



Inclusion Australia:

**A qualitative response to the Royal
Commission into Violence, Abuse, Neglect
and Exploitation of People with Disability**



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October 2020

Acknowledgments

Inclusion Australia acknowledges the traditional owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respects to community members and Elders past, present and emerging.

This submission is a result of the collective power of listening to self-advocates, family advocates and paid advocates together. Inclusion Australia acknowledges the courage of the people who have told their own story in the hope that this contributes to positive change for all Australians with intellectual disability.

This submission includes two attachment papers commissioned by Inclusion Australia in 2020:

1. *Gathering the Evidence: Data on people with intellectual disability in Australia* authored by Associate Professor Angela Dew and Dr Cadeyrn Gaskin, Disability and Inclusion, Deakin University; and
2. *Gathering the Evidence: A limited literature review on violence, abuse, neglect and exploitation experienced by Australians with intellectual disability* authored by Dr Amie O'Shea and Dr Jennifer David, School of Health & Social Development, Faculty of Health, Deakin University

Inclusion Australia receives funding from the Australian Government, Department of Social Services to undertake systemic advocacy activities related to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This submission forms part of this work.

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Foreword

When Inclusion Australia (IA) recently consulted with people with intellectual disability about what is most important to them, the number one response was the right to be respected like anyone else.

They told us: *“We know when we are respected, and we are not respected. We feel it.”*

Respect is how we show our regard for each other.

Respect shows a person they are valued and taken seriously.

But people with intellectual disability in Australia are not respected.

For instance, prior to conducting the research contained in this document, IA conducted:

- A Data Review that ‘highlights the difficulties in accessing reliable and comparable information about people with intellectual disability in Australia’; and
- A Literature Review that shows ‘there is a lack of relevant research with which to understand both the experiences and needs of Australians with an intellectual disability’.

In other words, IA found that Australian governments had not gathered enough data and research to understand the needs of Australians with intellectual disability – let alone begin to formulate policies that respond to those needs.

As a consequence, Australians with intellectual disability are treated as second-class citizens: not respected enough to be counted, considered or included by their country.

With that in mind, IA conducted this Qualitative Review to uncover the real-life stories of the hidden violence, ignored need and blatant discrimination experienced by people with intellectual disability.

The horrifying stories contained in this submission are a stark reminder that abuses will continue while with intellectual disability are unseen and unheard.

Unsafe and scared

This report demonstrates the powerlessness of some people with intellectual disability, as well as the spectre historic institutionalisation.

The stories it tells are not hypothetical: they are happening right now.

IA campaigned hard for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission).

We campaigned because we knew the systems that were intended to protect people with intellectual disability have failed and are unsafe. We campaigned because negative attitudes enable discrimination. We campaigned because the system is segregated, and segregated systems make people invisible. We campaigned because congregate care breeds silence and violence, as well as coronavirus.

We campaigned because our members told us people with intellectual disability did not have the support and were too scared to share their stories with the Royal Commission – and found the Commission’s processes inaccessible.

As a national advocacy organisation, we therefore felt an obligation to amplify the voices of people with intellectual disability by conducting the research necessary to make this submission.

Free and equal

Currently, the process to contribute to the Royal Commission – either by submission, private session or public hearing – is difficult for many people with intellectual disability to navigate.

As a consequence, barriers of language, technology and procedure are keeping people with intellectual disability from telling their stories to the Royal Commission.

IA has no doubt the Royal Commission is acting in good faith and wants to make hearings and submissions accessible to all Australians, but currently its processes fit the needs of the Royal Commission. If the Royal Commission wants to be accessible its processes need to change – and fit the needs of people with intellectual disability.

According to Article 12 of the UN Convention on the Rights of Persons with Disabilities (the UN Convention), people with disability have the right to equal recognition before the law and the right to any supports they may require in exercising their legal capacity.

By denying the supports needed to help people with intellectual disability fully participate in Public Hearings, the Disability Royal Commission is in breach of Article 12 of the UN Convention.

This Royal Commission has the opportunity to make a real difference. It can model a new understanding of accessibility that replaces complex legal documents with plain language forms and supports decision making by people with disability. It can remove the privacy hurdles that prevent stories being heard by taking an informed and contemporary approach to consent. It can reassure people with intellectual disability that it ‘has their back’ through a public demonstration of its power to protect witnesses.

It is not the role of the Royal Commission to only ‘give people with disability a voice’ through evidence provided by families, advocates and expert witnesses. The real challenge is to find a way to help people take control of their own stories.

IA stands ready to help make this Royal Commission an international model of access.

We suggest that urgent priorities for the Royal Commission include:

1. Filling the identified research gaps about people with intellectual disability,
2. Committing to implementing the recommendations emerging from this submission, and
3. Working with IA to fix the problems people with intellectual disability are having with giving evidence safely.



Catherine McAlpine

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Background

Inclusion Australia (IA) is the national peak body for intellectual disability.

Founded in 1951 as the National Council on Intellectual Disability, IA's mission is to work to ensure people with intellectual disability have the same opportunities as people without disability.

IA is a federated body with state agencies in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia. Those agencies are: the Council for Intellectual Disability (NSW), Parent to Parent (Qld), the South Australian Council on Intellectual Disability (SA), the Speak Out Association of Tasmania (Tas), the Victorian Advocacy League for Individuals with Disability (Vic), and Developmental Disability Western Australia (WA).

Between October 2019 and June 2020, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) released nine Issues Papers seeking feedback on: education and learning; group homes; health care; the criminal justice system; emergency planning and response; rights and attitudes; employment; restrictive practices; First Nations people with disability.

In July 2020, IA decided to initiate a qualitative study of a representative sample of its members because people with intellectual disability were scared to share their stories independently, did not have the support to do so and the processes for doing were often inaccessible. The purpose of this process for making a submission in this way made it much more possible for people with intellectual disability to share their story with the Royal Commission and feel comfortable in doing so. IA framed the interview questions so that the study responded to each Issues Paper.

Between 27 July and 13 August 2020, IA interviewed 32 people. Of the 32 people interviewed: 13 had an intellectual disability and were self-advocates; 14 were paid disability advocates; and 10 had a family member with an intellectual or cognitive disability. On a state-by-state breakdown: 4 were based in New South Wales; 4 in Queensland; 7 in South Australia; 3 in Tasmania; 10 in Victoria; and 4 in Western Australia. The ages of those interviewed ranged from 20 to 70. Three identified as Aboriginal.

Due to coronavirus, the interviews were conducted over Microsoft Teams. Interviewees were asked to share their thoughts and experiences on subjects relating to the Issues Papers. The interviews were recorded. All interviewees agreed to speak to IA on the understanding that their identities would be protected.

This paper summarises the findings of those 32 interviews.

The names of all interviewees have been changed.

Introduction

‘Unattractive consumers’

This story encapsulates the systemic failings of governments in general and the disability sector in particular — and shows how those failings, which are effectively systemic abuse, endanger the lives of people with intellectual disability and their families.

Peter is 13. He spent the first three years of his life battling brain cancer.

His mother, Dawn, said:

‘Up until the age of three he was pretty much under the umbrella of the oncology team, and that’s kind of like the Ferrari of health care. It’s team led. It is comprehensive, multidisciplinary. It’s well resourced. It’s really the model of care that we need for disability management, too.’

Peter recovered from cancer but acquired a brain injury and hearing and vision loss during treatment. He has spent the past decade bouncing around the disability system.

Three years in a Ferrari health system. How would you characterise the 10 years since in the disability system?

Dawn: ‘Sort of a Datsun with a flat tire. ... The lack of ownership [by professionals in the system] is really, really awful.’

If anything, Dawn’s remark is an understatement. The system was more than ‘awful’ for Peter and his family. Over the past decade they have been systemically abused — categorised as a complex case and therefore left to their own devices to cope with untreated chronic health conditions, a lack of services coordination and minimal respite.

In the end, this systemic neglect led to Peter’s younger brother, Xavier, attempting suicide.

Professional negligence

It’s important to unpack the systemic neglect of Peter, step by step.

When Peter was 3 years old, he was diagnosed as autistic. His parents — both of whom are medical professionals — believe this was a misdiagnosis.

Dawn said:

‘They slapped an autism label on him at three because communication wasn’t working and behaviour was off and, you know, there was a delay and the triage of diagnosis says that that’s actually autism, where it’s actually brain injury, I believe ... there might be another possibility that there’s some underlying pathology.’

By the time Peter was 7 years old, undiagnosed health problems caused by his cancer treatment radically changed his behaviour. He became ‘very violent’, Dawn said, putting his head through nine windows in six months. In the end, Dawn was forced to take Peter to the local hospital for help diagnosing the cause of his change in behaviour, but the hospital didn’t help.

Dawn said:

'We were told after waiting eight hours that no one would be coming because it was neither neurology nor oncology, so we'd have to go home, at which point the psychiatrist, who we saw in the community ... managed to do a deal with someone working at the hospital to get us admitted over the course of the weekend. We were told to call an ambulance if things escalated.

'So, we were admitted as a psych patient, that's the only way we could get into the hospital, as a psych patient for a week, and he was sedated to his eyeballs and nobody came to examine this child until I insisted we weren't leaving until he was examined and someone [after five days in hospital] sent a junior registrar down to do a cursory look over him and couldn't find anything wrong. We were discharged.'

Two weeks after the hospital stay, Peter's face ballooned.

Dawn said:

'He had three septic teeth. Then they operated on it as an emergency and we were discharged and six weeks later the face started to get red and painful again and the behaviour started to escalate and I wrote to the specialist, the dentist, and said, "Like, I think we still got this problem," and she sent me this message back and said, "Well, you know what, these kids get these problems."'

Dawn sighed as she remembered the dentist's dismissal of Peter's suffering. She said the three teeth that caused his violent behaviour were black and crumbling when they were extracted.

Peter spent the next year bouncing between dentists and specialists. He is now 13 years old and has chronic dental problems. Dawn said Peter's behaviour escalated whenever he was in pain. When that happened, Dawn locked herself in a room with Peter's 11-year-old brother, Xavier. She said:

'If he's really kicking off ... we'll lock ourselves in his [Xavier's] room until things have calmed down a bit, because we've, we've pretty much set up the place so that we can remove ourselves and he can't do too much damage and he's safe — you know what I mean? But we can't, certainly can't, lock him away, and I wouldn't want to, but we actually need to be able to remove ourselves if there's a problem. ...

'Two weeks ago, they had to call the police because my husband was working and he [Peter] had me by the throat. He smashed my head into the wall, but he was holding his face. And, you know, Nurofen and Panadol used to work quite well with him, but it's becoming less and less effective. ...

'It goes from zero to 10 very quickly. I mean, he does have a frontal-lobe injury ... [but] we will have weeks where he's really good. Like, just beautiful. And he'll be singing and happy and joyful and there won't be any single incident. And then we'll go into this frenzied — like, attacks on people where we need two big male support workers to take him out for community access. ... It's such a change, an extreme change in the child, and it always coincides with holding his face and waking up in the middle of the night.'

Lack of training

For Dawn, managing her son's medical appointments has become a full-time job, including multiple visits to hospital emergency departments.

She said:

'It's happened to us a few times where we've just been put in a waiting room waiting for a specialist for hours at a time with him physical and the doctor will come and will push his computer on a little trolley to take a history, but he'll stand between us and the door with his back out the door so he doesn't get hurt. But they're happy to leave me there on my own with this child who's belting me. How can you say that that's okay in terms of health intervention?

'I think there's the presumption that it's not pain and suffering. It's behaviour. Even though you can say to them, "This is not what he is usually like and this is an escalation in his behaviour." ... I come from a nursing background. My husband's a doctor. I know that sometimes you don't have the answers to manage this. And I know, certainly in nursing training, they don't have any training, disability training, anymore. We used to have specialist disability nurses and they would go down a disability stream of education. ... The under-skilling of nursing and health care professionals in these situations is really obvious. ...

'The frustration for us over this whole process is the lack of ownership and the lack of team coordination. Yeah, it's like the buck stops with nobody.'

What you're talking about, then, is really a sink-or-swim system of healthcare for your son?

Dawn: 'Yes. ... And going forward it's going to be harder and harder to manage that because he is quite physical and you know, in some of my reading I came across his awful turn of phrase that stuck with me forever, but I think it probably, you know, probably reflects the attitude — "unattractive health care consumers". ... They are time consuming, they're expensive and they're difficult to manage and difficult to get a resolution out of, and I think that's where someone needs to have a really good look at how we deliver health care, because it serves no one well if people are developing chronic illness because of neglect. ... What I think would be really important, and I think it would probably eventually be cost effective to the government, was actually: each person with a complex disability falls under the management of a team and that team will manage that person from, you know, their childhood, too.'

Currently, Dawn said people with disability fall through the system's cracks unless they have the support of a strong family or advocates:

'It's up to the parents to push really hard. ... I just always worry about the people who are too tired or don't have the language skills or English skills or can't be bothered. Or a single mum with two or three kids on the [autism] spectrum. How are those people managing? ... It's kind of almost an elitist thing. ... If you don't fight hard in your corner, that person will rot.'

Restrictive practices

The system's bureaucratic methods make life much harder. For example, Dawn said, documenting the restrictive practices required to manage her son's escalating behaviour required multiple interactions with doctors, specialists, and panels:

'We're really struggling with our behaviour clinician at the moment. He's not really available. ... He was due to redo our behaviour support plan ... and he's gone on leave without it finished.'

As a consequence, Peter had not been able to have a break away from home for a year.

Dawn said:

'We had an incident report two weeks ago where – we've got a dog and [Peter] went to sit on the dog and the support worker redirected him ... and put in an incident report, mistakenly thinking

that's what you had to do. And then we had calls from the [NDIS] Quality and Safeguards Commission. We all had to do an hour-long sort of interview about what restraints were in place, even though it became very quickly clear that... he was just redirected. And we've since put a thing together about the difference between restrictive practice and redirection.

'We do get a lot of it. ... It's incredibly time consuming ... and I feel like while we're doing the right thing, putting in the paperwork, [and] that the other people that aren't even doing the paperwork and just not bothering. We're the conscientious ones. It's the ones they never hear from [that the Quality and Safeguards Commission should worry about]. ...

'The paperwork's extraordinary. And, so, if you change a restrictive practice, ... the restrictive behaviour support clinician has to rewrite the behaviour support plan. We have to go to the GP, get the GP to write to the school or any other providers he's in contact with. We have to write all the different medication forms for each of those providers from the GP. And then we have to submit it to the Quality and Safeguards Commission, who then review it and approve it.'

Dawn said Peter's behaviour required changes to his medication every three weeks. That meant that she had to navigate a paper storm every three weeks to get her son's updated behaviour support plan approved by the Quality and Safeguards Commission.

'I just spend hours doing it. I spend my life doing it,' she said.

COVID-19

Peter's school has been very supportive. Dawn said that the school community, which has lost families to suicide, provided him with constant support in the classroom and the playground:

'Last year he smashed one of the teacher's head into the wall and she was off with concussion for a week. And you know I always feel very grateful that he still has a space there and that they've been able to manage. ... We've really hit the education jackpot at that school.'

The COVID-19 lockdown disrupted Peter's support network, with the family losing support workers. Dawn said that the loss of a support worker was difficult because the only time Peter had a break was when he was attending school or on an outing:

'We don't actually have out-of-home respite. It [respite] is when the workers will take [Peter] on a train into the city or will go somewhere out.'

Dawn said Peter was rejected for out-of-home respite care because of his complex needs. 'The family is constantly knocked back for respite, because the services don't want challenging kids,' she said.

In other words, services are set up in such a way that they do not help the families most in need. Dawn said there was an urgent need for support for people with complex support needs because 'then you could hope for a little bit more than they come back alive and they haven't been abused, which is the kind of thinking at the moment. ... If we had really good rest ... then that would, that would be a good thing. We actually got a really big [NDIS] package this time because last time I took it to the media ... but you can't buy the services.'

In the meantime, Dawn said, she used her spare time to fight for systemic reform:

'You can fight your own corner for your own child, but you kind of have to fight the bigger fight because there's other people who don't have the fight left in them anymore.'

Findings

This submission is built on the personal stories of people with intellectual disability. Stories that the Royal Commission needs to hear. IA did not limit the scope of what people wanted to say. However, to assist the Royal Commission, our findings are grouped in themes that correspond to the Issues Papers published by the Royal Commission to date.

First Nations people

First Nations people reported additional discrimination because of their disability and culture.

Restrictive practices

Families wanted greater external oversight of extreme restrictive practices and more support to improve quality of life.

Advocates were deeply concerned about the NDIS Quality and Safeguards Commission's lack of independence.

Advocates reported that some psychologists and psychiatrists were diagnosing mental health conditions to evade restrictive practices rules.

Advocates linked overuse of restrictive practices with poor training and availability of resources.

Employment

People with intellectual disability saw a connection between the low quality of education they had received and their poor outcomes in employment.

People with intellectual disability reported discrimination in their treatment at work and with wages.

People with intellectual disability wanted more support to train for and gain access to open employment — as well as support to find additional work while in open employment.

People with intellectual disability wanted Australian Disability Enterprises (ADEs) to be reformed so that they helped clients gain the skills needed for open employment.

Rights and attitudes

People with intellectual disability reported being routinely harassed in the community.

Family members said that people with disability's rights were often ignored, making them practically powerless.

Advocates said there was an urgent need for independent oversight through initiatives like community visitor programs.

Advocates in almost every jurisdiction reported multiple cases of child protection taking the children of people with disabilities without cause.

Advocates said there was an urgent need for legal reform, including guardianship.

Emergency planning and response

People with intellectual disability reported that their rights had been overlooked during the COVID-19 pandemic.

Family members said the COVID-19 lockdowns gave support workers too much power over people with intellectual disability.

Advocates were concerned that the COVID-19 lockdown would both cause and hide a spike in abuse against people with intellectual disability.

Advocates said the national response to the COVID-19 pandemic revealed an urgent need for strong, proactive oversight of the care of people with intellectual disability.

Criminal justice

Advocates said people with intellectual disability were often at the mercy of the justice system — their complaints ignored if they were the victims of crime, and their rights often not understood, and therefore inaccessible, if they were accused of a crime.

Advocates said the behavioural issues of people with intellectual disability were often criminalised by the justice system.

Advocates said the lack of services and supports in the corrections system for people with intellectual disability meant they were more likely to be abused in the justice system.

Advocates said people with intellectual disability often ended up in the justice system because the disability support system had failed.

Health care*

People with intellectual disability said health care professionals discriminated against them.

Families reported being lied to by health care professionals.

Advocates said health care professionals lacked the training to support people with disability.

Advocates reported cases where health care professionals had medicated people with intellectual disability for non-medical reasons.

*Note IA's separate health submission contains more expansive discussion and recommendations

Group homes

People with intellectual disability reported being racially vilified, discriminated against, restrained, and assaulted in group homes.

Families said that people with intellectual disability living in group homes did not have choice and control — their lives were controlled by service providers.

Advocates said service providers were using National Disability Insurance Scheme funding to create a new generation of small, privatised institutions.

Advocates said support workers were poorly trained and underpaid — increasing the risk that people with disabilities received sub-standard care.

Education and learning

People with intellectual disability said they were bullied and received sub-standard educations in primary and secondary schools — and were excluded from accessing tertiary education.

Families said they were discriminated against in mainstream schools.

Advocates said that special schools grouped students with complex needs in the same class, even though the students ranged from 4-to-17 years of age.

Advocates saw a connection between people with intellectual disability's systemic neglect in education and their lifelong neglect and exploitation in the community and economy.

First Nations people with disability

First Nations people with disability are proud of their Aboriginal heritage. They also reported double discrimination because of their disability and culture.

Tim is 20.

He has autism and intellectual disability. His grandmother was part of the Stolen Generation.

Tim is proud of his Indigenous heritage, but feels he has to constantly prove the bona fides of his identity as well as his disability.

'It's not just my disability,' Tim said. 'It's also my [Aboriginal] heritage as well I've had to prove; so, it's just been a bumpy ride the whole way through.'

Eileen is in her 50s.

She was removed from her family and placed in an institution as an infant. She suffered years of abuse in institutions as well as family violence when she was released.

Eileen was not told she was Aboriginal until she was an adult, after her release into the community. She now lives independently, has connected with her Indigenous community and become a confident self-advocate. She is concerned that people with intellectual disability — particularly people living in group homes — are being manipulated into not speaking out to the Royal Commission.

Eileen said:

'I reckon people out there with disabilities and intellectual disabilities if they want to have the confidence to tell their story on what happened to them in these institutions. ... They should have the right to come and tell you. ... They shouldn't have the staff telling them what they can say and what they can't say.'

Calum is 22.

Calum said: 'Not knowing my rights, I was scared. I didn't know what to say. ... I had to shut up and put up with it. ... I got into a lot of fights at high school. I got bullied quite a lot and picked on quite a bit because of my Indigenous side. ... That all came out in the end. They were so bottled up inside it was getting to the point where sooner or later it was going to come out of me. And it did ... like an earthquake.'

Case Study: Racism and disability

This is the story of an Aboriginal man taken into care as an infant.

Calum is 22. He is Aboriginal.

He was removed from his mother as an infant. His father, who is deceased, was Aboriginal.

He was brought up from infancy by a foster parent he calls 'Mum'.

When he was 16, Calum was removed from his foster home against the wishes of his Mum and placed in a group home. In the group home, he said he was racially abused for being Aboriginal by a support worker.

'I didn't feel safe,' he said.

'I was still coming out of the idea of living with my Mum still. I still didn't understand why they would do that to me and make me go somewhere where I wasn't comfortable. ... I was trapped in this little room and they made me feel like I was useless. They wouldn't let my friends over; they wouldn't let me do anything.

'It felt like I was trapped, that's what it felt like when I was in the group home. It didn't feel like anything. It just felt like, "You're a bad child. You've been placed here. We'll just dump you here."'

Calum said that the group home had too many rules to keep. At one point, he went to a party and missed his curfew. He said the group home called the police and reported him for absconding. Calum said the police were 'really nice' and returned him to the group home, but he felt that the support workers were trying to control his life.

'I just wanted to be by myself.'

He now lives in a one-bedroom apartment: 'At the moment I've got no girlfriend or nobody except for my dog, really. So, it kind of is a bit lonely.'

He is trying to reconnect with his Aboriginal relatives.

Restrictive Practices

Family members were pragmatic on the subject of restrictive practices. They wanted restrictive practices monitored and minimised — even eliminated — but were concerned by the broad definition of the term ‘restrictive practice’. They wanted a greater oversight of extreme practices and more support to improve individual quality of life.

Jane lives with her adult daughter, Ava, who has an intellectual disability.

She said the definition of restrictive practice needed to be ‘more balanced and defined’.

‘Restrictive practices are overbearing, but there is also overbearing oversight of minor practices,’ she said, giving the example of a parent who was not allowed to use a seatbelt for a wheelchair that was used to keep their child from being thrown from the chair during a seizure.

‘I think restrictive practices should be eliminated,’ Jane said, ‘but I need people to look over what is a restrictive practice.’

Advocates and disability services workers had concerns about the use, reporting and investigation of restrictive practices. They said staff often did not understand the definition of restrictive practices. They said the definitions of restrictive practices varied between jurisdictions. They said the reporting mechanisms were too bureaucratic and time consuming, which increased the likelihood that families would not report. And they said the NDIS Quality and Safeguards Commission was a ‘toothless tiger’ because it was not proactive, was not independent of the Federal Minister for the NDIS and lacked the resources to inspect or investigate. In Victoria, advocates reported a new trend that sounded like a throwback to the medical model, with some psychologists and psychiatrists using mental health diagnoses as cover for the use of chemical restraints.

Brian is an advocate. He said he had a ‘feeling of unease’ about the NDIS Quality and Safeguards Commission:

‘I hear anecdotal complaints about it as just being, you know, yet another bureaucracy that's very focused on systems and data and not very responsive to individual circumstances. ... With restrictive practices, you know, their main focus seems to be on getting reporting of what's happening and ensuring that there is a behaviour support plan in place. That doesn't tell me much at all about what's really happening in the life of that person. ... You can have the best behaviour support plan in the world. ... To what degree it's actually being implemented at the coalface is another matter altogether.’

Brian said that the legislation establishing the Quality and Safeguards Commission needed to be amended to strengthen the Commission’s independence:

‘The legislation establishing it says that it's subject to the direction of the Minister ... except in relation to individual cases. So, that gives enormous sort of scope for political interference and for it to ... keep the Minister happy as opposed to being a fearless watchdog.’

He said the legislation governing the NSW Ageing and Disability Commission, which has a similar role to the NDIS Quality and Safeguards Commission, had been amended to give the Commissioner more control over the direction of investigations.

The Commonwealth, he said, could easily follow the lead of NSW.

Stephen is an advocate.

Recently, he visited more than 60 disability service sites and asked the staff whether they knew their employer's restrictive practices policy. 'I didn't meet one staff member who knew the restrictive practices policy of their organisation,' he said.

'I went to this one house and they'd put up a fence so that people couldn't get into the kitchen and, in guiding rather than scolding mode, I said to the supervisor, I said, "You understand that that fence is a restrictive practice." And they said, "No, it's not. It's just a fence to keep people out of the kitchen." ... There's been a significant emphasis in the use of restrictive practices ... but many of the locks on refrigerators were basically so people couldn't get into the fridge and spill the milk.'

Lisa is an academic and advocate.

