



Australian Government  
Department of Health and Aged Care

# Annual Progress Report 2022

National Roadmap for Improving the Health of People with Intellectual Disability





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# Foreword

The National Roadmap for Improving the Health of People with Intellectual Disability ([the Roadmap](#)) was released in August 2021. The Roadmap is a 10-year program developed through a series of roundtable discussions with stakeholders held between August 2019 and March 2021.

The Roadmap seeks to put people with intellectual disability at the centre of the reform process. It sets out comprehensive actions to improve their health outcomes. It outlines how we can create a health system where people with intellectual disability are valued, respected and have access to high quality, timely and comprehensive health care.

The Roadmap is an Associated Plan of Australia's Disability Strategy 2021-2031 ([the Strategy](#)). The Roadmap supports the Health and Wellbeing Outcome under the Strategy. Associated Plans provide a coordinated, long-term approach to how governments work to improve outcomes for people with disability, including attaining the highest possible health and wellbeing outcomes throughout their lives.

The Roadmap also acknowledges the health issues raised in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ([Disability Royal Commission](#)).

The Australian Government has demonstrated its ongoing commitment to the Roadmap through its investment of \$43.3 million to date. This includes a total of \$23.9 million over four years and ongoing to establish a permanent National Centre of Excellence in Intellectual Disability Health.

This first annual progress report documents the work that has been undertaken to implement the Roadmap between August 2021 to November 2022. Some significant actions have already been taken in the first year, but there is much more to be done.

I greatly appreciate the dedication and ongoing support the Roadmap receives from stakeholders to ensure that the wide range of actions are progressed and implemented.

I look forward to continuing to work with people with intellectual disability, their families and carers, and advocates and stakeholders across the health and disability sectors to support the implementation of this important program.

## **Simon Cotterell PSM**

Chair, Roadmap Implementation Governance Group  
First Assistant Secretary, Primary Care Division

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# Introduction

The National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap) was released in August 2021. As part of the Roadmap program, the Department of Health and Aged Care (DHAC) is required to publish an annual progress report. This is the first annual progress report, covering the period August 2021 to November 2022.

The Roadmap is divided into 10 elements (Element B has 4 sub-elements which 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 DHAC
- 74 actions have been identified as the collaborative responsibility of DHAC and other external agencies
- 15 actions have been identified as being the responsibility of agencies external to DHAC

The actions are listed in the Roadmap, which is available on the DHAC website:

[National Roadmap for Improving the Health of People with Intellectual Disability](#)

## How we collected and collated data for the report

The Roadmap Implementation Governance Group (RIGG) Secretariat sent a request to 63 organisations for input on progress against Roadmap actions. Responses were received from 43 organisations. A list of organisations that responded is at **Appendix A**.

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

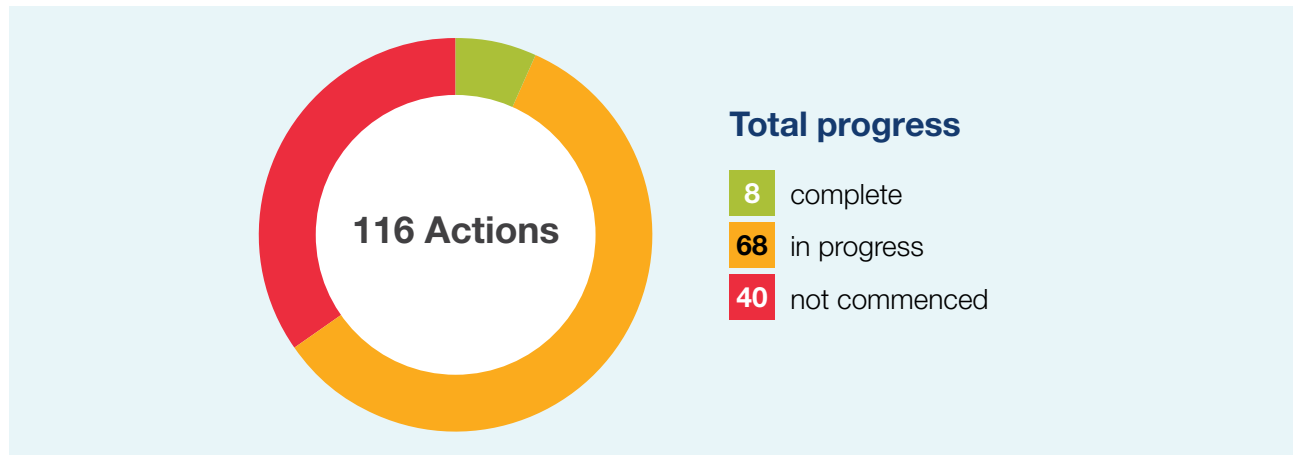
The information provided by organisations was collated for each action and reviewed for relevance. Each action was assigned a status, as follows:

- **Not commenced:** no activity was reported against the action, or the activity reported did not address the action.
- **In progress:** at least one organisation is undertaking an activity 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 address the action
  - activities that partially address the action, for example, activity is about diabetes only, but action is about chronic health conditions.
- **Completed:** no further activity is required for the action.

## Summary of progress

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

The chart below gives a summary of progress of Roadmap actions during the reporting period.



