



Australian Government  
Department of Health

# National Roadmap

for Improving the Health of  
People with Intellectual Disability

July 2021



## Copyright

© 2021 Commonwealth of Australia as represented by the Department of Health.

This work is copyright. You may copy, print, download, display and reproduce the whole or part of this work in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation:

- (a) do not use the copy or reproduction for any commercial purpose; and
- (b) retain this copyright notice and all disclaimer notices as part of that copy or reproduction.

Apart from rights as permitted by the Copyright Act 1968 (Cth) or allowed by this copyright notice, all other rights are reserved, including (but not limited to) all commercial rights.

Requests and inquiries concerning reproduction and other rights to use are to be sent to the Communication Branch, Department of Health, GPO Box 9848, Canberra ACT 2601, or via e-mail to [copyright@health.gov.au](mailto:copyright@health.gov.au).

# Foreword

People with intellectual disability and their families and carers deserve access to high quality health care that meets their needs and supports them to lead healthy and active lives. The National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap) is a landmark document that puts people with intellectual disability at the centre of the reform process and sets out a comprehensive range of actions to improve their health outcomes. It will form part of the Primary Health Care 10 Year Plan, which is currently under development.

The Roadmap is the culmination of a series of consultations with a broad range of stakeholders, held between August 2019 and March 2021. In this process, the Department of Health consulted: people with intellectual disability; family members and other carers; advocacy organisations; clinicians and researchers; peak bodies; universities; disability service providers; state and territory health and disability agencies; other relevant Commonwealth agencies; and a number of health professional regulatory bodies, boards and councils.

The Australian Government greatly appreciates the commitment and participation of these stakeholders in developing the Roadmap.

The Australian Government is also very conscious of the issues about the health system that have been raised in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The Australian Government is committed to taking action to improve the health of people with disability, particularly people with intellectual disability.

In recognition of the need for urgent and targeted action, the Australian Government has invested \$12.7 million through the 2021-22 Budget to implement priority actions under the Roadmap to:

- promote the uptake of annual health assessments for people with disability, using best practice assessment tools;
- improve tertiary education curricula for health professionals so they are better equipped with the knowledge and skills they need to provide high quality care to people with intellectual disability; and
- scope a model for a new National Centre of Excellence in Intellectual Disability Health that provides national leadership on the health care of people with intellectual disability, and can be a central hub of expertise and resources for all health and disability service providers across the country.

These initiatives build on the Primary Care Enhancement Program that is being implemented in four Primary Health Network (PHN) regions: Central and Eastern Sydney; Central Queensland, Wide Bay, Sunshine Coast; Western Victoria; and Tasmania. The Council for Intellectual Disability, who have been critical to the development of this plan, and the PHNs, are developing materials and supports for general practices to help them better engage with and care for people with intellectual disability.

I look forward to working with everyone involved to ensure the vision and actions outlined in this document are achieved, resulting in real and positive changes in health outcomes for Australians with intellectual disability.

**The Hon Greg Hunt MP**

**Minister for Health and Aged Care**

# Contents

Foreword.....	iii
Executive Summary.....	v
Glossary and List of Abbreviations.....	vi
Introduction .....	1
National Roadmap at a glance .....	4
A. Improved support for people with intellectual disability and their families and carers .....	6
B. Models of care for people with intellectual disability .....	9
B1. Developing better models of health care.....	9
B2. Better use of existing MBS items.....	12
B3. Continuity of care, care coordination and integration within the health system. ....	13
B4. Better coordination with other sectors .....	16
C. Support for health care professionals to provide better care for people with intellectual disability .....	18
D. Improving oral health for people with intellectual disability .....	22
E. Research, data and measurement to support continuing improvement.....	25
F. Emergency preparedness and response.....	27
G. Arrangements for oversight, monitoring and implementation of the National Roadmap.....	30

# Executive Summary

Approximately 450,000 people, or 1.8 per cent of the Australian population, have intellectual disability.<sup>1</sup> Compared with the general population, people with intellectual disability experience:<sup>2</sup>

- more than twice the rate of avoidable deaths;
- twice the rate of emergency department and hospital admissions;
- substantially higher rates of physical and mental health conditions;
- significantly lower rates of preventative healthcare.

