# Inclusion Australia response to the issues paper on healthcare for people with cognitive disability

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

## August 2020

Inclusion Australia Response to the Issues Paper on healthcare of people with cognitive disability of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability August 2020

### Acknowledgments

Inclusion Australia acknowledges the traditional owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respect to community members and Elders past, present and emerging.

This submission was prepared for Inclusion Australia by its NSW member, Council for Intellectual Disability.

This submission includes an attachment paper: *Health Inequality and people with intellectual disability – Research Summary* authored by Professor Julian Trollor MB BS(Hons1), FRANZCP, MD and Dr Jacqueline Small MBBS MHP(Hons) of the Faculty of Medicine, The department of Developmental Disability Neuropsychiatry 3DN.

Inclusion Australia receives funding from the Australian Government, Department of Social Services to undertake systemic advocacy activities related to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This submission forms part of this work.

## Contact

Inclusion Australia (NCID) Limited

ABN: 60 084 254 809

Catherine McAlpine

Chief Executive Officer

PO BOX 336

Nunawading, Victoria, 3131 Australia

P: 1300 312 343

M: 0419 530 524

E: [catherine.mcalpine@inclusionaustralia.org.au](mailto:catherine.mcalpine@inclusionaustralia.org.au)

E: [admin@inclusionaustralia.org.au](mailto:admin@inclusionaustralia.org.au)

W: www.inclusionaustralia.org.au

# Inclusion Australia

## Submission to the Disability Royal Commission on neglect and abuse of people with intellectual disability in relation to healthcare

### Who we are

Inclusion Australia is the national voice for Australians with intellectual disability. We bring together groups across Australia who are connected to people with intellectual disability and who share the vision of inclusion in all parts of Australian life.

Inclusion Australia and its member organisations have had a long-standing focus on the health inequalities experienced by people with intellectual disability.

### Stark health inequalities

Research shows the following inequalities for people with intellectual disability when compared with the general population:[[1]](#footnote-1)

* 2.5 times the number of health problems
* 38 to 53 percent potentially avoidable deaths compared with 17 percent for the general population
* Early indications of future increased ill-health such as obesity and psychiatric disorder
* Under-diagnosis of chronic and acute health conditions
* Higher rates of potentially modifiable cardiometabolic risk factors
* Under-representation of consultations with GPs addressing physical and preventative health issues
* Significantly less likely to be prescribed preventative health medications
* Higher prescription of psychotropic medication, even after allowing for elevated incidence of mental illness
* Double the usage of emergency departments and hospital admissions, with each admission costing twice as much
* Much higher rates of potentially preventable hospitalisation
* Five times more likely to experience mental health admissions of over a year, and three times as likely to be admitted more than three times a year
* 1.6 times more face to face contacts with community mental health services, and each contact is 2.5 times longer
* Die many years earlier, 27 years in one large Australian study.

In 2008, the National Health and Hospitals Reform Commission reported that people with intellectual disability face “stark health inequalities”.[[2]](#footnote-2)

Factors contributing to these inequalities include:[[3]](#footnote-3)

* Communication challenges between health professionals and people with intellectual disability
* Diagnostic overshadowing – that is, the assumption that symptoms are part of a person’s intellectual disability rather than a health condition that requires treatment
* Workforce challenges – including inadequate workforce training on communicating with and addressing complex health care needs of people with intellectual disability
* The lack of targeting of people with intellectual disability in health promotion and prevention strategies
* Inadequate uptake of Medicare annual health assessments
* The lack of societal value attached to people with intellectual disability
* Inadequate focus on healthy lifestyles and promoting good health in disability support services
* Poverty and other social disadvantage

Training on the health of people with intellectual disability in university medical and nursing schools is very low:

* A median of 2.6 hours’ compulsory content across 12 medical schools (with one university standing out with 12 hours)[[4]](#footnote-4)
* No intellectual disability content in 52 percent of nursing schools and very limited content overall[[5]](#footnote-5)

### National policy framework

A range of key documents support national action on the health of people with intellectual disability. These include:

#### UN Convention on the Rights of Persons with Disabilities 2006 (CRPD)

People with disability “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. This includes “the same range, quality and standards of free or affordable health care as provided to other persons” and health services needed because of their disabilities. (Article 25)

#### National Disability Strategy 2010-2020 (COAG 2011)

The COAG strategy is intended to guide policy and program development by all levels of government and actions by the whole community. The strategy commits all governments to six key outcomes, one of which is that people with disability attain the highest possible health and wellbeing outcomes throughout their lives.

