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Executive Summary

People with intellectual disability represent around 1.8 per cent of Australia's population and have some of the worst health outcomes of any population group across a range of indicators, with very high use of public hospital services and life expectancy 27 years lower than the general population.

Australian governments at Commonwealth, state and territory level have since 2021 engaged in efforts to start to improve the health of people with intellectual disability through short term measures under the 10 Year National Roadmap for Improving the Health of People with Intellectual Disability.

There are elements of good practice in intellectual disability health care emerging from implementation of the National Roadmap, including support for the National Centre of Excellence in Intellectual Disability Health, national standards and frameworks in some areas, the National Disability Data Asset and ongoing support for MBS telehealth.

Individual states are leading in other areas with the emergence of specialised intellectual disability health and/or mental health services in four jurisdictions, disability liaison officers in one jurisdiction, and uneven improvements to Easy Read availability, health passports, reasonable adjustments and emergency planning.

More work is clearly needed to implement the many remaining elements of the Roadmap and to address the issues that people with intellectual disability continue to report:

- poor experience of interactions with the health system
- high levels of presentation to public hospital emergency departments
- the continuing occurrence of adverse events

- little attention to improving the experience of and outcomes for First Nations people with intellectual disability and people with intellectual disability from culturally and linguistically diverse backgrounds
- poor communication and low levels of understanding of intellectual disability health among generalist health and primary care providers
- Funding systems that do not support quality care for people with intellectual disability.

The need for ongoing action has been strongly reinforced by the Disability Royal Commission with its finding of ongoing systemic neglect of people with cognitive disability in the Australian Health System and many recommendations for action.

As next steps to maintain real progress, the National Centre of Excellence recommends that an incoming Federal government in 2025:

1. Commit to continued, timely and full implementation of the National Roadmap with the full involvement of people with intellectual disability. Existing investments, including in the Down Syndrome Health Ambassador Program for which funding terminates on 30 June 2026, should be continued.
2. Invest in primary care for people with intellectual disability through:
 - a) better funding for longer consultations under the MBS
 - b) specific MyMedicare-linked payments to incentivise continuity of care
 - c) capacity building from Primary Health Networks to upskill staff, develop patient pathways and support best-practice care coordination
3. Pursue comprehensive implementation of the Intellectual Disability Health Capability Framework and embed training and continuing professional development for the health workforce, including by:
 - a) incorporating the Framework in accreditation standards and university curriculums to address future health workforce capability
 - b) funding scholarships for Continuing Professional Development (CPD) in intellectual disability health to upskill the existing health workforce.
4. Make people with intellectual disability a priority focus in the next National Health Reform Agreement, including through:
 - a) the activity-based funding (ABF) formula
 - b) better system-wide data via an intellectual disability indicator in all health settings

- c) Commitment from Commonwealth and State/Territory governments to ensuring people with disability receive appropriate supports in hospital.

Introduction

As we complete the first triennium of the National Roadmap on Improving the Health of People with Intellectual Disability, head into the 2025 federal election year and emerge from the establishment phase of the National Centre of Excellence on Intellectual Disability Health, it is timely to take stock of progress in improving the health of people with intellectual disability in Australia.

In this report, the National Centre of Excellence on Intellectual Disability Health provides a summary of progress on improving the health of people with intellectual disability and makes recommendations for next steps for an incoming federal government.

Background

Around 1.8 per cent of the population¹, or around 490,000 Australians in 2024², have intellectual disability. People with intellectual disability experience significant health inequities compared to other Australians, including³:

- median age at death of 54 years, some 27 years earlier than the general population
- a very high proportion of potentially avoidable deaths (38%), more than double that of the general population
- 1.6 times the rate of emergency department use, longer wait times and twice the rate of hospital admissions
- higher rates of mental illness, including 3-4 times the prevalence of psychiatric disorders among young people
- higher rates of obesity and other potentially modifiable risk factors for chronic disease
- Lower use of preventative healthcare services and significant barriers to care in general practice.

¹ Trollor J & Small J (2019) Health Inequality and People with Intellectual Disability – Research Summary

² Australia's population was 27,204,809 people at 30 June 2024. Australian Bureau of Statistics (June 2024), [National, state and territory population](#), ABS Website, accessed 15 December 2024.