It is critical that collaborative action is taken to address these health inequities. Australia is a signatory to the Convention on the Rights of Persons with Disabilities. Article 25 of the Convention states:

*‘Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability...’*

The National Roadmap sets out a vision for a targeted set of reforms across the health system to ensure that it meets the needs of people with intellectual disability in an integrated and holistic way, to improve their health outcomes. The actions outlined in the Roadmap will help develop a health system in which people with intellectual disability are valued and respected and have access to high quality, timely and comprehensive health care that supports them to attain the best possible health outcomes across the course of their lives.

The key objectives of the Roadmap are to:

- improve support for people with intellectual disability, their families and carers,
- develop better models of care for people with intellectual disability,
- provide support for health professionals to help them deliver quality care for people with intellectual disability,
- improve the oral health of people with intellectual disability, as a central requirement for improving their general health and overall wellbeing,
- strengthen research, data and measurement to monitor the health outcomes of people with intellectual disability, and assess the effectiveness of initiatives in improving their health, and
- improve emergency preparedness and response to ensure that the needs of people with intellectual disability are considered and met.

The Roadmap has a strong focus on strengthening the communication between health professionals and people with intellectual disability. This will help ensure that people with intellectual disability are empowered to make more informed and better supported decisions about their health care, in consultation with health care providers. The delivery of person-centred, trauma-informed and multidisciplinary models of care are emphasised throughout the Roadmap.

An extensive consultation process was undertaken to develop the Roadmap. The actions prioritised in the Roadmap lay out an ambitious but necessary agenda for improving the health of people with intellectual disability. Implementing many of these actions will require significant commitment and cooperation from the Commonwealth, state and territory governments, educational institutions, health care providers and professionals, and other stakeholders.

Importantly, it will require engagement directly with people with intellectual disability, their families and carers, and support workers.

The Commonwealth Department of Health will establish a governance group that includes health and disability sector stakeholders, to oversee and provide advice on implementation of the Roadmap throughout its lifespan.

---

1 Australian Institute of Health and Welfare (2003). Disability Prevalence and Trends. Available at: <https://www.aihw.gov.au/reports/dis/34/disability-prevalence-and-trends/formats>

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

# Glossary and List of Abbreviations

## Allied health professionals

University educated professionals who work autonomously and use evidence-based practices to prevent, diagnose and treat various conditions and illnesses. They often work in multidisciplinary health teams to provide specialised support to suit an individual's needs, and may use technicians, assistants or support workers to implement part of their treatment plan for the client.

## ABS

Australian Bureau of Statistics

## ACSQHC

Australian Commission on Safety and Quality in Health Care

## AIHW

Australian Institute of Health Welfare

## ASSCID

Australian Society of Special Care in Dentistry

## Carer

For the purposes of this, a carer is defined as someone who gives unpaid care and support to a relative or friend who has intellectual disability.

## CHAP

Comprehensive Health Assessment Program

## COVID-19

The disease caused by a new strain of coronavirus. 'CO' stands for corona, 'VI' for virus, and 'D' for disease. Formerly, this disease was referred to as '2019 novel coronavirus' or '2019-nCoV'.

## Disability Royal Commission

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

## Disability service provider

A person, business or organisation who delivers disability services.

## Disability supports

Assistance or products that help a person with disability in their daily life and help them participate in the community and reach their goals.

## Disability support worker

A disability support worker is anyone who is employed or otherwise engaged to provide disability supports and services to people with disability.

## **DSS**

Commonwealth Department of Social Services

## **Easy read**

Easy Read uses clear, everyday language matched with images to make sure everyone understands. Easy Read documents help to reach people with disability, including people with intellectual disability; people with English as a second language; and people with lower literacy levels.

## **NDDA**

National Disability Data Asset

## **NDIA**

National Disability Insurance Agency

## **NDIS**

National Disability Insurance Scheme

## **NDIS Commission**

NDIS Quality and Safeguards Commission

## **PCEP**

Primary Care Enhancement Program for people with intellectual disability

## **PHN**

Primary Health Network

## **Supported accommodation**

Supported accommodation refers to housing that provides in-home support and a higher level of care for people with particular needs. This includes supported independent living, specialist disability accommodation, medium term accommodation, short term accommodation, amongst other congregate residential settings.

## **Support worker**

See above definition under 'Disability support worker'.

