



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**

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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

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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.

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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

- 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

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://doi.org/10.1136/bmjopen-2017-024899) 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.

- 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

Factors contributing to these inequalities include: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

² National Health and Hospitals Reform Commission (2008) A Healthier Future for All Australians, Interim Report, pages 54-55.

³ National Health and Hospitals Reform Commission (2008) NSW Ombudsman, periodic reports on reviewable deaths of people with disability www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths; Disability Services Commissioner Victoria, **Review of disability service provision to people who have died 2017–18** www.odsc.vic.gov.au/2018/12/20/poor-disability-support-practices-highlighted-in-review-of-deaths-of-people-with-disabilities-in-victoria/; **Emerson E and Hatton C (2007)** Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication, 51 JIDR Part 2, 866-874.

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
- No intellectual disability content in 52 percent of nursing schools and very limited content overall⁵

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

⁴ Trollor J, Ruffell B, Tracy J, Torr J, Durvasula S, Iacono T, Eagleson C and Lennox N (2016) Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught [bmcmededuc.biomedcentral.com/articles/10.1186/s12909-016-0625-1](https://doi.org/10.1186/s12909-016-0625-1).

⁵ Trollor J, Eagleson C, Turner B, Salomon C, Cashin A, Iacono T, Goddard L and Lennox N (2016) Intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught [www.sciencedirect.com/science/article/pii/S026069171630106X](https://doi.org/10.1016/j.scimed.2016.06.006).

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

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

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

⁶ gcidd.centre.uq.edu.au/
www.cddh.monashhealth.org/
www.svhm.org.au/our-services/departments-and-services/v/victorian-dual-disability-service
dhs.sa.gov.au/services/disability-services/centre-for-disability-health

⁷ Northern Adelaide Local Health Network (2019) Recommendations and Summary of the Review of the Centre for Disability Health.

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

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

⁸ NSW Ombudsman, 'Report of reviewable deaths in 2014 – 2017: Deaths of people with disability in residential care' (Report, 31 August 2018).

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

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People with ID: a minority group with significant health inequality, which requires action.

About 1.8% of the Australian population have intellectual disability (ID), or approximately 450,000 individuals (1). These individuals:

- have extremely poor health status (2-3),
- have multiple barriers to timely, affordable and appropriately equipped health services (4-5),
- experience a mismatch between health needs and accessible services, which has a major impact,
- have substantially elevated mortality rates above the general population, including elevated deaths from potentially avoidable causes (6-10).

Available data highlights much higher rates of ill health, greater service use, but lower rates of detection and poor access to preventative healthcare:

International research has clearly demonstrated the substantial health needs of people with ID:

- in general practice on average, people with ID have 2.5 times the number of health problems than people without ID (3).
- young people with ID are more likely to experience poor health and are at an increased risk of mental health problems during their transition to adulthood than the general population (11).
- people with ID have higher rates of potentially modifiable cardiometabolic risk factors than the general population. These include higher rates of psychotropic prescription and polypharmacy, lower rates of physical activity (12-13), and higher rates of obesity (14).

- A review of published data from 2011-2015 showed that people with ID have higher unmet needs and lower use of preventative health services compared to people without ID (15).
- People with ID have under-diagnosis of chronic health conditions and lack of active management of risk factors. For example, a landmark Dutch study demonstrated double the proportion of missed metabolic syndrome (MetS) diagnoses compared to the general population, and under detection of hypertension by 50% (16).

Australian research is congruent with international data and has shown:

- that people with ID have on average 5.4 medical disorders per person, half of which were previously undetected, and that compared to controls, people with ID had increased cardiovascular risks, medical consultation rates, hospitalisation and mortality (2).
- that in a representative sample of 582 young people with ID aged 4-19 years, about 40% of young people with ID had psychiatric disorders which persisted over 4 years. Clinically significant change in symptoms with either deterioration or improvement occurred in around 14% of the sample. Psychiatric disorder was 3-4 times more prevalent in young people with ID than in the general population. Less than 10% of these young people receive specialist services for a problem which is numerically as large as schizophrenia (17).
- that in Australian children followed longitudinally, significantly higher rates of obesity were observed among six to seven-year-old children with intellectual impairment when compared with their 'typically developing' peers (18)

Australian data shows that people with ID experience high mortality and a very high proportion of deaths from potentially avoidable causes.

