Australian Government

Department of Health, Disability and Ageing

Annual Progress Report 2024

National Roadmap for Improving the Health of People with Intellectual Disability

Preface

The Australian Government released the National Roadmap for Improving the Health of People with Intellectual Disability (the ID Roadmap) in August 2021.

The ID Roadmap outlines a 10-year vision to create a health system where people with intellectual disability are valued, respected and have access to high quality, timely and comprehensive health care. It seeks to put people with intellectual disability at the heart of the reform process.

The ID Roadmap is an Associated Plan to Australia's Disability Strategy 2021–2031 (the Strategy). The ID Roadmap also supports health and wellbeing outcomes under the Strategy.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) highlighted the critical need for national reforms to address serious health care inequities for people with intellectual disability in Australia. The ID Roadmap acknowledges the health issues raised in the Disability Royal Commission.

Implementing many of the actions of the ID Roadmap requires significant commitment and cooperation from Commonwealth, state and territory governments, educational institutions, health care providers and professionals, disability representative organisations and other key stakeholders.

This report documents the efforts to implement the ID Roadmap from 1 December 2023 to 31 December 2024.

As at 31 December 2024, the Australian Government has invested a total of $47 million to implement priority actions under the ID Roadmap. This includes $23.9 million to establish a National Centre of Excellence in Intellectual Disability Health. It is important to acknowledge that many activities featured in this report were funded by sources other than the Australian Government, reflecting the shared commitment and cooperation across the sector. Where specific funding details are available, they have been clearly indicated.

Note on terminology: The Australian Government acknowledges that people use different words to talk about their identity. The ID Roadmap was published in 2021 and used language that was preferred by many at the time. The department has adapted some of the language used in the ID Roadmap in this report. The department recognises that language continues to change and evolve and aims to use appropriate terms in this report.

Contents

Introduction

As part of the ID Roadmap program, the Department of Health, Disability and Ageing (the department) is required to publish an annual progress report on implementation. This is the third annual progress report, covering the period 1 December 2023 to 31 December 2024. The first two reports, covering the periods 2021/2022 and 2023, are available on the **health.gov.au** website.

In addition to the annual progress reports, in November 2024 a **Short-Term Actions Communique** was published to provide a high level update on the progress of the short-term actions under the ID Roadmap. Short-term actions were identified in the ID Roadmap for completion within 1-3 years, and the Communique served as a timely report to assess progress at the end of that 3-year period.

The ID Roadmap is divided into 10 elements, A through G. (Element B has four sub-elements that are addressed individually.) Each element has a theme, desired outcomes, and actions that contribute to achieving those outcomes. The information in this report is presented against each element.

There are 116 discrete actions in the ID Roadmap, of which:

- 72 are short term (1-3 years)
- 31 are medium term (4-6 years)
- 8 are long term (7-10 years)
- 5 relate to governance and are ongoing for the term of the program.

Of these 116 actions:

- 37 actions have been identified as being the responsibility of the department
- 58 actions have been identified as the collaborative responsibility of the department and other external agencies
- 21 actions have been identified as being the responsibility of agencies external to the department.[1]

The actions are listed in the ID Roadmap, available on the **health.gov.au** website.

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[1] Note changes compared to previous reporting - reflecting a 2023 review of all Roadmap actions and ongoing responsibility.

How the department collected and collated data for the report

The ID Roadmap Implementation Governance Group (RIGG) Secretariat asked 53 organisations for input on progress against Roadmap actions. A total of 43 organisations responded (Appendix A).

The department sought input against the specific themes from the ID Roadmap. The department collated the input received and reviewed activities for relevance to the goals of the ID Roadmap. Where activities were aligned with specific actions, the actions were assigned a status, as follows:

- **Not commenced**: no activity has been reported against the action during any reporting period, or any activity reported did not address the action.
- **In progress***: at least one organisation has undertaken an activity during the life of the ID Roadmap that directly addresses the action. This includes:
    - activities that are small, related to a pilot or geographically limited
    - actions where there are no activities reported by the lead organisation, but relevant activities are being undertaken by supporting organisations
    - activities that are for the general population, or people with any type of disability—not specifically intellectual disability—but which address the action
    - activities that partially address the action, for example, activity is about diabetes only, but action is about chronic health conditions
    - activities that have been undertaken that address the action in a previous reporting period, but not during the reporting period for this report.
- **Completed**: no further activity is required for the action.

*It is expected that, due to their nature, many Roadmap actions currently in progress will continue throughout the life of the ID Roadmap and beyond, in contrast to those with discrete endpoints. Therefore, in this report, we have specified the *in progress* actions that are *ongoing* to ensure transparency and accountability across the sector.

National Roadmap: Summary of progress

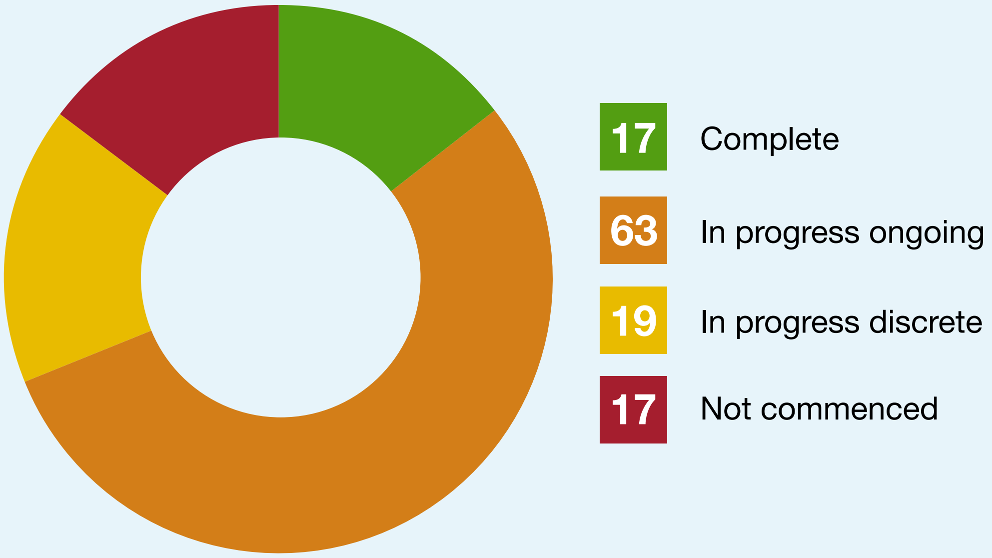
The department has endeavored to include as much information in this report as possible about the many activities reported by organisations. However, the department prioritised activities that have clear and specific relevance to improving health outcomes for people with intellectual disability in line with the desired outcomes under the ID Roadmap.

