair until two days before I left the hospital.'

Jaycee contracted methicillin-resistant staphylococcus aureus from all the 'crawling around' and injuries.

She 'steers clear' of the hospital that traumatised her.

'I suffer with PTSD from my accident anyway, but this has just made it a hell of a lot worse.'

Jacky

'I took the gamble in telling them my diagnosis, because I hoped that they would have some sort of terms to work with me. But unfortunately the gamble didn't pay off.'

Jacky is in her 50s and lives with post-traumatic stress disorder (PTSD), attention deficit hyperactivity disorder (ADHD), functional neurological disorder, fibromyalgia and anorexia.

'I give off the impression I have confidence, but behind it I'm going mad,' Jacky told the Royal Commission. 'I never thought I would get beaten down.'

Jacky ran a business for many years before joining a government department. She struggled to concentrate in an office with lots of people. 'It was then it started coming to light,' Jacky said.

When a psychiatrist diagnosed Jacky with ADHD and PTSD, she told her colleagues.

'I made a conscious decision to let them know ... You look around and they are, like, literally averting their gaze.'

Jacky asked her managers for reasonable adjustments.

'My psychiatrist recommended ... flexibility in the workplace with the ability to work from home, which was tried and tested through COVID. It had worked very well. And to bring my dog into work.'

Jacky's managers rejected the psychiatrist's recommendations, including the dog.

'You wouldn't say to someone who had a white stick and a guide dog, "How blind are you, really?" You know, wheelchairs, "Keep it outside, it's distracting." And yet they felt that they could ... They [also] told me about things like the psychiatric report wasn't valid.'

Her managers then restricted her work. Jacky felt she was being bullied and her mental health deteriorated.

'To be told ... "You're not able to do that," I mean, it's just all very, very belittling and it's humiliating.'

After a meeting, her managers told her to leave until she could prove that she was '100 per cent fit'.

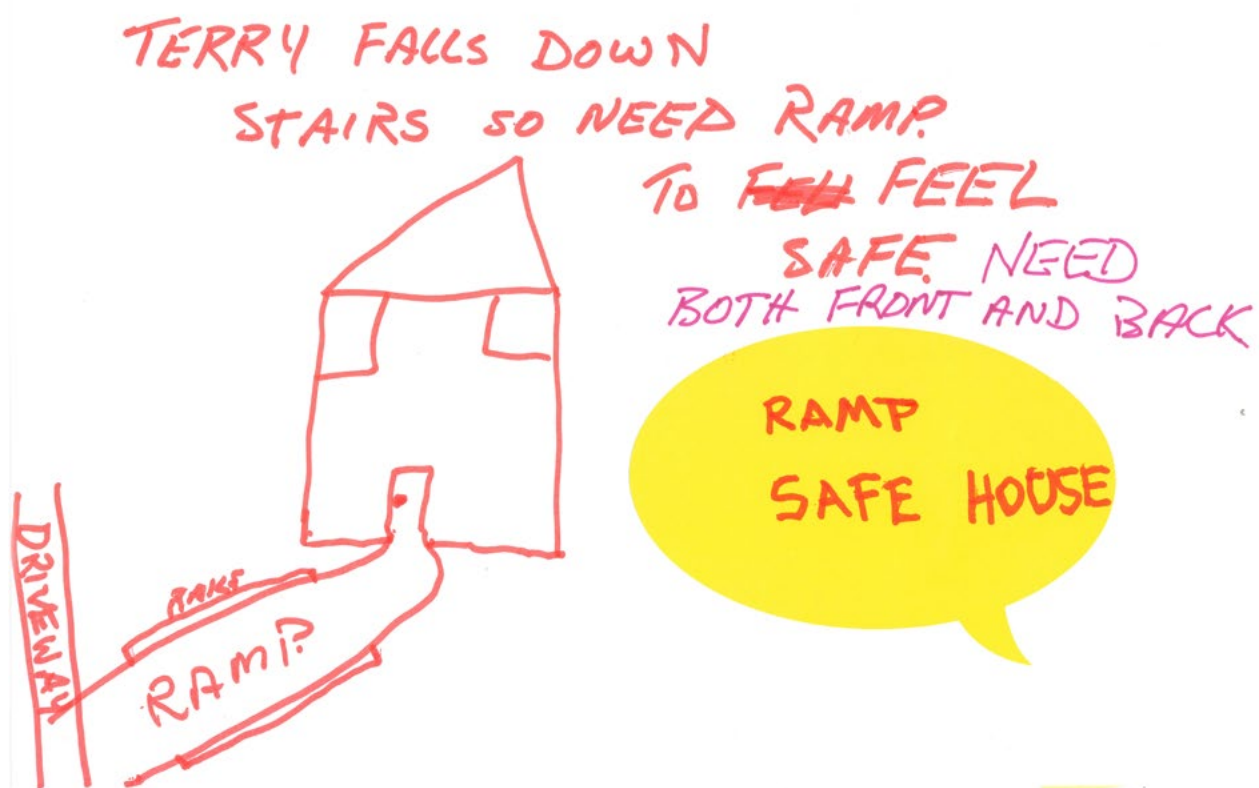
'Not, you know, able to work, but 100 per cent better. So long as I had to be fixed completely. And that was it. And that was the last time I heard from them.'

Jacky said she's since received little support.

'This was a career I absolutely adored, and unfortunately it's brought back old eating disorders which have now put me in hospital and are now affecting my life with the impact it has had on my body, and so it's gone completely.'

Jacky is still technically employed by the department, but feels 'bitterly disappointed'.

'It's their big message at the moment. Their strategic plan is mental health in the workplace ... They talk about it, but it's as if they don't walk the walk ... I've just been shattered by the attitudes of people and their lack of understanding.'



Artwork by Leanne Cohen

Adelyn

Adelyn, a primary school teacher, transferred to a special education school about 10 years ago.

‘It was a pretty rundown sort of school,’ she told the Royal Commission. ‘I actually taught out of an old demountable that had mouldy carpet and a broken air-conditioner.’

When the government gave the school a grant to upgrade, the school built informal ‘breakout spaces’. The school put locks on the doors.

‘[The] door was lockable ... so if you were in the breakout space you couldn’t get back in unless someone ... opened the door. Softfall on the floor, and then metal walls. And in summer it would be 45 degrees. In the winter it would be freezing cold. And it didn’t matter [whether it was] rain, hail or shine, the leaders of the school would put kids in there.’

Adelyn said the breakout spaces were misused to restrain students.

‘The most horrific from my experience was me watching them put [a] six-year-old ... in there, who was actually in my class, and he was in there for minutes, door shut, screaming hysterically.’

Adelyn said instead of using ‘trauma-informed’ practices or offering him something to eat, ‘that was the response’.

‘It just became the culture of the school that whenever someone was distressed or had an outburst, whether it was violent or not, they were put in the breakout space.’

Adelyn said staff locked students up without telling parents.

‘It wasn’t written into a behaviour management plan. It is against everything we stand for in special education.’

Adelyn said the school’s use of restraints to deal with behaviour increased while she was there.

‘When I say restrain, I mean four staff pinning leg, leg, hand, hand, on the ground, student’s head bashing on the ground, and the principal or one of the assistant principals would not give the command to let go of the student until the student had exhausted themselves ... And that would have happened every day.’

Eventually, Adelyn complained to an education department officer, but it later became ‘obvious that the person had told the principal’.

‘I got treated very badly ... I didn’t know what else to do so I moved schools.’

Adelyn now teaches students with disability at a mainstream school where 'every single student in [her] faculty is engaged in some form of mainstream class'.

'They're integrated into whole school sport, year-group camps. It has completely changed my philosophy.'

She told the Royal Commission that one of her students, who first arrived at the school 'pretty much non-verbal', recently went on a school camp.

'[One] teacher actually burst into tears when she came back from the camp, because she just could not believe how the other students from mainstream had included him and supported him. And he climbed every rope and he was up on the trapeze and did rock-climbing, you know, encouraged by all of the mainstream students, and that's something that you just wouldn't get in [a special school].'

Lyndon

Lyndon is in his 40s and has attention deficit hyperactivity disorder (ADHD) and Hashimoto's disease, an autoimmune disorder.

Lyndon said doctors told his parents he had 'minimal cerebral dysfunction' before he started school.

'Never in a million years did it ever occur to me that minimal cerebral dysfunction is ADHD.'

Lyndon said because his disorder wasn't described as ADHD, he received no help at school.

'I had it beaten into me that my behaviour was wrong, that I was wrong, that I was naughty, obtuse. I was told that I was the "naughtiest little boy" that a particular teacher had ever met, when I moved to a new school. My nickname was "fuckhead" in primary school.'

Several years ago, before his ADHD diagnosis and after a series of personal crises, Lyndon experienced 'what you'd describe as a psychotic breakdown'. He lost his job and his marriage.

'The life of fatigue and always struggling, and never understanding why, and I snapped. I just snapped. I just, I couldn't do it anymore.'

One day, he saw a description on the internet of people experiencing certain mental health symptoms.

'And when I realised it was adult ADHD, it just blew my mind. It was nothing like I'd ever considered.'

Lyndon received an ADHD diagnosis at a public hospital.

'They have one thing they will do, which is a confirmatory diagnosis. And then you're on your own ... They provide a list of bulk-billing psychiatrists and they follow that statement with a, "You can try these, but I do know that they don't bulk-bill for ADHD patients, and in fact will often charge more."

Lyndon, whose only income now is a Centrelink JobSeeker payment, also needs medication to control the inflammation from Hashimoto's disease.

'I receive \$680 a fortnight. I pay \$500 a fortnight rent. Just one of my medications – because I have to get three medications types privately, otherwise I can't get them at all – just one of them is \$120 a fortnight. Another is \$40 and another is \$20. You know, it doesn't take a rocket scientist to work out the maths. I've been going backwards for a very long time.'

When Lyndon recently became homeless, friends helped him find temporary accommodation. He said ADHD means he struggles to understand time, ‘to understand the steps that it takes to get up from an alarm clock, get out of bed, brush your teeth, get your coffee made ... Things that are automatic to neurotypical brains don’t exist in my mind.’

Lyndon said he tried and failed to access the NDIS.

‘The irony is that ... there’s a time limit [to supply documents], which I wasn’t made aware of ... Realistically, I need to access some serious high-end specialists if I’m going to get back any kind of quality of life.’

Quinton, Denis and Zoey

Zoey's teenage sons, Quinton and Denis, are autistic, but were initially diagnosed with attention deficit hyperactivity disorder (ADHD).

When Quinton, the eldest, started at a private high school, Zoey gave up her job as a teacher and moved to a town near the school.

'The idea was that they would start going to school, get used to it and then we would remove our support and they would manage in boarding. But it's not really quite how it worked.'

A psychologist diagnosed Quinton with autism in his first year in high school.

'He was finding different classrooms, different kids, you know all of that, very difficult ... he was originally bullied in class, verbally, had things thrown at him. He became really distressed, withdrawn. It was horrible.'

Quinton wrote to the principal to ask if he could change classes. 'The principal didn't even write back to him,' Zoey said.

Quinton started self-harming and his psychologist recommended an assistance dog.

'He has this behaviour that dogs respond to him ... [Quinton] credits [the dog] with saving his life because that's really where we were at. And the psych has put in writing, you know, said, "[The dog] has been better than any medication we've tried."

The school refused to let Quinton bring the dog onto the grounds.

'Which was completely ridiculous because people would just walk their dogs through the school grounds, because the school had dogs in boarding houses.'

Zoey said the school tried to introduce a policy that would give the principal the right to veto assistance dogs.

'They would ask things like how it would mediate [Quinton's] disability, which just is ignorant.'

It was only through the intervention of a senior staff member that the principal eventually allowed Quinton to bring his assistance dog to school.

Around that time her other son, Denis, who was then at the same high school, reported being assaulted by other students. Denis developed post-traumatic stress disorder.

'I had always said to [Denis], you know, "If you want to leave, you just say." And one day he just messaged me, "Well, I can't do it anymore." ... The boy that we thought was going to go to uni has left school as fast as he can, you know.'

Both Denis and Quinton left school before finishing year 12 to take up apprenticeships.

‘We have been resilient and we have really worked hard. We have adapted to doing each thing for each kid that would help them. But essentially we, me, I am left with a grief because we were aggrieved, we were hurt by this school.’

Charlene

'I have advocated for myself, positively, through all these experiences and I'm not listened to. It's like, because it's invisible, it doesn't exist.'

Charlene is in her 30s and has functional neurological disorder (FND).

'Parts of my brain stopped talking to each other,' Charlene told the Royal Commission. 'It initially started with blackout, an inability to talk ... [I] was paralysed, seizures all the time, not able to communicate with anything but my eyes ... And my husband having to basically stop working and look after me.'

Before being diagnosed with FND several years ago, Charlene was teaching at a university and finishing a PhD.

'The university system, they just were like, "You're sick, okay, come back to us," and only when I tried to connect with them ... just before the end of the year, they were like, "When are you coming back? Hurry up and get back."'

Charlene asked the university for reasonable adjustments to let her return to her study and work.

'They were like, "Well, we don't have anyone with a disability in the postgraduate area. So, we don't know how to help you and we don't have any financial supports for you." ... You know, it was, like, "Sorry, good luck."'

Charlene had to leave her study and job.

'Anyone that I know who has had a disability in that sector has just been pushed out. The [university is] like, "They're just not performing or they're not able to do it." Multiple people with research scholarships etcetera all just pushed out.'

After leaving the university, Charlene entered the graduate program of a government department, which asked her to complete her studies but promised to make reasonable adjustments.

'Sounds great, got in ... They weren't ready ... They would just use the whole, "She's not performing," when, realistically, it was all about them. Simple things such as not providing an appropriate workstation, not providing the appropriate work. Sometimes even not actually stimulating me mentally enough.'

Charlene said her FND 'flared up really badly' and she couldn't finish her study.

'They kicked me off the graduate program.'

Instead, she was given a part-time job in the same office.

'I wasn't allowed to progress because I wasn't there five days full time. Other individuals, because I was [at that time] performing well, used my disability as a reason to not allow me to promote or get promoted.'

Charlene told the Royal Commission she's on extended leave because her workplace hasn't found a solution.

'I've had to give them all the solutions, [but] I may have to quit because it's that bad ... I've had to bring up the word "discrimination" multiple times now. We'll see how that goes.'

Jacqui

Jacqui, early 60s, has an autoimmune condition, fibromyalgia, rheumatoid and osteoarthritis arthritis and health issues. She is unable to walk long distances or use most public transport.

Jacqui told the Royal Commission she has to work 'because the disability pension is not sufficient to meet [her] medication and disability needs'.

Jacqui is registered with a disability employment service (DES) provider and receives a mobility allowance which covers work-related transport costs. 'It's worth about \$140 a fortnight, so it's not an amount I can afford to throw away.'

Over the past 10 years Jacqui has used three DES providers.

'We are not wanted by the job providers. They want to deal with people who work full time and people who can go outside to work. They find us too much of a challenge.'

Jacqui would like to work two days a week.

But DES providers 'absolutely flat out refuse to help [her] find anything more than the eight hours'.

Jacqui suspects the DES is paid a fee for each person they place in a job. Recently, the DES provider asked her to 'split a job' with two other people with disability.

Over the years, DES staff have routinely failed to lodge her job plan every three months with Centrelink.

On the rare occasions that they have, Jacqui says they've failed to provide the correct information.

Each time, her mobility allowance is reduced or cancelled and she has to battle for months to have it reinstated.

Recently, a DES staff member questioned Jacqui's disability.

'She wanted my medical records to try and prove that I could catch a bus.'

Jacqui told her she didn't have to provide her medical records to DES staff.

The woman became 'nasty'. She threatened to not only 'kick [Jacqui] off' her mobility allowance but also 'kick [her] off of [her] disability pension'.

'For some reason, she had got it into her head that I wasn't disabled.'

Jacqui complained to the manager and the Centrelink office, who confirmed she didn't need to provide her medical records.

Next time Jacqui saw the DES staff member, the woman conceded she wasn't allowed to ask her for her medical records. Instead, she asked Jacqui to sign a form allowing her to contact Jacqui's doctor directly.

Jacqui was incredulous the woman was trying 'a sneaky back way' to get her records.

Jacqui made a complaint to her member of parliament, and the next time she went to the office the staff member had left.

A new staff member suggested Jacqui apply for the NDIS, assuring her it would fund work-related transport costs.

Jacqui was shocked to discover the application required not only doctor reports but also a \$3,000 occupational therapist assessment.

The NDIA rejected her application because she was 'in remission'.

'I don't think [the NDIA] understands what remission means for rheumatoid arthritis people. It's not the same as cancer ... It just means a temporary lessening of symptoms.'

Jacqui feels she has no choice but to continue to engage with the DES.

'I have dealt with them now for 10 years, and I will continue dealing with them, but I'm doing this so other people don't have to go through this. Because most people just could not tolerate the amount of abuse I put up with.'

Gustavo and Armando

Gustavo and Armando are twin brothers in their 40s.

‘[Gustavo] was diagnosed ... in his teenage years with paranoid schizophrenia,’ Armando told the Royal Commission. Health workers give him antipsychotic treatment at his home once a month.

When their mother died about a decade ago, Armando ‘naturally just took over’ as Gustavo’s carer.

‘There was a will. There was myself, my brother and my two sisters, and everything was divided equally. There were two properties. One is the house, the principal home that we have been living in for a long time.’

In the will, Armando and his two sisters were trustees. He took the necessary steps to become Gustavo’s guardian and financial administrator.

‘Just so I could attend to his, like, Centrelink affairs and talk to his doctor ... To make sure that the treating team were aware that I was legally able to do stuff on his behalf.’

He didn’t renew the guardianship for a couple of years because ‘it’s a lot of work’. But when Gustavo changed doctors, he had to reapply.

Armando said his sisters got a ‘dodgy lawyer’ to say that he was ‘unfit to be administrator or guardian’. They wanted to ‘kick’ him and Gustavo out of the family house, he said, ‘because they didn’t want to sell the other property’.

‘Basically, they just wanted him out so they could maximise their inheritance. But they can’t take advantage of someone with a disability. They have to look after his best interests as a trustee.’

Armando said Gustavo needed a stable home and ‘there was no reason to displace him’.

‘You know, my mum cared for him in that house and there’s quite a bit of memory there ... He has been living there for the last 20 years and he doesn’t want to move.’

But the sisters pursued the matter before a tribunal ‘because of money’. Armando fought and told the sisters, ‘We’re not kicking him out unless you have got a better solution.’

A couple of years ago, a public advocate visited the home and concluded, ‘Gustavo wishes to remain in that house and we don’t see any reason for us to be appointed.’

Armando was reinstated as guardian and he and Gustavo continue residing in the family home.

‘You wouldn’t do it for the money. If someone is doing that role, then it means they sincerely care about him.’

Today, the sisters are still trying to ‘kick them out’. They have refused to accept any solution Armando offers, like purchasing the other house outright.

He said his sisters play no role in caring for Gustavo.

‘You know, I’m the one with him every day and making sure that he is okay – and they don’t even send him a Merry Christmas message or anything like that.’

Brayan and Leighton

Brayan is in his 50s. He has intellectual disability and schizophrenia.

‘[Brayan] functions with an instructional age of eight years,’ his mum Leighton told the Royal Commission. ‘[He] has reasonable communication skills, but can be hard to understand at times.’

When he was two, Brayan began ‘hearing voices’. Leighton said one day, when he was still in primary school, Brayan held her at knifepoint ‘pleading with “the devil” not to make him do it’.

Brayan’s behaviour later came to the attention of the police and he was made a ward of the state. Leighton was granted shared guardianship.

After he turned 18, community services put Brayan in a flat by himself with support workers. One day, he went into a shop with a butter knife.

‘His plan was, in his deluded mind, to rob them of \$10 and stand in line and buy a [hamburger].’

Doctors diagnosed Brayan with schizophrenia.

‘This began [Brayan’s] long journey in adult institutional care and recommended long-term institution care.’

While he was in one institution, a magistrate ordered the public trustee to manage Brayan’s finances. Leighton, who wasn’t informed at the time, has since discovered the terms of the order, ‘which cannot be overturned’, are lost.

‘It’s been a 22-year legal battle to try and unravel that.’

She said the public trustee makes errors.

For example, the trustee once paid rent to two service providers at the same time after Brayan moved.

‘It was probably six or eight months before I got a statement from them and identified that they had paid two rents.’

When Leighton asked the trustee to recover the money, it took months.

‘[Brayan] has not used his funds for many years and he has a large amount of money, and that’s because I’ve paid for everything for him. I’ve had to pay for incontinence pads ... dental treatment ... I’ve paid for all sorts of things and I have no problem paying for those things because I’m his mother.’

Leighton said even though the trustee isn't spending Brayan's money, it's still charging him administrative fees, 'eroding into his principal'.

Although staff at various institutions robbed and abused Brayan over the years, Leighton said he's is now 'happy, well-adjusted and has a good quality of life' in a group home.

'I feel that it needs to come back to better education and employment of suitably trained staff and not just taking people with no training and no knowledge.'

Alaya

Alaya was employed by a community care provider in the early 2010s. When she left the organisation she submitted a letter outlining her serious concerns about the organisation's operations. She returned to their employment a year or so later after management assured her they had made positive changes and were committed to providing quality services.

When she started her new job, she found many of the previous problems remained. Some had become worse.

One of the issues was the lack of disability sector experience within upper management and the board. Another was that people working in supported accommodation tend to perceive their clients as 'children'. There is a lack of knowledge about the National Disability Service Standards and how they should be applied.

'There was no training on, I don't recall, like, human rights actually being talked about,' she said. 'And that's where I don't feel like, even now in the [Royal] Commission actually existing has increased people's focus on human rights, but there's a long way to go. That's not a standard part of the training sector until maybe very recently.'

Alaya said she directly witnessed incidents of violence, neglect and abuse of residents, and the provider had no safeguards in place to keep residents safe. She was concerned by management's failure to respond appropriately and transparently to serious concerns raised by staff and residents, for example by reporting to families or the police.

Alaya said she tried to encourage a culture of increased reporting, but management discouraged complaints. Some staff were fearful of speaking out, others felt it was futile.

'People would say, "Well, but I won't speak up about this, because it's happened, and this person left, and that person left, and I've seen it before and I know how they deal with it.'"

It was also difficult for residents, who typically had high behaviour support needs, to make complaints.

Alaya spoke about one resident, Phillip. '[He] would kind of be destroying things, and shouting and biting himself when he was talking about something that was distressing.' Staff were often frightened and would lock themselves in their rooms.

Additionally Phillip, like many other residents, was isolated, with very limited access to anyone who wasn't a support worker. 'So that was a real barrier to him being able to report and be heard by another party, because there were so few people who would actually engage with him to start off with.'

In the face of management's continued resistance to change, Alaya decided to report her concerns to an external body.

It wasn't easy to find out where to go. Alaya said she 'called every line available'. One oversight agency said it couldn't investigate because Alaya herself didn't have a disability and wasn't a family member. She was referred to several other regulatory bodies, one of which encouraged her to make a public interest disclosure.

Alaya made a public interest disclosure, but it didn't remain confidential. She felt deeply uncomfortable in the workplace, and eventually left the organisation. She has had no information since about the investigation her disclosure prompted.

Alaya continued to work in the disability sector, but still carries the weight of that earlier experience.

'It is the kind of stuff that keeps you up at night, or that you try not to think about too hard, because every time this comes up or, you know, someone mentions the company, always there's names and faces come back, and you wonder what their lives are like, and whether there was more that could have been done.'

Dirk and Roz

Roz is in her 60s and fosters several First Nations children with disability. For more than 15 years, her foster children attended a special education school in her regional town.

‘It was a very welcoming place, but now it’s like Fort Knox ... At the moment you go there, you feel like you’re not even welcome,’ Roz told the Royal Commission. ‘I did mention that I was going to be speaking to you and they laughed. There’s no respect.’

Roz said the school hasn’t tried hard enough to get help for her foster son Dirk, who has Down syndrome and is hearing impaired.

‘[Dirk] ... had a teacher at the beginning of the year who was signing, but then they haven’t got any teachers [now] who can sign.’

She said the school isn’t employing enough specialists to help the teachers.

‘Now, there’s more than one child who has got fetal alcohol [disorder spectrum]. There’s more than one child who’s Down syndrome. There should be aides to assist and help and that’s not being done.’

Roz said the school employed one support worker who ‘turned up at school drunk’.

‘When I brought it up with the principal, I received a letter from the solicitor representing him that I shouldn’t talk about him. And, as a guardian, I have every right to ensure that [the children are] safe.’

Roz said she learnt the person had taken children to a bar at lunchtime.

‘I believe if you’re supporting someone in a working environment, you do not take them to the [bar] for lunch. You don’t sit around drinking while you’ve got that client.’

Roz said her faith in the school is so low that she felt ‘so grateful for COVID’ because she could homeschool the children ‘around the table looking at how they achieved’.

‘I just feel that [the school] should be accountable to ensure that anyone working there is qualified for a start, who understands disabilities. But also, to ensure that the aides don’t turn up drunk!’

Gaye

'I've worked in government my whole life. I know how you slip through the cracks. It's easy to do. I don't have a problem with that [for myself], but when I hear it with so many people, that's what tells you that there's something really wrong out there.'

Several years ago Gaye developed peripheral polyneuropathy, a neurological condition. 'I can't feel anything from the neck down,' she told the Royal Commission.

Gaye's in her 50s and needs a power wheelchair to access the community and a hoist to prevent her falling in her home. Four years ago, the NDIS agreed to support her.

'My first plan said, "Hoist lift chair, shower commode, bed, wheelchair." I've been fighting the NDIS for four years to get that equipment.'

Gaye said the NDIS 'lost the quotes' for the equipment and spent so long responding to her occupational therapist's reports they became 'out of date'.

Gaye asked the Administrative Appeals Tribunal to review her funding. Meanwhile, she asked the NDIS why the wheelchair and hoist still hadn't arrived. 'They came back with a response of, "Looked into it. The funds can't be released while you're at the AAT.'"

'I'm pushed around in an office chair ... I feel like I'm living in a third world country. I cannot believe that the most vulnerable in society can be left with such suffering.'

Gaye regularly falls because she can't feel her legs, so she can't access her shower without the equipment.

'I've gone seven years without [a shower]. Like, what sort of world am I living in where I don't have access to running water?'

Without a wheelchair, Gaye is also stuck at home.

'People complain about being in lockdown. I've been in lockdown for seven years, you know? And then when I've complained to the NDIS about not being able to access the community their answer is, "We pay [for] a support worker." Well, what do they think the support worker's doing? Carrying me on their back? Like, they seem to think that as long as they're paying for support hours that's all a disabled person could possibly need.'

The NDIS also told Gaye she qualified for specialist disability accommodation.

‘But they approved it over a year ago now ... I wanted a house, but they came back with a two-bedroom, two-participant [shared] apartment.’

Gaye told the Royal Commission the NDIS is taking away her independence.

‘I’m not actually going forward to independence, I’m going backwards into dependence.’

Mervyn

‘When you have a teacher tell you, “If you’re going to your employer about an incident of abuse or neglect, be prepared to look for another job” that is really not reinforcing a positive aspect within the industry as a worker.’

Mervyn, late 50s, sustained a workplace injury some years ago and was ‘deemed permanently disabled’.

Two years ago, he secured a job as a support worker through a disability employment agency.

At the same time, he is completing a certificate 3 in individual support disability and community care.

Mervyn told the Royal Commission that he’s concerned he wasn’t required to complete the core modules of his training before starting work with people with disability.

Employers only required him to complete a questionnaire and do two ‘buddy shifts’ shadowing another support worker.

‘Having someone just coming off the street, and especially coming from a disability employment agency, perhaps they really don’t have the fundamental skills to fulfil those roles.’

In one role, Mervyn supported Luke, who is autistic, non-verbal and has intellectual disability.

One time, Luke started to behave violently, ‘grabbing the mother by the hair and dragging her around the house and breaking walls and things’.

Mervyn contacted his employer for assistance.

Instead of sending another support worker, the employer sent Luke’s father, who lives apart from Luke and his mother.

Luke’s father couldn’t supervise him adequately. ‘The father’s level of care for his own son wasn’t focused, let’s say,’ Mervyn said.

Luke ran out onto the road twice, and Mervyn had to intervene to prevent cars hitting him.

Following the shift, Luke’s NDIS support coordinator asked Mervyn not to submit an incident report.

Mervyn ignored her and made a formal complaint to the NDIS Quality and Safeguards Commission. The Commission didn't respond because 'somehow [the complaint] was routed to an advocacy agency'. An advocate inadvertently alerted the provider, who immediately stopped giving Mervyn shifts.

Mervyn found another job supporting people with dementia. He said the level of abuse and neglect was so concerning he left the organisation.

More recently, Mervyn has been supporting clients with psychosocial and intellectual disability.

He said most of his colleagues take clients to a shopping centre for a coffee. 'The needs of the client are not being met.'

Mervyn recently took one client to an arts centre, which was quieter, reducing their anxiety.

Mervyn supported a man, just out of rehab, who was using his support workers to drive him around to deliver illegal drugs. Mervyn reported the incident to his employer who immediately cut his shifts from 36 hours per week to two.

Mervyn is currently considering three job offers.

'The industry is in such demand for warm bodies ... I still haven't finished my qualifications.'

Keanu and Harlow

Keanu is in his late 20s and lives in a group home. He is autistic, non-verbal and needs 24-hour care.

His mother Harlow told the Royal Commission that when Keanu was in his late teens he had a new support worker who came to the house every Thursday. Harlow, a single parent who was studying at the time, was out of the house while the support worker was there.

One day she came home and her daughter, a few years younger than Keanu, told her, 'There's something wrong.'

The support worker had abused Keanu in a way Harlow still cannot talk about. 'I'm sorry. I have to skip that,' she said.

Harlow phoned the support worker's employer and told them what had happened.

As she made inquiries in the days that followed, she found others in Keanu's circle of care had been aware of something amiss with the support worker. 'The bus driver said to me, "Every Thursday when [Keanu] is dropped off and this guy is there, he doesn't want to come off the bus."' Another support worker took Keanu to one of his favourite destinations. Staff there told this support worker that 'when he comes with this other guy, [Keanu] is very, very agitated'.

'The problem is nobody ever told me anything.'

The service provider dismissed the worker. But when Harlow sought further action, its attitude to Harlow became hostile.

'They just went on the defensive full-on and absolutely didn't want to engage with me unless I saw the lawyers, and I didn't know where to turn.'

She spoke to Keanu's support coordinator who said there was nothing she could do.

Harlow contacted a disability advocacy agency. The CEO advised her not to pursue the matter because the service provider might respond by reducing Keanu's supports. 'You're going to be penalised,' they warned.

Harlow reported the matter to the police who arranged for a forensic psychologist to interview Keanu. But the investigation didn't proceed because, being non-verbal, Keanu could not name or identify the support worker.

Eventually Harlow gave up.

‘I’m on my own. I come from a different country. I’ve been – I was in Australia for 20 years but when you have a child with disability, you don’t – your social network is gone ... I’m divorced. No social network, nothing ... It was very, very difficult.’

Harlow told the Royal Commission that the support organisation went on to make her life very difficult. It reduced the amount of care she could access for Keanu, and his regular support workers suddenly became unavailable.

‘I went in a financial situation where I could barely buy milk for my kids. I was very distressed. There was no help. I couldn’t pay for my rent ... So it was a full disaster.’

Harlow experienced suicidal ideation and was admitted to hospital. Staff there organised a meeting attended by ‘everybody’ – her GP, psychologist, nurses and a manager from the support organisation. As a result, the hours of care Keanu had lost were restored.

‘So that was wonderful. And then when I got back home, I got a housing commission house and I was saved.’

These events motivated Harlow to train as a disability worker – ‘the beginning of my journey,’ she said. Her first job was in the group home where Keanu was living, and she has since had numerous different roles in the sector.

She remains puzzled by the way the support provider responded to her.

‘Why was I treated that way? I didn’t want to harm anybody. I just wanted a little bit of justice.’

Louisa and Lachlan

In the early 2000s, Louisa had a stroke. She was in her late 50s. It left her ‘very disabled’, her husband Lachlan said. The left side of her body hardly functions and she has a range of other issues affecting her sight, tolerance of heat and cold and short-term memory.

After the stroke Louisa spent nearly a year in hospital. The couple accepts she will not recover any further.

‘Louisa, she’s said to me many times, it’s just about having some quality of life and keeping her independence for as long as she can,’ Lachlan said. ‘She enjoys her life if she can just get the services she believed she was promised under this system.’

Louisa is supported through the NDIS, which has paid for a wheelchair, bed, pressure mattress, a shower chair and a ceiling hoist.

The couple’s NDIS local area coordinator helped them put together a good plan, for which they are ‘more than grateful to the people of Australia’. But there has been a big difference between the services promised and those delivered.

They feel the system has let them down.

There is no accountability on the part of the service coordinators, Lachlan said. There is only the option to withdraw from the service agreement, and finding alternative providers is not always easy.

‘When you start saying, “Well, why aren’t you finding these services ...?” you get, “You are welcome to exit our service as per the service agreement.” This is the sort of thing you get non-stop.’

Sometimes support workers don’t turn up, with little or no notice. Or they arrive exhausted or sick after doing long shifts elsewhere. Lachlan said they feel under pressure to turn up because they don’t want to leave people without services. ‘These agencies don’t put processes in place to have the backup people ready,’ he said.

Charging for services that aren’t needed is another problem. One example was a service agreement that included a fee of \$5000 for a nurse to regularly check Louisa’s Webster pack, even though the medications were packed at a pharmacy and double-checked.

‘It’s just all about trying to generate as much income out of a disabled person as they possibly can.’

Dealing with these matters is difficult. Under the previous system, the couple had a case manager who they contacted if issues arose. ‘But under the NDIS we have multiple people and none of them seem to have accountability or responsibility of anything.’

Lachlan said a lot of people with disability and their carers are 'just too scared to say anything because they think that there will be consequences to it'. He described contacting a provider about being left with no support when a support worker took two weeks leave.

'As I started complaining about the level of service and things like that, that's when [the provider] said, "Well, we're going to have to withdraw services. We give two weeks notice from today."

When Lachlan asked why, the provider said it was a health and safety issue – support workers were getting wet when they showered Louisa and had to bend over to lift her leg into the wheelchair. Lachlan says providers often use health and safety concerns 'as a weapon' in this way.

Lachlan made a formal complaint about the provider to the NDIS oversight body. More than a year later, there has been no outcome.

He describes himself and Louisa as ordinary people.

'To be honest, I'm just Louisa's husband. I was not trained to be a coordinator of all these services. I do not understand the NDIS.'

Xavier

Xavier has worked as CEO of several disability organisations for nearly a decade. One of these, in a regional town, provides residential care to children with disability who are in the child protection system.

Xavier advocates for continuity of care for clients from long-term staff with specific training in disability, access to behavioural and other specialists and a safe, secure environment for people with disability. But he says negotiating with government about meeting the needs of children in care can be 'quite tricky'.

Government focus is on protection of the child rather than their disability needs, he said. They have a 'very poor' understanding of children with disability.

'It seems to me that the foster care system is not very well set up for particularly children with disabilities whose disabilities are very complex or where they have disabilities and they also suffered trauma, and as a result have a long-term mental health related problem.'

He described the case of a boy who had been in more than 30 foster homes by the time he was eight. He had harmed children so had been put with families where there was no interaction with other children.

Xavier's service made a long-term plan that set goals of independent play, interaction with other children in the house and getting him into school.

'He was eight years old and he really had never attended school – any form of educational institution. So that was our aim.'

As the boy made progress, the department began to appreciate the complexities of his situation – and to understand that 'there are some children that shouldn't go into foster care, they're better off to go into some form of residential care'.

Xavier also spoke about the difficulty of being in a regional town with limited access to services.

Many of the children had mental health issues, he said. But there was no youth mental health service in the town. When children needed treatment, the service had to take them to an adult facility.

'If they were having some sort of psychotic episode, they would get taken to [the nearest regional centre] where there was at least some form of area where they would address the needs of teenagers. But it was an old and antiquated facility and the staff were trained to deal with mental illness, but they were not trained to deal with children with a disability who had a mental illness,' Xavier said.

Where possible, one of Xavier's staff would go too.

‘Sometimes that wasn’t possible and – and that was very distressing when that happened ... knowing that those young people were going to be in a place where they weren’t being supported by someone they felt comfortable being around.’

He was also concerned about the lack of options when someone becomes violent. Staff are required by law to call the police and, when they arrive, the police call an ambulance.

‘It’s like there’s one answer for everything. No matter who the young person is, once they get to a certain point, it’s the police and ambulance. There’s no other choice. There’s no outreach or anything like that. NDIS doesn’t have any specialist workers to help. It’s just your only choice.’

Xavier says his most important message for the Royal Commission is that more needs to be done to help families stay together.

‘There are many parents who don’t have the resources that they need to be able to understand and look after their child in a way that they can keep them at home.’

He says government intervention strategies are often misguided.

‘They don’t know how to support the families to look after the child. And not just that, but if the parents themselves have some form of disability then it becomes even more complex because they don’t know how to work with the parents either.’

Margaret

Margaret is in her 40s and is autistic. Several years ago, she started a remedial massage business in a regional town.

'I just started doing a bit of massage from home,' Margaret told the Royal Commission. 'I thought, if anyone goes out of line dad might be there with a shotgun ... Not literally, but you know what I mean.'

One of her clients started asking her to travel away with him.

'Which I thought was odd because he was married.'

The day Margaret moved her workplace out of home and into a shop in town, the same client 'grabbed [her] across the thighs'.

'I immediately dropped my hands and jumped back as we're supposed to do. He apologised and then he behaved himself, for a while.'

At later sessions, she noticed he was 'playing with himself underneath the blankets when [she] was massaging him'.

Margaret said because the man recommended her to a lot of other clients, she felt obliged to let him do that.

'I was fairly lonely and I was fairly vulnerable ... Here was someone paying me attention. It was unwanted attention, but I still developed a crush on him.'

When she realised she had feelings for him, she told him she couldn't have him as a client anymore.

'I actually sent his business a box of chocolates and I said thank you for your support. I was trying to smooth things over and he actually came up to me and he thanked me for doing it. And then a week later he's accusing me of stalking.'

Margaret said the man spread gossip about her.

'Whenever I went out into town I was treated like I was a monster.'

The man even rang her father to accuse her of stalking.

'One of the things mum and dad were always worried about was that ... I would be sexually assaulted because I couldn't pick up on the body language or the signs of it.'

Margaret said the man harassed her for years.

‘He kept on saying I was obsessed with him ... but he wouldn’t leave me alone. Like, he kept on making gestures at me when I was down the street ... He was online the other night telling me I was a prostitute.’

One day, a friend who knew the man told Margaret he had harassed ‘other women who were vulnerable’.

‘Drug addicts or alcoholics, people who wouldn’t be credible.’

Margaret said she recently learnt the man now worked with a disability service provider.

‘I really hope he doesn’t hurt someone else. Like, I really struggled with it ... I nearly committed suicide over it.’

Sahara

‘We don’t all sit around in our wheelchairs shooting the breeze, you know. We try and get businesses too, and work and all those kind of things as well.’

Sahara is a First Nations woman in her 60s. She has an acquired brain injury (ABI) from an aneurysm a decade ago.

Sahara has trouble speaking, writing and remembering things, but before the ABI she was ‘smart’.

‘I knew I was really smart from when I was a kid. And the only attention I ever got was for being smart. I was so vain about my brain.’

Sahara was poor as a kid – ‘real poor, no money. If there was any money, you got fed.’

‘I eventually went to uni and then I went and learnt more about computers, and I loved them.’

Together with some business partners, Sahara founded a start-up company.

One day the aneurysm burst. When she woke from the coma, she struggled to speak.

‘I used to mix up words on my emails and all that, and I had expressive dysphasia and memory problems.’

Sahara believes that when her partners learnt of her ABI, they used it against her.

‘They’ve registered [the product I developed] in their own name behind my back.’

Sarah said her name was removed from the copyright and she can’t find the business documents to prove her case.

‘All of a sudden they’re rubbing my nose in it saying that they’d paid [for the trademark], not me. That it was in their name, not mine.’

She contacted several authorities, but was recovering from her aneurysm at the time and struggled to speak.

‘I get treated like I’m some crazy old loony person who’s got a quarter of a brain, you know, who’d be useless.’

Sahara said she wouldn’t have been exploited if she hadn’t had the aneurysm.

‘They wouldn’t have got away with that if I wasn’t completely disabled. And everywhere I went, you know, I would try and speak and I was falling over my words and, of course, everybody would be sitting there thinking ... “This poor woman, she’s going on making out she was a business woman and she used to write stuff, when really she’s, you know, pretty close to stupid.”’

A lawyer told her if she wanted to take civil action, ‘Save your money up.’

‘Everyone was treating me like I was making it up because, at the time, I couldn’t speak very well ... They made me feel twice as bad as I ever did myself. They made me so ashamed of being alive.’

Sebastian

Sebastian is in his 50s and lives on a small farm. He has been using a wheelchair since a logging accident about 20 years ago.

'A small sapling tree ... hit me and, basically, wiped me out,' Sebastian told the Royal Commission. 'I don't know anything from the day that it happened till I woke up in hospital a couple of months later ... They cut a big piece of bone out of my head because of swelling.'

An insurance company supported Sebastian after the accident.

'I was quite happy to go back to work. Take me a few years to redevelop life in a wheelchair and get going again, but [the insurance company] weren't in that.'

Sebastian said the company wouldn't let him do much at all.

'Quite often you'd asked for something and it was always, "No, you can't have that," or, "You're catastrophically injured. You can't do that." I've always said to the people, "You're sitting in an office in [the city] and don't know my life, my history, the people who I know, my skill and my abilities."'

Several years ago, the company approved modifications to Sebastian's home and employed a builder to manage the work. Sebastian said the builder was 'slack' and did a bad job.

'In the start of this project, I said to them, "This builder's bad." They said, "No, he's a project manager. He'll look after it." Towards the end of it ... the builder made my life hard to even get to my own garage.'

The builder was also abusive.

'I said to [the company] one day, "If someone had come and ridiculed you because you can't walk, or mock you or abuse you, they'd probably get in trouble. But because I'm in a wheelchair, you think it's okay that someone can do that?" It still eats me up a bit today.'

Sebastian said the company didn't want to help fix the damage. After he complained, it 'signed [him] over' to another insurance company.

'They treated me like a reasonable person. They take my word. They talked to me in a good manner.'

To repair the previous builder's shoddy work on his house, the new company sent a project manager.

‘He was in a wheelchair, too. He sort of said, “You know, people just don’t get it.”’

When Sebastian needed help on his property, the new insurer stepped in.

‘[The previous company] would just say, “No, that’s too hard,” or, “No, we can’t do that.”
... I take my hat off to [the new company] and thank you very much.’

It’s now helping him replace his all-terrain wheelchair for the farm.

‘I try and fault everybody, just so you can improve. I haven’t been able to fault [the new company].’

Eliau and Wren

Eliau was diagnosed with attention deficit hyperactivity disorder (ADHD) a few years ago when he was seven. His mother Wren said that in the years following, she knew there was something else going on.

‘Things were just getting worse and worse, and harder and harder, him falling behind at school, all that kind of stuff,’ she told the Royal Commission.

He was diagnosed with autism when he was 10.

Wren says Eliau is small for his age and people often think he is younger than he is. He is sensitive, especially to being called names. Wren had been in a relationship with a violent partner who’d abused her verbally. She ended the relationship, but one legacy for Eliau is that name-calling, one name in particular, is extremely triggering.

‘At the new school most of his issues stemmed from that. He was constantly called that name. I suppose, you know, kids are quite nasty. As soon as that particular name was given he’d lose it. So then every time a kid had an issue with Eliau, that’s what they’d call him.’

Wren said the school knew how triggering this was for Eliau – she’d told them when he started there. Despite that, the school responded to his behaviour and not its cause.

‘The kid calling him names was never consequenced for that, and it just continued.’

This was just one of many frustrations Wren had with the school. She met with staff and made plans for the best way to support Eliau and manage his behaviour, but the school didn’t follow them.

‘It just didn’t matter what I said to the school, they would do the opposite to what I was asking them to do.’

She explained the situations likely to trigger her son’s destructive behaviours, but the school put Eliau in those situations regardless.

‘Sometimes they’d do the plan, but in their voices I could hear, they’ve rung me, and they’re freaking out, and I’m, like, “You need to calm down.” “We’re calm. We’re calm.” I’m, like, “Dudes, you’re not calm ... if you’re speaking to Eliau like that, you’re not going to get anywhere with him.”’

During one episode, a teacher left bruises on Eliau’s arm while restraining him. The school had previously said they couldn’t use touch – stroking Eliau’s hair, for example – to help settle him. ‘I would prefer that they touched him to calm him rather than touching him causing bruises,’ Wren said.

The school, which hadn't completed the relevant paperwork to get Elian additional support, suspended Elian three or four times over the course of six months. They saw him as a 'naughty kid' and his mother as a 'pain in the butt that kept ringing them'.

'I couldn't cope anymore with it,' Wren said. She decided to move him to another school.

Their experience at the new school, a Catholic one, has been very different. 'They actually listen, and they take on board what I've said.'

Wren feels supported by the staff. 'They've never once made me feel like a bad mum. They've never judged me.' One told her, 'At the end of the day you're the mum, and you know this kid better than he even knows himself. Who am I to come in, and try and tell you what would work better for your child?'

Elian has been at his new school for six months. He has not been suspended and staff have had no problems with him. Wren is sure the difference is that the staff have had disability training. She believes it should be mandatory in all schools.

'I just think it comes down to the staffing, what they understand. And they're just so kind, so caring.'

Ashley and Whitney

Ashley, early 20s, has intellectual disability and schizophrenia. She attended a disability support unit of a public school.

About four years ago, in her last year of high school, she became friends with a girl who attended the mainstream school.

Whitney, her mother, told the Royal Commission that the friend gave Ashley a mobile phone and showed her how to use different apps.

Ashley started going out more. She told Whitney that she 'legally couldn't tell her what to do' and couldn't stop her from going to her friend's house or staying overnight at her friend's house.

One time, Ashley was staying with her friend and they went to the movies. Some adult men approached them, and her friend suggested they hang out with the men.

Ashley later told Whitney that the men were 'pouring alcohol down their throats' and she didn't like it and 'wanted to come back home'.

Whitney suspects Ashley may have been sexually abused.

Shortly after, Ashley 'went downhill quite dramatically and started becoming very different'. Ashley met a guy and stayed over at his house and started to refuse to come home.

She eventually moved in with him and his mother. She rarely contacted Whitney and when Whitney went to see her, the guy refused to let her in.

Whitney asked Ashley's school principal for help and discovered Ashley was only attending school about twice a week. Together they tried to convince Ashley to improve her attendance, but weren't successful. Ashley stopped going to school and never completed year 12.

Ashley eventually contacted Whitney and told her that her boyfriend was violent, 'pushing her into walls and on beds'. She said she was using marijuana and her boyfriend's mother was pressuring her to buy cold and flu medicine at different chemists.

Soon after, Ashley and her boyfriend had a big fight and split up. Ashley moved to a house with about 18 residents. Three of the residents were females – one girl had been in the disability support unit with Ashley.

Whitney discovered residents in the house regularly used drugs and were involved in other illegal activities. A neighbour told Whitney she was worried about what was happening to 'the girls in the house'.

Ashley's housemates took her to Centrelink to apply for Youth Allowance and would take her payments from her.

'I went to the police station so many times. I explained my daughter's disability. I took all the paperwork, all the diagnosis paperwork, everything to back up and prove that she has special needs ... asking them to help me to get her out of the house and away from these people. I was told that I couldn't do anything about it. It was her choice, that the police couldn't do anything. Their hands were tied, until something happened and she came to them.'

Whitney made an application for guardianship. The public guardian became Ashley's guardian and Whitney said they have been good at managing her money. But they haven't done anything to assist Ashley leave the house and move somewhere safer.

In the last two years, Ashley has had two children, both born with disability and removed immediately after birth.

'She's going downhill more and more every day, every week. I don't get to see her very often. More for the fact that it's too dangerous for me to go and see her.'

Stephen and Bernadette

Stephen was always quick tempered, and as a child Bernadette was frightened of him. Growing up she thought her father's behaviour was to do with power and control.

'I worked out later on he was doing it out of anxiety and fear because of his disability. He could go from nought to 10 in one second flat and, you know, it's what I would call a rage when I was a child. But it's what I would now call he went in and out of psychosis.'

As an adult, Bernadette worked in the health sector. An early job was in an institution for people with disability. In that role and others that followed, Bernadette gained a much better understanding of her father. She met people who were like him and came to recognise he was autistic.

He also had a genetic disorder that affected his brain and contributed to his extreme behaviour. Eventually it left him unable to walk. After treatment for further symptoms, he developed rapid onset dementia. Bernadette's mother could no longer care for Stephen at home and he was placed in aged care.

He had a formal diagnosis of autism by then, but getting to that point wasn't easy. People like Stephen 'won't get themselves help so you've got no chance of getting them diagnosed,' Bernadette said.

'And it's also the cost. You know, the cost of getting a diagnosis, like, for over the age of 18, it's horrendous. And then the other issue, we don't have the expertise. We absolutely don't have it.'

Stephen's behaviours and complex needs made it difficult to find an aged care facility that would accept him. Bernadette had to advocate fiercely on his behalf, eventually approaching the Attorney-General in her state.

'The aged care [homes] are private, and they can pick and choose who they want and who they don't want, so people like my father have got nowhere to go,' she told the Royal Commission.

Bernadette had difficulty accessing Stephen's medical records at the aged care home. 'There's no transparency,' she said.

On one occasion she visited him and found he'd been given morphine. She asked why, and was told 'because he's screaming in pain'.

It turned out Stephen had been given morphine for about five weeks, and he still screamed every night. Other staff told her the administration of morphine was a way of 'getting rid of him'.

'You could tell they were fed up with him, you know,' said Bernadette.

'I said, "He's not screaming in pain ... His screaming is behavioural." With her advice, staff were able to settle Stephen through the night.

Bernadette believes that support workers and health professionals are not equipped to recognise the particular impacts of ageing and autism. 'Nobody's got any idea,' she said.

Her greatest fear over the years was that her father's behaviour would land him in prison. And she's certain that a lot of older people in prison are like Stephen – living with undiagnosed autism compounded by other issues that produce unpredictable, difficult behaviour. She emphasised the need to support people like her and her mother in their role as carers.

'Something's got to be done to protect the carers. Because if the carers give up then it's the community that are going to suffer, and the person, because they're going to end up in the prison system,' she said.

Lilah

Lilah, mid-50s, has attention deficit hyperactivity disorder (ADHD).

When Lilah was three, doctors told her mother she was hyperactive and gave her an epilepsy drug 'to calm [her] down'.

At school she tried to be 'appropriate' and 'a good girl', but was 'always in trouble'.

She told the Royal Commission this was 'quite devastating', and no matter how hard she tried it was never good enough.

'I grew up feeling really bad about myself ... It had a really bad impact on my self-esteem and my self-worth.'

By the time Lilah was a teenager, she 'was struggling' and started experiencing depression and anxiety.

'I put myself in harm's way ... and was raped ... and then I developed an eating disorder, an alcohol problem.'

Lilah said by the time she was 18 she wanted to suicide.

She travelled for a couple of years and then went to university.

'Although I did well ... I didn't reach my full potential ... As much as I worked on myself and stuff, it felt like there was always something missing ... I still would make social mistakes no matter how much I tried.'

Lilah got married and had a son, Mikey. Not long afterwards, the marriage fell apart.

Mikey struggled at school. Teachers told her he was being deliberately naughty, but Lilah didn't agree.

The school started making judgemental comments about her parenting style. She knew Mikey's behaviour had nothing to do with her parenting because she was 'doing everything by the book'.

'I started reading about ADHD and started thinking to myself, "I'm absolutely sure this is what's going on for my son."'

Lilah took Mikey to a paediatrician who suggested she should also get tested.

Tests confirmed both Lilah and Mikey had ADHD.

'I literally fell apart. I was so scared that he would have an awful life. I wouldn't wish that on my worst enemy. I don't want any other child to ever feel the way I felt about myself.'

Lilah had counselling, quit her job and did an ADHD coaching course. The course was 'crap', so she started to do her own research.

She began helping other people with an ADHD diagnosis.

'The aim is to, as far as I'm concerned, to get kids and adults to learn how to set themselves up for success and protect themselves from harm.'

Lilah and Mikey both take ADHD medication.

'Without medication you can never get to know yourself, you can never become confident at regulating ... When I first took medication ... it was like this space appeared in which I could stop and think for the first time.'

Mikey has also developed anxiety and depression but 'his self-esteem is intact'. He puts post-it notes everywhere to remind him what he needs to do. Lilah says he does it in an 'empowering way' not a disempowering way. The notes help him 'scaffold'. He doesn't have to feel bad because he forgot to do something.

'He is going to be okay. It's not an easy life, having ADHD, but ... [he's] got self-awareness, self-acceptance.'

Lilah is doing a postgraduate course studying ADHD.

'This is too important. I can't have kids experience what I experienced ... It has to change.'

Zane and Morgan

Zane is a teenager with Down syndrome. He lives with his foster mother, Morgan.

‘He came to us with an ear infection. You know, he was hearing impaired because the ear infections had been left,’ Morgan told the Royal Commission. ‘He [also] had massive trauma behaviour. He could show no emotion – couldn’t laugh, couldn’t cry, couldn’t hold him, couldn’t hug him, you know. He was terrified of the bath and the shower because they were used as forms of punishment.’

When Zane started kindergarten at the small local primary school, he needed trauma-informed support.

‘[It] was the best place for [Zane] to be. It was a community school. It was a small school. The psychologist said it’s perfect, that there’s no massive noises going on in the playground, it’s quiet.’

Zane had a ‘brilliant’ team to support him.

‘All the therapists came to the school and everybody was on board and on the same page with what was going on with [Zane]. So, then we got a notification that they were going to close the school.’

Morgan enlisted the community to try to keep the school open so Zane wouldn’t have to transfer to a bigger school.

‘The consistency of having that small environment school – that cannot be replicated. And he won’t last long at the bigger schools, so he would have to go into a special school.’

Morgan feared that if Zane’s behaviour deteriorated as a result, the department of community services would remove him from her care.

In her battle with the education department to keep the small school open, Morgan said she was ‘called an antagonist’. Someone from the education department tried to have her ability to make decisions for Zane removed.

‘There was one point there ... where it was almost reading between the lines, I [believed] potentially I would lose the children if I didn’t do as I was told.’

Less than two weeks before the school was due to close, the department told Morgan it would remain open until Zane went to high school the following year. When she asked for a longer period for Zane to transition to his new school, she received a 'scathing response'.

'I wrote to the ombudsman, and other people had written to the ombudsman. He wouldn't look at any of our complaints.'

Zane was eventually given an extra term to transition to high school. Morgan said she is studying to help other families navigate the 'systemic culture' of the education department.

Christian

Christian, late 50s, was diagnosed with epilepsy in his 30s.

Following his diagnosis, he took some time off work to learn how to live with epilepsy.

When he returned to work, he was promoted to a new job which required him to drive long distances. He told the Royal Commission no-one had told him he shouldn't be driving.

'I got picked up by the police because I was driving funny. They thought I was drunk.'

Police breathalysed him. Although his blood alcohol level was zero, they told him to accompany them to the hospital for a drug test.

Christian explained he had epilepsy which caused partial seizures. The police officer wasn't fully convinced, but decided not to drug test him.

Christian had to go to court and hand in his licence. He said there was a mix-up and he ended up having a drink driving conviction recorded.

He had to leave his job and look for another one.

He said that when he tells people at job interviews he has epilepsy, 'It's like I've either sworn at them or punched them in the mouth, because it puts them off.'

His marriage broke down because his wife couldn't cope with the seizures.

Christian believes his epilepsy was used against him in the family court. He was denied access to his children because his ex-wife told the court his sons weren't safe in his care.

He wishes he could have been supported to see his children.

Christian said there had been so many times he'd had a partial seizure and people thought he was drunk, he decided to get a medical bracelet. On one side it says he has epilepsy, and on the other side, 'Treat me with care.'

'Instead of judging people, have a look at their wrist. Because maybe instead of criticising them saying "This guy's drunk," maybe you'd be saying, "Oh, we'd better get this guy an ambulance."'

Christian said police often ignore the bracelet and don't understand epilepsy.

Recently, he was at the train station and had a partial seizure.

'I don't even remember the police approaching me. When I came out of my seizure I'd been sprayed with capsicum spray and all that sort of thing.'

Police told Christian they'd asked to see his travel card and he had refused.

Christian told the officer about his epilepsy, but the officer said it 'didn't look like' he was having a seizure.

An ambulance arrived and Christian asked the officer why he'd called an ambulance if he didn't believe he was having a seizure.

Christian doesn't apportion blame. 'It's not the police's fault, because it comes down to the training. They don't really understand epilepsy.'

Christian receives a Disability Support Pension but would like more support to help him with day-to-day activities.

He has applied for the NDIS, but isn't eligible because the NDIA considers epilepsy a health condition.

'People like myself who's an epileptic, you do need some extra help from time to time. You go to get it but there's barriers to why you can't get it for different reasons.'

Frankie and Jazlyn

In the late 2010s when Frankie was in his early 40s, he was in a car accident that left him with a brain injury. He lives alone in a public housing unit in the ACT. He needs 24-hour care and support.

Frankie's legal guardian is his older sister, Jazlyn. She told the Royal Commission that neither this role, nor her position as close family, give her the access or authority she needs to ensure Frankie is well looked after. Navigating between the funding agency, the service provider and the support workers to achieve good outcomes for Frankie is difficult and frustrating.

'It's a cast of, it feels like thousands at times. It's a circus, but it's not enjoyable. There's a lot of people with their hands, feet and faces in the trough, and, you know – all activity, little action.'

Jazlyn wants Frankie to have care that prioritises his wish for independence, but also manages the other needs set out in his care plan – 'healthy living, social interaction and exercise'.

'I'm not asking for more or less than he's entitled to. I'm asking for the appropriate, timely delivery of services that meet my brother's actual needs,' she said. 'And there's so much insincerity and people just turn away or they box tick.'

One of her concerns is whether Frankie's medical needs are being met.

'When I've asked for his, you know, a summary of his medical appointments from last year, "We can't provide that to you as a family member, there are privacy issues." I said, "Well, redact it as appropriate and provide it to me as the legal guardian." I have yet to sight that information.'

Another concern is Frankie's diet. He gains weight easily and has seen a dietician to get advice on his eating.

'He gets a menu, gets lists of things he should be eating, but on Monday when he goes for a shop with the carer, [it's] bags of Twisties, instant coffee fully caffeinated, sauces full of salt and fat, and things he's not supposed to be eating.'

Jazlyn asked the support worker to shop according to the menu prepared for Frankie. The support worker said it would be 'restrictive practice' to intervene in Frankie's choices, and they'd been told that was not permitted.

Jazlyn told the Royal Commission that no limits are placed on Frankie's intake of alcohol and caffeine, despite concerns about past drug misuse and his sensitivity to stimulants. No-one ensures he takes his medications appropriately. Support workers do not take him out to agreed-to weekly activities. He has not been given the support he needs to find work.

‘The practice is poor. It is inconsistent. When I query it, “It’s how things are done.” When something isn’t right, for me to challenge it becomes “restrictive practice”.’

Jazlyn is ‘irritated’ that the requests she makes as Frankie’s guardian are ignored – ‘because it’s not easy or because a person is sitting in an office believes that they somehow know more about my brother than I do.’

She believes Frankie’s wellbeing is impacted by the lack of proper care from people who have their own interests at heart. ‘It’s the maintenance of a system, not the blossoming of a man’s life.’

She urged the Royal Commission to recommend greater accountability so ‘people are accountable and there is a chain of evidence’.

‘The policies that have been written and the, you know, the paperwork is not sufficient. It just means that they’ve been written. It doesn’t mean that they’ve been actioned,’ she said.

‘I want an evidence log. Not just words, but actual photographs. Show me that you’ve done what you say you’ve done.’

Paxton and Paisley

During the COVID-19 pandemic, Paisley's family spent months in lockdown overseas. Lockdown was especially difficult for her son Paxton, then in his final years of primary school.

Paxton is autistic, and has vision impairment and obsessive-compulsive disorder. He has severe eating issues and requires special meals. He has eczema which is kept in check by access to fresh air and a clean environment.

Lockdown in the overseas city was very strict, and Paisley decided to bring Paxton and his sibling home to Australia. 'So that they could go to school and go to the doctor or, you know, just live a life that was impossible to have over there at that time,' she explained.

With the support of the government agency her husband worked for, Paisley arranged with the health department to waive two weeks of quarantine, and for the health department of their destination state to agree that two weeks hotel quarantine there would be enough.

Paisley sent the department detailed information about Paxton's needs. 'One of my sons, [Paxton], has autism and quarantine will be very difficult for him and we need access to services to support this major transition,' she wrote.

She asked for laundry facilities, as frequent washing and drying of Paxton's bedding and other items is an essential part of managing his eczema. She asked for cooking facilities so she could prepare the special meals Paxton requires. She asked for access to fresh air and space for him to move around.

The department acknowledged they'd received the information. But when the family arrived, no-one at the airport knew anything about them.

'They didn't know we were arriving. There was nothing. There was no clue. They held up the whole airplane and took us off and interviewed us – the police did – but we did have the paperwork, thank goodness.'

That night they stayed in a small hotel room, with none of the supports or facilities requested.

'We were all very distraught when we were put in this tiny, dark room without any sunlight or fresh air or access to anything, and knew at that time that we were going to have a big eczema breakout. Well, the next morning, what did we have? A big eczema breakout all over his whole body.'

The family was moved to another hotel, to a room that did have kitchen facilities but no washing machine or dryer. It was also very dusty.

'They gave me one of those Dyson hand vac things to vacuum, you know, the stick cleaner, and the canister would fill up every single day.'

Paxton's eczema became so bad he didn't want to go to the toilet because it was so painful, or to walk anywhere in the room because he was terrified of the dust. 'So that's pretty much how he had to stay for two weeks.'

Paisley emailed the department every day, sending photos of their situation. Finally, two days before their quarantine was due to end, the department offered the family another place to stay. It had a balcony – but nowhere to cook or do washing.

'So basically, they told us, "You can feed your child or give him fresh air. What would you like?"'

Paisley accepts this was an 'unprecedented' time. But she questions the lack of support she received.

'To throw our most vulnerable people under the bus first is not really a good society,' she said. 'I would have done anything not to have put this little boy through what he went through.'

Darya and Winter

Darya is seven. She is autistic and has attention deficit hyperactivity disorder (ADHD) and other disabilities that make the school environment difficult for her.

Issues arose early on when Darya was a preschooler. Winter, her mum, was unhappy that the principal would not allow changes that would have helped Darya settle in. She followed up with the education department, but staff told her there was nothing they could do.

‘The department lady said to us basically, “I’m department, they’re department – I really can’t help you.” ... We were kind of left with no option but to leave the preschool.’

Winter formally submitted her concerns to the department.

‘I made a – sort of a report about the principal’s behaviour and how she didn’t provide reasonable and necessary accommodations to Darya in preschool. But to my surprise, that was flicked by the department back to the principal to respond to. I was like, “Wow, this is the person that I’m writing to you about and then she’s responding to the complaint directly to me.” I found that really disconcerting.’

Darya moved to a different public school, but problems quickly emerged there too. The strategies in place to smooth her transition to school life were dismantled with no warning. When Winter asked the principal why, he replied, ‘There will be no special provisions for Darya despite her disability. She will just fit in like everyone else.’

There was an incident where a teacher grabbed Darya and pulled her away from Winter, which was extremely distressing. Winter reported the teacher to the education department.

Once again the department asked the principal to investigate. In due course Winter got a reply. ‘This assessment has found there to be no evidence of inappropriate conduct.’

‘So that was the first sort of kick in the guts for us to say, “Wow, is this really how the department and schools react when parents are brave enough to come forward and make a complaint and, you know, want to see change in the way things are handled?”’

Winter had explored other options for Darya, but there weren’t many. She has a high IQ, so isn’t eligible for a place in a public-school support unit. She briefly attended a school for autistic children, but it didn’t work out. Winter tried to enrol her at Catholic school, but they said she needed a special school.

‘My jaw dropped to the ground ... I think this has to be noted, that in 2020 gatekeeping still happens.’

Eventually, Winter re-enrolled Darya at her first school.

'[The department] said she would have all this support. But as it turned out, as soon as the department left, the school kind of almost ripped up everything the department had said,' Winter told the Royal Commission.

'What I understood was the department really wanted to help but it remained at the school level. And if the school wasn't interested, there was nothing the department could do to intervene.'

Finally accepting the school was not able or willing to give her daughter the support she needs, Winter withdrew Darya and is currently homeschooling her. She thinks she might have to continue homeschooling until Darya can go to high school.

Darya told the Royal Commission she misses her friends and eating at the canteen.

Jakobe and Ivory

Jakobe is a First Nations man in his 20s. He is autistic and has trouble speaking.

His mother, Ivory, said that when Jakobe started primary school, his teachers ‘were like the grandmothers he never had’. ‘That’s how warm and beautiful these women were,’ she told the Royal Commission.

After being diagnosed with autism, Jakobe moved to a school that had special education classes.

‘They rearranged his diagnosis to where he’s being looked at like he’s got [attention deficit hyperactivity disorder] ADHD. And they were forcing medication on him, and if he didn’t take medication he wasn’t able to go to school.’

Jakobe kept running away from school.

‘I felt medicating him made him worse ... My son spent more time on the streets of the community than in class.’

Ivory pulled Jakobe out of school and tried to homeschool him, but said she received ‘no support, nothing’.

A social worker helped Jakobe return to school after several years. Ivory said she later discovered Jakobe’s high school had ‘red-flagged’ her with family services because the school didn’t know where she was.

‘I thought that was pretty insulting.’

Ivory said other government services subjected her to ‘unbelievable discrimination’.

‘[I was] looked at like a liar, a criminal, an alcoholic, somebody who abuses substances, drugs [and] not one drop of concrete evidence. I’m that stigmatised to this day.’

Ivory said she receives a Carer Allowance and Jakobe now gets the Disability Support Pension. They spend most of it on rent.

‘I’ve applied for NDIS and I haven’t got no answers.’

A couple of years ago, someone falsely reported a firearm on her property. Ivory said police violently raided her home, traumatising Jakobe.

‘It is really scary for me to know that my son doesn’t stand a chance ... I don’t sleep well knowing that when I pass, my son has no-one.’

Meadow

‘These accommodations are put into our student access plan, they’re approved at the start of the semester. But then we have to spend the rest of semester making sure they’re in place and often fighting for them as well. And explaining to course coordinators ... why these accommodations are needed, and explaining to them what they need to do.’

Meadow, mid-30s, has a neurological condition that causes non-epileptic absence seizures.

She is currently studying at a large university.

Meadow told the Royal Commission that ‘bureaucratic hurdles’ prevent students with disability accessing appropriate accommodations in ‘a timely and stress-free manner’.

Meadow has tics, which are worse when she’s stressed. She needs to complete exams in a room by herself. ‘It’s not just for me, it’s also for other students.’

At the beginning of the semester, Meadow completed a student access plan and the university approved her need for a separate room.

Two days prior to completing the first quiz of a subject, Meadow discovered her request had been ‘lost in the system’.

She had to email and make several phone calls to be able to sit the quiz in a separate room.

‘The time and energy I used on this caused me immense stress, and it was basically impacting my ability to study for the quiz.’

Meadow’s request was approved but later, for another subject, she had to go through the process again.

Meadow said she discovered that although the university approves accommodations in the student access plan, central exam organisers and the course coordinator are responsible for implementing the accommodations.

Ultimately, it’s the course coordinator’s decision.

‘Even after they’re approved ... course coordinators can say that they won’t implement these things.’

Meadow said coordinators sometimes refuse because they don’t know how to implement accommodations.

'It's not an effective system and I think it is also wasting a lot of resources, especially human resources.'

Another time, Meadow had been having a series of seizures and couldn't move or speak for several days. When she was able to communicate, she requested an extension for a report that was due. She acknowledged her request was late but told the university it was unavoidable because of her seizures.

The university refused to give her an extension because her request was 'not made prior to the due date, as per university rules'.

'I ended up having to appeal, which was like doing another assignment.'

Meadow's appeal was successful and she received an extension.

'Every time we face one of these barriers, it is like being told that we don't belong here and we are not wanted here.'

Meadow believes universities should build accessibility into the course profiles of every single course.

Elisabeth and Delilah

Elisabeth is in her 70s. Her daughter, Delilah, works in the disability sector.

'[Mum]'s got multiple disabilities in terms of cognitive, mental health,' said Delilah. 'If we go back to 10 years ago, she was a caring person but she struggled with mental health for a long time. She's experienced [abuse] for a long time from her husband, my dad.'

Delilah told the Royal Commission that her father broke her mother's ribs, tried to strangle her and 'threatened to kill her'.

'It was about money, it was often about money. And so I rang police ... and they said to me that my mum will be, like 10 or so in line to get the service because of the multiple times that she's laid allegations.'

Delilah said she complained about that response, but the police integrity office dismissed her complaint.

'The senior sergeant, whatever, from that station rang me about my complaint. He ends up yelling at me on the phone ... because I was asking, "Where's the forensic risk assessment on my dad?" And he said, "Well, he's always going to be a risk. Why are they living together?"'

Delilah said the police were 'minimising, facilitating and enabling' her father's violence.

When Delilah tried to get an intervention order for her mother against her father, the magistrate told her it was 'on her mother to leave'. Another time, a social worker asked why didn't she get her mother out of the house.

'I had tears rolling down my face and I said, "How? How am I supposed to get her out of the house?" I'm riddled with arthritis. My mum is bigger than me. She's also volatile.'

Delilah said the justice system is unable to help her mother escape domestic violence.

'They were asking us to take her in ... We love her, but she needs professional help. Her trauma, her disability, it's multitude. It's physical. And we've got children, and the trauma for me to take her in, I can't do it!'

Delilah fears her mother's case will end up in the coroner's court.

'The systemic response ... to people who experience mental health, domestic violence, family violence, or as we call it intimate partner violence, the systemic response across the board ... is extremely bad. It's appalling.'

Mercy

Mercy is an advocate for children with disability who are gifted. She spoke about the current debate around disability and education – who should be in the average classroom, and what should be expected from teachers.

On one side, she told the Royal Commission, are proponents of ‘full inclusion for everyone, all the time, regardless of level of impairment occasioned by the disability’.

‘And on the other side are people, I guess, like me.’

Mercy said ‘inclusionists’ believe all schools for specific purposes (SSP) should be shut down.

‘Everyone should always be in the same classroom, and – according to them – the regular classroom teacher, with the proper training, should be able to meet the needs of virtually everyone in that classroom.’

In this environment, she believes, the needs of children with less obvious disability will not be met.

Mercy is concerned for children like hers, who have dyslexia, attention deficit hyperactivity disorder, motor dyspraxia and difficulties with handwriting. These disabilities have not resulted in behavioural issues. ‘They annoy no-one. They don’t kick people. They don’t hurt people.’ But their needs, Mercy says, are often not recognised by the education system.

‘What I’m hearing from people on my side of the divide is, “They’re not interested in us. They’re only interested in severe autism, non-verbal, severe physical disability. We don’t see ourselves represented.”’

She gave an example of a child with vision impairment who was allowed enlarged print in a year 3 government test. ‘No problem at all.’ The child did very well in the test and was accelerated a year, so then was in year 5 and doing the test again. This time the education department didn’t want to approve the use of enlarged print.

“‘Well, you can’t have that anymore, because you can’t have a disability if you’re so smart you could be accelerated.” Sort of – “You’re trying to put something over on us because the child is clever, and you should be just” – to the parents – “you should just be happy that the child is clever.”’

The inclusion model is problematic for teachers too, she said.

‘What I’m hearing from teachers is, “I didn’t sign up for this. I signed up to teach English and math and science and history. I signed up because I like teaching little children ... who are ready to learn. If I’d wanted to be a nurse or a social worker or a wellbeing officer or somebody who oils wheelchairs or somebody who inserts feeding tubes, I would have signed up for that at uni.”’

Mercy feels that momentum is behind the proponents of full inclusion, and parents and educators with other views feel silenced.

‘We’re getting all these kids whose needs are not being met, whose parents are not called to your hearings, who have learnt not to say any of this in public ... They don’t want to hurt the child with severe disability, they don’t want to hurt feelings of the parents of that child, but they have to keep their own children’s best interests at the front of mind.’

‘You’re just not allowed to say all these things. I have a list of things that I’m not allowed to say.’

Mercy wants to see more research on the impacts of inclusion. ‘Is it true that the other kids in the class don’t suffer? Is it true that it’s good for them?’

Mercy said those on her side of the debate feel like the result of the Royal Commission is ‘just going to end up being recommendation after recommendation about redoing the whole education system, so that all the SSPs are shut down and the parents have no choice’.

‘And that is of worry,’ she said.

Kassidy

Kassidy is a First Nations woman in her late 50s. She lives with emphysema, depression and anxiety, and receives the Disability Support Pension.

Kassidy also has two daughters with disability. She told the Royal Commission they've had to 'fight through [their] teeth' to find safe housing.

Kassidy is currently living in a government housing unit, 'a high-rise'. Her home is in a 'pretty high crime area' where there are lots of 'outlaw gangs'.

'You couldn't even run a bus there of a night unless the bus driver got bashed to bits.'

Kassidy said she lives in fear because of a general lack of security.

'There are no locks on the downstairs fire door, no grills, no windows on the bottom one or the top ... We've got no intercoms.'

She said the building is unsafe because of drug users, 'scams' and loiterers.

Kassidy said the living conditions are exacerbating her mental health issues, particularly 'sleep deprivation' due to constant noise. Her room is right near the elevator. Because her neighbours 'run a few drugs', the noise is constant.

'[The noise] nearly sent me off my bloody head,' Kassidy said. 'Mowers at 12 o'clock at night ... And a lot more goes on there too. Men in my yard all the time ... I've been their prisoner, basically.'

Kassidy pointed to 'very, very discriminative' attitudes from 'government departments and agencies' in regards to her situation. 'They held us down.'

She said her complaints went nowhere because of 'the corruption of police and their mixture with local criminal gangs and outlaw gangs'.

Witnessing the effect of poor housing on other tenants, especially young people, has led to Kassidy becoming a passionate advocate.

She's particularly concerned about the mental and physical wellbeing of children. The environment they live in is 'all concrete'.

'There's no grassed area. There's not a play area. There's not a blade of grass. There's nothing ... That's unacceptable.'

Jo-Anne

‘People aren’t aware of this invisible illness ... No-one sees me on a bad day when I’m struggling or can’t get up in the mornings, and I’m dribbling and I’m trying to get it together, and I’ve got to ring a health line because I’m so shattered from the trauma that’s still coming up.’

Jo-Anne is a First Nations woman in her late 50s who lives with mental illness, post-traumatic stress disorder (PTSD) and major depression caused by child sexual abuse.

‘I was put on the disability pension at a very young age, because I was totally debilitated from all my childhood abuse,’ Jo-Anne told the Royal Commission.

A few years ago, she had a ‘mental breakdown’ after conflict with a family member.

‘It just did my mental health in ... It triggered all the abuse from my childhood and I regressed for six months and started chain-smoking and drinking again after 18 years sobriety.’

She felt ‘so isolated’ and, ‘fighting against suicide’, contacted a mental health crisis service.

‘And they said, “You have to go into the mental health ward.” So, I signed myself in voluntarily, and that was huge in itself.’

But Jo-Anne had difficulty accessing appropriate medical and legal services when in need, and says this is common for many First Nations people. ‘There’s no advocacy ... There’s not many that deal or talk to the people with mental illness.’

Jo-Anne says dealing with the NDIS is ‘frustrating’.

‘It’s like the crap I’ve got to go through just to try to get treatment that I know will help me is absolutely insane, the red tape.’

‘I think all these service providers that are working with people in the NDIS should be in partnership with a reconciliation body, have their staff trained and know what’s culturally appropriate ... Because what runs deep in my blood more than anything is respect.’

She wants to continue advocating on child abuse, domestic violence and alcoholism.

‘I’ve been a voice in the community for years,’ she said.

Matias

‘I feel like if I try and participate I’m going to get hurt – and it’s stayed with me since childhood. I’m still living the same kind of scared existence that I developed as a child.’

Matias is in his late 40s and is autistic. He was only diagnosed recently.

‘I spent 20 years chasing my tail trying to figure out why I didn’t fit in with everyone else,’ Matias told the Royal Commission.’

As a result, Matias said he had been ‘isolated’ and shut out his whole life. ‘Ostracised at school, ostracised from participating generally and ostracised from the family.’

As a private-school student in the 1980s, Matias described his upbringing as ‘privileged’. But because he was ‘larger than other children’ and ‘seen as a nerd’, his classmates bullied him. ‘To the point where I developed a childhood eating disorder,’ he said.

The school put Matias in cadets. ‘Back in the day it was, “We’ve got a fat kid ... We’ll march him around the paddock.”’

Boys ‘who had been given the job as corporals’ shouted at him, like ‘drill sergeants’ from army movies because they thought him ‘uncoordinated’.

‘You know, from the latest Clint Eastwood movie that they had watched ... Those kinds of things just stick in your head your whole life.’

After school, Matias studied property valuation.

‘And I was a property analyst for property developers when I first finished university. But I had problems in the workplace, and so I had to drop out.’

Ever since, he has struggled to find and keep work because of his disability.

‘People on the autism spectrum are actually quite good at getting technical things done ... but no good at the job interview process.’

Matias feels he misses out on adequate DES support because of his late diagnosis.

Meanwhile, his interaction with the NDIS has been a ‘constant battle’.

He said many autism organisations only look after children.

'I think they know how angry and messed up all these undiagnosed autistic adults are, it's too hard for them to deal with.'

After working a few months as an Uber driver, Matias became homeless during the COVID-19 pandemic. He was sleeping in his car.

He is now living in a hotel room, where his only visitors are support workers.

'They've basically been my paid friends over the course of the pandemic and helped me exercise and participate a bit socially.'

But the childhood bullying has scarred him for life.

'That's what I've been suffering from my whole life, the anxiety of that fight or flight response syndrome ... I should be in the prime of my life, but I'm afraid of participating in society because I feel totally ostracised.'

Jeffery, Alvin and Elora

Jeffery, age eight, is autistic.

Alvin and Elora, Jeffery's parents, told the Royal Commission that as a two-year-old, his behaviours were 'very challenging'.

Shortly before Jeffery turned six, his behaviours became 'worse and worse' and his parents 'weren't able to keep him safe'.

Jeffery cut a power cord with a butter knife, almost electrocuting himself. Another time he managed to get out of the yard, rode his bike onto the road and was nearly hit by a car.

Alvin and Elora had done multiple parenting courses over the years, but didn't know what to do.

Because Jeffery wasn't yet six, doctors couldn't legally 'start that journey of trying to figure out what medication would help change his behaviour'.

As Jeffery's behaviours escalated, Alvin tried to find someone to help.

'Going to the hospital first of all wasn't even an option, because he was in such a state we wouldn't have been able to keep him safe in the waiting room.'

Jeffery's usual paediatrician was away and child mental health services couldn't assist them.

Out of options, Elora took Jeffery to a doctor at the local health centre.

The doctor prescribed an antipsychotic medication and an antihistamine. He said he'd given the medication to children before.

The local pharmacist raised concerns about the medication and suggested Elora only give Jeffery half the prescribed dosage.

A day or two later, Jeffery had a severe dystonic reaction to the medication.

'He was sitting next to me,' Elora said, 'and I noticed he was starting to get quite agitated and disoriented, and kind of shuddering a little bit. And then it stopped. So, I looked at him, and then a few minutes later it did it again – it was almost like a seizure. It was his whole body seizing up.'

Jeffery stopped breathing and they rushed him to hospital. Doctors said Jeffery's airways had been compromised because of the medication the GP had prescribed.

'The thing that obviously shook us up the most was, had this happened at night he would've stopped breathing and we wouldn't have heard. It's as simple as that.'

Several days later, Alvin wrote a complaint to the manager of the health centre.

At first, the doctor blamed Elora for not giving Jeffery the right dose of medication.

Alvin met the doctor in person and advised him that Elora had only given half the dosage.

The doctor became distressed, admitting he had never prescribed the medication to a child before. He promised never to do it again.

‘We didn’t pursue anything civil, because the fact he wasn’t going to give it to a child again was enough.’

Alvin believes there should be allowances for medical professionals to prescribe medications such as Ritalin, instead of antipsychotics, before a child turns six.

‘You’d think that the risk compared to an antipsychotic for a five-year-old compared to Ritalin – it’s a huge difference. And that would be at the discretion of a paediatrician on a case-by-case basis.’

Damari

‘When I went to homeless services that were designed by people who have experienced violence and are homeless, I was told, “This program is for women and children only.” ... So, there’s women and children, not so much for guys out there.’

Damari, early 40s, has autonomic dysfunction, postural orthostatic tachycardia syndrome and post-traumatic stress disorder (PTSD).

Until a few years ago, he lived at home with his mother and father.

He told the Royal Commission that his father physically and verbally abused him ‘on a daily basis’.

Damari’s mother was his carer and he said he ‘lost [his] independence’ and stayed at home longer than he should have.

‘It eventually took its toll on me where I got PTSD. I started to recognise that I had to get out of there, because I was seeing for the first time physical manifestations, like, where I was not functioning, and I was having nightmares about it.’

A short time ago, Damari’s father told him he wanted to have him ‘locked away’. He rang an ambulance and told paramedics Damari had schizophrenia. They took him to hospital but doctors released him immediately. One of the paramedics told Damari his father was abusing him and there were people who could help him.

A short time later, Damari went to police and obtained an intervention order against his father.

His father went to police two days later and accused Damari of being violent. He also told police Damari had schizophrenia. Damari believes, because of that, police thought he was ‘making things up’.

Police arrested Damari and officers started referring to him as ‘that guy who thinks he doesn’t have schizophrenia’.

The judge was more understanding and granted him bail, but he had to stay away from his parents.

Damari moved to a motel, but his only income was the Disability Support Pension and he couldn’t afford to stay.

‘I ended up homeless for three months,’ he said.

'I tried to go for one of my relatives to charge my phone and they didn't want to have anything to do with me because ... my father had then gone and done this smear campaign of telling the same lies to all the family, friends and relatives. So, I was basically ostracised and cut off from everyone.'

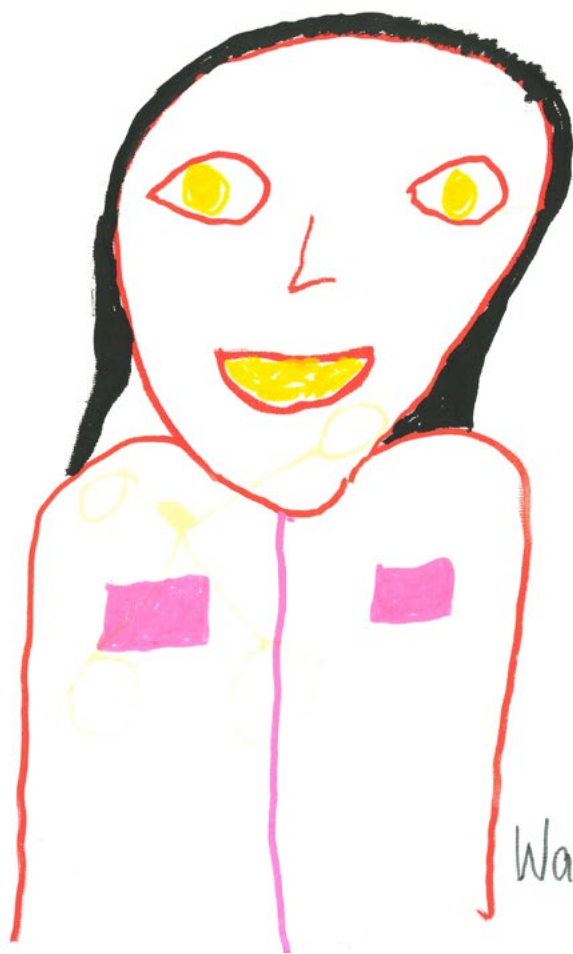
Eventually he found some supported disability accommodation and was able to stay for two weeks.

He moved to a private rental where he lived for a year and a half. But when the owner of the property died, Damari became homeless again.

He tried to get some support through victims of crime but he was seen as the perpetrator and was unable to access their services.

Damari is in the process of trying to find public housing.

'At the moment I feel like I'm still stuck in survival mode. I'm taking it day to day.'



RODNEY
2021/05/05

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Artwork by Rodney Smith

Jaylen

Jaylen, in his early 50s, has an intellectual disability. About 20 years ago, after a series of assault charges, a court placed him on a supervised treatment order (STO). This covers his medication, requires him to be under supervision and limits where he can go and how many hours a week he can be in the community.

Jaylen lives in a group home with four others. With assistance from Marjorie and Jane, he told the Royal Commission about how the disability services provider has lately been using the STO as a restrictive measure to prevent his participation in the community.

One of Jaylen's complaints is that there are 'lots of restrictions and invasiveness' in his private life. Some of these were imposed during the COVID-19 pandemic, but have not been lifted since.

These include paying rent but having no say in how the home is managed. A room where Jaylen spent time doing large jigsaw puzzles and other activities was turned into an office. A gate that used to be left open is now kept locked.

'He's so upset about it because it didn't used to be locked, and for him it means he can't wave to the neighbours and that's really important for him, to feel that he's part of the outside,' Marjorie said.

There are now fewer staff and there are often not enough people to look after residents. 'It restricts what they can do in the day,' Jane said. With no staff member available to accompany him on a walk or other outdoor activities, Jaylen must wait for his NDIS support worker to come.

'What do I do? I have to wait – sit around and wait for 4 o'clock in the afternoon ... to go out for tea. I've got nothing on ... Yes, just sitting in the house twiddling my thumb, doing nothing,' Jaylen said.

'Every time – every time I want to go out of the yard and the staff keep saying, "If you leave the yard or this house, we can call the cops on you."'

Marjorie said she sometimes feels the service provider just makes rules up. Freedoms enjoyed by others aren't available to Jaylen. She recalls this happened during COVID-19 lockdowns when Jaylen wasn't allowed to go on a particular walk.

'And I heard you say, "Why can everyone else go and I can't go and do those things?" You were treated differently.'

Jaylen has family members he could visit but, again, he has to be accompanied. He told the Royal Commission that when his parents were in a serious car accident, the provider would not allow him to visit them at the hospital.

It is very frustrating. 'Sometimes the blood pressure – I've got a BP in my room. I check my blood pressure. Sometimes it's 172, right over my limit.'

Jaylen would like 'just to go to places on [his] own without the staff for a change' and see his friends.

'I don't want [the services provider] to interfere with my life anymore.'

Mary-Kate

As a small child, there was a lot of fighting and abuse in Mary-Kate's home. Her parents separated when she was six and she remained with her mother. At primary and then high school, she had to care for her mother who became deeply and sometimes suicidally depressed.

'School was my only stable place, so I did my best to do well there,' Mary-Kate said. But over time that became more difficult. 'I was completely isolated, ashamed and deprived,' she said. In high school she developed social anxiety and depression that she tried to conceal. It affected her capacity to study and she barely passed her final school exams.

'This has led to an extremely difficult life of just struggle with severe depression, social anxiety, you know, and they are crippling. Absolutely crippling,' Mary-Kate told the Royal Commission.

By the time she was in her early 20s, Mary-Kate was also dealing with 'excruciating' back pain, the result of multiple car accidents. 'So at this point ... I entered the world of daily chronic pain which causes depression in itself.'

Now in her early 50s, Mary-Kate has had chronic pain ever since. It has limited her ability to work and enjoy a normal life. When her father died she inherited some money, enough to buy a house in regional Victoria. This has been problematic too, with mistakes and faults in construction of the home leaving her fighting for compensation.

To meet the costs of repairing her home, Mary-Kate has had to work harder than her body can tolerate. She is angry that the federal government reduced the number of health support visits it covers, as she depends on these to keep functioning.

'They reduced the chiropractor – that was one thing that helped me – down to five visits a year. Five visits a year, that is disgusting. I'm needing them twice a week. Physio. Now it's five visits for everything per year,' she said.

Access to free counselling has also been cut back. 'That's down to 10 meetings a year,' Mary-Kate said. She was seeing a counsellor regularly and finding it very useful.

'I saw her for two years ... I was actually getting somewhere with her and then funding stopped. I had to – you know, had to retell my story and dredge it up maybe 15 times to different counsellors because, you know, funding.'

With the help of her doctor, Mary-Kate is applying for NDIS support. She said she'd been slow to apply because of her sense that people in her situation, whose disability is invisible, receive very little help.

‘There needs to be a lot more done about the fact that, you know, that the walking ones, with back pain and neck pain and all that kind of thing, we are still kind of hidden.’

She is concerned about the level of funding available to people in her situation.

‘Just because I’m receiving a disability pension ... it doesn’t mean that I don’t have the mental processes to be able to manage money and budget. And the problem is you can only do so much with what you’ve got. It’s not an issue of mismanagement. It’s not having the resources. The DSP [Disability Support Pension] needs to be doubled immediately. You know, for people – we want a life, you know.’

Briggs

‘They don’t understand I have the power, I have the money to spend on providers in certain budgets to do certain things. I’m just getting so fed up going to different providers. I don’t know what to do any more.’

Briggs, early 40s, is autistic and has Tourette syndrome and depression.

Briggs told the Royal Commission he has ‘experienced mistreatment ... from numerous NDIS providers and other services’, and it has caused him ‘a lot of harm and distress’.

One provider supplied support workers who often didn’t turn up. ‘I’m out the front waiting for someone to turn up who never turned up ... At least have the decency of telling me.’

The provider required Briggs to give them 48 hours notice if he wanted to cancel a service, but didn’t treat him with the same respect.

‘It’s not a two-way street. It’s a one-way street, and it’s just unfair.’

One time, Briggs organised to be picked up from a local leisure centre but the support worker didn’t turn up. Briggs had to walk home in 42-degree heat. While the provider didn’t charge him for the appointment, it was a very stressful situation.

Support workers were often distracted and would drag Briggs around while they did their own chores.

One time a support worker picked up other clients Briggs didn’t know, even though it was supposed to be a one-to-one service. The support worker then made Briggs and the other clients wait in the car while he did other things. Briggs believes the worker made a claim for all three clients.

Often providers charged Briggs at the highest rate but would send support workers who didn’t know what to do.

‘Support workers did not do very much, and I kept having to tell them what to do. So, it was more like I was telling them what to do as a supervisor instead of them working with me to do things.’

Once, Briggs met with a physiotherapist who told him she could not provide the services he needed. The provider charged Briggs for a 30-minute appointment.

One provider provided a cleaning service. The cleaner didn’t do the job – she sat in a chair for most of the time, looking through her mobile phone.

‘I found with a lot of these companies, a lot of them tend to get away with the problems. So it happens, not just to me but everyone else ... They turn around and say, “Oh, too bad. There’s nothing you can do because you get paid from the government.”’

Briggs was registered with a disability employment service for many years. He is concerned they received a lot of money from the government for advertising, but didn’t do much to help him.

‘They go through a lot of staff, and a lot of staff tell me they don’t like being here. A lot of staff I’ve talked to, six months later they’ve moved, gone to another company.’

Brigitte and Richie

‘[Richie] self-harms, he hits daily. This is a beautiful little boy with Down syndrome who had no behavioural issues before all this kicked off. He should always have had these supports in place, and he just didn’t.’

Brigitte is autistic and has attention deficit hyperactivity disorder (ADHD). She is mum to nine-year-old Richie who is also autistic, has Down syndrome, ADHD and post-traumatic stress disorder.

A few years ago Richie started school at his local state school.

The principal told Brigitte that Richie was the first child with intellectual disability he had ever come across. After a short time, he decided Richie could only attend school once a fortnight because of his disability.

The principal and teachers punished Richie for his behaviours instead of using de-escalation strategies. No-one formally reported the incidents or told Brigitte what was going on.

Richie started to self-harm, repeatedly banging his head on the floor. His behaviour changed towards Brigitte. ‘He’d grab my hair and try and pull me onto the ground.’

Brigitte discovered the principal would lock Richie in a room for most of the time he was at school.

After six months the principal withdrew Richie’s enrolment, saying he didn’t meet new school-readiness indicators.

When Brigitte pointed out this was contrary to school policy, he changed the policy. He effectively excluded all children with disability from the school.

Around this time, Brigitte applied for NDIS funding on Richie’s behalf.

It took about eight months for his plan to be approved because the NDIA lost the paperwork.

The initial plan was insufficient, so Brigitte requested a review.

In a phone call lasting almost three hours, a staff member kept telling Brigitte to ‘lower her voice’. Brigitte explained she was autistic and couldn’t change the tone of her voice.

‘She was constantly trying to lead me into saying and admitting that it was my lack of capacity as a parent leading to [Richie]’s deficits, instead of his disability.’ The staff member offered Brigitte parent training. ‘Parent support gets misconstrued as parent training.’

Richie’s plan remained unchanged and underfunded.

When Brigitte needed to have surgery, she applied to the NDIA for short-term accommodation for Richie.

The process was so difficult to navigate she ended up sending him to stay with a friend in a different state.

Brigitte is now focusing on her own disability and recovery while Richie recovers from the trauma he experienced at school.

'I've had to put my son on blood pressure medication to bring down his anxiety. I've put him on Ritalin as well. My son takes four medications a day. He didn't need any of these. He was such a happy kid.'

Frederic

Frederic is in his 60s and has borderline personality disorder and post-traumatic stress disorder (PTSD) due to childhood sexual abuse. He also lives with chronic back pain.

Frederic went to 'seven different primary schools and three different high schools'.

'I was ... basically reacting to trauma,' he told the Royal Commission. 'I really believe that there should be more access to psychologists in primary schools. A lot of people on disability have just had a traumatic childhood.'

Frederic started seeing mental health professionals in his late 30s. He was 'trying to get back to work at that stage', but 'it didn't work out'.

About 15 years ago, he was referred to a pain clinic for back problems. Doctors found 'evidence of spondylosis', and he was booked in for a spinal injection.

A senior doctor was supposed to oversee the procedure, but Frederic said he was 'basically left alone with an unsupervised intern'.

The intern handled him roughly.

'He stuck the needle, pulled the needle out ... three times. On the third time after he pulled it out, I said, "What the heck you doing?" ... I found the whole process incorrectly done. I could not understand why he wasn't supervised fully through the procedure. It was humiliating and triggered a lot of things.'

The experience sparked flashbacks for Frederic of childhood abuse. He said the medical team knew of his trauma, but made light of it.

Frederic made a complaint to the hospital but said it 'was never followed through'.

Through his various interactions with the hospital, Frederic feels medical staff stigmatised him based on 'false documentation' about substance abuse.

'I've definitely seen in my hospital records a statement of me being a heroin addict.'

Frederic thinks this has come about because of his involvement over several years in methadone programs related to his chronic pain. 'It is not true. It is ridiculous,' he said.

'The false documentation' has been passed on to other health professionals who have then been reluctant to give him appropriate treatment, leaving him in 'full-blown pain'. 'They believe that all pain's in the head,' Frederic said.

Doctors have also put him 'on dangerous combinations of medications' because of inconsistent medical records. Twice he was admitted to the emergency department 'with a thumping in the heart' because he had been prescribed drugs that clashed with his methadone treatment.

For a few years, Frederic said, he was 'just not getting the right treatment, not getting the right chances'.

The experience made him deeply distrustful of the medical system. 'It does leave me seeing the darker side of society,' he said.

He is still trying hard to set his medical records straight, but says 'the process of rectifying the documentation is virtually impossible'.

Frederic stopped antipsychotic medication about seven years ago and says his 'mind's a lot clearer' now. He recently found a new GP, who he is happy with, and a psychologist is helping him 'work through the disability'.

Frederic said 'the best medication' he ever had was learning life skills in programs for people with disability.

'I did gardening and music ... that's really beneficial. There needs to be more things like that.'

Julianne, Aydin and Brixton

Julianne has Asperger's syndrome. Aydin and Brixton, her sons, are both autistic. Aydin has obsessive-compulsive disorder and experiences suicidal ideation and depression.

Julianne told the Royal Commission she left her husband, the boys' father, about 15 years ago because of 'terrible abuse'.

Julianne and the boys moved to a house near a small local primary school. When they first met the principal, Aydin stood very close to her to introduce himself. She pushed him away, saying she didn't want more people like him at school. When Brixton asked her what she meant she said, 'with autism'.

The principal refused to enrol the boys at the school.

Julianne made a complaint to the education department. Six weeks later, the principal said they could start but only attend half days. Julianne ignored her and took them for full days.

Around this time, Julianne told the principal that she had Asperger's syndrome.

'I wasn't allowed to have a meeting with any teacher, because once I said I was on the spectrum, it was just all over.'

At open day, Julianne noticed posters around Aydin's classroom. There were photos of Aydin with words such as '[Aydin], sit down' and '[Aydin], open your pencil case.'

All the students' artwork was displayed. Julianne and the boys tried to find their artwork but couldn't. Julianne asked the teacher, who replied, 'Oh, theirs wasn't good enough.'

The bullying 'was rampant'. The teacher sat Aydin beside the 'biggest bully' so he could 'learn to be tougher'.

Aydin was 'so frightened of that class' and so terrified of going into year 5 that he tried to suicide. His psychiatrist suggested he repeat year 4, but the principal refused to allow it.

The day before school went back, Aydin had a catastrophic collapse and was admitted to hospital. 'He couldn't sleep. He couldn't eat. He had vomiting. He had diarrhoea. He was panic-stricken. He was sobbing.'

Doctors intervened and the school finally allowed Aydin to repeat year 4.

Despite knowing there were parenting orders in place and there was to be 'no contact with the father', the principal organised a meeting with him without informing Julianne. Aydin's father wanted his son to commence year 5 and the principal told him they would place him in year 5 the following Monday.

Julianne refused to send Aydin to school.

The principal called police. They visited Julianne's home and found no cause for alarm. The principal maintained she was concerned Aydin was suicidal. But police documents showed the principal asked them to do a welfare check because she was concerned about Julianne's mental health.

Julianne made a written complaint, but nothing came of it.

She then went to see the education director, but he refused to see her.

In a phone call, the director told Julianne that if she continued to make trouble and complain about the principal, he would 'make things so much worse for [her]'.

Julianne went to the school to talk to the principal. The principal physically forced her out of the office, injuring Julianne's arm in the door.

The regional director told Julianne not to go to police, saying they wouldn't believe her because she is 'mentally ill'. He said he would fix it if she didn't make a complaint.

The principal alleged that Julianne had assaulted her.

Julianne was told she could not approach the school or speak to anyone except under strict arrangements. She had to follow a script if she wanted to speak to any staff member.

When the boys transitioned to high school, the bullying continued. When Julianne raised concerns, she was told she should expect them to be bullied as her children 'were weird, and weird children get bullied'.

Julianne felt she had no choice but to homeschool both boys.

'I think [Aydin]'s life is over, really. It'll just never be okay. Never. He was so destroyed by what happened to him. [For Brixton], there's a chance.'

Blaire and Anaya

Blaire experienced a lot of trauma growing up. She had a difficult relationship with her mother, left home early and ended up living on the streets. She is now in her early 20s and living in medium-term accommodation provided by a homelessness services provider.

Blaire's grandmother Anaya is her main advocate and source of support. She told the Royal Commission that Blaire has intellectual disability, autism, emotional dysregulation and a sensory impairment.

Blaire lives near Anaya's home and close to her GP, psychologist and the place where she volunteers. This proximity is important. Blaire has a phobia of public transport and walks everywhere with a service dog.

Both Blaire and Anaya are grateful for the accommodation, but currently the provider is putting pressure on Blaire to move out. They've proposed alternative housing more than an hour away by public transport.

'So they don't even address that she walks everywhere with a service dog cause she's frightened of public transport. How do they think she's going to get to me?' said Anaya. She feels the provider has 'boxes to tick' but no culture of care.

'What makes it even worse is that ... they try to make it sound like, "Oh, yeah, it's gonna be great,"' Blaire said. 'But I feel like I've heard those kinds of lines too many times, because I always end up very – not only disappointed, but I've always felt like I've been lied to. Like, I just feel like when it comes to these things I feel like I've been taken advantage of because of my disability.'

Anaya worries that Blaire doesn't have parents to advocate for her in the system.

'So what happens in the homeless sector is she just has to put up with anything she gets. And it really doesn't respond to anyone as an individual and as a human being. It treats you like, you know, a piece of meat, really – or a number – to push you around and give you, you know, what's available.'

Their dream is that Blaire could use her NDIS funding to secure a home. 'Even if it's a little one-bedroom across the road from me, or in the same street, or around the corner,' Anaya said. 'If it was just there, in amongst the shops so she can walk to all her doctors and the shops, and she can carry [the shopping] home on her own.'

But Anaya doesn't have much confidence in the NDIS. They were excited about it to begin with, but so far there's been a high turnover of staff, a lot of paperwork and a lack of expertise.

'None of them understand or have the wisdom as, say, a social worker might have, or a psychologist, to really have a thorough understanding of [Blaire] and setting goals. So now if I don't come up with it or think about it, it just gets neglected ... So then it reinforces my fear that I'm letting her down over and over again – because I don't know what I don't know, and they don't help you.'

Giovanna

'I feel like I have to avoid people from work because I was just a burden to them. But it was really up to them to do something about it ... I thought I failed, but it's not my fault. I can't help acting like that.'

Giovanna, mid-30s, has schizophrenia.

Not long ago, Giovanna was building a display for a national mental health day at work when she had a 'psychotic break' in front of her managers.

Giovanna told the Royal Commission she was feeling 'really isolated' and tried to communicate how she was feeling through the display. She began to have 'delusions' about her managers and started running around and 'screaming like a banshee'.

Giovanna had worked at the organisation for 10 years and had never behaved like this before.

'Something was going on with me, but nobody stepped in to help ... they just treated me like I'm a danger.'

Giovanna believes her managers should have called an ambulance or a mental health crisis and assessment team.

'If someone is having a heart attack, they call the ambulance. So, if someone is having a mental health crisis, call the triage team.'

Instead, her bosses treated the incident as a 'performance issue' and tried to manage the situation themselves.

'My boss leaned over me and called me "mad". I had a work colleague scream at me and abuse me. I wasn't aware there was an issue. I wasn't aware of my behaviour.'

Her manager eventually called security.

Following the incident, Giovanna's managers and colleagues blamed her, discriminated against her and bullied her.

'They said, "You need to speak up," while I was going through this. "You need to tell us what's wrong." ... They completely violated me. They called me "an adorable idiot", things like that. And, "She's a nutter."'

Giovanna made a discrimination complaint to the state human rights commission.

The CEO sent a survey around to all employees, seeking suggestions on how to 'improve' the workplace and make it more 'inclusive'.

Giovanna quit her job, moved home and has started taking new medication.

She is currently enrolled in an art course and helps run some art classes. She feels staff and other students are 'very supportive' and 'switched on'.

'Don't be afraid of mental illness, because people with mental illness, they are just like regular people ... They want the same things, they want employment.'

Alastair

Alastair, early 70s, is a ‘completely recovered schizophrenic’.

He takes medication and has regular medical check-ups. His mood is stable and he’s done a lot of ‘hard work’ on his personal mental wellbeing.

Alastair told the Royal Commission he knows ‘first-hand what it’s like to experience stigma ... because you are mentally ill’.

Alastair’s neighbour has verbally abused him daily for the past 20 years.

He calls him names such as ‘effing weirdo, schizo, freak’. Alastair uses a walker, and lately his neighbour has been yelling out that he’s ‘a paedophile’ and ‘a paedophile cripple’.

The neighbour’s cousins, who also live in the street, have thrown stones at Alastair. The neighbour told him ‘they have always run the street and always will’.

Alastair never responds.

Over the years, he has reported the neighbour to police, but they told him they ‘can’t intervene in any way whatsoever’ because verbal abuse is not a crime.

‘I think we should make verbal abuse of the mentally ill or the previously mentally ill a crime.’

Alastair said his neighbour has also vandalised his property. His bed has been set on fire, windows have been smashed, the lock at the back of the house has been superglued and palings on the front fence have been smashed.

Alastair has reported the damage to police but said they refuse to inspect it.

He believes this is because there are old notes on his medical record saying he ‘suffers from a paranoid delusional disorder’.

Police believe he has a mental illness and, he said, they side with the neighbour.

The neighbour took out a restraining order against Alastair and taunted him about it.

One time, Alastair was in his backyard gardening and the neighbour walked up to the back fence. He told Alastair the police would be there any second because the plants were less than 20 metres away and he was breaching the restraining order.

Police arrived and arrested Alastair. The neighbour told police Alastair had climbed the fence and threatened him and told him, ‘You’re going to die.’

Alastair's psychiatrist intervened and Alastair had to go to hospital for a couple of weeks.

'I'm very, very angry about that.'

When he arrived at hospital, staff described his presentation as a 'tall, thin man in dirty clothes, continually trying to clear his throat and was unshaven'.

Alastair said he'd been gardening when he was arrested, which is why his clothes were dirty.

He wants staff to 'end the pejorative descriptions of patients'.

Birdie

‘I thought it was unfair for him to attack me because I’m the only one who had a disability in the whole family ... So, it was a bit hard.’

Birdie, early 50s, has an intellectual disability.

When she was six years old, she said, her father would attack her in the chook pen. ‘Every evening he used to attack me because I didn’t do the housework or something like that.’

The first time Birdie’s father raped her, she was a teenager.

‘He always wanted me to have my own room, sort of thing, and we always had it away from the other kids ... And every house we moved in, he used to build that bedroom, you know. Like, this is your room. He used to put a bedroom door so I couldn’t get out or escape ... That was a bit scary.’

Birdie told the Royal Commission that after her father had sex with her she would have a ‘scalding’ hot shower and scrub her body because she felt dirty. ‘I wanted to wash myself all the time because I hated what dad did to me.’

At 21, Birdie told her nan about the abuse and went to counselling.

She was able to get away from her father and started working for a large disability employer.

For more than six years, Birdie said, two of her bosses sexually abused her. They would take her up to the paddocks near the work site and come to her home.

The men made her give them oral sex. ‘He got me and pushed me down to do it but my head’s down and that. I didn’t like that. It was a very scary thing to do ... He held me down.’

At night, the men were drunk and ‘barged in through the door’ and would ‘force her into her bedroom’. She tried to make excuses for why she could not have sex but they ignored her.

Birdie said she told her supervisor about the abuse. The supervisor did nothing and told Birdie not to tell the police.

‘I wanted the policeman to come and talk about it.’

Birdie has found it difficult to cope during the COVID-19 pandemic.

‘It is very hard for me to wear a mask with COVID because I feel like I’m suffocating and it reminds me of people having their hands over my mouth to keep me quiet. They all did that.’

Francesca

Francesca is in her 50s and has a disease of the spinal cord that reduces her mobility and memory.

‘Neurologically, it’s damaged my whole body,’ Francesca told the Royal Commission. ‘But mentally I’ve got the intelligence. It’s just extracting the information is just a bit more difficult.’

About a decade ago, after leaving a military career, Francesca enrolled in a university course. Despite promising to support her disability, the university ‘refused to provide’ an assistant and additional time to submit assessments.

Francesca transferred to another university where a lecturer accused her of misconduct for not using antiplagiarism software before submitting an assignment. Francesca said that, in an apparent effort to remove her from the university, a senior staff member told disability support staff ‘not to provide any supporting documents’ for her disability plan.

‘[The staff member] then said that if I fail one subject, she’ll have me removed and excluded for five years. It was full-on targeting for 12 months.’

Francesca enrolled in a higher degree course at another university a few years ago.

‘I had one lecturer who ... abused me in front of a fellow student. He kind of basically said, “You don’t have much intelligence.” You know, “Why are you studying here?”’

Francesca said she returned to the original university to finish her degree, and is now receiving high distinctions with the help of a disability officer who is ‘just magic’.

‘She does a weekly, you know, phone call to me at the moment. She knows I’ve got it, she supports me for that, which is great.’

Peggy

Peggy is in her 50s and lives with depression.

‘It’s like diabetes,’ Peggy told the Royal Commission. ‘Like any other medical condition, you control it, you monitor it, you keep it in check and you can live a normal life. But the problem is society don’t let us live a normal life.’

Peggy also lives with trauma – her father raped her when she was three. Peggy said her parents continued to abuse her into her teens.

‘My mother locked me up in a psychiatric ward at the age of 17 because I tried to kill her.’

Peggy said the abuse continued in the mental health unit.

‘They used to jab me with an injection in my bum, knock me out in a seclusion room with no wall, no window, a mattress, plastic mattress and a bucket in the corner all fucking day ... They had me naked on the mattress even though I was totally knocked out.’

Peggy said that one night several patients in the unit raped her after she refused to have sex with a staff member. The next morning, the other staff didn’t believe her.

‘They go, “Oh, you, you’re an attention seeker. You’re delusional. Didn’t happen.” So they insisted that I have a shower and wash all over.’

Peggy told the police what happened, but no-one was charged.

‘All they want to do is see mentally ill first, and person second.’

Peggy said people assume she has a personality disorder. She would like to have a piece of paper ‘like a vaccination certificate’ to prove her diagnosis.

‘No, I do not have schizophrenia. I have depression. Here’s the evidence ... I’m simply saying that you need the paperwork to prove it because people don’t believe you.’

Nasir

Nasir is from a culturally and linguistically diverse background. He is in his late 60s and has lived in Australia for nearly 20 years. He has a successful working life in the public health sector and has been a minister in his church for more than a decade. He lives with bipolar disorder.

Nasir told the Royal Commission that with his daughter's help he has found ways to manage his condition. He prays, meditates and writes. '[I try to] connect with people, speak to people, look outside myself,' he said.

'There are three important things for a person who is mentally ill. That is sleep, exercise and diet. Those things I look after.'

Nasir told the Royal Commission that in his culture and community, mental illness carries a lot of stigma. People with disability are seen as less capable and less able to contribute. That means they may be socially excluded and considered inappropriate partners for marriage. They may also have difficulty finding work.

He believes it is possible to address such stigma, though it takes time. He said an important first step is to educate people so they see a person with disability as more than a label. 'Like "schizophrenic" or "autistic". And what I want to say is that, you know, she is not that label,' he said.

He feels there are strategies that could help build understanding of people with disability and mental illness. One is to celebrate their creative achievements through exhibitions. 'Arts, poetic exhibits, music exhibits, because there's an immense talent in those communities.'

Nasir spoke of the difficulties he has faced in finding adequate mental health support for bipolar disorder. He said he had been to six psychiatrists and five psychologists before he found the 'right person'.

He has had negative experiences with these professionals, two of whom caused him significant harm. One prescribed medication that had negative side effects. Nasir complained to the Australian Health Practitioner Regulation Agency, but the complaint did not proceed.

He feels that people with disability face significant obstacles when seeing health professionals, with their requests to change medications often ignored. As a result they're forced to cycle through health professionals until they find one who will listen.

Nasir told the Royal Commission it is wrong to frame disability as a negative. Rather, he said, it should be seen as a special ability.

Van

Van, early 40s, has attention deficit hyperactivity disorder and lives with depression and post-traumatic stress disorder.

About 10 years ago he worked as a security guard at a large hospital.

Van told the Royal Commission that his supervisor 'loved violence'.

On Van's first shift, they passed a mental health patient waiting to be transferred. The supervisor told Van, 'That guy's an f-wit. He deserves to be drooling.'

A week later, Van saw another security guard 'dropping his elbow' into a patient's face while the patient was 'completely restrained' on the bed.

Another time, Van heard a nurse tell his supervisor not to 'punch the patient'.

'It's the last thing I could have imagined could be happening in a hospital.'

Van's supervisor began to criticise him, telling him he was 'too standoffish in interventions' and needed to 'take part' more.

'I clarified from him what he wanted me to do, which was completely contrary to both my martial arts training and my security training ... and that was basically just crash-tackle the patient at one of the earliest opportunities.'

Van told his supervisor it was too dangerous to 'tackle people' and he wasn't prepared to do it.

His supervisor began to threaten his job.

A few months later, Van was going off-shift and was in the control room watching the security camera feed.

He saw a man wake up after an operation, become 'delirious and panicked', desperately trying to pull at the wires and tubes hanging off him.

Van's supervisor used excessive force to get the man back to bed and 'choked him unconscious and nearly killed him'.

Van's supervisor was removed from his position and redeployed to a non-security role in the hospital.

Van made a complaint about all the incidents he'd seen, which led to an investigation.

Van's colleagues discovered he had made a complaint and began to threaten him.

'No-one had these officers reprimanded for making threats against me.'

Van went on stress leave and was admitted as an inpatient at the same hospital.

'I've lost my health, lost my mental health, nearly lost my home.'

Jaylin

‘The Disability Discrimination Act says, as long as your dog is clean and healthy and goes to the toilet outside, and can hold their bladder overnight, then they’re an assistance dog.’

Jaylin, late 20s, has bipolar disorder, borderline personality disorder, post-traumatic stress disorder and lives with anxiety, depression, agoraphobia and atypical anorexia.

Jaylin told the Royal Commission that she’s unable to leave the house without either her partner or her assistance dog, Marla.

Jaylin’s ‘pretty proud’ of Marla because she was one of the first dogs that didn’t belong to an organisation to pass her public access test and receive her accreditation.

The first time Jaylin was admitted to the hospital adult mental health unit, they allowed Marla to accompany her.

But the second time the hospital refused, saying Marla was ‘unfit for purpose and that she would never make an assistance dog’.

Jaylin challenged them but they told her ‘it’s policy’.

Frustrated, Jaylin asked to see the policy and discovered it was still being drafted.

‘How can it be policy when they are still drafting it?’

Jaylin is suing the hospital. ‘The fact that [Marla] meets the Disability Discrimination Act protocols means she’s an assistance dog regardless of what anyone says.’

Jaylin has also been ‘fighting the NDIS’ about Marla.

Eighteen months ago, the NDIA agreed to fund the cost of training and maintaining Marla, including food, insurance and vet bills.

At a recent plan review, they refused to fund these costs because Marla is not ‘reasonable or necessary’.

‘They couldn’t give an explanation as to why they’d made that decision ... given 12 months prior she was reasonable and necessary.’

Jaylin asked for a review of the decision.

‘They looked at it again and they said, “No, the dog’s still not reasonable and necessary.”’

Jaylin is taking the matter to the administrative tribunal.

Brie

Brie, late 60s, has post-traumatic stress disorder, depression, a hearing impairment and physical disability.

In her early 20s, Brie was raped in her workplace.

She told the Royal Commission that other women she worked with were also sexually abused.

Brie made a complaint to her employer and asked them to provide psychological support. Her employer dismissed her complaint.

Brie reported the rape to police many years later, but no-one was criminally charged.

Brie continued to work for the employer and her mental health deteriorated.

Her employer eventually acknowledged she did have a psychological injury and paid her compensation.

Brie said that a short time later her employer reassessed her injury. They determined she had a 'pre-existing psychotic impairment' and forced her to repay the compensation money.

'They've been so abusive to me for so many years ... and I've got to pay them back \$900 a month for the rest of my life.'

Brie has attempted to challenge the ruling several times but says she has been unsuccessful because she can't access affordable legal support.

'This is why people commit suicide,' Brie said. 'And I thought, "You know what, I'm going to live to 100 just to annoy them and I'm not going to commit suicide."'

Brock and Violette

Brock, early 20s, has Asperger's syndrome and tics.

Until recently, he was completing an educator traineeship and working at a before-and-after-school care centre.

Violette, his mother, also worked at the centre.

Brock's traineeship had to be delivered online because of the COVID-19 pandemic.

Violette told the Royal Commission that Brock preferred face-to-face learning and struggled with online learning. For example, Brock preferred to provide short verbal answers, rather than written responses.

But the training provider refused to offer adjustments to the training.

The supervisor at the centre offered to help Brock, suggesting she ask him questions, record his answers and then help him type it all up. But when he went into the centre to study the supervisor was never there to help.

Brock was unable to keep up with the workload and the provider refused to grant an extension.

Staff often bullied Brock and made 'disgusting' sexist comments. Violette believes this was because he was the only male in a female dominated workplace.

Violette reported the bullying to management, but they refused to act unless Brock raised the issue himself. Brock didn't want to create any trouble.

Brock was unable to complete his traineeship by the deadline and the centre terminated his employment.

'He never had anyone complain. No parents complained about him with their child. Whereas these other three people have had broken arms in their zones, because they were too busy talking to each other, they weren't watching the children. But yet they turn around and said that he wasn't watching his zone.'

The centre filled his position the same day he was terminated.

Kelvin and Jaelynn

Kelvin, now in his late 20s, was diagnosed with a progressive form of rheumatoid arthritis when he was nine.

In high school, despite the pain and frequent hospital admissions, Kelvin had an active social life, played the guitar, was a talented artist and played sport.

After finishing year 12, he wanted to move out of home like his friends. His mum, Jaelynn, paid for a private rental and the NDIS funded a disability service provider to provide supports.

Jaelynn said the support workers were 'glorified babysitters' and didn't know how to support Kelvin.

After a couple of years, Kelvin's arthritis became much worse.

Jaelynn begged the provider to purchase basic equipment such as a walking frame, an adjustable bed and an electric can opener because Kelvin didn't have the strength to pull the ring. The provider refused because the items weren't in his NDIS plan.

Jaelynn didn't know Kelvin could have applied for a plan review, and the provider didn't tell her.

Kelvin's mental health began to deteriorate. He stopped seeing his friends and became increasingly isolated.

'I tried everything I could to have him taken to ... the mental health clinic. But it was like a revolving door there. You can be admitted one day and out the next.'

Kelvin stopped opening the door to the support workers and refused to see Jaelynn.

The provider did nothing, and continued to charge him.

Kelvin became severely malnourished. Unable to get out of bed, he would lie in his urine and faeces. He wrote 'help' in blood and faeces on the walls.

The people in the other units, hearing Kelvin screaming out in the night, demanded the real estate agent evict him.

Kelvin's brother had to break into the unit to rescue him. Jaelynn believes if he hadn't, Kelvin would have died.

Around the same time, the provider withdrew their services because Kelvin ran out of funds.

Jaelynn was shocked the provider just wiped their hands of him. 'He's unwell physically. He's unwell mentally. You know, he's malnourished. He's virtually on death's door.'

Desperate, Jaelynn took Kelvin to hospital and begged them to admit him for an extended period. They refused, discharging him at 3 am. He had no transport to get home and physically couldn't walk from the ward to the entrance. It was 'horrific'.

Jaelynn found emergency respite accommodation. Initially, because of COVID-19 restrictions, he was by himself. But when restrictions eased, five people moved into the home – all non-verbal with intellectual disability.

Kelvin wasn't allowed to have anyone visit him at the home or drink alcohol.

Support workers didn't know anything about rheumatoid arthritis. They suggested Jaelynn buy him some 'adult nappies' even though he was continent.

Kelvin found living in the home 'soul destroying'.

He ended up threatening a staff member and was evicted. Jaelynn doesn't condone threatening behaviour, but said Kelvin was physically incapable of acting on the threats.

Jaelynn found another provider. They placed him with a man who hoarded and didn't shower. Kelvin found this very distressing because he couldn't move around the home and hygiene was very important to him.

Kelvin had to leave when he again threatened a support worker.

Kelvin is now living with one other man who has psychosocial disability. Jaelynn is not sure if it's a good fit.

Recently, Kelvin had to have an operation and spent some time in rehab with other people with physical disability. 'And he thrived because he realised, "I'm not alone here."'

Jaelynn hopes she can find Kelvin a home with other young men who have 'either lost limbs in accidents, or arthritis ... That was where he mentally thrived.'

'A lot of these organisations, they really don't care about who they put in with who in group homes, as long as they receive their money.'

Alexandra

Alexandra, early 40s, has cerebral palsy and uses a wheelchair.

When Alexandra was in her mid-20s, her mum became ill and was no longer able to give her adequate support.

Alexandra moved to an aged care facility where she was the youngest resident. She stayed until the facility shut down, then moved to a disability facility.

'I would not recommend anyone to go in there. It's shut down, thank God.'

Next, Alexandra moved to a unit owned by the state government.

'I was living there on my own. They thought, "She should be okay. She can do this, she can do that. We'll just go in and out once in a while to see if she's okay." It failed. It failed miserably. I kept falling over, crashing into things.'

From there Alexandra moved to shared supported accommodation, where she stayed for about five years.

One evening Alexandra used a lighter to remove the plastic around a box of chocolates. She had a spasm and set herself on fire. Another resident heard her screaming and told staff Alexandra was in trouble. They dismissed her saying, 'She's alright, she's fine.'

'Like hell I was,' said Alexandra.

When staff eventually arrived Alexandra was on fire, her hair alight, the plastic from the chocolates melted into her skin. She was hospitalised with severe burns that left her with significant scarring.