She said:

'Challenging behaviours are often connected to a chronic health issue that had not been identified. If you can communicate then people with disability are less likely to have to act out.'

Lisa cited the case of a non-verbal man, now in his late 20s, who had been categorised as problematic in school. After leaving school, his family established a communication system — and he started telling them about the underlying issues that were causing his behavioural escalations. As a result, his family began to deal with the underlying issues and systematically remove his restrictive practices.

Lisa said:

'We keep seeing behaviour-based programs and they're not addressing communication.'

Anna works in disability services.

She said restrictive practices were overused because most staff lacked the training and expertise required to work with clients with complex support needs.

She said that many staff members didn't understand what a restrictive practice was, and many disability services weren't reporting restrictive practices.

Lillian is an advocate.

She said the reporting requirements were too cumbersome. She was concerned families were 'going underground' to avoid reporting the use of restrictive practices on a person with disability.

She said many of the issues with the overuse of restrictive practices were connected to the disability sector's inability to cater to the needs of clients with complex support needs.

Lillian said:

'It's really hard to actually engage providers to work with people who ...they're kind of going, "Actually, it's too hard, and it's not cost effective."'

She said the inability of the system to deal with people with complex support needs pushed many families into extreme situations. Families try to muddle through on their own, self-managing, but if something goes wrong, they end up with their child under state care. If the family or participant are seen to be troublemakers, the family bounces from one service provider to another.

Part of the danger, Lillian said, was that disability services operated by state and territory governments used to be the 'provider of last resort' for families in crisis, but, under the NDIS model, the last resort had become hospital emergency departments.

She said:

'But there's only a few [hospital] beds and they're meant to be transitional until ... accommodation is sourced, but I think people are kind of getting stuck. And it's a thin market of people who are actually qualified to do this kind of work with support workers and behaviour support practitioners.'

Sophie, an advocate, said:

'My understanding has always been that you have to try every single other thing first and then, worst case scenario, everything failing, you can use this restrictive practice until we find something better. But if people are only funded once a year for one load of intervention for positive behaviour supports, there's no way that's going to happen.'

Hannah is an advocate.

She said there was an urgent need to set a nationally consistent framework governing the use of restrictive practices.

'Principles need to be debated and set,' she said. 'For instance, at what age can you lock up a child in an adult setting? It's easier to get a restrictive practice put in place than it is to get the resources that can be dedicated to work out and put appropriate supports in place [to deal with the underlying issues that are driving extreme behaviours].'

Hannah was also concerned that some states, such as Tasmania, did not have enough protections, such as community visitor programs, in place to protect people with disability from abuses.

Vicky is an advocate.

She said:

'Positive behaviour support ... that's the best way to reduce and eliminate restrictive practices. As far as what groups are vulnerable, I would say in my experience where there is two or three people that live in the same [group] home ... and it wasn't their choice, inevitably restrictive practices are brought into the home to make it easier for the staff. ... People with intellectual disabilities are particularly vulnerable to restrictive practices.'

To illustrate the vulnerability of people with intellectual disabilities, Vicky spoke of the recent case of a man who was, she said, left to die in an aged care facility. The man, who had an intellectual disability and self-harmed, had spent his life in State-run group homes. At the age of 64, he was moved to residential aged care. In the aged care facility, he was drugged and locked in his room because 'they were so short staffed'.

Vicky said:

'There's always a reason for behaviour – always a reason for behaviour. You take away triggers. Give someone a really good quality of life where they are happy in their life and you're just reducing the risk of them to display any harmful behaviours. ... It's best practice around the globe, and if you do it well, it works.'

Donald is an advocate.

He said a new trend was emerging:

'There seem to be more psychologists now or psychiatrists who are being called on to diagnose or to assess behaviours of concern and they're prepared to call it – particularly for people with autism – categorize that as a mental health issue rather than a behavioural issue. And once you go into that model then they avoid the same sorts of safeguards that are there through the senior practitioner. ... So, this use of medications to deal with behaviour is just a complete reversal of everything we fought for the last 30 years and I can just see it's going to lead to more people just being put back in those corners and medicated out of their heads. That's the other reason why we need a NDIS Commission with independent statutory power and with the resources to actually ensure that the workforce is trying to actually implement behaviour plans ... and actually teach people to support people within those plans. ...

'Whoever has the power to apply the label that describes who they are and what they are. Whoever has got the power to apply that lens, very quickly becomes an empire, and there's all these vested interests that all fall in behind it. And the person who is the subject of it's got no power at all. We see this deconstructing – this dedifferentiation – of disability. And people might think, "Yeah, that's good because we're all human beings, et cetera." But what it really does, that

plays into the bean counters' hands, who just say, "We don't need to do specialist things. Everybody can just be treated the same." ...

'The cohort that comes to my mind immediately is people with intellectual disability and autism. And the reason that they are so susceptible ...is they can really challenge people's skills. They can challenge routines. And any response to something that's annoying is to try and shut it up or to put it down. And so, when people were back in the institutions, it was easy; you just threw a cup full of meds into them. Or you'd do what they used to do at Mayday Hills and you just throw all their medications into their meals. No individual medications — they were all on the same things — and chuck it into this big pig bowl and just dish it out. It was like something out of *One Flew Over the Cuckoo's Nest*. That's what it was. When people were in institutions, that's exactly what happened. My early experiences of going into institutions and trying to support or help people who are just sitting in corners, rocking back and forth, rocking back and forth — out of their brains, basically.'

Case Study: A life in shackles

This is the story of a man in his 30s.

Adam has been in the disability system since he was a child.

His advocate, Clare, said he was the victim of the worst restrictive practices she had seen. The biography of Adam is what Clare calls 'folklore' because disability files are archived every 12 months. As a consequence, the official story of what happened during his childhood and early adulthood is buried.

Clare said:

'What I've been told is – by staff who've known him for a really long time – is that he was sent away to a residential school as a child and they had him chained to the floor. They put bolts in the floor to chain him to. ... He landed in one of Victoria's disability institutions as a young person and what I've heard is that he was restrained with in handcuffs for up to 23 hours a day, and that those restraints have caused his shoulder cuffs to basically rust downwards, which has also made him hyper anxious — because he's been subjected to many takedowns by staff — and his response to the world now is hyper vigilance. And, if in any way made anxious, hyper violent.'

Adam lives alone in a secure unit. He has one service provider: 24 hours a day, 7 days a week.

'I went into his home,' Clare said. 'It is not a place you would want to live, someplace anyone would want to live. It's dilapidated, it's depressing. He's been there a long time, and it's overlooked by the institution that he previously lived in. ... He is captive.'

Since 2016, Clare has advocated for the NDIS to include a goal in Adam's plan 'to explore housing options' so that he at least has the opportunity to have some choices about where he would like to live.

Clare said:

'And because I don't have a formal role and because the NDIS doesn't recognise advocates anywhere on their system as having any legitimate role — we do not exist in their system as an entity at all — I have no possible way of contesting that a goal should have gone in the plan because what right do I have to say that he should have the chance to consider other options. And my question is: what right does anyone else have to say that he should not?

'The weight at the moment leans in the favour of keeping things how they are because anything else would be a decision, and that's how people's rights become meaningless. He has a right to look for other options, but I could not get a goal in the plan. Not in the first or second [NDIS] plan could I get that housing goal in there even though I specifically asked and everyone at the meeting agreed that it should happen. And in the third plan I said to the planner, "You will be putting a goal in there that says that he is going to be looking around." And she said, "I think that we would need a guardian for that." And I said, "It's not a decision to have options put in front of you."

'I also asked for independent support for decision making, I asked for the funding of an independent facilitator from a registered NDIS service provider to develop a circle of support

made up of volunteers who would be willing to start exploring what his will and preferences look like within a framework — within a proper framework. “No.” “Why not? Why not?” “Because it’s a duplication of supports.” “How is it a duplication of supports?” “Because we funded support coordination.” I said, “The support coordinator would have a conflict of interest if they were facilitating the decision-making circle, don’t you think?” A support coordinator is supposed to take the person’s direction. And she said, “Well, then he needs a guardian.” And they will not fund independent support for decision-making. And I have asked for multiple [NDIS] participants who have no family, maybe one provider, maybe a day program and one provider; no one else to advocate for them and literally, absolutely zero capacity to find their way out of these systems. Zero capacity to find their way out ... and I cannot get the NDIA to fund support for decision making.’

Adam’s latest NDIS plan includes the option to explore other housing options but support for decision-making was denied. He still lives in the shadow of the institution where he was restrained for up to 23 hours a day.

‘It’s an extreme example,’ Clare said, ‘but everything springs from there.’

Employment

People with intellectual disability were concerned about employment. Many saw a connection between their poor education their limited options in the economy. All believed that more needed to be done to secure open employment for people with intellectual disability. All believed that people with disability were chronically underpaid because of the instruments such as the Business Services Wage Assessment Tool. All wanted Australian Disability Enterprises (ADEs) reformed.

People with intellectual disability have nuanced views on ADEs or sheltered workshops.

Ted is 56.

He said ADEs should be reformed rather than shutdown — and focus on helping people with intellectual disability transition to open employment by operating more like TAFEs and certifying clients for employable skills.

Ted completed a six-month TAFE course over two years. He said: ‘Every person can pass most things; they just need to be given more time.’

Ted also wants people with intellectual disability to be paid at least the minimum wage.

He lives independently, drives a car and has worked at an ADE for many years. A decade ago, a new manager decided to reassess Ted’s work capacity and cut his wages by \$10 an hour.

Ted felt trapped: ‘The other people were getting normal wages and there’s things that they can’t do that I can do. ... If I did not agree with it, I would have lost my job, so it was pretty rough.’

The manager who cut Ted’s pay has since left, but he has continued to work for the reduced wage. ‘I can never get back up,’ he said.

People with intellectual disability said they wanted more opportunities to break into open employment — and more support to move to other jobs once they gained open employment.

Nick is 32.

He said he wanted mainstream employment opportunities ‘cracked open’ for people with disabilities — and believed that forums should be held to promote the benefits of employing people with intellectual disability. ‘I think we need to put a big investment into getting people with disabilities into the workforce and into proper paid jobs,’ he said.

Nick said working outside the confines of an ADE or day program had made him independent: ‘It gives me a lot of freedom to do what I need to do.’

The underpayment of people working in ADEs also concerned Nick.

He said:

'The award wages, I think that, you know, it needs to be a big issue around people with disabilities getting proper wages because what they receive now is absolutely ridiculous. They don't get a fair go. ... It's not right. This is Australia. It's not fair.'

Calum, 22, wanted to train as a cabinet maker, but wasn't able to access pre-apprenticeship classes in his special school. He tried to catch up in TAFE, but, without support, fell further behind and dropped out. He made food deliveries on his electric bike for an online platform until they discovered he didn't drive a car and sacked him.

Calum said:

'They need to change the system because ... we can still work normal. We're different, but we still got the capacity to be working like other people.'

Penny is in her late 30s and works in open employment.

She said people with disability could only access an employment agency if they worked more than eight hours a week.

Penny works less than eight hours a week, but is having problems at work and, without alternative employment, does not feel she can afford to raise the issue with her employer.

She explained: 'It's not as easy to change [a job] ... because it's hard to get past the interview stage.'

Family members said it was extremely difficult for their relatives with disability to find work.

Jane said her adult daughter, Ava, who lives at home, had spent three years of work trials in an ADE, packing cutlery, but was not offered ongoing employment after leaving school. Jane has now helped Ava start a micro-enterprise.

Wendy's daughter, Kate, who is in her 20s, does not have a job.

'She'd love a job. But we haven't been able to [find one],' Wendy said.

Wendy said Kate spent four days a week in a day program:

'If she didn't have that ... She doesn't really have any other interests. She's got no friends, ... she did have one really good friend ... but the girl died about a year after she started going to high school because of a heart condition and, you know, that's actually quite a common occurrence for children with a disability, that their friends die because they are not necessarily well. Not many other kids have to deal with that.'

Advocates reported that most ADEs failed to teach people with intellectual disability the skills they needed to transition to open employment.

Stephen cited a South Australian review of day programs that was funded with three aims: give participants new skills; let participants meet new people; move participants towards employment.

He said:

'There was no requirement from the [government] department that funded these organisations for them to report on what was happening for their clients. And in that environment, basically, what happens is that whatever you do is good enough. Who cares? As long as you don't get beaten, raped, or have your money stolen, that's all that matters. Again, a pretty low floor of involvement. ... I haven't seen much evidence that it's better anywhere else.'

Vicky said ADEs were 'just segregation'

She said:

'I supported a man with Cerebral palsy. He had some issues with speech and was in a wheelchair and had a poor education because he went to special school ... but he had a lot of capacity.'

Vicky said that when her client went to a disability employment agency, they referred him straight to an ADE. She went to the agency and complained, demanding that they find job placements in open employment.

'Over the next six months, he had a range of job placements, including Bunnings,' she said. 'Then he did another job placement at an early learning centre. That led to a job. He's now been there for six years, and he's a very valued employee.'

Amy is an advocate. She said there was a need for cultural change to pave the way for employment.

She said:

'It's a genuine surprise to most people that someone with intellectual disability could have not just a job, but a career and have different jobs. ... It's not even discrimination, necessarily. It's just total lack of awareness that that's a possibility.'

'I think there are [ADE] places from what I hear that do a better job than others. And, so, probably like any of these issues it's about acknowledging the fact that we don't have great options for people with intellectual disability in pretty much any area of life. And, so, it's not about throwing everything out and starting everything from scratch, because that's never going to happen and it would be problematic anyway, but ... you must have a sense of the future and you must have a sense of: how do you get there ... in disability enterprises and other employment.'

'If you want people to be included in the workplace then what are the concrete steps that you're going to take to make sure that that happens? And not just kind of hide behind the way that

things have always been. And if you really feel that things are worth hanging onto, then you have to have some kind of measurement for it. ... With a disability enterprise, like, what are they doing that's so great? How are you measuring that?'

Case Study: The not-so-sheltered workshop

This is the story of a sheltered workshop.

Most but not all Australian Disability Enterprises or ADEs—the rebranded names of sheltered workshops—are charities.

Some are businesses.

Advocates became involved with one ADE that wanted to sell its business to a mainstream employer. That meant all of the employees with disability had to either move to another branch of the ADE or remain there and transition to open employment.

‘We were brought in to work with each of the employees to decide whether they wanted to stay and move to another ADE or stay at this business and move into mainstream employment,’ said Kelly, an advocate.

‘But what it meant for that [mainstream] employer was they couldn’t pay them \$3-an-hour and even less in some instances. They actually had to pay the award wage. So, they all had to be assessed. ... [Assessing the capacity of the employees] just highlighted how discriminatory that existing process was because these people were assessed on the job that they were doing and every one of them came out much higher than they were being paid. ... There were six people who were earning \$7-an-hour assessed as being able to work at 100 per cent capacity.’

Is that workplace typical of ADEs?

Kelly: ‘Yes.’

How many employees were in that workplace?

Kelly: ‘35.’

And six of the 35 were 100 per cent. What proportion were being paid less than their capacity?

Kelly: ‘Ninety-nine per cent. They were highly skilled. Some of them had forklift licences. Some of them had warehousing certificates. They were actually doing the work. One of the forklift drivers was being paid less than \$10-an-hour.’

The advocate said:

‘We need a national disability employment strategy. ... There needs to be a transition away from segregated employment. ADEs were actually supposed to be a transition for people into mainstream employment, proper employment, but that never happened. ... Once they’re in there it’s a life sentence.’

In 1985, the Hawke Government released *New Directions: Report of the Handicapped Programs Review* – a policy document committing the Commonwealth to phasing out sheltered workshops and transitioning people with disability into open employment.

Nothing happened.

Rights and attitudes

People with intellectual disability interviewed felt confident talking about their human rights – reflecting the fact that they were self-advocates directly involved with the work of IA. However, they believed that many other people with intellectual disability were not aware of their rights. They were concerned that lack of awareness put other people with intellectual disability at risk. All reported being routinely ignored and harassed in the community.

Wayne is in his 50s.

He said: 'We need to look at how people treat us ... They need to ask us what we want. Instead of telling us, ask us. Some people don't do that. ... They always talk to the person next to you. That's rude.'

Luke is in his 30s.

He said his rights were 'very well respected'. However, he said that he only felt '70 per cent or 80 per cent safe' when he was in the community.

Luke said:

'Whenever I go outside in the community, I always wear sunglasses so I can blend in a little bit and that makes me feel a lot safer when I'm out. The only time when I don't feel safe is when I take the train. On my way home during the pandemic the trains are always empty, and I always like to be in a packed carriage so I feel safer but when I'm in a train with not many people I keep an eye out ... in case someone comes up.'

Tim said he was 'really reluctant' to trust people.

He said:

'I've had to work [for my rights]. ... There has been a lot of obstacles to get over to get to the point I'm at now. ... You have to, like, prove you're capable in some senses. ... If you automatically have a label on your saying you've got a disability of any kind, you have to prove that you're capable to fit into the community.'

Calum said he had been recently 'hassled' by a bus driver who accused him of not tagging on with his travel pass and said she didn't like driving 'people like you'. He said: 'I don't like [public transport] because ... it's not safe for people with disabilities.'

Calum made an official complaint to the bus company.

He said he only began to understand his rights after leaving foster care at the age of 18. 'The simple fact is that we seem to be left out of our rights. We're not told what they really are,' he said.

An incident underlines Calum's point.

At 17, Calum was told he had to go to court. The court hearing was to appoint a guardian, but that was not explained to Calum.

He said:

'They just told me to go to court. ... I'd never been to court before, so I was scared of going in there. I thought I did something wrong. That's the only reason I thought I was going into court. I thought I did something really bad.'

It was only after turning 18 that Calum understood his life was controlled by a guardian. He worked, but didn't have control of his own money, couldn't travel interstate to visit his family, wasn't allowed to buy new shoes and wasn't able to see his friends when he wanted. 'It was like being a kid,' he said. 'It was making me feel bad. Feel depressed. I felt really down.'

With the support of advocates, Calum won his independence from his guardian.

He now works and lives independently.

'I get to choose,' he said. 'I just want to live an average, normal life. ... Just being like a human being.'

Eileen said people with disabilities were targeted by online scammers on social media platforms such as Facebook.

She said:

'People manipulate you to try and get money out of you. Or if you've done a will to try and get your will. So, it's all dangerous.'

Penny believed that the NDIS has changed service providers' attitudes to people with intellectual disability.

'It seems to me more on the dollar value ... rather than promoting choice and control,' she said.

With the transition to the NDIS, Penny found that her service provider gave her less of a say about the support workers she let into her house. In the end, she fired the service provider and now uses her NDIS package to directly employ her own support workers.

Penny said many people with intellectual disability did not have choice and control and were 'a little bit railroaded' by service providers.

'You've got to be able to yell,' she said. 'That's why advocacy is important. ... They stand beside the person with a disability while they speak up for themselves. ... Independence is the most important thing.'

Martin used to work in disability services. He now has a disability and does not work. He spent two years as a client of a service provider, but now directly employs his own support staff.

Martin said:

'I found the more I wanted independent choice the less they [the service provider] wanted to negotiate. ... They like doing things with a minimum of staff supervision. ... A lot of the support workers I had been sent by this organisation I have actually had to mentor. They'd be lucky to have Cert 3 [qualification]. ... They are virtually unskilled.'

Martin said his experience made him worry about people with intellectual disability who couldn't navigate the service system:

'I've got a reasonable amount of knowledge under my belt and they were sending me people that were all but untrained. How do these people that have intellectual impairment, that don't have access to an advocate [cope]?''

Family members said that, although people with disabilities had theoretical rights, they were often practically powerless.

Angela, a disability worker who advocates for a relative, said:

'Some families and a lot of organisations take away a lot of the rights of people with a disability, which I've found working in the sector as well as having a family member with a disability. ... People with a disability should be training people, like support workers or people in the sector, about how [they want] to be treated. It should be everywhere, you know, within the NDIA; everywhere.'

Jane, whose adult daughter, Ava, has a disability, said:

'There's assumed rights for everyone but there's perceived modified rights for people with intellectual or physical disability, where people think, "Maybe they don't need all those rights," or "Maybe they don't have the same capacity to take on the responsibility those rights give them." There should be modifications to allow everyone to have those same rights.'

Jane said that people were more likely to build a ramp so that a person in a wheelchair could access a building than explain human rights in Easy Read to people with intellectual disabilities.

She said:

'People can come to understand that a person in a wheelchair is still a full person, but as soon as they see the shape of eyes of someone [such as a person with Down syndrome] in a supermarket

they make a quantum leap about how they're going to interact with that person based on nothing but the shape of their eyes.'

Jane said society should assume the competence of people with intellectual disability:

'It all comes down to scaffolding. If you didn't speak, if English wasn't your first language but your input was valued, I would find a way for you to understand what I want and what you can give. ... I would find an interpreter. ... But people don't afford the same cognisance to people with an intellectual disability, who would have the same capacity to give information if they had "interpretation". ... It all goes back to assumed competence.'

Advocates in every jurisdiction were concerned about the rights of people with intellectual disability. All agreed that — legally speaking — people with intellectual disability had the same human rights as any other member of the community. All agreed that — practically speaking — those human rights are either ignored or assumed to not apply to people with intellectual disability. All agreed that there was an urgent need for independent oversight through initiatives like community visitor programs — which have been run down or abandoned by most jurisdictions. The horrifying death of Adelaide woman Ann Marie Smith in April 2020 amplified advocate concerns. Another disturbing finding was that almost every jurisdiction reported cases of child protection taking the children of parents with disabilities without cause.

Kelly has advocated for the rights of parents with disabilities for 20 years.

'There's an absolute overrepresentation of parents with intellectual disability in child protection cases,' she said. 'It's clearly discrimination. Parents are scrutinised far more than any other parents because of their intellectual disability. There's very little belief [by child protection] that they can learn skills to parent their children.'

'There needs to be a human rights framework put over the top of it ... from the perspective of the [UN] Convention, you know, the right to family and the right to parent. The court process is very unfair to these parents because there's a huge imbalance of power. ...'

'If you've got a parent with an intellectual disability who's about to have a baby there's — even in the NDIS — ... a real battle to get funding for that parent to develop the skills as a parent. They don't see that as within the scope of the NDIS. ... Research shows that people with intellectual disability can learn parenting skills, but they need to learn in the environment where they will be parenting — in other words, their homes.'

'They're right against it from the start because the child gets taken away and they ... have access to that child for maybe an hour a week. And, so, how can they develop the skills within that timeframe to demonstrate that they can be capable parents? It's just this great big vicious circle. ... Once the child is taken away it is absolutely, really impossible to get the child back and for there to be any meaningful opportunity for them to develop the skills.'

In 20 years of practice Kelly said she was only aware of three cases when a parent with a disability recovered their children from child protection.

One of the three cases where a parent recovered their children is illustrative because it was caused by two branches of the same government department.

In this case, a mother with a disability had her twins taken into state care as infants. When the twins turned 16, the long-term case management branch of child protection wanted the mother to take them back to live with her and their 2-year-old sibling. The 16-year-old twins started living with the mother and began expressing an interest in sex. The mother became concerned that her 2-year-old child might be abused by one of the 16-year-old twins.

The second branch of child protection, dealing with short-term intervention, and threatened to take the 2-year-old into care for protection. In response, the mother started sleeping in her car with the 2-year-old to protect the toddler from the teenagers. Despite the fact that the 2-year-old had been placed at risk because child protection insisted that the mother take her 16-year-old children back, child protection intervened and took the toddler.

With help from advocates, the mother won her child back.

Kelly said that, while child protection did not hesitate to take a child from a parent with a disability, they were often reluctant to support a child with complex support needs, citing a case where the Department refused to support a neglected, at-risk child despite strong lobbying from advocates and the child's school. 'I firmly believe that if that child didn't have such complex support needs and she didn't have a disability that she would have been removed immediately,' she said.

Another advocate, Natalie, said:

'We are having a lot of cases coming through of very poor practice in child protection, very poor understanding of intellectual disability and enormous discrimination without having an understanding of what discrimination looks like. It's the same in the criminal justice system. These are inherently oppressive systems based on blaming people for their behaviour.

Natalie said the taking of children from parents with intellectual disability was not just an Australian issue. It was a global issue, she said:

'Intellectual disability and impaired cognition are inherently seen as a risk factor, which in itself is incredibly discriminatory because it's not about the person's skills to parent. It's about linking cognition to parenting. ... Parenting is not rocket science. It's a set of skills that you can learn. ... We know what the research tells us about attachment and trauma for children — of being removed from parents — and, so, instead of providing support for parenting we have this really bizarre system where we just take the children away and traumatize them. That's also incredibly discriminatory, that we're not pumping in support for parents with a disability to be able to parent.'

Natalie knew of at least one case where the trauma was multigenerational. In that case, three generations of a family with intellectual disabilities — a grandmother, daughter and grandchild — had been taken into state care. The grandmother and mother had both been in foster care. The cycle of abuse was completed when the grandchild was taken by child protection and placed in

the care of her great-grandparents — because the grandmother had originally been abused by the great-grandfather.

The advocate said the grandchild, who has autism, was taken for the wrong reason:

‘One of the things that we found that was really difficult to overcome was there were all these reports about injuries to one of the children and that they just assumed it was abuse and yet the mother and the grandmother were saying, “We don’t understand it. He just hurts himself all the time.” ... What child protection hadn’t taken into account was the fact that children with autism can have difficulty with spatial perception and also a higher pain threshold.’

