



Our Health STILL Counts

Act NOW to end healthcare inequality for people with intellectual disability

Key points

- People with intellectual disability experience inadequate primary care and much **higher rates of avoidable hospitalisations and preventable deaths** than other Australians.
- This issue **directly affects over two million Australians** – approximately 500,000 people with intellectual disability and their families and supporters.
- The Disability Royal Commission reported that people with intellectual disability are exposed to **ongoing “systemic neglect”** in the Australian health system.
- Failure to remedy this neglect is causing **needless human suffering and huge financial cost to the health system and the NDIS**.
- We seek a **renewed** commitment to the National Roadmap that will reduce the health inequalities facing people with intellectual disability and suggest key priorities and actions that will improve the quality and continuity of their care in the health system.

Summary of recommendations

1. Commit to timely action on the **National Roadmap for Improving the Health of People with Intellectual Disability**.
2. Make people with intellectual disability a **priority population** for funding of enhanced quality and continuity of primary care.
3. Ensure health professionals receive training in **intellectual disability health** and communication.
4. Make people with intellectual disability a priority in the next **National Health Reform Agreement**.

The problem

Australians with intellectual disability face stark physical and mental health inequities, resulting in:

- **Lower life expectancy** – dying 27 years earlier than the general population, with 38% of those deaths being potentially avoidable, over twice the rate in the general population.
- **Higher avoidable hospitalisations** – approximately four times the rate of avoidable hospitalisations compared with the general population.
- **Major deficits in preventative health** – including a lack of early diagnosis and treatment.

People with intellectual disabilities often have multiple and complex health conditions. These are compounded by many factors that contribute to stark inequalities including:

- **Communication issues between health professional and patient** – health professionals lack training in accessible communication techniques, which impacts a patient with impaired communication and/or inadequate support to communicate.
- **Rushed appointments** – meaningful inclusion, proper communication, and facilitation of informed consent require health professionals to spend more time with people with intellectual disability.
- **Diagnostic overshadowing** – health professionals mistakenly assume symptoms of treatable health conditions are related to the patient's existing disability. Delays in treatment can worsen health problems and cause distress for people with intellectual disability.
- **Conscious or unconscious bias** amongst health professionals regarding patients with intellectual disability, including prejudicial assumptions of limited decision-making ability and incapacity to cooperate with treatment.
- **Under-skilled workforces** – too few health professionals have basic or specialised skills in intellectual disability health.
- **Inadequate disability support in hospital** – hospitals confine their roles to health conditions only. NDIS provides inadequate disability support in hospitals. Holistic needs are not met, and poor discharge planning occurs.

For First Nations people with intellectual disability, these factors are compounded by experiences of individual and systemic racism and a lack of fair access.

The cost of inaction

Australia is dehumanising people with intellectual disability by not meeting their healthcare needs, while also increasing their reliance on external support and compounding the multi-layered inequalities they already face.

This inadequate healthcare also results in significant ongoing costs – financial, social, psychological, and physical – to family members who support and care for people with intellectual disability.

For government, inaction results in considerable financial costs:

- The cost of treatment of avoidable chronic and acute conditions.
- The costs of avoidable hospitalisations.
- The cost to the NDIS of increased support needs due to poor health.
- The cost to the economy of reduced workforce participation by families and by people with intellectual disability themselves.

Action to date

Successive governments have taken **significant first steps** towards addressing these issues, most notably:

- The development and initial implementation of the 10-year **National Roadmap for Improving the Health of People with Intellectual Disability**.
 - Between 2020 and 2022, the Coalition Government allocated \$47.2m towards actions on the Roadmap.
- In 2022, the incoming Labor Government committed to the National Roadmap and to funding a permanent **National Centre of Excellence in Intellectual Disability Health**. \$23.9m was allocated for the Centre's first four years.
 - The Centre is led by the **University of NSW** and comprises nine research, advocacy and clinical bodies, including the **Council for Intellectual Disability** and **Down Syndrome Australia**.
- Reporting in 2023, the **Disability Royal Commission (DRC)** had a major focus on health issues. The DRC found that people with cognitive disability experience ongoing “systemic neglect” in the Australian health care system. The DRC's final report made wide-ranging recommendations for action, including:
 - Requirements for health professional training;
 - Funding adaptations and supports such as extra time that people with disability need in health care settings.
 - For people with disability to have a support person in health settings;
 - Including people with disability in national health agreements;
 - Improved data collection;

Much remains to be done if people with intellectual disability are to receive equitable health care.

