

Action on systemic neglect in the NSW health system

In a nutshell – where things stand

People with intellectual disability have the same right to live long and healthy lives as other members of the community. This does not happen. People with intellectual disability often die early and from preventable causes. The Disability Royal Commission found that they face ongoing “systemic neglect” in the Australian healthcare system.

What needs to happen in the next term of parliament

We seek four commitments:

- 1. Top priority: ensure equity of access to intellectual disability health teams by establishing teams in the eight Local Health Districts that do not currently have them and expand funding to the existing teams.**
2. Mandate training of NSW Health workers on unconscious bias against people with intellectual disability.
3. Implement the NSW Health Intellectual Disability Mental Health Strategy, which is currently being finalised.
4. Provide statewide availability of support and sedation to people who find it hard to accept treatment that they do not understand.

Why it needs to happen

Compared to the general population, people with intellectual disability

- are twice as likely to have potentially avoidable deaths;
- die 27 years earlier and have four times the rate of potentially preventable hospitalisations;
- experience twice the rate of mental illness; and
- have poor access to preventative healthcare.

The health system needs to fix these inequalities. This is an urgent issue, as NDIS reforms underway may reduce health related supports provided by disability services.

1. Intellectual disability health teams

NSW has been a national leader in recognising the need for specialised intellectual disability health teams to back up mainstream doctors in the same way that other specialists do. Just like other groups with distinct and often complex needs, people with intellectual disability need access to specialist teams. Just like we have paediatricians and geriatricians, we need specialists in intellectual disability health.

There are now small multidisciplinary intellectual disability health teams in seven of the fifteen NSW Local Health Districts (LHDs) providing health assessments for people with complex health needs and capacity building for other health services across the LHD. While the teams do have outreach roles in other LHDs, they are small and there is considerable inequity in access to them.

The intellectual disability health teams are backed up by other key services:

- Two statewide mental health hubs, one for children and one for adults.
- The Complex Care Service run by the Centre for Disability Studies.
- The professor of intellectual disability mental health at the University of NSW

The intellectual disability health teams have recently been [positively evaluated](#). The Disability Royal Commission recommended that the teams should be available nationally.

The key need now is to provide equal access to the teams across the state by having teams in all LHDs and increasing the funding to existing teams.

2. Unconscious bias training

Recent cases have highlighted life threatening unconscious bias by hospital clinicians in responding to people with intellectual disability. See for example:

- [Proper care would have given Finlay a chance - Council for Intellectual Disability](#)
- [People with intellectual disability continue to receive substandard healthcare as program to train doctors risks closure - ABC News](#)

The next government needs to make training on unconscious bias mandatory for all NSW Health workers.

3.The Intellectual Disability Mental Health Strategy

People with intellectual disability have very high rates of mental illness but poor access to skilled mental health treatment. They are high users of mental health services, but poor mental health care leads to repeat stays in hospital. Mental health professionals lack necessary skills to work with the specific needs of people with intellectual disability.

NSW Health has been finalising an intellectual disability mental health strategy. This strategy should be implemented in the next term of parliament.

4.Support and sedation pathways

People with intellectual disability often miss out on vaccinations, blood tests and other treatment due to lack of access to the supports and sedation they need to tolerate treatments they may not fully understand.

In its role in the National Centre of Excellence in Intellectual Disability Health, CID led a national [Roundtable on Models of Support and Sedation for Healthcare Interventions for People with Intellectual Disability](#). The top priority action identified at the Roundtable was for state health agencies to build on existing models of good practice towards comprehensive statewide support and sedation services

NSW Health should deliver on this action in accordance with a model of care currently being developed by the National Centre of Excellence in Intellectual Disability Health.