Alexandra and her father made a complaint, but nothing happened.

'They covered it up. I got the blame.'

Because Alexandra has spasms and seizures, she is not supposed to operate her wheelchair on her own.

One day she wanted to go to her friend's place. The support worker was busy and told her she'd be okay and to use the two-way radio.

As Alexandra was coming down the path she had a seizure. She ended up in the middle of the road, where a car crashed into her. The driver didn't stop and left her lying on the road. Eventually a passer-by called an ambulance.

Another time, Alexandra wanted to visit her mother who was living in a nursing home. She asked the provider for a support worker to come with her. They told her that she was not a baby and could go by herself.

On the way, Alexandra had a seizure and fell down nine steps. The wheelchair landed on top of her. Paramedics had to resuscitate her on the way to hospital.

Alexandra had surgery and now lives with metal plates and screws in her face. She has permanent loss of vision in one eye. Several her teeth were smashed.

The accident had a profound impact on Alexandra and her family. 'It took my independence.' Alexandra and her father tried to take legal action, but couldn't find a solicitor to help them.

Alexandra moved to another complex, which she described as a 'hell hole'.

Staff gave her another resident's medication and she ended up in hospital.

Another time a resident physically assaulted her, trapping her wheelchair so she couldn't escape. Staff saw the assault but did nothing to stop it. When her father visited some hours later, he was shocked by her injuries and took her to the doctor. She had nerve damage to her eye.

Following the incident, Alexandra asked to move but was told there was nowhere else for her to go. An advocate helped her find new accommodation.

Alexandra now lives in her own unit. Staff assist her with personal care, medication and meals. She says it's better, but staff don't listen to her and are slow to respond when she asks for help.

'They want it their way. But because I'm fighting back and not putting up with it anymore, they're getting their back up.'

They tell her if she doesn't stop complaining she will have nowhere to live.

'I'm scared of losing my home.'

Benji and Kit

‘As his family we have been forced to spend much of our time fighting fires, continually pleading for action during crisis, revisiting his care plans frequently, spending countless hours lobbying and ... establishing our credibility.’

Benji, Kit’s brother, died unexpectedly in 2021.

Fifty years old, he had attention deficit hyperactivity disorder, bipolar disorder and type 1 diabetes.

Kit told the Royal Commission that throughout Benji’s life, it was a constant ‘battle’ to secure medical and mental health treatment for him.

‘Because he had type 1 diabetes, he could not manage this when his mental health declined. I had lost count of the number of times myself or other family members would find [Benji] unconscious, scoop him from the floor, a chair, his car on the side of the road, and rush him to hospital.’

Kit said it was only after he experienced ‘almost total mental and physical collapse’ that anyone would take their pleas seriously.

Over the years, doctors would stabilise Benji then immediately discharge him. The family would beg the hospital to transfer him to the mental health unit and treat his mental health issues, but they’d often refuse.

‘My brother had a long history of masking his mental health conditions during mental health assessments, even when he was unstable. His situation placed enormous burden on our family and emergency services.’

In 2019, Benji was living independently with limited in-home supports in a small town. His physical health had been declining for some time and he’d developed a severe infection in both legs. His vision was impaired and he was incontinent.

A new support worker tried to turn things around for him. She helped him with his diet and medications and took him to health appointments.

A few months later, the COVID-19 pandemic ‘sealed [Benji]’s fate’.

Because of the restrictions, the provider cancelled Benji’s supports without telling Kit. She only found out when the support worker contacted her, concerned about Benji.

Benji’s mental health deteriorated. He stopped taking his diabetic medication and couldn’t manage the infection in his legs.

Kit struggled to find treatment or support because service providers and clinics were shutting down or limiting their operations.

Eventually Kit managed to find a mental health clinic willing to assess Benji. Even though he was clearly disorganised, dishevelled, without his medications and unwell, the treating team found his mental health was stable and he did not need to be admitted.

They suggested Kit move Benji to a town with more resources, 'forcing the NDIS to become involved'. They said Benji would have access to 'a range of accredited support agencies, services and specialist care'.

Kit said she had her doubts but 'was desperate'.

Benji relocated, transferred to a new NDIS provider, and limited in-home supports resumed.

However the cleaner often refused to work because of the state of Benji's house and Benji would tell support workers to go away.

Kit spoke to the NDIA on many occasions, begging them to move Benji to a facility with 24/7 care, to no avail.

Unable to manage the infection in Benji's legs, Kit took him to hospital.

As was the pattern, as soon as doctors treated the infection, they discharged him despite 'his clear inability to administer his diabetic medication because of his mental state'.

A few days later a support worker found Benji unconscious and called an ambulance.

Benji died later that day.

The provider told Kit they didn't conduct welfare checks because they were respecting Benji's right to say 'no'. It's likely he had been unconscious for days.

After an independent investigation, the provider admitted to catastrophic, systemic failures.

'I want vulnerable Australians like my brother protected during times of crisis and supported when they are well to achieve the best life they can and seek their own level of independence. I would like families acknowledged and valued for the incredible resource they provide as enduring informal support.'

Nicholas and Uma

Uma, a First Nations woman, has worked as a disability support worker in group homes for many years.

‘That was just something that I was passionate about ... And I really believed, quite naively I suppose, in the system. And that sort of came crashing down.’

About 10 years ago, a co-worker rang Uma at home and asked if she could go up to the hospital. One of the residents, Nicholas, who is non-verbal and has intellectual disability, had been injured while in bed and needed an operation. Uma assumed something had happened with the bed rail.

She couldn’t go to the hospital because she’d worked too many days straight, but asked if they could put the phone to Nicholas’s ear. She told the Royal Commission she wanted to reassure him everything would be alright.

When Uma turned up for work a few days later, staff were dressing Nicholas’s wound.

‘I just thought the injury was horrendous. So, I went up and had a look at the medical notes, and I was livid. And I remember saying to one of the co-workers, “How in the hell did that happen?” And she said to me, “It was a plastic urine bottle.” And I said, “If it’s got bloody razor wire on it, yes, sure.”’

One of Uma’s co-worker asked her not to cause any trouble.

‘And I thought right then, there was the coverup starting.’

Uma told them it was mandatory to report the incident. She followed protocol, contacting the department who then contacted police.

Management were ‘furious’, telling her they’d investigated the incident and were ‘satisfied it was an unfortunate accident’.

Uma spoke to a doctor at the hospital who told her ‘for an injury like that there should have been a lot of blood’.

She asked around and discovered somebody had not only washed Kevin’s sheets, but all his bedding.

The police investigation was a sham, Uma said. Officers made disparaging and sexual remarks about Nicholas and didn’t seem to take it seriously. Uma confronted one of the officers.

‘If it was a three-year-old that had been raped, what would you do? Would you not investigate it?’ she asked. ‘And he said, “Yes, of course.” And I said, “Well, [Nicholas] deserves an investigation.”’

Police refused to allow an independent person to help Nicholas make a statement.

‘It was like we were stopped at every step of the way.’

One night, Nicholas – using ‘yes’ and ‘no’ – told Uma and a colleague that another support worker had attacked him. Police refused to act on this information because they said he’d been coached.

Sometime later, Uma rang the department to follow up her initial report. She discovered management had not sent the original incident report, but one they wrote some days later.

‘It was covered up, and it’s not good enough. It’s just not good enough.’

When Uma contacted police for an update, they told her Nicholas’s brother didn’t want to continue the investigation.

Uma told them, ‘This is mandatory reporting, and it’s out of [Nicholas]’s brother’s hands. It’s out of [management]’s hands. This has to be investigated.’

The officer told her he believed she ‘had it in for management’.

‘I felt really let down on behalf of [Nicholas], and I felt like basically he was telling me I was a liar.’

Soon after, Uma was diagnosed with multiple sclerosis, her marriage broke down and ‘everything just fell apart’.

Nicholas started having nightmares and couldn’t sleep.

‘Being the whistleblower, we were basically forced out of our job ... I can say in my conscience I’ve tried. I’ve tried my best. And that’s something that I had promised [Nicholas].’

Bianca, Tristian, Quin and Rhett

Bianca, Rhett and their teenage sons, Quin and Tristian, are autistic.

When Quin started primary school, Bianca discovered the Australian education system 'wasn't geared for autistic people'.

The family moved overseas and the boys attended 'autistic-specific schools' where the focus was on 'accessing the national curriculum'. The schools had psychologists, occupational therapists and speech therapists onsite.

'We're talking massive amounts of specialised support to support them, and they did very well,' Bianca told the Royal Commission.

The family had to return to Australia a couple of years ago.

Bianca enrolled the boys in a high school that had a good reputation.

At the time, Tristian was non-verbal.

Soon after he started, his behaviour changed and he became 'quite violent'. He would hit out at Rhett when he picked him up from school.

Bianca and Rhett spoke to the school about what was going on. The school blamed Rhett.

'It's just your husband's autistic. He probably just doesn't know how to manage his son.'

Later, Bianca and Rhett discovered the school had been using restraint and seclusion to manage Tristian's behaviours.

Tristian recently apologised to Rhett.

'You know Dad, you used to pick me up and I used to hit you and yell at you and I want to say, "I'm so sorry." Because, you see, the teachers were hurting me and I didn't have the words. I couldn't tell you and I was trying to just let you know that something was happening.'

During this time, another autistic child at the school started assaulting Tristian. The school minimised the incident, calling it a boundary issue rather than an assault.

The school refused to move Tristian to a different classroom. Being in the same classroom every day left him 'very damaged'.

Bianca's primary contact at the school began to behave inappropriately, she said. He would have long conversations with her, sharing very intimate details about his life. Sometimes he would touch her when she didn't want him to.

Bianca made a complaint to the principal. He gave her 'a big talking to', telling her she didn't know about personal boundaries because she was autistic. He said that she'd 'crossed boundaries' with the staff member.

Bianca felt angry and embarrassed.

'Suddenly all of the communication channels with school completely stopped,' she said.

Teachers stopped making reasonable adjustments for the boys and refused to speak to her.

She contacted the regional education office hoping they could act as a buffer between her and the school.

But during a phone call, they accused Bianca of having a 'violent meltdown', saying they would implement a 'communication plan' to protect the health and safety of their staff.

Bianca told them she had recorded the call. She felt she was 'assertive', but didn't 'swear at them and didn't make threats'. They refused to listen to the recording or engage any further.

The communication protocol meant Bianca 'wasn't allowed to talk to any teachers ... wasn't allowed to make phone calls to the school and ... wasn't allowed to email individual teachers'.

Bianca moved Quin to a new school. However, the regional office told her they didn't support the placement and Quin wouldn't be able to attend unless she agreed to the same communication protocol with the new school.

'I was put in a position ... [to] sign a protocol that I really didn't feel was fair, or have social services involved with our family.'

Bianca is in the process of moving both boys to new schools.

'Other parents can just take their child out of a school and move them, but when your child is tied with special needs funding, that choice and control is taken away from you and that's where we're at now ... I think we're seen as being very inconvenient people, because we're asking questions and we're asking for information.'

Sonja and Isobel

‘I can’t even put into words what it’s like to be called a liar by a medical doctor. I mean, it’s utterly devastated me. And it’s utterly devastated my daughter. She’s lost her faith in doctors.’

Isobel has a neurological disorder and post-traumatic stress disorder. Her daughter Sonja, early 20s, has a medical condition, selective mutism and lives with post-traumatic stress disorder.

Isobel’s ex-husband, Sonja’s father, was abusive. ‘Abusive in a way that was life-threatening to both of us,’ Isobel told the Royal Commission.

Isobel said police didn’t help her and every attempt to apply for a restraining order was unsuccessful.

One time, her ex-husband put all their belongings in a pile in the loungeroom and set fire to them. Isobel grabbed Sonja and managed to get out of the house.

‘He chased us and tried to smash our car and our windows and was sort of ranting and raving that he was going to kill us.’

Isobel drove to the police station and reported the incident. Police told her it was ‘not illegal to burn your own house’.

Isobel and Sonja went into hiding.

At the time, Sonja was about four and had stopped talking. She was often so distressed she would hide under furniture and shake uncontrollably. Therapists told Isobel that Sonja’s exposure to domestic violence had caused behaviours that mimic autism.

Isobel homeschooled Sonja because she couldn’t speak to anyone except Isobel and was easily triggered.

As a teenager, she became ‘extremely lethargic’ and was often unwell.

‘She was bedridden at times, for long periods of time. And she had ... very severe heart palpitations where she would just pass out.’

It took several years before doctors were able to diagnose her correctly. ‘It’s quite a frightening disorder because blood doesn’t reach your head.’ Sonja can seem fine, then suddenly can’t see or feel her hands, and loses consciousness.

At 18, Sonja applied for the Disability Support Pension. Despite doctors and specialists providing detailed information about her disability, Centrelink rejected the application.

Isobel helped Sonja appeal the decision. The administrative tribunal overruled Centrelink, agreeing Sonja was eligible for the Disability Support Pension.

'I thought that was the end of it and she would get her disability support payment, and the next minute I'm getting documentation saying that Centrelink had decided to fight and appeal their decision.'

Centrelink had a team of lawyers, Sonja only had Isobel.

Centrelink demanded an independent psychiatrist assess Sonja.

'He basically called me a liar,' Isobel said, 'That the domestic violence ... was a made-up story and [Sonja] didn't have any of those things.' The psychiatrist said if Sonja had regular psychiatric sessions and was medicated, 'she could be fixed'.

Later, a doctor told Isobel the independent psychiatrist has never sided with a patient and is the 'go-to person for a report that can win in court'. 'So, he makes an awful lot of money,' they said.

Sonja lost the appeal.

'All of her doctors are just in disbelief that this has happened.'

Since then, she has unsuccessfully applied for the Disability Support Pension three times.

Sonja started receiving a JobSeeker payment, which is conditional on her meeting certain work and study obligations.

Isobel said Sonja has been unable to meet the obligations. Centrelink frequently threaten to cut her payments. One time, Sonja 'had an absolutely massive attack, which landed her in hospital' for three days.

After six months, Centrelink again demanded Sonja complete a course or they would stop her payment.

'That has pushed her to the point where she's wanted to end her life.'

Sonja's current job agency contact person has been more accommodating. She was 'horrified' when she saw all the medical evidence. She is in the process of compiling a report to support Sonja's application for the Disability Support Pension.

Ryleigh, Kaylie and Adan

Ryleigh, early 40s, has cerebral palsy and is non-verbal. She lives in a group home and requires 24/7 care.

A few years ago, Ryleigh communicated to her parents, Kaylie and Adan, that a new staff member was hurting her when she moved her.

Kaylie and Adan put it down to inexperience and lack of training. They spoke to management and put up signs in Ryleigh's room showing how she communicates when she's in pain.

The signs were ignored.

Months later, Ryleigh started screaming in bed at night. Her parents couldn't understand what was going on and spoke to management. But they didn't seem to care.

Kaylie and Adan brought Ryleigh home for about six months to try and figure out what was happening. They had a bone density scan done and found Ryleigh had osteoporosis, and there was evidence of old and recent fractures.

Management investigated but found no evidence staff had caused the fractures. They organised an occupational therapist (OT) to conduct some staff training.

Ryleigh is small and light and has metal rods in her back. During the training Kaylie showed staff how to roll her without hurting her. But the OT intervened saying staff members shouldn't do this because they might 'break a nail'. Adan was 'stunned'.

Ultimately, management sided with the OT. Staff were no longer allowed to move Ryleigh at night. Adan felt frustrated that no-one considered pressure sores or bed sores or Ryleigh's safety.

'They just don't seem to realise they're dealing with human beings,' he said. 'They're not dealing with a doll or a lump of meat on the bed there. And they need to show them more respect and have the proper empathy.'

Once the fractures healed, Ryleigh returned to the group home. But she refused to sleep in her bed and stayed in her wheelchair.

Her parents couldn't understand why and placed a camera in the room. They were careful to only have Ryleigh's bed in the video to protect others' privacy.

The video showed Ryleigh crying and staff telling her to 'shut the fuck up' and go to sleep. Staff told her to stop looking at the signs her parents had placed around the room to communicate her pain.

Staff did not engage with Ryleigh while they changed her, instead swore and complained.

They 'told her off' for bullying them and, as a punishment, stopped her from socialising with other residents.

Ryleigh used eye gaze communication with her parents, spelling out the names of staff who were being mean to her. Her parents told management what was going on, but initially didn't tell them about the video.

Further recordings showed staff saying, 'Come on piss face, let's get you changed.' They changed Ryleigh in the bathroom even though they knew it was painful for her.

Then came videos of staff swinging Ryleigh in her hoist and behaving sexually inappropriately with her. Ryleigh has no gag reflex, and female staff members made jokes, sticking objects down her throat.

Management were 'gutted' when they saw the footage and immediately referred it to police.

Police charged several staff members and the provider terminated their employment.

However Ryleigh's care continues to be poor quality.

Staff leave her soapy and wet after her shower and she develops rashes. They don't take the time to feed her properly.

Recently she was unwell and went to hospital. Doctors thought she had a blockage in her bowel but it turned out she was malnourished and had nothing in her bowel.

Ryleigh's parents have made complaints to the NDIS Quality and Safeguards Commission who 'ticked all the boxes', Adan said, but are ineffectual.

Adan wants staff to stop covering for each other.

'If you just make a mistake, just own up to it. Put your hand up. Don't hide it. Don't lie about it ... It's not about people getting a slap on the wrist. It's a matter of making sure that people get the right care.'

Gerard and Calissa

‘My son is a business commodity, that’s what he’s become. To be bought and sold by service providers ... But his life never changes. The abuses never change. The restrictions never change.’

Gerard, now in his late 30s, acquired a brain injury when he was five.

After the injury, he began to run away and Calissa had to frequently call police to find him.

When his seizures increased, the family moved to the city to get better medical support.

But things got worse. Gerard was on 12 different seizure medications. They reduced the seizures, but he developed increasingly aggressive behaviours.

Calissa wanted the hospital to investigate what was going on, but ‘over the years [she] found out there is no knowledge in hospitals’. ‘They don’t research disability,’ she told the Royal Commission.

The department of family services advised the only way to help Gerard was to ‘hand him over’ to the public guardian and ‘walk away’.

‘There starts ... the downfall of my son,’ Calissa said. ‘He’s been pushed from pillar to post, service provider to service provider.’

Although Gerard was only a child, the public guardian placed him in secure accommodation for adults with mental illness.

Staff physically and sexually abused him.

Gerard wrote about the abuse, describing one of the men. Calissa and Gerard made several complaints to police, but ‘there were no repercussions’ because Gerard ‘can’t articulate’.

‘Every night, for years, he wore clothes, layers and layers of clothes. Surrounded himself with 10 pillows. Had every blanket in the middle of summer. So that he wouldn’t get abused.’

Gerard had never committed a crime, yet for a period of two years the institution had him living ‘in a cage’. ‘No activities. No social stuff. No training,’ said Calissa. According to the institution he had to be locked up because he was ‘so dangerous’. But not ‘so dangerous’ they wouldn’t let Calissa take him home on the bus – a four-hour commute.

Calissa lobbied government bureaucrats and ministers to see Gerard’s living conditions. ‘And when they did come down, they saw nothing. They saw nothing about the people in the cages.’

Gerard was eventually released in the early 2010s and lived with Calissa for several months.

Since then he's moved from home to home, provider to provider.

Gerard's NDIS package is more than \$1 million per year.

He's been on the same care plan for years and Calissa says the funding only benefits the provider. 'The latest care plan is the absolute abuse and fraud in this system.'

As an activity, support workers 'trained' Gerard to find coins by throwing them in the backyard. When they take him out they keep him occupied by making him look in gutters and bins for coins.

The provider hired a dietician to help Gerard lose weight. She charged thousands of dollars to advise support workers to stop giving Gerard cola.

'I have, in the last two years, been fighting bitterly to get my son under the care of [a neuropsychiatrist] and his team of specialists.'

The neuropsychiatrist says Gerard's behaviours are linked to his medication and more could be done to improve his quality of life. But the guardian and provider refuse to allow a medication review or for the specialists to work with him.

'There are ways out of this. There are doctors who really want to help. Genuine doctors ... But he's locked into a system that's so inflexible, so lacking in innovations, so lacking in research ... and he will never improve because [he's] not intended to improve.'

Ledger, Augustine and Leanna

Ledger, 13, is autistic and has attention deficit hyperactivity disorder (ADHD) and fetal alcohol spectrum disorder (FASD). Augustine, his older brother, is autistic and has ADHD.

Their aunt Leanna, a First Nations woman, recently became their full-time carer. Leanna's mother and the department of child protection are their guardians.

Leanna told the Royal Commission that she and her mum had to 'push and push' for Ledger to receive a FASD diagnosis.

'I think there's a bit of a stigma ... but I feel like some doctors are a little reluctant to diagnose FASD, because it's a sensitive topic and it has all kind of variables in it.'

Ledger 'struggled' at school, and Leanna and her mum 'fought endlessly and fiercely' for Ledger's right to have an education.

Teachers labelled him the 'naughty Aboriginal child'. They excluded him from class and forced him to sit alone 'in his own classroom'. The school refused to allow him to attend class excursions without family support.

'He would sit in his classroom ... all day. It was just like a babysitting service ... The school didn't have the skillset to support [Ledger] in his learning.'

One day there was an incident at school. The principal called police hoping they might be able to help.

'They actually started handcuffing, putting his hands behind his back. They were pushing him down onto the ground, grabbing his legs.'

The school principal intervened, telling police, 'Stop, this is not what I called you to do.' She told them to leave. Police said she was making a mistake because 'he's just going to get worse as he gets older'. The principal never called them again.

Ledger has recently transitioned from primary school to high school.

The school did not arrange any transition supports and the high school was not prepared or resourced to accommodate Ledger.

Leanna refused to allow him to sit 'by himself every day of high school doing nothing'. She told the high school 'he deserves an education' and demanded appropriate emotional and educational supports.

'That was a little bit of a nightmare. But at the end of the day ... everything has gone really good. And we've all put in the hard work, like all – even [Ledger] has put in the hard work.'

Until Leanna's mum became a guardian, the department of child protection had been Ledger's sole guardian. They never applied to the NDIS on behalf of Ledger or his brother.

Recently, a new child protection support worker made an application. The NDIA approved \$12,000 plans for both boys but this was substantially less than requested and did not meet the boys' needs.

Leanna said it seemed the NDIA expected them to go through a review process to get more funding, rather than proactively seek the information they would need to approve the initial application.

'It broke me. I actually broke down and cried. That whole process was horrible.'

The NDIA reviewed the plans. Although they have similar needs, Ledger's plan is three times as much as Augustine's. Leanna believes this is because two different decision-makers reviewed the plans.

Leanna believes all government departments 'need to lift their game'.

'Don't be lazy, don't make it a cop-out that they don't have the skills or they don't have the funding. Because we're just setting up our kids to go through that whole continuum of not participating in the world. Not becoming independent so they can go for a job and be employed. [Stop] looking at them like they're just an Aboriginal kid that is just naughty.'

Zander and Annabeth

Zander, mid-50s, has an intellectual disability. Annabeth is his sister and guardian.

At 18, Zander moved into a group home. Ten years later, Sunny moved into the home.

Sunny's behaviours were volatile and he would regularly assault Zander and the other resident.

Zander's family asked the disability service provider to remove Sunny, but they refused. Over the years the violence increased.

Zander tried to hide from Sunny, retreating to his room. Staff were also scared of him and unable to address his behaviours. Zander's father tried to work with Sunny's parents to find a solution for both men, but they refused to engage.

All Zander's father could do was install a lock on Zander's door so he could lock himself in his room.

About five years ago, the violence peaked and Annabeth applied for a personal protection order on behalf of Zander.

'Usually when you apply for a personal protection order you get a hearing or ... immediately an interim is granted and then you [have] a full hearing,' Annabeth said. 'You get a decision fairly quickly, particularly when there's physical violence allegations.'

After two hearings, the magistrate arranged for an advocacy group to interview both parties and prepare a report for the court. This process added months of delays and didn't appear to be of benefit to either man.

During the process, Sunny continued to assault Zander. The disability service provider suggested staff make sure he was locked in his room. Zander's father ended up sleeping on Zander's bedroom floor to keep him safe.

After more than 12 months, the magistrate found there had been personal violence, but did not grant a personal protection order.

One evening, the resident assaulted Annabeth, Zander and a staff member. Annabeth rang police and Sunny's parents immediately removed him from the house.

‘I had to walk that fine line of putting [Zander]’s best foot forward as his guardian, not wanting the other man to be subject to potential criminal possibilities. There’re far too many people with disabilities in the criminal justice system. We didn’t want another one.’

A year ago, someone assaulted Zander at the supermarket.

Support workers thought it was someone from Zander’s day program but weren’t sure.

‘Carers and the support staff and the family were very afraid that [Zander] would be assaulted again.’

Annabeth asked the supermarket if she could view the CCTV footage so she could identify the assailant. She explained that if it was someone Zander knew, support staff would be able to keep them apart and keep Zander safe.

The supermarket refused.

Zander made a statement to police but was still not able to access the CCTV footage. Police had identified the person but wouldn’t give Annabeth or Zander his name.

After lodging a Freedom of Information request, police released a pixilated version of the footage.

Annabeth applied for a personal protection order. During mediation she met the assailant’s mother.

Annabeth was able to come to an agreement with the mother to keep Zander safe, without having to involve police or courts.

‘My strong view,’ Annabeth told the Royal Commission, ‘is that the institutions across society ... not the people, but the processes and practices adopted in those institutions, do actually perpetrate and encourage abuse and neglect.’

Nina and Saffron

‘The things that I have seen happen to my daughter have been atrocious.’

Saffron’s 27-year-old daughter, Nina, is autistic, has intellectual disability and is non-verbal.

A few years ago, Nina went to live in her first group home.

Saffron, an experienced support worker, thought she knew what to expect but was shocked by the things she saw.

In one home, Nina lived with a person who would ‘get a razorblade and slice themselves or try and strangle themselves’. Saffron told the Royal Commission that Nina, who had already experienced ‘so much trauma’, couldn’t process this behaviour.

‘If you place someone in the house that self-harms, you have someone with autism that has not witnessed that type of behaviour before, you’re causing possible trauma to those clients.’

Saffron removed Nina from the home.

At another home, Saffron arrived one day and there was ‘this awful, putrid smell ... like a dead animal’. She tried to work out what it was and, as she moved closer to Nina, she realised it was Nina.

‘Her private area was just matted in just horrible faecal matter and whatever else, and I had to cut that away. The doctor said she could have died.’

Saffron removed Nina and reported the provider.

Over the years, support workers have locked Nina in a car on a hot day by herself, overmedicated her and incorrectly medicated her. Support workers have used illegal drugs and dealt drugs while working.

One time, instead of giving Nina her asthma medication, staff put bowls of boiling water in her room to create steam and locked the door.

At Nina’s last home she was ‘showing signs of being in fear’. Saffron spoke to staff who fobbed her off and told her Nina ‘was happy’.

Nina’s distress increased, and Saffron asked to see recent incident reports.

‘The first thing I read was, “[Nina] was strangled to the point of turning blue. Staff had to remove the other client off her by hurting the other client. No medical intervention given to [Nina].” Another incident through the same provider, [Nina] was king hit to the back of the head by the client. A 10-centimetre haematoma was noted, no medical intervention given.’

Saffron reported the provider to police and the NDIS Quality and Safeguards Commission, to no avail.

Saffron said staff don't report incidents 'to the higher-ups' because there is no accountability and they fear repercussions. As a support worker who has reported incidents herself, she has lost work or 'had to resign because of bullying'.

'I was locked in a room and threatened, due to the fact that what I'd seen, I reported. I then took it further ... and I was told to shut my mouth and not say anything or I wouldn't have employment anymore.'

Since bringing Nina home, the NDIA has been trying to reduce her package by \$100,000. 'They said because I'm mum, I can do [the work].'

'I want to try and get [Nina] into her own home so she can have that independence and it goes back to being mum and daughter, not daughter and a carer again.'

Saffron refuses to send Nina to another group home and has been trying to find a private rental for her. 'But we are being knocked back and I believe it's because of her disability,' she said.

'I've offered above market rent. So, a place that was worth \$300 I offered up to \$380 and they still refused her. And their response is, "We do not legally have to tell you why we are refusing you." So, I can't get a place for [Nina] at the moment.'

Saffron said it is difficult to keep being knocked back.

'It's putting a strain on my marriage because, [Nina]'s behaviours can be quite full-on. She does not sleep, so she's awake throughout the night. [She]'s got a lot of trauma.'

Kathleen

Kathleen was born on a farm in the late 1960s. At two, Kathleen was diagnosed with cerebral palsy. The doctor told her parents to put her in an institution and forget about her.

Kathleen's parents refused to do this, but struggled to find support. It was a two-day journey to a specialist centre in the city for physical therapy.

At five, Kathleen was able to board at the centre.

She slept in a dormitory with five other girls. The nursing sister in charge told her not to cry, be quiet and go to sleep or she would hit her. 'As a much-loved youngest child of a large family, I had never been hit in my life, so I was quite frightened,' she told the Royal Commission.

Staff would drag the children out of their beds at 5.30 am. They would place them on the floor beside their clothes and tell them to get dressed, with no support.

If Kathleen felt tired and did not want to walk around, they would put her in a large standing frame made of heavy board and 'iron things' with buckles and straps that wrapped around her limbs and restrained her. She had to stand in the positioning device for 30 minutes.

Kathleen said staff forced children to walk in calliper splints and restrained them in standing boxes.

When Kathleen was about seven, one of the male nurses sexually abused her.

The person in charge of the centre allowed the nurse to take Kathleen to his house or his parents' house for the weekend.

'I didn't know how to deal with my feelings. I felt like I had been harmed, but there was no way that I could point to the harm. There was no way that I could name the harm. I actually didn't even speak about it until I was about 15.'

Kathleen's schooling was almost non-existent. For the first three years, all she did was sticker books. No-one taught her the curriculum.

In high school she returned home and did distance education. She began to read widely and teach herself. She was in her 20s when she graduated.

'It wasn't until I was actually 22 and a bit and finished school that I decided that I wanted to go to university. Everyone thought it was just a bit of an experiment or joke.'

Kathleen's only support was her mum, who couldn't leave the farm. Kathleen convinced the Chancellor to allow her to study externally.

'So, the only time that I actually attended university was to graduate.'

Kathleen excelled. She said university was 'amazing' because it was the first time she was able to learn at the same pace as the other students.

'It felt so good to be treated as an equal in that space, and to be treated as someone who was capable of doing things.'

Now in her early 50s, Kathleen is a successful businessperson.

Recently, she's become concerned about her health.

Her first breast screen appointment, at a public clinic, wasn't set up for women with disability. It was 'awkward' and they kept telling her it was 'so difficult'.

Next time, Kathleen went to a private hospital. Someone helped her undress and they adjusted the procedure so she could sit and lie down. It cost \$400. She worries this is not affordable for most women.

Recently, she was at a meeting with 20 women with disability. Only two had ever had a pap smear.

Kathleen said preventative health matters because as a person with disability, 'in a hospital you are likely to die'.

'You are likely to not get the aggressive antibiotic treatment ... You're likely to not be supported to eat or shower or toilet adequately. It's not safe ... We just are still treating people with disabilities like third-class citizens that are not humans, and that's appalling.'

Cleo and Carolyn

Cleo is in her early 40s. She has an intellectual disability and an acquired brain injury.

For most of her life, Cleo has lived at home with her mum Carolyn, her dad and her sister, who also has a disability. A disability service organisation provided therapies, in-home supports and programs.

In the early 2010s, the organisation spoke to Carolyn about offering independent supported accommodation to some of their clients.

Carolyn and other parents liaised with the government and secured funding for a 'special type of accommodation that wasn't a group home' but was comprised of 'individual villas'.

The villas were finished about four years ago. But there were problems with staffing from the beginning.

'[Cleo] likes to know what's happening today, tomorrow and the next day ... She likes to know who's going to work with her,' Carolyn explained.

But the provider failed to secure additional staff and the roster constantly changed.

Communication was poor. Carolyn constantly had to explain the same thing to different support workers.

'On two occasions we had two key workers who did brilliantly, absolutely wonderful. However, they moved on and weren't there anymore. And then from then on, the last key worker she had, which was for about 18 months, never wrote any notes, never had any meetings, never spoke to me about anything.'

Carolyn believes Cleo was 'neglected in many ways'.

Cleo has a medical condition and gets upset if her chin isn't shaved twice a day. Often this wasn't done, or there wasn't a female staff member who could do it.

Staff mismanaged Cleo's medication, often forgetting to give it to her or giving it to her at the wrong time. They also failed to follow the pharmacist's instructions and stored medication incorrectly. 'On one occasion we actually found that thyroxine, which is supposed to be kept in the fridge, kept in the freezer, and that destroys it. That was a major issue.'

Staff didn't help Cleo make her bed each day, which meant her blankets were on the floor and she complained about being cold. Staff told Carolyn that Cleo didn't want the bed made, and she 'was asking them to commit a restrictive practice'.

Staff also refused to help Cleo with cleaning or washing up as it wasn't their job.

Carolyn checked with the NDIA who assured her that staff were supposed to help Cleo with cleaning. It took a long time before staff would do this.

Cleo liked to wash her own clothes, with a bit of help. Staff refused to supervise her, resulting in the washing machine 'blowing up'.

Carolyn arranged for a dietitian to attend after a support worker 'cooked raw macaroni in a frypan with oil and put tomato sauce over the top of it'. The dietitian provided simple menus and put a big poster on the wall. Staff ended up losing the cookbook and, after a while, couldn't be bothered.

Staff constantly removed food from Cleo's fridge and gave it to other residents. Often her fridge was completely empty.

After three years, Cleo wanted to come home.

'I think it was emotional abuse, so that she made up her mind that she couldn't put up with it and she would go home to her parents, who are ageing, and who absolutely needed this to be successful.'

Addilynn

‘There is no legal protection for the aged and disabled living in a strata home.’

Addilynn, late 60s, was diagnosed with a rare form of muscular dystrophy about 12 years ago. She is prone to trip and fall and uses a walking aid.

Addilynn has owned a ground floor unit of a strata complex for more than 20 years. Support workers help her live there independently.

Addilynn can only access her unit through the garden because she can no longer use the stairs to the main door. The garden is poorly maintained and, until recently, Addilynn had to navigate broken sandstone blocks, mud and water to get to her unit.

Over the years she has repeatedly asked the building’s strata committee to maintain the garden and common areas of the building so she can access them safely.

‘For disabled and the aged, the garden is a place of refuge, relaxation and sanctuary,’ she says.

As part of Addilynn’s NDIS funding, an occupational therapist (OT) conducted a safety assessment of her home. The OT recommended the NDIS pay for a concrete slab to be laid in front of the unit.

Because it is common property, the strata committee would only approve the works if Addilynn signed off on the creation of a by-law requiring her to personally maintain the slab and obtain consent of all the other unit owners.

Addilynn thought this was too onerous and her relationship with the strata committee deteriorated further.

The concrete slab was finally installed, but only after she used her retirement savings and commenced proceedings in the administrative tribunal.

This took a lot of effort and caused Addilynn anxiety, stress and hardship.

Addilynn has been asking the strata committee to fix her gate and the broken intercom system for years. They keep fobbing her off, telling her they need more quotes.

A few months ago, her gate became ‘badly jammed’ because of the rain.

Her support worker arrived but couldn’t budge the gate and couldn’t get in.

Addilynn tried to open another door but physically couldn't open it because of muscle weakness. She told the support worker to buzz unit 1 and ask them to let her in the main door. But the intercom was broken and the support worker couldn't find anyone to help her.

Addilynn was trapped and had to call police for assistance.

She is 'highly, highly stressed' living in the unit.

'What if it was at night and I couldn't get out or nobody could come to me or I had a fall and nobody could get to me?'

Cathy

‘In this particular case, just not being listened to, the communication, the lack of education, lack of staff, lack of funding – it’s lack of everything. And [in] this particular case, it proved fatal.’

Cathy is a disability support worker and mental health recovery worker.

Between the late 2010s and early 2020s, she worked for a non-government mental health organisation. She had no prior experience and said she had to learn on-the-job. Initially her manager told her they would visit her every three months, but this never happened.

Cathy supported Andy and his partner Peta in their home for several years. Andy had bipolar disorder and type 1 diabetes. Peta had catatonic schizophrenia.

Peta wasn’t able to care for herself and Andy was her mainstay of support.

When Cathy first met them, they were sleeping late, not eating properly and taking their medication at the wrong time of day. This affected their health and Andy would often have hyperglycaemic attacks.

Cathy helped them sort out a schedule and supported them to better manage their medication and meals. She took them to appointments, helped them clean their flat, wash their clothes and connect with the community.

At the start of the COVID-19 pandemic, Cathy’s employer told her she was no longer allowed to visit Andy and Peta in their home and had to support them via phone.

‘That made no sense to me,’ Cathy told the Royal Commission.

‘When it came to COVID, I was stunned that the employer turned around and said, “No more.” Surely, there’s got to be a way – to flag them as being really, really fragile and needing better treatment – than to be abandoned.’

Cathy decided to ignore her employer and went to see Andy and Peta.

‘Everything just unravelled and it only took a matter of weeks.’

Andy had become incontinent and he and Peta had developed cellulitis.

Cathy tried to raise her concerns but there was ‘no reporting procedure’ except a trail of emails.

‘I don’t think I ever got listened to.’

Andy's family were trying to help but his mother was elderly.

The family ended up taking Andy to hospital and waiting seven hours in emergency. Andy didn't eat, and by the time a doctor saw him his mental health was extremely fragile.

Andy was admitted to hospital and then transferred to a mental health unit. Peta was admitted to a different hospital and stayed there for months because she couldn't look after herself.

Cathy's employer terminated its care agreement with Andy and Peta because they were 'too fragile'.

The new provider moved Andy and Peta to accommodation away from Andy's family.

Cathy spoke to the new provider to 'give them a bit of insight' into Andy and Peta.

'Didn't get listened to at that point either.'

About a week after being in their new home, one of the support workers accidentally broke a photo frame that had a picture of Andy and his dad in it.

Andy 'lost control' and 'ordered the worker out'.

The next day when the support worker turned up, Andy refused to let them in. Sometime that day, he had a hyperglycaemic attack and lost consciousness.

The following day, the support worker found Andy unconscious on the floor and rang an ambulance.

Doctors weren't able to revive Andy and he died. He was in his early 50s.

'Why wasn't it reported? Why weren't the police sent around to double check on their welfare? Or why didn't an area coordinator go around and check and sort the system out? Because we warned them you couldn't leave them like that. So, to me, it was avoidable, absolutely avoidable.'

Kayden

Kayden's parents came to Australia in the late 1980s shortly before he was born.

He told the Royal Commission that as a child, his parents referred to him as a 'bit stupid' and 'a bit slow'.

In preschool, Kayden's mother took him to see a specialist who diagnosed him with attention deficit hyperactivity disorder (ADHD). She was so 'ashamed of the condition', she didn't tell anyone. She was scared he would be taken away and have to go to a 'special school with autistic kids'.

'She was so fearful that she did everything in her power to brush this ADHD away.'

Meanwhile, Kayden struggled to control his impulses and became increasingly frustrated.

In primary school, he was suspended for fighting and violent behaviour.

In high school, he dreamed of academic and sporting achievements but couldn't 'get his shit together'.

'I could just never sit down and focus and get something done and I thought that was just normal. I thought it was normal to ... feel angry, to be impatient.'

Despite 'trying and trying', Kayden wasn't able to organise his thoughts.

Following school, he completed a business diploma but only achieved mediocre marks. He started working in his father's convenience store.

Kayden struggled with day-to-day life and became depressed. He developed a drug addiction which led to psychosis and a criminal conviction. Kayden had a falling out with his father and was charged with assault.

'There was no justification to my behaviour. I was wrong.'

Kayden saw a psychiatrist with his mother. The psychiatrist asked if Kayden had been diagnosed with ADHD as a child, but his mother said no. The psychiatrist prescribed antipsychotic medication, which had adverse effects because of Kayden's ADHD.

Kayden began seeing a psychologist. He stopped taking the antipsychotic medication and stopped smoking cigarettes, but still had trouble focusing.

His father became sick and Kayden took over the family business. He didn't succeed because he was disorganised and not able to take responsibility.

A few years ago, Kayden pleaded guilty to a domestic violence charge. He said he was drunk and squeezed his wife's thigh too hard.

'Just unacceptable. My behaviour was out of control, being too drunk.'

Through the court process, Kayden saw a psychologist who wrote a letter to the court suggesting he had ADHD.

About a year ago, Kayden had a breakdown. He asked his aunty if there was something wrong with him. She explained that he had been diagnosed with ADHD as a child.

'I had to find out from having unacceptable behaviour, from being a bad person in the community ... that I was actually diagnosed with ADHD during childhood.'

A psychiatrist confirmed the ADHD diagnosis and Kayden started taking medication.

When Kayden told his mother, she asked him not to tell anyone he had ADHD.

She said, 'You know what, if you took ADHD medication when you were young, you'd probably be a mad drug addict, you know. You'd probably be out of control.'

Kayden says the medication has the opposite effect. It helps him control himself and 'be productive'.

'You're going to be less likely to have addictive impulses. Even less likely to be impulsive.'

Kayden has recently returned to university. He was able to obtain special assistance which allows him to see an organisational psychologist who helps him with his timetable.

'If someone just told me [I had ADHD] ... I would have been able to make individual decisions for my life, which I feel I was denied the right to. I was denied my human right to know that I had this problem. I didn't even have the chance that someone else had, to be the best they can.'

Laurence and Janine

Laurence, early 50s, has an intellectual disability.

At 18 he moved to a group home. Janine, his mum, wanting him 'to have money and to be as independent as possible', set up a bank account for him.

After a couple of weeks she noticed 'half of it was gone'. She asked the disability service provider what was going on, and they told her Laurence 'likes to eat out and is extravagant'. The provider asked for access to Laurence's Disability Support Pension.

Concerned, Janine applied for guardianship to protect Laurence's money.

She was 'taken aback' when the provider strongly opposed the application. They claimed the family mistreated Laurence by dressing him in second-hand clothing and treating him in a derogatory way.

The court ruled in Janine's favour, dismissing the provider's claims.

In the years that followed 'hostility began to be more obvious', Janine told the Royal Commission. Staff and management 'resented' the family coming to the house and asking questions.

Staff started treating Laurence poorly, calling him names such as 'big ears'.

One staff member was 'cruel'. Whenever she was on shift, Laurence would ask Janine if he could come back home for a while.

Staff smoked and drank alcohol in the house, encouraging the residents to do the same. They laughed when residents become intoxicated.

One time a staff member gave Laurence the wrong medication, which caused significant distress. The staff member claimed they were dyslexic and couldn't read.

Staff gave the master key to another resident who had lost his key. He would 'force his way' into Laurence's bedroom at night. Laurence became so frightened he would blockade his room with his furniture.

Management often employed children of staff members. Sometimes an untrained 16-year-old would be the only staff member in the house with six adult men.

When Laurence's family made complaints, management labelled them 'dysfunctional'. At one stage, the manager told Laurence's family never to come to the house without calling ahead.

‘There was the whole sense the place was really a charity and we ought to be grateful that [Laurence] was being cared for and weren’t we relieved of a huge burden.’

Laurence loved going to work and liked to start early. But this was inconvenient for staff so they changed his roster.

‘We discovered it when [Laurence]’s wages started to go down and he had lost \$100 in three or four weeks. So we went over and asked [the provider] and they just said, “Yes. It was impossible to get him there by [then].” And that was the end of that.’

‘Somehow or other’ a staff member contacted Laurence’s superannuation and had herself instated as his nominee.

Janine ‘nearly had a fit’ because there was quite a lot of money in the account.

While investigating the superannuation issue, Janine discovered staff were ‘double dipping’ and claiming a meal allowance, even though the residents were paying for their meals when eating out.

An auditor investigated the complaint, and the provider reimbursed the residents around thousands of dollars each.

Janine said that, over the years, two residents died because of neglect.

One man died after being scalded with boiling water. Another died because staff weren’t properly supervising him while he ate – he choked to death.

‘[Laurence] still bears severe traumatic scars from those 26 years.’

Huxley and Winifred

Winifred is the grandmother and primary carer of eight-year-old Huxley.

At six months, immediately after Winifred started caring for Huxley, she noticed he wasn't meeting developmental milestones. She took him to a GP who suggested they wait and see if he settled in her care. Six months later, still unable to verbalise, the GP recommended Huxley see a paediatrician. It took another seven months of Winifred 'kicking and screaming' to secure an appointment.

'It is my firm opinion that any child brought into care should be seen by a paediatrician within a very short period of time, because we lost so much time,' she told the Royal Commission.

Huxley was diagnosed with a chromosomal condition and autism.

He received early childhood development support and spent two years at an 'amazing' kindy.

When it came time to transition to primary school, Winifred viewed 11 schools including three special schools. Huxley wasn't eligible for special education because he didn't have intellectual disability.

The local state school 'sounded amazing', saying 'everything we wanted to hear'.

Huxley was able to spend some time with the prep teacher and was excited about starting at 'big boy school'. Winifred, financially stretched, needed to return to full-time work.

'Literally days before commencing, everything started to go pear-shaped.'

The after-school care provider withdrew their offer of a place and the prep teacher became unwell.

The principal decided to replace the prep teacher with casual teachers and rotate teacher aids.

During the next year there were '50 million different teachers' and no routine.

'[Huxley]'s anxiety was so high, he couldn't even wee. His sensory issues were huge. And how they managed him was just appalling.'

Teachers blamed Huxley and 'disciplined and shamed' him in front of his peers.

One time, a teacher gave every student an award except Huxley because he 'didn't deserve it'.

'[Huxley] was continually dysregulated. He was poo painting. He had trouble sleeping. He couldn't urinate.'

The principal began to pressure Winifred to have Huxley assessed for intellectual disability so they could transfer him to a special school.

Then one day, Winifred noticed bruising on Huxley's torso. He told her the teacher aide had pinched him because she was angry. Winifred informed the school, requesting the aide not work with Huxley. The guidance officer told her she should have used her discretion as a parent not to report the abuse, because she was not a mandated reporter like them.

Later that day, the school advised her there would be an 'investigation' by an external party.

That night, the guidance officer sent an email listing 11 different staff who would be supervising Huxley the following week. Winifred says this was their way of making it impossible for him to attend. She felt they had no choice but to leave.

Winifred made a complaint to the education department. During a meeting, the regional director told her they had placed an 'instruction ban' on Huxley banning him from every state school. Future enrolments would need to be approved and facilitated through the department.

Winifred believes the 'instruction ban' is 'unlawful'.

Huxley is now at a new school that is 'happy to work collaboratively'. Winifred said staff are 'beautiful' and 'amazing' and have welcomed her son into the school.

Justine

Justine worked for the NDIS in a regional area for several years. She visited residents living in group homes operated by one of the region's biggest disability service providers.

Justine told the Royal Commission that when she first met Mark he was in 'significant pain'. He was 'grimacing and crying' and shifting around in his wheelchair. A belt held him in place in the chair.

Justine asked Mark if he was alright and what was going on. He was non-verbal except for the occasion 'yes' or 'no'. The support worker said Mark had pressure sores on his bottom. Mark's wheelchair looked 'ill-fitting' and Justine questioned whether he should stay in the chair. The support worker told her Mark stayed in the chair all day until he went to bed at night.

Mark had a special mattress for his pressure sores. Justine discovered staff had turned the power off because they didn't know how to use it. His mattress was almost completely deflated and had been that way for weeks, if not months.

Justine couldn't find any record of a doctor or medical person treating Mark's pressure sores.

A week later she returned to see Mark at the appointed time. There was no-one in the office and she couldn't find anyone around. She had to leave without seeing him.

Justine completed an incident report and management suggested she raise her concerns with the support coordinator.

As a result, a community nurse came to the home to teach support staff how to properly care for Mark and the other residents, who were also seriously neglected. She told Justine that Mark had been admitted to hospital multiple times because of lack of basic care.

The community nurse discovered Mark didn't have a pressure care plan and staff didn't know how long he should be left in his wheelchair. Staff left Mark sitting in urine-soaked continence pads that exacerbated the pressure sores and caused skin infections. They had been inserting suppositories incorrectly causing Mark pain and discomfort.

About six months later, Mark was rushed to hospital after losing consciousness. Doctors discovered he had fractured bones, internal bleeding and pneumonia. The fractures were not new, but no-one knew when or how they had happened. Mark died a short time later.

Justine submitted a detailed incident report. A complaints officer immediately emailed telling her no further action was necessary and the incident was closed. Justine was surprised because of 'the severity of neglect'. She'd been waiting for a police officer to contact her about Mark's death.

Justine followed up, asking if police had been contacted. The officer told her police would not investigate 'third-hand reports', and any report would need to come from someone with direct contact with Mark.

Justine continued to raise her concerns about the incident.

Her supervisors asked if she was 'emotional'. They told her they were 'disappointed in her actions' and to 'drop the subject'.

Justine refused and wanted evidence they'd reported the incident to police.

She doesn't believe police were ever contacted.

'I really hope something does happen to [the provider] ... I would hate to think that there's probably more [deaths] to come or more neglect to come from out of that service.'



Artwork by John Marshall

Emmalynn

‘Disability seems to be a real catch-22, in me trying to get a job or me trying to do some education, tertiary education. I don’t feel like ticking the drop boxes saying I am a person with disabilities. Because I know from experience that that entails a bit of prejudice and almost patronising behaviour from people.’

Emmalynn, early 20s, doesn’t feel comfortable defining her disability.

She lives in a regional city and said she had ‘limited choices’ about the schools she attended.

In primary school, the special education unit was a 10-minute walk from the rest of her cohort. She didn’t really engage with the other kids in the unit because, except for having a disability, she felt they didn’t have ‘much in common’.

Emmalynn’s transition to high school ‘wasn’t fabulous,’ she told the Royal Commission. The nearest school with a special education unit was 30 minutes away, so she was separated from her neighbourhood and primary school friends.

‘I didn’t have the opportunity to have play dates ... or hang out after school because they were just too far away.’

At school, Emmalynn found the subject choices ‘tricky’.

She did drama, which she ‘absolutely enjoyed’. But in second semester she had to do another subject. She wanted to repeat drama but the principal gave her ‘the thumbs down’.

‘The drama around not being able to attend drama, made me slowly disengage from school.’

Emmalynn disengaged completely after one of the teachers became frustrated and called her a ‘moron’.

‘I was in tears because I had never experienced a teacher just acting out like that and losing his cool completely.’

Emmalynn took a break from school and then in year 11 ‘decided to give it just one more try’.

She was very good at English and writing stories and wanted to do an advanced English subject.

The teacher told her she belonged in English communication, not the advanced class.

Emmalynn became disheartened and stopped going to school.

She decided to 'seek out some training ... maybe get a little job'. She saw some ads for a large disability employment service (DES) provider and registered with them.

At the first meeting, a staff member asked Emmalynn to describe her disability.

'The wanted me to tick some boxes' on a list of 100 conditions. But Emmalynn didn't identify with any of the conditions. 'So, I had to explain myself for 10 minutes of what my condition entailed.'

Emmalynn told them she loved plants and horticulture and would like to work in a retail store or garden.

'He told me "no", he doesn't have any industry connections, and that I would have to go out on my own and apply by myself. Whereas I thought training entails helping me write a resume or helping me to gain resilience in the workforce.'

Over the next 12 months, Emmalynn hardly heard from the DES except for 'a few phone calls'.

Each time she spoke to them, she felt 'very depressed, like it was something [she] had done wrong'.

Eventually, Emmalynn went in to see them. They told her, 'Oh, we have nothing for you.' They said she was no longer a client.

'And that was the end of that experience with the DES, and it really shook me.'

Not long after this, Centrelink contacted her and questioned her about her jobseeking.

Emmalynn became concerned that her experience with DES would affect her disability support payment.

'I've got a bit anxious, because I have no other mode of earning a living. It kind of felt like a threat that I had to re-join that employment workspace ... I'm not eager to join the DES ever again.'

Katelyn

Katelyn, a psychologist, spoke to the Royal Commission about a former client, Ruby, who has intellectual disability.

Ruby, 60, was living in an aged care facility and her sister, Ella, was her informal guardian.

A few years ago, Katelyn started seeing Ruby for behaviour support. Ella told Katelyn that Ruby was often aggressive, had obsessive-compulsive disorder and an eating disorder. Katelyn said this was not reflected in Ruby's case file and was not what she experienced.

'[Ruby]'s articulate, she's well-presented, she's really friendly. She has some difficulty in interpreting social interaction and communication, so she has a tendency to be a bit too touchy-feely with people in inappropriate contexts.'

Quickly, Katelyn discovered staff were using restrictive practices and punitive strategies to manage mild behaviours.

Ruby wasn't allowed to use the dining room or kitchen because she didn't understand the concept of a communal fridge and would take food that wasn't hers.

If she did manage to 'steal' a biscuit, staff would isolate her in her room or refuse to allow her to go on outings. One time she had to stay in her room for a week.

'I suspected that her food stealing behaviour ... was a result of her simply being hungry. Because they would have meals there at about 5 pm. She goes to bed at probably about 11 at night. So she has got six hours not having any access to food between mealtimes and going to bed.'

Katelyn asked Ella if Ruby could have some food in her room, but Ella believed it was 'wrong' to eat outside of mealtimes.

Katelyn tried to explain that the restrictive practices were 'leading to an escalation in behaviours'.

She asked if she could speak to staff and develop other strategies to support Ruby.

Ella didn't appreciate Katelyn's comments and refused to let her speak to staff or management.

Katelyn consulted her manager and they agreed she should talk to the residence manager. But the residence manager had a good relationship with Ella and refused to do anything without her support.

Soon after, Ella started phoning Katelyn's managers and directors, calling her 'incompetent' and making false accusations.

Katelyn contacted the public advocate and provided details of the restrictive practices being used.

She also contacted the NDIS Quality and Safeguards Commission. They couldn't do anything, even though Ruby was an NDIS participant, because the aged care facility wasn't an NDIS provider.

They suggested Katelyn contact the Aged Care Quality and Safety Commission, who couldn't assist because Ruby wasn't yet 65.

Eventually the public guardian spoke to Ruby and the residence manager, and determined Katelyn's allegations were unsubstantiated.

But Ruby was scared of her sister and wouldn't have wanted to make a fuss, Katelyn said. She considered this an 'insufficient way of investigating the situation'.

Ultimately, Ella refused to allow Katelyn to work with Ruby and requested copies of all case notes and psychological reports.

'I've basically lost all contact with [Ruby]. I have no idea how she's going or how things have progressed. My fear is that she is now even more restricted, because in sharing some of her information and sharing some of her story ... she may now no longer have access to someone to talk to.'

Sarah and Ursula

‘They sort of treated her and myself as if we were a nuisance, as if she was taking up too much hospital time, as if her life had no value.’

Ursula’s sister, Sarah, was born with ‘snow white hair’ in the mid-1950s with intellectual disability.

At seven, doctors told Sarah’s parents she needed medication to help her sleep, which could only be administered by a trained nurse in an institution. The family moved house to be close to her.

About 10 years ago, Ursula and Sarah, who was in her late 50s by then, were on holidays.

Sarah started having problems with her bowel, and doctors at the hospital said she needed an operation. Ursula asked them to make Sarah comfortable until she could get her home.

Back home, doctors at the local hospital refused to operate.

Sarah became more unwell. She looked like she was ‘10 months pregnant’ and refused to eat.

Ursula took her to another hospital. Doctors ignored Sarah’s bowel issues. ‘They just said she was badly behaved, she had a psychiatric illness.’

Ursula tried to tell them Sarah didn’t have a psychiatric illness but was in pain.

‘She was never badly behaved. She was just a gem. Everybody loved her, and she was very easy to manage, and she had impeccable table manners. You could take her to the best hotels and she ate beautifully, and was never a nuisance or noisy or anything like that.’

Doctors decided to give Sarah ‘shock treatment to make her eat’. Ursula refused to allow it, telling them she was taking Sarah home.

‘They got the security guard onto me, so I had to let her stay.’

Sarah was admitted to a locked ward, making it difficult for Ursula to visit.

During the shock treatment, staff knocked Sarah’s front tooth out. While she was there, no-one helped her shower or helped her with her teeth. They left her in the same clothes for four days.

Eventually Ursula was able to go in and support Sarah.

‘It was bad practice ... The labelling of her having a behaviour problem when she’d never had a behaviour problem was terrible,’ Ursula said. ‘My sister was never the same again after she came out of the psychiatric ward.’

Back home, Sarah's problems with her bowel persisted and Ursula organised for her to have elective surgery.

Two days after she was discharged, Sarah started having problems with her bladder and Ursula took her back to hospital. Doctors treated her and discharged her the same day.

A week later, unable to pass urine, Ursula took Sarah to the local hospital. Ursula believed she had a urinary tract infection. Doctors disagreed and an X-ray showed no changes to the bowel. They discharged Sarah, advising Ursula to increase Sarah's fluids.

A few days later, a locum doctor visited Sarah at home and found her chest, abdomen and temperature to be normal.

The next day Sarah collapsed, and paramedics took her to the local hospital.

Sarah deteriorated rapidly and died later that day.

The autopsy concluded she died because of sepsis and renal failure. Ursula commissioned an independent report and disputes these findings.

Ursula believes people with disability should be treated in a separate section of the hospital by doctors and nurses who are trained to treat people with disability.

'My sister had about six admissions to the hospital in that year she died, and every single admission they called it a "social admission" ... like, I couldn't cope with looking after her because she was so difficult.'

Alayah

‘It was just horrible. I just felt like they didn’t want me as a person with a disability. They didn’t want me in the workplace.’

Alayah, early 40s, is a school counsellor.

About 10 years ago, symptoms of her fibromyalgia and myalgic encephalomyelitis became worse and she found it difficult to spend a full day at work.

She made an informal arrangement with her manager to arrive at work later in the mornings and work from home in the afternoons.

A few years later, the education department raised concerns about the arrangement and asked Alayah to submit ‘evidence’ of her disability. A few years after that, the department suggested she undergo a ‘fitness for duties’ assessment.

At the beginning of the COVID-19 pandemic, Alayah’s doctor recommended she work from home because she was more vulnerable to serious illness. At the time, everyone was beginning to work from home and it wasn’t an issue.

As other staff began to return to work, Alayah’s doctor advised her to stay home because of the risk to her health.

Alayah told the Royal Commission her managers ‘were not supportive’. They told her she was ‘an essential worker’ and the ‘only one’ working from home, and they might need to ‘reconsider’ her role.

Shortly after, they moved her to a primary school.

Eventually, Alayah’s doctor cleared her to return to work and she asked to return to her substantive role at the high school.

Human resources asked her to provide more information about her disability and the adjustments she required. Alayah asked to continue to work from home in the afternoon.

The department refused to allow her to return to the high school and limited her role to project-based work at the primary school.

A few weeks later, Alayah’s manager informed her she needed to undergo a psychiatric and rheumatology assessment. Alayah queried the psychiatric assessment because she ‘didn’t have a psychiatric injury and wasn’t claiming to have one’.

Her manager told her that she talks about her pain conditions but ‘we don’t know it’s a disability’.

Ultimately, Alayah felt she had no choice but to agree to the assessments.

At the beginning of the session, the psychiatrist told Alayah she'd been asked to assess whether Alayah was a 'risk to children'. She said, 'We take the safety of children very seriously and so I will be doing a full psychiatric assessment on you starting from childhood to now.'

The psychiatrist asked personal questions about Alayah's childhood and family. She asked about her medication, relationship status and use of dating websites. Alayah was shocked because no complaints had been made about her performance.

'I guess going through that, it was the whole thing of just being not believed that I have a disability, and it just wasn't a supportive process. It was like an investigative process. It really was trying to prove I don't have a disability rather than just accepting I do.'

Nadira and Lyn

Nadira is in her late 30s. She has an acquired brain injury, diabetes and needs help with personal care and day-to-day activities.

A couple of years ago, Nadira started receiving supported independent living (SIL) funding through the NDIS. She lives by herself and a SIL provider manages her support needs. But Nadira is unhappy because the support workers don't listen to her.

Lyn, her mum, told the Royal Commission that when Nadira is agitated she can be difficult to understand. 'But the thing is you need to just take time and let [Nadira] talk, and then once you let her talk you can then work with her and work through her problems.'

If certain support workers are rostered on, Nadira doesn't like staying in the house and either roams the streets or goes to Lyn's house.

Lyn asked the public guardian if Nadira could change providers but the guardian refused.

'The public guardian said it was my fault, that I should be taking her back every time she comes over. I took her back four times in one day ... And every time I took her there she'd walk back. And it's a two-hour walk!'

Not long ago Lyn asked the public guardian if she could take Nadira on holiday, but they said no.

While Lyn was away, Nadira came to Lyn's and stayed.

The provider rang police who rang Lyn. Lyn said they should contact the public guardian.

Neither the public guardian or provider came to see if Nadira was okay the whole time Lyn was away. The provider continued to charge for 24/7 care.

Nadira loves bowling and is very good at it. Lyn has encouraged the support workers to take her bowling to help them form a relationship, but they refuse. Sometimes they drop her off at the bowling club and leave her to find her own way home.

Nadira complained to Lyn that the support workers use their mobile phones when they're driving. Lyn raised it with the public guardian and provider. Nadira spoke to police officers about it. No-one believed Nadira.

Nadira kept complaining, saying she didn't want to drive with them. Lyn suggested she take a photo with her phone the next time it happened.

Nadira did take a photo and told the support worker what she'd done. The support worker grabbed her arm and demanded her phone. Nadira managed to get away and told the support worker to tell the truth or she'd show the photo.

The support worker finally admitted she had been using her phone while driving. The next day Nadira was badly bruised, so much so that Lyn took her to the doctor. Nobody ever apologised to Nadira.

After this, Nadira didn't want to be at the house anymore. When she walked in, she would get very upset. 'She's traumatised,' Lyn said.

'[Nadira] has lost trust in everyone ... She's lost trust in the police, she's lost trust in the [public guardian]. She's lost trust in everyone because in the time she's been crying out for help, no-one has listened to her.'

Although Nadira is not living in the house, Lyn says the provider continues to charge for support.

Nadira went to the public guardian's office and asked to see her NDIS plan. Lyn said after this, the guardian agreed to change providers.

Lyn's been cleaning Nadira's house, getting it ready for the new provider.

'She needs stability and consistency.'

Dangelo and Ariella

Dangelo, 60, has schizophrenia and obsessive-compulsive disorder. Ariella, his sister, has been his guardian for 10 years.

After their mother died, Dangelo's share of her estate went to the public trustee.

Around this time, the mental health accommodation provider suddenly moved Dangelo from shared supported accommodation, where he'd been happy, to a house by himself.

Ariella told the Royal Commission she believes the provider moved Dangelo because he had money and could pay more for accommodation.

Dangelo had never lived alone before, and his new house was dilapidated, with three bedrooms and a large back yard. Dangelo needed a controlled environment and struggled to manage on his own.

'On the one hand, you are grateful that he has got somewhere to live, you are grateful that they are assisting and helping. But at the same time you are afraid to speak up, because they won't look after him.'

It took two years of lobbying to find something more suitable. But by then Dangelo didn't want to move.

About four years later, an 'abrupt, rude' officer from the accommodation provider contacted Ariella about the poor condition of Dangelo's house.

'That was when the fun and games started,' she said.

The officer asked to see inspection reports.

Arielle didn't have any and tried to push back, arguing the agency was responsible for inspections and maintenance. The officer demanded Arielle fix the house.

Dangelo was very unwell at the time, repeatedly washing himself with disinfectant and dishwashing liquid. He refused to let people into the house.

Arielle felt she had no choice but to do the repairs herself.

Dangelo became heightened by the smell of the new paint. He began to self-harm and developed cellulitis.

Less than a year later, the provider told Ariella that Dangelo would have to move. Ariella felt this was unfair because of the time and money they'd put into fixing the house. The provider refused to reimburse them for what they'd spent and began to issue eviction notices.

Dangelo's self-harming and cellulitis became so bad he was admitted to hospital. Doctors changed his medication but it didn't help his anxiety.

When Dangelo returned home, no-one followed up about his mental health because he'd been admitted as a general health patient. He stopped taking his medication and began 'destroying half the house' as he became increasingly unwell.

The provider issued more eviction notices.

Ariella asked to see alternative accommodation, but nothing was suitable for Dangelo's needs.

Ariella took her brother back to hospital, which transferred him to a recovery centre.

Ariella has returned to work so she can afford to buy a bigger house with a granny flat for Dangelo.

Ariella said her own mental health has suffered trying to care and advocate for Dangelo. She believes there needs to be greater mental health support for carers.

'Doing such a difficult job, and we are under scrutiny all the time. We are judged, we are criticised, but there we are, doing the job and looking after someone. I pride myself in that.'

Elliana

Elliana, mid-60s, has Parkinson's disease, rheumatoid arthritis, central auditory processing issues, debilitating migraines and psychosocial disability from childhood trauma.

'I'm discriminated against by the federal, state, medical and disability models of management, for having more than one health condition,' she told the Royal Commission.

'To access funding under the NDIS, I cannot talk about my needs not being met by the medical model.'

Elliana said she is 'forced to choose' which NDIS-recognised medical condition 'is the most disabling'.

'There's this artificial break between health and disability, when they're intrinsic together. They're bound together. Health and disability are bound together. And we put a dividing line down with structures, 'Disability this side. Health care that side'. It doesn't work like that.'

Elliana said she is 'terrified of the NDIS' and doesn't trust them.

When she first received funding, about seven years ago, she was told the funding was 'for life'.

Recently she discovered she will lose her NDIS funding if she isn't able to implement 'improvement goals' or needs more home support or enters an aged care or disability residence.

'My disabilities are discriminated against due to age, and because I cannot improve my degenerative disabilities with intervention.'

When Elliana rings the NDIA to discuss her needs, she is passed around or told to email.

The last time she rang, she said it took 40 days for the NDIA to respond.

Often, the NDIA suggests she look at providers' websites.

'If I want a service I am overwhelmed by choice and grandiose websites promising the world. I never can work out who can promptly do the job.'

Elliana receives funding for mental health support. But she needs crisis support, which the NDIS doesn't fund.

She finds it difficult to find mental health service providers or support workers with mental health crisis training.

'I'm constantly told by these service providers' delegates, "I have just the right person for you." No-one asks what type of person I would like – it's not part of the model.'

Elliana's medical conditions and disability have affected her teeth. The NDIS does not fund oral health care.

Because Elliana is not able to find appropriate supports, her NDIS package is underspent. She is worried she will lose her funding.

Elliana believes the NDIS business model benefits the providers, not the person with disability or support worker.

For example, a provider will charge her \$50 per hour but only pay the support worker about \$18 per hour.

The first time Elliana used respite care, the provider charged \$4,500 for four nights sleep over. The support worker, she said, received around \$140 per night.

'There are amazing models of care out there that we could be working with. We don't have to reinvent the wheel.'

Erik and Annabelle

Erik, late 50s, is autistic and has intellectual disability and health issues. He is non-verbal and requires 24/7 care.

Annabelle is his full-time paid carer and life companion.

Annabelle and Erik first met almost 30 years ago when she was a respite carer.

Soon after the NDIS trial began in their area, Erik's other part-time carer became unwell, which left Annabelle with no respite.

The local disability services provider wouldn't assist unless they managed Erik, so he signed up with them. They insisted that he required support workers rather than part-time carers, but were then unable to find suitable support workers. Annabelle said the money allocated for those support workers then 'disappeared' – it certainly wasn't passed on to her to cover the care the support workers were supposed to provide.

For the next four years Annabelle had no respite.

Annabelle asked the NDIA for a wheelchair for Erik, some physiotherapy and for an orthopaedic surgeon to examine his feet. The local area coordinator (LAC) said there was no funding for these items and she would need to 'value add'.

Annabelle lived on a property and, with one of her siblings, decided to offer respite for people with disability.

They were 'inundated'.

Annabelle asked the LAC if they should become a registered provider. The LAC advised against it saying they'd get 'bullied' by the local disability services provider.

The LAC then capped their fees.

About six months later, Annabelle heard that other services were charging more than double her capped fees for similar services. She found out the LAC had made a deal with the local provider who managed Annabelle's clients. The provider was charging the client more and keeping money for themselves for every period of respite at Annabelle's.

Annabelle couldn't afford to continue offering respite.

'That was about shutting down all private opposition, building [the local provider] up to this massive conglomeration.'

Annabelle believes the local provider was making it difficult for her so she would relinquish care of Erik. They saw Erik as a 'cash cow'.

The financial exploitation continued until the NDIS trial ended and the NDIA 'rescued' them.

Erik and Annabelle were able to change providers, signing up with a small family-oriented provider.

'They're just beautiful, you know. They're bending over backwards for us.'

Evan

Evan, early 20s, has an intellectual disability.

He told the Royal Commission he finds it hard to process information, particularly when he's stressed.

Evan's been living in independent supported disability accommodation for a number of years.

He said the CEO of the accommodation would visit almost every day and harass him about the rent.

Evan paid the rent via bank transfer but the CEO never gave him receipts. The CEO constantly threatened to raise the rent and Evan was very worried about becoming homeless.

Recently, the CEO arrived unannounced to do an inspection of the house. Evan said the CEO started to get angry, asking about unpaid rent.

Evan told him he had paid the rent, but the CEO kept asking for more and 'continued to berate him'.

'I felt the CEO provoked the situation. He was even putting his fist in the air to try and get me to fight him.'

He told Evan to 'get [his] stuff out of the house'.

'It upset me that he could make us homeless and I hit him in the face and kicked his car.'

The CEO called police.

Police did not believe Evan and would not let him explain his side of the story.

'I was not offered a support person to advocate with me when the police were questioning me. I am not sure if this is because they saw me as capable to talk to them alone. But I have difficulty processing information and I should have been able to have a support person with me.'

The police and court processes were overwhelming for Evan.

'Paperwork from the police or lawyers should be easy to read and not too wordy. With the paperwork from the police, they need what the charges are, and explain why you got charged ... because there's a lot of people out there who don't actually understand.'

Evan's lawyer told him to plead guilty, but didn't explain what having a criminal record would mean.

'None of the charges were against any children, but I have problems getting a Blue Card. So, I can't coach my children's sport team and might not be able to get a placement in my teacher TAFE course.'

No-one told him about the appeal process or about legal organisations that could support him.

When Evan eventually did find legal support, he was 'out of time' and couldn't appeal.

Evan believes police need more training to work with people with disability.

Evan would like to be a support person for people with disability in court so he could help them understand what happens in court.

He tried to contact a police liaison officer to talk about his ideas but couldn't get anyone to return his calls.

'With those people through the courts like myself, to help them go through the process and to understand what they did and why they did it in the first place ... The system is broken. We need to fix it badly.'

Conner

Conner is in his early 40s and has cognitive impairment. He lives with post-traumatic stress disorder and other mental health issues.

Connor told the Royal Commission that when he was in primary school, someone ‘working in the education department’ sexually abused him. Subsequently, he was given electroshock therapy.

‘I was eight years old, with the electric shock treatment. And I’ve just been trying to deal with it ever since ... trying to figure out who I am,’ he said.

Conner had to fight for anyone to believe him about the abuse.

‘I had tests to find out if I was tampered with ... to find out where I was damaged by the perpetrator. And that’s when I started to get believed.’

He said there had been reports of ‘perpetrators being around the school and there was no protection’.

Conner said teachers at his public school assaulted him as a way of ‘keeping [him] quiet’.

‘Because I was misbehaving. So, their way of dealing with me as that misbehaving child was throw me in a concrete room, hold me down and squirt molasses down my throat.’

Growing up, Conner ‘was put in and out of homes’ and ‘passed around from service to service’ in the child protection system.

A lot of his childhood memory ‘disappeared out of [his] head’ because of the electroconvulsive therapy.

Conner was ‘kicked out’ of high school in year 6 and has ‘been trying to survive since’.

‘I was living on the streets. Couch surfing, trying to work, trying to find jobs. Things like that, you know what I mean. That’s where I was put on a disability pension from the age of 16.’

For years Conner sought justice over the sexual abuse, only to be ‘called a liar’. Education officials ended up acknowledging the abuse, though ‘records of that disappeared’.

‘There’s evidence of the molestations at the school, but I’m getting told there’s no responsibility from the education department because of the timeframe.’

Today, Conner struggles to get the right support from mental health services and the NDIS.

'The mental health system's now rejecting me for asking for help ... I'm still stuck on the wrong plans, I'm still fighting to get the right supports in place ... I've been constantly accused of being that mental person, that traumatised child.'

Conner said he 'can get suicidal sometimes'. 'I've been taken of my own free will to hospitals, because I've had a mental episode.'

At other times, after he's been 'venting' on mental health support lines, the police have turned up and handcuffed or 'crash tackled' him.

'I will get taken to the hospital, instantly thrown into an isolation room, where you're just locked in a room where there's one bed and four walls, with security sitting at that door constantly. To make you feel like you're ... that low piece of rubbish.'

Conner said it 'hurts – emotionally' to be treated as though he's 'full-on suicidal'.

'They don't understand that I'm not actually going to hurt no-one. I'm not going to hurt myself. I'm just venting, to try and get my pain out ... And I get classed as "mentally crazy".'

He believes more face-to-face support would help cut down on his visits to psychiatric wards.

'When I was a lot younger, they used to have a lot of like drop-in centres ... where people would go ... and get that.'

Erik, Elianna and Devin

Erik, 20, has vision impairment and lives with anxiety and depression because of childhood cancer. Elianna and Devin are his parents.

'In a way, [children with cancer] are kind of given this halo. Everybody likes to think that they're inspirational and wonderful, and, "You're such a brave family". But in terms of policy and support, it's just not there,' Elianna told the Royal Commission.

As a child Erik was often sick or having treatment. This affected his ability to attend school and build relationships with his peers.

Erik's primary school tried to be supportive but, because of the way the education department classified his disability, could only offer limited educational supports.

Elianna asked the education department to pay for a tutor to support Erik while he was in hospital but they refused. Ultimately a charity stepped in, funding resources to help him learn to read.

When Erik returned to school after treatment, teachers failed to take Erik's compromised immune system seriously. For example, Elianna provided Erik's class with hand sanitiser at the beginning of the year – the teacher returned it at the end of the year, unused.

At the start of high school, Elianna and Devin gave the teachers a presentation about surviving cancer and how best to support Erik.

The feedback was positive.

Erik did very well for the first couple of years, attending mainstream classes except for maths.

In year 9, the school transferred him to the learning support unit for all his classes. His parents believe the school did this because of NAPLAN.

From then on, the school encouraged Erik to take non-academic subjects with flexible assessments. Erik could complete an essay but needed assistive technology or a scribe to support him. They suggested he do oral assessments instead.

Devin believes the school's attitude was, 'Just let him be lucky to be alive, rather than actually live a life of meaning.'

Elianna and Devin fear for Erik's future.

'You have to question the wisdom of saving your child's life, if you're worried they're going to be a homeless person as an adult once you're gone and you can't fix it anymore.'

Aisha and Adalyn

‘Every day I just want to work. That’s all I think of.’

Aisha, early 20s, was born with a genetic syndrome resulting in cognitive impairment, respiratory issues, an inability to regulate her body temperature and poor muscle tone.

About five years ago, Aisha signed up to a school leaver program with a disability employment service (DES).

Her mother, Adalyn, who is her full-time carer, gave the DES detailed information about Aisha’s disability.

Aisha completed the two-year program in 15 months.

Adalyn was concerned. ‘How can participants finish way ahead of schedules when they haven’t learnt enough skills?’

She believes the DES didn’t respect Aisha’s cultural background, didn’t take the time to understand her disability and only wanted to rush her into a job.

The DES immediately found Aisha a job with a florist. Following an unpaid trial, the DES asked her to sign a supported wage employment contract.

‘Maybe I signed something like about work, but I don’t know,’ Aisha said. ‘They haven’t explained it to me.’

Adalyn said her daughter didn’t understand what she signed, and no-one told Adalyn about the contract or the supported wage system.

The DES conducted Aisha’s employment services assessment using an out-of-date health report, despite Adalyn supplying updated information. Adalyn believes the florist and the DES ‘were cutting corners on safety’ and didn’t conduct a workplace health and safety assessment. They asked Aisha to ‘tick boxes’ but didn’t listen to her. ‘I don’t think they understand me,’ she said.

Aisha’s supervisor frequently changed her tasks. They gave her laminated pictures to explain each task, but she couldn’t understand them.

Despite her low muscle tone, Aisha had to use heavy meat cleavers and knives. She had to carry heavy buckets of water, which she would spill all over herself. ‘Yeah, wet. Yeah, wet ... All the time wet ... Then dries off, and then get wet again.’

She also had to mop the flower freezer with the door closed, to save money. It was very cold in the freezer, and when she finished her hands would shake.

If she complained, her supervisor told her to be respectful and warned that if she spoke up she would lose her job. Aisha was scared and didn't say anything to her mother.

'I never speak anything ... cause I'm fired.'

Aisha said the DES was meant to provide support but didn't. Sometimes DES staff would visit her after she finished her shift and tick some boxes, but that was all.

'But I got breathless ... Sick. Coughing. Tired ... And then I've got a sore leg ... Even when I went to the toilet, I had this sore leg ... Couldn't move my leg.'

Adalyn did not realise how unwell Aisha was. She developed pneumonia and had to be hospitalised.

She left the florist and still feels disillusioned.

'What about my rights? My inclusion, participation ... my individual outcome?'

Adalyn believes the DES failed Aisha.

'[The DES] is not a culturally responsive service to people with disability from culturally and linguistically diverse backgrounds. They don't understand the sensitivity – our language, our culture.'

Lane and Laylah

Lane is in his 40s and has Down syndrome. For many years he resided at a supported independent living home.

Laylah, a psychologist, met Lane and his parents a couple of years ago on her first day in her 'dream job' working at the home.

'They were highly distressed about the care that he was receiving,' Laylah told the Royal Commission. 'He had lost 10 kilos and he was on a complete liquid diet. Sometimes he had scrapes or cuts on him.'

Lane's mother was 'crying through the whole session' with Laylah. She told Laylah staff were locking the door when they came to visit so they couldn't get in. The house manager was 'disrespectful' to them – 'Swearing ... Sometimes she'd call her a "bitch" or something.'

Laylah's job was to write a behaviour support plan for Lane. A previous psychiatrist had authorised 'chemical restraint' for him – 'He was on a very, very high dose of antipsychotics.'

'But then he had lots of other restrictive practices that were not authorised.'

Laylah asked the psychiatrist about that.

'Why he was on such a high dose of medication? Why he's not able to eat? ... Because there was nothing in place to actually show there was a reason why he should be on a liquid diet.'

Laylah said the psychiatrist was 'sneaky' and 'wasn't helping'. When she visited Lane, she found him 'highly sedated'.

'He could hardly open his eyes. It seemed like he was really hungry and thirsty as well. He asked for water a few times and was told that he needed to get it himself ... They were pushing him to do all of these things himself that he wasn't capable of, like pour boiling water into a cup.'

Laylah noticed 'quite a few issues' – including incidents of physical restraint – in Lane's records.

One support worker 'physically removed him from the toilet because he was taking too long'. Another wouldn't let him have a bath.

'And he sat there crying for an hour on the toilet, you know, in his own house.'

Laylah started putting together a report. She had to 'go digging' as staff didn't provide information she asked for and were watching her and taking photos.

Laylah spoke with the agency of her ‘really big concerns’ about Lane’s care. The home was blocking Lane’s phone communication with his parents, which a compliance officer described as ‘a restrictive practice’.

Laylah talked to the house manager about Lane’s diet. She told her, ‘He’s starving. He’s asking for food. He’s only having milkshakes ... Most of his behaviours of concern are around wanting food.’

One of his meals was ‘like a fish milkshake’. ‘That’s something you would joke about giving someone as a punishment,’ Laylah said.

At a team meeting, she tried to teach staff ‘the basics about restrictive practices, what the legislation was’.

‘I thought, maybe they just don’t understand neglect. In the end, I think they did understand, but they were just doing their own thing.’

She warned them of the ‘serious consequences for engaging in unauthorised restrictive practices’. ‘But they were just cutting me off. They wouldn’t even let me talk.’

Three days later, the agency fired Laylah for breaching its code of conduct.

She helped Lane’s parents make a complaint to the NDIS Quality and Safeguards Commission.

‘They were elderly, they didn’t know what to do ... They said, “We didn’t know about our rights until we met you.”’

Laylah described Lane’s treatment as ‘horrific’.

‘It’s nothing short of domestic violence, really. He was their cash cow, and they were restricting him from his own family who cared about him.’

Didier

Didier is in his early 30s and has cerebral palsy, intellectual disability and mental health issues.

Ever since his childhood he'd 'never really had a voice', he told the Royal Commission.

'When I was growing up, there was no interest in my views even though I was really intelligent. My limitation on speaking or getting encouragement to speak was very limited.'

Didier had severe anxiety attacks at high school. Because of his learning difficulties, he faced 'bullyism behaviour' from classmates.

'I used to get bullied about my understanding and all that kind of stuff ... People were always negatively downing a person without dealing with the problem.'

During his education in Queensland, he encountered 'systematic discrimination' against people with disability. People were constantly making decisions for him because they didn't think he was capable. They would perpetuate fear – of living in the world, engaging with the world and getting the most out of life.

'Like, if I asked, "Oh, is it safe to go to a nightclub?" My teacher would say, "No. It's dangerous." They will drill that into you.'

Disability services now do the same, Didier says. They put breaks on his ability and freedom by not offering adequate opportunities.

'A lot of disability organisations tend to say, "We want to enhance their independence." But they're not doing anything ... They're just giving us a limited thing to do, like bowling or camping ... They're getting a little bit better gradually, but it's not enough.'

He said the barriers on learning create a culture of dependency. Instead, services should be encouraging people with disability 'to stop having that fear and be who they want to be'.

Didier said the blocks on participating in society continue in higher education. He worked in disability advocacy at a university.

'And according to the statistics, [people with] disabilities are getting hungrier for higher education. But there's still some barriers that are stopping them to have that freedom of choice.'

The bias leads to limited job opportunities and workplace abuse, Didier said. He's often worked in the hospitality industry – the only jobs available to him were 'kitchen roles'.

'For the large part, it's just a one-man kitchenhand. We do everything – floors, dishes, prep, basic cooking, cleaning out the bench, occasionally a floor runner.'

Even though 'restaurant or bar managers or HR ... are well up-to-date on knowledge' about disability rights, they 'consciously will forget'.

In peak season 'chefs start getting real greedy behaviour', demanding staff be on duty excessive hours and 'pushing the person with disability to their limits'.

Aylin and Jaime

Three years ago Aylin, mid-30s, went to work on a Friday, experienced chronic headaches, went to hospital and never went to work again.

Her husband Jaime told the Royal Commission it was ‘just something that came out of the blue’.

Doctors diagnosed Aylin with postural orthostatic tachycardia syndrome (POTS). During an attack, her blood pressure drops rapidly and blood can’t get to her brain. She experiences cognitive issues and faints. Repeated attacks damage her nervous system and cause mobility issues.

Needing support, Aylin applied for NDIS support.

She and Jaime said the process was long, frustrating and not transparent. Each time they contacted the NDIA about the application ‘everything was progressing’. But after four months the NDIA admitted they had lost the application and Aylin needed to reapply.

The NDIA initially rejected Aylin’s application. They based their decision on an assessing doctor’s ‘well wish’ that she might be one of the lucky ones who recovers.

Jaime said most people reading the report would interpret his words as a nice way to ‘sign off’. The doctor clearly believed Aylin’s condition was permanent, making the point that less than five per cent of people recover, and they are usually teenagers.

Aylin applied for an internal review. The NDIA confirmed the original decision saying, ‘We googled it and you’ve just got blood pressure problems.’

Aylin and Jaime felt completely dismissed by these processes.

‘The staff within the NDIS have little to no understanding about complex health conditions,’ Jaime said.

‘[Aylin]’s cardiologist is not only one of the top specialists in the country, but in the world in POTS, and until they essentially have someone of his calibre to say that she’s not a total and permanent disability, then I can’t see how they can reject it.’

Aylin appealed the decision, taking the matter to the administrative tribunal. She said she and Jaime found it difficult to find out information about the process, and community-based organisations had limited capacity to assist.

Lawyers represented the NDIA, whereas Aylin and Jaime represented themselves.

'[Aylin] found it humiliating through the process because she had to prove her disability through a range of physical tests as opposed to what she had been diagnosed with by her medical specialists,' Jaime said.

After 18 months, the NDIA eventually conceded.

'And in that time,' Aylin said, 'I regressed to the point I was at hospital three times a week because I had no early intervention or no help.'

The NDIA approved limited support but refused to fund the home modifications Aylin needed to retain some independence.

Jaime took the matter to the administrative tribunal a second time.

Meanwhile, Aylin requested increased allied health support but the NDIA refused to deal with her claim.

'What they had stated was that the NDIS does not make approvals on any requests or claims whilst there is an administrative appeal in place,' Aylin said.

Jaime felt he had no choice but to discontinue the appeal.

The NDIA reviewed Aylin's plan and significantly reduced her funding for mental health and allied health supports. They also removed her ability to self-manage her core funds. Jaime feels these decisions were made to punish Aylin for fighting so hard against the NDIA's earlier decisions.

Aylin said NDIA staff often suggested she ask family, friends or even her children to assist with certain tasks.

"You lose your relationship dynamic. It's no longer [Jaime] and I, husband and wife. I say to people he's my carer and then my husband, because he has to do so much for me.'

'We've lost a lot of friends. People are burnt out from helping us ... My parents are in their 60s. My mum's retired on disability and my dad is pretty much retirement age. We can't expect them to do everything all the time, but the truth is we do – we have to, we don't have a choice.'

Presley

'I was diagnosed with a personality disorder, which was kind of in vogue back then, because it wasn't recognised that females could be autistic.'

Presley was only diagnosed with autism recently, in her early 30s.

'It wasn't picked up, and that led to some significant disadvantages for me – the worst of it came when I was a teenager,' she told the Royal Commission.

'I was labelled lazy or defiant or manipulative. At the age where my peers were getting jobs and entering the workforce or going into further study, I was very isolated ... I had very significant social anxiety, which kept me from going outside and participating in life in general.'

Presley was 'eventually admitted to a psychiatric hospital'.

'I was treated for a mood disorder ... That was the beginning of many diagnoses, essentially.'

Psychiatrists later diagnosed her with borderline personality disorder and she spent a lot of time 'locked' in seclusion and 'heavily sedated' over the next three years.

'There was more time spent diagnosing and medicating people than actually looking at the root causes of the problem and helping them belong in society. I became institutionalised, without a doubt.'

Presley said another patient raped her when she was on an open ward. Despite 'plenty of DNA evidence', a court found him not guilty on the basis he did not understand 'that consent was not given'.

'Being diagnosed with a personality disorder, there was plenty of ammunition to attack my character, to say that I was at risk of engaging in behaviours which would entice people to want to do that to me.'

Over the years, Presley said she had been discharged a few times, but 'just ended back up in these psychiatric institutions'.

'Because still the anxiety, the social phobia, my communication hadn't been treated, or supported.'

Once, when she was allowed to go interstate to live with her father, she said he 'molested' her when he was drunk. Two days later, Presley overdosed on her prescription medication and was in a coma for several days.

'I'm lucky to be here and to have survived that experience. And it's not that I necessarily wanted to die, I just didn't really know how to live in any way, shape or form.'

When she was about 20, she said she was 'released' to go and live with friends on a farm.

'And it was probably the first time I just had the basics of what every human needs – stable relationships, food, fresh air and good activity.'

She came off all the medications and within a few months was living independently for the first time.

'I had the confidence to get my first flat. I had to really build up very slowly some skills ... I did some study and got a job. From there, essentially it was onwards and upwards.'

Presley got a certificate of education and today works in TAFE. A few years ago 'a psych review' found all the other diagnoses, including schizoaffective disorder, were wrong. 'And had they been true, I wouldn't be able to function as well as I am right now.'

But Presley said the 'label' of a personality disorder sticks.

'There's a piece of paper that follows me, and the way people treat you or speak to you is different. So, you are often just disregarded or not believed ... And all those times of not being believed when I did speak up for myself, affects me to this very day.'

As an advocate for people with autism, Presley is determined to put that right for others. She was inspired by a female support worker who helped her when she was at her lowest moment.

'What I remember is the way she made me feel. She picked me up from the hospital and took me to the beach for a walk, side by side, and just talked to me like a normal person. And that in itself was more than anything anybody had ever done.'

Tinsley and Eduardo

Tinsley had cerebral palsy. She was blind and non-verbal. She was in her 50s when she died about a year ago.

‘She was well looked after ... from the age of five,’ her uncle Eduardo told the Royal Commission. ‘All that time she was fine while she was in government care. Her difficulty was when the NDIS came along.’

At that point, Tinsley was moved to a supported living residence run by a private accommodation provider in New South Wales.

Eduardo quickly ‘found holes in her care’. The home did not have Tinsley’s health care plan and was not meeting her ‘complex care needs’.

‘The problem was she needed more intensive care from capable people. They didn’t know how to look after [her].’

He noticed Tinsley’s health deteriorating. She was ‘self-harming and all that’.

‘That’s what was occurring through the whole two years, which was pretty stressful. Going down to meet her and seeing her discomfort, and slowly losing weight.’

He said Tinsley needed ‘familiarity’.

‘Her acute self-harming would occur because people were involved with her that don’t know how to look after her. So, her anxiety would grow.’

A hospital worker believed a worker at the home was ‘punching’ Tinsley in the eyes, and informed the provider and Eduardo. ‘For a month she was getting black eyes that she never had before.’

He tried to ‘get answers’ from the service provider. For more than 30 years, he said, staff had kept the family informed. Now, ‘no-one was communicating’.

Eduardo met with the disability service provider’s CEO and found out the provider had never visited the home. The management told him if he wasn’t happy he could ‘go to another service provider’.

Eduardo feels his niece was neglected because of cost-cutting measures that made it fail on ‘nursing ratio’ and quality of care. He said it was more interested in helping people with a disability ‘with employment and day programs’.

'[Tinsley] isn't able to do any of that. She just sits there. They weren't prepared to spend that money. That's what it boils down to. They weren't looking after the ones that are going to cost them money.'

Eduardo complained to the NDIS Quality and Safeguards Commission, submitting evidence about Tinsley's worsening health. The reply he got was, 'We are not the police ... we don't physically go out and investigate.'

'That's what I had to deal with. They said it was all satisfactory ... That's when I realised, they weren't here to support these people ... that was their attitude.'

Eduardo started to 'scream out' for help for Tinsley, 'because [she] couldn't scream out'.

'If she could have screamed they would have had to take notice. Life is all about communication, so that was her downfall. She just fell through the cracks.'

He feels privatised disability services are getting 'rubber stamped' but often 'don't meet the standards'.

'It fails, sadly, for a lot. They can see that no-one is overseeing.'

Dwayne and Kristina

Dwayne is autistic and has oppositional defiance disorder and attention deficit hyperactivity disorder.

‘He [is] extremely intelligent,’ his mum Kristina told the Royal Commission. ‘Always seeking interaction with others, which is what makes him vulnerable ... That desperate need for the best friend and fitting in has really opened him up to some harmful situations.’

Kristina said that when Dwayne started at a private school, he gravitated to the ‘cool kids’ who manipulated him.

‘It was probably grade 1 where things started to fall apart at the school, where the kids identified that he could be targeted to do something for fun and that he would get in trouble. Which is what happened.’

The school made things worse by excluding Dwayne.

‘He wasn’t allowed to go out at recess and lunch with some of the others, and these particular kids would ... taunt him. The school never really communicated any of this stuff with me.’

Kristina said she learnt about the exclusion practice from other parents whose children ‘were quite distressed at how [Dwayne] was being treated’.

Kristina withdrew Dwayne from the school and enrolled him in another private school that ‘associate themselves as being ASD [autism spectrum disorder] friendly’.

‘He didn’t have any support. They didn’t have teacher aides. Yet they were promoting that they had this interest or experience.’

Dwayne’s behaviour deteriorated at the end of primary school.

‘That year was a devastating year, he was in trouble all the time and there was no supports and their strategy, again, was to remove and exclude.’

Kristina said the school employed an unqualified person to write Dwayne’s support plan.

‘They basically couldn’t manage him. And he’s intelligent so he’s worked out this person has got no credibility, no backbone. So he can dance rings around them as well.’

One day, other children goaded Dwayne into a fight. The school expelled him.

Dwayne began to run away from home, and child protection placed him in out-of-home care.

'One of his behaviours is he ... creates stories when he doesn't get what he wants or when he wants something,' Kristina said. 'So, twice he's made allegations against me and [child protection] were involved.'

The NDIS recently funded Dwayne's complex support needs, including two support workers in out-of-home care.

'No mother wants their child to be out of home. No mother wants their child to be in a two-to-one setting [where] you've got two [support workers] and one child. No person wants that, let alone the quality of some of the carers, which is another issue. [But] that's where he's sitting at the moment.'

Despite having two support workers, Dwayne continues to abscond. One day, he was found living in the home of a stranger. Kristina told the police.

'[The police officer's] response to me was, "Oh, I'm just taking this as a sleepover, you know, 12-year-olds can have sleepovers." I was like, "Sorry, who are you? I'm his mother!"'

Kristina said the NDIA is threatening to remove funding for Dwayne's two support workers and she is 'box ticking continuously'.

'We've got police involved, fighting with [child protection] because they need to be involved, but they say it's NDIA, and all this back and forth. We're continuously going through ... crisis after crisis. ... He's been put more and more at risk and he's vulnerable to further abuse, to sexual abuse.'

Zola and Bernard

Zola and Bernard met on the first day of primary school in the late 1960s, at a school for children with physical disability.

They became instant friends, rarely apart for the next 50 years, until Zola died a couple of years ago.

‘From a husband and carer perspective, I just wanted what she wanted, what made her happy,’ Bernard said. ‘She wanted to get married, we got married. She wanted to have a baby, we had a baby. She wanted to get a job and live a life like everybody else.’

In the mid-1990s, Zola approached a nearby disability residential village about a job.

Bernard told the Royal Commission he wishes Zola had never taken the job.

The village paid Zola less than \$2 an hour. The premises were not accessible. There were no grab rails in bathrooms and many doors were not wide enough for her wheelchair. There were no disabled car parks and the bitumen was unsealed, making it unsuitable for wheelchairs.

Bernard said there was a ‘wall of discrimination’ between employees with and without disability. Staff yelled at Zola, spoke down to her and called her names. Management pushed Zola to complete tasks that were not safe, such as lifting books in and out of filing cabinets.

One day, Zola’s wheelchair became stuck in the carpet near her desk. She fell, injuring her knee, back and neck.

Hospital staff wouldn’t treat her until they had a worker’s compensation claim number. The employer refused to cooperate because it would ‘put up their premiums’.

Bernard had to engage solicitors to resolve the issue. He was ‘completely blindsided’ when the insurer claimed Zola’s disability was a ‘pre-existing condition’ and she wasn’t eligible for compensation.

Zola’s health deteriorated and her mobility and independence decreased. She went from being able to stand, to being unable to weight-bear at all.

The family had to move to a home the department of housing had modified.

The main bathroom was ‘completely unsuitable’. The porous tiles shredded the wheels of Zola’s wheelchair and Bernard had to line the bathroom floor with sheets.

Zola couldn't use the toilet because it was too high and on the wrong side of the room relative to her 'good hand'. She had a serious fall when trying to use the toilet by herself and became afraid to go to the bathroom alone.

A few years ago Zola needed to have a colonoscopy, but could not complete the colonoscopy preparations at home because of the toilet.

Bernard repeatedly asked the hospital to allow Zola to complete the preparations in hospital, but they advised it must be done at home.

Zola didn't know what to do and kept delaying the procedure.

Bernard tried to get the department of housing to modify the bathroom. When they refused, he bought and installed a new toilet himself, but couldn't seal the floor. Zola had to spend the entire day sitting on the toilet while she completed the preparations.

Eventually, Zola was diagnosed with bowel cancer that had spread to her liver.

Doctors gave her mild chemotherapy which 'didn't do anything for her'. 'They told her to go home and die,' Bernard said.

Bernard found a liver surgeon at a different hospital who removed most of the liver. As an outpatient, Zola started strong chemotherapy. She developed a urinary tract infection and had to be admitted to hospital.

Bernard said hospital staff were extremely lax about infection protocols even though they knew Zola was on chemotherapy and had virtually no immune system. He was horrified when they placed her in a general ward 'with people who had the flu'.

'It was because she was presented as palliative care, they didn't give a damn,' Bernard said.

Zola contracted influenza and died.

'In the 60s, 70s and 80s, people with disabilities were teased, ridiculed, given a low self-esteem, belittled, bullied, beaten up ... We thought [those days] were gone ... However, adults with disabilities are still being discriminated against, are still sneakily being bullied and taken advantage of.'

Bowen

‘It’s like I wake up and go to war every day, because you basically have to change everything about yourself and who you are as soon as you walk out that door just so you can manage in the everyday world.’

Bowen is a First Nations man in his 30s. He is autistic and has attention deficit hyperactivity disorder (ADHD).

‘I was identified as a smart, gifted child who had what we’d now see as a lot of the key indicators of being neurodivergent,’ Bowen told the Royal Commission.

Bowen dropped out of high school after a ‘bout of very serious depression’.

‘And that led to me being misdiagnosed with a borderline personality disorder ... People who normally would’ve been diagnosed [with autism] between sort of the ’80s and the 2000s are something of a lost generation of autistic because this is when it sort of fell out of vogue.’

Bowen eventually returned to school and went to university to complete a master’s degree.

One day a few years ago, when he was presenting a paper at an academic conference, he met a colleague who was autistic.

‘Sharing stories with them, I identified in myself a lot of similarities.’

Bowen found a psychologist who diagnosed him as a ‘textbook case’ of ‘high-functioning autism’. ‘And ADHD ... which sort of rocked my world quite a bit.’

The diagnosis cost several thousands of dollars, most of which his health insurance didn’t cover.

‘What a lot of people don’t talk about is the ongoing cost [of appointments and medication] ... I joke that I work to afford my support network, so that I can work, so that I can afford my support network, so that I can feel strong enough to go to work.’

Bowen wants to buy a house, but worries the expense and the ‘regular payments to the psychologist’ in his bank statements will impact how much he can borrow.

When he declared his diagnosis to his employer, it didn’t help him.

‘There’s a lot of, “Hooray, we’re disability-inclusive.” And, “We believe in everyone.” But only certain type of disabilities. Like, “We’re more than happy to put a ramp in for someone who has a wheelchair.” But someone who maybe thinks a bit different or needs certain allowances in other areas – that’s too much.’

For example, Bowen said he's more productive when he works from home, away from the 'noises and fluoro lights' of an office.

'There was resistance to allowing me to log in remotely to finish my work once I got home. It was like, "It has to be done at work between this time and this time, and otherwise you're not performing.'"

Bowen's manager told him he wasn't 'a good cultural fit'.

'I've been passed over for management opportunities that other people within the organisation thought that I might get. And [the opportunities] have gone to people with ... less time within the organisation, who are less qualified. Once or twice I'd put it down to just bad luck. But it consistently keeps happening which, you know, you sort of start to see a pattern there.'

Lexie

‘What they said in the orphanage is that we’d all amount to nothing. And I don’t want to feel like that. I want to feel like I achieve something in my life, or become something.’

Lexie is a 60-year-old First Nations woman living with anxiety, depression, post-traumatic stress disorder and chronic medical conditions. She has panic attacks and self-harms.

As a child Lexie lived in an orphanage run by a church, and then with a foster family.

Lexie told the Royal Commission that staff at the orphanage and members of her foster family emotionally, sexually and physically abused her.

In primary school, teachers told Lexie she had ‘special needs’ but she doesn’t remember getting additional support.

She attended several primary and high schools and there were always problems with her records.

‘My name got changed so many times, everywhere you went. And then your education stuff’s in all different names.’

Lexie was bullied and physically abused at every school she attended.

She developed anxiety and extreme nervousness, which caused incontinence. Staff would then punish her for being incontinent.

Lexie said the problems with her records made it hard to get a job. ‘When you go to go for a job, you’ve gotta prove who you are, and it’s been ... messy.’

Lexie wanted to work as a teacher aide but was not able to because she struggles to read and write. ‘There’s not much out there I’m qualified for.’

Lexie works as a cleaner in a special needs school. ‘I felt very comfortable working there, because of my own literacy and health issues.’

Recently, she has had to take leave because the work causes her severe pain. She sometimes spends days in bed following a shift because of her sciatic condition.

Lexie has discovered that acupuncture and massage help her manage the pain.

‘They take all my pain out of my whole body ... I can get around for a good week or a week and a half after I’ve attended that.’

She asked the NDIS to fund these therapies but they refused, 'which is really upsetting'.

She also wanted the NDIS to help her with her literacy. They told her someone could take her to the library, but she feels 'there could be more achieved'.

Lexie is critical of Centrelink. She believes staff don't understand and adequately support First Nations people with disability. She finds the application process frustrating and discriminatory.

'My voluntary work is what I really like to do,' Lexie said. She visits families and takes food packages to people in the community. To help fund her transport costs, she applied for the Centrelink Mobility Allowance but was unsuccessful.

Lexie is very worried about what will happen to her when she gets older. She doesn't want to end up in a facility run by a church.

'I do worry about aged care, and a lot of our people ... We've sort of lost a lot of faith in religion, Christianity ... because [of] many of the things they did to me in the home, with the devil and the scaring tactics ... I want to just see more healing, a healing journey for a lot of our people. A sense of belonging somewhere.'

Magnus

Magnus, late 40s, was born in Australia but grew up in a country where it was 'a criminal offence to be gay or bisexual'.

As a young bisexual man Magnus lived in fear.

'[I was] bullied, threatened every day because I had visible mental health issues, with the severe depression, but underlying there was a psychosis there.'

In his early 20s, back in Australia, he attended a community mental health clinic after an attempted suicide.

The psychiatrist insisted Magnus did not have psychosis and gave him antianxiety medication, which had severe side effects. Magnus slept for 13 hours a day and was insatiably hungry when awake.

Magnus returned overseas briefly and was able to access more appropriate medication.

Back in Australia again, Magnus attended the community mental health clinic and saw the same psychiatrist. The psychiatrist diagnosed Magnus with schizophrenia and prescribed clozapine.

Magnus said the psychiatrist did not tell him about the significant side effects of the drug. He felt constantly dizzy and experienced memory loss and couldn't form new memories.

He asked if he could discontinue the medication, but the psychiatrist dismissed his concerns as imagined and part of his psychosis. When Magnus refused to consent to the drug, the psychiatrist said, 'If you don't take this medication, you'll get no medication.'

Magnus asked to see a different psychiatrist but the clinic refused. 'There was no right to a second opinion.'

Magnus made a complaint and requested his health records, but was told he couldn't access his own files as the files contained distressing content and it would not be in his best interests.

Magnus stopped taking the clozapine and discovered many services refused to support him. A counselling service refused to treat him because they considered him too much of a suicide risk.

'None of the services were available to me ... If you have a mild mental illness and you aren't on medication, you receive no help.'

Magnus eventually saw a different specialist and was diagnosed with a heart condition caused by the clozapine. Nine months later he was diagnosed with non-Hodgkin's lymphoma which, according to his haematologist, is also associated with clozapine use.

Magnus now takes a different medication and has had minimal side effects for the past 15 years.

He recently developed a serious issue with his bowel, which he attributes to his past use of clozapine. He had to have surgery to remove his colon and anus and now lives with a colostomy bag. This has had a profound impact on his quality of life.

‘Being queer and losing your colon and to have no anus is basically the end of your sex life.’

Magnus considers himself both mentally and physically ‘profoundly disabled’ and feels isolated from society.

‘I find on a physical level now, I’m not accepted in the queer community. If I mention neurological problems, they’ll ask me how I developed them. If I tell them I have schizophrenia, it’s almost like social ostracism.’

Magnus has moved to a different city but said his diagnosis of schizophrenia makes things difficult.

Recently he went to hospital because he was having problems with his stoma. He said once doctors saw the schizophrenia diagnosis, they didn’t take his concerns seriously and discharged him. Later that night he returned to emergency and had to be admitted to hospital.

‘I think sometimes the hospitals, if you have a psychosis or a schizophrenia diagnosis, you do not get the same level of care that other patients would.’

Magnus believes if he had been given appropriate medication, he could probably have worked and had a relatively normal life.

‘What happened to me is far worse than anything I’d ever dreamt about ... having reduced quality of life, having the stigma of psychotic illness and all the limitations in my life that would bring me all the disbelief.’

Laurel

‘Living in rural areas, our mental health is real. But it doesn’t matter what we’re suffering, nothing is happening to give us natural justice – except God.’

Laurel is a First Nations woman in her 60s living with mental health issues and diabetes. She lives in a regional town of South Australia where she has struggled to get disability supports.

‘There isn’t enough access with the hospitals and any kind of social services for disabled people. It’s very limited and restricted,’ Laurel told the Royal Commission. ‘I know that for whatever’s ailing me, I need counselling so that we can really get to the grassroots of helping me sort out my head.’

Laurel said she’d applied for NDIS funding three times and has been ‘rejected outright’.

‘They just keep closing the doors, one door after another.’

She faced ‘constant barriers’ with her application because of a lack of available medical and legal support. The assessments required are expensive, and appointments hard to come by.

‘For mental health I’ve been on the waiting list for six years to see a psychiatrist. How much longer do I have to wait, you know?’

Initially health professionals doubted her. ‘I’ve suffered a lot of abuse and – mental and physical – and they just didn’t believe it.’

Now, she says, ‘there’s not enough psychiatrists or psychologists out there’ to help – and those she’s seen have been ‘teenyboppers’.

‘And they’re trying to tell me what to do with my head. They’re children, for goodness sake ... And this is the sort of thing that I am up against.’

Laurel said rural areas need psychiatrists ‘that are real people, not children’ to care for people like her.

She also needed legal advocacy for her NDIS applications, but ‘nobody wanted to part with any legal aid’ to support her.

‘Every legal place shut me out, and I couldn’t believe it, because I wasn’t capable of putting down my full story without support. I had to do it myself and I fumbled every time.’

At one hearing, the NDIA barrister was an 'outright bully', Laurel said. 'He just did my head in.'

Laurel currently travels to the city for health care a few times a year.

'At home, they still don't believe it when I say that there's something wrong with me ... The doctors sit and say, "no, no", until it's almost too late. I've died nearly three times because of their mistakes. That's how it's been, and it has a profound effect on my mental health.'

Nursing staff at the local hospital are 'too scared' to come near her. 'They think you're diseased.'

The journey to see specialists takes Laurel about four hours and is costly. She believes the support she needs should be available at home.

'And I know that a lot of the agencies have got the funding – especially Aboriginal funding – for all sorts of programs that can be implemented, but no.'

After a 'five-year disadvantage' seeking NDIS supports, Laurel has now surpassed the eligibility age limit.

Without funding, she's had to choose between the prohibitive cost of her 'disability expenses' – the medication and health care – and healthy food.

'All I can afford is processed foods ... That has actually enhanced my disability quite a bit.'

Chaya and August

Chaya is in her 30s. She started developing symptoms for borderline personality disorder (BPD) about 10 years ago.

Her dad, August, told the Royal Commission it took nearly four years for Chaya to start receiving treatment.

‘With [BPD] you get anxiety and depression, and if you don’t understand what you have ... the symptoms of the illness get worse.’

A few years ago, doctors diagnosed August’s wife with cervical cancer.

‘Twenty days after my wife was diagnosed, we had a complete team. A holistic group of people were actually treating her ... We were confronted with how quickly this was happening, compared to our daughter’s situation.’

August said the medical system treated his wife’s cancer with more respect than it treated his daughter’s mental illness.

‘Both these illnesses do kill people in Australia. In the case of cervix cancer, the number is 238, I think it is. And in the case of [BPD] ... I have a personal belief that it’s far greater.’

August described the empathy that doctors and the community showed during his wife’s cancer treatment as ‘humbling’.

‘Amazing empathy. But if I talk mental health, no empathy.’

August said psychological support was ‘hard-coded’ into his wife’s cancer treatment plan. ‘In my daughter’s case, we have to fight for it.’

Chaya is supported by the NDIS and was pregnant when his wife was being treated for cancer. When doctors admitted Chaya to hospital in her third trimester, the NDIS cut her funding while her plan was being reviewed.

‘We protested and eventually got that corrected about six weeks later. However ... during the time she had the birth ... she had no support from any of the professionals because all the meetings were actually not being managed.’

August said doctors gave Chaya ‘varying levels of pain medication, including opioids’.

‘What I learned was [the pain medication] directly impacts the rate and effect of her mental health medication, impacting her anxiety and depression. Not one doctor talked about that. Not one doctor pointed out that the effect of those pills [combined with other drugs] can kill you.’

In contrast, 'every single day' during his wife's cancer treatment, hospital staff told August how carefully they were managing her medication.

'We were given an almanac that tells everybody what's happening with [her] medication, and the connection between lots of different pills that she was taking to get through the treatment.'

Chaya now has a medical team supporting her, but August is worried the NDIS will cut her funding again.

'That's like my wife going through chemo and radiation treatment and right in the middle of that we stop. We just say, "We're not doing any more radiation treatment anymore. We're going to stop it." ... The community would react and that's, I guess, my point. If it was this situation with my daughter, no-one would care.'

Hendrix and Jacoby

Hendrix has dementia and early onset Alzheimer's disease, and has lived in an aged care residence for about six years.

'That was one of the best facilities in South Australia in my opinion,' his brother Jacoby told the Royal Commission. 'But it deteriorated when the change of manager came in, everything went astray.'

Before that, there were monthly meetings where residents and family could 'share concerns about food or – or about care issues' at the nursing home. But the new manager put a stop to that.

'She wouldn't allow people to open up and raise an issue. She decided that, no, she would deal with it one-on-one in the privacy of their own room and would not share.'

Jacoby saw this as a way of silencing the critics. 'Anything that came up as a negative issue was covered over, it wasn't mentioned.' People 'were intimidated' to speak out about problems.

One resident was usually 'very outspoken about care issues', but 'all of a sudden, he became very quiet'. 'They're going to kick me out,' he told Jacoby.

Jacoby said his brother's care 'diminished greatly over that period'.

'Having a family member deteriorate in front of your eyes is a problem.'

A couple of years ago, the home 'decided out of the blue' to put Hendrix on opiates, against his doctor's recommendation.

'The care manager talked a locum GP into authorising this medication change – not his normal GP, not myself.'

The manager ignored Jacoby's power of attorney for his brother. When Jacoby complained that the home was 'doing things without even asking for consent', the manager said, 'We're being proactive.'

'And my brother, his rights are being abused with these sorts of incidents that occur. The documents are there, but no-one seems to police it and providers don't care because it's all too hard.'

Jacoby said he witnessed many other cases of neglect at the home. One man developed pressure sores – 'a big indicator of poor management in aged care' – and died. All the complaints were 'covered up'.

'Everything we complained about was factual, except management wouldn't accept it. If we complained, then we were harassed.'

He feels homes should make it easy for families to keep checks on the quality of care, and wants to see the complaints mechanism improve.

'The providers for disability services, aged care services, whatever, should have a standard procedure so any person can walk in and check to make sure that they go along with what's been recognised.'

About a year ago, a quality and safety assessment resulted in the removal of the management at Hendrix's home.

'[But] within three months they just rewrote a couple of policies ... and got their full accreditation.'

Jacoby said it was 'disgusting' that could happen, without 'getting the stories of the family about needs to improve'. Especially after such 'an emotional process' that was 'very stressful for family members'.

'Myself and residents and family have all be complaining about lack of communication and poor staffing, critical problems and avoidable deaths, and the list goes on and on ... and they don't get anywhere.'

Amit and Jayne

Jayne is in her 50s and cares for her former husband, Amit, who has an acquired brain injury (ABI). Twenty years ago, not long after the birth of their son, doctors removed a tumour from Amit's brain.

'Life had just begun. We had just bought our house. We just had our first child,' Jayne told the Royal Commission. 'We were working hard. And our business was about to take off. I think I was traumatised for a very long time, but you've just got to keep going. Because there's no choice.'

Jayne, who lives with an autoimmune disease, said the hospital discharged Amit with little ongoing support and she struggled to care for him, herself and their son.

'We separated [several years later] because ... He has looked at me like I was just someone there to look after him.'

Later, because there was no other support, she moved back in to care for him and help him learn to live independently.

'I knew he could relearn and I knew there was help there, but we couldn't afford the help. And there was no other help for people around our area ... Like, never have we been offered a mental health plan.'

Jayne said as Amit's mobility and mental health deteriorated, so did hers.

'I had a bit of a breakdown ... And never have [local health services] ever, you know, helped with [Amit]. And I asked questions and I looked for, you know, solutions and help. And nothing.'

Jayne said for years, no-one explained Amit's disability to her.

'I had never even heard of ABI until I started the NDIS journey. I never heard of psychosocial until about two months ago ... Like, nobody has even suggested any assessing for that. It has been a lot of years where the door just keeps getting closed.'

A few years ago Jayne helped Amit join the NDIS.

'They did the first plan without my knowledge ... They would have just rung him and he would just go, "Yes, whatever," because he has no idea. This is the man that doesn't remember what you say to him as you're saying it to him.'

Jayne said because she 'worked very hard to live as normal a life as [they] can', all the things she did to support him weren't included in his first plan.

'I was hoping for therapies and behaviour management and daily living skills, because his behaviour is not acceptable.'

When Jayne asked for a review, a woman from the NDIS told her to 'stop living in the past and to get on with it'.

'Then, the next woman that came out told me that I should think myself lucky that someone was coming out because they were so understaffed and so busy.'

Jayne said the NDIS eventually increased his funding, but it still includes fewer than 20 hours a year of physiotherapy.

'Now, this is a man that needs consistent, ongoing, regular movement and exercise. And he's like an old man – he shuffles ... he's incontinent ... And we're still three years down the track [and] don't even have safety rails in our house.'

Initially Jayne employed a support coordinator to help her navigate the NDIS, but they 'rorted the system' by charging for services that never happened.

'She knew how to rort people like me, because I knew nothing at the time.'

Jayne said she still struggles to get adequate support.

'It has changed me as a person ... And what it has taken away from my son and I, you know? And I'm tired and I just want some peace.'

Layton

Layton injured his back in a workplace accident in his early 50s. Some seven years later he is still in constant pain and uses a walking stick and frame to move about. It is difficult for him to get up and sit down, to do household tasks and to walk any distance.

Because Layton was on a work-for-the-dole program when the accident happened, he wasn't entitled to any compensation. 'There's no help, which I think is wrong, and it stinks and it's disgusting,' he said.

Layton applied for a Disability Support Pension five times before he was successful.

He then applied for support from the NDIS – a process he described as 'a nightmare from whoa to go'.

'You ring them up and they just seem to make up their own rules as they go along.'

Eventually Layton met with an NDIS planner, who provided information that turned out to be incorrect. He told Layton that he wouldn't lose any of his existing benefits by accepting the NDIS package, but Centrelink cut his mobility allowance. He told Layton the NDIS would fund a mobility scooter, but in fact it covered only a quarter of the cost. Layton couldn't afford the rest.

Layton's back has been getting increasingly painful and he has developed additional health issues. Several years ago he became suicidal.

Layton contacted a charity that provides mental health services and ended up with a volunteer role in the organisation.

'So I'd do that quite a bit, every week, and that sort of made me feel a little bit better. But, you know, it's hard to try and keep your head in the right space if you understand what I mean when all you're getting is around and around in circles,' he told the Royal Commission.

Layton is at a loss to understand how the NDIA makes the decisions it does.

'I've got friends ... where I volunteer, [who] can walk, do their own housework, do everything and they've got \$120,000. I've got \$27,000.'

This doesn't meet his expenses let alone allow him to save for a mobility scooter.

Layton's back condition is inoperable, so all he can do is manage the pain. He takes medication and exercises. His preferred exercise is hydrotherapy, but he lives in a regional area where the nearest pool is four kilometres away.

'No buses go past there, so I need to get a mobility scooter. But that's not going to happen because they don't want to, you know, come up with the money. They say, "Oh, well ... we'll pay someone to pick you up, drop you off."

But Layton says his NDIS funding can't stretch to that. 'I don't know, I really don't know. What can you do?'

Layton would like the NDIA to develop one set of rules, and for people who work there to know what those rules are.

'Like, if I ring someone up and they're supposed to know it and they say to me, "Well, I don't really know," well, how do you get on?'

Layton has a new care coordinator who is going to help him get his NDIS package reviewed, but there is no certain outcome to the process.

'They warned me that this is going to be good for me, or they could completely wipe it all off and I don't get nothing. So, you know, back to square one if that happens.'

Jamila

Jamila is a First Nations woman. She had surgery on her eye when she was a child and, around the same time, was diagnosed with intellectual disability.

Jamila attended both mainstream and special schools and graduated high school.

Now in her late 20s, Jamila lives with her grandmother and another person who uses a wheelchair.

‘I have responsibilities for running a household and caring for both people,’ she said.

About three years ago, Jamila gave birth to her first child. At the time she was in a relationship with a man who is not the child’s father.

Jamila said the violence ‘was horrific’ – her partner regularly threatened to kill her.

The department of child protection removed Jamila’s daughter and placed her in foster care.

It was a terrible time for Jamila – she had postnatal depression, and a month later her father died. ‘I had no support,’ she said.

Jamila told the Royal Commission that since then, she has done everything the department has asked her to do so she can be reunited with her daughter. She left the relationship, goes to counselling, has completed multiple parenting courses, got her driver’s licence and is studying for a certificate in child care.

But the department refuses to return Jamila’s daughter. They told her ‘a very close bond has formed with the carer’.

‘They have used my disability to their advantage and basically everything I have done, they haven’t taken into account.’

The department won’t allow Jamila to spend time with her daughter without supervision.

‘I don’t know my daughter. They have stopped me from having a bond with her. COVID has stopped me in a very bad way. They want to keep her until she is 18, and I will only see her three to four times a year. My dad was Aboriginal and so is she. The court orders don’t say anything about that at all.’

Jamila’s daughter has language delay and needed to see a specialist. The department wouldn’t allow Jamila to attend the appointments or be involved in any of the NDIS assessments.

‘[I have] just been cut out of the whole parenting role,’ she said.

Last year, Jamila started a new relationship and is pregnant with her second child.

The child's father has been in trouble with the police. The department has threatened to remove the new baby and has told Jamila if she lives with her partner she will never get custody of her daughter.

Jamila said the department doesn't want to acknowledge how far she's come.

'I am a confident woman managing ... a household. Not to mention the steps taken to learn to make sure I am a good parent ... I want my daughter back. And I want to be with her ... I love her to bits. I do everything for her.'

Titus, Kase and Nayeli

Titus has a rare genetic disorder. He is non-verbal and needs 24-hour support. He is in his late 20s and lives at home with his parents, Kase and Nayeli. For the past eight years he has attended a day care centre run by a not-for-profit provider.

Kase told the Royal Commission that when Titus first started at the centre it was ‘very well run’. They offered ‘good services, good training and people that cared.’

Since the introduction of the NDIS, things have changed. Some staff lost their jobs, and those who remained have greatly increased workloads. A fortnightly schedule of different community access activities has been cancelled, and instead a support worker takes Titus to the park for the day.

Kase and Nayeli spoke about their concern that the NDIS has provided cover for people to profiteer, with little scrutiny or oversight to keep them in check. They gave an example of wanting to improve access for Titus at their house, a project that required three new wooden steps.

‘The quote we got from someone who worked with the NDIS was \$10,000 to do that, and of course we didn’t pay it. We got it done for \$1,800 by somebody else that we got independently,’ said Nayeli.

Kase said that since they signed up to the NDIS, ‘almost every company [they’ve] dealt with has sent out fictitious invoices’. Invoices don’t provide details of what work has been done or a breakdown of costs. There are caseworkers who charge \$25 for every email or phone call.

Many other people would just pay it, not even ask,’ Nayeli said.

‘The money is just flowing off the portal for people. Just self-enrichment. And I think we are smart enough to know that if these expenses aren’t reined in then it’s going to impact the NDIS overall.’

Kase described contacting the medical specialists Titus needs to see.

‘Each one you ring up, the first question they ask is not, “What do you need? Who has referred you?” It is, “How much money do you have in your budget?” That’s the first question.’ Whatever the amount, that’s what they charge. ‘You know, I just find that offensive,’ Kase said.

Kase and Nayeli believe the NDIA should standardise invoices so they provide details about the work that has been done and the specific costs. But in their experience the NDIA is not interested in an oversight role.

'If you go to the NDIA and you make a point to go, "This is happening, and this is happening," the NDIA now takes the position of, "We can't do anything about this because this is a private company,"' Kase said. But, he points out, the NDIS is funded by government. "Without our money they don't exist."

The NDIA has also ended Kase and Nayeli's access to respite care. The NDIS funds the person with disability but not their carers. 'People can't get it as part of their package. You can't say, "I need respite for X number of weekends in a year" because it's – the NDIS is not for us,' Nayeli explained. 'This is leaving a lot of parents at their wit's end.'

