NATIONAL CENTRE OF EXCELLENCE IN INTELLECTUAL DISABILITY HEALTH

Response to the recommendations on health issues of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Summary

Why we need action

The National Centre of Excellence in Intellectual Disability Health (“The Centre” or “we”) supports the call from the Disability Royal Commission to take urgent action to improve the health of all people with disability. The Royal Commission’s recommendations to improve health care for all people with disability will make a difference to the lives of people with intellectual disability. For example – making sure all health policies and programs show how the needs of people with disability will be met will help people with an intellectual disability.

We also think it is important to remember that people with disability are a diverse group. They have a wide range of needs, circumstances and experiences.

That means some of the changes recommended by the Royal Commission need to be targeted so that they meet the needs of particular groups - such as people with intellectual disability.

People with intellectual disability die on average 27 years earlier than the rest of the population. More than 38% of their deaths could have been prevented.

These outcomes won’t change without targeted action and dedicated initiatives.

We need to listen to people with an intellectual disability

People with intellectual disability have spoken out and said they want actions and programs that are specifically designed to meet their needs. They want to have a say in how those actions are designed and rolled out so they know they will work.

People with intellectual disability and their supporters fought hard for the introduction of the National Roadmap for Improving the Health of People with Intellectual Disability (you can read more about the Roadmap below). They are worried that broadening it to include other cognitive impairments would mean the actions won’t take into account their needs and experiences – and that the outcomes that are important to them might not be achieved.

For example, the core skills and experience that health professionals need to work well with people with intellectual disability have now been developed. People with an intellectual disability have been involved in designing them.

This work is ready to be rolled out. It should not be delayed any more.

Rolling out the work that has already been done will give everyone a chance to learn what works well. It cancan then be improved or adapted for other groups.

Why we need action for First Nations people with disability

We also strongly support the Disability Royal Commission's recommendations that focus on the needs of First Nations people with disability. We think there is a lot we can learn about inclusion from First Nations people with disability. We also know that we have to address both racism and ableism to improve outcomes for First Nations people with disability.

To improve outcomes for First Nations people with disability, we must draw on both the Royal Commission and the priority reforms outlined in Closing the Gap.

Why we need action beyond health

Many of the recommendations made by the Disability Royal Commission in other areas will also help improve the health of people with disability.

For example making sure people with disability can:

- find and keep good jobs
- find and keep affordable, accessible and safe housing
- make their own decisions with any support they need

will also have a positive impact on people's health.

It is important to remember all of these areas are interconnected. If we want good outcomes for people with disability we need work in all areas.

Background information

Who is the Centre?

The National Centre of Excellence in Intellectual Disability Health is a key initiative under the National Roadmap for Improving the Health of People with intellectual Disability.

The Centre is looking at ways to improve health care for people with intellectual disability. It looks at ways to improve the expertise and experience of health professionals and services so they can better meet the needs of people with intellectual disability. It also provides support for people with intellectual disability and their families to find and connect to health services.

The work of the Centre includes a particular focus on improving outcomes for First Nations people with intellectual disability, those living in rural and remote locations, and people experiencing homelessness or facing mental health and drug and alcohol issues.

The Centre is based at the University of New South Wales. Nine organisations are working together in the Centre. The organisations bring together clinical expertise, research experience and strong advocacy. The nine organisations are:

- University of New South Wales, including the Department of Developmental Disability Neuropsychiatry
- Centre for Disability Studies at the University of Sydney
- NSW Council for Intellectual Disability
- Down Syndrome Australia
- First Peoples Disability Network
- Intellectual Disability and Autism Service at the Mater Hospital
- Queenslanders with Disability Network
- Telethon Kids Institute
- University of Melbourne

The Centre's work is supported by a broader network of 20 partner and 36 collaborator organisations, including state health departments, universities, primary health networks, peak bodies, First Nations community-controlled organisations and local health districts.

How will people with intellectual disability be involved in the Centre?

People with intellectual disability, their supporters and representative organisations are involved in every aspect of the Centre’s work. People with intellectual disability are involved in governance, designing and rolling out initiatives. They alsoin provide feedback about what is working well and where it can be improved..

You can watch a video about people’s hopes and dreams for the Centre at 3dn.unsw.edu.au/nceidh

What is the National Roadmap?

The National Roadmap for Improving the Health of People with Intellectual Disability was released by the Australian Government in 2021. The roadmap aims to:

- improve support for people with intellectual disability, their families and supporters
- develop better models of health care for people with intellectual disability
- support health professionals to deliver quality care for people with intellectual disability
- improve the oral health of people with intellectual disability
- improve monitoring of the health of people with intellectual disability
- ensure that emergency plans and responses meet the needs of people with intellectual disability.

