



PEOPLE WITH DISABILITY
AUSTRALIA

**A voice
of our
own**

We Belong Here

**Our Nation Must End Exclusionary Systems that
Harm People with Disability**

People with Disability Australia's response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability *Promoting Inclusion* Issues Paper

**JULY
2021**

About PWDA

People with Disability Australia (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation—we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation. We help individuals by advocating for their interests, and groups through our systemic advocacy efforts. We also encourage people to engage in self-advocacy.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement. We employ many people with disability.

We have a vision of a socially just, accessible, and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are recognised, respected and celebrated.

PWDA is committed to human rights and believes human rights are for everyone, regardless of race, religion, ethnicity, indigeneity, disability, age, displacement, caste, gender, gender identity, sexuality, sexual orientation, poverty, class or socio-economic status.

Our organisation was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. DPOs are organisations that are led by, and constituted of, people with disability. We are a DPO and work as a disabled people's representative organisation, representing the interests of our members.

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Copyright information

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Executive Summary

People with Disability Australia's submission *We Belong Here: Our Nation Must End Exclusionary Systems that Harm People with Disability* was made in response to the *Promoting Inclusion Issues Paper* released by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission) in December 2020.

PWDA's July 2021 submission argues that *authentic inclusion* must include ending the *exclusion* people with disability face in everyday life on Australia's shores.

That exclusion involves the use of exclusionary systems, such as the segregated workplaces run by Australian disability enterprises (ADEs), and so-called special schools for students with disability.

People with disability experience violence, abuse, neglect and exploitation in these segregated spaces, both because people are vulnerable, and vulnerable in these settings, and because they are secreted away places where minimum standards of behaviour are less likely to be enforced. Our human rights are breached in these settings and are breached by their very existence.

These are spaces where *inclusion* is talked about but does not exist authentically. Instead, these are places where a *predatory tokenism* is adopted, where *ingrained ableism* allows abuses such as below-minimum-wage hourly rates and unreported sex crimes to continue, benefitting people such as business honours while allowing harm against people with disability to go unchecked.

The exclusion people with disability experience extends to our decision-making, with Australia having a web of *guardianship* and *substituted decision-making regimes* in place that breach Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Human rights-breaching exclusion is particularly allowed under Australia's interpretive declaration on the CRPD and this must end. The declaration must be revoked, forcing a termination of the guardianship laws that have allowed many abuses against people with disability in breach of their human rights, including forced sterilisation and abortion.

In this submission, we examine the ways in which people with disability are excluded across the social spectrum, and how our exclusion promotes violence, abuse, neglect and exploitation. We also present strategies for moving beyond tokenistic gestures that fall short on real action to address the exclusion of people with disability, realising

authentically inclusive practice via a human rights framework that prioritises equity and social justice.

We make key recommendations to the Disability Royal Commission on what commissioners should recommend to the Australian Government.

Our recommendations provide a simple way forward for ending exclusion and working towards real, authentic inclusion.

1. Australia must make genuine efforts to fully implement the CRPD

Australia must make genuine efforts to fully implement the CRPD and meet its CRPD obligations. The nation must enshrine the ideals of the convention across the policy sector.

The guiding principles¹ of the CRPD cite inclusion as an essential part of the framework guiding its operation. As a signatory to the CRPD, Australia has a responsibility to make concerted efforts toward dislodging exclusionary thinking and practice, to enact inclusive policy, and reframe a wider culture of consciousness about disability.

People with disability must have equal recognition before the law and enjoy all rights and freedoms on an equitable basis with others.

The human rights of people with disability must be acknowledged, normalised and enacted.

2. Australia must revoke its interpretive declarations on the CRPD

Australia must revoke its interpretive declarations on the CRPD to ensure people with disability can fully enjoy our human rights.

There can be no equivocation or exceptions made when it comes to the implementation of our human rights.

The interpretive declarations to the CRPD must be revoked.

3. Australia must invest in the authentic inclusion of people with disability at all levels of decision-making

Australia must invest in the authentic inclusion of people with disability at all levels of decision-making.

¹ United Nations, [Guiding principles of the convention](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html), *United Nations Convention on the Rights of People with Disability*, United Nations, 2006, accessed 5 July 2021.
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html>

The CRPD affirms that our inclusion must be integrated far more widely across social interfaces and intersections. Number 3 of the general obligations found in article 4 maps this assertion:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.²

Australia must ensure inclusion is authentic on its shores.

4. Australia must end segregated systems

Australia must end its segregated systems that include segregated schools and workplaces.

The nation must develop plans to end or phase out all segregated systems for people with disability, with a focus on broadening the scope of mainstream systems to become fully, authentically inclusive and accessible.

5. Australia must end the outsourcing of decision-making for people with disability

Australia must end the outsourcing of decision-making for people with disability.

People with disability must be empowered systemically to make our own decisions, with an end to restrictive guardianships, mental health orders, and an end to policy that leaves us out of decision-making processes relating to our own lives.

6. Australia must improve staff training for planners and reviewers

Australia must improve staff training for government-appointed planners and reviewers.

Whether at Centrelink or the National Disability Insurance Agency, staff members responsible for making major decisions about the supports that people with disability have access to need fit-for-purpose training to avoid causing harm or trauma via uninformed or unintentionally biased (ableist) decision-making and decision-making practices.

² United Nations, [Article 4 – General obligations](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html), *Convention on the Rights of Persons with Disabilities*, United Nations, 2006, accessed 5 July 2021.

7. Australia must legislate for the longevity and stability of lifelong supports

Australia must legislate for the longevity and stability of lifelong supports.

Australian government agencies responsible for managing disability support must identify where supports are going to be needed long term, and keep accurate records to ensure lifelong supports are not subjected to unnecessary and traumatic review processes.

