

# Council for Intellectual Disability **POSITION STATEMENT ON HEALTH**

January 2019

## **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:

- 38% of deaths are potentially avoidable, more than twice the rate of the general population.
- 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 mental health treatment.
- Twice the rate of hospital admissions.

[Read research summary](#)

**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 in 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 statewide network of intellectual disability health professionals 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.

### **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:

- My Health Matters resources for people with intellectual disability and GPs 2018 [www.nswcid.org.au/my-health-matters.html](http://www.nswcid.org.au/my-health-matters.html)  
[www.nswcid.org.au/my-health-matters-gp-resources.html](http://www.nswcid.org.au/my-health-matters-gp-resources.html)

- Deadly Disability Discrimination campaign 2017-2018  
[www.nswcid.org.au/deadlydiscrimination.html](http://www.nswcid.org.au/deadlydiscrimination.html)
- National Roundtable on the Mental Health of People with Intellectual Disability 2013 and audit on action, 2014  
[www.nswcid.org.au/what-we-do/advocacy.html](http://www.nswcid.org.au/what-we-do/advocacy.html)
- Development of Healthier Lives fact sheets for people with intellectual disability and their families and service providers, 2009  
[www.nswcid.org.au/health-fact-sheets.html](http://www.nswcid.org.au/health-fact-sheets.html)
- 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.  
[www.nswcid.org.au/images/pdf/Posn\\_with\\_endorsements\\_0414.doc](http://www.nswcid.org.au/images/pdf/Posn_with_endorsements_0414.doc)
- NSW Roundtable on the Health of People with Intellectual Disability, 2006

In our advocacy, we have worked closely with 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/Publications/health-care-of-people-with-ID.pdf](http://www.health.nsw.gov.au/disability/Publications/health-care-of-people-with-ID.pdf)
- Three new pilot intellectual disability health teams set up by NSW Health 2010-2012. Extended to Statewide reach for intellectual disability health teams, 2018.
- Many incremental enhancements in mental health care for people with intellectual disability following CID's National Mental Health Roundtable, 2013 [www.nswcid.org.au/images/pdf/IDMHR\\_audit\\_report\\_1114.pdf](http://www.nswcid.org.au/images/pdf/IDMHR_audit_report_1114.pdf)
- Inclusion of people with intellectual disability in a wide range of health initiatives including the 5th National Mental Health Plan 2017.