Lisa said the impact of child protection policies to take the children of people with disabilities was ‘devastating’.

She gave two examples of child protection actions.

In the first case, the mother was a woman with a disability who had been abused as a child by her father, removed from her parent and placed in care, then abused in care and returned to her parents. In 2017, the mother, now in her early 20s, had her first child taken by child protection because she had an intellectual disability and had been in care.

Lisa said:

‘The poor woman is then having to give her child up to go into the exact same system that she encountered abuse in. That is incredibly traumatising. ... Her second child was taken at birth. She had been told she would have five days, but they [child protection] reneged and took the child at birth.

‘Once a child is placed into care a mother has to prove that she has capacity as a parent, but it’s incredibly hard to prove your capacity as a parent if you’ve never been a parent. ... Many of them [parents with a disability] will fail the test because they have no idea [about how to parent]. So, then they have supervision orders put in place so they can maintain some contact, but they’re all supervised visits and you’re trying to help them develop a bond with their baby, but they’re in a very fragmented situation.

In the second case, another mother with a disability had two children in two different foster homes. The mother was determined to visit her children twice a week. As a consequence, she was spending four days a week travelling on public transport to see her taken children.

‘It’s devastating. It’s really shocking,’ Lisa said.

Brian said community attitudes towards people with disability had improved since the 1980s, but there was an urgent need for widespread, systemic reform.

He said:

'We're still in a situation where most states have got guardianship legislation which is in ... various states of antiquity, and you know it's not for want of law reform reports sort of guiding the way forward. We're still in a situation where ... this whole notion of supported decision making is seen as a bit weird in relation to people who are perceived as inherently lacking capacity. And you know the paternalistic approach ... is still one that resonates very strongly with politicians and bureaucrats.'

Brian said reforms should be guided by a commitment to self-determination:

'Self-determination is about treating a person the way they want to be treated rather than treating them how you would want to be treated. It's about taking the time and effort to get to know and understand the individual.'

Without a systemic commitment to self-determination, he said, bodies such as guardianship tribunals were 'not listening sufficiently to the person with disability' and 'taking a paternalistic approach'.

On the positive side, he was adamant that community attitudes had improved:

'People with intellectual disability are much more visible and part of their communities. And I think that's led to a change in community attitudes. And when I think about the revolting scare campaigns that were waged in the '80s, in relation to people moving from institutions into group homes and how easily local communities were stirred up into seeing these as dangerous "other" revolting people. ... a scare campaign in New South Wales ... was about "these people, they shit all the time and so they're going to overload the sewerage system." ... That was pushed by the institutional staff.

'I'm not defeatist at all about changing attitudes. I think that community attitudes have changed positively, but we've still got a long way to go.'

Another advocate, Donald, said:

"People don't really think deeply enough about what it [self-determination] really means. They think it's about simply about giving a person a choice between two or three options — do you want tea or coffee? and at what time of day? — ... when it's something much more fundamental. ... There is this real question of: Are people able to assert their will and take control of their own decision making and their own life? And that only comes, that self-determination light only shines, when there's these other things going on in that person's life. The endorsement ... that they are a valued, equal human being. When people are listening to them when they express themselves ... and not just patting them on their head. ... For people with disability it's been this disempowerment cycle.'

He said that advocacy was a 'critical driver' of self-determination:

Advocacy at its most powerful understands that it is there to empower the person to speak up to assert their rights, but every moment it stays in front of the person it runs the risk of disempowering that person. And so this is a subtle, nuanced process, the empowerment process of the advocate being prepared to stand up in front and defend and protect people who are not

able to protect themselves...and then ultimately standing behind and supporting that person to grow.'

'And when I say advocacy... it's not as effective having self-advocacy without advocacy and vice versa. Advocacy that purely stands in front of people and represents them I'm very suspicious of because of the power of that representative role.'

Numerous advocates expressed concern about the lack of advocacy and self-advocacy groups in South Australia. The South Australian Government defunded disability advocacy in the mid-2000s.

One advocate, Amanda, said:

'An important point is about the state government kind of wiping their hands of disability now and really saying, "Well, that's NDIS." But there's so many people that aren't covered by NDIS and then organisations like SACID [South Australian Council on Intellectual Disability] and, you know, other kinds of volunteer- or consumer-led organisations who are independent of the NDIS are really important in being a place where people can come to get advice or information that is free of that link to the NDIS.'

Another advocate, Stephen, said:

'What really concerns me is the abuse that occurs basically through acts of omission. The things that don't get done. ... Over the last few years, I've done some consultancies ... looking at day programs where people, you know, they leave their house or their parent's house, and go to some day program. And there are some [day programs] that do really good things ... people are learning things, but there are many where they just sit around and do nothing and families describe it as day custody and, largely, people are not learning skills. ... In my view they're not reaching potentials that they could, and in my view, that's being abused.'

Stephen said that the issue was directly related to bad governance by the boards of service providers:

'This [lack of oversight by CEOs and boards] is endemic in the system. I mean, it's the reason that we're having two Royal Commissions [in aged care and disability services]. There are boards where people, you know, have been on a board for nine years and have never met a person with an intellectual disability. ... With governance generally. You know we're not doing this terribly well in Australia. ...

'It starts with a commitment from the board. Stop believing your bloody publicity. ... Find out what's going on and be committed to fixing it. ... You know the thing that really concerns me is that if we concentrate on, you know, the bashing, the rapings, the stealings, okay, we might suppress them. But if we were to lift the quality of the system to a different level ... they [abuses] are less likely to appear in a population that is more connected and more confident.'

Stephen had worked with providers to create mechanisms to properly measure whether services met the needs of clients. He said it was sometimes difficult, but almost always possible, to create client-focused measurements:

‘These things can then be used as a mechanism for continual improvement. More importantly, they give a message to staff that these are things that we [the provider] are taking seriously and you need to lift your game. ... One of the things that's occurred in our systems that we get an equilibrium of comfort. It's where workers are not having to sort of bust their boiler and where management is not having to nag, you know, give them a hard time and make their lives difficult. ... So, you get this sort of equilibrium of comfort. Where you know nothing bad happens ... but nothing good happens [because] basically no one gives a rats-arse.’

Lillian said that the best way to change community attitudes to people with intellectual disability was to focus on schools.

She said:

‘I think it starts from education. Like, we don't get education right. So, you know, if you've got kids who are segregated from, you know, primary school, then you know other typical kids grow up having never seen another person with a disability or a difference. Then how do we expect anyone to kind of be included? Plus, teachers aren't actually taught how to teach kids with disabilities, so I think it's like a six-month thing, maybe, at university.’

Amy said there was a need for legal reform in every jurisdiction, but no appetite for change from government.

She said:

‘Legal change is a long way off. ... There's just not a lot going on. At the same time as the NDIS Act has all those nice statements about building capacity, and you know all that kind of stuff, but the guardianship system and everything associated with it is out of step with the NDIS.’

Amy said there were limited options for including people with intellectual disability in decision making around their own lives:

‘The state has an obligation not only reform guardianship laws to meet the UN Convention, but also to appreciate that by reforming laws you're also providing some structure, education and guidance for families or services, or anyone interacting with people with intellectual disability, to see them differently.’

Currently, she said, the ‘binary approach’ taken to legal capacity — where people either did or did not have capacity — limited the system’s ability to enable self-determination.

Amy said:

‘The idea of stretching out the idea of capacity and moving more to assessing support versus assessing someone's individual capacity is, I think, really critical to the rest of it ... because then

that leads to adulthood where decisions need to be made. And, of course, not everyone is going to be able to be full decision makers and but, even there, it's important that the focus is still on: How can someone be involved to the greatest extent possible for them in their situation? And how can decisions still be made centrally to that person, even if it's just their likes and dislikes? Even if they're not able to be very clear? ...

'We've signed up to the UN Convention and we put in our excuses for Article 12 [regarding equal recognition before the law], which I completely understand because our guardianship system just is much more advanced than most of the rest of the world. It does a lot of the things that other countries are still aiming for, but it still has that binary presence that I think really shapes a lot of other experiences. So, I think we need legal change and the legal change has to cover ... a concept of support rather than individual capacity.'

Case Study: Frightened of child protection

This is the story of a mother with a disability who gave birth in a private hospital because she was concerned she might lose her baby to child protection services.

Penny is in her late 30s. She has a physical disability. Her husband has an intellectual disability.

The couple have a 3-year-old child who was born in the private health system.

They opted for a private hospital for two reasons.

First, Penny had previously suffered a miscarriage in the public health system — and had numerous problems with doctors in the hospital. ‘They would speak down to you and I don’t think they would treat you that way if you didn’t have a disability,’ she said.

‘I went private the second time around, so we paid a bit more to go see private doctors and I found I got treated better. People would explain things to me properly and would treat me like a normal human being instead of someone with a disability.’

The second reason Penny went private is shocking.

She said she was worried that, if she was in a public hospital, she would be judged by medical professionals as an unfit mother because she had a disability and reported to Child Protection.

‘I was frightened of that [having trouble with child protection]. ... I think if I was in the public system it would have been different, but because I was in the private system there was probably less judgement there because I had the money and the means to pay.’

Emergency planning and response

People with intellectual disability reported that their lives had been detrimentally impacted by COVID-19. They also felt that their rights had been pushed to the margins. Rather than opening up new opportunities for connection and inclusion, many people with intellectual disabilities are finding that the reliance on video conferencing technologies such as Zoom was creating a new barrier to inclusion.

Wayne is in his 50s.

He said the pandemic had isolated him.

Wayne said he found it difficult to use technology for online communications. 'It's very difficult when there's so many people talking at once. It makes it hard for us to be involved,' he said.

As a consequence, Wayne was forced to decline numerous invitations to participate in online forums and conferences.

'I don't like it,' he said.

Penny said that the lives of people with intellectual disability had gone backwards during the pandemic.

She said service providers and support workers had unilaterally denied the rights of people with intellectual disability by not letting them travel or have visitors — going against public health advice.

'Even when people were allowed to travel or see people, the support workers were keeping people with intellectual disability segregated,' she said.

In addition to segregation, Penny said she started seeing new bumper stickers during the pandemic that read: 'I'm a support worker. That's my superpower. What's yours?'

She found those bumper stickers disrespectful.

'It's sort of downgrading to the person with a disability,' Penny said. 'It [COVID] is making them [support workers] more powerful than the client. I think that's something that's coming out of corona[virus]. They were going backwards a bit to being more institutionalised and support agencies were having more control.'

Family members were alarmed by the lack of transparency during COVID-19 lockdowns. Many felt like their relatives with disability were at the mercy of support workers.

Angela advocates for Carly, a 50-year-old relative with a disability who lives in a group home.

During the first wave of the COVID-19, Carly's group home went into lockdown for two months and closed to outside visitors and service providers. During the lockdown news broke of the alleged manslaughter of Adelaide woman Ann-Marie Smith by her support worker.

'I was worried she was at risk,' Angela said. 'She was ringing all the time; she was anxious as hell.'

Normally, Angela, who lives several hours from the group home, would receive telephone calls from Carly once-a-month. During the lockdown, she said Carly called her twice a week – a significant increase in calls that she said suggested a heightened state of anxiety. This worried Angela because she knew that Carly, who is physically frail, lost weight when anxious, but she was unable to see her relative on a video call.

Angela said:

'They didn't even offer to set up Skype or anything. They just put it on the speaker phone and then she had a support worker there all the time, so I couldn't ask any questions about what the support workers were doing. ... I didn't even see her. I couldn't see if she was losing weight.'

Wendy said that, during the COVID-19 lockdown, her adult daughter Kate was left on her own for 48 hours without any support worker.

'The whole thing is that no one takes responsibility if there's not a parent or a family member that's around that's going to be following up and making sure it happens for that person,' she said. 'Look, and you know COVID was terrible because all [she] did was sit in her room and watch TV or be on her iPad for two months.'

Advocates said the national response to the COVID-19 pandemic was revealing. It revealed that the health and wellbeing of people with disability was often an afterthought. It revealed that there is an urgent need for strong, proactive oversight of the care of people with intellectual disability, particularly residents of group homes or in the care of a single service provider. And it revealed that – contrary to claims that reform takes time – the system was able to change practices and policies quickly.

Brian said:

'My biggest fear remains, what's happening due to lockdown in supported accommodation? You know, whether there's a whole lot of unacknowledged, unreported violence occurring because people are just really frustrated. ... We've had lots of reports of service providers taking very inflexible approaches to things like whether there should be any visitors and very inflexible approaches as to whether people should be, you know, getting out on community access. ...

'What we've constantly been advocating is that support providers need to be taking a balanced individual approach ... rather than you know what I think has been happening too often, you know, just head office at the service provider saying, "Right, group homes are locked down. No visitors. No outings," or whatever. ... That sort of suppression of people's rights and normal lives ... should happen in a balanced way.'

During the first lockdown, the Speak Out Association of Tasmania became alarmed at the lack of accessible information for people with intellectual disabilities.

Speak Out started a live feed on its Facebook page at 5.30PM every night, interpreting the latest information and rules for people with disabilities, as well as answering questions. Seemingly overnight, the number of active users on Speak Out's Facebook page increased by more than 1,000 per cent.

One advocate, said:

'We also found that the public health hotline had no idea about the disability sector and how it ran.'

Speak Out contacted the State Government to offer advice. For instance, the Government changed its language because Speak Out told it that words like 'lockdown' and 'social distance' were often misunderstood and frightened people with *intellectual* disability.

Belatedly, Speak Out was granted \$15,000 to fund its COVID-19 Facebook live feed. The live feed gave the advocates additional insight into how the pandemic was impacting people with disabilities.

The advocate said:

'People who lived independently but received some in-home support, they became institutionalised because their providers were saying no. ... One of them said, "We can't come and get you and take you to the supermarket. You'll have to walk to the supermarket and the support worker will meet you there.'"

The person with a disability had a significant vision impairment and could not walk to the shops unaided.

The advocate said:

'She became more institutionalised because she had no way of getting out. ... There were a whole heap of standards that were applied to people with disability that weren't applied to the rest of the community. ... The public health regulations were saying one thing and yet the providers were imposing aged-care standards on group homes ... It just made people far more vulnerable.'

During the first wave of the COVID-19, a 30-year-old woman with a disability called Abbey contacted Speak Out.

Abbey was terrified. She had been told by a family member that she was not allowed to leave her house because of the pandemic and that she would receive a \$16,000 fine if she did leave her house.

Abbey told Speak Out that she thought she could leave her house. The reason she thought she was allowed to leave her house was that Speak Out had been streaming live updates on its Facebook page every night, interpreting the latest COVID-19 information and rules for people with intellectual disabilities.

Speak Out told Abbey she was right. Advocates then took Abbey to a local police station. At the station, a police officer told Abbey she could go to the supermarket and have two visitors to her house. He then warned her that some police interpreted the pandemic rules differently.

‘She was still terrified,’ a Speak Out advocate said.

Two days later, Abbey had a reason to be terrified.

A woman identifying herself as a police detective called Abbey and told her she was not allowed to leave her home. The detective told Abbey the police were watching her and could arrest her if they wanted.

When Speak Out heard of the phone call, the issue was raised with the Anti-Discrimination Commissioner, Equal Opportunity Tasmania. In the end, a senior police officer came to Abbey’s house and explained that she was right, and no one wanted to arrest her, and that some police were over-zealous.

Speak Out said Abbey still had not recovered from ‘this trauma that they put her through.’

The police detective who made the threatening phone call has never been identified.

Another advocate, Lillian, said:

‘Interestingly, they [the NDIA] could respond and change things quickly — couldn’t they? — to respond to COVID[-19], so it’s like, okay, so you could put, like, a blanket thing out saying everybody can get an iPad if you don’t have one for tele-health or video conferencing. ... There are ways that they can actually make, you know, changes — even, you know, sending people a draft of their [NDIS] plan before actually signing off on it. ... [Or] having some accommodation, some dwellings for want of a better word, just for transitional [stays] so, you know, this person is in crisis. ... But there just isn’t.’

Case Study: From lockdown to homeless

This is the story of how the coronavirus-related hard lockdown of a public housing tower in Melbourne forced a young woman with an intellectual disability to be physically restrained by police, made an involuntary patient at a hospital, become briefly homeless and reliant on charity to survive.

Celine is 25. She has an intellectual disability and mental health issues and lives in a public housing tower in Flemington.

Celine is a participant in the NDIS, receiving more than 40-hours support a week for disability and mental-health related needs.

On Saturday, 4 July 2020, the Victorian Government announced the immediate lockdown of her public housing tower. Many tower residents — including Celine — did not know of the lockdown until Victoria Police arrived to secure the perimeter. Celine, who has had negative interactions with the justice system, became extremely distressed when she saw the police.

By Saturday night, Celine had suicidal thoughts. Her support worker spoke to Celine on the phone and became concerned that she might attempt to overdose on her medication. Over the weekend, the support worker received conflicting advice from Victoria Police — receiving police advice via telephone that no-one could enter the tower and receiving police requests from Victoria Police members at the scene to enter the tower and confiscate Celine's medication. The support worker told Victoria Police that they should call a Crisis Assessment and Treatment Team (CATT). In the end, Celine remained alone in her apartment on Saturday and Sunday. During this time, she received minimal help from her support coordinator, but around-the-clock phone assistance from her disability support provider.

On Monday, Celine called VALID asking for advocacy support. She also called the State Member for Melbourne, Ellen Sandell and Triple-0. By this time, Celine was running out of food, medication, cigarettes and pet food for her cat. She was also making threats to harm herself and others with a knife, gun or needle. VALID advocated for a physical wellbeing check and wrote a briefing email for Ms Sandell, which was forwarded to the office of the Victorian Premier, Daniel Andrews.

At lunchtime Monday, Celine called VALID and said she had taken her pills. 'She sounded sleepy and groggy over the phone,' a VALID advocate said.

At 3.30PM Monday, Celine was permitted to leave the building. VALID called Flemington police station and requested that Celine be met by a mental health worker when she exited the elevator because she was scared of Victoria Police.

Celine was met by Victoria Police when she exited the elevator and became extremely agitated. Several members of Victoria Police tied her to a gurney with straps and she was taken to the Royal Melbourne Hospital (RMH) as an involuntary psychiatric patient. 'She was very traumatised because the police had to manhandle her,' the VALID advocate said.

At the RMH, a psychiatrist assessed Celine and reassigned her as a voluntary patient. At VALID's request, the Office of the Public Advocate (OPA) intervened — asking the hospital to keep Celine as a patient until VALID could organise alternative accommodation through the NDIS the following day.

On Monday night, the RMH's head doctor agreed to OPA's request, but after a staff shift change the hospital discharged Celine at 7AM Tuesday morning. That meant Celine was effectively homeless, without food, money, medication or a change of clothes.

Celine walked the streets, then caught a train to St Albans, spending the day with a friend who is a known user of crystal methamphetamine (or ice). Celine was concerned that Victoria Police were following her; VALID was concerned she might use ice.

By Tuesday lunchtime, the advocate had arranged for the NDIS to approve funding for alternative accommodation and a serviced apartment was rented in Maribyrnong.

Celine's friend drove her to the serviced apartment on Tuesday afternoon. By this time, she had not had her medication since Sunday. She was unable to access crisis payments from Centrelink or the Victorian Government for two weeks. During those two weeks, she relied on charity vouchers from Ozanam House and the St Vincent de Paul Society for food and clothes.

On the Thursday, Celine went to a Centrelink office with a support worker to ask for a crisis payment but was ejected from the office and banned for six months because Centrelink erroneously believed she should still be in the tower lockdown in Flemington. 'They didn't give her a chance to explain,' the VALID advocate said.

Celine stayed in the serviced apartment for three weeks, then returned to her Flemington flat.

The case of Celine underlines the complexity of the systems navigated by people with disabilities. Celine has an intellectual disability, but — to reach a place of safety — had to juggle relations with a wide range of people and organisations, including two service providers, the Department of Health and Human Services, Victoria Police, the OPA, Ozanam House, the St Vincent de Paul Society, Centrelink, a State Member of Parliament, the RMH and the NDIS. Many of those organisations have limited understanding of the needs of people with intellectual disability.

As no single Government agency took charge of the situation, Celine was forced to navigate this complex, multilayered system with the support of VALID.

Celine is now looking for a new support coordinator and is pursuing complaints against Victoria Police through the Ombudsman and to the Victorian Equal Opportunity and Human Rights Commission.

Criminal justice system

Families said people with intellectual disability often didn't understand how the justice system worked or what was criminal conduct.

Wendy said her adult daughter, Kate, had poor impulse control and no understanding of the consequences of her actions:

'She takes people's credit cards where she can get them and uses them to buy all the [smart phone] apps and things that she can. ... She's done it to my sister. She's done it to me. She's run up thousands of dollars in, you know, charges and I suspect she's done it to other people as well. No one has ever made a complaint to the police about it, but if there was a complaint made to the police about it, then I have been told by the police that there would be likely to charge her. And the problem with that is that she does know at some level that it's wrong to do that, and obviously she's smart enough to go and do it, but at the same time she is no understanding of the consequences of that action and what illegal is. ... She has very poor impulse control.'

Wendy said Kate found some laws difficult to comprehend:

'She was talking to another young boy and was sharing quite a lot of pornographic material. ... That boy then started sharing pictures of young girls with her. The difficulty in explaining to her that that was illegal to go and do that — it was a real challenge. ... At first, we tried the gentle approach of talking about it and then — see, this is the thing. You get to the stage where you get so frustrated and you say, "If you don't stop doing this we'll have to go to police about it or will have to go and speak to the boy's parents."'

Advocates said that people with intellectual disability were often at the mercy of the justice system — their complaints ignored if they were the victims of crime, their rights often not understood and therefore inaccessible if they were accused of a crime.

Jessica, an advocate specialising in the justice system, said:

'One of the things I think that's hugely problematic ... is the criminalisation of behaviour. When institutions closed a lot of those people who came out of institutions became caught up in the criminal justice system because they came with a range of behaviour that was socially unacceptable. ... And when you have people who've been used to institutional life and those standards, you know, the terrible shock of coming out into a society that doesn't accept that kind of behaviour is terrible. And it's really, really traumatising to people.

'Over the years I've worked with a number of clients who've been convicted of sexual offences — very kind of low-level sexual offenses — that were exactly that cohort of people. They're men in their 50s and 60s who grew up in institutions ... There was no idea that people with intellectual disability might want to have a sexual relationship.

'I worked with a man a few years ago who had that exact life story. He'd grown up in an institution, had spent a lot of time in institutions. As an adult he had a lot of very problematic

behaviour, including sexual behaviour and fire lighting. ... And, so, he lived in a group home, and he had been convicted of sexual offences on a few occasions, but the time that I encountered him was just after he'd been convicted of masturbating on a bus [in 2014].

'He used masturbation to self-regulate and to self-soothe. He had huge anxiety and found it very difficult to go outside ... due to his institutional upbringing. ... And so, there were times when he became incredibly anxious and, you know, he would do things like run away from people, run home and cry. ... But also, masturbation was one of the things that he did when he felt really upset and unable to cope.

'He was on a bus. One day he started to feel really anxious. He started masturbating. ... The bus driver diverted the bus and took him to the police station. He was held at the police station. He was interviewed. He didn't understand any of it. He was a man with a moderate intellectual disability and schizophrenia. He didn't really understand what was going on.

Jessica said that people with a cognitive disability found it very hard to not speak in an interview:

'So, this guy of course went to the police station, had an ITP [independent third person], broke down crying, unable to deal with it, incriminated himself. So, of course, then there's absolutely no chance that the person can plead not guilty once they've done that. And then the pathways for that kind of thing in the court system are so limited that, basically, even though that behaviour was accepted for him in an institution ... the result for him is being criminalised.'

Jessica said her client received a suspended sentence:

'Even though the justice system is very gentle on people like that, it's still the fact that that behaviour is criminalised, the message that he then receives is: your behaviour is not safe and if you go out in public, there's a chance the police might come and pick you up and take you to be questioned, which is an absolutely terrifying experience. ...

'You can't really understand that you're not going to prison. ... It can really change the way that they live their lives. It can mean that they become scared to do normal activities because they're not able to identify what might get them into trouble and what won't. I've had lots of people I've worked with who haven't understood that they're allowed to have an adult sexual consensual relationship, because as soon as they did get into trouble for any kind of sexual behaviour, the message they get is, "Well, I guess I'm not allowed to have any sexual behaviour."'

Jessica said:

'For a person who displays offending behaviour in the community, the first response should be from a disability system. It shouldn't be from the criminal justice system. It shouldn't be pathway into incarceration and a lifetime of torture. There should be greater funding for forensic disability services in the community that actually have human rights as the focus and quality of life and aren't about the risk-treatment paradigm, because you know what you find frequently for people with intellectual disability who offend is that their quality of life in the community is terrible anyway. And so, there are times where the offending is a protest against that. So, it might be a protest against kind of restriction discrimination.

'If there are disability services that are able to wrap around a person and create the kind of life that gives the person agency and self-determination, then there is likely to be less need for the criminal

justice response. ... There needs to be a much, much, much bigger response from the state to manage people when their needs are related to disability. ...

'It's about cognitive privilege. ... As soon as you start talking about anyone with a cognitive problem, there's so much discrimination and so much of people saying, "Well, that's not what we do. We do this thing and we can't work with people like that because they won't understand our program." ... The state needs to invest in addressing discrimination in this area, to address the reasons why people end up in prison.