1. Introduction: What does inclusion meant to you?

At People with Disability Australia, we have a vision of a socially just, accessible, and *inclusive* community, in which the human rights, citizenship, contribution, potential and diversity of all people are recognised, respected and celebrated.

Inclusion is integral to any equitable policy involving people with disability and must begin with honouring and hearing the voices of people with disability in debates, action, policy and any directive being made on our behalf.

In its *Promoting Inclusion Issues Paper*, the Disability Royal Commission has acknowledged that *inclusion* is complex, requiring a rights-based approach, an understanding of the experiences of people with disability in different settings across our lifetimes, and an understanding of the intersection of disadvantaged identities many of us face.

We hold that authentic inclusion of people with disability begins with a rights-based, social model approach, where the idea of disability as deficit is actively challenged and rejected, and people with disability are valued and respected as full citizens with equitable access to rights, safety, freedom, autonomy, and communal systems and resources.

To fully answer the question: “What does inclusion mean to you?” it is vital to examine how the *exclusion* of people with disability is perpetrated and normalised in Australia, and how certain contemporary notions of inclusion and diversity are currently failing to address it.

Debates about inclusion often struggle to address the complex tensions that exist between belonging, access, integration, identity and empowerment.

If inclusion is understood as a positive action undertaken by those who inherently belong, creating space for those who do not, *predatory tokenism*, undertaken with no real challenge to the status quo, while maintaining ableist structures of power and deeply held ableist beliefs about who inherently belongs, can be misrepresented as a form of inclusion.

As an example, the promotion of *Australian disability enterprises* (also called ADEs or sheltered workshops) as positive examples of inclusive employment practice is highly misleading when people with disability are being paid a fraction of the minimum wage serving enterprises that profit from their labour.

Positive story-telling campaigns, presenting people with disability actively participating in what is called meaningful employment are routinely used to promote these enterprises, and exist for the purpose of comforting and reassuring non-disabled people, smoothing out the jagged edges of an inherently exploitative system, reinforcing the widely held ableist belief that a segregated workplace is a supportive endeavour, and that the labour of disabled people is worth inherently less than the equivalent labour of people without disability.

How did we arrive at these beliefs? How did they become ingrained?

Ingrained ableism is defined by University of Dundee Professor of Disability and Ableism Studies Professor Fiona Kumari Campbell as the “seduction of sameness as the basis to equality”³. It asserts the notion of an *ideal citizen* – a framework that conjures a particular body, skin, class, gender and racial typology for the so-called *average citizen*.

University of Illinois College of Medicine Professor of Disability and Human Development, Lennard J. Davis, demonstrates how this construct emerged with the creation of the field of statistics. The emergent fascination with statistical trends and tendencies essentially supported eugenic thinking where exceptions to a *statistical standard deviation* from the average could be considered deviant, and therefore subject to exclusionary and segregational practice.

The history and heritage of eugenics in correcting or eliminating disability informs the current tremulous nature of our place within social consciousness and the ongoing perpetuation of violence and abuse against disabled bodies.

The *outsiding* of people with disability remains a feature of policy and practice in Australia today, evidenced by (for example) our modern segregated systems of education, housing, and employment, where people with disability are offered so-called *special options*⁴ rather than equitable access to mainstream systems that authentically include us.

Requirements around who needs to be included in mainstream systems are still heavily defined against the benchmark of the so-called *normal body*, with inclusion framed as conditional entry into that norm rather than an expansion of what constitutes the norm that authentically includes all people.

For this reason, where *authentic inclusion* is the aim, it is not enough to simply promote inclusion within existing systems. Authentic inclusion requires a deep examination of the

³ Fiona Kumari Campbell, *Contours of ableism: The production of disability and abledness*, Palgrave Macmillan, Houndmills, 2009, p. 4.

⁴ Disabled People’s Organisation Australia, *Segregation of people with disability is discrimination and must end: Position paper*, Disabled People’s Organisation Australia, September 2020, p. 3, accessed 5 July 2021.
https://dpoa.org.au/wp-content/uploads/2020/11/Segregation-of-People-with-Disability_Position-Paper.pdf

ways in which people with disability are culturally, systemically and legally *excluded*. In Australia, this starts with conversations about how our human rights can be more effectively implemented, equitable access to information, systems, and resources, and the active dismantling of segregated systems.

Authentically inclusive practice requires a radical challenge to ingrained and normalised practices of exclusion and segregation and the arbitrary concept of *normal* upon which they are built.

Authentic inclusion enacts the right of people with disability, not just to exist, but to be part of, and integrated within, the everyday realities and normalities of life – *belonging*.

This authentic inclusion works to dislodge ongoing ableist cultures of abuse and neglect of people with disability, and must be supported by a range of civic, political, social and economic rights, so that people with disability are supported by legislation, education, and representational networks of meaning that normalise difference and venerate complex embodiments, neuro-types and emotional repertoires.

A wider understanding of belonging must be actively circulated – supported by integral societal laws, values and interfaces that apply to everyone equitably.

2. People on the outside experience abuse

People with disability experience being *outsiders* as a common daily occurrence in Australia. We are frequently denied equal access to the resources and opportunities that enable the autonomy and self-determination that people without disability can generally afford to take for granted.

The exclusion of people with disability from mainstream systems and services such as education, employment, healthcare, transport and rental/housing markets translates into a lack of access to the visibility, protections and freedoms inherently offered by those systems, leaving us subject to both subtle and overt forms of abuse, violence, neglect and exploitation.

Studies and reports, such as *Shut Out: The Experience of People with Disabilities and their Families in Australia*⁵ and the *World Report on Disability*⁶ by the World Health Organisation demonstrate the relationship between a culture of exclusion and experiences of abuse.

Exclusionary practices create *segregated populations*, hidden from general view in places such as so-called special schools, segregated employment situations (ADEs), specialist congregate disability living situations, and forensic hospitals (where people with disability can be legally subject to indefinite detention).