³ Trollor J & Small J (2019) Health Inequality and People with Intellectual Disability – Research Summary

⁴ Accessed at: <https://www.health.gov.au/sites/default/files/2024-12/roadmap-implementation-governance-group-rigg-short-term-actions-communique-november-2024.pdf>

National Roadmap and Roadmap Implementation Governance Group (RIGG)

In 2021, following extensive consultation, the Australian Government released the National Roadmap for Improving the Health of People with Intellectual Disability. The Roadmap set out a series of short term (1-3 years), medium term (4-6 years) and long term (7-10 years) actions that represent the expert consensus of people with disability, their supporters, researchers and government policy makers on the targeted reforms needed across the health system to improve health outcomes for people with intellectual disability. The Roadmap received broad support from people with intellectual disability, their families and supporters, state and territory governments and, in the 2022 election, both the Liberal-National Party Coalition and the Australian Labor Party.

We are now at the end of the short-term period of Roadmap implementation and entering the medium term.

The Roadmap Implementation Governance Group (RIGG), established in 2021 to oversee implementation, issued a communique in November 2024 providing an update on implementation.⁴ The RIGG highlighted the following achievements to date:

- establishment of the RIGG to oversee implementation
- establishment of the National Centre of Excellence in Intellectual Disability Health to provide national leadership in intellectual disability health, lift the capability of health services, provide online support and serve as a repository of expertise, resources and research in intellectual disability health⁵
- publication of the Intellectual Disability Health Capability Framework, which sets out capabilities, learning outcomes and guides for universities and accreditation authorities to support the inclusion of intellectual disability content in the training of health care professionals⁶

⁵ Accessed at: <https://nceidh.org.au/>

⁶ Accessed at: <https://www.health.gov.au/resources/publications/intellectual-disability-health-capability-framework?language=en>

⁷ Accessed at: <https://www.health.gov.au/resources/publications/primary-care-enhancement-program-evaluation-report-executive-summary?language=en>

⁸ Accessed at: <https://www.health.gov.au/resources/collections/comprehensive-health-assessment-program-chap-annual-health-assessment-for-people-with-intellectual-disability>

- completion and evaluation of a four-year pilot of the Primary Care Enhancement Program for People with Intellectual Disability⁷
- updates to the Comprehensive Health Assessment Program (CHAP)⁸ and launch of a campaign to promote uptake of MBS-funded annual health assessments
- funding for health ambassadors⁹ to 30 June 2025 to promote awareness of intellectual disability health
- continuation of MBS telehealth for general practice, allied health and specialist care
- capacity for people to self-identify their intellectual disability to their usual general practice under the MyMedicare voluntary patient registration initiative to support continuity of care and better data¹⁰
- enhanced cross-sectoral collaboration and engagement across the health and disability sectors
- Public annual reports to provide updates about implementation of the Roadmap and maintain accountability for implementation.

The RIGG noted 56 of 72 short-term actions have commenced, but with only nine complete.

The RIGG has worked with the Department of Health and Aged Care to prioritise the outstanding short-term actions and to commence implementation of medium-term actions and issued a communique in November 2024 available at

<https://www.health.gov.au/committees-and-groups/roadmap-implementation-governance-group-rigg>.

⁹ Accessed at: <https://www.downsyndrome.org.au/advocacy/health-ambassadors/>

¹⁰ Accessed at: <https://www.health.gov.au/our-work/mymedicare/patients>

National Centre of Excellence in Intellectual Disability Health

The National Centre of Excellence in Intellectual Disability Health ('the Centre') was launched by the Assistant Minister for Health, the Hon Ged Kearney MP, in October 2023. The Centre is funded with an initial grant for \$22 million for its first four years from the 2022-23 Budget. It is operated by a consortium of nine organisations, including the Council for Intellectual Disability, Centre for Disability Studies, Down Syndrome Australia, First Peoples Disability Network Australia, Queensland Centre of Excellence in Autism and Intellectual Disability Health, Queenslanders with Disability Network, University of Melbourne, University of New South Wales, and The Kids Research Institute Australia.

Alongside getting itself established, in 2024 the Centre began significant work in the following areas:

- Sharing best practice.

The Centre held a Conference in August 2024 which shared best practice in inclusion and innovation in intellectual disability health. The Centre supported webinars and Q&As for health professionals to help support better care and launched its own website as a platform for information sharing and online support. It shared resources on improving palliative care for people with intellectual disability and promoted the Intellectual Disability Health Capability Framework.

- Research.

The National Centre published new research on intellectual disability health education, created PhD opportunities at the Centre, and opened Innovation Seed Funding Grants opportunities in January 2025.

- Advocacy.

The Centre conducted significant advocacy to Commonwealth and State governments to support the implementation of the Disability Royal Commission recommendations, the continued implementation of the National Roadmap and to support inclusion of intellectual disability health issues in the next National Health Reform Agreement. The Centre also engaged with local and regional health services, including to support implementation of the Coroner's recommendations from the 2024 inquest¹¹ into the death in hospital of Finlay Browne, a young man with intellectual disability.

¹¹ Accessed at: [https://coroners.nsw.gov.au/coroners-court/download.html/documents/findings/2024/Inquest into the death of Finlay Browne .pdf](https://coroners.nsw.gov.au/coroners-court/download.html/documents/findings/2024/Inquest%20into%20the%20death%20of%20Finlay%20Browne_.pdf)

Other government initiatives

The Centre also highlights the following initiatives from Commonwealth, State and Territory governments which are helping to establish a baseline of good practice in improving the health of people with intellectual disability.

Commonwealth

- The Assistant Minister for Health and Aged Care, the Hon Ged Kearney MP in July 2023 convened a roundtable on procedural support and sedation to facilitate access to health care for people with intellectual disability. This has given momentum to work in some jurisdictions to improve awareness of pathways to access procedural support and sedation and to establish more specialised and flexible service delivery models.
- The Australian Commission on Safety and Quality in 2024 issued a National Safety and Quality Health Service (NSQHS) Standards User Guide for the Health Care of People with Intellectual Disability. The guide was developed in response to significant evidence of poor health outcomes for people with intellectual disability in Australia's health system. It aims to support health service organisations and clinicians in providing safe and high- quality health care to people with intellectual disability.
- The first release of the National Disability Data Asset, including data about disability, health and social security payments, will begin to improve the evidence base on the health experience, outcomes and better policy for people with intellectual disability.
- The development of a Disability Inclusive Emergency Management Toolkit by the National Emergency Management Agency to start to address the higher risk of death, injury and neglect experienced by people with disability in disasters.

New South Wales

- NSW Health maintained its Statewide Intellectual Disability Health Service, with Specialised Intellectual Disability Health Teams in six local health districts and individual clinical positions in other districts. An evaluation of this Service commenced in 2024 to report in 2025.
- NSW Health also maintained two Statewide Intellectual Disability Mental Health Hubs, one for children and one for adults, and funded a chair in Intellectual

Disability Mental Health at the University of New South Wales. The Mental Health Hubs were evaluated by the University of New South Wales in 2023, with the evaluation showing the Hubs achieved success across a range of intended outcomes.

- In September 2024, NSW Health issued a Policy Directive on Responding to the Health Care Needs of People with Disability setting out mandatory requirements for NSW Health services and staff to provide safe, inclusive, person-centred, integrated and trauma-informed care to all patients.
- NSW Health funded the Physical Disability Council NSW (PDCN) to support development of a prototype of a digital Care Passport. This prototype or preliminary app helps people with complex care needs, including people with intellectual disability, to document their unique health care needs for use across their health care journey.
- NSW Health's Agency for Clinical Innovation (ACI) also developed and published the Virtual Care in Practice Guide, which included content to create broader awareness of considerations and adjustments required to support clinicians and administrative staff to provide virtual care to people with disability. This content was developed in consultation with the ACI Intellectual Disability Health Network.

Queensland

- The Queensland government funded the Queensland Centre of Excellence in Intellectual and Developmental Disability Mental Health at the Mater Hospital to provide additional specialised mental health supports for people with intellectual disability.
- The Queensland Health 2022-24 Disability Service Plan made some important commitments to improve care for people with intellectual disability. These include: Easy Read communications; workforce training, priority access lists and other initiatives in oral healthcare for people with intellectual disability; research to improve preventative healthcare for people with intellectual disability; co-design of a model of service in mental health, alcohol and other drug responses for people with intellectual disability; promotion of the use of health passports by people with disability; and investigation of the need to develop specialised intellectual disability health training for Queensland Health staff.

- The Queensland Health Campaign “See Me, Hear Me, Respect Me” was rolled out to 90,000 Queensland Health staff and in hospitals. It was co-designed with Queenslanders with Disability Network and included people with intellectual disability and has been important in raising awareness across all healthcare staff about better communication and care for patients with disability including patients with intellectual disability.
- Queensland Health is also developing guidance on reasonable adjustments for people with disability including intellectual disability. The guidance aims to support hospital and health services to operationalise their responsibility in providing equitable and accessible healthcare.
- In 2024, Queensland Health issued an updated “Julian’s Key” Health Passport for people with intellectual and physical disability following extensive consumer and clinician engagement.

Victoria

- The Victorian Department of Health supports Disability Liaison Officers (DLOs) based in 23 metropolitan and regional health services to provide support so that people with a disability can access essential healthcare. This includes arranging reasonable adjustments and providing communication and psychosocial support. The DLO program champions and supports delivery of service improvements aligned with Inclusive Victoria: State Disability Plan 2022–2026. DLOs also support delivery of Disability Action Plans and develop disability competency in health services. The DLO program responded to more than 34,100 referrals between December 2020 and the end of June 2023.
- The Centre for Developmental Disability Health at Monash Health supports mainstream health services across Victoria to build their capacity to address the health needs of adults with intellectual and associated developmental disabilities.
- Dental Health Services Victoria’s (DHSV) Smile Squad school dental program has improved access to oral care for children with disability through annual mobile dental examinations and follow-up treatment needed for children attending government schools. Services were delivered by 22 agencies skilled in working with people with disability, providing care to 2,869 students in the 2023 RIGG reporting period.

- DHSV has also provided a range of training and support services to dental agencies and oral health clinicians. This includes protocols and guidelines for working with people with disability, and a trial of Smile Squad specialist school kits to help students with intellectual disability feel more comfortable while receiving oral health services.

South Australia

- SA Health maintained the South Australian Intellectual Disability Health Services (SAIDHS), formerly known as the Centre for Disability Health, as a state-wide, specialised health service. SAIDHS provides medical and mental health care for adults with diagnosed intellectual disability and complex needs. Complex needs may include autism, mental illness, behaviour or communication issues and other complexities which have been difficult to manage in community services, such as GP and community mental health services.

Western Australia

- Health service providers have been considering the needs of people with intellectual disability in their emergency preparedness planning. This includes developing personal emergency evacuation plans and ensuring critical staff are available to support the safe evacuation of people with intellectual disability.

Tasmania

- The Tasmanian Department of Health maintains a Community Forensic Mental Health Service, a confidential state wide service for Tasmanians with mental health issues and/or intellectual disability who are involved with the criminal justice system, or assessed as high risk of becoming involved with the criminal justice system as a result of their mental health and associated behaviour.

ACT

- The ACT Digital Health Record records all interactions between a person and ACT public health services, and work is being implemented to include details of a person's disability and any reasonable adjustments required.

The National Centre and its consortium members have been major contributors to these reforms and the effective implementation of them.

More work is needed

Significantly more work – including ongoing policy development and investment – is needed if Australia is to address the major health inequities faced by people with intellectual disability, one of the most disadvantaged groups in our population.

While quantitative data is not yet available to assess whether there has been progress in addressing disadvantages in people with intellectual disability's experience in the health system or health outcomes, qualitative inputs to the Centre, its consortium members and partners continue to show:

- High levels of poor experience of interactions with the health system, in emergency departments, hospitals, general practice and other settings, consistent with evidence given to the Disability Royal Commission.
- High levels of presentation to public hospital emergency departments in the absence of reliable access to known and trusted general practice or community-based mental health providers.
- The continuing occurrence of adverse events arising from miscommunication, diagnostic overshadowing, unconscious bias, the availability of a patient's usual support people and other avoidable causes in health settings.
- Low levels of health literacy and health system literacy among people with intellectual disability, their families and supporters and insufficient supports to improve this.
- Poor implementation of supported decision-making for people with intellectual disability in health settings.
- Little attention to improving the experience of, and outcomes for, First Nations people with intellectual disability in health settings.
- Similarly, little attention to improving the experience of, and outcomes for, people with intellectual disability from culturally and linguistically diverse backgrounds.
- Poor communication and low levels of understanding of intellectual disability health among generalist health and primary care providers, including clinicians

and administrative staff.

- Funding arrangements that do not support quality care for people with intellectual disability with provision for longer care sessions, quiet environments and care coordinated around the patients' needs to minimize the time and difficulty of interacting with a complex, fractured system of care.
- Insufficient attention to the needs of people with intellectual disability in emergency planning and preparedness.

The need for ongoing action has been strongly reinforced by the Disability Royal Commission with its finding of ongoing systemic neglect of people with cognitive disability in the Australian Health System and many recommendations for action.

The Centre makes an analysis of emerging good practice and gaps in that practice using a broad environmental scan methodology grounded in our knowledge and expertise in intellectual disability advocacy, research, practice and experience. This analysis also draws on the Royal Commission Final report, and the continuing experience of people with intellectual disability in the health system as reported to the Centre. This can be found in Attachment A - Intellectual Disability Health: A Scorecard 2025. Based on this analysis, we would recommend that an incoming federal government in 2025:

1. Commit to continued, timely and full implementation of the National Roadmap for Improving the Health of People with Intellectual Disability. Significant consultation and co-design went into the development of the Roadmap, which was supported by the Disability Royal Commission. It continues to represent the expert consensus at national, state and territory level about what needs to be done to improve health and the health system for people with intellectual disability. There is a major risk of drift or reversals in progress unless governments continue to commit to implementation.
 - For example, funding for the Down Syndrome Australia Health Ambassadors program ceases on 30 June 2025. This program has evaluated positively and ceasing it now would reverse the gains that have been made in improving the education of health professionals on intellectual disability health.
2. Invest in primary care for people with intellectual disability, consistent with directions emerging from the Primary Health Care 10 Year Plan, the

Strengthening Medicare Taskforce and later reviews and reports. Building continuity of quality care for people with intellectual disability in general practice is vitally important if their care is to be managed in more appropriate and cost-effective settings in the community, rather than as currently through emergency department acute presentations which often lead to long and avoidable periods in hospital. Successful policy to build the capacity of general practices and to appropriately support them to provide continuity of care for people with intellectual disability may require a combination of approaches:

- a) Better funding for longer consultations under the MBS, which will benefit all people with complex needs by better supporting more time with their doctor.
 - b) specific MyMedicare-linked payments to incentivise continuity of care from GPs and to help practices provide wraparound services, including nurses and other health workers, to appropriately support patients with intellectual disability. The General Practice in Aged Care Incentive could provide a foundational model here that could be further developed and adapted specifically for people with intellectual disability.
 - c) Capacity building from Primary Health Networks to upskill general practice staff in intellectual disability health, develop patient pathways and support best-practice care coordination for people with intellectual disability.
3. Pursue comprehensive implementation of the Intellectual Disability Health Capability Framework ('the Capability Framework'), which has been developed under the National Roadmap, and embed training and continuing professional development for health professionals. This would include:
- a) Working with universities and accreditation bodies to ensure the Framework is incorporated in accreditation standards and university curriculums to address future workforce of doctors, nurses, dentists, pharmacists and allied health professionals. This would help ensure Australia's future workforce of health professionals is better equipped to care for people with intellectual disability. The National Centre of Excellence could undertake additional work to support dissemination of the Framework with funding of \$2 million over five years.
 - b) Funding scholarships for health professionals to undertake Continuing

Professional Development (CPD) in intellectual disability health. This would address the need for better understanding and capability in the existing health workforce to care for people with intellectual disability. The scholarships would be available to health professionals who have undertaken basic modules in the area and want to further develop their skills, for example to support them providing continuity of care for a regular cohort of patients with intellectual disability in their general practice.

4. Making people with intellectual disability a priority focus in the next National Health Reform Agreement. This would include:
 - a) Funding support for the time and systems needed to provide appropriate care for people with intellectual disability in hospitals and specialised health settings. The activity-based funding (ABF) formula for state and territory-operated hospitals and health services should include a loading to account for the additional complexity and time required. While there are other existing patient complexity loadings in the ABF system administered by the Independent Hospital and Aged Care Pricing Authority, these do not address the particular disadvantage and behavioural complexity experienced by people with intellectual disability.
 - b) Improving system-wide data collection through an intellectual disability indicator across all health settings. This would enable better data linkage, and better measurement of health outcomes and health system outcomes for people with intellectual disability. Improving the quality of care, outcomes from care and the efficiency of care for people with intellectual disability can only occur if we understand what happens to them in the health system. Currently this can only be done, and only partially, through the National Disability Data Asset, which is in its formative stages.
 - c) Commitment to systems to ensure that people with disability receive appropriate supports in hospital, where adverse events from miscommunication or absence of behavioural supports can be fatal. This would include a commitment from states and territories to properly implement reasonable adjustments for people with disability in hospitals and a commitment from the Commonwealth to allow all NDIS participants to access their usual NDIS supports while in hospital.

Together, implementation of the above recommendations would represent a major advance in implementing the National Roadmap and improving the health system for people with intellectual disability, and for all Australians.

Attachment A: Intellectual Disability Health: A Scorecard

Updated May 2025

Legend

Green: Implementation on track
Amber: Implementation at risk
Red: Implementation stalled or not started

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
1	National Roadmap for Improving the Health of People with Intellectual Disability	All	<ul style="list-style-type: none"> 10-year Roadmap issued by Commonwealth in 2021 with broad support as expert consensus Continued political support uncertain <u>Recommendation</u> 1. Incoming government recommit to implementing National Roadmap in full	
2	Accountability for Implementation of National Roadmap	All	<ul style="list-style-type: none"> Roadmap Implementation Governance Group in place Annual reporting on progress 	
3	Cross-sectoral collaboration across health and disability sectors	All	<ul style="list-style-type: none"> Some progress under National Roadmap but requires continued attention, e.g. supports in hospital settings; palliative care 	

Attachment A: Intellectual Disability Health: A Scorecard Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
4	National Centre of Excellence in Intellectual Disability Health (NCEIDH)	Commonwealth	<ul style="list-style-type: none"> Implemented in full with ongoing Commonwealth funding 	
5	Primary Care Enhancement Program (PCEP)	Commonwealth	<ul style="list-style-type: none"> Implemented in four PHN regions, evaluated and extended to mid-2026 pending further evaluation 	
6	Comprehensive Health Assessment Program (CHAP) and MBS annual health assessments (AHAs)	Commonwealth	<ul style="list-style-type: none"> Updates to CHAP completed AHAs campaign implemented Evaluation needed to measure outcomes Additional financial incentives recommended to support implementation 	
7	Funding for health ambassadors	Commonwealth	<ul style="list-style-type: none"> Implemented to 30 June 2026 Ongoing funding certainty needed 	
8	Continuation of MBS telehealth	Commonwealth	<ul style="list-style-type: none"> Implemented on ongoing basis 	
9	Continuity of care in primary care	Commonwealth	<ul style="list-style-type: none"> MyMedicare system allows self-identification with intellectual disability in data While longer health assessments are funded, primary care funding model encourages shorter consultations No incentives for general practice to provide continuity of care. 	

Attachment A: Intellectual Disability Health: A Scorecard

Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
			<ul style="list-style-type: none"> Continuing low skill/comfort in general practice and other primary care settings with people with intellectual disability <u>Recommendation 2</u> <ul style="list-style-type: none"> A. Better MBS funding for long consultations B. MyMedicare incentives for continuity and wraparound care C. PHN capacity-building for practices 	
10	Intellectual Disability Health Capability Framework	Commonwealth	<ul style="list-style-type: none"> Framework completed. 	
11	Implementation of Intellectual Disability Health Capability Framework	Commonwealth	<ul style="list-style-type: none"> Implementation of the Framework not commenced in universities and accreditation authorities. <u>Recommendation 3</u> <ul style="list-style-type: none"> Mandatory application in course accreditation standards and university curriculums, including NCEIDH implementation support 	

Attachment A: Intellectual Disability Health: A Scorecard Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
12	Training for health professionals and health students in intellectual disability health	Commonwealth	<ul style="list-style-type: none"> Fund scholarships for Continuing Professional Development (CPD) in intellectual disability health to upskill the existing health workforce. 	
13	National Safety and Quality Health Service (NSQHS) Standards User Guide	All	<ul style="list-style-type: none"> Australian Commission on Safety and Quality in Health Care (ACSQHC) issued User Guide in 2024 Implementation up to states and territories. Implementation monitoring arrangements unclear NSW has Policy Directive on Responding to the Health Care Needs of People with Disability, and Virtual Care in Practice Guide QLD has Disability Service Plan 	