'People with cognitive disability in general – so brain injury and intellectual disability – should have the right to have their offending related needs addressed by disability systems, not by the justice system. It's almost like they need a translator or something [to navigate the justice system].'

Jessica said another glaring issue was the lack of services and supports in the justice system for female offenders with disability. In Victoria, for example, she said that the Department of Health and Human Services ran the Forensic Disability Program that worked with offenders with a cognitive impairment to reduce recidivism.

She said:

'It was only last year that they [DHHS] even considered the idea of taking women there [to the Program], which meant that any woman who had committed a serious enough offense and needed treatment just didn't have that option, had to sit out a sentence in prison because there was no other option. ...

'There's one woman [aged in her 20s] that I worked with last year who was unfit to be tried, so she ended up on a custodial supervision order, so she ended up doing a stint in prison. Often, when people end up in prison on a custodial supervision order ... it's because of lack of support and services in the community. ...

'In that woman's case, it was because she didn't have the support available to be in the community, so she ended up in prison for about six months. ... She's a woman with a moderate intellectual disability, she presents as very, very, very naive. Very unable to cope with the prison environment. If she'd been out in a mainstream unit, she would have been taken advantage of in about 20 seconds. Her interests were kind of talking about makeup and jewellery and Taylor Swift, painting her nails. Very kind of feminine and girly, but not necessarily in a conventional way.'

Jessica said the only safe place in the prison system for such a naive inmate was the mental health unit:

'And, so, the staff in the mental health unit had to provide extra resources to be able to basically supervise her 24/7 because they weren't able to leave her on her own. ... She also had borderline personality disorder and was very much unable to manage emotion. She was not able to regulate herself and so she would become incredibly distressed and at times, when she became very very distressed, they were not — they weren't really able to manage her and so she ended up having to sometimes to be secluded, essentially, because that was the only way that they could manage it.

'So, her time there was incredibly stressful and difficult ... because the staff put in so much work and to try to make her feel safe and to try to help her to manage that she became very dependent

and very reliant on the staff, and so then it meant that it was much harder for her to transition out of prison.'

While in prison, the woman made friends with another inmate, who then died by suicide.

Jessica said:

'The impact of prison for people with disability is so much greater and the punishment is ... so beyond what it is for any other member of the community because ... you're not just punishing them by withdrawing them from society and making them feel bad. You're also causing massive impact on their mental health. ...

'We take a person who we acknowledge is not able to understand the wrongness of their own conduct. We accept that she's not able to understand the legal process. We accept that in some senses she's not guilty because she's not able to be held accountable. And yet we put her in prison and make sure that she stays in prison for a length of time where she becomes completely disconnected from her community and that she's traumatised by what she sees around her. She's traumatised by the fact that she doesn't have disability-specific support that is able to work on living skills and capacity building. ... And then we expect her to go out into the community again after this incredibly damaging experience and function ... and not go and offend again.'

Another advocate, Sophie, said:

'I've certainly had examples of people who were left in a jailhouse ... because legal aid was refused and the public trustee wouldn't release funds to pay for legal representation, which is not particularly good for someone who's not able to communicate verbally.

'I had a gentleman who, unfortunately, made the choice to stab one of my support workers and threaten somebody else. The police came and he was arrested and he was taken to the local courthouse and I had a phone call from the legal aid lawyer he was given that day, saying that he wasn't communicating with the court, but that my choice as the manager of the service was to either have him going to ... our forensic mental health service here ... or allow him back in the house that day with those residents ... because there was no in between. So, I had to choose. ... I tried to refuse to choose and I think I even cried at the man and said, like, "You can't make me do this," but I ended up having to choose for him to be detained for the safety of other people. And that's not [my] decision to make.'

Vicky said police could be both overbearing and understanding — illustrating her point with two stories about Trevor, a man with an intellectual disability.

In the first case, Trevor became upset and threatened a support worker. The police were called. When the police arrived, Vicky offered to help talk to Trevor to calm him down. The police ignored the offer — immediately subduing Trevor with capsicum spray and manhandling him into a divisional van.

In the second case, Trevor burned down his house.

'I met him at the police station where he was interviewed,' Vicky said. 'We took him to the hospital and in the hospital they said, "He can't stay here. He's not sick." I said, "See the man who's extremely agitated? He's just burned his house down." ... I said, "There's nowhere to go. It's not safe in a motel." And then my big bosses called me and the guardian [had] said, "Just relinquish care to the hospital. Just walk out."'

Vicky said that the police deemed it wasn't in the community's interest to press charges for the fire: 'Another person would have been charged with arson.'

Another advocate, Donald, said that there were 'lots' of examples of police demonstrating 'gross indifference' towards the rights of people with intellectual disability.

He said:

'We had young woman with Down syndrome who was raped, but the police weren't interested in really taking a statement. We had to also do things to get them to take a statement. And then you know when it went to court ... we couldn't take any further because the other side made it very clear that to the process would rip her to bits. ...

'I got an email from the sister of a young man with autism. ... She still hasn't got over — I'm sure that her brother hasn't either — an experience at St Kilda police station a few years ago where they went in to ask for some assistance for something. And they were waiting, and her brother started to demonstrate his behaviours. And the police reacted. Jumped on him, basically. Applied a knee to his neck. Incredibly traumatic. And, luckily, it was caught on video. ...

'Police have been increasingly used to sort out problems in group homes. ... Staff, these days, will just, rather than try and mediate or try and resolve issues between ... residents and staff or residents and residents, they'll phone the cops. And the cops get very sick of that, so they sometimes come in more frustrated than they should be. ... Systemically, at that frontline, it is the failure of the system and it's the abuse of the police, putting them into roles that they should not be in. The staff themselves need to be skilled. They need to have crisis-response teams. There needs to be a whole lot of things to back up that support right before they start phoning the police. It's just way over the top. ...

'The failings of the service system often show themselves up, show up and play out in the justice system. Lots of people get to the justice system that are only there because the disability support system has failed them.'

Case Study: Torture

This is a story of how the criminal justice system treats people with intellectual disability.

Keith was 19.

He had an intellectual disability and schizophrenia. He had grown up largely within the child protection system, been fostered, experienced trauma and, by the age of 13, started using drugs.

'He had become quite heavily reliant on heroin at one point and then subsequently ice, and so his offending was, you know, armed robberies, car-jackings, that kind of thing,' an advocate said.

'He ended up in prison and when he first went to prison, he went off his anti-psychotic medication and so psychosis started to come back. His behaviour became really unmanageable. He went to Thomas Embling [forensic psychiatric hospital] for a while, was treated, was stabilised, went back to prison. Then, you know, his behaviour was not manageable from that point on, despite the fact that he was technically mentally well, and so he ended up in management.'

In the Victorian corrections system to be placed in 'management' — which is colloquially called 'the slot' — means that an inmate is locked in their cell for 23 hours a day, receiving meals through a slot in their cell door and allowed out for one hour to exercise by themselves.

The advocate said:

'Some of the very worst stuff I've seen in the justice system is people with intellectual disability being held in management units, which again is not uncommon. Often, people with intellectual disability when they go to prison, if they are pretty street smart ... they might go to a mainstream prison unit or they might go somewhere where there's some level of protection, but it's not a specialist unit. But then there are specialist units for people with intellectual disability, but often their behaviour can't be managed in that unit, and so the only other option is ... the slot. ... Some people end up there for months. ... There have been a few women with cognitive impairment who've been in the slot for months at a time.'

The advocate vividly remembered visiting Keith after the 19-year-old after he had been in management — and therefore solitary confinement — for more than a month:

'I went to visit him in management and he came out in handcuffs and leg shackles and was handcuffed to the table and I was basically told not to not to go anywhere near him because he might hit me. ... He was a completely different person. He was just, he was just broken. ... If you look at the UN definition of torture it [the slot] fits the definition of torture. It was cruel and inhuman treatment for a person with disability.'

Health care for people with cognitive disability

People with intellectual disability said medical professionals discriminated against them. They said their family members were often expected to speak for them.

Tim, 20, said:

‘The medical system just needs to stop being so stringent ... because they just presume ... they won’t actually respect you as a person. They expect the person that with you to answer all the questions when the person that has the disability is right there.

‘When I fractured my knee last year I was stuck in a wheelchair for a couple of weeks, so I couldn’t physically walk for a little while ... And when I went to the hospital for the first time the medical professionals did not look at me in the eye because they had my personal profile in their hand and they saw the word autism and they looked at my dad and asked him everything from my name to, you know, what school I went to — yadda, yadda, yadda — and then when he went to my school information I was like ... “Excuse me! I’m right here in front of you. Ask me the questions.”’

Luke said he often had to explain his disability to doctors because it was ‘so rare’.

Eileen receives healthcare from an Aboriginal community health centre. She said she often took a case worker with her for gynaecological check-ups because of a history of abuse.

Families reported being lied to by health care professionals.

Miranda died at the age of 42.

Her parents, Ewan and Evelyn, said her premature death was caused by the misconduct of her doctors.

Miranda was born with Down syndrome in 1972. Like many children with Down syndrome, she had a heart condition. In most cases, those heart conditions can be corrected with surgery.

In Miranda’s case there wasn’t any corrective surgery because her doctors did not tell Ewan and Evelyn that there was a problem. Instead, when they took their infant daughter to the hospital their doctor treated her ailments — Miranda had pneumonia 13 times during her life — and told her parents to take her home and ‘make a pet of her.’

‘He just lied,’ Ewan said of the doctor.

'We've had this experience with medical practitioners not telling you something — thinking a sentence of death is a good idea,' Evelyn said. 'The medical practitioners did a disservice to her by not saying she had a heart defect. They really hid that.'

The family moved to Adelaide when Miranda was 5 years old. That was when they found out, from their new doctors, about their daughter's heart defect — and that it was too late for corrective surgery.

Advocates said that the behaviour of some medical professionals towards people with intellectual disability pointed to a chronic lack of training, as well as an assumption that people with intellectual disability were not able to give consent. They also spoke of cases where people with intellectual disability were medicated for non-medical reasons.

One advocate, Amanda, said:

'We've just run some workshops for one of the hospitals here. ... They have had some patients with intellectual disability and limited ability to be able to communicate and we were really surprised at things that we thought would just be basic practice went happening. Like when the person was admitted. They come, the hospital wasn't given like their positive behaviour support plan, which, you know, was critical for them being able to be consistent in their approach with that person. And, so, they were definitely seeing some challenging behaviour from that person, but the hospital staff didn't seem to be aware that that should be something that they should ask for. ... Those kinds of things can often restrict people's rights being respected, so they're not treated as fairly as someone without a disability because that information hasn't been passed on.'

Sophie, an advocate who has worked in disability care, said doctors medicated people with intellectual disability for non-medical reasons.

'They've had a general anaesthetic administered in order to get a teeth cleaning. ... The other big thing that I've always noticed myself is the assumption [by doctors] that a person can't consent or understand for themselves, rather than assuming that they are able to and then sort of being corrected if the case is otherwise. The assumption is always that a person needs somebody to make a decision for them. ... There doesn't just seem to be that mainstream knowledge that people are people.'

Sophie said had supported a man with Down syndrome who did not like having his haircut or nails trimmed. A doctor's solution to the issue was to prescribe Midazolam.

Sophie said:

'The doctor, happily, without asking too many questions prescribed him to have Midazolam administered to knock him out completely, and he would wake up half an hour later with his hair cut and his nails cut ... by support workers. So, before he went to work that day, he would be sedated along with his coffee and then he would wake up shorn like a sheep.'

What would he do when he woke?

Sophie: 'He would be upset. ... I would assume that he felt violated.'

In another case, Sophie spoke of an incident when a dentist took extreme measures to treat the resident of an institution.

She said:

'They also have their own in-house dentist so all the people that lived in this institution got their dental care done on campus. In some ways he [the dentist] was fantastic. If the client didn't want to get out of the car, he would come out and he would do a check-up in the car seat. But there were other times ... I just thought of a time we had a person who kept punching himself in the face, so we took him to the dentist, and they worked out he had a big abscess on his tooth. And he wasn't happy to be at the dentist. And the dentist said, "Right. Now we've got to hold him down and pull the tooth out or we call an ambulance and he is going to go to hospital for three days."

The dentist gave the patient a local anaesthetic, then he was held down and his tooth extracted.

Case Study: Press the buzzer for help

This is the story of a group home resident who was taken to hospital, left unattended and moved to a palliative ward. She survived.

Carly lives in a group home and requires around-the-clock care.

A few years ago, she had a medical emergency and was taken to hospital.

Carly's support workers left her at the hospital. They didn't call her family.

Carly, who doesn't use words to communicate and is unable to move her hands, spent the night in hospital without any support.

Carly's cousin and advocate, Angela, drove four hours to the hospital as soon as she was told of the hospitalization. When she arrived, Angela was shocked when she heard a nurse tell Carly to ring the buzzer if she needed assistance.

Angela said:

'It's physically impossible for her to ring a buzzer! So, when I went and complained about it, they put a baby monitor in the room.'

To make matters worse, during her first night in hospital – when she had no support – Carly was given medication that thinned out her mucus, placing her at risk of aspiration, and moved to a palliative care ward.

'I'm surprised it didn't kill her,' Angela said. 'And nobody rang me when they left her at the emergency department. ... She wasn't even outside the nurses' station; she was down the hall.'

Later, after Angela complained, the group home sent support staff to help at mealtimes.

Carly still lives in the group home.

Group homes

People with intellectual disability saw group home as mini-institutions — places where they couldn't choose who to live with, what to eat or what to do. They reported feeling stigmatized in the community because of living in a group home and discrimination within group homes by support workers. And they reported being assaulted in group homes.

Vincent, 56, lived in a group home that housed between 9 and 12 people until 2019.

He hated the group home. At the group home, he slept in a room just large enough to squeeze in a single bed, was regularly assaulted by another resident, was not allowed to choose his own meals and given food that he couldn't eat because he has Type 2 Diabetes, and woken at 5.30AM every Saturday by a support worker and told to clean his bathroom. 'It was bloody annoying,' he said. 'It's too early at the weekend.'

Vincent said he didn't feel safe in the group home and, for years, would lock himself inside his room with a padlock.

When his mother died in 2010, Vincent said that support workers cleaned out her house and threw away his personal possessions.

Vincent now lives with a friend in a house with modern amenities.

He wants to see all the residents of group homes to be released and given the choice to live where they want with who they want.

Nick, 32, lives independently.

He said:

'Where I live there's a lot of disability residential homes here. But you know what's amazing is you don't see them. You don't see people with disabilities around because I really have to say this, and this is quite honest, is we talk about inclusion in the community, all right, but in group homes from what I've seen around my area there's only one or two people we see out there with a disability. Otherwise you don't see them. We talk about inclusion. We talk about freedom of choice. Well, I believe it's not happening. ...

'Institutions are horrible ... but see, with the group homes in a way I believe they're like a mini-version because you don't get to choose who lives with you. You don't get much choice. You know, you don't get to say ... like if you want to go and have a coffee or something you don't have freedom of choice. So that's why I think that group homes become a little bit like a mini-institution.'

Donna is in her 50s.

She that people in the community didn't want group homes:

'Where I live they were going to put a group home around here and all my neighbours put a petition out to say they didn't want people with a disability living in their street and I found one of the neighbours that said it and I said, "Well, hang on, you don't want people with a disability living in your street." I said, "I'm living in your block of units." ... They shut up.'

Family members said the concept of 'choice and control' was often inverted at group homes, with staff instead of people with intellectual disability making the choices and having the control.

Miranda, who had Down syndrome, lived in a group home after she left her parents' house.

She shared the house with four other people with disabilities.

Before moving to the group home, Miranda had run her own micro-business, making pasta — but a staff member wouldn't let her cook. At the group home, she didn't get to choose who she lived with and the front door and the refrigerator were both locked by staff.

Once a fortnight, Miranda would spend the weekend at her parents' house.

Often, she did not want to return to the group home.

Angela advocates for her cousin, Carly, who lives in a group home.

She said:

'There needs to be a lot of lot more training for support workers around people's rights, including the UN Convention on the Rights of Persons with Disabilities.

'Group homes are mini-institutions. ... My cousin would really like to move out. ... She doesn't like the people that she lives with, [but] the organisation just try and keep her there. ... It gets swept under the carpet.'

Angela said that Carly often lost access to the staff she preferred:

'When she does tend to like one of her support staff, I find that ... they get moved on. ... Other support staff don't like to be shown up, I think.'

Angela said Carly was dependent on staff for around-the-clock care and support:

'I worry that she doesn't get treated fairly because I guess she's so vocal and stuff like that as well that people don't like it. Certain support staff don't like her because she's vocal and not as compliant as the other clients in the house. ... She's not happy, but she's a big — she's a big earner for this service provider and they have control over her day-to-day life, almost 100 per cent.'

The group home staff have complained about Angela advocating for Carly. They have told her she shouldn't be allowed to speak up for her relative because she works in the disability sector and, therefore, has a conflict-of-interest.

Advocates, like people with intellectual disability, saw group homes as mini institutions. Many advocates were concerned service providers were using NDIS funding to create a new generation of group homes that were little more than privatised institutions. Often these group homes are one-stop-shops for residents, meaning they are seldom visited by anyone other than the employees of the service provider running the group home. Unsupervised, siloed care such as this is a recipe for abuse and neglect.

One advocate, Kelly, said:

'There are new types of housing opening up under the NDIS that absolutely replicate institutional environments. There is no national plan for the closure of residential institutional environments and we need to, really need to, develop more genuine community-based housing and support options for people with a disability and increase the amount of affordable and accessible accommodation.'

She said the privatisation of institutions under the NDIS often falsely invoked choice and control:

'They're using the old "choice and control" as a way of saying, "Well, it's people's choice to live here." But if there are very few other options or people don't know what is possible then they're not going to ask for it.'

Kelly gave the example of a new-breed of institution that was using NDIS funding to expand from 80 residents to more than 100 residents — and building the new housing near a sewage site.

'No one else would buy a block of land there. I wouldn't,' she said. 'Why is it okay for that to happen for people with a disability?'

In another example, Kelly spoke of a congregate living development that was known locally as the 'veggie patch'.

'It's a target for drug users and for people to come and target people and, you know, pretend that they're their friends and then to rip them off for their money,' she said. 'People with disability are seen as less than everyone else with less value in the community.'

In South Australia, advocates were concerned by the termination of the community visitor program in 2019 and the possibility of more undiscovered cases of criminal neglect and abuse like the case of Ann-Marie Smith in Adelaide. When South Australia did have community visitors, advocates said they would often give disability service providers a week's notice before inspecting a group home.

The NDIS Quality and Safeguards Commission told one advocate they would not make unannounced inspections of group homes.

A disability worker said:

'They used to ring up, give us a week's notice and let us know when they would be coming, exactly what they were going to be looking at and doing. It was up to us to contact the people that lived at that house's families to invite them to come along and talk if they wanted to, and which we could obviously have made the choice not to do. But they didn't attend every single service that we had.'

An advocate said:

'Letting people know they're coming — it's a chance to clean up their act, you know, polish the floors and put the smellies out and all that sort of stuff, you know.'

During the initial rollout of the NDIS in 2016, VALID was employed to advocate for people with disability without next-of-kin or guardians living in State Government-run group homes.

They took part in 275 NDIS planning meetings for some of Victoria's most marginalised, institutionalised citizens.

People who, a VALID advocate said, 'had nobody else'.

'I met what people called the kings and queens of various institutions,' the advocate said.

'This is code for the most violent people; so, if you are the king ... it meant that nobody could touch you. And they were also the people who had no family, and they were also the people who had been most brutalised. And in meeting those people — many, many, of them — I learned a lot about the difference between rights and reality. And the truth is that all of those people have the *right* to move into a home of their own, to choose who they live with, to choose who supports them to make their own decisions, to have presumed capacity, to access supported decision making, to exercise their legal rights. All of those rights, they are enshrined in the UN Convention, they are in the NDIS Act — blah, blah, blah. I don't think I succeeded in bailing one of them out [of a group home], regardless of their request for me to do so, because everything was set up for them to stay there. ...

'Advocates had very little capacity to influence what happened in their meetings. ... I met a lot of people in that time who told me, very clearly, they wanted to move out. I asked for that goal to be included in the NDIS plan at the planning meeting. I don't know what happened after that. We were not funded to provide any follow up. All we can do is hope that support coordinators and house supervisors bring the goals to life.'

The advocate said that the transfer of housing from institutions to group homes and the transition away from State Government-run services to non-government providers had opened a gap — with the state governments no longer providing last-resort housing for people with complex support needs.

The advocate said the places of last resort housing for people with intellectual disability were now hospitals, aged care facilities or prison: 'That's a much harsher end game for people with intellectual disability than existed before.'

In addition, the advocate said the lack of protection for group home residents meant none of the most marginalised people with intellectual disability were likely to appear before the Royal Commission: 'How will you give evidence about your group home when you have to go home to that group home? Are you for real?'

Martin — a man with a disability who previously worked in the disability sector — said he received minimal training before his first shift in a group home:

'My first day on the job at this particular organisation I was working at I had my interview at the transitional house and started my first day of work and then I was there for about 10 minutes to be shown how to do it. And then everyone left. And I was there to do the job. ...

'I had no training whatsoever. ... That's something that surprised me.'

Sophie, who had worked in disability services and residential care for children, said that the lack of mandatory reporting was appalling.

She said:

'I've moved from working in the mainstream disability space to residential care for children who can't live with their parents ... in my two years' work ... I've had to do investigations for the Department on 12 occasions my staff have reported my own staff. And another eight times members of the public have reported my staff. So, 20 investigations I've personally had to do in two years. My entire time working in disability [services], which was the 12 years prior to that, I've never been asked to investigate any neglect or abuse allegations or claims against support workers because there's no mandatory reporting and it's not people's legal responsibility to have to report.'

Amanda said group home residents who received all their care by one service provider were more likely to be at risk of abuse.

'The people who are in those group homes that are only supported by one service probably are more likely to have limits on their decision making,' she said.

Sophie said that, without informal supports from families or advocates, staff in group homes assume decision-making roles.

'Even when there are formal things in place around guardianship,' she said, 'the opinion and the decision-making really still goes back to the staff being paid to look after them because they're informing the decision of the legal guardian. And I think that that for me has never felt particularly right. Like, if we wanted to go back to a place where people had no choice and the staff were making all the decisions for them, then why put, you know, the Office of the Public Advocate in

place and make it *seem* as though there's someone helping making decisions when, realistically, it's still the staff — just via a third party.'

Penny, a self-advocate, described group homes as 'mini-institutions' because residents couldn't choose where they lived, how they lived or who they lived with. She said the lack of choice and control increased the risk of violence and abuse.

Lillian, an advocate specialising in housing issues, said housing was a human rights issue for people with disability. Outside of group homes, she said, people with intellectual disability often had limited housing options, and often ended up living alone, isolated and vulnerable. She said that there was a need for more creative, flexible housing models.

Lillian said:

'I know a lot of folks ... who, you know, just get lonely and just need to have some folks around but don't necessarily need to have that paid support all the time.'

Another advocate, Stephen, said that — unlike in aged care — the NDIS Quality and Safeguards Commission didn't have the power to act proactively:

'They've got no proactive capacity. ... They respond to complaints. Well, you know there are many people who are really able to complain, but there are many people who can't complain.'

Stephen said that the disability sector had gone backwards since the rollout of the NDIS:

'It's gob-smackingly disconnected. It's a fragmented system. You may remember how the Productivity Commission said when it was doing its review of disability services that it was a broken system, yes? In many ways it wasn't a broken system, it was an underfunded system. ... We've actually gotten an even more broken system now.'

Advocate Vicky said:

'I just don't think there's enough checks and balances to safeguard people.'

Advocate Donald said that group homes were only ever meant to be a 'point of transition' towards individualised living for people moving out of institutions:

'The group [home] plans were only ever supposed to be a waypoint, a point of transition where people could, you know, basically debriefing institutional structure, develop skills, and then move into more individualised lifestyles ... but it became an end point. ... It becomes an end in itself because all those vested interests rally around it and capture people. That's what goes on.'

'We've got clients with close to \$1 million [a year] spent on them, but their life hasn't improved since institutions because of the crap services around them. Because it's all about the structures, the institutional structures, the institutional mindsets of people without a real commitment to an understanding of what it takes to tap into the potential of the person and to support them to take control and to assert their own life. That's what's really sad. ... After 45 years of closing the institutions and building community-based models it's all still about the structures, about the models, but the true mission of being able to unlock people's potential — no one is talking about that because that requires real resourcing, that requires you to actually have staff who are trained, who have serious skills. ...

As a consequence, Donald said, group homes had become institutionalised:

'We have to, as well as putting pressure on to get people into more individualised lifestyles, we have to keep the pressure on around the quality issues — you know, the training of staff, the effective management; all of those things, to ensure that people are supported probably.'

In Victoria, Donald said, the worst cases of abuse were usually found in group homes that had 'imported' the culture of the institutions when they employed the former staff from those institutions.

He said:

'We imported staff with the same, you know, attitudes towards people into the group home structure, and they just set up camp ... and in some areas of Melbourne they've just really been running the show for a long time as a real power block. And, so, any resistance against that sort of power has been very difficult. So, the idea that power should be shifted from the staff and from the service system and from the bureaucracy to the person with disability, you know, there's a massive power struggle. And there's very little power on the consumer side.'