Restrictive practices such as guardianship or mental health orders that limit the physical freedoms of people with disability often occur quietly, hidden in plain sight but outside of the normative experience.

Add to this the systemic lack of equitable access to systems such as transport, communication, finance, legal representation, consensual family planning and other resources that enable independence and self-determination, and you have a culture of exclusion that permits and facilitates hidden cultures of control, violence and dependence.

⁵ National People with Disabilities and Carer Council, [Shut out: The experience of people with disabilities and their families](https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia) [National Disability Strategy Consultation Report], Australian Government, 2009, accessed 5 July 2021.

⁶ World Health Organization and The World Bank, [World report on disability](https://www.who.int/disabilities/world_report/2011/report.pdf), World Health Organization and The World Bank, 2011, accessed 5 July 2021.

The segregated spaces that exist in Australia shape an environment where the systemic debilitation or weakening of people with disability is permissible and normalised because it takes place outside the rules that apply to what is viewed as *more legitimate* members of the community.

By contrast, a *proactive culture of inclusion*, that facilitates equitable access to systems designed for universal participation, would naturally assume a right to autonomy, to being citizens who are both accounted for and accountable in society.

3. The violence of exclusionary language

Authentic inclusion of people with disability only becomes possible when the violence of *exclusionary language* is drawn out, acknowledged and interrupted or confronted. This starts with identifying where language is being used to sanitise abusive or exploitative systems.

Some examples of exclusionary language are:

- a person without disability might “take a walk” while a person with disability is “accessing their community”
- a non-disabled person might “have a job” while a person with disability is “supported to participate in meaningful work”
- non-disabled people might “rent or buy a home”, while people with disability are “provided with accessible housing”
- non-disabled people “use services”, while people with disability “access supports”
- non-disabled people have “experiences”, while people with disability have “life outcomes”.

The language used around disability persistently works to *pathologise* our activities, remove agency and emphasise the apparently benevolent nature of the people and systems managing our access and participation, while simultaneously *erasing the exclusionary practices* that placed us outside in the first place.

The systemic *outsiding* or debilitation of people with disability and subsequent rehabilitation into normative experiences and systems are not a binary. Rather, they are a continuum of exclusion where both aspects are used to maintain our marginalisation.

But where the *systemic exclusion* of people with disability is erased through sanitising language, and disability is framed as an inherent deficit or lack, disability itself becomes both the commonly accepted explanation for *and* justification of our exclusion. Our position on the outside is framed as a default or natural state, relieving the system of culpability in what is then presented as the inevitable injuring of people with disability attempting to navigate the segregated systems to which we are relegated.

Returning to the example of sheltered workshops, National Disability Services (NDS), a membership organisation whose members consist of non-government disability service organisations, has arguably set out to sanitise the language used to describe the exploitative, segregationist employment practices which financially benefit its members.

There is an organised campaign by NDS on behalf of its members to counter negative media attention attracted by Disability Royal Commission and Fair Work Commission hearings, including a published strategy to share “positive case studies” which “directly demonstrate that supported settings are safe, happy and meaningful places and provide valuable life outcomes.”

In this example, an *exclusionary system of employment* has led directly to the establishment of a segregated system, in which people without disability are empowered to legally exploit people with disability, paying their workers well below minimum wage. Sanitised language has then been employed to present exploitative practice as an altruistic endeavour, providing “support” and “meaning” and “valuable life outcomes”.

Exclusionary language is effectively deployed to justify, sanitise and validate what people view as abusive practice.

4. Tokenistic/predatory participation

Authentic inclusion requires examination of the way in which hierarchies of authority are occupied by people with specific identities, and a radical challenge to the structure of those hierarchies.

When people who are white, male, heterosexual, middle-class and able-bodied are codified as normal or *default*, with identities defined against these traits codified as *other* or *deviant*, a very limited perspective comes to define the everyday operational practices and experiential realities of organisations and institutions.

Where this lack of diversity is recognised as problematic, increased *participation* by those of us deemed as other is oftentimes touted as the solution. Individuality and uniqueness might even be celebrated as inherently beneficial to an organisation or structure, with value attributed to the diversity we represent.

However, to encourage and facilitate participation by people with disability in practices and experiences established for and by people without disability, without first radically challenging the ways in which those practices preclude authentic participation and inclusion, ultimately leaves us open to harm.

If the participation of a person with disability is itself framed as the intervention into the existing structures of injustice and ableism, it becomes the responsibility of the excluded to facilitate more authentic inclusion within a system that inherently disempowers us to do so.

It's a commitment that can lead to exhaustion and burnout due to the emotional labour involved in identifying, rendering and changing existing exclusionary structures. Radboud University Assistant Professor of Gender and Diversity Laura Dobusch and her colleagues explain the conditional nature of *inauthentic inclusion*.

The conjunction of a person's uniqueness with organisational benefits reveals the conditional character of this approach to inclusion: It 'remains conditional upon (...) adding something deemed to be of value (...). Arguably, this means simply replicating rather than tackling hierarchies of recognition in the name of "inclusion"'.⁷

People with disability are regularly added to corporate boards, charitable roundtables and advisory committees to perform an idealisation of an *inclusive workplace*.

⁷ Dobusch, L, Holck, L and Muhr, SL, [The im-/possibility of hybrid inclusion: Disrupting the 'happy inclusion' story with the case of the Greenlandic Police Force](https://doi.org/10.1177/1350508420973310), Organization, 2020, p. 4 of pp. 1–23. <https://doi.org/10.1177/1350508420973310>

This way of practicing inclusion invites participation on the condition of lending legitimacy to societal structures built on principles of exclusion, rather than authentically embracing diverse voices and visions of what an *inclusive society* might look like.