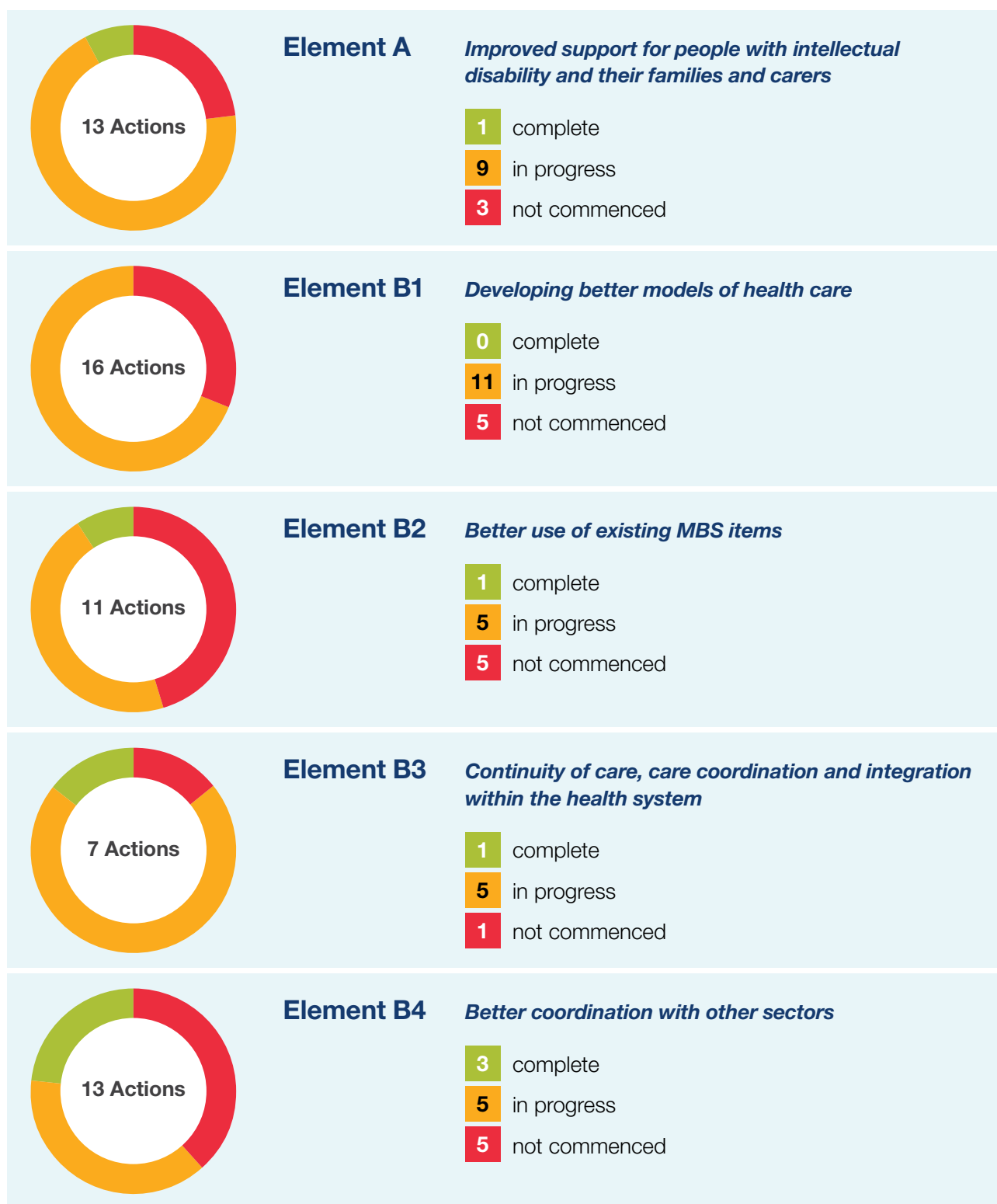
The dashboard on the following pages gives a quick overview of progress for each element. More detailed information about activities is provided in the individual sections for each element.<sup>1</sup>

We have endeavoured to include as much information as possible about the many activities reported by organisations. We prioritised actions 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 the activity did not clearly address a Roadmap action, we have either reduced the information or, in some cases, did not include it.

<sup>1</sup> **Note:** 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. We have adapted language used in the Roadmap in this report. We recognise that language continues to change and evolve and endeavour to use appropriate terms in this and future reports.

# National Roadmap: Annual Progress Report 2022 Dashboard

The Roadmap has a total of 116 actions across 10 themed elements. Of these 116 actions: **8** are completed, **68** are in progress, and **40** have not commenced. 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
- 13 in progress
- 7 not commenced



### Element D

*Improving oral health for people with intellectual disability*

- 0 complete
- 4 in progress
- 10 not commenced



### Element E

*Research, data and measurement to support continuing improvement*

- 0 complete
- 7 in progress
- 1 not commenced



### Element F

*Emergency preparedness and response*

- 0 complete
- 7 in progress
- 1 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
- 9 actions are in progress
- 3 actions are not commenced

## Completed action

The Council for Intellectual Disability, people with intellectual disability, their families and carers, Primary Health Networks (PHNs) and other experts to work together through the Primary Care Enhancement Program (PCEP) to co-design and develop resources to:

- promote health literacy and advocacy skills among people with intellectual disability, their families and carers
- support people with intellectual disability and their families to make informed decisions about health care and treatment options

Highlights of activities being undertaken to deliver Element A include:

- A number of Primary Health Networks (PHNs) are undertaking activities to promote better use of My Health Record and other tools such as health passports by people with intellectual disability, their families and carers.
- The Department of Social Services (DSS) administers the Information, Linkages and Capacity Building (ILC) grants program which funds projects in the community to refer people with disability (including those with intellectual disability) to relevant local services, and to work with mainstream services to implement strategies for greater inclusion.
- Down Syndrome Australia's ILC funded Health Ambassadors Project team has presented to several PHNs about inclusive communication in health.
- Health authorities in New South Wales, Queensland, South Australia and Western Australia as well as DHAC all report increasing use of accessible formats such as plain language and Easy Read resources for health communications.