Are any areas of Victoria more problematic because of institutional cultures?

Donald: 'Pleasant Creek and Aradale in particular, and McCallum house in Ballarat. So, a lot of group homes were built as people came out of those institutions and staff were redeployed and, basically, it was business as usual. ... If you go to the northern region of Melbourne you've had Caloola and Janefield and Kingsbury and Larundel, and so a lot of group homes are spread across there and they get the same thing. ... there's something cultural about the southern region where a lot of these ideas of self-determination never sort of caught hold and there's these other forces at work there. Eastern Metro and Western, there's a more enlightened approach; probably, when I think about it, it probably had to do with people in the Department, you know, who had an advocacy sort of spirit.'

Case Study: He died alone with \$100,000 in the bank

This is the story of a man with Down syndrome who died alone at the height of the COVID-19 pandemic.

Gabriel was 60. He had Down syndrome and, after being relinquished as an infant, grew up in Kew Cottages.

When the institution closed, Gabriel was moved into a group home in Melbourne's suburbs.

In early 2020, during Victoria's first COVID-19 lockdown, VALID received a telephone call from a support coordinator. The support coordinator said Gabriel needed an advocate.

According to the support coordinator, Gabriel had fallen in the group home and broken his hip. He had surgery, but the hospital rehabilitation program — which was not geared to the needs of a person with an intellectual disability — had failed. Gabriel's hip joint had frozen and he could only be moved with a hoist. His group home could not accommodate a hoist, so he was effectively homeless in hospital.

During the pandemic, Gabriel was moved from hospital to a transitional aged care facility to wait for another placement.

The group home was legally required (Residential Tenancies Act 1997) to notify the Office of the Public Advocate of Gabriel's changed living arrangements but failed to lodge a Notice to Vacate. Instead, the hospital, group home and transitional aged care facility debated what to do with Gabriel. The support worker told VALID that there were not any decision-making supports — Gabriel did not have a say in his own future.

The support coordinator told VALID that Gabriel had spent four months in hospital and the aged care facility and was missing the other residents of the group home, who he had known since childhood.

'He was crying the whole time he was there. He was distressed and afraid and calling out for people from his house who weren't there,' a VALID advocate said.

'The support coordinator said, "Can you please help? I don't know what to do. They're all pushing for aged care. The provider's for it, the hospital's for it. I think they're going to sign off on it. I don't think it's right. I don't actually think this is what should happen.'"

Gabriel died the day after the support coordinator called VALID.

When a VALID advocate asked the aged care facility why an otherwise-healthy man suddenly died she was told 'it was his time to go'.

There was no investigation into Gabriel's cause of death. VALID did not have the authority to request a coronial inquest.

Shortly after Gabriel's death, VALID was told that he died with more than \$100,000 in savings — money saved on his behalf by a state-appointed administrator over six decades in the disability system.

That money could have been invested to aid Gabriel's rehabilitation or secure housing of his choice. But the money wasn't spent. Nothing was done.

Gabriel died afraid and alone.

Education and learning

People with intellectual disability reported common experiences in education and learning. In mainstream schools, they were often bullied. In special schools, they often received sub-standard educations. And they were practically excluded from accessing tertiary education.

Ted, 56, went to a mainstream school in a regional area.

'I did get picked on a little bit,' he said.

The other students teased Ted, calling him 'Goo-Goo Gaga' because he spoke differently. He said that the worst of the teasing stopped after his teacher intervened in grade 4.

When Ted was in year 7, a teacher encouraged him to write a novel about his outback travels with his father, while the mothers of students spent time helping teach students in the remedial school classes.

Ted now lives independently, holds down a job and has had a driver's licence for almost 40 years, but struggles with reading.

He said that the NDIS should allow participants to use their funding to buy educational software and apps that help bridge gaps on their literacy and numeracy.

Wayne, in his 50s, went to a special school. His three children went to mainstream schools.

He said his children were teased at school, but school staff intervened and stopped the teasing as soon as he raised the issue. Most of his negative experience came from interacting with other parents.

Wayne said:

'Some of the parents are nice, some are mean, and they don't talk to you. I think it's important for them to talk to you as a parent. They've got kids, I've got kids. ... The attitudes of people need to change.'

Donna is in her 50s.

She said she was frequently bullied in school and had to be walked home from the bus stop by a friend. 'She used to have to walk me home from my bus stop because the kids from the primary school and the high school used to pick on me,' she said.

Donna said:

'I did not learn anything in the special school. I've taught myself how to read and write. I have a dictionary. I write up words from the dictionary and learn how to do things like that.'

Nick, 32, lives and works independently despite his sub-standard education.

He said:

'I was at special school. I went out of there when I was 18. I couldn't write. I couldn't read. It's quite an amazing thing because, like, when I went to a special school, they had a lot more focus on ... it was somewhere to go for people. They didn't actually teach us maths or life skills, if you know what I mean, and ... we didn't have years like from, say, grade one to, say, grade 12. Basically, they said, "Well, you'll go to day service or a sheltered workshop. And that's it."'

Nick said:

'Many people with disabilities never get the opportunity to go to tertiary education because they are not supported, or even told that university or TAFE is an option. They're very smart, but because they don't have the knowledge around where to go ... they're not told about disability liaison units, they're not told about, you know, you can get us a full support in the actual university. They're not told this stuff, so when they do, if they do want to go to university, they look and go, "It's too hard." ... It is just not an encouraging environment for people with disabilities.'

Calum, 22, said his maths went backwards after he was sent to a special school as a teenager.

'They would give me baby work,' he said.

Calum wanted help to become a cabinet maker but didn't receive support at school and became frustrated and angry.

He said:

'They [the school] just used me for my funding for the money and they treated me badly in high school and really did not listen.'

Calum said he wanted to study social work at TAFE but had been told he could only access the course online, without support.

He said he was discouraged: 'I do need somebody there with me.'

Penny, in her late 30s, works in open employment and lives independently. She was educated in an institution until the age of 7.

She said:

'When I came out, I couldn't read or write, and my parents decided to place me into a mainstream school. Now, I was very lucky that I had a teacher's aide. She was only funded to work with me for five hours a week, but she worked with me five days a week, unpaid, and I believe that's the only reason why I can read or write. There's not enough funding given to aides in schools. ... if I didn't have that I wouldn't be where I am today.'

Penny said she experienced verbal and physical bullying 'all the time' when she moved into a mainstream high school and received minimal support from teachers. She was placed in a segregated class set up to handle disruptive students. The class was so bad, she said, the teachers' aides refused to take her to the classroom and kept her in their office. She said the school only took action when she was 16 and threatened to drop out.

'If you don't have someone who's very vocal on your side you kind of get left out and subjected to lots of horrible stuff,' she said.

Penny said she was lucky that her parents were pushy:

'When I was about 17 ... there was another guy whose cerebral palsy was exactly the same as mine, probably not even as bad as mine. His mum sent him to a mainstream school, but he didn't get as much support, so he ended up going to [a special school]. He was in Year 12. I was in Year 11. He couldn't write as well as me. He could walk better. Couldn't read. ... He goes to day services [now]. He doesn't have what I have, which he could've if his parents had pushed as hard as mine did and if he'd had as many opportunities as I had.'

Families said that they were often made to feel unwelcome — and discriminated against — in mainstream schools.

Ron and Pam wanted to send their daughter, Miranda, to mainstream school.

Miranda, who had Down syndrome, had already attended a mainstream kindergarten — once Ron agreed to attend alongside his daughter and act as a volunteer aide.

In Adelaide, they found a supportive mainstream primary school with a welcoming Prep teacher. Miranda did well during her first year at primary school, learning to read and write, but things changed when she had a different teacher for grade 1. The new teacher didn't want Miranda in her class. Halfway through the year she was expelled from her mainstream school.

'The special school wasn't quite stimulating enough,' Ron said.

After that, Miranda went to a special school, but — despite her record as a quick learner — her reading never improved. She dropped out of school and started working in a sheltered workshop at just 15.

Miranda quickly became bored at the sheltered workshop, but never returned to school.

'It's not what you want,' Pam said of her daughter's time in the sheltered workshop. 'She should have stayed at school longer.'

Wendy sent her daughter Kate — now in her 20s — to the only private secondary school that accepted her after she was bullied in primary school.

She said:

'I was told at the primary school not to send her to the local high school because she wouldn't survive. ... And you know what the problem is with the special school system is that I just don't

think that they do enough [educating]. ... You need to be able to read and write to the best of your ability for you to be able to make it in society, and I don't know if that's what she would have got at a special school. ... In terms of choice for children with a disability they really do need to ensure that there's more choices.'

At the private secondary school, Wendy said the staff behaved as though they were doing 'a big favour' by letting Kate attend.

She said:

'We were told when we went to the school that they would only keep her if they were absolutely assured of our commitment as parents to ... make sure that we supported the school at all steps of the way. So, I just felt that we had a bigger burden placed on us as parents, too, and really had no rights in relation to schooling. It was at the whim of the education provider. ... We were once told that they didn't think we were making enough of a commitment and that they might have to decide not to keep her on because of the resources that she was using.'

Wendy said the students at the school, which was a Christian college, were 'really good' to Kate. The deputy principal was not.

'On the last day of school,' she said, 'I was speaking to the deputy principal and I said to him, "Look, I'm very grateful for what you did in taking [my daughter] on and bringing her through this school," and whatever. And then he turned around and he said to me, "Had we known how difficult it was going to be, we wouldn't have accepted her." I was absolutely shattered.'

Advocates said that the educational system failed students with disabilities in mainstream and special schools — and excluded them in tertiary education.

One advocate with expertise in education, Lisa, said:

'We are absolutely not doing our duty as educators. I think it is criminal ... that young children are starting school without robust communication systems. No child should start school without a robust communication system in place. Our system has completely failed if that is happening. ... The use of Augmentative and Alternative Communication does not hinder speech development. In fact, there is evidence that AAC can accelerate speech development. ...

'Teachers and therapists are not taught how to teach people with disabilities – let alone communicate with them. Education departments have an attitude towards communication that it's not their job, it's the task of the speech therapist. But communication is fundamental to teaching. ...

'I am consistently frustrated by education departments that don't recognise that having their teachers understand how communication systems work is absolutely paramount to the success of kids' learning, because if they cannot communicate with them and they can't communicate to them they absolutely cannot demonstrate their learning.'

Lisa said she was also frustrated that schools neglected their responsibility to teach people with disabilities and instead — in mainstream and special schools — focused on functional skills.

'There's nothing more functional in life than communication skills and literacy skills,' she said.

She said educators took a passive approach to people with disabilities – waiting and seeing whether they developed speech and communication skills on their own before teaching them more skills when they should be immersing students in other forms of communication. She said an over-reliance on Applied Behaviour Analysis for kids with autism was a mistake when the feedback from many adults with autism was that ABA was ‘tantamount to abuse for people with autism’.

Lisa said:

‘It’s not about teaching someone to say what you want them to say. That’s not communication. Communication is supporting someone to say what they want to say, when they want to say it, to whoever they want to say it, however they want to say it. Not on demand. ... I am really worried that we are setting up kids who ... are already more at risk of physical and sexual abuse than any other category of child. They already have minimal communication, which puts them more at risk because they cannot report it, and yet we put them at risk further by not giving them access to words like “no”, “stop”. ... That’s my biggest concern, that we are setting kids up for more abuse because we are not giving them the opportunity to have power language.’

Lisa was also alarmed by the tendency in special schools to ‘lump together’ students with complex needs — who often range in age from 4 to 17 — in the same class and referred to as the ‘wheelie class’ or the ‘multi class’.

She said:

‘When I’ve questioned principals on that ... they’ve said, “Oh, well, that’s what the parents call them.” They are literally lumping kids together where it doesn’t matter, “That one’s four and one’s 17, they can all be in the same class.” I mean that’s just ridiculous. ...

‘There is nothing special about special schools. Because it’s not special education. It’s segregated education. ... We’ve got decades worth of evidence now that says kids do better in mainstream school even if it’s dire. Even if it’s a terrible experience they’re tending to do better. ... That’s because ... they are still in an environment where they are surrounded by rich, age-appropriate language models ... [and] they’ve got access to the curriculum.’

Finally, Lisa said that instead of quarantining students with disabilities with teacher’s aides they should be placed with the most talented teachers:

‘Our kids who have the most difficulty learning are being taught by the people that have the least training and the least experience.’

Vicky has worked in mainstream and special schools.

She said special school channelled people with disabilities into a lifetime of segregation. Specialist settings were, she said, babysitting services rather than educational services:

‘If all children went to mainstream schools and there wasn’t one curriculum for all, everyone learns at their own abilities, they’d have grown up with diversity ... they’d just be accepted in society’

Case Study: The self-educated self-advocate

This is the story of how a special school failed to prepare a young man with a disability for the world beyond the school gate — so he prepared himself.

Nick is 32.

He was illiterate when he left special school at 18.

Before leaving school, a teacher asked Nick what he wanted to do after graduation. He said he wanted to work as a public speaker and a self-advocate.

Nick said:

‘Basically, my teacher said, they looked at me and go, “Too-hard basket.” That’s a direct quote, that is. She goes, “Look. I’m going to be completely honest with you. You’re probably going to be in a CRU [community residential unit] and in a sheltered workshop or a day service.” ... That was my first career advice.’

Nick was sent to a day service after graduation — his options were limited.

He said:

‘I went to a day service for five years and one of the things I wanted to learn was how to read and they said, “Oh, we’ll just put him in a creating-a-newsletter program. He can learn that way.” And I said, “No. I would like to learn how to read properly. You know, *read* and *spell*. And they go, “Too hard.” ... I was expected to stay there forever basically, and I said, “No, I’m not doing that. You know, I’m going out there and getting a job and doing what I need to do to survive.”’

Nick left the day service. When he started working at an advocacy agency, he was sent to literacy classes and taught to read and write. He is now a public speaker and self-advocate.

Recently, Nick returned to his special school for a reunion. He met the teacher who told him he belonged in a sheltered workshop.

Nick recalled the conversation:

‘I said, “You know what I do for work now?” I said, “I do exactly what you told me I couldn't do.” And I wasn't being nasty about it, I said, “You need to encourage people a little bit more.” She goes, “Oh, sorry.”’

Recommendations

In 2007, the Australian Government ratified the United Nations Convention on the Rights of Persons with Disabilities (the UN Convention).

In 2011, the Commonwealth, state and territory and local governments agreed to implement the *National Disability Strategy 2010-2020* – a policy framework with a ‘human rights imperative’ that would ‘help ensure that the principles underpinning the Convention are incorporated into policies and programs affecting people with disability, their families and carers. It will contribute to Australia’s reporting responsibilities under the [UN] Convention.’¹

With that in mind, IA’s recommendations-for-action are categorised according to the articles of the UN Convention.

Article 5: Equality and non-discrimination

- Fully implement the UN Convention
- Make self-determination the foundational policy aim of all disability-related services and supports.
- Measure and report at least biannually on the implementation of the National Disability Strategy
- Harmonise and update the nation’s guardianship laws
- Amend and update the Disability Discrimination Act to bring it in line with the UN Convention

Article 6: Women with disabilities

- Ensure gender-based violence services are accessible to women and girls with intellectual disability
- Develop and implement initiatives to address violence against women with intellectual disability

Article 7: Children with disabilities

- Assume competency and ensure children and young people with intellectual disability can participate in consultations, decision-making processes and policy developments affecting their lives.

¹ *National Disability Strategy 2010-2020*, Council of Australian Governments, 2011.

Article 8: Awareness raising

- Develop a national strategy to promote the human rights of people with intellectual disability

Article 9: Accessibility

- Make all public transport accessible — including the national rollout of Easy Read signs, maps and timetables

Article 10: Right to life

- Ensure the training of all health professionals includes education about the human rights of people with intellectual disability – including the right to access proper care and treatment to sustain life

Article 12: Equal recognition before the law

- Fund systemic and individual advocacy organisations in every state and territory that have specific expertise in intellectual disability
- Reform any laws or policies that have the purpose or effect of denying or diminishing recognition of any person with an intellectual disability before the law

Article 13: Access to justice

- Ensure that people with intellectual disability can access the same legal protections and redress as the rest of the community

Article 14: Liberty and security of the person

- End the imprisonment of unconvicted people with intellectual disability
- Reform any laws or policies that enable deprivation of liberty and forced medical interventions on the basis of intellectual disability

Article 15: Freedom from torture and cruel, inhuman or degrading treatment or punishment

- Review all justice system interactions with people with intellectual disability to ensure that they have person-centred and accessible support

- Boost community-based forensic disability services
- Extend the powers of the Offices of the Public Advocate / Public Guardians / statutory appointees with similar powers into corrections facilities – and, in jurisdictions without an OPA, establish or enable independent visitor programs to visit corrections facilities
- Establish a national framework for the approval, use, monitoring, reporting and minimisation of restrictive practices

Article 16: Freedom from exploitation, violence and abuse

- Establish a national independent visitor program for group homes and people with disability receiving care from one service provider
- Reform legislation governing the NDIS Quality and Safeguards Commission to boost its powers and safeguarding its independence
- Establish an accessible complaint and redress scheme for all people with intellectual disability who have experienced violence, abuse, exploitation and neglect
- Require the board members of service providers to randomly visit one of their services at least once a year

Article 17: Integrity of the person

- Nationally legislate uniform and enforceable laws that prohibit unnecessary medical interventions.

Article 19: Living independently and being included in the community

- Ensure people with intellectual disability are able to choose where and with whom they live
- Close residential institutional environments and develop genuine, community-based housing and support choices for people with intellectual disability
- Create social and community housing alternatives to group homes.
- Reform the operations of the NDIS — making the scheme more flexible, less bureaucratic and easier to navigate
- Ensure every person with an intellectual disability has access to an independent advocate whenever required
- Include people with disability in the governance of all disability-related organisations

Article 21: Freedom of expression and opinion, and access to information

- Develop a *Plain Writing Act* – requiring government agencies to communicate in clear, direct language
- Have Easy Read guides to suburbs and towns in every Post Office and available for printing on municipal websites

Article 23: Respect for home and the family

- Commission a national inquiry into the removal of babies and children from parents with disability

Article 24: Education

- End segregated education
- Make disability supports universally available in early childhood
- Require that every child starts school with a robust, individualised communication system
- Establish post-school literacy programs for people with intellectual disability

Article 25: Health*

- Establish multidisciplinary health care teams to work with people with disability with complex needs
- Employ disability support workers in public hospitals to help people with intellectual disability navigate the health system
- Resource the creation of a national network of intellectual disability health specialists to enhance the capacity of mainstream services to cater to the specific needs of people with intellectual disability.
- Develop a national mechanism that enables the collection of disaggregated data on the health of people with disability

*Note IA's separate health submission contains more expansive discussion and recommendations

Article 27: Work and employment

- Develop and implement a national disability employment strategy
- Employ career guidance counsellors to help people with intellectual disabilities find open employment
- Reform Disability Employment Services and Australian Disability Enterprises to make open employment possible for everyone
- Make training more accessible and increase pay rates for workers with intellectual disability



Inclusion Australia

Inclusion Australia:

A report for Inclusion Australia

**Prepared by: Associate Professor Angela Dew and Dr Cadeyrn Gaskin,
Disability and Inclusion, Deakin University**

September 2020



**INSTITUTE FOR HEALTH
TRANSFORMATION**



Disability and Inclusion

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Executive summary

Inclusion Australia commissioned this report to collate recent data on people with intellectual disability living in Australia with a focus on prevalence, demographics, government support, restricted decision-making, schooling, employment, living situations, and access to technology. Compilation of the report involved systematic searches of relevant databases for peer-reviewed literature and an environmental scan of relevant websites.

Across Australia, numerous definitions of intellectual disability have been used for data collection and research, including those based on clinical diagnosis (of intellectual disability or IQ), support needs, and functioning. Data on intellectual disability tend to differ depending on which definition is applied. Estimates of the prevalence of intellectual disability range from 8.5 to 17.0 cases per 1,000 people based mainly on clinical and support needs data, and 63 per 1,000 people based on functioning (difficulties with learning or understanding).

Some areas lacked any accessible evidence. For example, we found limited or no publicly available information about the numbers and characteristics of people with intellectual disability accessing government services administered by the Department of Social Services, the Department of Education Skills and Employment or Aged Care.

The compilation of data for this report, highlighted the difficulties in accessing reliable and comparable information about people with intellectual disability in Australia. There is a need for agreement on definitions of intellectual disability to inform consistent data collection at Commonwealth and state and territory levels to enable comparison and accurate reporting to inform the provision of relevant supports and services including advocacy.

The proposed National Disability Data Set should go some way to filling these gaps but only if data are recorded and reported in ways that are meaningful to researchers, advocacy groups, policy makers, and others who seek to use it including using consistent definitions to assist with identifying those who have lifelong intellectual disability.

Introduction

The aim of this report is to provide an evidence-based overview of the Australian population of people with intellectual disability and identify data gaps². In commissioning this report, Inclusion Australia recognised their lack of access to a current, legitimate data set that accurately describes the size and status of the Australian population of people with intellectual disability. In seeking to provide input to the Disability Royal Commission, Inclusion Australia identified this data gap as hampering the Commission's understanding of the profile and context of Australians with intellectual disability. Inclusion Australia noted that the Disability Royal Commission has neither published a research agenda, nor indicated an intent to undertake any specific research about people with intellectual disability.

The term 'intellectual disability' encapsulates a broad and diverse array of experiences and characteristics. Intellectual disability can involve difficulties with communication, memory, understanding, problem solving, fine and gross motor skills, and self-care. Historically, the terms 'borderline', 'mild', 'moderate', 'severe' and 'profound' were applied as classifications of severity largely based on a person's IQ and daily skills as assessed by suitably qualified psychologists using standardised measures. Over the past 30-40 years, there has been a significant shift in the way disability, including intellectual disability, is described and conceptualised. Rather than reference to individual diagnostic measures and labels, the social model of disability highlights the disabling barriers presented by society that impact on a person's life. Under the social model, it is these social barriers, rather than a person's individual impairments, which create disability. The World Health Organization's International Classification system, revised in the 1980s, reflects this shift introducing measures of a person's functioning and participation <https://www.who.int/classifications/icf/en/>.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2011) enshrines universal rights for all people with disabilities. As important as the convention is, there is a danger as identified by Professor Tom Shakespeare (2013), that people with intellectual disability, who may be less able to represent their views and needs, may be overlooked within the rights movement as the voices and concerns of people with physical and sensory disability are foregrounded. Professors Jennifer Clegg and Chris Bigby (2017), used the term dedifferentiation to describe the shift away from a specific focus on intellectual disability to a position where broad commonalities of 'disability' predominate. Clegg and Bigby raised concerns that a focus on the rights and needs of people with disability as a broad group can obscure the diversity of those with intellectual disability and overshadow the additional support needs of this heterogeneous group. In particular, according to Clegg and Bigby, due to dedifferentiation the needs of people with the most severe and complex intellectual disabilities may be ignored and/or tokenistically represented by others.

In preparing this report, the difficulty of extracting data specific to people with intellectual disability was highlighted and it became evident that a major challenge in sourcing and accurately reporting on the population of people with intellectual disability was inconsistency in defining who and what this term refers to.

² The report does not cover data on medical and health outcomes for people with intellectual disability. Professor Julian Trollor from UNSW Sydney provided a statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability, which comprehensively addresses these topics.

Definitional issues

Variations in the definition of *intellectual disability* introduces challenges when interpreting available statistics. Definitions used in compilations of statistics on intellectual disability include clinical diagnosis, self- or proxy-reported diagnosis, assessed or reported IQ, support needs, and functioning (self- or proxy-reported difficulty learning or understanding things). In the research reviewed, clinical diagnoses have been made using the criteria in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5; American Psychiatric Association, 2013) and, for older data, the 4th edition of this manual (DSM-IV; American Psychiatric Association, 2000). In some cases, an intellectual disability diagnosis may have been self- or proxy-reported, such as in the hospital medical records with comorbidity codes of *intellectual disability*, *mental retardation*, and *pervasive developmental disorder* (e.g., Lee, Heffernan, McDonnell, Short, & Naganathan, 2016). Some researchers (e.g., Haysom, Indig, Moore, & Gaskin, 2014) administered measures of IQ and defined intellectual disability as full scale IQ scores below 70.

For some datasets, the collection of data on clinical diagnoses has been replaced with obtaining data on support needs (e.g., levels of educational need (Bourke, de Klerk, Smith, & Leonard, 2016)). Level of support needs may be associated with severity of disability. (Bourke et al., 2016) In national surveys, functional, rather than diagnostic, definitions of intellectual disability have usually been applied (Lee et al., 2016). Since 1981, the Australian Bureau of Statistics (ABS) has conducted quinquennial surveys on disability - the *Survey of Disability, Ageing and Carers (SDAC)*. These surveys provide widely-used and detailed information on the extent of disability in Australia, its effect on daily living and participation in the usual activities of the community, and the need for, and receipt of, assistance.

In the 2001 (and subsequent) full population census seven questions were added to collect information on the prevalence of disability in the Australian population. These questions were designed to be used in conjunction with the more detailed *SDAC* data. In both the census and *SDAC*, disability is defined as "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months" and intellectual disability as "difficulty learning or understanding things" (Australian Bureau of Statistics, 2019b). The conditions grouped under the umbrella term 'intellectual disability' included attention deficit disorder, attention deficit hyperactivity disorder, autism (all forms - including Asperger's syndrome), dementia (all forms), Down syndrome, dyslexia/reading disorder, dyslalia, epilepsy (all forms), head injury, intellectual disability, and stroke (Australian Bureau of Statistics, 2018). For the purposes of compiling this report, which has a focus on people with lifelong intellectual disability, this broad grouping of conditions affecting cognitive functioning makes the task of extracting information specific to the defined group difficult.