To achieve this outcome, the strategy specifies policy directions, including:

* All health services being able to meet the needs of people with disability
* Timely, comprehensive and effective prevention and early intervention health services for people with disability
* Universal health reforms and initiatives addressing the needs of people with disability, their families and carers

#### **National Disability Insurance Scheme (NDIS)**

There is a strong nexus between the complementary responsibilities of the NDIS and health services. If people with intellectual disability have good disability supports, they are less likely to develop health problems. Health conditions are also much easier to treat when people have good disability support. If people do not receive appropriate health services, their disability support needs may be much greater and more expensive.

There also needs to be strong national and local collaborative relationships between the health and NDIS systems to address demarcations between the responsibilities of the two systems.

#### 5th National Mental Health and Suicide Prevention Plan 2017

The Plan notes that although people with intellectual disability are two to three times more likely to have a mental illness than the general population, they encounter significant barriers to treatment and often have complex needs that require a coordinated approach across multiple service systems.

The Plan states that actions in the Plan and related activity by governments require specific and appropriate application to diverse groups, specifically including people with intellectual disability.

### Three key areas of action

To address the health inequalities facing people with intellectual disability, action is needed on three fronts:

1. Improved capacity in the mainstream health system to respond to people with intellectual disability
2. The establishment of a national network of specialists in healthcare for people with intellectual disability as a consultancy and educational resource to the mainstream system
3. Better support in the disability service system for healthy lifestyles, access to appropriate health care and implementation of health professional advice

### Action to date

#### State and territory health departments

There have been inadequate and varying levels of response to the health needs of people with intellectual disability by state and territory health departments.

The strongest response to date has been by NSW Health with:

* A network of intellectual disability health specialists across local health districts. There is a specialist intellectual disability health team in six out of fifteen Local Health Districts (LHDs) and an outreach worker in each of the other LHDs. There are also two statewide mental health specialist hubs, one for children and young people and the other for adults. All of these services provide consultancy advice in relation to people with complex health care needs and capacity building across LHDs.
* The Intellectual Disability Network in NSW Health’s Agency for Clinical Innovation, which promotes capacity building and innovation across the state, including by producing educational resources. In particular, the network has developed The Essentials, which is a guide for LHDs on how to respond better to the needs of people with intellectual disability.

Action in other states has been more modest, although Victoria, Queensland and South Australia have established specialist research, education and clinical centres.[[6]](#footnote-6)

South Australia, for example, has the Centre for Disability Health (CDH). This is a statewide, non-crisis service which provides advice, assessment and consultation for adults with intellectual disability and complex needs. CDH aims to support mainstream medical and other health professionals in providing health care to people with intellectual disability and complex needs through specialised advice and assessment, training and education.

With the introduction of the NDIS there were discussions about the future of CDH as the service transitioned to SA Health. In 2018 a review of CDH made a number of recommendations that were endorsed by SA Health. Recommendations included that that a new service model be developed for the CDH to see it established as a statewide centre for clinical leadership, research and education for people with intellectual disability and complex presentations.[[7]](#footnote-7)

To implement these recommendations the Centre for Disability Health Project was established and tasked with developing a new model of care for CDH. The new model is due to be released soon.

#### The federal Department of Health

Until recently the federal Department of Health’s response to the inequalities facing people with intellectual disability was extremely limited. One positive initiative was the creation in 2006 of Medicare annual health assessment items for people with intellectual disability. The items are a research-validated tool for better health promotion and identification of undiagnosed conditions.

In 2019, there was a major step forward with Health Minister Greg Hunt initiating a roundtable and national roadmap on the health care of people with intellectual disability. The COVID-19 pandemic has delayed finalisation of the roadmap. However, the Department of Health has in the meantime issued an expression of interest for four of the 31 Primary Network Health Networks around Australia to be lead sites in programs to improve primary health care for people with intellectual disability.

#### Action in disability services

Prior to the NDIS, disability service departments around Australia undertook initiatives to improve the health care of people with intellectual disability. For example, Queensland, NSW, Victoria and Western Australia obtained licenses for the CHAP tool to facilitate high-quality annual health assessments.

The NSW government disability agency issued detailed health policies and procedures for supported accommodation, including requirements for annual assessments of health, mental health, nutrition, and swallowing, and individual health plans. With the implementation of the NDIS, providers are no longer required to adhere to these policies.

South Australia also had policies and guidelines for health supports in disability services, and these may in fact still apply since registered NDIS providers need to be on the South Australia Disability Service Provider Panel.