- Both New South Wales and Queensland health authorities are implementing best practice protocols to support people with intellectual disability to navigate their health systems. For example, New South Wales is implementing the REACH escalation tool for patients, family and carers in health care settings. Queensland Health employs staff who perform disability liaison officer functions across the state.
- The Australian Digital Health Agency (ADHA) is working with Carers Australia to increase awareness and uptake of digital health (including My Health Record) with carers.
- DHAC continues to provide funding to SANE Australia to run a pilot of specialised digital mental health services and interventions. The pilot aims to improve access to mental health services for people for whom mainstream services may be challenging, including those with co-occurring conditions such as intellectual disability and autism. The pilot is currently available in 13 PHN regions across Australia. SANE is working closely with PHNs, clinicians and other organisations in the mental health sector to build a range of referral pathways so people struggling with complex mental health can be referred to and participate in the pilot.
- South Australia is working to reduce sedation needs for children and young people undergoing procedures. This is achieved through improved distraction techniques, including providing access to virtual goggles and other IT support.

### **Spotlight: Development of resources for the Primary Care Enhancement Program (PCEP)**

The NSW Council for Intellectual Disability (CID) was engaged by DHAC through the PCEP to work closely with stakeholders to develop health literacy resources for people with intellectual disability.

All materials developed for the project were co-designed, with input from people with intellectual disability and their families, four lead PHNs, clinical and academic experts, disability service providers, and the Department of Health and Aged Care.

The four PHNs involved in the PCEP are:

- Central and Eastern Sydney PHN
- Central Queensland, Wide Bay and Sunshine Coast PHN
- Primary Health Tasmania PHN
- Western Victoria PHN

The resources were based upon a comprehensive needs assessment. The aim was to understand the perspectives of people with intellectual disability and their supporters, and identify currently unmet health care needs.

PCEP resources are available on the Department's website:

[Primary Care Enhancement Program for people with intellectual disability](#)

The four PHNs involved in the PCEP are continuing to promote the training and resources through a range of avenues and targeted activities.

The PCEP project is currently undergoing evaluation to help inform the decision to roll out nationally, which is a decision for Government.

# 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 general practitioners (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 LGBTI.

### Progress

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

- 0 actions are completed
- 11 actions are in progress
- 5 actions are not commenced

Highlights of activities being undertaken to deliver Element B1 include:

- Australia's Disability Strategy 2021 – 2031 (the Strategy) was released December 2021 and is the overarching framework to drive action to improve outcomes, including the health and wellbeing outcomes, for the approximately 4.4 million people with disability in Australia. The Strategy was developed by all levels of government together with people with disability, their families, carers, and representatives and will drive change over the next decade to uphold the rights, inclusion, and participation of people with disability in all areas of Australian life. All governments have committed to driving action under the Strategy including through this Roadmap.
- Training and resources for health professionals developed by CID as part of the PCEP feature sections devoted to reasonable adjustments for people with intellectual disability.
- DHAC is working with states and territories to implement the new National Mental Health and Suicide Prevention Agreement, which came into effect in March 2022. Priority population groups include people with cognitive disability and/or autism.
- The ADHA is building relationships with consumer peak organisations to improve their understanding of the needs of people with intellectual disability.

- The Royal Australian College of Physicians (RACP) is currently developing an online learning resource on providing healthcare to people with cognitive disability. Key topics within the online learning resource include person-centred care and transitions, the barriers to preventive health care and the trauma experienced by people with intellectual disability in the healthcare system.
- The Darling Downs and West Moreton PHN was involved in a pilot program of a palliative care service to provide services to patients with intellectual disability in a preferred place, including in their home.
- A number of programs, plans and strategies reported apply to the wider population, but may positively impact people with intellectual disability, such as:
  - *The National Aboriginal and Torres Strait Islander Health Plan 2021-2031*
  - *programs to improve maternal and child health and wellbeing for and with Aboriginal and Torres Strait Islander families*
  - *a new model of trauma-informed recovery care for people who have experienced family, domestic and sexual violence (FDSV) to support the National Plan to End Violence against Women and Children 2022-2032*
  - *an Implementation and Evaluation Plan to support the National Preventive Health Strategy 2021-2030*

There is an opportunity to ensure the health needs of people with intellectual disability are considered and included in such programs, plans and strategies.

### **Spotlight: Department of Developmental Disability Neuropsychiatry (3DN) Improving palliative care services for people with an intellectual disability**

3DN are currently undertaking a mixed-methods research project, funded by the Department of Health and Aged Care National Palliative Care Projects, that will lead to the co-design, trial and preliminary evaluation of a tailored model of palliative care for people with intellectual disability.