Commitments we seek

We seek **renewed commitment** to further **robust action** on the stark health inequalities facing people with intellectual disability, including:

- Full and effective implementation of the National Roadmap for Improving the Health of People with Intellectual Disability.
- Action on the health-related recommendations of the Disability Royal Commission.
- Ensuring that the proposed national system of foundational disability supports meets the health-related needs of people with intellectual disability.
- Including the specific needs of First Nations people with intellectual disability in all action in line with the National Agreement on Closing the Gap.

We also seek commitment to three key priorities:

1. Making people with intellectual disability a priority population for the funding of enhanced quality and continuity of primary care.

(For example, a **General Practice Intellectual Disability Health Incentive Payment** similar to the recently established General Practice in Aged Care Incentive.)

2. The comprehensive implementation of the Intellectual Disability Health Capability Framework ('the Capability Framework'), which has been developed under the National Roadmap, including:

a. Incorporation of the Framework in **accreditation standards and university curriculums** for doctors, nurses, dentists, pharmacists and allied health professionals.

b. **Implementation of Continuing Professional Development (CPD) actions** outlined in the National Roadmap, including funding scholarships to health professionals who develop skills beyond basic CPD training modules in intellectual disability health.

3. Making people with intellectual disability a priority focus in the next National Health Reform Agreement, including coverage of:

a. **Funding approaches for better care:** activity-based funding must include a loading to account for the additional complexity and time required in managing hospital care.

b. **Improving system-wide data collection** through an intellectual disability indicator across all health settings, data linkage, and inclusion of people with intellectual disability in **measured health outcomes**.

c. The development and implementation of **systems to ensure that people with disability are appropriately supported in hospital**, including with their usual NDIS supports and reasonable adjustments from hospitals.

Contact

For more information, or to speak with our advocates, please contact:

advocacy@cid.org.au, or phone 1800 424 065.

NSW Council for Intellectual Disability (CID): www.cid.org.au

Inclusion Australia: www.inclusionaustralia.org.au

Down Syndrome Australia: www.downsyndrome.org.au

Australian Association for Developmental Disability Medicine
www.aaddm.com.au

Queensland Centre of Excellence in Autism and Intellectual Disability Health -
Mater Research

www.materresearch.org.au/our-research/research-programs/groups/queensland-centre-for-intellectual-and-developmental-disability



References and further reading

The National Roadmap for Improving the Health of People with Intellectual Disability.

www.health.gov.au/resources/publications/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability

Coronial findings on the death of Finlay James Browne 2024.

www.coroners.nsw.gov.au/documents/findings/2024/Inquest_into_the_death_of_Finlay_Browne_.pdf

Department of Developmental Disability Neuropsychiatry. ID Health Data Portal. 2020 [cited November 2020; Available from:

www.idhealthdataportal.unsw.edu.au

Salomon, C., et al., Primary care for people with an intellectual disability—what is prescribed? An analysis of medication recommendations from the BEACH dataset. *BJGP open*, 2018. 2(2).

www.ncbi.nlm.nih.gov/articles/PMC6184100

Trollor, J., et al, Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ open*, 2017. 7(2): p. e013489.

www.bmjopen.bmj.com/content/7/2/e013489

Weise, J., et al, Primary health care for people with an intellectual disability: an exploration of demographic characteristics and reasons for encounters from the BEACH programme. *Journal of Intellectual Disability Research*, 2016. 60(11): p. 1119-1127.

www.ncbi.nlm.nih.gov/27278719

Weise, J., et al, Primary health care for people with an intellectual disability: an exploration of consultations, problems identified, and their management in Australia. *Journal of Intellectual Disability Research*, 2017. 61: p. 399–410.

www.ncbi.nlm.nih.gov/28116807