For people with disability, who remain on the edge of citizen rights, belonging remains a state of labour. Without adequate safeguards and operational policies to effectively enforce a more authentic vision of inclusion, people with disability will continue to exist within everyday networks that normalise abusive and neglectful behavioural patterns.

An authentic approach to inclusive community-building would enable the strengths of difference to embolden and sustain the community or organisation, cultivating belonging and togetherness.

5. Labouring to belong

People with disability are exhausted. We are exhausted because when you are on the outside, and your access requirements are considered extraordinary and radical, the system inevitably requires detailed and exhaustive justification before granting you access to basic resources.

Having been actively excluded from the systems designed to uphold the rights, freedoms and access of the *average person*, we are routinely required to demonstrate and emphasise our difference, our perceived deviance and deficit, with carefully collated evidence that may or may not be considered enough to justify our basic needs being met, let alone full admission to the independence and self-determination generally enjoyed by people without disability.

The systems ostensibly designed to facilitate our inclusion as full citizens with financial and physical independence, such as the Disability Support Pension (DSP) and the National Disability Insurance Scheme (NDIS) are conditional upon rigorous application processes that force us to reflect, in detail, upon our difference and all the ways we are excluded, to prove that we are the *deserving* recipients of *special efforts* toward inclusion.

This process, accompanied by the implicit threat of living (and potentially dying) without equitable access to basic resources, is inherently traumatic, and reinforces the power dynamic whereby those who are perceived to *inherently belong* can dictate the terms and conditions by which those of us on the outside may potentially be brought in.

Making matters worse, this is rarely a one-time process. The DSP is regularly reviewed, as are NDIS plans, making long-term planning and stability very difficult to achieve for people who must depend on these systems.

The anxiety associated with impending reviews, often run by strangers with no stake in the outcome, who exist within an ableist culture that will potentially influence decision-making, is always just below the surface. Changes to the landscape in the form of new legislation or policy also occur with stressful regularity.

This is not authentic inclusion. It is a system that provides a tenuous, temporary, conditional form of inclusion that must be actively maintained and continuously defended by the recipient, who remains in a perpetual state of stress.

People with disability are exhausted.

Despite its flaws, the NDIS has been a relatively coherent attempt to implement the social model of disability, actively acknowledging people with disability as full members of society

with a right to hopes, dreams and life-choices (a radical break from the traditional focus on deficits).

The NDIS was envisioned to facilitate people with disability to live on our own terms, rather than having the amount and type of assistance we are entitled to mandated by our diagnoses and medically defined categories of disability and impairment.

Our NDIS was designed to treat people with disability, not as a burden on the social system, but as people entitled to flexible systems of funding that service our needs as citizens with the right to pursue our goals. The NDIS is also a way for Australia to implement its National Disability Strategy⁸ (the primary vehicle by which we are meant to implement the United Nations Convention on the Rights of Persons with Disabilities⁹ (CRPD), an important step toward authentic inclusion.

For this reason, it is disappointing that the NDIS has also replicated the lack of stability associated with more traditional welfare systems.

To demonstrate, assistance animals have long been an essential part of the disability access repertoire and provide essential service within the everyday lives of people with disability.¹⁰

In the Australian *Disability Discrimination Act 1992*¹¹, assistance animals are defined as “animals which have been specially trained to help a person with disability mitigate the impacts of that disability, and which have behaviour appropriate to access public spaces”.¹²

Most obviously, this includes the seeing-eye dog and the seizure dog which warns of an impending incident. It also includes support animals that perform a therapeutic function for their owners, though these type of assistance animals cause a great deal of scepticism

⁸ Department of Social Services, *National Disability Strategy 2010–2020*, Department of Social Services, 2011, accessed 5 July 2021.

<https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>

⁹ United Nations, *Convention on the Rights of Persons with Disabilities and Optional Protocol*, United Nations, 2006, accessed 5 July 2021.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>

¹⁰ Nepps, P, Stewart, CN and Bruckno, SR, *Animal-assisted activity: Effects of a complementary intervention program on psychological and physiological variables*, *Journal of Evidence-Based Complementary and Alternative Medicine*, vol. 19, no. 3, 2014, p. 211 of pp. 211–215, accessed 5 July 2021.

<https://doi.org/10.1177/2156587214533570>

¹¹ Commonwealth of Australia, *Disability Discrimination Act 1992*[Federal Register of Legislation], accessed 19 July 2021.

<https://www.legislation.gov.au/Details/C2016C00763>

¹² National Disability Insurance Scheme, *Participant-trained assistance dogs*, NDIS, 2021, accessed 2021.

<https://www.ndis.gov.au/about-us/publications>

within the wider public as their purpose is sometimes perceived to be an extension of the pet role.

Ignorance of the training involved in preparing these animals, who might facilitate and soothe complex anxieties and stresses, fails to acknowledge the nuanced functional assistance being offered.

This is an example of an *ableist bias* that might impact the decisions made concerning an NDIS participant's support.

Case Study: Molly Marsham

In May 2021, NDIS participant Molly Marsham appeared in front of the Joint Standing Committee on the National Disability Insurance Scheme during its investigation into the introduction of the (now abandoned) plan to introduce independent assessments. Molly was not part of the trial for independent assessments but she'd had a negative experience with an NDIS planner that she believed was relevant to the investigation.

When Molly arrived to testify in front of the Joint Standing Committee, she was visibly distressed and unable to speak. Molly's mother read aloud from her prepared statement.

Paraphrasing, Molly considers herself an NDIS success story. Her psychiatric assistance dog Zuli was initially funded through the scheme, based on reports from Molly's neuropsychiatrist. Having Zuli close by and taking care of Zuli provided Molly with emotional support and structure that enabled her participation in environments and activities that were previously inaccessible to her. She described Zuli as "my friend, my confidante and, above all, my independence," and clarified:¹³

"Without additional NDIS support I'd have followed the costly path of disability education and restrictive employment, the judicial system for violence and the mental health system for outbursts. Instead my path involves education, success, positive contribution to society and, above all, advocacy for those who do not have the support, the ability or the opportunity to state their case."