This project will incorporate large, linked datasets and qualitative data to examine access to and the impact of palliative care for people with intellectual disability. 3DN will consult nationally with people with intellectual disability, carers, and professionals, and will translate their findings into the co-design, trial and preliminary evaluation of a tailored model of palliative care for people with intellectual disability. This tailored service model will be piloted within the South Western Sydney Local Health District from 2023.

3DN will also develop and launch a toolkit to improve the accessibility and quality of palliative care services for people with intellectual disability. They will also establish a mechanism for improving national data collection about people with intellectual disability receiving palliative care services, enabling benchmarking of service provision.

## 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
- 5 actions are in progress
- 5 actions are not commenced

### Completed action

DHAC to explore licensing options that support the incorporation of the CHAP tool into GP practice software.

Highlights of activities being undertaken to deliver Element B2 include:

- A number of PHNs have developed resources and taken steps to improve the use of relevant MBS items by health providers when treating people with intellectual disability.
- RACP will highlight annual health assessments and relevant MBS items in their online learning resource.
- The South Australian Intellectual Disability Health Service is promoting the free use of the CHAP to GPs.

## Spotlight: Promotion of annual health assessments and the CHAP tool

Evidence shows annual health assessments are an effective way to identify unmet health needs in people with intellectual disability.

A number of organisations are taking actions to promote the uptake of annual health assessments for people with intellectual disability, including:

- North Sydney PHN produced a video training module for the CHAP tool
- Central Eastern Sydney PHN promote the uptake of annual health assessments in Continuing Professional Development (CPD) and at training events, and include information about annual health assessments on their website and in newsletters
- Primary Health Tasmania PHN have ongoing engagement with key partners such as advocacy groups to promote annual health assessments
- the NDIS Commission has published a practice alert for providers on the need for annual health assessments
- CID periodically promotes annual health assessments via social media and advocacy

Availability of the CHAP tool is important for delivering Roadmap actions aimed at increasing the uptake of annual health assessments. DHAC has explored licencing options that support the incorporation of the CHAP tool into GP practice software.

Although it occurred after the close of the reporting period for this Annual Report, DHAC advises that in December 2022 it acquired a licence to update and publish the CHAP tool. The tool will be made available on the DHAC website in 2023.



## 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
- 5 actions are in progress
- 1 action is not commenced

### Completed action

DHAC to support continuation of MBS telehealth access (via telephone and video) for general practice, allied health and specialist care that will promote continuity of care for people with intellectual disability.

Highlights of activities being undertaken to deliver Element B3 include:

- eHealth NSW operates the HealthNet Platform, delivering a variety of clinical information to My Health Record, including discharge summaries, event summaries and specialist letters designed and completed by specialist clinical units providing direct patient care to people with intellectual disability.
- The NSW Education Centre Against Violence is co-developing an audio-visual resource to support Violence, Abuse and Neglect service practitioners in working with people with intellectual disability.
- 3DN's ILC-funded web-tool Intellectual Disability Mental Health Connect has been developed to assist people with intellectual disability, their support networks, and professionals to navigate New South Wales intellectual disability mental health pathways and offer professionals with the tools to provide collaborative approaches to service delivery.
- Queensland Health is promoting state-wide use of Julian's Key Health Passport which supports improved communication of health care needs, coordination and delivery of care for people with disability. Ongoing improvements to Julian's Key will be made based on the recommendations of an external evaluation completed in 2021.
- Several PHNs have been active in projects to better identify patients with intellectual disability and include reasonable adjustments in care pathways.



- Primary Health Tasmania (PHN) is collaborating with the Tasmanian Health Service to map the patient journey to improve coordination of care at the hospital interface. Input is being sought from people with intellectual disability, their family and carers.
- The NSW Health statewide Intellectual Disability Health Service provides an assessment and care coordination service for people with intellectual disability and complex health conditions.
- NSW Health Intellectual Disability Mental Health Hubs provide tertiary care for people with intellectual disability and complex mental health needs as part of a targeted clinical pathway. The Hubs have a positive impact on improving access to mental health care, build the capacity and confidence of providers to work with people with intellectual disability and contribute to further promoting the role of mental health services in working with people with intellectual disability.
- The South Australian Intellectual Disability Health Service (SAIDHS) is developing partnerships with paediatric health care providers to support transition of care to adult services.
- The Health Pathways Resource developed by Adelaide PHN has SAIDHS referral pathways information embedded to assist clinicians direct their patients to appropriate providers and resources.
- Individuals and carers of people with intellectual disability in South Australia have access to resources via the SAIDHS website which provide information to assist with finding a GP. These resources are available to people who may not require specialist care through SAIDHS.

### **Spotlight: Medicare Benefits Schedule – permanent telehealth items**

As part of the response to the COVID-19 pandemic, the Australian Government expanded access to telehealth in March 2020 through temporary MBS telehealth items. As of 1 January 2022, MBS telehealth arrangements became ongoing, with more than 200 telehealth services being made permanently available.

The permanent telehealth arrangements provide a wide range of telephone and video services that support chronic disease management, autism, pervasive developmental disorder and disability.

DHAC continues to support the ongoing monitoring and review of telehealth, including the work of the MBS Review Advisory Committee (MRAC). MRAC will monitor the use and impact of permanent telehealth arrangements for both patients and practitioners over the next 12 months and provide advice for Government consideration of future and ongoing arrangements.