## **Trauma-informed**

Services or care that do no harm i.e. they do not re-traumatise or blame victims for their efforts to manage their traumatic reactions, and they embrace a message of hope and optimism that recovery is possible.



# Introduction

## Defining intellectual disability and the scope of the Roadmap

Intellectual disability is traditionally seen as a form of developmental disability characterised by impaired cognitive abilities and reduced ability to manage common demands of day-to-day life (adaptive functioning). A person with intellectual disability may have difficulty with thinking skills that impact planning, problem solving, abstract thinking and learning. They may also experience difficulties with communication, social skills and independently managing daily activities.<sup>3</sup>

The Roadmap specifically includes the following groups of people, in addition to people with an established diagnosis of intellectual disability:

- people who have a suspected intellectual disability, but have not had a formal assessment and diagnosis;
- people with autism and/or other developmental disabilities who also have intellectual disability.

This approach recognises that health challenges are prevalent among people across the intellectual disability spectrum. It is also based on evidence that shows that a significant proportion of people with intellectual disability have not had a formal assessment of their disability, and that this may have negative implications for their health.

## The human rights context

The United Nations Convention on the Rights of Persons with Disabilities (ratified by Australia in 2008) recognises ‘that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’.<sup>4</sup>

Article 25 of the Convention states that people with disability have ‘the right to the enjoyment of the highest attainable standard of health without discrimination’.<sup>5</sup>

Article 3 emphasises the rights of people with disability to respect for their inherent dignity and autonomy including the freedom to make their own choices.

The Constitution of the World Health Organization, of which Australia is a founding member, recognises that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.<sup>6</sup>

3 Trollor, J. (2020). Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, dated 11 February 2020. Available at: <https://disability.royalcommission.gov.au/system/files/exhibit/STAT.0049.0001.0001.pdf>

4 UN Convention on the Rights of Persons with Disabilities. Available (including Easy Read) at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

5 Ibid, pg. 18

6 Constitution of the World Health Organization, pg 1. Available at: <https://www.who.int/about/who-we-are/constitution>



## The National Roadmap as part of the Primary Health Care 10 Year Plan

Under its Long Term National Health Plan, the Australian Government has committed to developing and implementing the Primary Health Care 10 Year Plan, designed to make primary health care more patient-focused, accessible and integrated, and better able to provide preventive health and management of chronic conditions.

The 10 Year Plan will include reforms to address the challenges facing the health system. It acknowledges that more needs to be done to improve access to timely, affordable and accessible health care, including for rural and remote communities, Aboriginal and Torres Strait Islander people and communities, people with diverse backgrounds and lived experiences, people with disability, older people and hard to reach and at-risk groups.

The Roadmap forms part of the Primary Health Care 10 Year Plan. While the actions prioritised throughout the Roadmap focus predominantly on improving primary health care for people with intellectual disability, many also target improvements that can be made across the health and disability systems. This recognises the need for action across systems, across levels of government, and in the interaction between systems, in order to improve the health outcomes of people with intellectual disability.

## Consultations in developing and implementing the Roadmap

An initial roundtable was held on 2 August 2019, which developed a first draft outline of the Roadmap.

A second roundtable was scheduled for April 2020, but was delayed because of the COVID-19 pandemic.

A series of consultations, roundtables and targeted group discussions were held between 2 November 2020 and 31 March 2021 to inform the further development of the Roadmap. An online questionnaire was also circulated to roundtable participants to identify issues that needed to be addressed.

Groups and organisations consulted included:

- people with intellectual disability;
- family members and carers of people with intellectual disability;
- intellectual disability advocacy organisations;
- clinical and academic experts;
- peak medical, nursing, allied health, oral health and pharmacy organisations;
- universities;
- disability service provider organisations;
- state and territory health and disability agencies;
- Primary Health Networks;
- the National Disability Insurance Agency (NDIA);
- the NDIS Quality and Safeguards Commission (NDIS Commission);
- the Department of Social Services;
- the Australian Commission on Safety and Quality in Healthcare;
- some health professional regulatory bodies, boards and councils.

The Roadmap has been informed by the recommendations and proposed actions put forward during the consultation process.<sup>7</sup>

A final roundtable was held on 31 March 2021 to consider the draft Roadmap.