National Disability Data

A further challenge in preparing this report was the lack of a national central database collecting, compiling, analysing and reporting on data related to people with disability generally and people with intellectual disability specifically. Longitudinal data is especially lacking. In recognition of this lack of data, the Commonwealth, states, and territories are jointly developing a cross-jurisdictional national disability data set.

An 18-month pilot phase commenced in early 2020 to identify the most effective ways (and potential barriers and solutions) to share, link and access the data. The pilot will also focus on privacy protections such as methods for de-identification and information security. The pilot is co-governed by nine partners representing the Commonwealth and all states and territories, the National Disability Insurance Agency (NDIA) and the Australian Institute of Health and Welfare (AIHW). A Disability Advisory Council guides the pilot. The Council members have expertise in disability policy, advocacy, social investment, research, service provision, business, economics and law. The Council includes those with experience working with a wide range of people with disability, including people with complex needs, people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds, and people living in regional and remote communities.

When completed, this linked and shared data should provide a better understanding of how people with disability are supported across multiple service systems including services, payments and programs. Without consistent and 'joined up' data capacity for identifying and reporting on disability, the ability to measure, report on, and improve outcomes for people with disability is limited as demonstrated in the compilation of this report. It will be important to ensure that data related to specific disabilities, such as intellectual disability, are collected and reported in ways that allow comparison within and across datasets.

Search Method

Within the allocated time and budget constraints and accommodating definitional caveats and, in the absence of a central database, a systematic search of peer-reviewed literature and an environmental scan of relevant websites were conducted for the preparation of this report. In addition, several academics with expertise in intellectual disability research were contacted to verify search strategies and ensure potential sources of data were included.

Systematic searches were run on 17 August, 2020 involving four electronic databases (CINAHL, MEDLINE, PsycINFO, and Web of Science Core Collection) using search terms for *intellectual disability* and *Australia* (full search terms are provided in Appendix A). Limiters were set for language (English) and article type (peer-reviewed papers), and the searches were restricted to the year 2010 onwards. The searches returned 1,928 database entries, of which 1,001 were duplicates. Screening the titles and abstracts of the remaining 927 entries resulted in the exclusion of 896 papers. Further screening of the full texts of the remaining 31 papers resulted in 16 of them being excluded. The remaining 15 papers (Abdullahi, Wong, Bebbington, et al., 2019; Abdullahi, Wong, Mutch, et al., 2019; Aitken et al., 2019; Bourke et al., 2016; Carroll, Townsend, Brown, & Nankervis, 2015; Foley et al., 2013; Giudice-Nairn et al., 2019; Graham, 2012; Gray et al., 2014; Haysom et al., 2014; Lee et al., 2016; Man, Wade, & Llewellyn, 2017; Nielsens et al., 2018; Webber et al., 2010; Webber, McVilly, & Chan, 2011) were included in the review. The environmental scan involved searching government and disability-related websites for data related to intellectual disability. Sites included: the ABS, AIHW, NDIA, Department of Social Services, Department of Education, Skills and Employment, and specific disability organisation websites.

Findings

Prevalence of intellectual disability in Australia

The most recent national prevalence data were sourced from the ABS (2019a). In interpreting these statistics, as noted earlier, the definition of intellectual disability used by the ABS is broad and includes people with other forms of cognitive impairment besides lifelong intellectual disability. In addition to the ABS data, two studies by Australian academics, one from Western Australia and the other from New South Wales, are provided as they indicate consistency in prevalence estimates.

Table 1 Prevalence of Intellectual Disability in Australia

Source	Datasets	Sample	Measure	Findings
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	The prevalence of ID in was 17.0/1,000 live births (95% CI: 16.7, 17.4). This rate represents an increase from the prevalence rate calculated for births from 1983 to 1992 (with follow up to 1999) of 14.3/1,000 live births.
Lee et al. (2016)	Administrative data from the NSW Government departments of education, pensions, health, and disability	Approximately 57,000 with IDD receiving services in NSW in 2003	Mix of measures, including clinical/ medical assessment, IQ testing, comorbidity codes in hospital medical records, school information, and disability service assessments	The estimated prevalence of people with IDD receiving services in NSW was 85/10,000 people in 2003. By 2043, the researchers predicted that there will be 135,900 people with IDD in NSW, with a prevalence of 135/10,000 people.
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	Of the estimated 4.4 million people with disability in Australia (17.7% of the population), 6.5% had intellectual or developmental disorders (similar to 6.3% in 2015).

Note. CI=confidence interval, ID=intellectual disability, IDD=intellectual developmental disorders, NSW=New South Wales. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.”

Prevalence of intellectual disability internationally

To contextualise the Australian data, international evidence is included which indicates that the prevalence of intellectual disability is 10.37 per 1,000 population (95% confidence interval [CI]: 9.55 to 11.18) (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). In the meta-analysis of 52 studies that produced this prevalence rate, differences between studies were apparent. Prevalence rates were:

- Lower in higher income countries (9.21 per 1,000 population; 95% CI: 8.46 to 9.96), such as Australia, than in middle income (15.94 per 1,000 population; 95% CI: 13.56 to 18.32) and low income countries (16.41 per 1,000 population; 95% CI: 11.14 to 21.68);
- Higher in child/adolescent samples (18.30 per 1,000 population; 95% CI: 15.17 to 21.43) than adult samples (15.94 per 1,000 population; 95% CI: 13.56 to 18.32);
- Higher in random household surveys (15.78 per 1,000 population; 95% CI: 13.73 to 17.86) than in data from hospitals or administrative registries (9.35 per 1,000 population; 95% CI: 8.60 to 10.10) and school-based studies (7.04 per 1,000 population; 95% CI: 6.35 to 7.73);
- Lower when the American Psychiatric Association’s Diagnostic Statistical Manual (DSM) or the World Health Organization’s International Classification of Disease (ICD) were used for diagnosis (8.68 per 1,000 population; 95% CI: 7.89 to 9.48) or disability schedules (American Association on Intellectual and Developmental Disabilities; International Classification of Functioning, Disability and Health; or some disability criteria) were used (6.41 per 1,000 population; 95% CI: 4.89 to 7.93), than when the administration of psychological instruments was used in conjunction with clinical judgement (14.30 per 1,000 population; 95% CI: 12.70 to 15.91).

What these statistics serve to show are that the prevalence rates in most studies fall within a fairly narrow range, but that variations seem to occur due to multiple factors, such as the population in focus and how intellectual disability is measured.

Severity of intellectual disability

The ABS (2019a) and Western Australian study by Bourke and colleagues (2016) referred to in Table 1, also reported on severity of intellectual disability. Again, definitional differences make comparison of these data problematic. It was not possible to find data which included a breakdown by conditions associated with intellectual disability (e.g., Down syndrome, Fragile X syndrome etc.) or which reported multiple disability diagnosis.

Table 2 Severity of intellectual disability

Source	Datasets	Sample	Measure	Findings
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	Prevalence rates according to severity were: <ul style="list-style-type: none"> • mild or moderate ID (IQ=40-69) was 15.0/1,000 live births (95% CI: 14.6, 15.3) • severe ID (IQ<40) was 1.2/1,000 (95% CI: 1.1, 1.3) • unknown severity was 0.9/1,000 (95% CI: 0.8, 1.0).

				These rates represent an increase in prevalence from births between 1983 to 1992 (with follow up to 1999) of 10.6/1000 for mild or moderate ID, 1.4/1,000 for severe ID, and 2.3/1,000 for unknown ID.
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	As a percentage of the Australian population, 3.2% had profound limitations and 2.6% had severe limitations. ^b Of those with profound or severe limitations, 12.1% had intellectual or developmental disorders.

Note. CI=confidence interval, ID=intellectual disability.^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.”^b Profound limitation defined as “greatest need for help, that is, always needs help with at least one core activity.” Severe limitation defined as “needs help sometimes or has difficulty with a core activity.”

Demographics of people with intellectual disability

The following four tables provide demographic data related to age range, sex, and cultural diversity of people with intellectual disability in Australia. Data from the ABS (2019a) and the NSW study by Lee and colleagues (2016) reported in Table 3 shows that the majority of people with intellectual disability are aged under 40 years of age with the largest proportion aged between 5-14 years. With increased life expectancy due to better health care, lifestyle and environmental conditions, the Lee et al (2016) study projected an increase in the proportion of the population with intellectual disability in the 65+ age range from 10/10,000 (1.8%) in 2003 to 50/10,000 (6%) in 2023.

Age ranges

Table 3 Age ranges of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Lee et al. (2016)	Administrative data from the NSW Government departments of education, pensions, health, and disability	Approximately 57,000 with IDD receiving services in NSW in 2003	Mix of measures, including clinical/ medical assessment, IQ testing, comorbidity codes in hospital medical records, school information, and disability service assessments	<p>The estimated number (and prevalence, in brackets) of people with IDD receiving services in NSW in 2003 was:</p> <ul style="list-style-type: none"> • 32,000 aged 0-15y (240/10,000 people), representing 56.1% of people with IDD • 15,000 aged 16-39y (60/10,000 people), representing 26.3% of people with IDD • 9,000 aged 40-64y (40/10,000 people), representing 15.8% of people with IDD • 1,000 aged 65+y (10/10,000 people), representing 1.8% of people with IDD. <p>The researchers predicted that number (and prevalence, in brackets) of people with IDD in NSW in 2043 will be:</p> <ul style="list-style-type: none"> • 59,600 aged 0-15y (290/10,000 people), representing 43.9% of people with IDD • 42,500 aged 16-39y (110/10,000 people), representing 31.3% of people with IDD • 25,600 aged 40-64y (70/10,000 people),

				representing 18.8% of people with IDD <ul style="list-style-type: none"> 8,200 aged 65+y (50/10,000 people), representing 6.0% of people with IDD
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	ID was the most common grouping of disabilities affecting children (aged 0-14y). Of the 4.7 million children in Australia, an estimated 208,800 (4.5%) had ID. Of those aged 0-14y, ID was almost twice as common in boys (5.8%, n=137,800) than girls (3.1%, n=70,600). ID was more likely to be reported for children aged 5-14y (6.1%, n=189,200) than those aged 0-4y (1.1%, n=17,800).

Note.ID=intellectual disability, IDD=intellectual developmental disorders, NSW=New South Wales. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.

Sex

Data from the ABS (2019a) and Western Australian study by Bourke and colleagues (2016), are consistent in reporting that intellectual disability is more common among males than females. The ABS (2014) notes that this difference between males and females may possibly be due to the fact that boys have higher rates of some conditions that are more commonly associated with intellectual disability (e.g., autism) or may be more likely to be diagnosed with intellectual disability due to behaviours of concern identified at school.

Table 4 Ratio of males to females with intellectual disability

Source	Datasets	Sample	Measure	Findings
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	There were more males (65%) than females (35%) in the cohort. The prevalence rate was 21.7/1,000 for males and 12.2/1,000 for females. The prevalence ratio was 1.78 (95% CI: 1.71, 1.86).
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from	Self- or proxy-reported difficulty learning or	Of the 4.7 million children in Australia aged 0-14y, ID was estimated to be almost twice as common in boys (5.8%,

		cared accommodation)	understanding things ^a	n=137,800) than girls (3.1%, n=70,600).
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Note. CI=confidence interval, ID=intellectual disability. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.

Cultural diversity

Estimates of intellectual disability among Aboriginal and Torres Strait Islander people consistently show higher levels than for the non-Indigenous population. These data indicate differences between Aboriginal and Torres Strait Islander people living in metropolitan, regional, and remote areas and associations between intellectual disability and social disadvantage.

Table 5 Aboriginal and Torres Strait Islander people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Haysom et al. (2014)	Data collected as part of the NSW Young People in Custody Health Survey	295 young people, representing 65% of the NSW Juvenile Custodial Population from August to October 2009	Wechsler Adult Intelligence Scale – Fourth Edition (WAIS-IV) Australian and New Zealand Language Adaptation for young people aged 17 years and over	Results from the cognitive assessments (Full Scale IQ) were: <ul style="list-style-type: none"> • 13.6% (n=40) had extremely low IQ (<70) • 32.2% (n=95) had borderline IQ (70-79) • 31.5% (n=93) had low average IQ (80-89) • 21.4% (n=63) had average IQ (90-109) • 1.3% (n=4) had high average/superior IQ (≥110). Compared with non-Aboriginal young people (n=147), Aboriginal young people (n=148) had significantly lower Full Scale IQ scores (e.g., 20.3% vs 6.8% for Full Scale IQ<70). After adjusting for disparities in social disadvantage, however, Aboriginal origin was no longer a significant risk factor for ID (Full Scale IQ<70).
Carroll et al. (2015)	ABS’s National Aboriginal and Torres Strait Islander Social Survey, 2008 and National Health Survey, 2007–2008	Indigenous and non-Indigenous adults within Australia aged 18-64y	Self- or proxy-reported difficulty learning or understanding things ^a	National prevalence estimates of ID were: <ul style="list-style-type: none"> • 7.6% for Indigenous adults • 2.5% for non-indigenous adults. Estimates of ID with profound or severe core activity limitation were: <ul style="list-style-type: none"> • 2.1% for Indigenous adults • 0.8% for non-indigenous adults. Prevalence estimates for Indigenous and non-Indigenous Australians with ID by geographical location were: <ul style="list-style-type: none"> • 9.1% vs 2.3% for major cities • 8.9% vs 2.8% for regional areas

				<ul style="list-style-type: none"> • 3.4% vs 5.4%^b for remote areas.
ABS (2019c)	National Aboriginal and Torres Strait Islander Social Survey, 2014-15	Aboriginal and Torres Strait Islander people	Self- or proxy-reported difficulty learning or understanding things ^a	<p>For Aboriginal and Torres Strait Islander people aged 15+, an estimated 8% had intellectual impairments.</p> <p>Of the estimated 36,400 people with intellectual impairments, the distribution according to severity was as follows:</p> <ul style="list-style-type: none"> • 30.7% profound/severe disability^c (n=11,200) • 27.1% moderate/mild disability^c (n=9,900) • 42.1% other disability^c (n=15,300).
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	Aboriginal children had a higher prevalence rate (39.0/1,000 live births) than non-Aboriginal children (15.7/1,000).

Note. ABS=Australian Bureau of Statistics, CI=confidence interval, ID=intellectual disability. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.” ^b Estimate has a relative standard error of 25-50%, indicating it should be used with caution. ^c Profound=always needs help/supervision with core activities, severe=does not always need help with core activities, moderate=has difficulty with core activities, and mild=uses aids to assist with core activities.

The findings of two studies in Western Australia, are equivocal with respect to any possible association between intellectual disability and maternal country of birth (Abdullahi, Wong, Bebbington, et al., 2019; Abdullahi, Wong, Mutch, et al., 2019). Studies specifically reporting on the prevalence of intellectual disability among culturally and linguistically diverse groups are lacking.

Table 6 Maternal country of birth of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Abdullahi, Wong, Bebbington et al. (2019)	Western Australian Register for Autism Spectrum Disorders	4,776 cases notified to the Register between January 1999 and June 2017	DSM-IV and DSM-5 criteria	<p>Compared with children from Australian non-Indigenous mothers, risk of diagnosis with ID was higher among children with ASD whose mothers were foreign-born from:</p> <ul style="list-style-type: none"> • Low-income countries (RR=2.16; 95% CI 1.63, 2.86) • Lower-middle-income countries (RR=2.19; 95% CI 1.77, 2.70) • Upper-middle-income countries (RR=2.16; 95% CI 1.66, 2.81)

				<ul style="list-style-type: none"> High-income countries (RR=1.76; 95% CI 1.33, 2.32).
Abdullahi, Wong, Mutch et al. (2019)	Western Australia (WA) Mid-wives Notification System (MNS), the WA Birth Register, the Intellectual Disability Exploring Answers (IDEA) database, and the WA Register of Developmental Anomalies (WARDA)	765,064 singleton livebirths in Western Australia from 1980 to 2010	Various criteria based on IQ and cognitive functioning	Adjusted analyses showed no associations between ASD with intellectual disability and mothers who were foreign born. In addition, the relative risk of intellectual disability only was lower for children of foreign-born mothers from lower-middle-income countries than for children of Australian-born mothers of non-indigenous backgrounds for children born from 1980 to 1996 (aRRR=0.67; 95% CI 0.56, 0.80) and those born from 1997 to 2010 (aRRR=0.73; 95% CI 0.57, 0.92).

Note. ASD= autism spectrum disorders. CI=confidence interval, ID=intellectual disability. ^a Estimate has a relative standard error of 25-50%, indicating it should be used with caution.

Government support of people with intellectual disability

Access to government data reporting on the support provided to people with intellectual disability was difficult to source within the time-period and resources available. The Department of Social Services website <https://www.dss.gov.au/disability-and-carers/publications-articles> provides information about available financial support for people with disability and carers but there is a lack of readily available data on the numbers and breakdown of people with disability accessing this support. In collecting data on people with people with intellectual disability, DSS uses the following definition “[Intellectual disability] applies to medical conditions appearing in the developmental period (age 0-18) associated with impairment of mental functions, difficulties in learning and performing certain daily life skills and limitation of adaptive skills in the context of community environments compared to others of the same age. Intellectual disability may be associated with Down syndrome, autism, etc.” (Australian Government Disability Services Census, 2008, p. 148). In the absence of access to data, some sections below only report eligibility criteria.

Disability Support Pension

The Department of Social Services administers the Disability Support Pension (DSP). According to the DSP demographic data tables (June, 2020) “DSP is an income support payment for people who are unable to work for 15 hours or more per week at or above the relevant minimum wage, independent of a Program of Support due to permanent physical, intellectual or psychiatric impairment. A DSP claimant must be aged 16 years or over and under Age Pension age at date of claim, however once in receipt of DSP, a person can continue to receive DSP beyond Age Pension age”. Eligibility for DSP is assessed based on Work-related Impairment Tables (updated in 2011). Table 9 defines intellectual disability eligibility as “low intellectual function (IQ scores of 70 to 85) resulting in functional impairment, which originated before the person turned 18 years old.” Assessment is conducted, after the person turns 16 years of age, by a qualified clinical psychologist using Wechsler Adult Intelligence Scale IV (WAIS IV) or equivalent contemporary assessment. An assessment of adaptive behaviour is also required in the form of either the Adaptive Behaviour Assessment System (ABAS-II), the Scales for Independent Behaviour – Revised (SIB-R), the Vineland Adaptive Behaviour Scales (Vineland-II) or any other standardised assessment of adaptive behaviour. Assessors use the Assessment Tables to report on the impact of intellectual disability on intellectual function according to: “no (impact), mild, moderate, severe and extreme”.

The June 2020 DSP demographic data tables report people with “intellectual/learning” disability as the third largest group of the total 754,181 DSP recipients (after “psychological/psychiatric” and “musculo-skeletal and connective tissue”). In the 12 months to June 2020, a total of 113,410 people with “intellectual/learning” disability received the DSP with the majority (66,589) male and aged 25-54 years (71,239). <https://data.gov.au/search?q=DSS>

Disability Services Data Collection

The Disability Services Data Collection (formerly known as the Disability Services Census), collects information each year from disability services funded by the Department of Social Services including: supported employment services (also known as Australian Disability Enterprises), advocacy services, respite services for carers of young people with severe or profound disabilities, information/referral services, and alternative formats of communication (including print disability services).

Disability Employment Services – are funded through The Department of Social Services to assist people with disability to find and keep employment. Disability Employment Services (DES) providers include for-profit and not-for-profit organisations. DES providers have experience supporting people with disability and working with employers to ensure their practices support the employee in the workplace. Disability Employment Services are divided according to:

- Disability Management Services (DMS) for “job seekers with disability, injury or health condition who need assistance to find a job and occasional support in the workplace to keep a job”.
- Employment Support Service (ESS) “provides assistance to job seekers with permanent disability to find a job and who need regular, ongoing support in the workplace to keep a job.”

The Disability Employment Services summary report for the month of August 2020 indicated that 3.4% (10,028) of those using DES had intellectual disability. Of these, 357 were receiving DMS support and 9,671 ESS support. Caseload characteristics are not cross-tabulated by disability type so further interrogation of the data specific to those with intellectual disability was not possible.

<https://lmip.gov.au/default.aspx?LMIP/Downloads/DisabilityEmploymentServicesData/MonthlyData>

Department of Education Skills and Employment

The annual Nationally Consistent Collection of Data on School Students with Disability (NCCD) collects information about Australian school students who receive an adjustment to address disability <https://www.education.gov.au/what-nationally-consistent-collection-data-school-students-disability> The term ‘cognitive disability’ is used to describe “total or partial loss of a person’s bodily or mental functions and a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction”.

National Disability Insurance Scheme (NDIS)

In early 2020, the NDIA released the report *People with Intellectual Disability in the NDIS* (NDIA, 2020). According to the report, as of 31 December 2019, people with intellectual disability represented almost 40% (109,138 people) of all participants with an approved plan. Of these, 78,992 participants reported intellectual disability as their primary disability, making up 23.3% of all Scheme participants with an approved plan. The majority of participants reporting intellectual disability as their primary disability were previously receiving Commonwealth or state and territory support. The proportion of participants with a primary intellectual disability who met the access requirements were reasonably consistent across all states and territories. In contrast with the ABS (2019a) data on age distribution of people with intellectual disability, the NDIS reported that, compared to all Scheme participants, a considerably lower proportion of participants with an intellectual disability were aged 0-14 years. Most Scheme users with intellectual disability as a primary or secondary disability were aged 15-44 years. The proportion of NDIS participants with an intellectual disability who identified as Aboriginal and Torres Strait Islander (6.9%) was slightly higher than that of all participants of the Scheme (6.1%), with the greatest difference reported in the Northern Territory. There was a lower proportion of participants with a primary intellectual disability who identified as Culturally and Linguistically Diverse (6.8%) compared to all participants within the Scheme (8.9%).

Restricted Decision-Making

Guardianship

Guardianship is the term given to “the regime of control, management and substitute decision-making exercised by another person on behalf of a person with decision-making disability who does not have capacity and is in need of such support”. Guardianship can be informal through adult family members, and/or formal through a publicly appointed guardian or advocate. Guardianship includes decisions about welfare and health but does not cover decisions about financial affairs as these are matters for a financial manager (may also be called an administrator).

http://www.idrs.org.au/pdf/Guardianship_and_administration_laws_across_Australia_by_Ben_Fogarty.pdf

Restrictive practices

Some people with intellectual disability may display behaviours of concern resulting in development of behaviour support strategies. Behaviours of concern (also known as challenging behaviours) include aggression toward others, self-injury including unintentional or deliberate self-harm, or destruction of property. Behaviour support strategies to address behaviours of concern may include a set of practices identified as restrictive practices. These practices effectively restrict a person’s rights or freedom and may include environmental restraint, physical restraint, mechanical restraint, chemical restraint and seclusion. Behaviour support plans that include a restrictive practice, must be developed by a registered behaviour support practitioner and approved by a mechanism for restrictive practice authorisation. The use and effectiveness of restrictive practices, which were inconsistently regulated across Australia, may be considered a contravention of an individual’s human rights as articulated in the UNCPRD. The Australian Law Reform Commission (2014) identified the need for a nationally consistent approach to the regulation of restrictive practices. Consequently, in 2016, the NDIS Quality and Safeguarding Framework was agreed to by all states and territories at the Council of Australian Governments to work towards the reduction and elimination of restrictive practices.

Two studies by Webber and colleagues (2010; 2011) reported on Victorian data for people with intellectual disabilities receiving restrictive practices. The restrictive practices included chemical and mechanical restraint and seclusion.

Table 7 Chemical and mechanical restraint and seclusion of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Webber et al. (2010)	Database of cases of chemical or mechanical restraint or seclusion reported to the Senior Practitioner of Victoria’s Department of Human Services	27 people with ID who were in receipt of compulsory treatment orders (CTOs) during the year from July 2008 to June 2009 and a sample matched for age and	Measure of ID not reported	Comparing people with ID on CTOs with the matched sample, people with ID on CTOs: <ul style="list-style-type: none"> • Were subjected to chemical restraint (96% vs 98%) and mechanical restraint (4% to 11%) in similar proportions as the matched sample, but were more likely to be subjected to seclusion (44% vs 5%) • Received more administrations of four types of medications: (1) anti-androgens (47% more), (2)

		gender in receipt of restrictive practices (n=498)		anticholinergic (45% more), (3) mood stabilizers (38% more), and (4) antidepressants (33% more) <ul style="list-style-type: none"> • Received fewer administrations of two types of medications: (1) benzodiazepines (68% less) and (2) sedatives (87% less).
Webber et al. (2011)	Database of cases of chemical or mechanical restraint or seclusion reported to the Senior Practitioner of Victoria's Department of Human Services	30,932 episodes of restrictive interventions relating to behaviour interventions involving 2,102 people during the year June 2007–July 2008	Measure of ID not reported	<ul style="list-style-type: none"> • The 2,012 people subjected to restrictive interventions represent approximately 9% of people with ID in Victoria who were in receipt of government-funded disability support services • Restraints were either routine (65.5% of episodes involving 94% of people), PRN (27.0% of episodes involving 27% of people), emergency (7.5% of episodes involving 23% of people). • Restrictive practices were either chemical restraints (82.7% of episodes involving 96.2% of people), mechanical restraints (11.2% of episodes involving 9.0% of people), or seclusion (7.6% of episodes involving 7.0% of people) • 10.7% of people received more than one type of restrictive practice.

