



Australian Government
Department of Health and Aged Care

Annual Progress Report 2023

National Roadmap for Improving the Health of People with Intellectual Disability





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Preface

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

The 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 Roadmap is an Associated Plan to Australia's Disability Strategy 2021–2031 ([the Strategy](#)). The 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 Roadmap acknowledges the health issues raised in the Disability Royal Commission.

As at November 2023, the Australian Government has invested a total of \$43.3 million to implement initial priority actions under the Roadmap.

Substantial progress has been made since the release of the Roadmap, with a significant increase in the number of actions in progress compared to last year. This report documents the efforts undertaken to implement the Roadmap from December 2022 to November 2023.

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Introduction

As part of the Roadmap program, the Department of Health and Aged Care (The Department) is required to publish an annual progress report on implementation. This is the second annual progress report, covering the period December 2022 to November 2023. The first report, covering the period August 2021 to November 2022, is available on the [health.gov.au website](https://www.health.gov.au).

The 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 Roadmap, of which:

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

Of these 116 actions:

- 27 actions have been identified as being the responsibility of the department
- 74 actions have been identified as the collaborative responsibility of the department and other external agencies
- 15 actions have been identified as being the responsibility of agencies external to the department.

The actions are listed in the Roadmap, available on the [health.gov.au website](https://www.health.gov.au).

A number of actions in the Roadmap are the responsibility of, or involve collaboration with state and territory government agencies. Accordingly, the department sought their input to this report.

How the department collected and collated data for the report

The Roadmap Implementation Governance Group (RIGG) Secretariat asked 63 organisations for input on progress against Roadmap actions. A total of 33 organisations responded (**Appendix A**).

The department provided each organisation with a list of relevant actions. It differentiated between actions they have responsibility for and actions they are supporting. Many actions need input from several organisations.

The department collated the information received for each action and reviewed it for relevance. Each action was 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 reporting period for this report that directly addresses the action. This includes:
 - activities that are small, related to a pilot or geographically limited activities
 - 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.

The department has endeavoured to include as much information in this report as possible about the many activities reported by organisations. In doing so, the department prioritised activities that have clear and specific relevance to people with intellectual disability.

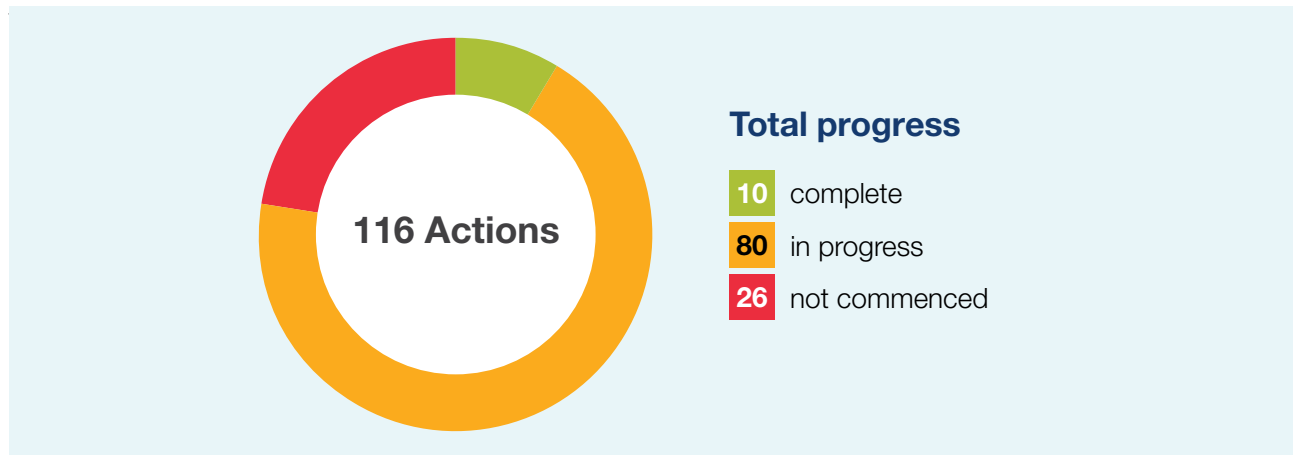
In some cases, information about individual activities has been summarised to help manage the length of the report. Where there was insufficient information provided, or no clear evidence that people with intellectual disability are being prioritised, or where the activity did not clearly address a Roadmap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

The Australian Government acknowledges that people use different words to talk about their identity. The 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 Roadmap in this report. The department recognises that language continues to change and evolve, and endeavours to use appropriate terms in this report.

National Roadmap: Summary of progress

This report, including the progress summary and the dashboard is based on the responses the department received. There may be other relevant activities under way, however the department is unable to report on these without input from the responsible organisations.

The chart below gives a summary of progress of Roadmap actions at the end of the reporting period (30 November 2023).

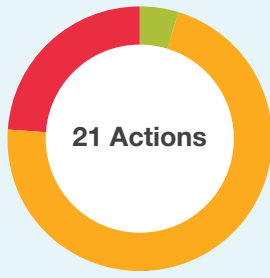


The dashboard on the following pages gives an overview of progress for each element. More detailed information about activities is provided in the individual sections for each element.