Nayeli told the Royal Commission there are no answers to their greatest fear. 'What happens to our kids when we die?'

'I just cannot imagine what would happen to him if anything happened to us ... If I got too old and I couldn't do anything ... I would consider taking him with me because I wouldn't know where he was going, what would happen to him, what was on offer. I would have no level of comfort because there is nothing.'

Novah and Avalynn

Novah, 21, has Down syndrome. She lives with her family and has a job with a supportive employer.

Novah's mum, Avalynn, told the Royal Commission the employer has been 'fantastic'.

'The general manager actually said to me, "What can I do to help?" He is the first person in 21 years who has said, "What can I do to help?" Nobody else has said that.'

At the public school Novah first attended, the principal told Avalynn her daughter 'would never achieve anything'. The school psychologist told her she needed to accept Novah's disability. 'I'm traumatised over what that government school did to me,' Avalynn said.

She is concerned that Novah and others like her are 'denied the basic rights of citizenship' because of the barriers they face participating in society.

She said these barriers exist partly because the services that are supposed to help them – the NDIS, schools, disability agencies – segregate Novah and others with disability, so they're mostly unseen.

'So when we go out shopping you get stared at. It's like going to the zoo. We're the zoo.'

The problems begin in the education system, she said.

'We have to beg for our kids to even get educated. We've had a horrific experience from the education system. And it's like "Shut up, just stay at school. What more do you want?"'

Yet, she points out, education really matters and is key to avoiding isolation later. Too often kids with disability are excluded.

'So we're telling normal children and normal parents – it's okay, you don't have to put up with those people.'

She feels people with disability are often underestimated and patronised.

'You get the service providers, "Oh, let's make a macaroni picture." I mean, my daughter's 21. Don't demean her and give her something that a five-year-old would do. And then you bundle them all together ... "Oh, we've got a weekend away, let's do 18 to 65-year-olds." Oh my God, really?'

She explained that in trying to build opportunities for Novah, she keeps hitting dead ends.

'I wanted the local libraries to provide suitable activity for people between the age of 18 and 54. They don't want to. They do it for earlier, kids before they go to school. They do it for over 55s. But they refused to do it. It is not their role to cater for somebody like my daughter.'

Avalynn says that for people with intellectual disability, connecting with others socially is difficult, particularly when support workers are happy to sit with their clients and watch TV for three or four hours.

**'Or by being told "Oh yes, you can go to a park to form friendships."
... How would you like it – an 18-year-old being friends with a four-year-old? And where is that dignity and respect?'**

Avalynn has become an advocate for increasing the visibility of people with disability and creating connections in their local communities. She sometimes feels the fight is too hard, and wonders if she has done Novah a disservice by wanting more for her.

'It's like, you know, little orphan Annie, where you took somebody out of an orphanage for complete luxury, and then put her back. So have we done our daughter any good? Should we have just ignored her, so she didn't know what [she] could be? ... I don't know. But I think that's how all parents feel ... You will have heard a lot of parents just say what I've said.'

Giovanni and Martina

Giovanni is in year 6. He and his mother, Martina, are both autistic.

'I am an exhausted parent, who has tried to advocate and fight for the right of my child to an inclusive and abuse-free education within the state school system,' Martina told the Royal Commission.

Giovanni attended a primary school in Queensland. Before he started, Martina met with the principal to agree on a transition plan. The school's head of inclusive education was present too.

'She was fantastic ... I really felt that she understood the process and that we were setting him up for success, rather than setting him up to have a difficult time.'

Giovanni was excited and 'looking forward to going to school'. But Martina said 'it became apparent really quickly' that the support wasn't there, which was 'one of the biggest shocks'.

Martina had informed the head teacher that she'd recently left Giovanni's father, and that both she and her son were 'victims of inexcusable domestic and family violence'.

The principal also knew Martina had applied for sole parental responsibility, but a court order meant the father was still involved. He was 'in the teacher's ear' and 'coaching her from the sidelines', Martina said.

'So I think that anything that I had to say about [my son's] disability and his needs was completely dismissed.'

Martina had 'many interactions with the principal that were manipulative and abusive' or 'deliberately overt in their warnings'. The principal was 'constantly monitoring' her.

Once, Martina was working at the school crossing, watching as her mother dropped Giovanni off to class.

'As usual, he didn't want to go and he didn't want my mum to leave. My mum was calming him and about to leave.'

The principal 'witnessed this distress', but 'without introduction' steered Martina's mother away and said, 'Come on, nanna, it's time to leave.'

Often the principal would have staff 'coax him away' in a similar manner. Martina said the idea was always to separate Giovanni from his family, 'regardless of the distress it caused'.

The school's 'failure to provide adequate supports' impacted Giovanni's 'mental and physical health'. He had a 'big meltdown and shutdown', and for months had 'debilitating' agoraphobia.

'He just didn't speak, didn't eat, didn't wanna sleep. He would have a panic attack if we were to

try and leave home ... He couldn't get to a psychologist because the agoraphobia was so bad.'

Giovanni is now doing distance education and things have improved.

'We're back down to a sort of calmer space ... It's a very insular world we are living in. But I do make sure that he keeps contact with the school friends and we invite them over to sleep.'

Martina feels her son was 'pushed out' of mainstream education. She has left the door open for Giovanni to return to school, but for now, 'he's terrified'.

'I think since then there's been so much trauma, the idea of being in a room full of people ... It's really intimidating.'

She said schools need to individualise the 'vague framework' of reasonable adjustments, 'because every child obviously has a different need ... a different disability'.

Roslyn

Roslyn is in her 30s and is autistic. She told the Royal Commission she was diagnosed in high school and was 'doing very well' until she was admitted to a hospital mental health unit.

'The people put an estate guardianship and trustee order on me ... I don't know who asked for the trustee and guardianship order.'

Roslyn was then moved into a group home.

'I didn't want to live in a group home. I couldn't have my cat in the group home, and my cat was my best friend for a long time because I didn't have many friends in school. So that didn't help.'

The group home provided little support to Roslyn.

'They didn't understand me, and I went to hospital a lot and even ended up in jail. And that was scary because I didn't know why I was in jail for a week.'

Roslyn was told she'd assaulted someone, but has no memory of the arrest. She was given no advocate in jail. At that time, the public trustee and public guardian were making decisions for her.

'One time, I remember I wanted to go to the dentist ... and the trustee said yes, but the public guardian said no, I couldn't go to the dentist.'

Another time, when doctors tried to discharge Roslyn from a mental health unit, the public guardian wouldn't let them.

'The public guardian said that I had to stay in the mental health unit longer, and I don't know why I had to stay there longer, but the doctor said I was allowed to go home ... Then the doctors wouldn't let me go home after that.'

Roslyn said when her father became guardian, he took her out of the group home 'because he didn't like one of the support workers in the house'.

'I moved back with my mum and dad and they started putting rules on me ... like I can watch TV only for an hour ... I can only see Christian people, Christian counsellors, and I didn't use a behavioural management therapist because there wasn't a Christian one.'

Roslyn said she 'got sick of the rules' and moved out of her parent's home. Her sister is now her guardian.

'That was a better decision. My sister's done really great with all the handing over and everything. So it's been really good.'

Brittany and Ileana

Ileana is a First Nations woman in her 40s. Her daughter Brittany goes to primary school and is autistic.

'[Brittany] experienced trauma quite young when she was pulled out of [Country] and her life changed very quickly,' Ileana told the Royal Commission. This happened when the family moved to access therapies for Brittany. It was a difficult time for her.

Things didn't go well at Brittany's suburban mainstream primary school.

'One of the challenges I find is that her disability is invisible to the eye. She's very approachable, beautiful, engaging,' Ileana said. 'And it's not until behaviour becomes tricky that it becomes visible.'

Teaching staff failed to provide the support Brittany needed or recognise her learning style, which was rooted in stories and her cultural identity. The principal used 'techniques' with Brittany 'that were red flags', and had Brittany's therapist removed from the school.

'That became really scary, because we knew [Brittany] wasn't safe,' Ileana said.

Teachers made Brittany feel like she was 'naughty', which was highly distressing to her. She became so fearful of school she didn't want to go. She 'deeply regressed'.

'We couldn't get her to the front gate. She was wetting her pants coming home with different clothes that weren't explained.'

Ileana found a new school for Brittany, that is 'like a unicorn'. There are better teacher-to-student ratios and there is the sense that parents and teachers are working together for the benefit of students.

'The kids are all in together. There is no H Block or special unit. All the kids are together, whether they're blind, autistic, Down syndrome, cerebral palsy – they're just in the class together, and they're writing programs for kids ... They've got structure, support.'

Brittany is enjoying school again.

'She has not looked back. And she runs through the gates there.'

Zya

Zya, a registered nurse, worked as a support worker in group homes for nearly three decades.

‘When I came to Australia I couldn’t get a job, so then I did some volunteer job,’ Zya told the Royal Commission. ‘I feel like it was so rewarding when I worked with disability ... so I really want to share.’

Zya kept a diary, documenting cases of abuse and neglect at group homes.

She said sometimes her service provider didn’t give sick or injured residents timely medical attention. For example, one day she arrived at work to find a man in pain with his leg ‘swelling and blue’.

‘I ask one of the staff, I said, “What’s happening?” He said, “He had a fall this morning,” and I said, “But nothing been done about it?” I read quickly the report [and] there was nothing being done.’

When she contacted a manager, they told her it wasn’t an emergency. When she returned to work three days later the man was still in pain, so she took him to a doctor.

‘He had to have all these medical procedures and everything.’

The service provider moved Zya to another group home.

‘I work for [years] in this house, it was awful. English my second language, I don’t know what word I can use. I never see residents treated that bad when I was in that hell.’

Zya was often rostered alone on shifts and had to shower and lift residents without help.

‘One day, one of the residents ... actually fall on me. I hurt my back. Then I have to go and WorkCover ... And then when I came back they say, “We don’t want you here.”’

Zya documented staff overmedicating one resident, who later vomited blood. When she made a complaint she was ‘suspended for a couple of weeks for writing all this’.

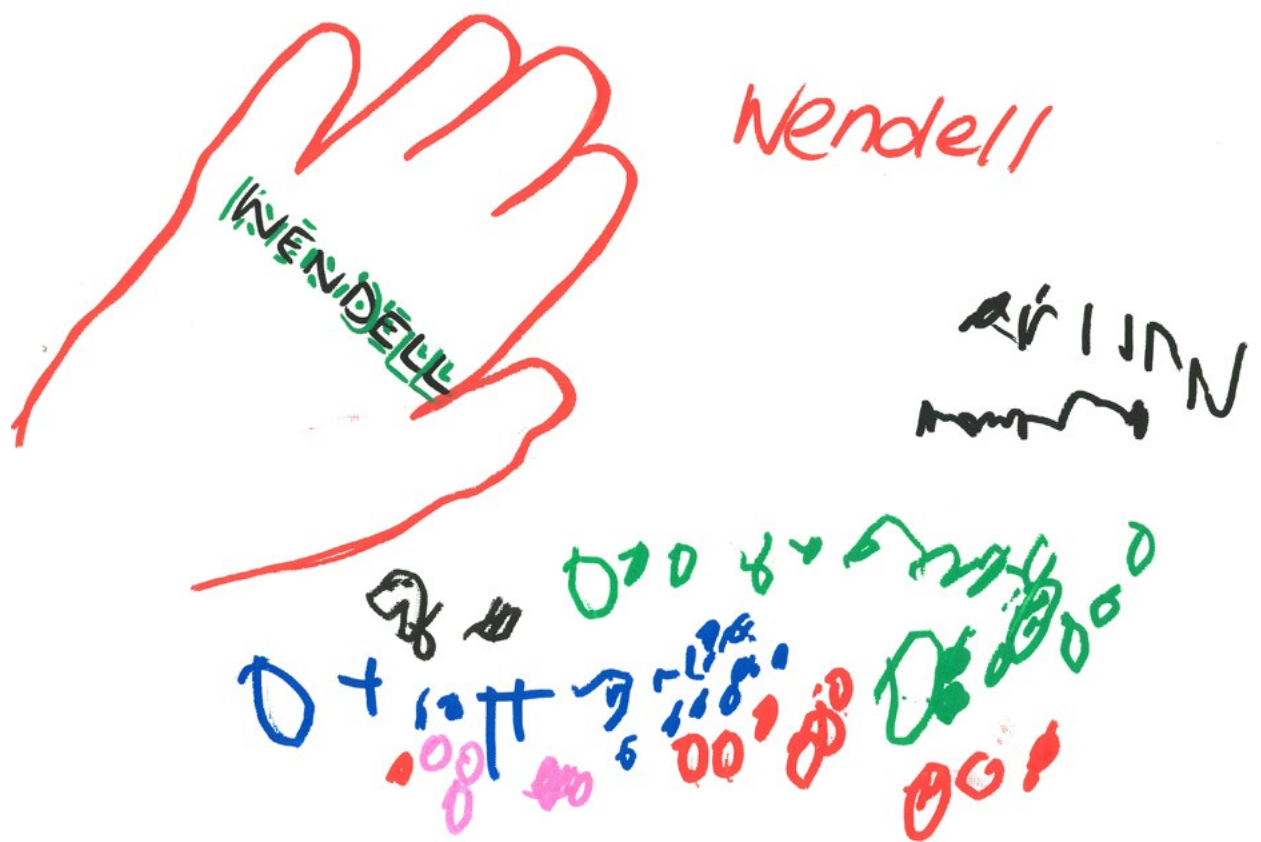
The service provider regularly gave residents food that was past its use-by date.

‘They make food for months, they keep it in the fridge ... Salami and all this thing, and they put it in the freezer and then they take it out and they use it for a week. And I told the supervisor, “I know that it’s expired. You can’t give that to residents.” She said, “You’re here to make the sandwich.”’

Zya said one of the residents developed food poisoning.

Another time, staff took a wheelchair away from a resident for several months because she was annoying them.

The service provider sacked Zya for documenting the abuse she witnessed.



Artwork by Wendell Harper

Aubrey and Michaela

Aubrey is a young First Nations girl who is autistic and has attention deficit hyperactivity disorder and generalised anxiety disorder.

Michaela knew her daughter was 'different' when she began having meltdowns in preschool. Aubrey would cry when Michaela dropped her off. After she left, the teacher would tell Aubrey she 'needed to act normal'. This annoyed Michaela and prompted her to move Aubrey to another school.

Grade 1 at the new primary school went smoothly for Aubrey. 'She loved her teacher.' If her usual teacher wasn't there, the school allowed Aubrey the flexibility to go to another class with another teacher she liked. 'She still had anxiety but not ... as it is now.'

Problems emerged the following year when two teachers taught Aubrey's class in a job-share arrangement. Michaela told the school this wouldn't work for Aubrey because 'kids on the spectrum don't deal with different people'. The school said the two teachers were similar personalities and it would work.

Michaela 'gave it a go', but Aubrey became increasingly anxious. Her anxiety would begin to mount a day or two before the second teacher's day.

As the school seemed unwilling to make suitable adjustments, Michaela kept Aubrey at home on the day the second teacher worked.

Aubrey attended school during the COVID pandemic to keep her in a routine.

Aubrey excelled during that period. Limited class sizes meant less stimulus and a closer relationship with the teacher, who was able to give Aubrey the attention she needed.

Once normal classes resumed, there was too much stimulus and she no longer had as much of the teacher's attention. Aubrey began having meltdowns. The school started suspending her.

'To me, suspending a kid with a disability out of something they can't control, is cruel.'

The school suspended Aubrey for four days. To avoid further suspensions, Michaela asked that next time teachers contact her before Aubrey's behaviour escalated. The school agreed.

Two days later they suspended her again, offering no reason. Michaela asked the school to implement a behaviour plan for Aubrey, but they refused.

The morning after the next suspension, Michaela noticed pinch marks on her daughter's leg. Aubrey seemed reluctant to tell her mother how she got them, but eventually told her, '[The teacher] pinched me with her fake nails.'

Michaela approached the school principal about the incident, but felt 'shafted' when she received no response. She was told the 'case is closed'.

Michaela escalated the matter to the departmental regional office, but felt she 'got ignored'. 'I was trying to ring ... no-one was returning my calls.'

When the school suspended Aubrey for 10 days, Michaela – with the support of Aubrey's doctors – removed Aubrey from school for six months.

Aubrey had 'ups and downs' during that time.

'We've had holes punched through the walls ... I've been bitten, sworn at, spat at.' Aubrey attacked family members, and said she wanted to die. 'Tell the police to shoot me dead,' she told her mum.

Michaela finally found a new school which Aubrey is slowly adapting to.

Michaela believes the current system of inclusive education doesn't work. She says schools don't use the funding they receive for inclusion measures on teacher aides and supports for students with disability, but divert it to other projects.

Finnley, Izaiah and Davina

‘I dropped him off at school a happy, functioning, interested, curious, quiet little boy. And then within years he became this dysfunctioning, sad, upset, isolated, traumatised, loud, self-harming child who had lost any ability that he arrived with.’

Davina is a sole parent, the mother of teenagers Finnley and Izaiah, who are autistic.

‘My eldest son [Finnley], he loves to cook and he loves to be in nature and he’s a very peaceful, sort of, quiet, very active young man,’ Davina told the Royal Commission. ‘My youngest son [Izaiah] is very cheeky. He is very creative. He loves to build things. I think he built his first clock when he was seven ... He’s incredibly smart in a way that I will never be. But, of course, he has his challenges.’

Although Finnley doesn’t speak much, he could read and count before he started kindergarten. ‘He had beautiful penmanship. I mean, his writing from the age of four was incredible,’ his mother said.

When he started school, however, he stopped reading and writing. Davina said the school resisted showing her Finnley’s individualised education plan.

‘There was lots of music and movement and stacking blocks and colouring in shapes and I thought, “My God, he has got stacking blocks years ago.” ... They didn’t expect him to be able to read and write.’

Davina moved him to another private school where he came home ‘sad and frustrated’ every day.

‘They said, “You know ... he’s just not interested in learning. He can’t really learn. We let him just run around outside in the yard.”’

Davina recorded Finnley reading a book aloud that night and played it to his teacher the next day.

‘I shouldn’t have to go to these lengths to get them to teach my child to read and write.’

Davina said whenever there was a problem with Finnley, the school asked her to pick him up.

‘There was never an expectation in the school that they would have to figure this out themselves.’

Davina enrolled Finnley at another school.

‘Within a year ... [Finnley] had completed [a state reading competition] for the first time. He got the school award for mathematics for the first time. Nothing changed with Finnley in that year. It was the teacher that changed.’

Davina said Izaiah had similar experiences when he transitioned from kindergarten to year 1. One day, the school told Davina that Izaiah kicked a teacher.

‘They may as well have said, “You need to come get him. [Izaiah’s] turned into a penguin,” because it was so far out of what I’ve ever seen him do.’

Davina said a meeting at the school turned into an ‘ambush’ by three staff members.

‘They had a piece of paper and they read out a list of all the things that he had done wrong that term.’

Davina asked them why they hadn’t told her about his behaviour when it happened.

‘And, “Why are these things happening? Because this was not behaviour I have ever seen anywhere else before.” And they were just basically saying, “Well, he’s just a bad kid and it’s his disability.”’

The school increasingly asked Davina to help them manage Izaiah and take him to school activities.

‘I need to work to provide for my kids, [and] that’s on an hourly or a project basis. Every time they call me in, I lose a day’s pay. And when they’re calling me in every day, I lose the contract ... Every time they ask me to do their job for them, I lose pay and they get paid regardless. They don’t understand the impact.’

Davina told the Royal Commission that Isaiah is ‘being damaged’ by an education system that isn’t equipped, and teachers who aren’t trained to help him.

‘My children ... have both been traumatised at one point or the other and developed mental health issues as a result of that. Both of my children have been medicated for anxiety,’ Davina told the Royal Commission. ‘They didn’t need it until they had bad teachers.’

Kerryn

A doctor diagnosed Kerryn, who's in her 50s, with chronic fatigue syndrome nearly 30 years ago.

'I was bedridden and I was unable to do many self-care activities,' Kerryn told the Royal Commission. 'I couldn't brush my own hair. I couldn't cook for myself. I couldn't eat sitting up ... If I did maybe push myself to sort of get out and play with the kids for half an hour, then I would have some very dreadful days to follow.'

Kerryn gave up her nursing career and asked Centrelink for support.

'I was eligible for a sickness payment ... But there were certain [reporting] requirements involved, which were exhausting for a person who's already sick.'

Centrelink rejected her application for the Disability Support Pension (DSP).

'I decided to appeal. And so, I had my doctor's certificate from my doctor who was currently looking after me with my chronic fatigue.'

Kerryn said she appeared before a panel of three people to answer questions for 45 minutes.

'I normally couldn't really sit up at all ... They just fired questions at me, very judgemental questions, to try to disprove my condition ... Just saying things like this: "You look, you know, like there's nothing wrong with you. You look perfectly fine." And I would say, "You can't see it. It's inside. It's fatigue. It's inside of me.'"

When asked what it felt like, she described the feeling of shaking inside. Kerryn said when a panel member asked her to hold out her hand, they accused her of lying because her hand wasn't shaking.

'They [said] words to the effect of, well, "See? See? You're lying. Just proved that you're lying," kind of thing ... That's what the whole interview was like.'

The panel rejected Kerryn's appeal. Afterwards, she developed post-traumatic stress disorder and feared getting out of bed in case she was being watched.

'I was very afraid these government officials were calling me a liar. So, I became more reclusive than I already was.'

When Centrelink changed the way it assessed eligibility, it gave Kerryn the DSP.

'In the end all I did was stroll into the office, meet with a nurse, and she said, "Oh, you poor thing. That's terrible. And of course, here you go, green tick.'"

Kerryn said nearly 30 years later, she still worries about going back to work or studying.

'I'm afraid they might [say], "Well, if you could do one hour's work, then you're lying to us."'

Kerryn said she was initially reluctant to tell the Royal Commission her story of 'this very small thing that happened to [her]'.

'Then I thought about what impact that one meeting has had actually on my life and it's, well, it's quite an impact. And I thought that it's worth recording. It was wrong. It was wrong the way that I was treated.'

Rinaldo

Rinaldo is in his early 20s. He has cerebral palsy, an intellectual disability and uses a wheelchair.

Over the past couple of years he has tried several disability employment services in his efforts to get work.

'But nobody's helped whatsoever,' he told the Royal Commission. 'I've been through, I think, five or six consultants.'

One of the latest providers he turned to was 'the worst'. The company had 'more clients than it did support workers' and wasn't doing its job. Rinaldo felt the director 'put on a facade' and made lots of empty promises.

'She dressed up her company and dressed herself up like she was God's gift ... She was rah-rah-rah, she was going to be doing that for me ... leading people with disabilities into a false sense of security.'

Rinaldo said the director exploited him and other clients, 'keeping' them onsite during gaps between shifts 'so she could benefit'. 'She was sly and would make it so that a support worker is going to be paid for the gap.'

The agency was overcharging him but 'providing a crappy service all around'.

'I would be getting served about eight invoices in a week ... I need to go over those invoices with a fine toothcomb, because nine times out of 10 they would overcharge you three or four hours just because they could.'

Other clients were also unhappy about being 'ripped off'.

'She reeled us in, you know, hook, line and sinker and then it certainly went downhill from there – I just think the way they do things is completely wrong.'

The 'tipping point' came when the director heard Rinaldo and others planned to leave the company. 'Four hours later when I'm at home I got a termination of services.'

The agency continued to send Rinaldo bills after he left.

'I had \$6,000 I had to pay them. I said, "That's all been paid. As far as I'm concerned, I don't owe you anything."'

He reported the provider to the NDIS Quality and Safeguards Commission which, he says, 'just swept it under the carpet'.

'It says, oh, we're there to help you. I've reported so many things – and [provided] various documents I was requested, but they did nothing.'

He believes current laws stop people with disability speaking out about injustices, instead of protecting them when they 'holler'.

'I want people with disability to be taken seriously and to be heard – it was disgusting the way that we were treated. People should be allowed to say, hey, this company's done this, instead of being censored for fear of, you know, being taken to court for slander.'

For the past eight months, Rinaldo's been with another disability employment service.

'I actually got a job at [a large retail outlet]. I've been there for almost three months. It was no thanks to them I got that job. I did it all on my own.'

He hasn't let his consultant know.

'Why should she get commission when she actually didn't get me a job? That, to me, is in a way taking advantage of me. I feel like they should be doing a lot more.'

Ridge and Shay

‘They treated [Ridge] as yesterday’s garbage, and they threw him to the kerb to die because he had a disability. Because in their own words, he was “deadwood”.’

Ridge was married with a young child when he suicided a few years ago at the age of 30.

Ridge had intellectual disability and was autistic. He was able to read simple sentences but found complex documents difficult to understand. Shay, his mum, described him as a ‘beautiful soul’ who would do ‘anything for anybody’.

Following high school, Ridge worked at a large retail store as a ‘trolley boy’.

When management ‘questioned his capacity’ and refused to let him work on the checkout ‘because of his disability’, he left.

Ridge’s next employer gave him the opportunity to work on the checkout. ‘He was a valued employee and he loved his job, until the company fell over.’

Ridge moved to a smaller retailer. Management and other workers harassed, bullied and intimidated him daily, calling him a ‘retard’ and ‘idiot’. He found the environment so stressful he resigned after a couple of months.

Next, he got a job at a large hospital providing general support. Initially it was a good experience and he was given a lot of work.

Then one day, Ridge was involved in an accident and taken to the hospital where he worked. It soon became general knowledge Ridge had an intellectual disability. Managers and colleagues started treating him very differently.

Ridge’s supervisor constantly criticised and harassed him. He referred to him as ‘deadwood’. Other workers told him they wanted to ‘rid the workplace of people with a disability’.

‘[The hospital] had, I believe, a systematic, toxic culture and attitude regarding people with disabilities,’ Shay said.

Shay made a complaint to the health minister and premier about the bullying, but department officers kept fobbing her off and gave her the run-around.

‘They wouldn’t even see me. They didn’t want to talk to me, they didn’t want to discuss it.’

One day, Ridge accidentally walked into the back of a colleague with a wheelchair. Management gave him the wrong form to fill out, knowing he could not read.

A few days later, management organised a meeting with Ridge, but without his nominated support person or a union representative. They told Ridge another staff member had reported him for 'staring'. They presented a document for him to read and gave him a resignation letter to sign.

'[Ridge] was very overwhelmed and told them he could not read it. It was still sealed when we collected the paperwork.'

Ridge left the meeting upset. He rang Shay crying, telling her that they had made him resign. Before hanging up, he told her he'd 'meet [her] on the other side'.

Shay immediately rang an ambulance and Ridge's wife and rushed to his house.

Ridge had tried to hang himself and was unconscious.

A few days later, Shay had to turn off Ridge's life support.

The hospital later admitted liability and made a payment to Ridge's wife and child. However they continued to maintain they have the right to speak to employees without a support person.

'I believe that if I had been called as [his] support person on the day of the meeting with management, [Ridge] would still be alive today – 1,000 per cent.'

Kerrie

Kerrie, also known as 'Aunty Kerrie', is a 75-year-old First Nations woman. She has physical disability and medical conditions and receives supports through My Aged Care.

During COVID-19, Kerrie's supports were reduced and she couldn't use all her My Aged Care funds.

During a home visit, Kerrie showed her plan manager her worn-out bed and sofa. She asked if she could use the unspent funds and get 'a proper bed ... something firm but that cushioned [her] prolapse disc'.

The manager sent an occupational therapist (OT) to assess the bed and sofa.

Kerrie told the Royal Commission that the OT asked inappropriate questions, for example, whether her grandchildren would sit on the sofa when they visited.

A short time later the manager contacted Kerrie and 'tried to talk her into getting an electric bed ... and an electric chair with a massager'.

Kerrie said all she wanted was a 'normal' bed and sofa.

The manager told her she needed to choose the furniture at a store in town.

Kerrie tried beds and sofas and, in the end, chose a sofa.

Time passed and when the sofa didn't arrive, Kerrie rang the manager about the delay. The manager told Kerrie her boss from the city would ring her.

'And I think this is where everything seemed to go wrong,' Kerrie said.

An hour later the boss called, again asking Kerrie if her grandchildren would be sitting on the sofa. Kerrie told her of course they would.

'What are they going to think if I tell them I'm the only one that can sit on that settee?'

The woman told Kerrie the department doesn't like to fund expensive furniture because Kerrie 'may not be here in six months'. Kerrie became very upset, wondering if the woman knew something she didn't, and asked if she was dying.

The woman didn't answer, but told Kerrie she wanted her to use the unspent funds on additional services. The woman 'kept pushing' her, suggesting someone could help her to shower. Kerrie told her she did not need someone to shower her. The woman told Kerrie she didn't believe she should have an aged care package.

'By this time, I was crying,' said Kerrie.

Kerrie told the woman to 'stop talking down' to her and intimidating her. She told her she was being culturally and psychologically inappropriate, as Kerrie is an Elder.

'I consider myself to be a very strong woman who has overcome many obstacles in my life. And these words, they made me feel like jelly. They took me to places that I've spent most of my life trying to get away from, trying to forget.'

After this, Kerrie's health significantly deteriorated and her GP had to monitor her high blood pressure.

Kerrie made a complaint to My Aged Care. The woman contacted her and apologised, admitting she was 'out of order'. She told Kerrie the plan manager would go to the furniture store with her.

'I ended up laying on all the beds again ... I just felt that I was disrespected, and I'm strong. And still, the shame of going into that shop all the time, having me laying on things. They'll think I've got dementia there, too.'

Kerrie found a bed that was 'unbelievable' and 'seemed to work for [her] back'. But she is still waiting to hear from the provider about when she will get it.

'Where we come from, you're part of the sharing. It tastes sweeter when you share ... Now, that young woman ... and this one other, too, the manager, they should know. I shouldn't have to be saying this ... I'd say that is culturally inappropriate ... And she's got to be educated.'

Judson and Makenna

Judson is in his mid-50s. He is autistic and has a cognitive impairment. He lives with his sister Makenna and her husband in Western Australia.

Judson used to live in supported accommodation.

Makenna told the Royal Commission that Judson first moved into supported accommodation in the early 2000s when their mother became too frail to care for him. His first home was in a complex of several units managed by a large services provider. The support staff had their office in the garage adjoining Judson's unit, which they could enter through a sliding door.

'We thought fantastic, because [Judson] is more vulnerable than the other four because the other four clients were in wheelchairs but they were competent, mentally competent,' Makenna explained. This living situation worked well for some years.

But problems began to emerge. Judson had a fall and broke his ribs and the doctor didn't follow up with the family. He got repeated infections on his feet. When Makenna visited she found him sleeping in soiled sheets, and his place was dirty. Support staff did not have their own bathroom or kitchen and were using Judson's, entering his unit anytime, day or night.

Management was using Judson's pension to pay huge utility bills that included the cost of running the office. 'They never reimbursed that money,' Makenna said.

The family decided to move Judson. The provider made this difficult, applying new fees and then insisting they had no records about his care to release to the family. Makenna eventually found these records, hidden in Judson's unit – poorly kept and revealing a history of cover-ups about incidents.

Judson moved to a new unit with a different provider, who organised a live-in support worker.

The new provider charged Judson a significant monthly fee for support services that it never supplied.

The support worker the provider had organised demanded Makenna give 72 hours' notice before visiting. They set up a pet-minding business in the unit, despite Judson's fear of animals. Makenna tried to terminate her employment, but the provider took the support worker's side. The family had to pay her compensation.

Makenna described other instances of neglect and abuse and the provider's obstructive practices that made it hard – and costly – to change unsatisfactory arrangements.

One weekend, Judson came to stay with Makenna and her husband. Over that time her husband suggested Judson move in with them permanently.

‘Why doesn’t he move in here?’ he said. ‘Why don’t you become his carer ... because you know this is never going to stop. This is always going to be a problem because obviously, you know they’re not going to care for your brother like you.’

With NDIS funding, Judson now has a package of care from two providers and a private support worker. Makenna is able to monitor who is employed and supervise their work. She has peace of mind that Judson is well looked after.

Makenna is grateful to the NDIS for making it possible to look after Judson in her home, in an environment where, finally, he feels safe and receives the support he needs.

The NDIS is ‘brilliant’, she says. ‘Now ... he can’t be exploited, he can’t be defrauded, he can’t be – he’s in a safe place.’

Abram and Jill

Abram was born in the early 1960s with a genetic condition. He was autistic, had intellectual disability, epilepsy and schizophrenia. He was mostly non-verbal but could communicate. He required 24/7 support and supervision as he sometimes self-harmed by hitting himself.

Abram lived in supported accommodation until he died suddenly in his sleep in 2020.

His sister Jill told the Royal Commission that Abram's 'cause of death is unknown' and she is sceptical about the provider's explanations as to what happened.

When Abram started living in supported accommodation, Jill couldn't fault the standard of care. But during the last 10 years the quality declined significantly.

About 10 years ago, Abram was unwell and the provider arranged a specialist appointment.

The specialist did not speak to Abram or make eye contact with him and only spoke to the family.

The specialist told Jill and her parents Abram had kidney failure and had six months to live. He refused to provide dialysis treatment because of Abram's disability.

'I was just so angry,' Jill said. 'I thought, "How can you say that? You don't know him."'

Shattered by this news, the family sought a second opinion. The second specialist spoke to Abram directly in a way that he could understand. 'A completely different diet, different medication, and it lengthened [Abram]'s lifespan by 10 years at least.'

Two years later, another resident pushed Abram and broke his femur. The provider refused to believe Abram because no staff had witnessed the incident.

Abram 'didn't make up stories' and was very clear that the other resident had pushed him. The family reported the incident to the ombudsman.

The injury significantly affected Abram's mobility.

The provider moved Abram to a new purpose-built group home with four other residents.

Jill became concerned about the provider being Abram's NDIS plan manager as well as his disability support provider.

The provider had stopped providing regular financial statements and 'there was a lack of transparency regarding NDIS funding'.

Jill discovered the provider was charging for speech therapy even though Abram could speak. Jill asked them if they were misusing Abram's NDIS funds and requested a meeting to discuss his plan. It took two years for the meeting to happen.

Two year ago, Abram fell and broke his femur again and was taken to hospital.

The provider and the hospital argued over who was responsible for providing support for Abram and didn't communicate about his support needs.

Abram needed to eat pureed food so he didn't choke. The provider did not share Abram's food plan with the hospital, which provided standard meals. When they took the food away, Abram went hungry. The provider also didn't share information about his medications and there was a delay in giving him pain relief.

Jill ended up sleeping in Abram's room so he wasn't alone.

Hospital staff would not communicate with Abram appropriately. Jill told a nurse that Abram was exhibiting signs that he was in pain because he was self-talking and hitting himself. The nurse asked Abram how much pain he was in on a scale of one to 10. Jill told the nurse that Abram would not understand that concept. The nurse then repeated the question to Abram louder.

When Abram died the police became involved. The coroner was unable to identify a cause of death.

The doctor who had been treating Abram for his kidney disease contacted Jill and thanked her for the opportunity to treat him.

'She has never had such a patient as [Abram], a gentle man, a gentle soul, lovely to care for, and would like to know what caused his death. So, she was really very concerned about it.'

Cathie

‘I felt like I was just going through the washing machine of abuse and neglect. And I don’t want to say it destroyed my life. It felt like it did, but it has made me see life through a different lens.’

Cathie is a First Nations woman in her 20s living with anxiety, depression and borderline personality disorder.

‘All [my] family members [have] been diagnosed with mental illness and intellectual disabilities,’ Cathie told the Royal Commission. ‘There was a lot of stigma with regards to disability in my family ... A lot of neglect and Stolen Generations in their lives that made it hard for them to value me.’

Cathie worked in a restaurant for many years before a First Nations organisation offered her a traineeship.

‘I felt really proud to work for a black organisation, being a proud strong black girl.’

Cathie said she declared her disability, but the company increased her workload and made no reasonable adjustments.

‘I chose to accept a role in a higher level, stressful, confidential environment. So, given my pre-existing issues that I had, it was up to me and it was my own responsibility [to deal with them].’

Cathie said she often worked 12-hour days.

‘I sort of drowned in the workplace ... They weren’t compassionate or caring at the time ... I just, at the time, wanted support from strong Aboriginal executive at an organisation that I thought I worked at. But I never got it.’

Cathie said, instead, she was given performance assessments where she told her manager she was feeling overwhelmed. Her manager told her to ‘just get on with it’ and later began criticising her work. Not long after disclosing that she was also a victim of family violence, the organisation dismissed her.

‘It essentially broke my heart, because I had a dream to run that place in, like, 10 years time.’

Cathie said she became homeless for two years.

‘I just moved into my own house, like, five days ago,’ Cathie told the Royal Commission. ‘But it’s just been hard. I guess that the level of abuse that I endured in my life, I don’t know how I’m still standing today to be speaking to all of you.’

Zuri

‘It was just a life of just surviving. There was never nurture in my life.’

Zuri is a First Nations woman in her 60s. She is legally blind in one eye. A member of the Stolen Generations, she lives with intergenerational trauma from childhood neglect and abuse.

‘Not having parents or guardians really contributed to my psychological way of being,’ she told the Royal Commission.

Zuri was made a ward of the state very early in life. The woman who adopted her mother later took Zuri and her sister into her charge. They weren’t ‘legitimately adopted out’, they ‘were stolen’, she said. ‘She was a very bitter, angry, horrible woman ... She was just a tyrant, just so cruel.’

When ‘Nana’ was abusing her, Zuri used to say, ‘God blind me.’

‘And well, what’s happened?’

When Zuri was seven she returned to live with her mother, who had become an alcoholic.

Zuri went off the rails in high school.

‘I really felt that nobody did care for me. So it was just me looking after me ... I was the biggest rebel.’

She also had her first operation on her eyes.

‘I lost my sight significantly and I couldn’t continue school because I couldn’t see the blackboard.’

Zuri’s mother told her sending her to university would ‘just be a waste of education’.

When Zuri was ‘caught shoplifting’, she was ‘put in a hostel for being an uncontrollable child – in moral danger’.

In her late teens, the state tried to ‘rehabilitate’ Zuri in a home for the blind. She again experienced a ‘feeling of rejection’.

‘Once upon a time, if you had any type of disability you were locked up because you were an embarrassment to society.’

After that she was ‘in the bikie scene, the fashion scene, the fitness industry scene, the surf scene, the church scene’. She always felt like a misfit, because she didn’t have ‘the faculties that everybody else had’.

'There was never any supports around me. Basically, I had to live by my gut, as opposed to living by the law or going to school and getting that education that everybody else gets, because that's how you operate in this system.'

She did everything to get out of the rut of 'no education'. About 14 years ago she studied social sciences at university, but failed as she couldn't do the assessments due to 'reading fatigue'. 'I was shattered. You get excited and then fall.'

Recently, Zuri returned to Country to work on First Nations projects for a community health organisation. She says there is a lack of culturally-appropriate services for First Nations people with mental health issues.

'I've gone through so many different counsellors and psychologists to help me, because I don't fit in this system.'

She is supporting a women's group and feels they are on the right path to 'being heard, being seen, being listened to, being taken seriously'.

She is passionate about teaching children 'where they fit and how they fit'.

'To really allow kids that whole self-determination. It starts from when they are little. If they are seen and heard, then they will be confident people. You're a seed just like a tree, you know, and your roots will go deep.'

Cassandra

‘I will have to start at the very beginning because my neurologist said that my disability probably was caused through trauma, childhood trauma.’

Cassandra, a First Nations elder, has a physical disability, medical issues, borderline personality disorder and lives with chronic depression.

Cassandra told the Royal Commission that her mother physically and emotionally abused her.

‘I developed a river in my mind and when this was happening to me, I used to go in this river to block out what was happening to me,’ she said.

To get away from her mother she married at a young age. Her husband turned out to be violent, abusive and had substance abuse issues. She had ‘a complete breakdown’.

‘I couldn’t even go to the letterbox to get letters out, I was so scared.’

Cassandra’s employer gave her a relocation grant to help her leave, but her husband took the money.

Around this time her health deteriorated and she couldn’t walk far without collapsing. She was diagnosed with cancer and a neurological disorder that causes muscle wastage.

Cassandra couldn’t access support and felt she had no choice but to stay with her husband.

‘I couldn’t even go to the toilet, I was that bad. I was in nappies and I was in a wheelchair.’

Cassandra said her husband gave her opiates and she became addicted. One time he gave her too much and she overdosed. He told the hospital she attempted to suicide. The hospital was suspicious because Cassandra had bruises on her wrists.

Eventually she got support from a domestic violence service and was able to leave.

Soon after she got an assistance dog, Jerry. ‘He saved my life,’ she said.

As her mobility declined Jerry would help Cassandra pick things up. If she was cold, Jerry would put the covers on her.

One time she had passed out and Jerry alerted the neighbours. When they arrived, Jerry was sitting on Cassandra’s chest. The neighbours called the ambulance who told Cassandra if Jerry hadn’t been on her chest she would have died.

About three years ago Jerry became ill and died, and Cassandra applied to the NDIS for a new assistance dog.

The NDIA rejected the application saying it wasn't reasonable or necessary for her to have an assistance dog.

'The Discrimination Act states that an assistance dog is necessary for a person with a physical disability and the NDIA are coming up with all this garbage ... if you're deaf or if you're blind, yes you can have a dog. So, they're discriminating against me because I have a physical disability.'

Williamina

Williamina, now in her late 40s, has difficulty with her mobility, speech and breathing.

As a small child, she had treatment once a month at the home of a physiotherapist who was 'physically and emotionally abusive'.

'All she ever did, really, was say "Walk." And I didn't understand how to walk ... I didn't know what to do. And then she would hit me if I didn't walk or didn't do exercises. And so I became very, very scared of her.'

Williamina spoke of numerous hospital admissions during her childhood for a series of operations on her groin area. Afterwards, the surgeon would bring groups of medical students to her bedside.

'He always used to prod around that area and show them the scars and all of that stuff... And I always remember feeling very, very, very vulnerable, because all these students were basically looking at my vagina, really.'

The matron at the hospital managed the children's ward 'like it was a library'. 'Nobody was allowed to talk and nobody was allowed to move.' Williamina slept with her boots and callipers on, which was painful, because staff found it too much trouble to remove them. She believes they sometimes sedated her.

Williamina experienced segregation at school which, she says, impacted her social development.

'I had trouble making friends. I still have low self-esteem and still feel very different to the rest of the world.'

Williamina trained in social work and, about 15 years ago, was employed by a religious institution in a pastoral role.

Soon after, she disclosed to a senior official in the institution that she'd had a same-sex relationship with a friend who was married.

The institution responded by launching an investigation. A team of lawyers went to her home to interview her and asked her extremely personal, invasive and patronising questions. 'Like, "Have you ever had an orgasm?", "Have you ever had a boyfriend?" ... I really felt like they were talking to someone that had a cognitive disability.'

Despite 'having committed no sex offence whatsoever', the institution continued to harass Williamina and sent another lawyer to ask more questions.

'If I was a man who was married and had kids and all of that stuff, I don't think they would ask questions like, "How many boyfriends have you had?" And, "Do you know what it is to have sex?" And, "Did you have an orgasm?", "Tell us what happened." And all that sort of stuff. I actually think it was quite voyeuristic.'

They then sent her to see a psychologist who concluded that she was 'immature' and too focused on her disability.

'And yet I was asked so many questions about my disability. They didn't focus on me as a person.'

The psychologist suggested Williamina was a danger to herself, being a target for people interested in 'unusual fetishy things'.

'It absolutely made me think, "Okay, anyone that wants to have sex with a donkey will want to have sex with me." That's what he's basically saying.'

Williamina doesn't identify as gay and, looking back, says the affair was 'just something that happened'.

She believes the institution's response was discriminatory and 'more about disability than it was about [anything else]'.

Rya and Anisa

‘There is nothing worse than being a victim of sexual abuse and not being believed.’

Rya, Anisa’s youngest child, is autistic and mostly non-verbal.

A few years ago Rya, then six, started behaving in an oversexualised manner.

Rya communicated to Anisa that her disability support aide at school was sexually abusing her.

Anisa made a complaint to the school and police. She told the Royal Commission that the school denied the allegations and wouldn’t investigate. Police attempted to interview Rya without any support from Anisa or a disability support person.

Anisa took Rya to a psychologist who worked with her for several months. Rya disclosed graphic details of the abuse and said the disability support aide was also sexually abusing other students.

Despite this, police refused to investigate further.

Anisa said police believed she was manipulating Rya into telling people she was abused.

The department of child protection became involved.

‘Child protection were clearly gunning for me and treating me like I had done something wrong, while at the same time I struggled to rehabilitate my child with zero support ... All government-funded agencies fobbed me off, fobbed off her autism.’

The department of child protection told Anisa her story was ‘fantastical’. They accused her of being ‘mentally ill, a drug abuser and a child abuser, with no evidence’.

The department removed Rya from Anisa’s care. Anisa has no visitation rights and can’t see her daughter until she is 18.

‘I spend many waking hours regretting having stood my ground. There have been many times where I just want to die.’

Alejandro

Alejandro works in disability services as a support worker and is part of an online advocacy group. His son Mateo, 19, has a rare genetic and neurological disorder. He is non-verbal and uses a wheelchair. He lives at home with his parents.

Alejandro told the Royal Commission he became a support worker because of Mateo.

‘[I wanted] to learn as much as I could. To be a professional in that environment. To be able to advocate for the needs of my son.’

Working in group homes in the 2000s was at times very shocking, he said.

He recalled an incident where a client spat in the face of another support worker, who threw him to the ground and forcefully restrained him face down on the floor. When the police arrived, they insisted the client apologise to the support worker and to them for giving them trouble. No-one noted that the support worker had assaulted the client.

Alejandro tried to file an incident report, but the process was too difficult and he gave up.

In his experience, staff working with people with disability often treat them inappropriately.

‘A lot of it – working in those environments, a lot of it becomes normal. And it’s really frightening.’

At the time, life at home with Mateo was very difficult. It was before the introduction of the NDIS, and the family was getting by with a ‘minimal’ level of support through a government funding package.

Eventually, the stress and exhaustion caused Alejandro’s wife to have a psychotic episode and she was admitted to hospital. The psychiatrist told them she shouldn’t just return to the situation she’d come from – that it was ‘untenable in terms of her mental health to live in that environment’.

Alejandro recalls the time as ‘surreal’. He was still working as a support worker.

‘I’d be going out to see people who wanted to get some free compression bandages, or something like that – and here my wife was in the psychiatric ward. And my profoundly intellectually and physically disabled child there for me to look after as well ... It was terrible. It was just – it was, you were just on this wave of things.’

The NDIS has made life easier.

‘We’ve got an excellent group of support now,’ Alejandro said.

Tricia

Tricia is in her late 50s and has a cognitive disability. She lives with complex trauma and a brain injury caused by childhood sexual and physical abuse.

‘My mum said she was going to kill me when I was a child,’ Tricia told the Royal Commission. ‘She got my head, punch in the wall. She got stick, she got straps. She got – everything thrown at me.’

At school teachers were cruel to Tricia. ‘Because I’m illiterate, I can’t read or write or anything. I told the teachers that I can’t do it.’

Tricia’s mother pulled her out of school when she was about 12.

‘She was wasn’t a good person at all. She didn’t send me to school, she didn’t took me to doctors, she didn’t took me anywhere.’

Tricia said her eldest brother raped her repeatedly – and her mother encouraged him.

‘Every time he was weird with me, he bashed me up. Mum set me up ... She said to me, “You do what your brother wants you to. You go make his coffee. You go make his lunch. You go get his dinner.” Like I’m a slave to him.’

Tricia begged her mother to foster her out.

‘I said to mum, if she didn’t want me why did she put me into someone else’s place?’

She tried for years to get away.

‘Police, the welfare, I was pleading to them to get me away from her. But no, the welfare said, when I was 12, “You go to your mum.” The police told me, “You go to your mum.”’

The police threatened to arrest her if she ran away from her mother again.

‘What I used to do is camp under the bridge. And that’s when the police seized me ... Even when I was in my 20s they told me I had to stay with her.’

Later, when Tricia was in a violent marriage and wanted a protection order, the police response was much the same.

‘The police say, “Oh, just let it go. Don’t need to worry about it. He’s not doing anything wrong.”’

Her former husband caused her a spinal injury and Tricia has used a wheelchair since. She can’t understand why, as a child and as an adult, police refused to protect her.

‘There is child molesting, there’s violence. It should have been stopped

... Why can't I get the public to help me? Someone help me, I have to fight by myself.'

Tricia has four children. After her traumatic childhood she wanted to show them 'what a parent should be to their kids ... how to love a child'.

'I gave them what they need ... They got discipline but not bashing or anything.'

She's still trying to get justice and compensation for the sexual abuse, but her lawyers 'wouldn't touch it'.

With NDIS support, Tricia is now seeing a therapist. She often wakes up at night screaming, reliving her trauma. She's had trouble finding stable housing, but a community agency is helping her with her application.

If she gets 'a nice little place' she wants to be a foster carer.

'To show how I can look after kids ... These kids would get a proper care and attention, all the good educations, which is what kids really need.'

Mathilde

‘Going through the NDIS is the opposite to helping. To me it felt like it was designed to keep you out. It feels like an impenetrable wall of difficulty.’

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

‘I’ve never actually had anyone give me a proper diagnosis of what’s going on,’ she told the Royal Commission. ‘These are lifelong things that have just never been addressed.’

When she was a child, Mathilde was ‘sick all the time’. Doctors treated her for a problem of ‘nerves’. Attention deficit hyperactivity disorder (ADHD) was something reserved ‘for hyperactive boys at school’.

‘They were just giving me so many drugs ... I was put on some sort of medication and that was it. I mean, this was back in the 60s so I doubt that there were any child psychologists anyway.’

As an adult she continued to ‘get sick a lot’ but lacked ‘the resources’ to get the right help.

‘I’d recognised from a young age that my mental health was very limited, the way that things would manifest in my physical health.’

In her 30s she met her future husband, who was bipolar. ‘Things just kind of snowballed from there.’ Mathilde had two children, but as she looked after her husband her mental health problems ‘escalated’ and she had a breakdown.

‘It was an abusive relationship, there was domestic violence. Everything felt like it was just piling on.’

The marriage ended in the early 2000s and Mathilde spent the next decade engaged in legal battles. By then she was on a disability pension.

She found the isolation of the pandemic beneficial. ‘I’ve been able to process things ... I used it to deal with some trauma and neglect.’

Mathilde realised she needed help from someone ‘equipped to diagnose mental health conditions’, and asked her doctor for a referral to a psychologist.

‘Because of not having the finances, I’ve been seeing counsellors through community centres. It’s always been about domestic violence or trauma. It never looks into the whole picture.’

Mathilde feels there is ‘inadequate’ support in the NDIS funding process for ‘somebody with psychosocial disability’. Her initial application was rejected.

‘You just get on the merry-go-round and get referred back to the people that have referred you on to the other people, so it’s like a hamster wheel. If you have to do that yourself, it’s horrible.’

The second time, she got help and was successful.

‘The feeling of being acknowledged is huge. Actually having support for the first time in my life, it sometimes feels overwhelming because I’m so not used to it.’

Mathilde now has an NDIS recovery coach with mental health expertise who is ‘fantastic, a great help’. She hopes it might lead to a full diagnosis. Reading about undiagnosed adult women with ADHD, she is ‘relating very strongly to that’.

‘I’m really looking forward to moving ahead and having NDIS support to just find a way to get back to doing what I’m good at ... It’s the first time that I’ve felt like I could achieve.’

Foster, Malik and Anderson

Foster is 12 and Malik, his brother, is 10.

Foster is autistic and has an intellectual disability. He is non-verbal. About a year after these issues were diagnosed, Malik was born. He has the same disabilities.

Both boys began attending a special school when they were four. Over the years, both have come home with a range of different injuries. Anderson, their dad, has catalogued a long list of them, including black eyes, strap marks and bruises. He told the Royal Commission he is certain staff at the school are responsible, and that the injuries occur when they try to manage Foster and Malik's behaviour.

'I think generally what's happening is that they run it as a school, they try to run it similar to a normal, standard school.'

This means children are made to do things like change classrooms.

'Now, if the child doesn't want to go because they're happy where they are, they say, "No, I'm gonna make you go." And then that's when it starts up. They grab the child, they start, you know, cornering the child. Of course, the child understands now he's being cornered by these adults. He'll start screaming. Then they say, "Oh look, he escalated far too much. Grab him, take him down and put him there." ... And so their cure for autism when the children get upset is to bring violence to the table.'

Anderson has reported his boys' injuries to the school.

'And every interaction with the school has been the same, where they just ignore you,' Anderson said. 'I've even said to the principal, "Why is there such cruelty? What's the benefit in bashing these little children?" And she just looked out the window. She just refused to answer.'

Other children at the school have also been hurt. Anderson said other parents have told him it's better not to report these incidents.

'They've all said basically that, "Don't make trouble. These people have your children." And I've said, "But that's why I'm making trouble. It's because they have our children."

Anderson has tried to hold the school to account. He has reported to the school's oversight body within the education department. One response noted Anderson did not provide enough information – which he disputes – and another that the incidents he reported were not significant enough to require action.

‘You just realise that they’re just like, they’re not interested. They’re not here to help you, or discuss it. They’re clearly [here] to protect the department ... You can do whatever you want – physically, sexually, emotionally, psychologically – to these children. They are yours to abuse. This is the message that gets sent down to these people who do it.’

Anderson has now reported the school to the police, the ombudsman and his state and federal MPs. Each time he is referred elsewhere or told that the education department is handling the matter satisfactorily.

Anderson is now pursuing legal action against the education department. He wants to see it held accountable. ‘Yeah, there’s nothing,’ he said. ‘There’s no help whatsoever.’

Matteo

‘Ever since my disability, it was just obvious that you had to work three times harder than everyone else just to prove you are adequate.’

Matteo is in his early 40s and uses a wheelchair. He lost both of his legs in a terrible car accident 20 years ago.

Prior to the accident, Matteo was training for his dream job.

‘I was 24, invincible and everything was on track career-wise. I’d been doing really well.’

After having ‘just over 60 operations’, he realised he couldn’t continue on the same career path.

‘I didn’t know what to do. I got my life back as best I could.’

He started applying for jobs – ‘basically anything office, administration based’. He said he was ‘not naïve’ about the workplace discrimination in store for him. ‘That’s the way the world is, unfortunately.’

Interviewing was an ‘interesting process’ because he didn’t mention his disability.

‘I mean, it’s pretty obvious when I turn up in a wheelchair minus two legs, you can’t hide it. And so, you could see the attitude change. They were lovely on the phone, but as soon as you rocked up they didn’t want to know you.’

His first job in a bank was ‘actually awesome’.

‘The thing always lacking was reasonable adjustments. A special keyboard or mouse, something to do with the computer.’

Matteo held back from asking for these things.

‘You certainly don’t want to rock the boat, because otherwise you won’t get the job.’

Matteo drives to work. About eight years ago, he started working for a government department where parking ‘was always a big issue’. At a nearby council car park, ‘it was just luck of the draw’. Sometimes, after driving around for half an hour, he’d go home for the day.

There was a ‘massive car park’ in the office basement with ‘disabled spots by the lift’. ‘Some of the assistant directors parked in those spaces.’ Matteo asked for an ‘accessible spot’, but management said no.

'[I] pushed the request for parking a bit more ... Then they started finding issue with anything I did. Ultimately, I got bullied and harassed ... I clearly annoyed the wrong people.'

He took time off work and became so depressed he considered suicide.

'It was probably the worst year of my life.'

Matteo won a workers' compensation claim and left the agency.

He then went to work for a disability agency. He 'never imagined it would discriminate'. However the employer was not 'open to flexible working arrangements' to help Matteo manage the excruciating 'pain attacks' he periodically experiences.

Matteo feels the jobs he's applying for are 'going to people that don't have disabilities and don't have the level of experience anywhere near [his]'.

'They don't want me, that's a very clear message. They're always claiming to be the employer of choice for people with disability, but they're not demonstrating that ... Across the board, not just with me.'

It's not about giving 'token positions', he said. 'That would be the most damaging thing for employees with a disability. But as long as they have the capability.'

Matteo knows how vital workplace inclusion is.

'Since having my accident, work is probably the important thing in my life. To me if things are going well at work, things are going well in my life.'

Yuna

Yuna, in her early 60s, has medical issues that include breast cancer and chronic pain from a spinal condition that impacts her mobility. She has lived with depression since she was a teenager.

Yuna worked for many years in mental health services in Australia and overseas.

‘I have experiences from both sides of the fence with regard to so-called mental illness and don’t always believe that illness is the right description of what is occurring for me or for the patients I have been involved with,’ she told the Royal Commission.

Yuna has come to see that the depression she experiences is caused by childhood trauma, which needs specific care to recover from.

She is grateful to the counsellor who helped her recognise this and believes all health professionals need training in trauma and trauma care.

As a patient, seeing someone without that expertise is expensive.

‘It costs me time, energy and my life force on a huge level dealing with other people’s assumptions about me or things that relate to what I would call invisible illness,’ she said.

Yuna decided she wanted to work in mental health services after she attempted suicide in her teens. An ambulance took her to hospital and the paramedic advised her not to cry – if she did, she’d be hospitalised for longer. ‘I thought well, that’s really not fair. It doesn’t seem appropriate,’ Yuna recalled. She resolved to be someone who would ‘encourage people to cry’.

‘And I did. I got a lot of people to cry, while I was working. Obviously not because I did anything to them but, you know, if they wanted to cry I would encourage it.’

She believes she understood even then the importance of trauma and trauma care – ‘but there wasn’t the language’.

Yuna stopped working in health services after an incident in the mid-2000s. At the time she had casual employment as a nurse at a hospital-run group home. One night when she was the only person working there, she narrowly escaped a sexual assault by one of the residents.

It didn’t occur to her to call the police.

‘I mean if they had come, what would they have done or said? I imagine they would have said “Well, nothing happened,” and on one level, I believed that too, nothing happened,’ she said.

‘So I was okay that night, but then I started to deteriorate. About two weeks afterwards, I would say that I had symptoms of PTSD.’

Yuna sought worker's compensation in a claim that took years to resolve. The process was debilitating and exacerbated her health issues. 'I have never recovered from the treatment that I received by the legal process,' she said.

'Basically, before this thing happened to me at work, I was actually living the life that I wanted to live. I had a fiancée, I had a whole bunch of friends and I was working a lot and ... I was never frugal but I had money.'

These days she lives alone.

'I am reduced to more or less living in my pyjamas and lying down in bed watching the TV,' she said. 'There are times when I feel very sad about that.'

Melany

‘Everything could be done better. The staff could have more training to understand me and my disability. They should know more about my rights and treat me with respect.’

Melany is in her late 30s and has cognitive impairment that makes her repeat things.

‘It’s part of the way I am,’ she told the Royal Commission. But since primary school, people have been ‘bullying and abusing’ her for it.

‘During the two-hour bus trip to school, staff on the bus would tie my hands behind my back with a rope, as they said I couldn’t sit still.’

In her 20s, Melany moved into supported independent living.

‘I had very, very bad treatment there. I was bullied by staff and other clients. They were very nasty to me.’

She said the staff treated her like a ‘kindergarten child’.

‘Sometimes I get sent to my room for my behaviours. I was in my bedroom most of the time.’ Workers only let her out for meals. ‘[I was] upset and alienated most of the time ... My parents were not allowed to go to the group home to visit. Often I wasn’t allowed to go places.’

Once on a group trip, staff wouldn’t let her participate in any activities or even have ‘a drink and a snack’.

‘On the way home, they stopped the van and made me get out and stand beside the road by myself and I was scared.’

Melany developed sleep apnoea, but wasn’t allowed to rest when she wanted.

‘I was always tired and, so, sometimes my behaviour wasn’t good. The way they treated me made me more upset and very unhappy and made my behaviour worse.’

One evening, a male staff member ‘dragged her into the shed’ and left her there for two hours.

‘We were all sitting at the table having dinner and I started to laugh at the peas. They were on my plate in a funny pattern. He grabbed me by my shirt neck. I thought I was going to choke.’

The supervisor knew but ‘didn’t care’, Melany said, just as when other housemates assaulted her.

‘Staff used to let other residents hit me ... run the walker into me. Didn’t care and didn’t stop it. They lashed out and hit me. They were always bullying me and nasty.’

Once her father turned up and ‘could hear her screaming’.

‘Staff locked me in the van at night and it was freezing cold.’ They’d put her there ‘because she was playing up’.

‘They were horrified because dad was there and he wasn’t allowed.’

Not long after that, the provider ‘threw her out’.

‘They just dropped me off at my parent’s house and left. I was scared and shocked.’

For a while, Melany attended a day centre that also ‘treated her nasty’. One day, they wouldn’t let her go on an outing after she ‘came in crying’. They made her walk for six hours as a ‘consequence’.

‘And wouldn’t let me stop once, and I wasn’t allowed to have a drink of water. It was a punishment. I think this is abuse and nasty.’

On another occasion, the group went on an outing.

‘I was asking about Christmas in July, repeating it. They weren’t happy, so they made me sit in the van and locked it.’

Melany now lives in a house on her own.

‘I got a car and the [support] staff drive it for me, wherever I want.’

She also has an advocate ‘who stops bad things happening and makes people listen’ to Melany.

‘There should be more people to help us speak up,’ she said.

Kyler

Kyler has a speech and language disorder. When he was about 10, child protection services placed him in foster care in the regional town where he had grown up. He lived in several different homes and remembers this time in his life positively. He had friends in the town and felt 'comfortable' there.

In his early teens, he was moved to group accommodation in another regional town.

'There was things that should not have happened,' Kyler told the Royal Commission. 'That is when I experienced hard experiences. It was not just me, but the other kids as well.'

Kyler described a regimented environment with strict rules and routines. The accommodation was in separate cottages with security glass, alarms and locks on the doors and windows.

'If they done some bad stuff – the kids in the complex – they had to stay in their cottages and they got locked doors. It means you can't go in or out of the complex.'

Kyler said police were constantly at the group home, bringing back kids who'd got into trouble or who were trying to run away. 'I see the police involved nearly every day because the kids have bad lives,' he said.

He said lack of trained staff was a big cause of problems.

'Kids don't have the right person to look after them or they don't have the knowledge ... Most of them don't have experience with kids. Most of them are out of, let's say a corner shop, and they started working for youth support,' he said.

'Staying there for myself makes me feel like a prisoner ... All I wanted to say is it should be shut down years ago ... They should not be looking after disabled people if they don't have the training. They should not be looking after any person who is disabled.'

Kyler said he was not properly supported by his social services case worker. The case worker didn't give him information about the disability pension or help him apply for it. He organised for the state guardianship to manage Kyler's affairs without Kyler fully understanding the consequences. He is upset he can no longer manage his own money as he wants to.

He is also unhappy about the amount taken from his pension for rent and other costs.

'They take advantage of disabled people, of their pensions. And it makes me mad that I get \$65 a fortnight ... Maybe it's good for the company, but how about the clients? They can't go on a holiday, they can't do something they want. They can't buy a car. They can't do anything they want with their life savings.'

Kyler is now in his early 20s. Since he turned 18 he has lived in several different group homes. He is concerned that the NDIA allows housing providers to accommodate people with very different needs together.

'How are companies going to deal with ... anyone who breaks the law, drug users, high-functioning people, people like me, and aged care? How are they going to manage all of that into one? They should be in one section in the one house,' he said. 'Aged care people should be with aged care. Law breakers should be with law breakers with procedure in place. High function should be with high function. Make the process easy. Make the rent for disabled people a little bit less. Have new legislation to stop that. When it is all fixed it will be different.'

Nyomi

‘The way clients were treated is absolutely dehumanising. They’re treated like dogs.’

Nyomi is in her late 30s and works as a disability support worker.

A couple of years ago, she was working at a home providing supports for elderly people with mental health problems. She told the Royal Commission she witnessed extensive ‘neglect, abuse and gross misconduct’.

‘It was horrid working with that organisation ... I have witnessed the use of physical restraint or forceful pushing of clients ... Their practice standards are absolutely appalling.’

Two residents in the home were women in their 60s with high-level personal care needs.

Once, one of the women had her leg stuck in-between the bed rails. ‘Staff would just turn the TV up and sit in the lounge room and make like, “No, she wasn’t calling out.”’

One support worker, a registered nurse, was always ‘refusing to assist in changing a client’s incontinence pads because they weren’t dirty enough’. ‘If the client wanted to get up or go to the toilet, she would say, “No, do it in your pad.”’

She also told the woman ‘her pussy stinks and it’s disgusting’, and withheld food from her because she ‘hadn’t been a good girl’.

The woman had psychosis and would ‘repeat the same old stories’, Nyomi said. ‘A lot of the staff didn’t want to be there with her, ... even though she has the highest care needs.’

The woman also had epilepsy. ‘A lot of her seizures were going unchecked. The staff weren’t recognising seizures. They didn’t know what a seizure looks like.’

Nyomi said staff at the home were poorly trained. Once she needed assistance getting a resident ‘out of the bathroom and into bed’. The staff member refused as she ‘hadn’t completed manual handling training’.

‘Nobody at this site had a background in aged care and didn’t know how to use a lifter. So they would either ignore clients or place themselves at risk.’

Sometimes there was only one staff member on duty, particularly at night.

‘They intentionally left clients in bed and didn’t interact with them. They would sit down with their phones and they would sleep on shift.’

Because the clients were spending more time in bed, they put on 'significant amounts of weight'.

The other resident 'came from an abusive home environment' and was 'very depressed'.

'[She] would not want to get up. She didn't want to leave the house. She didn't want to shower. But staff just left her in her bed and ignored her.'

Once, Nyomi heard her 'calling out for help'. 'I opened the bathroom door to find her alone and naked in the bathroom. I could not find the other staff member onsite.'

The nurse had left the woman 'dripping wet and naked' and was 'outside on the phone'.

Nyomi and others reported incidents like this to the provider, but 'they just continued not to act'. The manager 'blocked' their complaints to a health service accreditation body.

Nyomi turned to the NDIS Quality and Safeguards Commission, which did 'absolutely nothing to assist'. A couple of months later, the disability service provider fired Nyomi and other staff members who had spoken out.

'I was terminated for whistleblowing.'

Louie and Leyla

Leyla is the mother of Louie, who is autistic and is in primary school.

‘[Louie] was happy at school in year 1. He was excited to go to school,’ Leyla told the Royal Commission. “‘Go away, mum, I’m going to school” type of boy, you know? And that made me proud because being autistic’s damned hard.’

In year 2, things changed when a new teacher took over the public school’s special needs unit. Previously, Leyla walked Louie into the unit each morning to give the staff an update. The new teacher wouldn’t allow parents inside the unit or to talk to staff.

‘We had to stop, drop and go. And it was like, what are they hiding? Why are we not allowed in the classroom anymore, you know?’

One day, Leyla arrived to find the unit surrounded by a high fence.

‘To get into the special needs unit, you need to get through this gate ... But we weren’t allowed to talk to the teachers. So, that was a strange behaviour from this new educator.’

The school changed the safe space for children with disability into a room for staff.

‘It got replaced with a photocopier and a coffee table so ... they weren’t even looking out for him, you know? Not only [did] my son use the safe space, but others did as well.’

A few weeks into the new school year, Louie was taken out of the special needs unit and placed in a mainstream classroom.

‘To throw a child, overwhelming in this class of 28 kids, he’s, you know, not coping. Then they were threatening him, “If you don’t do your work we’re going to call your mum.”’

Louie’s behaviour deteriorated.

‘They’d basically ring me up by 9.30 and say, “Come and pick up [Louie]”, you know. “His behaviour is not acceptable.” So, they were putting him in the too-hard basket.’

One teacher gave Louie a balloon to chew, a ‘major choking hazard’. Another teacher gave him worksheets downloaded from the internet.

Leyla heard a rumour the school was trying to get rid of several students with disability, including Louie, because their needs were ‘too complex’.

‘What really upset me, on the last days of school ... the principal herself dragged my son across the play area with two arms ... This is the day she expelled him.’

Leyla said the school rang later to tell her Louie had headbutted a window and she should take him to a doctor.

‘My son could have had a concussion ... She didn’t even give him first aid at school.’

Leyla enrolled Louie in an ‘amazing’ local Catholic school.

‘On day one he was allowed to take off, run, meet some new friends, play soccer or basketball. This was huge for him ... He’s putting his uniform on at the weekends. That’s how keen he is to go to school now.’

Leyla said the difference between the schools is profound.

‘It’s not just school, it’s the educators. If you go into a school and you have a great relationship with those educators and they know your son and you’ve got a good relationship from the start, it’s going to be okay.’

Carole and Clint

Clint didn't know his daughter, Carole, was autistic until she started primary school.

'At the time we had no idea. You know, we knew very little about the wide spectrum of autism,' Clint told the Royal Commission.

When Carole was a toddler and struggled to make friends, a childcare worker told Clint to take her to a child psychologist. Clint said they turned out to be 'a total quack'.

'[They] started recommending unproven, unscientific magnetic treatment that measured energy waves. I'm not kidding. We walked out soon after.'

It wasn't until she started kindergarten that teachers referred Carole to a paediatrician, who diagnosed autism. Clint said the diagnosis was 'like a weight was lifted off [his] shoulders'.

'We now knew what the problem was, right? And we could then seek guidance and do a lot of research.'

However after her diagnosis, Carole's school wouldn't let her attend school activities. '[She] was frequently and routinely excluded from activities, games and even playing with her friends at lunchtime.'

For nearly a year, Clint said, the school's support teacher made Carole sit alone in a room while her friends played outside.

'She would eat her lunch and then, when she was finished eating, someone would come and get her and take her to learning support for the remainder of the break.'

When Carole jumped around to regulate herself, the teacher tried to stop her.

'Every time [they] said, "It looks silly ... you can't do that at high school because everyone's going to laugh at you."'

When Carole's behaviour deteriorated, the school started suspending her.

'They had these very strict rules and if she stepped out of line, [she] had to go home. So that was the response, and any kid with autism is going to have trouble ... For six years, [Carole's mum] was forced to wait by the phone, waiting for a call that would inevitably come from the school to go pick our [Carole] up.'

At the end of primary school, Clint struggled to find a private high school that would accept Carole.

'We found that in almost every case, the private/religious schools would say that they were inclusive, but it was certainly a case that you are welcome as long you can do the same as everyone else.'

Clint recently enrolled Carole at the local public high school that 'does a really great job in terms of inclusion'.

'She has missed zero days of [high] school, [whereas] across her six years of primary schooling ... we conservatively estimate that she missed greater than 150 days of school ... We're fortunate that she is incredibly smart and sort of managed to still keep up.'

Claudette

'I ran out of doctors. You know, when a person's really crook, like me, there should be more consideration, just don't brush me aside.'

Claudette is a First Nations woman in her 60s. She lives with chronic pain and depression.

About a decade ago, she was diagnosed with sternoclavicular joint disorder, which makes her clavicle 'pop out' of place.

'It just jabs into my sternum so it prompts me to get pain in my chest,' she told the Royal Commission. 'I have pain with every movement. I've lost the rotation of both shoulders because of that. I can't do any domestics, I can't brush my hair or get dressed anymore.'

Claudette said 'doctors have never done anything' for her. She can't understand why. 'You can see the bloody thing plain as day.'

She 'blames' the first doctor she saw for not 'following up on anything'.

'He didn't fix me up in the first place. He diagnosed it, but he never did anything else about it. He just left me.'

When Claudette asked, 'How come my collarbone's popping out?' the doctor said she'd 'stretched a tendon'.

After 'trying to make appointments after appointments', she 'didn't bother going back'.

'He'd always find some excuse not to see me. He didn't want nothing to do with me.'

Claudette tried to look after herself. 'I got to the point where I was really sick. I had to go and get another doctor.' Since then, she's seen about 10 doctors.

'They've never done anything for me. I kept going from doctor to doctor because they didn't want to deal with this. I realised they're not going to fix me. Going from doctor to doctor is painful.'

She would go to the hospital with pains in her chest, 'but they'd still do nothing'.

Because of this, she can't get disability support.

'They rejected me four times because I didn't have enough medical evidence. This is a very unusual condition. I've asked doctors time and time again to research it, and because they didn't, my NDIS fell apart and my DSP fell apart.'

Claudette also has to 'deal with the pain' alone.

Her first doctor put her on 'a lot of medication, a lot of painkillers'. She's 'been in and out of hospital' because of the opiates he prescribed. Now the only drug she can take is aspirin, which is problematic as she is 'a chronic asthmatic'.

Claudette has resorted to makeshift solutions, such as straps to stop her bones 'clinking' together painfully at night and a back brace.

She said she'd 'been through four surgeons' – one of whom treated her 'like a dog'. Recently, she saw a new specialist.

'When I finally got to see him, he turned around and said to me he could fix any bone, but he couldn't fix my bone.' The surgeon didn't explain why. 'He just shut me down.'

Claudette was so depressed she considered taking her own life.

'I had to suffer with this for 10 years, and the people that I've spoken to, they've let me down.'

Currently she's seeing a doctor through Indigenous health services, who she describes as her 'last hope'. She's also attending a pain management clinic.

For support, Claudette relies on two young relatives who live with her. 'They help me get dressed as well as things I can't do. They've got to learn how to bloody cook because I can't cook anymore.'

She has just started getting some supports through a community disability service, including someone to clean her house. A health worker is helping her with her medical situation.

Claudette was born on an island.

'As soon as I can get back on my disability pension, I just want to go home. I've got family over there that can really help me.'

Meriah

Meriah is in her mid-60s and lives with anxiety, depression and post-traumatic stress disorder. In the 2000s she left a violent relationship and went to live with her family. She then moved into supported accommodation for people with mental health issues.

Meriah paid the provider 60 per cent of her government benefit. She told the Royal Commission it was difficult to meet expenses with what was left, but she appreciated having a home.

‘I was happy to have a room to myself and start to get myself together. And I was in town, so I was close to a bus link. I walked everywhere, got myself to doctor appointments and started the process of getting on the list for housing, et cetera. So, I was managing.’

Initially Meriah felt well supported by the organisation. But the level of care and attention gradually diminished as managers and staff came and went.

‘When they first came to see me they made an effort. They took the time, they signed me up, they took me in and I got support. And then it dwindled off and the support worker that I was supposed to have was never available ... I was told, “We’re not here to counsel you. We’re not here for counselling. We’re not – we don’t care about your medical issues.”’

One day another resident sexually assaulted Meriah. She reported the attack to police. Management advised Meriah to keep away from the man, but took no other action to protect her or other residents. Meriah thinks they didn’t believe her account of what had happened.

Several years later the man assaulted another resident. This time management evicted the man. But they also evicted Meriah and the other victim, with just a few days notice.

Meriah is still shocked by what happened.

‘To chuck me out and say, “We’ll leave it up to somebody else.” They were supposed to be the primary carer!’

Homelessness is ‘traumatic’, Meriah told the Royal Commission. ‘You can’t do anything, you’ve got nowhere to live. Nowhere to look after yourself ... It is a major thing that they actually made me homeless.’

Meriah found help from mental health and sexual assault support groups. It was a difficult period.

Six years ago she moved into a department of housing home. She said it saved her life. Even so, she still worries.

‘I’m still scared I’m going to get chucked out again or somebody’s going to make trouble for me and make me move ... I’m really trying to behave and not upset anyone, you know, by saying anything or doing anything ... It just terrifies me to be homeless.’

For several years after she was assaulted, Meriah was so traumatised she could barely speak. She sustained herself by making art, initially as part of a group activity organised by the mental health support organisation.

'I couldn't express myself verbally, but at least I could paint and that was also an experience because it was like interacting with people again, socialising, getting a bit of support, but I wasn't even talking about my problems, just doing the art,' Meriah said.

Painting offers Meriah a way to talk, yell and scream without speaking aloud and without upsetting anybody. It allows her to be herself.

'It just takes my mind off of everything when I start to paint. And I noticed that with the other people with their mental illness, how beautiful their paintings are, how intelligent, how wonderful, how inspiring they are to me. And then someone said that I was that to them. So, it was that interconnection [and] sharing, it was just so marvellous.'

Diego and Aleah

‘Someone had said recently that nobody is disabled. You are only disabled by the environment that you are in.’

Aleah is mum to Diego, who’s in primary school and has a rare genetic condition that causes developmental delays and behavioural issues.

‘This kid, he is bright, he is bubbly, he’s intelligent, he’s funny. He’s very loving,’ Aleah told the Royal Commission. ‘And yet, the other flipside is what the hospital saw ... They all view him as a naughty, aggressive child, when actually he’s really frightened of the world around him and can’t cope.’

A few years ago, Aleah took Diego to the hospital after a negative reaction to an antipsychotic medication doctors gave him as part of a trial.

‘He was pulling out his feeding device frequently, which is a result of him having the dystonia. So, I was burnt out because I was dealing with increased challenging behaviours and aggression ... I was in crisis, needing help.’

A hospital staff member told Aleah to leave.

‘They were saying that his issues are not health, they are disability. And I kept saying to them, “No, there’s something else going on.” But they didn’t want to believe me.’

Aleah said the staff member blamed her for not being able to manage Diego’s behaviour.

‘And basically gave me an ultimatum of ... “You either take him home ... or if you’re not coping you relinquish care of your child.”’

After Diego kept pulling out his feeding tube at home, Aleah took him back to the hospital where they gave him more antipsychotic medication.

‘All of the drugs they were giving him gave him dystonic reactions, so he couldn’t speak, he couldn’t walk, he couldn’t do anything, and had ongoing muscle tremors. And they kept fobbing me off saying that it wasn’t anything they were doing and that it’s just his disability.’

The doctors put Diego in a room and, because of his aggressive behaviour, removed most of the furniture.

‘The room was basically just a cell of nothing, no fresh air ... The doctor said to me, “Well, we’ve tried every medication we can think of. We’ve got nothing else. You’re just going to have to sort it out in the community.”’

Aleah became so distressed she took an overdose and was admitted to hospital.

'It's just horrible when, living with disability, life is hard enough. And then to feel like you're a burden and a problem and a nuisance to the healthcare sector, and a funding kind of burden as well, I just got so overwhelmed that I just didn't know what else to do.'

Aleah eventually found an advocate to help her communicate with the hospital. Diego no longer takes antipsychotic medication. His behaviour has improved and he's back home.

'I went to a healthcare facility expecting help. But they basically just wanted to throw drugs at him to sedate him and to make him more compliant, and didn't listen to anything that I was telling them.'

Aziel

‘If disabled people can’t use them, what’s the point of having disabled toilets.’

Aziel has cerebral palsy and uses a walking frame.

When he arrived in Australia 10 years ago, he was happy to discover his primary school was mostly accessible and he could get around independently.

But there was one big problem – the toilets.

Every toilet, including the accessible toilets, had swing push or pull doors. With his walking frame, Aziel couldn’t open the doors.

Aziel needed his teacher aide to help him go to the toilet.

In high school, he hated having to rely on his teacher aide and was often late back to class after lunch or recess.

He found it embarrassing and shameful.

Leaving school, Aziel found the situation was much worse.

He discovered there were very few public places he could go by himself. Aziel told the Royal Commission almost all public toilets at beaches, sporting ovals, shops, train stations and rest areas have doors that are inaccessible.

‘I’m just stuck at home. I can’t go anywhere at all,’ he said.

Even if someone is with him, many accessible toilets are locked.

Recently, Aziel discovered the bigger shopping centres have installed accessible toilets with push-button doors.

Aziel believes governments and councils should follow suit.

‘They won’t be upgraded until the government actually steps in.’

Aziel also wants governments to invest in new technology that allows people with disability to use a digital key to unlock doors of public toilets that need to be locked.

‘If the bathrooms are good I could go out more,’ he said.

Jianna

‘I would’ve gone to university straight out of high school but for what happened in my primary and secondary education. So everything in my life got pushed back at least 20 years ... That makes an impact on what happens after that. It pushes everything in my life back 20 years.’

Jianna, early 60s, was diagnosed with dyslexia when she was five. It profoundly affected her reading, writing and spatial awareness. She struggled with words, maths and playing sport.

At the time dyslexia wasn’t really understood and ‘the cane was still in use’. When Jianna made mistakes reciting her times tables or spelling words, the teacher would cane her.

The first time it happened she was so surprised she pulled her hand away and broke her thumb on the edge of the desk.

Jianna’s mother came up to the school, demanding to know what was going on. In response, the school transferred Jianna to a remedial class.

‘Not that the caning really stopped, it just stopped on the hand. We copped it on the backside or the back of the legs.’

Being in the remedial class, other students excluded her and called her names such as ‘retard’.

In grade 7 the teacher would hit her with a ping pong bat for not being able to do long division.

‘And that was pretty much the way everybody with any kind of learning disability was being [treated].’

High school was a bit better because Jianna had different teachers, but she still struggled with maths and sport.

In her final year the maths teacher would pick her up by her ears and drag her out of class.

‘I don’t think I was inside for an entire class, or even part of a class, really, for my entire last year of maths. She thought it was beneath her dignity to have me in her class. I was a waste of her time and space.’

Because maths was compulsory for the HSC, Jianna was not able to graduate and her dream of going to university had to be put on hold.

Her parents tried to intervene, but there weren’t any formal complaint mechanisms they could follow.

Jianna finally enrolled at university in her early 30s.

She did well on her first essay but failed a multiple-choice exam because of her dyslexia. The professor spoke to her and referred her to the disability support unit. Jianna hadn't known support was available – 'I didn't get anything in the orientation pack.'

The university gave her 15 minutes extra for exams, and all multiple-choice exams were changed to essay style assessment. She was able to complete her assessments and graduate.

Jianna has had a very successful career but said she has never told her employers about her disability.

'I would like to think that one day there'd be a world in which I would disclose my disability. But I would never put it on Facebook, I would never put it on LinkedIn, I would never disclose it ... because I think it would be absolutely fatal to my getting work and to my holding down a job. Because I think it would just be so prejudicial, in people's assessments of my ability to do the job, that I would not get work.'

Everleigh

Everleigh is in her 40s. When she was in her teens, a neurologist told her she had epilepsy and prescribed medication.

'I have been having seizures since I was five,' Everleigh told the Royal Commission. '[The medication] basically caused me major depression. Cry all night, sleep all day depression ... I was just drugged out of my head.'

Everleigh lived in the country and the diagnosis meant she couldn't get a driver's licence.

'Being a country kid without a driver's licence is just considered absolutely abnormal.'

She couldn't get a job in her town because 'they wanted you to have a licence'. At one unsuccessful job interview, the interviewer noted her epilepsy.

'I couldn't ... be classified as disabled enough to be on the disabled pension. So, I was doing work-for-the-dole.'

Everleigh enrolled in university, but the medication made it hard to study and didn't stop the seizures. After she developed anxiety and depression, a psychiatrist referred her to a specialist for a second opinion.

'[He] took one look at my medical history and said, "Who the hell told you you had epilepsy?" ... He diagnosed that it's neurocardiogenic syncope, or vasovagal syncope. So, it's heart related. You know, stress, too much adrenaline, heart stops.'

Everleigh told the family doctor who years earlier had referred her to the neurologist who misdiagnosed epilepsy.

'[He said], "Oh, yes, I thought it was something like that." ... I said, "Why, if you knew that was the case, why didn't you say something earlier?" And he said, "Oh, the neurologist/specialist had told me that, and I don't argue with them."'

Everleigh said she'd been medicated for epilepsy unnecessarily for seven years.

'And I'm now wondering how many patients [the neurologist] ... was calling epileptic, and I'm wondering whether they were.'

Yulia and Janette

‘My mother is now probably at the stage where she won’t remember me, her husband or her grandson. We’ve lost three years of my mother’s time.’

Yulia is in her 80s and has Alzheimer’s disease. She lives with her son, who has ‘cut her off’ her from the rest of the family, her eldest daughter Janette told the Royal Commission.

‘She’s isolated. She doesn’t see her sister, she’s not seeing her family. She doesn’t see anyone. Her own husband of 63 years ... My mother’s been entrapped.’

Janette described her brother as a jobless ‘long-term drug abuser’ who is ‘mentally unstable’. He and another sister, her paid carer, are ‘financially abusing’ Yulia.

Yulia and her husband had been ‘travelling back and forth’ to their homeland for a decade. When she fell ill a few years ago, her husband returned only to be ‘denied access to see his wife’.

Janette said her brother ‘coerced’ her mother into giving him enduring power of attorney.

‘And all of a sudden, we’re in this situation where we find out that my sister and brother are stealing from her ... They changed locks, we cannot access my mother. My mother was in a very vulnerable situation, because he had withdrawn money out of her account. My sister did the same.’

Janette said her brother ‘violently threatened’ her and her family. Her father was terrified he would ‘sell the house’ and ‘throw [her] mother’ out.

‘This has left both my parents in a very, very volatile situation financially.’

The brother was ‘physically attacking’ her and her family and ‘making death threats’. ‘The police charged him – we had an AVO against him for two years.’

Because of this, Yulia is living in a ‘negative environment’.

‘She’s got dementia. She cannot make informed decisions, and she’s influenced by comments around her.’

The brother and sister are being ‘intentionally cruel’ to her.

‘They tell her every day that nobody loves her, nobody wants to see her. That’s a form of emotional and mental abuse. They tell her I don’t love her, they tell her that I’m going to burn her ... It’s a traumatic experience.’

Despite that, the public guardian refuses to remove Yulia from her brother and put her in respite care.

Janette said she's 'been blocked'.

'The guardians have refused access, the trustees have blocked emails and correspondence. I've had 18 applications before the tribunal.'

The office keeps saying 'give us evidence', but Janette says they've seen plenty.

'They see the evidence that they're exploiting her. They have built up an \$8,000 Mastercard debt on their own personal things. I also presented affidavits from friends, saying she cries when she wants to see us. She wants to get out of the house because they're totally controlling her.'

Janette doesn't understand why 'a government body' doesn't investigate, and instead leaves her mother 'in an isolated environment with her two abusers'.

'I thought the duties of the public guardian is to ensure that these two people are caring for my mother.'

Aarya

'I had been involved with child safety all my life and I can't seem to escape from them. I feel like I am being punished for being a child in care.'

Aarya is in her 40s and has an acquired brain injury that causes gaps in her memory.

'I sustained two head injuries in foster care,' Aarya told the Royal Commission. 'They don't know how that [first] head injury was sustained, but with the second one ... I didn't want to be removed from this orphanage [and] they just picked me up by the legs and smashed my head against a floor.'

Aarya is also deaf.

'I became deaf from my head injuries that I sustained ... By the time [I was] in foster care, the people that was raising us, they kept calling me a spastic.'

Aarya said she was sexually abused in foster care and later in life.

'All my children were conceived by sexual abuse, rape ... [But] the worst thing for me is that my children were removed from my care.'

Aarya said that when she was pregnant with her first child, child safety officers told her they would remove her baby 'because [she] was a person with disability'.

'I was a safety risk to my child. This was the same department I was sexually abused by as a child ... It gives me trauma to remember what happened to me in my childhood and I am still seeing it happen until this day to my children.'

A few years ago, when she was pregnant, her partner beat her and 'left [her] to die'. Her baby was born with disability.

'Child safety said it was my fault for not protecting my unborn baby. I was tied up, so I couldn't protect her.'

To escape her partner, Aarya lived in a refuge with her baby. One day shortly after a hospital appointment, child safety officers arrived with police.

'The child safety officer stated that they were removing my child as I had not answered their phone calls that morning.'

Aarya said she showed them her hospital documents, but was told they 'looked fake'.

'They took my ... child roughly from me. They did not allow me to hug her or give her a kiss or comfort her.'

A judge later returned the baby to her. During another pregnancy, doctors warned her stress was putting her unborn baby at risk of disability.

‘Child safety stressed me so badly.’

Aarya told the Royal Commission she worries the child safety department is still putting her children at risk of developing disability.

‘It gives me trauma to remember what happened to me in my childhood and I am still seeing it happen until this day to my children ... I am worried about the injuries my children are getting while not in my care.’

Rene and Marlene

Rene is a First Nations man in his early 20s. He has dyslexia, dyspraxia and a congenital heart condition.

'I have managed to maintain a very happy bubble for him to live in,' his mother Marlene told the Royal Commission. 'I just wanted him to be able to live as much as possible if his life was shortened.'

Schooling him 'with his dyslexia' in the early years was 'a very hard journey'.

'He started to get behind and the kids started to bully him – and he wasn't immune to the bullying ... He struggled, and a paediatrician said, "You are going to have to get him out of school to give him half a chance."'

Marlene and Rene moved interstate for 'fresh air, sunshine and a fresh start'. She decided to homeschool her son. He was 'very much a home boy', 'frightened to be out in the world and needed encouraging'.

When Rene was in high school, the education department started 'threatening deregistration' if Marlene didn't register Rene for homeschooling under his father's name.

She was 'panicking' because of the 'constant threat' of her ex-husband taking Rene back.

Rene wanted to do a 6-month course in wildlife management. Marlene had to 'fight like crazy' for approval for him to do that at the same time as homeschooling.

Teachers gave him 'no support at all' for his dyslexia.

'They did the English comprehension test, and because he had passed with 65 per cent they said he doesn't need support.'

Marlene noticed Rene was 'getting behind' and not finishing assignments. When she asked teachers about it they said, 'Oh, he's probably not going to pass.'

'[I] couldn't believe what was happening ... He'd been working with animals since he was nine years old. Many, many hours of volunteer work. And he was just lovely with animals ... Yet he's going to fail.'

In year 10, the education department deregistered Rene 'because of his lack of progress in writing and maths'.

Because of the deregistration, Centrelink accused Rene of skipping school and claimed thousands of dollars in child support payments. Marlene was 'petrified' after using all her savings to school him.

The deregistration process also triggered family law proceedings. Rene was 'so distressed', he ended up having a breakdown.

Following a long period of counselling, today he is 'happy and he's working'.

'And, you know, he's everything that I hope I raised him to be. These kids who are on the spectrum are so talented and so amazing.'

Salem

‘The psychiatrist and the nursing staff, they were acting like high school bullies pretty much to me. Just like name calling and stuff like that. And I was just doing my very best to stand up for myself even though I didn’t have the energy to.’

Salem, early 20s, is autistic and has fibromyalgia and Ehlers-Danlos syndrome. They told the Royal Commission they have ‘very complex chronic health issues’ and ‘there’s been times where [they] need a wheelchair’.

As a child Salem was exposed to domestic violence, bullying and hate crime.

Last year Salem was experiencing chronic bladder pain and having trouble urinating, and called an ambulance. Although Salem had previously had transphobic experiences at a nearby hospital, they agreed to go there because their mother and support worker would be there to ensure they were not mistreated.

On arrival Salem was separated from their mother and support worker and put into an ‘interrogation room’ – an empty locked room for a mental health assessment.

A male nurse immediately gave Salem some form of morphine or opioid medication despite Salem’s protests – they’d previously had bad experiences with opioid medication.

Salem was not permitted to go to the toilet, even though they had not gone to the toilet for almost 40 hours.

Salem told the Royal Commission they were left alone in the ‘interrogation room’ for a long time.

‘I was just like desperately asking for help and for someone to call my mum or my support worker. But the staff were very frightened by me asking for that.’

Eventually a psychiatrist came to see them but he wasn’t wearing a mask. Salem refused to speak to him until he put a mask on.

He asked Salem questions about their mental health and demanded they tell him their biological sex.

Salem tried to tell the psychiatrist there had been ‘some kind of misunderstanding’ and they were there for a medical issue.

‘I was in so much physical pain that it wasn’t easy for me to say what was wrong.’

The psychiatrist refused to listen. Frustrated Salem threw a water bottle and asked for a lawyer.

The psychiatrist accused Salem of assault and called security. Salem was admitted as an involuntary patient for being 'hostile and violent'.

In hospital, staff injected antipsychotic medication without Salem's consent and refused to allow them to take their usual medication.

Staff routinely laughed at Salem.

'They would like mock and invalidate me about my gender and my physical disabilities just all the time.'

Staff refused to use Salem's preferred pronouns, and one staff member told them they 'just need Jesus'.

'There were lots and lots of pamphlets for ECT [electroconvulsive therapy]. And I found that really triggering because I was given ECT [before] and I didn't need it and it was very traumatic and one of the worst things I've ever been through.'

Salem asked staff to remove the pamphlets but they refused. Salem was terrified they were going to make them have ECT again.

Salem is vegetarian and lactose intolerant and couldn't eat the hospital food. Staff believed Salem had an eating disorder which was another reason they needed to be detained. They also accused Salem of 'being addicted to self-harming' even though the scars were old. 'They just threatened me.'

After four weeks Salem was allowed to go home. 'It was very traumatic,' they said.

Kace, Quincy and Madisyn

Kace, 16, and his younger brother Quincy are autistic. Quincy also has attention deficit hyperactivity disorder.

Both Kace and Quincy experienced significant abuse and neglect at primary school. Madisyn told the Royal Commission she had to move them several times because she knew 'it wasn't safe for them'.

In high school the abuse and neglect has continued.

'We've battled a lot of issues of bullying within the school, both verbal and physical – assault, harassment, being kicked, punched, pushed into walls.'

Two years ago, Kace was doing his homework in class when one of his classmates started punching him in the arm, calling him 'idiot', 'slow' and 'a retard'. Kace didn't respond. The boy then took Kace's glasses, grabbed him and started hitting his head against the desk several times. Kace panicked and started stimming – hitting his own head against the desk. He hadn't done this for several years and afterwards felt bad about it.

Kace told a friend who suggested he make a complaint, but Kace didn't want to get the teacher into trouble. He also didn't believe anyone would care.

'Because every time I complain or say something, nobody hears me, nobody helps me. What's the point of saying anything?'

When Kace got home from school he told Madisyn, who encouraged him to make a complaint.

The school was apologetic about the incident and said they would try and help Kace. But nothing happened.

'[Kace] didn't go to school the next day,' Madisyn said. 'He didn't go to school the day after that either because he just couldn't manage to even get out of the house. This is always a struggle ... anxiety going to bed ... waking up in the middle of the night thinking about school and bullies and people attacking him. He doesn't want to go out in public because he's worried that if people look at him physically, that they are going to either verbally assault him or physically attack him. That is how he feels constantly every day of his life.'

A few months later, Quincy had a fall in a science class. He was 'skimming' – splashing water on his face. Instead of following Quincy's behaviour plan, the teacher belittled him and told him to stop.

Quincy's foot slipped, he fell backwards off a stool and hurt his tail bone. He was in pain, but the teacher told him to get up. 'You'll be right just keep going. You have to keep doing your work and stop being so ridiculous,' they said. Quincy couldn't keep going because he was in pain. The teacher told him to go to student services – 'You are just misbehaving.'

Student services sent him back to class.

Quincy sent Madisyn a message telling her he had hurt his back, and a short time later the school sent her an email advising her he had been misbehaving.

Madisyn collected Quincy and realised his pain was real. She took him to the hospital – he had fractured his tail bone as a result of the fall.

Madisyn made a complaint but it went nowhere. 'There is literally nowhere for us to go because nothing, you are not heard anyway.'

'I have literally got no trust in the school,' she said.

'We absolutely love school holidays. It's like we're released. They can be kids. They can try to be happy for some of that time.'

I want to work more hours
and be ~~like~~ treated like everyone else
at work. and work the same hours and
get the same pay as my friends at



I want the same
support workers that I
have now I don't want
different people and
strangers coming into
my house

they give me awards
that say I do the best
job but they still don't
pay me the same as
everyone else



Artwork by Kalena Bos

Carmella and Rachael

Carmella has cerebral palsy, vision impairment and attention deficit hyperactivity disorder.

A couple of years ago Carmella started kindergarten. The school said it 'had never had a child with that level of disability before', but was willing to 'do whatever's needed'. It built a ramp up to the classroom and made the toilets accessible. 'For the first little while it seemed like everything was okay,' her mother Rachael told the Royal Commission.

Teachers promised to 'modify the environment, so that it was more supportive'. But they quickly decided she didn't have 'severe communication needs'.

Midway through the year, the school still hadn't provided Carmella with a visually accessible reader so she could point to letters to spell out words.

'They were still assessing her verbally, saying to her, "Make the sound for this letter." She can't make that sound. And then they were going, "Oh, she can't do it," so they'd fail her.'

Rachael hired therapists, 'trying to get [the school] to make adjustments ... but they just refused'.

'In the end, she had zero interest in the school ... That was kindergarten, it was horrible. Then year 1, it was a disaster.'

Carmella had 'spent the whole year inside in kindergarten', so Rachael wanted to make sure her teachers took her outside on the playground during breaks.

'They just didn't get it.' They left her 'sit and play with toys' indoors, and she was 'on her iPad half the time'.

'She was segregated from her peers at recess and lunch, she was kept locked inside a classroom. She missed out on all of that socialisation which is so critical, particularly for a child with communication difficulties.'

Once, teachers 'physically restrained' Carmella in her chair during recess.

'She was trapped up against the table. They'd left her for 10 minutes screaming, with the timer on.'

Rachael met with the principle about it. He said, 'She's not the only child with a disability we keep inside all lunch.'

At that point the relationship with the school 'really broke down'. Rachael was getting 'almost daily notes' saying Carmella's 'been rude today ... she's been misbehaving in class, screaming'.

'Behaviours are an expression of an unmet need,' she'd reply. 'So maybe you should work on meeting those.'

Still, they would punish Carmella.

'This is a child who uses a wheelchair or a walking frame for mobility, has limited speech, requires so much support in so many areas of her life. And they were sending her to the principal's office and berating her.'

Before the bell went, teachers were supposed to take Carmella out of class first. 'Because she can't see where people are coming from, so she gets really overwhelmed.'

Once, 'all the kids stampeded' when she was still in the room and she 'panicked and ran for the door'. She 'scratched a little girl's face' trying to get her out of the way. Teachers took her 'to the front office and made her stand in front of this little girl'.

'She was in full-blown panic mode,' Rachael said, 'It wasn't intentional. So, where's the value in humiliating her publicly? ... [Carmella] was totally devastated.'

Carmella is now at a new school whose attitude is that 'she can and should learn what all the other kids are learning'.

Rachael hopes that by high school, Carmella will be 'independent, and take herself off to class ... like any other kid'.

At her previous school that idea 'was not even on their radar'.

'She missed out on two of the most crucial years of her education and learnt nothing. The difference has just been extraordinary, and I think it just shows that inclusion can be done, and it shouldn't be that hard.'

Piper

Piper is a student who has needed exceptional determination to gain entry to her program of study. She is in her early 30s and has attention deficit hyperactivity disorder (ADHD), depression and anxiety.

Piper told the Royal Commission that year after year the agency responsible for the university admissions test refused to allow adjustments in the way she sat the exam. Finally she hired a lawyer to pursue the matter and the agency gave in. When Piper sat the exam yet again in conditions that reflected her special needs, she passed in the top 15 per cent of her cohort.

The years-long dispute exacerbated Piper's depression and anxiety '100 per cent'.

'I had many major breakdowns trying to get into [my course], because the injustice ate me alive, because I knew that I was capable of studying ... But they just would not let me in because unfortunately my disability stopped me from scoring high enough in that exam. And the people who ran the exam stopped me from performing equitably.'

Piper experienced further barriers when she applied for university. The university she first applied to gives special consideration to applicants who can demonstrate lifelong hardship or disadvantage by awarding them bonus points.

'Guess what, I've had ADHD, I've had lifelong hardship since pre-primary, struggling at school, struggling in high school, being disengaged – lucky that I just happened to have enough intelligence ... to get through high school.'

Piper applied for the full number of points. The university gave her one.

'They said to me, "No, that's not disadvantage." She wonders who is deciding 'what constitutes hardship or disadvantage'.

'You can't just pick and choose, a little group of you sitting at a table, deciding if this person has struggled enough.'

Piper noted that the Disability Discrimination Act requires universities to provide alternative entry pathways for all degrees. According to her research, they do not do this for medicine and law degrees except for First Nations students. She believes this needs to change.

'I am not advocating for a free pass into medicine or law school for people with disabilities at all. There are inherent requirements that you need as a doctor and as a lawyer ... [But] when there's processes that prevent people from participating equitably, there should be an alternative pathway.'

Piper believes there are many more professionals with disability or mental health issues than people know, who have not disclosed because of the stigma attached. This needs to change, she said.

‘You know, you need people in the system to advocate ... to normalise and reduce the stigma.’

Piper said her persistence was possible because she is ‘a very strong person, very empowered and very resilient’. Many people aren’t like that, she said. They might try once or twice, and then they give up.

‘And they’re not in [this field] now, and we’ve lost an amazing [professional] because there was no alternative pathway. And therefore there are less ... professionals advocating for disabled people, and less ... professionals with disabilities to prove to society that it is not a limitation.’

Brodie

‘The problem is, these employment service providers and the disability service providers, they simply don’t care about your medical conditions.’

Brodie is in his mid-40s and lives with a physical disability and mental health issues.

‘I’ve got congenital scoliosis. It’s not a major disability, but it does affect my capacity for physical labour,’ he told the Royal Commission.

Brodie said this ‘hadn’t been an issue’ in many previous jobs he’d held, some of which had been complex and high-powered.

About a decade ago he was having trouble finding work, so he turned to employment services. That’s when the problems began. ‘They all ignored my medical certificates,’ he said. It was all about ‘ticking boxes’.

‘They look at you as a number and at how much revenue they can claim from you. So you’re just going around in this system and not finding work. That’s what happened to me.’

The ‘tipping point’ was when one agency found him a six-week job at a local business. At the end of it, Brodie said the provider tried to ‘bribe’ him with a voucher.

‘They were trying to get me to sign off to say that I’d worked for 13 weeks continuously.’ Brodie refused, saying that would be ‘committing fraud’ for them. ‘When I questioned that, they reported me to Centrelink.’

Centrelink suspended his payments, leading him ‘down a path to anxiety and depression’.

‘It’s broken me down over a number of years. After that, I was taken out of that system and put into the disability employment system.’

About three years ago, he was in ‘still in a period of recovery’.

‘I was having positive behavioural therapy with a psychologist and I was improving to the point where I was going to be functional.’

Brodie signed up with a government employment agency that promised they would respect his health issues. Agency staff were ‘relentless’ in booking him appointments. ‘But they were utterly hopeless at finding me work,’ Brodie said.

Despite ‘doing what [he was] supposed to’, the provider kept reporting him to Centrelink.

‘To take away someone’s only source of income when they’re desperate is devastating. It wasn’t like I was trying to avoid work.’

Even when Brodie was on medical exemptions, they'd say he wasn't turning up to appointments.

'Basically they abused their position by reporting me to Centrelink, and that's why I'm in therapy right now. The whole suspension thing set me off. The psychological manipulation and damage they've caused still boggles my mind.'

Brodie's been on the Disability Support Pension for a few months. He would prefer to work, but he wanted 'to get away from' employment agencies.

'They've damaged me. I've been repeatedly traumatised by the system, it made me unemployable.'

The scoliosis had just limited Brodie's 'capacity for certain types of work', but now, he says, 'the psychological side of things is limiting all manner of work'.

'People who are supposed to help you find work, you'd think it's in their interest. Why would they push you to the opposite extreme?'

Kaliyah

Kaliyah, in her late 50s, described herself as ‘a woman with multiple disabilities’. They include cognitive impairment, memory processing difficulties, an acquired brain injury and post-traumatic stress disorder.

She is also a survivor of domestic violence, perpetrated by her ex-partner Michael. ‘So I have a lot going on in this body of mine,’ she said.

‘And my thoughts are that it’s hard enough dealing with abuse, domestic violence, family violence as a normal person, but it is extremely damaging to manage everything that I’ve had to manage with all of those disabilities.’

Michael is abusive and violent. He is also Kaliyah’s Centrelink-registered carer.

‘A lot of the time that perpetrator tried to silence my words. He was going around telling everybody that I was crazy, not to listen to me because I was just crazy and mental,’ Kaliyah said.

Michael has breached an apprehended violence order (AVO) many times, but when Kaliyah reported him to police, they took his side.

Recently, they arrested Kaliyah. Michael had taken out an AVO against her and accused her of breaching it. She was taken to the police station, where no-one explained what was happening and officers suggested she didn’t have a cognitive impairment or an ABI at all.

‘I have a brain injury and they treated me like a normal person ... So it was a terrible situation,’ she said.

The matter was dismissed in court, but Kaliyah continues to live in fear of Michael’s visits.

Kaliyah is searching for alternative accommodation where she can feel safe, but has so far been unsuccessful. She feels let down by the domestic violence housing services she has dealt with, which stopped helping her after a certain time had passed.

‘I needed them desperately but they treated me like I was a normal DV victim and that I just needed to hurry up out of their system and get on to something else,’ she said.

‘So what’s happening is I don’t hardly have time to build that trust with any of the workers. They’re not establishing that I have disabilities and I just need to take my time slowly, and I might be longer than other women who don’t have disabilities. But they’re just rushing me through the system.’

Kaliyah wants Centrelink to remove Michael from his role as her carer, but staff at the local office refused. She asked Centrelink to give the payments he receives as her carer directly to her, but this was also refused. She applied for a Centrelink crisis payment, which was approved – but they paid it to Michael, as her carer.

‘I thought that was unbelievable.’

Kaliyah applied for NDIS support but wasn’t successful.

‘I asked “Can I please know the reasons why?” and [it’s because] some person made a decision in some department. When I tried to get the reasoning off that person I could never get a hold of that person.’

She intends to appeal but says it’s hard to ‘appeal something you don’t even know the reason for’.

Kaliyah said Michael’s abuse and the difficulty of moving on to a life without him has impacted her health.

‘It’s caused me to have no control over my bladder, one of the incidents. It’s caused me to be hospitalised so many times. It’s caused, it’s caused me to be at my lowest in life.’

Keiran and Meagan

‘These kids with potentially high intellect are being so badly treated.’

Meagan is in her 60s and was diagnosed with autism a few years ago. She told the Royal Commission being autistic explained many difficulties she had at school.

‘I couldn’t handle the school. I failed at school ... I didn’t talk until I was about seven or eight years old and ... it was the autism, I know now.’

Despite her problems at school, Meagan excelled in a number of careers, including nursing, where she worked in an intensive care unit.

‘Because of my autism traits, my hypervigilance, they chose me to do those things. They could see that I was really good at it. And I would never be allowed anywhere near those places now [after the diagnosis].’

Meagan is ‘up on the latest research’ in autism. She advocates for her grandson Keiran, who’s in primary school and is also autistic.

‘Before he was going to school, he could read age-appropriate books. He knew all of the letters of the alphabet. He could count backwards and forwards ... He was ready to go to school, but the education department in their wisdom put him in a special ed unit.’

The unit was noisy and Keiran, who loves maths and reading, sat alone for several years and received little education. His behaviour deteriorated.

‘If I asked you to read “Mary Had a Little Lamb” every day for three years, how angry would you be?’

Meagan said when she eventually confronted the school, the teachers weren’t aware Keiran could count and read to a grade 5 level.

‘I said, “Do you understand that he has that capability?” and they went, “No.” And I said, “Well, how much formal education do you do in this special ed unit? ... No wonder his behaviours are escalating. He’s bored.”’

Keiran’s parents enrolled him in a new school where he was put into a mainstream class. Meagan said ‘everything was good’ until a new teacher took over and insisted on controlling his behaviour by punishing him with isolation.

‘We pulled him out when he stopped eating, stopped drinking, had excruciating stomach pains and was wrapping himself in a blanket.’

Keiran’s parents enrolled him in a country school.

‘[It had] a fantastic learning assistance program. They had a fantastic parent participation program ... He’s overcome most of his trauma ... and he is actually doing grade 4 and 5 schoolwork in little patches.’

Meagan said few teachers know how to work with autistic children.

‘They don’t have the support in the classrooms. Quite often the parents of these kids don’t even understand the autism themselves. So okay, I get that, [but] they’re taking advice from the education department, [which is] is so archaic that it causes more problems.’

Cruz and Elliana

Elliana is the grandmother of Cruz, who has fetal alcohol spectrum disorder (FASD).

He also has a lot of behavioural and mental health problems ‘that come under that same umbrella’, Elliana told the Royal Commission.

Cruz often has ‘meltdowns’ and ‘can’t do social’. ‘He’s 11 going on about six.’

Elliana said Cruz was ‘discriminated against’ throughout primary school. ‘It was very much shame, blame and stigmatisation through the whole system.’

Teachers and principals ‘excluded and isolated’ him.

‘He wasn’t accepted. He wasn’t allowed to be included. He was expelled from two different schools. He had to do things, and he couldn’t. And it was just seen to be very much naughty behaviour. So he missed a lot.’

Elliana said Cruz was ‘hog-tied’ in his education. He was ‘sent home and expelled for a few years’ and ‘didn’t attend school from prep until year 4’.

After he got a diagnosis, Cruz returned to school for one hour a day. He had support workers ‘to come in and help get him back into school’.

‘Still, he was made to feel that he was just a bad boy, by the teachers, everyone. When he has a meltdown it’s, “Get out, and get down to the office.”’

Once, the principal ‘dragged him’ to his office from the playground.

‘He told me he was an ex-child worker in a youth detention place, and he said to me, “This is where he’s gonna end up. You know that, don’t you?”’

Elliana said Cruz had no classroom supports because the education department doesn’t recognise FASD as a disability.

‘A lot of children with ASD (autism spectrum disorder) or any other condition would get teacher aide assistance. He wasn’t able to.’

Cruz left primary school with ‘a core belief that he’s no good, he’s just a naughty child’. ‘His biggest fear is not being accepted.’

Today, he’s in year 6 and ‘doing so well scholastically’.

‘After finding the right teacher who understands, he last year got top in English.’

Elliana says it has been 'awesome' to see the change. 'He wants to go to school now, he loves school. He won't miss school.'

She still worries about 'keeping him out of the justice system'. Education is critical.

'My biggest hope would be to see him be able to participate in normal community life. The main thing is the school. If we can get the teachers right and the education right, he thrives.'

Cruz will go to a private school next year.

'Because I do think he's got the ability to go a long way. He just needs a structure and he needs a little bit of help, which he didn't get at primary school. [The new school is] aware, and I've done training for them and they've been wonderful.'

Soren

Soren, mid-50s, lived in a group home for many years with different people.

He told the Royal Commission support staff weren't 'looking out for [him], they weren't doing the right thing'.

Staff never consulted him when other people moved into the home, and they bought things for him without asking him.

Every month the residents had to attend a prayer night at a local hall and watch a video.

Soren didn't like going. 'They make me go,' he said.

Staff would not take Soren to the toilet when he needed to go and would leave him in soiled sheets.

One time, Soren asked a staff member to take him to the toilet. 'She told me to go back to my room and sit down.' Soren knew he wasn't well but it was hard to get anyone to listen to him. Ultimately, he ended up in hospital. 'My bowel was sort of impacted.'

Recently, staff stopped following Soren's food management plan. He became very unwell and his stomach was bloated. 'A day came, I didn't get out of bed,' he said. 'And my sister rang the ambulance.'

Soren said the nurses told him that the support staff didn't look out for him when he was eating and drinking, and some of the food and water went into his lungs. 'I had to be on a respirator.'

Soren was in hospital for three weeks. He said the nurses were good to him and his sister came to see him and helped him.

Not long after leaving hospital his sister helped him move out of the group home into some temporary accommodation.

Soren didn't want the group home to know where he was because he was scared staff would come and get him. 'I didn't want them coming around ... and knocking on my door.'

Soren is now living in a place on his own with a support worker. He is very happy.

'I have my own private space,' he said.

Soren is looking forward to making some new friends.

Noe

When Noe was 17 he had a workplace accident that badly injured his back. He is in his early 40s now, and for the past 20 years or so he has been unable to work. He experiences pain every day, he told the Royal Commission. He manages it with medication and rest.

Noe receives a Disability Support Pension and NDIS funding. He spent years trying to access this support. To prove to doctors, specialists and other health services that his disability is genuine, he had to participate in numerous pain management and rehabilitation programs, sometimes for up to a year, and sometimes more than once.

Noe kept records of his interactions with the medical profession – ‘for my own sanity,’ he said.

These reveal doctors and specialists doubting Noe’s account of his experience and ignoring his concerns. His GP, in particular, was not supportive. He paid no attention to Noe’s requests for scans and other tests, reporting to other health professionals that there was no particular need for any clinical investigation and making negative comments about Noe.

‘He is not the brightest of men,’ he wrote in one referral.

The GP’s reports were also contradictory. For WorkCover, he wrote one saying Noe was fit for modified duties. When he wrote to an occupational therapist, he said Noe had been investigated thoroughly – which Noe disputes – and that he was unfit for all work.

Noe summed up his situation over this time as participating in ‘multiple different programs’ that he was ‘unable physically to do’. His doctor ignored the evidence of his disc problems.

‘He didn’t think they were major problems, and that’s why they said we had to go through rehabilitation ... I went through so many years of different rehabilitation clinics – I was sent all over the place.’

A physiotherapist reported back to the GP that Noe could not do even the lightest of exercise, but the GP ‘didn’t take any note of that’, saying he ‘doesn’t believe more or less the impact of what the disc problems are showing that I can’t do the things’.

Noe tried to change his GP but couldn’t find anyone who would take him on.

‘When I’ve rang up and I’ve actually attended other GPs, they say, “Go back and see your other doctor because we don’t know your history. It’s too long.”’

Noe believes his GP’s communications about him ‘severely impacted’ his care. Specialists did not assess him with an open mind, contributing to his difficulties accessing support payments and NDIS funding.

Several years ago he had to undergo yet another review of his disability pension. The doctor he saw read through his file.

‘He goes, “What are you even doing here for a review?” He goes, “You don’t need to be here.” He goes, “I’m just going to sign this, and you don’t have to worry.” That’s a doctor that could see everything that I’d been through and – and that was hugely helpful to me.’

Noe has a different GP now, as the previous one left the practice. His issues with the system continue. He has several health problems that have been dismissed by medical professionals. The NDIS is refusing to pay for equipment he needs.

‘These are just all ongoing things,’ he said.

Scarlette and Shepard

Scarlette is in her 40s and lives with a cognitive disability.

'I was so lucky to be brought up in the community and raised in the community by my family who wanted me to live in the community and have the opportunities like everyone else.'

Scarlette told the Royal Commission that her friend, Shepard, wasn't so lucky.

'[Shepard] lived in large residential institutions, a residential setting, most of his adult life. ... He had a wicked sense of humour and a keen eye for the ladies. He loved to dance in his wheelchair.'

Scarlette said she met Shepard more than a decade ago at an advocacy meeting.

'He wanted to live in his own normal home. He wanted to live in a place where he had his own letterbox. Instead, the mail got delivered to his service provider and it was already opened before he opened it.'

His support workers often left Shepard in bed for long periods of time.

'He also told me that he felt really embarrassed because he was put on a commode, wheeled down the corridor past all the bedrooms to get to the bathroom and only had a towel covering his knees.'

Scarlette said Shepard was often in bed before 7 pm 'because it suited the staff'.

'When he came to the advocacy meetings he got to stay up until about 8.30 and he loved it, but he really loved when he came to functions and he got to stay up late and have a few beers on the side. Isn't that normal for anyone?'

One evening several years ago when Shepard arrived at a meeting, Scarlette said she 'knew that he wasn't well'.

A few weeks later he was taken to hospital to treat kidney stones.

'They said when they opened him up all of his organs were infected and they couldn't do anything.'

Shepard died the following night.

'[Shepard] had a urine bag. Surely there would have been signs that he had kidney problems. He would have been in an enormous amount of pain ... At [Shepard's] funeral, people were saying he's in a better place now. All he wanted to do was live his life in his own home with his own friends.'

Scarlette said his death should have been investigated.

‘I think if he didn’t have a disability he wouldn’t have died from kidney stones.’

Andreas and Lois

‘My worry is children like [Andreas], who is in a government system already with child protection. Who is looking out for their NDIS money? Who’s making sure that it’s actually going to them and making sure it’s not just people, you know, taking profits for things that they haven’t done?’

Andreas, almost 10, is autistic and has Down syndrome. He’s been living with his grandmother Lois for about a year. Prior to this he lived in a different state with his mum, and then with foster carers.

Andreas’s mum has ‘some serious drug issues’ and over the years all of his siblings have come to live with Lois.

Lois said things are complicated with Andreas because she has to deal with child protection, who are his guardians, and the NDIS.

‘The [NDIS] budget that he got was a huge budget on paper but when you looked into it there was only a few thousand for OT [occupational therapy], a few thousand for speech therapy. The bulk of the money was for respite care, which isn’t what [Andreas] needs ... He actually needs the help.’

Lois believes Andreas needs therapy to address his trauma and other mental health issues. But the NDIS planner refused to listen to her and didn’t respect her point of view. She feels the planner saw ‘child protection’ and ‘drug addict’ and made assumptions that she couldn’t be trusted and was ‘trying to get something for nothing’.

Child protection ‘don’t want to involve her at all’, Lois said, and because of this no-one is keeping an eye on the services the NDIS have funded.

‘They’re very distant to the whole thing and don’t really care too much ... but they’re the ones with all the say. They’re the ones signing at the end of the day for anything.’

Child protection accidentally copied Lois on some emails and she discovered a number of therapists and respite services were charging for services they weren’t providing.

‘I made several complaints and I was basically ignored. It was, like, it doesn’t matter. It’s government money, anyway. But the way I see it, it’s there to help [Andreas], who has a disability, has a lot of things going on in his life, didn’t get the opportunity as a little person to have the services he needed.’

Lois asked to be listed on Andreas’s NDIS plan so she could oversee and audit the invoices coming in, but child protection refused.

Lois has asked child protection if she can become Andreas's guardian but they've said no. They were willing to transfer guardianship to the child protection department in the state Lois lives, but the department refused.

Since living with Lois and his siblings, Andreas has started speaking.

'Just spending time with people, being read to, talked to, you know, all the things that normally would happen in a family, he's come along so far. And I just think that if he actually had all the services that were offered to children in his situation, the potential for [Andreas] to make him independent or to maybe have a job or to be able to read a bus timetable ... those basic skills, I think, would be there,' she said.

'It's sad that he missed out on any early intervention and things like that when he was young because of his mum, but now it's sad that he's missing out on it because he's caught up in a different system.'

Remington

Remington is in his late 60s and has schizophrenia and intellectual disability. A few months ago, he moved into a group home in Sydney and is not happy there.

‘I want to move to somewhere else,’ he told the Royal Commission, ‘I don’t like it very much. They’re mean to me.’

Remington likes being his ‘own boss’ and finds it really hard after 20 years of independent living. Previously he lived in a government housing unit with disability supports.

Staff at the home make him have dinner earlier than usual, and he has a lot less choice. ‘I get very mad because they rush me.’

Remington lives with three others. One man in particular is ‘not very nice’.

‘I don’t get on with him. He smokes in the house.’

He misses his mates and his bird, Helen, who ‘got away’.

The home won’t let him have a landline to stay in touch with all the people he misses – he’s a ‘prolific phone caller’. But ‘they don’t listen’ to his needs.

Through his housing history, Remington has ‘struggled to balance loneliness with independence’, his advocate told the Royal Commission.

The government housing unit had been Remington’s ‘first home that was his’. He was ‘very fit and agile’ when he was living independently. ‘He used to track all the way around the city to coffee shops and meetings,’ the advocate said.

But his support needs became greater. He ‘was not feeling safe at night’.

‘I was scared of falling,’ said Remington.

‘There are things he very much misses about his unit, but it was also very much not right for him,’ said his advocate.

The lack of independent living choices for people who require overnight support, but ‘don’t have a spinal cord injury or something of that nature’, left Remington with no choice but to move back into a group home.

‘Once he gave up his housing department lease, the notion of getting that back, let alone getting an NDIS plan with overnight supports, is virtually impossible,’ Remington’s advocate said. ‘When your options are a group home or community housing, you don’t have the degree of flexibility.’

The only thing that makes Remington happy at his current home are the support workers he brought with him. ‘They take me out every day ... I’m able to get around.’ They take him to the shops and the bank, but also to the beach.

One worker has been ‘a really positive influence in his life’ and made him ‘much more confident about going out to new places and trying new things’.

Remington wants the home to understand ‘the right way to do things’ for him, so his life there improves.

Ariah

Ariah is in her 20s, has a cognitive impairment and lives in a group home.

'I get growled at [by staff],' Ariah told the Royal Commission.

Ariah has sore feet because her shoes don't fit. 'I need new shoes,' she said.

Recently, Ariah asked staff to use the house car to pick her up from an outing because it was painful to walk to a bus stop to get home. But they refused.

Ariah's finances are controlled by the public trustee, which has agreed to give her money so she can buy new shoes.

'I need money for my shoes. But I don't have no money in my bank yet.'

Ariah said she was taking paracetamol for the pain, but staff stopped giving it to her.

'They said, "No, you're fine," and they said, "You too much have [paracetamol]. You will be sick one day." It makes me upset because it's not my fault I have sore feet. It's the shoe hurt me, the big shoes. And they said, "No, [Ariah], too much [paracetamol] all the time.'"