During a routine check-in and planning session however, an NDIS planner expressed doubts about Molly's ability to properly care for the animal, going so far as suggesting Molly may harm Zuli and that Zuli herself was vicious (according to Molly's mother, no evidence was presented to support either claim).

¹³ Joint Standing Committee on the National Disability Insurance Scheme, Joint committee – Thursday, 20 May 2021 – Independent assessments – Final, Parliament of Australia, 20 May 2021, accessed 16 July 2021.

<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommjnt%2F60e1afa7-6d93-4200-aa56-fb015063e285%2F0000%22>

Molly was instructed to obtain a report from an occupational therapist if Zuli's ongoing and required training and assessments were going to be funded. The report from her neuropsychiatrist, that was considered appropriate to support the initial funding, was no longer considered sufficient evidence.

Molly ended her testimony by saying: "I don't like demands at all, and would prefer 'why isn't's'. Questions I would like answered are: Why did the NDIS planner question my assistance dog? Why isn't there accurately recorded supporting information by the NDIS?

This is the second time NDIS planners have accused me of harming Zuli and accused Zuli of being vicious and we have needed to waste time and a huge amount of money arguing my case ... Why isn't there a recognition of psychiatric assistance dogs as being a critical support for some participants? ... and why doesn't the committee review and amend [transcripts] in such a way that participants do not feel shame, despair and the endless need to fight and justify challenges all the time? Participants with lifelong challenges have lifelong challenges! Finally, why isn't there a review of planner training to include an understanding of complex cases, assistance dogs and recognising when a participant is under stress?"

6. Systemically and legally excluded

We have talked about the need to examine and deconstruct the ways that people with disability are actively excluded within existing systems. In this section, we will take a closer look at some of the ways people with disability are legally and systemically excluded in Australia.

Excluded from human rights

The United Nations (UN) defines *social inclusion* as:¹⁴

the process of improving the terms of participation in society for people who are disadvantaged on the basis of age, sex, disability, race, ethnicity, origin, religion, or economic of other status, through enhanced opportunities, access to resources, voice and respect for rights.

The UN has formalised what respect for rights of people with disability looks like with the United Nations Convention on the Rights of Persons with Disabilities¹⁵ which came into force in 2008.

The Australian Government is nominally on board with the UN's inclusion goals for people with disability, having ratified the CRPD¹⁶ on 17 July 2008, however, it has also actively softened this commitment by publishing Australia's interpretative declaration on the Convention on the Rights of Persons with Disabilities¹⁷.

This interpretative declaration on the CRPD states:

Australia recognises that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported

¹⁴ United Nations Economic & Social Affairs, Chapter 1, [Leaving no one behind: The imperative of inclusive development](#) [Report on the World Social Situation 2016], United Nations, 2016, p. 17, accessed 16 July 2021.

<https://www.un.org/esa/socdev/rwss/2016/full-report.pdf>

¹⁵ United Nations, [Convention on the Rights of Persons with Disabilities and Optional Protocol](#), United Nations, 2006, accessed 5 July 2021.

[https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext)

[Fulltext](#)

¹⁶ United Nations Department of Economic and Social Affairs – Disability, [Entry into force](#), United Nations, 2021, accessed 5 July 2021.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.html>

¹⁷ Australian Government, Attachment A – Australia's interpretative declaration on the Convention on the Rights of Persons with Disabilities, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: The Australian Government's Background Paper on the United Nations Convention on the Rights of Persons with Disabilities – Part 1 – Australia's position and interpretive approach*, accessed 5 July 2021.

<https://disability.royalcommission.gov.au/system/files/2020-09/Australian%20Government%20Position%20Paper%20on%20the%20UNCRPD%20-%20Part%201%20-%20Australia%E2%80%99s%20position%20and%20interpretive%20approach.pdf>

or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards;

Australia recognises that every person with disability has a right to respect for his or her physical and mental integrity on an equal basis with others. Australia further declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards;

Australia recognises the rights of persons with disability to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others. Australia further declares its understanding that the Convention does not create a right for a person to enter or remain in a country of which he or she is not a national, nor impact on Australia's health requirements for nonnationals seeking to enter or remain in Australia, where these requirements are based on legitimate, objective and reasonable criteria.

The interpretative declaration actively limits the rights and freedoms that people disability enjoy in Australia and its territories under articles 12, 17 and 18 of the convention, which respectively address equal recognition before the law, rights protecting the integrity of a person, and liberty of movement and nationality.

The interpretive declaration explicitly excludes people with disability from their inalienable human rights, permitting our systems and institutions to limit our physical freedom, engage in harmful restrictive practices, and place discriminatory limitations on our legal rights as Australian citizens. The interpretive declaration is leaving us unprotected from particular forms of state-based violence, abuse, neglect and exploitation.

The Australian Government¹⁸ has acknowledged the important role that human rights play in the treatment of people with disability, and the importance the Disability Royal Commission must place on our human rights in its activities and recommendations.

In its 16 June 2020 background paper on the convention to the Royal Commission, the government noted:

1 The Australian Government recognises the important work of the Royal Commission. In particular, the Australian Government appreciates the human rights-based approach that the Royal Commission has taken and the priority it has placed on the United Nations Convention on the Rights of Persons with Disabilities (CRPD) when inquiring into violence, abuse, neglect and exploitation of people with disability. This is consistent with the Royal Commission's terms of reference, which refer to the CRPD and the obligations Australia has to promote the human rights of people with disability. To assist the Royal Commission, the Australian Government has prepared this background paper addressing Australia's international human rights obligations.