National Roadmap: Annual Progress Report 2023 Dashboard

The chart below provides information on progress of actions for each element.





Element C

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

- 1** complete
- 15** in progress
- 5** not commenced



Element D

Improving oral health for people with intellectual disability

- 0** complete
- 7** in progress
- 7** not commenced



Element E

Research, data and measurement to support continuing improvement

- 0** complete
- 8** in progress
- 0** not commenced



Element F

Emergency preparedness and response

- 2** complete
- 6** in progress
- 0** not commenced



Element G

Arrangements for oversight, monitoring and implementation of the National Roadmap

- 1** complete
- 2** in progress
- 2** not commenced

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

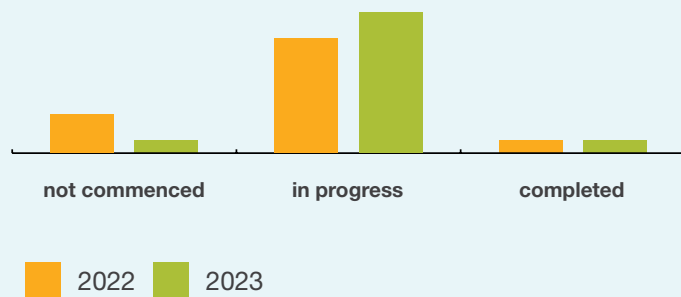
Desired Outcomes

- 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.

Progress

There are 13 actions in Element A, comprising 10 short term and 3 medium term actions.

- 1 action is completed
- 11 actions are in progress
- 1 action is not commenced



Highlights of activities being undertaken to deliver Element A include:

- The Department of Social Services opened applications for its Disability Representative Organisations grant opportunity. This will provide funding of up to \$10.208 million over 2 years from 2024–25 to 2025–26 to organisations to provide systemic advocacy for Australians with disability.
- The Government is providing funding of \$493.5 million over 5 years from 2022–23 to support the establishment of 58 Medicare Urgent Care Clinics (Medicare UCCs) across Australia, all of which are operational. Medicare UCCs are easing pressure on hospitals, and giving families more options to see a healthcare professional when they have an urgent, but not life-threatening, need for care. The clinics are required to provide accessible and inclusive services, including for people with physical and intellectual disability.
- NSW Health provided funding to 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.

- As part of an Australian Government Information, Linkages and Capacity Building (ILC) funded health project, Down Syndrome Australia developed a comprehensive eLearning program targeting General Practitioners (GPs), other health professionals and health students. The program includes specific modules on prenatal screening and postnatal diagnosis, and the importance of clear and correct information during this time.
- Western Victoria Primary Health Network (PHN) has been running an accessibility trial activity in two GP clinics. They will then develop a framework for clinics for promoting accessibility inclusion at all touchpoints across the organisation.
- NSW Health's Agency for Clinical Innovation (ACI) developed and published the Virtual Care in Practice Guide. The guide included content to create broader awareness of considerations and adjustments required to support clinicians and administrative staff to provide virtual care to consumers living with a disability. This content was developed in consultation with the ACI Intellectual Disability Health Network.
- Several organisations continued to develop and maintain resources in Easy Read format:
 - Queensland Health has continued to ensure that communication resources including website information are inclusive of disabilities and are written in Plain English and Easy Read. In October 2023, they co-delivered a mental health and wellbeing roundtable for people with intellectual disability, disability service providers and key stakeholders from the disability sector. The purpose of the roundtable was to gain a better understanding on the communication needs of people with intellectual disability.
 - Western Victoria PHN and Tasmania PHN have been undertaking activities to promote Easy Read Health Fact Sheets and PHN resources, for example through conferences and the Special Olympics.
 - The department has continued to update its COVID-19 Easy Read resources during 2023.

Spotlight: Establishing the National Centre of Excellence in Intellectual Disability Health

The department undertook an open competitive grant opportunity to select and fund the host for the National Centre of Excellence in Intellectual Disability Health (the Centre). The successful applicant was a 9-member consortium led by the University of New South Wales (UNSW), and also including the NSW Council for Intellectual Disability (CID), Down Syndrome Australia, First Peoples Disability Network, Queenslanders with Disability Network, the Centre for Disability Studies at the University of Sydney, the University of Melbourne, the Telethon Kids Institute, and the Mater Intellectual Disability and Autism Service. The Centre has been funded approximately \$22 million over 4 years from 2022–23.

The Hon Ged Kearney MP, Assistant Minister for Health and Aged Care officially launched the Centre on 13 October 2023. As part of its core functions, the Centre will provide a central repository (to be known as the Knowledge Exchange Hub) of intellectual disability health content and resources for people with intellectual disability, their families and support providers, health services, health students, health professionals and their educators.

People with intellectual disability will be directly involved in creating and running the Centre, and in its governance structures.