With the implementation of the NDIS, we are concerned that there may not be adequate national safeguarding mechanisms in place to ensure appropriate health supports in NDIS funded services. There is minimal coverage of health supports in the standards of the NDIS Quality and Safeguards Commission as compared with the requirements in the NSW state government policies and procedures.

In early 2020, the NDIS Commission committed to better promote health supports, including through provider alerts and guidelines. However, except in relation to swallowing issues, the Commission has still not moved toward standards and quality indicators for health supports in disability services.

The NSW government funding for the CHAP licence expired in mid 2020. The Victorian and Queensland licences are currently up for renewal. The Western Australia licence expired some years ago.

#### Deaths review

From 1998, the Community Services Commission NSW and then the NSW Ombudsman had a role in reviewing deaths of people with disability in supported accommodation. This role focused both on the adequacy of disability supports and the adequacy of healthcare and provided an invaluable lens on the causes of deaths and the adequacy of healthcare more generally.

In 2016, the Queensland Public Advocate completed a review of deaths of Queenslanders with disability in supported accommodation over the period 2009-2014.

From 2017, the Disability Services Commission Victoria also had the role of reviewing disability services provided to people with disability who had died.

With the implementation of the NDIS, deaths of service recipients must be reported to the NDIS Commission as a reportable incident. However, the NDIS Commission does not have the clear and detailed role that the NSW Ombudsman had, and only has jurisdiction in relation to the actions of disability support providers and not the health care system.

To complement the role of the NDIS Commission, the NSW Ombudsman is for the time being continuing to review deaths in relation to the role of the health system.

The periodic reports of the NSW Ombudsman’s death review role and the reports in Queensland and Victoria show the value of a clear and comprehensive deaths review system. For example, the most recent report of the NSW Ombudsman highlighted problems in disability services, including at least 42 preventable deaths resulting from treatment delays, partly due to disability support staff not being sufficiently active in seeking medical help. The report also found a major problem with medication errors in disability providers.[[8]](#footnote-8)

### Recommended action

For people with intellectual disability to have the same opportunity as other people to lead long and healthy lives, we recommend the following actions.

#### In the health system

1. Values based training for all health professionals – both in tertiary education and ongoing – including coverage of the equal value of people with intellectual disability, the identification of intellectual disability, how to communicate with people with intellectual disability, and adjustments to standard clinical practice. People with intellectual disability and family members should be employed as trainers.
2. Comprehensive allowance for the extra time people with intellectual disability need for accurate and respectful diagnosis and treatment
3. A national system to ensure GPs offer comprehensive, high-quality annual health assessments to people with intellectual disability
4. Each state and territory establish a network of specialised intellectual disability health teams
5. Funding of university-based centres of excellence
6. Specialist recognition and training programs in the physical and mental health of people with intellectual disability
7. Each primary health network to have a program to enhance primary health care to people with intellectual disability
8. All government health initiatives being required to consider what action is needed to make the initiatives work for people with intellectual disability

#### In the disability support system

1. Comprehensive support and education to people with intellectual disability to maximise their role in their own health care
2. Similar support and education for families and disability support workers in healthy lifestyles, health promotion, recognition of signs of illness, and facilitating access to appropriate health care
3. The NDIS to fund participants with complex health needs to engage a health facilitator to coordinate access to appropriate health supports
4. The NDIS Quality and Safeguards Commission to establish strong standards, workforce capabilities and monitoring systems in relation to health care

#### Other

1. Establishment of a national data collection and analysis system on the health status of people with intellectual disability, and a national system of review of deaths focused on both the health system and the disability support system
2. A requirement on funders of research to ensure that research is inclusive of people with intellectual disability
3. Federal and state governments to ensure that individual and systemic advocacy is available to support good health care for people with intellectual disability

1. See accompanying research summary and, in relation to rates of potentially avoidable deaths, Trollor J, Srasuebkul and Howlett S (2017) [bmjopen.bmj.com/content/7/2/e013489](https://bmjopen.bmj.com/content/7/2/e013489) and Office of the Public Advocate (Qld) (2016), Upholding the right to life and health: a review of the deaths in care of people with disability in Queensland [www.justice.qld.gov.au/\_\_data/assets/pdf\_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf](http://www.justice.qld.gov.au/__data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf). [↑](#footnote-ref-1)
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7. Northern Adelaide Local Health Network (2019) Recommendations and Summary of the

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8. NSW Ombudsman, ‘Report of reviewable deaths in 2014 – 2017: Deaths of people with disability in residential care’ (Report, 31 August 2018). [↑](#footnote-ref-8)