In some cases, information about individual activities has been summarised to help manage the length of the report. Where there was insufficient information provided, or no clear evidence that people with intellectual disability are being prioritised, or where the activity did not clearly address an ID Roadmap action, we have either reduced the information or, in some cases, not included it.

The chart below gives a summary of progress of ID Roadmap actions at the end of the reporting period (31 December 2024).

Progress of ID Roadmap actions

(End of reporting period 31 December 2024)



Element A: Improved support for people with intellectual disability and their families and carers

Desired Outcomes

- People with intellectual disability and their families and carers are empowered to make informed, supported decisions about their health care, in consultation with their health care providers.
- Improved health and health systems literacy among people with intellectual disability, and their families and carers.
- People with intellectual disability are better supported to navigate the health system and access appropriate health services.

Highlights

- The Commonwealth Department of Social Services funded disability advocacy organisations under its **Disability Representative Organisations** (DRO) program for 2024 to 2026. The program supports DROs in providing systemic advocacy for people with disability in Australia. It serves as the primary mechanism for people with disability and their representative organisations to communicate their views to Government on systemic issues affecting them. Several of these DROs are members of the RIGG, including Down Syndrome Australia, First Peoples Disability Network and Inclusion Australia.
- The NSW Ministry of Health launched the new NSW **Health Accessible Communications Policy** and online hub in August 2024 to help staff develop accessible communication, including development of Easy Read versions of documents. Furthermore, an Easy Read version of the policy was developed by the Council for Intellectual Disability (CID).
- WA Health launched an Easy Read version of the **Hospital Stay Guidelines**, which provides information for people with disability and their support networks about how to prepare for a stay in hospital (what to expect, their rights, and what to expect post-discharge).
- The South Australian Intellectual Disability Health Service (SAIDHS) developed a series of Easy Read resources, covering a variety of important health topics. The *Having an ultrasound* resource ensures people with intellectual disability can understand and feel comfortable with the ultrasound process. The *Sleep apnoea* resource helps people with intellectual disability recognise the signs and seek help.

- The Victorian Department of Health remains dedicated to the Disability Liaison Officers (DLOs) program which is based in approximately 20 metropolitan and regional health services. DLOs support people with a disability to access essential health care by arranging reasonable adjustments and providing communication and psychosocial support. During this reporting period, the DLO program responded to nearly 10,000 referrals, with around 20% coming from people with intellectual disability.
- The Down Syndrome Health Ambassador Program activities in 2024 included:
  - A total of 31 presentations delivered or co-delivered by Health Ambassadors with Down syndrome. Most of these were delivered to health care workers and medical students, equipping them to do a better job with people with intellectual disability.
  - Developing the **Easy Read booklet on coeliac disease**. This resource is designed to help everyone, especially those with Down syndrome, understand coeliac disease better.
  - Promoting Down Syndrome Australia's **two health apps**, the *Good Health App* to support people with Down syndrome maintain a healthy lifestyle and the *Health Record App* to record medical information.
- As part of the Australian Government's Competitive Digital Mental Health Program (2025–28), SANE Australia was awarded $27.3 million to deliver the **SANE Australia guided service**. This nation-wide service is a 15-week guided recovery program, for people with complex mental health conditions, including those with co-occurring conditions such as intellectual disability.
- Women with Disability Australia launched **Neve**, an Easy Read/plain English initiative that provides an accessible online resource hub designed to support and empower women, girls, and gender-diverse people with disability. The website offers information on topics such as health, safety, and rights. It also features a section for professionals looking to increase their skills and knowledge in working with women and gender diverse people with disability, including access to online training and factsheets and resources in plain English and Easy Read.
- The My Story PANDDA Award was inaugurated at the 35th Annual PANDDA Conference, held on 14 and 15 October 2024. The award honours individuals (or family members) with lived experience of intellectual developmental disability who actively participate in conference presentations relevant to nursing, health care and support of people with intellectual developmental disability. It recognises the invaluable contributions of self-advocates in improving nursing care. This award is jointly presented with Dr Virginia Howie and her daughter, Tessa Howie.
- CID has taken steps to enhance health literacy among people with intellectual disability by developing and publishing new Easy Read health guides. The **Signs of Sickness** guide provides clear and simple explanations of common symptoms and what they might indicate. The **How to Find a New Doctor** guide offers straightforward instructions on the process of finding and choosing a new doctor.

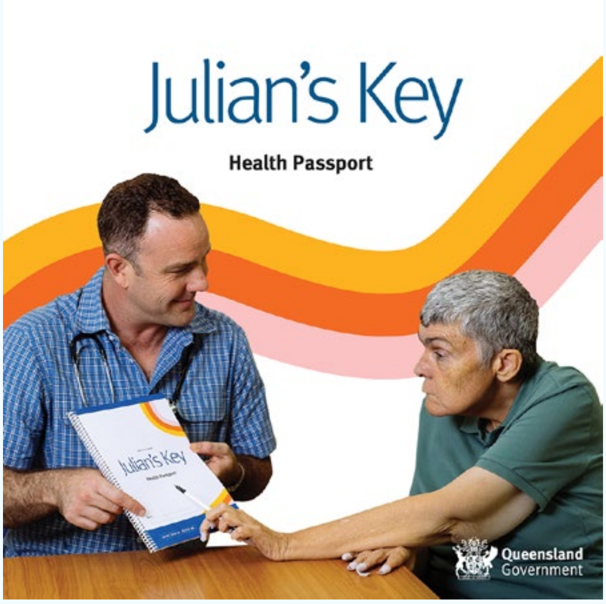
Spotlight: Julian’s Key Health Passport

Julian’s Key was first developed by West Moreton Hospital and Health Service in memory of a young man with intellectual and physical disability, Mr Julian Klass. In 2019, Julian’s Key was adopted by Queensland Health. **Julian’s Key Health Passport** is a consumer-controlled communication tool designed to improve care of people with disability while in hospital. It captures important information about a consumer as decided by the consumer and has been co-designed by Queensland disability community members.