Note. ID=intellectual disability, PRN=pro re nata (as required).

Schooling

As previously reported, within the available time and resources, no publicly available information was found on the Department of Education, Skills and Employment website that provided data on the number or characteristics of people with intellectual disability in mainstream education (public, independent or Catholic), segregated settings, or being home schooled. One peer-reviewed article by Graham (2012) provided information comparing enrolment of Indigenous children in NSW Schools for Specific Purposes. Graham noted the difficulties of accessing education data.

Table 8 NSW Indigenous children in schools for specific purposes

Source	Datasets	Sample	Measure	Findings
Graham (2012)	NSW DET Schools Locator database, My School website, school websites and annual reports, plus other sources	4,466 students enrolled in 113 Schools for Specific Purposes in 2009	Inferred from enrolment at traditional Schools for Specific Purposes	Indigenous Australian children have equal chances of being enrolled at traditional Schools for Specific Purposes (serving children with autism or intellectual, physical, and sensory disabilities) as non-Indigenous children.

Note. ID=intellectual disability, NSW DET=New South Wales Department of Education and Training

Employment

According to the ABS (2012), of the estimated 4 million Australians with disability, 2.2 million were of 'prime working age' between 15-64 years. Levels of employment for people with disability are declining with workforce participation for this group dropping from 54.9% in 1993 to 52.8% in 2012 (Australian Bureau of Statistics, 2012). The UNCRPD (United Nations, 2011) recognises persons with disabilities have the right to work on an equal basis with others. The Australian government's National Disability Strategy 2010-2020 (Council of Australian Governments, 2011) similarly identifies the importance of paid employment to economic security, social inclusion, physical and mental health and wellbeing, and sense of identity. Hence, increasing access to employment opportunities for people with disability is crucial to increasing economic security and personal wellbeing. People with disability, including many with intellectual disability, want to work (Department of Education Employment and Workplace Relations, 2009). Barriers to their employment exist both at the systemic policy level and at the employer level. At the systemic policy level, despite government recognition of the importance and value of employment for people with disability, translating this into practice remains a challenge with Australia ranked 21 of 29 OECD countries in employment of people with disability (PWC, 2011).

The NDIA (2020) report on people with intellectual disability notes that for Scheme participants over the previous two years, the percentage with a primary intellectual disability in paid work increased from a baseline of 18% to 25% in year two for those aged 15 to 24, and decreased from a baseline of 38% to 36% for those aged 25 and over. Overall, the percentage of participants with a primary intellectual disability in employment remained stable and higher than the full Scheme at 33%. The ABS (2019a, 2020a) data reported in Table 9, indicated 14 – 18% of people with intellectual disability aged 15 – 64 years were in full or part time employment and 60% were not in the labour market.

Table 9 Employment of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Foley et al. (2013)	Survey sent to families identified through the population-based Down Syndrome Needs Opinions Wishes study in Western Australia	203 families of people with Down syndrome aged 15-30y in 2009, 164 of whom had left school	Diagnosis	Post-school, the young people with Down syndrome were engaged in: <ul style="list-style-type: none"> • Sheltered employment (39.0%) • Open employment (25.6%) • Alternatives to employment (25.0%) • Training (10.4%).
Gray et al. (2014)	Australian Child to Adult Development Study in NSW and Victoria	354 people with ID aged 20.5-37.6y when followed up at Wave 5 in 2008-2009 (Wave 1: 1991-1992)	Diagnosis, with severity based on the results of existing cognitive assessments and DSM-IV ranges	Living circumstances at Wave 5: <ul style="list-style-type: none"> • Mild impairment (IQ=50-69) <ul style="list-style-type: none"> - Mainstream ^a (21.6%, n=24; Wave 1: 29.5%) - Non-mainstream ^b (65.8%, n=73; Wave 1: 70.5%) - No organised activity (12.6%, n=14; Wave 1: 0%)

				<ul style="list-style-type: none"> • Moderate impairment (IQ=36-49) <ul style="list-style-type: none"> - Mainstream ^a (16.0%, n=25; Wave 1: 17.5%) - Non-mainstream ^b (79.5%, n=124; Wave 1: 81.9%) - No organised activity (4.5%, n=7; Wave 1: 0.6%) • Severe impairment (IQ=20-35) <ul style="list-style-type: none"> - Mainstream ^a (0%, n=0; Wave 1: 4.3%) - Non-mainstream ^b (96.0%, n=72; Wave 1: 95.7%) - No organised activity (4.0%, n=3; Wave 1: 0%) • Profound impairment (IQ<20) <ul style="list-style-type: none"> - Non-mainstream ^b (100%, n=8; Wave 1: 100%).
ABS (2019a, 2020a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^c	<p>The labour force statuses of the estimated 327,600 people with ID aged 15-64y living in households were (percentages for people with disability provided in parentheses for comparison):</p> <ul style="list-style-type: none"> • 13.8% employed full-time (28.3%) • 18.2% employed part-time (19.6%) • 5.5% underemployed (4.8%) • 6.9% unemployed (5.5%) • 61.2% not in the labour force (46.6%)

Note. DSM= Diagnostic and Statistical Manual of Mental Disorders, ID=intellectual disability, NSW=New South Wales. ^a Mainstream=mainstream daytime activity (e.g. mainstream school, technical and vocational training, or a paid job), ^b Non-mainstream= activities specifically for people with ID (e.g. special school, special unit in a mainstream school, day activity programme or sheltered workshop). ^c Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.”

Living situations

The NDIA (2020) report on intellectual disability noted that a higher proportion of Scheme participants with a primary intellectual disability live in supported independent living (17%) compared to all participants of the Scheme (7%). The report notes that “As a result, total average committed supports are higher for participants with an intellectual disability. Notably, the utilisation of core supports for participants with a primary intellectual disability receiving supported independent living supports is much higher (89%) compared to those that do not have such supports in their plan (67%)” (p. 23).

Three studies were found in the peer-reviewed literature reporting on living situations for people with intellectual disability. These studies reported on very different aspects of housing using different data sources making any comparative comments difficult. The study by Gray and colleagues (2014) used data from the NSW and Victorian Australian Child to Adult Development Study demonstrating that people with mild and moderate levels of intellectual disability were more likely to be living at home than those with severe or profound intellectual disability who were more likely to be living in care. A study by Aitken and colleagues published in 2019 reported on data from the Household, Income and Labour Dynamics Australia (HILDA) Survey showing that of the 109 respondents with intellectual disability, the majority (34%) were living in housing owned outright but that this housing was in poor condition. A study by Nielsson and colleagues (2018), reviewed the medical records of people accessing mental health clinics in homeless hostels in central Sydney and showed that 5% of residents had an intellectual disability with 62% of this group having been homeless for a year or more.

Table 10 Living circumstances of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Gray et al. (2014)	Australian Child to Adult Development Study in NSW and Victoria	354 people with ID aged 20.5-37.6y when followed up at Wave 5 in 2008-2009 (Wave 1: 1991-1992)	Diagnosis, with severity based on the results of existing cognitive assessments and DSM-IV ranges	<p>Living circumstances at Wave 5:</p> <ul style="list-style-type: none"> • Mild impairment (IQ=50-69) <ul style="list-style-type: none"> - Home ^a (76.6%, n=85; Wave 1: 94.7%) - Care ^b (9.9%, n=11; Wave 1: 5.3%) - Independent (13.5%, n=15; Wave 1: 0%) • Moderate impairment (IQ=36-49) <ul style="list-style-type: none"> - Home ^a (69.9%, n=109; Wave 1: 90.3%) - Care ^b (19.2%, n=30; Wave 1: 9.7%) - Independent (10.9%, n=17; Wave 1: 0%) • Severe impairment (IQ=20-35) <ul style="list-style-type: none"> - Home ^a (26.7%, n=20; Wave 1: 63.9%) - Care ^b (73.3%, n=55; Wave 1: 36.1%) • Profound impairment (IQ<20)

				<ul style="list-style-type: none"> - Home ^a (2.5%, n=1; Wave 1: 47.1%) - Care ^b (87.5%, n=7; Wave 1: 52.9%).
Nielssen et al. (2018)	Medical records of a consecutive sample of people presenting to mental health clinics at the three large homeless hostels in inner city Sydney between 21 July 2008 and 31 December 2016	2,388 patients, 119 (5.0%) of whom had ID	Psychiatric diagnosis (no further information provided)	<p>Of the 119 people with ID, 74 (62.2%) had been homeless for more than a year. The pathways to homelessness of the 45 people with ID who had been homeless for less than a year were:</p> <ul style="list-style-type: none"> • Loss of other accommodation (40.0%, n=18) • Loss of public housing (26.7%, n=12) • Release from prison (24.4%, n=11) • Discharge from psychiatric hospital (8.9%, n=4). <p>In comparison, 1,314 (57.9%) of people without ID had been homeless for more than a year. The pathways to homelessness of the 955 people without ID who had been homeless for less than a year were:</p> <ul style="list-style-type: none"> • Loss of other accommodation (46.5%, n=444) • Loss of public housing (20.4%, n=195) • Release from prison (20.8%, n=199) • Discharge from psychiatric hospital (12.3%, n=117).
Aiken et al. (2019)	Household, Income and Labour Dynamics Australia (HILDA) Survey (11 th wave)	17,612 individuals aged 25-64y; 109 with intellectual impairment	Reported functional impairment relating to difficulty learning or understanding things affecting everyday activities having lasted, or expected to	<p>Compared to people without disability, those with intellectual impairment were more likely to be:</p> <ul style="list-style-type: none"> • Living in homes that were owned outright (33.9% vs 24.0%) • Public renters (18.4% vs 1.5%) • Living in unaffordable housing (19.1% vs 7.6%) • Living in homes that are derelict, very poor, poor, or average quality (41.8% vs 30.5%). <p>They were less likely to be:</p>

			last, 6 months or more	<ul style="list-style-type: none"> • Living in homes with mortgages (20.3% vs 42.7%). <p>No difference between people with intellectual impairment and those without disability for:</p> <ul style="list-style-type: none"> • Private renting (26.1% vs 29.5%).
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Note. DSM= Diagnostic and Statistical Manual of Mental Disorders, ID=intellectual disability, NSW=New South Wales. ^a At home with family (or foster parents), ^b In care (group home or large residential).

Custody

Professor Leanne Dowse and colleagues (2014) at UNSW Sydney (2014) note that estimates of the prevalence of intellectual disability among prisoner populations vary significantly depending on how intellectual disability is defined. They cite a 2011 study estimating that 77% of NSW juvenile detainees scored below the average range of intelligence functioning. Significantly, 20% of young Indigenous persons in custody had an intellectual disability and 39% were reported to be in the borderline intellectual disability range. Table 11 includes a study by Haysom and colleagues (2014) which reported on the population of young people in NSW juvenile custody in 2009 indicating that 46% were identified as having borderline or extremely low IQ.

Table 11 People with intellectual disability in custody

Source	Datasets	Sample	Measure	Findings
Haysom et al. (2014)	Data collected as part of the NSW Young People in Custody Health Survey	295 young people, representing 65% of the NSW Juvenile Custodial Population from August to October 2009	Wechsler Adult Intelligence Scale – Fourth Edition (WAIS-IV) Australian and New Zealand Language Adaptation for young people aged 17 years and over	<p>Results from the cognitive assessments (Full Scale IQ) were:</p> <ul style="list-style-type: none"> • 13.6% (n=40) had extremely low IQ (<70) • 32.2% (n=95) had borderline IQ (70-79) • 31.5% (n=93) had low average IQ (80-89) • 21.4% (n=63) had average IQ (90-109) • 1.3% (n=4) had high average/superior IQ (≥110). <p>Compared with non-Aboriginal young people (n=147), Aboriginal young people (n=148) had significantly lower Full Scale IQ scores (e.g., 20.3% vs 6.8% for Full Scale IQ<70). After adjusting for disparities in social disadvantage, however, Aboriginal origin was no longer a significant risk factor for ID (Full Scale IQ<70).</p>

Parents with intellectual disability

An under, but increasingly reported cohort includes people with intellectual disability with children. Table 12 includes a study by Man and colleagues (2017) which estimated a prevalence of parenthood at 8.0% of people with intellectual disability.

Table 12 Parents with intellectual disability

Source	Datasets	Sample	Measure	Findings
Man et al. (2017)	ABS's Survey of Disability, Ageing and Carers, 2009	61,900 survey participants in 24,800 private dwelling households sampled from April to December 2009 (number with ID unreported)	Self- or proxy-reported difficulty learning and understanding things	An estimated 17,000 (95% CI: 11,500, 22,400) people with ID aged 15-64y in private dwellings were parents. The prevalence of parenthood was 8.0% (95% CI: 5.9% 10.8%) of people with ID. Of all parents in Australia aged 15-64y and living in private dwellings, an estimated 0.41% (95% CI: 0.30%, 0.57%) had ID. Compared with people with ID, the likelihood of parenthood was greater for: <ul style="list-style-type: none"> • People with other disabilities (OR=3.1; 95% CI: 2.2, 4.4) • People without disability (OR=5.0: 95% CI: 3.6, 6.9).

Note. ABS=Australian Bureau of Statistics, CI=confidence interval, ID=intellectual disability.

Access to technology

Table 13 reports data from the ABS SDAC (2019a, 2020b) indicating that, over a three month period, almost 65% of people with intellectual disability aged 15+ years had used the internet, 51% had used SMS, 41% had used social media, and 20% had used email.

Table 13 People with intellectual disability with access to technology

Source	Datasets	Sample	Measure	Findings
ABS (2019a, 2020b)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	<p>With respect to the last 3 months, of the estimated 432,500 people with ID in Australia aged 15+ and living in households (percentages for people with disability and primary carers, respectively, given in parentheses):</p> <ul style="list-style-type: none"> • 64.9% had used the internet (71.5%, 85.5%) • 50.9% had SMS contact with family or friends not living in same household (61.9%, 76.3%) • 40.7% had social networking/chat room contact with family or friends not living in same household (42.3%, 53.8%) • 20.1% had email contact with family or friends not living in the same household (39.8%, 49.0%). <p>Reasons given for people with ID not using the internet in the past 3 months were (percentages for people with disability and primary carers, respectively, given in parentheses):</p> <ul style="list-style-type: none"> • Have no need/no interest, 8.4% (2.2%, 8.5%) • No access to a computer or mobile technology, 19% (6.2%, 15.2%) • Cost, 29.8% (14.6%, 37.6%) • Privacy or security concerns, N/A (18.1%, N/A) • Lack of confidence/knowledge in accessing the internet, 10.7% (5%, 15.6%) • Can rely on friends/family to use the internet for them, 17% (7.4%, 23.1%)

				<ul style="list-style-type: none"> • Lack of assistive technology, np% (20.9%, 47.7%) • No time, 0% (23.9%, N/A) • Internet services not available/of too poor quality for use in local area, 48.2% (20.2%, 39.4%) • Other reason, 12.6% (8.6%, N/A)
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Note. N/A=not available for publication. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.

Gaps and Recommendations

The compilation of data for this report, highlighted the difficulties in accessing reliable and comparable information about people with intellectual disability in Australia. As noted previously, there is a need for agreement on definitions of intellectual disability to inform consistent data collection at Commonwealth and state and territory levels to enable comparison and accurate reporting to inform the provision of relevant supports and services including advocacy.

Gaps

We were unable to find any publicly available data to report on the breakdown of prevalence by specific conditions (e.g., Down syndrome, Fragile X syndrome). Similarly, data indicating multiple diagnoses is lacking. Government data related to those with intellectual disability in aged care, and those receiving education and skills training, those with Guardianship and financial management is similarly lacking. A breakdown of the numbers and types of accommodation for people with intellectual disability is not available.

Recommendation

The proposed National Disability Data Set should go some way to filling these gaps but only if data are recorded and reported in ways that are meaningful to researchers, advocacy groups, policy makers, and others who seek to use it including using consistent definitions to assist with identifying those who have lifelong intellectual disability.

Appendix A: Search terms and result numbers

(N= 1,928)

MH "Intellectual Disability+" OR TI ("intellectual* disab*" OR "learning disab*") OR AB ("intellectual* disab*" OR "learning disab*")

AND

MH "Australia+" OR TI (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart)

Limits: 2010-, English language

MEDLINE results: 525

MH "Intellectual Disability+" OR TI ("intellectual* disab*" OR "learning disab*") OR AB ("intellectual* disab*" OR "learning disab*")

AND

MH "Australia+" OR TI (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart)

Limits: 2010-, English language

CINAHL results: 611

DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease" OR TI ("intellectual* disab*" OR "learning disab*") OR AB ("intellectual* disab*" OR "learning disab*")

AND

TI (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart)

Limits: 2010-, English language, peer reviewed

PsycInfo results: 345

(TI=("intellectual* disab*" OR "learning disab*") OR AB=("intellectual* disab*" OR "learning disab*")) AND (TI=(Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB=(Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart))

Limits: 2010-, English language, articles

Web of Science Core Collection results: 447

References

- Abdullahi, I., Wong, K., Bebbington, K., Mutch, R., de Klerk, N., Cherian, S., . . . Glasson, E. J. (2019). Diagnosis of Autism Spectrum Disorder According to Maternal-Race Ethnicity and Country of Birth: A Register-Based Study. *Journal of Autism & Developmental Disorders, 49*(9), 3611-3624. doi: 10.1007/s10803-019-04068-z
- Abdullahi, I., Wong, K., Mutch, R., Glasson, E. J., de Klerk, N., Cherian, S., . . . Leonard, H. (2019). Risk of Developmental Disorders in Children of Immigrant Mothers: A Population-Based Data Linkage Evaluation. *Journal of Pediatrics, 204*, 275-275. doi: 10.1016/j.jpeds.2018.08.047
- Aitken, Z., Baker, E., Badland, H., Mason, K., Bentley, R., Beer, A., & Kavanagh, A. M. (2019). Precariously placed: housing affordability, quality and satisfaction of Australians with disabilities. *Disability & Society, 34*(1), 121-142. doi: 10.1080/09687599.2018.1521333
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4th ed., Text Revision)*. Washington, DC: APA.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: APA.
- Australian Bureau of Statistics. (2012). Disability and Labour Force Participation (cat. no. 4433.0.55.006). Retrieved August 31, 2020, from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4433.0.55.006>
- Australian Bureau of Statistics. (2014). Intellectual Disability, Australia, 2012 (cat. no. 4433.0.55.003). Retrieved August 3, 2020, from <https://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/4433.0.55.003?OpenDocument>
- Australian Bureau of Statistics. (2018). Survey of disability, ageing and carers (SDAC 18): Household survey questionnaire [cat. no. 4430.0]. Canberra: ABS.
- Australian Bureau of Statistics. (2019a). Disability, ageing and carers, Australia: Summary of findings, 2018 (cat. no. 4430.0). Retrieved September 1, 2020, from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features152018?OpenDocument#>
- Australian Bureau of Statistics. (2019b). Disability, ageing and carers, Australia: Summary of findings, 2018 (cat. no. 4430.0). Retrieved August 30, 2020, from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4430.0Main%20Features52018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>
- Australian Bureau of Statistics. (2019c). National Aboriginal and Torres Strait Islander Social Survey, 2014-15 (cat. no. 4714.0). Retrieved August 3, 2020, from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4714.0Main+Features100022014-15?OpenDocument>
- Australian Bureau of Statistics. (2020a). 44300DO085_2018 Survey of Disability, Ageing and Carers: Use of technology (data cube for cat. no. 4430.0). Retrieved September 1, 2020, from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02018?OpenDocument>

- Australian Bureau of Statistics. (2020b). 44300DO090_2018 Survey of Disability, Ageing and Carers: Use of technology (data cube for cat. no. 4430.0). Retrieved September 1, 2020, from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02018?OpenDocument>
- Australian Law Reform Commission. (2014). Equality, Capacity and Disability in Commonwealth Laws (DP 81). Sydney: ALRC.
- Bourke, J., de Klerk, N., Smith, T., & Leonard, H. (2016). Population-Based Prevalence of Intellectual Disability and Autism Spectrum Disorders in Western Australia A Comparison With Previous Estimates. *Medicine*, 95(21), 1-8. doi: 10.1097/MD.00000000000003737
- Carroll, M., Townsend, C., Brown, A., & Nankervis, K. (2015). Population statistics as a source of intellectual disability prevalence data and possible indicators of co-occurring challenging behaviour in Indigenous adults. *Journal of Intellectual & Developmental Disability*, 40(3), 304-308. doi: 10.3109/13668250.2015.1041465
- Clegg, J., & Bigby, C. (2017). Debates about dedifferentiation: Twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group. *Research and Practice in Intellectual and Developmental Disabilities*, 4, 80-97.
- Council of Australian Governments. (2011). 2010 - 2020 National Disability Strategy. Retrieved August 21, 2020, from <https://www.dss.gov.au/ourresponsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>
- Department of Education Employment and Workplace Relations. (2009). National Mental Health and Disability Employment Strategy: Commonwealth of Australia.
- Dowse, L., Cumming, T. M., Strnadová, I., Lee, J.-S., & Trofimovs, J. (2014). Young People with Complex Needs in the Criminal Justice System. *Research and Practice in Intellectual and Developmental Disabilities*, 1(2), 174-185. doi: 10.1080/23297018.2014.953671
- Foley, K. R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., . . . Leonard, H. (2013). Functioning and post-school transition outcomes for young people with Down syndrome. *Child: Care, Health & Development*, 39(6), 789-800. doi: 10.1111/cch.12019
- Giudice-Nairn, P., Downs, J., Wong, K., Wilson, D., Ta, D., Gattas, M., . . . Kirrali-Borri, C. (2019). The incidence, prevalence and clinical features of MECP2 duplication syndrome in Australian children. *Journal of Paediatrics & Child Health*, 55(11), 1315-1322. doi: 10.1111/jpc.14399
- Graham, L. J. (2012). Disproportionate over-representation of Indigenous students in New South Wales government special schools. *Cambridge Journal of Education*, 42(2), 163-176. doi: 10.1080/0305764X.2012.676625
- Gray, K. M., Piccinin, A., Keating, C. M., Taffe, J., Parmenter, T. R., Hofer, S., . . . Tonge, B. J. (2014). Outcomes in young adulthood: are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*, 58(8), 734-745. doi: 10.1111/jir.12069
- Haysom, L., Indig, D., Moore, E., & Gaskin, C. (2014). Intellectual disability in young people in custody in New South Wales, Australia - prevalence and markers. *Journal of Intellectual Disability Research*, 58(11), 1004-1014. doi: 10.1111/jir.12109
- Lee, L., Heffernan, M., McDonnell, G., Short, S. D., & Naganathan, V. (2016). A system dynamics modelling approach to studying the increasing prevalence of people with intellectual

- developmental disorders in New South Wales. *Australian Health Review*, 40(3), 235-243. doi: 10.1071/AH14150
- Man, N. W., Wade, C., & Llewellyn, G. (2017). Prevalence of parents with intellectual disability in Australia. *Journal of Intellectual & Developmental Disability*, 42(2), 173-179. doi: 10.3109/13668250.2016.1218448
- Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities*, 32, 419-436. doi: <https://doi.org/10.1016/j.ridd.2010.12.018>
- National Disability Insurance Agency. (2020). People with Intellectual Disability in the NDIS 31st December, 2019.
- Nielsen, O. B., Stone, W., Jones, N. M., Challis, S., Nielsen, A., Elliott, G., . . . Large, M. M. (2018). Characteristics of people attending psychiatric clinics in inner Sydney homeless hostels. *Medical Journal of Australia*, 208(4), 169-173. doi: 10.5694/mja17.00858
- PWC. (2011). Disability Expectations: Investing in a Better Life, a Stronger Australia. Retrieved August 21, 2020, from <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>
- Shakespeare, T. (2013). *Disability rights and wrongs revisited (2nd ed.)*. London: Routledge.
- United Nations. (2011). Convention on the rights of persons with disabilities. New York, 13 December 2006. Treaty series. New York, NY: United Nations.
- Webber, L. S., Lambrick, F., Donley, M., Buchholtz, M., Chan, J. B., Carracher, R., & Patel, G. (2010). Restraint and seclusion of people on compulsory treatment orders in Victoria, Australia in 2008-2009. *Psychiatry, Psychology and Law*, 17(4), 562-573. doi: 10.1080/13218719.2010.498770
- Webber, L. S., McVilly, K. R., & Chan, J. (2011). Restrictive Interventions for People with a Disability Exhibiting Challenging Behaviours: Analysis of a Population Database. *Journal of Applied Research in Intellectual Disabilities*, 24(6), 495-507. doi: 10.1111/j.1468-3148.2011.00635.x

Gathering the Evidence: A limited literature review on violence, abuse, neglect and exploitation experienced by Australians with intellectual disability

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1. Background

In Australia, approximately 668,100 Australians (2.9%) were identified as having an **intellectual disability** in 2012 (Australian Bureau of Statistics, 2012). However, it can be difficult to determine what this means in practice. This is partly because *intellectual disability* itself is a contested concept, understood in several different ways. From a medical perspective, intellectual disability is characterised by an IQ of 70 or under plus deficits in adaptive behaviours such as communication or learning (Intellectual Disability Rights Service, 2009). In response to this medicalised approach, the social model of disability was presented by disability advocates to highlight the social and environmental construction of disability. The social model was a critique of the individualising medical focus on disability (Oliver, 1990). Subsequent developments have led to Shakespeare's (2013) interactional model of disability, which acknowledges both the material, lived individual experience of disability and the environmental and systemic barriers which create, or increase disadvantage (Goodley, 2016).