---

<sup>7</sup> While the initial outline of the Roadmap identified each component for implementation within the short term (1-2 years), medium term (3-5 years), or long term (6-10 years), these were adjusted to align with the timeframes outlined at the time in the Primary Health Care 10 Year Plan. Short term is now defined as within 1-3 years; medium term is now defined as within 4-6 years; and longer term is now defined as within 7-10 years. The outline of the Roadmap also proposed single timeframes for implementing broad categories of activity. This approach has been revised, so that under each component of the Roadmap, proposed actions and priorities have been identified for the short, medium and longer term.

## Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission), was established in April 2019 in response to community concern about widespread reports of violence against, and the neglect, abuse and exploitation of, people with disability.

The Disability Royal Commission has held several health-related hearings to date. The Roadmap takes into consideration a range of issues that have been raised in these hearings and the associated reports.

The Disability Royal Commission is due to deliver a final report to the Australian Government by September 2023. The findings and recommendations from the final report will also be taken into consideration in the implementation of the Roadmap.

## The National Roadmap is an Associated Plan to Australia's Disability Strategy 2021-2031

The National Disability Strategy is the national disability policy framework under which all governments are working towards an inclusive society that ensures people with disability can fulfil their potential, as equal members of the community. It provides national leadership towards greater inclusion of people with disability, and guides activity across all areas of public policy to be responsive to people with disability. Under the Strategy, governments have committed to drive their mainstream services and systems to improve outcomes for people with disability.

The Roadmap is an Associated Plan to Australia's Disability Strategy 2021-2031, which is due to be released later this year. The Roadmap will also support health and wellbeing outcomes under the Strategy.

## Approach to Implementation of the Roadmap

In developing and implementing actions under the Roadmap, all parties should involve people with disability, their families and carers and, where appropriate, disability service providers and disability support workers, at each step.

Implementation of the Roadmap will be overseen by a governance group with representation from:

- 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.

Further information is provided under Element G – Arrangements for oversight, monitoring and implementation of the National Roadmap.

# National Roadmap at a glance\*

Short term (1-3 years)	Medium term (4-6 years)	Long term (7-10)	Desired outcomes
<b>A. Improved support for people with intellectual disability and their families and carers</b>			
<p><b>Develop</b> resources to improve health literacy and advocacy skills among people with intellectual disability, their families and carers.</p> <p><b>Support</b> people with intellectual disability to become advocates and health ambassadors.</p> <p><b>Develop</b> models of health navigators and disability liaison officers in health services.</p>	<p><b>Support</b> the active participation of people with intellectual disability as part of the multi-disciplinary team, including participation in decision-making and case-conferences.</p>		<p><b>People</b> with intellectual disability have improved health literacy and are supported, along with their families and carers, to make informed decisions about their health care in consultation with their health care providers.</p>
<b>B1. Developing models of health care</b>			
<p><b>Identify</b> and promote best-practice models of care, especially for transition to adulthood.</p> <p><b>Develop</b> tools for health professionals to support provision of reasonable adjustments and supported decision making.</p> <p><b>Develop</b> and implement best practice guidelines and clinical standards to support the needs of people with intellectual disability.</p>	<p><b>Refine</b> digital health solutions to better support digital communication among medical and other specialists, primary health care providers, and people with disability and their families.</p>	<p><b>Ensure</b> digital health technology supports best practice models of care for people with intellectual disability.</p>	<p><b>Better</b> models of care are developed that provide people with intellectual disability with quality health care that is person-centred, trauma-informed, and enables reasonable adjustments.</p>
<b>B2. Better use of existing MBS items</b>			
<p><b>Implement</b> measures to better promote the use of annual health assessments and other relevant MBS items to people with intellectual disability, their families, carers and support workers.</p> <p><b>Support</b> GPs, practice nurses, people with intellectual disability and their supporters to access and use the Comprehensive Health Assessment Program (CHAP) tool.</p>	<p><b>Measure</b> uptake of annual health assessments and evaluate measures to increase uptake.</p> <p><b>Review</b> and consider potential modifications to MBS items for people with intellectual disability.</p> <p><b>Consider</b> changes to primary health care funding models to support extra time doctors need to provide appropriate care for people with intellectual disability.</p>		<p><b>People</b> with intellectual disability regularly undertake annual health assessments which identify and action unmet health needs and promote good health.</p>
<b>B3. Continuity of care, and better care coordination and integration within the health system</b>			
<p><b>Continue</b> MBS telehealth access for general practice, allied health and specialist care.</p> <p><b>Promote</b> voluntary patient registration with general practice.</p> <p><b>Strengthen</b> connections between primary health networks, local hospital networks and local disability services including through development of care pathways for people with intellectual disability.</p> <p><b>Promote</b> better use of My Health Record by clinicians, and people with intellectual disability, their families, carers and disability support workers.</p> <p><b>Leverage</b> existing digital platforms and programs for health providers to promote the health of people with intellectual disability.</p>	<p><b>Promote</b> uptake of case-conferencing technology that facilitates multidisciplinary team-based care.</p> <p><b>Identify</b> ways of expanding local multidisciplinary intellectual disability health services.</p>		<p><b>The health</b> system is better integrated across all levels of care, allowing for more coordinated, multidisciplinary health care. People with intellectual disability have improved continuity of care, including across key transition periods.</p>
<b>B4. Better coordination with other sectors</b>			
<p><b>Develop</b> resources and pathways to connect health and disability services.</p> <p><b>Develop</b> resources and training to improve health literacy of disability support providers.</p> <p><b>Develop</b> best practice quality standards for prescribing psychotropic medication.</p> <p><b>Review</b> NDIS Practice Standards and Quality Indicators for updates to support healthy lifestyles and optimal access to health service.</p>	<p><b>Consider</b> funding models and options for better supporting NDIS participants' access to health services.</p> <p><b>Identify</b> opportunities to embed reforms that enable better coordination between the health and disability sectors in the next National Health Reform Agreement with states and territories.</p>		<p><b>The health</b> and disability systems have better linkages, supporting more effective communication and coordination between health care professionals, disability support providers and people with intellectual disability, their families and carers.</p>