Following extensive consumer and clinician engagement, Queensland Health launched an updated Julian’s Key Health Passport in November 2024. The new version aims to address key recommendations from the Julian’s Key Health Passport Evaluation including:

- improving accessibility of information
- making the tool more applicable across a wide variety of health care settings and needs
- incorporating Julian’s Key into clinical processes and embedding as part of a task-focused health service culture upon admission to hospital.

Information within a consumer’s Julian’s Key Health Passport will help health care workers to provide personalised treatment and care. Information has been categorised into key themes such as *About me, My disability, My support needs* and *My medical history*. Depending on a consumer’s needs, health care staff can readily access information to help them provide the best care possible.



Available in printed and print-at-home writable PDF formats, users can download the digital version from the Julian’s Key Health Passport website. Alternatively, they may request a printed copy by emailing Queensland Health at **JuliansKey@health.qld.gov.au** or by calling 13 Health (13 43 25 84).

Element B: Models of care for people with intellectual disability

B1: Developing better models of health care

Desired Outcomes

- Better models of care are developed and implemented for children, youth, adults and older people with intellectual disability.
- Transition points are considered and better managed.
- Models of care are person-centred, trauma-informed, and incorporate reasonable adjustments.
- Models of care are multidisciplinary, where appropriate. Models of care include GPs, medical specialists, nurses and midwives, allied health professionals, dental practitioners, and pharmacists.
- Models of care include strategies to ensure good communication between health professionals and improve linkages between the health sector, the National Disability Insurance Scheme (NDIS) and other disability and social support services, including family where relevant.
- Models of care are intersectional and tailored to meet the needs of people with intellectual disability who live in rural and remote areas, who are First Nations people, from culturally and linguistically diverse backgrounds, or who identify as LGBTIQ+.

Highlights

- The NSW Ministry of Health published the **final report** and Easy Read summary of an external evaluation of the two statewide **Intellectual Disability Mental Health (IDMH) Hubs** – one for children and adolescents, and one for adults. These hubs provide services for people with comorbid intellectual disability and mental health conditions. The evaluation was conducted to report on implementation and outcomes and provide recommendations for future service development. Key findings from the evaluation indicate that people who accessed services from the IDMH Hubs experienced a 28% reduction in emergency department visits following support from the hubs.
- The SAIDHS established the Healthcare Access Service in partnership with Modbury Hospital, Benson Radiology and SA Dental to provide health care under sedation for people with intellectual disability. This service operates monthly and had provided care to 18 patients at the time of reporting. Patients seen through this service have access to blood tests, vaccinations, imaging, dental, podiatry, ENT review, ophthalmology review, physical examination and preventative health screening including cervical screening.

- WA Health introduced a disability identifier in its patient management system. The identifier activates the use of the **Disability Health Profile Form**, which has been implemented at one health service provider and barcoded for state-wide use. This form records relevant information about a person's disability, including their needs, triggers, supporting behaviours, and necessary adjustments. This enables the care team to best meet the patient's needs, while also enhancing the collection of disability related data.
- CID launched its *Just Include Me – Inclusive Health Practice* e-learning module on the HETI My Health Learning system (NSW Health) and through the Medcast learning platform. Topics in the module include *Inclusive healthcare*, *Communication essentials*, *Behaviour as communication*, *Consent and decision making*, *Reasonable adjustments*, and *Virtual care*. The course is funded by the Australian Government Department of Social Services and formally accredited with the RACGP.

Spotlight: Australian Commission on Safety and Quality in Health Care's resources to support the health care of people with intellectual disability

The Australian Commission on Safety and Quality in Health Care continues to develop resources to support health care professionals to deliver safe and high-quality services to people with intellectual disability. In 2024, the Commission published several relevant documents related to the National Safety and Quality Health Service (NSQHS) Standards.

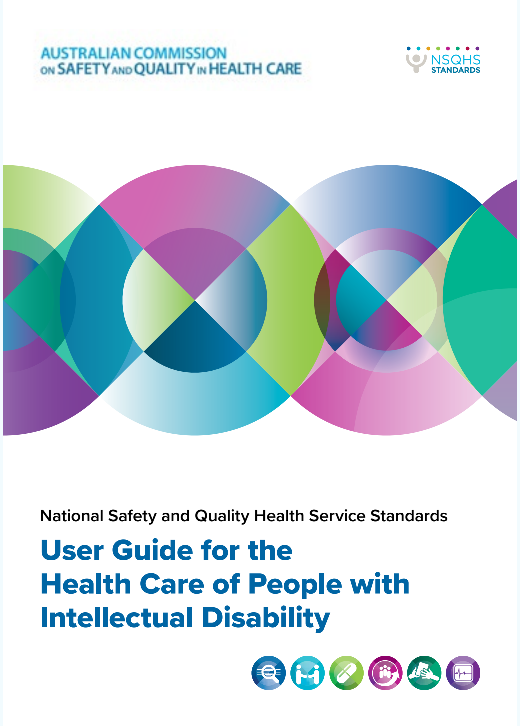
The **NSQHS Standards User Guide for the Health Care of People with Intellectual Disability** supports the Standards and is consistent with the recommendations of the Disability Royal Commission. The User Guide was developed in response to significant evidence of poor health outcomes for people with intellectual disability in Australia's health system.

The User Guide provides:

- information on how each Standard is relevant to health care for people with intellectual disability
- key actions under the Standard relevant for people with intellectual disability
- evidence-based strategies for improvements by action
- resources for organisations and clinicians.

Intellectual disability and inclusive health care fact sheets resources were developed to accompany the User Guide and assist health service organisations and clinicians support people who live with intellectual disability, by addressing the barriers faced in accessing health care.

The three fact sheets provide information on **communication and positive behaviour support**, **transitions of care**, and **polypharmacy**. They outline strategies to provide better support and improve care for people with intellectual disability.



AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

NSQHS STANDARDS

National Safety and Quality Health Service Standards

User Guide for the Health Care of People with Intellectual Disability

B2: Better use of existing MBS items

Desired Outcomes

- Increased use of annual health assessments and other MBS items for people with intellectual disability.
- Increased use of the Comprehensive Health Assessment Program (CHAP) tool by GPs in providing health assessments to people with intellectual disability.
- More comprehensive health plans for people with intellectual disability developed that include action on health promotion, disease prevention, and chronic disease detection (for example, such as hearing and vision testing, and cancer screening).
- Better communication between primary health care providers and people with intellectual disability, their families and carers, support workers and disability service providers, about preventive health and chronic disease management.

Highlights

- The department progressed the review of all MBS health assessment services, including those for people with intellectual disability, to consider the efficacy and effectiveness of these interventions within primary care. This review included a public consultation between July and September 2024 and publication of a **Review of MBS Health Assessment items Discussion paper**, which presented key findings to inform stakeholder feedback on the future of MBS health assessment items.
- National Disability Services (NDS) promoted the CHAP tool on their website and during disability support provider network meetings related to health needs of people with intellectual disability.
- Inclusion Australia was funded by the department to develop an **Easy Read guide to the CHAP**. Co-designed and user-tested by people with intellectual disability, the Easy Read guide assists people with intellectual disability and their supporters to fill out Part 1 of the CHAP, prior to attending an appointment with their GP. The Easy Read guide to the CHAP is hosted on the department's website.

Spotlight: Promotion of annual health assessments for people with intellectual disability, and digitisation of the CHAP tool

The Department of Health, Disability and Ageing's project to **improve the implementation of annual health assessments for people with intellectual disability** has made strong progress since the 2023 annual report, with a campaign to promote awareness of annual health assessments and the CHAP tool, and further development of a digital version of the CHAP.

The department and Inclusion Australia developed a one-year, national campaign to improve awareness of and reduce barriers to annual health assessments for people with intellectual disability. The **It's Doctor Time!** Campaign was launched in August 2024, and was co-designed with people with intellectual disability, their families, GPs, health professionals, disability groups, service providers, and government agencies. As part of the campaign, easy-to-understand resources were developed for people with intellectual disability, their families and supporters, General Practice staff and other medical professionals, and service providers, including Easy Read factsheets (in English, Arabic, Vietnamese, and Simplified Chinese), conversation cards, social stories, videos, animations, posters, a jingle, a quick guide to the CHAP, video scripts for GPs, a service provider policy statement template, supporter kit, GP Kit, and media kit.

Work in previous years secured a licence for the department to make the CHAP freely available, allowing updated PDF versions (for young people and for adults) **to be published on the department's website**. To make conducting an annual health assessment for a person with intellectual disability easier for GPs, the department has been working closely with the Australian Digital Health Agency to develop a digital version of the CHAP, to be integrated into GPs' clinical software. Stakeholders, including people with intellectual disability, their supporters and GPs, continue to be consulted during this development, and it is hoped that the digital CHAP will be available to GPs in 2026.

B3: Continuity of care, care coordination and integration within the health system

Desired Outcomes

- Better continuity of care for people with intellectual disability.
- Better communication and trust between health professionals, people with intellectual disability, their families and carers.
- Better integration across the health system, including primary, specialist and hospital care, allied health, oral health, and pharmacy.
- Improved communication and coordination among health professionals and greater provision of appropriate multidisciplinary care that meets the needs of people with intellectual disability.
- Improved GP access to intellectual disability health specialists and clearer referral pathways for GPs to specialised intellectual disability health services.

Highlights

- By the date of publication, 8,366 people had registered with My Medicare and indicated an intellectual disability.
- The independent clinician-led MBS Review Advisory Committee (MRAC) provided its final report in May 2024 on its post-implementation review of MBS telehealth to the Australian Government. The MRAC post-implementation review considered contemporary research and more than 450 submissions from public consultation, and its final advice emphasised that telehealth was more likely to be comparable to in-person care when it is provided in the context of a continuous clinical relationship.
- The MRAC considered options for optimising telehealth, including for patients who experienced difficulty accessing care generally and using telehealth. Relevant recommendations included:
    - aligning telehealth eligibility criteria of General Practitioner and Nurse Practitioner telehealth services to emphasise continuity of care (MRAC recommendation 8), which the government has agreed to commence from 1 November 2025
    - re-introducing patient end support services (MRAC recommendation 10), which is an ongoing consideration of the Government.

  These MBS items recognise when clinicians assist patients to participate in telehealth consultations and shared care with a remote non-GP specialist.
- Nurses from the SAIDHS have been liaising with people with intellectual disability and their supporters, and health professionals in hospital outpatient services to negotiate reasonable adjustments and improve communication.

- Women with Disabilities Australia collaborated with Jean Hailes for Women's Health to develop two new Easy Read fact sheets, aimed at empowering women with disability to take charge of their health: **When you go to the doctor**, providing practical tips and guidance on how to prepare for doctors' appointments, communicate effectively with health care providers, and advocate for individual needs; and **Your women's health care team**, introducing the diverse range of health professionals relevant to women's health, including GPs, pelvic floor physiotherapists, gynaecologists, endocrinologists, dietitians, and psychologists.
- The Brisbane South PHN and Metro South Health **Disability Health Forums** are a partnership initiative launched in November 2024 to celebrate Disability Action Week 2024. These Forums will bring together more than 30 representatives including people with disability, disability peak bodies, research institutes, the NDIS, primary health care (Brisbane South) and hospital/specialist health care (Metro South). The forums aim to improve engagement between people with disability, disability peak bodies, and primary and hospital health care. This initiative seeks to support continuity of care, integrate health care and disability, address the health needs of people with disability within health service initiatives, and foster joint partnerships and initiatives.

Spotlight: Primary Care Enhancement Program updates

The Primary Care Enhancement Program (PCEP) provides funding for four pilot PHNs to support health professionals to provide better services for people with intellectual disability. An evaluation was conducted over the initial 4-year pilot period ending June 2024. The **Primary Care Enhancement Program Evaluation Report – Executive Summary** and the Easy Read version were published in September 2024. The Australian Government invested a further $3.7 million to continue the PCEP pilot in the existing four PHN regions for a further two years to 30 June 2026. This decision was made as part of the Australian Government response to the Disability Royal Commission. Highlights of the PCEP for 2024 include the following.