¹⁸ United Nations Department of Economic and Social Affairs – Disability, [Entry into force](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.html), United Nations, 2021, accessed 5 July 2021.
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.html>

In particular, this paper focuses on the Australian Government's interpretation of Australia's obligations under the CRPD and the Australian Government's position with respect to a number of cross-cutting concepts under the CRPD.

The government argued in its background paper to the Disability Royal Commission that "Interpretive declarations do not purport to, or in fact, exclude or modify the legal effects of a State's obligations under a treaty."¹⁹

We disagree. In fact, it is difficult to ascertain what purpose the interpretive declarations could possibly hold outside of modifying the legal effects of Australia's obligations under the CRPD.

To promote the authentic inclusion of people with disability, the Australian Government must enshrine our human rights into law. This begins with revoking the interpretative declaration on the CRPD.

Excluded from access to information and public resources

Authentic inclusion of people with disability would mean ensuring equitable access to all publicly available information and resources.

This is a huge area, encompassing everything from the accessibility of the built environment to transport to accessible communication technology to the availability of appropriate mobility devices.

When will all publicly available films and videos be both captioned and audio described?
When will all public announcements and websites come with an Easy Read translation?
When will all trams and tram stops be made accessible for wheelchair and scooter users?
When will all public queues come with appropriate seating options?
When will all public buildings be fragrance free?

Our systems of communication and access are designed for and by people without disability, consistently considering and catering for a narrow set of access needs, defined by the arbitrary benchmark of the average citizen (discussed in the introduction).

Consideration of access needs outside of these constraints is considered extraordinary, rarely worked into the fabric of the system with the same comfortably predictable consistency.

¹⁹ United Nations Department of Economic and Social Affairs – Disability, [Entry into force](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.html), United Nations, 2021, accessed 5 July 2021.
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.html>

Our recent experiences of adjustments made during COVID-19 lockdowns have illustrated just how easily systems can be changed when the access needs of non-disabled people are the motivator.

As one PWDA member has said:

Disabled people have been saying for decades that flexible work-from-home arrangements would give us access to paid work. We were told that this was unreasonable. Disabled people have said for decades that Telehealth appointments would improve our access to healthcare. We were told that this was unreasonable. But when abled people needed access to these things to keep the ship afloat, they were arranged within a matter of weeks. The way is there. All we need is the will.

It was a very effective demonstration of who – in the eyes of our governments, health administrators and employers – inherently belongs, and who does not.

The COVID-19 vaccination rollout on the other hand was a very effective demonstration of how the equitable consideration of people with disability is routinely forgotten, even in the development of new systems and policy.

Example: COVID-19 and the vaccination rollout

On 19 January 2020, a man flew into Melbourne from Guangdong, China. On 25 January 2020 he was identified as the first case of COVID-19 in Australia.

Through rigorous lockdowns and border closures, Australia has not yet experienced a major outbreak of COVID-19. To date there have been 31,898 cases and 912 deaths²⁰, the bulk of these in Victoria (820 deaths), and recent deaths in New South Wales²¹.

In February 2021, the Australian Government began the rollout of its COVID-19 vaccine. To date, only 11% of the population has been fully vaccinated.²² This number represents a systemic failure to widely and effectively vaccinate the population, attributable to a combination of supply and storage issues, changing health advice regarding the safety of the AstraZeneca vaccine, and confusion around who is eligible for the vaccine according to the official phases of the rollout.

²⁰ Johns Hopkins University and Medicine, [Coronavirus Resource Center](#), Johns Hopkins University and Medicine, 22 June 2021.

<https://coronavirus.jhu.edu/region/australia>

²¹ Wikipedia and others, [Coronavirus disease Australia](#), Google, accessed 5 July 2021.

https://www.google.com/search?q=case+of+covid+in+australia&rlz=1C1CHBF_en-GBAU920AU920&sxsrf=ALeKk01jNHb8eGSx39Ei4N1uHblZdxtO0Q%3A1625483452576&ei=vOjiYP3Dlr_G4-EPj4C1qAw&oq=case+of+covid+in+australia&gs_lcp=Cgdnd3Mtd2l6EAMyAggAMgYIABAWEB4yBggAEBYQHjoECCMQJzoFCAAQkQl6BAqAEEM6BAguEEM6CggAELEDEIMBEEM6CAqAELEDEIMBOg4ILhCxAXCDARDHARCjAjoFCAAQsQM6CAguELEDEIMBOg4ILhCxAXCDARDHARCvAToFCC4QsQM6CAguEMcBEK8BOqIILjoFCAAQyQM6CAghEBYQHRAeOgkIABDJAxAWEB5KBAhBGABQ84UFWLcQBWDkqwVoAnABeACAAacDiAHCMZIBCzAuMTEuMTQuMi4xmAEAoAEBqgEHZ3dzLXdpesABAQ&scient=qws-wiz&ved=0ahUKEwj9kZ3e5cvxAhU_4zqGHQ9ADcUQ4dUDCA4&uact=5

²² Op. cit.

World Health Organisation (WHO) guidelines state; “Equitable access must be a guiding principle for all immunization programmes.”²³

People with disability are a high-risk group for COVID-19. Co-morbid conditions make some of us more susceptible to the ill effects of the virus (including death). Congregate living situations – and the essential need for interaction with support workers (paid or unpaid) – can make social distancing measures difficult if not impossible for some people with disability to achieve. Inaccessible sinks and handbasins have also been identified as a barrier to COVID-safe hygiene measures in some specialist disability accommodation.

WHO’s policy brief on *Disability Considerations for COVID-19 Vaccination* identifies “difficulty in communicating symptoms; inaccessibility of transportation, health facilities and telehealth services; gaps in support and assistant service; and discriminatory triage procedures”²⁴ as all having an impact on protection against COVID-19 infection.