Ariah's been unable to access her money for several weeks and can't buy many of the things she needs, such as shoes, and the things she likes, such as soft drink. Ariah said staff treat her like a child.

'It is making me upset and mad.'

Deanne

Deanne is a First Nations disability support worker in her 60s. She has worked for more than two decades in youth detention centres, mostly with First Nations youth.

‘Children with disabilities and in particular First Nations people shouldn’t be placed in a general correction centre,’ she told the Royal Commission. ‘They can’t cope with the environment.’

Instead, there needs to be a solution that ‘fits those young people’.

‘Not just take kids out of their home, chuck them into detention and tell them now you behave yourself.’

Deanne said their problems just get worse in these facilities.

‘Especially when it comes to self-harm or health issues. Cultural separation. A lot of the young people that come in can’t understand what people are asking them, particularly those with things like autism.’

The punitive approach ‘doesn’t help those poor young people try and make the changes that we are all asking them to make’.

‘You do something wrong, the first thing they do is cancel your visits, cancel your contact with family. They know how much they are looking forward to that.’

Once she saw staff treating a girl ‘with severe brain damage’ like that.

‘All she would get is consequences and consequences. They stopped her phoning mum, took away her family contact. Those things should not happen to people with disabilities. You should never use their family as a consequence.’

Prison staff are ‘combating negative behaviour with negative behaviour’.

‘I don’t see the understanding that’s helping these kids. How is it deterring them from recommitting crime?’

On top of that, she said children get no mental health care in detention.

‘They don’t dare use any of that therapeutic stuff anymore. There’s no time. It’s get here, get there, do this, do that, and if you don’t, lock them up on their own.’

Deanne has seen many children with disability put in prison ‘then just released into the general populace’.

'Those young people get lost, and they are vulnerable. Other people take advantage of them. And hence, we lose them.'

The supports that once existed have gone.

'I used to be able to do things like doing reintegration into community. Taking boys out of the youth detention centre, whether it's meeting family, setting them up in flats.'

Without the supports, these kids end up 'continuously incarcerated' – and it's very hard to 'break that cycle'. 'They get out, and then they're back again for something ... They really don't have a chance.'

Deanne wants to see early intervention.

'I know one young person who told people for years that he heard voices, but because he was young they wouldn't diagnose him, they wouldn't help him. And he is now no longer with us.'

'We need to start helping children when they say they need help. We don't listen to them. It hurts me that we lose young people, particularly with disability. And it could have been avoided.'

Anisha and Esmae

‘I’m just supporting what they want as a couple. And there’s nothing wrong with people who have a disability to be in a relationship.’

Anisha, early 30s, has been in a relationship with Mitch for about 10 years.

Esmae, Anisha’s mother, supports them ‘very much ... because, you know, why not?’

‘They attended a day program together. They have a beautiful relationship,’ Esmae told the Royal Commission. ‘They dated for a year ... and [Mitch] became part of our family ... They have feelings. They’re allowed to.’

About five years ago, Anisha wanted to move out of home and live with Mitch.

Esmae explored the possibility of supported independent living with the NDIS.

‘One of the goals in [Anisha] and [Mitch]’s NDIS plans was to be a couple and be supported as a couple.’

Anisha and Mitch found a provider who was happy to support them. They moved into a home with another friend from the day program, Kate.

Anisha and Mitch started seeing a relationship psychologist who specialises in working with people with intellectual disability.

For 18 months they lived very happily together. ‘That home felt like a home,’ Esmae said.

Then the CEO resigned.

‘When she left, other staff just kept dropping and were leaving and there was a whole big change in the organisation.’

Suddenly, the provider terminated the accommodation agreement and refused to help Anisha, Mitch and Kate find somewhere else to live.

Esmae said it was challenging to keep them all together.

‘It was so hard because I had to do a lot of the groundwork.’

Esmae ended up renting a house from a family member. It took multiple meetings with CEOs and management for one provider to finally agree to provide services.

About a year later some of the senior staff left. New staff were casual, inexperienced and the support deteriorated.

'I did my very best to work alongside with them so that they could understand [Anisha's] situation and her relationship and her needs.'

But staff started judging Anisha and Mitch.

'They manipulated [Mitch] to believe that it was not good for people that have a disability to have a sexual relationship.'

The provider refused to allow Mitch and Anisha to see the relationship psychologist.

Anisha struggled with the changes and it affected her behaviour. '[Mitch] was also suffering.'

Eventually the provider separated Anisha and Mitch, moving Mitch to another group home. Esmae begged the CEO to keep them together but the CEO was dismissive saying, 'They don't even have a sexual relationship so why should they live together?'

Esmae contacted Mitch's guardian, the public trustee, but they sided with the provider.

The provider refused to allow Anisha to visit or contact Mitch.

'[Anisha] suffered the loss of [Mitch] moving away, she became very emotionally unstable. I found it really hard to explain what was happening. And then she stopped eating.'

The provider terminated the agreement with Anisha and Kate and they had to move to another group home.

Staff physically and verbally abused Anisha. One time, Esmae found her with a broken nose and two black eyes. When she asked what happened the CEO told her it was 'a mystery'. Esmae demanded to see the incident report and CCTV footage but they refused.

Esmae made a complaint to the NDIS Quality and Safeguards Commission. Nothing came of it so she found another provider.

'They've just housed her in a very nice homely place and they've matched her properly with the other ladies that live there. She's in a happy place now ... They are supporting their relationship.'

Anisha and Mitch see each other regularly.

'I have to advocate for my daughter and [others] because it's not just her that's suffering, it's lots of other people who don't have a voice. And who's going to voice for them?'

Jovie and Jovanni

‘These people with disabilities are just as important in the community, and possibly even more than some abled people, because they teach people empathy and love.’

Jovanni is the father of Jovie, who’s in her 40s, has cerebral palsy, uses a wheelchair and lives in a group home.

The public guardian has made decisions for Jovie for the last two decades.

‘Ever since my daughter’s been part of the [guardian’s office] her rights have been diminishing, her quality of life has been diminishing,’ Jovanni told the Royal Commission. ‘The biggest nightmare is having to watch my daughter suffer all these years, and being with helpless hands.’

Jovanni, who’s separated from Jovie’s mother, said the guardian and the group home are increasingly restricting his access to his daughter. He’s now allowed to see her for only a few hours a week, before the home’s evening curfew.

‘We’ve got to get [Jovie] home at [a certain time], right? And if we don’t arrive there at [that time], we’re not allowed to go inside the house. We have to drop [Jovie] off in the front gate.’

Jovanni said staff medicate Jovie in the evenings because there’s ‘only one carer in between the whole lot during the whole night’.

Quote: ‘That’s why they dope them, so they can sleep all night ... My daughter’s always saying about a pill, “Dad, they give me a pill and put me in bed. I’m a ... woman [in my 40s]. It is not even dark.”’

Jovanni said he recently asked her psychiatrist to review her medication.

‘This psychiatrist is writing that my daughter is so severely disabled mentally that she can’t [make her own decisions], which is not true ... [My daughter] has got a strong mind and she knows what she is doing.’

Jovanni said the home keeps changing staff.

‘Almost every week there’s two new carers there. Now, I asked, “How long have you been here?” “We’re just here training.” I said, “Really. My daughter is a guinea pig again.”’

Jovanni has tried unsuccessfully several times to become his daughter’s guardian.

‘There’s nothing advancing. My daughter is going backwards.’

Kody and Mack

‘No-one has helped us, no-one has done anything. It’s just constant nothingness. And then every time I call the NDIS no-one can answer any questions.’

Kody is autistic and has global developmental delay. He lives in Queensland with his father, Mack, and attends primary school.

‘He’s a great little kid, it’s just he’s pretty taxing on what he needs with care,’ Mack told the Royal Commission.

Kody attends ‘a normal little school’, not a ‘very great school in the way of understanding of things’. But he enjoys going and ‘tries to make friends’.

Mack said the school doesn’t acknowledge Kody’s disability. When he tried to tell teachers that Kody ‘feels unsafe because someone is bullying him,’ they ‘just didn’t care to listen’.

When he was about six, the NDIS assessed Kody and said he could get funding and a number of supports.

Mack had to submit evidence of Kody’s disability within 28 days. He included reports from an occupational therapist and clinical psychologist. Both ‘outlined every single thing he needs’ and ‘stated that he had autism level 2’.

‘Then two days later, I get an email that he had been removed from the NDIS.’

The NDIS officer admitted to Mack ‘she hadn’t even read the reports’.

‘It’s pretty crazy to think of it and how bad they’ve treated us ... It’s been a hell of a ride since then.’

Mack lives with post-traumatic stress disorder.

‘It’s flaring up due to the NDIS mistakes and not even giving us support we needed from day one. It’s hard when I don’t get any support for him at all. You know, the only thing we have at the moment is a psychologist.’

Mack said the upshot was that they ‘lost a house’ and have been ‘blacklisted on the rental market’ because of ‘the way [Kody] is’.

‘He throws things around. If he had something for dinner and didn’t want it, he doesn’t go put it in the bin like a normal child does, he hides it.’

Mack and Kody ended up living in 'a squatter's house'. The Queensland floods had left two rooms of a private rental house intact.

Mack managed to get Kody's funding reinstated, but wanted the plan reviewed. He met with a support worker from a disability support service to discuss Kody's goals.

'He wanted to be more social, to go spend time at other places and do things out in public ... [but] not one of them were included.'

'The local area coordinator completely stuffed the plan up. She didn't care.'

Instead she had written down on Kody's plan, 'my dad will do this, my dad will do that'.

'I actually specifically stated I cannot,' said Mack.

Kody is on less funding now.

'All this is affecting him badly and we're trying to deal with it.'

He's awaiting 'a full review' after an internal review officer agreed the 'plan needs to be looked at 100 per cent'.

Mack just wants his son 'to have the supports that he needs'.

Alaiya, Marina and Saige

‘I think only once one [public] guardian turned up in the whole time that I was actually at [the] house ... And I said to my CEO, how are these people going to make the actual connection and know what their client’s needs are?’

Saige was a First Nations disability support worker in a supported independent living home in a regional town.

A few years ago, several women with psychosocial disability lived in the home while they transitioned from prison to the community.

‘They were all sort of like, you know, dishevelled,’ Saige told the Royal Commission. ‘Didn’t know what was going on, didn’t have much future from what they were saying and didn’t have any bright outlook on anything.’

When Alaiya first arrived at the home, Saige said she could tell ‘there was something not right’.

‘And I rang the prison and I asked what medication she’s on.’

‘Oh, she’s on nothing,’ was the response.

Saige organised for doctors to assess and treat Alaiya’s disability.

‘We found out she loved doing art. Now, this is a big thing ... this lady went from, “I don’t want to talk to nobody,” to where she actually sold her paintings.’

Another resident, Marina, frequently absconded at first. But later she enrolled in a TAFE course.

‘She’s like, in the end, “Aunty, I give up. I’m staying. I’m not running away.”’

Saige, who speaks several languages, said her cultural connection and ability to speak their dialect helped the women improve in ‘leaps and bounds’.

‘There were so many little elements to get them – I don’t know if I could say “better” – so much further holistically ... They actually had safety. They had great help. They had security. They had trust.’

Saige was so proud she invited the women’s guardians to the house, but only one showed up during the time the women were there.

‘I’m still proud of them. They had achieved what they wanted to achieve. And from what they had achieved, we were then going to get these ladies out into the community into their own houses ... And then the walls basically came crashing down.’

Saige said a disgruntled former staff member made a complaint against her. Although a departmental audit cleared her, the public guardian heard of the complaint and removed the women, against the advice of First Nations service providers.

‘When the guardians actually came into the house to take the girls away, I said, “Can you please at least tell the girls where they’re going?” And the guardians said, basically put their hand out in front of me and said, “Stop it, [Saige]. We know what we’re doing. They’re going to a safer place.” ... I still to this day do not understand why they were actually removed.’

Saige said it turned the women’s lives ‘upside down’.

‘Aunty, you were supposed to protect me,’ Alaiya said to Saige. She then ‘closed down for a few months and wouldn’t talk’.

Marina later broke a leg trying to return to the house.

‘She put all her medications in her hand and she swallowed them all, because she wanted to, you know, like, hurt herself.’

Saige lost her job when the house closed. Some of the women went back to prison.

Reagan and Adriel

‘My sister’s safety and welfare is being put at risk due to lack of management, lack of incident reporting and lack of accountability. To me, it is just a very, very poor situation.’

Adriel’s sister Reagan is in her 60s and has an intellectual disability. Reagan lives in a supported independent living home in a regional town, and Adriel manages her NDIS plan.

‘I’m watching my sister very, very closely, looking [out] for her personal safety and welfare,’ Adriel told the Royal Commission.

Recently, the supervisor of Reagan’s house told Adriel that his sister and another resident had an argument.

‘She was blamed for the incident and she felt very distraught when I spoke to her on Skype. I did ask the house supervisor for a copy of the incident report and I still haven’t got that.’

A few months later Adriel was told a member of the public saw Reagan being forced to ‘walk or exercise in the rain’ and looking ‘distraught’. In another incident, a support worker verbally abused Reagan, who was ‘very visibly upset’.

‘That’s a third incident in this situation that is going undocumented.’

Adriel contacted the service provider, who promised to investigate the verbal abuse. When he followed up two months later, a manager told him it was ‘not company policy to divulge that information’ for privacy reasons. The manager also said Reagan had agreed with the conclusions of the confidential report.

‘I find that very strange from the point of view that we’re now talking about my sister whose capacity would rate between a five and seven-year-old, and this ... manager is signing off an incident report on my sister’s say so. That is just outrageous to me.’

Adriel said he never discovered what happened, but learnt the service provider transferred the support worker who verbally abused Reagan to another house.

‘Whatever happened was significant enough for the company to transfer the person away from the house, but [they moved them] into another employment situation. They are just transferring the problem from one house to another.’

Adriel complained to the NDIS Quality and Safeguards Commission.

'I've got the form here. It says that Quality and Safeguards Commission will contact you within five working days. No contact at all.'

Weeks later he was told his complaint would be investigated, but 'nothing came back'. When Adriel made a freedom of information request for documents relating to the verbal abuse incident, he was told he was 'on a fishing expedition'.

'Unless I had a specific document, they would not disclose anything to me. Well, I sort of understand what they're saying. I get that, but I'm hamstrung because I don't have any documentation to ask them about.'

Adriel asked the NDIS Quality and Safeguards Commission to investigate the incident, but hasn't heard back.

'So, I'm a little bit perplexed as to what to do.'

Adriel said there's a 'lack of transparency, a lack of accountability from pretty much everyone'.

'Is it a more systemic problem? Am I looking at a regional issue because of the management structure and traceability? ... The overriding problem, though, is the safety and welfare of my sister, and ... the information I'm getting is very scant at best.'

Truett

Truett is a First Nations man in his mid-30s. He has an intellectual disability and an acquired brain injury from a major car accident about five years ago.

Truett was in prison when he spoke to the Royal Commission. He was trying to work with welfare services to organise visits from his young son Matty, but the process was full of obstacles he didn't understand.

'You know, the more I explained to them that ... I don't know what I'm doing, not even did they say once, go and speak to a lawyer or anything. But, no, it was just – I'm just another numbnut. I'm just another Koori in their way. Yeah, whatever. Written off to the side. And it's disgusting.'

A few years ago a court ordered a paternity test. Truett agitated to have it done, but it didn't happen till more than a year later.

'So it should have been done and the more I rang up, phone call after phone call after phone call after phone call, and getting nowhere.'

In the meantime, he hasn't been allowed to see Matty except on video link.

Truett says welfare workers do not care about his situation.

'They told me what they wanted me to hear, get rid of me off the phone and then nothing happened. And it's really, really depressing.'

He also feels they are deliberately provoking him.

'They're making up whatever they can to try and get me to go off my head so that then they can go, "Right, that's it. No contact allowed." They're doing whatever they can to try and make me flip out, while I've been trying to do everything the right way ... doing everything the way I should. And it's been difficult for me but I'm trying.'

Truett said that being a father 'means the world'.

'I deserve to go to wrap him in my arms. I deserve to go and, you know, like, him and I have been robbed all of this time and all this stuff ... and that's just wrong.'

Gabby

Gabby is in her 60s and has ‘multiple diagnoses of a psychiatric nature, but mostly particularly trauma’. Gabby lives in public housing which she describes as a ‘Kafkaesque dystopia’.

‘Living here [is] a kind of trauma pinball machine. It’s the best way to describe what living in social housing for me is like ... Tenants live in fear on a continual basis.’

Gabby told the Royal Commission that despite laws giving her rights as a tenant, she doesn’t feel safe.

‘Which just seems to me fundamental, if you’re a person who’s come in with a very intense trauma history ... homelessness, psychiatric hospitalisations, and so on and so forth, and a drug and alcohol history, to come into here and then just experience repeated re-traumatisation, unsafety, with no right to safety, it just seems incredible to me.’

For example, one of Gabby’s neighbours makes so much noise the ‘glass will shake on your table and the windows are rattling’.

‘I lodged a complaint and the [housing] department went in and spoke to this tenant. And as soon as they left he started screaming my name calling out, “[Gabby], you fucking cunt.” Sorry about the language, but I’m just being honest. Screaming that. Now, I have to pass his door every day on the stairwell. I’m an older woman with arthritis.’

Gabby said the neighbour continues to make noises that wake her up several times a night.

‘I have bipolar disorder as well and sleep is the biggest thing for wellbeing for someone with bipolar ... It’s really a struggle to have a day-to-day life.’

Another tenant installed a surveillance camera in a public area.

‘I complained about that, got victimised by him. He ended up buying a great big dog ... What [the department is] doing now is allowing [him] to abuse other people, and the abuse is extensive and not addressed.’

One night, there was a fire in her building.

‘I look after an elderly neighbour ... a person with disability, vision-impaired, prone to falls, has [an emergency telephone] system in her home, right? [The department] put her in a hotel apartment, a roomful of mirrors with tripping hazards ... no phone.’

Gabby said her elderly neighbour ‘kept banging into the walls because she didn’t know they were walls because they were mirrors’.

‘She had no accessible toilet, no accessible shower, no food ... No planning with regards to the placement of a person with disability in an emergency.’

Gabby won’t let friends visit her public housing unit because it’s not safe.

‘I don’t have relationships because it would be completely unmanageable. I would not want to expose anyone else to the kind of world that I live in.’

Gabby told the Royal Commission people with disability living in public housing need a new system that protects them.

‘Nobody is looking at any of this and so nobody sees the problem, except people who have to endure this.’

Chester

‘Every day that I’m in here I’ve been crying out for help and yet I still get no help. It’s like I’m not even there.’

Chester is a First Nations man in his 30s with an acquired brain injury.

‘I have been in custody now for about four years, yeah, and the first year I came in off the streets.’

Chester told the Royal Commission some of his family members died not long after he went to prison, but the prison did not provide any counselling.

‘I was waiting to talk to some counsellors, like for grieving, like I have no counsellor talking to me yet. So, they said I had to go to another jail. And when I went [there] they said, “You didn’t get your counsellor down there?” I waited for counsellors to come see me there and no-one came to me.’

Chester was receiving NDIS support before he went to prison. Since being in custody he’s had no contact with the NDIS, until recently when someone came to visit him.

‘She’s saying, “NDIS has been trying to find you, but this is the only place where they found you.” So, all that time I was locked up they did not know where I was. And I’m thinking, how can that be, you know? I’m in custody ... They should know where I am ... I mean, I waited almost four years.’

Chester said because of his brain injury, he can’t read or write. He struggles to understand what some of the prison officers tell him because ‘they just like to talk over me, big words’.

‘One of the [prison] officers put paper in front of me for NDIS ... he didn’t explain what that money was for or ... where is that money going, you know what I mean? He just made me sign it because he came up to my cell and, like, he’s standing in front of me, like pressuring me into signing it because he knows I can’t read.’

Neale and Katrina

Neale is in primary school and has autism and attention deficit hyperactivity disorder (ADHD).

‘The diagnoses change. So, it’s developmental delay and then moved into autism and then ADHD gets added in,’ his mum Katrina told the Royal Commission. ‘As a family we don’t use the labelling so much ... but unfortunately, to access the support and fit within the systems, those labels allow you to manoeuvre your way through the system.’

Katrina said that since Neale started kindergarten, his school has kept her in the dark about his education plans and funding.

‘We’ve struggled from day one to be informed and empowered to advocate and know how to navigate through the Department of Education.’

For example, Neale’s support needs will increase as he gets older. Katrina applied for extra funding, but when the department denied her request, no-one told her.

‘It’s such a hidden thing. Even now we do have integrated funding for [Neale] ... you’re not told how much funding. They won’t disclose anything. So we got told it was a “significant amount”, but what does that mean?’

Katrina said the secrecy makes it difficult to work with the school to support Neale.

‘At no point in time was there ever a discussion of how we might be able to look at other opportunities to support [Neale]. He then just became more disengaged, would sit at the back of the classroom or in the storeroom or ... go for more walks outside of the school, leave school. And that was just accepted.’

At one point Neale refused to wear a school uniform. ‘Why would I wear the uniform?’ he’d say. ‘I know I’m different.’

Katrina said mental health issues ‘started really escalating at that point’ until, one day, Neale ran away from school and sat in the road. Yet no-one offered him the services of the school counsellor – ‘ever ... until last year, when [Neale] stopped going to school’.

It wasn’t until one teacher decided to be Neale’s advocate at school that things changed.

‘He now happily wakes up and goes to school every day. He mostly wears the school uniform. He is much happier in himself. Yeah, and that’s come through getting additional funding and having an advocate within the school who is committed to looking out for him.’

Katrina said Neale has made friends, but is now scared about what will happen when he goes to high school.

'Remember how I've had to always walk around the playground on my own and I didn't have any friends?' he'll say to his mum.

'And so, he's got this whole history of loneliness and vulnerability that he's taking with him into high school,' Katrina said.

Katrina is determined to keep Neale in mainstream schools despite his experience.

'If we put [Neale] in a special school or even the unit within a mainstream school then he's on a curriculum of life skills. And that then narrows the scope of [his] education, employment, exposure to diversity in every way and inclusion in every way. So we'll continue the fight for support, which is the by-line of education and, you know, human rights.'

Kaye and Gillian

Kaye is a First Nations woman in her late 20s. She is autistic and has attention hyperactivity deficit disorder and intellectual disability. Kaye describes herself as having 'a mental state of a 10 to 12-year-old'. 'I'm young in the head,' she told the Royal Commission.

Kaye says support services don't seem to understand this.

'All they say is, I'm an adult. No, I'm not. Through my low intellect, I can't understand things.'

Kaye's disability has made her 'vulnerable to abuse most of her life', said her mother Gillian. 'She's a very friendly, loving caring person, but she's also a target for unscrupulous people.'

Kaye said her uncle 'sexually abused' her when she was a child. She didn't tell her mother because she was 'terrified of him'.

Since then she's been in 'multiple relationships that were either abusive financially, mentally, physically or sexually'.

'With her disability, she's desperate to have people like her,' Gillian said. Sometimes her 'maturity levels' lead her to do 'silly things'.

In her late teens Kaye wanted a boyfriend. 'And I posted to Facebook, "I would do anything for love."' She ended up with a 'predator' who was 'doing horrific things to her'.

'Police said there was nothing they could do,' said Gillian.

When Kaye left him, disability services placed her in a group home.

'We were not to have locked doors. And there was boys and girls there. I had no privacy anywhere,' Kaye said.

Once, a man came into her room at night. When Kaye yelled at him, he punched her in the face. Management said she'd 'provoked him'.

'These people were meant to be caring for us, but it was always my fault. Nobody ever took my side.'

After '13 months of pure hell', Kaye was 'suicidal'. The government put her in a community 'wellness clinic'.

'They told me that there was nothing wrong with me and that my medication was poisoning me.'

The organisation took Kaye off her medication and she had 'a five-week psychotic episode'.

Next, her disability service provider put her with a host family. 'I told them, all I needed was somebody that could be nice and treat me okay.' But it was 'the opposite'.

'They were like the army. I have to be up at a certain time, or I wasn't allowed to eat breakfast. And I was not allowed to eat if I didn't eat what they were eating.'

Kaye 'lost 20 kilos in two weeks' and was 'hallucinating'. 'I was sleeping under my bed in a sleeping bag, I was so scared.'

Kaye ran away and was reported missing for a week.

'The next host family used her as a live-in babysitter,' Gillian said, 'although she was the one that needed caring for.'

Authorities then put Kaye in a unit on her own, without support. Gillian was against this given her daughter's history of being 'used and abused'.

Kaye got into a relationship with 'a very dangerous man' who was just out of jail. He 'cut her off' from her family and 'controlled every aspect' of her life.

'He had me in his grip within the first week. He was drugging me in my sleep without my knowledge.' Kaye was 'beaten daily' and 'strangled unconscious' several times. 'I'm lucky I made it out alive.'

Police saw Kaye with 'bruises from head to toe', Gillian said, but 'it didn't matter' – 'She was an "adult".' Agencies refused to carry out welfare checks when she was being 'beaten, raped and tortured every single day'.

'So many people could have stepped in,' Kaye said.

Now Kaye is 'off the drugs' and she is 'a completely different person'.

'I lost my identity, I lost who I am. I still have trouble with finding out who I am.'

Vee

'I've got a lot of self-harm scars on my arms ... I hadn't self-harmed in ages when I met [Macy], but she asked about them ... She was making me feel comfortable to disclose that stuff straight up, and at the time that felt good because people are not always very nice about it. And now I look at that and it doesn't feel very good.'

Vee, late 30s, is autistic, has attention deficit hyperactivity disorder and a medical condition that affects her spine and joints, causing severe pain. In her late teens and early 20s, Vee struggled with her mental health and spent short periods of time in a psychiatric unit.

A few years ago Vee and her partner, Macy, separated. At the time they agreed to share custody of their children.

However, a few months later, Macy re-partnered and began proceedings to remove the children from Vee. Macy and her lawyers argued Vee's disability made her an unfit parent.

Three weeks before the first hearing Macy's lawyers subpoenaed Vee's GP, psychiatrist, rheumatologist and district health service. Vee said the lawyers were looking for hospital records from her teens and 20s.

'I don't think I quite realised at the time that [Macy] would actually use stuff like that against me.'

Macy's lawyers asked Vee to have a psychiatric assessment and she agreed.

'I knew that it wasn't necessary,' Vee said. 'It was just an easy thing to sort of like go, "Yes, whatever."'

The court date was pushed back and Vee became homeless for a short period. Macy began withholding the children and didn't give Vee the opportunity to make alternate arrangements so she could spend time with them.

At court, Macy's lawyers produced a GP report with handwritten notes on it. Vee said she saw the word 'suicide'.

The lawyers then spoke to the judge who addressed Vee.

'The judge questioned whether I was being truthful and whether I was trustworthy based on this word "suicide" and me saying that I wasn't suicidal.'

The judge ordered another psychiatric report.

At first Vee refused but her lawyer advised to 'just get it done'.

'The experience of the actual assessment was really, really horrible ... He asked me if I consent, and I was like, "I don't. I don't consent. I'm being forced to do this." ... And then he asked me about sexual abuse from when I was a kid. I had no idea that that was going to come up at all ... That alone was very, very traumatic.'

When Vee saw the report, she was shocked to see the psychiatrist had described her as a 'young woman of mixed-race appearance'. She couldn't understand the relevance and found it racist. The psychiatrist said he believed she had 'overstated her abuse'. While he didn't think there was an issue with her capacity to parent, he said he couldn't make an assessment because he didn't see her with her children.

During this time Macy's new partner started asking Vee about her diagnoses, accusing her of 'faking autism'. Vee was upset by the accusation but more upset Macy had shared her private information when she had asked her not to tell anyone.

Macy's lawyers began questioning Vee's financial capacity.

'She wanted to know had I applied for the NDIS, had I applied for Centrelink, had I applied for Legal Aid, had I got a job, was I studying, all of these things.'

Vee didn't feel safe disclosing this information to Macy and asked her lawyers if there was 'a safer way' to proceed. There wasn't.

Ultimately the judge agreed Vee wasn't a risk, but accepted Macy's lawyers' arguments about 'security and stability'.

Vee could no longer afford lawyers.

'I just basically got bulldozed.'

Vee lost her right to shared custody and is only able to see her children a couple of days each fortnight.

Vee believes the family court process is skewed against people with disability and trauma.

Alianna and Marceline

Alianna is in her early 20s and is about to start a TAFE course. She is autistic and has cognitive impairment but has chosen not to seek any NDIS support for her study, or to identify as disabled in the TAFE system.

She asked her mum, Marceline, 'Mum, do I have to tick that box? ... If I tick that box they are going to treat me differently straight away.'

Marceline told the Royal Commission that TAFE will be Alianna's first in-person formal learning since year 8, when she withdrew from the mainstream high school where she attended a special education class.

'She had some moments where special ed teachers had called her a moron and an idiot ... Her perception was that those who should have been keeping her safe and supported actually were not doing that.'

Marceline made a formal complaint but it 'went nowhere'.

'After that incident she didn't leave our home for two years. She didn't leave our home at all. She was terrified of the outside world,' Marceline said.

Marceline is a trained special education teacher. Lack of specialised training for special education teachers in mainstream settings is 'a massive issue', she said.

'[The attitude is –] Oh, there's that PE teacher who had cancer on their lip, so we will just make them a special ed teacher. Or here is a teacher who's not performing in the classroom so they can be a special ed teacher.'

Alianna wanted to enrol in a special school but her intellectual capacity was marginally too high to meet the criteria.

'A special school setting would have been a wonderful opportunity for her because she would have actually gained some really valuable skills and developed friendships,' Marceline said.

Instead she tried another mainstream school. Marceline asked for some special measures to give Alianna time to adjust, but the school resisted. Instead the principal called her to a meeting. Numerous school staff members were present and Marceline asked them what they knew about Alianna and her needs.

'Not one of them could tell me anything about my daughter. They had just made assumptions. She's special ed, has disabilities and whatever came after that. They indicated to me that they wouldn't ... continue her enrolment at the school unless she was medicated. And I asked if any of them were psychologists, psychiatrists, paediatricians, and they all said no. I said, "How dare you suggest that you have the right to tell me whether my daughter requires medication or not."

And I called the meeting to a halt.'

Marceline said that advocating for Alianna is often difficult because she fears that speaking up might result in the loss of services.

She said this is an 'absolute fear' for her and many others. 'How am I going to be treated if I really say what I'm thinking or what I feel?'

Alianna completed high school by distance education. As she starts at TAFE, Marceline hopes for the best.

'We've been talking to her about re-imagining herself, creating the new [Alianna] ... She doesn't know who she is or what she is, and that's based on she doesn't feel she has any rights.'

Rayden

‘The culture is quite scary. There seemed to be no concern actually for the residents. None whatsoever.’

Several years ago Rayden started working for a disability service provider.

‘I’ve had quite a commercial background and it was just my piece to give a bit back to this community,’ Rayden told the Royal Commission.

He decided to visit the residents in the provider’s group homes.

‘It became apparent very quickly that there was a lot of neglect in the houses.’

Rayden saw homes that didn’t comply with fire, pest and ventilation regulations.

‘AC systems not working and not being maintained in the middle of summer. So you go into the house – and it’s not been the best of summers this year – but you can be 38, 39 degrees and there’s residents in there with no aircon working.’

Rayden said that in a ‘majority’ of homes there was ‘the strong odour of urine and faeces’.

‘There were leaking roofs and there were buckets in bedrooms and it wasn’t getting rectified. A lot of the properties were in ... very poor condition, that you wouldn’t want yourself to stay in or your family member to stay in.’

In one home the floorboards were ripped up and the doors were locked. ‘It was just diabolical.’

‘We’ve turned up at one residence, see, and there was someone painting in a bedroom. And I just said to the person I was with, “Are they one of our workers?” They said, “No, it’s a family member.” So you find family members trying to, you know, paint the walls or whatever, do some maintenance work and [at] their own expense.’

Rayden said he tried to get the compliance issues fixed but ‘the organisation was pushing back because of the cost’.

‘Obviously they get the funding from the government and the NDIS and I just found that very strange, the resistance about getting contracts in place and compliance in place.’

Rayden said the organisation appeared to sometimes bypass normal recruitment practices and employ ‘a friend of a friend’.

‘It does appear that only jobs get done if certain people or certain contractors do the jobs. But obviously they’d be inflated prices. So it does appear that people are being rewarded for having connections with service providers.’

Rayden said it looked like public funding was being ‘distributed inappropriately’ in a company making millions of dollars profit.

‘When you’ve got people living with leaking roofs, which smells of faeces, which smells of urine, work health and safety issues, no ramps ... For me, I just find it unacceptable.’

Kye

'I think non-disclosure agreements are used as a form of hiding things.'

Kye is a senior scientist working for a large government department. He has depression and anxiety and was recently diagnosed with autism.

Kye told the Royal Commission he has always had difficulty understanding and communicating with people. He said he has a 'scientific sort of understanding' that A plus B causes something to happen. But he often finds 'what is happening isn't matching what is being said'.

A few years ago, working at a different government department, Kye had an 'interpersonal conflict' with a team member. The rest of the team ganged up on him and began excluding and bullying him to the point it had 'massive repercussions on the team' and how it functioned.

Kye's mental health deteriorated and he asked management to intervene to help the team 'return to a respectful workplace'. Management told him repeatedly it wasn't a work issue. '[It] was clearly impacting work,' he said.

Kye believes if management had admitted there was an issue they would have had to admit staff were bullying him.

The department did not renew Kye's contract – 'that's how they solve a problem'. When he made a complaint, management argued he was on a short-term contract and they'd followed correct procedures.

He engaged a lawyer and lodged a worker's compensation claim and discrimination complaint.

Kye said the department treated him 'dishumanely' throughout the legal process. 'The way they handled it wasn't very nice.'

Eventually, they reached a settlement agreement. However, it contained a strict confidentiality clause preventing him from speaking about his experiences or criticising the department. At first Kye refused to sign the agreement, but the department refused to settle without the clause. He felt pressured and his psychologist was worried it was impacting his health.

Kye's finances were dwindling and he didn't feel like he had a choice.

'It was either accept it or abandon it completely or have an even worse breakdown, then not have financial resources.'

Kye believes the confidentiality clause is a form of abuse.

Lorne

Lorne is in his 40s and has cerebral palsy. He lives independently and uses a walking stick and motorised scooter.

A few years ago, Lorne had a permanent job in IT in a regional organisation.

'We get a new [manager and] I didn't really fit in his ideal working scope,' Lorne told the Royal Commission.

The manager asked Lorne to halve the number of hours he works.

'Twenty-one hours [a fortnight] isn't enough hours to live off.'

Lorne said the manager suggested he move within the organisation to another region to keep his hours, but that meant finding new support workers and a house to suit his disability.

'It's a little bit more complicated for a person with disabilities to relocate to another job compared to an abled person ... So what choice did I have?'

Lorne resigned to find another job that matched his abilities, but discovered Disability Employment Services (DES) providers would only help him find work for eight hours a week.

'Their obligation is only to find you eight hours a week ... Once they find you employment, you are really, for the rest of your life, you've got no option to expand your employment opportunity goals.'

Lorne is able and willing to work 30 hours a week, but said the DES wouldn't help him find a suitable job because of his particular circumstances.

'I think the problem is, is actually the funding. It takes more time to help employ a person with a disability over a jobseeker.'

To get by, Lorne applied for the Disability Support Pension (DSP).

'I'd rather be off the DSP. [But] Centrelink ... are saying that if you're able to work more than ... eight hours a week, you should be on JobSeeker ... But the thing is ... there aren't enough jobs out there to suit my disability to do that.'

To try to get off the DSP, Lorne recently applied for five jobs on his own, and received five interviews.

'As soon as they see my physical disability, they question. They go through the motion, but at the end of the day if they've got another candidate ... they will go to an able person.'

Blaise and Frieda

‘He was never not black across his arms, he was never not bruised. He was just fighting to survive until he got to come home again.’

Blaise is in his 30s and has ‘profound intellectual disability’.

When he about two, Blaise ‘lost all his speech’ and began having ‘aggressive outbursts’. ‘He’s howled in frustration all of his life,’ his mother Frieda told the Royal Commission. ‘[He] just explodes, and he hits.’

This has made it hard to find Blaise supports. Children’s respite centres were ‘ill-equipped to take him’.

At an early intervention centre he attended for about six hours a week, Blaise spent most of the time in isolation. When he ‘overloaded’, staff locked him in a room alone until he calmed down. ‘They found him unmanageable, so that was the way they dealt with it,’ Frieda said.

From there Blaise went to several government-run respite centres.

‘With the hitting and the smacking and all the locked doors and the locked food. That’s the only option we had ... It’s what you now call restrictive. But it was abuse – emotional and physical – for my son.’

When Blaise was four he attended a day care program where he was ‘getting smacked a lot’.

‘It came to a head one day when I walked in to pick him up, and the worker was lifting her arm as high as she could and hitting him repeatedly, and he was cowering on a chair.’

At the next respite home, staff were locking him in his bedroom and ‘under the house in the storage area’.

Blaise started self-harming, but management ‘treated it as a joke’ and ‘refused to meet’, while disability services ‘wanted it brushed under the carpet’.

When Blaise was about seven, he started going to programs at a centre for autistic people.

‘This was a period in his life where it really worked ... It was a really good education, and a really good culture for him to be in.’

With the right care his behaviour was ‘manageable’. Each time he was back in the public system, Frieda noticed a ‘total deterioration in his capacity’.

'If you stop delivering an intensive support around him, he loses skills.'

As a teenager Blaise moved into community housing with disability supports. His support workers asked Frieda if they could 'build a courtyard for barbecues' at the house.

'It wasn't for barbecues, it was for lockdown. And it became a cage for [Blaise].'

They'd either 'drag him out' there or throw his 'treasure bag', full of his favourite possessions, so he would 'chase after it'.

'Rain, hail or shine, he was locked out ... The abuse that went into getting him out there is horrendous. Basically, they'd employed thugs.'

Blaise used to come home with 'a big, fat belly from the psychotic medication' and bruises from being smacked and 'hit with a wooden spoon'.

Police told Frieda they couldn't do anything. 'He's not a credible witness, he's non-verbal,' they said.

Since then Blaise has lived independently with NDIS supports. He still has 'separation anxiety from mum and dad' as a result of the abuse.

'I suppose, we've been the only safe place, really ... We truly believed in [him], and we still [do] today.'

Tracie and Beverley

Beverley's siblings are in their 40s and have intellectual disability.

'My siblings only left home in recent years,' Beverley told the Royal Commission. 'They used to live with mum and dad, and because mum and dad are ageing they needed to move out of home and get used to the idea of being away from mum and dad. They have struggled with that.'

Beverley's siblings are all supported by the NDIS. One day, her sister Tracie met a worker from a service provider that had set up a shop in a shopping centre to attract business.

'All of my siblings, they started to call the workers there their friends.'

The worker pressured her siblings to switch service providers.

'[He] kept on coming around to my parents' home. And on one occasion dad was actually in the hospital, so mum called me to say "Hey, can you get around here quick, [the worker's] coming, he's on his way.'"

Beverley said these 'very heavy-handed sales techniques' happen 'quite a lot'.

'A lot of the providers, [are] treating people and the NDIS plan like an electricity plan. Like, "Show me your plan" ... to see what their funding is and I just felt it was inappropriate. These are very vulnerable people. It's not an electricity bill where you're just trying to get people to change provider.'

Beverley said service providers are also offering her siblings supports they don't need.

For example, her sister Tracie used to work in open employment at a restaurant. She wanted to change jobs and approached an employment agency, which sent her to a service provider. The service provider convinced her to pay them to find supported employment.

'They originally wanted to take, like it was \$70,000 per year of [Tracie's] NDIS funding, which is ridiculous when she's got the ability and capability [to work in open employment].'

Beverley told the Royal Commission service providers are taking advantage of her siblings when they should be helping them improve their lives.

'The system is feeding each other and they're not building capacity. ... My sister [Tracie], she's got the ability to learn, she could learn how to teach other people how to cook ... so why can't she do that as a job, to teach other people with disabilities to do the same thing?'

Anne

‘If you say you’re autistic, it’s like, “You don’t belong, we’ve got no space. We can’t give you any sensory accommodations.” And it’s not right. Because it doesn’t stop someone from doing a job.’

Anne is a librarian in her 40s. She was diagnosed with autism about five years ago.

‘That year, I had been doing a lot of reading and a lot of thinking and went, “Oh, gosh. I’m autistic. I’m just not weird,”’ Anne told the Royal Commission.

She started working for a local library just after that.

‘I had really high hopes ... that they would work with me. Because they had all this wonderful literature about supporting staff, and they had award-winning disability policies.’

Anne approached her manager for advice ‘on how to get workplace accommodations and things like that’. She presented her medical certificate and suggested it ‘go to HR’. Her manager told her ‘to keep it quiet’.

‘She went, “No, no, no, they’ll discriminate against you.” She then asked me to regularly check in with all the other team. And, you know, just say, “I might do weird things occasionally. Is everyone okay with me?”’

Anne had ‘a very friendly, professional, supportive relationship’ with her colleagues.

‘They’re like, “Oh my God! You’ve been told that you have to explain your weirdness?”’ Because that’s something I’ve had to do all my life, I’m like, “This is normal.” And they went, “No, it’s not.”’

Over the next year, Anne found her manager ‘incredibly manipulative and abusive’.

‘When I would say to her, “I’m struggling with this thing or that thing,” she would tell me to my face, “Suck it up. Everybody else deals with it. You have to as well.”’

Anne started having health issues including chronic fatigue and wanted to switch to part-time work. The ‘2IC’ and HR came to see her and gave her ‘a voluntary medical severance’.

Anne wanted to stay at work with reasonable adjustments.

‘But it was deemed as disadvantageous to the business that I get an extra 10-minute break and that I work part time.’

The 2IC was a 'recognised bully', Anne said. She'd heard her 'mocking autistic people'. She wouldn't agree to Anne leaving the counter if she felt 'overwhelmed' or was 'experiencing sensory overload'. She told Anne 'everybody in the library has to have exactly the same physical capacity'.

'And I went, "Well, we don't."'

Anne asked for a transfer to another library but was told there was no job for her.

Anne won a dispute process and was ready to 'get back into work'.

'But, no, they sent me to a psychiatrist.'

The 'horrendous, horrible psychiatrist' didn't acknowledge 'anything about autism'. Their report stated '[Anne] has a personality disorder of an unknown nature that needs further investigation,' and that she was a hypochondriac.

'It recommended that I don't work with either the public or with co-workers ... And that was profoundly hurtful.'

Anne felt 'broken'. She 'had a mental and physical crash for a few months'. She said her workplace chose to 'harm' and 'disempower' her because of her disability. They 'excluded and ostracised' her.

Anne now has a new job at a different library. When she started, she asked her boss for a 'chat about reasonable adjustments'.

'And she's booking an OT for me to come and help. And that was just such chalk and cheese.'

Darian and Halle

Darian, eight, has chromosomal deletion. He is autistic, has speech and vision impairment and heightened sensitivities. 'Any of those senses can tip over at any given time and come out with some very dangerous behaviour outlets for himself and those around him,' his mum Halle told the Royal Commission. 'He sees the world in a very different way.'

Four years ago Halle, who has a physical disability and uses a wheelchair, applied to the NDIS for supports for Darian.

They referred her to an early childhood early intervention (ECEI) coordinator. She said staff have been 'nothing short of a nightmare' to deal with.

Halle had trouble getting staff to speak to her or respond to her emails and was given a lot of misinformation.

'[It felt like they were] just trying to make you give up and go away, and bully and intimidate you to, bluntly, piss off, without actually saying that of course.'

Darian's clinical psychologist suggested Darian would benefit from a support dog. Halle was sceptical, admitting she was 'very naïve' about support animals. The psychologist explained trained dogs are very successful helping children with heightened sensitivities to regulate behaviours.

Darian's first NDIS application included funding for a support dog, therapies and a support worker.

The NDIA rejected the application because they didn't believe his disability was permanent.

'I actually got to speak to one of the access team people that turned my son's case down, and I asked him ... "Can you fix a missing chromosome? Can you cure autism? Because ... if you guys know something I don't, that there's a cure out there for my son, I'll leave you alone and go and do it."'

Halle gathered further medical information and applied again.

'I was ringing the NDIS info line for two months every single day trying to sort out getting my son onto the NDIS.'

After three applications, the NDIA eventually approved funding. But only for limited therapies and six hours of supports per week – Halle had requested 18. There was no funding for an assistance dog.

Halle requested a plan review. Initially staff told her plan reviews 'don't happen' in ECEI, but Halle spoke to an NDIS plan coordinator who told her it was possible.

After 'a hell of a battle', Darian's plan was reviewed and the NDIA approved funding for an assistance dog, but declined other supports.

Halle believes Darian is not getting the therapies and supports he needs and it is damaging his progress.

The NDIS does fund a behaviour therapist, but Halle has found it nearly impossible to find one in the area she lives.

Darian's support dog recently arrived and has been an 'amazing calming' influence on the whole family. He is a huge assistance to Darian, who is now able to calm down in 20 minutes instead of three hours.

'I honestly would not believe it possible if I hadn't seen it for myself,' Halle said.

Sierra

‘When the doors are locked, that’s when abuse happens.’

Sierra advocates for people with cognitive disability living in group homes.

‘We hear it all the time from service providers that there’s not enough funding. There’s not enough cream on top for them to train staff, so they basically just bring [untrained] staff in,’ Sierra told the Royal Commission. ‘And these are services getting bigger and bigger and bigger.’

Sierra said many cases of abuse appear to be unreported in a system where there’s poorly-trained staff and a lack of transparency. A few years ago, for example, she learnt of an executive at one service provider who allegedly took their partner on holidays with a client.

‘The client paid for everything. A client who didn’t drink paid an additional [amount] a day for unlimited alcohol. And he was not a drinker. So we’ve basically had a number of whistleblowers that have come to us and said, you know, “This is what I saw during this time.”’

The same service provider asked another client with an intellectual disability to sign a service agreement stipulating that ‘if she had problems in the service, she would not contact her parents’.

‘And I saw this agreement. She showed it to her mother and her mother said, “No, she’s not signing this.” Then a number of days later ... [the service provider] just left her.’

The service provider retaliated.

‘They just withdrew their service. The client didn’t know what to do. She was sitting in the dark by herself until about 7.30 at night, when her mother rang her and she said, “No-one’s here. I don’t know what’s going on.” So, they just walked out and left her.’

Sierra said the service provider had also asked other clients to ‘withdraw [thousands of dollars] out of an account and take it to the office’.

‘And when they questioned it, they were told it was none of their business.’

When she raised ‘a number of issues’ with the service provider’s board, they told her the matter was ‘confidential’ and they were ‘dealing with it’.

‘There were no charges laid, there was no police involvement and the [executive] now works for another disability organisation.’

‘[Since then] things have gone even further downhill,’ Sierra said. ‘They have gone through something like 50 staff in less than two years.’

Sierra referred the service provider to the NDIS Quality and Safeguards Commission multiple times.

‘We know that parents have [also made complaints and] we would hope that things would change ... but we don’t see any evidence of change whatsoever ... So I guess, you know, [service providers] are not at all afraid of them.’

Sierra told the Royal Commission she is advocating for a woman with another service provider who wants to leave her group home ‘because of the staff’.

‘Very inexperienced staff have been recruited from off the street, basically, very little training and so, you know, very little understanding of mental health.’

Despite the woman’s health ‘deteriorating on a daily basis’ and her being ‘subjected to abuse’, Sierra said the provider and the woman’s family persuaded her to stay in the home.

‘Her family have said to her ... “If you move out, I won’t talk to you ever again.” ... The provider is using that as a way of keeping [her] in the house, and I think it’s all driven by the funding ... It’s a terrible situation.’

Jennie and Deb

Jennie was a ‘floppy baby’, her mother Deb told the Royal Commission. She didn’t do ‘normal baby things’ or walk until she was two and a half. Doctors said she was ‘severely retarded’. Just over 10 years ago a specialist provided a new diagnosis. Jennie is autistic.

Now in her early 60s, Jennie shares a housing department home with another woman, with support from a service provider. This has been the arrangement for close to 30 years and it works well. Before that, Jennie’s housing and care were very problematic.

As a young child, Jennie went for respite care to a facility for people with disability or mental health illnesses. ‘As time went on we asked if we could board her during the week and bring her home at the weekends. That was refused,’ Deb said. Instead, Jennie became a full-time resident at the facility.

Deb was caring for her other children, her husband and her ageing mother.

‘I just had to deal with things. I felt I couldn’t cope so it was suggested that we place her in there which we did. But we were there, always there for her. We would go up all the time. We missed her and the children came with us when they were young.’

Jennie lived at the facility for the following nine years. Staff didn’t allow the family to enter the building and they never saw inside it. But they trusted that Jennie was being well cared for.

‘We never really suspected anything at all,’ Deb said.

One day, a nurse advised Deb to access Jennie’s records.

These revealed a horror story of abuse and neglect, including punishment such as leaving Jennie outside in freezing weather and refusing her entry to the building.

‘Some of it’s just such disgusting behaviour for people that are meant to be caring for another human being who can’t care for themselves.’

The family brought Jennie home and explored other options.

Deb and her husband established a group home where Jennie could live, but when the government withdrew funding for services, it became unsustainable. Jennie returned to her family.

‘I came out one day ... and [Jennie] was at the door here, naked, and she was using her bowels. It was everywhere. So I couldn’t – that was it, I just ... I couldn’t take her anymore. So I got her showered and everything, I rang my husband and told him I was taking her back,’ Deb said.

Jennie went back to the facility, but Deb became a fierce advocate on her behalf, calling politicians every day and standing outside parliament to press her cause.

Finally she secured new accommodation for Jennie, the place she still lives in now. Through the service provider, Jennie has a care coordinator who has a good understanding of her needs and encourages her to learn new skills.

The health facility where Jennie first lived has closed down now. Deb described it as 'hell'.

Staff there tried to make Jennie 'normal', she said.

'She wasn't ever going to be normal ... but there was just never any training, there was nothing there. Even all the things that were suggested ... Things that they should have been doing and they didn't do it, they just didn't. They couldn't be bothered, it was the too-hard basket. They just wanted to go to work and have a slack shift because there was just not enough people there to support the behaviours and the people and their needs.'

Brinley

‘It’s engrained into the police culture that these women are laughed at, humiliated, interrogated and punished for making the complaint in the first place.’

Brinley is a First Nations woman in her 50s. She is autistic and lives with post-traumatic stress disorder.

Brinley lived with a violent partner for more than a decade before she finally turned to the police. In her experience, she told the Royal Commission, police ‘openly discriminate against women reporting domestic violence ... especially women with a disability’.

‘When I did report domestic violence, I was always surrounded by men in the house who were quite adversarial. Never once, even after I requested it, would they send a female to the house.’

A couple of years ago, there was a violent break-in at her home. Brinley said the attackers physically restrained her and ‘tried to murder’ her.

When she escaped and reported it to police, Brinley said their attitude was, ‘Does she sound believable?’

Finally, she ‘got them to take some action’ and the matter went to court, with the offenders pleading guilty.

‘But I became homeless for six months. My mental condition became critical, I nearly died.’

Brinley said that in the regional area she lived in, there was no place for her to turn to for help as a ‘victim of violent crime’.

‘[Helplines] refer us to support services, but we then fall through the cracks because there’s nowhere for you to go as a woman with a disability.’

Prior to the break-in, Brinley spent three decades working in the disability sector ‘doing occupational therapy and rehab’. She helped set up a community visitor scheme, where ‘you would go around and visit vulnerable people in the community ... then put the appropriate support in place’.

She eventually found support herself at a community family violence program for First Nations people. Now, she wants to see that idea go nationwide.

‘If we had a community-based organisation where people could be referred by anyone and they could refer themselves, it would help.’

This would allow women 'to sidestep' the police.

'If these people were able to connect with a visitors program like this, it would be identified very quickly what supports they need in place in order to leave domestic violence without a whole big police kerfuffle.'

Brinley is doing a support coordinator course so that she can get her idea 'up and running'.

'Because it works. It worked for me. It has worked for people that I have been involved with, and it could just change people's lives ... There are too many women dying. And the cure is community connection, and that can be set up for nothing.'

Donal

‘The NDIS have made so many mistakes.’

Donal, early 60s, has health issues, is an amputee and uses a wheelchair.

Around the time of the NDIS roll out, Donal started having problems with his powered wheelchair. He could no longer get spare parts and the manufacturer suggested he get a new chair.

Donal contacted the state government disability services program and discovered he needed to sign up to the NDIS.

After an initial meeting with an NDIS provider, Donal said he wasn’t ‘even out the building’ when he received a text from Centrelink cancelling his mobility allowance. Donal relied on his mobility allowance to pay for transport costs and has had trouble making ends meet ever since.

‘We were living a modest life on the pension ... We could always survive. Once we were shoved on to NDIS, we lost all our backup ... There were times where we had to ask for help to pay the phone bills and things like that.’

Donal told the Royal Commission that dealing with the NDIS has been ‘pretty much a shambles from the start’.

His first plan included funding for a feeding tube and other items he didn’t need. He struggled to find someone from the NDIS or Centrelink to sort it out. He said one man was ‘quite rude’ and told him he could get a job.

Donal’s health started to decline. He had a series of small strokes because of the ‘stress and upset’. He became less mobile and needed 24/7 support.

‘They’ve got to do everything for me. I can’t walk like I used to. I can’t use my hands anymore ... I’ve got to get people to do things for me.’

Donal is no longer able to operate the controls of his wheelchair.

He has had to ask the NDIA to review his plan several times to increase support. He’s often left short while he waits.

A few months ago Donal’s plan expired and, after some scrambling, the NDIA gave him a temporary plan.

The support workers agreed to continue working, offering to delay invoicing.

However, the NDIA have refused to reimburse the support workers and blamed Donal for using funds that weren't approved. He said the temporary plan didn't have sufficient funds to pay the support workers.

'Instead of NDIS owing up to their mistakes and paying for it, they're trying to pass the buck to us.'

Donal now has a new plan. He says there is less money for support workers but other areas are inflated. He's noticed physiotherapists, occupational therapists and other therapists have started charging 'double what they would privately for NDIS services, sometimes triple'.

Donal needs an electric bed. A friend found one for about \$6000, but through the NDIS it's almost double that amount.

Donal would like to go back to how things were before the NDIS.

'Pretty much scrap the NDIS and go back to the old system. The old system worked perfectly.'

We all matter and should feel ^{like} we belong
We should build each other up to be mighty and
Strong.

We all have a voice and should be heard,
No matter how big or small the word.
We deserve fairer pay
~~No matter in what~~

In our employment in every way.

We should be paid, as everyone else
We are all ~~equal~~ ^{work} boys and girls
We as hard as all the others

We all matter as sisters and Brothers

We shouldn't be separated in to special groups

We should all mingle in one bowl of soup.

We want a family to love and hold.

To tell our story loud and bold

We can be great mothers and fathers

And our life can paint a beautiful canvas.

Our children can grow to be brave and bright
and bring much happiness and light.

Yes we all different, but all the same,

We all matter no matter our name.

We all should treat ~~thoes~~ each other with
Care.

Look after each others welfare.

We are all individuals with our own
special touch.

Help each other by love each other much.

By Jasmine Smith

Sep-2021

Treated fairer
in employment
By abolishing
Supportive
Wage

Ellouise and Christiane

‘Her house became a total institution because this support worker team operated as their own little entity. And this is why they are resistant to anyone providing any sort of directional guidance to them.’

Christiane’s sister, Ellouise, had intellectual disability with ‘high complex needs’. She was in her mid-60s when she died a year ago.

‘Her communication was probably at the level of a five or six-year-old,’ Christiane told the Royal Commission. ‘But she was functioning.’

When she was in her 30s, disability services moved Ellouise ‘into a small two-bedroom townhouse in a public housing complex’, with ‘one-on-one 24/7 care by support workers’. Christiane became her legal guardian.

For many years following the switch to the NDIS, things went well.

‘She had a personal trainer and was attending a gym twice a week. She was swimming ... They were taking her to the movies, taking her out for coffee, to lunch, so I guess she regained some aspects of life that we take for granted.’

Christiane had some concerns about the support workers. ‘Particularly around the finances ... They used her card.’

When COVID arrived ‘the wheels really fell off’, and her concerns about support workers became ‘quite elevated’.

‘I needed to give consent, I needed to know about any medical procedures as her guardian, and that was problematic. They resisted that.’

Christiane also wanted her sister’s medications reviewed. One was ‘a very strong psychotropic medication’ – a possible side effect was ‘life threatening constipation’.

‘I think there was negligence. There was complacency. They were resistant to advice, not just from me.’

Ellouise was a diabetic. A dietician gave support workers ‘express instructions on what to do around her constipation’, but nothing seemed to change.

Once, Ellouise was admitted to hospital ‘semi-comatose’. She was diagnosed with sepsis and required resuscitation, but the support worker didn’t inform Christiane for hours.

There were many ‘conflicting stories’ about what had happened.

'The support worker who was with her at the time had been dismissed ... and that was all the detail I got.'

In a later report, Ellouise's physiotherapist 'stated that her admission to hospital was due to a fall'.

Christiane told the provider she 'did not have confidence in the support workers' and 'wanted a change of team'.

'I asked if they were vaccinated and I was told it was not mandated.'

A few months later, one of her support workers got COVID and Ellouise had to isolate.

'I was not advised about that until two days later,' said Christiane. Senior management met with the NDIA about how to manage the situation, but Christiane was 'not invited to the meeting and didn't hear anything further'.

Christiane said the providers' treatment of her sister was unacceptable. There was 'no transparency, no accountability'.

'People can be abused and there's no sort of external intervention. These people are exceptionally vulnerable – their communication is an issue for them, isolation is an issue for them.'

When doctors put Ellouise on life support, she 'was constipated, she had a blocked bowel', Christiane said.

'I was providing direction to them. I was saying to them these things needed to be addressed, but nothing happened. She died.'

Christiane is still waiting to hear from the NDIS Quality and Safeguards Commission.

'The lack of response tells me it's not working.'

Aretha

'I get no supports. I get no privacy. I get no security. I get no safety. I get no human rights, basically.'

Aretha, early 40s, is autistic, has attention deficit hyperactivity disorder, agoraphobia, borderline personality disorder and post-traumatic stress disorder.

'I'm a forgotten Australian, a victim of crime, female, vulnerable, a victim of domestic violence.'

Aretha is also a First Nations woman but, because she was institutionalised as a child, has no proof of her Aboriginal identity.

'[They] took me out of home and I was supposed to get all of this stuff in care. None of it was provided.'

In her preteens, a staff member in the institution she was living sexually abused her. It was 'swept under the rug' until many years later. Police arrested and charged the perpetrator and he went to prison.

Aretha told the Royal Commission the department's neglect has profoundly affected her life.

No-one cared about her education and she left school in year 8.

'I've never worked. I've never had anything. I've never had anywhere and I've never had anyone, because I've just survived.'

For several years Aretha's been living in community housing. She said it's not a good area, residents are predominantly male and use drugs.

A few years ago, a neighbour assaulted her. Police charged the neighbour and the court issued a restraining order.

Recently another neighbour made violent threats and Aretha has had to go to court.

Aretha said she feels exposed and unsafe.

'I don't even have a fence. I can't even be in the backyard hanging clothes on the line without some stranger coming around the corner ... I can't have any windows open, no doors open.'

The department of housing have approved an urgent transfer but refuse to give Aretha a two-bedroom flat, which they know she needs.

'I've got to go and have operations on my hands. So, I need somewhere for someone to stay, but there's absolutely nowhere for anyone to stay.'

The options the department has provided are ‘disgusting’ and Aretha is stuck where she is.

‘I’ve filled in the transfers forms. I’ve done everything. I’ve done it three times, and they reckon I haven’t done anything. And I filled in serious incident reports and everything like that. They still haven’t done anything.’

Aretha wants someone to help her. She has NDIS funding but except for six hours support per week she ‘can’t spend [her] funding’ because she doesn’t have a support coordinator.

‘I’m supposed to be going swimming. I was supposed to be getting my meals. I was supposed to have all this other stuff done.’

Recently Aretha received compensation for what happened to her when she was a child.

‘I got [compensation] ... but I’m still unsafe. I don’t even know how to talk to them. I don’t even know how to say it.’

Aretha believes the department of child protection should provide ‘after-care support’ because she was in their care and they are ‘responsible’ for what happened to her.

Candice

‘I was a person that loved life. And obviously, I’m quite far from the person I was.’

Candice is in her late 40s and lives with short-term memory loss and other cognitive problems as the result of an ice-skating accident.

‘I have, like, retrograde amnesia, so I don’t remember, um, like a lot of detail,’ Candice told the Royal Commission. ‘I’ve really needed ... my family to help fill in the gaps.’

When she fell on her head, she ‘hit the ice and bounced a few times’.

‘I didn’t even know who I was or what day. I didn’t know my family ... Um, there wasn’t a lot of thought processes.’

Doctors discharged her after a week in hospital with a diagnosis of concussion. An MRI showed ‘no structural changes’.

But back home, Candice ‘wasn’t functioning’.

‘I really couldn’t be left on my own. I wasn’t capable of making a cup of coffee or knowing what time it was cognitively ... I was really just struggling to manoeuvre around the house.’

With the concussion diagnosis, Candice has ‘battled’ to get NDIS support for specialist rehabilitation therapies.

‘It’s really critical ... in the first year or two to get these therapies. To help rehabilitate ... while my – my brain’s still trying to repair ... To help me build strategies to function ... I need to learn the skills to know how to remember things.’

Candice has no private health cover. Once a week she sees an occupational therapist, a neuropsychologist and a social worker at the hospital ‘for five hours of back-to-back therapies’.

‘And I appreciate their support ... But it’s been a bit futile, because cognitively ... after an – even an hour, I can’t remember what just happened let alone going into another therapy ... I’m jelly.’

The cost of trying to provide the ‘evidence’ to the NDIS has been prohibitive.

‘I had to spend thousands of dollars ... They’re still requiring – um, more assessments.’

Candice feels the public health system should cover those costs for as long as she ‘falls through the gaps’ of funding eligibility.

‘The NDIS, its definitions are very black and white ... Life’s not black and white.’

Candice paid for a neurological assessment to help with her application. She says it confirms that her symptoms correspond to ‘a traumatic brain injury, not a mild concussion’.

She says the ‘cognitive impairment’ hasn’t improved greatly over the past few months. Communication is challenging and this has led to ‘social isolation’.

‘It’s about the way our community views disability ... it’s not an inclusive society ... There’s lots and lots of settings where the barrier is an attitude towards disability. We’ve been totally excluded.’

Candice is not sure she’ll ever return to work.

‘I’m still not navigating the home adequately ... I’m hopeful for the future ... But I need these therapies. I need the resources that we can’t afford to, to have a, a meaningful life.’

She really wants ‘to learn how to be a mum and a wife again’.

‘I can’t figure this out myself. I need specialists to help me on that journey ... But I’ll, I’ll never give up.’

Marcus and Rebbecca

Marcus is autistic and in his teens.

When he joined the NDIS several years ago it was ‘really the first time he’d received any funding to help with his therapies’, his mum Rebbecca told the Royal Commission. ‘We self-funded what we could up until that point.’

But when the NDIS insisted Marcus’s support plan be ‘agency-managed’, they ‘lost all of the support workers [they] had paid privately to train’.

When Marcus’s behaviour deteriorated and he had to move out of home, one of his new support workers suggested he share a house with Marcus under an individualised living options plan, so he could give Marcus more support.

After Marcus had moved in, the support worker became controlling and started sending Marcus abusive texts.

‘We started to learn what was exactly happening at that house while [Marcus] was there. [Marcus] was his slave.’

Rebecca said the worker made Marcus do ‘every single little bit of cooking, of cleaning, toilets scrubbed, lawnmowing, vacuuming, you name it’.

‘[Marcus] ended up coming back to my house ... He will carry that [experience] with him for a very long time, and it took us a very long time to even convince him to let us bring new support workers in after.’

Edwina

Edwina is in her 30s, has cerebral palsy and uses a wheelchair. She recently moved into a public housing unit.

‘They told us it was [a] disabled [unit], it’s going to meet your needs,’ Edwina told the Royal Commission. ‘Okay, it’s got a wheelchair bathroom and wider doorways and hallways and stuff, but that’s about it. It doesn’t meet my needs as a person in a wheelchair.’

For example, Edwina has to twist to load the dishwasher, hurting her back. The stove top is ‘at least an arm’s length away’ and the control button for the heater is above her head.

‘So way above my eyeline, and one of those old gas systems where you had to press this ignition thing to light it – and I don’t have that dexterity in my hands to press this ignition button. I don’t have the strength in my fingers to hold this down and twist at the same time.’

Edwina said when she pointed out the problems, the housing department suggested the NDIS pay to further modify the apartment.

‘They push everything back on to NDIS ... It feels like they just pass their responsibility on to other people just so they’re not accountable for caring and looking after people with disabilities.’

Edwina lives in a regional town. During the COVID-19 pandemic, one restaurant practiced social distancing by moving its tables into the carpark, covering an accessible parking space.

‘This is a town with limited parking and even more limited disabled parking, and one of these businesses put their patio thing right over a disabled park.’

It meant she couldn’t park near the shops. When she pointed it out, the local council told her it was a ‘business responsibility or a [roads department] responsibility’.

Edwina said her access to other services was also unfairly restricted during the COVID-19 pandemic. For example, she was summonsed to jury duty during the pandemic, but was excluded when she told the court she used a wheelchair.

‘Because of COVID, they have to create more spacing. So, their first option was to take out the wheelchair dock in the jury duty space ... I understand why they needed to create these spacings, but it was still quite insulting to be told that, you know, once these kinds of disasters hit, that you’re the first to go.’

Mathis

‘I am a Deaf person and Auslan is my language – my first language, not English.’

Mathis, mid-30s, is Deaf and has cerebral palsy and a vision impairment.

Not long ago he spent about 18 months in prison.

Mathis told the Royal Commission that police, courts and the correctional system failed multiple times to help him access language.

When he was arrested police didn’t arrange an interpreter and expected him to communicate using written English.

‘They get really, really angry that I can’t communicate with them. You know, it’s very difficult for my brain to be able to process the information, write it down.’

Sometimes police did supply an interpreter, but Mathis needs an interpreter ‘every single time’.

‘It doesn’t matter if it’s short or a long meeting or a short conversation. I do definitely need one. I don’t want to have to write down in English.’

Mathis also wants more male interpreters.

‘It’s very difficult a lot of the time. You know, it’s embarrassing, and I’ll need a male interpreter for specific situations.’

In court, Mathis’s criminal proceedings were protracted and delayed because he didn’t have interpreters. He said it was very difficult and unfair.

‘When I went in to jail, there was no interpreters at all that were provided to me.’

Prison officers had no patience communicating with Deaf prisoners.

One time, officers who were wearing masks because of COVID-19, instructed prisoners to line up. Mathis couldn’t lip-read and was confused about what was going on and what they wanted him to do.

‘They wouldn’t put their masks down for me and then, you know, they slapped me right across the face. My glasses flew – you know, fell off, and it really, really hurt.’

Prison officers placed him in a small room by himself. He had no access to an interpreter and couldn’t communicate with the officers outside the room. He had to wait until they opened the door in the morning to communicate with them.

Mathis said there should be some form of video system in the room. The officers could provide an interpreter and Mathis would be able to access his first language.

Without interpreters, Mathis couldn't speak to his family or friends like other prisoners did. He couldn't attend therapy for the required offender management programs.

'I need to be able to have access to improve myself. And I can't improve myself.'

Mathis wants more training about Deaf awareness for people working in the criminal justice system.

'We need more interpreters, especially in that system.'

Keenan, Junior and Amani

Keenan and his younger brother Junior are autistic. They are in their late teens, Junior in his last years of school and Keenan now enrolled at TAFE. Amani, their mother, described them as ‘what you’d call high functioning’. They love learning, she said. ‘They’re like sponges.’

She told the Royal Commission the education system failed to meet the needs of her sons.

Both boys started their education at a private school. Staff were unsympathetic and didn’t seem to understand the characteristics of autism.

‘They’d, you know, ring up and complain about a particular behaviour but you’re like, “But they’re acting normal for autism.”’

The school wanted to ‘fix’ the boys’ autism, Amani explained. It wanted them to ‘act like everybody else’.

‘But I’m sorry, they may never be able to act like anybody else because their brains just don’t function that way. And I’ve just, you know, I’ve got a real fundamental issue about trying to fix something that just because they think differently or act differently does not mean that the problem is necessarily theirs.’

The principal exerted ‘intense’ pressure on her to shift Keenan to a school for autistic children. Amani felt she was being bullied.

‘I would get phone calls every single day. Come up, fix something, you know, he needs help with toileting – which he didn’t – he has got upset about something, he threw his lunchbox, the kids don’t want to play with him ... And every day I would get a phone call from the principal saying when are you moving him to [the school for autistic kids]?’

Eventually she enrolled the boys in satellite classes for autistic children.

Her main concern here was the lack of focus on academic learning. ‘It’s [all] life skills,’ Amani said.

When Keenan finished year 6, he had a reading age of 15 – not because of the school’s efforts, said his mother.

For their high school years, Keenan and then Junior went to a public school with a support unit. Keenan had been enrolled in private schools since birth, but they turned him away. ‘They all said, “No, we don’t want to take him.” It was just a flat out no ... No reason,’ said Amani.

At first, the principal at the public school didn’t allow Keenan to study mainstream subjects. Amani felt frustrated by the assumption her sons could not manage academic learning.

'These are boys that have Asperger's with really high IQs ... And they just are not challenged,' Amani said. '[Underestimating their abilities] limits what they can do when they leave school ... If you're not giving them the opportunities that similarly aged individuals have, then you're setting them up in, like, with a disadvantaged future to start off with.'

Eventually the school relented, but as a student in the support unit Keenan didn't have access to specialised subject teaching. Amani, not a teacher herself, had to provide this at home.

'We would get report cards that were all about behaviour. Nothing – no marks, never get marks back on assignments if they did them ... yes, feedback was so difficult to get.'

She would like to see schools offer academic learning in an environment that also provides the special support that children like her sons need. Without that option, parents have to make a difficult choice.

'If I had put them into mainstream they would have not been at school, they would have been suspended continuously. So you either pick the mental health path or you pick the academic path. That's the two options we were given, and they didn't fit in either.'

Geoff and Linda

Linda is the mother of Geoff, who's in his teens and has attention deficit hyperactivity disorder (ADHD), generalised anxiety disorder and depression.

'He has the biggest heart,' Linda told the Royal Commission. 'He has the best banter. He is a comedian that keeps everybody going. He loves that social connection and he loves to be bringing people together.'

Linda and her family moved to Australia several years ago. When Geoff started school, his behaviour deteriorated.

'We put it down to the trauma and that big change, that big shift for him.'

At his first public primary school, Geoff was bullied. Linda moved him to another school.

'From day three or four of him being at that school was when the communications came with regards to [Geoff's] inappropriate behaviour in the classroom – not listening, distracting others ... We tried to work with the school to help them understand not only his neurodiversity, but the ... severe anxiety ... '

The school began suspending Geoff for up to nine days at a time. It never sent any schoolwork home with him.

'So for him, if he missed those days then was expected to go in a classroom, the classes were way ahead. So of course he's going to act out and not be able to do the work and stuff.'

Linda said the school also excluded Geoff 'and other children with a disability' from certain parts of the playground.

'So [Geoff's] mental health deteriorated dramatically, and to the point where he attempted to take his own life.'

Linda enrolled him at another school, which also tried to exclude him and reduce his days 'rather than come up with any solutions'.

Linda said schools struggle to support children with ADHD, but are funded to support autistic children.

'All schools kept pushing for us to try and get an autism diagnosis ... because of the allocation of funding.'

Linda said the NDIS has twice rejected Geoff's application for funding 'because he doesn't meet the criteria'.

Geoff's new school told Linda it couldn't support Geoff and that she should find 'an alternative education'.

'We've seen a huge amount ... of families choosing to homeschool because there is no suitable education [for kids with ADHD] ... You're not going to see ... the result of what that looks like for 20 or 30 years, but I don't think it's going to be a positive one.'

Instead of homeschooling Geoff, Linda found an independent school offering an alternative education.

'[He] went there actually for less than five days. He was able to have access to a vape because they allowed these kids to vape.'

Geoff's currently enrolled at a private school.

'He was just put in classes, like, doing year 2, year 3 work. There was no real plan for actually having to help [Geoff] to achieve what he's going to achieve at the end. But in terms of safety and understanding or disability, it's [an improvement] to what we experienced in that state school stuff.'

Juan

‘They treated me as if I had no will anymore, no intelligence, no ability to control myself.’

Juan is in his 40s and was once a ‘national champion’ in his sport. He was ‘very busy, very active,’ he told the Royal Commission. ‘I was doing back saults, I was diving, I was dancing.’

Several years ago, Juan acquired a brain injury during surgery. Nurses were saying he ‘was brain dead’, that he ‘was basically a vegetable’. It was a ‘harrowing experience’.

‘I wanted to tell them ... I was still conscious. I was still there, I just couldn’t do anything. I couldn’t even blink.’

Juan said his treatment by medical staff was humiliating.

‘They used little ties to restrain me to the bed because apparently ... I’d become a falls risk. I was saying, “Look, I’m still, like, a human being. I’m still cognitive.”’

After ‘three months of gruelling rehabilitation’, Juan went ‘from not being able to move, to being in a wheelchair, to being able to walk’. But he was struggling to ‘come to terms with the disability’, and asked to see a psychologist.

‘They gave me, I think, one or two free consultations at the hospital. Then they said, “No, you can’t do it anymore. That’s our budget.” It was a disaster and I felt so heartbroken.’

When he left the hospital he ‘had to fight’ for his dentist of 10 years to continue to provide him with dental care.

‘It’s like they see my disability as a risk ... but we’re all at risk.’

He hoped the discrimination would be a ‘one-off’, but it wasn’t. ‘People afterwards pigeonhole you ... It really does just wear on you,’ he said.

‘My experiences have been devastating to me. It has been death by a thousand cuts in many respects ... It literally is micro aggression upon micro aggression.’

Juan is a lawyer and was very ‘focused on work’ before his surgery. Since then, he’s had only a couple of years of employment. When he discloses his ‘condition’, employers rule him out.

In the community, Juan finds it ‘so difficult to explain to people reasonable adjustment’.

'People say I look normal, whatever that means, and so it's hard to explain to people why I can't fill out a form.'

He feels he has an 'invisible disability'.

'I struggle mentally with ... whether or not to make it visible. What, do you wear a T-shirt that says, "Look, I'm differently-abled"?'

Because of the brain damage, Juan has problems with coordination and communication. Once, a theatre company 'kicked him' out of a performance for 'being drunk and disorderly'.

He made a complaint of unlawful discrimination and the company apologised.

'I didn't want to get any damages or any benefit for myself, but I just wanted to make a point to say that you should train your people to recognise when someone's being "different",' he said.

'For me, it was never about disabled rights ... It's just about human beings. It doesn't have to be this hard. I don't know why people are so resistant to it.'

Juan is furthering his legal qualifications and will continue to challenge society's prejudices.

'I'm really fighting and trying to still have a life and contribute to society ... But I just can't do what I used to do, and I can't do some of the things that society says are mandatory. I don't think society needs to be designed like that. I really don't.'

Katiya

**'I never got the option to go into hospital like other rape victims.
How I've been treated as a disabled person, it's not fair, it's not right.'**

Katiya is autistic and has intellectual and physical disability due to a genetic disorder. She lives in public housing, 'with carers coming in twice a day'. She needs help with everyday things like showering and getting dressed.

'I don't work at the moment. I also have anxiety and depression. And I suffer from post-traumatic stress disorder.'

About a decade ago, an acquaintance raped Katiya. 'It took me about a week to come forward.'

Katiya said police gave her no support – they had an 'I-don't-care attitude'.

'When I told them that I had disabilities ... they didn't want to deal with me.'

Katiya said police officers didn't provide her with a disability advocate or let her speak with a female police officer. They advised her against calling her mum.

'They said that it would be in my favour not to have anyone present. [That] my story would have more of an impact – if I looked as if I had ... no-one around to support me.'

She said police maintained there was no evidence.

'The evidence was – it was everywhere. There was no excusable reason why they could not of gotten some kind of evidence. My DNA was in the room, it was in the toilet, it was on a cup, it was on my clothing.'

Katiya said the police didn't even get her to go to hospital to be examined for sexual assault. 'They knew the extent of the attack. They knew what he did. They didn't even investigate any of it.'

Police brought the man in for questioning, but didn't charge him. The first police report claimed Katiya was 'too frightened to pursue it'.

'I was frightened, but I did want to pursue it. They twisted what I had said ... They didn't want to have to deal with a severely disabled person ... they didn't give a rat's about me.'

Katiya said the first detective on the case promised that her 'case would be heard', but 'it never got to court'.

‘Why – how have police let him get away with raping a disabled person? They’ve shut me down. They’ve shut the pain down and said, “Oh, we’ve told you, there’s nothing we can do.” The mental abuse from their position of power has been absolutely disgraceful.’

Recently, Katiya sought unsuccessfully to have the case reopened.

‘I tried to get my voice heard ... To, you know, get him held responsible and the police responsible. My rights as a victim of crime have been violated so much.’

Cormac

‘Now my kids are going through all this stuff and there’s not much support for them ... Next generation is going to end up the same as this one if [governments] don’t start learning.’

Cormac, early 30s, has attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder and an acquired brain injury.

From a young age, Cormac was a ward of the state and lived in managed accommodation.

In primary school Cormac struggled to focus. He was ‘an outdoor kid’ and needed to be active all the time. He remembers repeatedly banging his head on the table because he liked the sound.

‘I used to do that every day in class ... and then they would send me home for a few days ... But then I would go back to class and just annoy everyone.’

In high school he was always in trouble for non-attendance and dropped out in year 9. He went back in year 11 but had similar problems.

‘Because of my ADHD I started off in the English ... but then I would just wander out of class and go to, like, the art class, the cooking class, the landscaping and then I joined up for building construction certificate 2 but because I kept jumping around and doing all that other stuff I just missed out on the attendance.’

Around this time he started taking medication for ADHD, but had difficulty accessing it because he was often homeless.

Cormac discovered ‘smoking weed’ calmed him and it was easier to get than his medication.

Still a teenager, Cormac became a father. Child protection didn’t offer him any parenting support and ‘forced’ him away from his son, making his partner ‘take out an intervention order’ against him.

He spent the few years mostly on the streets.

‘I kept going to [child protection] going, look, I’m under your care. You need to help me.’

Eventually they put him in a boarding house but he was stabbed and ended up back on the streets.

Services often turned Cormac away because he couldn’t prove his Aboriginality.

‘When I lived on the street and I could not [get anything] saying I am Aboriginal, or if I did get it, it only stayed with me for so long before I end up losing it.’

Cormac finds it 'annoying', because state and federal governments have so much information about him.

'Proof of Aboriginality should be passed down through the government. We are an Aboriginal country so why don't organisations know before you get there that you're Aboriginal.'

In his early 20s Cormac had a serious accident and acquired a brain injury.

He said there wasn't any support or rehabilitation.

'On the third day, they wheeled me in, stitched my head up and kicked me out of the hospital ... I was having problems. I was messed up for weeks.'

He struggled with his memory.

'I completely forgot how much time and stuff like that. I wasn't thinking. I was messed up locking myself away for eight years. Didn't really talk to anyone.'

In the last few years he has 'started to get out and do stuff'. He found a First Nations mental health worker who has identified some services that may be able to help him.

But it's taking time because the services need proof of his Aboriginality.

'On the [Services Australia] system I'm Aboriginal, but yet everywhere else they don't know. It's really, really annoying. Why do I need to keep proving and proving and proving? Once should be enough.'

Lucine and Lessie

Lucine, mid-60s, is Deaf and has an intellectual disability. She was married for many years to Keith, who was also Deaf.

‘They had a happy life,’ Lucine’s sister Lessie told the Royal Commission. ‘They had their own home. They didn’t need anybody just to support them, apart from, you know, family from time to time.’

About 20 years ago, Lucine became almost blind, when her eyes were very suddenly affected by an incurable condition. ‘After the initial shock of all that, she still managed to be very independent,’ Lessie said.

Keith died several years ago and soon after it became clear that Lucine would need additional support to manage in her own home. ‘There was a lot of things that Keith did for her that ... I guess that we all took for granted,’ said Lessie. Lucine started receiving NDIS funding.

A few years ago Lucine had surgery on her eyes. When she came home from hospital, her service provider said staff were not permitted to administer the eye drops. Lessie had to help Lucine herself, or ask a neighbour to give Lucine the eye drops four times a day.

‘So, I made a complaint to [the service provider] and said, “I’m not happy” – you know, “You have a duty of care. You’re being paid to do a service, and you’re not delivering it.” So about a week or so later I got an email from the managing director saying that they were ceasing services.’

Lucine had to move out of her home while Lessie organised new services.

‘She went downhill. She – her anxiety went through the roof. I had to take her back to her doctor. She’s now on antidepressants.’

Lessie said her sister desperately wanted to go back to her own place.

‘[Where] she was familiar, where every single bit of furniture was, where her milk was in the fridge, where her towels were, where the tea and the coffee and the Weet-Bix and all that was. And because she’s always been independent and lived independently on her own.’

Eventually Lessie was able to organise a new service provider, and Lucine has returned home. But her NDIS package doesn’t cover overnight assistance, which she needs.

When Lessie asked the NDIS for additional support, staff told her Lucine needs to move to a group home, which would be cheaper. Lessie pointed out that would mean losing access to the Deaf support workers Lucine has at the moment, and she would not be able to communicate.

'And this is my argument with NDIS – there's no choice and control. They haven't met her. They don't know her. They've never seen her.' Yet they have decided Lucine's supports are sufficient – 'I just am flabbergasted about that,' Lessie said.

Lessie has numerous concerns about the way Lucine's NDIS funding is managed. She has refused to sign off on some invoices because of the lack of detail.

'I said, "Can you please give me some dates that these things occurred, just a breakdown so that I can sign off on your \$45,000 for the month that you're asking for, or whatever it was." And they said, "Well, this is what she did." And I said, "Yeah, who with, what date?"

Lessie fears that asking such questions makes trouble for Lucine.

'It's just quite frustrating and upsetting to see someone that wants to stay and be – have the little bit of independence that she's got taken away from her. And I believe that it's against her human rights as a person. They haven't asked what it is that she wants to do ... You can't just take her out of an environment that she knows and wants.'

Raynes

‘I come from a non-English speaking background ... I am a woman of colour, so there is that intersection there. I’m also a survivor of child sexual abuse, so there is intersection there. And I also have disabilities.’

Raynes, early 50s, has a ‘longstanding history’ of post-traumatic stress disorder, depression and anxiety. She also has medical issues which cause pain and restrict her mobility.

In the late 2010s, Raynes began working remotely in the education sector. She was on rolling fixed-term contracts and had several contracts renewed.

‘There were never any issues with the way that I did my work ... and my managers were happy.’

At the start of the COVID-19 pandemic, Raynes’s entire team began working remotely.

Six months later, management asked all staff to return to the office.

HR gave Raynes a new contract but told her she could no longer work remotely. She explained her role ‘even pre-pandemic had always been remote’.

Until this point Raynes hadn’t told anyone about her disability because she ‘never had to’.

Raynes spoke to a lawyer who advised her to tell her employer she has disability and request reasonable adjustments.

Raynes put in a flexible working arrangement request under the Fair Work Act, with supporting letters from her doctors and psychologist. Her employer approved the request.

A short time later everyone in the team received full-time contracts. Raynes, however, had to go through ‘an external competitive process if [she] wanted to keep [her] job’.

Rayne was successful, but discovered the contract was conditional on her working from the office. She requested amendments to include her reasonable adjustments but HR refused.

Rayne wasn’t well at the time and was about to have surgery. She accepted the offer and asked to work from home for the first three months while she recovered. HR refused, threatening to withdraw the contract unless she accepted it in its entirety.

Raynes then asked if should take annual leave to recover from the operation.

HR refused and withdrew the full-time offer, offering a limited contract until she started working in the office.

Raynes's lawyer advised the employer was acting 'illegally', so she declined the offer.

'I was so demoralised, burnt out, exhausted by everything that had been thrown at me. I decided [my employer] did not have my best interests or health and wellbeing in mind, nor did they have any intention of treating me fairly.'

Raynes has not worked full time since then.

She investigated pursuing legal action but it was too expensive.

'I am limited by how much legal advice I could pay for, [and] community legal services are under-resourced and unable to keep up with demand.'

Raynes made a complaint to the Australian Human Rights Commission, but has discovered it is limited in what it can do.

'There is no legal jurisdiction or authority who is willing to consider the entirety of an employer's wrongdoing, or the reasonableness of their actions,' she said.

'The whole thing is diluted ... no-one looks at the cumulative impact. Employers get away with wrongdoing on multiple fronts.'

Leonel

‘The NDIA, once they get through these problems and make it sustainable, I think it’s going to be a brilliant thing, but at the moment it is soul crushing.’

Leonel is in his 50s and is blind, has diabetes and uses a wheelchair. Leonel shares a house with flatmates, including his ex-wife.

‘The only reason we’re sharing is because rents are very hard and [we’re on] limited incomes,’ Leonel told the Royal Commission.

Leonel is supported by the NDIS, which initially insisted his flatmates care for him and refused to fund support workers.

‘They were saying, “No, she’s your ex-wife, she has to do everything for you.” ... They’re saying, because I had the people here, I had to rely on them.’

Leonel said that included showering him.

‘Everything. Cooking, everything, and you know we had been separated for a number of years before I got on NDIS.’

Leonel said the NDIS also refused to fund anything that wasn’t related to his blindness.

‘I have multiple disabilities. I’m blind, I have diabetes, I have neuropathy really bad to where when I go out I have to be in a wheelchair because of balance and not having sight. I’ve had a number of falls ... They just kept saying that they only just looked at my blindness, not my whole disability.’

Leonel can’t feel with his hands and feet and has trouble with fluid retention. When he asked for a special chair and bidet to help him manage his continence, an NDIS officer told him he didn’t need the equipment.

‘They said ... well it’s cheaper if you wear pull-ups and urinate yourself out in public and I said, “Would you do that?” And they go, “Well, no, we wouldn’t, but it’s not about me.” You know, so that was pretty hard.’

Leonel said he had to complain to the Administrative Appeals Tribunal before the NDIS recognised his other disabilities.

'And that really upset me because everything was reasonable and necessary to ask for. Why did I have to wait all these years? And how much money did that waste? ... Like, I had to write assessments again and again and again, and they're expensive and it was the same stuff being said all the time.'

Leonel now has an NDIS plan that's helping him 'be more independent in [his] house'.

'My flatmates and I, the stress has gone now because I've got the support that I need and it's working well here. But the biggest thing is, I'm worried and I do stress about ... all the funding cuts. You know they put it in and then they cut it.'

Before being supported by the NDIS, Leonel said he sat at home 'pretty well isolated'.

'[Now] I can get out in the garden with support, because I do a full veggie garden with trees and everything and the support workers help me ... [It's] those little things that make me feel a part of the community again, if you know what I mean.'

Juliana and Ivana

‘People that are supposed to be looking over her just let this stuff happen.’

Juliana is a First Nations woman in her early 20s. She has cerebral palsy, uses a wheelchair and has high support needs.

‘Half of the stuff that happens to [Juliana] only happens because she can’t talk,’ her mother Ivana told the Royal Commission.

Juliana went to an educational support centre at a local school. When she was in year 8, Ivana got a call from the principal. One of the education assistants had reported to them that Juliana’s teacher had been tying her head to the headrest of her wheelchair.

Ivana struggled to take it in. ‘Because it sounded ridiculous. I didn’t understand why ... it would sort of happen.’

The principal reported it ‘to standards and ethics’ at the education department.

‘The school was really upset about it. I was in shock ... They couldn’t say how long it had been going on for. It was just sort of confusing.’

The state anticorruption body contacted Ivana and asked if she wanted them to investigate it. An officer commented that it ‘would be hard to interview’ Juliana.

‘The school said they couldn’t talk about it anymore. I wanted to know, I guess, more.’

Every time she asked the principal had they heard anything, he would say ‘we don’t know’, or ‘the teacher is on leave’.

‘I started to get a bit upset after a while ... Everything seemed to be about protecting the teachers ... not about protecting [Juliana].’

She wanted to know what the school had put in place ‘to make sure it doesn’t happen again’.

‘In the end they sent me a letter and it said that the allegations against this teacher had been substantiated and appropriate action had been taken. That was it.’

Ivana rang an education department official to find out more.

‘She just wouldn’t tell me anything, except that I could access through freedom of information. I was really angry.’

Ivana wishes she’d ‘pushed it’ further, but she was scared ‘to damage the really good relationship with the school’.

'I wanted them to look after [Juliana] ... I know what schools can be like. You just don't want to sort of get anyone too offside.'

She said there 'is no way that would happen' to a person who is not disabled.

'If [Juliana] had been able to talk and been able to come and tell me the first day that this had happened, it would not have got this far. But because she can't, it just goes on.'

Recently Juliana got a new NDIS plan and her supports have 'doubled'.

Juliana 'gets to go dancing ... and to art class' with her support workers.

'She goes to a cultural group for disabled Aboriginal people, it has got elders ... It definitely increases her capacity. She is starting a business with her sister. She has a really good life.'

Ivana says the NDIS is 'amazing', though she would like to see more First Nations support workers to advocate for things like education and health.

Perla and Isabella

‘If there is a situation where your child has a disability and it is going to be a long-term disability, I think it’s really important for families to have ... someone that will sit down with them and explain human rights.’

Isabella’s daughter, Perla, is in her mid-teens and has spent a lot of her life in hospital. She can’t eat or drink, is hearing impaired from antibiotic overuse and has mental health issues.

Perla and Isabella have got to know hospital staff quite well and have a lot of respect for them.

But over time Isabella has realised her human rights and Perla’s human rights were ‘being violated’. ‘People were taking advantage of the fact that I just did what I was told,’ Isabella told the Royal Commission.

‘A lot of parents are under the same misguided thought process when you go to hospital. You just take your child there, hand them over and they’re the experts. You don’t question them, you don’t disagree with them ... You just do what you’re told.’

Isabella said it has been uncomfortable speaking up. She’s worried staff will neglect Perla if she complains.

Over the years, Perla began to feel unsafe having male staff in her room and ‘was really scared that any doctor could come in and touch her’. When Isabella raised concerns something may have happened, the nurse manager dismissed her.

Isabella started teaching Perla to advocate for herself, telling her if she didn’t feel safe she could speak up.

Some doctors refused to give Perla information about the medication they were giving her and Isabella told her she could say no.

One time, an unfamiliar doctor started to put medication into Perla’s drip. Isabella demanded to know what he was doing and told him to stop because the drug causes Perla to become severely depressed.

After Isabella left, the doctor came back. Although Perla ‘spoke up for herself’ and said ‘no’, he ignored her and gave her the medication.

‘In the morning she rang me. She said, “Mum, see, I know you tell me all this stuff but none of it’s true, because they just do whatever they want.”’

As a long-term patient, staff assume they know Perla.

Not long ago, Perla was in pain and staff dismissed it as psychological – a reaction to some difficulties her parents were having. Isabella demanded they investigate and they found five ulcers in Perla's stomach. The doctor said it would have been excruciating.

Isabella has been helping other patients self-advocate, and the hospital has made some changes.

Medical staff must introduce themselves when they enter a child's room.

'They must say why they're there. They must say how long they're going to be a part of the child's care for ... It just gives the child sort of a bit of power over themselves and their room and their private space. The child can now turn around and say, 'Well, actually, I'm not comfortable with you.' Or, 'I like you/don't like you. I'm scared of you.'"

Isabella and Perla's dad struggle to support Perla and their other children. With no family in Australia it has been 'quite difficult and challenging'.

They don't 'tick the right boxes' for Centrelink carer payments or other supports, and have had to 'forfeit [their] careers' and juggle multiple part-time jobs to manage financially.

Social workers have suggested Isabella place Perla in foster care because foster parents would receive appropriate support and payments.

Isabella had hoped things might be better with the NDIS. But as soon as staff heard the words 'chronic pain' they immediately assessed Perla's disability as a medical condition.

'Since [Perla] was born we had phenomenal doctors that have been trying to advocate for her to get funding or services, and it's just constant rejection.'

Jav

Jav is a First Nations man in his early 20s. He was diagnosed with autism and attention deficit hyperactivity disorder (ADHD) when he was five.

Jav grew up in foster care. He said he missed out on a lot of his education. In his last years of primary school he was only allowed to attend for two hours a day because he was 'clearly crazy for them to deal with'.

As a young teenager he ran away from home, lived on the streets, got involved in gangs and started using ice.

'I used ice to settle me down because it's the only thing that's like Ritalin for me,' he said. 'It just settles me down and makes me – makes me feel normal. So I've been using ice since I was 13.'

Jav has been in and out of detention since then, and was in prison when he spoke to the Royal Commission. He has been in trouble for assaults on staff.

'You know, most of them are due to my ADHD and because they were treating me like – like an idiot. They were treating me with disrespect and – and in my head I was thinking, "Why aren't you respecting me?" You know, "I'm just trying to be me.'"

Jav said he has a history of self-harm.

'It's not me wanting to kill myself. It's me having a down moment and me needing time to pick myself back up again.'

Prison staff respond by putting him in a 'dress', or straitjacket, and placing him under observation.

'Then I've got to do two, three weeks in a dress. And it's not fair because I'm just having a down moment, and I lose everything from my cell – my music, my drawing stuff, I lose everything.'

He told the Royal Commission prison officers need better training in recognising and managing mental health issues.

'There's a difference between the people that are seeking attention or trying to bribe the system and manipulate the system and people like me ... that have real drama and nightmares and, you know. There's a big difference but they don't know that because they don't learn it. They learn how to deal us with physically, but they don't learn how to deal with us mentally. They don't understand mental health, and I think that's a big thing that needs to change.'

Sometimes, he said, all he needs is for staff to talk to him.

‘And I tell them, “Look, I’m having a bit of a bad day,” and they sit there for five or 10 minutes and have a chat to me, you know.’

Jav described being assaulted by prison staff and said they often respond to situations with unnecessary violence.

‘You know, you stand up too quickly, they drag you to the ground and start kneeing you, you know? They don’t need to always use that force.’

He said staff need to be better at de-escalating situations.

‘They need to learn how to – how to talk to us with a bit of respect, and then that will calm us down ... Then they’re talking to us and not yelling at us, you know, so they’re less of a threat which means we’ll calm down quicker. I know that from experience,’ he said.

‘Don’t treat us like we’re idiots. Don’t treat us like we’re abnormal. Treat us like we’re normal people, and we – most of us will act normal. And some of us can’t act normal because of our cognitive skills or because of our mental health or because of our disability. But if they understand them then they’ll understand that we’re not playing up. We’re just struggling. We’re just trying to live and trying to get by.’

Vickie

Vickie is in her 50s and lives with post-traumatic stress disorder (PTSD), anxiety and depression.

A few years ago, Vickie arranged with her service provider to have her house cleaned.

‘They didn’t clean me up, they cleaned me out,’ Vickie told the Royal Commission. ‘These people that were supposed to clean out my house, it was the stuff that I, in my debilitated state, that I asked them to save and they shoved under their shirts on the way out.’

Vickie said the cleaners took more than \$100,000 worth of her property including jewellery, clothes, furniture, appliances, art and even her medication.

‘And what was worse is on the front lawn I was having a psychiatric breakdown ... They did everything to conceal these objects. They didn’t walk up to me and say ... “Look, we’ve found strings of pearls,” or my jewel box with all the diamonds and aquamarines in, “Oh, do you want this jewel box?”’

Vickie said after the cleaners had removed everything from the house, she contacted the company to try to get some of her things back.

‘The guy who took the furniture away ... he only gave me back furniture which his staff had smashed ... The [other workers] who stole all my tens of thousands of jewellery, they didn’t even answer the phone calls where I asked them to give stuff back.’

Vickie said when she complained to the NDIS, her service provider ‘stopped providing services’.

‘So for six months I had nothing at all in the worst period, in one of the worst crises in my entire life.’

Police told Vickie that because she was at her house at the time, they won’t investigate. She said the cleaning company offered her compensation that didn’t even cover the cost of her PTSD treatment.

‘It’s left me even more isolated than before.’

Delora

Delora grew up within a conservative church community in a small town. As a child it was difficult for her to tell anyone that she was being abused by her parents.

‘Something I think about all the time was that life would be very different if children had the right to see a psychologist at school, without their parents’ permission,’ she said.

‘Like, if there were just visiting psychologists who were trained to screen for abuse – you know, emotional, physical, sexual or all the above. Because, I was kind of a bright kid, that probably looked for opportunities to try to reach out to other adults. But unfortunately back then, you know, you would get scolded by teachers for sharing private family business.’

Delora is in her mid-40s now. She is autistic, has attention hyperactivity disorder and complex post-traumatic stress disorder (PTSD). She received these diagnoses relatively recently.

‘I guess the stereotype when we were young was very much Hollywood autism, and women present differently when on the spectrum,’ she said. ‘And so unfortunately for, you know, a lot of women in that category, that diagnosis comes a lot later. And so does, you know, the grief with the kind of lost years.’

The diagnosis of complex PTSD has helped her understand herself differently.

‘Now that I know what it is and what that label means, I realise, oh God, I’ve had it my entire life ... I thought everyone had horrible memories pop into their head that just play, you know ... Unfortunately I was groomed from a young age to think that having any of those memories means you’re unforgiving and you’re a bad person.’

Delora would like to see government advertising that promotes awareness of the impacts of trauma, so people ‘could sort of see themselves and go, oh, hang on, maybe I’m not broken. Maybe it’s this, and maybe it’s that’.

Delora explained her different conditions make it hard for her to judge character and to set boundaries in her relationships. It has been difficult to get support that respects her needs, including from police when she reported an episode of domestic violence.

Delora has needed hospital treatment for an ongoing medical condition a few times, but has ‘escaped’ rather than take the risk of staying. Coming across as ‘neurodiverse or a little bit traumatised or teary’ can mean you’re put in a ‘crazy basket’, she explained.

‘The problem with going in their crazy basket is that you can act more crazy because you can tell that they’re not listening to what you’re saying. So if people sort of judge you as coming across crazy, whatever, they won’t listen to you and they will disregard important information.’

She asked the Royal Commission to recommend 24-hour disability helplines in hospitals.

‘That way if you’re in emergency at 11 pm, you could just call the phoneline and go, “Help, they’re not listening. Please help. Please help. They’re not listening.”’

Benno

‘I’ve got enough strategies when people don’t know how to sign. But that’s different when you’re in hospital. And, it’s different at work.’

Benno, late 70s, is Deaf and uses Auslan.

He told the Royal Commission that his biological father ‘didn’t like the idea of having a Deaf son’ and left not long after Benno was born.

Following school, Benno worked in different government roles for almost 20 years. He loved the work and was promoted several times. Eventually he applied for a management role but HR told him if he wanted to be a manager he would need ‘to bring in interpreters’.

‘It would have been a lot better money, but it just wasn’t an option for me.’

Benno decided to move to a regional area hoping to find similar work. But the region wasn’t as accessible as the city.

‘I was in there looking around for different jobs ... There were so many people who said, “Deaf people – no, you can’t – you can’t get that job. Deaf people can’t do that kind of job.”’

Eventually Benno found a job in construction.

He didn’t have access to interpreters and learnt on the job watching other workers.

It was almost impossible to understand anyone because they wore personal protective equipment (PPE), facemasks and gloves.

‘It wasn’t explained to me that it was essential for me [to wear PPE].’ No-one explained the dangers of the various chemicals or materials used to do the job.

‘I’d be looking up and dust would be getting into my eyes. I’d be breathing it in. I wouldn’t be wearing a mask. No gloves.’

Benno had to leave after about a year because ‘it was a really tiresome job’.

A short time later he had some health issues and took the company to court. After a few years he received compensation.

Around this time Benno was commuting to the city for work. There were more employment opportunities but it was expensive and hard on his relationship with his wife.

Benno successfully applied for the Disability Support Pension.

'It's good that I had that option. I'm not sure it gave me any satisfaction, but it was okay to do what we needed to do.'

Not long ago, Benno was feeling very unwell went to hospital.

He immediately showed staff a card requesting an Auslan interpreter.

'I waited, and I pressed the call bell. Showed them the card again. They just never ever looked for an interpreter. I was there all night until the morning. I was so frustrated. I didn't know what was going on. You know, people were just walking in, writing things down on bits of paper.'

Benno had to take pictures of the documents and send them to his daughter who explained what they were.

A short time later he returned to hospital and again was not given an interpreter.

He was transferred to a different hospital which was a little bit better. His children were able to support him and book the interpreters he needed.

'There was not very much communication with the family while I was in hospital. The barriers that I'd found in health care were really just awful, terrible ... Not being able to see my family. Not being well. But also, not having that access with the interpreter was hard.'

Gene

Gene is in her 30s and has postural orthostatic tachycardia syndrome, post-traumatic stress disorder (PTSD) and depression.

'I'm very isolated because, not only do I have my own chronic illness and disability, I also care full-time for my mum, who has a disability,' Gene told the Royal Commission. 'I can't socialise or work properly and I definitely just feel like a massive burden to everybody around me.'

Gene struggles to get doctors to believe she has a gastrointestinal illness.

'When I presented with the more severe gastric issues, they of course said, "You're young and female, you definitely have an eating disorder," when I had none of the signs of it ... Even with testing that proves objectively what's going on, I'm still called a faker and a liar.'

Once when Gene was admitted to hospital malnourished because she couldn't digest anything, a nurse tried to force-feed her.

'[They] forced me to eat every bite of a tray that was more than I would ever be able to eat in my life ... It was just more than I could handle and I got super unwell.'

Gene said another time when she couldn't eat or drink, a doctor removed her intravenous drip and she spent 'about 10 days with no fluids, no food, absolutely nothing'.

'I was having multiple falls. It was really dangerous and I just got yelled at and told, like, "Well, it's your own fault and if you're not going to do this then you get nothing.'"

Gene said her hospital experiences gave her PTSD and depression.

'The problem is often physical health leads to a mental health crisis, you then can't get help for either because no-one knows where to put you ... and your mental health is used against you, especially with digestive issues because, like, if you have anxiety you can often get some digestive issues so they always want to pass everything off as mental health.'

Gene said gastroenterologists at her local hospitals now refuse to treat her.

'You know, I'm a "crazy hysterical female". And what happens is that because they don't believe me and because that's all written down in my [discharge] notes, that then gets passed on to other hospitals.'

Gene flew to another city to see a specialist, who recently diagnosed her with a motility disorder that disrupts her digestion.

'I actually had to travel [to another city] just to go and see a doctor, which is crazy. But he was really, really good ... Everything just ran a lot better and I got a lot better care and I felt safer.'

Gene said many doctors have little understanding of the link between physical and mental health.

‘If you live with a chronic illness and you live with a disability, then you’re isolated and you can’t get the help that you need and you’re in pain and unwell 24/7. There’s no way that can’t affect your mental health. A hundred per cent it will. But then ... getting the help for that mental health is really difficult.’

Sarai

Sarai, in her mid-50s, has chronic fatigue syndrome (CFS). It took about 25 years for doctors to identify her debilitating condition, and in that time she developed complex post-traumatic stress disorder (PTSD). Sarai said CFS is still not well understood.

In the early 2000s, Sarai was so unwell she could hardly leave her bed. She had young children and lived on a rural property. She depended on her mother and on a support group that helped out with her kids.

Sarai told the Royal Commission that, despite her incapacity, it was hard to convince her GP she was really ill.

‘When you’ve got an invisible illness, you look okay but you’re actually not okay at a functioning level. So [if] your doctors don’t really understand your illness very well ... you know, if you’re not these obvious things that they’re taught to look for, then it’s – it’s almost “Listen, you’re not that bad.”’

In the mid-2000s Sarai started a round of visits to medical specialists. None provided a conclusive diagnosis, but one did refer her to a psychologist, with a note suggesting she might have CFS. ‘And that opened the door,’ she said.

Around this time Sarai started receiving in-home support through a service organised by the support group. ‘And that home help – it’s been massive,’ she said.

‘Like, it meant I’ve been able to go to work. I’ve been able to study. I’ve been able to keep on top of things because the energy to clean the house is massive. And by getting that help once a week, it means I’ve got energy to do other things. And I get to rest when I really need to, which means I’m less symptomatic.’

When the NDIS was introduced, the home help providers told Sarai she would now have to access the service through an NDIS package.

Sarai’s initial NDIS application was refused. She began an appeal, but withdrew from the process over concerns about confidentiality. She has not applied again because the process has become linked to past trauma and triggers a PTSD reaction.

‘I would ring the NDIA and I’d just burst into tears most of the time.’

The problem with the application process is partly that she has a diagnosis of complex PTSD, but it is CFS she needs support for.

'I'm under this psychological label. But really, I've got a physical illness. And that's – I need to be under [occupational therapists] and I need to be under physios. And the doctors don't send me there because they think it's psychological ... So, how do I get any evidence for the NDIS that you need. [Doctors] don't even know how to talk about my illness in the terms that the NDIA wants,' Sarai said. 'So I'm caught in no-man's land.'

Sarai hoped a neuropsychologist might be able to confirm her CFS, but it has been impossible to see one.

'You can't even get a referral to a public neuropsych unless you're in hospital.'

Sarai said there is now a 'humongous gap' between people receiving NDIS support and those who don't.

'I rang all of the organisations that would have previously helped someone like me, and they all said to me, "We would have been able to help you, but now we only help NDIS patients."'

Sarai is grateful for the help she has received. She lists Lifeline, several disability support groups, family counselling and some of the medical professionals she's seen.

'You get on with life and you do what you can. And, you know, you live a good life. And I guess for me, with NDIS, I ended up deciding it wasn't worth it. And thank you, thank you, thank you to the state government that did continue their duty of care, because they didn't take my home help away in the end. I've still got it.'

Raiden

‘How do you speak up for yourself when you’re on antipsychotics?’

Raiden is in his late 50s. He told the Royal Commission he was misdiagnosed with mental illness and ‘drugged out’ with antipsychotics for more than two decades.

‘In the past, I couldn’t get people to listen to me properly because I didn’t know I was dyslexic and had a processing disorder.’

Raiden was raised in an institution, ‘from eight to 18’.

‘And I went to an opportunity school, but I didn’t realise it was a disability school.’

He spent many years ‘feeling different, being treated different’.

‘And I didn’t understand that people didn’t understand me.’

Around the mid-1980s, he split up with his wife and ‘had a breakdown’.

‘I didn’t know where to go. I couldn’t go to family or talk to anybody, and I went to mental health. And then I found myself 22 years in mental health, and they didn’t address any of the problems ... I believed them for the first 10 years that I was ill.’

Raiden knew the root cause was something else, but the psychiatrists just said, ‘It’s all in your head,’ or “Change medication.”

‘And it was always antipsychotics ... and their tablets actually made me psychotic.’

Raiden believes mental health professionals were grossly negligent for misdiagnosing him for so long.

‘They should have realised that there’s more ... not give me a labelled name ... This should never have happened. And I’m not talking about myself – I’m talking about everybody.’

Raiden said that in his years in mental health wards, he witnessed a lot of abuse.

‘I should have got myself out of the system, and I’ve seen a lot of people in the system that shouldn’t be there ... I’ve seen people that are very sick be treated badly.’

Raiden is angry about the years he lost in institutions.

‘I’m really pissed at mental health. I really want to take them to court, but I can’t ... They didn’t diagnose me with dyslexia. They didn’t tell me I had a processing disorder ... Even children services didn’t pick up on it ... I only found out in the last two years with NDIS help.’

The NDIS paid for Raiden to have an assessment with a neuropsychologist, who found he'd had a learning disability and auditory processing disorder all his life. He says he is 'a lot better' knowing his diagnosis.

'My life is changing very slowly to what you would call normal ... It is not something that I have ever done.'

Brittany and Ileana

Brittany is a First Nations primary school student. She is autistic and has NDIS supports.

‘She’s very approachable, beautiful, engaging,’ her mother Ileana told the Royal Commission. At school Brittany needs ‘more structure and more support’ because her ‘feelings get really big’.

‘She does have the capacity, but it’s different,’ Ileana said. ‘Visuals or stories anchor her.’

Ileana is a teacher. She got Brittany therapy sessions ‘from the moment she was born’ to ensure she was ‘learning and growing’. And at preschool she ‘was able to be included’.

‘We did everything we could to make sure she had the best possible start to school.’

For year 1, Ileana enrolled Brittany in a special school. The principal told Ileana the teacher had ‘a background in special education’, which made Ileana ‘feel somewhat safe’.

But the first thing Brittany would say after school was ‘please don’t hurt me’.

‘Red flags’ accumulated.

‘The teacher didn’t give her a visual at the start of the day ... to get her through.’ Nor was she letting Brittany have her required nap every day or catering to her ‘sensory disability’.

‘And she was sitting in a room with a lot of noise ...’

The teacher’s response was, ‘If you’re heightened, I’m just gonna put you straight back into your place,’ Ileana said.

‘And it didn’t matter how many times I tried to explain to her she’s heightened ‘cos she is ... [not] getting support. The problem lies in the fact that she doesn’t understand what you’re saying.’

When Brittany is in a ‘red zone’, she needs to go somewhere quiet and ‘take breaths’ and get herself back to a ‘green zone’. Instead the teacher was ‘giving her strategies to cope’.

‘It’s a recipe for like total disaster,’ Ileana said. ‘And it just showed a glaring gap in the teacher’s misunderstanding.’

Ileana felt it was the school’s responsibility to have an ‘autism action plan’, including a sensory room. Because Brittany was ‘outside her comfort zone’, she was running out of the classroom.

Ileana tried to talk to the principal about her daughter’s need for ‘conceptualised learning’. Her response was, ‘We’re going to have problems.’ On another occasion she said Brittany ‘was not suitable for school’.

Ileana paid for Brittany's therapist to attend classroom to help teachers. The school 'removed' her, without a word.

'And that became really scary, because we knew [Brittany] wasn't safe.'

In the end, Brittany 'deeply regressed' in her behaviour and learning. Ileana said it had taken 'so many years of hard work to get her into a place where she was ... able to actually hear'.

Instead of building on that, the school 'derailed' Brittany.

"We couldn't get her to the front gate. She was wetting her pants on a number of occasions, which was really unusual behaviour. And it was very, very hard to watch that happen. And to watch her unravel so quickly ... it was kind of like your worst nightmare evolving."

Ileana realised she 'had to get her out of there'.

'And in the end she made her own choice.' At a meeting with the principal and teacher, Brittany 'turned up to the door and just said "No more."'

Brittany recently started at a new school. The difference is stark – like a 'unicorn' versus the 'devil', said Ileana.

The new principal told her, 'I really believe that [Brittany] will reach her full potential with us.'

When she feels safe, 'the sky's the limit', Ileana said. Today she 'runs through the gates as though they're not there'.

Grahame

Grahame, in his late 50s, used to work as a support worker in group homes. About 10 years ago he was diagnosed with post-traumatic stress disorder, depression and anxiety, and left his job. He developed these conditions after a period of being bullied and harassed in the workplace, for which he received workers' compensation.

Grahame said when he first worked in group homes he enjoyed the job.

'I connected well with the clients. They connected well with me. Then others would say, "Wow, [Grahame], you picked this up really quickly. You're really good at this job."'

He explained he was bullied because he wanted management to act on his reports of neglect and abuse.

'I am one that likes to apply policies and procedures. That's just what I'm like ... If somebody didn't apply the care plan, and put the client in danger, I would report it to management. And it came to a point, because there were so many breaches, that management would say, "What does [Grahame] want now? What's [Grahame] complaining about now?"'

'It's a lot easier to bully someone out of the industry than to investigate a report,' he said.

Grahame told the Royal Commission that often workers ignore reporting procedures. He believes one reason is the high rate of casualisation in the workforce.

'People fear to report neglect, abuse, bullying, harassment because they feel that their job is held at ransom ... So that's creating a cultural silence,' he said.

But he believes the main problem is poor management.

'The bottom line ... is management don't know how to manage, I'm sorry to say. They don't know how to manage conflict, disputes, bullying, harassment, differences between staff and other staff. They don't know how to match staff with the appropriate home ... There are some clients with complex needs and I cannot work with them. I wasn't trained enough, but they would still put me in that position.'

The result is that management play 'a key role in keeping things hushed'.

'Even though there is consistent training on abuse and neglect policy, a care plan, reporting, although ... it's our duty of care to report, it's not put in place ... So an organisation can put all these policies into place, but the person who makes the report becomes the victim.'

Grahame had pursued one case of abuse as far as he could.

'I followed procedures, I started from the shop floor, I went right up to local management, then regional, then state, then the CEO, then Ministers. And every step that I went I was silenced. Every step, I was silenced. Every step.'

He tried to be a 'voice' for the disabled, but feels his efforts were futile.

'Nothing changed. All the recommendations weren't put into place. So even to this day – so, I question myself. I've lost a career. I've lost relationships. And I'm thinking, what was the point? And I'm sure there are more – others out there that are thinking, like me, that if they ever apply the policies, nothing is going to happen.'

Ranald

Ranald is in his 50s and has an acquired brain injury, attention deficit hyperactivity disorder, antisocial personality disorder, dissociative identity disorder, schizophrenia and depression.

‘I had a hard time living my life with disability because I had to learn what a disability was,’ Ranald told the Royal Commission. ‘I had the common thing that most people go through with a disability – parents that have no education or understanding [of] a person with a disability.’

Ranald was born into a family ‘with a history of mental health disorders’ who, he said, had no idea how to help him. His parents weren’t aware a family member and another man raped him at home when he was a child.

‘I also wasn’t aware that this guy was a paedophile. I didn’t understand what a paedophile was. I didn’t understand about sex.’

The child protection department removed him from his family when he was in primary school and placed him in a boys home.

‘It didn’t stop there. As long as I was a state ward ... and [later] homeless on the street, I was getting sexually abused ... The system failed me from time after time, from the day I was born to this day. I am really pissed off and I think it’s criminal.’

Ranald said he never learnt to read or write and is ‘unable to place [himself] in a safe place or get help or do anything’.

Ranald has been convicted of a number of sexual offences.

‘The worst thing they did was placing disability people in jail. That is so fucking criminal. No-one’s got the right to do that to a disability person. They’re robbed of a life when they’re fucking born.’

Ranald is supported by the NDIS. When he was released from jail recently, he discovered the NDIS cut his funding. This was contrary to a report that Ranald needs more funding and a behavioural support plan to reduce his risk of re-offending.

‘You can’t live unless you have a safe environment and a structural foundation around your day-to-day life, whether you want to work, whether you want counselling, whether you want to go to TAFE.’

Ally and Nii

‘There’s a huge unmet need, there’s a gap for complex clients like [Ally].’

Ally, early 30s, is non-verbal, has physical and cognitive disability and requires 24/7 care.

About 10 years ago she moved to a group home.

Nii, her mum, told the Royal Commission the support ‘was okay, not too bad’ but the home was too far away and she wanted to visit Ally more often.

Recently Nii contacted a large disability provider about accommodation nearby. They convinced her they could support Ally’s complex needs.

‘I trusted them, you know. They had a good reputation and the therapists talk highly of them ... They reassured me that all their staff are being trained and screened.’

The provider moved Ally to transition accommodation while they waited for the NDIA to review her supported independent living (SIL) funding.

Almost immediately Nii became concerned about the lack of staff and the high turnover of casual staff. No-one was able to get to know Ally and personalise her care.

When Nii tried to talk to staff and offer suggestions, they ignored her. When she made a complaint, they restricted her visits to a set time each day.

‘I feel very bullied, very intimidated by them. And the way they talk to me with no respect at all. When I tried to open my mouth and discuss, all I hear is, “Stop [Nii]. Stop.” That’s how they talk to me.’

After a few weeks Ally stopped eating and drinking and was crying a lot of the time.

‘Her face looked dehydrated, she went really skinny, she was dry, she was pale.’

Nii took Ally to hospital and they admitted her immediately.

Nii discovered the home was providing poor quality food – ‘pre-cooked frozen vegetables with very little meat and very little value in it’.

Staff were also ‘force-feeding’ Ally.

‘They had one person on the right and one person on the left holding her down.’

By the time Ally got to hospital she was psychotic and was there for almost a month.

Nii believes the provider was only interested in money.

‘They are not interested in providing ... sufficient support for complex needs clients. They are very happy to take the funding. They see [Ally] as a cash cow. They love her funding. They still chased the SIL portion of [her] funding when she was in hospital even though they did not provide care for [her] for the [time] she was hospitalised.’

Nii refused to pay the provider because she felt they were ‘ripping off NDIS’.

When Ally was discharged the provider refused to take her back, and Nii had to quit her job to look after her.

Nii made a complaint to the NDIS Quality and Safeguards Commission but is not confident anything will happen.

‘This is a provider who thinks they’re above the law ... They bully us ... they protect their own interests ... they just want the dollars.’

Trudy

‘Transphobia needs to be called out, it truly does. So, it’s not just about disability, it’s also about who you are as a person with disability. My gender should not come into it. But unfortunately it does.’

Trudy lives with spinal injury and complex post-traumatic stress disorder [PTSD].

‘Since birth I’ve always just seen myself – I’m just a girl,’ she told the Royal Commission. My brain has never registered male anatomy, it’s only ever registered female anatomy.’

Trudy said from when she was five, her brother raped her. ‘Other people’ raped her as well, into her 20s.

‘There’d been a lot of physical scarring and trauma ... and recovery has been very long, very hard, very slow,’ she said. For many years her PTSD was undetected.

Trudy became an NDIS participant about four years ago.

‘It was the hospital that signed me up. I didn’t know anything about it ... So, I just got a plan, and for the first year of it, it was very rough.’

Trudy ‘didn’t understand things’ about her funding.

‘But there was no help or assistance ... And it’s very hard for participants to get accurate information that actually helps.’

‘A whole year went by’ before she got support workers. Then a couple of years ago, Trudy ‘got a really bad plan’ and ‘the NDIS has been absolute fucking hell and a nightmare ever since’.

Trudy says a ‘huge problem’ is the support coordinators, who have discriminated against her because of who she is ‘as a person with disability’.

‘Just because I’m me, transgender, I – I have to live on edge ... I’ve never had anyone in the NDIS actually talk to me or treat me like a person.’

She also feels coordinators used information she shared with them ‘to be antagonist’. After a review of her funding she ‘basically got the same plan, which is completely insufficient’.

Trudy finds it impossible to hold NDIS staff accountable. The only avenue is to lodge a formal complaint and ‘it goes nowhere’.

‘As a participant you get attacked by the NDIS ... You have no rights. And we really need to give greater protections. There needs to be faster, more simpler avenues for help. There needs to be accountability.’

About a year ago, Trudy had ‘full [gender affirming] surgery’.

‘And when I woke up from surgery, everything matched. Life became truly perfect.’

‘There’s only one thing that was still in the back on my mind. I knew my plan would run out of funding early.’

She said her NDIS coordinator ‘out of the blue’ gave her ‘a plan that was fucked’.

Trudy is waiting on the outcome of another review. Her passion is interior design and she wants to go back to study, ‘but that had been really hindered by coordinators’.

‘I’m trying to grow, I’m trying to get somewhere. The NDIS won’t fucking let me.’

Michael

During the COVID-19 pandemic, Michael started working for a bank.

He soon got a promotion and a contract. Michael said he was excelling at his job and his first manager 'was very supportive'.

'I'm quite good at pattern-seeking and that sort of work was really conducive to the way that I think.'

Michael 'found the work was so easy' and would be 'lent out to other teams to help them do stuff'.

Several months into the job, Michael got his 'final formal autism diagnosis, which had been years in the making'.

'So when I was hired, of course I couldn't tell them that I had autism because I didn't have the paperwork to back me up.'

His manager gave him the day off so he could go to his assessment. 'Nothing changed for about a month', but then he got a new team leader.

'I found out later why they picked [her] was because ... they didn't think someone who was autistic would be capable of being a team leader.'

Michael asked to participate in a future leaders program. Other managers approved it and 'it was all in motion', but his team leader said no. She said 'it's not the right time', and it wouldn't be until Michael 'sorts this stuff out'.

'I was like, "Well, I'm never not going to be autistic" ... And after that meeting she rarely spoke to me again in person. She would see my messages and not reply to them.'

At one point, Michael had to isolate and informed his work he wasn't coming in. His team leader told him 'to go and get tested' and that his 'equipment would be dropped off' to him.

But that same day the recruitment agency called Michael and said his contract had been terminated.

'I said, "What for?" And, "Well, [your boss] said you're bad at communicating so you've been fired immediately. We're going to pay you ten days."

Michael said he had 'no warnings, no exit meetings'. He tried to contact the employer's disability team but got no reply. His team leader 'immediately took four weeks leave' and 'was unavailable for questions'.

'Then she didn't approve the – the payslip. So they ... screwed me at every point and it was so difficult.'

Michael made an unfair dismissal complaint. He was awarded some compensation and a written apology from his former employer.