- **Country to Coast Queensland PHN** worked to develop a series of online education modules and a quality improvement toolkit, scheduled for launch in early 2025. The modules focus on best practice primary care, including continuity of care, support for complex needs, and preventative care. By incorporating consumer stories co-designed with individuals with intellectual disability, the training will equip health professionals with practical tools for more responsive and person-centred care.
- **Central and Eastern Sydney PHN** delivered their *Primary Care Intellectual Disability Inclusion Program* to 21 general practices, involving two education sessions on intellectual disability health care and two quality improvement activities. These activities helped correctly code patients with intellectual disability in clinical software and develop a recall and reminder process for annual health assessments. Feedback showed a significantly boosted confidence among GPs and practice nurses in providing health assessments for people with intellectual disability. A **suite of resources** was also developed to support patients and carers in accessing primary care and assist practices with health assessments, communication strategies, and reasonable adjustments.
- **Primary Health Tasmania** delivered regional face-to-face workshops and developed draft **foundational resources for transitioning from paediatric to adult health services**. They also began the development of three foundational e-modules on: *Welcoming patients with intellectual disability*; *Improving health appointments and supported decision-making*; and *Transition from paediatric to adult health services*.
- **Western Victoria PHN** commissioned St. Vincent's Hospital Victorian Dual Disability Service to deliver targeted mental health training in identifying mental health indicators in people with disability and supporting appropriate referrals. They also commissioned specialist training by Steve Moss from the UK on using the Moss-PAS to identify mental health descriptors, aiding comprehensive referrals from GPs to mental health services. Additionally, they developed and released the **Supporting Inclusive Practice Framework for Youth/Adult Mental Health Services** to help organisations deliver equitable services through inclusive practices, partnering with people with lived experience.

B4: Better coordination with other sectors

Desired Outcomes

- Health professionals better understand the NDIS and referral options to appropriate services.
- Increased focus in the NDIS and other disability support arrangements on promoting good health, supporting preventive health care, and timely access to health services.
- Disability providers and the disability workforce have better health literacy, enabling them to better support people with intellectual disability to access health care.
- Better linkages, and more effective communication and coordination between health care professionals and disability support providers.
- Better linkages between health care and aged care providers supporting older people with intellectual disability.
- Increased collaboration between health and disability services to reduce the use of restrictive practices in disability and health services.

Highlights

- In 2024, the Commonwealth and state and territory governments commenced negotiations on the next National Health Reform Agreement 2025–30 Addendum. Discussions considered the recommendations of the National Health Reform Agreement (NHRA) mid-term review, including improving the transition of people with disability out of hospital where they are eligible for the NDIS and ready for discharge; reviewing mechanisms to ensure continuity of care for NDIS participants during a hospital stay to ensure optimal patient outcomes; and setting out roles and responsibilities including accountability and escalation mechanisms to address market failures in rural and remote primary care, aged and disability care.

Spotlight: The Australian Commission on Safety and Quality in Health Care's Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard

The Australian Commission on Safety and Quality in Health Care has released a new national **Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard**, designed to ensure safer, more effective treatment practices.

The **campaign to promote the Standard** was launched in May 2024. The campaign communications kit includes various resources such as social media images, newsletter banners, infographics, and suggested messaging to help organisations and individuals support the campaign. The Standard has been developed in response to concerning trends in the misuse and overuse of psychotropic medicines within the aged care and disability sectors. By providing practical guidance and encouraging consistent practices across all health care settings, the Standard aims to improve the quality of care and enhance the overall wellbeing of people with cognitive disability or impairment.

The Standard represents a significant milestone in health care, outlining clear steps to promote responsible and appropriate use of psychotropic medicines. While these medicines are often used to manage behaviours of concern such as aggression and agitation among people with cognitive impairment, the Standard emphasises the importance of non-medication interventions as the primary method of addressing these behaviours.

Psychotropic medicines should only be considered for behaviours of concern as a last resort option when other strategies have failed or when there is a high risk of harm to the person or others. When they are used appropriately, regular monitoring, review and communication is essential to maintain patient safety. The Standard has a strong emphasis on the need for individualised care plans that cater to each person's unique needs. It also underscores the importance of collaboration with the person, their family, support people and others involved in the person's care. The Standard has been endorsed by over 25 key professional and consumer organisations. The Clinical Care Standard web page includes an **Easy Read version**. It also has a launch video, where an expert panel discuss key challenges and best practice including informed consent, assessment, non-medication strategies and follow-up care when medicines are considered necessary.

Element C: Support for health care professionals to provide better care for people with intellectual disability

Desired Outcomes

- Health professionals are better equipped to communicate with people with intellectual disability and have better knowledge of the different ways people with intellectual disability interact with health professionals and communicate their health needs and preferences.
- Health professionals and staff of health services treat people with intellectual disability and their families and carers with respect and dignity, and provide services in an appropriate, supportive and sensitive manner.
- Improved access to appropriately trained and culturally sensitive health care professionals for people with intellectual disability, including First Nations people, people from culturally and linguistically diverse backgrounds and those who identify as LGBTIQ+.

Highlights

- During 2024, the National Centre of Excellence in Intellectual Disability Health (NCEIDH) progressed a number of pieces of work relating to the desired outcomes under this element of the ID Roadmap. These include:
  - **co-designing its Knowledge Exchange Hub**, which will be an online space where people can share information, access resources and connect with each other about intellectual disability health.
  - the NCEIDH's **first national conference**, bringing together academics, clinicians, advocates and people with lived experience of intellectual disability.
  - a 4-year **research project** on addressing health inequalities experienced by people with intellectual disability, determining how these gaps affect people with intellectual disability, and developing better responses in health care for people with intellectual disability.
  - the establishment of the **National Intellectual Disability Clinician Network**, to bring together health professionals such as nurses, psychologists, doctors and allied health professionals across Australia who work with people with intellectual disability, to share knowledge, best clinical practices and models of care; for multidisciplinary discussion of complex issues affecting clinical practice; and co-hosting of webinars and podcasts on clinical and capacity building issues.

