Access to Health

November 2025

“When I was in hospital, the staff treated me differently because of my disability. They would not give me any medication, and I was in pain. They talked to mum and not me.”- CID member

Goal: For people with intellectual disability to have the opportunity and support to lead long and healthy lives.

What CID wants

We want the NSW Government to:

1. Expand **specialised intellectual disability health teams** (SIDHTs) so that there is a strong team in each Local Health District (LHD).

2. **Build knowledge and skills for** working effectively with people with intellectual disability by making the ‘Just Include Me’ training program, in particular the **unconscious bias module, mandatory for all NSW Health staff**.

3. **Ensure government health services** allow sufficient time for health professionals to respond to the needs of people with intellectual disability.

4. Include an **identifier in the NSW Single Digital Patient Record for people with intellectual disability**, which records the adjustments they need when receiving health care.

5. Require that the needs of people with intellectual disability be embedded in all health policy development.

CID is also part of the National Centre of Excellence in Intellectual Disability Health. We want the Federal Government to:

- Fully fund and implement the **National Roadmap for Improving the Health of People with Intellectual Disability**.
- Make progress towards a consistent disability identifier.
- Improve health professional education and training.
- Improve primary health care for people with intellectual disability.
- Include people with intellectual disability in all major health initiatives.

Where things stand

There are approximately 550,000 people with intellectual disability in Australia. They receive substandard primary and hospital health care that does not meet their needs. As a result, they suffer stark health inequalities compared to the general population. These include:

- Four times the usual rate of avoidable hospitalisations.
- Twice the usual rate of avoidable deaths.
- Dying 27 years earlier than the general population.

Case study

When Danielle was 37, she complained of pain in her pelvis and said that she could not walk. Her father took her to the hospital. While waiting in the emergency department, the pain was making Danielle anxious and upset. When the emergency ward doctor saw her distress, he assumed she was having a meltdown because of her intellectual disability and sent her home.

A week later, Danielle's pelvic pain was still bad. Her father contacted the intellectual disability health team in her area. As a result, she was treated by a doctor who had training in intellectual disability healthcare. This doctor helped Danielle to get an X-ray, which revealed that she had a fractured pelvis.

The doctor also ascertained that Danielle's anti-epileptic medication increased her risk of osteoporosis and obtained a bone density scan. The scan confirmed that Danielle had severe osteoporosis. Danielle was then given regular drug infusions to treat the osteoporosis.

CID's previous advocacy on health:

- Medicare funding for people with intellectual disability to have annual health assessments (2006).
- The NSW Health Service Framework to Improve the Health Care of People with Intellectual Disability (2012).
- Three new pilot intellectual disability health teams set up by NSW Health (2010-2012). Extended to six teams with outreach workers in other Local Health Districts (2018).
- The creation of the National Roadmap for Improving the Health of People with Intellectual Disability (2021).
- Funding of the National Centre of Excellence in Intellectual Disability Health (2022).

Where to from here

CID will continue its advocacy on health issues in NSW. Through its work with the National Centre of Excellence in Intellectual Disability Health, CID will continue to advocate on Federal health issues.

"We need better health care for people with intellectual disability so we can live better and happier lives. Doctors need to have training to be skilled up and support people. It is important to keep learning."
- CID member