

Queensland Election 2024:

Joint Statement on the Health of People with Intellectual Disability

We seek commitments for action on the stark health inequalities facing the 100,000 Queenslanders who have intellectual disability. With their close families, this is over 400,000 voters.

This is a joint statement from Queenslanders with Disability Network (QDN), Queensland Centre of Excellence in Autism and Intellectual Disability Health (QCEAIDH), Australasian Society for Intellectual Disability (ASID) Queensland Branch, Parent to Parent Association Inc., Down Syndrome Queensland, Community Living Association, Endeavour Foundation, and Multicap.

Queenslanders with intellectual disability die 27 years earlier than the general population. They also experience over twice the rate of potentially avoidable deaths and around four times the rate of avoidable hospitalisations.

The Disability Royal Commission found that people with cognitive disability experience ongoing “systemic neglect” in the health care system, prompting wide-ranging recommendations for action.

We seek commitments from political parties to six immediate priority actions:

1. Provide funding to extend the role of new specialised intellectual disability mental health teams across the state to broaden to physical health in each Hospital and Health Service.
2. Provide funding to extend the role of the Queensland Centre of Excellence in Intellectual and Developmental Disability Mental Health (delivered by Queensland Centre of Excellence in Autism and Intellectual Disability Health) to broaden its scope to physical health in addition to its existing focus on mental health.
3. Establish procedural support and sedation services in each Hospital and Health Service across the state for people with intellectual disability who require additional support to access investigations for their health care including dental care.
4. Introduce the requirement for mandatory training in intellectual and developmental disability for Hospital and Health Service staff.
5. Enhance access to palliative care, including ensuring people have choice about palliation at home and in shared living arrangements, for people with intellectual disability.
6. Ensure availability of Easy Read and other accessible health information for people with intellectual disability that is culturally inclusive.

Background

Equitable access to health care is a right of all Queenslanders as set out in the *Queensland Human Rights Act (2019)* in Section 37. This aligns with *Australia's Disability Strategy 2021-31*.

Queensland's Disability Plan 2022-27 outlines an outcome area for health and wellbeing, with the aim that "people with disability attain the highest possible health and wellbeing outcomes throughout their lives" (p.16). This reflects the human right stipulation in Article 25 – Health of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) "that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability".

Healthcare for people with disability is crucial to enable individuals to live full, purposeful, and meaningful lives, including accessing education, employment, housing and creating a connection to community. However, people with intellectual disability do not have access to quality health care. This has resulted in stark health inequalities with individuals dying an average 27 years earlier than the general population and 38% of deaths were potentially avoidable. An even greater gap occurs for First Nations peoples who have intellectual disability. Targeted action and dedicated strategies are needed to make sure that these outcomes change. People with intellectual disability have specific and very complex needs. They need specialised teams to back up mainstream health services to provide care.

The Commonwealth and Queensland Government responded to the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability on 31 July 2024. The Royal Commissions' recommendations to improve healthcare of all people with disability will help people with intellectual disability. The National Roadmap for Improving the Health of People with Intellectual Disability also outlines key actions for Commonwealth and State/Territory Governments to take actions to improve the healthcare and health outcomes for people with intellectual disability.

It is critical that actions are taken to continue to prioritise the actions needed to address these inequalities and improve access to services and care to people with intellectual disability of all ages and in all parts of our state.

In the [Queensland Disability Reform Framework](#), reforms that are targeted for disability support in healthcare in Queensland are welcomed and all parties are urged to endorse and commit to implementing these (under Outcome 2.1 – 2.1.14, 2.1.15, and 2.1.16).

In this joint statement, we examine additional priorities for healthcare support including:

1. Access to quality healthcare for people with intellectual disability
2. Integration of mental and physical healthcare for people with intellectual disability
3. Mandatory training for hospital and health staff about people with intellectual disability
4. Standardising sedation pathways for people with intellectual disability
5. Improving palliative care access for people with intellectual disability

6. Providing accessible format communications in healthcare and integrated healthcare support for First Nations and culturally and linguistically diverse (CALD) people with intellectual disability, that will enable cultural safety and sensitivity.

Access to quality healthcare for Queenslanders with intellectual disability

Queenslanders with intellectual disability receive substandard healthcare. The health workforce lacks knowledge, experience and confidence to work with people with intellectual disability and this affects health outcomes. People with complex and high support needs are a group that require additional expertise.