- The Queensland Government is investing $6 million over three years to establish the **Queensland Centre of Excellence in Intellectual and Developmental Disability Mental Health**. The Centre aims to improve the mental health and wellbeing of people with intellectual and developmental disability through clinical advice, research, and education.
- **Queensland Health** and **Queenslanders with Disability Network** co-developed and rolled out the *See Me. Hear Me. Respect Me.* campaign, which works to raise awareness of the communication needs of people with disability, especially among health care workers.
- NSW Health Intellectual Disability Mental Health leads and champions were provided 'Train the Trainer' training developed by the University of NSW Department of Developmental Disability Neuropsychiatry, to train and support mainstream mental health clinicians to deliver accessible care for people with intellectual disability.
- NSW Health's Education Centre Against Violence (ECAV) has co-developed resources to support Sexual Assault Service practitioners to work competently with people with intellectual disability. These resources promote best practice and are available on **ECAV's website**.
- Down Syndrome Australia hosted the World Down Syndrome Congress in Brisbane. A Health Professionals' Day was held as a pre-conference session, where over 100 health care professionals heard presentations on a range of topics including Down syndrome regression disorder, dementia, prenatal screening, health service delivery, sleep, and osteoporosis.
- National Disability Services partnered with VALID (a peak advocacy organisation for adults with intellectual disability) in Victoria to lead a co-design project with people with intellectual disability, carers, disability providers and mental health sector representatives. It aims to improve the understanding of Mental Health and Wellbeing Local Service workforce of the needs and supports for people with disability.
- PANDDA continued to provide continuous professional development webinars. In 2024, webinar topics included:
    - Ageing, dementia and frailty in people with intellectual disability
    - Supporting health literacy for people with intellectual disability living in group homes.
- PANDDA and the Australian College of Nursing collaborated to develop **Principles of Intellectual and Developmental Disability Nursing** training. This unit of study is designed for nurses who work with people with intellectual and developmental disability in a variety of settings.
- CID published a **Let's Yarn factsheet and poster**, featuring inclusive communication tips for health professionals working with First Nations people with intellectual disability.

- HeartKids published a series of **online education modules** focused on neurodevelopment delay and childhood-onset heart disease, designed to support health professionals to improve in various aspects of care for children with disability including:
    - Identifying patients at high risk for neurodevelopmental disability
    - Educating, engaging and supporting carers to improve neurodevelopmental outcomes in childhood-onset heart disease
    - Supporting neurodevelopment in childhood-onset heart disease in a primary and community care setting.

Spotlight: Intellectual Disability Health Capability Framework

In April 2024, the department published the **Intellectual Disability Health Capability Framework** as part of the **Curriculum Development Project in Intellectual Disability Health**. The Framework outlines key capabilities, learning outcomes and guides for university and accreditation authorities to improve intellectual disability health training for health students. The Framework aims to ensure the future health workforce can deliver better care to people with intellectual disability.

The Framework was developed in collaboration with people with intellectual disability, their families, supporters, and carers to draft the Framework. Universities, health professionals, and academic experts also helped to develop the Framework through the Expert Advisory Group.

Appendix 2 of the Framework includes a **Capacity Assessment Tool** to help education and accreditation providers evaluate their ability to integrate elements of the Framework into their curricula or standards. The tool also provides an easy way for health educators and accreditation providers to identify opportunities for further integration of intellectual disability health capabilities.

The next phase of the Curriculum Development Project will involve development of education resources to support the implementation of the Framework across the pre-registration education sector. The University of New South Wales Sydney (UNSW Sydney) is developing a suite of education resources to help health educators apply the core capabilities of the Framework into pre-registration health curricula. It is expected that the resources will be able to be adjusted to suit a range of undergraduate health disciplines. UNSW Sydney engaged in a co-design process to design and develop the resources, involving people with intellectual disability, their supporters and families. The resources are expected to be finalised and published in 2025.

Element D: Improving oral health for people with intellectual disability

Desired Outcomes

- People with intellectual disability are supported to maintain dental/oral hygiene as a vital preventive health measure.
- Oral health care is integrated into general health care.
- Establishment of an oral health data collection on people with disability, including intellectual disability.
- More oral health promotion done in the disability sector.
- Training for dentists, dental therapists and hygienists to include modules on oral health care for people with intellectual disability during undergraduate training and continuing professional development.
- Better access to dental services for people with intellectual disability in the private and public sectors.
- A national approach to dental care for people with intellectual disability is developed and linked to a National Oral Health Plan.

Highlights

- Dental Health Services Victoria and **genU** partnered in an Oral Health Champions program to promote oral health for adults with disability accessing supported accommodation or respite services. This included delivering oral health training to 33 disability support workers, with an estimated reach of at least 260 people with intellectual and developmental disabilities.
- Dental Health Services Victoria developed an educational video, **Pharmacy teams supporting oral health: example interaction with a person who has a disability**. This video is part of a series designed to support pharmacy teams to deliver evidence-based oral health advice.
- In 2024 all four **Smile Squad** specialist hubs were operational, commencing services in Geelong and Bendigo in May 2024, and in Latrobe from September 2024, complimenting the Royal Dental Hospital Melbourne. These hubs offer government school students a range of specialised dental services that not all general dentists are able to provide, which includes treatment under nitrous sedation and general anaesthetic where needed.
- Eligible Tasmanian dental patients now have an alternative to general anaesthesia in a public hospital, and can receive sedation in a community dental setting. This pathway is ideal for those with phobias, behavioural issues, or procedural complexities (including some people with intellectual disability). It offers quicker access to dental surgery, reducing hospital theatre demand and easing pressure on dental clinicians.

Element E: Research, data and measurement to support continuing improvement

Desired Outcomes

- Health outcomes for people with intellectual disability including health status, health service utilisation, and health outcomes are recorded, analysed and reported at a national level.
- Experiences of people with intellectual disability are captured throughout the patient journey.
- Targeted research drives the development of evidence based tools/strategies and initiatives to improve the health of people with intellectual disability and the health services provided to them.
- Research includes people with intellectual disability during design and implementation.

Highlights

- The National Centre of Excellence in Intellectual Disability Health (NCEIDH) prepared for the 2025 launch of its **Innovation Seed Funding Grants** for health and disability organisations. The purpose of the grants is to support:
    - innovative projects in intellectual disability health that align to the NCEIDH's priorities
    - inclusive projects that have people with intellectual disability and their families in meaningful roles
    - collaboration in intellectual disability health.

  The grants are an important opportunity for the NCEIDH to support the efforts of its Partners, Collaborators and other organisations across health and disability sectors to improve the health of people with intellectual disability.
- The Australian Bureau of Statistics (ABS) undertook a review of the statistical Standard for Severity of Disability, also known as the **Short Disability Module**. The ABS is expected to release the updated version in 2025.

- The ABS commenced the Disability Data Measures project to investigate and provide recommendations for collecting disability status information in population surveys in Australia. This project, funded by Departments of Health, Disability and Ageing, and Social Services, is a response to Recommendation 12.5 (a nationally consistent approach to data collection) of the Disability Royal Commission.