## 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

### Completed action

- CID, PHNs, other experts to work together as part of the PCEP to develop resources to improve health professionals' knowledge of the NDIS, disability support arrangements and referral options to appropriate services.
- NDIS Quality and Safeguards Commission to review and update NDIS Practice Standards and Quality Indicators, where appropriate, to support healthy lifestyles and optimal access to health services for people with intellectual disability.
- NDIS Quality and Safeguards Commission to include in its Workforce Capability Framework a strong focus on the role of the disability workforce in supporting healthy lifestyles and access to health services.

Highlights of activities being undertaken to deliver Element B4 include:

- DHAC engages Diabetes Australia to administer the National Diabetes Services Scheme (NDSS). Relevant activities under the NDSS targeting people with disability and diabetes included updating the resource *Effective communication with people who have an intellectual disability about their diabetes*, and resources to assist people with intellectual disability and diabetes and their carers, including information about living a healthy life with diabetes, resources supporting consultation with a health professional about diabetes, animated videos about diabetes, and videos about healthy eating.

- DHAC is delivering and redesigning the Quality Use of Diagnostics, Therapeutics and Pathology (QUDTP) Program, which provides funding to improve the way medicines and medical tests are prescribed and used, and contributes to the implementation of Australia's National Medicines Policy and the National Strategy for Quality Use of Medicines (QUM). From 1 January 2023, the Australian Commission on Safety and Quality in Health Care (ACSQHC) will take on stewardship for QUM and other functions to support the Program, leveraging the ACSQHC's expertise and system-wide reach.
- The National Disability Insurance Agency (NDIA) is committed to increasing the number of Health Liaison Officers in hospitals and providing induction and training in the new streamlined NDIS process to assist timely and safe discharge of NDIS participants, including those with intellectual disability.
- Health authorities in Queensland have employed nursing or allied health professionals to support people with disability in navigating health services. In Western Australia, Health authorities have employed Occupational Therapists and Social Workers to lead the integration of health and disability service provision.
- The Northern Territory Disability Action Plan includes actions to improve the health-disability service interface, including reviewing roles that connect people with intellectual disability with health services in remote and urban regions.
- CID, through their work on the PCEP, created a suite of clinical and practical resources for health professionals to assist them when working with people with intellectual disability. These include information relating to the NDIS, for example writing reports and providing evidence for the NDIS, and considerations for using telemedicine for a person with intellectual disability.
- In Queensland, the Metro North Hospital and Health Service trialled a Behavioural Emergency Response Team (BERT), with the potential to provide in-reach to supported accommodation for people with complex or challenging behaviours.
- In South Australia, SAIDHS have established a working relationship with the local area coordinators to support NDIS participants to access appropriate services for their needs.

### **Spotlight: Australian Commission on Safety and Quality in Health Care – psychotropic medication clinical care standard**

The Australian Commission on Safety and Quality in Health Care (ACSQHC) has commenced the development of a clinical care standard as part of the implementation of the *Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People*. The [joint statement](#) was released in March 2022 by the ACSQHC, the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission, and addresses the important issue of inappropriate use of psychotropic medicines with people with disability (including people with intellectual disability) and older people as a form of restrictive practice.

# Element C Models of 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 LGBTI.

## Progress

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

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

## Completed action

DHAC to consult on establishing a National Centre of Excellence in Intellectual Disability Health that leads research in intellectual disability health, synthesises and disseminates research, and supports the translation of research findings into practice.

Highlights of activities being undertaken to deliver Element C include:

- DHAC is delivering a number of projects that relate to education and training of health professionals, including PCEP and the Curriculum Development Project.
  - PCEP training and resources are being promoted and delivered to health professionals in four PHN regions.
  - The Department is working closely with PCEP stakeholders to ensure the project is on track and responding appropriately to the needs of health professionals and people with intellectual disability. During 2022 DHAC engaged an external evaluator for the PCEP to assess the effectiveness of the pilot.
  - The Curriculum Development Project aims to support universities and accreditation authorities to provide the knowledge, skills and attitudes for health professionals to better meet the care needs of people with intellectual disability.
  - Work to date includes design of an Intellectual Disability Health Capability Framework, and a scoping and gap analysis study by the University of Queensland into pre-registration education on intellectual disability health.

- DHAC has established an Intellectual Disability Health Education and Training Expert Advisory Group to provide expert advice and guidance on the implementation of education and training actions under the Roadmap.
- The Australian Government has provided funding for the Chair of Intellectual Disability Mental Health at the University of New South Wales to build mental health workforce capacity to meet the specific needs of people with intellectual disability.
- The NSW Agency for Clinical Innovation continues to develop and implement the *Essentials*, a resource for building capacity in health services to provide high quality care to people with intellectual disability across New South Wales.
- 3DN has produced an e-learning platform for health professionals on how to provide better mental health care to people with intellectual disability. This includes modules on communication, consent, privacy, decision making, identifying and responding to abuse and neglect, and behaviours of concern.
- “Every Nurse’s Business”, a free online education program building the capacity of nurses to deliver health services to people with Intellectual Disability and Autism Spectrum Disorder, funded by the NDIS ILC grants scheme, has been developed by Southern Cross and Western Sydney Universities with an advisory group of carers and people with lived experience, in partnership with the Australian Nursing and Midwifery Federation, Australian College of Critical Care Nurses, Australian Primary Health Care Nurses Association, Professional Association of Nurses in Developmental Disability Australia, College of Emergency Nursing, and University of New South Wales.
- 3DN and the Royal Australian and New Zealand College of Psychiatrists have collaborated toward development of a Certificate of Advanced Training in intellectual disability for trainee psychiatrists.
- NSW Ministry of Health collaborated with UNSW and Flinders University to develop the NSW Health Sexual Assault Services and New Street Services Access Strategy for People with Disability 2021-2025, which has included the creation of a Co-Design Advisory Committee of which there are four members with intellectual or cognitive disability.
- In Western Australia, service guidelines and service delivery measures are being implemented to improve accessibility of health services for people with intellectual disability including revision of the Hospital Stay Guidelines.
- The RACP has developed an online learning resource, featuring topics such as communication (including reasonable adjustments), informed consent and decision making, and violence, abuse, neglect and exploitation of people with intellectual disability.
- The RACP has also approved specialist training positions in intellectual disability health.