Element B Models of care for people with intellectual disability

B1: Developing better models of health care

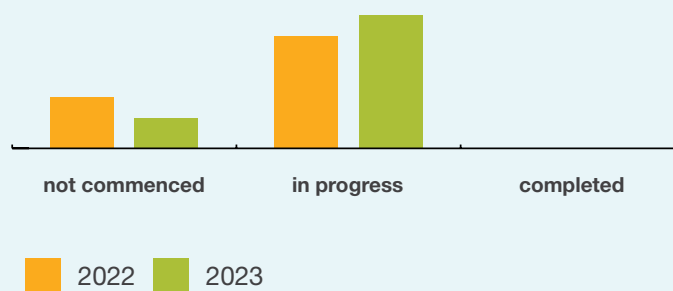
Desired Outcomes

- 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+.

Progress

There are 16 actions in Element B1, comprising 6 short term, 4 medium term and 6 long term actions.

- 0 actions are completed
- 13 actions are in progress
- 3 actions are not commenced



Highlights of activities being undertaken to deliver Element B1 include:

- In July 2023, Assistant Minister for Health and Aged Care the Hon Ged Kearney MP held a roundtable on procedural support and sedation to facilitate access to health care for people with intellectual disability. Roundtable participants made a series of recommendations, including:
 - improving awareness of new and existing pathways and services to access procedural support and sedation, and
 - establishing more specialised and flexible service delivery models including specialised community/ outpatient clinics and home services.

- Through work funded by the ILC Grants, CID has produced a series of online learning modules and accompanying resources for health professionals, along with accessible resources for people with intellectual disability. One of those modules focuses on reasonable adjustments, along with a co-designed checklist to support reasonable adjustments in primary care settings and communication about those adjustments when making referrals.
- Tasmania PHN has had initial engagement with six general practices through its Practice Improvement Team. The team provides in-practice support for primary care teams with a focus on providing quality healthcare, communication and implementing reasonable adjustments for people with intellectual disability.
- The Centre for Developmental Disability Health (CDDH) has been linking Monash Health's Disability Liaison Officers with Monash Health Behaviour Support Practitioners to give a collaborative and informed joint approach to managing complex inpatient situations with trauma informed practice. CDDH is collecting data on the effectiveness of this joint approach.

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

The Australian Commission on Safety and Quality in Health Care (ACSQHC) developed resources to support healthcare professionals to deliver safe and high-quality services to people with intellectual disability. In February 2023, ACSQHC published three new resources offering strategies to address safety and quality risks in health care for people with intellectual disability. These are based on Four Steps to Inclusive Health Care (*plan with me, understand me, communicate with me, act with me*) and include:

- [Intellectual Disability Actions for Clinicians fact sheet](#) – for healthcare professionals to inform making reasonable adjustments for a person's intellectual disability to create an inclusive environment and facilitate meeting the National Safety and Quality Health Service Standards.
- [With Me: Intellectual Disability Actions for Clinicians infographic poster](#) – this can be displayed in health services to inform clinicians about people with intellectual disability and the provision of inclusive health care that is safe and high quality.
- [About Me: Questions to Ask About Reasonable Adjustments Easy Read fact sheet](#) – an Easy Read document for people with intellectual disability that aims to support people with intellectual disability, their supporters and clinicians to talk about the person's disability and what they need to make their health care accessible.

ACSQHC and the department have been working closely to address the needs of people with intellectual disability in the National Safety and Quality Health Service Standards. A critical activity has been the development of a NSQHS Standards User Guide for the health care of people with intellectual disability. This resource was drafted for targeted consultation in late 2023, with release planned for mid-2024.

B2: Better use of existing MBS items

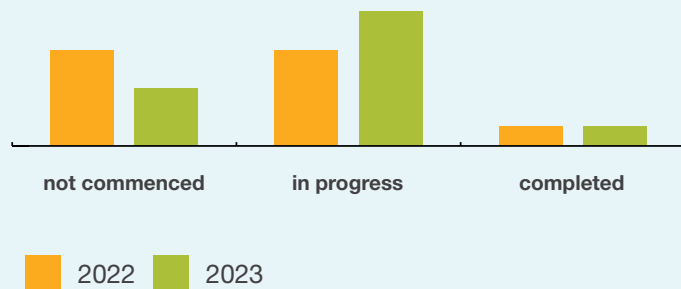
Desired Outcomes

- 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.

Progress

There are 11 actions in Element B2, comprising 8 short term and 3 medium term actions.

- 1 action is completed
- 7 actions are in progress
- 3 actions are not commenced



Highlights of activities being undertaken to deliver Element B2 include:

- From 1 November 2023:
 - New Medicare Benefits Schedule (MBS) Level E items for general attendance consultations of 60 minutes or more by GPs and medical practitioners commenced, providing higher benefits to patients.
 - Triple bulk billing incentives were introduced for GPs when they bulk bill children under 16 and Commonwealth concession card holders. The triple bulk billing incentives apply to the most common GP consultations:
 - all face-to-face general attendance consultations more than 6 minutes in length
 - all telehealth general attendance consultations which are between 6 and 20 minutes in length
 - longer telehealth phone and video general attendance consultations where a patient is registered through MyMedicare.
- With input from the RIGG and the Intellectual Disability Focus Group (Element G), the department developed a communications plan to guide activities to support and encourage people with intellectual disability, their families, support providers and health professionals to engage with annual health assessments and the CHAP. Under this plan, the department will engage an external supplier to develop resources and support a promotional campaign to increase awareness of AHAs among people with intellectual disability and their supporters.