Queensland Health is establishing specialised intellectual disability mental health teams in each hospital and health service under *Better Care Together 2022-2027*. Healthcare for Queenslanders with intellectual disability and physical health needs should be supported by specialised intellectual disability health teams, similar to those established in New South Wales Local Hospital Districts.

Recommendation 1: Provide funding to extend the role of new specialised intellectual disability mental health teams across the state to broaden to physical health in each Hospital and Health Service.

Integration of mental and physical healthcare for people with intellectual disability

The Queensland Centre of Excellence in Intellectual and Developmental Disability Mental Health has been established under *Better Care Together 2022-2027* to build the capacity of the Queensland healthcare system to better support the mental health needs of Queenslanders with intellectual disability and support the new mental health teams. This initiative is welcomed but leaves a gap for the physical health needs of this population. We call for the expansion of the funding that has been provided to [Queensland Centre of Excellence in Autism and Intellectual Disability Health](#) to encompass physical health.

Recommendation 2: Provide funding to extend the role of the Queensland Centre of Excellence in Intellectual and Developmental Disability Mental Health (delivered by Queensland Centre of Excellence in Autism and Intellectual Disability Health) to broaden its scope to physical health in addition to its existing focus on mental health. This includes specific research for First Nations people with intellectual disability, ensuring alignment to goals under implementation of [Closing the Gap initiatives in Queensland](#).

Standardising sedation pathways for people with intellectual disability

Many people with intellectual disability cannot tolerate basic health screening and tests such as x-rays, blood tests, immunisations and dental procedures while awake. At present, there are no standardised pathways for people with disability who require sedation. This means many individuals miss out on standard care and vital treatments, contributing to poorer health outcomes and preventable deaths.

The National Roundtable held in July 2023 explored the lack of reliable access to sedation, and provided a series of concrete recommendations to establish and standardise accessible pathways to sedation.

Recommendation 3: The incoming Queensland Government establish procedural support and sedation service in each Hospital and Health Service and implements all recommendations at a state level from the [Roundtable discussion with the Assistant Minister for Health and Aged Care, the Hon Ged Kearney MP about procedural support and sedation to facilitate access to health care for people with intellectual disability.](#)

Mandatory training about intellectual and developmental disability health for all hospital and health staff in Queensland

Queensland research demonstrates hospital and health staff lack knowledge, experience and confidence when providing health care to people with intellectual and developmental disability. A pilot project, tested with over 700 hospital staff, found staff who completed a short online course about intellectual disability and autism health care improved their knowledge, attitudes and confidence around working with people with intellectual disability and those on the autism spectrum. Over 80% of staff also reported they changed the way they work with patients with intellectual disability and those on the autism spectrum after completing the training. Support is needed to implement the training statewide and to mandate all staff to complete this vital training.

Recommendation 4: The incoming Queensland Government introduces minimum requirements for mandatory training in intellectual and developmental disability health for Hospital and Health Service staff.

Improving palliative care access for people with intellectual disability

A lack of effective integration between the state health system in Queensland and the National Disability Insurance Scheme's rules has led to problems around continuity of care for those accessing palliative care. Continuity of care and the ability to choose who supports you at this difficult time is a vital element of effective care. These issues have been documented by Palliative Care Australia in their [submission to the NDIS Review](#).

The University of New South Wales, through an [ongoing Commonwealth-funded project](#), has developed a tailored model of best practice in palliative care for people with intellectual disability with supporting toolkits. Queensland-specific research is needed to ensure interactions between Queensland Health and NDIS funding rules are better integrated reflecting best practice.

Recommendation 5: The incoming Queensland Government improves palliative care access for people with disability by funding implementation research to embed best practice palliative care supports for people with disability across Queensland Health and NDIS systems.

Providing accessible format communications in healthcare that are culturally inclusive

It is essential that all people with disability can access information about health and healthcare in Queensland in the formats that work for their communication needs, including Easy Read. Whilst we welcome 2.1.15 under Outcome 2.1 in the Queensland Disability Reform Framework ensuring that “information is appropriate and accessible”, we want to ensure this applies to all communication about important health issues and health arrangements across the Queensland healthcare system.

Recommendation 6: The incoming Queensland Government through Queensland Health commits to the provision of accessible communications about health and healthcare for all people with disability, including but not limited to Easy Read that is culturally inclusive.