So far, there are four projects funded as part of the roadmap. The Centre is one. The other three are:

- Primary Care Enhancement Program PCEP, initially in four Primary Health Networks
- Improving the implementation of annual health assessments for people with intellectual disability
- Curriculum development in intellectual disability health

You can read more about the roadmap at health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability

Why is health such an important issue for people with intellectual disability?

There are about 450,000 people with intellectual disability in Australia. Their health outcomes are significantly worse than other people in the Australian community.

Compared to the general population people with intellectual disability have:

- Reduced life expectancy (on average 27 years)
- More than double the rate of avoidable deaths
- Four times the rate of avoidable hospitalisations
- Substantially higher rates of physical and mental health conditions
- Difficultly accessing preventative health care

Rates of disability amongst First Nations people are almost twice that of other Australians. First Nations people with intellectual disability experience both racism and ableism trying to get their health care needs met.

Why do we need specific responses for people with intellectual disability?

People with intellectual disability often have complex heath needs. They often have multiple conditions. They also often struggle to get good preventative care – which means by the time they reach the health system they need a higher level of care.

Some initiatives to improve health outcomes for all people with disability will benefit people with intellectual disability. For example - identifying and providing the adaptations and supports that people with disability need in health care.

But people with intellectual disability also need targeted actions to meet their specific needs. For example - providing important documents in Easy Read.

People with intellectual disability, their families and representative organisations also need to be involved in designing and rolling out programs so everyone can be confident they will work well.

During the Royal Commission many people with intellectual disability and their families spoke out about the way they had been treated in the health system. It took a lot of courage for individuals and families to speak out about the trauma they had experienced. There were also lots of people who sadly could not speak about their experiences. Continuing to fight for change is the way we honour their stories and their lives.

The National Roadmap is great. Are there other initiatives as well?

State and territory governments also have a range of programs and initiatives underway. For example, the New South Wales government have funded intellectual disability heath teams in six of 15 local health districts. They also run two state-wide mental health hubs.

The South Australian government also run a dedicated health service for people with intellectual disability.

The Australian Government is also developing a National Roadmap to Improve the Health and Mental Health of Autistic People.

The National Agreement on Closing the Gap should help improve health outcomes for First Nations people with disability.

What changes did the Disability Royal Commission recommend?

We support the following recommendations made by the Disability Royal Commission. But to get good outcomes they must also consider the specific needs of people with intellectual disability, including First Nations people and other communities experiencing intersectional disadvantage and discrimination.

1. General health recommendations

- Recommendation 6.31 - embedding the right to good health care in key policies and in legislation.
- Recommendation 6.31 - ensuring people with disability are allowed a support person in health settings.
- Recommendation 6.32 - detailing and funding adaptations and supports that are needed in primary health and hospital.

- Recommendation 11.14 - establishing a disability deaths review scheme in each State/Territory.
- Recommendation 5.4 - review of national health agreements to better include people with disability.
- Recommendation 12.5 to 12.8 - improved data through a nationally consistent approach, disability flags in mainstream services and the National Disability Data Asset.
- Recommendation 6.35 to 6.40 - enhanced measures to regulate and minimise restrictive practices.
- Recommendation 6.41 - prohibiting non-therapeutic sterilisation except with informed consent.
- Recommendation 4.9 - legislating the right to equitable access to health services. This must include:
    - the right of First Nations people with disability to receive health care that is culturally safe and inclusive and recognises the importance of their personal connection to community and Country.
    - The right to health services that are safe, sensitive and responsive to intersectional experiences and needs related to factors including sex, gender identity, sexual orientation, ethnicity, language, race, religion, faith or spirituality, socio-economic status, age, neurodiversity, culture, residency status, geographic disadvantage and experience of trauma.
- Recommendation 9.1 - establish a First Nations Disability Forum to lead the implementation of the Disability Sector Strengthening Plan and Investment Fund.
- Recommendation 9.12 - developing disability-inclusive cultural safety standards.

It is also important to remember that many of the recommendations made by the Royal Commission in other areas will also have a positive impact on the health of people with disability. This includes recommendations about:

- Protecting and realising human rights in practice
- Support for decision making
- Peer support and self advocacy
- Employment
- Education
- Housing and homelessness
- Criminal justice
- Improvements to the National Disability Insurance Scheme

2. Recommendations to improve health worker training and accreditation

The Royal Commission made some recommendations to improve health worker and student training. These recommendations are aimed at improving outcomes for all people with a cognitive disability.