- Several organisations have also been promoting and supporting engagement with annual health assessments for people with intellectual disability:
 - National Disability Services ran a webinar and developed resources to support disability providers to maximise use of the CHAP.
 - Central and Eastern Sydney PHN has promoted the CHAP through continuous professional development events, CESPHN Disability Network and other stakeholder channels, and through in-language health literacy community workshops and resources targeting Vietnamese, Korean, Indonesian and Chinese communities.
 - Tasmania PHN has promoted the CHAP through online and face-to-face training events, and in-practice support for primary care professionals.
 - Prof Nick Lennox, Senior Medical Adviser for Disability and Health in the department's Primary Care Division, led several workshop presentations for disability service providers and nurses on annual health assessments for people with intellectual disability and the CHAP.
 - Other organisations, including Down Syndrome Australia, promoted the availability of the Adult CHAP on the [health.gov.au](https://www.health.gov.au) website through social media and newsletter channels.
- In 2023, Darling Downs and West Moreton PHN expanded mapping of the CHAP in their HealthPathways programs across their entire region.

Spotlight: Annual Health Assessments and the CHAP – laying foundations for improved implementation

In December 2022, the department acquired a permanent licence enabling it to develop, publish and integrate the CHAP into GP software. A 2023 adult version of the tool was updated and made freely available for download from the [health.gov.au](https://www.health.gov.au) website.

The department has also been working to develop the Young Person CHAP (for people with intellectual disability aged 12 to 18 years), which will be available for free download alongside the adult version on the website by April 2024. A 2024 version of the Adult CHAP will also be published.

In June 2023, the department engaged the Australian Digital Health Agency (ADHA) to support the integration of the CHAP into GP clinical information systems, to make it easier for GPs to conduct and complete the CHAP. Initial work through this project has included completion of a research and discovery phase to identify different pathways for integrating the CHAP into GP software and development of a prototype solution for integrating Part 2 of the CHAP. A meeting of the Intellectual Disability Focus Group was held to provide input on this work. The ADHA also conducted interviews and workshops with families and carers, disability support workers and disability sector representatives, practice nurses and GPs to inform their research and discovery work.

It is anticipated that integration of the CHAP into GP software will be achieved by 2026.

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

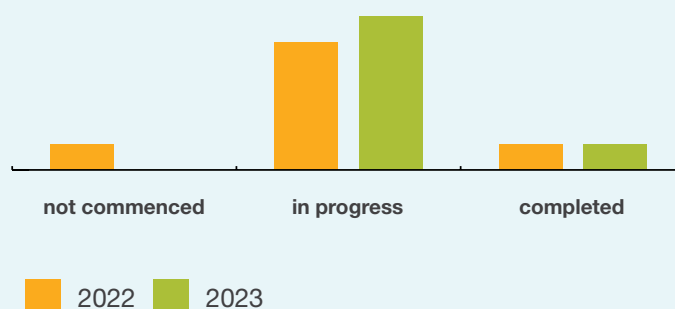
Desired Outcomes

- 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.

Progress

There are 7 actions in Element B3, comprising 6 short term and 1 medium term action.

- 1 action is completed
- 6 actions are in progress
- 0 actions are not commenced



Highlights of activities being undertaken to deliver Element B3 include:

- The Australian Government's 2023–24 budget invested in digital health technologies to build a more efficient, connected and collaborative health care system, which includes upgrading My Health Record (MHR). The upgrade will ensure MHR is easier to use, compatible with the information and billing systems that health practitioners are already using, and connects the health system so that patients can access and securely share their health data.
- The triple MBS bulk billing incentives introduced in 2023 (see Element B2) cover telehealth services that are longer than 20 minutes for eligible patients registered with the practice through MyMedicare.
- Gippsland PHN has been doing ongoing promotion and awareness work to register and embed the use of MHR across Gippsland health services. This has potential to allow for targeted work to support continuity of care and integration for the intellectual disability cohort.
- The NSW Health Agency for Clinical Innovation has developed a paediatric genomic testing pathway for patients aged 10 and under with a suspected genetic condition. This pathway explains how to access Medicare rebatable genomic testing for children under 10 who have moderately severe global developmental delay or intellectual disability or dysmorphic facial features and one or more major structural congenital anomalies.

- Western Victoria PHN has developed patient profile templates that include critical information about reasonable adjustments tailored to the person for their health care accessibility needs, and connector points. This profile is recommended to alert receiving clinicians for referrals about the person's needs.
- In the ACT, the 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.
- Healthdirect's Video Call Service received funding throughout 2023 to support GPs nationally and a range of jurisdictional health services, as well as Healthdirect's national Pregnancy, Birth and Baby Service and After Hours GP Helpline. The Video Call Service facilitated over 318,387 GP consultations during the reporting period. The department's Video Call Service Fund Provider Committee, comprising Healthdirect, the Australian and state and territory governments, continues to meet regularly to discuss the development, implementation and support of the Video Call Service as a clinical tool across the Australian health care sector.

Spotlight: Introduction of MyMedicare

In 2023 the Australian Government introduced a new system of voluntary patient registration called MyMedicare. MyMedicare aims to create a stronger relationship between people and their primary care team to get better continuity of care and easier access to telehealth consultations. On 1 October 2023, MyMedicare opened to all Australians with a Medicare card.