Intellectual disability, whether congenital or acquired, can also be understood in terms of the support an individual requires (Intellectual Disability Rights Service, 2009). This approach acknowledges the moveable nature of disability and the varying requirements that an individual may have at any given period of time.

Inclusion Australia aligns itself with a human rights context to understanding intellectual disability. A human rights model of disability emerged in response to the polarisation of social and medical models, which faced almost equal levels of critique, as they positioned or were applied to people with intellectual disability in particular (Degener, 2017). Taking a human rights approach to intellectual disability brings the focus back on to their rights articulated in law, including those stated in the United Nations Convention on the Rights of Persons with Disabilities which Australia ratified in 2006 (United Nations, 2006).

Inclusion Australia focuses the provision of inclusive and holistic policy advice with the aim to drive systemic change in Australia. Consequently, this literature review examines an underreported area of disability - the extent and context of violence, abuse, neglect and exploitation experienced by Australians with intellectual disability. The specific aim of this review is to gain further understanding of the issues specific to people with intellectual disability, acknowledge gaps within the evidence base and establish points for change in the disability sector more broadly.

Definitions and terminology

For consistency in this review, the definitions used by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (Commonwealth of Australia, 2020) are used to define the following terms referred to throughout.

Violence and abuse “cover a range of behaviours towards people with a disability. These could include assault, sexual assault, constraints, restrictive practices (physical and chemical), forced treatments, forced interventions, humiliation and harassment,

financial and economic abuse and significant violations of privacy and dignity on a systemic or individual basis.”

Neglect *“includes physical or emotional neglect, passive neglect or wilful deprivation. Neglect can be a single significant incident or a systemic issue that involves depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment.”*

Exploitation *“is when a person takes advantage of someone else. This could include improper use of another person or the improper use of or withholding of another person’s assets, labour, employment or resources including taking physical, sexual, financial or economic advantage.”*

Responses to experiences of violence, abuse, neglect and exploitation towards people with an intellectual disability in Australia range from protection under national legislation such as the Federal Disability Discrimination Act (1992) to international approaches including the Convention on the Rights of a Person with Disabilities (United Nations, 2008). In Australia, individual support services such as National Disability Abuse and Neglect Hotline also play a role. The most recent reporting from July-December 2019 suggest that 35 of the 229 calls to the hotline for this period were from people with an intellectual disability (Australian Government, 2019).

2. The extent of violence, abuse, neglect and exploitation experienced by Australians with intellectual disability

There is limited incidence and prevalence data exploring the extent of violence towards Australians with an intellectual disability. When data is collected, often this data does not distinguish between disability types. Where possible data focusing specifically on Australians with an intellectual disability has been referred to in the following discussion.

Violence in Australia

Data collated by the Australia Bureau of Statistics (ABS) (2016) has estimated that 7.2 million Australians aged 18 years and over have experienced violence since the age of 15. Of these Australians, men (3.7 million) were more likely to experience instances of physical violence than women (2.9 million). However, women (1.7 million) were more likely than men (428,800) to experience sexual violence.

The ABS (2016) further estimates that 16% (1.5 million) of women and 11% (992,000) of men experienced physical and/or sexual abuse before the age of 15. Further, about 2.5 million Australian adults (13%) experienced physical and/or sexual abuse during childhood. While it is likely that the prevalence of child abuse and neglect is underestimated, current figures suggest that of those children reported to child protection services approximately 26,400 (aged 0-12 years) had one or more child protection notifications substantiated in 2017-2018 (Australian Institute of Health and Welfare, 2020).

- **7.2 million** Australians have experience violence since the age of 15
- **2.5 million** Australian adults have experience physical and/or sexual abuse during childhood
- **26,400 children** (aged 0-12 years) had one or more child protection notifications substantiated in 2017-2018.

Recent anecdotal evidence indicates that there is an increase in violence in Australia. While police in Australia respond to a domestic violence matter every two minutes (or 5,000 matters on average every week), evidence indicates that particular social events contribute to notable spikes (Connery, 2019). For example, in New South Wales, on NRL grand final night there is a 20 per cent increase in family violence incidents which police respond to (Blumer, 2016; Cunningham, 2018). Similarly, as reported in several media publications, the lockdown measures currently in place in metropolitan Melbourne to address COVID-19 has contributed to a 'huge increase in referrals' to domestic violence organisations (Kehoe, 2020; Mills, 2020; Pfitzner, 2020). To address this increase in demand, the Victorian State Government has implemented a \$20 million support package (Clayton, 2020).

Violence towards people with a disability

The Australian Bureau of Statistics (2016) reports a higher proportion of Australians with a disability experiencing violence than those who do not have a disability regardless of their sex. It should be noted that these statistics only consider individuals who live in private dwellings. As was noted earlier, there is limited incidence and prevalence data exploring the extent of violence towards Australians with an intellectual disability specifically. Incidence of violence among Australians with a disability varies according to age, with violence being more common in younger Australians living with a disability (12.7% among those aged 18-24 and 12.5% among those aged 25-34 years). Of those Australians with an **intellectual disability**, 14.3% (67,900 people) reported experiencing violence. In 2016, this represented 12.2% or 58,200 people experiencing violence in the last 12 months. Furthermore, 5.5% or 26,200 Australians with an intellectual disability experienced sexual violence in the last 12 months.

- **67,900** individuals with an intellectual disability reported having experienced violence
- **26,200** individuals with an intellectual disability reported having experienced sexual violence
- **58,200** individuals with an intellectual disability reported having experienced violence in the previous 12 months

An intersectional analysis of violence in Australia

A closer exploration of the data allows us to consider the experiences of violence and abuse as they intersect with factors such as gender, sexuality, indigeneity and age for people with intellectual disability.

Women with Disability Australia (2020) have described how women and girls with disability experience all forms of violence at higher levels of intensity and frequency, for longer duration and with more significant injuries as a result. When it comes to interacting with service systems, women with disability are less likely to receive supports to address violence, are less likely to be believed when reporting their experiences, and are denied the right to legal capacity enshrined in the United Nations Convention on the Rights of People with Disability (United Nations, 2008; Women with Disabilities Australia, 2020). While robust data is lacking, it is clear that women with disability experience violence and abuse at higher rates than other groups, with research reporting that 40.9% of women with a disability experience intimate partner violence (violence perpetrated by a current or former intimate partner) with these women significantly more likely to experience multiple incidents of violence (Disabled People's Organisations Australia, 2019). This is confirmed by Krnjacki et al. (2016) who indicate that while women with a disability are less likely to experience physical violence, they are more likely to experience sexual violence, partner violence and stalking and harassment than men with disabilities. Although comparatively outdated, further evidence suggests that women with an **intellectual disability** experience higher rates of sexual violence, abuse and exploitation (Dowse et al., 2013).

Among Indigenous Australians, of those who have a disability, 33% experience an **intellectual disability** (Dudgeon, 2014), with rates of violence perpetrated against Indigenous Australians being approximately 10 times higher than against non-Indigenous Australians (Disabled People's Organisations Australia, 2019). There is no data exploring violence against Indigenous Australians with a disability. Data which considers individuals experiencing multiple forms of oppression is lacking and this makes understanding their experiences of violence, abuse, neglect and exploitation difficult to ascertain via an academic review of the literature.

In Australia, data shows that lesbian, gay, bisexual, trans, intersex and queer (LGBTIQ) people with disabilities are more likely to experience violence than those without a disability (Leonard & Mann, 2018). Disability service staff attitudes and beliefs, reported as more conservative and more strongly associated with negative ideas of risk (Charitou et al., 2020), have the potential to negatively influence the experiences of LGBTIQ people with disability. This may also extend to workers capacity to provide effective support and recognise violence and abuse in LGBTIQ contexts, as well as potentially placing people with disability around staff who hold discriminatory views (O'Shea, 2020). Along with a lack of policy or training clarity around protection of sexual rights, this lack of systemic support can lead to an under-recognition of violence and abuse in non-heterosexual relationships, as well as increasing the risk of abuse or neglect.

To date, there is no known prevalence data on violence against people with a disability from culturally and linguistically diverse (CALD) backgrounds. However, it is acknowledged that women with a disability from CALD backgrounds underreport instances of violence against them, likely enhanced through intersecting linguistic and cultural barriers and a limited awareness of the criminal justice system (Disabled People's Organisations Australia, 2019; Frohmader, 2015).

Finally, it is acknowledged that children and young people with a disability experience higher rates of violence and abuse compared to other children, with children who have an intellectual disability experiencing higher rates of abuse. Evidence also suggests that children with a disability are more likely to experience sexual abuse when compared to their peers (Robinson, 2013).

3. The links between context and the experience of violence, abuse, neglect and exploitation by Australians with intellectual disability

There does not appear to be adequate research which focuses on Australians with intellectual disability and their experiences of violence, abuse, neglect and exploitation and the environment in which they reside. However, evidence does tell us that Australians with a disability are more likely to experience violence (physical, emotional, sexual) from a carer or family member than a stranger (Victorian Government, 2015). There is no evidence to suggest that remoteness of geographic location influences experiences of violence among Australians with disability.

Evidence from the Senate Inquiry into violence, abuse and neglect against people with a disability in an institutional and residential care setting documented many instances of violence, abuse and neglect (or the risk thereof) (Commonwealth of Australia, 2015). In several submissions provided to the Senate the inference was made that it was a 'culture' of neglect which occurred whereby individuals were often isolated and exposed to violence. It was further acknowledged that abuse was facilitated by a lack of transparency and accountability (Commonwealth of Australia, 2015).

Partly in response to such concerns, the NDIS Quality and Safeguards Commission was established in 2017 as part of the NDIS Quality and Safeguarding Framework. Via the independent Commission, the Framework provides a consistent national approach to ensure NDIS providers operate and deliver services of high quality (Australian Government, 2018). The NDIS Code of Conduct explicitly requires NDIS providers and workers to 'take all reasonable steps to prevent and respond to all forms of violence, exploitation, neglect and abuse...[and] sexual misconduct' (NDIS Quality and Safeguards Commission, 2020). The NDIS Worker Screening Database will soon be available as a national clearance for workers providing NDIS services and supports to ensure that staff 'don't present an unacceptable risk to people with disability' (NDIS Quality and Safeguards Commission, 2019). However, we note the recent media reporting on the unfortunate death of Ann Marie Smith in April 2020

and the subsequent manslaughter investigation by South Australian Police. A taskforce established to investigate the incident identified 14 'safeguarding gaps' and several recommendations for improvements at state and federal levels (Department of Human Services, 2020). This suggests that there is significant work still to be done in ensuring that people with disability are safe within the services designed to support them.

4. How Australians with intellectual disability report (or do not report) violence, abuse, neglect and exploitation

As evidenced within this review, Australians with intellectual disability are more likely to experience violence than most other population groups in Australia. This evidence also suggests that people with a disability face barriers in the reporting of this violence and need further protection from it occurring again. According to Fraser-Barbour et al. (2018) these barriers can be grouped into three key categories.

- 1. A lack of confidence in the capacity of mainstream services ability to engage with people with an intellectual disability*

According to Fraser-Barbour et al. (2018), of particular concern is the assumption that an individual with intellectual disability is inherently vulnerable and unable to fully participate in the disclosure of violence. Further concerns levelled by participants in the Fraser-Barbour et al. (2018) study was negative attitudes towards people with intellectual disability. Finally, beyond the disability sector, attitudes towards individuals with intellectual disability appeared to be that individuals with an intellectual disability were limited in their capacity to report experiences of violence and also their ability to access appropriate support services.

- 2. A lack of integration between mainstream services and the disability sector in the provision of support or reporting measures*

Currently it is acknowledged that there is a lack of 'intersection' between the criminal justice and social justice systems. While it appears that there are opportunities to engage in 'round table' discussions in the criminal justice sector, there is a need to adapt this approach to include interactions with the disability sector (Fraser-Barbour et al., 2018). It has been suggested that transitioning to the NDIS may be problematic and contribute to competition between service providers in terms of funding, resources and information. Leadership within organisations is recognised as a means to address this barrier, particularly if this is mandated at government level (Fraser-Barbour et al., 2018).

- 3. A lack of training among service providers in how to respond to people with intellectual disability experiencing violence and reporting these experiences*

An inability to effectively respond to people with intellectual disability experiencing (and reporting) violence and abuse is acknowledged as a significant barrier in further reporting.

Participants involved in the Fraser-Barbour et al. (2018) study note that people in all levels of service provision need to be better trained in how to sensitively respond to people with intellectual disability. Participants identified that specific considerations were required including a trauma informed approach, greater public awareness and conversation within the sector. It is felt that advocacy and leadership is a 'driving force' in ensuring that individuals are not 'lost in the system' (Fraser-Barbour et al., 2018).

Similar research undertaken by Australia's National Research Organisation for Women's Safety (ANROWS) explored the barriers faced by women with disability in accessing justice (Mahar, 2018). This report documented several barriers. As was outlined by Fraser-Barbour et al. (2018), women with a disability were often not acknowledged or believed (Mahar, 2018). Particular challenges faced by women with disability appear to focus on their safety and security. That is, the ability of a service provider to support women accessing services safely and without the risk of further violence. Mahar (2018) also noted that pre-existing assumptions about a women's ability to contribute to the reporting and disclosure of violence was a key barrier in the provision services (Mahar, 2018). Finally, Mahar (2018) recognised the importance of not only developing a robust evidence base but also the need for multidisciplinary training as a means to support best practice service provision.

5. The role of other safeguards in uncovering violence, abuse, neglect and exploitation against Australians with intellectual disability

As detailed throughout this review there is a clear lack in tangible evidence that documents in a meaningful and usable way the incidence and prevalence of violence towards Australians with intellectual disability. Safeguarding measures which aim to provide individuals with an opportunity to report such experiences again often lack a specific focus. There are however some resources which draw on the academic evidence base and evaluation emerging such as 'Sexual Lives & Respectful Relationships' which is a peer-based education program for people with intellectual disability that in part aims to educate individuals with an intellectual disability around issues such as violence and abuse (Frawley & O'Shea, 2020).

Other resources focus on the ways to report abuse from within the disability sector. The NSW Ombudsman (2017) has established several guides designed to assist in reporting abuse and neglect including, a resource guide for disability services which outlines what staff need to do if it happens in their service and a flow chart on responding to alleged abuse and neglect. The NSW Ombudsman also provides multiple training resources which vary from half to full-day training focusing on responding to and report abuse and/or neglect in disability services (Ombudsman New South Wales, 2017).

Further resources focus on the provision of services for people with a disability more broadly. For example, People with a Disability Australia along with Domestic Violence NSW (2015) has put together a policy document which outlines a collaborative approach to

supporting women who have experienced domestic violence in seeking treatment. Similarly, ANROWS (2020) has begun reporting on the impact of early intervention violence prevention support for women (8-18 years) with disability who are at risk of domestic and family violence. The researchers from ANROWS (2020) concluded that training and capacity building in those people working in support services is essential and further, that there is a need for national policy to acknowledge the intersectional nature of domestic and family violence and disability

6. Gaps in the available research and recommendations for future change

Perhaps the most significant gap within the research to date is the lack of focus on individuals with intellectual disability. Of the limited evidence which is available, little to no evidence focuses specifically on those individuals with intellectual disability. As a consequence, developing an in-depth understanding of the experiences of Australians living with intellectual disability and the support services they require remains difficult.

Currently there is a lack of relevant research with which to understand both the experiences and needs of Australians with an intellectual disability. Based on the available literature, following measures should be implemented.

1. Collating specific incidence and prevalence data that focuses on people with intellectual disability.
2. Establishing a portfolio of evidence gathered from individuals with a lived experience of violence and intellectual disability.
3. Building confidence among service providers as to the capacity of people with intellectual disability. This may come in the form of specific organisational training or workshops such as those provided by the NSW Ombudsman.
4. The provision of further cross discipline/institution opportunities to ensure the consistent reporting of abuse or violence among people with intellectual disability.
5. Using an advocacy-based framework to evaluate and further develop safeguarding measures targeting the reporting of violence and/or abuse toward Australians living with intellectual disability.
6. Continuing the development of robust evidence-based safeguarding measures to assist in the reporting violence and/or abuse among Australians living with intellectual disability. This may involve the evaluation and assessment of already established support services or programs occurring in a community setting.

7. References

- Australian Bureau of Statistics. (2012). *Intellectual Disability*. Retrieved from <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4433.0.55.003main+features102012>
- Australian Bureau of Statistics. (2016). *Personal Safety*. Retrieved from <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4906.0~2016~Main%20Features~Key%20Findings~1>
- Australian Government. (1992). *Disability Discrimination Act*. Retrieved from <https://www.legislation.gov.au/Details/C2016C00763>
- Australian Government. (2018). *NDIS Quality and Safeguarding Framework*. Retrieved from <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-quality-and-safeguarding-framework>
- Australian Government. (2019). National Disability Abuse and Neglect Hotline. Retrieved from <https://www.dss.gov.au/disability-and-carers/publications-articles/general/national-disability-abuse-and-neglect-hotline-data-0>
- Australian Institute of Health and Welfare. (2020). *Australia's children*. Retrieved from Canberra: <https://www.aihw.gov.au/reports/children-youth/australias-children>
- Blumer, C. (2016). Australian police deal with domestic violence every two minutes. *The ABC*. Retrieved from <https://www.abc.net.au/news/2016-04-21/domestic-violence/7341716?nw=0>
- Charitou, M., Quayle, E., & Sutherland, A. (2020). Supporting Adults with Intellectual Disabilities with Relationships and Sex: A Systematic Review and Thematic Synthesis of Qualitative Research with Staff. *Sexuality and Disability*. doi:10.1007/s11195-020-09646-z
- Clayton, R. (2020). Victorian Government puts \$20 million towards ‘new way’ of reducing family violence during coronavirus crisis. *The ABC*. Retrieved from <https://www.abc.net.au/news/2020-08-19/family-violence-coronavirus-funding-help-perpetrators-leave-home/12567136>
- Commonwealth of Australia. (2015). *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*. Retrieved from https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report
- Commonwealth of Australia. (2020). Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from <https://disability.royalcommission.gov.au/>
- Connery, T. (2019). Guys, The Footy Grand Final Is Not Some Excuse For You To Attack Women. *GOAT*. Retrieved from <https://goat.com.au/afl/guys-the-footy-grand-final-is-not-some-excuse-for-you-to-attack-women/>
- Cunningham, M., Booker, C. (2018, 27 September). ‘One of our biggest nights’: Plice brace for spike in family violence. *The Age*. Retrieved from <https://www.theage.com.au/sport/afl/one-of-our-biggest-nights-police-brace-for-spike-in-family-violence-20180927-p506ax.html>
- Degener, T. (2017). *A new human rights model of disability*. Paper presented at the The United Nations convention on the rights of persons with disabilities.

- Department of Human Services. (2020). *Safeguarding Task Force*. Retrieved from <https://dhs.sa.gov.au/latest-news/safeguarding-taskforce>
- Disabled People's Organisations Australia. (2019). *Violence Against People with Disability*. Retrieved from https://dpoa.org.au/violence-abuse-exploitation-neglect-people-disability-australia-available-data-march-2019/violence-against-people-with-disability_dpoa_march-2019/
- Dowse, L., Soldatic, K., Didi, A., Frohmader, C., & Toorn, G. v. (2013). Stop the violence: addressing violence against women and girls with disabilities in Australia: background paper.
- Dudgeon, P., Milroy, H, Walker, R. (2014). *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice*. Retrieved from <https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/working-together-aboriginal-and-wellbeing-2014.pdf>
- Fraser-Barbour, E. F., Crocker, R., & Walker, R. (2018). Barriers and facilitators in supporting people with intellectual disability to report sexual violence: perspectives of Australian disability and mainstream support providers. *The Journal of Adult Protection*.
- Frawley, P., & O'Shea, A. (2020). 'Nothing about us without us': Sex education by and for people with intellectual disability in Australia. *Sex Education*, 20(4), 413-424. doi:10.1080/14681811.2019.1668759
- Frohmader, C., Sands, T. (2015). *Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings*. Retrieved from Sydney, Australia: http://neda.org.au/sites/default/files/2017-12/ACDA_Sub_Sen_Inquiry_Violence_Institutions.pdf
- Goodley, D. (2016). *Disability studies: An interdisciplinary introduction* (2 ed.). London: Sage.
- Intellectual Disability Rights Service. (2009). *Introduction to Intellectual Disability*. Retrieved from http://www.idrs.org.au/pdf/IDRS_%20Introduction_intellectual%20disability_17Feb09.pdf
- Kehoe, J. (2020). Melbourne lockdown sends domestic violence 'through the roof'. *Australian Financial Review*. Retrieved from <https://www.afr.com/policy/health-and-education/lockdown-weaponises-domestic-violence-20200806-p55j2r>
- Krnjacki, L., Emerson, E., Llewellyn, G., & Kavanagh, A. M. (2016). Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study. *Australian and New Zealand Journal of Public Health*, 40(1), 16-21. doi:10.1111/1753-6405.12498
- Leonard, W., & Mann, R. (2018). The everyday experiences of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability. *Analysis & Policy Observatory*.
- Mahar, J. M., Spivakovsky, C, McCulloch, J, McGowan, J, Beavis, K, Lea, M, Sands, T. (2018). *Women, disability and violence: Barriers to accessing justice - final report*. Retrieved from <https://d2rn9gno7zhxqg.cloudfront.net/wp-content/uploads/2019/02/19024604/Maher-et-al-Horizons-Research-Report-1.pdf>
- Mills, T. (2020). New reports of family violence spikes in COVID-19 lockdown, study finds. *The Age*. Retrieved from <https://www.theage.com.au/national/victoria/new-reports-of-family-violence-spike-in-covid-19-lockdown-study-finds-20200607-p55096.html>

- NDIS Quality and Safeguards Commission. (2019). Workers Screening Requirements. Retrieved from <https://www.ndiscommission.gov.au/workers/worker-screening-workers>
- NDIS Quality and Safeguards Commission. (2020). NDIS Code of Conduct (Workers). Retrieved from <https://www.ndiscommission.gov.au/workers/ndis-code-conduct>
- O'Shea, A., Latham, J, Frawley, P, Trezona, A, Beaver, S, Lewis, J, Mountford, R, Rose, M. (2020). *More than ticking a box: LGBTIQ+ people with disability talking about their lives (ahead of print)*. Retrieved from Geelong, Victoria:
- Oliver, M. (1990). *The politics of disablement*. London: Macmillan International Higher Education.
- Ombudsman New South Wales. (2017). A quick guide - Early response to abuse and neglect in disability services. Retrieved from <https://www.ombo.nsw.gov.au/news-and-publications/publications/guidelines/disability-reportable-incidents/a-quick-guide-early-response-to-abuse-and-neglect-in-disability-services>
- People with Disability Australia. (2015). *Women with disability and domestic and family violence: A guide for policy and practice*. Retrieved from http://dvnsw.org.au/pwd_doc1.pdf
- Pfitzner, N., Fitz-Gibbon, K, True, J. (2020). *Responding to the 'shadow-pandemic': practitioners views on the nature of and responses to violence against women in Victoria, Australia during the COVID-19 restrictions*. Retrieved from Victoria, Australia: https://bridges.monash.edu/articles/Responding_to_the_shadow_pandemic_practitioner_views_on_the_nature_of_and_responses_to_violence_against_women_in_Victoria_Australia_during_the_COVID-19_restrictions/12433517
- Robinson, S. (2013). *Enabling and protecting: proactive approaches to addressing the abuse and neglect of children and young people with disability*. Retrieved from <https://disability.royalcommission.gov.au/system/files/exhibit/EXP.0007.0001.0335.pdf>
- Robinson, S., Newton, BJ, Smyth, C, Parmenter, N. (2020). *Violence prevention and early intervention for mothers and children with disability: Building promising practice*. Retrieved from <https://d2rn9gno7zhxqg.cloudfront.net/wp-content/uploads/2020/06/25091735/valentine-RR-PC-DFV.pdf>
- Shakespeare, T. (2013). *Disability rights and wrongs revisited* (2 ed.). Oxon: Routledge.
- United Nations. (2006). Convention on the Rights of Persons with Disabilities. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- United Nations. (2008). *Convention on the Rights of Persons with Disabilities*. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Victorian Government. (2015). People with a disability who experience violence, abuse or neglect Retrieved from <https://www.betterhealth.vic.gov.au/health/servicesandsupport/people-with-a-disability-who-experience-violence-abuse-or-neglect>
- Women with Disabilities Australia. (2020). *Submission to the House Standing Committee on Social Policy and Legal Affairs' inquiry into family, domestic and sexual violence*. Retrieved from Hobart, Tasmania: <https://wwda.org.au/wp-content/uploads/2020/08/Submission-to-the-House-Standing-Committee-on-Social-Policy-and-legal-Affairs-Inquiry-into-family-domestic-and-sexual-violence2.pdf>