'Which basically said, "We'll try not to let it happen to anyone else again." It's like, well, that's a bit – that's useless.'

Michael is now working with a government agency. His team leader is 'fantastic' and Michael has no problems attending NDIS appointments.

'I later found out that he is dyslexic, and so he gets it ... I don't need to explain anything else to him because he – he knows. He's got that lived experience.'

Moss

Moss is in his 40s and lives with complex post-traumatic stress disorder (PTSD), adjustment disorder and separation trauma caused by his experiences with child protection.

‘I had my innocence robbed, my childhood robbed and I’m paying the price still to this day,’ Moss told the Royal Commission. ‘I’ve had trauma since the day I was born. No-one has taught me emotions, no-one has taught me feelings, so I do have problems coping.’

Moss said the physical, mental and sexual abuse he experienced in the child protection and juvenile justice systems impacted his life ‘catastrophically’.

‘I’ve been in and out of custody [for more than 20 years] and I’ve been misdiagnosed, I’ve been placed on copious amounts of psychiatric medication.’

Moss said the police were ‘fully aware’ of his complex PTSD. During a recent incident, police asked him to remove his shoelaces in case he self-harmed. When Moss refused he was ‘grabbed around the neck and choked’ and ‘thrown onto the ground’.

‘Another constable proceeded to drop his knee very forceful into my chest. Blood squirted everywhere, I had to argue for the ambulance to turn up to take me up to hospital.’

When he recently had suicidal thoughts, Moss told the police. They took him to a community health service at the local hospital.

‘I ... spoke with their peer support worker. I’ve never met one before, but was great ... I found that very comfortable and exciting that someone wasn’t reading it from a textbook, they were experiencing it through life. It wasn’t something they went to university to learn, how to try to connect or cope or understand, which I found that valuable.’

Moss was told to return the next day to be admitted to hospital, but when he did return, the hospital told him to leave.

‘When I got turned away less than 24 hours after wanting to commit suicide, that’s when I realised there needs to be big, big change in this country.’

Stacey

Stacey is a First Nations woman in her 30s who lives with a chronic heart condition and post-traumatic stress disorder.

‘I’ve come to be what I am today,’ Stacey told the Royal Commission, ‘through negligence with, you know, the diagnosis of what I’ve got.’

About nine years ago, Stacey was ‘taken by ambulance’ to hospital.

‘Couldn’t breathe properly, found out that I had double pneumonia, was admitted to the ICU. My chance of death was high, I think it was 85 per cent.’

Stacey spent four days in hospital.

‘They ran every test they known ... all these blood tests and swabs and stuff. They couldn’t find what was wrong with me.’

Doctors released her, but ‘never discharged’ her.

‘They never contacted my doctor for any follow-ups or anything.’

Several months later, Stacey was working-out at the gym.

‘I ended up getting severe stabbing pains in my chest. Went to my doctor, my local GP.’

The doctor told her she was too young to have a heart condition. ‘It’s just your ribs pinching your muscles, so don’t worry about it,’ they said.

Stacey went back to see doctors ‘continuously’ over the following month.

‘The last doctor told me it was all in my head. So I kind of just learnt to live with the pain.’

Stacey was ‘in and out of hospital over 10 times’ until, after almost two years of unresolved pain, she eventually got a diagnosis – rheumatic heart disease.

Specialists ‘couldn’t explain’ how she got it.

‘The only thing they came back to was the fact that I was an Aboriginal woman and I’m more than likely to get it.’

Stacey continued to work. But about four years ago, she was having a lot of health problems and her cardiologist said ‘enough is enough’.

'I can no longer work due to my disability ... I came down to a decision where, you stop working and start living.'

Stacey applied for the Disability Support Pension, but Centrelink wouldn't accept the report she provided 'as medical evidence'. She's onto her seventh case worker and ninth review.

Stacey has applied for an NDIS plan. Meanwhile her greatest support comes from a community-based health service.

'It's called, like, a one-stop-shop, I guess, in our lingo. So you go there and there's many services attached to it.'

Stacey has access to a counsellor, a dietitian, a speech therapist and an Aboriginal health nurse. She's also attending wellbeing classes.

'They're also there to support with letters for NDIS. So, these are all good things ... having that sort of support.'

Stacey tried unsuccessfully to sue the hospital that missed her heart condition, 'for all the wrongdoing they've done'.

'I did tick the box that I was Aboriginal ... Maybe I would've got tested for rheumatic fever.'

The lack of a 'proper diagnosis' has been a 'burden of life'. She wants to help 'put some education out there' so there's better prevention for children at risk.

'Because it's uncommon and unknown, doctors just don't run tests for it. They don't even consider putting it out there and educating Aboriginal people or health services on it.'

Niamh

‘Perhaps it’s time to ask ourselves at what cost do we pathologise diversity instead of embracing it.’

Niamh, late 40s, lives with psychosocial disability and works in the disability sector.

As a child she was sexually abused and, in her teens, her best friend died.

Niamh started to see a psychiatrist who didn’t believe she was ‘processing her grief fast enough’ and prescribed antidepressants.

She began experiencing severe depression and suicide ideation and the psychiatrist diagnosed her as bipolar and gave her antipsychotic medication.

Niamh wanted a second diagnosis, but because she lived in a rural area she could only see her psychiatrist’s associate who supported the bipolar diagnosis.

Some years later, following many medication changes and dosage increases, Niamh went to see a new psychiatrist in the city.

After looking at her trauma history, the new psychiatrist didn’t agree she was bipolar. He believed she had cyclical depression and many of her symptoms were side effects of the medication.

He asked Niamh if she would like the diagnosis removed from her health records.

‘I looked at him in disbelief and asked if that was even possible. It was and he did. That man, that professional gave me an incomprehensible gift that day.’

Niamh came to realise that her grief and trauma had been pathologised.

Around this time Niamh, working for a group home, met Jason who had intellectual and psychosocial disability.

Niamh discovered that a few years earlier Jason been living in supported accommodation with a number of housemates including his fiancé.

At some point the disability provider restructured and moved the residents into different homes.

‘[Jason] was separated from his fiancé without understanding what had happened or why their home didn’t exist anymore. He had no means of contacting his fiancé or rekindling their relationship. An administrative decision had been made that dramatically impacted [Jason] and his fiancé and they had no power or agency in that decision.’

After the move, Jason had an 'episode of psychosis where he became completely catatonic'.

Although he was a young man the provider moved him to an aged care facility.

After some time, he moved to the home where Niamh was working.

Niamh still finds it hard to comprehend what happened to Jason and his fiancé and friends.

Over time Jason has become less institutionalised and has 'regained his sense of agency'.

'I think that grief is being pathologised instead of honoured in our society, and I wonder how many people are prescribed medications that send them into a mental health decline and that the side effects themselves are taken as evidence of mental illness ... I wonder how many people like [Jason] end up in acute mental health crises because decisions have been made about them without them, leading to displacement and destruction of treasured relationships.'

Chrissy and Beverly

‘Many of the carers of people with intellectual disability are worn out. They come from different backgrounds. They themselves have their own burdens. Many are aging. So they need accessible support ... We don’t need blocks and processes and procedures.’

Beverly is in her 70s and is the full-time carer of her daughter Chrissy, who has schizoaffective disorder.

‘Chrissy is brilliant. I’m very proud of her,’ Beverly told the Royal Commission. ‘But she needs support. She needs people in place of me who would genuinely take care of her.’

Beverly and Chrissy live in a regional town where, before the NDIS, ‘families took much of the burden’.

‘We hoped that there would be new, wonderful ideas ... I didn’t think that in 2016 my carer role would extend to almost the last six or seven years being totally consumed by fighting a battle for my daughter.’

Beverly, because of her ‘age and health’, hoped that when the NDIS was rolled out, Chrissy’s transition to the new system would be fast. Chrissy needs funding to live independently of her mother in supported accommodation.

However the NDIA felt Chrissy should remain at home, cared for by her mother. After several inadequate support plans and a funding cut, Beverly took the matter to the Administrative Appeals Tribunal (AAT).

Beverly said a legal aid lawyer represented her while the NDIA ‘had three legal people acting on their behalf’.

‘They were extremely reputable people from reputable firms, which can scare you.’

Just before the AAT hearing the NDIA ‘granted virtually everything’, including funding for supported independent living (SIL). But Beverly is still worried.

‘People that we know in this area have had SIL ... [then] they have had funding, without notice, cut for no reason ... I wonder how sure I can be in the future of [Chrissy’s] support by the NDIS.’

Chrissy is also now funded for specialist disability accommodation, but Beverly says there’s none available in their town.

‘We wanted her to stay in her own local community. She’s now looking [at another town]. ... If I look at what accommodation is now here, there is nothing. So over those years, from 2017 to now, I struggle to see what improvements there are for people with intellectual disability.’

Anne-Marie

Anne-Marie is in her late 50s and lives with complex post-traumatic stress disorder (PTSD).

'I developed post-traumatic stress disorder as a child ... especially due to the violence at the hands of my father and my mother,' she told the Royal Commission.

Anne-Marie said she was five or six years old when 'feelings of terror started to be part of [her] memory'.

'People shouting and screaming and running around at night and fighting ... And my psychologist has helped me work out that PTSD pretty much manifested in me at that age. And to me this is the origin of disability in my life.'

In her teenage years, Anne-Marie said, her grandfather and 'young men in the neighbourhood' sexually abused her. When her mother found out, she 'took a rod' and beat her on her 'bare backside'.

Anne-Marie became pregnant when she was 15. Her mother gave her an ultimatum to either work with her, as a prostitute, or leave home.

'So I left home and I was 16 ... and life was really hard. I was very isolated. I had no support services at all. They just didn't exist then.'

Anne-Marie couldn't talk about her chronic trauma until she was in her late 30s.

'I received no support or diagnosis or recognition ... And so, I grew up with that as part of who I am ... It will never go away. And really, I'm still learning how to live with it. It has been a long journey. Not only is the violence in itself a terrible thing, but the impact that it has on people like me for the rest of our lives.'

Anne-Marie also has autoimmune disorders including thyroid eye disease, which she puts down to her 'trauma history'.

'The damage to my eyes won't heal and that vision impairment plays into PTSD ... Once I'm triggered I can't see properly and I can't focus.'

About four years ago, Anne-Marie got her doctorate. She is now teaching part time, but struggles.

'The stresses produce responses within me that are difficult, and ... in the workplace it's very challenging.'

She says her employer makes no adjustments for her.

'I can't really explain to my employer what's happening for me. I can't talk about psychosocial disability ... people don't understand it. They just think you're crazy and that you're probably not fit for work. And so, trying to have my particular needs accommodated is very difficult.'

Anne-Marie believes violence-induced disability is a huge social problem, yet largely unrecognised.

'I think there are a great many women in particular, and some men out there, who have experienced horrific violence, who have disabilities resulting from that and who don't actually realise that they have a disability.'

She doesn't feel anyone is speaking up about it and 'would like to address those issues in public'.

Shona

Shona is in her 70s and has paraplegia after a fall several years ago. She uses a motorised wheelchair.

Shona was still working and caring for her son, who has Down syndrome, when she was injured. Because she was over 65 at the time, she wasn't eligible for the NDIS.

Shona receives a \$50,000-a-year aged care package.

'My aged care package, as I've said before, I'm very grateful. I get that to pay for the carers, but [the support's] gone down ... to one and a half hours a day because prices have gone up.'

Shona said the cost of disability support services and equipment rose after the introduction of the NDIS, and she's cut back to save money.

For example, instead of paying a nurse several hundred dollars to change her catheter, which takes about 10 minutes, it's cheaper to travel to a public hospital.

'Out of my pension I usually pay about \$265 a week on stuff to do with [living with a disability]. That's before I buy food.'

Shona pays an agency about \$400 a month to manage her support package, whereas if she was in the NDIS that fee would be about \$100 a month. To buy expensive equipment, such as her wheelchair, she has to raise money.

'The [aged care package] is taken up completely with wages. [The wheelchair] is \$20,000, which my friends and family helped raise.'

Shona uses her superannuation to modify her house.

'For the last five years my super's gone down by about \$30,000. So, about \$6000 a year.'

Shona would like a short holiday to visit her son who now lives in another city, but the cost of disability accommodation with a support service is prohibitive.

'The cost of staying in this lovely ... complex, it's [more than \$700] per night, and if I add the carer it was something like [\$1100] per night. Not per week, per night ... [but] they're happy to tell me over the phone, "We're NDIS covered."

If she had been a few years younger when she had her fall, Shona said she would have been eligible for NDIS funding and able to afford the support to continue living an active life.

'I don't like whingeing, but when I hear about people that get so much because they're on the NDIS, as against aged care, it's so frustrating.'

Sheridan and Anne-Maree

‘I think the NDIS don’t realise that there are participants who will be on the system for their whole life and that their development is very slow and they do require a lot of assistance, but the value of their life is the same as everybody else.’

Anne-Maree is the mother Sheridan, who’s in her teens and lives with a rare genetic mutation that causes developmental delay and intellectual disability.

Before the NDIS, Anne-Maree struggled to find an organisation able to fully support Sheridan.

‘I had been supported with an average of eight hours a week for her condition, which was not enough and led to a lot of mental health problems for myself and my husband,’ Anne-Maree told the Royal Commission.

When the NDIS started, Anne-Maree spent 18 months preparing Sheridan’s application.

‘I had done everything I thought was required ... to represent her needs and wants and dreams.’

Several months later, the NDIA refused most supports as being ‘not reasonable and necessary’.

‘We asked for some extra support of about 25 hours a week plus wheelchair, shower chair, change table, some of these basic things ... and these items were identified by her therapists and ourselves as lasting a long time and provide her with the goals of capacity-building and a quality life. They were all denied.’

Anne-Maree asked the Administrative Appeals Tribunal (AAT) to review the decision.

‘The entire process with the AAT was just stalling. Every time we had a case conference they were late, needed an extension ... That was about a year of just going back and forth and we got nowhere.’

After Anne-Maree described Sheridan’s plight to politicians, the NDIA approved the supports and equipment she asked for.

‘[But] the process ended up in neglect for [Sheridan]. She was at risk of seizures that are life threatening. It put my family in a horrible situation ... Without her family she would not have – I don’t think – survived, to be honest.’

Anne-Maree now manages Sheridan’s plan, often with little guidance from the NDIA or help from service providers.

'I stay away from providers, to be completely honest, when it comes to support workers, because they can't provide continuity of care. They cannot provide the skill levels that are required.'

Anne-Maree said the NDIA seems confused about the 'extremely blurry' line between medical conditions and disability.

'It's so mind-boggling what we can and can't do for these complex kids that have health and disability concerns ... So [Sheridan] has seizures, which is on the list. But some things can't be included.'

Anne-Maree said she's dreading the next review of Sheridan's plan.

'Her condition is becoming more challenging ... I'm just quite scared that they'll come back and say we don't need funds, "We're going to take some [back]." Yeah, and I don't need the pain. I think that's what I want to share. We want to be supported.'



Artwork by Crystal Alderson

Demetrius and Zuni

Zuni's nine-year-old son, Demetrius, lives with attention deficit hyperactivity disorder.

'It's been a struggle since he was in preschool with education,' Zuni told the Royal Commission. 'When you have the right teacher, that is a dream year. And when you don't, it's a nightmare.'

When Demetrius started primary school he had only just been diagnosed. His doctor informed the school of things Demetrius would 'struggle with' and gave them 'a list of strategies they could use to easily divert his behaviour'.

But the school ignored this advice and said medication was the 'only answer' to his 'problems with emotional regulation'.

Every time Zuni asked teachers to make allowances for him, they'd say 'no, it's the same rule as everybody else'.

'They were reluctant to implement very, very simple measures ... as simple as how you to talk to him.'

Teachers often 'lectured' Zuni on her son's disruptive behaviour.

Once they asked her to come and 'remove' him from an athletics carnival. When she arrived she found Demetrius sitting with his school friends. 'His behaviour wasn't any different to any of the other children,' Zuni said.

The school 'pressured' Zuni to discipline Demetrius, and 'threatened suspensions ... for violence'. 'But he is not a violent child,' she said.

On one occasion the principal rang and said Demetrius 'kicked the goalkeeper' while playing soccer. Because a younger child was involved, he said Demetrius should have known 'to use less force'. The child's parents said Demetrius was 'a bully' and 'wanted the school to do something about it'.

'This is the extent of it,' Zuni said. 'It is not like my child punched another child in the face.' She told the school to be 'reasonable' – 'It was a game of soccer.'

But she said the school persisted in blaming Demetrius.

'Several times a week I was getting calls to discuss these kinds of incidents. The teacher would just launch into this petty thing that happened ... It's almost like they were looking for reasons to pin some of this stuff on him.'

She described the treatment as 'derogatory and degrading'. 'His teachers would discuss his behaviour with me, right in front of the other pupils and students.'

Zuni feels the school discriminated against Demetrius after she shared 'all the information' on his disability, 'thinking it would help him'.

'But it backfired and isolated him. And they have formed a view that has been kind of impossible to change.'

Eventually Demetrius got an individualised learning plan, but teachers kept telling Zuni they 'can't teach him ... he needs a one-on-one all day'.

Zuni felt she had no choice but 'to pull him out of school'.

'He was refusing to go because he doesn't trust his educators. They have let him down so many times.'

The social isolation has been 'hugely impactful' on Demetrius's self-esteem.

'He has been deprived of experiences and connections with other children. The impacts on his life and education and friendships are devastating, and the school has no idea.'

Zuni wants to get Demetrius back to school and 'reengage his love of learning'.

'Because he is a really intelligent child ... But all that depends on if he is going to get a good teacher. Whether the school is okay.'

Dax and Cullen

Dax is in his teens and has Duchenne muscular dystrophy.

‘He likes playing cricket and he likes being outside,’ his dad Cullen told the Royal Commission. ‘He’ll play table tennis with the best of them and get in line with his scooter, and he just uses that as another set of legs and doesn’t see it as a disability.’

A few years ago, Dax struggled to walk. Cullen asked his school for a full-time aide to help him.

‘[Dax’s doctor] ... wrote specific letters requesting the school to please provide support for an aide and for supervision ... The school was getting [funding], but they were choosing not to spend it or put it in the right area for him.’

One day, Dax slipped at school and injured his leg.

‘Once he actually had the slip ... he could no longer walk. So it’s been [a few] years ... since he hasn’t walked.’

Dax still uses the electric scooter he used before the injury. He needs a motorised wheelchair, but Cullen said the NDIA keeps rejecting his application.

‘He hasn’t been walking for [a few] years ... and we’ve given like, you know, 80-page reports saying why he needs certain blah, blah, blah, blah, but they still are rejecting [the wheelchair]. You know, it’s absolutely madness.’

Instead, Dax relies more heavily on the electric scooter.

‘I get on my knees, lift his bum, and he can use his legs to manual transfer. He can’t walk ... but I have to sort of swing him over and I can get him onto his electric scooter.’

Cullen said Dax’s strength is deteriorating and his support needs are increasing, but the family still has to ‘crawl over 20 kilometres of broken glass to get anything as far as equipment goes’.

‘We need all these assessments and reports done by allied health workers that are costing thousands and thousands of dollars for the NDIS because they say, “We need a new report,” and then it doesn’t get looked at. They say, “The report is six months old. You need to re-date it or you need to get re-evaluated.”’

Cullen said he’s trying to give Dax a normal life, but constantly needs to ‘educate people on what best practices are’ to keep him safe.

‘I don’t mind taking them on and educating them and correcting them,’ Cullen told the Royal Commission. ‘I’m just sort of watching and hoping that something comes from this Commission, and I hope there’s some real positiveness that comes from it. That’s what I’m hoping for.’

Miguel

Miguel is in his early 60s and has cognitive problems due to a brain injury. He has been with the same disability service provider for most of his life.

When he was about 30, the company moved him into a hostel where a staff member physically abused him, Miguel told the Royal Commission.

‘The person who did this told me the next time ... would be better. And they also told me that they did these things to other people in the hostel ... and that they liked it.’

The abuse ‘messed with his mind, and made him feel really sad and unsafe’. It’s had a negative effect on his life. ‘It makes me sad and upset a lot,’ Miguel said. He has difficulty trusting other people.

In the early 2000s, the provider relocated him to a group home where he lives today. He tried several times to tell staff and management about the abuse.

‘They didn’t want to listen to me,’ he said. ‘I was so upset afterwards. I spent a lot of time in bed and in my room. I cried a lot. I yelled a lot. [They] wanted me to move houses. They said I was too noisy and needed to leave. I didn’t want to.’

Miguel said the provider first forced him to move to another room. He ‘didn’t like that’, because it ‘wasn’t comfy’ and there was no natural light.

‘[They] tried to kick me out of my room and kick me out of the house. [They] gave me eviction notices twice.’

Miguel went to an appeals tribunal to ‘fight the evictions’ and won both times. But he’s not happy at the hostel. He struggles to have any privacy because ‘there’s no room’.

He said that since COVID the house has been short-staffed and support workers are negligent in their duties.

‘Staff are sometimes on the internet all day ... not giving me medication at the right time ... [They] often forget and I have to remind them. Once my tongue was bleeding and wouldn’t stop. I asked the staff to call the nurse on call.’

The staff member ‘had no idea what a nurse on call was’.

Support workers won’t take him to see a doctor or dentist when he needs to, or get prescription medicine for him. Miguel said the manager asks him ‘to stay in bed ... up to 2 pm some days’.

Miguel says the hostel relies too much on his family to support him, and he’s ‘too old’ for that.

'I don't need my family to take me to everything. They don't need to know everything about my life. I need some independence.'

The provider has a new CEO who has 'put some time in' getting to know him. She's met with him several times 'to try and help with this issue'.

Miguel hopes it will lead to him having more say in his living arrangements.

Beryl

Beryl's in her 50s and lives with a degenerative disc disease, cervical spinal stenosis, anxiety, depression and trauma.

Several years ago, Beryl's doctor diagnosed her with functional neurological disorder (FND), a chronic condition involving weakness, tremors and pain. Some doctors are sceptical of the symptoms because of the difficulty pinpointing the cause of FND.

'I was having chronic backache at the time of the diagnosis, but no substantive investigation took place into this,' Beryl told the Royal Commission. 'I feel that because of the FND diagnosis, I don't deserve anything. I feel devalued and not treated well. All my physical symptoms seem to be dismissed.'

Beryl said that since the FND diagnosis, she's had trouble getting doctors to treat her other medical issues.

'This label has blocked me from receiving proper care. If the label was not mentioned, then I feel I could explain my symptoms and the doctor could assess me properly on those rather than just going by the label.'

Beryl said when she had trouble with her speech, the doctor 'pointed to the side of her temple and said, "We are here to talk about this and not this," pointing to [Beryl's] mouth'.

Beryl has osteoarthritis, but 'because they link it to FND' doctors refused to treat her pain.

'Although there is a clear physical evidence of stenosis and degeneration ... all this gets ignored ... "It has to be from FND," [they say]. It cannot be from advanced degenerative disc and decompression needing surgery, even though I have that in writing.'

Beryl said she has applied for NDIS support several times, without success.

'I am finding that my health is deteriorating. ... I don't get any home help. I don't get any health management. I am desperate to move forward with my life, but I find I am having to battle constantly.'

Diane

Not long ago Diane, early 30s, had a random accident at the beach and injured her spine. She has paraplegia and uses a wheelchair.

Shortly after she left hospital she returned to work two days a week in a different, temporary role. When the role ended her employer terminated her contract because they said she wasn't able to perform her usual duties.

'I was still fully capable of working, they just didn't give me the opportunity,' Diane told the Royal Commission.

Her managers 'strongly discouraged' her from making a complaint. 'I just knew there was no way that they were going to let me stay.'

Diane's employer also provided her housing, so she needed to find alternative accessible housing for her and her dog.

'I've lived alone since I was 20, and I didn't see why I should have to go and live in a group home because I have a disability.'

Diane found a supported disability accommodation (SDA) unit in a complex nearby and contacted the accommodation provider.

'They were just amazing at helping me with the application process,' she said.

But the NDIS refused Diane's request, instead approving 'improved livability ... in a share house'.

'I'm in a wheelchair, I need fully accessible. I didn't get it ... Wheelchair users need a minimum of fully accessible because that gets you the bathroom that's accessible, and the same with the kitchen.'

Diane contacted a second provider and inspected an SDA unit in another complex. Even though she didn't have the right funding, they would allow her to move in on the basis she asked the NDIS to review its decision. If she wasn't successful, she would have six months to vacate the property. Also, she would have to use their supported independent living (SIL) provider.

'I had to give them four hours a day at a cost of 100 grand a year ... but I wasn't able to get out of bed until 10 am because their early morning slots were full.'

Diane was shocked.

'They say it's all about choice and control yet they were forcing me to use their SIL provider.'

Unsure what to do, Diane went back to the first provider and asked them to help her challenge the NDIS decision.

‘I was fortunate ... they have connections with people and they made a couple of phone calls. And then I got a phone call [from the NDIS] apologising, and just said, “Human error” and I got given fully accessible ... and I got sole occupancy so I could live alone.’

Diane’s dog, who had been badly abused, became unsettled after the move so she sent him to behaviour training for a short while. Two days before he was due to come home the support provider sent her a pet safety agreement.

They wanted Diane to muzzle and tie up her dog and to accept unlimited liability for any damages. If she didn’t sign the agreement they would withdraw their services.

‘This caused a lot of tension between me and them ... I thought that I was not going to have a carer, and I felt like I was being threatened. I feel like when you have a disability you are a bit more vulnerable.’

The provider eventually came to an agreement with Diane, but over time reduced or cancelled services, often with no notice. They would blame the COVID-19 pandemic.

Diane is slowly transferring services to a new provider and has found them so much better. ‘The difference in service is crazy.’

Autumn

Autumn is a First Nations woman in her 30s who lives with workplace-acquired brain and spinal injury. She has mobility issues and experiences sensory overload and seizures.

Autumn told the Royal Commission that in seeking disability supports she's 'faced nothing but systematic racism and neglect'.

Her former government employer denied her a pension, so she turned to an Aboriginal community health provider in her regional town.

'At first I felt safe under their care. I very quickly realised that that care management is not actually run by Indigenous personnel ... and they have no Indigenous carers.'

The organisation provided in-home care.

'I started facing care abuse to the point where it ticks everything but sexual abuse,' Autumn said.

Support workers weren't 'letting her rest', causing her to have seizures from 'neuro-overstimulation'. She said there was a lot of 'medical harm and abuse'.

'I was left in bed with shingles for two days untreated. I'm immunosuppressed. I had a cyst form on my face, and I never received treatment and it burst ... These carers were incapable of even calling my doctors. I was missing medical appointments.'

Autumn said staff neglected hygiene and safety standards.

'They were leaving trip hazards everywhere. They were letting loads of washing build up in the house ... They were supposed to do food checks and I was left eating mouldy food out of my fridge.'

Autumn said the government eventually offered her more hours of care than the community organisation, so she switched providers.

Autumn was living with her father, who is Deaf, when the new support worker first visited.

'That carer then made a false report that my dad and I were arguing and she felt unsafe.'

Based on that report, the provider insisted Autumn be 'supervised' during subsequent support sessions.

‘Having to be forced to be baby-sat like a criminal was the most degrading thing I’ve ever faced. They did not let me have any independence.’

Autumn reported the ‘racism’ to the government department managing her support, but they ‘ignored it’.

‘When you are Indigenous [they] do not want anything to do with you.’

Autumn is still struggling to get adequate supports and is spending ‘several thousands’ a year on health care. ‘I’ve had no assistance off anybody.’

Raf

‘My right to communicate using facilitated communication has been targeted.’

Raf, late 20s, is autistic, non-verbal and has a number of neurological conditions affecting his behaviour.

Sometimes he will vocalise loudly and move uncontrollably. Other times he can appear withdrawn or flat.

Raf said that because of his behaviours people assume he has intellectual disability instead of being cognitively different.

‘They really don’t seem to acknowledge that non-verbal people are intelligent,’ he told the Royal Commission.

In school, teachers put Raf in with the ‘kids with intellectual disability’ and his education was ‘understimulating’. His parents had to pay for private tutors and other supports. He said it would be ‘wonderful’ to go to university or TAFE, but it is ‘really unusual for people like [him] to study’ because there isn’t enough support.

Raf uses facilitated communication and needs specialised equipment and an experienced, trusted facilitator to help him communicate.

In recent years the NDIA has withdrawn support for facilitated communication. Raf is concerned the agency doesn’t understand the importance of facilitated communication, which makes it hard for him to have a voice and speak up.

‘It’s important to realise that facilitated communication is not accepted by many including the NDIS ... I want to keep silent so my funding is not compromised. It is always a risk with each review – got to be very careful.’

Bevan

Bevan is in his late 50s and has a genetic disorder that affects his bones.

Bevan told the Royal Commission he was sexually abused as a child in primary school. He has post-traumatic stress disorder and depression, 'obviously driven' by that experience, he said. He is seeking compensation, but the process is drawn out and complicated and Bevan believes the government is trying to avoid responsibility.

'They're trying to make out that, at best, I don't suffer from complex post-traumatic stress disorder,' he said. 'They're seeking to kind of strategise for later on when there might be liability that, you know ... "He's got a personality disorder or he's got some other, you know, mental health designation."'

Bevan says he's seen that happen before.

'Means you can get expert witnesses with different testimony and different judgement on what a person is and is not.'

Bevan's school years and early 20s were troubled. 'I was certainly treading a thin line, and there was also a lot of at-risk behaviour,' he said.

'So, you know, this is where the trauma is still kind of affecting me as a person, because it's now unresolved trauma, and it's kind of gone into the unconscious.'

Luckily, he had the support of good friends, he said. With their help, 'I was able to kind of straighten out my life.'

Bevan trained as a teacher and worked in regional schools for several decades in different roles. He observed over the years that very often students who should have been identified as having a disability were instead labelled 'bad'. Trauma wasn't recognised either.

'Some of the elements of antisocialness and criminality and so forth, these are just behaviours that are, you know, are brought on by trauma.'

He believes that placing kids with disability in mainstream schools is better in theory than in practice.

'Getting kids mixing with, you know, integrating with other kids – fantastic idea and it has lots and lots of benefits. But, you know, the difficulty remains on the quantity ... So if one teacher is loaded up with several complex kids, you know, that is very difficult. And if they've got emotional regulational difficulties and those sorts of things, that's a very difficult situation to be in.'

Tracey

Tracey is in her 60s and has a physical disability that prevents her from standing and walking for long periods.

Several years ago she applied for a job as a support worker with a disability service provider.

'When I first got the job with [the provider] I was so excited because I thought I had the support, the needs, the understanding of my disability,' Tracey told the Royal Commission. 'For the first [few] years, may I say, I did. I had a wonderful time. Then I put my hand up and I asked for help for something, and it all just went down from there.'

Her employer moved to a new building that had no lift or accessible parking.

'Terrible disabled access. It's amazing how many buildings that disability services are in that have no disability parking ... I don't know how these companies can get away with it.'

Tracey asked for 'things that had already been part of [her] daily working to be put back in place'.

'I was called a whinger. I was called a troublemaker. I was called all these things. Not, "We should look at all these and see what we can do about that because that's not really fair."

Tracey said she felt 'humiliated and embarrassed'. When she began to self-harm, she admitted herself to hospital with anxiety and depression.

'I took this out on myself because I thought I was asking too much and being a problem to other people, and I should never have been made to feel that way.'

Tracey said the service provider 'should know better' because it supported people living with mental illness.

'I'm now struggling to get back into the workforce with my disabilities and now the mental health diagnosis.'

Tracey told the Royal Commission a government agency recently interviewed her for a job.

'They asked the question; how do I think my disability will affect my job. If I thought my disability was going to affect that job, I wouldn't have applied for it. They didn't ask able-bodied people how their problems will affect their job ... They just tick off boxes.'

Zora

Zora, now in her mid-50s, has an acquired brain injury caused by an accident when she was a young child. She also has epilepsy, with frequent seizures that are becoming more severe.

When she was seven, child welfare took Zora from her adoptive mother who had been physically and emotionally abusing her. They placed her in a group home operated by a religious organisation and managed by a cottage mother.

As a 10-year-old, some older boys living in the home sexually assaulted her. She didn't tell anyone about it for many years.

She was also sexually abused over an 18-month period by a man who lived at the property. She told a friend what was happening, the friend reported the abuse to the cottage mother and the matter was investigated.

'I was interviewed by the police and the director, the psychiatrist and other staff of the home, and I wasn't believed by anybody. At, you know, 14, 15, I wasn't believed.'

Years later, Zora returned to police to report the man again. She was concerned he might still live at the property and be abusing others. Police told her all the records of the previous investigation had been lost. 'I still feel they didn't believe me,' she said.

Zora did eventually get an apology from the organisation that ran the home, but it felt insincere. It didn't help her. Instead, it prompted thoughts of taking her own life.

'The apology has made it worse for me actually, in my opinion, because ... I went to a lot more thoughts of, like, "I don't want to be here anymore." It's like I want to go for a walk at night and not come home the next day. But I have to beat this,' she told the Royal Commission.

'And I've got friends that – who love me and like me – so I can't do that to my friends, and I can't do that. You know, let people win.'

Zora is certain her disabilities arise from the abuse she has experienced. Her main concern now is that other children might be disbelieved as she was.

'I just don't want this to happen to anybody again,' she said. 'I mean, if people report things – if they are kids or whoever – I want them to be believed, you know ... [They] have to be believed.'

Zora enjoys time she spends with a support group for people who used to be in care.

'It just offers support for us to go and meet each other and talk, and we go on outings and, you know, we can talk about how we lived in the home, or ... we just – we just talk about daily things. We don't have to talk about our lives at the homes.'

Socialising is not always easy for her.

‘I put up a wall so people don’t ask me, “What’s wrong?” because I don’t want to explain every time why I’m down ... So, you know, if I have a good day the wall goes down a bit, if I have a bad day it goes back up.’

Huw

Huw is a veteran in his 50s.

'I've suffered brain injuries and spinal and hearing loss and so on from explosions and gunfire, so most of my disabilities have been acquired,' Huw told the Royal Commission. '[As a result] I'm either too blunt or I'm possibly rude. I don't know. [It's] something in the way I process information or language or communicate.'

Several years ago, Huw worked for an organisation that he thought would provide an 'inclusive or progressive environment'.

'The reality doesn't match with the brochure ... They will seek to add you to their corporate social responsibility bragging metrics to say, "Look at the disability, LGBT, whatever, people we employ." So, you end up being a concession.'

Huw said the office he worked in was open plan, but not suitable for people using wheelchairs or who are hearing impaired.

'If I don't have inserted earbuds, I can't hear or I have to try and lip-read ... Trying to speak about that in the workplace only invited harassment.'

Huw is immunocompromised and asked to work from home during a COVID-19 outbreak.

'They wanted us all in the office during COVID because there was no plan, and if you requested to work from home or you requested concessions and you didn't disclose your medical condition ... people were terminated or they were persecuted.'

One day, after Huw sent an email, the organisation fired him. Huw was told only that the 'tone in the email' was wrong.

'I still don't know what I said or did and I continued to try and get that information.'

Huw said he had 'one of the best performance reports' at the organisation, but people misunderstood the nature of his disability.

'I for all intents and purposes don't look or sound like a person with disability, but once mental and cognition issues are introduced the default assumption by most people is that you're stupid. I may be many things, but I don't think I'm stupid.'

Huw has since struggled to find another job because when 'one or more disabilities' is declared or detected, he's fired. He says there's now a 'black mark' against his name.

'I've been persecuted. My privacy has been breached. I've been humiliated. ... It's getting tiring.'

Abe and Iggy

‘Right from the start we had to fight intensely for him to be adequately accommodated. There was just very few beds in the entire state that were appropriate for somebody with a severe acquired brain injury under 65.’

About 25 years ago Abe, then in his mid-40s, had a heart attack.

‘Once he woke up it was really obvious, pretty much straight away ... that he was severely damaged,’ his daughter Iggy told the Royal Commission.

Abe had acquired a brain injury and had almost no short-term memory. Not knowing where he was made him highly distressed.

‘He was so violent ... so out of touch with reality.’

Abe moved to an isolated short-term rehabilitation ward with a nurse and 24/7 security. But the hospital couldn’t handle him and tried to make his family take him home. Abe’s wife refused.

‘His wife and [teenage] daughter were going to be able to manage the violence and agitation when a hospital full of staff could not manage it? I’m not quite sure how they thought that would work.’

The first time Abe punched Iggy, staff didn’t seem to care. But later that day he punched a nurse and they strapped him to a chair.

‘They left him in the chair all day, every day ... Mum was begging them to untie him and they wouldn’t do it. Mum tried everything ... including going and talking to our local member of parliament.’

Staff told her the only way to untie him was to take him home.

‘He learnt to bounce the chair around the room to try and move a little bit ... He wanted to get into a different position to see something else.’

After a while Abe moved to a brain injury unit.

‘[They were] three of the worst years,’ Iggy said. ‘[They] used a lot of chemicals.’

Staff also used physical restraints, locking Abe in a room for long periods of time. He had no access to the outdoors and no engagement with staff, who preferred to play games on their computers.

Abe loved his football team and watched a recording of them winning a game over and over again.

‘It was pretty much the only activity he ended up getting,’ Iggy said. ‘It doesn’t help people who are intensely brain damaged to not have poor behaviour when they’re so intensely bored all the time.’

At one stage, Abe’s wife noticed he was in pain and realised it might be his teeth. She discovered no-one had brushed his teeth for two years. The dentist was disgusted Abe had been left in pain and discomfort for so long. Ultimately, he couldn’t save many of Abe’s teeth and he had to get dentures.

Despite the dentist writing to the hospital, staff continued to neglect Abe’s teeth. They kept misplacing his dentures, which meant he couldn’t chew his food properly.

Staff would also lose his reading glasses. ‘He couldn’t even do something like sit there and watch TV or read a newspaper because he couldn’t see properly.’

Staff refused to leave a water jug in his room and he ‘had very limited access to water’.

Eventually Abe moved to another medical facility where he stayed for many years. ‘It was the best place he could have been, but that didn’t mean it was ... okay,’ Iggy said.

‘He actually knew where things were, he was orientated, he could find his way to his room ... He had his own room with an ensuite, so he could at least go into his room and shut the door and be by himself.’

Despite promising Abe a bed for life, in his early 60s the hospital transferred him to an aged care facility.

‘I think moving to the aged care facility basically killed him because he didn’t know where he was.’

After a few months, Abe had a heart attack from the ‘constant stress of being disoriented’ and died.

Ahmad and Khalani

Ahmad's disability is 'complex' and he needs 'intensive support,' his mother Khalani told the Royal Commission.

A disability service organisation offered to apply to the NDIS on his behalf when he was three. Ahmad was rejected.

Six months later Khalani applied again, with the same result. She was told Ahmad didn't qualify for NDIS funding because of her visa status.

When Ahmad was four Khalani made another application and again was unsuccessful.

'I've submitted a total of seven applications to the NDIS, only for all of them to be rejected.'

Khalani decided to move her family interstate 'in hope of reapplying for the NDIS'. A social worker at the children's hospital assisted her with the application and Ahmad was 'finally accepted'.

However, because of the COVID-19 pandemic Ahmad couldn't access services. Clinics were either closed or not accepting new clients. The special school where Ahmad was enrolled remained closed for the entire year and Khalani had no choice but to keep him home.

Khalani managed to find one clinic willing to put Ahmad on a waiting list. However, by the time the clinician assessed him he was rejected because he was 'too old' for the program. Khalani was frustrated because she hadn't been told this when she put Ahmad on the waiting list.

She said the experience has affected her whole family and her eldest child 'was so upset about things and cried every day'.

Khalani recently found a clinic in another city that will accept Ahmad, and she is about to relocate the family again.

'The multiple rejections from the NDIS have cost me opportunities of helping my child. My top priority is for my children and not myself, and it seems like that has been disregarded.'

Layla

Layla is in her mid-20s and is blind. She wrote to the Royal Commission about the ostracism and ‘subtle discrimination’ she has experienced throughout her lifetime, particularly during her schooling, due to her disability.

‘In school, I struggled to fit in,’ Layla said. ‘The kids, I would say they didn’t know how to handle my disability.’ This resulted in them excluding her from social activities – from parties and outings. Sometimes Layla would express her sadness about this and the kids would apologise and say ‘next time’ or make some excuse, but it never changed.

‘Because I was battling quite a lot during school, my self-esteem was just getting lowered. I had no confidence in myself and I started beating myself up thinking, you know, if I wasn’t born completely blind then this would never have happened. But then I realised it’s not my blindness that gets in the way. It’s attitudes.’

It was a similar situation in the classroom. Occasionally someone might ask her if she wanted to join their group for a particular activity, but often no-one did and Layla felt ‘too shy’ to ask if she could join.

This ostracism has had a lasting effect on Layla.

‘I do have anxiety issues and I am working on developing my confidence and my self-esteem. Because I was, basically throughout school and high school, I felt intimidated. At times I felt just worthless really.’

Layla also told us about the ‘subtle discrimination’ that continues to happen to her as an adult. Layla gave examples of times she wanted to volunteer or ‘try out’ for things.

‘There were times where people were making it very difficult for me. They kept saying, “Do you think you’d like to bring your mum next time or a friend?” and it’s like, well, no. This is my thing, you know, this is my thing that I want to do.’

On one occasion, someone at a volunteer group called a taxi for Layla and showed her out. Apparently, says Layla, this ‘was eating into their own volunteer duties’. Later, someone rang and told Layla, ‘It is difficult when someone’s got other things, and we’re not trying to be patronising, but do you think you’d like to bring a friend next time or have a friend come with you because it will be too difficult for you?’

‘Just basically making it difficult for me,’ is how it felt to Layla. ‘I think you guys are just saying that you don’t want me. I just have the feeling that you’d rather not say you don’t want me. So making me decide to pull out of my own accord because they were deliberately making things difficult.’

Another time, someone called the group together to ‘lecture’ people about not having to ‘pussyfoot’ around Layla ‘just because she’s blind’. They were saying that Layla should be treated like everyone else, but they made it sound like it was Layla’s fault that people were ‘pussyfooting’ around.

One time at school, Layla was given extra time for an exam. A teacher expressed her displeasure that Layla was getting ‘special treatment’.

‘I felt that the misunderstanding and sort of emotional bullying increased because it was like they didn’t understand the difference between special treatment and adapting.’

Layla believes it would make a real difference if people could understand the difference between ‘adaptation and special treatment for disabilities’.

‘I’m working ... part-time now, and I feel that the job that I have been given by work is like a godsend. That’s how I feel, because there are a lot of people in the job around my age, but they’re very open-hearted and they seem to understand. They don’t feel like I’m being treated specially, or I don’t think they do. It’s just accepted that things are a little bit adapted for me so that I can do my job properly like they can.’

Noah and Rosie

Noah is almost a teenager and is homeschooled by his mother, Rosie. This isn't by choice – it's because Rosie believes it's the safest option. Rosie told the Royal Commission that Noah was bullied and abused in specialist and mainstream schools. Before the bullying started, Noah was a 'happy, witty, energetic, fun loving child,' Rosie said.

'They were supposed to protect, encourage and build self-esteem, yet it crushed him.'

Because he is autistic and has attention deficit hyperactivity disorder and a mild intellectual disability, Noah's first school was a specialist school. Not long after he started he complained of bullying, but the school said it was 'all in his head'. Even when Rosie witnessed another child attack Noah, the school continued to deny there was a problem.

So Rosie moved Noah to a mainstream school. However, the school soon complained the class was being put into lockdown because of Noah's behaviour.

One day when Rosie came to collect Noah, she found him locked in a small room. Rosie knew there had to be a trigger for Noah's behaviour because it wasn't happening at home, but the school blamed Noah and regularly suspended him. 'I know my child isn't perfect but [he] doesn't act out for attention or for the fun of it,' Rosie said.

When a teacher told Noah he was 'a horrible person' and 'nobody likes him' and that 'even your mother doesn't like you,' Rosie realised he was also being bullied by the teacher.

Rosie said the school asked her to medicate Noah, but she refused. Instead she enrolled him back into the specialist school, feeling she had no other choice.

When the behaviours started again, Rosie decided to attend all excursions and events to figure out what was triggering Noah's behaviour. She witnessed him saying, 'stop it, I don't like it' or 'you're annoying me, leave me alone' when the children did things he didn't like. But Rosie said the children ignored his pleas and kept annoying him.

When she brought this to the teachers' attention they suggested if Noah was medicated he'd be more accepting of other students' behaviour. Rosie reluctantly agreed but said, 'It was the worst decision I ever made.' Her happy, witty boy disappeared and Noah became 'a zombie'. He put on 40 kg and the behaviours didn't stop. He was often restrained and banned from attending outings and other events.

Then one day at a sporting event, Rosie watched a student hit Noah with a baseball bat. As Noah struggled to breathe, the aide laughed and said Noah probably deserved it. Rosie couldn't believe it. Everyone had witnessed the incident, but still Noah was blamed.

‘He was standing there doing nothing and [that child] just hit him in the neck with the bat.’

Noah refused to go to school for a while. When he did return, Rosie organised a meeting with the teacher so Noah could tell her what he needed to help his behaviour. He asked for his desk to be moved to a corner and for partitions to be used so the kids wouldn’t bother him and sit on his desk, eating and dropping their food. The teacher refused to accommodate Noah’s request and suggested he sit in the utility closet or outside. They also suggested Noah’s medication be increased.

Rosie was horrified and decided to homeschool Noah. The school threatened to report her if Noah didn’t attend school while there was no homeschool registration in place.

‘Do as you like,’ Rosie said.

Noah is now homeschooled. Rosie told us he is off the medication and attends numerous group excursions each week without incident. He is also seeing a psychologist who is treating him for the trauma he suffers from the bullying he experienced at both primary schools.

Simon and Alice

Simon has physical and intellectual disability. In the early 2000s he worked in a disability enterprise, which he loved. He had friends there and it was important to his mental health. His sister, Alice, told the Royal Commission that ended the day one of the workers raped him.

Alice reported the attack to the police. Simon was interviewed by the sexual assault unit and by a psychiatrist, who confirmed that Simon's behaviour was consistent with having been raped.

Alice said she also reported the attack to the management of the disability enterprise, who acknowledged that something had happened to Simon but did not use the word 'rape'.

When Simon told his family what happened and then the police, he had to relive the trauma. However police did not proceed with the charges as there were no witnesses to the rape and the prosecutors said Simon would not make a good witness at trial.

Simon would not return to the disability enterprise. Since the rape, Alice said, he's been scared of men and difficult to take out. He no longer has contact with his friends from the disability enterprise and has spent 10 years socially isolated in his room.

Alice said the disability enterprise never followed up with Simon or offered him a position anywhere else.

'We were totally disappointed at the lack of care and concern expressed for Simon when this awful thing happened to him.'

Simon was offered a position at a different disability enterprise a decade later when Alice got the local member of parliament involved. But he was unable to interact with the other people there as he was afraid of men and physical contact. He was scared both at the disability enterprise and on the bus getting there, Alice said. He stopped going and now relies on a female carer to take him out.

Alice believes that Simon was raped because of his physical and intellectual disabilities and because his attacker didn't think Simon would be able to report the attack, or that people would believe him.

'Our concern is that the rapist faced no consequences. He had the ability to continue and perhaps next time rape somebody who cannot speak ... '

'Disabled people need to be believed when they tell us about abuse and violence, and special allowance needs to be made in courts so the perpetrators can be brought to justice.'

Eddy, Gill and Libby

‘I cannot let our son rot in prison.’

When Eddy was born the umbilical cord was wrapped around his neck, restricting oxygen to his brain and damaging his frontal lobes.

As a child, a family member sexually abused him. His behaviour became ‘more difficult’, his mother Libby told the Royal Commission, and he became withdrawn.

She says Eddy’s ‘biggest problem’ is impulse control. If he sees something lying around he will take it. When Libby or Eddy’s father Gill ask him why, he says ‘it was there’.

At high school, Eddy was disruptive and would get into fights. The school would isolate him in a ‘quiet room’ and he spent most days alone. He started running away and lived on the streets.

Eddy ‘got into drugs big time’, stole cars and in his late teens went to prison.

No-one involved in the justice process understood Eddy, his disability or ‘what to do with him,’ Gill said. And there were no programs to support him in prison.

Now late 40s, Eddy has been incarcerated for nearly 30 years.

One time he was part of a release program and lived in supported accommodation. Gill said the support workers were young, not well trained and didn’t speak much English. Eddy struggled to communicate with them.

The provider garnished Eddy’s Disability Support Pension to pay for living costs and gave him \$20 a day for tobacco. ‘I can’t emphasise enough the value and importance that [Eddy] places on his tobacco. It’s everything to him. It’s his world,’ Gill said.

One day Eddy asked for his payment a day in advance. When the workers refused, Eddy became upset and threatened them with violence. He didn’t hurt them, but was charged with multiple offences.

Eddy was sent to a secure mental health unit. Staff supported him and successfully advocated for him to be considered unfit to plead.

He then went to a facility for people who have been charged with a crime but found unfit to plead.

Gill and Libby were hopeful Eddy would be well supported, but he rapidly deteriorated physically and mentally.

Gill begged the centre director to let Eddy have his tobacco pouch.

'[Eddy] was looking at the clock all the time, his anxiety was rising, his frustration, waiting for a cigarette.'

Eventually things became too much and Eddy damaged some property, demanding to be sent to prison so he could smoke his own cigarettes.

Eddy is back in prison.

This NDIS has approved a package, but won't release funding, organise housing or support staff until they have a prison release date. The board won't provide a release date without funding and a support plan.

Campbell and Magdalena

‘He fell through the cracks because he was really so normal. He still today goes under the radar, and people just think he’s a bastard.’

A few years ago, Campbell started school.

Year 1 was ‘an absolute nightmare,’ his mum Magdalena told the Royal Commission. He couldn’t sit still, ‘wasn’t able to cope and he’d get frustrated’.

The school ‘was incredible’ and offered to help Campbell and Magdalena.

The head of learning arranged an appointment with a paediatrician who diagnosed Campbell as autistic.

The school came up with a series of reasonable adjustments and an individual education plan (IEP) for Campbell.

‘When he had a bit of a meltdown [the head of learning] would give him what I have now learnt is a “brain break” and take him for a walk to the chickens – they’d collect eggs.’

The head of learning also attended all Campbell’s appointments and would take him back to school afterwards.

Campbell started to take medication on school days.

He repeated year 1 and ‘it was amazing’.

In year 2 there were several staff changes.

The new head of school ‘was there to clean up the school and he didn’t want any rubbish’. He sidelined the head of learning who was ‘horrified’ but couldn’t do anything.

‘She was really nervous ... She didn’t want to lose her job. He was very intimidating.’

Campbell started to have major meltdowns.

Magdalena discovered his new teacher wasn’t implementing the reasonable adjustments in his IEP.

The head of school suspended Campbell. He called Magdalena in for a meeting but when she asked if Campbell’s ‘usual people’ could attend, he refused.

'He was awful ... He was actually having a go and speaking down to me as a parent ... I was trying to tell him that [Campbell]'s on medication and we're going through the paediatrician, can you please be a little bit patient and understand ... But he didn't want to know anything.'

The head of school believed Campbell was naughty and needed consequences.

Then a few weeks later, during a meltdown, Campbell threw a chair at his teacher.

Magdalena immediately went to the school and tried to understand what had happened. The head of school said there were no triggers for Campbell's behaviour. When she asked about his IEP and reasonable adjustments he didn't seem to know what she was talking about.

The head of school told her Campbell was 'no longer welcome at the school'.

Magdalena loved the school and wanted Campbell to stay. She asked for 'the opportunity to fix the problem', but the head refused.

Magdalena contacted a disability advocate and 'used what money [she] had left in the bank to pay for a private lawyer to communicate to the school'.

The lawyer asked for a meeting as per school policy.

'That's when they started saying they didn't expel [Campbell] and they wanted a meeting but I didn't want it and it was all my fault.'

Magdalena made a complaint to the Australian Human Rights Commission. She wanted the school to admit they were lying and to apologise for discriminating against Campbell.

She said the commission was very supportive but the school refused to accept any liability or offer an apology.

The commissioner suggested she could pursue the matter in the Federal Court but she couldn't afford further legal representation.

Campbell is now at a local state school. It has been hard to make new friends but he has reasonable adjustments and a teacher who understands his needs.

Grey and Adelynn

Grey and Adelynn, husband and wife, are in their early 50s. Grey has intellectual disability and difficulty reading and writing. Adelynn has physical disability.

About 10 years ago they made reciprocal enduring powers of attorney (EPOA) and wills. They included their children except for one, who Grey didn't wish to include because of a falling out.

Not long after, Grey had a stroke and acquired a brain injury.

Adelynn told the Royal Commission he 'bounced back' and regained most of his physical health, but had several mental health issues.

A few years ago Grey had another stroke and his behaviour changed. He would verbally and physically abuse Adelynn and she wasn't able to live with him anymore.

Adelynn spent a long time taking Grey to doctors to obtain a diagnosis so he could be properly supported.

She spoke to his day program provider about increased support and supported independent living (SIL).

The provider was enthusiastic and found a place near where Adelynn lived, just across the state border.

They arranged for Grey to sign the accommodation agreement without informing Adelynn as his EPOA.

Adelynn 'went off'. She was concerned because the NDIS had not yet approved funding for SIL. She worried she and Grey would be personally responsible for the accommodation if the NDIS said no.

No longer able to trust the provider, Adelynn started looking at other options.

The provider then 'cut [Adelynn] out' and continued to ask Grey to sign documents, including the lease agreement.

'He signed it, but the problem with that is I was the enduring power of attorney ... because he was deemed to not have the capacity.'

The provider contacted Grey's children and argued Grey did have capacity. They told Adelynn the EPOA 'was not worth the piece of paper that it's written on'.

Grey moved into the accommodation even though the NDIS still hadn't approved the SIL funding.

‘The whole thing that I think is, it’s all revolved around money for the company,’ Adelynn said. ‘As soon as the companies say, “Are you NDIS?” the dollar signs just flash up in their eyes.’

Adelynn applied to the state administrative tribunal for guardianship, but because Grey was living in a different state she had to make another application to that state’s tribunal.

The child not included in Grey’s will became involved.

‘They’re influencing him to do things that he would not normally do or say ... As I’ve said, I’ve known him for a very long time.’

The tribunal appointed Grey’s daughter as his guardian.

Marita and Nicki

When the department of child protection removed Nicki's nephew and nieces from their parents, she and her partner, Marita, agreed to be kinship carers.

'The parents have had a long history with substance abuse and family violence and just general neglect, not being able to care for kids,' Nicki, a First Nations woman, told the Royal Commission.

The children all live with disability.

'We were literally given children, told that they have a disability [but] absolutely nothing about the disability, nothing. No documentation,' said Marita.

Marita and Nicki were told one of the children has a chromosome abnormality.

'The other two ... are still not diagnosed yet,' said Nicki. 'So we did the genetic test to see if they had the same genetic abnormality ... but they don't. But there are other, you know, issues. We just don't know what they are. Is it cognitive, is it [autism] or whatever? Trauma?'

Nicki said the department of child protection had been 'involved with the kids ever since they were born'. Yet, despite 'very visible, obvious disability', the children remained undiagnosed and unsupported for several years.

'I place a lot of blame on the department for not pursuing that from an early intervention ... In this case they haven't really been advocating for these children.'

Nicki said the children came to their home with NDIS packages, but with no services in place or information about how to access them.

'We weren't given anything,' said Marita. 'We weren't given phone numbers to NDIS or to care workers ... We literally had no idea about how much funding, how to even navigate it at all.'

Nicki said one child has 'significant social, emotional, perhaps a cognitive delay', but accessing services without a diagnosis is 'an uphill battle'.

'It is really hard trying to plan for an NDIS plan when you don't know what their diagnosed issues are ... And service providers would be like, "If you want to address the trauma, we need to have a long time to do that." ... And then unpacking what is trauma, what is a disability, you know, it is just, yeah, so hard.'

Nicki said because it's unclear what disabilities the children have, their funding doesn't match their support needs.

'And that is why I got in this big row with this NDIS lady ... She is like "You don't need that support any more." Like, you don't understand the situation that we are in and how these kids present. And while they are not all completely diagnosed, there are things that still come up that require [funding].'

Nicki said, for example, she and Marita are exhausted and need respite care for the children.

'[The NDIS officer] is like "Oh, but they go to school." And I am like "Yeah, and I work full-time and I have still got other kids that we need to care for." ... [They're] asking people that are under the pump, under pressure and already exhausted to continue to exhaust themselves when we know there is funding available, but we can't get access to it.'

Marita and Nicki have since handed the care of two children to other family members.

'In the end it just got too much for us. We got burnt out physically, mentally, emotionally. In ways I didn't even know you could get burnt out, I was burnt out.'

Nicki said she and Marita are willing to be kinship carers, but need better support.

'Like foster carers get a lot of support, you know, they get training. We didn't get any training, nothing. Like, it was only stuff that we have sorted out ourselves.'

Simona

Simona is in her late 20s and is bisexual. She lives with chronic post-traumatic stress disorder (PTSD).

She moved to Australia about five years ago. 'I was self-managing my disability pretty successfully without any intervention and medical treatment,' she told the Royal Commission.

A couple of years later, she met someone and 'ended up marrying'. The relationship was 'abusive'.

Simona's wife was her visa sponsor.

'The entire time I was married ... she constantly used the threat of withdrawing her sponsorship ... The abuse was in every corner of my life. I couldn't escape it.'

Simona's PTSD symptoms 'just continued to get worse', but she struggled to access appropriate health care.

'The first time I wanted to seek psychological help my ex-wife refused to allow me to see a doctor. She had full control over our finances.'

That was just one of the many instances of 'coercive control or systems abuse'. Once, her then-wife contacted the immigration department and told them their 'relationship had ended'.

'She told me, "You're going to get communication from the department. They're going to tell you that you have 28 days to leave," and I became suicidal. She really pushed for me to admit myself to hospital. I was obviously – I had a mental breakdown.'

Simona was unhappy with the way the hospital treated her and filed a complaint. In doing so, she discovered doctors had been treating her for borderline personality disorder (BPD) rather than PTSD.

'My ex-wife was able to influence that to a huge extent,' she said. Simona said her ex misled emergency and health workers to avoid being caught 'perpetrating family violence'.

'That really allowed her to shift the blame on me ... It's pretty much going to prevent me from ever being able to receive appropriate care in the public system. Now that I have in my file that I was diagnosed BPD, that I don't have PTSD.'

Simona has seen 'several psychologists and psychiatrists to review that diagnosis'.

'They have all said that I don't have any symptoms of ... BPD, but that I very clearly do have PTSD. But there's nothing you can do, once that diagnosis is there.'

Health workers continue to give her ‘strategies’ for regulating her emotions rather than treat her PTSD.

Simona still can’t access the NDIS, and her ex-wife has withdrawn her visa sponsorship.

‘I am just in limbo on a bridging visa. It’s been like this for years.’

She’s currently ‘working on’ her immigration status, but feels government agencies are ‘applying a much more critical lens’ because of both her sexuality and her disability.

‘There’s no recognition that I have a disability until it’s used against me in the systems that I’ve sought support from.’

Meanwhile, Simona has to source her own psychology services.

‘Which has been incredibly difficult, and I can’t really afford the services that I need.’

Lawson, Asa and Clarisse

Lawson and his younger brother Asa are autistic.

About five years ago Lawson, then almost two, stopped sleeping.

‘He would only eat white things,’ his mum Clarisse told the Royal Commission. ‘He didn’t like his hands dirty and we had no idea about what this was.’

At the time, Clarisse was living in the city and doctors told her Lawson would grow out of it.

Clarisse struggled to care for him and Asa, still a baby.

‘We got to a point where I was losing my mind, like literally, so I had to relocate with my two little ones to [a remote community] to live with my mum.’

The community clinic suggested Lawson was autistic, and an allied health team provided support while he waited to be assessed.

**‘It took us to go to a remote community for someone to say,
“Hang on, your son is different. Why don’t we get some
more support for you and get this testing done?”’**

However, it took two years to get all the testing done.

‘Back then, it was a two-and-a-half-hour drive ... and that included 90 kilometres of dirt road. I had to drive in for the assessment, drive back out and then drive back a few weeks later.’

At first the doctor diagnosed Lawson with global development delay. ‘Luckily’, Lawson had a meltdown in his office one time – the doctor realised Lawson was autistic and changed his diagnosis.

The doctor assisted with the NDIS application process, submitting all the required documentation.

While they waited the allied health team provided support. They ‘were amazing’ and ‘got [Lawson] speaking’.

When Lawson’s NDIS funding was approved, the allied health team’s support ceased because they were funded by the state government.

‘We had all this funding with the NDIS, but the only thing that we actually received ... was with [therapy], which was four sessions a year. There’s no respite services, there’s no further testing, there’s no classes that I could take.’

Asa, now two, started 'displaying behaviours' similar to Lawson. Clarisse spoke to the visiting paediatrician who referred Asa for testing.

'Because my oldest had already been diagnosed, the path to get my second son diagnosed was way too easy ... It was then trying to get him on to the NDIS that was the problem, because the system had changed.'

It was the parent's responsibility to make the application and submit the documentation.

'Trying to get all of these documents together from all these different organisations and these doctors, it was a mission. I was having a meltdown myself.'

Clarisse felt she had to move to a regional city to get the help she needed.

Initially things improved. She submitted Asa's NDIS application and found an organisation to provide occupational therapy, speech therapy and a social worker for Lawson.

But there was a high turnover of therapists, support coordinators and support workers. Support was unreliable and inconsistent. Communication was poor.

'There's always a middleman. We don't actually speak directly to the people who are organising the stuff for our kids.'

When Clarisse did manage to speak to staff they were rude. Clarisse refused to deal with one woman who spoke to her 'like [she's] a "dumb black fella"'.

By the time Lawson started school, supports were still not in place.

'It got to the point where the school got involved and the school called a meeting for everyone to pull their heads in and actually start supporting the boys.'

Clarisse said the school has been very good to both boys, and for the first time there is support.

'There needs to be a lot more support with diagnosis and more education on identifying these things.'

Bailey

Bailey is in her early 30s and receives a Disability Support Pension. She trained as a nurse, but has been unable to work for several years due to complex disability and health conditions.

Bailey explained that her medical history is long and complicated. In addition, as a child she moved interstate several times to live with different relatives after her mother died.

‘I’ve been chronically unwell since I was born and I’ve lived in four states of Australia and over 40 different homes. My medical history is everywhere.’

In recent months she has been trying to gather her medical history together as she seeks further government support and prepares for legal proceedings.

Some medical services refused to release records unless she visited in person to sign a release form. Some required payment of between \$50-\$100 to consolidate her records and send them to her. She has made freedom of information requests and had help from a disability advocate to collect additional documents for an NDIS application.

Bailey was recently diagnosed with a major depressive disorder. One of the surprises in her medical records was that she had already received that diagnosis when she was 12. ‘I wasn’t aware and that just – that blew my mind,’ she said.

‘I believe I haven’t been properly diagnosed over time due to the lack of continuity of care and my medical records being everywhere. It’s hard for any practitioner to get the clear picture or understanding of the complexities of my circumstances or my health needs.’

This has also made it difficult to gather the evidence required to convince funding agencies. Her NDIS application was successful in relation to her psychosocial disability, but she needed more documentation to prove her physical disabilities. She has been waiting for months to see the healthcare provider, and then will have to trust them ‘to write a report that accurately reflects [her] complex history and needs without misrepresenting [her] or making errors of either omission or inference’.

The process has been ‘really frustrating’.

‘Some of those documents took months to procure and because of errors, they’re redundant,’ she said.

Bailey is also following up on a complaint of police negligence related to sexual abuse she experienced as a child. She has put the complaint – to a state-based human rights agency – aside for now because she can’t access the support she needs to pursue it.

'I guess I can only access advocacy for one issue at one time. [I've] been engaged with an advocate for the last two years for the NDIS process and they're actually – there aren't multiple services in my locale to be able to access more than one,' she said.

'Yeah, it can be really hard with complex needs ... to have to prioritise one single area of an issue and follow that through while ignoring another.'

Meanwhile, she is in demand as an advocate for others.

'Living in so many places, meeting so many people, having been a nurse and navigating many systems, I do often have friends or family that come to me for advice or support of bureaucratic processes. I provide that support while I'm at a loss for it myself. And I guess because I'm articulate, empathetic and I do understand, I can be that strong face for somebody else. Not so much for myself.'

Jonti and Gayle

‘When he was diagnosed we sort of expected a bit of bullying or discrimination to come his way, but not at three and not by a teacher.’

Gayle is the mother of Jonti, who was diagnosed with autism during a COVID-19 lockdown.

‘So that was good and bad,’ Gayle told the Royal Commission. ‘It was good that he did quite intensive therapy over that time with speech and OT [occupational therapy] ... But then the downside of that is that he has had very limited social contact with his peers, and then we came out of it and started [preschool].’

Gayle met Jonti’s preschool teacher the day before he started.

‘[The teacher] straightaway suggested holding back. Don’t come to [preschool], send him to childcare where he can get an assistant and an aide. They’ve never had an autistic child currently diagnosed. All of that sort of stuff.’

Gayle offered to fund a support worker, and Jonti started preschool ‘so enthusiastic’.

But the teacher quickly began excluding Jonti from the classroom, sometimes sending him and his support worker outside to play by themselves.

‘Not included in show-and-tell and that sort of stuff ... He wasn’t sort of included in the class.’

Gayle said the teacher phoned after-hours ‘quite worried about ... what to say to the other children about [Jonti’s] “broken brain” ... And it was like, um, okay.’

Another time, Gayle asked the teacher why Jonti wasn’t allowed to stay for show-and-tell that day.

‘His language was really derogatory. He was, “What? You want him to stay? He attacks the children and he curls his little hand up and claws and kicks them.” And, you know, it was just a big sort of rant and [I was] speechless, which is not like me. And also, I’m not much of a crier, but I usually just go from fine to pissed off. And I remember getting off the phone and I was shaking.’

Gayle made several attempts to speak to the preschool’s management committee about the teacher’s behaviour, but they ignored her until she engaged a lawyer.

Gayle said the school told her Jonti presented a ‘safety issue’, but didn’t show her any incident reports. The school engaged an education department officer to assess Jonti’s behaviour.

‘I’m like, “So is he a safety risk? Is there any violence?” And [the officer’s] like, “No, not unless [they] call snatching a toy violent,” and I’m like, “Apparently, yeah.”’

Gayle withdrew Jonti and tried to enrol him in another preschool, but ‘didn’t get a spot’.

‘We were “that family”. So they heard of us before ... There was one I tried to get into outside of our area and [Jonti] didn’t get it, but [a friend’s son] did about a week later. He doesn’t have a disability.’

Gayle said she ‘rang everywhere’ and eventually enrolled him at a preschool in another suburb. The teachers there were much better at dealing with Jonti’s behaviour.

‘The teachers were beautiful and kind and accepting and not judgmental ... So they just didn’t see him distressed or his anxiety or the challenging behaviours. They could also see the empathy, all the kindness ... and they were very respectful all the time.’

Allegra

Allegra is in her early 40s and was 'diagnosed pretty late' with attention deficit hyperactivity disorder (ADHD).

'I was just so glad to have a reason. Just so many things were affecting my life,' she told the Royal Commission. 'I've had problems at work, problems sort of understanding and getting on with people – relationships ... My emotional regulation was a challenge for a lot of my life.'

Because she had a university degree, people put it down to 'bad behaviour'.

'I've come up against that a lot and I still do and, you know, some of my behaviour was definitely poor. I got diagnosed and started taking medication and it was like day and night.'

But one day, as she grappled with 'this big diagnosis', Allegra was 'exhausted' and left her medication on the train.

'Basically, it's amphetamines. I had to go off these cold turkey and it was really unpleasant and I ended up in emergency at the [local] hospital.'

Allegra fell asleep at the hospital and 'woke up about eight hours later'. Her partner had been calling her all night and thought 'something terrible had happened'. Nurses made no attempt to contact her family, she said. No-one knew where she was.

'I just grabbed my stuff and, like, ran for the nearest exit, and the door was locked. So, like, I was pretty panicked and the staff sort of ... backed me into a corner. And I just flipped out and I started shouting and, like, throwing my stuff.'

Allegra felt she was being held against her will.

'So, yeah, I was hysterical, crying, and they rallied security ... Police turned up and, you know, like I don't think it warranted that. I wasn't threatening people.'

Allegra 'apologised to the staff' and they discharged her.

During a follow-up with her mental health care team, she learnt medical staff had given her 'about five different types of drugs'.

'At one point, one of their doctors said, don't continue to give this particular drug because my reaction ... I was really talking in gibberish and, like, really disorientated.'

Twenty minutes before her 'anxiety' attack, doctors administered more drugs including Valium and antipsychotics.

'A whole lot of stuff that I never take ... just to sedate me, basically.'

A few months later, police contacted Allegra and said the hospital was alleging she assaulted staff and broke equipment.

‘They charged me with assault and property damage. I was teaching at the time ... If I get an assault charge ... that’s my job. It rocked my entire world.’

In a report, Allegra’s psychiatrist said she had ‘acute delirium from the cocktail of drugs’. The matter was ‘thrown out of court’.

Allegra believes hospital staff ‘labelled’ her ‘a particular way’ after she disclosed she was using a drug used to treat ADHD. That’s why staff ‘treated her so poorly’.

Allegra is now determined to avoid hospitals at all costs.

‘Like, if I had a psychiatric concern, I would never go to a hospital. I would tough it out at home.’

Cheryl

Cheryl was diagnosed with Asperger's syndrome in her early 30s.

Now in her early 50s, she works in a state government department. She had been excited to start in the role, but as she nears the end of her contract she feels let down and disappointed.

Cheryl has had a range of jobs and likes to work. She actively seeks employment and training opportunities. She particularly enjoyed an internship in a government department, which had been set up by a group that helps organisations employ people with disability.

'The staff there were just completely beautiful people, showed me what I had to do ... "Please come back and show us when you are finished." And I got all that amount of work done for them because they had been so supportive. That was the best work experience that I had ever had.'

In contrast, in her present role she has experienced discrimination from managers and others that has undermined her confidence and made her feel like a failure.

Cheryl began in the new role just as the COVID-19 pandemic began. Only a few days after starting her job, a lockdown began and there was a shift to working from home. This was difficult for Cheryl, but her manager offered no support.

'There was no set communications, I felt, about my working hours, what I would do and what I would do on a regular basis.'

Her team performed various jobs, but the manager gave Cheryl a single repetitive and uninteresting administrative task. Her manager wasn't happy with the way Cheryl did the task, but hadn't properly explained how she wanted it done. Some months later, she finally did.

'I said, "Why didn't you tell me that in the first place?" "Well, you should have known that, you should have understood that." But it was like, no, you are supposed to give me clear instructions. You are supposed to supervise me.'

When others in the team eventually returned to the office, a senior manager advised Cheryl to keep working from home.

'I was told ... "Oh, look, you will be too distracted." These are his words. "You will be too distracted by the noise and by the lights because it is too bright for you." And I normally wear a cap and combat the lights, I normally wear a cap." You wouldn't go and do your work, you would be too social and you would be saying hi to everyone when they need to do their work. You wouldn't be able to concentrate on your work.'

Cheryl also had discouraging interactions with the person appointed as her mentor.

'She rang me one day ... [and] said, "This role doesn't suit you, does it?" She was trying to talk me out of it ... "You are better off doing a carer's role where you take someone for a walk or take them shopping or take them to the hospital, navigate the hospitals."'

At another session with the mentor, she reported to Cheryl all the achievements of other people with disability in the group, without mentioning Cheryl's.

'I sat there and I was crying,' Cheryl said.

Cheryl wants to 'work and grow and learn' but said this experience has had significant impacts.

'I feel like I've lost all my skills, my self-esteem, my confidence. I feel like I'm nothing.'

Pandora and Tory

‘In my client’s room – she is a heavy wetter – as soon as you walk in you get the stench of urine. To tell you the honest truth, I wouldn’t even put my dog in there.’

Tory is a disability support worker and nurse in Queensland. A couple of years ago, she started working at a group home for people with intellectual disability.

During her employment, Tory observed many ‘failures’ in ‘the duty of care to protect the residents at the home’. She was particularly concerned about Pandora, a First Nations woman in her late 40s – they’d ‘become friends’.

The only male resident was ‘constantly bullying and harassing’ Pandora and ‘putting fear into her’. She’d been incontinent ever since, Tory said.

‘One day I witnessed ... that her [continence] aid was not changed for the full day and she had dry faecal matter stuck to her bottom and broken skin around her rectum area.’

Tory believes Pandora let staff know she needed changing, but they ignored her.

‘Even though [she] speaks one-word sentences, she will tell you ... “Dirty, dirty”. She’s repetitive.’

Pandora had not seen a dentist for two years until Tory took her.

‘She kept saying “sore, sore, sore” ... The dentist at the hospital found out that she had a big abscess in her front tooth.’

Many clients ‘missed medical appointments’ due to lack of staff. Tory said Pandora had none of her ‘internal checks’.

‘There was a lot of neglect.’

Staff gave clients expired medications and didn’t keep ‘medication records’. Once, a worker ‘left another client’s medication out on the counter unattended’, and Pandora ‘came along and swallowed them’. She was under observation in hospital for 24 hours.

Tory said the ‘abuse and neglect’ at the home was widespread. One day, a resident ‘collapsed due to severe dehydration’, because there was ‘not enough water or fluids given in the home’. Staff weren’t brushing residents’ teeth – one woman had ‘no teeth left’ as a result.

The home was filthy, Tory said.

'I seen cockroaches coming out of the toaster, dirty dishes coming out of the dishwasher ... The cleanliness of the rooms were absolutely putrid.'

About a year ago, Pandora fell in the shower as 'there were no grab rails or anti-slip mats'. Staff 'didn't do anything'.

'The next morning, when I came back on shift ... [Pandora] come to me, "Sore, sore". I personally had to go call the ambulance.'

Pandora's hand was fractured.

Pandora made complaints of 'inappropriate touching' by the male resident. 'I have found bite marks on her body, bruises on her body,' Tory said.

But Tory said written reports she'd made of all these incidents 'mysteriously disappeared'. They'd 'either been ripped up or shredded'. She ended up reporting them to the provider and 'escalated the matters to the NDIS Quality and Safeguards Commission'.

The provider fired Tory.

**'I was informed that I have breached privacy and confidentiality.
To my understanding, duty of care overrides [that].'**

The provider 'banned' Tory from visiting the house and she became increasingly concerned for Pandora's safety.

'She wanted me to come in and read her stories ... She didn't understand ... and she just started crying.'

Tory fought to get Pandora out of the home.

'I found a unit for her and she has myself and five other carers that look after her 24/7.'

As Pandora's 'long-time family friend', she now has enduring power of attorney.

Dick

Dick is in his mid-50s. He has cognitive and physical disabilities and receives the Disability Support Pension. He lives in a unit owned and managed by a government housing agency. There have been many problems with the property over the years, and in trying to resolve them Dick has found agency staff unsympathetic and unhelpful.

Problems have included the floor giving way, and repeated issues with damp, leaks and flooding from the bathroom in the unit above.

‘I’ve had mould since the day I moved in ... I lost 21 pairs of shoes and half my possessions to mould within the first six months, through flooding and that from outside.’

Eventually Dick’s ceiling collapsed because of leaking from the upstairs unit.

‘Housing wanted me to move out, leaving all my possessions in here, and put all my animals in a boarding kennel for three months. My dogs and me have never been separated,’ Dick said.

Dick asked for repairs and for modifications that would allow him to be safer, but these were refused without explanation.

‘Housing says I can’t have timber floors, I’ve got to have carpet or vinyl. I’m not allowed to have security grills on the door or windows ... But I’ve got neighbours that have got grills on their windows, and they’ve got timber floors ... And my next-door neighbour, she’s turned around and – she’s just had a whole unit renovated. New bathroom, kitchen and all that for years now, and all of that. And they polished her timber floors. But for some reason, I’m not allowed to have a timber floor.’

At one time Dick was using a mobility scooter to get around and asked for an internal ramp to be built.

‘And Housing refused to put in a ramp, or even a temporary ramp, basically just don’t do it. And yet the unit next door to me has a ramp in it,’ Dick said.

He is also frequently bothered by antisocial neighbours who have lived in the building for years. He complained to the housing agency, who told him to write a letter or send an email explaining his concerns.

‘Well, I don’t know how to use an email. I don’t even have an internet plan, and I have trouble writing letters. So you’ve got to be patient.’

Dick hand-delivered his letter of complaint to Housing.

‘When I went in there, [Penny], she said, “Oh, I can’t submit that. That’s disgusting, that writing,” and she retyped the letter for me. That’s why I don’t like writing, coz people make fun of my writing. It is like, as I’ve been told, I write like a 12-year-old.’

Dick receives NDIS funding which pays for a cleaner, but there have been multiple staff changes and the support workers are often unreliable, either turning up at unscheduled times or not turning up at all.

‘I said to [the NDIS care coordinator], “Sorry, [Annie], I don’t want ‘em back.”’

He hasn’t had a cleaner since.

‘Now, I struggle doing cleaning – that’s why I don’t want carpet, it’s so hard to vacuum. I have a bad back, bad neck, back shoulders, permanent headache. I used to walk a lot. I can hardly walk now, with all the slips and falls I’ve had in this unit.’

Creed

Creed is a First Nations man in his 40s who has antisocial personality disorder, a cognitive impairment, post-traumatic stress disorder (PTSD) and depression.

'[I was] abused sexually by [a family member]. Then eventually I got kicked out of home,' Creed told the Royal Commission. 'In the past, because I never did trauma treatment, my anger was, oh, pretty bad. Yeah, it always led to jail.'

When Creed was in jail, the doctors 'didn't really sit down and talk' to find out the cause of his depression.

**'They go, "Yeah all right, you've got depression. Here, take this [tablet]."
And that's it ... I've seen quite a few guys kill themselves over small things.'**

Creed said one man he knew diagnosed with depression 'ended up hanging himself'. Another First Nations man went to the office to ask for help 'because he wasn't coping'.

'The workers turned around and said, "Go back to your unit, we'll talk to you the following day about it." Then they ... found him dead.'

Creed said he received appropriate trauma counselling only after finishing his sentence.

'When it comes to PTSD and that sort of thing it's taken me, what, like 20-odd years, right, to actually finally get counselling. And basically a treatment for PTSD and for depression.'

Creed's advocate told the Royal Commission there's never been a plan to help Creed transition from jail into the community.

'There just isn't the resolve to work with people with disabilities [leaving jail] in a way that helps them to move on. And now that we have NDIS we have the ability of support services to come up and provide a less restrictive response, and it's just not happening.'

Jin

Jin is in her late 60s and has an acquired brain injury from an accident in the early 2000s. She was not at fault in the accident and didn't immediately file a claim for an insurance payout.

'I just tried to get myself well. I got myself a special chair and a mattress and all the rest of it ... At the time I wasn't aware of all of the injuries that I had.'

Eventually Jin did seek compensation, in what became a 10-year argument with the insurance company. The matter was finally settled in court for an amount Jin was not happy with and felt she did not agree to.

'My lawyers settled against my instructions,' she said. 'They hadn't done the work and I didn't know they hadn't done the work and – yeah ... I spent, you know, over a hundred grand, just myself out of my own savings, and ended up with virtually nothing.'

She now has 'a lot of distrust in the legal profession' and said her experience with the justice system has been 'really bad'.

After a fire in her home in the early 2010s, Jin moved to private rental accommodation which she was able to afford because of the subsidy she received from a state government housing agency. In the mid-2010s, the owners ended her lease and she had to move out.

At this time rental accommodation in her city was increasingly hard to find and rents were going up. 'I was in a very bad situation,' Jin said.

The housing subsidy scheme required her to find her own accommodation.

'So they were saying, "You find a place in the private market and we will subsidise it according to the way that we would subsidise you if you were a housing client."'

But when she found somewhere and moved into it, it turned out the agency had changed the way it calculated the subsidy. Jin had to pay much more of her Disability Support Pension on rent than she'd anticipated, leaving her with nearly nothing to live on.

Jin felt powerless and bullied in her negotiations with the housing agency.

'They were just saying, "Well, if you don't like it we'll make you homeless," basically. "We'll make you responsible for the whole of the rent. You won't get any subsidy at all if you don't like our figure." It was horrible. You know, I – I'd wake up every morning with a pile of bricks on my chest ... But there was nothing that I could do.'

Jin could not understand how the agency calculated the subsidy, and it could not or would not explain it to her.

Jin enlisted the support of her local MP and pursued other processes, including a freedom of information application.

At the end of it all she still has no answers, and has further depleted her savings. There is no way for her to appeal the agency's decision.

'It's a pretty serious thing that they're getting away with,' Jin told the Royal Commission.

'Yes. I think that they've, sort of, in a way – they've sort of robbed me of my savings and of my time. I could have been using all this time that I've had to invest in trying to keep a roof over my head ... I can't afford to do anything really, because I know [my savings] will run out soon and I don't know what I'm going to do then.'

Nicky and Kath

‘Abuse, it doesn’t start with a large bruise, it doesn’t start with an assault on someone, it begins way before that and after with an attitude. It is about how people think, and it is an attitude that is rampant in this industry.’

Kath told the Royal Commission her daughter Nicky was a ‘busy and able child ... with a really bold personality’. Nicky loved dancing, riding bikes and horses. She has intellectual disability and is non-verbal.

When Nicky was about 20, in the early 2000s, Kath became seriously ill and Nicky had to go into supported accommodation.

‘She went into two places and she was abused in both places.’

In the first place, a friend was visiting and noticed Nicky had bruises up her arms and around her neck.

Kath made a complaint but the home accused her of ‘making a mountain out of a molehill’.

‘Many people saw the bruises, so it wasn’t that they didn’t believe she had them. It was just ... these things happen and what are you making a fuss about ... That was really my first introduction into how accepted bruising and trauma to a person was.’

Kath insisted the home investigate.

‘Their report said that nothing happened.’

The child protection unit then investigated and concluded ‘harm had happened’ to Nicky.

Kath brought Nicky home and tried to find some support. But after a while Kath became ill again and she had to send Nicky to another home.

‘This was a place where she was just never the same child ever again.’

The provider placed Nicky in a house with three older women who had been ‘institutionalised’ for most of their lives.

Kath said ‘as awful as some of the bruising were’, they were a ‘minor part’ of what happened.

‘One woman dragged her off the toilet on a daily basis so she couldn’t even just sit on the toilet and have that privacy.’

Nicky shut down and would sob uncontrollably, ‘almost resigned to her situation’.

Kath raised her concerns and tried to find out what was going on. The home 'bulldozed' her, painting her 'as a liar not to be trusted'.

When Nicky eventually came home some years later, she was 'scared of everything'.

'She had to be forced to come out of her room. She needed to have food in front of her all of the time, which she would hide so no-one could take it.'

Nicky told Kath to call her Nicola because '[Nicky] died'.

Kath tried to find out what had happened to Nicky and get her some help.

The home told her she was 'being silly' and refused to give her access to Nicky's records. She had to contact the relevant government department to get the home to release them.

Kath was shocked at the 'rewriting [of] history'. Nicky and Kath were 'the problems, not the victims'.

'As hard as all of that was and as horrific as it all was for [Nicky], we could have moved forward more than we have with our lives had we been given the support that we so desperately needed and some guidance,' Kath said.

Kath has found it very difficult to find suitable accommodation for Nicky.

'It should not be so hard to find a home for someone as adorable as [Nicky]. When I can no longer do this and when my time comes, I want to be prepared and to be able to go with knowing, not just thinking, I really knowing that my daughter will be cared for.'

Alexandre

Alexandre, who is in his mid-30s, was hit by car when he was a child.

‘I was 10 turning 11 when it happened,’ he told the Royal Commission, ‘and it left me with a lot of permanent, long-term disabilities. But it’s primarily the traumatic brain injury and spine injury and countless other issues.’

As a teenager, Alexandre ‘had to build a very thick skin’.

‘So by the time I became an adult I was pretty used to the abuse ... the bullying ... the name-calling and such, like anyone else who grew up in that time.’

Alexandre said he ‘didn’t get any help’ when he went to university. There weren’t any ‘fixes’ back then.

‘But now there is. There’s new technology, new medications.’

Yet he feels the ‘mentality is exactly the same’.

‘[People] don’t see past your disability,’ he said. ‘When you’re in a wheelchair, by definition, people are looking down on you. Physically and metaphorically.’

Alexandre has experience working as a disability consultant and mentor, and has been ‘on several statewide committees’. He really wants to ‘help people in drug and alcohol rehab’, because he’s ‘lived it’.

‘I had to go through some very difficult times, you know, suicidal ideation. Basically, I went through drug and alcohol problems ... I can help people with trauma ... My entire life’s journey has got to this moment where I am ready, willing and capable to help.’

But Alexandre says ‘the entire system from top to bottom’ is ‘hamstringing’ him.

He recently applied for a few openings in suicide prevention and mental health. They were ‘consumer advisory positions’ calling for someone with ‘lived experience’ of disability, yet he was knocked back each time.

Alexandre says these jobs never go to a person with disability. It’s ‘a friend of a friend who has a sister who is disabled’ who gets them.

He said it’s not fair that his lived experience is being overlooked.

‘You know, I don’t get any credit because I don’t have any academic qualification ... Because I’ve got the brain injury it’s very difficult for me to study.’

‘[People] don’t expect you to succeed,’ he said. This leaves him with an ‘an overwhelming sense of hopelessness’.

‘You keep hearing, “You do have value. You can give back to society.” But the minute you try, it’s barrier after barrier after barrier ... Without my career, my life means nothing.’

The thing that keeps Alexandre going is his desire to help others who are also ‘alienated and isolated’.

‘All I want out of my life is to take the experience, take the pain, take the abuse, take the bullying, take what I learnt and help people. That’s why I’m so passionate about speaking in public and advocating for people with disabilities.’

Brooks

Brooks is a First Nations teenager who lives with mental health issues.

His stepfather sexually abused him when he was a baby and he has had bowel surgery to repair the damage.

Brooks went to live with his father. But when he was about seven, his dad went to prison and the government placed Brooks into a foster home. Initially he had 'a really good time'.

'They bought me stuff, they took me to the movies ... They were so kind to me ... it was like a perfect family.'

But Brooks started to 'give backchat' and get 'cheeky', and things 'just went downhill from there'. His foster mum got her sons to 'bash' him, he told the Royal Commission.

'They started flogging me ... then they just used to do it for fun. It became amusement for basically the boys and their friends ... They used to duct-tape me to, like, the treadmill and put it up to the highest speed.'

They also put an electric dog collar on Brooks's neck.

'And they try and chase me around with that shit on my head.'

They also threw firecrackers at Brooks's feet. Once he took the explosives to school and 'blew up the boys toilets block'. The school expelled him.

A couple of years ago the brothers took Brooks out with a friend, supposedly to go to McDonald's. Instead they took him to a farm and used him as 'target practice'. All of them were armed with shotguns and rifles.

'And then they will tell me to run out on the field ... They used to have things like little orange discs and I had to throw that and they'd shoot it. And they would shoot at my feet too. They always missed purposely, but yeah, it made me cry.'

Brooks said his foster brothers and foster father sexually abused him.

'I don't know why people rape these days. It's frigging disgusting ...'

He felt they were punishing him for his behaviours.

Meanwhile, his foster mum 'dosed' him up 'morning, afternoon and night' on a cocktail of drugs used for depression, schizophrenia and autism. A couple of times she gave him an 'overdose' of an antipsychotic drug, causing him to lose consciousness.

'When I woke up ... she just injected me some more.'

The physical and emotional abuse went on 'for a period over six years'. Brooks said his child support officer was aware, but she accused him of lying.

Child protection services are 'stuffed', Brooks said.

'They don't give people a voice ... I'm sick of the system. I actually hate it. It doesn't work and it's never worked. They took me off my dad and now he's, you know, at home struggling.'

Brooks feels children like him shouldn't 'be taken away from their families in the first place'.

'Like if they're not junkies and if the people are trying to start their life round and actually look after their children, then why remove them?'

At least, he says, child protection services should foster children out to 'people who give a damn'.

'I've been trying to get back to my dad ... [They] just won't allow that. There's no reason for them not to ... My dad has done so much just to try and help me.'

Brooks is currently in a youth detention centre. He's trying hard not to think about his foster family.

'The thing I'm angry about, is they have a nice happy life now. But what do I have? I'm in here, crying every single night because ... I just don't know how my family are.'

Brooks wants to 'get out of frigging jail' and live with his dad.

'That's all I want. The support with my family.'

Erica

About 40 years ago, when Erica was in primary school, a car struck her as she was running across the road.

'I was knocked unconscious for three and a half weeks and I wasn't meant to survive,' Erica told the Royal Commission. 'I had to learn to do everything again, like walk and talk and eat and all that normal stuff.'

Erica had an acquired brain injury (ABI) as a result, and struggled with fatigue, impaired speech and short-term memory loss. Nonetheless, she was so 'focused on work and pleasing [her] parents' she finished school and became a trainee nurse in a hospital.

'After a year of being there, like, I was good with the patients, but they said I lacked confidence.'

The hospital tried to sack Erica, but she successfully appealed. She felt the hospital then tried to make her leave by refusing to make reasonable adjustments for her ABI.

'They wanted to fuck me up and they did ... They put me onto the worst ward imaginable – burns. I was meant to be going to oncology, you know, where I would've been really good because I'm good with talking to patients.'

Erica struggled with the multitasking needed in a burns ward, and the hospital 'sacked [her] anyway'.

She continued her training at university where she 'did really well' and won an award. When she became a registered nurse, her first job was at a faith-based hospital.

Erica said she never considered herself 'good enough', but one of the pastoral members of staff was kind to her and sometimes 'put his arm around [her]'.

'I thought nothing of it at the time.'

One day, when Erica was dealing with a family crisis, the staff member invited her to his office and kissed her.

'And his whiskey breath and then he's hugging me and I'm sort of in shock.'

She left his office and later told him that if he did 'something like that again' she'd report him.

Later, a hospital administrator took her aside and 'physically pushed' her out the door.

'[They] said, "You're not coping with being at work. We don't want you to ever come back, not ever. Not even to visit. You're never to enter this place again."

Erica said she feels 'a bit' like it's her fault because she has an ABI and she isn't 'as quick' at reading other people's intentions.

'I never thought about it as abuse. I just thought it was a guy sort of trying to be nice.'

Erica told the Royal Commission her constant effort to try to 'appear normal' with an ABI 'leads to further exhaustion and depression'.

'Add abuse to that and, well, for someone with an ABI they will assume that it is all their fault. I certainly did.'

Eliel and Vicki

‘Animals are treated far better than my child has been treated.’

Eliel, almost a teenager, is from a culturally and linguistically diverse background. He is autistic and non-verbal, and has intellectual disability and sensory processing difficulties.

Vicki, his mum, enrolled him in a special school because it had a secure environment and a good swim program.

‘My son would have got completely lost in a mainstream school ... Back when he was five, absconding was our biggest issue,’ Vicki told the Royal Commission.

From day one, Eliel had extensive supports in place including clinician support, occupational therapy, behavioural management plans and a communication device.

‘He presented at that school with all the resources they needed to support him in his educational setting.’

Not long after Eliel started, he ‘took off’ out of the school grounds.

The school addressed the single incident but didn’t put a long-term risk management plan in place. Over the years, Eliel continued to abscond. One time he ran out onto a busy road. The school told Eliel’s education support worker not to tell Vicki about the incidents.

Then in year 3, Eliel started to come home with unexplained bruising.

‘There was an incident when he got off the bus with a swollen eye ... He would have bruising on the back of his shins ... He would have bruising on his arms in the shape of finger marks.’

Eliel’s behaviour started to change and ‘he became very aggressive’.

When Vicki gave him his uniform or handed him his school bag he would put them back in the cupboard.

Vicki asked the occupational therapist to assess Eliel at school, and she spent the morning with him. ‘You need to get him out of there,’ the therapist told Vicki. ‘He needs to be in an environment that recognises his capabilities.’

‘The final straw’ for Vicki was seeing the new swim instructor physically manhandle Eliel. He pushed him against the wall and was talking to him as if he was verbal.

‘It was nothing short of just heartbreaking.’

Vicki made official complaints but said the school and the education department dismissed them.

'It was so condescending. I felt vilified, I felt ridiculed. I've never felt this way in my entire life, the way this principal made me feel.'

She felt her only option was to withdraw Eliel from the school.

The new school, which has a mix of verbal and non-verbal students, is a two-hour drive away. But Eliel is doing better there. He's 'like a new child'.

'There's two big things I've noticed in his new school. You will never see a staff member on a mobile phone, and you will never, ever see a staff member touch a child. There's no hand-holding, there's no pushing.'

Vicki would like an independent complaints body comprised of people with disability and parents of people with disability to oversee schools and government departments.

Alf

‘I do want to live on my own but it’s just gonna take a long, long time.’

Alf, early 40s, is autistic and can’t read or write.

For many years he lived with two other men in a house owned by a woman who was their carer.

In the late 2010s she became sick. Workers from a disability service provider moved the men to a caravan park and then a private rental.

Alf told the Royal Commission he wasn’t given any choice about the accommodation or the disability service provider.

‘I would’ve rather lived on me own,’ he said.

The owner of the house would often turn up unannounced.

Support staff did not respect the residents.

‘It was pretty wrong what they did to me, [and the] two other people.’

There was a lot of arguing and fighting between staff and the other residents.

‘I actually stayed out, stayed in my room because there was conflicts at the place.’

One ‘boiling hot day’, Alf was sitting in the air-conditioned loungeroom when a support worker started arguing with a resident.

They both started ‘blaming [Alf] for stuff that [he] didn’t even do’ and made him go to his non-air-conditioned bedroom and stay there all day.

The same support worker wouldn’t allow him to have friends over.

‘My friends [would] come over to the house ... and [the support worker] said, “Get your effing friends out of the house because you’re putting everyone at risk of COVID.”’

Staff wouldn’t let Alf’s girlfriend visit and he had to travel to her house to spend time with her.

Staff never took the residents out, not even to the shops.

‘They would do all the shopping and we didn’t have a choice.’

Alf spent most of the time in his room watching DVDs. He told staff he wanted to leave the house but they ignored him.

It became so awful he had 'bad thoughts like committing suicide'.

One day, Alf told staff he had numbness down his left arm and asked them to call an ambulance.

Staff ignored him and did nothing, telling him 'They won't take you.' It turned out Alf was having a heart attack. Eventually, they took him to a GP.

In hospital recovering, Alf made a complaint about the provider.

'I didn't want to be there. It was pretty appalling what they were doing.'

A support coordinator helped him change providers and move to a new home.

Alf loves his new home and can have friends over.

Staff are happy for him to have his girlfriend stay over but are waiting on her parents' permission – she's in her late 30s.

Alf would like to live with his girlfriend.

'My girlfriend said as soon as I can get a place she'll move in with me.'

Jacki

‘I actually had to change my name legally from my birth name because of all the trauma ... [I said on the form], “I am a shadow of my former self. I have no identity. I need an identity.”’

Jacki is in her 50s and has spina bifida, post-traumatic stress disorder and a hearing impairment. She uses a wheelchair.

‘Everything started when my mother passed away ... before my 12th birthday,’ Jacki told the Royal Commission.

Jacki’s father placed her in a hostel run by a disability service provider. Not long after, her foot was scalded in the shower.

‘I ended up with a blister. They popped it. They put all these chemicals in it. It was a water burn. It scarred. I have two scars from it. One on my ... foot and ... from where they took the skin, because they had to skin graft that one.’

Jacki was transferred to another hostel where a resident sexually abused and raped her. She told the principal at her special school.

‘I told him of the abuse ... but he said, “I’ve seen you with your top up, so don’t come to me, you slut.”’

One day after school another man raped her. Three months later, during a hospital visit to treat an infection, doctors told her she was pregnant.

‘They told the facility that I was pregnant. The facility then threw me out. I had no family to go to ... but the child that I miscarried got thrown down the toilet and I’ve never recovered after that. It’s all haunted me my whole life.’

Jacki eventually married, but divorced her husband a decade ago.

‘I had to leave my first husband and our house ... So I’ve lived a complete and utter shit of a life. Excuse me for saying that word, but I feel like I’ve lived a shit life.’

Jacki moved into a group home. One day a loose screw on a wheelchair cut her, causing an infection so severe she was in a coma for several days. When she recovered, the hospital transferred Jacki to a nursing home ‘because they couldn’t cope’ with her.

‘I was in my bedroom at [the nursing home] for five years, 24 hours a day in a palliative dementia ward. Because there’s no place for disabled people other than that.’

Several years ago, ‘to get out of the nursing home’, Jacki moved into supported disability accommodation (SDA), where she’s living now.

‘The stovetop is broken here so I can’t use it. I’m 24 hours in my bed because I have a pressure sore still and ... I’m up for one hour. I can make my breakfast, go around the block, get back into bed.’

Jacki said the SDA is short-staffed so she has to lift herself in and out of bed.

‘Please forgive me for being blunt, but ... I’ve had to clean up my own shit.’

Jacki told the Royal Commission she also has an abscess in one tooth and has been waiting months to see a dentist. She fell recently and needs more NDIS supports, but she said her support coordinator hasn’t yet organised them.

She’s also waiting for her service provider to move her into purpose-built accommodation.

‘I’m sick of waiting for year after year.’

Marisha and Iliana

‘I think that there are a lot of challenges that aren’t seen in the world of mental health issues ... My daughter was just lost in the cracks.’

Marisha, now in her 30s, was a ‘very stressed child and very agitated’, her mother Iliana told the Royal Commission. For a while, the ‘underlying problems weren’t found’.

A renowned authority on Asperger’s diagnosed Marisha when she was in her late teens.

‘She has the majority of traits ... she was in the self-harm ward and bulimic.’

Marisha was ‘a clever kid’ with high grades.

‘She was accepted to university, but there was no support to get her from high school to university. There was no understanding of girls [with Asperger’s] ... There needs to be someone who takes those children to the university once a month like, to introduce them.’

Marisha was ‘so anxious’ after visiting campus ‘that she overmedicated herself on drugs ... and ended up in the mental health ward for two months’. She didn’t get to university.

Since then, mental health professionals have failed to agree on Marisha’s condition, making it difficult to get the right supports.

‘She’s gone from Asperger’s to bipolar, anxiety, depression, post-traumatic stress disorder and now they say borderline personality disorder,’ said Iliana. ‘She’s been in about six different hospitals ... and she even paid for private health cover last year to go to a private hospital, hoping that she would get more help.’

Instead, it led to ‘another diagnosis’ and a change in drugs.

‘She’s had so many medications and she’s very, very down at the minute because it’s been very hard ... One private hospital took her off her bipolar medicine, put her back on ... With the medications they give her, the more diabetes sets in and then, a binge eating disorder. She says her head’s foggy.’

Iliana blames mental health professionals.

‘Everybody is not working together to communicate – the clinical psychologist is not working with the psychiatrist to work out what her problem is. It’s just become more and more complex.’

Iliana says hospital staff refuse to listen when she tries to give them ‘background information and help’.

‘I’m not believed ... If you at least work together with the family members ... but a lot of times we’re discarded.’

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Artwork by Damian Colpo

Milan and Kym

As a child, Milan used to hear voices. 'I just thought, you know, it's a kid thing,' said his mum Kym. But it wasn't something he grew out of.

Milan started misbehaving when he was about 10. There were a lot of kids in the family and Kym had her hands full.

'I was just so busy, you know, as a mother. And he was just – like, you could be – everything would be fine, and then next minute he'd just go on a crazy fit out of nowhere, and he'd be gone, and you'd be just left standing there going, "What just happened?"'

At high school Milan's behaviour deteriorated and he started taking illicit drugs. 'And I think it just spiralled out of control,' Kym said.

In his early 20s Milan went to prison for the first time. He's been incarcerated many times since then, spending more time in prison than out.

People told Kym his behaviour was because of the drugs. When she called the mental health helpline it was the first question they asked: 'Is he on the drugs?'

But eventually Kym realised his behaviour was not related to drug use.

Kym recently gained access to Milan's prison records and found that in the mid-2010s he had reported hearing voices, bizarre dreams and paranoia. The doctor wrote in the notes that Milan should be reassessed if the issues continued to rule out psychotic disorder.

But this didn't happen.

As Milan's behaviour became increasingly erratic – including self-harm, assaults and eventually a suicide attempt – Kym raised concerns with prison staff.

'My son needs to get a psychiatrist to diagnose him,' she told them. 'I reckon he's got schizophrenia.'

They told her they didn't have the funding.

Kym contacted mental health services, but a mental health nurse told her there was 'nothing wrong' with Milan, that 'he's only got behavioural problems'.

'But you know, the thing is, what they've done is, they've put a label on him, seeing him as he's aggressive and drug-seeking,' said Kym. 'He's not on drugs when he's in prison.'

It was only when Milan seriously attacked someone that the prison finally had him properly assessed. He was diagnosed as schizophrenic.

Milan, now in his early 30s, is on medication and in regular contact with a mental health service.

'He's not doing any of the episodes or carrying on ... He's a lot calmer. He's not the same person that he used to be,' Kym said.

She is angry that he wasn't diagnosed sooner, both for his sake and that of the person he assaulted.

Milan had been arrested for relatively minor offences, so by the time his matters came to court he had already served any prison sentence on remand. But being on remand, he couldn't access services available to sentenced prisoners.

'They're in prison once. They're in prison twice. The third time ... when there's someone like [Milan], it is the norm. He would do stuff to get put back into jail because he just couldn't deal with anything. And it's like, "Hang on. There's something wrong with this person. This is not normal behaviour."'

Kym wants courts and prisons to do better with repeat offenders like Milan.

'I say my son is a bi-product of the system, a revolving door, and he's fallen through the cracks.'

Cassius, Arnaud and Melinda

Cassius is a primary school student who lives with an anxiety disorder that affects his communication.

‘As he progressed through to, you know, prep and year 1, he was talking with us ... starting to open up, doing his readers at school with his teacher,’ his mother Melinda told the Royal Commission. He was having speech therapy every week, but he ‘wasn’t talking a lot at school’.

In year 1 there was ‘an incident’, and Melinda went to the school. She found him ‘locked in a room ... distraught’. The school said Cassius had ‘kicked the deputy principal’. They wanted to ‘suspend him indefinitely’, but allowed him back once a psychologist diagnosed him.

Meanwhile, Cassius’s parents ‘thought maybe something had happened to him’.

‘He went from wearing a short sleeve shirt and shorts to wearing a done-up at the neck, long pants even on a 40-plus degree day,’ Melinda said. ‘We couldn’t work out what was going on ... And that’s what he’s told us, he does it for protection.’

About a year after the incident, Cassius disclosed that somebody at the school had sexually assaulted him.

Melinda believes the perpetrator saw him as ‘an easy target’ because ‘they think he doesn’t talk’.

‘But he does – he talks perfectly outside of school where he hasn’t been abused.’

Cassius’s father, Arnaud, said the school was ‘neglectful’ and tried to ‘bury the abuse and sexual assault ... of a person with disability’.

‘Even though they knew what had happened ... they tried to cover it up by trying to put the blame onto our son ... onto his poor behaviours with his anxiety ... All they wanted to do was to shut us down.’

Teachers kept telling Cassius ‘he’d done a bad thing’. They often sent him home early for ‘bad behaviour’.

‘They weren’t interested in anything we had to say in [his] defence.’

Once a teacher reprimanded Cassius for ‘wetting his pants’ when, in fact, his pants were just damp from playing outside. Another time, he was ‘accused of sexual assault’ for touching a teacher on the arm to tell her something.

‘He was wrongly accused of so many things. He was just an easy target because he didn’t have a voice at school. It was just too easy to blame him all the time,’ Melinda said.

'There were so many times where the poor kid ... he wanted a bit of extra time to finish his work ... they'd snatch it away. He used to get frustrated.'

She believes teachers were deliberately 'making him more and more anxious and more and more angry'.

'He copped the discipline. There were days of suspension, 10 days the first time, one day, three days, five days.'

Before the abuse, Cassius was 'going really well at school', Arnaud said, but then the school 'artificially generated' these 'poor behaviours'.

In the end, the school wanted to expel Cassius. His parents enrolled him in a new school for year 5.

'It's not a special school, but they have bent over backwards ... and his learning is starting to increase again,' Arnaud said.

'He really wants to learn,' Melinda said. 'When he was having those suspensions, he was devastated. He used to say, "I'm missing out on so much." ... He just needs someone understanding ... and then you get – great success.'

Jezza and Peta

Jezza, late 50s, has schizophrenia.

Some years ago, he had an accident and acquired a brain injury. He uses a wheelchair and needs support. Following the accident, the public trustee and the public guardian began managing Jezza's affairs.

The public trustee sold Jezza's home for a substantial amount and he became ineligible for the Disability Support Pension. Jezza had to move into aged care because there was no disability accommodation available.

Jezza wanted to get out of aged care and move closer to his sister who lived in a regional area several hours drive away. He had supported independent living (SIL) funding but Peta, his NDIS support coordinator, was unable to find a suitable property near his sister. 'He's quite heavy-handed with his wheelchair so it needs to be sturdy, built solid, wide walls, wide doors and that sort of thing,' Peta said.

Peta told Jezza he had enough money to buy a home near his sister and 'turn it into SIL accommodation'.

She suggested Jezza build a granny flat at the back of the house and put the SIL provider in the front. 'There'd be other people with disabilities,' she told the Royal Commission 'so there's some company for him as well.' He would be able to live off the income from the rental.

'That was the grand plan and [Jezza] was thrilled, you know, really thrilled about it.'

Peta spoke to the public guardian who thought it was 'a great idea'.

She then spoke to the public trustee who wanted more information.

Peta jumped through 'all the hoops'. She found an accommodation planner to source the property and several SIL providers willing to manage the property and guarantee the rental.

The providers made presentations to the public guardian who chose a preferred provider.

But the public trustee dragged their heels, asking more questions.

'This went on, I kid you not, for a year.'

Peta organised a meeting with the trustee, guardian and SIL provider.

Prior to the meeting the guardian told her the trustee wasn't going to approve the plan.

Peta persisted, telling the trustee and guardian, 'This is his money. This is going to give him an income for the rest of his life and he can live happily in his own property.'

The public trustee refused to release Jezza's money, without giving 'any real reason'.

'I understand they have to ensure that he's going to have money for the rest of his life, but he would have had money for the rest of his life. It was a win-win situation.'

Peta was so disappointed for Jezza.

'The feeling of self-worth and the empowerment that it would have given him ... I can't even tell you how much that would have been for him.'

The guardian told Peta to find Jezza another SIL home, but Peta had tried and there was nothing available.

'These people are adults ... They are able to make their own decisions ... I just think that the guardian is supposed to be representing ... what [Jezza] wanted, and this is what [he] wanted ... She went and joined the trustee and then made it impossible for [him].'

The guardian withdrew her approval for Peta to work with Jezza.

Jezza is still in an aged care home.

'It's not their money ... What quality of life is that?'

Maple

‘I got a voice and they’re not hearing it or my children and that automatically breaks my heart. I just need them to give me back my dignity.’

Maple is a First Nations woman in her 40s. She has an acquired brain injury (ABI) and has been living with depression since being assaulted 10 years ago.

Maple lived independently in her own unit until recently, when the Office of the Public Advocate (OPA) persuaded her to move into a hostel for people with mental health issues.

‘They slapped these orders on me. They get to decide where I stay,’ Maple told the Royal Commission. ‘They lied to me. They said, “Well, you give your unit up, [Maple].” This is what they said. “And we’ll accommodate you in a couple of months time.” You know? And low and behold, they’re attempting to keep me at [the hostel] for good.’

Maple doesn’t like the hostel because there are a ‘lot of arguments between the staff and the residents’ and she is monitored.

‘It’s not a nice environment.’

Maple wants to move back into her own unit because the hostel won’t let her children stay with her when they visit.

‘I feel like leaving and walking ... I was going to sell my TV and just go with a bag and I was out of there.’

Maple feels like she can’t ‘have a life’ without the approval of the OPA and the public trustee.

‘[The trustee] voiced his concerns about me because I am giving 20 or something dollars for my children ... when I can. And that goes way back and years back with our mob, you know? ... [The trustee] said, “No, no, no, [Maple]. You can’t be sending money to your children” ... So it’s soul destroying, yeah.’

Maple was given compensation after the assault, but she doesn’t know how much money is in the bank.

‘The public trustee wouldn’t tell me how much that I had compensation-wise because of my head injury.’

The trustee lets Maple have \$100 a week. She puts \$20 aside, saving up for a mobile phone.

‘I left [the OPA] a message once ... and I said, “Look, I’m not a 12-year-old kid, you know, like when you’re a ward of the state.” I said, “I feel like a ward of the state all over again. Being monitored. Being watched. That’s exactly how I feel.”’

Maple said no-one at the hostel or the OPA office acknowledges her First Nations identity.

‘These fellas don’t understand our ways. It just breaks my heart. I’ve been through so much in my life and these guys are nothing.’

Roderick

Roderick is in his 50s and has a learning disability and attention deficit hyperactivity disorder.

More than a decade ago, Roderick worked as a train guard.

‘When I applied I never said I had a disability or anything like that,’ Roderick told the Royal Commission. ‘I didn’t want to disclose it at all. I was quite scared disclosing anything like that.’

After a few years Roderick decided to switch to a trade, to ‘shore up [his] future’ in the railways department.

Roderick told his managers he had a learning disability and asked for reasonable adjustments to apply for an apprenticeship.

‘I didn’t want to be looked upon as being getting favourable treatment or anything like that. I just wanted to try and blend in with the crowd and just do my work.’

Roderick scored highly in the test and did an apprenticeship through TAFE.

‘[TAFE] were superb in helping me out, but they’ve got a disability support manager there ... They supported me 100 per cent.’

When Roderick finished his apprenticeship, he was given a job in an area of the railways in which he had little experience. His colleagues bullied him because he didn’t have the skills.

‘I need to do a job five or six times to get it. I just needed more practice.’

He took sick leave because he ‘couldn’t handle the harassment’.

‘I wasn’t sleeping very well at all. I started arguing with my wife, my children. I was getting very aggressive ... It was quite a tough time in my life.’

Because of all the leave he was taking, Roderick’s managers sent him to a department psychologist to be assessed.

‘I didn’t know at the time, but that ... assessment was to try and terminate my employment ... [The psychologist] said I wouldn’t be able to do that job anymore or either of my jobs, train guard or [trade] position.’

Roderick disagreed and paid for another psychologist to review that assessment.

‘Most of the results were within normal, you know. I was just a normal human being, but I picked up things a bit slower.’

As a result of that review his employer refrained from sacking him, but did demote him to his original train guard position. They said he wasn't fit for duty in his trade.

'I'd gained that qualification, so for them to say I'm not fit for duty for that role when I'd just passed the licensing requirements for that role [was] a bit hard to swallow.'

Roderick has since applied for more than 50 jobs within the department and 'hasn't got one of them'.

He discovered later that one of his managers was 'after [his] scalp'.

'She said, "If I didn't know you had a disability, I wouldn't have tried to terminate you." That's her own words.'

Nari

‘I wasn’t able to speak and pronounce words properly. Nobody was able to diagnose me being dyslexic. They just like said to my mum, “We don’t know what this is.”’

At school, Nari struggled to learn to read because the words were not ‘staying still on the page’ and ‘were jumping all over the place’.

Nari tried to tell teachers what was happening but they ignored her. As she got older they told her she was ‘lazy’ and ‘not trying hard enough’.

The school moved her to the learning centre, but no-one was able to help her.

‘My voice just wasn’t heard by the teachers ... Teachers need to be educated about [dyslexia].’

After leaving school, Nari enrolled in a photography course at a tertiary college.

‘I didn’t have a lot of support because I still wasn’t really aware that I was dyslexic. All I could tell people was I had learning difficulties, and trying to explain to people was just a bit hard.’

Lecturers told her she was ‘never going to amount to anything’, but she was determined to ‘prove them wrong’.

Nari finished her course and loves being a photographer. But she has found it hard to get a job.

‘My disability is on the inside. When people look at me, some people can tell, some people can’t tell.’

Nari has mixed feelings about being on the Disability Support Pension.

‘I desire to work, and it’s like trying to just find that something where I can work.’

Nari was eventually diagnosed with dyslexia in her late 20s.

‘I didn’t really notice that my brain is trying to read from right to left ... My brain is like reading it backwards. If it’s backwards I can read it no problem. And then if you get letters and numbers and put them all together and make a message, I can read that no problem.’

Nari has discovered computer software that is helpful, but it is slow and ‘frustrating’.

‘I feel like Australia’s behind with different things like technology and not being able to pick things up.’

Nari believes people have very little understanding of dyslexia.

‘I don’t feel like I’ve had a lot of opportunities because of my disability ... I have struggled ... I didn’t really know what my disability was.’

Krystal and Nat

Krystal is about to start high school. She is autistic and has epilepsy.

‘She’s really, really brilliant. She was born into the world smiling,’ her mum Nat told the Royal Commission. ‘They would do IQ tests and say, “She has a very low IQ. She’s basically untestable.” And right from then, we knew life was going to be a challenge with the system, because we could see her intellect.’

Krystal is non-verbal. When Nat enrolled Krystal in kindergarten, the teachers ignored her.

‘We would ask them about her day and they would say, “Oh, she just was outside.” Like it must have been about two hours just looking at the tree.’

Nat took Krystal out of kindergarten and taught her at home, where she discovered Krystal communicates best through a technique using letter boards.

‘She told us she wanted to go to school. So, very nervously, we sent her to [a special school]. And then we started talking to them about how she communicates and what she needs.’

Nat said the teachers were supportive at first, but ‘weren’t really interested’ in helping Krystal learn academically.

‘The bar is really low, you know ... [The teachers] weren’t really interested in what I was saying about her academics and I think it’s because they just had no idea of what to do.’

Nat said she taught Krystal literacy and numeracy at home, ‘because if she can’t show them she knows, they don’t believe she [can do it]’.

After a couple of years in which Krystal became ‘bored doing the same thing’ at the special school, Nat enrolled her in a mainstream school for several hours a week to give her a better education.

‘The amount of times that professionals and teachers don’t listen to the personal experience of the parent is just shocking to me ... That’s why we decided to try dual enrolment ... If I had let it go, nothing would have ever happened. I had to be dogged.’

Krystal is about to start the dual enrolment with a mainstream high school, and the NDIS has agreed to fund her personal care needs and a support worker.

‘Once [the high school] really saw what she can do with her communication partner and why it’s such a necessary support for [Krystal], they were amazing. I think they were actually excited about it. And we’ll see how it plays out.’

Aryan and Juanita

‘Nobody seemed to be able to help him, whether it be in the [health] system, whether in the school, whether the supports in the various agencies.’

As a toddler Aryan was ‘hyperactive’, his mum Juanita told the Royal Commission. Doctors diagnosed him with Asperger’s syndrome and recommended he attend childcare ‘for the socialisation’.

At childcare, staff couldn’t control Aryan and suspected he might be autistic. ‘They didn’t like how he ran around too much and he didn’t have body awareness and he couldn’t queue,’ Juanita said.

In primary school, Aryan ‘jumped from one school to another’ because staff and parents complained he didn’t ‘fit in’. They suggested Juanita try a different school.

‘He was just quite full-on, in the sense he’d climb everywhere. He had so much energy and he never actually deliberately would hurt people, but then he did just through his sheer physicality and his nature.’

Juanita said she could understand how difficult it was for teachers, but no-one seemed to understand how difficult it was for Aryan.

In year 2, Aryan was in trouble from day one and Juanita had to pick him up from school regularly. When he did attend, the school isolated him and kept him away from his peers – even in the playground.

One day ‘something broke in [Aryan] inside’. He could no longer sit on his own, and ran up and down knocking over tables and chair. When the acting principal grabbed Aryan, he hit her.

The school rang police, who removed Aryan and ‘locked him in a little room all day’. Juanita was terrified they’d ‘put him in jail’.

Aryan had to participate in restorative justice, but no-one ever spoke with him about ‘his side’ of what happened. When Juanita raised this, the facilitator apologised saying she’d got too caught up with the school’s side of things.

She told Juanita he was ‘never going to get a fair deal’ and suggested she transfer him to a school with an autism unit.

Not long after Aryan started, the person in charge left and the autism unit fell apart. The school later apologised for letting Aryan down.

Without support, Aryan’s behaviour escalated and his mental health deteriorated. He resisted intervention or treatment.

Juanita felt she had no choice but to obtain a psychiatric treatment order for him. The hospital told her police would attend, but she expected them to be a background presence.

Four police arrived and put Aryan in the back of a police van. Juanita asked to accompany her son, but police refused.

‘It was like he was a criminal, you know? This child was escorted out of the building. I have to say, as a parent that was really soul destroying and I was not expecting that to happen.’

Aryan’s parents didn’t blame police. ‘I cannot really fault what the police have done. They’ve tried to help. Some are better than others, but that’s life ... It’s just unfortunate the system that they had to apply is not optimal,’ Aryan’s dad said.

At the hospital, Aryan was locked in a small room near the nurses’ station. He stayed there for about four weeks until a bed became available.

Aryan’s parents had to fight to be allowed to see him. Juanita said it was a punitive system – the goal posts always changing. Sometimes staff would cancel her visits because Aryan refused to shower. The next day he would shower but they still wouldn’t let Juanita visit because he refused to eat breakfast.

One time, Juanita found her son smashing his head and bloody hands against the wall, repeating, ‘I’m never getting out,’

‘I just feel that all of this stuff is just so traumatising for such a young person.’

Aryan’s last day in the school system was year 5.

Now in his mid-20s, Aryan isn’t able to participate in society.

‘He knows what happens when he goes out – he just gets poor experiences. And that just reinforces the bad treatment and discrimination that he’s had to date.’

Matt, Sally and Clement

Matt, late teens, is autistic and has attention deficit hyperactivity disorder.

Sally, his mother, told the Royal Commission that Matt's 'always had sensory issues relating to his mouth and teeth'.

'The family has had to work really hard to maintain dental hygiene.'

Matt won't allow anyone, not even Sally or his dad Clement, to examine his teeth. For dental exams, Matt goes to hospital and has a general anaesthetic.

One time, Matt tried a desensitisation program with a 'really good dentist' over a number of sessions. The closest he got was sitting in the chair and putting the glasses on.

About three years ago, Sally noticed one of Matt's teeth was discoloured and he was having difficulty eating crunchy food. She contacted the dental clinic and booked an appointment at the local hospital.

Three months later, Sally rang the hospital to find out what was going on. The hospital said they had the booking and would be in touch.

Six weeks passed, Sally rang again and they told her the same thing.

Meanwhile Matt's tooth was starting to go black and he was refusing to eat certain foods. He was in pain and his behaviour at school began deteriorating.

Sally rang the hospital again and discovered they'd lost the booking. Upset, she managed to convince them to put Matt back on the list.

By this stage, Sally was extremely worried Matt would lose the tooth. She contacted a paediatrician who agreed to give Matt some heavy sedation so a dentist at the clinic could examine his tooth.

With Matt heavily sedated, the dentist had a look and told them might be able to do a quick, temporary filling until they could get him to hospital.

He went to make a start when Matt, who seemed asleep, told him not to touch his mouth.

'So even under a huge amount of sedation, he's hyper, hyper aware of what's going on around him,' Clement said.

The dentist wasn't keen on 'losing a finger' and stopped the procedure.

Sally tried to find a private dentist who did twilight sedation but they told her they 'didn't deal with kids with disability'.

Desperate, she rang the dental clinic again and the receptionist put her through to the head dentist.

He apologised that the system had let them down and managed to organise a hospital theatre immediately.

'The disconnect in all of this is that the [hospital] booking system was separate to the dental system,' Clement said. 'The booking people just took a booking for theatre, and they would just keep pushing it back because they didn't understand the dental side of it.'

Clement said 'it's always a battle' when Matt goes to theatre. He requires a lot of sedation to calm him prior to the anaesthetic and needs about eight extra support staff in the room.

The first time Matt had his teeth examined 'he literally stood up in the middle of the theatre' because the sedative had started to wear off.

Sally said it has taken a long time to get medical staff to listen to them and make allowances for Matt's disability.

'You're not in a wheelchair, you haven't got any obvious signs of a disability, and so people – and I think it's just a hangover from many years ago where people just go, "Well, you're just a naughty child."'

Matt's tooth had deteriorated so badly the dentist wasn't able to save it.

The dental clinic has since overhauled the hospital booking system and has introduced twilight sedation so most people with disability won't need to go to hospital.

'Kids shouldn't need to go to the hospital to have dental work,' Sally said. 'It should be done in a localised clinic setting where they can have familiarity and have visits and feel comfortable in the space and see the same faces as they come in.'

Meilani and Aniyah

Meilani is in her early teens. She has cerebral palsy and intellectual disability and uses a wheelchair.

Her family arrived in Australia a few years ago under the refugee settlement program. A community charity helped enrol Meilani in a special school for people with intellectual disability.