MyMedicare provides practices with more comprehensive information about their regular patients, while giving patients and their care team access to additional funding packages, tailored to their health needs. The department is working to ensure that people registered with MyMedicare will have the option to self-identify that they have an intellectual disability. People have had the opportunity to provide that and other information about their disability from 6 April 2024.

The department worked with the University of Sydney across 2021–2022 to develop optional questions about disability for MyMedicare.



B4: Better coordination with other sectors

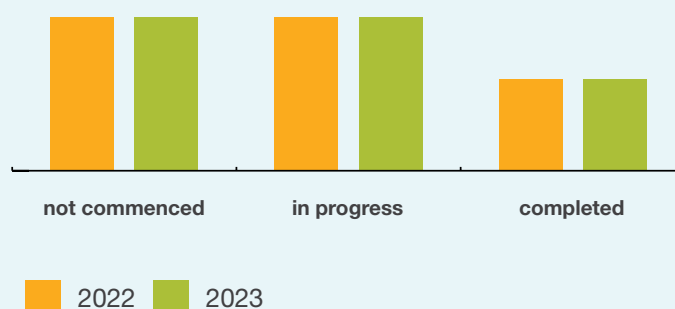
Desired Outcomes

- 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.

Progress

There are 13 actions in Element B4, comprising 9 short term and 4 medium term actions.

- 3 actions are completed
- 5 actions are in progress
- 5 actions are not commenced



Highlights of activities being undertaken to deliver Element B4 include:

- The ACSQHC has been working with the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission (NDIS Commission) in preparing for the launch and implementation of the *Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard* in mid-2024. This work aligns with the goals and work under the Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People, which was released in March 2022.
- Gold Coast PHN's Care Finders program supports vulnerable older people, including those with intellectual disability, who have no one else who can support them, to inform them about and apply for support services.
- 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 has responded to more than 34,100 referrals between December 2020 and the end of June 2023.

- The NDIA's Hospital Liaison Officers (HLOs) continue to provide a link between state and territory hospital staff and the NDIA. They are working to ensure current and prospective participants have NDIS supports in place on discharge. HLOs have supported the Hospital Discharge Exemplar Project, leading to improved consistency and confidence in hospital discharges. This has been beneficial for participants and families, health providers and the NDIA, with substantial decreases in time waiting for discharge. Expansion of the role of the HLOs is being thought about, considering the recommendations made in the Disability Royal Commission's Final Report and the NDIS Review.
- [The Mid-Term Review of the National Health Reform Agreement \(NHRA\) Addendum 2020–2025 Final Report](#) was delivered on 24 October 2023. The Health Ministers of the Commonwealth and all states and territories commissioned the review. The review is a requirement of Clause 21 of the Addendum. The review's first recommendation states that:

The NHRA should:

- a. be framed as a **single collaborative health system Agreement** that acknowledges that health system performance is a function of the hospital, primary, disability, aged care and prevention sectors working effectively together, in the interests of the consumer and system sustainability and which clearly sets out roles and responsibilities, actions and accountabilities of the parties.

The Mid-Term Review made other relevant recommendations about how the next NHRA can continue to support people with disability eligible for the NDIS to transition out of hospital when they are medically ready for discharge; review mechanisms to ensure continuity of care for NDIS participants during a hospital stay to ensure optimal patient outcomes; and set out roles and responsibilities including accountability and escalation mechanisms to address market failures in rural and remote primary care, aged and disability care.



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

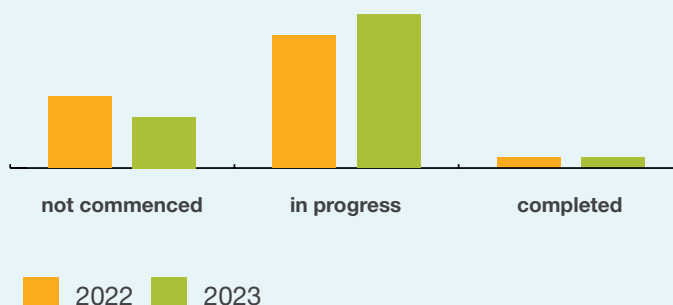
Desired Outcomes

- 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+.

Progress

There are 21 actions in Element C, comprising 9 short term, 11 medium term and 1 long term actions.

- 1 action is completed
- 15 actions are in progress
- 5 actions are not commenced



Highlights of activities being undertaken to deliver Element C include:

- In June 2023 the department engaged a team at the University of NSW to consider the practical application of the Intellectual Disability Health Capability Framework. The Framework sets out core intellectual disability health capabilities and learning outcomes with the aim of improving pre-registration education for health professionals. This team will assist with the development of education resources and tools to support Framework uptake and integration by accreditation authorities and pre-registration education providers. This work will continue to support promotion and uptake of the Framework until June 2025.
- In Queensland, the Specialist Mental Health Intellectual Disability Service ECHO project provides clinicians state-wide with regular tele-mentoring clinics. These focus on assessment of people with intellectual disability with Mental Health conditions. Queensland Health is currently 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.