  Project activities include consulting with people with disability and the wider disability community, research experts, and relevant Commonwealth agencies and jurisdictions on contemporary best practice for collecting disability information and any recommendations for improvements and better alignment across data sources.
- The NDIS Quality and Safeguards Commission **released the report of an analysis** of 9,062 deaths among 526,515 people accessing disability services under the National Disability Agreement (NDA) from 2013 to 2018. The study builds on an earlier Australian Institute of Health and Welfare report, and aims to identify all contributing health risks for potentially avoidable deaths in people with disability.
- As part of a formal collaboration, the SAIDHS and the College of Nursing and Health Sciences, Flinders University were awarded a Medical Research Future Fund (MRFF) 2024 Survivorship Care and Collaborative Research Prioritisation grant. The grant supports a project focused on *Co-producing cancer survivorship resources with and for people with intellectual disability*.
- Griffith University and Metro South Health's **The Dignity Project** is a multi-year qualitative research initiative which seeks to explore the hospital journey experiences of adults with intellectual disability. During 2024, key activities included formation of a lived experience advisory group of people with intellectual disability, development of Easy English participant information and consent materials, and recruitment, interviews and data gathering with research participants.
- The PANDDA Nursing Research Scholarship opportunity for Honours Students was established in 2024, to support nursing students pursuing research focused on improving the health and wellbeing of people with intellectual and developmental disability.
- Macquarie University's **Listen to Me** project, a 3-year MRFF project co-producing a digital Patient-Reported Experience Measure (PREM) suitable for people with intellectual disability, commenced in 2024. The project has a consumer leadership group, all of whom either have lived experience of intellectual disability or are family members who support people with intellectual disability accessing health care. In 2024, the team established an inclusive governance structure, formed a co-production group, conducted a co-production workshop series, and together co-produced the Listen to Me digital PREM prototype. In November 2024, they commenced user testing with version 2 of the PREM.
- The Kirby Institute's (UNSW) **Vax4Health project**, which aims to improve vaccination coverage of routine vaccinations for students with disability attending NSW Schools for Specific Purposes, completed stakeholder interviews with students, parents, school and health staff to understand the barriers and facilitators to vaccinations.

Spotlight: NHMRC targeted research grants – Improving long-term health outcomes for people with intellectual disability

Four projects were funded by the NHMRC in 2022 to develop the evidence base for future policies, interventions and other initiatives that will improve the long-term health outcomes and quality of life for people with intellectual disability. Project updates for the reporting period are as follows.

Bridge to Better Health: A cluster randomised controlled trial for capacity building in intellectual disability health for general practice. (Lead: Dr Catherine Franklin, University of Queensland)

The **Bridge to Better Health** project aims to improve health care for patients with intellectual disability by enhancing practice nurses' ability to conduct annual health assessments. In 2024, the project hired a specialist nurse to support practice nurses and aid recruitment, created educational videos with indelabilityarts, and developed an educational module. Recruitment started in South East Queensland through general practices and a **dedicated webpage** for participants to register.

GeneEQUAL: equitable and accessible genomic healthcare for people with intellectual disability. (Lead: Dr Elizabeth Palmer, University of New South Wales)

As part of the **GeneEQUAL** program of research, this project aims to develop guides and resources for inclusive genomic health care. In 2024, the team conducted interviews with 28 people with intellectual disability and 29 families/supporters, and body mapping with 12 individuals. These activities informed the first draft of the *Guiding Principles for Inclusive, Person-Centered and Respectful Genetic Health Care*. The team also presented at conferences and published two open access papers with Easy Read versions (**1, 2**).

Reducing potentially preventable hospitalisations and building health literacy for children and adolescents with intellectual disability. (Lead: Assoc Prof Jenny Downs, University of Western Australia)

The project on **improving health access for children and families living with intellectual disability project** is investigating the use of health services for children with intellectual disability, how health service use can be optimised for better care and be available across the community. In 2024, the team interviewed 55 caregivers to explore involving children in health care decisions and began analysis. This data will inform a co-designed parent-coaching intervention. The team also published three open access papers (**1, 2, 3**).

Equitable access to health and disability services for Aboriginal and Torres Strait Islander children with intellectual disability. (Lead: Prof Sandra Eades, University of Melbourne)

The project aims to **improve the health and wellbeing of Aboriginal and Torres Strait Islander children with intellectual disability** by identifying effective care models. In 2024, the team partnered with the NDIA to analyse geographical differences in diagnoses and NDIS participation. They also engaged with Aboriginal agencies in Western Australia to submit an ethics application for a study comparing service use before and after the NDIS introduction. Preliminary analysis was underway.

Spotlight: Development of a National Disability Data Asset

The **National Disability Data Asset** (NDDA) connects existing de-identified information from different government agencies. The NDDA will be used to provide a complete picture of the programs and services used by people with disability including people with intellectual disability. This will mean governments will have better quality information to improve programs and services and improve opportunities and outcomes for people with disability.

The NDDA is inclusively co-governed through the Council, Charter and advisory panels, which means that governments and the wider disability community share responsibility and decision-making for the NDDA. In late 2023, Disability Ministers approved the Council members, which include people with disability, representatives from the wider disability community, experts including the Disability Discrimination Commissioner, and representatives of the Australian and state and territory governments. The Council is responsible for providing strategic direction for the NDDA and ensuring that it is used only for purposes that align with the disability communities' expectations. The Council is led by two co-chairs, Luke Mansfield (Department of Social Services) and Catherine McAlpine (Inclusion Australia). More information about the Council is available on the **Council page** of the NDDA website.

The NDDA Charter is a document about how the NDDA should be used and contains principles and rules for the NDDA. The Charter was written by members of the wider disability community. The Council will guide the use of the NDDA through the Charter. The Charter was endorsed by Disability Ministers in June 2024. More information about the Charter is available on the **guiding principles page**.

The Council established three panels in 2024 to provide it with support and guidance, which include people with disability and disability researchers. This includes the Disability-informed Ethical Oversight Panel which will review all project requests and recommend if the project should proceed or be updated. The panel will only recommend projects be approved that are not likely to cause harm to people with disability. More information about the current and past advisory panels are available on the **advisory panels page**.

NDDA data were first released in December 2024. More data will be available throughout 2025. This means that researchers from accredited organisations can now apply to access the data.

The community members of the Council have created a plan for community engagement during 2025. This plan aims to build trust and understanding of the NDDA with people with disability.