Short term (1-3 years)	Medium term (4-6 years)	Long term (7-10)	Desired outcomes
<b>C. Better support for health care professionals to provide better care for people with intellectual disability</b>			
<p><b>Continue</b> to support roll-out of the Primary Care Enhancement Program (PCEP) which will provide greater support for primary health care professionals to provide more effective care to people with intellectual disability.</p> <p><b>Design</b> and develop intellectual disability competencies, curricula content, and tools and resources to develop health professionals' knowledge of intellectual disability and instil positive attitudes.</p> <p><b>Consult</b> on establishing a National Centre of Excellence in Intellectual Disability Health.</p>	<p><b>Embed</b> training and continuing professional development in medical, nursing and midwifery, allied health, oral health, and pharmacy training programs.</p> <p><b>Work</b> with states and territories to build on the proposed establishment of a National Centre of Excellence, by further developing a national network of specialised intellectual disability health services.</p>	<p><b>Work</b> with states and territories to expand the national network of specialised intellectual disability health services to ensure it supports people with intellectual disability living in every state and territory.</p>	<p><b>Health</b> care professionals have appropriate knowledge, skills and attitudes to provide quality, appropriate and disability-informed health care for people with intellectual disability.</p>
<b>D. Improving oral health for people with intellectual disability</b>			
<p><b>Promote</b> access to existing dental services including the Child Dental Benefits Schedule. Support implementation of 'hub and spoke' models of care in oral health.</p> <p><b>Expand</b> workforce training in oral health care for people with intellectual disability and develop professional development modules.</p> <p><b>Expand</b> oral health promotion to people with intellectual disability and their carers and support workers.</p>	<p><b>Consider</b> options for establishing an oral health data collection related to people with disability, including intellectual disability.</p> <p><b>Work</b> with peak oral health groups and states and territories to develop the National Oral Health Plan 2025-2035, with stronger data sharing arrangements.</p>		<p><b>People</b> with intellectual disability are supported to maintain dental/ oral hygiene as a vital preventive health measure; and their oral health care is integrated into general health care.</p>
<b>E. Research, data and measurement to support continuing improvement</b>			
<p><b>Examine</b> options for intellectual disability identifiers to be used that generate new data sets and can be linked with existing data sets and the proposed National Disability Data Asset.</p> <p><b>Develop</b> options for targeted national research that builds the evidence base on strategies to improve health outcomes for people with intellectual disability.</p> <p><b>Improve</b> data collection on the prevalence and impact of communicable diseases on people with intellectual disability.</p>	<p><b>Develop</b> national data asset that captures and routinely reports on health outcomes for people with intellectual disability.</p> <p><b>Work</b> with health care providers to adapt existing patient experience surveys to capture the experiences of people with intellectual disability throughout the patient journey.</p>	<p><b>Maintain</b> investment and focus on national, population based data collection and data linkage on the health of people with disability, to inform continuous improvement and further policy refinement and development.</p>	<p><b>Health</b> data on people with intellectual disability is routinely recorded and reported on at a national level, and evidence is used to drive improvements to health and health services.</p>
<b>F. Emergency preparedness and response</b>			
<p><b>Incorporate</b> learnings from Australia's COVID-19 response for people with disability into emergency planning and future emergency responses.</p> <p><b>Provide</b> greater clarity on Commonwealth, state and territory agency roles and responsibilities for responding to health emergencies for people with disability and the disability sector.</p>			<p><b>Emergency</b> preparedness planning and emergency responses consider the needs of people with intellectual disability, including tailored responses where appropriate.</p>