NSW linkage data indicates:

- people with ID experience a median age at death of 54 years, that is 27 years earlier than the general population (6), and a comparative mortality figure (CMF) that is very high especially in young-mid adulthood (CMF for 20-45 years is 4.0 (95% CI 3.1-5.2)) (8).
- multiple markers of premature mortality and a very high proportion of potentially avoidable deaths (38%), which was more than double that of the general population. Deaths are dominated by respiratory, circulatory, neoplasm and nervous system related causes (6, 8).

Western Australian linkage data shows that:

- people with ID aged 20 years and over were more likely to die prematurely than the general population. This study found high rates of potentially avoidable deaths, with people with ID being more likely to die from influenza/pneumonia, epilepsy, and cellulitis (10).
- children with an ID experience a 6-12 fold increased risk of mortality compared to children without ID (9). The most common underlying cause of death for children in this study were related to respiratory diseases. Potentially avoidable deaths, such as epilepsy and aspiration pneumonia accounted for one-quarter of deaths in the 11-25 years age group.



Primary care is the linchpin of accessible health care for people with ID, but Australian data suggests the current approach is suboptimal.

- Research by Lennox and others has highlighted a number of barriers that GPs experience in the delivery of care to people with ID (19-22).
- The effectiveness of comprehensive health checks for people with ID has been clearly demonstrated, with these checks being able to identify previously unrecognised disease and engaging GPs in health promotion in people with ID. (23)
- Carers of people with ID identify a range of barriers to primary care including a lack of knowledge and skills specific to ID, communication issues, negative attitudes towards ID, lack of flexibility and accommodation to an individuals need, and siloed approach to health care management (22),
- Data have been analysed from the Bettering the Evaluation and Care of Health (BEACH) program, regarding GP encounters relating to people with ID and compared to encounters representative of the general population. These data indicate that, compared to people without ID, those with ID had an over-representation of psychological, social and administrative reasons for presentation, and an under-representation of consultations addressing physical and preventative health issues (24). In an analysis of the prescribing data, people with ID were significantly less likely than the general population to be prescribed preventative health medications such as antihypertensives, and narcotic analgesics and modern antibiotics for infections (in favour of older style and less effective ones). They were more likely to be prescribed antipsychotic and anticonvulsant medication (25).

Poor Prescribing practices in people with ID may drive adverse health outcomes.

- After accounting for elevated prevalence of mental illness (26), psychotropic medication prescription and polypharmacy remain disproportionately high amongst people with ID (27-29).
- Antipsychotics are the most commonly prescribed psychotropic medication (30) and are frequently given in the absence of a psychiatric diagnosis (31). Antipsychotics are often given for challenging behaviour, a practice unsupported by evidence (32) and out of keeping with sector expectations.
- Psychotropic medication use in the general population has been associated with an elevated risk of cardiometabolic morbidity and mortality (33-34), and may thus drive some of the poor health outcomes experienced by people with ID.

People with ID use more hospital and ED services, and have higher associated costs

NSW Linked data has been used to examine health service use and costs for people with ID. This linkage work identifies 1.15% of the NSW population as having an ID and finds that people with ID:

- are over-represented in each major compartment of the health service system, including representing 6% of all mental health service users (35).
- have inpatient stays and admission costs which are twice that of the general population (36).
- have 1.6 times the rate of use of emergency departments compared to people without ID, and experience longer wait times, and higher likelihood of presentation via emergency

services (37).

- after their first ever admission for a mental health issue, are three times as likely to represent to emergency departments, and between 55-75 percent more likely to be readmitted at 1, 2-5 and 6-24 months after discharge than people without intellectual disability (38).
- require two and a half times the community mental health resources to meet their mental health needs compared with people without intellectual disability (39).

Linked data studies from Western Australia (40-41) also highlight the health needs of people with intellectual disability:

- children with ID were 1.6 times more likely to be admitted to hospital, had over twice the number of admissions, which were of a substantially longer duration than for those without ID and were admitted for substantially longer than for children without ID. (40)
- the risk of hospitalisation for children with ID was up to 10 times that of children without ID, with the greatest risk being for those with severe ID (41).
- During the last year of life people with ID had higher rates of presentation and admission for ambulatory care sensitive conditions (that is, conditions for which hospitalisation is thought to be avoidable with the application of public health interventions or early management delivered in a primary care setting) than people without ID (10).

Australian findings are congruent with international data which shows that people with ID:

- were four times more likely to incur high annual health care cost compared to those without ID. The greatest health expenditure was due to hospitalisations, continuing care/rehabilitation, and medications (42).
- are more likely to be admitted to hospital for ambulatory care sensitive conditions than people without an ID (43-45).

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