

Council for Intellectual Disability

POSITION STATEMENT ON HEALTH

2022

Our goal

People with intellectual disability have the opportunity and support to lead healthy lives and access health services that they need.

Where things stand

“The standard of health care for most people with intellectual disability borders on neglect”

- CID board member with intellectual disability.

People with intellectual disability experience stark physical and mental health inequalities including :

- Up to 50% of deaths are potentially avoidable.
- Dying up to 27 years earlier than the general population.
- High rates of undiagnosed and poorly treated health conditions.
- Low rates of health promotion and prevention.
- High rates of mental illness but poor access to appropriate mental health treatment.
- Twice the rate of hospital admissions with many admissions being avoidable.

“People with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system.” (Disability Royal Commission, Report of Public Hearing 4: Health Care and Services for People with Cognitive Disability)

PETER (not his real name) has intellectual disability and lives independently with drop in support. He was referred to the local mental health service by his outreach worker after he stopped going to work and was found in a self neglected state, refusing to get out of bed. The diagnosis given by the mental health service was ‘behavioural’. Peter was later diagnosed as deeply depressed.

CHRISTINE (not her real name) is a determined middle aged woman with intellectual disability. She uses a few signs but has no speech. She has a history of chest infections, bowel obstructions and anxiety. Christine was admitted to a regional hospital with diarrhoea and vomiting, including vomiting whole food that she had eaten three days before.

Two days later, a bowel obstruction was finally diagnosed. A nasogastric tube was inserted to drain Christine's stomach. Her guardian and group home staff warned the hospital that she would not understand or tolerate the tube and suggested sedation. No action was taken.

Christine pulled out the tube, inhaled much of the contents into her lungs and contracted severe aspiration pneumonia. She was moved to intensive care where she spent four weeks, nearly all of that time on a ventilator. She then spent another three weeks in a high dependency ward. The pneumonia has left her with chronic lung disease.

What's the solution?

CID's advocacy has focused on:

- All health services becoming accessible and responsive to people with intellectual disability. For example:
 - All health professionals should be trained to work better with people with intellectual disability.
 - Health information should be in Easy Read and other accessible formats.
 - Health professionals should take more time with people with intellectual disability.
- Establishing a network of specialised intellectual disability health services to backup ordinary health services. Specialised services are a normal health system response to groups with particular and often complex needs.
- Disability service providers supporting people to be healthy and access the right health care.
- Achieving national leadership by the federal government on the health of people with intellectual disability.

What CID has done

Since 2002, CID has had a major focus on advocating for improved health care. Some of our key activities have included:

- End Deadly Disability Discrimination campaign in the lead up to the 2022 federal election <https://cid.org.au/our-campaigns/end-deadly-disability-discrimination-2/>
- Advocacy in relation to the impact of COVID-19 including membership of the Australian Government Advisory Committee on the Health Emergency Response to Coronavirus for People with Disability.
- Major input by CID staff and members to the Disability Royal Commission hearing on health care February 2020
- Our Health Counts Campaign in the lead up to the 2019 federal election <https://cid.org.au/our-stories/our-health-does-count-our-advocacy-reaps-results/>
- Deadly Disability Discrimination campaign NSW 2017-2018 www.cid.org.au/our-campaigns/end-deadly-disability-discrimination
- National Roundtable on the Mental Health of People with Intellectual Disability 2013 and audit on action, 2014 www.cid.org.au/resource-category/health
- Position Statement on the Health of People with Intellectual Disability, 2008. Endorsed by 143 eminent individuals, 43 national organisations, and 182 state/territory and local organisations from around Australia.
- NSW Roundtable on the Health of People with Intellectual Disability, 2006
- Development of health education resources for people with intellectual disability, families and other advocates and health and disability services.

People with intellectual disability are at the centre of our advocacy.

“Our health counts! Can we count on you?” (CID chair Shua Hua Chan 2019)

We also work closely with families and intellectual disability health professionals and researchers.

What CID has achieved

CID's advocacy has been central to:

- The creation in Medicare of items for annual health assessments of people with intellectual disability 2006.
- NSW Health Service Framework to Improve the Health Care of People with Intellectual Disability 2012 www.health.nsw.gov.au/disability/Pages/health-care-of-people-with-ID.aspx
- Three new pilot intellectual disability health teams set up by NSW Health 2010-2012. Extended to Statewide reach for intellectual disability health teams, 2018.
- The National Roadmap for Improving the Health of People with Intellectual Disability 2021 and initiatives to implement the Roadmap. <https://www.health.gov.au/resources/publications/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability>
- Funding of the National Centre of Excellence in Intellectual Disability Health 2022.

¹Health status of people with intellectual disability – evidence summary 2021 prepared by Professor Julian Trollor <https://cid.org.au/wp-content/uploads/2022/02/UNSW-PWID-Health-research-summary-June-2021.pdf> and Upholding the Right to Life and Health, a Review of the Deaths in Care of People with Disability in Queensland 2016 http://www.justice.qld.gov.au/__data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf