



WE WAIT FOR THE RESPONSE OF THE POLITICAL PARTIES

Public statement by witnesses at the Disability Royal Commission hearings on the neglect and abuse of people with disability in the health system

We gave evidence at the Disability Royal Commission hearings that focused on the terrible experiences of people with intellectual disability in the Australian health system.

For many of us, this meant publicly baring our souls about highly personal and horrendous experiences. We risked further trauma to what we had already suffered.

We did not expose ourselves to public glare lightly. We did so in the hope that the Royal Commission would lead to fundamental reform, towards people with intellectual disability having the same opportunity to live long and healthy lives as other Australians.

The Royal Commission found people with intellectual and other cognitive disability to be suffering ongoing “systemic neglect” in the Australian health care system. In its 2023 Final Report, the Royal Commission made many recommendations for action, including:

- Funding the adaptations and supports such as extra time that people with disability need in hospitals and GP practices.
- Covering the health care needs of people with cognitive disability in accreditation standards and training curriculums for health professionals.
- Ensuring people with disability are allowed a support person in hospitals and other places where they get health care.
- Improving data collection on the health of people with disability.
- Covering the needs of people with disability in national health agreements.

For many years, governments have known about the stark health inequalities facing people with intellectual disability. The research shows inadequate health promotion and early diagnosis, leading to:

- four times the usual rate of potentially avoidable hospitalisations,
- 38% potentially avoidable deaths and
- people with intellectual disability dying 27 years earlier than the general population.

People with intellectual disability and their families have bad experiences of health care. Busy health professionals often do not take the time needed to maximise communication and accurately diagnose conditions. They often lack skills in working with people with intellectual disability, for example in maximising communication and knowing what health conditions tend to accompany particular causes of disability. They often mistakenly assume that symptoms are just part of the disability rather than manifestations of illness. Many health professionals have unconscious bias in relation to the value of the lives of people with intellectual disability.

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

We acknowledge actions taken by both sides of Government in the four years prior to the Royal Commission Report, including release of the 10-year National Roadmap for Improving the Health of People with Intellectual Disability and funding the National Centre of Excellence in Intellectual Disability Health.

These are valuable first steps. But first steps are not enough.

Now is the time to take strong and decisive action. Now is the time to fully implement the Roadmap and act on the Royal Commission Report. Lives depend on it.

As Australia heads to a federal election, we call on political parties and candidates to make strong new commitments to action.

Key commitments we seek include:

- Renewed commitment to full and effective implementation of the 10-year National Roadmap.
- Action to ensure all health professionals are trained in meeting the needs of people with intellectual disability,

- By making people with intellectual disability a priority population for primary care reform, supporting quality and continuity of care in general practice including GPs spending extra time with people with intellectual disability.
- A specific focus on First Nations people with intellectual disability in line with the National Agreement on Closing the Gap.

We wait attentively for the response of the political parties and candidates.

Jack Kelly

Tara Elliffe

Kylie Scott

Rebecca Kelly, parent, Launceston

Rachel Browne, parent, Bathurst

Jaquie Mills, parent, Perth

Toni Mitchell, parent, Toowoomba

Christine Regan, parent, Sydney

Jayne Lehmann, parent, Adelaide

Margot Elliffe, parent, Wollongong

Evelyn Scott OAM, parent, Sydney

Manya Anglely, parent and consultant pharmacist, Adelaide

Justine O'Neill, former CEO, Council for Intellectual Disability

Cathy Franklin, Director, Queensland Centre of Excellence in Autism and Intellectual Disability Health.

Julian Trollor AM, Scientia Professor, UNSW Medicine and Health

Jacqueline Small, President 2022-2024, Royal Australasian College of Physicians

Jim Simpson AO, Senior Advocate, Council for Intellectual Disability