- The NSW Health Agency for Clinical Innovation (ACI) held a Virtual Care Exchange Forum on *How to overcome communication barriers when delivering virtual care*. The forum specifically focused on patients/clients with intellectual disability. ACI has also developed an online resource called *The Essentials*. The resource aims to build capacity in health services for providing high quality care to people with intellectual disability. It is a self-assessment tool and includes a collection of supporting resources that can be implemented locally to support change. *The Essentials* is also used by the NSW Health Intellectual Disability Health Service and the Intellectual Disability Mental Health Hubs.
- The ACT has arranged for all Canberra Health Services (CHS) team members to have access to an introductory training course targeted at improving the capacity of health professionals in engaging with people with disability. CHS also completed an accessibility audit at the Canberra Hospital campus to inform ongoing improvements.

Spotlight: Primary Care Enhancement Program

The Primary Care Enhancement Program (PCEP) provides funding for four Primary Health Networks (PHNs) to support health professionals to provide better services for people with intellectual disability. Each pilot PHN has implemented a diverse range of approaches in delivering the PCEP within their region. They are contributing to an understanding of what works, for whom and in which contexts, with the final evaluation report being delivered in July 2024. In addition to workshop and webinar training based on resources developed by CID, PHNs have also engaged in the following activities:

- Central and Eastern Sydney PHN has extended its training and resources to disability service providers to enhance the skills of disability workers in understanding the importance of preventive healthcare for individuals with intellectual disability.
- Central Queensland, Wide Bay, Sunshine Coast PHN has created a PCEP education package that will be hosted on its Learning Management System and available by the end of 2024. The package reflects best practice primary care for people with intellectual disability, such as good continuity of care, comprehensive care for complex needs and preventive care.
- Primary Health Tasmania has developed a framework for in-practice support to deliver training to all staff within the practice. The framework includes a staff manual and in-practice training sessions, which are adapted to suit the needs of each practice.
- Western Victoria PHN is also trialling two peer support worker roles, a Telehealth Peer Support Worker and a Youth Peer Support Worker. Both roles are based in local health and mental health services and provide direct support to people with intellectual disability to upskill them in accessing healthcare both in-person and via telehealth.

Element D Improving oral health for people with intellectual disability

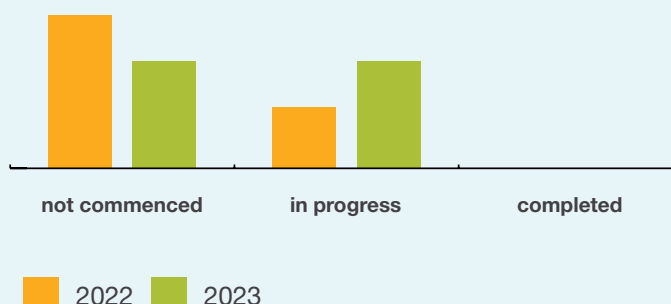
Desired Outcomes

- 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.

Progress

There are 14 actions in Element D, comprising 12 short term and 2 medium term actions.

- 0 actions are completed
- 7 actions are in progress
- 7 actions are not commenced



Highlights of activities being undertaken to deliver Element D include:

- 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.
- DHSV has provided a range of training and support services to dental agencies and oral health clinicians. This includes development of protocols and guidelines for working with a patient 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.
- NSW Health published the *NSW Oral Health Strategic Plan: 2022–2032* in early 2023. The plan works towards reducing the gaps to achieve good oral health outcomes for the NSW population, recognising people with disability may need additional support in accessing public dental services and good dental outcomes.

- Through Tasmania PHN, Oral Health Services Tasmania (OHST) has been a critical partner and supporter of the PCEP program. OHST were invited to present at regional face-to-face forums (target audience GPs, practice nurses and allied health professionals) in Hobart and Burnie. The main messaging included encouraging health professionals to look at oral hygiene and oral health care with patients with intellectual disability and to refer as appropriate. There has also been ongoing promotion of CID resources including caring for your teeth to primary care professionals and Tasmanian Health Service staff. These resources were also shared with OHST.
- Both the Australasian Council of Dental Schools and Special Needs Dentists are represented on the Education and Training Expert Advisory Group managed by the department. The Australasian Council of Dental Schools also had an expert adviser contributing to the department's Intellectual Disability Health Capability Framework Drafting Group.
- Western Victoria PHN has promoted the oral care needs of people with intellectual disability in their activities. This includes special needs dentistry, the overlap between oral care and the CHAP tool (Element D), and sedation programs to maximise oral health.
- The NDIS Commission published an updated Practice Alert on oral health for NDIS participants in January 2023.



Element E

Research, data and measurement to support continuing improvement

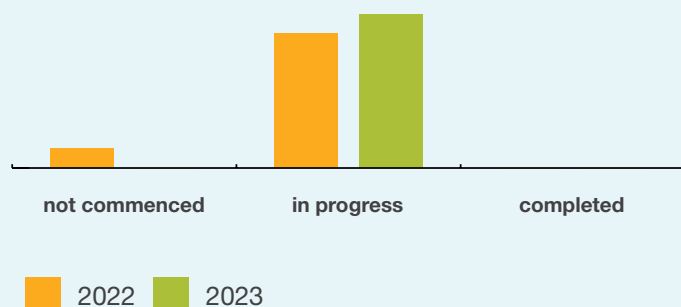
Desired Outcomes

- 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.