Element F: Emergency preparedness and response

Desired Outcomes

- Emergency preparedness planning and responses include people with intellectual disability and consider their needs.
- Emergency responses include timely, targeted actions that support the health and wellbeing of people with intellectual disability.
- Communications meet the needs of people with intellectual disability, their families and carers during national and local emergencies.
- The health and disability sectors are equipped to respond to the needs of people with intellectual disability during emergencies.
- Person-centred plans for people with intellectual disability are activated during emergencies.

Highlights

- The National Emergency Management Agency (NEMA) developed a **Disability Inclusive Emergency Management (DIEM) Toolkit** to address the increased risks faced by people with disability during emergencies. The toolkit has a broad audience, including government, emergency planners, and disability organisations, and includes research, best practices, and guidelines to standardise inclusive emergency planning across Australia. This includes an **Organisational Emergency Preparedness Profile** and a **Resource Map**. There is also an **Easy Read overview of the toolkit**.
- The Queenslanders with Disability Network (QDN) undertook Person-Centred Emergency Planning (P-CEP) workshops to develop emergency plans tailored to participants' individual support needs using the P-CEP framework, including people with intellectual disability. QDN also held **Building Inclusive and Disaster Resilient Communities** community forums in seven LGA areas in Queensland.

Element G: Arrangements for oversight, monitoring and implementation of the National Roadmap

Desired Outcomes

- Implementation of the ID Roadmap is overseen by a diverse group of health and disability stakeholders, including:
    - people with intellectual disability
    - families and carers of people with intellectual disability
    - representatives from the health and disability sectors
    - representatives of universities, professional colleges, and accreditation and registration bodies
    - Commonwealth and state and territory government representatives.
- Implementation of the ID Roadmap is conducted in an inclusive and transparent manner.

Highlights

The **Roadmap Implementation Governance Group** (RIGG) was established in November 2021 to provide oversight and monitor implementation of the ID Roadmap, ensure implementation is conducted in an inclusive and transparent manner, and ensure governments and other stakeholders are accountable for implementing actions outlined in the ID Roadmap.

The RIGG has been established to 2031 to align with the lifespan of the ID Roadmap.

The RIGG has members representing:

- people with intellectual disability, their families and carers
- representatives from the health and disability sectors
- representatives of universities, professional colleges, and accreditation and registration bodies
- relevant Commonwealth government agencies
- Australian and state and territory government representatives.

The RIGG met three (3) times during this reporting period. In addition, a time-limited Working Group was established during April to July 2024 to examine progress against short-term actions in the ID Roadmap.

As the ID Roadmap concluded its third year in August 2024, the RIGG published a **Short-Term Actions Communique** in November 2024 to provide a high-level update on the progress of short-term actions under the ID Roadmap in the first three years. The communique ensures transparency about implementation of short-term actions and identifies next steps.

During this work, the RIGG and the department noted that some short-term actions are more appropriate for completion within the medium-term timeframe of six years where there are complex levers in the disability sector, a requirement for multi-sector collaboration, or alignment with other reform timeframes. It was also identified that several short-term actions will be ongoing, rather than having a completion point.

The department published RIGG meeting summaries and the Communique on www.health.gov.au, including in Easy Read format.

During 2024, the department continued to engage the Intellectual Disability Focus Group for input on delivery of key projects, such as the Curriculum Development Project and development of the Intellectual Disability Health Capability Framework and associated education resources.

Appendix A: Organisations providing input to this report

Thank you to the following organisations that provided input to this report:

Commonwealth government agencies

- Australian Bureau of Statistics
- Australian Commission on Safety and Quality in Health Care
- Australian Digital Health Agency
- Australian Government Department of Health, Disability and Ageing
- Australian Government Department of Social Services
- Australian Institute of Health and Welfare
- National Disability Insurance Agency
- NDIS Quality and Safeguards Commission

Advocacy and professional organisations

- Aruma
- Australian Society of Special Care in Dentistry
- Australia New Zealand Academy of Special Needs Dentistry
- Australian Medical Council
- Department of Developmental Disability Neuropsychiatry UNSW
- Down Syndrome Australia
- Fragile X Association of Australia
- HeartKids Australia
- Inclusion Australia
- National Disability Services
- NSW Council for Intellectual Disability
- Professional Association of Nurses in Developmental Disability Australia
- People with Disability Australia
- Queenslanders with Disability Network
- Royal Australasian College of Physicians
- Royal Australian College of General Practitioners
- Women with Disabilities Australia

State and territory health agencies

- NSW Ministry of Health
- Queensland Department of Health
- South Australian Department of Health and Wellbeing
- Tasmanian Department of Health
- Victorian Department of Health
- Western Australia Department of Health

Primary Health Networks (PHNs)

- Capital Health Network
- Central and Eastern Sydney PHN
- Country SA PHN
- Country to Coast Queensland PHN
- Primary Health Tasmania
- Western Victoria PHN

Universities and research centres

- Macquarie University
- National Centre of Excellence in Intellectual Disability Health
- University of Melbourne
- University of New South Wales
- University of Queensland
- University of Western Australia

List of abbreviations

3DN	Department of Developmental Disability Neuropsychiatry, UNSW
ABS	Australian Bureau of Statistics
CHAP	Comprehensive Health Assessment Program
DLO	Disability Liaison Officer
DRO	Disability Representative Organisation
GP	General Practitioner
IMDH Hubs	Intellectual Disability Mental Health Hubs
LGBTIQ+	Lesbian, gay, bisexual, transgender, intersex, queer or questioning
MBS	Medical Benefits Schedule
MRAC	MBS Review Advisory Committee
NCEIDH	National Centre of Excellence in Intellectual Disability Health
NDDA	National Disability Data Asset
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Commission	NDIS Quality and Safeguards Commission
NHRA	National Health Reform Agreement
NSQHS Standards	National Safety and Quality Health Service Standards
PANDDA	Professional Association of Nurses in Developmental Disability Australia
PCEP	Primary Care Enhancement Program
PHN	Primary Health Network
Psychotropics CCS	Psychotropics Clinical Care Standard
RIGG	Roadmap Implementation Governance Group
ID Roadmap	National Roadmap for Improving the Health of People with Intellectual Disability
SDAC	Survey of Disability, Ageing and Carers

health.gov.au

All information in this publication is correct as at August 2025