\*The short, medium, and long term actions in this table are a subset of all the actions in each element outlined in this Roadmap.



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

People with intellectual disability, their families and carers should be supported and empowered to access and make informed decisions about health care. Many people with intellectual disability have low health literacy, making it difficult for them to understand how and when to access health services, and to know which services will meet their needs. The task of coordinating health care and maintaining a complete health record often falls to families and carers, and it is a significant challenge.

***‘Everyone needs to understand that people with intellectual disability can have a good life. We need great health care and support to get it, [and to have] the same quality of life as everyone else.’***

Judy Huett, Roundtable on the Health of People with Intellectual Disability 31 March 2021

Health literacy and advocacy skills are essential for enabling people with intellectual disability, and their family and carers, to become informed consumers and to advocate for their needs. Public health communication must be available in formats suitable to the needs of people with intellectual disability such as plain language and Easy Read resources. Valuing and using the skills that families and carers have in understanding and advocating for the needs of people with intellectual disability will significantly improve their interactions with health services.

More discussion on health professionals communicating with people with intellectual disability is addressed in Element C – Support for health professionals to provide better care for people with intellectual disability.



## Desired Outcomes

1. 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.
2. Improved health and health systems literacy among people with intellectual disability, and their families and carers.
3. People with intellectual disability are better supported to navigate the health system and access appropriate health services.

## Key Actions

### Short Term (one to three years)

1. 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.
2. Commonwealth Department of Health to work with PHNs, the NDIA and other disability organisations to:
  - promote better use of My Health Record and other tools such as health passports, by people with intellectual disability, their families and carers, and disability support workers, to improve the coordination and delivery of care;
  - better promote mental health and reproductive health services to people with intellectual disability, and connect existing services to a National Centre of Excellence in Intellectual Disability Health (refer to Element C).
3. Commonwealth Department of Health to work with PHNs, professional colleges and disability advocacy organisations to ensure balanced, evidenced-based information about intellectual disability and related diagnosis (e.g. Down syndrome) is available to parents during the pre- and post-natal period.
4. Commonwealth Department of Health and Department of Social Services (DSS) to:
  - work with state and territory health departments and advocacy organisations to identify ways of supporting people with intellectual disability to be health ambassadors, promoting awareness of health and intellectual disability to health professionals, disability service providers and support workers, families, carers and other people with intellectual disability;
  - develop options for improving access to health advocacy services for people with intellectual disability, their families and carers, with a particular focus for people with limited capacity and skills to advocate in relation to health;
  - develop an inclusive guide to practice for health care providers, focusing on inclusive communication and other reasonable adjustments.
5. All government health authorities to routinely use formats such as plain language and Easy Read resources in health communications to support better communication with people with intellectual disability about health issues and health care. These should also be culturally appropriate for Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) communities.

6. State and territory governments to consider employing disability liaison officers in their health systems and developing best practice protocols for supporting people with intellectual disability, their families and carers.
7. Commonwealth Department of Health to work with PHNs to develop models for health system navigators to help guide and support people with intellectual disability with complex needs through the health system.

### **Down Syndrome Australia's Health Ambassador Program – Inclusive Communication**

Down Syndrome Australia's Health Ambassadors are a group of people with Down syndrome who inform others about how to communicate and include people with Down syndrome in their health conversations.