## Spotlight: National Centre of Excellence in Intellectual Disability Health

DHAC has responsibility for delivering the National Centre of Excellence in Intellectual Disability Health. In 2021-22, scoping and co-design of options for the National Centre was undertaken by DHAC in collaboration with clinical and academic experts, intellectual disability advocacy organisations, people with lived experience and carers, state and territory health departments, and existing specialised intellectual disability health services. The scoping and co-design work was led by Nous Group. The final report by Nous Group on the outcomes of the scoping and co-design was formally accepted by DHAC on 7 March 2022.

In the October 2022 Budget, the Australian Government announced funding of \$15.9 million, making a total commitment of \$23.9 million over 4 years from 2022-23 for the National Centre. Funding will continue beyond those 4 years.

The National Centre will, as part of its core functions, establish a central hub of expertise, resources and research in the health care of people with intellectual disability and information for people with intellectual disability and their families.

The core functions will also include:

- lifting the capability of health services in meeting the needs of people with intellectual disability through:
  - development of clinical reference material and training programs and resources
  - disseminating best practice models of health care and learnings about how to improve mainstream health services, and
  - providing a mechanism for supporting access to clinical expertise in intellectual disability health in states that do not have specialised intellectual disability health services.
- providing online support, including an online portal to help connect people with intellectual disability to appropriate health services, and providing health resources and information for people with intellectual disability and their families.

DHAC will undertake a competitive grant process in 2022-23 to select and fund a consortium to establish and operate the National Centre.



# 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
- 4 actions are in progress
- 10 actions are not commenced

Highlights of activities being undertaken to deliver Element D include:

- The RIGG has discussed the oral health actions in the Roadmap and recommended priorities.
- DHAC has commenced the Fifth Review of the *Dental Benefits Act 2008*. The Review Panel is considering uptake of the Child Dental Benefit Scheme by children with intellectual disability. The Review Panel is expected to provide its final report to the Minister in the first quarter of 2023.
- Queensland Health has established a dental program for patients with complex needs that operates from the Oral Health Centre in Brisbane with referral from community clinics. The Oral Health Centre and the University of Queensland School of Dentistry offers post graduate special needs training programs.
- NSW Health has commenced the 'Improving the Oral Health of People with Disabilities' project, which was developed in consultation with key stakeholders, carers of children and adults with disability. The project aims is to improve health literacy and oral health information to enable carers to support those in their care. Supporting resources have been developed in an accessible format.
- In South Australia, SAIDHS works closely with Special Needs Dental Unit to develop referral pathways for consumers to access to appropriate oral care needs.
- Western Australia Health is promoting new publications to assist patients to access care.

## Spotlight: PHN promotion of oral health training materials to non-dental health professionals

PHNs have engaged in a range of activities to promote the oral health of people with intellectual disability targeted at non-dental health professionals, in acknowledgement of the role that primary health care professionals play in oral health interventions. Some of the activities include:

- Central Queensland Wide Bay Sunshine Coast PHN:
  - has engaged a special needs dentist/educator as a member of their PCEP Advisory Group
  - is collaborating with a special needs dentist to localise referral pathways and PCEP resources
- Primary Health Tasmania PHN is:
  - promoting CID resources (which include oral health information) to peak bodies, general practice and state health services, and has resources on their website
  - incorporating oral health into information sessions to raise awareness of the importance of oral health for people with intellectual disability
- Western Victoria PHN is:
  - hosting webinars for primary health professionals targeting oral health as part of holistic health and wellbeing for people with lived experience
  - working with stakeholders on various oral health resources and disseminating and promoting resources in networks
  - presenting on special needs dentistry to the Intellectual Disability Stakeholder Group (through the PCEP SPIDAH project)
  - collaborating with interstate professionals for potential future trials such as state-wide dental vans to deliver services and oral health promotion
- Central Eastern Sydney PHN is:
  - embedding oral health content in CPD and in-practice training
  - establishing service navigation to relevant community and specialist oral health services





# 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
- 7 actions are in progress
- 1 action is not commenced

Highlights of activities being undertaken to deliver Element E include:

- The Commonwealth, states and territories and stakeholders in the disability sector are working together to establish the National Disability Data Asset (NDDA) to improve inclusion and opportunity for people living with disability in Australia. In 2022 this has included work to progress the design of the NDDA, including the design of governance arrangements. One of the first three national priority areas for data sharing, linkage and analysis is health outcomes for people with disability.
- The *Culture is Inclusion – First Nations-Disability Data Scoping Study*, led by the First Peoples Disability Network Dr Scott Avery, an esteemed Worimi scholar from Western Sydney University, aims to build a profile on the prevalence of disability in the Aboriginal and Torres Strait Islander population and will contribute to the NDDA.
- Data linkage
  - DHAC, in collaboration with DSS, people with lived experience and disability stakeholders, is leading the integration of Commonwealth and jurisdictional data sets on mortality, hospitalisations and ICU admissions.
  - The 2018 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) has been linked to the Multi-agency Data Integration Project (MADIP) providing potential rich insights about support needs of people with disability, older people and their carers. NDIS data for active scheme participants has also been linked to the MADIP. This allows analysis of the service use and sociodemographic characteristics of in-scope NDIS participants.
  - The Australian Institute of Health and Wellbeing (AIHW) also supported the NDIS Commission in ongoing access and use of these linked data to facilitate their research and indicator development in relation to mortality.

- The ABS manages the statistical *Standard for Severity of Disability* 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.
- DSS is funding the AIHW to report on progress against outcome framework indicators from *Australian Disability Strategy 2021-31*, which includes a specific set of health and wellbeing outcome measures. AIHW will produce an annual report and will update data quarterly.
- The AIHW has provided expert advice to DHAC on potential options for introducing disability identifiers, including sub-groups like people with intellectual disability, to data collections related to primary health care and infectious disease surveillance.
- Health authorities in New South Wales and Queensland have worked toward developing patient experience surveys to better capture the experiences of people with intellectual disability.

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

In 2021 the National Health and Medical Research Council opened a Targeted Call for Research for improving the health of people with intellectual disability. The purpose of the program is to develop the evidence base for future policies, interventions and other initiatives that will improve the long-term health outcomes and quality of life of people with intellectual disability.

Following peer review by an expert panel, on 21 October 2022 four projects were announced as successful:

- Dr Catherine Franklin (University of Queensland) – *Bridge to Better Health: A Cluster Randomised Controlled Trial for Capacity Building in Intellectual Disability Health for General Practice*
- Dr Elizabeth Palmer (University of New South Wales) – *GeneEQUAL: equitable and accessible genomic healthcare for people with intellectual disability*
- Assoc Prof Jenny Downs (University of New South Wales) – *Reducing potentially preventable hospitalisations and building health literacy for children and adolescents with intellectual disability*
- Professor Sandra Eades (University of Melbourne) – *Equitable access to health and disability services for Aboriginal and Torres Strait Islander children with intellectual 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.

## Progress

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

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

Highlights of activities being undertaken to deliver Element F include:

- Commonwealth, state and territory health departments developed targeted advice for people with disability about the COVID-19 pandemic and made information about the COVID-19 pandemic available in accessible formats.
- People with disability at heightened risk from COVID-19 were included in:
  - Australian Technical Advisory Group on Immunisation advice on COVID-19 vaccines, and
  - Pharmaceutical Benefits Scheme eligibility criteria for COVID-19 oral treatments.
- Governments formally recognised disability support workers as an essential workforce, such as through explicit mention of disability support workers in isolation rules, exempting them from restrictions to enter premises where a COVID-19 positive person was in mandatory isolation due to the essential nature of the supports provided.
- New South Wales:
  - implemented of the High-Risk Setting Pandemic Payment for eligible workers including members of the disability workforce
  - provided targeted communications of timely advice for disability providers through COVID-19
  - engaged with provider peaks and unions for advice on resources to support outbreak management and provision of COVID-19 Chief Health Officer advice to the disability sector.
- DSS partnered with Inclusion Australia and led a text message communication campaign to more than one million Disability Support Pension and carer payment recipients on the fourth dose and anti-viral medication.

- National Disability Services has collated resources in an Emergency Hub that can be shared with providers. Resources include NDS and specialist tools, and links to emergency services related tools. Specific COVID outbreak and prevention tools are continually revised and updated to meet current contexts.
- Deployments of supplies from DHAC through the National Medical Stockpile (NMS) focused on supporting frontline health workers to ensure the continuation of care, and support priority populations, including First Nations people and the aged care and disability sectors.
- The NMS supported people with disability and their support workers through the provision of Personal Protective Equipment (PPE) when it could not be sourced commercially. The NMS also provided rapid antigen tests (RATs) to a range of stakeholders, including those participating in the NDIS Supported Independent Living program.
- DHAC has also provided online COVID-19 infection control training targeted at a range of care workers, including disability support workers.
- In South Australia, the Local Health Networks maintain a vulnerable communities register to identify patients that may need support in the event of an emergency.



## **Spotlight: Establishment of the Health Emergency Response to COVID-19 for People with Disability and the Disability Health Sector Consultation Committee (DHSCC)**

The Australian Government regularly engages with intellectual disability organisations and other stakeholders (including representatives of the disability support sector) on the needs of people with intellectual disability in the context of the COVID-19 pandemic. The primary forums for this engagement are the Advisory Committee on the Health Emergency Response to COVID-19 for People with Disability (Advisory Committee) and the Disability and Health Sector Consultation Committee (DHSCC). State and territory governments also participate in these forums.

The Advisory Committee was stood up to provide advice on the health needs of people with disability, their families and disability service sector during the pandemic. The Advisory Committee continues to meet regularly.

The Advisory Committee and its Communications Working Group includes representation from CID.

In addition to developing a range of tailored guidance materials for people with intellectual disability and their supporters, DHAC has hosted six webinars tailored to people with disability and their carers, as well as 178 webinars for the health sector.

The Advisory Committee, or a similar body, will be an enduring feature of the Government's health emergency response for people with disability. This forum will be retained, ready to be 'activated' in an emergency. The nature and extent of the ongoing arrangements will be designed in collaboration with people with disability and their representative organisations.

DHAC has engaged Nous Group to develop an independent report on the lessons the Advisory Committee has learned throughout the COVID-19 pandemic. Publication of the report will be a decision for Government.

The DHSCC was established to provide a forum for:

- health and disability sector representatives
- health professionals, academic experts
- people with lived experience, and
- Commonwealth, state and territory government agencies.

The DHSCC meets quarterly and aims to discuss policy matters relating to health and disability support services for people with disability. Governance arrangements are shared between the Department of Health and Aged Care and the Department of Social Services.

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

## Introduction

DHAC is responsible for actions for the oversight and monitoring of the implementation of the Roadmap. These include establishing a governance group to:

- oversee the implementation of the Roadmap throughout its lifespan, and
- provide advice on implementation

The actions under Element G are ongoing for the duration of the Roadmap program.

## 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
  - Commonwealth 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.

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

## Completed action

DHAC to establish a governance group to provide oversight and monitor the implementation of the Roadmap.

Highlights of activities being undertaken to deliver Element G include:

- DHAC established the RIGG in November 2021. The RIGG oversees and advises on the implementation of the roadmap, including the prioritisation of actions for implementation.
- The 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
  - Commonwealth and state and territory government representatives.

The RIGG meets three times a year. The RIGG met four times during the reporting period: in November 2021, and in March, August and November 2022. Meetings included regular updates on the progress of the four Roadmap projects being delivered by DHAC.

RIGG meeting summaries are published on DHAC's website including in an Easy Read format.

### **Spotlight: Establishment of the Intellectual Disability Focus Group**

DHAC 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 Advisor, Disability and Health.

In August 2022, feedback from the Focus Group was sought on the draft of the Intellectual Disability Health Capability Framework for the Curriculum Development Project (see Element C). Input from the focus group was incorporated into the draft version of the Capability Framework that was released for public consultation in November 2022.

The Focus Group will continue to meet on an ad-hoc basis to provide input to the DHAC projects at key points in their delivery.



# Appendix A Organisations that provided input to this Report

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

## Commonwealth 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)  
Commonwealth Department of Education, Skills and Employment (DESE)  
Commonwealth Department of Health and Aged Care (DHAC)  
Commonwealth Department of Social Services (DSS)  
National Disability Insurance Agency (NDIA)  
NDIS Quality and Safeguards Commission (NDIS Commission)

## Advocacy and professional organisations

Australian and New Zealand Academy of Special Needs Dentistry  
Council for Intellectual Disability (CID)  
Department of Developmental Disability Neuropsychiatry UNSW (3DN)  
Down Syndrome Australia  
First Peoples Disability Network  
Health Professions Accreditation Collaborative Forum  
National Disability Services (NDS)  
Professional Association of Nurses in Developmental Disability, Australia (PANDDA)  
Queenslanders with Disability Network  
Royal Australasian College of Physicians (RACP)

## State and territory health agencies:

NSW Ministry of Health  
Northern Territory Department of Health  
Queensland Department of Health  
South Australian Department of Health and Wellbeing  
Western Australia Department of Health



## Primary Health Networks (PHNs)

Adelaide PHN

Brisbane North PHN

Capital Health Network - Australian Capital Territory PHN

Central and Eastern Sydney PHN

Central Queensland, Wide Bay, Sunshine Coast PHN

Coordinare - South Eastern NSW PHN

Country South Australia PHN

Darling Downs and West Moreton PHN

Gippsland PHN

Healthy North Coast – North Coast PHN

North Western Melbourne PHN

Primary Health Tasmania PHN

Rural Workforce Agency Northern Territory – Northern Territory PHN

South Western Sydney PHN

Sydney North Health Network - Northern Sydney PHN

WentWest - Western Sydney PHN

Western Australia Primary Health Alliance – Perth North, Perth South, Country WA (PHN)

Western NSW PHN

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
AIHW	Australian Institute of Health and Welfare
CHAP	Comprehensive Health Assessment Program
CID	NSW Council for Intellectual Disability
CPD	Continuing Professional Development
DHAC	Commonwealth Department of Health and Aged Care
DSS	Commonwealth Department of Social Services
FDSV	Family, domestic and sexual violence
GP	General Practitioner
ILC	Information, Linkages and Capacity Building
LGBTI	Lesbian, gay, bisexual, transgender and intersex people
MBS	Medical Benefits Schedule
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
PANDDA	The Professional Association of Nurses in Developmental Disability Australia Inc
PCEP	Primary Care Enhancement Program
PHN	Primary Health Network
PPE	Personal Protective Equipment
RACP	Royal Australian College of Physicians
RIGG	Roadmap Implementation Governance Group
Roadmap	National Roadmap for Improving the Health of People with Intellectual Disability