Progress

There are 8 actions in Element E, comprising 4 short term, 3 medium term and 1 long term actions.

- 0 actions are completed
- 8 actions are in progress
- 0 actions are not commenced



Highlights of activities being undertaken to deliver Element E include:

- The department worked with its Advisory Committee on the Health Emergency Response to COVID-19 for People with Disability (COVID-19 Disability Advisory Committee) to produce data on COVID-19 associated mortality among people with disability, including people with intellectual disability. Work also commenced to develop an article for publication in a peer reviewed journal on COVID-19 mortality for people with disability. This work is progressing, using data linked through the Person Level Integrated Data Asset.
- The Australian Bureau of Statistics (ABS) manages the statistical Standard for Severity of Disability. The ABS has been updating the standard and expects it to be released in 2024. The standard provides a set of questions and data items that can be used in population surveys to determine disability status, disability type, disability group and any associated workplace or education restrictions. The standard is used in ABS household surveys such as the National Health Survey, Personal Safety Survey and General Social Survey. The inclusion of the standard in household surveys allows for the analysis of the characteristics and perspectives of people living with disability.
- The ABS completed enumeration of the Survey of Disability, Ageing and Carers (SDAC) early in 2023 and is preparing data for publication in June 2024. SDAC is the recommended source of disability prevalence in Australia, and is designed to measure and give data on a range of disability related concepts (such as severity and type). It informs areas including need for and receipt of assistance with activities, availability of public transport in local areas, and patient experience. The survey collects information from three target populations: people with disability, people aged 65 and over, and carers of people with disability or a long-term health condition or older people. The SDAC identifies six disability groups based on particular types of disability, including intellectual disability.
- The department commenced a data linkage project to investigate uptake of annual health assessments among people with intellectual disability on the NDIS and/or Disability Support Pension.

Element F Emergency preparedness and response

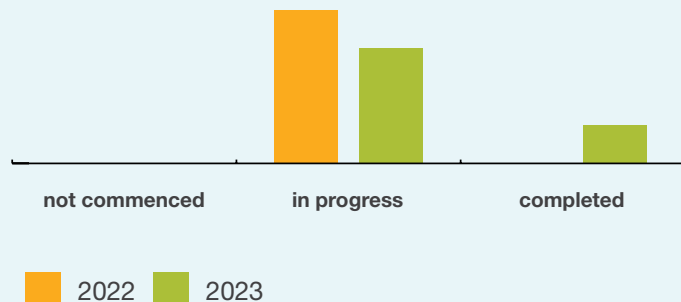
Desired Outcomes

- 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.

Progress

There are 8 actions in Element F, comprising 8 short term actions.

- 2 actions are completed
- 6 actions are in progress
- 0 actions are not commenced



Highlights of activities being undertaken to deliver Element F include:

- The COVID-19 Disability Advisory Committee met regularly throughout 2023 to give advice on the health care needs of people with disability, their families and the disability service sector during the pandemic. It was agreed that the Advisory Committee would continue to meet into early 2024. An independent report on the lessons learned by the department's COVID-19 Disability Advisory Committee was finalised and published on the [health.gov.au](https://www.health.gov.au) website.
- The Disability and Health Sector Consultation Committee met quarterly in 2023 and received updates on the COVID-19 response for people with disability and the disability sector.
- The Communicable Diseases Network of Australia issued guidance *Control and public health management of outbreaks of acute respiratory infection (including COVID-19 and influenza) in disability residential services* accessible through the www.health.gov.au website.
- In Western Australia, health service providers have been considering the needs of people with intellectual disability in their emergency preparedness planning. This included developing personal emergency evacuation plans and ensuring critical staff are available to support the safe evacuation of people with intellectual disability.

Spotlight: Establishing an Inclusive Australian Centre for Disease Control

The Australian Government committed \$90.9 million to support the establishment of the Australian Centre for Disease Control (CDC) in the 2023–24 Budget. This commitment followed a consultation process on the scope and functions of a CDC in 2022, to which the COVID-19 Disability Advisory Committee provided input.

The department's Australian CDC Establishment Taskforce engaged regularly with the COVID-19 Disability Advisory Committee throughout the second half of 2023. The Taskforce received feedback on how the Australian CDC can be inclusive of people with disability and people with intellectual disability. This included seeking feedback on a proposed governance model for the Australian CDC, noting that final decisions are a matter for Government.

While outside of the reporting period, an interim Australian CDC was established within the department on 1 January 2024. The interim Australian CDC has continued to work with priority populations through existing forums, including the COVID-19 Disability Advisory Committee, to support development and expansion of an Australian CDC.

The main priorities of the interim Australian CDC are to prepare for future pandemics, lead the national response to future infectious disease outbreaks, and work to prevent communicable diseases.