The Health Ambassador project takes a multifaceted approach including supporting people with Down syndrome to act as expert health ambassadors, developing communication, Down syndrome webinars and easy read health resources. This project will help to address gaps in communication and improve health professionals' skills in communicating with a person with Down syndrome.

### **Medium Term (four to six years)**

1. Commonwealth Department of Health to work with the Australian Digital Health Agency, states and territories, PHNs and other partners, to:
  - ensure people with intellectual disability, their family and carers are supported and empowered to access digital health solutions that enable better communication with medical and other specialists and primary health care providers;
  - explore the use of emerging technologies to reduce barriers to health care for people with intellectual disability.
2. Commonwealth Department of Health to work with states and territories, PHNs and other stakeholders to support the active participation of people with intellectual disability as part of the multidisciplinary health care team, including participation in decision-making and case-conferences where appropriate.





## **B. Models of care for people with intellectual disability**

### ***B1. Developing better models of health care***

The term ‘model of care’ broadly defines the way health services are delivered. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event.<sup>8</sup>

People with intellectual disability need timely, affordable and accessible health care that meets their needs across their lifespan, notably including the transition to adulthood. Models of care across the health system need to be built on person-centred, disability-integrated approaches, with decision making shared between health professionals, people with intellectual disability, their families and carers, and support workers. When health professionals listen to the needs of people with intellectual disability and make reasonable adjustments when delivering health care, patient experiences and health care outcomes are greatly improved.

***‘Treat us the same as everyone else. Give people more time and take the time to explain things properly and clearly. Be patient with people and be respectful.’***

Leonie McLean, Targeted Group Discussion 14 December 2020

<sup>8</sup> NSW Agency for Clinical Innovation (2013). Understanding the process to develop a Model of Care: An ACI Framework. [https://www.aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0009/181935/HS13-034\\_Framework-DevelopMoC\\_D7.pdf](https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0009/181935/HS13-034_Framework-DevelopMoC_D7.pdf)

Trauma-informed approaches are especially important for people with intellectual disability, many of whom have experienced neglect or abuse in their lives, and may have significant fear associated with health care interventions. Models of care may need to incorporate a range of reasonable adjustments to reduce distress and trauma, and ensure high-quality health care. This may include adapting communication methods, adjusting surroundings, taking additional time, and involving support people in care provision.

## Desired Outcomes

1. Better models of care are developed and implemented for children, youth, adults and older people with intellectual disability.
2. Transition points are considered and better managed.
3. Models of care are person-centred, trauma-informed, and incorporate reasonable adjustments.
4. 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.
5. Models of care include strategies to ensure good communication between health professionals and improve linkages between the health sector, the NDIS and other disability and social support services, including family where relevant.
6. Models of care are intersectional and tailored to meet the needs of people with intellectual disability in rural and remote areas and those with Aboriginal and Torres Strait Islander, CALD, and LGBTI backgrounds.

## Key Actions

### Short Term (one to three years)

1. Commonwealth Department of Health to work with state and territory governments, professional colleges, PHNs and researchers to identify and promote innovative and bestpractice, person-centred models of care and develop tools to support care for people with intellectual disability that leads to better health outcomes for people with intellectual disability and address:
  - care across the lifespan, including palliative care;
  - transition points across the lifespan, such as the transition to adulthood and preparation for that transition;
  - the health, wellbeing and support of carers;
  - health promotion, disease prevention and chronic disease management;
  - the specific needs of people with intellectual disability living in rural and remote areas, and those with Aboriginal and Torres Strait Islander, CALD and LGBTI backgrounds.
2. Commonwealth Department of Health to collaborate with the Australian Commission on Safety and Quality in Health Care to develop an Intellectual Disability Clinical Care Standard and review key policy documents to ensure they support the needs of people with intellectual disability of all ages, including:
  - the National Safety and Quality Primary Healthcare Standards, and
  - the National Safety and Quality Health Service Standards.
3. The Council for Intellectual Disability, PHNs and other experts to work together as part of the PCEP to adapt, develop and promote resources that support primary health care providers to plan for and implement reasonable adjustments to support people with intellectual disability in accessing and receiving health care.

**4.** Commonwealth Department of Health to:

- work with the Australian Digital Health Agency, states and territories, PHNs and other key partners, to refine digital health solutions to better support digital communication among health care providers across different settings and people with disability and their families and carers;
- work with states and territories to promote the Healthdirect Video Call Service for rural and remote patients as well as those patients who have difficulty leaving their residences.