Meilani had never been to school before, her mother Aniyah told the Royal Commission. ‘She cannot – understand anything,’ Aniyah said via an interpreter. But she ‘is a good student’, and tries hard. ‘What she has done in learning at school, it’s for her mind.’

Meilani’s family provided the school with reports from a paediatrician on her disability and learning capacity, and she attended for a couple of hours a day. When the family inquired about a full-time education for Meilani, the school requested a report from an occupational therapist (OT).

Meanwhile, the principal agreed to slightly increase Meilani’s class time. However he wouldn’t let her use the toilets at school until an OT had instructed the staff on how to hoist her safely. The family struggled to access an OT, so she was unable to go to school for the rest of the year.

The family moved interstate and Meilani now goes to a purpose-built high school for students with intellectual disability. She has learnt to write her name and likes school, even though ‘it’s difficult, it’s so hard for her’.

However the family is now having problems getting Meilani to the school.

‘They say their bus is too big to come through my street ... no bus can come to pick her up from home.’

The family lives in a housing estate. Cars and ambulances pass through the streets without a problem, Aniyah said.

‘I don’t understand. This bus is a special bus for disabled children.’

The school told Aniyah her only choice was to wheel Meilani to the bus stop.

‘It’s a long distance,’ she said. ‘It may take 20 minutes ... even in the raining and with this cold weather.’

Aniyah asked the school to provide a smaller bus to access the street, but it refused. She feels the school is discriminating against her family and spoke to them about it.

‘I say, “Why we can see this bus going to take other children, disabled children? Why just me?”

‘They say, “No, that’s the way. That’s the way it is.”’

Graziella

Graziella is a disability support worker who lives with a spinal injury and chronic pain.

'I acquired my disability from a car accident about 15 years ago,' she told the Royal Commission. At the time she was working in group homes and doing postgraduate study in disability rights. She 'did rehab' for a couple of years, then continued her academic work.

The university was good at making reasonable adjustments.

'And I probably took that a little bit for granted,' Graziella said, 'cos my jobs after that have not been as easy in that way.'

Graziella left to work for a major disability services provider. 'I didn't see a lot of people with disability in the office,' Graziella said.

Initially Graziella worked full time. When that became difficult, she asked to drop some hours.

'As the day goes on, if I have to work too long hours I'm in a lot of pain,' Graziella explained. '[But] they just refused to accommodate.'

Graziella then worked in parliament for a few years.

'You can't really do bed days ... and they were great. They made sure my office was in the right space, really close to a lift, and I had no problem from anyone.'

A couple of years ago, she returned to the disability services sector. Despite working for 'a massive organisation', she's the only employee with a disability. There's 'no affirmative action policy in place' and 'no desire' to have one.

'There's no-one in the executive leadership team ... with any disability sector experience at all, let alone lived experience of disability. They've all come from corporate backgrounds.'

Graziella started out with the human rights team ensuring people with disability had jobs.

'There were several positions vacant, so I filled them all with people with disability ... from our customer base.'

This caused 'huge problems with HR', who 'wanted to call them supported employees' and pay them supported wages.

'They weren't. They were colleagues, they were peers ... I didn't let them,' Graziella said.

‘We’re talking about people who were going to be given three hours a fortnight – and they wanted to pay them less, treat them less. They were supposed to be embedding human rights in the organisation. It was very tokenistic.’

From the outset, Graziella’s employer promised her workplace adjustments, but they never happened.

‘A footrest, things like that, I buy for myself. But there’s just no understanding that that kind of stuff is needed.’

Graziella was ‘always onto them’ about improving accessibility in the office – ‘not just around physical disability, but quiet spaces, safe spaces.’ She tried to introduce disability awareness training for ‘all the corporate types’, but they ‘didn’t like being pulled up about language’.

The agency removed advocacy and hiring duties out of Graziella’s role.

‘And it was very clear that they were breaking up the dissenting voice in the team ... I talked too much about disability.’

‘People don’t want you to talk about your disability. They get very uncomfortable.’

The employer still allows ‘no accommodations’ when Graziella is having ‘a bit of a bad day’.

“Have you tried Panadol?” – I get that from people working in disability!

Cayson and Safara

Cayson, early 20s, has Asperger's syndrome and lives with depression.

'He lacks social skills and has difficulty controlling his neurological impulses,' his mum Safara told the Royal Commission. 'He's almost like an overachiever, he likes to pressure himself to perform.'

Cayson attended a private school where he was bullied 'psychologically and emotionally'.

Teachers told Safara, 'He's a very good student except when it comes to exams.' During exams he had meltdowns.

Students made fun of him. 'He felt ridiculed,' Safara said.

The school didn't do anything about the bullying and didn't offer him any adjustments.

In Cayson's final year, one student repeatedly made fun of him. Cayson retaliated and sent the student an email – 'Stay away from me. Leave me alone or else I'm going to kill you.'

The student made a complaint and the school immediately reported Cayson to police. The senior head told him he couldn't go to school while the police investigated.

Cayson was distraught. 'They make me suffer and now they're piling it all on me,' he told Safara.

Cayson had a breakdown and was 'rushed to hospital because he got suicidal'. He remained in hospital for three weeks.

'It's so much stress during all the time. We got a lawyer because we thought they'd go on and charge him.'

However, police considered it a mental health issue.

Safara begged the school not to expel Cayson and to investigate the bullying.

'They didn't want to do anything. And all the time they were thinking of expelling him.'

The other boy 'didn't want [Cayson] there' and his family pushed the school to expel him.

The hospital spoke to the school, telling them Cayson was very vulnerable and his mental health was fragile. They reminded the school he had Asperger's syndrome and argued he'd only acted because he'd been provoked.

After much deliberation, the school decided not to expel Cayson.

However, they would only allow him to come to school to attend his core subjects. This meant he often had to leave the school for long periods and have to return later in the day. The school made Cayson quit all extra curricula activities.

Safara asked the education board for 'a fair hearing', but they refused.

She then made a complaint to the Australian Human Rights Commission, but the school refused to cooperate.

Safara said Cayson is 'still traumatised by the experience' and continues to take medication and receive counselling.

'He still says he doesn't really like to socialise anymore, and he's too apprehensive to make friends.'

Cillian

Cillian is in his 20s and has Asperger's syndrome and cognitive impairment. At school he attended a special unit 'for kids on the autism spectrum'.

'At the time it was still labelled ED, which stands for emotionally disturbed,' his mother told the Royal Commission. She arrived at the school one day to find 'a cage put around the class'.

Cillian described the unit as 'a prison' where the school 'locked' the autistic children. 'I call it exclusion in an inclusive setting,' he said.

Initially he was going to the ED unit for some lessons.

'And then [in high school] I was pulled away from mainstream and permanently put in dummy brain baby class where you could not do anything,' Cillian told the Royal Commission. 'I was taken, like physically taken out of the class by some people in suits and basically thrown into the autism unit against my will.'

One teacher, who Cillian 'adored', was against the move and 'broke down in front of the class'.

Cillian said the school treated children with learning disabilities like 'bloody nutcases'. They also handed out suspensions and detentions in a 'very discriminatory and unfair' way.

His teacher, 'a baby mammoth', would 'beat and hit children' and 'go berserk'.

'She used to shriek and scream at kids who were having their own disabled issues or problems at the time ... yeah, and that happened heaps.'

A group of students bullied Cillian and his mates in the ED unit. '[There] were heaps of bully cases reported to teachers,' he said.

The school promised to act but did nothing, and Cillian and his friends would just 'get beaten up again'.

Cillian decided to take things into his own hands.

'I marched into the principal's office and said, "You need to do something about bullying, otherwise I'm going to set up a taskforce to deal with all the crimes committed around school and everything."'

Cillian went ahead with the taskforce – a 'non for profit organisation' for dealing with bullies.

'We knew who the naughty ones were ... and we'd check in with the teachers. How many marks does this kid have until they're expelled, or this or that.'

It gave him a sense of purpose.

'I loved it. I was the boss of it. I ran it and recruited people.'

But it didn't help him academically.

'There was some subjects I really tried as hard as I could in, even though I was, ah, highly immature ... But it was somewhat too late already ... And pretty much by the end of school years, food tech was the only out-of-class subject I was allowed to do.'

Cillian ended up making a complaint to police about the teacher who abused him, but they didn't prosecute. He feels police, like everyone else, labelled him 'a fruit loop'.

People often treat Cillian this way. He is very tall and has a speech impediment. People frequently 'refuse [him] service' or tell him, 'you're drunk' when he's not.

'Disabled people are discriminated against full-on, just because they might be red in the face, have a droopy eyelid, anything.'

Cillian is now looking for work, but says his lack of qualifications leaves him open to exploitation.

'My first somewhat official job was a trolley boy ... They illegally paid me under supported wages.'

The company claimed it was 'supervising' him so it could pay him 'the wage of a 16-year-old'.
'There was no supervision whatsoever,' Cillian said.

'The only job that I feel I'm cut out for is security.'

He's been going through a pre-screening course to see if he has enough skills, but he fears people who have 'the looks' will get hired first.

Graciela and Saoirse

Graciela died about a year ago.

Saoirse told the Royal Commission her daughter was ‘vibrant and high-functioning and just a sweet, beautiful soul’.

She had Down syndrome and was in her early 20s.

A couple of months before Graciela died, her oxygen levels were very low and she had a fall.

At the emergency department of the local hospital, a nurse gave Graciela oxygen but the doctor dismissed her symptoms as sleep apnoea and sent her home.

A few days later, Graciela’s oxygen levels dropped again. She couldn’t stay awake and lost mobility. Saoirse knew something was seriously wrong.

A different doctor at the hospital was more helpful. But otherwise, ‘nobody listened’.

Graciela’s health continued to decline and no-one knew what was wrong. A specialist told Saoirse that people with Down syndrome ‘don’t live as long as we do’ and suggested an end-of-life care plan.

Saoirse was horrified.

‘She’s 22 years old. She hasn’t been to hospital in 10 years. She’s just got Down syndrome.’

The doctor made fun of Graciela’s weight pretending to be an ape, saying, ‘You know, she’s really big.’

Saoirse demanded a different doctor.

Most staff seemed ignorant about people with disability and how to care for them.

‘Hospitals are geared towards regular people. And there’s just no accommodations made ... This is a place that treats vulnerable and disabled people. How do you not accommodate disabled people?’

Graciela needed a hoist and several people to lift her or roll her safely in bed. Staff either didn’t know what to do or tried to take shortcuts.

‘She’s really super-super-sensitive and they’re doing all these invasive things to her and she’s got no choice because she can’t move anything and she can’t talk by this stage. And they’re still persisting with physio and with this theory of ... sleep apnoea ... low muscle tone.’

Some nurses tried to communicate with Graciela, but none of the doctors did.

‘It seemed like nobody was in charge. We were getting bits and pieces, different people in and out.’

After several weeks, doctors decided to transfer Graciela to a hospital in the city.

Doctors conducted multiple tests but nothing was conclusive.

By this stage Graciela was very hot and couldn’t use her arms or legs.

Saoirse suspected she had a specific disease and suggested she needed blood transfusions.

One evening, nurses were changing Graciela’s bedding. As they rolled her over blood began to gush out of her nose.

The nurses panicked but eventually got her upright and controlled the bleeding.

A short time later, Graciela started to vomit. Saoirse tried to find a nurse but couldn’t.

She alerted a security guard and within minutes doctors and nurses appeared.

It took an hour or so to stabilise Graciela and take her to ICU. They wouldn’t let Saoirse go with her because of COVID-19.

‘Being a person with disability who can’t talk and communicate or anything, even if she was in ICU we should’ve been allowed ... because we knew her needs.’

Doctors told the family to prepare themselves and say goodbye, but a short time later Graciela began to improve.

A few days after Graciela left ICU, doctors stopped her anti-nausea medication. She choked on vomit and died.

‘The next day we just drove home in shock ... We can’t help but feel if we were listened to earlier, even if she had still died, she could have had a much more happy and peaceful transition.’

Georgie

‘My biggest frustration is coming across so many people who have been withheld from access to language, and it’s not fair for these children. We are not providing these children with the opportunity to succeed or meet their potential.’

Georgie is an Auslan interpreter and educator who works across several schools.

A few years ago, Georgie started working in a class with four Deaf students. She was working in tandem with another interpreter who had been with the students for some time.

Georgie quickly realised the other interpreter was unqualified, used fingerspelling and had little experience working with the Deaf community.

Georgie told the Royal Commission the other person was really a ‘communication aide’. The school had paired her with the students because she was from a similar migrant background.

‘While the teacher was teaching, the only adjustment that was made was for this communication aide to fingerspell. That led to several gaps in content ... I could see the students trying to connect the dots between what was being said in the classroom, what they were seeing on paperwork, and the communication aide.’

One student had challenges with literacy, so fingerspelling was useless. The student was ‘completely disengaged’.

Georgie engaged with the students and discovered they didn’t understand the language the aide was using.

Georgie started signing to the students in Auslan. They quickly became interested in what they were learning and were able to respond appropriately and give their answers in Auslan.

The classroom teacher later told Georgie how wonderful it was to see these students finally engaging with the content being delivered.

‘I think that we really need to make sure that education for Deaf students is delivered respectfully and appropriately and in a language that they can access.’

Georgie also works as a tutor for Deaf students.

However she can only meet with students about 50 per cent of the year because their NDIS funding is ‘pathetic’.

'The funding just isn't there. And I'm already charging half my usual rate, or half the rate of speech therapists or ... other professionals ... I'm working really hard on a minimum rate for this child, and still there's inadequate funding.'

Georgie believes the education system treats Deaf students as disabled and focuses on what they can't do.

'I think it's really important that children can arrive at a point where they realise they're not disabled in terms of their inability to do things but rather they're a CALD [culturally and linguistically diverse] group. I really love it when I see students mention this CALD identity because I feel like that message has gotten across.'

'Early intervention for Deaf children is critical and should be a priority. There are just so many areas where systems fail Deaf children and Deaf people.'

Kehlani

Kehlani, a First Nations woman with schizoaffective disorder and bipolar disorder, grew up on a remote mission.

‘I was abused by other mission kids,’ Kehlani told the Royal Commission. ‘It wasn’t all bad ... I got straight As in year 12. But I had no support from anyone for a long time. [And] I really wanted my mum.’

Kehlani married when she was ‘very young’.

‘My husband locked me up. I sort of feel like I’ve been locked up forever. All my life it feels like I’ve been fucking locked up, you know?’

After giving birth to a son, Kehlani developed postnatal depression and child protection officers took her son away.

‘They must have thought I was trying to hurt him or something. But I didn’t have ... anyone to support me. No-one. So I gave my son up to stay with someone else, you know. And that hurt me.’

After she lost her son and her mother died, Kehlani started drinking.

‘I’ve had these [disorders] since my baby, since my mum died. That’s when it first happened.’

When she discovered her husband was abusing one of her children, she told a family member. Her family arranged to have her admitted to a mental health unit in a city hospital.

‘They put me on injections after a long time and it ... made me like a zombie because I didn’t have any feelings or thoughts. I never joined in with anyone. I never spoke to anyone.’

Kehlani said that after she left hospital, her family didn’t want her back.

‘I’ve been homeless for 10 years, walking the street, getting high on the junk just to stay awake so no-one don’t touch me. I’ve never had a place to stay. I never had a home. I sleep on old men’s couches. I sleep with old men just to get a bed, just to get a feed ... This mental illness is my biggest fault in my life.’

Kehlani’s been sent to prison several times. When she spoke to the Royal Commission, she was in prison for stealing drugs.

‘They all know I’ve got a mental illness, but they still treat me really bad the officers, the prisoners and the [mental health staff] and everyone. And when I speak up they don’t like it. Because I stick

up for other prisoners as well, for Aboriginal girls who don't know how to [speak] full English.'

Kehlani said that one day, a prison officer 'spoke nasty' to a girl and 'she went and hung herself'.

'It maybe wasn't just because of that, it was an accumulation of things. But, you know, she is dead now that young girl.'

Kehlani said the psychiatrist she sees in prison 'doesn't listen' to her problems.

'Maybe she's teaching me how to regulate my emotions and shit. I've been doing that all my life. People swear at me to my face. I didn't swear at them.'

Kehlani said she'd like First Nations women in prison to receive more psychological support and education 'because mental health is a very fine line'.

'I would have been a lawyer or I would have been a doctor if people would have supported me in my lifetime. But I've just been chucked out on the outskirts, on the fringe.'

Jordon and Lin

Jordon is in high school and has a chromosomal condition that causes physical and intellectual disability.

His mum, Lin, told the Royal Commission that when she tried to enrol Jordon at his local primary school, they didn't want him.

'I was told he couldn't go there ... [that] they couldn't support him there.'

Lin insisted.

'I knew that that was his right and I was determined that he would finish his primary schooling there ... I advocated for the whole seven years he went there.'

Lin said Jordon had 'no way of telling' her what went on at school and the school's communication with her was poor.

'I never really knew day-to-day what was going on. I didn't know where he was, who he was with. I just didn't seem to be entitled to any of that information regardless of how much I asked for that information.'

Years later, Lin applied for Jordon's school records, which the principal initially refused to release.

'I spoke to the regional office and they contacted him and told him to get the records. Even at that time he only gave me some of it ... I'm not entirely sure that I have everything.'

Lin discovered that in one six-month period alone the school recorded many incidents, 'none of which had been reported' to her.

'[Jordon] was in a state of distress the majority of the time and it really explained all the behaviour that they were complaining about because they were just so ill-equipped to understand, to know how to support him. There was no focus or interest on his wellbeing.'

One incident report described Jordon crawling on the floor.

'They spoke about him in a terrible way. ... Even the woman in the office spoke about him poorly. ... She described what he looked like in the classroom, crawling around on the floor sneezing because he had hay fever one day, and referred to it as "disgusting".'

Another time, a teacher smacked Jordon.

'Apparently, he was climbing on [furniture] and the ... teacher was on the other side of the room and walked over and smacked him.'

The principal told Lin it only happened once, but Jordon at that time began saying things such as 'angry', 'naughty boy' and 'smack'.

'And all of that language still continues now, even after I've taken him out of school.'

Lin said Jordon's occupational therapist reported the incident at the time and a government social worker rang her 'concerned that possibly he shouldn't be there'.

'I felt like the focus should've been ensuring with the school that they were protecting him, but [it] was about questioning my decision [to send him to that school].'

Kason and Lindy

Kason is autistic, has dyspraxia, a stutter and speech delay.

He started school just before COVID-19 hit.

‘I was worried about taking him in and out of lockdown,’ his mum Lindy told the Royal Commission. ‘So we decided to keep him at home [for a] year. It was actually amazing, it was so good.’

During this period, Lindy had some issues with the school and decided to change schools.

The new school agreed to provide supports and to allow Kason’s allied health therapists to come to the school.

When Kason returned to the classroom, Lindy noticed changes in his behaviour. He stopped sleeping through the night and always had to have a hat on. His social anxiety increased and he would chew his fingernails down to their beds.

‘My son’s teacher, I don’t think she understood disability at all. I think that sometimes when he was anxious or shy or he would come into himself, she just thought he was being task avoidant.’

Lindy spoke to the school and discovered they weren’t providing additional support even though they were receiving around \$30,000 per year.

If Kason was having difficulties they would take him to the chicken coop.

‘And he hates chickens.’

Lindy asked if Kason could use the therapy room at school for some occupational and speech therapy, but they refused to allow therapists at the school.

Kason developed allergies and a constant cough and the school told him to stay home.

The teacher said she didn’t have the time to send schoolwork home.

After about six weeks Kason was ready to return, but Lindy didn’t want to send him back until the school agreed to provide supports and allow therapists to support him.

The school refused to make any changes.

Lindy contacted the education department. They recommended homeschooling through distant education, but Kason’s therapy team was not supportive.

Lindy attended a meeting with an advocate, the school and the department. The school agreed

to provide limited support as Kason gradually returned to the classroom. They offered Kason 'a storeroom', because the therapy room was 'booked out', and insisted on meeting all his therapists. Lindy agreed even though the cost of five one-hour meetings was significant.

The next day, the school told Lindy they'd rethought the proposal. They couldn't allow therapists and wanted Lindy to support Kason at school.

Lindy refused and asked for another meeting.

During this meeting the assistant principal told Lindy the therapy room had been contracted to an external party by the school council.

When Lindy expressed surprise, the meeting was suspended for a few moments. When it recommenced, the assistant principal said there had been a misunderstanding and the therapy room was always available for Kason to use. He also denied the school had offered a storeroom for therapy.

Lindy asked for the minutes of the previous meeting. They'd removed all negative comments about the school and misrepresented what she said.

Lindy told the school she wanted to enrol Kason in another school.

There was a zoom meeting but Lindy, the advocate and Kason's paediatrician were all kept on mute. 'We all typed in the chat, "We can't unmute ourselves." And they said no, we are using a hands-up function for this meeting.'

The school pressured Lindy to approve the outstanding minutes. Lindy's advocate told her that it was the most discriminatory meeting involving the department she had ever attended.

Lindy is at the 'end of [her] rope'.

'I think that teachers as well as principals need training in autism, human rights and discrimination.'

Eris

Eris, 70, is autistic and has attention deficit hyperactivity disorder. She was only diagnosed recently, since she turned 65, making her ineligible for the NDIS.

‘You know, that business about if you’re going to be disabled, do it before 65 because hey, if you don’t, you’re screwed.’

The diagnosis has given her new understanding of issues she’s dealt with for much of her life, including depression and complex post-traumatic stress disorder, and frustration about how health professionals have treated her.

‘So the kinds of things that you hear from people ... You know, the doctors that say to you when you come in after a suicide attempt, you know, “Stop messing around, I’ve got someone over here who’s having a heart attack that’s really ill, I need to get to them.” You know, all the doctors that, you know, didn’t even bother to ask me about my menopausal state. So, you know, no-one linked perimenopausal with the baggage that I had, to say, “Okay, this may be why she’s off the rails.”’

Eris recognises now she has always been neurodiverse and believes it made her vulnerable, in particular to a sexual assault when she was a child.

Eris didn’t report the assault at the time but tried to do so later, twice. The first time the matter didn’t advance because it was too long after the event.

It was also too late the second time. By then legislative changes meant an investigation was possible, but the perpetrator was no longer alive.

‘I know that when I couldn’t proceed with the police [the first time], that had a profound effect on me because, you know, you kind of build yourself up to this point when you’re going to do this big thing and then they say, “Oops, sorry, too long ago.” So then you let it die down. Then you build up again – “Oops, sorry, he’s died.” So, you know, same old same old.’

Police had no process in place to help Eris receive this news.

‘I can recall no feedback from them at all and no closure other than, “Oh, thanks. He’s dead. See you later,” and that was it.’

People in medical-legal sectors need better training, she said.

‘I just want there to be more focus on people actually being trauma-informed.’

Eris explained that she has found her own ways to effectively manage her mental health.

‘I have a personally curated mental health first aid toolkit of techniques learnt over 35 years of psychosocial treatment therapy,’ she said. ‘It includes mementos that have positive

connotations. So when things are tough, I just rummage through my box – you know, pull out things, cards, things that are meaningful ... I'm not into tarot but I like the cards. When I'm feeling down, when I can feel myself starting to slip ... I go to my box and rummage.'

She would like to see education for teenagers that helps them develop similar strategies.

'I think there should be a subject, you know, like people in bushfire zones and flood zones are encouraged to prepare an action plan ... I just think that if there could be that kind of process where a kind of a – that kind of mental health curation. Prepare a toolkit ... You know, what would, what could that look like? You know, what things could you do? Say you were on your own and you had to survive, you know, what would keep you propped up mentally? Like, for me it's, you know, literally my box of tricks.'

Lainey

‘It’s a matter of you’ve got to push, push, push. And then if they don’t like the pushing you’re going to get responses that your conduct is pathological.’

Lainey, a First Nations woman, has bipolar disorder, vestibular migraine disorder, complex post-traumatic stress disorder and chronic fatigue syndrome.

She’s been living in a community housing complex for people with disability for several years. The complex is in a ‘leafy suburb’ of ‘big yards, big houses’.

Lainey told the Royal Commission she has lived in various public and private housing, but this is the first time she feels she’s ‘stigmatised in the community’.

‘It’s very much mum, dad and the kids’, and the lack of diversity is ‘probably a part of it’.

Although the complex is ‘beautiful’ and a ‘very high-quality build’, the provider doesn’t manage it very well. Lainey is frustrated the provider denies the issues she ‘can see with [her] own eyes’. It is ‘plain gaslighting’ and ‘really a crummy approach’, she says.

‘It’s only eight units in the block ... some people have some quite difficult problems, behavioural problems.’

Once, Lainey made a complaint to the provider about another tenant who was engaged in illegal activity. When the provider refused to do anything, Lainey contacted the police. She said police didn’t take her seriously.

Another time a neighbour in the house next door installed two large air-conditioners about two metres from Lainey’s unit. It’s so noisy that even with the window closed she feels she’s being ‘bludgeoned by the air-conditioner’.

Lainey complained to the provider who suggested she complain to the council. When no-one did anything she complained to the police who told her it was a council matter.

Lainey has contacted the council several times wanting information about whether the noise is lawful.

Council don’t give her the information she needs and fob her off.

‘I’m at the stage now ... the general manager there, he’s written me a letter now saying, “You’re a consistent complainant. If you write any more letters it will serve no purpose. We’ll keep them on record but you won’t get any answers.” Well, I thought, I haven’t had any answers.’

Lainey believes people treat her differently because of her disability.

'I use advocates quite often, only because I feel I won't be taken seriously because I've got a lot of diagnoses over my head.'

Lainey said it been 'very distressing' dealing with the provider and council.

'I'm terrified that I'm going to have to have an unliveable home through this summer period.'

Lyle

Lyle is in his 40s and lives with complex post-traumatic stress disorder (C-PTSD) and developmental trauma.

'I had a very sick mother who was a narcissistic abuser. So I grew up in pretty much an emotional vacuum,' Lyle told the Royal Commission.

When he was in his 20s, Lyle had 'some significant mental health concerns'. His doctor misdiagnosed him with bipolar disorder and borderline personality disorder.

'The treatments haven't been effective. There's been an over-reliance on medication ... but not really getting to the bottom of the condition. I have to say I haven't been able to function at all well.'

Lyle's C-PTSD wasn't diagnosed until a couple of years ago.

'I've been out in the community since I was 20 with a chronic identity problem, with PTSD symptoms, but not even a safe place in which to heal, to have treatment.'

Lyle said the misdiagnosis made his conditions worse.

'We're dealing with the peripheral symptoms as opposed to the underlying problems. Hence, why I can't seem to ever get to where I need to be with treatment.'

Lyle said Medicare won't fund the intensive treatment he needs for C-PTSD. Without treatment, he can't earn a living and is now homeless.

'Needless to say I fell into a massive hole because there was no funding to ... see psychologists.'

Lyle told the Royal Commission he's currently living in the garage of a stranger who saw him on the street and offered him a place to stay. Because he's homeless, Lyle has struggled to apply for the NDIS.

'I had to submit via email. And then you have to wait for a written reply. Now there's a problem with that in that if you don't have a physical address it's very hard to receive mail. Being homeless I had to basically constantly stake out post boxes.'

The NDIS rejected Lyle's first application for support because it didn't consider his condition 'serious and ongoing' and because there were 'adequate services' to support him.

Quote: 'I was a dead man walking for [more than a year]. I was so dissociated, so symptomatic, that I literally couldn't even move. I was just, "If I don't get treatment, I'm going to die."'

It was only after he appealed to the Administrative Appeals Tribunal that the NDIA agreed to

support him. Lyle said he still can't adequately treat his C-PTSD because neither the NDIS nor Medicare will cover all the clinical costs.

'[The NDIA] haven't even bothered to even look at clinical services. Every time I mention that it's like a dirty word. They don't even want to go there. So now that's led to secondary problems of homelessness now. And the stress that I've been under for the last three years waiting ... it's just got worse.'

The NDIA has given Lyle funding for accommodation, but he still can't access it. He'd like to discuss it with his NDIS coordinator and his care planner, but they keep cancelling appointments.

'I've never met either of these individuals. Neither of them have mobile phones that they ever pick up. I've just got an email trail back and forward. And I've been imploring them to please come and meet me or find someone who can come and meet me so we can establish a treatment plan, a housing plan. And months have gone by and nothing has happened to that effect.'

Lyle said his plan has tens of thousands of dollars earmarked for therapeutic supports he needs, but hasn't seen.

'I finally got two hours in my budget for therapy, two hours a week ... The rest is spent ... paying people to not turn up. It's a self-feeding machine that they only pay themselves. I don't know who's working for who.'

Margarita and Tomaso

Margarita is in her teens and is autistic.

‘I didn’t really understand the point of school,’ she told the Royal Commission. ‘Back then I didn’t know I have, like, a disability.’

Her parents knew Margarita had developmental problems, but teachers kept saying ‘she will grow out of it’. At high school, she felt lonely and found it ‘a really scary place’.

‘I think it was just social anxiety ... I found it hard to speak to people and stuff. I kind of, like, freaked out a lot.’

Teachers weren’t providing any supports.

As Margarita increasingly struggled with learning difficulties, students – especially the boys – bullied her. They began touching her ‘in bad places’ and spreading ‘very mean’ rumours about her.

‘My mum would come home and she would tell me off for things I didn’t even do because someone would make it up.’

One kid in particular was teasing her and she had several breakdowns, her father Tomaso said. The school did nothing to address it.

Margarita made a note in her diary that she ‘planned to get this boy ... to kill him and then to kill herself’. On discovering this, her mother took her to child mental health services, who found her to be ‘just a normal teenage girl’. Unhappy with this assessment they went to an autism association, which made a similar assessment.

‘But we knew something was wrong with her,’ Tomaso said. He took Margarita to a paediatrician who diagnosed her with autism.

‘But still we didn’t get any help.’

Several weeks later, Margarita tried to harm the boy.

‘She was charged with attempted murder and put into [a youth detention centre] straight away.’

Margarita spent more than six months in solitary confinement. ‘I went mentally crazy because of it ... I just became this bad person,’ she said.

‘As soon as I had gone into jail, I developed this violent behaviour that I had never had ... I just, I just gave up ever behaving.’

Margarita said the prison psychologists ‘didn’t know what they were doing’.

‘I was telling this one woman how I was feeling ... she was just drawing, she wasn’t even listening.’

Tomaso watched his daughter ‘go downhill very quickly’. She was ‘angry and sad’, locked up in ‘a small cell’ with a ‘caged outdoor area’.

‘For adolescents who commit an offence, why are they put into a mainstream detention centre and not a facility for their disability or mental condition?’

On her release, community services placed Margarita in her father’s care. He tried to get her a volunteer job but, as Margarita explained, after ‘11 months of complete isolation’ she ‘wasn’t mentally stable’. The government assessed her as ‘not able to be out in public’ and ‘put full restrictions on her’ and ‘forced’ her to move into a community house.

‘She didn’t have any proper therapy for nearly 12 months,’ Tomaso said.

Eventually she was allowed to move home.

Margarita feels if she’d had support at school, received ‘some sort of proper therapy’, none of this would have happened.

‘My life is back on track now, but only because I started going to church. And ever since I have been doing that my life has been good.’

Blaze and Aviana

Blaze, 30, is autistic and has attention deficit hyperactivity disorder, a sleeping disorder and anxiety.

In his final years of high school he went to a small private school. His mother Aviana said the school 'didn't support disability'.

'They didn't understand it ... I had to argue with great intensity, almost to the point of having to – close to threatening, not quite – to get accommodations. They didn't think that it warranted it, even though we had medical documentation galore.'

Blaze became suicidal, Aviana said, so she withdrew him from the school and sent him to another one that specifically catered to academic students with autism or mental health issues. Unlike the previous school, this one assessed students' work with exams rather than assignments.

'My son would only sit exams, he would not do assignments. The assignments made him so anxious because he couldn't get 100 per cent in the assignments, so he was just distraught.'

Blaze did well at the school and secured a place at university. Despite his academic abilities, Aviana said, it didn't work out.

'He couldn't cope with all the students and he couldn't cope with the pracs and all the assessments where you're with people all the time ... He failed miserably.'

Blaze experienced severe migraines and became extremely ill.

Aviana was Blaze's advocate, but the university's disability officer wouldn't recognise her role.

'She said, "I don't want you ever coming again, he has to advocate for himself."'

Aviana said the university has lots of policies about how people with disability should be treated.

'But the thing is they don't implement them. They don't implement the Disability Discrimination Act or the Disability Standards for Education. When I'm told I was not to come again, that is against the actual Act ... So, you know, there's policies and an Act, but there's also people who are employed by the government, or the university in this case, who didn't understand it.'

Unable to access the support he needed, Blaze withdrew from university.

Blaze enrolled at another university and that didn't work out either. He then enrolled at TAFE, studying for a certificate. Although he failed that course, TAFE encouraged him to enrol in a diploma, with fees of \$5000.

'He failed every subject except one because he didn't hand the assignments in,' Aviana told the Royal Commission.

'So that's another complication that people with disabilities [face], getting into debt unnecessarily, and without their real understanding ... They're just, you know, going, "I've got to do something."'

Too often, she said, they end up with debt and no qualification.

'And then you continue the social disadvantage.'

She would like to see TAFE fees reduced. Subsidies exist for people on a Disability Support Pension, but not others with disability.

'A lot of people who have got disabilities who haven't been classified or verified or diagnosed, whichever term you wish to use, are always at a significant disadvantage financially, socially, emotionally, family-wise because of these issues.'

Emerald and Kairi

Emerald, early 30s, is a First Nations woman.

In her late teens she had a psychotic episode and was admitted to hospital under an inpatient treatment order.

Doctors gave her an antipsychotic drug that is usually only prescribed after trying other medications because it can damage the heart valves.

Emerald had a cardiac episode and doctors had to restart her heart.

For the next few months, she moved between the medical ward and the mental health unit. Doctors in the medical ward would say to her mother, 'Kairi, tell [the psychiatrists] not to give her any more [of the drug].'

Kairi told the Royal Commission the psychiatrist secured an involuntary treatment order. No-one was able to interfere with his medication order.

Emerald was scared to take the drug and would throw it away. The psychiatrist threatened her with seclusion if she did not cooperate.

Around this time the public guardian became involved and sidelined Kairi. She had no say in what happened to Emerald and believes the guardian simply agreed to whatever the psychiatrist wanted.

The psychiatrist began experimenting with different medications. Emerald started 'becoming like a zombie' and 'frothing at the mouth'.

Nurses privately raised their concerns. For a short time the hospital intervened and Emerald was able to stop taking the 'cocktail' of medications.

She started to improve.

Against Kairi's wishes, the psychiatrist and guardian 'teamed up' and sent Emerald to a mental health rehabilitation unit a long way from her home.

'Part of rehabilitation is meant to be spending time with your family, seeing your animals and trying to reintegrate back into the family and society. None of this was done. None of it.'

Emerald was meant to be there for six months, but ended up staying two years. She became extremely malnourished, dropping to less than 50 kilograms.

‘But in that time of two years that she was in there, they continued to experiment on her, trying her out with all these different drugs. None of it worked. There were allegations of a sexual assault in there ... The guardian ... he was informed about the sexual assault that occurred in there and nothing was done about it. Nobody was investigated or anything like that.’

Kairi said Emerald’s guardian was disrespectful, obstructive and abusive.

He would not let Kairi attend mental health hearings, would not consult her or provide her information regarding decisions that affected Emerald. Kairi said that she ‘was at loggerheads’ with him for years.

By the time Kairi got Emerald ‘out of there’, her relationship with the guardian had ‘broken down irretrievably’.

Emerald moved to disability accommodation. She had no choice as the only other option was returning to the mental health unit.

Kairi believes the provider and the guardian are ‘in cahoots’.

The guardian refused to allow Emerald to visit Kairi, who often ran away because she was lonely. At one stage staff promised to bring Emerald for home visits, but it never happened.

Staff often prevent Kairi from visiting.

When they allow her to visit, Kairi gives Emerald money to buy the things she needs as the guardian doesn’t give her enough. At one stage, Kairi says, the guardian completely cut-off Emerald’s money.

Kairi said the provider ‘lies about things’ and doesn’t provide the services they promise in their shiny brochures. No-one helps Emerald engage with the community – they just buy her cigarettes and take her to McDonald’s.

‘Leave them sitting inside a big house by themselves. No company. No rehabilitation whatsoever.’

Recently Emerald’s long-term guardian left. Kairi is yet to meet the new guardian.

Gert

‘They keep denying people, just so they wear them down and they give up. And that’s what they want. Anything and everything is a fight for clients.’

Gert is in his late 40s and lives with a chronic kidney condition.

‘I’ve had mental health issues since a young child but nothing really specifically diagnosed or managed,’ he told the Royal Commission. ‘I live alone, I have my dog and minimal support.’

Prior to his recent kidney transplant, Gert was on dialysis treatment for a few years. ‘Basically, I got to the point where my kidneys were failing because of an immunity issue.’

During this time, he tried to access the NDIS.

‘I was not well enough, could function to a point, but ... I would need the most services until the transplant.’

Within 24 hours, he was told he ‘didn’t qualify’ because he ‘functions too highly’.

‘I held down a few hours of work a week, I had the degree ... Basically, they weren’t going to touch me.’

Gert straightaway asked for a review.

‘And I started jumping up and down at 12 months because I hadn’t heard anything.’

Gert said he wasn’t asking for ‘a whole lot’. He needed some domestic help with cleaning and cooking and a support worker.

‘To take me out for a coffee, out to the beach, just so I could get out of the house ... I’m highly involved in the church, but some days I couldn’t get there.’

Again, the NDIA knocked him back. It doesn’t consider Gert’s kidney condition permanent and they ‘keep claiming it’s a health issue’.

‘The condition I have is for life,’ he said, ‘and it’s highly likely, whether in six months time or 15 years time, I will be back on dialysis.’

After two years ‘of backwards and forwards’, Gert turned to the Administrative Appeals Tribunal (AAT) arguing that his physical health was impacting his mental health.

Gert’s counsellor and psychologist provided evidence that he was ‘isolated’ and needs support to get out in the community. The NDIA had an occupational therapist do a functional assessment at Gert’s home ahead of the hearing.

'She just waffled on about ... other supports he could get, which he can't,' said Gert's advocate. She also claimed that he'd 'have time' for house chores if he 'didn't work, didn't socialise'.

Gert successfully argued the permanence of his condition with the NDIA before the appeal. But 'within 30 seconds' at the hearing the NDIS barrister overturned that.

'He was just so obnoxious ... It was horrific what I had to go through ... Half the problem is I shouldn't have had to have gone to the AAT.'

'And I found that just the whole process was unfair and unreasonable. They were holding all the power. It was deny, deny, deny. And their moral and ethical procedures were pretty in the grey area.'

Gert has had no supports for about seven years now. Many health services he once relied on were 'cancelled when NDIS came in'.

Gert's last hope is a basic home care package with aged care services.

'Because I fall through the cracks so much. There's no-one else to support me.'

Lester

Lester is a retired disability support worker in his 60s. He has a son who is autistic.

'[He] came into the system when things were very positive [in the 1990s],' Lester told the Royal Commission.

Lester used to work as a tradie and his son lived at home. Lester said he 'never really saw the bad side of disability' until he changed careers and became a support worker at a psychiatric hospital.

'It was absolute filth that people were living in. But I saw them transition into houses that were, you know, you're going from institution to palaces. The [group] houses were beautiful.'

Lester said despite the better accommodation, some staff who also transitioned from institutions to group homes brought the institutional culture with them.

'The old-school of the institutions is still clear and present in the hierarchy of disability service provision. There's old-school people in there who you wouldn't let look after your dog.'

Lester said that when he first worked in a government-run group home he assumed he'd be 'walking into a, you know, a well-run place'.

'And what I walked into there was, the house had been allowed to slide.'

For example, staff ate the residents' food and used their money. Lester said he saw a cook regularly serve 'a glutenous muck' they called fried rice. 'It was slop.'

Lester said one resident developed an infection because he lay in a wet bed.

'Every day his bed was soaking wet because they weren't managing his incontinence ... So every morning, you know, his bed would be soaked, the floor would be soaked and you'd go through the same process every morning. And I tried to make them aware of this stuff.'

Lester reported the neglect and abuse, and suffered the repercussions.

'Management let [the perpetrators] off, and I got targeted by the house super and the house staff and management and I got moved.'

Lester said he was given fewer shifts and lost income.

He retired several years ago.

'If you work, you know, with people with disability, you share experiences with them. But these people in [the department] and management didn't share experience. There was no humanity to the way they did the job, no empathy, no, perhaps, looking for how I can improve these things.'

Bartholomew and Delta

‘In 20 years, nothing has changed. It’s still just as hard to get a diagnosis. It’s still just as hard to talk to a service provider who thinks they know everything about FASD and doesn’t know anything except that it exists. It’s still just as hard for children at school.’

Delta is in her 60s and lives with psychosocial disability. She is the mother of Bartholomew, who is in his 30s and has ‘full’ fetal alcohol spectrum disorder (FASD).

‘[This] means he has the facial features,’ Delta told the Royal Commission. ‘They are quite obvious when you know what to look for, but they were missed until I identified it when he was 17.’

Bartholomew had a lot of behavioural issues growing up. Delta sought help ‘to try and find out what was wrong with him’.

‘We went to GPs, paediatricians, psychologists, psychiatrists ... and of course mental health. But nobody picked it up. Not identifying it, not understanding it has caused our family so much stress.’

The ‘worst experience’ was with state disability services. A psychiatrist told Bartholomew ‘to take responsibility for his actions’ and not to come and see him ‘until he’d stopped smoking marijuana’.

‘[He felt] he’d been rejected and he refused to go to another medical professional for years, no matter how sick he was.’

The lesson, Delta said, is early intervention. Bartholomew’s diagnosis came ‘way too late for him’. In his 20s, he ‘was drinking and using drugs’ and ‘ended up going to prison’.

‘The secondary disabilities of FASD are inappropriate sexual behaviour, drug and alcohol issues, mental health issues, contact with the criminal justice system. So, he’s pretty much had the typical trajectory of somebody with FASD who didn’t have early intervention.’

Delta has been a community advocate for FASD for more than two decades, supporting ‘other people and other families’. She says ‘not one thing’ has improved in that time – FASD is more common than autism, yet there’s little knowledge of the condition. Doctors and the disability sector continue to ‘dismiss’ FASD.

Delta believes FASD should be aligned with autism for funding and support purposes – it ‘requires similar sorts of strategies and interventions’.

Delta says she pushed for Bartholomew’s rights ‘until the cows came home’.

‘The average person who doesn’t have the experience I do may never get a diagnosis.’

Today Bartholomew is 'better than he's ever been'. He's got an NDIS package and a 'psychosocial coach who understands FASD'.

'That makes a big difference ... they've established a rapport. And so I feel that if anything happened to us ... hopefully he would advocate on [his] behalf to get whatever he needed.'

Korbyn

‘I have a number of scars on my body, some on my hand, that remind me of suicide attempts for the way that I was treated both for disabilities and for other reasons.’

Korbyn, mid-50s, is a First Nations man. He has Parkinson’s disease, fibromyalgia, physical disability and breathing difficulties.

The government took Korbyn away from his mother as a baby and placed him in a home run by a religious organisation.

Over the next few years, he was physically and sexually abused, resulting in lifelong trauma and physical disability.

As a pre-teen he tried to suicide.

Throughout his life Korbyn has attempted to investigate his history in the hope of finding ‘some sense of identity’. But every time he’s asked for information about his mother, grandparents and great-grandparents, people have dismissed him.

‘I was always told that I did not have an Aboriginal history. I was not Aboriginal, that my skin was too pale, that my face didn’t look as it should have.’

Recently lawyers helped him with a freedom of information request. He discovered the government had classified him as an ‘Aboriginal youth’, but the specific details concerning his family connections were redacted.

Korbyn said governments pick and choose when they will acknowledge his Aboriginality.

Not long after he accessed the NDIS, a health worker told him to apply to the My Aged Care program instead because, as a First Nations man, he was ‘better suited’ to this system.

He soon realised the NDIA took the same view.

Puzzled, Korbyn sought clarification. He discovered that as a First Nations person living with a degenerative disease, he is expected to deteriorate faster than a non-Indigenous person, making My Aged Care more appropriate.

Korbyn felt forced into the aged care system ‘12 years too early’. He now finds himself stuck in a grey area between the NDIS and My Aged Care.

My Aged Care doesn’t fund many of the supports Korbyn needs.

He applied for the NDIS and was ‘put through the ringer’, treated like a ‘troublemaker’ and made to feel bad about asking for help.

The NDIA refused to fund a walking frame, telling Korbyn to apply to My Aged Care. But My Aged Care couldn't fund the one he needed. The NDIA then questioned whether this support was necessary for his disability.

Even though Korbyn's disability is degenerative, he has to constantly supply occupational therapy (OT) reports to justify his requests.

Korbyn has to sleep at a 40-degree incline to prevent him choking. It took two years of arguing with the NDIA to get a suitable bed.

'I had to have an OT film me – I'm 6 foot 5, I'm 160 kilos – rolling in a single bed, to prove that I need a bigger bed, to prove that I need a bariatric bed at all.'

Korbyn said it's 'ridiculous' it takes so long to get the supports he needs.

'As a result of some of those inactions, I can't use the toilet unaided, I can't use the shower unaided, I can't walk unaided, I can't sleep unaided.'

He has applied for a power-assisted wheelchair and is still waiting.

Not long ago, Korbyn was having trouble finding suitable housing and was offered a place in an aged care facility.

He refused and successfully advocated for supported disability accommodation.

Korbyn believes the NDIA sees him as a 'burden' costing too much money, so pushes him into the aged care system.

Korbyn wants to get out of My Aged Care and have the NDIS support him 'as it should'.

Catriona

Catriona is in her 40s and lives with depression, fibromyalgia and postural orthostatic tachycardia syndrome. She uses a mobility scooter.

‘When I stand up my blood pressure drops and I just pass out,’ Catriona told the Royal Commission.

More than a decade ago, when Catriona was in an abusive relationship and became depressed, doctors admitted her to a hospital mental health unit. She said the staff didn’t understand that she also had a physical disability and refused to acknowledge a letter from a specialist describing her difficulty walking and her blood pressure condition.

‘[A psychiatrist] said, “I’m not going to read the letter.” And ... then he just went away.’

Catriona said she later asked for a bedpan, but staff insisted she walk to the toilet.

‘I started to crawl over. They watched me crawl to the toilet and then they said, “There’s no need to crawl. You can get up and walk.” And so I tried to walk and then I passed out.’

When Catriona’s pulse climbed to 200 beats per minute, staff refused to give her water. When she continued to ask for help, they stopped responding and left her in her room.

‘In the end I had to call an ambulance from outside [the mental health unit] and tell them what was going on. And then the ambulance came ... and as soon as they got to me they put me on oxygen and an IV drip into me and took me to [another] hospital.’

Catriona said because the mental health nurses didn’t understand ‘the cross over between mental and physical health’ she can no longer trust mental health units to treat her appropriately.

‘I went straight back to the domestic violence situation at home, which people with disabilities are, you know, more vulnerable to.’

Several years ago, doctors again admitted Catriona to a mental health unit.

‘I was told I was quite depressed and I was told that they would try me on a new antidepressant medication.’

In the morning, because of her physical condition, she struggled to wake up and the mental health nurses left her in bed. When Catriona’s heart started racing, a nurse who said she wasn’t ‘trained in medical stuff’ told her not to worry.

When doctors eventually transferred her to a medical ward, the nurses there ‘weren’t trained for mental health’.

'The nurses there were like, "Now you're going to be a good girl and you're going to behave, aren't you? You're not going to be suicidal?" ... and that's a really inappropriate thing to say to someone who has a mental health issue.'

Catriona said she can't get appropriate care in hospital because staff are trained in either medical or mental health care, but not both.

'People with disabilities have mental health issues because of the high rate of domestic violence, the high rate of having a hard life ... [but] there is no accessibility for someone with physical disability to be able to go into the mental health unit and get the help they need.'

Gaetan

‘My life’s gotten worse as a result of ... involuntary psychiatric treatment.’

Gaetan is in his early 40s and lives with paranoid schizophrenia. His ‘schizophrenic illness’ emerged about a decade ago when he was studying medicine.

‘I just had a young family ... when I was first admitted,’ he told the Royal Commission. ‘I lost everything that I was doing at the time. I lost my career.’

Since his diagnosis, Gaetan has been in and out of acute mental health units under a compulsory treatment order.

‘More often than not’, it’s the police who take him to hospital and they’re ‘quite reasonable’, he said. ‘But it’s ... what goes on in the psychiatric wards ... that concerns me.’

During involuntary admissions, Gaetan said, nurses have given him medications that resulted in him ‘losing consciousness’.

‘Subsequently losing a day, waking up with bruises on my arm, not being able to explain those bruises.’

He feels mental health workers have mistreated him, particularly with ‘the microdosing’ of drugs without his consent.

‘I’ve had a number of experiences where I’ve been very, very concerned that I’ve been drugged without my knowledge.’

Gaetan has been on ‘seclusion cells’ for treatment.

‘It’s one thing to do something like hypnotise someone, possibly expose them to electroconvulsive therapy ... against their consent on the basis of legislation which seems to allow this stuff. But it’s another thing to do it without their knowledge altogether ... This stuff happens in seclusion.’

Once he was admitted during a schizophrenic episode.

‘I was very paranoid that patients and nurses had been delegated tasks to intimidate me, to torment me. And I got into such a state whereby I was dragged to the HDU, which is ... the high dependency unit.’

Gaetan was resisting, so four staff tackled him. One of them ‘looked like he was straight out of the Hell’s Angels’.

‘I make no bones about it. I can be difficult in there, because I feel like my rights are being violated, you know ... They injected me with something that made me feel like I’ve never felt before.’

Nurses told Gaetan it was a medication for anxiety. 'But it wasn't,' he said.

'And it's not the only time it's happened ... I just wanted the injection that I was having to be made up in front of me, so I could see.'

Until recently, Gaetan was under the care of the public guardian. His case manager was supposed to find him accommodation for when the hospital discharged him, but 'made next to no effort whatsoever'.

Once a nurse told him they could 'discharge someone to homelessness', which he found cruel. But it came to fruition when the case worker 'dumped' him with his bags at a caravan park.

'[Since then] I've been living in pubs, lodges ... those types of things.'

About a year ago, Gaetan 'got off the public guardian'.

'Because I was doing well ... It's just another thing that takes away your self-agency, your self-advocacy. I mean, my life was much harder ... I went downhill.'

Today he's on the NDIS, is working as a volunteer and recently found himself a flat to rent.

'I'm back in control of things, which I'm grateful for.'

Gaetan wants the 'behemoths' of the state mental health system to treat people with mental illness 'therapeutically' rather than 'punitively'.

Zaiden

Zaiden, whose health issues include fibromyalgia, sciatic arthritis, depression and anxiety, hasn't been able to work since the mid-1990s. In the early 2000s he began receiving a Disability Support Pension. Then in the early 2010s, he was involved in an accident which left him with permanent injuries.

'And basically, since then, things have not been at all positive ... and actual potential for actually improving the situation has pretty much evaporated,' Zaiden told the Royal Commission.

At the time of the accident Zaiden was staying with a family member while he looked for his own place. The accident upset that plan, and the stress of finding another home fractured his relationships with family.

'In the end ... I was basically forced to move out at very short notice.'

Zaiden moved interstate and found accommodation he thought was permanent but turned out to be short-term. Eventually he ended up in a refuge managed by a charity, which passed his case onto another service provider.

That provider, also a charity, placed him on a three-year government-funded program that provided him with transitional accommodation and expected him to re-enter the workforce.

Zaiden is now at the end of the three years and will soon be looking for accommodation again. He is unhappy with the quality of support caseworkers provided during that period.

'From the beginning it was just a consistent pattern of really not taking what I say seriously and not believing me ... At one point it became obvious to me, sort of. Things maybe weren't sinking in as to how dire my physical situation was and that I really needed to be placed in permanent accommodation asap rather than put through three years of [the program].'

Zaiden described numerous instances where caseworkers neglected or ignored his needs.

These included a senior caseworker calling Zaiden's doctor to cancel an appointment they were supposed to attend together. They assured Zaiden they would reschedule the appointment for the following day.

'You can't just ring up and say shift an appointment from today to tomorrow. At the moment it's a six-week waiting period,' Zaiden told the Royal Commission.

Other caseworkers consistently failed to show up to weekly appointments with Zaiden, despite his Centrelink benefits being dependent on regular meetings.

'We were supposed to be meeting once a week and it got to the stage where maybe one in four appointments would be fulfilled.'

Zaiden met with caseworkers to talk about his concerns, but it seemed pointless.

'Like, okay, we spent an hour discussing, you know, the simplest of things. "That's an hour of support that we gave him this week," you know, "making him reiterate things that he's told us 100 times before."

These interactions affect his mental health.

'Yeah, at times the attitude and the way they blatantly misrepresent the way things are, just everything basically, actually has me questioning my own sanity. But then I go – no, it's not me.'

'I said to them early on in this process, I said, "Well it just seems like all you can do, all you're willing to do, is put me in touch with other people" ... They kind of said the answer was, "Yeah, that's pretty much it." But then even that evaporated ... And in actual fact, like, just the simple way they operate has amplified my anxiety.'

Dominique

Dominique is in her 50s and has a congenital condition that fused the vertebrae in her neck. 'My hands are disabled and I have very limited head and shoulder movement,' Dominique told the Royal Commission.

About 30 years ago, she had surgery to try to save some function in one hand. On the operating table, unknown to her and against her wishes, a surgeon performed an experimental procedure.

'That operation failed dismally. It took another 40 per cent use of my hands.'

Dominique said she discovered that, because she was 'legally disabled' at the time, she couldn't sue for disability 'even if they made it worse'.

'It took seven years, you know, in therapies and exercises and thinking creatively, to finally regain my independence.'

Dominique then applied for a job in the public service that required her to drive.

'I had obtained the exemption to not wear a seatbelt because when the sash of the seatbelt is pinning me at my shoulder, basically, in a serious accident ... I would not survive. Seatbelt or not, it's not saving me. Whiplash is deadly for me due to the neck deformity.'

One day, a colleague admitted to her that he had assaulted another woman. Dominique reported it to management.

'That's when the bullying started.'

Dominique's employer told her she was no longer able to drive for workplace health and safety reasons. She believed there was no legal justification for their decision, but not being allowed to drive prevented her 'from meeting the inherent requirements of [her] job'.

'They were vicious. They were bullies. I mean I couldn't sleep. I couldn't eat. It was horrendous going through everything they were doing to me ... I did end up resigning for my own sanity, and settled. And I have not worked since.'

Dominique said the psychological impact was 'huge'.

'Psychology, you know, I never really deemed myself disabled until [the department] did what they did to me. So then, by the end of it, all I could identify myself as was a disabled person.'

Kristen

Kristen is in her 50s and has multiple sclerosis. A decade ago she moved into a nursing home.

‘I said to mum, “Mum, you’re not looking after me ... I’ll go to aged care. You live your life.”’

Living at the nursing home was ‘crap’. ‘You don’t want to know what it is like,’ Kirsten told the Royal Commission.

A few years ago, Kristen moved out of the nursing home and into specialist disability accommodation (SDA).

‘I love the apartment ... I can do what I want, when I want and how I want ... [but] the whole module is not good for everyone. It doesn’t work. The reason being [there’s] one staff for 10 high-needs residents. One staff between 10.’

The NDIS supports Kristen. She employs her own support worker during the day, but at night relies on staff of the service provider that runs the SDA. She can wait up to an hour for the only overnight support worker to respond to her buzzer.

‘At night time, why is there only one staff? And I’ve been told many times, “Just use a pad. Just use a nappy.” That is so degrading.’

Kristen said she pays more than \$60,000 a year for the SDA, but has no say in who the provider employs.

‘You should be able to choose what carers they want ... They’ve got to be highly qualified. At the moment ... I’m probably going to swear, but they’re pretty bad.’

The service provider’s staff appear to be untrained and often ‘stand there and twiddle their thumbs’ when Kristen asks for help.

‘They’re only in it for the money. Which is great – we all have to work for money – but you must have a passion. You must love your job as well.’

Kristen said the NDIA is slow to respond to her requests for help. The costs and wait times for equipment are ‘ridiculous’.

‘Whether it’s a commode or a wheelchair, as soon as you mention the word “disability”, wow, it goes triple the price. I’m praying. I’m still waiting for my wheelchair to get modified. It’s what, maybe over a year? Nearly one year.’

Kristen would also like the NDIA to fund a sex worker.

‘It’s good for physio and it’s good for your mental health and you’re killing two birds with one stone. Why can’t we have it once a month? Is it so wrong? ... I’d like to feel normal.’

Kiernan

‘Those organisations are really about controlling the client and holding onto their cash cow and going to whatever lengths they have to.’

Kiernan is in his 40s and has neuromyotonia, which causes severe muscle twitching, stiffness and cramps.

When doctors admitted Kiernan to hospital several years ago, his NDIS service provider stopped all his supports.

‘They didn’t make sure I had a mobile phone, wheelchair or anything like that. They just cut it off straightaway ... like zero notice,’ Keirnan told the Royal Commission. ‘My carers didn’t want to leave me just abandoned, so a couple of times they went in to ... make sure I had basic things ... As soon as the organisation found out they just forbid them to come and help me.’

Kiernan said he couldn’t charge his phone so he couldn’t let people know where he was. When he was discharged, he had no-one to help him get home.

‘I had to try to talk anyone who was going past to try to get someone to bring a hoist or something to get me out of bed into the wheelchair.’

He then had to load his belongings onto his wheelchair and leave the hospital.

‘I had to MacGyver my way out of the situation.’

Because Kiernan didn’t have his wallet to pay for a taxi, he had to ‘ride [the wheelchair] all the way home with all [his] stuff’.

Later when he returned to the hospital for major surgery, the same thing happened.

‘The provider would forbid me from having anyone ... It meant that I couldn’t get out of the hospital so I was stuck there for nearly a month.’

Kiernan hired his own support worker to help him get home. He said he understands that the NDIS doesn’t fund support workers in hospital, but it can lead to neglect.

‘There’s disability support and nursing. They’re two different roles ... I know that if I go into hospital again under NDIS rules ... I’m going to find myself in the same situation, stuck in hospital again for a month ... and having to ride [the wheelchair] home. And my condition is not as good as it was then.’

Not long after the hospital discharged Kiernan, his service provider asked him to sign a new contract.

‘They’re not like a residential tenancy contract, you know, an actual contract with sides. It just was all one-sided. They wanted six weeks notice for me to leave them ... But they were able to withdraw service without any notice.’

Kiernan said the organisation bullied his support workers to try to get him to sign the contract and told him if he didn’t sign, he couldn’t employ those workers independently for a period of time.

‘Time ... was important because I needed carers right away. I just left that organisation altogether. I didn’t get their services at all from that point. At that point I thought it was all over.’

The service provider then sent him a bill for several thousands of dollars, ‘for the time that they were denying [him] service’.

‘So they leave me abandoned with no service and send me a bill for that time.’

Kiernan ignored the bill.

‘I just thought that was absurd. And I also knew that I could prove that they didn’t supply that service because of conversations. I kept the emails [from them] making it clear that they were denying service.’

The service provider hired a law firm and a court sent a bailiff to his home demanding he pay the bill for services he didn’t receive.

Quote: ‘It was like robodebt on steroids.’

Kiernan persuaded a community lawyer to countersue, and the provider ‘withdrew their lawsuit’.

‘The amount of stress it caused me, I was shaking that much I couldn’t sleep ... It affected me health-wise over the long term.’

Seb

As a young man Seb, now late 50s, was diagnosed with schizophrenia. A doctor later told him he had post-traumatic stress disorder (PTSD), not schizophrenia.

In primary school Seb had very low grades, but no-one offered him any support.

In high school students bullied him and he found it very difficult to make friends.

Seb has experienced physical violence. One time someone broke into his home and threatened him with a gun.

Seb told the Royal Commission the health system only sees the schizophrenia 'label'.

'When a person is not labelled properly the system will come down on them. And then there is a paper trail for others to follow which is not correct.'

A few years ago, Seb hurt his leg and was having chest pains and had to go to hospital.

He told staff he'd had an argument with his family and was living in his car temporarily.

'Two security guards come and take me away, nicely, to psych services without any explanation, none whatsoever. Ended up putting me in hospital for 10 days, medicated. I felt like a prisoner in another country.'

Recently Seb moved interstate and said the hospital system there is better.

'They don't just grab you and lock you up and throw the key away. They allow you to speak, so they know where you're coming from,' he said. 'I believe patients should be helped to express their thoughts and feelings on situations ... so that people like myself don't get caught up in the system where they shouldn't be.'

Seb believes people see his 'poor education' and inability to express himself as a weakness and have 'exploited [him] in many different ways'.

'They've overlooked me as a person and I believe I'm quite a nice person.'

A psychiatrist is treating Seb for his PTSD and has changed his medication.

'I believe with the right guidance and encouragement I can get back into the workforce. That would be nice. It doesn't help when you're poor.'

Clem and Viv

Viv is the mother and guardian of Clem, who's autistic and non-verbal.

'He's really quite violent at times,' Viv told the Royal Commission. 'I've been hit by [Clem] on a daily basis ... I'm now [over 70], so no spring chicken.'

Viv had to relinquish care of Clem more a decade ago because 'things were quite dire'. Clem entered a group home where, one day, another resident attacked him.

'All the staff were aware of what happening. This new client was actually targeting [Clem], trying to kill him.'

After several months, the police warned Viv not to send Clem back into the house. Viv said she asked the NDIA for emergency accommodation, but they told her Clem had to return to the same house.

'I said, "You're sending [Clem] back to be killed." And [the NDIS employee] said, "Well, that's the safest environment for him."'

After appealing that decision, Viv moved Clem to another group home.

'I dealt with 62 different personnel between NDIS and NDIA over the issues with [Clem] in the house and trying to get better supports for him.'

Clem began damaging the house. Viv proposed moving him to her preferred service provider, which employed staff who had worked with Clem before. However this provider wasn't registered with the NDIS.

'[An NDIS employee] denied the provider of choice. We went backwards and forwards ... We asked for him to have transition funding so he could transition out to somewhere else, to actually go into another accommodation place, and she denied everything.'

The group home eventually evicted Clem for damaging property and Viv has since struggled to find appropriate support. She bought Clem a house and employed a series of service providers, but they subsequently quit as well.

'They shouldn't just walk away. Like [Clem] is a 24/7 person so I've had to come back in irrespective of, you know, my health and ... do the support of him. I'm at risk ... I mean, he's given me concussion.'

Clem recently contracted COVID-19 from a support worker and had to isolate. The service provider told Viv it could no longer care for him.

‘I was due to have my first knee replacement on the Monday and I have very low mobility, I’m on a walker and find things quite difficult. It really blindsided me ... It was just a dreadful mess. So I found that really quite difficult because I couldn’t even shower [Clem]. I found it very difficult because I was in such a bad way with my knee.’

Clem’s most recent service provider also quit and claimed for services it didn’t provide. Viv said it’s becoming more difficult finding service providers that can support people with complex needs.



Artwork by Lorraine Cooper

Connie

Connie is a mental health professional. She was drawn to her work because of her own experiences as a teenager in the mental health system.

Connie grew up with abusive parents and, by the time she was 12, wanted to take her own life. She experienced severe depression and continued to have thoughts of suicide. At 16 she developed an eating disorder and spent time in an adult psychiatric hospital. She told the Royal Commission the nurses there were 'horrific'.

'The things that I was told about myself at that age were, "You drag everyone else around you down. You need to look in the mirror and smile more."'

Connie, now in her late 20s, was recently diagnosed with autism. She also has attention deficit hyperactivity disorder (ADHD), complex post-traumatic stress disorder and dissociative identity disorder. She is angry no-one diagnosed her autism earlier.

'I am very autistic and I am proud of that, and it's a huge part of my identity. But, you know, it should not, like, the signs have been there since I was one.'

That late diagnosis is 'not uncommon', she said, 'especially for females because the diagnostic criteria for autism are biased towards male presentations'. Medical professionals also often miss ADHD for the same reason.

'And it's just, like, it's actually a sexist issue that we are, like, our presentation is different. But it doesn't mean that we suffer less.'

The medical treatment Connie received as a teenager was not effective for someone with autism and ADHD.

'I was chemically sedated without consent. It was like, "You take this or we're pinning you down and forcing these drugs into you" ... So perhaps if someone had explored that further, they would've realised I didn't need to be on antipsychotic medications because I'm not psychotic. I have ADHD. I needed to be on stimulant medication because that is the correct treatment for ADHD ... So I spent 15 years receiving inaccurate and inappropriate diagnosis and treatment, and it got worse and worse because of that.'

By the age of 18, Connie was 'doing a little bit better'.

'I somehow poured myself into, like, reading's always been my thing. So I poured myself into reading every recovery book I could get my hands on. Coz I sort of realised no-one was going to get me better unless I did it myself, basically.'

Connie enrolled at university, where she ended up in an abusive relationship.

She is seeking regulatory consequences for the abuser, and is also pursuing a civil claim. She told the Royal Commission that following up these matters has had been very difficult for her.

'Like, financially, emotionally, it has broken me to do this. And I will get there, and I will get through it. But something has to change, because this is bullshit. And it's not good enough on any level ... Why is he still working? Why, as the victim, did I have to go through and do all of this and retraumatise myself again and again and again and again, and continue to have to do so? ... I am – I don't want to just tell my story, I want this changed. Like, I'm done just telling it to people. And I'm done with, "Poor you, poor you."'

Baxter and Melania

Baxter is in his late teens. He told the Royal Commission he likes motorbikes, computers and 'hanging out' with his mates. He has autism spectrum disorder (ASD), anxiety and psychosis.

Melania, his mother, has several children with ASD, 'all in varying degrees'.

'They've all had a hard time because we haven't had any supports,' she said.

Baxter was diagnosed at six. Melania said he had 'lots of learning difficulties' at school. He was 'really anxious' with 'quite significant dyslexia', but there 'were no supports in place'.

When he was about 15, Baxter 'became very unwell'.

'[He] started having these, like, psychotic features. So he'd have voices and whatever else. He didn't want to tell anyone ... he thought he was going crazy.'

A couple of years ago, Baxter made his first suicide attempt. 'He didn't know what was going on, so he thought his only way out was that,' his mother explained.

His parents had Baxter admitted to an adolescent mental health facility to 'keep him safe'.

After a couple of weeks, he went back to his family for a 'homestay', but his antipsychotics were yet to 'kick in' and 'it did not go well'. He had lots of 'psychotic episodes' and was 'very violent', Melania said.

'[One time, he] was sitting in the loungeroom, just slicing his arm and just – with blood coming out and with a knife – threatening to kill himself.'

Melania called an ambulance, but he couldn't be admitted to the adolescent psych ward as it was full. She told the Royal Commission there are less than two dozen beds in the state for acute adolescent mental health.

'They pick and choose ... Once you've been once, they really don't take you again ... So there was no-one to look after him.'

Melania tried to get Baxter into a private clinic instead, but staff said they were 'not qualified' to care for her son until he turns 18. Each time he needed care, there was 'nothing other than police and ambulance' to take him to the adult psych ward.

'That's traumatic. You've got police coming into the house ... but that's all I could do. Who else do I call on? There's no-one else.'

Melania said it has been 'ridiculously hard' to get Baxter an NDIS plan. A few months ago, he finally got a 'small allotment'. His diagnosis of 'ASD level 2 with psychotic features' limits his supports.

'[He] doesn't fit the mould because he doesn't have a diagnosis of schizophrenia or anything like that ... They don't take into consideration all the hospital admissions, all the inpatient admissions.'

Melania feels her son is a 'victim of neglect'.

'There is nobody there to kind of recognise, you know, [his] disability.'

She gets 'really peeved off' that psychiatrists won't diagnose him until he's in his 20s.

'It probably is schizophrenia and, like, [he] wants to just address it ... If all the symptoms are there ... and it does present around the age of 16, 17, and yet they still won't diagnose it.'

With the medication, his psychosis is 'all good now'. But Baxter's 'gone from 105 kilos to 220 kilos' in a couple of years, as his anxiety is 'so high'.

Melania is hopeful that he'll receive more NDIS supports to get him into appropriate housing. Baxter's support worker has already made 'a huge difference'.

'He gets eight hours, and he goes out ... a guy comes in and he goes out motorbike riding or whatever else.'

Freddie and Meg

Freddie, late 50s, has a rare genetic syndrome that causes development delay and learning disability.

Meg, his mum, is his only surviving family.

Freddie has been living in the same home for more than 15 years.

When the NDIS was established, a large disability service provider began managing the home.

‘The first year or so they were sort of on their best behaviour because ... it was like a probation,’ Meg told the Royal Commission.

After about year the old staff started leaving. New staff were casual and the standard of care declined. Meg discovered the new staff didn’t have any qualifications or experience. She believes the provider was trying to save money.

‘Our family are just cash cows, that’s all they are.’

Meg told the Royal Commission Freddie started suffering.

A speech pathologist had developed a feeding plan for Freddie to help him swallow and avoid choking. Staff needed to sit on his right and feed him slowly.

One lunchtime Meg arrived for a visit. She saw a staff member standing at the end of the table with his arm outstretched trying to feed Freddie.

‘The food was just all running out the side of his mouth.’

Meg asked the staff member what he was doing. He put the plate down and asked if she was going to make a complaint.

‘I said, “You can bet I am.” And that’s where it all started.’

The provider covered for the staff member and asked a speech pathologist to review Freddie’s feeding plan. Meg refused because he’d only recently been assessed.

‘I was assertive, they were quite frustrated with the fact that I could question them as the guardian.’

The provider became ‘vindictive’ and made an application to become Freddie’s guardian.

At the hearing, the administrator decided Freddie would be best served by the public guardian because the dispute was between the provider and the parent.

‘Ever since he’s been under the public guardian nobody’s caring for him.’

Now when Meg rings the house to ask how Freddie is, staff refuse to give her information, telling her to contact the public guardian.

Meg said the house is very cold and the heating is never turned on.

‘The staff ... they all come in rugged up ... and the residents ... they can’t create their own body warmth because they’re just sitting and they’re not moving around.’

More than one resident has died of pneumonia in the past year.

Recently an ambulance took Freddie to hospital.

Meg rang the home desperate to know what had happened and whether he had pneumonia. Staff told her to talk to the public guardian.

‘Under the public guardian I have been completely treated like a leper.’

Freddie did have pneumonia and is still recovering.

Meg said the public guardian doesn’t communicate with her about Freddie’s health and liaises directly with the provider.

‘They won’t even tell me he’s gone to the doctors ... I don’t exist anymore as his mother.’

Sandi

Sandi has worked as a disability support worker and team leader for more than 10 years.

Recently she worked in a home with several residents who have acquired brain injuries, cognitive disability and high support needs.

The home is purpose-built, state of the art. The television remote operates not only the television but the temperature, lights, blinds and some doors. The provider charges the residents a premium to live in the high-tech home. But the residents don't know how to use the system.

'It was great for all the fat cats to pat each other on the back during media interviews,' Sandi told the Royal Commission, 'but the house is so understaffed ... They're in this brand-new house. And they're just stuck in there doing nothing.'

Sandi was second-in-charge to a 'dodgy' team leader.

The team leader coerced residents to buy items for the home.

'They were things they never asked for and are unable to use.'

Recently one of the residents died.

The team leader had encouraged Sandi to buy furniture and machinery for the outside areas – he used a wheelchair and couldn't use the items. Sandi said he was 'very possessive of his things', telling her he hoped to give them to his sisters and nieces.

Just before his sisters arrived to collect his possessions, the team leader went to his room and unlocked his safe. She removed his moneybox – saying, 'I'll be keeping that for the house' – and all the receipts for the items he had bought.

Sandi asked her to give her the receipts but she refused.

Sandi told his sisters about the items. She then informed the team leader that the resident's sisters would be taking the items.

'She became really aggressive and said, "How did they know about them?" And I told her that I told them.'

The team leader organised a memorial for the resident. She collected several hundred dollars, but it never went ahead and she kept the money for herself.

Sandi said residents and staff were scared of the team leader.

The team leader once coerced a resident into putting utilities in his name so the home could get a pensioner discount. She then yelled at him to turn the heating off even though the home was freezing. She threatened him with the bills if he didn't, telling him she would make him pay.

Sandi also heard her threatening another resident, telling him she would send him to an aged care facility if he didn't do what he was told.

A resident who had a brain injury lost his inhibitions one day and grabbed the team leader's arm. She responded by grabbing him by the throat.

When Sandi told the team leader that staff morale was low, she didn't care. 'Oh well. If they leave, they leave,' she said.

Sandi made a formal complaint to the CEO and the NDIS Quality and Safeguard Commission.

About a week later, the general manager stood her down without pay because someone had made a complaint against her.

'I asked what the complaint was, because in [all my] years I've never had a complaint [against the general manager]. So they stalled and stalled.'

In the meeting, Sandi raised her complaint about the team leader but they shut her down.

Six other staff made complaints, but management responded, 'You're all in a click together.'

Management moved Sandi to a different home.

She felt she had no other choice but to resign.

Ita and Cristina

Ita is in her early 60s and has early onset dementia.

‘She was still laughing and joking around and she went on daily walks ... she was still living at home with my dad,’ her mum Cristina told the Royal Commission. ‘I should also mention that my mum is legally blind so that is another added complication.’

Ita recently fell in the shower.

‘The paramedics came and assessed mum and kind of said, “She’s fine.” So they popped her back into [bed].’

The next day, Ita was unable to move and Cristina’s dad called the ambulance again.

‘My mum had to wait six hours [for the ambulance] ... Because she had dementia and she comes across as someone who has dementia, I think that this was disability discrimination.’

The hospital discovered Ita had broken her hip and needed surgery. She later developed a urinary tract infection (UTI).

‘They didn’t actually treat her UTI for a week, you know. And they weren’t giving her any sort of medication ... UTIs can cause delirium and have very serious impacts on a person with dementia.’

Cristina said her mother’s behaviour deteriorated and staff struggled to give her physiotherapy. When Cristina and her father offered to help during a COVID-19 lockdown, the hospital denied them exemptions to attend therapy, even though they were allowed to visit to help feed Ita.

‘Like, she’s responding in these ways because she doesn’t know these people, they are strangers and she is stuck in a place she doesn’t recognise ... Every time I was there, she was calm. Every time.’

The doctors eventually decided to stop Ita’s physiotherapy.

‘They’re saying, “Well, she has advanced dementia. We can’t do that therapy. She’s too combative. She’s too aggressive” ... There was a lot of dismissal of her needs and I think it’s because she has dementia, you know, and they put her in the too-hard basket from pretty much the moment she arrived.’

Cristina said the hospital staff ‘didn’t have the patience’ and gave Ita antipsychotic medication to restrain her.

‘They didn’t explain to her what was happening, they didn’t even tell her what they were doing to her ... People treat their animals better than they treat people with dementia.’

Cristina said Ita can't go home because she is now bed-bound.

Cristina and her father applied to the NDIS for support, which 'at the start was amazing'.

'The hospital is adamant that mum needs two carers ... We were looking at supported independent living and supported disability accommodation because those seem suitable with two carers. The NDIS said, "Well, that's too much. We can't pay for two carers. It's too expensive."

Cristina said neither the hospital nor the NDIS are supporting Ita appropriately.

'This is a woman who went into the hospital joking and laughing and dancing and singing. And they refused to give her the care that would mean that she could leave hospital and go back home because they just said, "She's too demented," pretty much, you know, which wasn't the case.'

Luciano and Sigrun

Luciano is autistic and has apraxia, a motor speech disorder.

‘But basically, he’s a pretty smart kid,’ his mother Sigrun told the Royal Commission. ‘He had a comprehension level of more like a six or eight-year-old when we tested him ... but he didn’t have the language. Like, when he enrolled into prep, he had probably 100 words. So he’s very delayed with talking and stuff like that.’

In prep, Luciano got no support for his speech problems. ‘There was nothing ... It’s now turned into a language disorder and a speech disorder,’ Sigrun said.

Halfway through the year he became ‘really school-refusal’. It was at this point the psychiatrist diagnosed Luciano with autism spectrum disorder (ASD).

Sigrun moved Luciano to a new school that ‘indicated they would be more supportive’. She went to great lengths to explain his condition and that he was ‘not your typical ASD kid’.

Grades 1 and 2 went well. But in grade 3, everything ‘just went downhill’.

A new inclusion teacher came on board and immediately put Luciano in a foreign language class. Because he was struggling, the school decided he had an intellectual disability.

Luciano had ‘specific apps’ to support him in class. Sigrun had paid someone to train teachers how to use them. But the new teacher wouldn’t allow them, telling Luciano to ‘never bring them out again’.

‘They just grabbed some teacher and put her in the role of inclusion. They’ve never assessed him ... They treated him as intellectually impaired, they secluded and segregated him.’

Luciano became unhappy and started having ‘huge rages’.

Sigrun enrolled him in a state school for year 4. It promised to provide Luciano with the supports he needed, specifically occupational and speech therapy, but didn’t.

‘They put 60 kids in one room with two teachers and one support. So he wasn’t learning ... he’s getting frustrated. They’re giving him work that was beneath him. He felt that the teachers bullied him. He’d come home saying, “They’re not helping.”’

The school had extra funding to support Luciano’s reading, but ‘the only thing they ever did’ was a reading assessment.

Sigrun said the school never ‘properly assessed’ Luciano. It used an autism diagnosis to get funding for his educational adjustments, even though she had explained that Luciano wasn’t ‘suited underneath the ASD verification’.

Sigrun said the school has altered Luciano’s ‘entire file’ to the point that ‘is just false’.

‘They have adjusted his attendance records saying that he was there when he wasn’t. They put down that he loses his language when he becomes mad. They put down that he has issues to noise, which he doesn’t.’

Despite that, ‘none of these adjustments [for autism] were in place’. Meanwhile Sigrun was ‘begging for them to provide him with speech support’.

‘They were accessing both federal and government funding on behalf of my child. And the principal thinks of it as their pay packet.’

Luciano is ‘upset’ that’s he’s going into high school after making no progress, and Sigrun is scared.

‘I’ve had to push and fight for everything for this kid ... This last school was the worst ... I don’t want to keep fighting for what is actually rightfully his.’

Haylie and Isobell

Haylie is autistic and has cerebral palsy and epilepsy. She is non-verbal and uses a wheelchair. About 10 years ago, Haylie moved into a supported care facility when her mother, Isobell, could no longer care for her.

At first all went well. But after a few years the service provider brought a new client, Jasmine, into the home.

‘And this client is a very big client,’ Isobell told the Royal Commission. ‘She has extremely violent behaviours.’

Isobell said Jasmine ‘abused everybody’.

‘She punched people, she hurt them. It wasn’t just the clients. It was the staff. The other clients – as you know, the staff aren’t allowed to touch the clients – and they all used to be able to get away. But [Haylie], being in a wheelchair, couldn’t. So [Haylie] became a target.’

Isobell noticed that Haylie had scratches on her neck and her jewellery was broken, but staff at the home didn’t tell her that Jasmine was responsible.

‘So, they lied to me about so many things ... They said, “[Haylie] must’ve done it,” but I didn’t know that [Jasmine] was attacking her at that time and pulling at her jewellery and scratching her neck. I didn’t know this was happening, coz nobody told me.’

As a result of the assaults Haylie started to self-harm.

‘She had to start wearing a helmet because of her self-harming. She had to have a special harness added to the chair because she would throw herself out of the chair. She stands with difficulty now, whereas she used to be able to get out of the chair. She had no restraints before she went into the house. None. She used to be able to get out of the chair, get onto her bed by herself, do everything.’

One day when police were at the home they noticed the interaction between Jasmine and Haylie. ‘They said, “This needs to be stopped”,’ Isobell recalled. They went to court and asked for a restraining order against Jasmine, but the judge did not agree.

Isobell was not the only one concerned about Jasmine’s behaviour, and eventually the NDIS oversight body became involved and required the service provider to move her to a different unit.

Isobell hoped this would mean that Haylie’s place at the home was secure, as it was now a facility only for wheelchair users. But the provider asked her to leave.

'They don't want behaviours ... Well, that means they don't want the trouble,' Isobell said.

Isobell believes this is unfair, given Haylie's difficult behaviours are the result of Jasmine's abuse.

'I mean, she shreds her hands. She bites her hands so hard. She's got permanent scars, and she just shreds them. She's very, very angry ... I can't even control her now, and that really upsets me ... But, so, we're looking for houses for [Haylie], but it's going to be a really very hard transition, because she's going to be so stressed out because of what has happened in the past ... The way she is, she's not the girl that went into that house. She's a totally different, angry person.'

Choco and Amie

Choco, late 40s, is autistic and non-verbal and has intellectual disability and anxiety.

He lives in supported independent living (SIL) accommodation with two other men who also have high support needs.

‘He has had incidents in the past,’ his mother Amie told the Royal Commission, ‘where he has been hurt or neglected by staff’.

There was a house manager and a community access worker who, instead of taking Choco to his day program, would drive him to their homes. They would go inside and leave Choco outside in the car, sometimes for hours.

Another time, a former resident physically abused Choco until staff eventually removed the resident.

The service provider addressed the incidents, but they caused Choco’s anxiety attacks to become more frequent and intense.

‘He will drop to the ground ... sweating not wanting to be moved.’

Recently Amie noticed severe bruising on his arms. She believes a support worker tried to pull him up during an anxiety attack.

Amie says there is ‘a large input needed from staff to be able to support all three men’, and there isn’t enough funding to adequately staff the home.

Over the past couple of years, the NDIA has cut the men’s funding and the provider has reduced staff numbers.

Sometimes there is only one staff member ‘trying to deal with everything’ – support, personal care, shopping, food preparation, washing and cleaning.

Amie tried to get the NDIA to fund some housework, but ‘they have doggedly refused to do this’.

Staff don’t have time to help the men participate in the community or do capacity building activities.

Choco has a communication device but staff need to be able to respond to him immediately, which is not always possible.

‘I think that adds to his frustration and to his sense of anxiety, because his needs can’t be met.’

Amie wrote to the NDIA detailing the neglect Choco and the men were experiencing and asked for a review.

'I expected to get a reasonable response from them, and I got absolutely nothing back ... no acknowledgment that they have received it.'

Amie has found it difficult to find someone to talk to.

'The whole system needs to change to make it more friendly for people to be able to access and use.'

In the end Amie had to go into an NDIS office and show them photos of Choco's bruising and further specialist reports to get a review.

'I don't necessarily hold out hope that it's going to make an enormous difference. I'm hopeful that we can make it better for [Choco] and the men in the house, but something has to happen in terms of this disparity between what the NDIS is saying they value and what they want to do to help people, and the fact that they're not staffing, in particular, the SIL funded group homes.'

Bridie

Bridie became a disability support worker 20 years ago.

'I just loved it,' Bridie told the Royal Commission. 'It felt like family ... It wasn't so much the staff, it was working with the clients. Yeah, I couldn't really care less about the staff, to tell you the truth.'

A decade ago Bridie was working for a government disability service when she developed epilepsy.

'Having epilepsy [I] saw the other side ... You have slurred speech, you can't remember things, and so people look at you like you're drunk or you're a bit of an idiot and, yeah, you develop a hell of a lot of empathy.'

Bridie lost her drivers licence, which restricted where she could work. She decided to enrol in a diploma in disability.

'I also left because at the time there was a staff person who was stealing in the house that I was working at and I put them in ... I felt that it should have been an instant dismissal, but they moved them to a house where the clients were more vulnerable ... It just broke my heart.'

Bridie said it took several years to get her epilepsy 'under control'.

When she returned to office-based work in a group home a few years ago, she discovered the service provider was no longer regularly reviewing client management plans. The clients' changing needs weren't being met.

'Every 12 months we'd do like an annual plan ... We don't do that anymore.'

One day, Bridie saw a support worker in an understaffed group home push a client and tell him to 'fuck off'. Bridie came out of her office to 'quieten the client down' while the support worker went outside to smoke.

'Then [the client] attacked me and my only escape route was back out to the office.'

She found the door locked and the client bit her. She calmed the client down, but when she was cleaning up she noticed her 'glove filled up with blood'. It was a couple of hours before she saw a doctor.

Bridie said when she reported the incident to management, they tried to link it to her epilepsy.

'My epilepsy has been the blame of everything since.'

Bridie developed post-traumatic stress disorder (PTSD) and took some time off work.

But management told Bridie she was 'having too much time off'.

When she returned to work for a few weeks, a manager 'raked [her] over the coals' and offered her a demotion.

'I can't go back there. No. It's not a nice place. It's really not.'

Salvador

‘They say I don’t need it, it’s not a part of my disability. I said, “You don’t understand nothing, mate. Everyday life is part of my disability.”’

Salvador is a First Nations man in his late 50s. He broke his neck playing sport about 30 years ago.

‘I was a sportsman in all codes’, he told the Royal Commission. ‘I didn’t know I was gonna end up in a wheelchair for the rest of my life.’

Salvador spent a couple of years was in hospital.

‘It took me nearly three years just to sit up ... The [sport] officials never come to see me at the hospital. No-one came to me at all. They left me for dead.’

In that time, Salvador lost his job and ‘had no house to go to’. He waited months for wheelchair-accessible public housing.

‘And then before I knew it, I ended up with no money. I had bills to pay. I’d lost everything ... We had no idea what the laws were for injuries at that time.’

Neither the sporting organisation nor health officials ever spoke with him about his rights to a compensation claim.

‘And they took advantage of me ... because we’re Indigenous. After you get hurt, you’ve got a three-year [statute of] limitations, but I didn’t know nothing about that.’

Salvador struggles to get by on the funds he has.

‘I’ve been on the disability pension most of my life, and I haven’t been anywhere, got anywhere.’

He’s also an NDIS participant, but would rather not be. A few months ago, he got a new plan that was meant to be self-managed. The training the NDIA promised ‘never happened’, so Salvador couldn’t authorise payments and ‘people weren’t getting paid’.

He’s now back on a managed plan with a new provider, but the NDIA won’t pay ‘tens of thousands of dollars’ in outstanding bills. They also keep knocking him back on support.

Salvador asked for a special mattress and accessible fishing lines. Each time he has ‘to go and spend three or four or five hundred dollars getting an OT to approve it’.

'I used to get things pretty quick, once upon a time. Now I've gotta go to ask mum and dad, Tom, Dick and Harry. It's unfair,' he said. 'I ask them for this and that, they won't give it to me ... So I just give up. I wouldn't bother to ask 'em for anything else.'

Salvador's family 'lives a long way' away. The NDIA won't fund one of his sons to be his carer, so he wants help 'to get to Country'.

He feels the NDIA has no cultural understanding of his needs as an Indigenous person with disability.

'It's hard to get everything. Hard to get money ... Nobody wants to employ an Aboriginal man at my age. I struggle now every day because of my injuries. I've lost a lot of weight ... I'm just full of skin and bones.'

Keilani and Min

Keilani was born overseas. She had missed development milestones and when she started school was still using nappies.

Keilani was diagnosed at school with global intellectual disability, and from that point the school communicated directly with government agencies and coordinated speech therapy, occupational therapy and physiotherapy. Her mother, Min, told the Royal Commission she didn't need to do anything. There was no application process and no need for independent assessments.

Then the family moved to Australia. Following a natural disaster in their home country, Min's husband sought a 'bright future' for them here.

Min found it very difficult to navigate the education system in Australia, and there was no-one to support her or advocate for her.

The local state school placed Keilani in year 4 because of her age. Min asked them to place her in a lower grade because she thought Keilani would struggle. The school refused.

After a few months, the vice principal told Min that Keilani needed to go to a special needs school. Min wanted her to stay in mainstream education and begged the school to provide more support.

Min discovered she had to apply for disability supports. But Keilani wasn't eligible for the state's disability program because of the family's visa status.

Everyone kept telling Min things would improve when the NDIS was established.

'When you go on the NDIS, [Keilani] is going to receive funding. You're actually going to be able to get access to support you need,' they said.

So it was a shock to Min when the NDIA refused support. 'No we can't pay. Because you are not a citizen of Australia, you can't have the caring you need.'

No-one told Min she could access other supports.

Without support, Keilani was excluded from education. Most days the teacher made her sit outside the principal's office.

'She developed these bad behaviours of throwing things around, not verbalising.'

Her socialisation and learning skills rapidly deteriorated.

Keilani is a good visual learner, but the school continued to use traditional teaching methods and refused to include disability inclusive strategies.

After two years Keilani left the school and moved to a religious school. But it was no better, and she had similar negative experiences.

Keilani's behaviour has continued to regress. She frequently slaps family members and support workers.

'[Keilani]'s potential is gone – I can't bring it back.'

Keilani is now in her final year of secondary school.

'My daughter is neglected. I don't want it to happen to any daughters or any kids. My daughter need to socialise. I'm begging for nearly 10 years, my daughter need friends. My daughter need friends. She hasn't got any friends.'

Kobe and Esperanza

Kobe is in his early 20s. He has cognitive impairment and a syndrome that causes frequent seizures.

Kobe's parents separated nearly a decade ago, leaving Kobe with his mother, Esperanza. Every few months, he would spend a weekend in respite care.

'I never really felt comfortable because I always feel that he is more comfortable and more safe with me. But for me to have that break, I needed to do that,' Esperanza said.

One support worker, Jackie, was familiar with Kobe's routine so Esperanza asked if she could be the one who was with him overnight.

One morning Jackie called Esperanza and told her Kobe was on his way to hospital. He'd had a seizure, fallen and hurt himself.

At the hospital Esperanza was shocked to find Kobe's injuries much more serious than Jackie's account had indicated. Medical staff agreed and called the police.

Eventually the matter ended up in court, and Jackie was found guilty of a crime.

It emerged that Jackie had a history of erratic behaviour, which the service provider had known about.

Esperanza feels badly let down by the provider's failure to monitor Jackie and keep their clients safe.

Both she and Kobe have been diagnosed with PTSD because of what happened.

'He is just not himself since,' Esperanza said. 'I think the centre has a lot to answer for.'

Esperanza is seeing a psychologist, trying to address the guilt she feels about 'putting [Kobe] in that situation'.

Initially Kobe returned to the same centre. 'I had no option,' Esperanza said. But when Kobe finally got NDIS funding, he was able to have support workers look after him at home.

Esperanza is 'very grateful' for the NDIS, but said it can be hard to find support workers who understand Kobe's needs.

'Sometimes the training isn't – they don't get the right fit of people. It is very hard to get a really good support worker that has got a good heart, because it is not their child, it is not their loved ones,' she said.

Esperanza told the Royal Commission she is concerned that abuse is happening 'too much'.

'I just feel I have got to share my story, because [Kobe] is vulnerable, and all these children and adults with disabilities, they can't fight back. They have got to be kept safe.'

Ellinore and Sandy

Sandy is a support worker for people with disability. In her former job she had a client, Ellinore, who was in her late 20s and had schizophrenia and intellectual disability.

Ellinore required 24-hour care and Sandy worked with her at a group home.

‘She had a lot of trust in me and liked me as a support worker,’ Sandy told the Royal Commission. She was ‘very difficult’ at the outset. Only two other support workers ‘were willing to work with her ... because she wasn’t hitting them’.

‘We understood her needs. As her behaviour support plans became more informed and more focused on communication and affirming her emotions, she became increasingly less violent.’

A few years ago, Ellinore started to tell Sandy that support workers had ‘hit her’, ‘hurt her’, or ‘exposed themselves to her’.

Sandy didn’t ‘know for certain’ it was true, but ‘took it increasingly seriously’ the longer she worked with her.

Ellinore was ‘occasionally, consistently violent’.

‘She had punched me in the face a few times. And so it was not beyond belief that a support worker would retaliate behind closed doors.’

The attitude of other staff troubled Sandy.

‘In conversations between myself and my co-workers, staff would say, “You know she’s not telling the truth,” or, “Well, we don’t have to report it because it didn’t happen.”’

She feels they were ‘not taking [Ellinore’s] disclosures of abuse seriously’ because of her mental illness.

‘I would have liked to have heard staff acknowledge that it was not their job to decide whether or not her disclosures were valid.’

Sandy was ‘generally reporting’ Ellinore’s disclosures to her manager. But management also played it down.

‘[They were] saying that she was only making so many reports with me because she trusted me.’

Together with Ellinore’s behaviour practitioner, Sandy decided to act.

‘I realised how much of a problem this was. And we started doing data collection so that not only myself was reporting this.’

Ellinore's mother reported the abuse to the police a year ago and they contacted Sandy to make a statement. Sandy said there 'wasn't a lot of transparency' around the investigation, but that at least one staff member was being prosecuted.

When Sandy left her job, the organisation was moving to train staff about identifying and reporting abuse, but she believes they are still not reporting all the allegations.

'I just think that there's so many more things that clients are sort of telling us is wrong, but we're just not listening.'

Sandy would like to see 'more training for mandatory reporting' across disability services.

She hopes the Royal Commission might help right these wrongs.

'As cynical as I am about this industry, I do, and I hope it's not naïve to think that this will bring about positive change.'

Euan

'I'm not going to lie, it feels pretty good to [think about] the person at school who said I would be horrible in a business job. It feels so damn good to be good at accounting. I look back at this not with anger or hatred, which I did for a long time. It's just satisfaction that I have proven [them] wrong.'

Euan is in his 30s and autistic.

'I'll probably start with school because that's kind of where, like, physically and mentally, it was at its worst,' Euan told the Royal Commission. 'Being the weird kid ... I got bullied pretty regularly.'

The other kids taunted Euan to get a reaction.

'Even when I try to find somewhere quiet to read a book or play my Gameboy or whatever, people come up, turn my Gameboy off, throw my book in the bin, tear pages out, and then what would happen is I'd react. Because I was the one always reacting, I was always the one getting in trouble.'

Euan loves history, but his school wouldn't let him study it.

'The other students said, "We don't want to study history with [Euan] ... Either he doesn't study history or we don't study history." And so they booted me from history.'

Euan studied history at university, but struggled because he'd missed so much at school.

'Having to learn how to study history while studying history means that my marks were never really good enough to seriously consider academia as a career. And then I just couldn't find a job.'

When he did get a food service job he was never promoted.

'They couldn't tell me why the other people interviewed better, which I just read as, "He's autistic. He's not like everyone who got promoted."

Euan returned to university to do a postgraduate degree in accountancy. He struggled to complete the degree without funding.

'At no point ... did [the university] take my autism into consideration ... so my degree took me three years instead of two.'

When Euan graduated he applied for a job at a large accounting firm.

'I didn't get the job and was gutted ... I thought my autism was going to be the reason I never get a job and I'm kind of stuck in shitty, dead-end jobs for the rest of my life.'

However, the firm called back and invited him to another interview. Euan asked a disability employment service to help him prepare for the interview. He got the job.

‘I’ve finally managed to find something that I’m good at that I’ve turned into a career ... I didn’t know what I’d need, what support I’d need here when I started, and it took a bit of time for us to realise what I need.’

Euan said the firm has a policy of inclusion and trains its staff to understand neurodiversity.

‘It’s funny, there’s a partner here who I reckon he’s probably autistic, and the amount of people that walked out [of a training session] and said, “I reckon [so and so] is autistic, what do you think?” I’m like, “Probably.” But that’s the thing, it’s like they’re embracing my autism and it doesn’t feel like I need to explain I’m autistic.’

Euan said he now feels comfortable asking for reasonable adjustments for deadlines and special equipment.

‘I’ve always had this kind of really slow start to jobs and then, once everything clicks, I shoot up and then all of a sudden I’m one of the best staff members there when given that opportunity.’

His managers meet Euan regularly to discuss his progress, so he knows exactly what’s going on. His colleagues include him in social events.

‘I’ve joined their quiz team with a whole bunch of people that I don’t really socialise with that much,’ Euan told the Royal Commission. ‘I’m a mine of useless information. Anything about Lichtenstein or history, I’m your man.’

‘It feels like I’m not the weird kid eating lunch on my own. I’ve never felt as included in anything be it work, school, social stuff. Like, I’ve always felt with social stuff lots of people just suffer my presence, whereas I don’t really feel that here.’

Zayden and Thad

Zayden, almost a teenager, has attention deficit hyperactivity disorder. Born with a hearing impairment, he needed extensive speech therapy to learn how to speak.

Zayden attended a few religious primary schools.

In year one, other students bullied him because he couldn't 'speak properly,' said his father Thad.

A few years later Zayden had an accident and sustained serious head trauma. He became blind in one eye and deaf in one ear for a period.

While recovering, Zayden returned to school. Two students in the year above bashed him and knocked him unconscious because of his disability.

Thad told the Royal Commission the school 'didn't do anything'.

A few weeks later the same group of boys attacked Zayden's older brother.

Thad and his wife attempted to raise their concerns with teachers and the principal, but the response was 'appalling'.

There was no action or interest at all and the couple felt that they were 'made to feel like [they] were the problem'.

'We found that the school was trying to manage the victims whilst not managing the bullies.'

Thad decided to move Zayden to a different school.

The school told him to 'stay silent' about the bullying or they wouldn't provide a letter of recommendation.

Students and teachers at the new school bullied Zayden, and his mental health deteriorated.

Thad made a formal complaint to the school.

'The principal denied the complaints and then threatened to exercise disciplinary action against my wife and me if we chose to pursue the complaints. We found this to be quite extraordinary, and we found it to be counterintuitive and counter to any of their policies.'

Thad then complained to the regional director of education about the violence and bullying in both schools.

The regional director referred the matter to an independent body.

However the body was not independent but closely associated with one of the schools.

‘We were never told who was investigating. We have never received a copy of the conclusions. We were only told that three of our complaints out of, I think, approximately 15 were upheld. We don’t know what occurred in terms of any consequences at the school for any of the perpetrators or any of the culture at the school.’

The body referred Thad’s enquiries back to the school.

He then contacted the regional director but never got a response.

‘They made it extremely difficult to even communicate with them. So, they basically shut the door on us.’

Zayden is now at a different non-religious school.

‘We’ve lost our community, we’ve lost our friendships.’

Sharlene and Ebony

Sharlene was in her 50s when she died. She was autistic and lived with drug-induced Parkinson's disease.

'She was a victim of years of polypharmacy. In other words, prescription drug abuse, taking up to 14 medications at a time,' her cousin Ebony told the Royal Commission. 'She was dizzy, but it wasn't from her disability dysfunction that her mother tried to claim was still a problem so as to keep her drugged.'

When Sharlene was a baby, her parents took her to hospital because she 'didn't crawl or walk or smile'.

'Her motoric skills were delayed, but following the age of two there was no follow-up through [the hospital], which allowed her mother to conceal [Sharlene's] special needs.'

Ebony said Sharlene's mother found a doctor who 'would write out all the scripts that she demanded'.

'[Sharlene's parents] didn't provide a hygienic home for her. They didn't provide any social stimulations for her.'

When doctors admitted Sharlene to hospital over the years, 'there was no outpatient clinic follow-up in the mental health system'.

'It's left to the GPs to do this. The GPs can't do it usually and the patient and the patient's families themselves are not reliable enough to present for a 12-month review.'

Ebony said that, as a result, Sharlene never received the treatment that could have helped her.

'Had there been follow-up through the public health system ... or if one particular local clinic had been given the responsibility to review her, then she could have at least received counselling to help her understand herself, which she totally missed out on. And [her mother] wouldn't have gotten away with creating her syndrome.'

About 10 years ago Sharlene 'lost her mobility almost entirely'. Because her parents were about to move into a nursing home, they appointed Ebony as Sharlene's guardian. That's when Ebony discovered Sharlene's history of over-medication.

'I was the one who eventually went through her medications and got her admitted to hospital to be weaned off them. She got her mobility back with gusto, and all the aggression that goes with it.'

Ebony struggled to find accommodation for Sharlene. After a nursing home expelled Sharlene for assaulting staff, she lived in a hospital psychiatric unit until a room was found in an 'autism small group home'.

'It took far too long to get her in there ... [Sharlene] has since passed away, but the reason I'm telling the story is I believe that she could have had a better life.'

Lyall, Helga and Milly

‘[Lyall’s] been ripped apart from his family and all his rights have been taken away.’

Helga’s brother, Lyall, has Down syndrome and uses Auslan to communicate.

‘They say he’s non-verbal, but he can talk and he can express exactly what he wants and how he feels,’ Helga told the Royal Commission.

Helga and her mother, Milly, are trying to re-establish contact with Lyall after the department of child protection placed Lyall and his younger siblings with different foster parents several years ago.

‘Every time we’d visit him on access he’d be so happy to see everyone and he’d cry and throw himself on the ground when it’s time for everyone to leave,’ said Helga.

A couple of years ago, before he’d turned 18, Milly was visiting Lyall and he ‘asked to come home’.

‘I said to him I wasn’t allowed to take him,’ said Milly. ‘And he immediately went and got my bag, shoved it on my shoulder and told me to get out. And it broke my heart. And I said to him, “Do you want to come home?” And he said, “Yes.” So I actually took him.’

Child protection wouldn’t let Milly visit Lyall after that. She discovered later that her other children were also denied contact with Lyall.

‘When I found out that they hadn’t had no contact with [Lyall], I rang the [department] and I said, “What is going on? Why are [his] younger siblings not having contact with their brother?” And she said something along the lines of, because there was some fear of me taking [Lyall, again].’

‘Because [Lyall] wanted to run away that day, they’ve blocked [Lyall] from the rest of his family,’ said Helga.

When Lyall turned 18, his family applied for guardianship.

‘We all went to the guardianship board and we agreed for [another sibling] to get guardianship of [Lyall], because we know this is what [Lyall] wants, you know. And it got denied.’

Milly said Lyall was at the hearing, but the board never asked him what he wanted.

‘[Lyall] had no-one representing him or interpreting for him.’

Instead, the board appointed a public guardian.

'I contacted [a child protection officer] to see what will happen now with access, because I had access through Zoom contact right up until he turned 18,' said Milly. 'He said, "Do not contact me at this department anymore."'

They told Milly that Lyall's foster parents would contact her.

'I'm still waiting to hear contact from them ... I have not seen [Lyall] since my last Zoom contact which was ... a bit over a year now.'

McCoy

McCoy, in his early 30s, is a university student. He typically gets distinctions and high distinctions and is soon to graduate. He lives in a housing department apartment with 24-hour care, as he has cerebral palsy, uses a wheelchair and cannot manage alone. He receives NDIS support.

McCoy has had a series of issues with different service providers and support workers. His interactions with one service provider some years ago were so negative he had a breakdown that left him with social developmental delay.

‘The worst kind of emotional abuse that they inflicted on me, or was inflicted by this staff member ... I went from a very confident young man to having a nervous breakdown at the end of year 12 – so bad was her harassment – and needing psychiatric care.’

He told the Royal Commission about other support workers who dropped him on the floor, refused to push his wheelchair and wouldn’t give him anything to eat when they went on outings.

He described ‘one of the worst carers’.

‘She would constantly ingrain into me that I was a bad person, and that I shouldn’t be doing this, I shouldn’t be doing that, I shouldn’t be asking questions ... She thought I was making excuses because of my disability. And I just felt, by the end of her shifts, that she – I was exhausted, and I was glad to see her go.’

He has also experienced poor care during stays at hospital.

‘They leave me in faeces, wet urine pads ... They gave me no food. I was forced to feed myself, even when I couldn’t. I couldn’t even get proper nutrition.’

McCoy said it is difficult to follow up these matters. In his experience, service providers don’t respond to complaints. ‘They’re not budging,’ he said.

He hopes the Royal Commission will recommend the establishment of an oversight body to manage complaints such as his.

‘Somewhere where you can go to, to air your grievances, totally independently from the NDIS.’

McCoy doesn’t believe the NDIS Quality and Safeguards Commission is adequately fulfilling this function. And while he appreciates the NDIS support he gets, he doesn’t think they have got it quite right.

‘I don’t think they listen to people with disabilities, and I don’t – I think they treat us like second-class citizens,’ he said.

‘They’re providing me with care, but it’s not the care that I need. And I still think that the organisations, although they have a mandate to ... listen to people like us and to take into account our wishes and to do what we want, I still think it’s very much not my life, my choice ... if you know what I mean.’

Kirsty

‘Since the NDIS has come in it’s been a lot more difficult to access health care because of the diagnoses that they have on my file. They have misinterpreted what’s going on.’

Kirsty is a mental health advocate in her late 20s who lives with physical and psychosocial disability.

‘[I have] a lot of chronic health issues and things like global developmental delay and speech issues, and a lot of psychosocial issues,’ Kirsty told the Royal Commission.

She has been an NDIS participant for about three years. Initially it ‘opened up a lot of doors’ and helped her function better.

‘I had all of these supports and all of these things that were really helping me. I was really improving.’

Kirsty had a support worker four days a week to help with housework and personal care, to take her to appointments and help her be ‘able to live independently’.

‘It helped me so much that I actually got promoted ... at my work ... [helping] people with mental health issues, which is something that I always dreamed of.’

But then Kirsty got a new plan and ‘everything went awry’.

‘All that support that was helping me to get to where I was ... got taken away. And I was like, left to try and carry this all on my shoulders.’

The NDIS planner found Kirsty ‘only had a psychosocial disability’ and cut her personal care hours from 15 hours a week to three.

‘Even though I submitted all of the evidence to show that I always had issues with my mobility.’

Her support coordinator left and was not replaced, so Kirsty missed ‘the opportunity to appeal’. She has been dealing with ‘adversarial’ and ‘unskilled’ support workers for several months.

‘I have experienced very extreme neglect and dereliction of duty of care. There were many times that I felt like I was a neglected dog.’

Kirsty said that during this time she has had a ‘decline in health’ and been to hospital several times.

‘I’ve been in severe and persistent pain. I hurt my foot ... because I was alone. I haven’t been able to walk since.’

As a result she has ‘not had proper access’ to the bathroom, shower, her balcony or kitchen.

‘And I’ve lost almost all of my independence, and it’s caused me a lot of harm again.’

The NDIA was aware she’d ‘suffered an acute episode’, but was still ‘unable and unwilling to change her support’.

‘It’s all been diagnosed as mental health so it’s very difficult to get that support.’

Now, with the help of an advocate, she is ‘collecting evidence’ for a review of her plan.

Meanwhile, Kirsty feels ‘lucky enough to have a very, very great boss [who] lives in and works in mental health’. His support means she can continue to work.

‘For the last few days it’s all been about, “We want to help you.”’

Giavanna

'I even got told that I must be cursed, I'm a devil or something, because of my disabilities.'

Giavanna is in her 20s. She found out she was autistic in her first year of school.

'That was when all the trouble started with my autism,' she told the Royal Commission. 'A lot of the kids really didn't understand me ... and so I was an outsider. I went to seven schools growing up, all because of the lack of understanding, not just by the students but by the teachers.'

After her diagnosis, Giavanna said the deputy principal 'targeted' her.

'She tried to watch to see if anything I did at school was something that she could call my parents on and suspend me for. They pretty much would message my mum and be like, "[Giavanna's] not suited at this school. She won't get anywhere."

Once the teacher suspended Giavanna 'for a whole week' for 'having an anxiety attack' about national assessment tests.

'I got kicked in the face at school by kids that were misbehaving. I got my front teeth smashed out, and she didn't suspend them or anything.'

The education department then 'made' Giavanna go to another school. They said it was her 'last choice' and put her in a class 'for kids with behavioural issues ... kids that just don't wanna learn'.

'And they taught me kindergarten work when I was in year 7, year 8 and year 9. They refused to give me my year work ... Yeah, refused to help me with anything. And they didn't let me go on school excursions because of my autism.'

The school excluded Giavanna from outings after she'd had 'a meltdown'.

'A girl was bullying me on the playground, and I got upset ... They never let me go on school camps.'

Other students bullied her too.

'There was one girl that was bullying me constantly. And I got chased around the school, and I would go to the support unit staffroom to say, "Look, I'm getting chased. I really need some help," and they would just dismiss me. She threatened to kill me in front of a teacher ... And he just stood there and did nothing.'

During year 8, the bullying got so bad Giavanna's parents pulled her out of school.

When she started at a new school, a test showed she had 'learnt nothing' in the past two years.

'My maths skills, everything was still at year 7 level. And so in year 10 it was mainly [my parents] helping me get back into mainstream classes, back up to my year level.'

By the end of the year, Giavanna was 'fully mainstream again'.

'I got to pick my classes for year 11 and 12 to do the HSC ... I did a pathway into uni.'

Giavanna's university lecturers were 'so understanding' of autism. She wants the same from school teachers 'so the next generation ... won't have to hide in the shadows'.

'Because there's teachers going in having no idea of autism, no knowledge of it.'

Today, Giavanna has 'severe depression and just a lot of anxiety' and trauma from what she went through in high school.

'But I've lived independently and finished uni since then ... Even though those people at school told me that I would get nowhere in life ... I managed to do that on my own.'

Freddi

‘They turned me away just because of my disability. I felt like they didn’t believe what I was saying.’

Freddi is a First Nations man in his early 30s who has cerebral palsy and epilepsy. He was in foster care from the age of two.

‘I’ve been through hell since I was 13 to 19,’ he told the Royal Commission. ‘I was physically and mentally abused by my foster parents and sexually abused by them as well.’

Freddi’s foster dad was his uncle. ‘I don’t know how that worked. They never explained it to me properly,’ he said

‘I was basically bashed on a daily basis. I was threatened many times with a gun to my head. I was put in the boot of a car and taken in the middle of nowhere and threatened that if I told anyone that I was sexually abused, I will be shot.’

Freddi has a son as an ‘outcome of the sexual abuse’ by his foster mother. He told social workers often ‘when that was going on’, and asked to be removed from his foster family’s care.

‘But, basically, they wrote it down and never followed up on any of the allegations properly ... They refused to remove me from the care,’ he said.

Freddi said social workers didn’t believe him despite the ‘bruises all over [his] body’.

‘So I didn’t know where to turn. I didn’t have no-one to talk to. I didn’t know what to do.’

He also reported it to teachers at his school, but again ‘no-one took any action’.

‘I felt like no-one was out there listening to me ... I felt like I was very alone. I was a very confused person during that time ... The teachers did not want to help me in any way. So, basically, I just did not accomplish my full potentials.’

Freddi went to the police a few times. They didn’t believe him either, he said, because his foster parents made him out to be a liar. He feels it is unjust that charges were never laid against them.

When he was about 20, he broke free and moved interstate to be with his partner, now husband, whose family is ‘very supportive’. But Freddi needs a lot more help to deal with his trauma and depression.

‘Like, because my mental health is pretty bad at the moment.’

His NDIS service provider recently 'stripped' him of his support worker who he had 'a very close bond with'. He's struggling to find advocacy services to help him with that.

'There's not many ... out there that will work with us because they think that we're stupid. They don't even attempt to take us on.'

Freddi wants to see system change, so that foster agencies and schools give 'a child with a disability more confidence in their ability'.

Catelyn

Catelyn's daughter has a cognitive disability and seizures. Several years ago, Catelyn began working for her daughter's service provider.

'I looked after my daughter for 30 years before I decided to get a job,' Catelyn told the Royal Commission. 'I was such a happy person ... I'm not the same person as what I was before I started working there. I've had a lot of PTSD [post-traumatic stress disorder] from just being there.'

Catelyn said that when she started working, the company provided little training.

'We just had to basically watch the other staff member, what they did, and hope for the best.'

She said things haven't changed.

'New people come on board to work at the place and they've never worked in the disability sector in their life, or with mental health or whatever ... And they'd give one worker one hour to train them for that person to do an active overnight [shift] on some high-needs clients, which is wrong.'

The service provider also employed family members and friends who had no qualifications.

'So if anything's brought up to the management, like going through the proper complaints process, nothing's done with them because they're family and friends.'

Catelyn said she saw a number of incidents and injuries.

'It wasn't until [a client] actually fell off the back veranda in their wheelchair that something was done and a ramp was put in. So they waited for somebody to hurt themselves before something was done.'

Catelyn said to save money the service provider 'cut corners' and reduced staff ratios.

'There's clients that go 10 days without a shower.'

The company also employed just one person to maintain several homes.

'He hasn't got all the qualifications to do maintenance on the houses ... They don't get proper professionals in. So there's, you know, blocked drains. It always smells, the drains. And the toilets get clogged and he temporarily fixes it.'

One day, another support worker 'inappropriately touched' her daughter.

'Management turned around and said, "Well, did she have behaviours? Did she react to the inappropriate touching?" I'm sorry, but she doesn't have the cognitive ability to understand that it was wrong.'

Catelyn discovered later that management never reported the incident. She had made a complaint to the police, but they told her they 'were not going to take it any further'.

'I mean if it was a child – a normal child or a normal adult – that had this sort of stuff happen to them there'd be, you know, the child protection people at the police station. They would have got involved. That wasn't even done. It was like my daughter wasn't nobody.'

Catelyn is no longer with the service provider.

'Just the way that the management treat you is shocking. Like, there's been so many workers, so many good workers leave there over the last two years that I was there.'

Deandre and Leisa

In the early 2000s Deandre, a First Nations man in his early 40s, was seriously assaulted. He suffered a traumatic brain injury and has lived in residential care ever since. Though by no means old, the only option available to him after the assault was an aged care facility.

Deandre's daughter Leisa said the facility was not appropriate for him. He was 'surrounded by older, frail people', and was expected to behave as they did. Yet although he had neurological damage that impacted some of his physical abilities, he was 'still a young man'.

'He was expected to sit and do puzzles or crosswords, which were beyond his capability. Crosswords and puzzles – he didn't enjoy those and so he began acting out a lot.'

Eventually, under pressure from management at the home, Deandre's parents moved him to a lower care facility. Deandre absconded, and after that was moved to several different homes before ending up in the closed dementia ward of a facility in another small town.

Leisa explained that Deandre's injury had caused him to have poor impulse control, so he acted very suddenly on any thoughts that came into his mind. He might knock his chair over getting up, bump the table or push past people in the corridor. It made him a 'very high risk' to the elderly patients around him.

'Again, it was really not a suitable environment for him. But again, it was really all that there was. We didn't – we weren't given any other options.'

In the early 2020s, Deandre was diagnosed with dementia. He was sent to a mental health unit for treatment, and the facility where he'd lived for more than 10 years by that time refused to let him return.

Leisa tried to find somewhere else for him to go, without success. She also referred the facility to the aged care oversight agency for breaching its contract with Deandre. Under its direction the facility allowed him to return, but he returned to a situation Leisa described as 'extremely stressful'.

'The staff didn't want him there. The residents didn't want him there. The residents' families didn't want him there. He was constantly copping abuse for behaviours that he simply couldn't control. He had a lot of ticks and he had some verbalisations associated with those ticks, and it was a really hostile environment for him.'

Leisa organised support workers to take Deandre out and employed a specialist to formulate a plan that would help manage his behaviours.

'And none of this – none of this was enough ... They just wanted to sedate him.'

One day Leisa found out that staff had sedated Deandre without the necessary permissions or required medical protocols in place. She complained again to the aged care oversight agency. It upheld her complaint and required the facility's director of nursing to 'set the remedy for the situation, which was simply that they need to follow the rules around sedation,' Leisa said.

'I did not think that was right ... There were no repercussions for the people involved. No personal repercussions, no professional repercussions,' she said. 'It's not fair that some of our – some of the nation's most vulnerable people don't have adequate protection. That there are more consequences ... to dropping rubbish on the street than there is to abusing, neglecting or otherwise mistreating a vulnerable person.'

After a wait of several years, Deandre now lives in specialised disability accommodation funded by the NDIS.

In organising Deandre's NDIS support Leisa, as his legal guardian, felt excluded and ignored.

'As an unpaid carer I have just felt so undervalued,' she said. 'I constantly have to find myself justifying my position as a carer, but also my formal position as a guardian in insisting on my rights as that guardian. And getting people who are paid in the industry to actually do the bare minimum of their job. It's really frustrating.'

Jasmin

‘Government departments are buying software, hardware that meets their needs, but they’re not actually doing it to meet the needs of disabled people. That’s going to be an impact for years and years to come of disabled people not actually being able to do their job.’

Jasmin, late 40s, is vision impaired and uses assistive technology and bioptics – a small telescopic device that sits on her glasses.

She has worked in the public service for many years and told the Royal Commission that people with disability who work there are marginalised.

‘They’re actually not seen as part of the team.’

Some years ago, a new manager decided to change the seating arrangements in the office. Jasmin told them she couldn’t move because of the glare from the windows. The manager ignored her. Jasmin’s desk faced the window and she had to close the blinds. The manager hated the blinds being closed and would make ‘passive aggressive comments’. As soon as Jasmin walked away from her desk the manager would raise the blinds.

Jasmin made a complaint to her director and HR. Her director spoke to the manager who said it was only an issue because Jasmin was ‘an introvert and easily offended’.

‘I was extremely upset about that personal attack.’

A short time later, the department rolled out new software.

No-one in IT had tested the software with assistive technology users.

‘Accessibility requirements are not even considered as part of procurement processes, or even as part of design and development when it comes to software.’

Jasmin couldn’t do her job.

IT suggested she sit at another computer. ‘There’s constant ongoing ignorance.’

Not long after this, the team moved to a new building. They told Jasmin she couldn’t move until they had completed the appropriate disability assessments.

Jasmin ended up organising the assessments.

‘No-one gave a shit, and it was so humiliating.’

When she eventually moved they refused to provide screens to block out the glare.

'I finally put in a workers compensation claim because I couldn't work anymore and was too stressed.'

After three months her doctor told her she was fit to return to work, but the workplace refused to take her back. It took a year before she was able to return.

Jasmin moved to a new department but had the same software issues.

She had to attend a training course and reminded IT several times she needed assistive technology.

'When I got to the training course, they said that it wasn't installed because there was a personality conflict in the team ... At the operational level, you've got these fights going on all the time, in every single department, about how security overrides assistive technology.'

Sometime later, the department rolled out software for a new project. They told Jasmin there weren't enough assistive technology users working in the department to include them in the project.

She pointed out it was a legal requirement.

'And they're like, "That might be true, and you can go ahead and lodge a human rights claim."'

The following year, Jasmin was in a staff meeting. Her supervisor started teasing her about a personal health matter that she had divulged in her security assessment.

Jasmin was horrified her privacy had been violated and lodged a disability discrimination complaint. The complaint 'went nowhere'.

'That caused immense distress for me, because it's personal information that I don't want in the public domain.'

Jasmin's most recent workplace experience has been mostly positive. Initially her director refused to acknowledge working from home as a reasonable adjustment. Jasmin made a complaint to HR and this issue eventually resolved.

'In order for me to keep my job anywhere, I had to go through these [complaint] processes and it's changed, fundamentally, who I am as a person ... I now have significant anxiety.'

Reilly

‘These people ... They go from one person to the next person to the next person to the next person, and it’s making these people rich.’

Reilly is in his 40s and has cerebral palsy.

One day he was in a shop and a woman started talking to him.

‘She saw that I had a disability. She kept inviting me back until she worked out that I was vulnerable,’ Reilly told the Royal Commission.

The woman persuaded Reilly, who’s supported by the NDIS, to drop his service provider and employ her and her husband instead.

‘She came to my [NDIS funding] review meeting. As soon as she heard that I had [more than \$100,000 in funding] they went home and she said to her husband that they need to work backwards from my total amount of funding to work out what they can pay themselves each week.’

Reilly said the couple invoiced the NDIS for services they didn’t provide.

‘They were charging [more than \$2000] a week at times that I knew nothing about. They told me that they were going to give me copies of invoices and stuff but never did.’

The couple also charged the NDIS when they took Reilly to church.

‘Even if I drove myself to the church, they’d still come in another car and sit next to me and charge that amount of time that they’d been there.’

When he told the woman he didn’t want her to come to his appointments, Reilly said she instigated a sexual relationship ‘to keep [him] around longer’.

The couple tried to isolate him from his family and make him dependent on them.

‘They didn’t want anybody to see what was going on.’

When Reilly approached another NDIS service provider to employ a support coordinator, the couple became angry.

‘[They] had me in tears because they said that if I was going to have a support coordinator, they couldn’t do the care and stuff. And at that time I didn’t know what to do.’

Reilly said the couple also threatened him. He eventually contacted the NDIS, which helped him call the police.

'[The police] said the report had to come from the NDIS because it's not my money they were taking, it's the NDIS's.'

Reilly said the NDIS is now investigating.

'You don't need to have experience [to be a service provider]. You just need to go and get an ABN and then create a business name and you can go out and start working for yourself under the NDIS, which they did.'

Reilly said he developed post-traumatic stress disorder and is scared to employ support workers.

'There's not a day that I don't wake up through the night and just grind my teeth ... I guess that's why I don't have trust to have any more carers and stuff come in. And I've been asked if I want carers, but I just can't do it. Can't do it.'

Zavier, Xena and Kensley

‘Children with ADHD are not choosing to be naughty ... They have a neurological difference that if you were to take an image of their brain it would be different to a person without it.’

Kensley is the mum of ‘two beautiful kids’, Xavier and Xena, who have attention deficit hyperactivity disorder (ADHD).

Xavier’s ADHD impacts ‘every aspect of his functional capacity in all areas of his daily living’.