We support these recommendations. But we would respectfully suggest the initial work must start with people with intellectual disability. This is because action under the National Roadmap has already included an comprehensive co-design process to develop a capability framework. This framework sets out the specific skills health workers need to work with people with intellectual disability.

The framework is ready for release. Rolling the framework out now will give everyone a chance to see what works well and where it could be improved. The framework could then broaden out to include other people with cognitive impairments.

The recommendations on training and accreditation include:

- Recommendation 6.24 to 6.26 - create a health workforce capability framework.
- Recommendation 6.27 - embed standards in accreditation of all health professional and in health curriculum content.
- Recommendation 6.29 - health colleges develop training content including for subspecialty training and continuing professional development.
- Recommendation 6.27 - Having people with disability as teachers of health workers.
- Recommendation 6.28 - Enhancing clinical placement in disability health services.

3. Recommendations to create specialist services

The Royal Commission recommended creating specialist services for people with a cognitive disability. They included:

- Recommendation 6.33 – creation of multi-disciplinary health teams in both state-wide and local health services. These services should provide assessment and clinical services for people with cognitive disability and complex or chronic health needs, and training for other health providers.
- Recommendation 6.34 – creation of a national network of disability health navigators focused on people with cognitive disability and complex needs.
- Recommendation 6.30 - the scope of the National Centre of Excellence in Intellectual Disability Health be expanded to include autism and other cognitive impairments.

The recommendation to create multi-disciplinary teams appears to be based on the New South Wales model. In this model there are six teams across the state based in local health districts. We support expanding this model to other states. An evaluation is being done at the moment which may identify ways the services could be improved. For example, at the moment the teams just do one-off assessments. There is not a chance to do regular reviews for people with very complex health needs. We think this should be included in an expanded model. The teams also need to do more work to make sure they are providing a culturally safe service. This work should be done in collaboration with First Nations people with disability and their representative organisations.

We are concerned about broadening the existing model to include more people with cognitive disability. At the moment, the teams in NSW are focused on people with intellectual disability and meeting their specific and often complex needs. The model was developed in collaboration with people with intellectual disability, their families and representative organisations.

We believe people with intellectual disability need their own dedicated specialist services. But we also recognise the diverse needs of the disability community. So we suggest creating similar teams focused on people with other cognitive disabilities. This work should be done in collaboration with people with a cognitive disability and their representative organisations. It should look at existing services, for example brain injury services, as well as gaps that must be filled.

All services need to be adequately funded. It is impossible to expand the scope of existing services without new funding.

We support the creation of health service navigators. But again we want to make sure the specific needs of people with intellectual disability are met. For example, while the health needs of people might not be very complex, their circumstances might make getting good care difficult. For example, they might need extra support because of their communication needs. Or traumatic experiences in the past may mean they find dealing with doctors upsetting or challenging. Navigators would need to be well trained to deal with all these issues. They would have to be well trained to ensure they worked in a culturally appropriate and safe way.

The recent NDIS Review also made recommendations about all people with disability, including NDIS participants, getting support from a navigator. More work is needed to make sure these roles work in a coordinated way. We don’t want overlap – or more gaps.

Why we think targeted action is needed

We welcome the recommendations of the Royal Commission – but we do want to make sure action addresses the particular health disadvantages experienced by people with intellectual disability.

We also want to make sure that all changes that will impact the lives of First Nations people with disability are informed by both the work of the Royal Commission and the priority reforms outlined in Closing the Gap. They must also be designed and rolled out in genuine partnership with communities.

.

We are also concerned that important work already begun under the National Roadmap might be slowed down while governments make decisions about the Royal Commission. Or they might be delayed while governments work out how to incorporate changes for people with other cognitive impairments.

We do not support broadening the work of the National Centre to include all people with a cognitive disability. The clear inequalities in health outcomes for people with intellectual disability led to bipartisan support for the National Roadmap. The Roadmap went through a detailed co-design process with people with intellectual disability, their families and representative organisations. It led to the creation of the National Centre. The Centre has already begun its work focused on the particular needs of people with intellectual disability. To introduce other areas of focus could delay and disrupt the Centre's important work.

People with intellectual disability and their families cannot wait any longer for change.

UNSW SYDNEY

3DN
UNSW
Department of Developmental Disability Neuropsychiatry

CDS
Centre for Disability Studies

cid
Council for Intellectual Disability

Down Syndrome Australia

First Peoples Disability Network Australia

mater

QDN
QUEENSLANDERS WITH DISABILITY NETWORK
NOTHING ABOUT US WITHOUT US

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

THE UNIVERSITY OF MELBOURNE