Attachment A: Intellectual Disability Health: A Scorecard Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
14	Inclusion of people with intellectual disability in National Health Reform Agreement	All	<ul style="list-style-type: none"> DRC recommendation People with intellectual disability currently not mentioned <u>Recommendation 4</u> <ul style="list-style-type: none"> A. Activity-based funding formula to recognised people with intellectual disability B. Intellectual disability health indicator across all health settings C. Appropriate supports in hospitals 	
15	Clear pathways for access to procedural support and sedation	All	<ul style="list-style-type: none"> Commonwealth led Roundtable July 2023 Some states implementing recommendations. 	
16	National Disability Data Asset	Commonwealth	<ul style="list-style-type: none"> First release in 2024 with further development planned to 2026 See Recommendation 4 re: need for intellectual disability identifier across all health settings. 	

Attachment A: Intellectual Disability Health: A Scorecard Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
17	Intellectual Disability Inclusive Digital Health Tools	All	<ul style="list-style-type: none"> • Australian Digital Health Agency has offered consultation on My Health Record • ACT developing disability inclusive tools in electronic patient records • NSW consulting on disability inclusion in Single Patient Digital Record. 	
18	Specialised Intellectual Disability Health Teams	States and territories	<ul style="list-style-type: none"> • NSW has teams in 6 local health districts and individual clinician in others • VIC funds Centre for Developmental Disability Health at Monash Health to provide statewide support • SA has statewide Specialised Intellectual Disability Health Service. 	
19	Specialised Intellectual Disability Mental Health Team	States and territories	<ul style="list-style-type: none"> • NSW has two statewide teams, one for children, one for adults, and funds a Chair in Intellectual Disability Mental Health at UNSW 	

Attachment A: Intellectual Disability Health: A Scorecard

Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
			<ul style="list-style-type: none"> QLD funds a Centre of Excellence in Autism and Intellectual and Developmental Disability Health at Mater Hospital. TAS has Community Forensic Mental Health Service for people with intellectual disability involved or at high risk of becoming involved with criminal justice system. 	
20	Disability Liaison Officers in hospitals and health services	States and territories	<ul style="list-style-type: none"> VIC only state to develop this model to date. 	
21	Specialised dental health services	States and territories	<ul style="list-style-type: none"> VIC implementing model for children as part of public school dental health program NSW has “special needs” dental services in Sydney and Western Sydney Local Health Districts Situation in other states unclear. 	
22	Easy Read communications	States and territories	<ul style="list-style-type: none"> NSW and QLD have clear commitments to improving the availability of Easy Read versions of important health documents. 	

Attachment A: Intellectual Disability Health: A Scorecard

Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
23	Training of hospital and health staff	States and territories	<ul style="list-style-type: none"> • NSW implementing Disability Inclusion training in some hospitals • QLD “See Me, Hear Me, Respect Me” campaign 	
24	Reasonable adjustments in hospital settings	All	<ul style="list-style-type: none"> • NSQHS Standards User Guide provides some guidance on reasonable adjustments but this could be further developed • QLD developing guidance on reasonable adjustments for people with intellectual disability • NSW policy directive contains some guidance but this could be further developed • Situation in other states unclear. 	
25	Health passports	All	<ul style="list-style-type: none"> • NSW and QLD have clear health passports arrangements • ACT developing parallel arrangement as part of its digital health record • Situation in other states unclear • Work needed on My Health Record to improve usability for people with intellectual disability. 	

Attachment A: Intellectual Disability Health: A Scorecard

Updated May 2025

#	Domain of good practice	Jurisdiction/s	Analysis	Implementation
26	Specific consideration of people with intellectual disability in emergency preparedness planning	All	<ul style="list-style-type: none"> • Recommendation of Disability Royal Commission and Kruk COVID-19 Inquiry • National Emergency Management Agency has developed Disability Inclusive Emergency Management Toolkit • WA only jurisdiction to specifically mention this in reporting to date. 	
27	Programs for First Nations People with Intellectual Disability	All	<ul style="list-style-type: none"> • Funding of First Peoples Disability Network by Commonwealth. 	
28	Programs for People with Intellectual Disability from Culturally and Linguistically Diverse Backgrounds	All	<ul style="list-style-type: none"> • Central and Eastern Sydney PHN developing easy read products in community languages as part of Primary Care Enhancement Program • No other specific programs known to Centre. 	