An equitable vaccination program would therefore prioritise the immunisation of people with disability.

There has been some emphasis on delivering vaccines to those living and working in specialist disability accommodation, however, targets for vaccinating this group are not being met, and people with disability living outside of these settings are being even further excluded.

As the Western Australian Disability Services Minister Don Punch told People with Disability Australia in a letter dated 15 July 2021, “given the risk COVID-19 poses to the health and well-being of people with disability, and disability support workers, it is imperative that all eligible people within this cohort choosing to have a COVID-19 vaccine, have prioritised access...I am disappointed that despite this risk consistently being raised at the very highest level over the past six months by Disability Ministers across the country, very little real progress has been made to date.”

Accessing vaccination hubs or clinics is simply not possible for some people with disability (people who are bed or housebound, people with limited independent access to accessible transport, people maintaining social isolation due to the heightened risk of complications or death if they contract the virus), yet media reports affirm that community nurses have been unable to distribute the vaccine during their home visits to people with disability. In-reach into people’s homes is still a rare service only offered by few GPs.

²³ World Health Organization and UNICEF, [Disability considerations for COVID-19 vaccination, WHO and UNICEF policy brief, 19 April 2021](https://www.who.int/publications/i/item/who-2019-ncov-vaccination-and-disability-policy-brief-2021.1), World Health Organization and UNICEF, 19 April 2021, p. 2, accessed 5 July 2021. <https://www.who.int/publications/i/item/who-2019-ncov-vaccination-and-disability-policy-brief-2021.1>

²⁴ Op. cit.

Access to vaccinations, and accessible information regarding *how* and *where* to access vaccinations has been also limited.

As it stands, fewer than 2% of people living in disability residential accommodation have been fully vaccinated.²⁵

Excluded from decision-making

People with disability are routinely excluded from the decision-making processes that govern our own lives. This may be explicit, as in the case of a guardianship or mental health order, or it may be more subtle, with the normalisation of systems that simply assume our absence within decision-making processes.

Coming back to the example of the COVID-19 vaccination rollout, we see how the decisions of people with disability are systemically de-prioritised:

Example: COVID-19 vaccinations and consent

In addition to the failure to provide equitable access to vaccines, the government's consent strategies for people with disability – a population with niche groups who require complex and nuanced consenting procedures – have been described by some as non-existent. A call on suitability for vaccination, for many people with disability, has been defaulted to health professionals and general practitioners before we are even consulted on our preference.

Instructions for disability service providers (many of whom provide accommodation services) say²⁶ that “the disability provider should consider the suitability for people with disability to receive the vaccine” but specify “the only people who are not suitable to receive the vaccine are those with: anaphylaxis to a previous dose of the same COVID-19 vaccine, or anaphylaxis after exposure to any component of a COVID-19 vaccine including to polyethylene glycol (PEG)”.²⁷

If there are concerns about the person with disability being able to receive the vaccine, providers are then directed to consult with the patient's GP. Only then is there mention of the person with disability offering consent.²⁸

²⁵ BBC News, [What's gone wrong with Australia's vaccine rollout?](#), BBC, 17 June 2021, accessed 5 July 2021.

<https://www.bbc.com/news/world-australia-56825920>

²⁶ Australian Government, [Clinical governance for COVID-19 vaccination at disability residential accommodation](#) [COVID-19 vaccination information], Australian Government, 2021, accessed 5 July 2021.

<https://www.health.gov.au/sites/default/files/documents/2021/03/covid-19-vaccination-clinical-governance-for-covid-19-vaccination-at-disability-residential-accommodation.pdf>

²⁷ Op. cit.

²⁸ Op. cit.

In securing this consent, “a consent package including a consent form template and relevant information is available to support this activity.”²⁹

The arbitrary and disengaged nature of this consent process does little to accommodate the complex nature of disability or the consent process required for different disabilities.

People with disability are removed from the consent process until the very last stage, where indicating their consent is only a final consideration in the vaccination process.

Excluded through segregated systems

Australia has developed a number of segregated systems that ostensibly support the needs of people with disability, but in practice enable the exclusion of people with disability. These are discussed at length in the position paper initially submitted to the Disability Royal Commission in September 2020 by a group of eight disability advocacy organisations (including PWDA), *Segregation of People with Disability is Discrimination and Must End*.³⁰

For the purpose of this submission, we will focus on segregated education, or what are dubbed special schools as an example of segregation as a form of exclusion.

Article 24 of the CRPD affirms that its signatories shall ensure an *inclusive education* system at all levels and life-long learning (emphasis ours).

Queensland University of Technology Centre for Inclusive Education (C4IE) director Professor Linda Graham has argued definitively that while various forms of cultural inclusion have increased in Australia with the diversification of communities through immigration and global flows and mobilities, education has not become any more inclusive.

Professor Graham has also argued that under the guise of *mainstreaming*, places such as England, the United States and Australia have actually increased segregation of students with disability.³¹

Pupil Referral Units (PRUs) in England, ‘behaviour schools’ in New South Wales and Flexible Learning Options (FLOs) in Victoria, for example, all share similar DNA in that they enrol students

²⁹ Op. cit.

³⁰ Children and Young People with Disability Australia, Women With Disabilities Australia, National Ethnic Disability Alliance, Australian Federation of Disability Organisations, Inclusion Australia, Disability Advocacy Network Australia, First Peoples Disability Network Australia and People with Disability Australia, [Segregation of people with disability is discrimination and must end](https://wwda.org.au/publication/segregation-of-people-with-disability-is-discrimination-and-must-end), Women With Disabilities Australia, September 2020, accessed 16 July 2021.