Kensley told the Royal Commission that Xavier’s transition into primary school was ‘awful for him, for us, for his school and his classmates’.

The school was not equipped or supported to assist him. The principal suspended him several times and he missed more than 80 days in his first year.

‘The pressure on a five-year-old to just behave was a recipe for disaster.’

Kensley and Xavier’s father paid for a psychologist, a speech and an occupational therapist and ‘did everything the school asked [them] to do.’

Year 2 was just as bad.

Kensley pleaded with the education department to help the school support Xavier.

In year 3, after an incident at school, Xavier was admitted to a children’s mental health ward.

‘He said things like, “I hate my brain, I wish I could be normal like everyone else, just kill me.”’

Xena did a ‘really good job of masking her ADHD’ and developed anxiety trying to fit in.

She struggled silently and was diagnosed almost a year after she started school.

Kensley paid for therapists to attend the school and the teacher started using appropriate accommodations.

But Xena’s anxiety didn’t abate and she was admitted to the children’s mental health ward.

She asked her mother, ‘Why can’t I be like everyone else?’ and told her she hated her ADHD. She said, ‘I’ve just had enough mummy, I can’t do it anymore.’

Xavier, now in year 4, has a teacher who ‘gets him’. The school is listening to his therapists and is supporting him.

‘There is a need for change on how kids like mine are supported, so they don’t keep thinking that they are broken,’ Kensley said.

‘I don’t want my children to end up sad and confused in their teens because they live in a society where they are judged, misunderstood.’

Elm and Valencia

Elm is a First Nations child with ‘severe intellectual disability’. When her mother died, child protection services placed her in the care of her grandmother, Valencia.

‘When we picked her up as a baby, she was very tiny,’ Valencia told the Royal Commission. ‘I said to them what does she need and any special needs? They said, no, no, just treat her like a normal baby. Well, it became evident pretty quickly that that was not the case.’

Elm has ‘a complex medical history’.

‘She’s got medical epilepsy, dysphasia, which is a difficulty swallowing ... She’s getting speech therapy ... She had special boots because her core muscles are very poor and her coordination is very poor’.

Currently Elm goes to primary school and is ‘really struggling big time’.

‘At the moment she’s in a year 4 class and she’s doing grade 1 work. She can write her name and she can write a few other words, but not many. Her maths is at a pre-primary level and she’s supposed to sit in a year 4 classroom and function. But she still doesn’t qualify for any education department support.’

The education department refuses to accept Elm’s level of intellectual disability. Even though she is on the NDIS with that diagnosis, ‘it has to be approved by a senior school psych’.

Instead, the department used its own testing criteria for children ‘from First Nations backgrounds’. Because it showed her ‘as higher ... in a borderline diagnostic range’, the government denied her funding and support.

‘It’s designed to be supportive and to be anti-racist, but it actually works against her,’ a lawyer for the family told the Royal Commission.

The school is doing ‘the best that they possibly can’ for Elm, ‘without any support whatsoever’ from the government, Valencia said.

‘But they still don’t have the resources that they need to adequately provide what she needs. And we want [Elm] in the mainstream environment because we do feel that that’s the best for her.’

Elm needs ‘sensory breaks’ and one-on-one support ‘to do physical things’, but there is not enough staff. The education department plans to reassess Elm at the end of 2023.

‘But why do we have to wait over a year when everyone already knows she needs help?’ Valencia said.

‘They say that by then she will have fallen so far behind that it will be obvious to them. But in the meantime, she’s got to fail for the rest of this year, all of next year, fail.’

She is ‘hugely concerned’ about what happens for high school.

‘She will be so far behind even if she does get the support.’

Meantime, she wanted Elm tested for fetal alcohol spectrum disorder (FASD), but the department of child protection ‘refused to allow it’. She wonders whether it’s a costs issue.

‘Or does it highlight their failure that they should have done it at the start.’

She’s ‘reluctant to challenge them too much’ from fear they will take Elm away. But she is determined to fight the ‘systemic issues that continue to fail these children’.

Because of her developmental problems, Elm is increasingly isolated.

‘Other kids don’t invite her to the birthday parties ... they’re interested in mobile phones and boyfriends. She is still into Bluey.’

Valencia said ‘it’s just not fair’ when the government say ‘she’s getting more help than anybody else’.

‘She deserves all the help they can give her ‘coz it wasn’t her fault ... We want her to be the best person she can be.’

Khari

Khari is in his 50s and lives with an amputated leg following a violent assault a decade ago. He also has trauma from being sexually abused in his 20s, just after he arrived in Australia as a college student.

‘Upon coming here, I suffered a lot of sexual abuse from this man who was a preacher,’ Khari told the Royal Commission.

‘I ended up finishing the college, went on to do my diploma. But after finishing the whole course ... I was suddenly [struck] with depression. Because there’s nothing I can do, verbalise what had happened to me. I didn’t know how to handle it and who to tell ... My life was on pause really.’

Khari began drinking and his marriage broke down.

‘I did everything I could to get my life together, by still following a path.’

In his 40s, he moved into public housing. One evening, some men who were living next door came into Khari’s home and attacked him.

‘And the violence that I received was horrific ... I passed out ... I had the amputation on my leg because it was affecting my kidney. Then I went to a rehab. And, so I need to get a wheelchair. So, the whole saga started ...’

Khari faced discrimination everywhere he turned.

‘And what I realised being disabled, if I had found it hard as a black person, it was three times as hard in a wheelchair. The conversations, the insults and the lack of help was amazing.’

Khari struggled to find support.

‘There was no-one to help me ... I’m going from this agency to that agency who have the same sort of mental view of a disabled African man in a wheelchair. What chances do I have?’

Centrelink took Khari through ‘countless interviews’.

‘And those interviews, they were trying to establish that I was disabled ... They look at you, they say, “Well, have you got the papers?” So, I feel very diminished, like they don’t even see me as a person. I have to have papers to say that I don’t have a leg. Hello? And anything, just for agency delay ... They delayed so much ...’

It took three years for Khari to get the Disability Support Pension.

Khari has found the lack of empathy 'very, very hard'. He said no-one in the government departments he has dealt with has ever asked him 'how are you? how's your leg? how are you feeling? what can we do?'

'It's a process for money. Very impersonal, very distant. You don't even feel it's a system that is there to take care of you, but for you to just be a number. For you not to say anything. For you to tick the boxes.'

Khari is 'trying to move ahead', but struggles with the injustice he has experienced.

'When we've come to a country like Australia, you first realise that your voices can be heard. You also realise that justice can be achieved. But I have not found that in both cases. It has not been easy. It has been extremely hard. There are many days where I felt like I didn't want to get out of bed.'

Felipe and Remi

Felipe is in his early teens and lives with Down syndrome, post-traumatic stress disorder and mental health problems. Due to domestic violence, he and his siblings were placed in child protection services for about a year.

‘In the whole child protection thing there was never consideration for him,’ his mother Remi told the Royal Commission. ‘Even, like, the judges, there was never any mention of help for him because he had a disability. They thought he probably doesn’t understand so it wouldn’t help. But that is so untrue.’

Agencies provided trauma support for her other children but not Felipe.

‘The other two kids are flourishing now, but my child with a disability, no, he’s just struggling. So I guess there needs to be a lot of education in the child protection field about emotional needs for kids with disability, with intellectual disabilities.’

Since then, Felipe has faced ‘systemic problems’ from education to mental health services.

‘My child, who was once a very outgoing, funny child is now very closed down and subdued and scared of everything just about. I think that some of the systems, government systems, have actually caused neglect.’

Felipe does not get a fair go at school because of ‘inequitable resources’.

‘He was in a special unit at a regular high school. The resources for the regular kids were great, the ones for the kids in the disability weren’t. It’s neglecting his purpose, you know, giving everyone else purpose but not the child with a disability.’

Felipe is very good at woodwork.

‘But there wasn’t the classrooms and the equipment ... because it was being given to the other kids.’

Remi had to organise it privately.

‘I just think that part of neglect led him to believe that he’s of no value really ... that he’s of no purpose. And that’s really added to [a decline in] his mental health.’

Remi has been unable to get Felipe ‘the psychiatric help that he needed’ in the public system. And private psychologists ‘weren’t interested ... weren’t comfortable to help because of his intellectual disability’.

Felipe can’t get a mental health plan. Remi blames ‘black and white thinking’ by the NDIA in refusing to understand that his ‘other difficulties are exacerbated by Down syndrome’.

Felipe needs more one-on-one supports in the home and 'extra social help' to get him involved in activities and establish 'peer connections'.

'It's very important to have peers around you for your mental health ... He does not have the capacity to ring his friends up, you know, come on, let's get together. He actually doesn't really have any friends.'

He was getting help from a small community agency, but 'it's funding is gone'.

'The government is pulling their money from all those smaller organisations and people like him fall through the cracks ... It's cutting out a lot of people that have complex needs,' Remi said.

'That organisation was the only one that would cater for his intellectual disability and mental health because he's out of the box. The NDIS just categorises, you know, Down syndrome, this is what they can have, autism, this is what they can have. That can lead to a lot of neglect as well.'

Without the support, Felipe's behavioural problems recently 'have gotten even worse'.

Remi is concerned 'his next moves could be to the juvenile system'.

'Even church told him he can't come back to youth group. So he's really not doing that well.'

Mirani

‘Anybody else that I’ve ever spoken to that’s gone through domestic violence does have a disability ... and it’s how it keeps you there and it’s how it’s used as a weapon. It’s weaponised against you.’

Mirani is in her 40s and has complex post-traumatic stress disorder (C-PTSD). When she was in her 20s, a doctor diagnosed borderline personality disorder (BPD) after an abusive partner broke her arm.

‘I said to [the doctor], “What does [BPD] mean?” and he goes, “It means you’ll spend your life in and out of a psychiatric hospital. You’ll never get married.” ... That’s also why I settled down so quickly, because I thought I was lucky that someone wanted me.’

Mirani told the Royal Commission her husband used the BPD diagnosis to abuse her for nearly 20 years.

‘Every time my husband would abuse me either physically, sexually, emotionally and I would cry [he would say], “Waterworks, here’s the borderline. So dramatic” ... He told me that if I left I’d be seen as an unfit mother because I’ve got a mental illness, that it was all my fault.’

Mirani said her family’s GP would also blame her disability for her husband’s behaviour.

‘I’d say, “Oh my husband is very angry.” And he’d say, “Well what are you doing? How are you behaving?” ... I would say, “I’m really depressed.” And he would say, “Well do you know how hard it is to live with someone with a mental illness like yours? You’re actually very lucky that your husband has stayed with you.”’

Mirani said the GP always took her husband’s side.

‘If I would go in with my husband to the GP he would talk to my husband about me. He would look at him and discuss what was wrong with me.’

When she once told the GP her husband sexually assaulted her, the GP said her husband ‘liked it rough’.

‘That was part of the cycle of the sexual abuse on me ... I just wish someone had asked me if I was okay.’

Instead, the GP increased her medication.

‘I went from a low dose of antipsychotics to a thousand milligrams. Now that’s what they give patients in hospital to sedate them, and I lived with that.’

When her daughter had stomach aches and she took her to see the GP, the GP told Mirani 'she's got tummy aches' because of the stress of having a 'stressed mum'.

'One day we were at the GPs and she dropped down with a stomach ache. And he went, "Oh is that what you're talking about? That's not normal." And she had coeliac disease.'

Mirani said despite her husband's violence, it wasn't until she left him and spoke to a family violence worker that she realised she was being abused.

During their divorce, the family GP supported her husband.

'I actually saw his referral ... that said, "Please support" my ex-husband's name "after the separation of his wife" in brackets "who has serious mental health issues".'

Mirani said since her divorce, a therapist diagnosed depression and C-PTSD, but told her she 'doesn't present as someone that has borderline [personality disorder]'.

Mirani has since returned to study, and she and her children are receiving therapy and 'finally starting to heal'.

'I hope by sharing that something good comes out of it for other people,' she told the Royal Commission. 'My biggest thing I think that needs to be looked at is how the medical professionals didn't support me to even see or help me understand, or even ask that basic question I never got asked – "Are you okay?"'

Sian

Sian, mid-30s, has schizoaffective disorder, fibromyalgia and complex post-traumatic stress disorder.

Her support dog, Asa, is very important to her.

Initially the NDIS funded Asa's training, vet bills and food. They also funded assistance with cleaning, shopping, going to appointments, community participation, physiotherapy and meal delivery.

Sian wanted to change the way she used her funding because she doesn't do 'any kind of interaction with the community'. She asked for a plan review.

During the meeting, Sian discussed her goals for her and Asa. The plan manager indicated the new plan would include funding for Asa.

But there was no mention of Asa in the new plan. Some assistance with cleaning and meal delivery had also been cut.

Sian told the Royal Commission she is 'very grateful for the NDIS and the assistance it provides', but she can't understand why the NDIS suddenly cut funding for Asa.

Sian's plan manager suggested she request another plan review.

'I don't know if I'm one of the only people that's had review after review, but when something is approved ... is there any way to make things easier or a little bit more user-friendly.'

Sian said dealing with the NDIS 'really triggered a lot'. She often felt like she was 'running around in circles' and the uncertainty was very stressful.

Recently Sian changed plan managers and the new manager is very helpful and can explain things to her. They have a lot of face-to-face meetings, which she says is really good.

Lynda

Lynda, mid-50s, sustained a brain injury when she was a teenager and lives with depression.

Lynda has worked as a disability support worker for many years. She is concerned about supported independent living (SIL) accommodation. She says many people who live in SIL homes don't have a choice about where they live.

'From my perspective, it's just a quieter form of control and domestic violence. Especially when it comes to non-verbal people and people with behavioural issues.'

Lynda told the Royal Commission the NDIS hasn't made any difference.

'[Residents] are quite often subject to what carers believe is appropriate behaviour modification, which could be yelling at them, which could be sending them to their room.'

In some places Lynda worked, support workers threatened residents saying, 'If you don't behave yourself you'll have no staff and you'll have no-one.' They told people they couldn't move house because of their behaviours.

'If you went into every SIL house with a behaviour, somebody would be living in domestic violence, whether it be verbal, psychological or physical or all three.'

Lynda said most SIL homes are dotted around the community and people can't leave their homes because it is not safe for them or the community.

Recently she worked in a disability village where people could leave their houses and safely visit their neighbours or participate in different activities.

'There's socialisation, there's friendship making, there's lots of group activities and it's open to the public.'

Lynda said many of the people who live in SIL homes don't have family or friends. These people are physically isolated and support workers are not allowed to hug or touch them.

'We're with them eight hours a day or longer. Some of them have 24-hour care. And to go a few days without touch is reprehensible.'

Lynda acknowledges there are people who don't want to be touched and respects their choice.

'We need to help them get used to touch, create bonds and then also allow those bonds to dissipate ... We need to create a written plan for change of carers with people who do form those bonds and help them learn to deal with the loss of a carer or the change of a carer.'

Lynda worked with one woman with intellectual disability who was very lonely. Support workers started 'playing matchmaker', but different support workers had different views on whether she should be having a relationship.

'They were encouraging her not to be friends with somebody and then encouraging her to be friends with somebody else. And then she wasn't allowed to see that somebody else ... It's just a psychological nightmare for this woman.'

Lynda organised a counsellor and encouraged the woman to speak to them.

Ultimately Lynda wants support workers to stop treating people with disability like children.

'We need intense work for our support workers to be able to create positive behaviour in a positive way. And we need people to understand that the hard discipline they gave their children might be working, but it's not right.'

Inclusion Matters

We need More people
with disabilities to
be included in
Sport and dance.
To Make us feel
Welcome and accepted.

I want there to be
no Support Schools.
everyone should be
Supported in Main
Stream Schools



We all Deserve
to all be
respected
and
treated
the
Same.

Monique

Artwork by Monique Crowden

Guss and Elissa

‘I believe that [Guss] was treated unfairly all throughout this process and his disability was used against him in the worst possible way – branding him something he is not, never has been and never will be.’

Elissa is the mother of Guss, who’s in his 40s, transgender and autistic.

‘[Guss] is like a big kid. He plays Lego, he watches all the kids movies,’ Elissa told the Royal Commission. ‘He’s not simple, he’s not dumb [but] I don’t think he’s mentally got any further than [a teenager] in regards to emotional growth.’

Guss lives at home with his mother. Several years ago, not long after his father died, police knocked on the door.

‘[Guss] opened the door and was immediately placed in handcuffs ... I said to the policeman in charge that [Guss] had a disability and could answer with an incorrect answer or an answer seemingly unrelated to the question.’

Elissa said the police interviewed him alone and then took him to the police station.

‘I didn’t know about that at the time [but Guss] said he was either told not to bring mum or there was no need to bring mum – he couldn’t remember which.’

Police held Guss for five hours.

‘You could imagine what this did to his anxiety all alone, by himself in a foreign place.’

Police interviewed Guss without a support person with him even though they knew he was autistic. They charged him with a child exploitation offence.

‘[Guss] didn’t talk to children or groom children. He didn’t have any photos of children or share anything with anyone in regards to children. He was in a chatroom ... I was told by the police that he did not say anything bad.’

Guss pleaded guilty and was given a probationary sentence, but Elissa said Guss did not understand what he admitted to.

‘[Guss] always tries to do the right thing and is quick to tell the truth. But he needed someone to be his go-between communicator and to look after his rights. Both his psychologists have mentioned he has a communication disability.’

Elissa said Guss ‘wanted to plead guilty because of the acute stress and anxiety he was under’.

'I was recently told [Guss] had three strikes against him with the police from the very beginning. One that he was transgender, the other with the paedophile [accusation] and I can't remember the third thing. But I think it was having a disability.'

Elissa now feels trapped in her home, isolated from family and community.

'This is a lifetime sentence for both of us. I have felt so weak for so long. Every time I think about this I just feel weak. So I haven't been able to sort of move forward to sort of help [Guss] with it ... He is absolutely terrified to have to go back to court.'

Elissa told the Royal Commission people with a communication disability need a lawyer 'from the very start that is not connected to police'.

'An unbiased person straight away. Because in our situation we were just a mess to start with and had no hope from the start.'

Seamus

‘They allowed me to run out of funding three times. They said they wouldn’t, but they did.’

Seamus is in his late 60s and lives with post-traumatic stress disorder (PTSD) due to childhood sexual abuse. About a decade ago, he started to develop symptoms of functional neurological disorder (FND) as a result of military service in Vietnam.

‘My PTSD existed before Vietnam. Vietnam just added to the trauma,’ Seamus told the Royal Commission. ‘Unfortunately, because of my childhood and the institutional abuse that I copped and my family, I figured ... in lots of ways, Vietnam was going to be a suicide mission for me.’

Seamus said FND, which is only just ‘starting to be recognised properly’, has left him in a wheelchair. He’s had most of the typical symptoms such as seizures, becoming non-verbal and limbs that ‘don’t work’. Sometimes he’ll ‘disassociate and shut down’.

‘If you’ve got trauma, you’re more predisposed ... What it means is, the hardware and the software of your brain doesn’t connect. And this is why I’m no longer walking. This is why I often lock up ... I haven’t walked for three years at all, despite every attempt under the sun.’

Seamus had been on the NDIS for a few years. As he went ‘from being able to walk ... to needing mobility aids’, he needed more support. But the NDIS failed to help.

‘The more our needs increase, the less money they give us.’

Because his condition ‘wasn’t identified in the very beginning ... it’s a battle,’ Seamus said.

‘When I first went into it, they just put it down as my PTSD and my acquired brain injury. Every time something else comes along ... you’ve got to bow to them to include that.’

He blames ‘misconceptions’ about FND for that, which held more sway than reports from his occupational therapist.

‘She’s had to put report after report saying the same thing, because they choose not to accept those reports but rely on reports that were written more than two years ago that simply weren’t even factual ... They still consider that we’re either liars or crazy.’

This led to Seamus being without a wheelchair when he needed one.

‘I was struggling, struggling because I had no money. I didn’t even have money to hire a wheelchair ... and having the people who pay my bills searching through Google to buy one. This is wrong. This is so wrong.’

Seamus ended up being ‘virtually homeless in a wheelchair for the best part of two years’.

During COVID lockdowns, he lived precariously, sleeping in 'probably 60 different places'. After being evicted from one accommodation 'without notice', he lodged a complaint with the NDIA.

'They allowed me to sleep in a public toilet for a week at one stage. They allowed me to sleep in my storage unit at one stage ... And, so, I fled in my van and moved sites in caravan parks ... I don't know how many places I've been in over two years, but thankfully all that's over.'

Seamus said he would still be homeless today if a federal politician hadn't intervened on his behalf.

'Now, I've got my own little department housing complex. But it wasn't the NDIS that helped me get what I needed.'

With the help of an advocate, he recently appealed the NDIS decision at the Administrative Appeals Tribunal and won. Today he has 70 hours of support a week and a new wheelchair, but is still concerned about the future.

'They said they'd come up with a good plan for one year and then we would look at it again ... I know full well if I hadn't been lucky enough to have got in under my PTSD back then, then right now I'd be in big trouble.'

Jules

‘As a person with a disability, and as an Indigenous person ... quite often we are not actually treated as a person. We are just treated as someone who doesn’t have a voice.’

Jules, early 50s, has spina bifida, progressive multiple sclerosis (MS), vision impairment and a genetic condition.

A few years ago, she was automatically transferred to the NDIS from the state government disability program.

Jules, her husband, an optic atrophy specialist and an MS specialist attended her first meeting with the local area coordinator.

‘Even before I got into the building, the wheelchair ramp was broken so my chair nearly flipped over. They didn’t seem to think that was a problem,’ Jules told the Royal Commission. ‘I got to the front doors. The doors weren’t automatic. They were massive glass doors. My husband had to open them to let me in. I went to use the lift, wheelchair barely fitted, so we had to go up separately.’

Jules said the receptionist ‘totally ignored [her]’ and spoke to her husband.

The planning meeting was adversarial, and the local area coordinator argued with both specialists.

The coordinator told the eye specialist that Jules didn’t need mobility orientation aids because she had glasses, and the MS specialist that Jules didn’t have progressive MS, was stable and able to work.

‘They were arguing about that and [the coordinator] goes, “Well, she can’t have primary progressive because our computer doesn’t have a check box for it.”’

The coordinator then told Jules she didn’t need a support worker because her husband could care for her.

Jules was clear her husband ‘couldn’t do it all’. The coordinator suggested Jules’s parents could help out.

‘By that time, we’d run out of time. We had got nowhere and I was in tears. By the time I left there I was suicidal. If I hadn’t had anyone with me, I wouldn’t have made it home.’

Jules made a formal complaint and the coordinator lost her job.

‘Training would have been better,’ Jules said. ‘She was ill-informed. She was let down by the system just as much as me.’

The next planning meeting was a lot better and the following year the NDIA placed Jules on the complex support needs pathway.

‘It was an amazing experience.’

But a short time later the support for her genetic condition was removed ‘because only kids get that and they grow out of it’.

‘I said, “I live this every day. This is part of my life.”’

The following year Jules’s funding was cut.

‘[The coordinator] basically said to me that I didn’t need the supports that I was given, that I was roting the system.’

The coordinator suggested ‘five or six sessions’ with a physiotherapist ‘would fix [Jules’s] MS’. The coordinator also argued Jules shouldn’t be spending so much on her continence aids – ‘We’re in COVID. You’re not going anywhere. You’re not doing anything.’

Jules had asked for a mechanical lifter to help her get off the floor when she slips. The coordinator asked why she couldn’t just stay on the floor until the ambulance arrived. ‘They told me that that is not money well spent. They told me if they gave me what I needed, no-one else would get anything.’

Jules has made a complaint to the administrative tribunal.

‘They’re watching every dollar and cent, but they will not apply common sense to these conversations ... Every time I have to contact them my mental health goes down the toilet.’

Emilee and Kenia

Emilee, in her late teens, has cerebral palsy and developmental delays. These were first diagnosed when she was about eight. Her mother Kenia told the Royal Commission that getting the diagnosis was difficult.

‘You go and have to fight to get a diagnosis that there is something wrong with your child. It’s absolutely unguided, unstructured, it’s enormous, you never know if you’re doing enough,’ she said.

‘There was no-one out there that sort of would put a framework to it. It was go to a bit of OT, go to a bit of speech therapy ... So I stepped out, looked after my own child.’

Kenia left her job and became Emilee’s carer, doing therapy with her for up to five hours a day.

She said seeking a diagnosis for Emilee and trying to locate advice for how best to help her alerted her to the need for information in a single easily accessible place.

‘My primary issue is there’s no roadmap that a parent can use to get an understanding of what their journey might look like with a best practice or at least baselines,’ she said.

Kenia would like to see better information sharing and opportunities for social connection occurring at the local community level, through government-supported models that recognise the expertise and insights of parents.

‘The answer is to define a roadmap that is far more bulletproof and has more checks and balances,’ she said. ‘[And] get it into communities so that parents can find each other, share their roadmaps.’

She believes funds are squandered through programs like the NDIS, and there are insufficient protections and safeguards for the private information people share with service providers and other agencies.

‘We need to start giving people – what’s the word – consent over the use of that data. And we need to be able to educate them and protect them in that use of their data.’

Emilee attends mainstream schooling, but both she and her mother ‘feel isolated’ in this setting. Emilee takes antidepressants to help her cope.

‘You know, you go to the school ... you put a tennis club together, you put a netball club together. They don’t have a disability club ... So, it needs to get to that level. There’s inclusive, but there’s also building up and socialising a community without exclusion,’ Kenia said.

She described different initiatives she had organised at Emilee's primary school, such as bringing occupational and speech therapists in for day-long sessions to work with students with disability. Though popular, this program was 'taken apart' when Emilee left.

'There's a thousand little cuts that happen every single day to me and my child ... I can name you hundreds of experiences where – and I just ran out of fight.'

Iona and Bobbie

Iona is autistic and has attention deficit hyperactivity disorder (ADHD).

‘She is a beautifully bubbly [woman in her 20s] who is highly articulate with lots of opinions as a young person should, and is a lot of fun to be with,’ her mum Bobbie told the Royal Commission.

Iona was diagnosed as a toddler.

‘We were lucky, I think, in that we had really good people around us and got an early diagnosis. So we knew what we were working with and we had the means to put lots of things in place to support her and to support us.’

Bobbie said the local primary school was ‘responsive’.

‘They were inclusive and she loved it.’

Iona attended a Catholic high school because of the support it provided.

‘The [school support worker] was a really good conduit between what was happening for her and talking to specific classroom teachers, to make sure that they knew ... He was just a really responsive person, I guess the kind of person that as a parent we often say, “That person really gets it.”’

When Iona left school to go to university, she struggled because the supports weren’t there.

‘If you are a person with ... a mild intellectual disability, there are a lot of services post-high school, [but] there’s a really big gap for the cohort that my daughter falls into where she doesn’t qualify for any of these other programs,’ Bobbie said. ‘She actually is just thrown out there into the world to survive.’

For example, at university Iona failed several subjects only because she didn’t complete the paperwork.

‘You have to go every semester and fill in forms and talk about all the issues and request it. And when you are someone who is lacking in executive functioning and organisational skills, getting all of those things in place every single semester always just doesn’t happen.’

Iona also struggles to find a part-time job.

‘For that age group ... the only options are things like retail and hospitality. And if you have autism and you’ve got lots of sensory challenges and you can’t stand noisy places, both of those places [aren’t suitable].’

Bobbie found a disability employment service, but ‘all they did with her was rewrite her CV multiple times’.

‘The biggest thing that I’m disappointed in around that life transition is the difficulties around inclusion and not having the same access to the same pathways and opportunities and supports. [Iona] doesn’t have those and she needs them essentially.’

Leroy and Marlee

Marlee is Leroy's mum. He is in his early 20s and has intellectual disability.

'He has always been a quiet person and he has a severe receptive expressive language disorder,' Marlee told the Royal Commission. 'However, he does know what he wants and what he feels. It's just hard to interpret, and he needs more time to think about what he wants to say.'

A couple of years ago, his parents enrolled him in a vocational education program 'to get him used to being at TAFE'.

'And we'll forever regret that decision,' Marlee said.

Towards the end of term 1, Marlee felt things were strange.

'Because for the first time ever, he didn't want to go to camp ... And then one night on the couch he said, "I can't take this anymore. Here, you read."'

Leroy showed his mother text messages from another student.

'And what I read shocked me.'

The student was asking Leroy to send him 'sexual pictures' and many of his previous messages were 'sexual in nature'.

'And I found out that he had been assaulted in the bathroom at TAFE by this young man sexually.'

Marlee immediately contacted the young man's parents and TAFE who said 'the lad' would do 'a two-week course on appropriate behaviour' and promised to get back to her. But she 'heard nothing' before Leroy began term 2.

'I was even more surprised to find that the perpetrator was still in his class ... As the term went on, [Leroy] was getting more and more distressed and he said, "He's trying to touch me all the time."'

Marlee took an advocate along to a meeting with teachers.

'Basically, I got nothing ... they would not take the other young man out of the classroom. And it became clear very quickly that the TAFE wasn't answering to anybody ... It was totally unreasonable for them to keep him in the same class let alone the same campus. Because the other lad had admitted what he'd done.'

Yet when Leroy complained 'that he'd been touched' or 'the other lad was trying to approach him', they accused him of 'making it up'. They even said he was 'making the other student anxious'. Leroy was made to feel 'that he was the bad guy'.

'They basically told him and myself ... nothing was happening and to back off.'

Marlee met with the dean who suggested that Leroy move campuses.

'And I said to her, "Well, it's not appropriate because he's done nothing wrong."

Meanwhile, Leroy was seeing a TAFE counsellor who 'did more damage than good'.

'She asked him if he was gay, and he felt the inference was that it was his fault, that he'd asked for it ... It was very offensive to him,' Marlee said.

'My son might have an intellectual disability, but he does know his gender identity and he does know what he wants or doesn't want to happen to his body.'

TAFE eventually gave Leroy a formal apology, but he 'continues to be traumatised by both the assault ... and the trauma that the TAFE inflicted on him'.

'It's going to be many, many years before he is able to let it go in any measurable way ... But finally having a proper job has boosted his confidence enormously.'

Mahira and Sita

Mahira is in her 20s. She is autistic and has intellectual disability.

‘She has got a lot of complex needs and she’s got an IQ level ... [of a] two to two-and-a-half-year-old,’ her mum Sita told the Royal Commission. ‘Everything that you do for yourself you’ve got to do it for her.’

Sita cared for Mahira at home until she moved into supported independent living (SIL) a few years ago.

‘I thought with my daughter moving out it would be a lot easier, but it’s actually made my life a lot more difficult.’

Sita said the support workers in her daughter’s SIL home watched television and ‘there was no monitoring’. The food was poor.

‘I had to come in, buy new groceries, put it in [the fridge]. Even complaints to the company, like, if I write emails it’s just brushed off.’

Mahira’s funding was also being ‘burnt up really fast’. Sita feared it would run out, but Mahira’s support coordinator reassured her that the NDIA would top it up when it reached zero.

‘I was also having a lot of issues in terms of neglect, food hygiene, lack of communication, lack of monitoring, a lot of different support workers coming in, so I pulled her out of there.’

She discovered the NDIA hadn’t topped up the funding and the service provider sent a debt collector to demand tens of thousands of dollars.

‘It’s very traumatic, it’s very emotional, it’s very draining. It’s tiring and I can’t function because of all the mistakes that people make. And we are the ones that are supposed to suffer.’

Sita found another SIL home, but discovered the service provider let Mahira’s poorly-trained support workers manage everything.

‘They’re left very much on their own ... and this is the feedback they tell me. They feel incompetent because they don’t have answers.’

Sita said she spent a lot of time ‘just letting the company know’ they’d forgotten something or medicated incorrectly.

‘I have to keep reminding them of GP visits. Even holidays, I have to remind them about holidays. So I feel that companies set up the place as liveable and then they just shove the support workers in there and then it’s just expected to run.’

One day, one support worker saw another worker smack Mahira.

'She reported it and the company actually did tell her not to inform me about it. But she did inform me two days later.'

Sita said the company was more interested in 'trying to cover up the incident'.

'I felt like my daughter was not seen as a person ... It's definitely neglect and ignorance from the company. It's discrimination. It's everything. So that was the last straw ... I just pulled my daughter out, straightaway took her out to another company.'

Mahira is now in specialist disability accommodation (SDA). The NDIA cut her funding because of the change in circumstances and Mahira now shares a full-time support worker with another person.

'That actually puts her in danger because she really needs full care. Like, you can't leave her alone because she puts things in her mouth. She's not aware of the environment. She has no danger awareness.'

Sita said Mahira's funding package still 'seems like it's a lot, but somehow it's just not enough'.

'I just can't understand why it's just not enough. I just think [the money] could've been used better.'

Correy

Correy is a First Nations man in his late 50s. A sporting injury in the 1990s left him quadriplegic.

His club paid him less than \$30,000 in compensation.

‘That’s equivalent to on the dole for a year. It’s left me in poverty. I can’t work. I don’t have any super ... I don’t have anything.’

Correy has been ‘broke’ and largely homeless since.

‘I’m always on the move trying to find somewhere to live ... trying to juggle the pension to make ends meet. I’m going to be homeless again soon, any day. I’m getting kicked out of my house.’

Correy needs 24-hour care and is on a Disability Support Pension and receives NDIS funding. His current housing commission flat is not wheelchair accessible.

‘It’s on the side of a hill ... I live in the loungeroom.’

The NDIA refuses to provide funding for a suitable house.

‘You got to fight for everything, I’m used to it ... I can’t even get an air-conditioning in my house ... All I do is put ice packs on my chest and go to sleep, coz I live in the tropics.’

The lack of support has stopped him for years from returning to Country, where he is an Elder.

‘I can’t practice my culture ... They just refused to build me a house.’

Correy is currently on dialysis and says he’s been ‘floated’ between three hospitals for treatment.

‘When you’re disabled, you get neglected by hospitals too. One time, I turned up, they thought I was dead because I wasn’t on the record. That’s how much they care about people with disability. Especially when you live in remote areas. You get lost in the system.’

Jaclyn

‘There seems to have been no repercussions for the teachers who didn’t believe me ... It just seems like they get away with it. As a child it’s very upsetting.’

Jaclyn, early 20s, started experiencing severe pain when she was in primary school. She was diagnosed with arthritis and a genetic condition that affects her health and mobility.

Teachers didn’t believe she had a disability and dismissed her symptoms.

‘I would have notes from my GP, my rheumatologist and my immunologist,’ Jaclyn told the Royal Commission, but it didn’t make any difference.

Teachers told her if she didn’t do what everyone else in class was doing she’d be in trouble.

One time, Jaclyn sprained her ankle because a teacher forced her to participate in a basketball game.

Sometimes Jaclyn would become so unwell she would ask the teacher if she could go to sick bay.

‘A lot of the times they would say in front of the entire class, “You’re just making it up again. You’re just exaggerating it again ... You can’t be sick this often.” But I was and I am.’

Jaclyn’s parents made several complaints.

‘They had meetings and everything. Nothing happened.’

Her parents moved her to different schools but teachers continued to doubt her.

Jaclyn’s mental health deteriorated and in year 11 she left school.

Jaclyn said the health system is just as bad.

While her regular GP and specialists have always treated and supported her, other doctors told her she was exaggerating.

‘I had one paediatrician who told me I didn’t have arthritis and all the pain was in my head ... I was seven years old.’

The paediatrician prescribed her antidepressants and her parents ‘fired him’.

In her teens Jaclyn developed an eating disorder that went undiagnosed.

‘It was completely untreated and spiralled to cause quite a significant amount of harm to my body.’

Jaclyn has experienced similar treatment in the workplace.

'I was told that I wasn't working hard enough, that I was faking it, you know, chucking a sickie, when I would have to take days off work because I physically was unable to work. I wasn't believed.'

One boss would be 'quite rude and short' when Jaclyn returned to work.

'It made me quite upset and it actually made me quite anxious and scared that I was going to lose my job. There really wasn't a way for me to deal with it.'

After a while Jaclyn felt she had no choice but to leave.

Jaclyn's mobility has started to decline and she needs to use a wheelchair more often.

Some days she is unable to leave her house because her suburb is not very accessible.

'I can't move the wheelchair on the grass. That just completely leaves me at home and takes me out of the community and isolates me.'

She also finds it hard to access mental health clinics.

'There have been quite a few mental health appointments that I've had to go to ... I have to go up a flight of stairs, and there is no lift or disability access available whatsoever.'

Jaclyn believes people with disability need to be involved in city planning.

'I live in a very poor area. It's just ridiculous that there's such a high concentration of disabled people in my area, and it just seems as if no disabled person was involved in the planning of the area.'

Ling

About a decade ago, Ling was attacked and punched while working as a supermarket security guard. Now in his 50s, he lives with post-traumatic stress disorder.

Today Ling receives an NDIS package for 'a carer and the cleaner', as well as counsellors. He struggles to find a bulk-billed psychologist, which means his 'severe' mental health issues are going untreated.

'My medication is not suitable for me and I want to see a psychiatrist. It's at least \$400. I can't afford that. And sometimes all the problem I have got is because I don't have psychologist.'

A couple of years ago, Ling set up a peer support group for people with disability in the Chinese community. He's hoping the NDIS will give the group some funding.

'I've got a few people they don't even know [about] the NDIS. Then I told them. They go to NDIS.'

Misha and Effie

Misha is autistic and in primary school.

When Misha was a toddler and still not talking, doctors told her mum Effie not to worry.

‘[They said], “It’s age-appropriate. Don’t get your knickers in a knot.” So they wouldn’t let me enrol him on the waitlist for speech pathology or anything like that.’

When Effie enrolled him in kindergarten, Misha became violent.

‘They just said he’s got oppositional defiance disorder and likely ADHD [attention deficit hyperactivity disorder], but “We’re not going to do anything about that because he’s too young.”’

Misha’s school suspended him the week he started.

‘You look at some of the things that happened, he was running away from the loud noises.’

When children bullied Effie, he lashed out. One day the school forced Misha to apologise to his bullies in a video. Other parents lobbied to have Misha expelled.

‘When they’re autistic it’s not visible. I’m just a bad parent and my kid’s just a little shit, yeah? And that’s the narrative with all the parents at the schools.’

A psychologist diagnosed Misha with oppositional defiant disorder (ODD) and attention deficit hyperactivity disorder (ADHD), but Effie said the medication had little effect on his behaviour. It wasn’t until several years later that another psychologist told her Misha was probably autistic.

‘I’ve been sitting in specialists’ offices since he was, like, under two years of age, and this is the first time hearing about it six years later.’

Effie said the psychologist stopped short of an official diagnosis because Misha’s behaviour was so bad she couldn’t complete the assessment.

‘So his behaviours are getting increasingly worse, you know? This kid is putting holes in every wall in my house. My husband and I got divorced. My car, he took a knife to my car.’

Effie said without a formal diagnosis, people blamed her for Misha’s behaviour.

‘All of these things now we know are sensory issues, totally related to his autism, but ... I’m crazy and, you know, we’re just a bad family.’

One day out of desperation Effie took Misha to a hospital emergency ward.

‘I was abused by the nurses ... They rolled their eyes. They didn’t treat us. They told us to go away ... It was like, “I need help.”’

When a psychologist finally saw them, she referred Misha immediately to a specialist.

‘So finally he gets diagnosed and medicated for anxiety as well ... All this is in the context of my son is about to turn 10, and 10 is the age of criminal accountability and he’s just, like, looking at a life as a criminal.’

Effie said Misha saw three paediatricians, eight psychologists and four speech pathologists before he was correctly diagnosed.

‘You can’t get a diagnosis so you’re just stuck in no-man’s-land.’

Misha is now supported by the NDIS.

‘This year we’ve just had the winning combination of meds, we’ve had the winning combination of support at the school with the [occupational therapist] ... And as soon as we’re in this sweet spot, they cut our funding.’

Effie says the NDIS is ‘shrouded in mystery’.

‘It’s like, “You want to make it extremely difficult?” And now they’re just cutting funding left, right and centre.’

Amos

Amos is in his early 50s and has bipolar disorder. In the early 2010s he enrolled at university for a second degree.

In his application, Amos provided documentation from his GP that explained his medical situation, how bipolar disorder affected him and how he was managing it. The GP noted Amos had a 'considerable' disability affecting his concentration and cognitive capacity.

'So, it's a "considerable" disability and it's somewhat episodic and, you know, sometimes it makes it difficult for me to study. And sometimes I don't study at all during semesters and have to take time off, which I spend a lot of ... just lying in bed, as I am currently at the moment.'

Amos registered with the university's disability service, but didn't check in with them regularly.

'I don't think I went and made one of these mental health disability plans or something like that. I think I just flagged that I might need some extra time for essays sometimes and, you know, I might need to take some time off.'

Despite having this information about Amos and his disability recorded in its system, after some years the university expelled him for 'slow progress'. When Amos inquired further, the person he met with explained that the university believed Amos had gone 'AWOL'.

'I said, "Don't be stupid. I can't be AWOL. I'm not in the army." He said, "That's what we call it, absent without leave, and you were absent without leave" ... Well, anyway they threw me out for being AWOL and then I wrote to them and tried to, you know, get un-thrown out, and they didn't listen to it.'

The university then charged Amos fees for the courses he'd been expelled from. Amos argued this decision and was successful.

'I fought tooth and nail about that and they must've thought, "Well, you know, he's on solid ground here" because they gave me my money back, which is pretty unusual.'

Amos passed his earlier courses with a high credit average and considers his expulsion to be unjust.

'So basically ... it would've been no difficulty for them at all to just let me progress, you know, at my pace ... It's not onerous on them in any way. It hurts no-one, and they have to make reasonable adjustments, and that was a reasonable adjustment.'

He believes universities should be required to justify these kinds of actions.

'I suspect this would be something like a reverse onus placed on the educational institution to, you know, maybe demonstrate that they had a good reason to throw you out.'

Leigh

‘When you add any kind of disability, I reckon domestic abuse has a whole different appearance.’

Leigh is in her 60s. She is blind and uses a white cane.

‘When I first met my husband, whilst my eye condition was degenerative, I was able to drive, [do] everything, back in those days,’ Leigh told the Royal Commission.

As her sight failed Leigh became more reliant on her husband, who she now believes has ‘a serious mental health issue’.

‘A lot of his abuse is verbal and emotional and he just goes on and on and on. And I know that if it escalates too high ... I would have an “accident”.’

Leigh said if they argued in the car, he would drive erratically.

‘And the faster we go, the less I can see. Okay? It’s just blurs coming at me and he knows that. So he used it.’

Leigh said she would ask to be let out and he would drive off. One day, he pulled over in the middle of a highway.

‘You know on the traffic side. And because he had been told that driving off leaving me in those conditions was considered domestic abuse, he no longer drove off. He just sat in the car.’

A passing motorist called the police.

‘When the police showed up it was a male and female. And the male well and truly yelled at me: “You don’t know how many people I’ve seen dying being hit by cars because they pulled over on the side of the highway.” He’s not yelling at my husband, who had the steering wheel. He’s yelling at me, who has no control.’

Leigh said the female officer realised she was the victim of domestic abuse and offered to drive her to a local train station.

‘As a non-disabled person in the earlier times of my life, it’s a great solution. But it’s a crap solution for somebody with any kind of disability. You’re putting me in a more vulnerable place where anything could happen.’

Leigh said she chose to get back into the car ‘and accepted continuing with the abuse’.

‘And trust me, he let me have it and made sure I knew that, “Don’t ever ask to be let out of the car again.”’

Leigh said her husband also controlled their finances. 'Leaving him would make me penniless,' she said.

'The constant, "Why don't you leave," and, "We can make it easy for you to leave" actually means homeless and penniless and disabled.'

Nevertheless, Leigh recently left her husband, only to discover she's not eligible for the Disability Support Pension.

'I'm not blind enough to be on a blind pension.'

Instead, she's applying for Jobseeker. Leigh told the Royal Commission she'd like to see the police and Centrelink have a better understanding of disability 'when domestic violence is involved', because she's often left with no choice but to return to her husband.

'Each time I'd tried to leave before, I end up homeless and penniless and no option. And because I've been alienated from friends and family I had, literally, nowhere to go.'

Kai and Beckett

‘NDIS plans in general are underfunding people with psychosocial disability. This results in systemic disadvantage, and thereby severe likelihood of homelessness.’

Beckett’s brother Kai, early 40s, has schizophrenia and bipolar disorder.

In his mid-teens Kai was admitted to a psychiatric hospital.

‘Some of those years were spent in locked wards, due to repeated absconding,’ Beckett told the Royal Commission. ‘My memories of those times are traumatic.’

For 20 years, Kai lived in the institution with 60 residents. Beckett said the provider gave up on Kai believing he was ‘never going to change’.

‘He’s received effectively zero assistance to develop independent living skills, and as a result he’s highly institutionalised.’

Kai needs support for almost all daily activities.

Someone needs to remind Kai to go to the toilet, shower and change his clothes.

‘He is unable to manage his medication without supervision. He needs a support worker to shop and prepare meals, to clean his room and to wash his clothing.’

Kai is unable to work because when he is unwell he will ‘vocalise psychotic thoughts’ or have ‘sexually inappropriate conversations’.

About four years ago, around the time of the NDIS rollout, the provider moved Kai to a group home with five residents. All the residents except Kai received supported independent living (SIL) funding. He wasn’t eligible because of his diagnoses.

The provider incorrectly instructed Kai’s mother ‘what boxes to tick’ when applying to the NDIS.

But the provider couldn’t justify the funding request. They hadn’t kept any incident reports, risk assessments or other relevant documents. They had also failed to keep Kai connected to psychiatric services and there were large gaps in his records.

The NDIA believed Kai’s ‘psychosocial condition was stabilised’ and, without evidence of his needs, funded him accordingly.

The provider then told Kai’s mum to lodge a retrospective change of circumstance form. Beckett said this was ‘rightly rejected by the NDIS’ who considered the issues ‘a failure of management’.

Beckett became involved and started asking questions. He noticed the provider was taking more and more money from Kai's pension despite providing no additional services.

The new manager reduced Kai's support.

Kai's behaviour deteriorated and the manager implemented a behaviour management plan.

'The manager was not qualified to design or implement positive behaviour management plans, nor did she obtain consent for the associated restrictive practices that were put in place.'

Beckett said the manager not only restricted Kai's behaviour, she also restricted the family's behaviour.

If Kai behaved inappropriately, the manager wouldn't allow his mother to bring him food, give him money to catch the bus or take him to the beach.

Once, Kai's mother didn't 'fully comply' and the manager threatened to evict Kai from the home. She told them no other home would take him because of his behaviours.

'The effect of these restrictions was to force my mother in particular to be much less involved in [Kai]'s care, which further isolated [Kai] and increased his dependency on the institution.'

One Christmas, Kai didn't turn up to a meeting on time because of his illness.

'In punishment, our family was forced to give [Kai]'s Christmas presents to the manager, and she would decide when he would get his Christmas presents – when his behaviour was good enough. This is incredibly cruel and manipulative.'

The provider has decided to close the home and has told Kai to find somewhere else to live.

Other providers have refused to take him because his NDIS plan is inadequate and there is very little documentation.

'We've been told by most of the providers he would need approximately eight hours a day of one-on-one.'

Kai only has about four hours per day, so there's 'a significant gap.'

Beckett has had several meetings with the NDIA to find a solution.

'Despite the best intentions of NDIS and the hope for choice and control ... right now, my brother is extremely likely to become homeless – a terrible outcome.'

Shepherd and Melia

In the mid-1990s Shepherd had a work accident and needed spinal surgery, which his wife Melia described as a ‘catastrophic failure’. He now receives a Disability Support Pension and was recently approved for NDIS funding.

Shepherd’s first surgery left him in ‘crippling pain’, Melia said, and several years later he required a second major surgery. About 10 years after that he again experienced extreme pain and returned to the hospital.

Doctors advised that Shepherd needed to be on a pain management plan to prevent the pain escalating and allow him to be active. Melia told the Royal Commission that Shepherd resisted the idea at first but eventually agreed.

The prescribed opioids stopped the acute and chronic pain attacks, and Shepherd was ‘able to then get back to maintaining his physical activity’.

Multiple specialists, GPs and an oversight board had endorsed Shepherd’s pain medication plan. But when he, Melia and their young son moved interstate, the health department there had a different approach to pain management and didn’t recognise any of these approvals.

The health department told Shepherd he had to reduce the dosage of his medication unless he had specialist support. This was extremely difficult to access where they lived.

Shepherd and Melia tried to convince the health department to change its position. ‘There’s no talking to them. They just don’t listen to you. They just do what they please,’ Melia said.

Meanwhile Shepherd’s health deteriorated, first as he tapered off his medication and then as his pain returned. He went to hospital several times and was either given medication after a long wait or not at all. Doctors did not even try to address his health issues. They never physically examined him.

‘They are not interested. They’ve never looked at [Shepherd] in hospital ... They never asked about what’s triggered the attack when he came in. There’s no history of that taken. It’s all where we live, we’ve got a limited income and he’s an opioid user and he’s been in before. And that’s the only thing that they focus on, is that he must be in there drug seeking,’ said Melia.

‘Because essentially you can tell them whatever you need to tell them and they don’t listen to you. They don’t write it down, they don’t update the medical records. They don’t put – they haven’t even got down some of his comorbidities, to this day, or his intolerances and allergies to medications, which are all in his medical notes from [the state where they lived previously].’

Shepherd consulted other doctors and specialists, but the health department still refused to approve his pain management plan without an assessment by the state pain management service.

The service is a long journey from their home. Furthermore, Melia explained, the service won't accept him if his condition is unstable – which it now is.

'He's not a candidate,' she said. 'And he's not a candidate because of what they've done to him. And this is the point: It doesn't matter whether he could even get there. Even if he lived around the corner from the place, he wouldn't be going because he's not a candidate. And he has the right of refusal, and that right has been taken away.'

Shepherd's health has deteriorated, as without pain relief he is unable to sustain the physical activity that was keeping him well.

'And this is the whole issue. They have got him so ill now and unwell and weak because he has had no pain management.'

She believes her husband has been punished because they argued with the system.

'Because we don't sit back and take it off them, that's why we have copped it so badly.'

Alun

‘I have gone through this alone. I stand alone. I fight alone and I feel quite alone now.’

Alun is in his 50s and lives with mental health issues, complex post-traumatic stress disorder and attention deficit hyperactivity disorder.

‘I am the survivor of childhood sexual abuse. I have a history of depression and of suicidal ideation,’ he told the Royal Commission. ‘I am currently receiving treatment for all of the above.’

About 15 years ago Alun and his then partner, who also lives with disability, took on a \$500,000 mortgage. He believes the mortgage broker exploited and ‘scammed’ them into entering into the agreement.

The company was ‘required under law’ to provide the couple with many documents before they signed anything, but Alun said ‘consumer protection and contractual obligations were completely and utterly ignored’.

‘I mean there were all kinds of precontractual disclosures and precontractual obligations ... all kinds of things that the broker was supposed to do. They were supposed to let us know. They did none of this.’

The broker knew Alun had cognitive difficulties understanding and filling out forms and exploited that.

‘For example, he sent us four pages from a 12-page application form. He said, “This is the application form. Sign here, here and here. Don’t worry about filling out the details. I’ll do that for you.”’

The company together with its accounting firm engaged in ‘misleading conduct and unconscionable conduct’, Alun said.

‘The relationship was collusive ... They were both morally corrupt ... I was not the only person who was defrauded.’

Alun turned to the financial ombudsmen, banks and law societies in his efforts to get justice. All the agencies were aware of his disability, but ‘no accommodations were made’.

‘Despite the fact I have documented lifelong learning delays and I’m disabled, I have been utterly unable to find any sort of substantial ongoing legal assistance whatsoever ... It was not addressed, and swept under the carpet. That is also a form of abuse.’

Alun feels the lack of available supports is indicative of 'systemic abuse' and 'impediments for disabled people across all platforms'. It's also 'a sad, tragic, horrible reflection of the legal profession'.

He would like to see 'a publicly funded Medicare-like legal assistance service' set up.

'Purely to protect the rights of the disabled people by acting in an ongoing legal intervention service provision. Advocacy I have found in my experience is a waste of space and a waste of time. If there is not legislation or at least regulation behind a request, then when push comes to shove, nothing happens.'

Fraser and Giselle

‘My [Fraser] suffered through many years of poor health care services, had variable care in hospital in his final weeks, and suffered terribly because he was not given adequate pain relief due to the attitudes of the nurses at the hospital ... His final weeks were a culmination of many years of abuse and neglect by health professionals.’

Giselle wrote to the Royal Commission about the experiences of her brother, Fraser, in the healthcare system. Fraser was around 50 when he died.

Fraser had Down syndrome, an intellectual disability and complex health issues that were ‘complicated by poor health care over many years’. Giselle said that some of Fraser’s additional health issues, such as poor hearing and vision, were treatable conditions ‘had he been given just mediocre health care’.

Giselle said there was an inconsistency in the way Fraser and his family were treated by hospital staff.

‘Sometimes he would be given pain relief and then at other times he was ignored. The family were keen to support his care in the hospital, sometimes this was allowed and at other times we were asked to leave despite being assured we were not interfering with care or other patients in the ward.’

In the weeks leading to Fraser’s death, Giselle approached hospital administration about a particular episode in relation to the support Fraser was receiving in the ward, but she says ‘this resulted in less care and pain relief for him’.

Giselle would like to see ‘people with disability have the same access to the full range of health services that all Australians have, including a dignified death’, and for healthcare professionals to be educated to ‘treat people with disability as humans’.

Parker

Parker works for a disability service provider and supports a family member who lives with disability. He wants the Royal Commission to be aware of the substandard conditions in some group homes and day services for people with complex intellectual disability.

‘The houses are without adequate/working heating/cooling. They are also dark and damp environments. One of these houses does not have a running hot water supply.

‘There have been numerous staff and family complaints raised about the inadequate state of these houses – to no avail.’

Parker hopes for a future ‘where all vulnerable persons have the same rights and courtesies that our normative society hold’.

Forrest and Georgia

‘If someone is injured on our roads or assaulted in the street the perpetrator would be charged and penalised. When someone with a disability is almost killed it is just too bad.’

A few years ago, staff at Forrest’s group home gave him the wrong medication. He ended up in an intensive care unit with multiple life-threatening illnesses. ‘He almost lost his life and suffered weeks of recuperation,’ his mum Georgia told the Royal Commission.

The group home admitted the mistakes it made and apologised, but Georgia is angry that no-one has been held to account. She made formal complaints to various bodies but believes this will have ‘minimal impact’ because ‘all they can do is ensure that policies are reviewed and staff training improved’.

‘Direct care of people with disabilities is often complex and requires carers to be skilled ... Until the disability industry is staffed with professionals providing the direct care to vulnerable people neglect will continue ... The most educated people in the industry at the moment are well away from the actual clients in administration or management roles. Clients desperately need people with expertise to care for them.’

After this episode, Forrest moved out of the group home and Georgia now cares for him in the family home. But Georgia feels anxious about this:

‘I am in my seventies and suffer health issues which remind me daily that I do not live forever and need to find a secure, safe living arrangement for my son. It is a daunting task knowing that the system of group home care is badly broken and there is no suitable alternative.’

Jack and Donna

‘Why,’ Donna asks, ‘do people with disability have to wait months and years for dental intervention, only to suffer in pain while waiting?’

Jack is in his 20s. He is autistic and has intellectual disability. Donna, his mum, told the Royal Commission she struggles to access timely or appropriate dental care for Jack.

Jack is dependent on others for all personal and access care and he is vulnerable when it comes to his dental health because he has a cardiac abnormality. If he contracts an infection, especially of the mouth, it could lead to potentially fatal cardiac disease.

Jack becomes anxious during dental procedures, so he needs to be under anaesthetic. There are only a couple of special dental units in the state that can provide this service. One of them is physically inaccessible to Jack, who can only walk very limited distances. The second is physically accessible, but Donna says that they normally have to wait 12 months or more to get an appointment.

Jack has now developed gingivitis and his gums bleed profusely, often covering his pillows with blood during the night. Donna told us that even with letters from the private dentist and Jack’s cardiologist, ‘he has had to wait 5 months even though the hospital knew he was in pain and bleeding’.

‘This is institutional neglect. I have pictures of the pillows covered in blood as a result of the bleeding of his gums.’

‘It is inconceivable that people like my son have to wait so long for much needed dental intervention,’ Donna says. ‘Dental services such as this I believe need to be in every hospital, not just two!’

‘As a person with a disability he is not considered a priority, if he was, there would be extended access to dental unit venues ... the needs of people with disability are not prioritised.’

Rhea

Rhea was diagnosed with autism as a little girl. Her family didn't receive any support for her treatment and the school system, they discovered, was ill-equipped to help Rhea get the education she wanted.

Rhea told the Royal Commission she had 'bad experiences' in primary school 'due mostly to teachers who were not equipped in any way with any sort of knowledge on how to teach a child with a disability'.

'I had trouble wording my questions in a way other than, "I can't do it,"' Rhea said. Teachers would send her to sit in a corner 'to watch as the other children received praise and rewards for good behaviour and doing their schoolwork'.

Rhea spent a lot of time banished to the corridor for asking too many questions, and for not asking questions and then not completing the work. One teacher kept a special diary of Rhea's 'faults', 'wrongdoings' and 'misbehaviour'.

'This particular teacher even had the other students of my class "reporting" to her on my behaviour and schoolwork.'

In high school Rhea 'fared slightly better' but – despite being 'high functioning' and having a good grounding in most subjects – she spent the first year in the disability support centre.

'This resulted in a lot of stigma and discrimination by the other kids for being a part of the "Special Retard Club",' Rhea said. Within a year she was back in the mainstream cohort, but could never 'shake off the stigma of that label'.

'As well, come subject selections, I was encouraged by most teachers to take the lower level courses "because of my disability". I feel as if I missed out on many opportunities during high school, and that because of my disability it wasn't even considered an option for me ...

'If nothing else, I would like to think that maybe, after this commission, no other child has to go through their schooling battling for recognition as an intelligent, functioning member of society.'

Tanner and Eloise

Tanner is nearly 20. He has scoliosis and disabilities that impact his vision and his ability to walk and talk. He also lives with chronic pain.

His mum, Eloise, told the Royal Commission that trying to get adequate health care for Tanner over the course of his life has been a constant battle.

‘Parents have to fight for help and they are often left to deal with the issues on their own.’

Tanner was in pain for extended periods.

‘Every two hours his colon would trigger a spasm, which is a strong pain, something that he could not deal with. He would cry for ... two hours, day and night, for three years,’ she said.

‘Our experience is that the health system does not deal with chronic pain issues very well ... The method is to medicate and once there is no answers the system will continue to trial various drugs.’

The only comfort Eloise could give Tanner was to hold him ‘like a baby and put a heat pack onto his belly’.

‘Once every specialist did their tick list with my son they then put us in a too-hard basket and left us alone.’

Eloise spent years researching Tanner’s condition. She consulted a naturopath and investigated Chinese medicine. She shared her findings about potential natural remedies with the complex care team at the hospital, but they had little interest.

‘All they really do is take notes [which] makes families feel they [are] just covering themselves.’

Eloise would like to see the establishment of specialist clinics focused on more complex care areas — along with ‘a new way of thinking ... not just pushing drugs’.

‘I see a future when doctors are not burnt out and confused as to what to do ... when disability will be treated by holistic care ... We have to listen to the families and people with disability.’

Brian

Brian has an acquired brain injury and was diagnosed with autism in his late 30s. Now middle-aged, Brian told the Royal Commission he has been discriminated against, stereotyped and ignored by Australian society for most of his life.

‘My existence has slipped through the cracks, it has been like I have no voice or am invisible. Society attacks me for my eccentric behaviour, or worse, stereotypes me as mad or insane because of my trouble with social cues or communication ... so I became a virtual recluse ... terrified of social interaction.’

Brian has also experienced discrimination from employers. He wants more to be done to prevent employers and society discriminating against people with hidden or non-apparent disabilities. ‘Stop the stigma,’ he said.

Brian told us he is now seeing a psychologist and has found some solace in making and sharing art, with help from a support provider.

Tomas and Patience

Tomas, in his early 20s, is autistic and has a range of health issues that require regular blood tests and occasional surgical procedures. His mum, Patience, told the Royal Commission they have had ‘terrible experiences’ in the health system.

‘It has taken over 20 years to find a hospital and anaesthetist who are willing to make suitable accommodations.’

Patience explained that because Tomas experiences ‘extreme anxiety’, he is unable to have blood tests without some form of anaesthesia. Tests in mainstream pathology services and in doctors’ rooms are impossible for him.

‘Hospitals have just abandoned the idea of giving him a blood test or other treatments because it is too hard and they are concerned about everyone’s safety.’

Patience believes public hospitals should have facilities, specialists and specialist anaesthetists to make necessary dental and medical procedures available and ‘less stressful’ for people who cannot otherwise access these essential services and ‘whose health and well-being are therefore compromised’.

Patience told us of her hopes for the future.

‘I think we have come a long way in our perceptions and treatment of people who have a disability. Just like other groups of Australians who have a history of violence, abuse, neglect and exploitation, the past must be acknowledged, corrected and for those who have suffered terribly, helped to a better future. I hope that our nation can adequately cater for and protect people with a disability so that the parents who love them, as they themselves grow old and face their own infirmity and death are not so terrified for their future. Our wonderful sons and daughters want the same things as everyone else, starting with love, a sense of belonging and well-being, opportunities to pursue their interests and joy.’

Barry

Barry is a First Nations man who uses a motorised wheelchair to move around his remote town. Recently, the motor broke.

‘It’s been now eight weeks I’ve been rolling around [the town], just me pushing along,’ Barry told the Royal Commission. ‘I’m getting very frustrated now because, I mean, you know, look whilst I like a bit of muscle, gee, my backside is getting pretty sore now.’

When the wheelchair broke, the local repairer sent the engine, charging cord and the chair’s wristband controller interstate to be repaired.

‘I waited for a while. Eventually I got word, “Oh yes, it’s being sent back now.”’

The engine arrived without the other parts.

“Whoops, we forgot to send the cord to charge [it] up.” ... And then they said, “Whoops, we forgot to put in the bluetooth wristband,” because the three need to work together.’

When all three parts arrived, the wheelchair still didn’t work. The parts were sent interstate again. Barry is still waiting.

‘The other problem I’ve got is my vehicle.’

Barry uses a hoist to take his wheelchair by car to the shops. The hoist broke, which means Barry can’t drive to the shops. Instead, he pushes himself there in the broken wheelchair.

‘The supermarket is on the other side of town and it’s a long way to push yourself.’

Barry said the repairer is waiting for parts and can’t tell him how long it will take to fix the hoist.

‘I’m sick of everything ... I really feel like, you know the people that do all these repairs and get things don’t actually think about the poor bloke who actually needs them to get on with life.’

Barry said he loves living in his small town, but people with disability are especially disadvantaged.

‘I feel as though we’re always forgotten, in a lot of ways, about things. ... I’m a very optimistic kind of person, but just sometimes there’s so much to be frustrated with.’

Issa

Issa is a young man from a culturally and linguistically diverse background who is currently in custody in a youth detention centre. Since being in custody he has been diagnosed with post-traumatic stress disorder (PTSD).

When Issa was diagnosed, his 'triggers' were explained to him. He told the Royal Commission he now understands his triggers are the result of the lifelong violence he experienced from his family members. He can react violently when he is triggered.

Because his PTSD was undiagnosed and he didn't understand anything about triggers, school was difficult for Issa. He was kept down twice, not because of poor academic achievement but because of his behaviour.

Issa says his triggers, together with the prejudice he experienced because of his cultural background, meant he never really made friends, had opportunities or the chance to succeed. He was heavily medicated with psychotropics to address his behaviour issues. But he never received treatment for trauma.

If PTSD was treated as a disability, Issa says, he may have had treatment before his behaviour and violence escalated.

Issa worries his brain is so damaged from trauma he will never change, will always have outbursts and will be in and out of the justice system.

Issa wants early intervention for childhood trauma to be mandatory and free. He believes it will reduce crime rates and improve lives.

Noa

Noa did a student placement at a residential facility in regional Australia.

She told the Royal Commission she was ‘disgusted by the way residents and staff were treated’.

Staff morale was poor. They called in sick regularly and the care manager refused to get agency staff to cover for them. The manager told staff ‘you have students, use them’.

Noa said this affected students and residents.

‘Students do placements to learn, not to work unsupervised on the floor.’

Often residents remained in bed, wet and dirty, until lunchtime. Sometimes staff had to leave residents in the shower alone. Staff were so busy they rarely had time to give residents morning or afternoon tea.

‘Residents can be seen left in their room staring at four walls.’

If staff complained and said they would ring their union, the care manager threatened to report them to HR and told them they would face disciplinary action.

One time the care manager completed an assessment for a resident and stated ‘he had behaviours when he was in the dining room’. But Noa said she never saw the resident in the dining room – he was always in bed.

One resident suffered bad skin tears when his support worker tried to take him to the toilet. The resident was in a lot of pain. His family and a registered nurse wanted him to go to hospital. Later that night, the man died in hospital. Staff wrote a serious incident report, but the facility manager changed the wording and downgraded the incident.

A female resident hated having showers and would scream. Instead staff gave her bed baths. Noa said, ‘You can find lots and lots of dry skin in her bed. It’s very confronting.’

Noa said there was also a shortage of medical supplies.

One time a resident was bleeding so badly staff needed to change dressings frequently. When they ran out of dressings staff had no choice but to put the dirty bandages back on.

‘Staff are always running and management just push them and threaten them. This has been my worst experience for placement.’

Amaya

Amaya is blind. When she was a child she was groomed and sexually abused by a neighbour.

At first Amaya enjoyed going to his house, playing games and being given treats. She told the Royal Commission there was very little affection at home and when the neighbour started touching her inappropriately, 'there was something warm about it'.

Amaya spent most weekends at the man's house. 'Due to my disability I did not have any local friends my age I could play with,' she explained.

The touching progressed to other sexual behaviour. When Amaya resisted, the man told her his behaviour was normal. Also, if she said anything, no-one would believe her.

Then one day, towards the end of primary school, there was a sex education class which included information about abuse. Amaya was horrified by what she heard.

'I did not want to believe what had been happening to me. There was a period of denial, then realisation, then fear.'

Amaya didn't want to go back to the man's house but was too terrified to tell her parents. She was sure they wouldn't believe her and would punish her. She tried to tell her doctor, but because she had no real sex education she struggled.

'I really couldn't explain what I was experiencing.'

In her first year of high school Amaya could no longer bear to keep quiet and told someone.

'To my amazement she believed me.'

Amaya's parents believed her too and supported her. However due to certain circumstances she had to continue living next door to the man, causing her great distress.

'Living in such close proximity to the abuser meant I would never know if he was watching if I went out into the yard.'

She began having panic attacks and tried to hang herself with a sheet.

'I really don't know how I carried on with my life.'

After some months Amaya made a statement to police and the man was charged. She had to go through a committal hearing, a mistrial and a second trial.

'I was in fear in front of the abuser both physically and emotionally. Being totally blind, I had no way of gaging his reactions or anticipating things. At times my credibility was questioned in being able to identify my abuser.'

Amaya said the man had the same lawyer throughout the whole process but she had a different person from legal aid each time. There was no opportunity to meet prior to an appearance and Amaya was only allowed to be in court when she was on the witness stand, so never knew what was said.

'The entire legal process was humiliating and at times soul destroying.'

Ultimately the man was acquitted. Amaya was given hard copy trial transcripts which she couldn't read. 'As a result, there are things I will never know,' she said.

'The affect was completely devastating ... My soul and heart had been taken away by a predator. He was still living next to me and there was nothing I could do about it.'

As soon as she finished school she moved out of home, and as a young adult Amaya began to feel stronger.

Until a taxi driver sexually assaulted her.

The taxi driver was charged and Amaya tried to use the lessons from her previous experience during the trial. But he was acquitted.

'The assault brought everything up again and has enforced my view that the legal system is not there to assist people who are victimised through crime.'

Amaya is determined the men who assaulted her will not overcome her.

'I am doing everything I can to make the most of life and to add value to it as much as I can.'

Damian

Damian, who is autistic and has obsessive-compulsive disorder, was having trouble sleeping. He consulted his GP who suggested a short course of antidepressants. Damian told the Royal Commission he wasn't depressed, but he was becoming more anxious because of lack of sleep.

Damian's GP advised him to introduce the new medication slowly. But the antidepressants made Damian feel awful.

'The biggest symptom was literally no sleep over the course of four days which was incredibly tough and has never happened to me before.'

He had other symptoms and couldn't work. By the weekend he was very unwell.

Damian admitted himself to the local hospital. After a short consultation the doctor told him he was bipolar and suggested antipsychotics.

This alarmed Damian but he was so unwell he wasn't sure how to proceed.

'I feel like maybe they should have asked more questions about my moods and how I was before the antidepressants before throwing around the term bipolar ... They should know anyone with autism has communication issues and that it is possible to miscommunicate or misinterpret especially when you have had no sleep in four days.'

Damian didn't want to take anything that would make him worse. He had also recently been treated for anorexia and binge eating and questioned the effect the antipsychotics might have.

'Inducing stress in someone who is clearly under a lot of stress only increases their stress.'

Ultimately Damian decided not to take the antipsychotics. The hospital discharged him after five hours and sent him home with medication to help him relax.

The following week he saw his GP and psychologist, who both reassured him he wasn't bipolar.

Damian has since received treatment to help him sleep and learnt there is much more the hospital could have done.

'My hospital visit could have been a safe haven but it is now a place of fear. I fear being misdiagnosed and I fear being given the wrong medication.'

Damian is aware some people might think he's overreacting. He explained, 'It is very unexpected for me to react the way I did to antidepressants, so it is very real that I could have had a reaction to antipsychotics.'

Orina

Orina had been studying but her experiences as a postgraduate student with vision impairment left her feeling she had to choose a different career. She said she still has ‘a lot of anger ... a sort of grief’ for what she has lost.

From the beginning, Orina’s supervisor gave her little support. In the first couple of sessions, rather than focusing on the accommodations Orina needed for her vision impairment, the supervisor wanted to discuss ‘an alternate career path’. The supervisor seemed to resent having to facilitate the requirements set out in Orina’s student access plan.

When Orina said that the glare in the supervision room was causing her significant problems, the supervisor told her to sit in the far corner of the room. This meant Orina couldn’t see or hear the supervisor. When Orina suggested they use another room, the supervisor was extremely reluctant.

At one point, Orina made a mistake with a client. She understood what she had done and quickly corrected it, but the supervisor wouldn’t let it go and kept referring to it. She belittled Orina telling her ‘the mistake was something she expected a year 8 student to understand’.

Part of the coursework involved administering assessments to clients, but the assessments didn’t have enlarged versions. Rather than helping Orina enlarge the materials, the supervisor told her ‘because you can’t see the original, you can’t do it at all’.

Orina organised a meeting with the university and her disability adviser to discuss the problem and work out a satisfactory solution. She was given a second supervisor and told that if the problems continued they would organise a mediation meeting.

But this didn’t happen. Towards the end of the semester, the supervisor told Orina she would no longer supervise her because the relationship was not working. The clinic manager rang her and said she had ‘failed the course and had to discontinue immediately’.

Orina made a formal complaint that ended up with the university senate, who agreed she should not have been failed but declined ‘the suggestion of discrimination’.

Before she could recommence her course, the department required her to sit a remedial assessment which involved many hours of psychometric testing with a fake client. They failed Orina again, saying she had been too disruptive to client rapport. Orina says this was in part caused by the enlarged papers.

Orina went to the executive dean. He told her ‘clinical neuropsych relies on visual and auditory assessment of clients, and that it requires a psychologist to have clear vision and hearing’. Yet Orina had disclosed her vision and hearing impairment to the regulatory body when she registered. ‘Why did they not come back and reject my registration if that was going to be a major issue?’ she asks.

Orina left the course. Soon after she found out that the supervisor had bullied other students as well. It confirmed her view that ‘there was a really systemic issue going on’.

Franklin

‘They thought my disability was my lot in life and ... that basic necessities of education would suffice for me ... I believe they thought the assaults, humiliation and harassment were part and parcel of the hurdles I had to conquer alone.’

Franklin has a neurodevelopmental disorder, which includes motor and vocal tics.

Franklin told the Royal Commission he was regularly harassed and assaulted at school because of his disability. Students would torment him, saying he was gay and calling him names related to his disability. Then the kids started cyberbullying him on Snapchat. The harassment and humiliation intensified, ‘akin to a blowtorch’.

Franklin ‘lashed out’, and the school suspended him.

‘The institution blamed me and poor choices I made for everything that happened ... However, I felt the school was trying use my behaviour to justify their negligence in failing to provide me a safe schooling environment free from discrimination in the spirit stipulated by the Disability Standards.’

Franklin’s dad complained to the school several times, and tried to get the school to provide an individual adjustment plan under the Disability Standards for Education 2005 (Cth) to support Franklin. But the school wasn’t interested. Franklin believes that the school never complied with the Disability Standards.

‘I think my previous school and the governing body did not believe they were legally obliged to comply with the Disability Standards because I am not severely physically or intellectually incapacitated.’

In his senior years, Franklin said, the school tried to restrict his access to particular subjects. His parents decided to move him to another school, despite the disruption.

Franklin is now free to study the subjects he chooses and has an annually reviewed independent learning plan.

‘Changing schools literally saved my life because I was at risk ... My current school complies with the Disability Standards and I feel safe, welcome and socially and educationally supported in that environment. I feel like I am now thriving.’

Zoe

Zoe is in her mid-30s. She is blind, has a brain injury and is almost non-verbal. She needs assistance to use a wheelchair and with most aspects of her life. She is supported by the NDIS.

Zoe has required full-time support since birth, and this care has been provided in the family home. Unfortunately the family home is on a very steep site and is unsuited to her ongoing long-term care.

About five years ago, Zoe's parents were able to use the proceeds from a medical negligence law suit and some family savings to buy a more suitable local building block on which to build a house for their daughter.

Council approved a home designed specifically to meet Zoe's needs, and in which her parents and siblings will continue to care for her over the medium to long term.

Zoe will own the home outright, so will be financially unaffected by the passing of her parents.

Zoe's parents told the Royal Commission they feel it is reasonable to expect the NDIS to help Zoe build the home in which she will live and be cared for, and that the NDIS should fund the disability related aspects of the home construction, just as it would any other specialist disability housing provider.

So far, enquiries made to the NDIA have not given Zoe's parents any hope of receiving this assistance. They are not sure if they are simply speaking to the wrong people, or if the NDIA believes parents and NDIS recipients should not be assisted to provide specialist disability accommodation?

To date, Zoe's parents have provided the financial assistance towards Zoe's house from their lifelong savings. But future assistance will eat into their superannuation. Zoe's parents can give some financial help, but can't afford to pay for it all.

Zoe's parents want the NDIS to support Zoe in the same way that it assists non-government organisations and others to build specialist disability accommodation.

They want the NDIA to assist the whole disability support community with specialist disability accommodation, not just those whose families are no longer able or wanting to provide the care personally.

Annabelle

‘People need to understand that stop means stop and to respect your choices. It can be hard having an intellectual disability because people don’t understand what disability you’ve got and they don’t always treat you with respect when they find out about it.’

Annabelle is the mother of two children and has experienced repeated domestic violence and sexual violence.

She told the Royal Commission the most recent sexual assault left her in hospital for two days. When she reported the assault she said police were ‘really good’.

‘They gave me suggestions about keeping myself safe.’

Annabelle also had a positive experience with police when she reported her ex-partner for domestic violence a few years ago. Police supported her to successfully apply for a domestic violence order.

‘They understood where I was coming from and told me the outcome.’

Annabelle also felt supported by legal professionals in the lead-up to appearing in court and on the day itself.

‘The lawyers and judges were helpful and I was able to understand what they were saying to me.’

One thing she suggests could be improved is the paperwork which she describes as hard.

‘It would be good if there was an easy read version for people with intellectual disabilities.’

In contrast, Annabelle feels there was very little support when she recently negotiated a new parenting plan with her ex-partner.

‘I don’t get any financial support for the boys even though our custody agreement is 50/50. He receives the family benefit and I pay child support to him for the boys.’

Annabelle says her ex-partner manipulates her and takes advantage of her, asking her to do him favours in return for time with the boys.

‘There should be more support for parents with disability to make sure that they don’t get taken advantage of.’

Annabelle says ‘it’s nice to understand that there is help and you can ring services to help’, but she would like ‘more support for women with disabilities who are experiencing violence across Australia’.

‘People with a disability are strong, brave and courageous.’

Nathan

Nathan's mum told the Royal Commission about the day she found her son trying to cut his wrists.

'He was 10,' she said. 'He was being treated so bad that he wanted to hurt himself.'

The problems started when Nathan was in grade 6 at a mainstream school about five years ago. Nathan is autistic and has attention deficit hyperactivity disorder and mild intellectual disability. But at that time Nathan had not yet been diagnosed. His mum thought a lot of his struggles were trauma related – but she was open with the school about Nathan's behavioural issues.

Nathan had a bad time at this school. Students and teachers bullied him.

One day Nathan's mum got a phone call from the assistant principal warning her that if Nathan misbehaved one more time they would suspend him. Nathan's mum was angry with him for being naughty.

One day Nathan came home crying and hungry. The teachers had given all the other children fish and chips as a treat, but hadn't given him any. His mum emailed the school, unhappy about how they had singled out her son.

But after sending that email Nathan's mum started getting phone calls from the school on an almost daily basis, telling her that Nathan was going to be suspended. They wouldn't give her any information about why.

Nathan was now having severe meltdowns and anxiety, so his mum got a referral for a mental health team, a paediatrician and counselling. It was at this point that Nathan was fully diagnosed. He then began to receive treatment.

Despite this, Nathan's mum said the school didn't seem to care about his disabilities. They continued to suspend him. He was having anxiety attacks every time he entered the school. He was still getting bullied and picked on.

The school was made aware of this, but it didn't act. Nathan's mum took his situation to the education department. This resulted in the school developing a behavioural plan that, his mum said, 'set Nathan up to fail'.

Then it happened – Nathan felt so bad about things that he tried to cut his wrists. Distraught, Nathan's mum begged the education department to let her take Nathan out of that school and find him another one. But they refused. 'No school would take my son,' she said.

Finally, the education minister was made aware of Nathan's situation and found him a new school.

Nathan is now in year 7 and his mum told us she is happy that he is doing well. But she also remembers what they experienced.

'Our family was torn apart. I resigned from my job. Until this day, the school has never been held accountable for the mistreatment of my child who has a disability. The school system is broken.'

Jones and Maryann

Jones is autistic and has a secondary anxiety disorder. His mum, Maryann, told the Royal Commission he has been neglected and abused in more than one school, and has been denied a proper education.

On one occasion, when Jones was in grade 2, his teacher dragged him across the courtyard, injuring his knees. Maryann complained to the deputy principal, who justified the action saying Jones was having a tantrum and the teacher needed to move him.

Later, Maryann learnt Jones was having his tantrum around the time the bell went for recess. The teacher wanted her coffee break, so she dragged him to the office so she could go to the staffroom for morning tea.

At another school, a teacher left Jones outside on a 26-degree day for most of the day without a hat or water, resulting in severe sunburn to his neck and legs. Maryann sent an email to the deputy principal with a photo that showed the sunburn.

The deputy principal wrote back telling Maryann she 'should put a shirt on him'. When Maryann pointed out that the official time-out period at that school is five minutes, there was no reply.

At the same school, a teacher locked Jones in a room with no windows or doorknob, and containing only a beanbag, for an extended period. On another occasion, they locked him in a breezeway for two hours.

'He was extremely distressed and could have hurt himself on the concrete floor or metal wash basins,' said Maryann.

At two different schools across a period of four years, Jones was not allowed to attend school full time. At the first school, Jones's parents were contributing to the payment of an aide, and the second school had level 3 funding from the department of education for an aide.

Despite this, both schools stated they did not have enough funding for an aide all day.

'He was being denied a proper education for 4 years,' says Maryann.

Maryann wants to see all children with disability able to access full-time education. She says that there should be more training for teachers on how to handle the behaviour of autistic children.

Alisha

Alisha has achondroplasia, which she describes as ‘a form of short-limbed dwarfism’.

‘The environment is not built for adults who are the average height of a seven-year-old child,’ Alisha told the Royal Commission, ‘so I have issues with reaching things on high shelves in supermarkets ... The main impact are the societal attitudes, discrimination, bullying, verbal and physical abuse.’

Alisha said that when she was six, her parents took her to a hospital specialist for a check-up.

‘I remember having X-rays of my body taken, then seeing the doctors ... who ordered a set of photographs to be taken of my body.’

Alisha said her mother talked to a social worker while her father went with her to have the photographs taken.

‘I remember entering a room where there was another man with camera.’

She said the man photographed her hands and feet. He then asked her to stand naked against a growth chart.

‘I remember being frightened and embarrassed as these people were strangers. There were at least two other men in the room as well as my father.’

She next attended the hospital as a teenager.

‘Again X-rays, but no photographs that I can remember.’

One day, when she was in her 20s, a specialist mentioned a computer database where Alisha’s childhood photographs had been uploaded for research.

‘They were unmistakably me. In the photographs my eyes were hidden by a black square which was supposed to keep my identity hidden.’

As Alisha watched, the specialist scrolled through each photograph.

‘And then there were two photographs I had no memory of being taken – the inside of my mouth and a photograph of my genitals from underneath, in between my legs. I was shocked into silence. I did not know what to say at that moment.’

Alisha said she didn’t mention her distress at the time, but ‘spent the next 24 hours at home feeling shocked, horrified, disturbed and crying’.

The next day, Alisha called a hospital social worker and told her 'how upset seeing those photographs had made [her]'.

'I was also upset that no-one from the hospital and clinic had contacted me to discuss the photographs with me and to seek my permission to be able to use them on the computer database.'

The social worker agreed to have the photographs removed from the database and sent to her.

'The photographs arrived with a hospital card with my name, childhood address and details had been included. Written in pencil on the card were the words "No Consent".'

Alisha said her father had no memory of the photo session, and the hospital 'never offered an explanation nor an apology'.

'I am still angry and hurt about this.'

Colm and Sacha

Sacha's son Colm is autistic and has several medical conditions that impact his continence. He goes to a state primary school.

'[Colm] enjoys spending time with other kids his age and likes to feel included, just like anyone else would his age,' Sacha told the Royal Commission.

Sacha said the school agreed to a continence care plan to manage Colm's medical conditions, which includes continence aids funded through the NDIS.

But when Sacha first gave the continence aids to the school as part of the plan, she received a 'derogatory phone call response that started with, "Who authorised your son to wear nappies?"'

'Staff at the school have consistently reported their confusion and mismanagement of the supports stated in his continence care plan.'

Sacha said that despite multiple meetings between Colm's occupational therapist and the school, Colm is left to manage most of his continence issues without support.

'This has resulted in accidents that have caused the other students to alienate him ... [Colm] has become very insecure about the consequential build of faeces in his underwear that the other students can smell.'

Sacha said Colm would 'benefit greatly' from having access to the school's disability toilet, but the school is using it as a storage room.

'There is a shower, however [Colm] is unable to access any part of this bathroom due to the amount of clutter. I have brought this to the school's attention multiple times, as I believe that it is their responsibility to ensure equitable access to disability specific bathroom resources, yet my concerns have continued to be disregarded.'

When Sacha asked the school for more support, the school responded by questioning her capacity to care for Colm and 'identifying [her] as a neglectful mother who had disregarded the concerns for [her] child's hygiene'.

One day, a government social worker came to Sacha's home, apparently after the school reported her.

'I felt so hurt by this, and asked her to smell all of my clean washed clothes because I was doing my best to ensure the school was adequately equipped with resources and that my son's dignity was maintained.'

Sacha said Colm felt it was 'all his fault' that the school reported his mother to the government.

‘Despite me continuing to reassure him and encourage him, I have had to seek additional counselling supports for him as a response to this.’

Sacha said organising meetings between Colm’s occupational therapist and the school, and the extra supports she provides the school, ‘has exhausted so much of [her] son’s NDIS funding’.

She is planning to remove Colm from the school, but fears the ‘repercussions of disclosing’ Colm’s continence issues to other schools.

‘The compounding impact of this experience has affected my mental health greatly, and the issues exhibited at school have overflowed into the rest of our family’s life.’

Aida and Emmaline

‘I believe that angels sometimes do come to this world in human form, and I believe that my sister was one of them.’

Emmaline told the Royal Commission her sister Aida was an ‘extraordinary person’. She fought for justice for people with disability and ‘strived to ensure her own and others’ human rights’.

Aida had muscular dystrophy and moved into a supported living facility in the early 1990s when she was in her mid-teens. She ‘hated it’, Emmaline said, and referred to it as ‘an institution’. She felt she had no voice, autonomy or independence.

Ten years later when Aida was in her mid-20s, she started to advocate for herself and others to gain more independence. She wanted to live in her own home with two other people with disability. She planned to employ support staff to help them with their daily needs. She convinced Emmaline, who was sceptical at first, and together they convinced her parents that it was a good idea.

Aida achieved her goal. She lived in her home for ‘quite some time’ and was ‘very happy’. She had more freedom and was able to make decisions for herself. ‘This included something we all take for granted such as having the opportunity to decorate our homes in a manner that fits our taste and comfort,’ Emmaline said.

In the late 2000s one of Aida’s roommates died and she could no longer afford the rent. Her parents offered to contribute but she wanted to be independent.

Aida moved into another supported facility where she had her own unit. Unfortunately the area was very hilly and wasn’t accessible in her wheelchair. She couldn’t have the level of independence or autonomy she was used to.

Over the next few months, Emmaline noticed Aida becoming ‘flat’ and ‘depressed’. Aida told her she hadn’t been showered for three days and had rashes under her arms and her groin. Emmaline took her to the doctor and Aida asked if he could write a note requiring she have daily showers.

Emmaline remembers getting very upset about this but Aida defended the support workers. Aida told her the problem was systemic – there weren’t enough workers rostered on to ‘meet everyone’s basic needs’. Aida also revealed she found it difficult to ask for a drink during the night because the workers were so busy.

Aida became more depressed and found it difficult to advocate for herself. She told Emmaline, ‘I’m back where I started, this is an institution, after all the hard work that I have done ... look where I ended up, I’m back in an institution.’

A few months later Aida's doctor became very concerned about her oxygen levels. Her breathing was shallow and she needed an oxygen tank to help her breathe. The doctor wanted her to go to hospital but Aida felt hospital staff weren't able to care for her 'individual needs and disability'. The problem wasn't so much the individual staff, Aida said, but the system.

At two in the morning, a week later, a support worker rang Emmaline. Aida had pain in her back and couldn't breathe and they'd called an ambulance. Emmaline rushed to the hospital only to find Aida wasn't there. The ambulance couldn't fit the oxygen tank in the vehicle and she had to wait for an access taxi.

When Aida arrived, the emergency department wasn't busy but they insisted on her waiting to be triaged. Emmaline intervened and begged them to look at her file.

'If I wasn't there to advocate on her behalf, I'm convinced that she would have died in her chair in the emergency waiting room.'

Aida's heart was failing and her blood pressure extremely low. She died a short time later.

'My sister fought for justice and equality her whole life, and there is still much work needed in this space to protect people with disabilities.'

Jaxson and Kelsey

Jaxson is autistic and has global development delay.

He started attending a childcare centre when he was four, two days a week. Kelsey, his mum, told the Royal Commission he seemed 'a more confident and explorative child and had begun to make new friends'.

During this time, Jaxson's therapists were helping him 'manage his toileting and personal hygiene more independently'. The goal was for him to be fully independent by the time he started school.

There was a support plan in place and Kelsey regularly spoke to staff about Jaxson's toileting. She packed several pairs of underpants and pants in his bag each day.

One day, Jaxson was playing outside and had a bowel motion. It was a loose stool and it leaked down his leg. He told the educator nearest him. She was supervising a different group and took him to the educator who was looking after his group.

This person then asked another staff member to help Jaxson wash and change his clothes. The staff member refused. Kelsey said she was told staff were concerned the children outside would be left with inadequate supervision.

The two staff members decided to change Jaxson outside in front of everyone.

They instructed Jaxson to stand on a plastic garbage bag, removed his pants, and left him 'exposed with only his t-shirt on'. Kelsey was told one educator stood in front of Jaxson 'to try and block him from view' while the other sprayed him with a garden hose.

That evening Kelsey noticed a pair of Jaxson's pants was missing. The next day the director of the centre told her what had happened and apologised. She'd reported the incident to the child abuse authority and encouraged Kelsey to do the same. The staff members were suspended pending an investigation.

Kelsey followed up with the education authority and police, but nothing came of the investigation. When she received the official incident report a month later, it contradicted what she had previously been told – there was no mention of the garden hose.

The staff returned to work and the director resigned.

Kelsey said Jaxson is 'traumatised'. He's fearful of the hose, toilet training, changing his pants, and is still refusing to wear underwear. He continues to be unable to go to the toilet or change without a 'substantial amount' of assistance.

When his mother changes him he says, 'I'm scared, don't hurt me.' She is no longer hopeful Jaxson will be able to toilet independently prior to starting school.

Additionally, Jaxson has become 'increasingly more aggressive' and has 'violent meltdowns'. He struggles to communicate his wants and needs.

Kelsey wants increased staffing and better support plans that respond to the challenges around toileting for children with disability. She says this will enable 'educators, therapeutic supports, the children and their families to work collaboratively towards a shared goal and ensure their safety'.

Russ

Russ has an intellectual disability. He is trying to support his parents, 'who are getting older and also have a disability'.

Russ had a job in open employment until the business he worked for closed. He then struggled to find a disability employment service that could find him another job. It took nearly a year before an Australian Disability Enterprise (ADE) offered him work.

Russ now works for the ADE washing cars and cleaning buildings.

'I was paid \$2 per hour while on trial and training.'

Russ told the Royal Commission that after nine months, the ADE increased his wage to \$3 an hour.

'I was upset about this,' he said.

'I would like to build my skills to go back to working in open employment and hoped that supported employment may have helped with this as a stepping stone.'

Russ said the ADE doesn't provide enough support 'to assist with any issues in attending work and staying at work'.

For example, it's difficult for Russ to travel to work. When he can't get there, no-one contacts him to see what's wrong.

He said the ADE also makes him feel that he 'didn't belong'. It initially didn't offer him a uniform, and it didn't tell him about the wage assessment process that resulted in him earning \$3 an hour.

Russ said his NDIS plan pays the ADE to support him and he assumes that means it will help him 'get to work and get better at work'. Instead, he feels isolated.

Russ spoke to his NDIS local area coordinator and the ADE's chief executive officer.

'It seemed that the responsibility was all mine.'

Russ said although the ADE has since increased its contact with him, he's worked only 10 days in five months.

'Sometimes everything does get on top of me.'

He hopes telling his story will help him 'move on from issues [he had] about the work place'.

'Being able to put it in writing and to tell someone feels good.'

Norman

Norman is in his 40s. He acquired a severe traumatic brain injury from a car accident about 20 years ago.

Norman has been admitted on multiple occasions to a forensic mental health facility over the last 10 years.

‘Whilst I was an inpatient, I was sexually assaulted by a male nurse. I immediately notified a female nurse multiple times on duty that evening, however, she dismissed my complaint and police request,’ Norman told the Royal Commission.

From that point Norman repeatedly expressed fears for his safety, but said he was ‘continuously told to go back to a dorm room that offered no protection’.

‘Despite multiple staff on multiple occasions noting my complaints and withdrawn behaviours in their case notes, nothing further was ever done about it.’

Norman said that during his admissions he was put in a room where he was ‘completely isolated’. Staff would often forget he was there and offered no assistance or access to counselling services.

‘It was clear that no-one believed me ... I was refused my own choice of doctor and nurse to get an independent assessment.’

Two and a half years after Norman’s first complaint, the facility finally filed the rape charges.

‘I believe they waited until relevant staff were no longer employed there to ask questions and investigate. They wouldn’t even go back to assess any of the names or dates and attempt to investigate, just stated they wouldn’t assist.’

A year later, with the assistance of an advocate, Norman made a complaint to the relevant complaints commissioner. Norman finally received a letter of acknowledgment of his accusations and that they had been handled in a negligent way. However they told Norman ‘there would be little achieved by conducting further inquiries into the complaint’.

This was because Norman no longer remembered the names of the nurses he had accused, and the staff he had complained to were no longer employed at the facility.

‘All these people failed to uphold a duty of care, despite it being a primary part of their role ... If they listened to me, followed the correct policies and upheld their duty of care, instead of covering up, things would perhaps be different today.’

Norman would like to see people, especially those in relevant positions, learn to be ‘more open minded’ towards people with disability. ‘If they would only just listen,’ he said.

‘I believe that people with a mental illness should be treated the same way as others with a disability ... This does not happen and those living with mental illnesses face much more discrimination and judgement, particularly regarding accessing services and the system that are there to protect them.’

Ashlyn and Trina

Trina's daughter, Ashlyn, is in primary school. She is autistic and has attention deficit hyperactivity disorder and anxiety.

'She requires help for self-care, dressing, safety and activities,' Trina told the Royal Commission. Before she started school, Ashlyn didn't speak and barely communicated.

In preschool, Ashlyn's teacher didn't talk to her 'at all' and excluded her from excursions. Trina said the preschool had low expectations and 'never properly tested [Ashlyn's] skills, rather assumed them'. The teacher recommended Ashlyn go to a school for severely intellectually disabled children and was 'shocked' when Trina said Ashlyn was 'going mainstream'.

Trina struggled to find a mainstream primary school for Ashlyn. One school told her she 'really needed to think whether this would be the right school for [Ashlyn] as they do not do much repetition'.

Another school said it didn't have enough support, and a third told her, 'We can't go around accepting all of you.'

"'You", referring to those with either autism or disability,' said Trina.

Trina eventually found a primary school willing to 'give things a try'.

'Things start going downhill. [The] new class teacher says to me in front of my daughter, "She is way behind everyone else academically."'

Trina said Ashlyn began 'having meltdowns and not sleeping well' after that.

COVID-19 lockdowns happened while Ashlyn was still in year 1, so Trina taught her at home. That's when Ashlyn started to communicate with Trina, first by touching her arm, and later by speaking.

'Turns out she is actually profoundly gifted ... and not mildly-moderately intellectually disabled as previously thought.'

Trina said that when the school reopened, Ashlyn continued to show 'unprecedented academic ability' for the remainder of her first year in primary school.

'She, for example, solves a problem using Pythagoras's theorem. From level two reader, she is placed on level 33 plus. She does comprehension exercises on sophisticated texts, including one on climate change.'

Despite Ashlyn's remarkable improvement, the school gave class academic and improvement awards at the end of year 1 only to children without disability.

Trina said the behaviour of Ashlyn's classmates reflect their teacher's discrimination. She heard one student talk to her daughter 'in a baby voice'. Another sent Ashlyn a card saying, 'I know how hard it is for you to learn.'

Trina said the school showed no 'acknowledgment or understanding of the impact of the discrimination that occurred'.

Ashlyn now refuses to return to school and Trina is homeschooling her 'whilst trying to work out how to re-enter school'.

Trina said a paediatrician has since flagged Ashlyn as 'profoundly gifted', demonstrating 'skills past year 12 academically'.

Blanche

Blanche has a rare disease that causes chronic pain.

'[I] avoid going out as I can be red in the face due to the flare up or nature of the disease,' she told the Royal Commission.

Blanche said some people react negatively to her appearance and, when her face is red, assume she is angry.

Blanche lives in regional Australia and travels for medical treatment, often staying overnight. She travels with her registered assistance dog.

'If I do manage to book a disabled room they are often dirty or I get an old room ... I have been denied accommodation so I purchased a motorhome so I can attend medical appointments and not get denied [accommodation] as suddenly all rooms become "booked out".'

Blanche said that once, when her motorhome was being repaired, she booked a room and was asked to pay a fee in advance to have it cleaned after she left.

'[People with disability] are expected to pay more than a person without a disability.'

Shop staff sometimes abuse Blanche when she shops with her assistance dog.

'I have experienced staff at various supermarkets yelling at me when I'm in the store. It is very embarrassing and distressing to be yelled at in an aisle, or [when] the staff wait at the checkout making [it] look like I stole something.'

She said this happens even when she explains to staff beforehand that she has an assistance dog.

Sometimes Blanche is denied entry. One shop owner told Blanche that although she knew she was legally required to let Blanche in, she 'chose not to'.

'It's easier to avoid people, but there is a point where you get tired of being treated differently.'

Dahlia

Dahlia has an intellectual disability.

A few years ago she was sexually assaulted. Four months after the assault she found out she was pregnant.

‘It was hard being pregnant,’ Dahlia told the Royal Commission. ‘I was really surprised about it and I got really depressed.’

Fortunately she had good family support and a good midwife. She was in her 20s at the time and went to the hospital for prenatal care every week.

Each week she also saw a social worker. Dahlia spoke to her about wanting to put the baby up for adoption. The social worker didn’t know much about the process and told her to look up information online.

Dahlia’s mum did lots of research and found Dahlia some support services.

But even with some support Dahlia found the adoption process complicated. She said there was a lot of paperwork and forms to sign.

‘I found it really hard to understand all the topics.’

There was no information in Easy Read, with simple language and images.

‘The birth was a bit hard, I had a C-section and it hurt with the stitches healing.’

Dahlia chose a closed adoption. She felt some people judged her for her choice and told her she should keep the baby. But Dahlia is clear – ‘I made the best decision for me.’

The day Dahlia was going home a doctor came and spoke to her about contraception. Dahlia knew what she wanted and told the doctor.

‘She told me that I had to wait until my mum arrived because I couldn’t make the decision because of my disability.’

This made Dahlia angry.

'I told her that my mum doesn't make decisions for me, I do, but she wouldn't listen.'

Dahlia wants more information in Easy Read for parents considering adoption. And she wants people to respect the decisions people with disability make.

'I hope that this doesn't happen to anyone else and that people can get the support that they need and stay safe.'

Nakoa

Nakoa was born overseas and has limited family support in Australia.

A few years ago, when he was in his late 50s, he had a stroke. He is unable to walk and uses a wheelchair. He needs help with personal care, to complete daily tasks and to access the community.

‘I depend on support workers to ensure that I lead a quality life.’

Nakoa told the Royal Commission that after the stroke, thanks to the NDIS, he was able to remain in his own home.

However he found the NDIS confusing. He wasn’t sure what service providers, support coordinators or plan managers actually did.

‘All I know was that I was receiving services as I had an approved NDIS Plan.’

But at some stage, Nakoa’s NDIS funds ran out.

His support coordinator at the time didn’t tell Nakoa this had happened. With no discussion he moved Nakoa to a nursing home, telling him it was a week of respite. Nakoa ended up being there for three months.

During this time Nakoa engaged an advocate. The advocate discovered Nakoa’s funds had been depleted weeks before he went to the nursing home. When the support coordinator realised the problem, he handed Nakoa off to the local area coordinator. The local area coordinator decided to send Nakoa to a nursing home.

The advocate discovered that Nakoa’s plan only funded 3.5 hours of support each day. This was not adequate – Nakoa was receiving 8.5 hours each day.

‘I had no idea what happened to my funds and why no-one put in an application to the NDIA for change of my circumstances to access more funding. It was surely foreseeable that the funds were running out, but no-one put in a review, as a result hence I was left without any supports.’

Nakoa’s advocate organised a new NDIS plan and service provider, and helped him leave aged care. Nakoa had to pay thousands of dollars for the three-month stay in aged care, leaving him in financial distress.

‘I was left with about \$70 in my account. I eventually went home. I had no money for medication or food. I had to rely on my friend to help me financially. I was distressed and anxious at this point.’

Nakoa complained to the NDIS Quality and Safeguards Commission and is waiting for the outcome.

‘All the events ... have caused me stress, upset and I couldn’t sleep which are not good for my mental health.’

Nakoa is keen to recover the money he lost staying in aged care, but there is no guarantee he will get it back.

Boston

Boston told the Royal Commission he was ‘misdiagnosed with a thought disorder’ when he was a child. It wasn’t until he was arrested in his early 40s – he was accused of touching several women and girls without their consent – he was diagnosed with autism.

Boston started seeing a psychologist who specialises in treating autism and paraphilic disorders. He said while ‘autism is not an excuse’ for what he did, he is ‘stuck with inborn barriers around socialising’.

Police charged Boston with multiple offences, which he described as ‘overcharging’ and unjust.

‘I was imprisoned for over a year, dragging me from my home which I rented, my home was given over to someone new. My Disability Support Pension was also immediately cancelled.’

In prison, Boston was attacked and ostracised by inmates and ‘barred from being able to keep up the work with [his] psychologist’. As a result, his mental health deteriorated.

Eventually a judge ruled that incarceration was inappropriate.

Boston was released, but ordered to report to a sex offenders management unit every month for several years.

‘I find the ... meetings to be an arbitrary interrogation held by aggressive and taunting ... police.’

Boston said the meetings are not designed or adapted ‘to meet the communication and social barriers faced by those with autism’. His anxiety escalates.

‘I find it difficult to give eye-contact, hold long conversations about private or personal questions and I get aggravated when they ask these questions.’

He is no longer able to attend the meetings alone.

Boston has complained to state and federal politicians and the state crime and misconduct authority.

‘I have found it difficult to make a complaint and have my voice heard.’

When he contacted his local MP, a staff member ‘mocked [him] and stated they will always believe ... police over other people’.

Boston wants systemic change to the way the criminal justice system treats people with disability. He wants police to be educated to understand and manage people with a disability, and to be held accountable for their actions.

Boston said incarceration and the abuse following his release have destroyed his life.

Levi and Violet

Levi is an adult with disabilities that include cerebral palsy and autism. He is non-verbal, uses a wheelchair and relies on support for all aspects of daily life. He is outgoing and determined. Levi's mum, Violet, told the Royal Commission about the neglect Levi experienced in a group home.

Levi's first time living in supported accommodation was a few years ago – he stayed only six months.

In that short time he lost more than 10 kg. He also developed a pressure sore on his coccyx. Staff did not acknowledge either the weight loss or the pressure sore, leading Violet to arrange for an external community nurse to deliver Levi's treatment.

Neighbours of the group home texted Violet on several occasions to express their concern for Levi's welfare. They could hear him, from inside their homes, knocking on the walls for hours during the early morning.

During this period, to help Levi settle, his psychologist changed his antipsychotic medication from PRN – taken as needed – to daily. Later, after Levi had already moved to new accommodation, Violet discovered that staff never actioned this change to his medication.

At Christmas, Levi was out with his family. When Violet dropped him home, there was only one staff member rostered on. Levi and at least one other resident required a two-person hoist to move between the wheelchair and the bed and for personal care. It took 'many attempts' for Violet and the distressed staff member to 'encourage' nightshift staff to come to the house.

Violet shared information with the house manager and accommodation provider each time an issue arose.

'I expressed my concerns weekly. On most occasions I was unaware of any changes or actions that had been taken to address the situation or my concerns and at other times I was told things had been changed or managed but with no obvious outcome.'

Violet believes that part of the problem was that the house had at least four different managers, who were looking after at least two other residences at the same time. Staff turnover was also high.

Levi moved to a new group home with a different service provider and he is now doing well.

'The difference in their approach and his wellbeing is amazing,' Violet said. 'He has gained nearly 10kg in weight since moving in and has returned to [reduced medication]. He is much happier and content in himself and the staff are in touch regularly with any concerns or questions.'

Violet would like to see a focus on ensuring advocacy for 'people with severe and complex needs'.

'I am relieved that I was able to be part of my son's life to prevent further mistreatment of him and to help him to find a home run by people who understand and respect him and his different needs.'

Cali

Cali's father worked as an accountant for a mental health institution in the 1960s. He told her stories of abuses of power committed at the institution.

Cali thought these abuses were a thing of the past, but 50 years later she found herself 'taken by police ... without warning or notification ... and locked up for a period of days'.

She told the Royal Commission she was at home one day when 'police came knocking ... in a very aggressive manner'. They told her if she didn't go with them they would use 'brute force' to get her into the car and take her to the hospital.

Cali had been a victim of 'hundreds of petty thefts' and was trying to do something about it. She reported each theft to the police.

'The police got fed up,' Cali said. She had a fight on the phone with a particular police officer.

'[It] provoked this officer into taking drastic and unwarranted action against me, to lock me up in a mental health institute for 7 days.'

Cali says she was given no warning.

'This was a total violation of my rights. I was not a threat to anybody. There was no indication of violence.'

Cali says she is never violent or angry.

'I am a cool, calm and collected person.'

'Being a victim doesn't make me mentally ill,' Cali said. She believes the police violated her rights and the assessing psychiatrist and the hospital 'just wanted to please the police officer'.

Cali said that in hospital, staff took away her electronic devices and withheld medication, causing her pain. She wasn't allowed dental floss in case she was suicidal.

'I had to do and say whatever I could to be released as soon as possible.'

When she was released she was distressed to find no-one had cared for her animals.

'My cat, when I got home, was starving.'

Cali would like compulsory notification in writing before a person is 'taken by force by police to a mental health hospital'. She believes it would give the person the opportunity to seek some help and support.

Cali said she will 'not be putting in a police report ever again'.

Sabina and Rose

Rose is in her early 20s, has cerebral palsy and autism, and loves to keep active and fit. She enjoys horse riding and other activities that implement her physio exercises. She recently started to learn the piano, which is also building fine motor skills necessary to use her augmentative and alternative communication device independently.

About 10 years ago, however, Rose went through a difficult time. She sustained a severe break in her arm which led to several months of hospitalisation over an eight-month period. Her mother, Sabina, told the Royal Commission that there were several weeks when Rose was hospitalised even though she did not need to be, due to insufficient community funded homecare supports.

During one of Rose's periods of hospitalisation, Sabina and Rose experienced 'bullying and deliberate failing of duty of care' from nursing staff. 'I can only guess this was an attempt to make us leave to free up the hospital bed,' Sabina said.

Late one afternoon – it was after close of business for a long weekend – nursing staff came into Rose's room and said that the physio and occupational therapist had instructed nursing staff to provide no further support for transfers from bed, toilet or the shower. Sabina would have to provide all transfer support for Rose for the rest of her stay. Yet, just that morning, Sabina had received an email from the hospital physio identifying that Rose required two people to actively support her with all transfers to ensure safety.

'Fortunately,' said Sabina, 'I had significant knowledge of Work Health and Safety laws and understood the hospital's obligation and liability risks. The behaviour of the nursing staff on the surgical ward that evening was negligent and bullying abuse'.

Rose had only been transferred from the paediatric ward days earlier, so Sabina went to see the nurses there. The paediatric nurse intervened and explained to the nurses that Rose needed two-person support for transfers.

Sabina waited with Rose in her room but 'still no-one came to support [her],' Sabina said.

'At that point I decided that I would assist Rose with continence support in her hospital bed rather than risk a fall attempting to support her by myself ... Mitigating falls risk was my initial concern and constipation and bowel care would have to be addressed the next day.

'I believe the Surgical Ward Nurse waited till close of business so I would have no-one to contact for support, what they did not bank on was that I had contact details for [an advocacy agency] outside of business hours who helped me process how to address this situation.'

When the nursing staff changed shift at 10 pm, Sabina asked to see Rose's medical records. This was refused. Then Sabina spoke with the hospital night manager, who reviewed the directive not to provide nursing support to Rose and overrode it immediately, organising nursing support for transfers.

For Sabina this demonstrates the importance of patients and supporters understanding their rights and the responsibilities of medical professionals, and the value of strong advocacy.

‘Many people would not have had the knowledge of work health and safety laws to have a good understanding of rights and the responsibility of the hospital,’ says Sabina.

‘Ongoing funding for disability advocacy services independent of NDIS is absolutely paramount to building capacity for people with disabilities and their family members. Without [an advocacy agency] building my capacity for nearly two decades I would not have had the skills to minimise risks others have put [Rose] in.’

Quinn and Natalie

Quinn has had problems accessing public dental services since he was young. He is autistic and non-verbal and needs a general anaesthetic to keep still and allow the dentist to be close to him.

Natalie, his mum, told the Royal Commission it wasn't until Quinn was 15 years old and part of an NDIS trial that a case worker helped her find an appropriate dental service. But the service could only be accessed every two years. If problems arose in between times, they were left 'high and dry'.

Which is why Quinn ended up at the city dental hospital with a dentist who dismissed him because of his disability. Natalie remembers the dentist saying it 'didn't matter if a 20-year-old young man lost all his teeth'. In his view Quinn 'had no mental capacity to care' and Natalie 'was only concerned' because it would bother her.

The dentist said this in front of Quinn. While he may not speak, Natalie said, 'he certainly has a lot of understanding and emotions and feelings'.

By the time they left the hospital Quinn was 'melting down' from the noise, the stress and the four-hour journey. The trip had been a waste of time. 'They wouldn't admit him for three years,' Natalie said.

Back home, with Quinn still in pain, Natalie went to the media. This triggered a change in policy and Quinn had his teeth fixed at the local service.

Everything was good for a few months until one of the fillings fell out. Natalie contacted the local service but they refused to help this time. They suggested Quinn have it fixed privately, which Natalie could barely afford.

Then a friend recommended a private clinic in the city that did sleep dentistry as an alternative to general anaesthetic. After a long trip and a long wait, Quinn was jittery and found it hard to sit still. Natalie said the anaesthetist reacted badly and inappropriately, yelling at Quinn and the nurses. He said he couldn't do his job if Quinn kept moving around. He also demanded Quinn's consent, which he couldn't give. Natalie left in tears. Quinn left shaken and still missing a filling.

The clinic was supposed to have offered Quinn a sedative before his appointment, but the it was running behind schedule and forgot.

Natalie told us she is desperate. In addition to the media she has spoken to her state and federal politicians. They have offered some assistance, but she is often told about a service only to find out that the service isn't available or isn't suitable.

‘What we have had to go through for dentistry I wouldn’t wish on your worst enemy.’

Natalie would like to see better access to public dentistry and training for all medical professionals in how to treat patients with disabilities. Basic respect should be at the top of the list. She would also like to see sleep dentistry available in regional areas for people like Quinn.

Jonah

‘I hope it doesn’t happen to anyone else and people with a disability are protected and stood up for.’

Jonah told the Royal Commission he has ‘high functioning autism’ and describes himself as ‘highly emotional’ and ‘sensitive’.

About 10 years ago, Jonah went to a youth centre where, he told us, he was bullied and physically intimidated.

‘I felt scared for my safety and the staff didn’t help me, the bully would often seek me out when I was alone and try and punch me ... The youth worker saw some of the incidents and never helped me. I didn’t feel comfortable speaking with the worker about it because it was clear she didn’t care.’

On another occasion Jonah spoke to a youth worker about another person spitting at him. The worker told him to ‘stop dobbing’.

‘It has been 10 years since the incidents and I am still affected. I don’t feel comfortable around males and find it difficult to trust services,’ Jonah said.

‘If the youth worker helped me when it happened there would be no issues. All they had to do was step in and protect me.’

Lucinda

Lucinda, late 40s, has intellectual disability.

In her late teens she started working for an Australian Disability Enterprise (ADE).

At first it was 'a wonderful happy workplace', her mum said. But over the years, management changed and 'it was never the same environment'.

Some years ago, Lucinda started having a relationship with a man who also worked at the ADE. He would stay at her place and sometimes she would stay at his.

Lucinda told the Royal Commission he turned out to be a 'dickhead'. He would drink and do drugs with his mates.

'He used to get me to buy him drinks from the bottle shop all the time. He would smack me, yell at me. He forced me to have sex – he would hold me down and it would hurt – it was really bad. His father and sister were horrible all the time.'

'The dickhead' would make Lucinda leave in the middle of the night and she would have to find her own way home. One night he told Lucinda to go home and a neighbour saw her crying and rang her mum and dad. Her dad 'blew up'.

The next day Lucinda told one of the support staff at work about what was happening.

Lucinda, her mum and the support staff member spoke to ADE management, who advised her to contact an organisation that supports women who are experiencing sexual violence.

Lucinda met a woman from the organisation and had 'a nice long talk'.

The woman and Lucinda's mum spoke to ADE management and told them Lucinda and the man needed to be separated at work.

'But I still had to work in the same room and have the same morning tea and lunch break with him.'

Eventually management moved Lucinda to the second lunch break.

'The dickhead started coming to the second break. Then I had to be moved again to the first break and he started coming to the first break. I would sit outside away from everyone for breaks, but he would follow me out there. He would yell at me.'

Before work, he would find Lucinda outside the workshop and yell at her.

'Staff would not do anything about it.'

It got so bad, Lucinda started leaving work early.

'I never felt okay to be at work. I used to get sick in the tummy all the time, and stay home when I could.'

About a year ago, after 30 years of employment with the ADE, Lucinda left.

'I never got a goodbye party. The staff there always got parties, but the staff with disabilities leave and they don't get parties.'

ADE management apologised to Lucinda's mum. They told her they were sorry for what happened to Lucinda and acknowledged they should have offered her counselling and found her somewhere else to work.

'They never told me they were sorry,' Lucinda said.

Ralf, Zak and Danni

Ralf is autistic and has intellectual disability. He is in his 30s and needs help showering, getting dressed and crossing the road. Danni and Zak are his parents.

‘He can’t prepare a meal for himself other than every morning he has [cereal] for breakfast,’ Zak told the Royal Commission. ‘He can put milk on [cereal] and put them in the microwave. He does that every day.’

‘We considered bringing him along today, but he’s actually working,’ said Danni. ‘So we’re speaking on his behalf as his adoring parents.’

Ralf works for an organisation that pays him an award wage for sorting [documents] several days a week.

‘He taught himself to read,’ said Danni. ‘But his comprehension level is pretty low. He only needed to be able to read [a title] ... he didn’t need to be able to analyse anything.’

Zak said Ralf’s employer also pays someone to work with him and support him.

‘With all the complications going on in [Ralf’s] life, his employment has been, after all those years, a really stable and positive thing.’

After several years, Ralf saved enough to get a loan that helped him buy a share in a flat, where he lives independently. Ralf pays for most of his own housing needs, which Danni said costs the NDIS ‘a whole lot less’ than supported independent living [SIL] accommodation.

Zak and Danni say the arrangement gives Ralf more control over his life.

‘We’re both now in our mid to late 60s. We’re looking to the future for [Ralf] about trying to get him set up so that he can be somewhat independent from us.’

The NDIS funds Ralf’s support workers, who teach him how to care for himself.

One day, Ralf’s NDIS plan manager called to say his funding had run out.

‘Like, nobody can come and see [Ralf] at breakfast time tomorrow ... because there’s no funding,’ said Zak. ‘All of a sudden the supports that [Ralf] needed just to be able to live and function and work [were] being stripped out from us.’

When they asked why, the NDIS told Zak and Danni they cut Ralf’s funding because they ‘hadn’t provided any evidence about [his] needs’.

Although Zak and Danni are Ralf’s NDIS registered nominees, someone had reviewed his support plan and the NDIS cut his budget without telling them.

Zak and Danni paid Ralf's support services until the NDIS restored 'a little bit of his funding'.

'But there was nothing there for [Ralf] to really develop his own living skills or to enrich his life in any way. It was just all survival sort of level stuff.'

Zak said they're still trying to reinstate Ralf's full funding.

'We are trying to establish some sort of secure future and pathway for [Ralf] which at the moment, you know, it's a bit opaque as to what that is.'

Lulu

Lulu is in her late 60s and has bipolar disorder.

Lulu told the Royal Commission her first diagnosis was ‘major depression’. About a decade ago, she was ‘recategorised as bipolar’ and admitted to ‘mental illness units’ several times under an involuntary treatment order.

‘I refuse to call it mental health ... This is a misnomer ... so that we’ll feel better and less stigmatised.’

Lulu said she’s had many ‘terrible experiences’ because of the attitudes of mental illness professionals who treat her in a ‘highly negative way’.

‘People who are suffering from bipolar, who are seen as psychotic ... are pushed into a category. It’s a convenient tool mental illness services use. They say, “It’s untreatable,” and “You’re out of control,” ... I’ve been told, “You’re bad.”’

Lulu feels staff hold her on wards longer than required for arbitrary reasons. Once a nurse judged her to be ‘a difficult patient’ and wouldn’t release her. He forbade her from speaking to her social worker or an advocate. On another occasion, after a suicide attempt a couple of years ago, she said nurses forced her to take medication without explanation. They didn’t shower her or change her clothes for several days.

‘And I saw a “working with families” pamphlet up on the wall, and it was about trying to help families cope with your illness. So I got my family to attend ... I spent the worst time of my life waiting and waiting and waiting to be called to this meeting. No, never called. I wasn’t included.’

Lulu said nurses refused to communicate with her about the meeting.

‘People who suffer from mental illness, no matter what their background is, they are so disenfranchised, so wiped out.’

She described this as ‘the fishbowl that exists in mental illness’.

‘Where it’s darker inside – a glassed-in area. They can see out, and you can see them, and it’s a powerful way of staff controlling you ... It’s intimidating.’

Lulu said she once had a really good psychiatrist who understood her, but he died a few years ago.

‘My psychiatrist said to me, “[Lulu], hospitals are not a good place.” ... But he would encourage me to go, when I was well enough to be alone, to a very positive environment in nature.’

Since then, she finds most psychiatrists are 'the bottom feeders from the medical schools' and don't help her recovery. One psychiatrist just 'grilled' and 'bullied' her and said she 'must accept the diagnosis'.

'A psychiatrist can so badly mess up a life.'

This makes it hard for Lulu to get help as she finds the mental health services helplines 'dreadful'.

'So if I become suicidal, depressed, anything, there is no service I can go to.'

Ashby and Beatriz

There are two primary schools in the town where Ashby lives – one public and one religious.

His mum, Beatriz, enrolled him in the religious school because his sibling was there and the school knew the family.

She provided extensive documentation about Ashby's disability – he has intellectual disability, epilepsy, vision impairment and anxiety. She included letters from his doctors recommending a full-time teacher aide to help him participate and keep him safe.

Beatriz briefly met the principal the year before Ashby was due to start school to explain his needs and the support Ashby required.

'We felt hopeful he would be able to attend the same school as his [sibling].'

Just prior to starting school, the principal invited Beatriz to a meeting with the learning support coordinator.

Beatriz expected the meeting to be about adjustments and support. Instead the principal advised the 'absolute maximum assistance' the school could provide was a teacher aide for four hours a week. They also told her they couldn't accommodate Ashby because of a medication his doctors had prescribed in case of an extreme emergency.

'We came away from the meeting with the message that [Ashby] was not welcome at the school, despite the school purporting to hold strong [religious] values.'

The family, including Ashby's sibling, was very upset.

Beatriz contacted the district religious education office and they confirmed Ashby couldn't attend the school.

'We are shocked that ... the [religious] education system is permitted to exclude children with disabilities by denying them the appropriate accommodations, despite these being available through government funding.'

Beatriz believes religious schools should provide the same supports and accommodations public schools provide.

'My hope is that children with disabilities are able to be included in all schools in Australia. I believe the experience of learning in an environment with disabled children present will also be of benefit to non-disabled children in better understanding and normalising disability, improving empathy and also reducing the discrimination and exclusion that disabled people are likely to experience as adults.'

Thelma

Thelma, late 50s, has a disability and is mother to an adult with disability.

Thelma and her adult child have been looking for work for a number of years. She told the Royal Commission they have registered with several different Disability Employment Services.

None of the services has been able to help her or her child find a job.

Thelma turns up for meetings week after week but there is 'no clear plan of how to get a person a job'. The consultants never offer any concrete suggestions that would help her find work.

'There only seemed to be a requirement to turn up for the appointment, no results were required or forthcoming.'

Thelma believes Disability Employment Services are exploiting people with disability.

'The system is completely flawed in that there seems to be no incentive for those agencies to actually get participants off their books and into work,' Thelma said.

'A fee for service structure does not work. People who work in trying to get people into the workforce should be paid for results not appointments.'

Thelma believes Centrelink should be expanded to return to the role of helping people find work.

'I hope that employers can see the value in having a diversified workforce and give everyone a chance.'

Martine

Martine, in her early 50s, lives in a small town where health services are under-resourced and under pressure, particularly in relation to mental health. It has been difficult, and at times impossible, to access the support she needs to manage the complex post-traumatic stress disorder (C-PTSD), depression and anxiety she lives with.

Martine told the Royal Commission her mental health issues are related to trauma from child sexual abuse. She feels she has to be careful when seeking counselling or psychological support.

‘There is a level of trust that needs to be built up before you are willing to broach the subject or trust someone with your story,’ she explained.

Continuity of care is very important to her, but she finds it difficult to access in her home town.

‘The problem is that every time I got to a place of trusting someone and sharing my story, the counsellor left town within a couple of months. I was left feeling abandoned and that what I had shared was too much for them to handle. That they had left because what I shared was so horrible that I had scared them off. I was left feeling rejected, dirty and unworthy. I would shove the emotions down for a couple of years, until I became so unwell that I was willing to give counselling a try again.’

For a while Martine saw a visiting psychologist, who came to town once a month. She decided to ‘jump right in the deep end’, assuming the psychologist would soon leave her role and hoping to make progress before that happened. For their third session, Martine had a two-hour appointment.

