National Centre of Excellence in Intellectual Disability Health

Australian Government Attorney-General's Department
Robert Garran Offices
3-5 National Circuit
BARTON ACT 2600

Sent via email: ddareview@ag.gov.au

10 November 2025

Dear Attorney-General's Department,

Review of the Disability Discrimination Act 1992 (The Act)

We write on behalf of the National Centre of Excellence in Intellectual Disability Health to provide input on the review of the Disability Discrimination Act 1992. We thank you for the opportunity to provide comment and applaud the Attorney-General's Department for their thorough and inclusive consultation process.

About us

The National Centre of Excellence in Intellectual Disability Health ('the Centre') is an important initiative supported by the Australian Government Department of Health and Aged Care. The Centre is a consortium of nine organisations including:

1. UNSW Sydney,
2. Centre for Disability Studies (University of Sydney),
3. Council for Intellectual Disability,
4. Down Syndrome Australia,
5. First Peoples Disability Network,
6. Queensland Centre of Excellence in Autism and Intellectual Disability Health
7. Queenslanders with Disability Network,
8. The Kids Institute and,
9. University of Melbourne.

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It also includes another 56 health and disability organisations as partners or collaborators. The vision of the Centre is to ensure that the 550,000 people with intellectual disability in Australia receive the highest attainable level of healthcare.

Executive Summary

The Disability Discrimination Act plays an important role in upholding the rights of people with intellectual disability in Australia. The review of The Act presents as a significant opportunity to seek greater inclusion of people with intellectual disability in their own health care and in all aspects of community that others take for granted. At the Centre, we advocate for the rights people with intellectual disability to have access to quality health care that is equitable to their counterparts. This includes the right to access health care that is free from discrimination.

People with intellectual disability face stark health and mental health inequalities and multiple barriers to accessing health care that meets their needs. The Disability Royal Commission found that 'people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system'.[1] In comparison to the general population, health outcomes for people with intellectual disability are characterised by:

- Premature mortality occurring 27 years earlier[2].
- More than double the proportion of potentially avoidable deaths[2].
- Four times the rate of potentially preventable hospitalisations[3].

Australia has committed to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which requires governments to promote opportunities and protect all human rights of people with disability.[4] This includes removing barriers and improving systems to support access, inclusion and dignity. The Act needs to work in concert with our commitments under the CRPD. In the review of the Act, we propose that a human rights-based definition is applied to disability that promotes respectful, person-first language and ensures effective remedies and accountability to support people with intellectual disability in all aspects of their life.

Experiences of health discrimination

Two of our Centre's consortium members, the Council for Intellectual Disability (CID) and Down Syndrome Australia (DSA), recently heard from many people with intellectual

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disability about their experiences of discrimination, especially in relation to the health care they had received. Their words are shared here:

"When I go to the doctor, they talk to my support worker, not me. I want them to ask me questions first. I can answer for myself. It's my health, and I should be part of the conversation."[5] - CID member with Intellectual Disability

"Time and time again, I have to ask Doctors to slow down or repeat things so I can process what they are saying. It is frustrating when people don't take the time to listen to me and understand the supports I need. As a result of NOT being treated as an individual and people having preconceived ideas, my health has been impacted by diagnostic overshadowing - doctors overlooking a health problem because of my disability. It has had a huge impact on my health and wellbeing." - Down Syndrome Australia Health Ambassador

"When I've had medical episodes on public transport, they think that I'm drunk. A lot of the time, they think I'm purposely causing trouble... Often, if someone's having a medical emergency or just needs a little bit of extra help, they can put quite extreme measures in place. I've had times when I've had medical emergencies and they decided to call eight police officers — because I fainted on a train."[5] - CID Member with Intellectual Disability

"All the nurse needed to do was make small adjustments to the usual process. She needed not look at me as Down syndrome, but look at me as an individual. This would have made my whole experience much better." - Down Syndrome Australia Health Ambassador

"When the doctor didn't diagnose me properly, I had all this pain, and he didn't listen to me. He just gave me antibiotics, he reckoned I was stupid and didn't check it. Then I went into emergency, and they didn't do anything either. Then I had a fit and after that they found out I had bowel cancer."[5] - CID Project Worker with Intellectual Disability

"Health is for everyone. But for people with intellectual disability there are many barriers to Inclusive Health. One is not including us in our decisions. People with intellectual disability should be included in every aspect of their health care and given the choice to make their own decisions. We want equal treatment, not special treatment. Inclusive health care is part of being included in the community." - Down Syndrome Australia Health Ambassador

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"I know that having a child with a disability, I'm privy to witnessing unconscious bias, labelling, diagnostic overshadowing… in statements, in comments by all clinical staff, even up until the very end when it was recognised how acutely unwell my son was, there were still excuses made as to why he was behaving like that or why he was exhibiting these signs and symptoms, and this, unfortunately, impacted what care and treatment he was going to get on that day… I think that there was time lost, there were moments lost, there was the ability for just one person to realise how sick he was and try and advocate for us to get him the help he needed, and it did not happen" - Rachel Browne (mother of Finlay Browne), Coroner's Report (2024)[6]

People with intellectual disability may experience poor quality of health care, delayed diagnoses and even life-threatening outcomes due to assumptions about the person's capacity or behaviour, unconscious bias and dismissing the perspective of the person's support network. To address this, the revised Disability Discrimination Act should set out:

- clear requirements for proactive, respectful engagement with people with disability and their support networks and,
- opportunities for legal recourse to challenge instances of harm.

The review of the Disability Discrimination Act needs to ensure these experiences of health discrimination are acknowledged with a view to preventing these in the future.

Recommendations

We make two recommendations to the review of the Disability Discrimination Act:

1. **Modernise the Act and embed a human rights model of disability.**

   "I want to be a part of the community - not just walk through it."[5] – late Michael Sullivan (AM), former CID board member.

   The Act must be underpinned by a human rights model of disability to reflect current community standards. It must recognise that people with intellectual disability, as demonstrated by the experiences shared here, are a diverse group who experience intersectionality that impacts their ability to be included and meaningfully participate in all settings. A human rights model uses respectful,

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person-first language and ensures effective remedies and accountability. The Act should include positive obligations for organisations to take proactive steps to foster inclusion and prevent discrimination in all public and private settings. This would mean a welcome, equal distribution of responsibility of enforcing the Act rather than all the onus falling on individuals with disabilities to report discrimination.

2. **Recognise support for decision making.**

"If you make decisions for yourself, that's it, you're free."[5] – Len, CID Project Worker

The Act should specifically incorporate the full support for autonomy and decision-making before the law. The Act should enshrine equitable access for people with intellectual disability in all aspects of their life — meaning capacity building, adjustments, and support for decision-making are clear as a result of the reviewed Act. If the supports for decision-making are protected in legislation, this would drastically change the experiences of many people with intellectual disability, some shared here, as they navigate the health system.

We strongly urge the adoption of these recommendations in the review of the Disability Discrimination Act. We welcome the opportunity to engage further on these recommendations with the view to building a legal framework that upholds the rights of people with intellectual disability to live a life free from discrimination.

Should you require further information about this submission, please do not hesitate to contact us at 1800 424 065 or at drivingchange@cid.org.au.

Sincerely;

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