<https://wwda.org.au/publication/segregation-of-people-with-disability-is-discrimination-and-must-end>

³¹ Graham, L, [Inclusive education for the 21st century: Theory policy and practice](https://ugc.futurelearn.com/uploads/files/d4/3b/d43b4b8a-ef3c-412f-ade7-4f33b2243d67/Graham_BookExtract_Chapter1.pdf), Allen & Unwin, Sydney, pp. 3–5, accessed 5 July 2021.

https://ugc.futurelearn.com/uploads/files/d4/3b/d43b4b8a-ef3c-412f-ade7-4f33b2243d67/Graham_BookExtract_Chapter1.pdf

with learning and behavioural difficulties whose social, emotional and academic needs have not been met in the primary phase of schooling. Their rationale for alternative provision is that these students have failed to thrive in mainstream schools and that they are deficient, not the system that failed them.

This is an example of how inclusion ideals can get hijacked by educational rationalists who affirm an educational value to segregation which services the student with disability by focusing values and attention exclusively in spaces that are supportive of their learning needs.

However, this attitude only reasserts the neglect of people with disability and marks them as separate from the mainstream or what we call the normal.

Instead of making mainstreaming approaches appropriately flexible and complex for all students, children with disability are singled out as the exception and are excluded.

This also results in a form of predatory inclusion “a process whereby members of a marginalized groups are provided with access to a good, service of opportunity from which they have historically been excluded but under conditions that jeopardize the benefits of access.”³²

Segregated education systems assert that they are inclusive but ultimately reinforce exclusion. Through these means a mechanism is handed to critics and conservative commentators who can easily claim that inclusion doesn't work. This is because the education system is not built for flexibility or nuance. A system not designed for people with disability will struggle to accommodate the nuanced delivery of service required for authentic inclusion. It will also not effectively serve students without disability because, as Graham highlights, studies consistently demonstrate that “practices that make schools inclusive for students with disability – such as universal design and accessible pedagogies – benefit all students.”³³

To retain segregation in education, even under the guise of equity, supports a culture of covert exclusion whereby children normalise the separation of students with disability from their non-disabled peers. A lesson that informs understandings of disability moving forward through the generations.

This exclusion is further exacerbated by people seeing requests or needs for reasonable adjustments as a student (or their supporters) being difficult or burdensome in mainstream schools.

³² Seamster, L and Charron-Chénier, R, [Predatory inclusion and educational debt: Rethinking the racial wealth gap](https://doi.org/10.1177/2329496516686620), *Social Currents*, vol. 4, no. 3, 2017, pp. 199–200 of pp. 199–207.
<https://doi.org/10.1177/2329496516686620>

³³ Op. cit.

Exclusionary and restrictive practices, such as locking students in classrooms, are also forms of violence. Exclusionary practices drive violence and abuse.

An example from Graham demonstrates the passive neglect such attitudes sustain.³⁴

[the] class featured two empty desks at the front of the room ... When we began observing, we assumed that a couple of students were absent on that day, hence the empty desks. However, about half an hour into the morning session, a teacher aide arrives with a student we will call 'Daniel'. Daniel and the aide sit at the two desks at the front of the classroom. The teacher does not even look their way.

This behaviour scaffolds the segregation of people with disability and normalises it in the everyday experiences of children with and without disability. This is a debilitating and demeaning structure for all involved and is not sustainable in the long term. Nor does it effectively meet Australia's obligations under the CRPD. Segregated practices in education permit marginalisation to continue and filter into all other areas of everyday life

³⁴ Op. cit.

7. List of recommendations

1. Australia must make genuine efforts to fully implement the CRPD

Australia must meet its CRPD obligations, enshrining the ideals of the convention across the policy sector. The guiding principles³⁵ of the CRPD cite inclusion as an essential part of the framework guiding its operation. As a signatory to the CRPD, Australia has a responsibility to make concerted efforts toward dislodging exclusionary thinking and practice, to enact inclusive policy, and reframe a wider culture of consciousness about disability.

People with disability must have equal recognition before the law, and enjoy all rights and freedoms on an equitable basis with others. The human rights of people with disability must be acknowledged, normalised and enacted.

2. Australia must revoke its interpretive declarations on the CRPD

There can be no equivocation or exceptions made when it comes to the implementation of our human rights. The interpretive declarations must be revoked.

3. Australia must invest in the authentic inclusion of people with disability at all levels of decision-making

The CRPD affirms that inclusion must be integrated far more widely across social interfaces and intersections. Number 3 of the general obligations found in article 4 maps this assertion:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.³⁶

³⁵ United Nations, [Guiding principles of the convention](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html), *United Nations Convention on the Rights of People with Disability*, United Nations, 2006, accessed 5 July 2021.

³⁶ United Nations, [Article 4 – General obligations](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html), *Convention on the Rights of Persons with Disabilities*, United Nations, 2006, accessed 5 July 2021.

4. Australia must end segregated systems

Australia must develop plans to end or phase out all segregated systems for people with disability, with a focus on broadening the scope of mainstream systems to become fully, authentically inclusive and accessible.

5. Australia must end the outsourcing of decision-making for people with disability

People with disability must be empowered systemically to make our own decisions, with an end to restrictive guardianships, mental health orders, and an end to policy that leaves us out of decision-making processes relating to our own lives.

6. Australia must improve staff training for planners and reviewers

Whether at Centrelink or the NDIA, staff members responsible for making major decisions about the supports that people with disability have access to need fit-for-purpose training to avoid causing harm or trauma via uninformed or unintentionally biased (ableist) decision-making.

7. Australia must legislate for the longevity and stability of lifelong supports

Australian government agencies responsible for managing disability support must identify where supports are going to be needed long term and keep accurate records to ensure lifelong supports are not subjected to unnecessary and traumatic review processes.



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AUSTRALIA**

For individual advocacy support contact the **Wayfinder Hub** between 9 am and 5 pm (AEST/AEDT) Monday to Friday via phone (toll free) on **1800 843 929** or via email at info@wayfinderhub.com.au

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