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

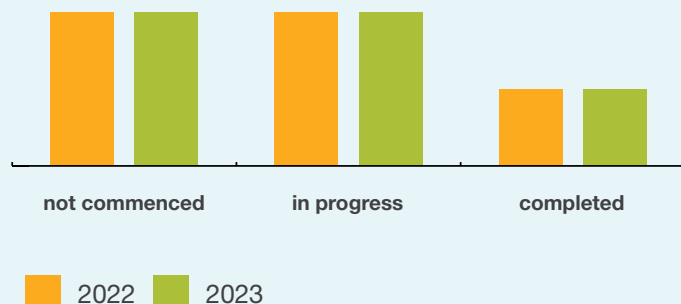
Desired Outcomes

- Implementation of the 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, accreditation and registration bodies
 - Australian and state and territory government representatives.
- Implementation of the Roadmap is conducted in an inclusive and transparent manner.

Progress

There are 5 actions in Element G. These relate to governance and are ongoing for the term of the program.

- 1 action is completed
- 2 actions are in progress
- 2 actions are not commenced



- The Roadmap Implementation Governance Group (RIGG) has 34 members representing:
 - people with intellectual disability, their families and carers
 - representatives from the health and disability sectors
 - representatives of universities, professional colleges, accreditation, and registration bodies, and
 - Australian and state and territory government representatives.
- The RIGG met five times during the reporting period. This includes two extraordinary meetings, one of which was a roundtable with the Assistant Minister for Health and Aged Care, the Hon Ged Kearney MP, on procedural support and sedation to improve access to health care for people with intellectual disability.
- The department published RIGG meeting summaries on www.health.gov.au, including in Easy Read format.

Spotlight: Consultation of the Intellectual Disability Focus Group

The department established the Intellectual Disability Focus Group in August 2022 to facilitate in depth consultation on projects being delivered under the Roadmap. The Focus Group consists of six members with intellectual disability and is chaired by the Senior Medical Adviser of the Primary Care Division. The Focus Group meets on an ad hoc basis to give input to the Roadmap projects at key points in their delivery.

During the reporting period the Focus Group met to consult on the following projects:

- March 2023 – Annual health assessments and the CHAP: the experiences of the Focus Group using the CHAP and how it can be made easier to use.
- May 2023 - Consulted as Technical Advisers for the evaluation of the (de-identified) grant applications for the National Centre of Excellence in Intellectual Disability Health.
- September 2023 – Intellectual Disability Capability Framework: discussion included the Framework design and development of a graphic representation of the core capability areas, what should be included in an inclusive summary of the Framework and the use of quotes from people with intellectual disability in the Framework.
- November 2023 – Annual health assessments and the CHAP: AHA appointment length, GPs using the CHAP on their clinical software, and how information is shared after the appointment (e.g. storing information on My Health Record).

Appendix A Organisations that provided input to this Report

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

Australian government agencies

- Australian Bureau of Statistics (ABS)
- Australian Commission on Safety and Quality in Health Care (ACSQHC)
- Australian Digital Health Agency (ADHA)
- Australian Institute of Health and Welfare (AIHW)
- Australian Department of Health and Aged Care (the department)
- Australian Department of Social Services (DSS)
- National Disability Insurance Agency (NDIA)
- NDIS Quality and Safeguards Commission (NDIS Commission)

Advocacy and professional organisations

- Centre for Developmental Disability Health (CDDH)
- Department of Developmental Disability Neuropsychiatry UNSW (3DN)
- Down Syndrome Australia
- First Peoples Disability Network
- Health Professions Accreditation Collaborative Forum
- National Disability Services (NDS)
- NSW Council for Intellectual Disability (CID)
- Queenslanders with Disability Network
- Royal Australasian College of Physicians (RACP)
- Royal Australian College of General Practitioners (RACGP)

State and territory health agencies

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

Primary Health Networks (PHNs)

- Adelaide PHN
- Brisbane South PHN
- Central and Eastern Sydney PHN
- Darling Downs and West Moreton PHN
- Gold Coast PHN
- Gippsland PHN
- Tasmania PHN
- Western Sydney PHN
- Western Australia Primary Health Alliance – Perth North, Perth South, Country WA PHNs
- Western Victoria PHN



Glossary

3DN	Department of Developmental Disability Neuropsychiatry, UNSW
ABS	Australian Bureau of Statistics
ACSQHC	Australian Commission on Safety and Quality in Health Care
ADHA	Australian Digital Health Agency
AHA	Annual Health Assessment
AIHW	Australian Institute of Health and Welfare
Australian CDC	Australian Centre for Disease Control
CHAP	Comprehensive Health Assessment Program
CID	NSW Council for Intellectual Disability
CPD	Continuing Professional Development
DLO	Disability Liaison Officer
DSS	Australian Department of Social Services
FDSV	Family, domestic and sexual violence
GP	General Practitioner
HLO	Hospital Liaison Officer
ILC	Information, Linkages and Capacity Building
LGBTIQ+	Lesbian, gay, bisexual, transgender, intersex, queer or questioning
MBS	Medical Benefits Schedule
Medicare UCC	Medicare Urgent Care Clinic
MHR	My Health Record
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
PCEP	Primary Care Enhancement Program
PHN	Primary Health Network
PPE	Personal Protective Equipment
RIGG	Roadmap Implementation Governance Group
Roadmap	National Roadmap for Improving the Health of People with Intellectual Disability
SDAC	Survey of Disability, Ageing and Carers
The department	Australian Department of Health and Aged Care