‘We got to the most difficult part of my story to tell and the session ended. She did not ask if I was all right, or if I had any support over the next month. She did not offer a phone call and she left me hanging in a state of trauma. She said that she would see me in a month’s time when she was next down, and I felt vulnerable and wanted to self-harm.’

Martine went to her doctor ‘looking for another solution’, but he was ‘unable to help’ Martine, or to ‘suggest anything’.

Martine saw counsellors at a sexual assault resource centre in another town remotely, but the centre lost its funding. Another organisation took over its role, and a counsellor there said they couldn’t help Martine.

‘She told me that my situation was too complicated and too difficult for them to handle. She was unable to even offer me another solution when I asked her where I could find more help.’

Without any mental health supports, Martine had a bad episode of C-PTSD and ended up in hospital. The hospital had full notes of her medical history, but she suspects no-one read them.

‘For the first three days that I was in hospital the only time that I saw a nurse was to have my blood pressure taken, temperature checked or asked if I had a bowel movement. I would really like to know how this helps me with my mental health.’

Martine is now seeing a psychologist at a mental health service regularly, face to face, and this is making a difference. She just hopes the service won’t be defunded.

‘The job that these guys do here has been amazing and I have seen changes within myself. I would love to see that extended. I would like to see, you know, government funding, you know, extended. And even, yeah, increased so more people in rural and remote communities can be helped.’

Dear Educator & Disability Royal Commission

What does it feel like to be Isolated, marooned and Islanded within the education system?

Imagine being on an island with your peers and classroom teacher.

The teacher announces "It's time to travel off this island, I need you to get into groups of three."

The paddle boats off the island require groups of three to paddle the boat.

The teacher announces, " Do not waste time, the tide is going out and you will be marooned here for several weeks".

Everyone starts to get into groups of three.

Every group I approach said,

" We don't want you in our group, you paddle out of sync with the rest of us "

I ask the teacher for help, telling her no one wants me in their group.

The teacher replies with " Summer remember our generic 5 conflict strategies for schools"

I run over to the last empty paddle boat.

I ask my teacher to explain to me please, just one last time how to paddle the boat.

I tell her I did not understand the instructions the first two times as they were confusing to me.

The teacher says, " Summer everyone else in the class understood my instructions clearly, you do not listen".

The teacher then has to move on and look after the other students because they are getting restless.

Everyone leaves the island but me.

I am marooned, isolated, islanded.

Kind regards one of many autistic students your system has failed



Poem by Summer Farrelly

Desiree

‘Employment is a big thing for me. It’s not easy being an older woman with a disability ...’

Desiree is in her mid-50s and was diagnosed with Asperger’s syndrome and attention deficit hyperactivity disorder (ADHD) about two decades ago.

Desiree told the Royal Commission her childhood ‘wasn’t always very easy’.

‘I felt a bit like the ugly duckling and a child with special needs. And when I grew up we didn’t have any of the inclusion and help that kids get nowadays. I didn’t have that understanding and help and because of that, in my 20s, I had quite bad mental health.’

Nonetheless, Desiree went to university in her 30s and studied law. She was on a Disability Support Pension but wanted to be as independent as possible. However since graduating, she has faced exclusion in the workplace due to ‘a lack of empathy and respect for neurotypical and neurodiverse people’.

A few years ago, Desiree participated in a public service traineeship program for people with disability. On completion she was placed in a government department where she requested ‘a list of adjustments fairly standard to someone with Asperger’s syndrome and ADHD’.

‘Help with sensory things ... not too loud noises and, you know, bright lights and smells ... If it is an eight-hour day, I would actually need 10 hours. My doctor had done a report suggesting certain things, but they just decided to put that in the bin and bring in their own person who had no health qualifications, who was just an HR person. She decided she was going to redo the report.’

That turned into ‘a very lengthy process’. After almost a year, Desiree said, there was still nothing in place.

‘And I got very stressed because I felt I had the capacity to do the job but I needed some proper reasonable adjustments. And also there were some poor behaviours. The issue of proper respect and zero tolerance of any social bullying or discrimination, that just didn’t happen.’

Desiree ended up with anxiety disorder and was hospitalised for weeks. She felt she was ‘collateral damage’ after this ‘bad experience’.

Desiree came out of hospital to find her NDIS funding had run out.

‘There was no support ... And I felt that was terribly, you know, inhumane. They had said that they would help me.’

Desiree went through a tribunal process to increase her NDIS supports.

'I felt the funding was important for my main goal which was finding and keeping a job,' she said.

'There are a lot of people out there with disability who would like to be working who are not able to.'

Because she feels excluded in the workplace, Desiree 'looks to support workers' for help with social participation. She feels they require 'different skills for dealing with psychosocial disability'.

'I'm quite shy socially, but I don't like to be too alone. And if they could just kind of help me bridge the gap ... They're not always able to do that.'

A career coach she's accessed through the NDIS has 'really helped' with employment capacity building, but Desiree says she still has to overcome attitudes.

'The workplace in Australia is still not really tailored to people with disability and that was definitely my experience. The public service or the private sector, wherever it is, needs to train their employees to be good towards people with disability.'

Stella

‘What we need as disabled mature women, we need a safe environment. And nobody’s helping me. Nobody.’

Stella is a First Nations woman in her 60s who is blind and has post-traumatic stress disorder after a sexual assault. She is a wheelchair user and is assisted by a guide dog.

Stella got her first NDIS plan in the early 2020s. The funding was cut when she went interstate to escape domestic violence. She told the Royal Commission she is ‘fighting’ to have it reinstated.

‘I have been looking for someone to help me get back on the NDIS. Nobody is willing to do that.’

Stella also has aged care supports. She feels that she’s ‘stuck between a rock and a hard place’ trying to get help.

‘There is not enough funding for people like me in My Aged Care. I feel totally abandoned by a system that’s there to help and guide and protect me.’

Stella has been struggling for three years to get secure housing.

‘The housing department hasn’t done shit. They had a proper letter ... from my GP, from my psychologist. And they both said that I needed a single dwelling, very secure, very quiet area to live in. Never got that.’

Instead, she said, the housing department has moved her to ‘unit after unit after unit’ and puts ‘druggies in with the disabled and the aged’.

In one unit, the door wouldn’t close and she felt unsafe.

Last year, her current unit flooded.

‘The sewerage come up through the pipes and the drains. The toilet overloaded ... Nobody does anything about it.’

Stella believes the housing department discriminates against her because of her disability, but also because she is a First Nations person. She doesn’t understand why she shouldn’t qualify for units ‘especially for the disabled’.

‘They’re being racist 70% ... They’re always discriminating against my guide dog because they don’t want him being in their apartments. But they definitely don’t want me ... If you’re disabled, they don’t want to listen to you.’

Stella said she faces the same mistreatment in the health system. A few months ago, she had a fall from her wheelchair.

'They wouldn't let my guide dog in that hospital ... I ended up with no pain relief expect for an aspirin that I bought at the bloody pharmacy. They patted me on the head like a dog and said, "Just go home and rest dear. You're fine."'

Recently, Stella had 'a breakdown ... a brain meltdown'. With inadequate funding, she couldn't get mental health supports.

'I had to hire private ... I was for eight months begging people, "Please come help me."'

Currently she's living in residential respite accommodation.

'It's filthy. It hasn't been cleaned.'

Support workers don't hoist her as instructed by her physio and often fail to shower her.

'There is no duty of care. I have to get out of there ... They just don't look after you. It's as simple as that. I paid for a bed but I'm not paying for the care because the care's a joke. I can only stay there for a bit and that's it, I'm homeless.'

Hillary, Robson and Coralie

‘The way I was treated wasn’t very nice. I reckon that if I had a chance to be a mum with my two kids I reckon things would have worked out better than they did.’

Coralie is in her 40s and has cognitive disability and dyslexia. Her son Robson lives with anxiety, and her daughter Hillary has cognitive disability.

‘[Their father] used to just domestic violence on me and [Robson],’ Hillary told the Royal Commission. ‘What I really wanted put in place, but I didn’t get, was a chance just to be a mum with two kids and some help, and take the dad away so that we can have a better life. But things didn’t work out that way.’

When Coralie was in hospital giving birth to Hillary, her husband stayed home with Robson.

‘His dad was supposed to look after [Robson]. [Robson] was outside riding around and one of the neighbours ... rang [child] protection and said that he looked like he wasn’t getting looked after properly.’

Coralie said she’d rung the police to remove Robson from his father’s care, but ‘the police said they just couldn’t move him because he’s the father’.

Coralie struggled to feed Hillary and stayed in hospital, but had little other support.

‘I was just doing it all on my own.’

She managed to bring Robson into hospital with her. One day child protection officers arrived and ‘took the two kids away’.

‘They reckon that I couldn’t manage looking after two kids.’

Coralie said she felt ‘trapped’.

‘What I really wanted put in place was a chance to be a mum, take dad away and get support ... They just wanted me to sign some papers, like, sign my kids over to them.’

Coralie can’t read or write and asked for someone to explain what was going on.

‘I couldn’t understand anything so I wasn’t going to sign anything before I knew what was going on. I wasn’t going to sign my kids away, you know, on orders till they were 18.’

Coralie said her children were eventually removed and placed in foster care. After her violent husband moved out, Coralie's case workers tried to return her children to her, but child protection 'wouldn't agree to it'.

'They didn't have a very good life in foster care. They got treated a bit wrong from the foster care people. But yeah, so that made it hard that my kids were supposed to stay with the same carer till they were 18, but they were split up.'

Robson was returned to Coralie when he was a teenager, after he was found living alone in a refuge.

'[Hillary] can't come home because it just feels like there's nothing there for [Robson] and her to be together ... That's hard because I thought she might come home and we'd settle down and be a little family like we wanted to be. But no, it didn't work out that way.'

Coralie said Robson has anxiety and she's having him assessed to see if he has another disability.

'I wish they did it in care, but they didn't.'

Coralie told the Royal Commission she was never given a chance to raise her own children.

'Instead of just taking the kids straight away, maybe just ... get me some help and the kids some help and things like that and then build it up so that we [could have all been] together still.'

Tamsyn

Tamsyn, mid-40s, is Deaf and uses Auslan.

In primary school, there were a few other Deaf kids in her class. The teacher didn't use Auslan, expecting them to lip-read.

'We had to sit behind each other, facing the front of the room, and try our best,' Tamsyn told the Royal Commission.

At the end of lessons, the teacher would test the class. Covering her mouth with her hand, she repeated similar words, such as 'bear' and 'pear' or 'six' and 'sixth'.

Tamsyn would have to 'wildly guess'.

'Every time I guessed wrong, she would smack me hard across the hand with an object.'

'It was exhausting. I was always physically in pain and it was very emotionally distressing. Looking back now I realise this was abuse,' she said.

'I am still traumatised by these experiences to this day. It means I am still upset and triggered whenever I have to lip-read.'

In high school, Tamsyn wasn't allowed to attend English lessons and instead went to a language class.

'Do you know why we couldn't be part of those classes? Because the Deaf students' literacy skills were so far behind those of the hearing kids.'

The language teacher didn't try to teach them what they missed. Instead she used signed English, repeating very basic literacy exercises.

In classes with hearing students, Tamsyn had no access to interpreters and no support.

At university, Tamsyn learnt about essays for the first time. She was shocked and disappointed teachers at school had had such low expectations of her.

'I really missed out because of how Deaf kids are taught, and this caused me to lag far behind my hearing peers for many years.'

Following university, Tamsyn worked in Deaf education.

'[One] workplace had a very strong "hearing culture" – all of the staff were hearing. No-one was interested in Auslan. The only way to communicate with other staff was to email them, or write notes back and forth.'

One staff member had a particularly negative attitude to Tamsyn. She would talk down to her and never treated her as an equal.

‘Her behaviour caused me a lot of harm.’

Tamsyn tried to book interpreters for staff meetings but was told no interpreters were available. When she complained, they told her that her meetings were not a priority – interpreters were needed at hospitals or police stations.

‘I would miss out on vital information, and I would fall behind. It was such a disappointment to me. I was often upset. I became unwell. This was not an easy time in my life.’

Following a review, the school asked all staff to commit to learning Auslan. But staff made excuses, saying they were too busy and had too much to do.

‘Everyone gave up on the idea and no-one could be bothered going. This created a lot of communication barriers for me in that workplace. I felt physically sick from the stress ... I lost all of my confidence.’

Tamsyn said it hurt so much because the organisation was a disability organisation specifically funded to provide services to Deaf people.

Niky

‘The scam continues. The cash grab continues. Another dodgy person associated with the NDIS making money off me.’

Niky is autistic and lives with psychosocial disability, post-traumatic stress disorder (PTSD) and depression. She told the Royal Commission she has faced many ‘systemic barriers’ getting help for her disability, ‘because [she’s] moved around and homelessness and stuff’.

A few years ago, Niky had only just ‘got a regular doctor’ and was ‘hormonally transitioning’ as a transgender person. She was struggling to find stable housing and said the crisis accommodation service was ‘crap to minorities’.

Niky applied for the NDIS through a mental health service provider.

‘They were a bloody great waste of time. They’ve screwed up so big with me ... Some bastard wrote schizophrenic from the first day and I just felt infuriated with that.’

At the first meeting, all of Niky’s medical records were ignored.

‘I told her extensively, you know, PTSD, social affective disorder, you know, fancy word for social anxiety, clinical depression ... Anyway, these are the documented things ... the official stuff, and she’s like, “I don’t need it” ... That was that.’

This left Niky without funding for almost a year.

The situation ‘dragged on’. One day, someone put down that Niky was ‘going to work towards a goal of employment’.

‘I’m like, “No, no, don’t put that. I’m on a pension. This is not a reality.”’

But no-one listened to Niky when she tried to raise these concerns.

Once, she visited the provider.

‘Not one single client in the waiting room. And they tried to prevent us from speaking to someone. They had nothing to do.’

Meanwhile, Niky said, housing services were treating her ‘exactly the same’.

‘They are treating people with disabilities and trauma like an inconvenience.’

When she finally got her first NDIS package, Niky exhausted all of her funds ‘trying to find out’ how to use it.

‘No-one would tell me, and they treated me like I was an idiot. That’s why it took three-quarters of a year to get a support coordinator, who was a deadbeat. The NDIS hotline couldn’t even tell me what a support coordinator does ... They ummed and ahhed. They know nothing. It’s a joke.’

Niky said her support coordinator never organised her essential supports. She ignored dozens of calls and emails, then ‘walked out’ on her.

All this time, she said, the provider was charging her for services that she didn’t have access to.

‘I need help getting to my counsellor. I engaged them for like a year or something. Not once did they drive me anywhere.’

Niky said the NDIS would not let her cancel her contract with the provider.

‘There is no accountability. No-one is looking into these services. I tried to report fraud.’

Niky now has a new coordinator who’s trying to get her a better NDIS package.

‘Look, she’s not perfect, but she’s a thousand times better, and she actually knows autism. She understands.’

Niky said this is rare.

‘NDIS people don’t really understand trauma and anxiety. They’re meant to be experts ... I think they think we’re going to recover and become productive members of society. But some people have lifelong conditions.’

The funding and housing struggles have exacerbated Niky’s ‘serious mental health issues’.

‘I’ve just been fighting these bastards that have denied me access to the things they’re meant to give me. I just want to get the hell on with my life.’

Kassandra

Kassandra's teenage son is autistic.

'He is a lovely kid. He is my practical child,' Kassandra told the Royal Commission. 'We knew there were some issues in kindy. Well, in preschool really, we knew. He got bullied quite a lot and in hindsight was missing a lot of social cues.'

Sandra works in the disability sector, but was shocked when a doctor diagnosed her son with autism in year 1. When she tried to get NDIS funding for early intervention she found he'd just missed the cut-off age.

'Often you will have children with disability being first diagnosed in year 1, but families and the children are unable to access the early intervention childhood supports at that stage because of the arbitrary cut-off date of seven years of age.'

Kassandra quit her job and borrowed money to get him support.

She said that, even with NDIS support, a disability diagnosis is a significant financial burden for most families. Women especially are 'penalised for being carers'.

Doctors also diagnosed her son with attention deficit hyperactivity disorder and anxiety, and put him on a trial to see which medications worked best.

'At one stage I had to take him to [hospital] emergency where the nurse proceeded to give me a lecture on drugging my child. Which was a bit hard to deal with when you have a child who's reacted so badly to a medication that's been prescribed.'

One doctor told Kassandra that her son's autism was partly caused by a 'lack of maternal engagement'.

'Parenting is the woman's fault. It's never the dad's fault. And they cop it, particularly single parents. I see a lot of it. They don't receive anywhere near the amount of support that they need in this space.'

There was also little help for her son at school, which put him in special classes.

'If you ever want to go to a very un-PC place about disability, go to a high school. They're terrible. So he refused to go there because he said that you were basically just putting a target on your back that said, "Bully me."'

One teacher told Kassandra it was 'too time-consuming' to teach her son, so she went back to work to pay for tutoring.

‘One of the things that I’ve been saddened by is the lack of understanding and tolerance for disability in the school communities. I’ve become aware that it’s not a mandatory part of training for teachers.’

Eventually her son graduated from high school and applied to university. However he failed to get into his preferred course because he misunderstood the midnight deadline and waited until midnight to send his application.

‘He goes, “They didn’t really mean midnight did they, mum?” and I went, “No mate they really didn’t mean midnight. It was before midnight.” ... I did try and explain [to the university that] it’s because he’s very literal and you told him midnight and so he did it at midnight and missed the cut off, [but] the university will not make any concessions on the basis of his disability.’

Ry and Mary-Anne

Ry, in his late 30s, is autistic and has post-traumatic stress syndrome, anxiety and depression. He lives in an apartment subsidised by his mother Mary-Anne, who helps out in many other ways.

'My role currently is support person/carer, facilitator, care coordinator, employer and overseer of [Ry]'s [NDIS] plan, fill-in carer and the only person who is advocating against the injustice of "the system" for [Ry]'s equal rights and his future in this disabled world,' she told the Royal Commission.

Ry applied for the NDIS about six years ago and was approved. Mary-Anne said they were optimistic at first.

'We believed all the publicity about how the scheme would help people with disabilities. I believed that [Ry] would have a better fulfilled life and we his family would not have to worry about him or his future. The publicity was full of promise and an answer to my prayers, or so I thought.'

The reality has been very different, with negative impacts on both Ry and Mary-Anne.

'[Ry] is overweight and is anxious and angry all the time ... Currently he is forgetting things and is very, very anxious due to the changes during the last three years with NDIS and his care. He constantly worries, as do I.'

She believes the way the NDIA has treated Ry constitutes abuse and neglect.

Each of Ry's plans has been disappointing.

A planner put the first plan together, including a budget, with no input from Ry or Mary-Anne apart from an introductory phone call. Mary-Anne complained, the complaint got lost and she had to assemble the paperwork all over again.

A second plan was submitted without their approval or consent.

Subsequent plans have reduced Ry's funding further.

'I am forced to remain as his carer,' said Mary-Anne.

A recent review of Ry's plan resulted in a cut-and-paste from someone else's plan. It even used their name instead of his. The reviewer has not looked at Ry's previous plans or his needs and goals, ignores the views of medical specialists and 'has not even read [Ry]'s accompanying reports'.

'[The reviewer] has used coercive control by quoting rules and legislation that do not apply in [Ry]'s case ... The NDIA/S set deadlines for us and we are obligated to meet them or suffer the consequences, which are severe. But they seldom meet their legislated deadlines and dismiss them with impunity. This is victim blaming, abuse from a position of power and coercion.'

The reviewer advised Mary-Anne to file an appeal to the Administrative Appeals Tribunal if she was unhappy.

Mary-Anne said this process takes too long and was a not a solution for Ry.

'What happens in the meantime?' she asks.

Mary-Anne says she has observed recurring themes in the way the NDIA operates. There is a power imbalance, where the views of parents and medical specialists are simply dismissed. Staff making critical decisions are poorly trained and do not follow the agency's own guidelines and rules. Lawyers and barristers are employed at great expense to fight against people with disability. And if you complain, your plan will be reduced.

'This is a pattern of behaviour that the NDIA uses to enforce compliance on people with disabilities. It is abhorrent ... I have never experienced this sense of helplessness before ... The constant wearing down – one problem is solved and another arises. There is no end to it all.'

Nazra

‘They were terrible. Jail would’ve been better. That’s where I wanted to go if I didn’t get out of the boarding house.’

Nazra is in her 60s and uses a wheelchair or walking frame to get around.

From her early teens, she was in and out of psychiatric hospitals.

‘I’ve been some horrible places,’ Nazra told the Royal Commission. ‘I’ve got schizophrenia they did say a long time ago, but not anymore. They said I had manic depression too.’

At one hospital, doctors gave Nazra electroconvulsive therapy dozens of times and ‘drugged’ her.

On her release, Nazra moved into a boarding house where she was physically and sexually assaulted.

‘We were treated horrible and there were people there that used to hit me and – and they’d rape me. And they used to drug us up on medication. The owner would hit people. He didn’t care who he had live there as long as he was making money ... Every fortnight we’d sign a withdrawal form and he helped himself to everyone’s bankbooks.’

Staff were stealing from residents and ‘shut them up’ with medication, Nazra said.

‘They take your clothes. They took everything.’

Nazra had a job in a workshop, but often went hungry.

‘One of the girls that worked in the kitchen there, sometimes, depending on how she felt, you wouldn’t get breakfast going to work, or lunch to take with you. And every time I got paid, she’d be down the station waiting for me to take all my money from me. The girl would take all my clothes. Everything I had, she wanted. And if I didn’t give it to her, she’d hit me.’

Nazra said the residence was filthy and dangerous and she lived in fear. The front door was left open all night. Once she saw another resident ‘get stabbed and die’.

‘The bathroom and toilets didn’t have any doors. You had to wear thongs in the shower because you didn’t know what you were going to tread in. The food was horrible. There were mice in and out of the pantry. There were mice everywhere.’

At one point, an ex-boyfriend of one of the staff sexually abused Nazra.

‘They split up, then he needed a slave, so he took me to his place and he used me.’

Nazra fell pregnant.

‘They made me have a termination and I had no choice ... I hated the boarding house so much, but I had nowhere else to go.’

Nazra eventually got a room in a share house through work.

‘And when I got there, it was like heaven.’

A few years ago, she had an operation.

‘That’s when my mobility went back, and I lost my independence.’

Nazra applied to the NDIS.

‘They transferred me to a disability place. And ever since then, it felt good.’

Nazra has extensive at-home care. She wants mental health services to stop suggesting that she goes into ‘supported accommodation’.

‘That gets me upset. I know what I want and I want people to listen to me. If I fall over and break my hip, I want to go to rehab and then come back home.’

She thanks the NDIS for her autonomy.

‘If it wasn’t for NDIS, I’d be in a nursing home because I couldn’t afford the care that I get now. I hate that idea ... I’d die of a broken heart. They remind me of the boarding house.’

Edmond and Collette

‘Diversity benefits everyone in the room. And a wonderful other side effect is that the kids without disability often feel less anxious because their culture is to accept all and that if they were to fall, there’ll be supports ready in place for them.’

Collette’s teenage kids have attention deficit hyperactivity disorder (ADHD) and her son, Edmond, is also autistic.

‘[Edmond] loves basketball, the outdoors, spending times with his dogs,’ Collette told the Royal Commission. ‘[He] has a few close friends who care for him very deeply as well.’

Collette is a teacher and said that when she sent her kids to school she didn’t expect them to be neglected.

‘It’s the story of long-term neglect of my kids and where it got them to. So both of them are at a pretty good state now and quite happy with their lives, but it’s been a long, hard road to that.’

For example, when Edmond started school the teachers didn’t know how to support him and the principal suggested she send him to a special school on the other side of town.

‘Me having the mother guilt and thinking, “I needed to do this for my son” ... and the school saying, “Well, you know, if he spends [a few] years there we’ve had other kids come back to us.” And that hope that that was going to be something that fixed him.’

Instead, the special school had such low academic expectations it caused ‘more damage’. Many of the other kids were non-verbal and Edmond started speaking less. Collette decided to move him to a mainstream school with a special education unit, hoping it would be more inclusive.

‘I thought it had lots of disability supports, but they just really pretty much all segregated all the kids within the school. And his distress just kept climbing.’

At first the school included Edmond in some regular classes, but a new principal put all the kids with disability in a building ‘fenced-off’ from the rest of the school.

‘[They] only came out for assemblies really. And there was then a cycle of teachers ... wearing out or getting physically hurt by kids that were all pent up in a unit at the back of the school. It wasn’t long after that that he totally unravelled.’

When the school closed the unit, it put Edmond back into in a mainstream class, but separated him from the other kids. Collette said when Edmond was bullied, a teacher told her it was ‘the way the world works’.

When Edmond started to self-harm Collette removed him from the school for several months.

‘Even though I had gotten a lot of information around that time around disability and inclusion and adjustments I wasn’t being able to make it happen for [Edmond] at school, even with all the knowledge I had.’

Collette said she’s spent the past few years learning from other families, rebuilding Edmond’s confidence and helping his high school be more inclusive.

‘Now I am able to advocate better for my kids and stand my ground ... This year I finally, after [years] of schooling, started to see things fall into place and he is beaming.’

Collette said Edmond is resilient, but will ‘carry scars’ of neglect from previous schools.

‘[I’m] really hoping that the outcomes of the Royal Commission can make it more clear what the pathways forward are. And I just hope when my kids’ kids head off to school that it’s a different story ... not the same old story of hardship and heartbreak.’

Lamond

Lamond began working as a house supervisor at a state-run group home in the early 2010s.

He said it was one of the 'more complex' homes in the system. The residents had profound intellectual disability and physical disabilities. Some needed two on one support for bathing, dressing and toileting, others for using equipment such as ceiling hoists to manage transfers between bed, wheelchair and bath. They all needed full support from a staff member for eating and drinking.

Most of Lamond's working hours were 'contact time', spent working directly with the residents. But as the years went by the list of tasks he had to manage in his non-contact time grew exponentially. Lamond told the Royal Commission that a report completed some years before he took the job at the home had found that a house supervisor's work could not be done in the allotted time.

'Yet my non-contact hours were still at the same level ... over 10 years later and were never increased on a permanent basis to help me cope with what was clearly an unmanageable workload.'

Lamond said that other reports published around this time identified similar issues. These included the number of responsibilities house supervisors had, difficulties with delegating tasks, staff training and rosters, and roles that were poorly defined. The reports proposed solutions but most weren't implemented.

Some that were implemented only compounded other problems.

One initiative related to staff training and development. This added about 12 hours to his non-contact workload every month, with no increase in the non-contact hours he was allocated.

Lamond found he could only complete his non-contact duties during hours scheduled for direct contact. This meant he had less time to spend with staff, supervising and guiding them in providing care to the residents.

'The importance of this was underestimated by management,' he said.

For example, to meet the residents' complex needs, staff had to know how to prepare meals and feed them safely according to their care plans.

'These plans would detail how food should be served (from cut into bite sized pieces to smooth puree), the consistency of fluids (from regular to extremely thick), how much should be given with each mouthful, where to place it in the resident's mouth (this depended on the individual resident's control of the muscles in their mouth and tongue and their ability to swallow) and how long to wait between spoonfuls ... This is not something you can explain just the once.'

Dressing, toileting, showering and using mechanical hoists and full body slings to transfer residents were 'just as complex and as vital' to ensure the safety of both residents and staff.

Lamond said that in his 'many years of experience' he found the most effective way to train staff was to work directly with them while providing support to each of the residents.

'It is not as simple as telling staff this is how it should be done. You need to be working hands-on as a role model,' he said.

Rather than making the recommended changes, the government took steps to privatise group home services. It began by cutting 'back of office' staff, responsible for functions such as payroll. House supervisors had to take on these tasks, and their workloads increased again.

Lamond believes the government created an unsafe workplace in group homes, which negatively impacted the care of residents.

'I think it illustrates the culture and attitudes, which start with government and slowly filters it way down through the public service ... The culture of saying how committed they are to people with disabilities and how important it is that people with disabilities have choice and control over all aspects of their lives. Yet the demonstrated attitude is one of complete disrespect for people with disabilities, their families and the staff working in group homes.'

Gordon

‘Once you’re put in here, you have no rights. People like me, you know, with a disability, have been abused. There’s no support and there’s no help and it feels like there is no end to it.’

Gordon is a young autistic man who lives with depression. He has been in prison for several months and told the Royal Commission he’s been denied disability supports and basic health care.

‘Still waiting to see mental health ... Still yet to see a doctor. And there’s no way for me to access any help. All this shit that they say you’re entitled to is non-existent.’

Prior to his detention, Gordon was participating in an autism support program

‘That benefits me in the right way. Like, there’s no support program in here for that. If I was on the outside, I’d have no problems, you know, being able to access it ... The more I’m in here, the more I mentally deteriorate.’

He also has an infection that’s gone untreated.

‘Still haven’t got my treatment that I was prescribed before I came in ... I’m starting to feel shittier and shittier.’

Gordon did once get to see a prison psychologist, but said they breached confidentiality and told prison officials his autistic behaviour was ‘threatening’.

Gordon said that in the detention unit for dangerous offenders where he is now being held, guards ‘physically assault’ prisoners after turning their body cameras off.

‘They talk to you like shit and abuse you. They think they have the right ... They are violating our human rights.’

Because of the ‘mistreatment’, Gordon has autistic meltdowns and often feels suicidal.

‘I’m getting to the point where I’m just ... Like, this place literally makes me want to give up. And the situation and the atmosphere doesn’t help. I’m not coping ... I should’ve been in rehab getting everything done.’

His social anxiety is exacerbated, and he’s now cut off from prisoners with whom he’d been able to form supportive relationships.

‘A few autistic people ... we’re alienated from ourselves.’

Gordon is angered by the way the prison treats people with disability.

‘Legislatively, it needs to be changed. I want some rights for the people who are like me, you know. All I care about is accountability when it comes to this system. I’m lucky that I can, like, stand up for myself at times, but there’s other people like me who just don’t have that ability. I can’t stand by and let people be treated certain ways ... It just doesn’t sit with me.’

One thing he would like to see in Australia is a formal ‘autism card’ he can show to authorities and health professionals, so they don’t make incorrect assumptions about his behaviours.

Sofie and Emilie

Sofie is in primary school.

'[Sofie's] a very social child who wants to be with people,' her mum Emilie told the Royal Commission. '[She] is an absolutely incredible little girl who was really looking forward to starting at her local primary school.'

The principal Emilie met was 'absolutely fantastic' and promised that Sofie would get everything she needed. However, there was a new principal the day Sofie started school.

'None of the agreed adjustments were in place.'

One of the things Sofie needed to start school was a stool so she could go to the toilet.

'When I found out that that wasn't ready I said, "Well, not a problem. I can bring it to the school." But I wasn't allowed to bring it into the school. They said that they would have to arrange for it.'

Sofie couldn't use the toilet without the stool and the school recommended putting her in pull-ups.

'I said to them, "It's not that she doesn't want to, but she can't. She can't sit on the toilet without support for her legs."'

Emilie said the disability toilet was partly used for storage, it was 'scary looking' and Sofie needed to get a key to use it.

'We had worked really, really hard to toilet train [Sofie] prior to starting school ... [Now] we had a child who was no longer toilet trained and who developed a severe anxiety for public bathrooms.'

The stool never arrived and the school wouldn't let Emilie provide one. She began to feel 'the whole process' was designed to make Sofie leave.

'We had fantastic support by the other parents, you know. No-one could understand why all of this was that difficult.'

Emilie also learnt that the school had a 'no touch' policy, after one of Sofie's support workers said she wasn't allowed to hold Sofie's hand.

'No helping on or off chairs in the classroom ... and under no circumstance give her a hug if she needed it because you're not allowed to.'

When Emilie asked why, the principal told her those things are restrictive practices.

‘It got to the point where one of our therapists ... said she can’t help [Sofie] in a setting like that because she would get complaints against her from the teacher for touching [Sofie] and for helping her with her handwriting.’

Emilie said the school also didn’t adjust the curriculum for Sofie.

Emilie was born in a country that has inclusive education where children with disability are usually supported in mainstream schools by teachers who have postgraduate degrees in special education.

‘Even just the expectations from the teachers, you know, they’re there to teach this child and they see it as their role as a teacher to figure out how this child learns.’

Emilie is considering moving her family back overseas so Sofie, in her ‘most important years’ of education, can have an inclusive education. In the meantime, to prevent further harm to her daughter, she’s enrolled Sofie in a school with a separate disability support unit.

‘I truly believe in inclusive education. But I am so scared that her next school won’t give her the support that she needs to thrive.’

Birrani

Birrani has physical disability.

'In this region ... lots of our mob have disabilities and are riddled with chronic disease,' he told the Royal Commission.

Birrani uses an electric scooter and struggles to get around.

The roads and footpaths are poorly maintained and not accessible. There is no ramped gradient from the road to the footpath or driveway.

'Sometimes people have to crawl into their yard.'

Many shops and buildings are inaccessible.

'Even if shops have ramps or good access, they don't have sliding doors so it's hard to get in,' he said. 'Even the NDIS office here isn't disability friendly. It's really hard for me to get my scooter through the doors.'

Birrani has had some problems with the NDIS.

'When people make the plan, [staff] don't sit down and explain it properly and slowly to people.'

People nod along, rarely asking questions out of respect or because they don't know what questions to ask.

'I reckon [staff] should just sit down and go one page at a time, not too quickly, just take the time to explain. Most mob here don't have the skills to understand these things – English is a second or third language.'

Staff should use visual aids and signs. He says this would be particularly useful when explaining details and numbers in the plan.

'Go right back to primary school level and show how much of the plan is gone and how much you have left to use.'

Support workers are in short supply and sometimes not very reliable.

'We need to be told what we are entitled to receive from service providers and understand what we can and can't ask for, and what they can't ask us to do. Some workers are different when the boss isn't there.'

Birrani sees the NDIS as a coach – overseeing the players and the roles they play. He says they could do more to help the service providers and support workers improve their service.

'I hope one day the NDIS could look at how things are here, and work with all these service providers to look at how we could have activities like day shopping, buses with ramps and going into [the city] and things like that. All organisations working with disability mob should work together, have a meeting every three months or something like that to talk about issues for people with disability.'

Vicente and Chantria

Vicente, in his mid-30s, has a ‘mild intellectual disability’ and Asperger’s syndrome. ‘Because of that, he has difficulty getting a job,’ his mother Chantria said.

Vicente has sought work through several Disability Employment Services (DES).

‘Some of them are good, some of them just want to take the money.’

She described one job placement Vicente had in a restaurant.

‘It was two full shifts in one day and I am sure that is illegal ... He said to me, Mum, I can’t do this anymore.’”

When Chantria complained to the DES provider, they apologised, but in the next breath told her Vicente would have to keep working there.

‘They wanted him to stay for the three months so that they got the Government hand-out.’

Chantria eventually got a job working in the DES sector and was able to observe firsthand problems in the system.

The organisation she worked for ran a factory and employed people with disability to work there.

‘They paid them very little because they already have, I believe, a government pension,’ she said.

Chantria’s job was to sit with the person she was supporting while they worked. She said that even on very hot days there was no air-conditioning – except in the office, where people without disability worked.

‘They had all the comforts. I thought that was really off.’

Chantria thinks there should be better monitoring and auditing of DES.

The organisation she worked for was one of the larger DES, with offices in several states.

‘You’d think they would be reputable. They are just not,’ she said. ‘The government shouldn’t just give money to organisations without checking them.’

Lisette

Lisette is in her 50s and has agoraphobia and other mental health issues. She has mobility issues and 'can't stand up for too long'. She is on a Disability Support Pension and has lived in the same social housing block for three decades.

'And at the beginning it was great.'

But for the past few years living conditions have 'deteriorated dramatically', and so has Lisette's psychosocial disability. 'On the basis of severe neglect that I have encountered,' she told the Royal Commission.

The housing department knows Lisette has a disability, but stopped helping her with repairs and maintenance at her home. This has left her in a stressful situation trying to deal with it herself.

'I almost had a nervous breakdown doing all the work. You know, I have an anxiety disorder. I don't want to be dealing with more anxiety than I have to.'

She has to endure 'rude staff' when she calls the department. They just sound 'annoyed'.

Lisette's concerns escalated with the arrival of new neighbours.

'They're extremely aggressive and belligerent and abusive and it's just – on the Richter scale of 1 to 10 it's a 22. The situation has gone so severe that lives have been threatened.'

Lisette is too scared to leave the flat.

'Basically, I'm housebound. So, I have been forced to endure this distress at an alarming level to the detriment of my mental health and physical health. And housing has done virtually nothing. "Yeah, yeah, we'll look into this matter," I've been told repeatedly for two years.'

Even after dozens of incident reports and police involvement, the department has failed to act.

Recently, Lisette took the housing department to a tribunal for 'neglecting to do their job'. She says the agency has failed on its duty of care by letting her live in a 'violent, aggressive, hostile' environment and ignoring her disability.

'The fact that I have to resort to legal matters, you know ... They need to be held accountable.'

Mahia

Mahia is a teenager with attention deficit hyperactivity disorder (ADHD) and dyslexia. She is also autistic, but her autism wasn't diagnosed until her last year of high school.

Mahia spent her first few years in primary school struggling to read, write and socialise.

'I had a lot of issues with food and not always eating it ... I struggled with making friends and I recall having some friends, but I ended up being bullied by them ... I would often have meltdowns after school.'

It was several years later – when her IQ, hearing and vision were tested – that a school counsellor suggested Mahia be tested for dyslexia.

'I was told I was in the bottom one per cent for reading and writing and they also basically said I was never going to learn how to read or write and there was no point in trying to teach me.'

A paediatrician also diagnosed ADHD and prescribed medication, which she said allowed her brain to 'slow down' and focus.

'I went up three reading levels at school the day I started it.'

Mahia said she remembered feeling relieved that the teachers would finally understand why she struggled.

'The teachers just took it as a label and never challenged me to succeed ... They never knew how to handle any of my diagnoses, which is very strange considering that they're teachers and they should know.'

She said when she became frustrated with schoolwork, her teacher made her sit in a corner, 'which is the completely wrong way to handle a situation like that'.

Mahia's mum helped her read and write at home. When she began to do well in spelling tests, Mahia noticed other kids were struggling.

'They weren't getting the support that they needed at that age like I had from my mum.'

Mahia went to several different schools and had similar experiences. By the time she started high school, Mahia said she hated teachers and became 'combative' because she felt unsupported.

‘I basically dropped out ... I know so many of my friends that could have done so well, but they had no support because of their ADHD or their learning difficulties or anything like that. And it was about at this year level, I think, for them as well that they gave up.’

When her mother became ill, Mahia went to live with her father who enrolled her in an independent school. She was treated better, but still struggled.

When she became ‘suicidal and depressed’ in senior high school, a paediatrician diagnosed autism. The diagnosis meant she received extra help and reasonable adjustments, such as more time to complete exams.

‘My attendance was at 90 per cent ... and I was finally at the top of my English class. Sorry. I’m just really emotional now.’

Mahia said the extra support came too late. No-one explained her career options ‘because everyone just assumed’ she’d drop out. She couldn’t catch up on some of the subjects she needed to get into university

She said all teachers need mandatory training to recognise and support learning difficulties and mental health issues in students.

‘I know that you can do [the] training, but it’s not mandatory. You just choose if you want to do it. And it’s just so crazy to me.’

Elton and Izobel

Elton is autistic and has attention deficit hyperactivity disorder.

His teacher, Izobel, told the Royal Commission that Elton finds it difficult to adjust to new environments and new people. He needs a predictable and consistent routine.

Elton receives funding for a learning support officer to help him learn for several hours each day.

But this doesn't happen, Izobel says, because the school 'shares' the learning support officers between funded and unfunded students.

In the first two weeks of the year, the school redirected Elton's learning support officer to assist the kindergarten teachers with new students.

Elton was left to navigate a new classroom, new classmates, a new teacher and a new routine without support.

'I had to lock the classroom door during lessons to ensure he didn't escape. I had to remove toys and distractions from the classroom as I could not adequately supervise him and the other students.'

Izobel said she was not able to meet the educational needs of any of the children in her class.

When Elton did eventually receive learning support, Izobel discovered it wasn't targeted to support his learning. The support officer, being a shared resource, wasn't familiar with his basic needs and wasn't sufficiently prepared to support him.

The learning support officers constantly rotate. Elton can have up to six different learning support officers in one week.

'There are some days when he has two different [support officers] on the same day. There is no supervision of [support officers] to ensure their expectations are consistent. The variation to their schedules means that I no longer plan lessons with the expectation of having a [support officer] present.'

Izobel is so busy managing behaviour, she rarely gets to spend time teaching Elton.

'I have listened to him read, one-to-one, once in eight months. Each day I am faced with the decision of whether to teach [Elton], or to teach the other students ... My best option for any success is to try and keep [Elton] settled while attempting to teach the other students.'

Towards the end of the year, Izobel spent some time out of the classroom. But she had to return several times, because Elton was screaming on the floor. There was no learning support officer in the room and the replacement teachers didn't know what to do.

'The individual teachers had not done anything wrong as such. The system is inadequately resourced to meet [Elton]'s needs.'

Izobel has made several complaints about the lack of support and resources for Elton.

'Everything is considered acceptable under the circumstances.'

Elton is expected to be in the system for at least 10 years but there seems to be no long-term plan for him, she says. There is no process or document outlining the purpose or goals of the funding he receives.

'The [education department] is neglecting the learning needs of disabled children. And in doing that, they are neglecting the educational needs of all children,' Izobel said.

'Neurodiversity needs to be celebrated and valued. Each person has something unique to offer, and when focusing on someone's challenges we are missing out on experiencing their potential.'

Teddy and Patsy

Teddy is in his 30s. He is non-verbal, has seizures and uses a wheelchair.

'[Teddy] is dependent for absolutely everything in his life from other people,' his mum Patsy told the Royal Commission.

Before Teddy started school, Patsy moved her family to the country town where her parents live.

'I thought that we would be able to get a bit of a community support around [Teddy]. Anyway, long story short, we didn't.'

Patsy and her husband struggled to care for Teddy themselves and couldn't find a service provider.

'I tried and tried and tried to find a way to keep him near us, but there was nothing available. The only thing they would talk about was foster care. And I wasn't prepared to do that. I wasn't prepared to lose him. And I thought if our family can't cope with his care, what is a foster family going to be able to do?'

Patsy found Teddy a provider and accommodation several hundred kilometres away in the city. He was 'well cared for', but after more than a decade she found a service provider in town and moved him back.

'We ... [were] thinking that that would be a better option. And then being stuck in this arrangement where it was just a nightmare. It was just a total nightmare.'

Patsy said Teddy's new provider struggled to get support staff.

'And the support staff that they employed they just didn't have the skills for the job, they didn't have the training for the job, they didn't have very much at all.'

The staff restrained him when he vocalised or tried to push them away.

'He got a pressure sore within ... weeks because they left him sitting all day in his chair, not changing him. I just call it the house of horrors.'

Teddy had several falls.

'He rolled off his shower trolley onto a concrete floor ... Another time he rolled down the concrete area outside, luckily onto the grass.'

One support worker who was rostered on at night would leave the house when they thought he was asleep.

Patsy tried to find another provider, but there was none.

When the NDIS started, she moved him into his own unit and took charge of his care.

‘I’ve handpicked all the staff ... None of them have certificate three or certificate four or any certificate whatsoever. They are just decent, caring people who I can train. We can do any training and education they require.’

Patsy deals with the NDIS and Teddy’s medical appointments and trains his support workers – ‘a full-time job’ for which she’s not paid. She said there is ‘a lot of goodwill squandered’ when service providers don’t properly train and support their staff.

‘They’re just expected to go in there and work with really complex people ... that to me is a huge element that’s missing. There’s so much money that gets allocated, but just the allocation of funds doesn’t make the system work well.’

‘The difference in [Teddy] now is just remarkable and people who have known him over many years comment on it because he feels safe now.’

Bruce

‘I’ve been well and truly punished by the system.’

Bruce is in his 50s and lives with undiagnosed mental health conditions.

‘I’ve been on disability pension without even being diagnosed with anything since I was 20 years old,’ he told the Royal Commission. ‘Mine is not a very good story about the system, the way they – they – they abused it. Like, I’ve just been left for dead, and I’ve had to deal with it all on my own.’

Doctors have never properly assessed Bruce for mental illness.

‘That’s why I can’t get any help. All I’ve been assessed with is uncontrollable anger that’s it. End of story. I’ve been to that many psychiatrists it’s not funny. I’ve been – I’ve been to all the social workers and all the deal. I tell them first that I – I’ve got a mental disability and I’ve got a frustration problem. Because that’s the only diagnosis anybody’s given me.’

Bruce wanted to be a tradie but has been hamstrung all his life in his efforts to work.

‘When I first got on the pension, you’re not allowed to work at all. Unless you’ve got a doctor’s clearance. And every time I’ve tried to get off the pension and do my own thing ... they more or less laughed at me.’

Bruce ended up in the criminal justice system about two decades ago. He blames the system, for neglecting his mental health.

‘Fines, more fines, more fines, more jail, more jail ... Because I was violent.’

On his release, service providers wouldn’t help him get ‘a real job’ or help him ‘get back into society’.

‘The system isn’t set up to help people. It’s only set up for the people that want to give up,’ he said.

‘And I don’t understand that behaviour. If people want to try they should have a chance to get to where they want to go. My life’s got no better, you know what I mean? I have no family, no nothing, and I’m dealing with violence and trying to keep myself in control. I spent the last 10 years just isolating myself. I don’t talk to anybody. Because I was that frightened of getting in trouble all the time.’

Health professionals fob Bruce off ‘as a bad-tempered upstart’ and deny him supports, so he’s been left ‘just trying to fix’ himself.

‘Because nobody else could apparently. Like, I tried it the doctor’s way ... but nobody takes responsibility. I’ve done anger management eight times, stress management, I’ve done everything you could possibly think of.’

Bruce hasn’t been able to get housing assistance and was recently ‘kicked out’ of his accommodation so he’s ‘got nowhere to go’. He does, however, have a caravan.

‘I’m a warrior. A survivor. I know I’ve always got that caravan sitting somewhere. If all hell break down, I’ve got a home.’

Manfred

Manfred has intellectual disability. He is currently in a correctional facility and hopes to be released soon.

Manfred grew up in a large family and had no access to support.

At school, teachers ignored him.

'I think the teachers at my school did not help me with my learning and did not take the time to assist me when they knew I was having trouble.'

Manfred lost interest in education and left school as soon as he could.

He got a job, but says there was no appropriate training or support.

'I think ultimately this lack of support through school and my workplace may have contributed to me turning to alcohol and drugs as I felt like I had no other way of getting through these difficult times,' he said.

'I genuinely feel that if I had received the necessary support in my younger years, my life may have turned out very differently and I might not have committed the criminal offences.'

Prison staff have treated Manfred fairly and with respect. He was able to access support for the first time in his life.

'I appreciate that the prison has been supportive and accommodating of my disabilities and it has helped me to prepare for life when I am released.'

Manfred made a couple of applications to the NDIS, but was unsuccessful.

A new psychologist helped him try again, and he was successful. The NDIS will help Manfred when he is released.

'Perhaps more support should be provided to ensure that people with disabilities in prison are able to more easily have their application to access the NDIS granted.'

Breda

Breda is a young woman with immune system disorders and 'severe complex health issues'.

A few years ago, the NDIS knocked back funding for home support in Breda's plan.

'I have waited for three-and-a-half years to get a response from NDIS appeals. I had the court hearing with the AAT and they won't enable me to engage with their process. I haven't been able to get a lawyer. I've tried everyone and none of them will help.'

The NDIA said Breda needed 'more evidence'. However a lack of 'specialist support coordinators' in her state is preventing her from getting updated reports from therapists.

'They're all at capacity. And I'm still in this fight with trying to find [a specialist] who knows anything about complex medical conditions and chronic infections.'

Meanwhile, Breda's trying to get an autism diagnosis.

'The NDIS won't help me pay for the assessment. They're just ignoring, like, a huge part of my disability.'

Breda has struggled to find affordable housing. Last year she found a place, but the service provider insisted that she sign a 90-day contract.

'They're all fucking defrauding the system. And I said I wouldn't sign it, it's over half my NDIS plan gone in one month ... Then they kicked me out, left me homeless.'

Breda said the NDIS did nothing.

'I ended up being left for dead with no support for eight months because of the fraud. It's really corrupted and they want to pay these like greedy providers \$10,000 a week for temporary short-term accommodation.'

Breda wants the NDIS to include disability housing in her plan.

'They refuse. They won't even listen. Able-bodied people in social community housing don't have to prove why they want self-contained housing. It's so unfair that I do.'

Breda said she's 'too unwell to engage with the system any more'.

'I've been through all the housing and homeless services ... and none of them will help me. The NDIS, like they want to fucking leave me homeless while my health gets worse and worse and worse.'

Warrick

‘A lot of people affected by disability and chronic illness do their best to hide it from employers due to fear of being targeted, especially out of fear of being fired. I would think this is more prevalent for those suffering mental illness.’

Warrick, late 30s, has bipolar disorder, anxiety, depression and chronic pain.

He has worked full time for more than a decade.

While his disability rarely impedes his ability to work, he takes more sick leave than a person without disability. He has to attend regular medical appointments – one medication is administered fortnightly – and occasionally spend time in hospital.

‘Over the course of the last financial year, not only has it cost me a significant amount of money seeing doctors, specialist and paying for medication, I also lost [tens of thousands] in wages,’ he told the Royal Commission.

Warrick constantly worries about keeping his job. He worries his employer will become tired of all the sick leave and reduced capacity and fire him.

‘You also don’t feel like you are a good employee, that you aren’t doing enough, that you’re the weak link in the team. It follows you home – the worry about your job, your abilities and your future – and for me, this can feed my depression.’

Following a recent flare-up, Warrick was admitted to hospital and couldn’t work for a couple of weeks.

‘I can’t rely on a consistent pay check. Unpaid leave affects my salary on a regular basis ... I have no sick leave to rely on when I need to take time off due to my disabilities. Something that the average person doesn’t need to worry about as much as a person affected by disability or chronic illness.’

Lately, Warwick has had to rely on family for financial support and a place to live.

‘It became apparent that I was not financially capable to live on my own any longer ... It is unlikely that I will live on my own again in the future.’

Warwick wants specific leave for people with disability or chronic illness to help minimise financial stress. He suggests GPs provide a letter to HR, not the person’s supervisor, confirming the person meets the criteria for disability and chronic illness leave.

‘While sick leave exists, this only protects the average worker. It provides limited and inadequate protection for a person affected by disability or chronic illness.’

Baylor and Dottie

Baylor works for a Disability Employment Services provider, which also operates several businesses employing people with disability. Baylor is autistic, has attention deficit hyperactivity disorder and Asperger's syndrome.

Dottie was a foster parent for Baylor when he was a child and is his main advocate now.

Lately, Baylor has been telling her about episodes of bullying and mistreatment in his workplace. His manager routinely abuses him.

'He's been yelled at, he's actually had his manager stand over him for reporting workplace health and safety incidences, shaking his finger in his face.'

One time, a supported employee was called to do a task that he didn't know how to do, so he asked Baylor for advice. Baylor didn't know either.

'They were too afraid to approach their team leader because he's one of the ones swearing at them,' Dottie said.

When they couldn't work out what to do, the supported employee burst into tears. As Baylor comforted him, another supported employee started crying as well.

'There was no-one there so [Baylor] runs up to the office, has to tell an office girl. She says "What are you doing here?" He said, "I need help, I need help."'

A general manager came to see what was happening, and sent Baylor back to work.

'Now, where is it right that a supported employee is having to support two other supported employees who are emotionally in trouble and he himself is upset? He did not even get asked if he was okay. He got told, "[Baylor], get back to work. Fuck off, get back to work." What do you do with that?'

Dottie said that Baylor is 'not the only supported employee who has been treated to swearing, denigration, disrespect'.

'But there's also an issue of neglect because he can't even tell me who his support worker is. He hasn't had one. And I've got an admission from senior managers that they are under ratio and yet they are billing [the NDIS] ... for providing supports they're not providing.'

Baylor is depending on Dottie for support.

'His words were, "Mum, can you fix this, can you fix this, not just for me but can you fix this for [Josh], for [Caleb], for [Bobby], for [Thomas]?"'

These are Baylor's peers. Some of them, Dottie says, have aged parents who 'don't understand the system'.

'[Baylor] has got absolute faith in me. And I said to my husband, "I can't let him down, I've got to try, even if I don't know what I'm doing. I've got to try.'"

Dottie has contacted the organisation to report what's happening, but at a recent meeting the manager told her she hadn't received any of her complaints. Dottie intends to follow up further with the NDIS Quality and Safeguards Commission and other agencies.

'I feel like you can't treat human beings like this. You can't swear at people in the workplace, you can't call them names. It's not acceptable. They're human beings.'

Marinella

Marinella, in her 50s, is under a community treatment order. She told the Royal Commission the 'treatment' she receives is 'barbaric'.

'I'm just a victim of domestic violence, and I've been put under the mental health act as a way of destroying me.'

Marinella's ex-partner was violent.

'He was always on spirits ... smoking, drugs. He used to belt me up quite often when I was with him. Once he knocked me to the ground and he cracked me ribs.'

She said her ex was behind her first involuntary admission to a mental health ward. He called the police and accused Marinella of violence.

'I'm not mentally ill. I don't hear voices in my head ... If you're a victim of domestic violence, if you've got a violent man, put them in a drug rehab place. Not the women. You know, it's wrong.'

Marinella spent a lot of time in a psychiatric facility at a regional hospital.

'I didn't have any say in it. And they wouldn't discharge me. It is just like a death camp. Yeah, and there's a lot of violence in there as well. You can get stabbed. And you can get belted up. I mean, I don't deserve to go in there at all. It was disgusting. The food and drink, you can't eat it and you don't have much of it. It's just like being in a prison.'

Marinella said the staff were also 'terrible'.

'They just do whatever they like. They don't care. And all the doctors and nurses are just students, or else [they don't speak English].'

Marinella no longer attends at the facility for treatment.

'They come round and inject me on my property ... These injections are dangerous and they need to be banned. I'm going to die if I have much more of it. I don't want to die. I don't really understand why I can't get a choice of what medication I take. It's like the dark ages here.'

She said that the nurse who comes every fortnight mistreats her.

'All he does is interrogate me and wants money off me. Thinks I'm an animal.'

Marinella is feeling increasingly helpless. She's not allowed to leave the area and has no community supports or a mental health advocate.

'There's no domestic violence women's groups or anything. There's not even a proper community centre here. I don't mind being on this disability pension, but nobody will give me a job. There's discrimination because I wasn't born here. And because of [my ex], I'm on an injection that makes me feel lousy and it's going to kill me ... I've got nothing to live for really.'

Ewan and Briony

Briony's husband, Ewan, is in his 50s. He is a double amputee and has destructive arthritis.

'It's in such a progressive stage that he's basically got no function,' Briony told the Royal Commission. '[Ewan] can't get a drink. He can't use a kitchen, can't cook. He can't do anything that you and I do. He's reliant on someone the whole time. So for me to go out, I can't do that.'

Briony's been caring for Ewan for two decades. A few years ago he joined the NDIS.

'We haven't been able to resolve anything. We've put in to get our bathroom modified ... Our [bedroom] isn't big enough. Every time we go and we ask for something we get turned down. They say it's not enough information.'

Briony said the NDIS's demand for reports drains Ewan's budget.

'We got told that the funds were really low, so we cut all of [Ewan's] services off. We cut off all his therapy, all his care, just to get us over to review date. Which then they couldn't give us the review date when we wanted it because they were too backlogged.'

Briony said no-one from the NDIA visits Ewan to see why he needs the support he's asking for, and she suspects no-one at the NDIA actually reads the reports from his specialists.

'I had one of the NDIA tell me ... "With a bit of therapy," she said, "your husband will be able to roll over and get himself dressed." And I said, "Are you reading the same report that I'm reading? ... He's a double amputee!"'

Ewan needs a new wheelchair that fits through the bedroom door and a new ramp to escape the house if there's a fire. Briony said the NDIA rejected these requests for not being 'reasonable and necessary'.

'At least if they came to the house they can see what they're talking about ... Then this "reasonable and necessary" might not come into it as much because then they can actually see that with these sorts of things it would give him more of a functioning life.'

Briony worries the lack of adequate support for Ewan is damaging her health, too.

'They say they need to support the carers, but they're not supporting the carers at all ... I don't know how much more I can keep fighting. Every time he gets rejected I feel like I'm losing a bit of myself.'

Fable

Fable, late 20s, is autistic. He has schizophrenia and complex post-traumatic stress disorder (CPTSD).

In primary school, Fable was non-verbal.

‘I was isolated from my peers and due to complex behaviours had alienated most of the staff, and I had a difficult relationship with my family.’

Fable said this made him an ideal target.

A teacher groomed and sexually assaulted him over a three-year period.

‘Something people do not often understand about child molesters is that they are usually very opportunistic but selective with their targets. It’s not just about attraction for them, it’s about who they feel they can get away with hurting. Often this means children with disabilities.’

Since this time, Fable has seen numerous psychologists and psychiatrists.

‘But finding someone who either specialises in or has a meaningful understanding of autism in adults is extremely difficult. Often people will downplay the severe impact of autism by saying, “Oh I think we’re all on the spectrum,” or “Just because you’re autistic doesn’t mean you’re any different.”’

Fable has asked for a referral to a psychiatrist experienced in CPSTD and autism. But there is no-one with this experience in the public health system in the area. Fable is on welfare and can’t afford a private psychiatrist.

‘I will need ongoing lifelong support.’

At the moment, Fable is ‘totally dependent on family’ for most of his emotional and financial support.

He’s scared if something happens, he would become homeless.

‘Homelessness is an absurdly common outcome, and only half of social housing applicants with disabilities are ever offered a pathway into social housing,’ he said.

Fable believes the NDIS needs to be more flexible.

‘Allowing NDIS funding to be used on things like housing, legal aid and so on, would allow people with disabilities to organise solutions to these problems and pose meaningful systemic action that is focused towards actually preventing future issues.’

Vidal

Vidal came to Australia with his family when he was a teenager. Now in his 50s, he has complex post-traumatic stress disorder (PTSD), a brain injury and various health issues.

'I have been diagnosed with complex PTSD because of all the trauma that I have reoccurring throughout my life,' Vidal told the Royal Commission. 'No-one can see our injuries, it's hidden. But it's difficult for us, especially for immigrants with a psychosocial disability.'

Vidal worked in a range of industries before getting a job teaching at a tertiary institution.

'My psychosocial disability [was] poorly understood. As an example, it looks that I'm angry when I'm not angry. It's just my facial expression ... or because I am a person that is constantly translating I have to take a second or two to speak to the other person. And because I do have a brain injury, after whole day doing all this I'm very tired.'

Vidal said even though he declared his disability to his employer, staff bully him.

'They call me names, they humiliated me because of my accent not understanding that I have a broken brain, that sometimes, you know, my brain doesn't come up with all the words.'

One manager, aware of Vidal's complex PTSD, mocked his accent and interrogated him after Vidal complained of being bullied.

'He said that there was no bullying cases in the workplace. And then he start accusing me of getting arrogant ... I couldn't speak. I couldn't properly say anything. I was just crying and asking him to stop. He didn't stop.'

Vidal also asked the institution for reasonable adjustments to help him work, such as taking short breaks and being able to wear noise-cancelling headphones when he's working in his office so he can concentrate.

'They send me a response [saying] it's not reasonable or practical to do any of that. So, basically they discarded completely my disability.'

Vidal became ill and took leave.

'When I saw my first psychiatrist, the psychiatrist confirmed that this was a case of bullying, direct bullying, and recommended to move me away.'

He applied to move, but 'nothing happened'. Vidal said the institution seemed to be trying to force him to retire.

‘They wanted to medically retire me, but my psychologists, psychiatrists, they all agreed that it’s not a problem with me and work. It was a problem with the bullies.’

Vidal complained to an independent investigator, which ordered the institution to improve workplace health and safety practices. Vidal still works there, but in another area.

‘They’re not giving me back my teaching position because the bullies are still there. They are protecting the bullies.’



Artwork by Laura Lewis

Bentley

Bentley, in his early 50s, has been hospitalised for mental illness numerous times. The first time was in his early 20s, when he spent about six months in the psychiatric ward of the hospital in the regional town where he still lives.

He described the ward as ‘derelict’. It was cold, with ‘paint flaking off the walls’, and other patients who were ‘just ranting and raving and carrying on’. He had never experienced anything like it before.

‘It was an absolutely terrifying trauma to my soul – just turning up in this hospital exposed to that and then given tablets that turned me into a zombie, a mindless dribbling zombie for months on end. It was horrific, absolutely incredible,’ Bentley said.

‘I remember, when I was first hospitalised, the effect of the medication they gave me was a cruel – like, I couldn’t sleep, I couldn’t relax, I was up pacing all the time, day and night ... and I went to talk to this nurse who responded by grabbing me and by force put me down on the bed and, like, pushed me further into the bed and said “Go to sleep.” But I couldn’t because of the effects of the medication.’

Staff gave Bentley food he struggled to eat – ‘Sweets and coffee, caffeine and junk ... white bread laid on.’ He didn’t want to eat it ‘because it’s just garbage food’.

‘There’s no nutrition, there’s no life in the food ... [but] the medication gives you this hunger you can’t control so you basically – if that’s health, well, I’m insane.’

These issues have been a constant during all his involuntary detentions for mental health treatment.

Bentley is particularly angry about the medication he is forced to take.

‘You’ve got no say, you can’t complain about this thing. If you do, you are strapped down on the bed or injected with sedation to put you comatose for a day or two, this sort of thing. It is abuse. And the side effects are abuse. It destroys the health of the person. It has destroyed my health.’

He is also angry that other treatments or supports aren’t available.

‘They don’t offer any answers. They don’t say a word and this has been going on for 30 years. They don’t validate or comfort, all they do and all they’ve ever, ever done is medication, junk food and being locked up. There’s no answers. There’s never been any answers, never a kind word or any friendships ... goodwill or affection, there’s none of that.’

Bentley told the Royal Commission his lengthy mental health history means he is stigmatised in the community.

'It's as though the person with a mental illness has no heart or soul and no intelligence or wouldn't have a clue, sort of thing, as if they're an absolute moron with no feelings. I've struck it so many times ... It's unbelievably arrogant and condescending.'

Bentley finds it hard to get work and says he been significantly underpaid because of his disability. He complained about one employer to the Fair Work Commission, which eventually found in his favour.

He would like to make a formal complaint about the treatment he's had in the mental health system, but is not sure where to do that.

'I've tried for 30 years to find someone to listen and actually make a complaint, but there hasn't been – there is no-one. There hasn't been anyone and that is just like such a torture. Absolute torture,' Bentley said.

Morgen and Jo-Beth

Morgen was suspended a few weeks after he started school at an independent school.

'My child had been displaying what they coined as "violent" behaviours at school within the playground,' his mother Jo-Beth told the Royal Commission.

Morgen had pushed another student who had pushed him first, and hit another student who had pushed him. He had also hit a student for no apparent reason.

The school demanded Jo-Beth sign a behavioural contract before they would allow Morgen to return.

Jo-Beth took Morgen couldn't get an appointment with a paediatrician for several weeks.

She advised the school and requested a meeting to discuss the behavioural contract. She wanted to include reasonable adjustments to support Morgen.

Jo-Beth was surprised at the number of people at the meeting. Morgen was the only child in the room, surrounded by adults.

The school refused to provide reasonable adjustments. In the absence of a diagnosis, they believed the issue was 'bad behaviour'.

A few days later, Jo-Beth was able to take Morgen to the paediatrician because of a cancellation.

The paediatrician diagnosed Morgen with attention deficit hyperactivity disorder (ADHD). He believed Morgen had another condition but needed more information from the school.

Jo-Beth tried to speak to the principal but they were not available. Jo-Beth left messages and sent emails.

A few days later, the school contacted Jo-Beth to collect Morgen. He had elbowed a student who refused to get out of his personal space.

'This student's parents were not called, and no injuries were sustained,' she said.

The principal told Jo-Beth that Morgen was 'no longer welcome' at the school.

'The principal stated that he hoped that [Morgen] "sorted himself out" so these same issues don't happen again. Then my child was told to collect what he had left at his classroom. It was such a traumatic experience for us both.'

The principal told Jo-Beth she could 'voluntarily withdraw' Morgen so it's 'not on his file'.

Morgen is now at a new school and is trialling ADHD medication.

His teachers say the medication is working well. His concentration has improved, he can complete tasks, is more organised and there is 'less hands-on behaviour' with other students.

'I hope that children with additional needs are better supported and become visible. That children with additional needs do not continue to be suspended and expelled for their behaviour.'

Jo-Beth believes independent and private schools need to be held accountable for their choices and that they 'stop picking and choosing who they want to educate'.

'All children have a right to an education no matter what.'

Sorel

'I love working with people and being a support worker, but I wish that I was never employed by [the provider] without the training I now have.'

Sorel recently started working as a disability support worker.

She had no previous experience and her university qualifications were in an unrelated field.

'On my first shift, the manager welcomed me, pointed and named each person working and being supported, and gave me a tour.'

The manager told Sorel she would need to give one of the participants their medication and help them shower.

'I had no idea that I needed to support people with medication or showering before I arrived. I felt silly for not knowing and felt it was my responsibility to learn on the go. I felt it was my responsibility for having taken the job with no experience.'

Sorel's supervisor was surprised Sorel had got the job without any prior training or experience.

On the next shift, Sorel worked with an on-call worker.

Neither of them had met one of the respite participants who was non-verbal, and there had been no handover.

Sorel had to call an off-duty staff member for information.

Most of the people Sorel has supported did not have adequate support strategies or behaviour support strategies in place.

One participant hit and pinched workers and other participants, sometimes drawing blood. The only strategy was to try and avoid her and move away. Sorel often had to put herself between the woman and the people she targeted.

At one workplace, Sorel had to support two people with very different needs. Both needed one-on-one support but 'supposedly neither of them had enough funding'.

'This limited the activities that could be done during the afternoons and weekend days ... For example, I could not go out walking or to the shops with them both as one of them walked very slowly and the other person walked very quickly and would sometimes wonder far away from me.'

Sorel said many of the staff didn't value choice and control.

Participants had no say in the day programs they attended or the staff who supported them.

Some staff didn't allow participants to choose their clothes each day, telling them some items weren't suitable or made them 'look promiscuous'.

'I believe that all support workers should have training to understand how their worldview should not come into a participant's choices.'

Staff often raised their voices and bullied a participant to do something, such as shower or take medication.

Sometimes staff would gang up on a participant until they acquiesced.

'I also at times bought into this pressure of thinking that I had to convince [a participant] to have a shower, otherwise someone would think I wasn't doing my job properly.'

One participant frequently refused her medication. The manager told Sorel to persist – the participant would eventually take it.

Sorel wondered if the participant didn't like the taste of the liquid. She asked the manager if they could try tablets.

The manager asked the doctor who prescribed tablets which the participant was happy to take.

'That's when I understood that it was part of my role to ensure that things like this are followed up and to not assume someone else had done it,' Sorel said.

Training and education and experience is about having the confidence to identify your own limitations, and be able to ask for help and advocate for others.'

Sorel believes there needs to be higher standards and prerequisites to become a support worker.

'I also feel that there should be a complaints body that enables support workers to complain more easily about the quality of an NDIS service provider or to raise concerns about the practice of other staff, so that things can be improved for everyone.'

Timmie and Wilbur

Timmie, now in his early years of primary school, was about three when his father Wilbur realised he might be autistic.

Wilbur is a single parent, caring for Timmie and his other children with little family support. He applied to get Timmie into the NDIS early childhood early intervention (ECEI) program. His first application was refused, but he was successful the second time.

In his first ECEI plan Timmie received generous funding, including for extras such as cleaning and gardening, which Wilbur hadn't asked for.

What he had asked for was a support worker to spend time with Timmie, helping him cook, use public transport and build other skills. He'd explained that as a single dad working full-time and with other kids to care for as well, his own opportunities for one-on-one sessions to help Timmie develop skills were limited.

Discussing Timmie's next plan with the NDIS planner, Wilbur made the same point.

'The one thing I impressed was the value of the support worker. I don't care about the cleaning, I don't care about the gardening ... But the one thing that I've got to keep – I need to keep that support worker for [Timmie].'

The new plan did not provide funding for a support worker.

The NDIA told Wilbur it would only fund support workers where supports in the home environment were not available. It sent Wilbur policy documents to explain its position, but Wilbur thinks the NDIA misunderstands the policy.

'I come back to the legislation in that it specifically states that the CEO and/or their delegate must take into account what is reasonable to expect of a family and for me the key word is reasonable. My question is, is it reasonable to ... expect me to have to reduce my work hours or give up work? I don't believe that that's reasonable, for there to be such a financial impact on the wider family unit,' he said.

'I would love for someone to provide it to me in writing where the NDIS has an expectation that ... I should take a financial burden and put my accommodation for my family at risk and my future sustainability and wellbeing at risk.'

For now Wilbur is paying the support worker himself.

'I couldn't cover all the hours, so [Timmie] only gets to see [the support worker] once a week and to save up the hours for a school holiday we've had to cancel the last three weeks.'

Timmie's behaviour has deteriorated as a result of the reduced hours, and he has tried to self-harm.

Wilbur said that with the supports they could access through the earlier plan, Timmie was making good progress. He was becoming more capable and his social skills were improving.

'Right now, all of that work is coming to a grinding halt,' he said. 'And if we lose that momentum now, it sticks. We never get it back.'

Wilbur recalled a young man he'd met with disorders much like Timmie's. His 'number one goal' was to have a 'life like everybody else'.

'And had he had the things that I'm trying to build for my son now, he could have done that.'

But this young man never was able to access early intervention, and now depends on medication, therapeutic supports and 'so many things'. '[It's] not good value,' Wilbur said. And for the young man, it's 'soul destroying'.

Wilbur wants Timmie's story to be different.

'I don't want to see the same neglect from funders occur again into the future and the same mistakes getting made at such a young age, impacting people all the way through their life.'

Bex

Bex is neurodivergent and has physical disability. They are transgender and non-binary.

'I move funny, talk funny, act funny, think funny, exist funny, study funny, learn funny, work funny. And because we train our society to pick on difference, to hate the different, the strange and the new – that ends in violence.'

Bex told the Royal Commission that they learnt to 'mask' from a young age.

'Literally doing my best to act like other people, hide all the little and big differences as best as I can.'

But the problem with acting, Bex says, is you can't keep it up forever. Bex would become exhausted, anxious and depressed and would 'inevitably slip-up'.

People would often react with violence.

'I've been beaten, had weapons pointed at me, used against me, I've been harassed, I've been followed, I've been yelled at, street harassed, I've been excluded.'

Sometimes the abuse was more subtle.

People would accuse Bex of acting weirdly or being on drugs. Others would tell them, 'You don't socialise well with our team, social group. Sorry, you're not a good fit for us.'

Bex has complex post-traumatic stress disorder because 'the trauma keeps going'.

For a short time, Bex had a full-time job. They carefully managed their disability for as long as they could. Eventually it became too hard and they couldn't sustain the energy, the focus and executive function required to do the job.

They discovered 'anyone who talks candidly about health or disability isn't hired or around for long'.

'Asking for accommodations is an incredibly intimidating experience.'

Over the years, Bex has needed to frequently engage with health services.

She finds it very difficult filling in 'endless forms to beg for help', following up with doctors, chasing and rescheduling appointments.

Being transgender and non-binary adds complications. Bex says the system doesn't even have options to record their details correctly.

A tick box for male, female or transgender serves no-one.

‘When you’re a minority group within a minority group within a minority group, it’s hard to find suitable advocacy, hard to find someone who can fight for your needs.’

Bex believes the NDIS is part of the problem, denying or delaying access to support.

‘With jargon and divisions designed to confuse, inconsistent applications of rules, random funding cuts, paperwork from hell, a straight up ignorance of the law and human rights in those delivering it.’

Bex believes a better funded Medicare system would work better.

‘Disabled people have a lot to contribute, and unless this goes to a universal access guarantee like Medicare was meant to be, you won’t be able to increase our social or economic participation. Too many of us slip through the cracks or, at best, spend all our energy fighting.’

Joaquín and Minoo

Joaquín went to a new school in year 4 after he was ‘assaulted by a staff member at his prior school’.

The school principal agreed under duress to take him into the mainstream program, and Joaquín had a full-time education assistant.

‘And he was actually doing really well, making new friends,’ his mother Minoo told the Royal Commission. ‘The class was a third full of autistic kids and seemed to be really inclusive with the different kids and their needs.’

But a few weeks in, Joaquín had a meltdown and the school isolated him in an ‘alternative learning space’.

‘Which was basically a corner in the library ... There was no integration with anyone else. He never played with kids ever again. He felt shamed.’

Joaquín started having frequent meltdowns and panic attacks because his ‘anxiety had risen’.

‘Being trapped makes me so angry,’ Joaquín told his mum. ‘I don’t deserve to be treated like that. I don’t want to be in a different class to the other kids.’

His teaching assistants didn’t help him when he was ‘upset or dysregulated’. They just ‘dragged’ him into ‘the calm room’.

‘That calm down room was never used for calming down, it was used for restraints,’ Minoo said. ‘He had four staff pinning him face down on the ground for more than three or four minutes. That only made him worse, and he’d fight back ...’

When Minoo went to pick him up, ‘he’d be in tears, sobbing’.

But staff saw his outbursts as ‘intentional’.

‘And on one of these occasions, he actually wet himself, and the principal dared say to me that he urinated on the carpet intentionally and now he’s going to be suspended. This was the pattern ... being punished for his autism and his autistic behaviours.’

Joaquín was suspended six or so times in a year.

‘As a result of the people who were mismanaging him ... He doesn’t act like that at home. He is like that if you don’t listen to him or if you take away his control and his autonomy like anybody would be.’

Each time, the principal would say, 'You need to make amends ... You need to fix your behaviour.' He was 'treated like a criminal ... and put on a behaviour plan'.

'He's autistic. His greatest weakness is his self-regulation, and if he doesn't have adults to help him regulate, he's not going to learn that skill,' Minoo said. 'All he's learning is you get punished for losing control. Punished and tortured.'

Minoo sees it as 'ableist and discriminatory'.

'None of the non-autistic children at this school were treated in this way. It's like their given right to abuse because the child is disabled.'

Joaquín started 'running away trying to escape school'. Eventually, the school expelled him.

'It was like good riddance ... He is such a beautiful, intelligent, caring and generous child, but not once did I ever hear anything nice about my child being said at the school, because nobody ever got to know him. They treated him like a dancing little monkey puppet.'

Brayden

Brayden, in his early 30s, was a fit and active person until about 10 years ago, when a bout of flu – or what he thought was flu – changed his life.

‘I just kept getting more and more pain and brain fogged and fatigued,’ he recalled. ‘And at first I thought it was sleep, so I went to a sleep centre to get treated. They treated my sleep apnoea, but I was still tired after that. And then they treated the delayed sleep phase but, yeah, I was still kind of fatigued and sore and everything after that.’

He wondered if he might have chronic fatigue syndrome, and was referred to a clinic that treated it.

‘Unfortunately, that wasn’t a very good experience.’

Brayden was diagnosed with myalgic encephalomyelitis (ME), which his doctor at the clinic understood as a mental illness. Treatment there and at the clinic Brayden went to next involved a lot of ‘probing’, with endless questions and psychological testing.

‘I guess they see it as a conversion disorder or a somatisation disorder, where they think that you have unhelpful thoughts running through your head that’s making you sick, even though you might not have that,’ Brayden said.

Brayden had been seeing a psychologist before he got ME, for help managing issues from his past. His psychologist had told him he didn’t need to see her any more. He was ‘pretty stable’, she said. But his treating team at the clinic didn’t agree.

‘They were like, “Well, all this past trauma that you thought that you were over and you’ve worked through with your psychologist, we believe this is why you’re sick,”’ Brayden said.

He found their attitude ‘re-traumatising’.

‘It’s not patient-focussed. It’s based on patient blaming. So rather than working with the patient and finding out what the issues are ... it comes from a thing where they believe that you want to be unwell or you’re faking it or you’re some type of hypochondriac, kind of, making it up for some secondary benefit.’

Brayden was prescribed medications and a program of graded physical activity that made his condition much worse. He experienced a lot of ‘gaslighting’ and ‘victim blaming’, he said.

‘You’re made to disbelieve yourself. Everything they say is true, and any experience that you have, even though you might be saying, “Look, I’m getting worse. I can’t keep doing this,” they’ll tell you, “Well, no. That’s – that’s wrong. You just think it’s worse.”’

Brayden now cannot leave the house and is unable to work.

After several applications he was recently approved for NDIS funding. The funding is not for ME, which the NDIS considers a health issue, but for his mental health, which has deteriorated over his years of struggle to get help with ME. The funding cannot be used for equipment or therapies that would reduce the impact of ME.

Brayden said the widespread misunderstanding of ME needs to be corrected with better education and training.

‘There needs to be more input from people with the condition, and ... people with lived experience.’

He compares his experience with that of a cancer patient who decides to stop chemotherapy because it makes them feel too unwell.

‘You don’t then have a doctor saying, “Well, no. You’ve got to keep doing chemo, otherwise I’m not going to give you any treatment or DSP or anything like that.” With ME, it’s like, “Look, I can’t do graded exercise. I’ve done it three times. Each time I’ve done it, it’s made me worse.” But then they say, “Well, you need to keep doing it or you’re not going to get your benefits or NDIS or anything else.”’

‘So there needs to be more education for doctors and specialists on how to treat the illness properly than just keep pushing this gaslighted narrative of ... “It’s all in their head. They just want to be sick.”’

Darlene

Darlene is in her 60s and had polio as a child. She uses a wheelchair and lives in a rural area.

'You know when you look at it on the map it's really not remote,' Darlene told the Royal Commission over the phone. 'I don't know if you can hear the birds singing, but the birds are singing right this minute ... I love it here. And that's all I want to do, I just want to stay in my own home and I want to have safety and functional independence and my own choice of daily routine.'

Darlene joined the NDIS when it was rolled out in her area several years ago.

'Part of what the planner wrote up in my NDIS plan [is] a whole section on home safety and modification ... so we're going to widen the bathroom, we can knock down a wall ... and just make it big enough for a wheelchair.'

Darlene can walk and stand for short periods, but needs handrails in her shower and on the front porch to stop her falling. She said occupation therapists (OTs) 'recoil in horror' when they see her bathroom. They want it to be modified for her wheelchair.

'So the trouble is this. When [the local] NDIA decision maker said no, she said no to everything ... The quotes weren't detailed enough or something, but she never said why ... She just said, "No, you can't have it," and therefore that meant all of those home modifications including handrails, absolutely everything, was knocked on the head.'

Darlene said that even though the money's in her plan, she still can't get a handrail.

'I asked for a handrail out in the front porch, which is pretty basic. It's just a metal rail, you know, it's not expensive.'

Darlene's since fallen twice and ended up in hospital.

'I knocked myself unconscious and I woke up in the dirt with gravel rash all down one side of my body and a massive big lump on my forehead that just come out in like an egg.'

She's now frightened to go onto the porch to water her plants.

'I've got thin bones to start with and any kind of fracture takes a long time for me. So at the moment I'm having nightmares now. I live in fear of falling again.'

To access her house Darlene uses a ramp that's not designed for a wheelchair.

'It sort of bows in the middle so you've got to take a bit of a run at going down and it's pretty steep.'

Because she can't safely use her shower, Darlene sits on the toilet and leans over a bucket to wash her hair.

'Sometimes it's months before I can wash my hair. It's just horrible.'

She said every time the NDIA rejects her submission and asks for more details, she struggles to get builders and OTs back out from town.

'Why would you bother coming out of town when you've got as much work as you could never finish in [town] ... So it's not that there's no OTs or builders or anyone, it's just you've got to get yourself slotted in.'

Darlene's now making a new submission because the NDIA never acknowledged her last submission and the quotes expired.

'I said [to the last planner] ... "That's insane. You mean you can't just use the previous one?" ... You want to tear your hair out, you know?'

Darlene can't understand why, if her NDIS plan is 'about safety' and has money for modifications to stop her falling, the NDIA still refuses after all these years to approve the work.

'If I stay in my own home it's going to save the government hundreds of thousands of dollars. If I end up fracturing that hip before I can get the hip replacement it's going to cost hundreds of thousands of dollars, you know, in the system. Surely it would be better to keep [me in my] own home.'

Atwood and Zay

Atwood was born with a rare genetic condition. He has physical and development issues and a nasogastric tube provides nutrition.

At 12 months, his mum, Zay, needed to return to work.

She contacted several childcare centres, but they either ignored her or refused to enrol Atwood.

Atwood's therapy service provider made some enquiries, but wasn't optimistic.

'A social worker told me that children like my son don't usually go to childcare. Their mothers usually have to give up work to look after them.'

Zay felt she had no choice and resigned. She was unable to pursue her career and the family had to rely on one income.

Atwood missed out on important social interactions with his peers.

'As I was new to the world of disability, I accepted that my son didn't belong at day care ... He was segregated from his community, and so was I.'

Zay told family and former colleagues about her resignation.

'Everyone was disappointed. But unfortunately, nobody was surprised given exclusion of children with disabilities in our society,' she told the Royal Commission.

'It would be wonderful to have some kind of a mentoring service for new parents of children with a disability, to help them find support ... It's just so hard to know what to do in those early days ... It's hard to also feel rejected by your community.'

Two years later, via word of mouth, Zay found a childcare centre 'willing to go above and beyond' for Atwood.

'But it was too late to save my career, and my son's developmental delays had regressed.'

The childcare centre is 'wonderfully inclusive'. Staff encourage all the children, helping them learn to play with Atwood.

'I hope that by teaching very young children about difference, we not only improve the outcomes for children with disabilities and their families, but we create an ideological foundation for all early childhood development, leading through to education, then into the workforce, and finally by setting the groundwork for a healthy inclusive society for the future.'

Annmarie

Annmarie is in her 60s and has progressive ataxia, which means she struggles to walk and uses a wheelchair. She also has difficulty swallowing and speaking.

‘I have no informal supports to help me so I am 100 per cent reliant on the help I get from NDIS for everything in my life,’ Annmarie told the Royal Commission. ‘I am grateful ... But it’s not enough and ... I worry about my future. Where do I end up?’

When the NDIS started supporting Annmarie a few years ago, it gave her access to funding but didn’t tell her how to use it.

‘I don’t know anything about how to implement that plan at the time. There’s no information ... I don’t know what support workers do, how they help you, any of this. It’s all new to me.’

Within a few months the NDIA reviewed her plan and slashed the funding because she didn’t use some supports.

‘I can’t even find me one physiotherapist, never mind a dietician and a physiologist, OT [occupational therapist]. All of those – to find it takes quite a bit of time.’

Annmarie said the NDIA reviewed her plan more than 10 times in the past few years.

‘I’m scared when the plan gets changed because I think, “Here we go again.” And I am less able to do this process and think about it and follow it because my cognitive started to decline too.’

Annmarie tries to advocate for herself, but stress makes her condition worse.

‘They are constantly taking away. I am constantly asking to put a bit more back please for that.’

For example, the NDIA agreed to fund specialist disability accommodation for Annmarie to live by herself, but after she moved into the apartment she was told she had to share.

‘I get told after a month it’s a decision made in error ... this becomes now something that has taken up my energy and time. How many months and hours that I have spent dealing with these errors in my plans?’

Annmarie said often when she goes to the Administrative Appeals Tribunal to challenge a decision, the NDIS admits it’s made a mistake and promises to fix it.

‘I want to understand what’s going on. I can’t keep doing this. Every time I get the plan, things I think are resolved and sorted and discussed start to get ripped out again and I have to address it.’

Farren and Lucien

Farren died a couple of years ago, in his early 20s.

‘He was born with profound intellectual impairment, epilepsy, and later on diagnosed with autism,’ his father Lucien told the Royal Commission. ‘He was very much a part of our family.’

By his early teens, Farren was exhibiting ‘violent and aggressive behaviours’.

‘He was, you know, damaging property, hitting out at family members.’

His parents were ‘screaming for more support from disability services’ to support Farren at home.

‘They never got back to us. We did get some regular respite after that, but he didn’t want to go to respite. He didn’t want to leave me. We were like two peas in a pod.’

Once, Farren ‘hit a carer’ at day care.

‘And because he was aggressive, they called an ambulance and the police arrived.’

Farren was taken to a hospital clinic where there were ‘more outbursts in behaviour’.

‘Sadly, we got involved with the child safety system.’

The agency placed Farren under a child protection order claiming that the family couldn’t handle his ‘condition or aggression’.

‘They split a loving caring family up ... And things just went downhill from there.’

Child services promised that Farren would have ‘his own home and get around-the-clock support’.

‘They said he’d get all the medical he needs. Get all behavioural support he needs. “You guys would get a bit of a break.”’

None of that happened, Lucien said. Instead, the agency put Farren in a cabin in a caravan park with ‘youth care workers supporting him’.

‘And he just freaked out. He was a toddler, cognitively. He couldn’t understand why he was away from his family and his siblings. He just lashed out at everything and everybody.’

Support workers left him screaming, Lucien said.

'There was no care plan. He should have been supported with disability specific trained carers, but he wasn't ... He needed someone to reassure him, to care for him, to help him understand what was going on. And of course, nobody could ... For two years, he was treated so very poorly.'

There was neglect, physical and psychological abuse and chemical and physical restraint over that time, Lucien said. Farren developed scabies, head lice, a skin picking disorder, an infection under his foreskin and severe anal tearing. He would often 'stick his fingers down his throat to induce vomiting' or cut himself.

Once, when an ambulance was called, 'three police officers pinned him down, handcuffed him and, bleeding, they threw him in a paddy wagon'.

'At the hospital, they used security guards to pin him down ... while he's injected with something.'

Farren would often spend several days in hospital.

'All that time as a family we were waiting for disability services to come up with some funding.'

In hospital reports, his doctors said 'that without the proper level of supervision and support, [Farren] is likely to suffer further harm, further hospitalisation, malnutrition and infection'.

Farren was eventually returned to his parent's care, but now with a diagnosis of post-traumatic stress disorder.

He died a couple of years later after having a seizure. Lucien said it was because he still didn't have 'all the supports that he needed'.

'They took away three and a half years of our family life with the child safety stuff while we're waiting for disability to come up with funding ... And you know, it's more than a tragedy. It really is.'

Denton

When Denton's employer discovered he had multiple sclerosis, they fired him.

'I was still capable of doing [the job] back then,' Denton told the Royal Commission. 'But now I can't. So, you know, that's what makes it hard.'

Denton, now in his 70s, was only in his 50s when his employer sacked him. The state government funded his therapy for several years, but one day the government axed the funding program without warning.

'The actual program that detailed all the things that I could do that were available to me as I progressed with my disability was gone. And no-one told me ... That left me in a black hole. I didn't know what to do.'

When the NDIS was rolled out, Denton wasn't eligible because he was just over the age limit. He was initially given access to the federal government's Continuity of Support program, but his access was withdrawn because of an administrative error.

'They just cut it. They just took it straight off.'

With fewer supports, Denton became weaker. To give his wife respite he agreed to enter a nearby aged care home for a couple of weeks.

'That was the worst two weeks of being in a home because they're not set up at all for disability.'

Denton said staff gave him a bell to ring if he needed help, but he often waited naked for more than an hour for someone to come.

'During the day I'd go home ... I actually used my wheelchair to go to my house to be there so I didn't have to be [in aged care].'

Denton said there were several young people with disability 'just sitting in their chair'.

'That's what I found was very disturbing ... It shouldn't be like that'.

When he left aged care Denton was so weak, a neurologist put him in hospital.

'I'd deteriorated so much from not having the hydrotherapy. That's the main thing I need is the hydrotherapy for stretching, which I can't do any other way.'

Denton now has access to hydrotherapy once a week, but relies on his wife to shower, dress and feed him.

Denton said his family bought him a wheelchair and modified his house.

'We've done it all ourselves. We haven't had any assistance.'

Claretta

Claretta is autistic and has major depressive disorder and post-traumatic stress disorder. She manages her NDIS plan using an online platform to hire a team of independent support workers.

Claretta told the Royal Commission there is a downside to these 'informal supports'.

'My disability is social, with the autism, so going in self-managing it's definitely been a baptism by fire. You're managing these people in different areas to support you, to meet your goals. And I think there's this grey area because they're unregistered. In most domains, there's been some issues in terms of abuse and exploitation. You know, the wrong people, the people that should not be working with vulnerable people, they see me as a commodity.'

One support worker lasted about a month. He convinced Claretta to hire both him and his partner and 'used manipulative tactics for his own agenda', she said.

'His role was to connect me socially ... At social events he just self-promoted and I was pretty much mute. He stood over me. And he was trying to just exploit as much as he could.'

Claretta said the man overcharged for services and pressured her to pay him more after seeing her 'credit score is really high'.

'He was just always money grabbing ... trying to get more money out of me. And he just turned into a creep. And he propositioned me for sex ... And I had to manage that situation because his partner was my primary support worker. And he's touching me under the table ... I was just so sad about the whole situation.'

Claretta reported it to the NDIS complaints line and spoke with her support coordinator.

'She swept it under the rug and talked to me in a mean tone. She said, "Oh [Claretta], that's finished now." And the conclusion was, when he was spoken to about it he denied it. And so that's just been left as it was.'

Because the NDIS 'did nothing', Claretta turned to the booking platform, which 'took it seriously and got him out of there'.

'I think that was the only thing that came out of it. The stress of that made me episodic. And I had stuff going on with my mental health. And once again, I had no supports during an episode. Like, it's been a pattern.'

Claretta continued to have problems with new support workers who were 'controlling and intimidating'. With one, 'it was just flat-out harassment'.

‘Sometimes I have had support workers that dabble in criminal activity. Now I know that I need to get them properly checked. They’ve got to have NDIS clearance check and a police check. I’ve learnt the hard way.’

Through all of this, she said, her support coordinators failed to help.

‘There’ve been times that I expressed to them that someone’s not treating me properly and they don’t do anything about it. You can’t rely on them.’

Sometimes she feels like switching to an NDIS managed plan because of the problems with unregistered providers.

‘It feels like a full-time job when it shouldn’t be ... You’ve got to work out who’s lying, who’s just feeding me bullshit so they can get the money. But if you give up power and control to an organisation, then I’m left waiting. And that instils a sense of helplessness. It’s a not a place that I ever want to be.’

Jonno and Dayton

Jonno began experiencing symptoms of epilepsy as a young child and was diagnosed with a syndrome that causes developmental delay and significant degeneration over time.

Now a young man, Jonno has reached the stage where he needs 'two-on-one 24/7' support.

Shortly before Jonno turned 18 his parents reported one of his support workers for not doing her job properly, and she lost her position as a result. Sometime later she retaliated by reporting Dayton and his partner to the child safety agency.

'[She] made up a whole pile of allegations ... Abusing our son, no support, no equipment, nothing in the house, not getting fed properly, no medical treatment and that.'

Her allegations triggered an investigation, which found them to be baseless.

'They put in writing that both me and my partner were fit to look after our son, and they apologised, because they had to investigate when someone makes serious claims,' Dayton said.

Jonno's parents thought the episode was behind them and, when he turned 18, they applied to become his guardians.

'[It's a] standard thing,' Dayton said, 'that 'everybody's got to do.'

But they were shocked to find the sacked support worker had lodged a request for the public guardian to take over that responsibility for their son. They only discovered this when Jonno needed guardianship forms signed to receive medical attention at hospital. The support worker had made 'the same false allegations' she'd made previously.

Dayton and his partner thought the matter would be easily resolved through a tribunal process. They had the letter from the child safety investigation, medical reports and evidence from other support workers.

However the tribunal judge accepted the fired support worker's story, deciding 'she's a professional person, so what she's saying will be the truth'.

'[The judge] already made her decision before we walked into the courtroom.'

The public guardian appointed a new service provider for Jonno's care and moved him to a different home. His parents now have very limited access.

'To get a visit was actually a nightmare,' Dayton said.

They were initially permitted one short visit per week, now two.

'They timed us to the minute ... And that was two support workers standing right beside me and my partner.'

There is no flexibility in the arrangement. If the allocated time doesn't suit, for work or other reasons, it's too bad.

'If you don't like that, you go without,' Dayton said.

Dayton and his partner went back to tribunal, seeking a review of the guardianship decision. Their supporting evidence was ignored again and the original decision upheld.

According to the public guardian, Jonno said he doesn't want to see his parents. Dayton doesn't know why this was given more weight than medical evidence he provided, which explained Jonno is non-verbal and cannot communicate.

Dayton has approached a solicitor to help them take next steps. The solicitor, who has other cases involving the public guardian, is not encouraging.

'There's no point,' the lawyer told Dayton. 'They're a law to themselves, you won't get anywhere.'

Carlton and Jessye

‘I have a non-verbal son with autism who’s been placed somewhere. He doesn’t understand why he can’t be at home and why he can’t see his friends.’

Carlton is a young autistic man in his early 20s with mental health issues.

His mother Jessye told the Royal Commission that not long after he finished school, he was taken from her by the public guardian.

‘And put under basically their control. And I was told, as a parent, that I have no say.’

The guardian placed Carlton in a group home. Jessye said there’s been ‘fraud, neglect, abuse’ under the service provider.

‘My son has suffered horrific abuse and bruising, which I’ve documented.’

Carlton is on a complex needs care package.

‘When this company became involved, they were given a million dollars.’

But for months, Carlton ‘had no therapies’ and ‘they stopped all his programs, stopped outings’.

‘They just drained his disability pension money. It’s always in debt. There is no money for him to be able to even buy himself anything, or just to go to the movies,’ Jessye said.

‘The supports that I had in place for my son, like an education program, he had his own therapists and stuff, that has all been taken away from him. All my people have all been sacked and they’ve just put in all these new people ... They basically are frauding the system. It’s just fleecing it. And they know they’re protected by the guardian.’

Jessye has been fighting for more than a year to have the guardianship order overturned.

‘Of course, I’ve tried everything. Every time I complain to the NDIS, the guardian shuts it down, saying there’s no issues.’

She recently appealed the guardianship at a tribunal but was unsuccessful. The hearing ignored evidence of ‘photos of locks on doors and restrictive practices being used’ at the home.

‘I supplied a five-page document ... and photos of what’s happened to my son and all the rest. And the member said, “We don’t have to look at evidence in this court. The guardian had said that he’s very happy with where they’ve placed your son.”’

Since then, Jessye 'is not allowed to step foot in the property.

'I've had all those rights taken away.'

Many parents have been 'banned access to properties' after they tried to get evidence of the abuse.

'The care company have come back to the guardian and said that the parents were abusing the staff and basically put bullying charges onto us as parents ... And therefore, the guardian believes them and are not involving parents or therapists or people that are advocating for my son.'

Jessye said the exploitation of Carlton under the public guardian is one of hundreds of 'horror stories'.

'Some of the stories are more horrific than mine. I need to get rid of the guardianship board and take control back.'

When Carlton comes home for weekends, he begs not to go back.

'Staff come to get him and he screams on the lawn. He rolls around and runs away from them – "No. No. No." I've sent videos to the guardian saying, "This is wrong. You're forcing something on my son." And I don't even get an answer back.'

Buster

Buster, late 40s, is autistic. He has cognitive disability, anxiety and trouble reading and writing.

Buster's been working for an Australian Disability Enterprise (ADE) for more than 20 years. He loves his job and told the Royal Commission he used to feel proud working for the organisation.

But in the past couple of years things have changed.

Buster's team has had to work without a supervisor or qualified first aid person.

Some days, he has turned up for work only to be sent home because it was raining. One time, his employer offered him alternate work at a different site, but he hadn't been trained to do that work and wasn't confident it would be safe.

Buster discovered his employer wasn't paying him for the days they sent him home.

'We are supposed to be offered training or alternate work on those days or if alternatives are not available, to be paid full pay.'

Buster had to use his personal and annual leave.

He made a complaint to his supervisor, but she refused to answer questions about the training, pay or conditions.

Soon after, Buster's employer told him they were thinking about selling the organisation. Buster asked about his job and pay but they wouldn't tell him anything.

'It caused my mental health to deteriorate and I had to seek regular counselling.'

Buster contacted the union who confirmed his employer was in breach of the employment agreement.

Buster's family and NDIS planner supported him to make a formal complaint.

Sometime later, his employer invited him to a meeting.

A senior manager apologised for taking so long to respond, and handed him a letter to read. She wouldn't get involved in a discussion, but could answer certain questions.

'I tried to read the letter, but I can't read well.'

Buster asked if his support person could come to the meeting, but the manager declined.

He asked the manager to tell him what was in the letter.

She read some information about the organisation's wet weather policy, and told him they would transfer him to a different job.

'I repeated many times that I didn't understand.'

'I stated that I should have my support worker with me to advocate for me. [The manager] stated something along the lines of, "That's it, we need to finish."'

Buster had to go back to work.

'The meeting left me feeling completely confused. I cannot read or write properly and have anxiety. I was put on the spot without my support worker and felt shocked.'

About a week later, the employer told Buster his job was ending.

'We were advised that we were being given two weeks' pay and not to return to the site.'

They told him he could apply for a different job at another site. He felt pressured into accepting a job he wasn't trained to do.

'[The organisation] did not treat me with the respect I deserve after being a loyal employee ... and should have kept us all informed of what was happening with our jobs. ... It seems that [the organisation] is all about the money and has forgotten the people they are supposed to be supporting.'

Germaine

Germaine is transgender and has intellectual disability.

She grew up in foster care and wasn't formally diagnosed until later in life.

Germaine was so neglected as a child, she feels stuck in her childhood and often dreams about being a child.

'My brain [is] so much broken,' she said.

At school, teachers and students bullied and ostracised her.

'I did not receive the education I deserved,' Germaine told the Royal Commission. 'I was not encouraged or supported to meet my potential in education or in sport.'

As a teenager and young adult, people who were supposed to look after her, exploited and abused her.

Now in her 30s, nothing's changed.

'I don't hurt others and I don't push my life choices onto anyone. But because I look and sound a bit different I am judged, verbally abused and treated like I'm less than human.'

Germaine said people in the community shun her.

'I have had people yell at me. Recently while standing at the traffic lights, a passer-by told me to do myself a favour and jump into the traffic.'

Germaine has been robbed, bashed and left to die.

'I am a quiet person and do nothing to be treated badly.'

Germaine has started having difficulties getting the medication she needs. A new doctor at the local clinic refuses to prescribe hormones to transgender patients.

Germaine's counsellor tried to help and accompanied her to an appointment.

'The doctor spoke to my counsellor, not me. I told the doctor, I have received a prescription for that medication at this practice previously. She took a long time reading through my file and then again said, I cannot write the prescription. You will have to re-book with another doctor.'

The doctor's religious beliefs prevented her prescribing the hormones to Germaine.

'In Australia we are allowed to be transgender. If they don't personally agree with that, they should not be allowed to put their beliefs onto their patients.'

It took a week to get another doctor's appointment.

Recently, police attended Germaine's apartment building looking for someone.

They knocked on her door and when she answered, accused her of hiding the person.

'They barged into my apartment. One officer held me while another searched through my apartment. They continued to question me about hiding him. Eventually they left without any comment. They treated me like trash.'

Germaine's accommodation provider treats her poorly and she finds it hard to complain.

She had no hot water for several months, despite repeatedly asking them to fix it.

Eventually she contacted an advocate and the provider finally fixed the problem.

The provider often inspects Germaine's apartment when she's not there.

One time she got home and found her front door open.

'I went in to tell them they left my property unlocked and the door open. They shrugged it off,' Germaine said.

'Life sometimes feels like hell in adulthood and I feel like a misfit and I need to hide away from the world.'

Germaine wants better education about disability and difference.

'Just because someone looks different they still deserve to be shown acceptance and respect.'

Jordy and Nyree

‘I just want to say that we do not ever want this to happen to another child again.’

Nyree is the grandmother of Jordy, who’s autistic and goes to primary school. Jordy also has an intellectual disability and is non-verbal.

‘He can understand everything you can say,’ Nyree told the Royal Commission. ‘We go kayaking, stand-up paddle boarding. He cooks with me with verbal instructions. He does activities all with verbal instructions.’

A few years ago Jordy started kindergarten at a private school.

‘It had a special needs centre and [Jordy’s] mum had already organised the assessments so [Jordy] started school with a full-time [education assistant] EA. And at that time he was the only special needs child in the centre and it was his funding that kept it going.’

Nyree said the special needs centre, when the family eventually saw it, turned out to be a ‘glorified storeroom’.

‘It has nothing in it that was to do with special needs. There was nothing in there and I have never, ever, in [several] years that he was there seen any work that he did, brought home or otherwise.’

Nyree said although the school said it would give him an inclusive education, it excluded him from his classroom.

‘He didn’t actually get taught by a teacher ... He was locked in [the room] with one assistant which I think is not an acceptable practice anyway. So he didn’t have access to the same resources.’

The school wouldn’t let Jordy play with his peers.

‘He was seen by people crying at this flyscreen door ... wanting to get out and play and he wasn’t allowed to.’

Nyree said when the school organised an annual dance, Jordy’s EA wouldn’t let him join in.

‘When all the children came in and the children all went on the stage, [Jordy] was taken to the side.’

Jordy’s teacher refused to tell his mum why he was excluded.

'[His mum] was absolutely sobbing because she'd been out, bought his little outfit and been playing, you know, the little dance at home for him.'

Nyree said the school also refused to tell them what Jordy was doing each day.

'If we knew what he was doing ... we could extend on that at home and build on it ... but they refuse to even use that. They said an absolutely no.'

Jordy developed anxiety. When he wet himself at school, staff put his damp clothes into his bag with his schoolwork and lunch.

Jordy's parents enrolled him in a nearby public school.

'This is a government school where they're raising their own funds to buy sensory equipment. And it's old, but the care and respect that they give the children is amazing,' Nyree told the Royal Commission.

'He walked into school today skipping and saying, "Happy, happy" ... He's treated with dignity at all times and he's cared and respected and valued.'

Ewen

‘I’ll tell you one thing mate, I had to stand up for my rights.’

Ewen is in his 50s and blind. Until recently he lived with his parents in a regional town.

‘I’ve had bad experiences with mum and dad [financially],’ Ewen told the Royal Commission.

The NDIS supports Ewen, but didn’t give him much choice about where he could live.

‘That’s what they said to me. Live at mum and dads or live in a group home.’

Ewen moved into a group home, which was fine when he arrived. But soon he noticed the support workers ordering the residents about.

‘Because we were mucking around in our own private home, like because it’s our place where we live in, it’s not their place ... they started saying things like ... “You’re not allowed to touch each other” or this, that and the other.’

One support worker told Ewan that if he reported ‘anything that’s in this house’ he would be ‘kicked out’.

‘I felt very frightened and scared ... I went straight to my room and couldn’t come out.’

Ewen said the other residents were also frightened. So, in spite of the threat, he told the manager of his service provider, who was ‘furious’ and launched an investigation.

‘[The support workers] had to not come back to the house at all while the investigation was happening.’

One day, without warning, they did come back.

‘I felt very nervous and I couldn’t even speak.’

Ewen said the investigation had cleared the support workers and recommended instead that Ewen get help for his behaviour.

When one of the support workers later organised a party for the house, they invited all the residents except Ewen, who felt they were punishing him.

‘I had to stay back and have tea at home by myself with a carer, of course, and I felt really upset and uncomfortable.’

Ewen said that although the behaviour of the support workers seems to have improved since then, they haven’t yet earned his trust.

Lisa Marie

‘They’re crucifying me. It’s criminal what they’re doing.’

Lisa Marie is being held involuntarily on a psychiatric ward.

‘I’ve been here for a year unnecessarily ... It’s just ridiculous. Because I’ve got bipolar disorder and schizophrenia.’

For years, she ‘had nothing to do with’ mental health.

‘I was free as a bird. I didn’t have to tell them anything.’

But a new psychiatrist had her admitted under an involuntary treatment order.

‘I was brought in by the police and ambulances. They’re just making it difficult ... Public guardian has taken over my financial and accommodation. They’ve got trust over me without my consent.’

Lisa Marie said she was ‘struggling’ to tell her story to the Royal Commission because doctors had drugged her up.

‘My speech is slurred because they gave me lorazepam, and I said I didn’t want it. They said I had to have it. Yes, they’ve got me on about eight tablets ... I don’t like it. It’s horrible. I can’t talk properly. I can’t spit out the word.’

Lisa Marie said she is meant to have a say in her treatment under ‘an advance health directive’ but ‘they ignored it’. In the past year, she’s had electroconvulsive therapy almost a dozen times.

‘They just went ahead. They do that without my consent also,’ she said.

‘The psychiatrist here is ECT-happy. I’m scared of her. She uses it for depression. It’s barbaric and it’s wrong. It’s torture. She uses it for all patients.’

The therapy is affecting Lisa Marie’s wellbeing.

‘I’m just trying – racking my brain after being bombarded with ECT and trying to remember things.’

Currently, she’s in isolation on the acute mental health ward.

‘I was in a community care ward ... They put me in the locked ward yesterday. I did nothing wrong. I’ve got no clothes ... haven’t had a shower ... The nurses are not looking after the patients. It’s very sad.’

She hopes to get off the treatment order and move in with friends.

'I want to get myself rehabbed ... But they seem to be headstrong on putting me in here. I just want to live my life. I had everything planned. Everything was working fine.'

She described the treatment order as a prison sentence.

'I've got no leave. I've got no nothing. Can't go out to socialise. Can't do anything. They basically put a stop to the whole lot.'

Caterina

Caterina, late teens, is autistic.

'I took longer than I should have to talk. I had speech difficulties,' she told the Royal Commission. 'I'd spin quickly in circles without stopping. I had meltdowns, and I had poor gross and fine motor skills ... I also had strong obsessions and extreme attachments to certain objects.'

In kindergarten, Caterina's teacher 'made it very clear' she wasn't like the other students.

'She stated on ample occasions that I wasn't a cute little girl but rather a strange child who was 'messy', lacked social skills, and was 'weird'.'

The teacher would make Caterina apologise to the class for not being able to have 'proper conversations'.

'She also told my parents that autism didn't exist, and that my well-documented autistic traits were just the result of a bad personality.'

The year 1 teacher continued the abuse. She would yell at Caterina for her slow speech, for not colouring inside the lines, for the way she wore her clothes and because she didn't like to be touched.

In year 2 and 3, teachers constantly told her to be less weird. They would yell at her and physically restrained her when she had meltdowns.

In year 4, Caterina started thinking about and planning suicide.

'For years I'd been ridiculed, mocked and outcast not by my peers but by my teachers, and it had a large impact on my self-esteem. To this day, it still impacts my self-esteem.'

Caterina was very talented at maths, rarely getting anything wrong. The teacher told her being smart didn't matter, because no-one liked her or wanted her around.

Sports teachers would use Caterina as an example of what not to do, calling her 'pathetic, stupid and weak'.

In her final year, Caterina and a friend became really invested in the rules of a sport they were learning.

The teacher yelled at them in front of the class, telling them they had social problems. The teacher felt bad for their friends who had to 'put up' with them because they were 'nuts'.

'I was crying and melting down at this point but he kept yelling at me. As usual, my friends were lovely and supported me a lot emotionally.'

Later, Caterina felt so humiliated and confused she started cutting herself.

Towards the end of the year, a teacher locked Caterina in a small cupboard because she didn't want to deal with her.

In high school, Caterina started to see a psychologist and was able to talk about some of the things that happened.

'My primary school was awful for disabled children. I've had countless conversations with other autistic students who had alarmingly similar experiences to me,' she said.

'I hope to see a future where autistic children aren't belittled, degraded, harassed and discriminated against by those in positions of power. Vulnerable children should be protected, not bullied, by teachers.'

Tad and Nici

Tad, late teens, has Down syndrome.

He works at an Australian Disability Enterprise (ADE) two days a week.

Tad loves going to work, his mum Nici told the Royal Commission.

Initially, he spent time in all areas of the business – packaging, recycling, landscaping, manufacturing and home maintenance – before choosing what he wanted to do.

Tad learnt how to do the job efficiently and safely by completing a certificate 1 and 2 – ‘a much-celebrated achievement,’ Nici said.

Staff support him to achieve success commensurate with his peers.

Nici believes Tad’s wage is fair and proportionate to his ability.

‘At an ADE he is able to communicate and participate as an equal rather than as someone “needing support” in open employment.’

Tad has made several new friends and enjoys seeing them in the breaks.

He looks forward to buying a hot chocolate from the coffee van.

He is stimulated, has become more independent and is learning about money. He has a strong sense of dignity, achievement and self-worth.

‘ADEs have progressed significantly from the days of sheltered workshops and it is inappropriate to consider the two in the same sentence ... This is not a sheltered workshop, this is a workplace providing real jobs for real people.’

Nici says it would be an ‘absolute travesty of justice’ if ADEs were abolished. Many people with intellectual disability would struggle to find work in open employment.

She worries Tad would end up in a meaningless day program, at best learning skills he would never use.

‘Those with an intellectual disability and those with both physical and intellectual disability should be given the opportunity to work in an environment that is safe and supportive, which could be open employment or an ADE, but they should have the choice as to where they wish to participate. We should not and must not assume that open employment is the panacea for everyone.’

Laurent

Laurent is undergoing rehabilitation in a mental health unit. Over the last decade he's experienced a lot of abuse in the system, he told the Royal Commission.

'I haven't had a good stay in mental health.'

A few years ago, he was on parole and in a rehab unit. Doctors got him to do a urine test.

'And they said it had come back positive, it was marijuana, and I said I never touched any marijuana ... I said I'll do another one ... and it came back negative. So they gave the one to parole that was positive, and they sent me to jail for a year.'

Laurent is now under an involuntary treatment order and says he has no say in his treatment.

'They force my medication on me. I was on a medication I was happy with. All of a sudden, they went and swapped my medication to a new one ... I get tremors from it, I get the shakes from it.'

Laurent has no-one to advocate for his rights. There's one support worker on-site.

'They can't do much for us, its talking to a brick wall.'

Recently staff put him in seclusion for two weeks just because he 'got upset'.

'They wouldn't give me my Bible ... They're still investigating that.'

Ziggy and Ellyn

Ellyn has physical disability. Her son Ziggy has intellectual disability.

‘He is a quietly spoken young man who thinks clearly before talking, and is a little slower,’ she told the Royal Commission.

A few years ago, Ziggy started having an intimate relationship with a woman who has intellectual disability.

The relationship progressed and she moved in with Ziggy and his parents. Ellyn and Ziggy’s father provided support.

Sometime later, Ziggy’s partner became pregnant.

Ellyn felt confident they would be able to parent with appropriate support.

Immediately after Ziggy’s baby was born, child protection became involved.

Some weeks later, they removed the baby, placing him into foster care.

‘It was evident that because of the mild intellectual disability of my son, he has been labelled as unable to care for his son or act as a parent.’

Ellyn says child protection dismissed the support she was providing and didn’t offer additional support or parenting programs.

‘This made it difficult [for Ziggy] to actively participate as a parent in his son’s life.’

Ziggy’s relationship broke down and he and his partner separated.

‘Access to his son has been at times hard, and he has now had to deal within the family court system.’

Ziggy wasn’t able to get funding for a legal aid lawyer because he had difficulty navigating the process.

Ellyn found a private lawyer and has paid some of the legal fees, but money is limited.

At one stage, the court offered to pay for an advocate. Ziggy declined because he didn’t understand what an advocate did.

A court-appointed child impact professional interviewed Ziggy without an advocate or a support person present.

The professional was swayed against Ziggy having more parental responsibility because of his disability.

‘She didn’t take into account that I am in substantial attendance for access and also work through any decisions with my son,’ said Ellyn

The next step is to take the matter to court, but neither Ziggy or Ellyn can afford the legal fees.

Ellyn believes there needs to be more support for parents with disability going through child access and custody processes.

Ziggy’s son is currently living with a maternal kinship carer. He rarely sees his dad or grandmother.

‘I hope that one day disabled parents are not seen as unable to be a parent. They may have some areas they need support, but can be a parent with supports in place.’

Lorenzo and Cindy-Lou

Lorenzo lives 'out in the sticks' with his mum, Cindy-Lou.

Lorenzo was diagnosed with dyslexia and other learning impairments at primary school.

The local school promised to provide learning supports, but 'that was just gobbledy-gook', Cindy-Lou told the Royal Commission. She and her husband wanted to pay for a teaching assistant to ensure Lorenzo didn't 'fall through the cracks'. But the education system didn't enable this and he was left to 'fall behind'.

'By the time he was about to leave primary school and go into secondary education, he could not put a sentence together. He was always ostracised because of his literacy skills. He couldn't run, he couldn't skip, he couldn't catch a ball and that's all part and parcel of this dyslexia issue.'

In year 12, the school changed its tune.

'It became important that he did pass all these assessments. It wasn't just good enough that he handed something in. It had to be of the calibre that was required.'

The school put pressure on Lorenzo.

'They wanted him to leave because his results would impact on all the other children's results'.

The system pushed him through 'with a deluded sense of his ability', Cindy-Lou said.

'Part of the disability impact is of course the literacy. He didn't get the skills to progress. And because he did not complete his HSC, he was compelled to go back to school. At which stage he had a psychotic episode, which the psychiatrists have directly linked to the pressures we put on him to learn to read and write.'

Today Lorenzo is 'crushed', she said.

'He is so broken we will never get him fixed. You believe you're doing the right thing ... I kept him at school because I believed in education. I believed the system would help him.'

Lorenzo's ability to 'find work and have a fulfilling life has been so compromised' by the learning failure, Cindy-Lou said.

'And the sad reality is ... it was picked up early. Now, in the end, it didn't help. He is never ever going to be the happy person he was ... Everyone should go and hang their heads in shame, absolute frigging shame.'

Bev and Mona

Bev had to give up her job due to the cumulative impacts of an autoimmune disease, post-traumatic stress disorder, eating disorders, depression and other conditions. She now receives funding from the NDIS and seldom leaves her apartment, as her mobility is impaired and she has extreme sensitivity to light.

Bev is too traumatised by her experiences to speak of them, so her support person Mona spoke to the Royal Commission for her.

Bev's difficulties began with a medical procedure about 15 years ago, which resulted in a series of infections and complications. Doctors put her on successive courses of very strong antibiotics.

Bev had a severe allergic reaction to the medications, with a range of consequences including extreme fatigue and severe weight loss. Medical specialists were not able to diagnose or treat her conditions. She could barely stand, work or look after herself, and in desperation contacted the state government health agency for advice.

The agency sent mental health professionals to visit her. Later the same day, different staff from the agency came to the door and told her she'd been placed under an involuntary treatment order (ITO). They told her to pack her bags and go with them. Bev had no-one to call and didn't know what her rights were. She did as they told her.

The health agency officers took Bev to the psychiatric unit at a hospital. She didn't understand why she was there. Eventually she saw a psychiatrist, who said she needed urgent treatment for a life-threatening eating disorder. He told her that if she didn't consent, he would reinstate the ITO. He wouldn't answer any of the many questions she had, or let her phone anyone to ask advice.

Staff put Bev in a single room and kept her isolated, constantly monitored by a nurse. During the first month of her stay, several nurses said they weren't sure if she actually had an eating disorder. They thought she might have some other undiagnosed problem. They saw how much she was eating, yet she continued to lose weight.

They expressed concerns about her treatment to the psychiatrist but he dismissed them.

When he met with Bev, he accused her of acting in some way to keep her weight low. He subjected her to daily tests, including physical searches and physical violation, to measure how much was in her stomach and what she was excreting.

Mona told the Royal Commission that for Bev, these intrusive tests and examinations were like 'being raped again and again'.

As months passed and Bev didn't reach her target weight, her treatment became more punitive.

Some of the nurses became abusive.

'[Bev] was made to stand there, practically naked with her pants down on public display while they yelled at her for not being able to go to the toilet,' Mona said.

They made her strip to stand on the scales and wouldn't let her see the result.

'They would simply say, "Oh Dr X is going to be really mad at you, you haven't put on any weight." The psychological pressure was horrific,' Mona said.

They used physical force to medicate her, and on one occasion gave her a drug that was meant for someone else.

'[Bev] was treated like she had committed a terrible crime – humiliated, degraded, subjected to psychological, emotional and physical torture ... She had a genuine medical issue that was receiving the wrong treatment and diagnosis and was being subjected to treatment that was ... horrifically abusive, profoundly traumatic.'

Bev was eventually discharged into the care of a psychiatrist in the private health system. She still hadn't reached her target weight.

'[Bev] did not have an eating disorder before she was taken from her home and incarcerated for an eating disorder. But she has very severe and dangerous eating disorders now ... To this day, she still experiences and relives every moment of those months of treatment ... It is extraordinary that she has managed to survive, considering what she's had to endure.'

Kieren

‘There are carers that have been in the industry for many good reasons –they have an understanding, they have family with a disability that they can relate to – but yeah, it’s really sad to see them just drop off like flies.’

Kieren is in his 30s and lives with a spinal cord injury from an accident more than a decade ago. He uses a wheelchair and catheter, and relies on well-trained support workers.

Kieren told the Royal Commission that during the COVID-19 pandemic service providers sent him untrained staff.

‘There’s just more random people coming through my doors and people who aren’t trained, who are inexperienced,’ Kieren told the Royal Commission. ‘And apart from the care support [there are] safety concerns.’

Kieren said support workers turn up without identification.

‘I don’t know who the stranger is, it’s just a name given to me by a text message. Yet I’m having a stranger in every time enter my house from an agency. That plays on my mind and is a major concern as well.’

Kieren said service providers often promise the workers they’re sending are ‘well-trained or have spinal specific training’, but he feels ‘like they’re just walked off the streets into this industry to take care of people’.

‘No qualifications, no training, no nothing.’

For example, a service provider recently sent him support workers who failed to drain his catheter bag and nearly killed him. As a result of that incident, Kieren developed post-traumatic stress disorder.

‘They have no bowel care training, nothing. If you ask them, “Where do you usually do all this? Who’s the majority of your clients?” they come across like, “I worked with people with intellectual disabilities.” It’s a common thing I hear. So, you know, there’s no transparency with companies and agencies.’

Kieren said his last service provider withdrew its support because it sent an untrained worker who injured himself lifting Kieren.

‘There was no training prior to them commencing, he was thrown into the deep end, no [occupational health and safety] OHS training, no manual handling, no training at all. He was just chucked in hands-on.’

Kieren said service providers seem to be losing the better-trained, experienced workers because good workers often aren’t paid any better than bad ones.

‘They’re not acknowledged for their hard work that they put in, not only for the organisation but for the client, and they’ve just gone.’

Ghislaine and Toniette

Ghislaine passed away a couple of years ago in her 40s.

Her sister Toniette told the Royal Commission that Ghislaine had been diagnosed with a rare genetic disorder in her early teens. After an acquired brain injury, she 'went from being this active, normal, full-on woman to a disabled person'. She 'just seemed to get lost in the system' and was 'not cared about'.

Ghislaine struggled to access disability supports. In her 30s, she eventually got into a palliative care home.

'There wasn't much around in those days for younger people with high complex needs apart from, like, an institutional-type thing, a hospital. But we didn't want that for her.'

For the few years prior to her death, Ghislaine had been in supported independent living, 'purpose-built for people with brain injuries'.

Toniette said Ghislaine always felt vulnerable at the home 'because she couldn't voice concerns'. Support workers 'talked down' to her and 'didn't seem to listen to her'.

'She was hard to deal with, she had a lot of involuntary movements ... She used to lash out as well, or not let people do things. Some of them just didn't know how to cope with that.'

Toniette said most of the staff had English as a second language, but were dealing solely with people with brain injuries. In 'heated and upsetting meetings', the service provider would blame Ghislaine for 'communication breakdown'.

'I said, "If you've got people who are not understanding and finding it hard to communicate with her, I am sorry, but they shouldn't be there or they need more training." To me, that is a breakdown on their part and on the carer's part.'

In the last 18 months of her life, things started to go downhill and the provider stopped the family from contacting Ghislaine.

'All the calls were screened.'

Ghislaine was alone and staff 'didn't even try' to spend time with her.

Toniette said nurses were carrying out procedures 'against her will'.

'The staff had made appointments to see her doctor without her knowledge. That's where we realised they were trying to find something to get her out of the house ... They wanted to discharge her into a nursing home. But we had no transparency, no honesty. They just used to put it back that either her care was becoming harder, or their staff might be in danger of catching something from her.'

Toniette was just about to move Ghislaine into a new house when the service provider had her sister hospitalised.

‘[The manager] said he’d spoken to the head of emergency ... and this doctor had told him that yes, she should be in hospital.’

But the doctor later said ‘he never told him that’.

Ghislaine was not ill at the time and didn’t want to go to hospital.

‘But she became unwell, deteriorated, and ended up in the ICU.’

Toniette wants to see better monitoring of disability support services.

‘To me, it’s necessary to have a watchdog ... More regulating like the spots checks and things like that. Speaking to the families, speaking to the clients.’



Royal Commission
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