### **Medium Term (four to six years)**

**1.** Commonwealth Department of Health to work with state and territory governments, professional colleges, PHNs, researchers and other key partners to improve the evidence base on integrating trauma-informed practice into models of care.

**2.** Commonwealth Department of Health to:

- identify ways of aligning work on better models of care with long-term reforms being trialled as part of the 2020-2025 National Health Reform Agreement;
- work with stakeholders to identify ways of increasing the number of funded, accredited training positions for physicians and psychiatrists specialising in the care of people with intellectual disability;
- explore options for promoting the use of home visit Medicare Benefits Schedule (MBS) items for people with intellectual disability (including visits to supported accommodation settings).

### **Long Term (seven to ten years)**

**1.** Commonwealth, state and territory governments to address the health needs of people with intellectual disability in future key strategies, plans, policies, initiatives, roadmaps and agreements. This includes the:

- Australia's Disability Strategy
- National Preventive Health Strategy
- National Oral Health Plan
- National Mental Health and Suicide Prevention Plan
- National Diabetes Strategy
- National Aboriginal and Torres Strait Islander Health Plan

## B2. Better use of existing MBS items

The MBS is a key component of the Medicare system. It lists a range of health services for which the Australian Government will pay a Medicare rebate, and provides patients with financial assistance towards the costs of these services.

*‘People with a disability can learn more about their overall health and maybe not have to rely on family as much... [The CHAP tool] helps people with a disability to have a better health care experience and plan’*

Person with intellectual disability, Targeted Group Discussion, 22 January 2021

There are a number of MBS items specifically relevant to people with intellectual disability, including annual health assessments. There is strong evidence demonstrating that annual health assessments are an effective way of identifying unmet health needs in people with intellectual disability.<sup>9</sup>

Promoting and supporting greater uptake of annual health assessments and other existing MBS items is critical for improving health outcomes for people with intellectual disability. Evidence-based tools that support this process, such as the Comprehensive Health Assessment Program (CHAP), should be readily available and accessible to GPs, practice nurses, disability service providers and support workers, families and carers. Responsibility for ensuring annual health assessments are completed should be shared across the health and disability sectors.

### Desired Outcomes

1. Increased use of annual health assessments and other MBS items for people with intellectual disability.
2. Increased use of the CHAP tool by GPs in providing health assessments to people with intellectual disability.<sup>10</sup>
3. 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).
4. 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.

### Key Actions

#### Short Term (one to three years)

1. Commonwealth Department of Health to:
  - implement measures to better promote annual health assessments and other relevant MBS items through health and disability networks, PHNs, professional colleges and associations, the NDIA and NDIS Quality and Safeguards Commission;
  - explore licensing options that support the incorporation of the CHAP tool into GP practice software;

9 Robertson, J., Hatton, C., Emerson, E., & Baines S. (2014). The impact of health checks for people with intellectual disabilities: An updated systematic review of evidence. *Research in Developmental Disabilities*, 35(10), 2450-2462.  
<http://dx.doi.org.ezproxy.library.uq.edu.au/10.1016/j.ridd.2014.06.007>

10 Disclaimer: Professor Nick Lennox, Medical Advisor for Disability and Health in the Primary Care Division, Department of Health, was involved in the development of the National Roadmap. He previously led a team which developed and trialled a health assessment tool, called the Comprehensive Health Assessment Program (CHAP). The CHAP has been commercialised by The University of Queensland's corporate arm, Uniquist. Revenue generated by this commercialisation is split in thirds with one third to Professor Lennox.

- develop resources, including Easy Read documents, that support people with intellectual disability and their families and carers to plan and prepare for annual health assessments;
  - establish a system for measuring the uptake of annual health assessments for people with intellectual disability (for example, through voluntary patient registration, re-establishment of a separate MBS item, or data linkage).
2. Commonwealth Department of Health to work with PHNs, the NDIA, NDIS Quality and Safeguards Commission, disability support providers and advocacy organisations to promote the uptake of annual health assessments. This should include exploring options that would require NDIS supported accommodation providers to facilitate all residents with intellectual disability being offered an annual health assessment.
  3. Commonwealth Department of Health, intellectual disability organisations, clinical experts, PHNs, and other health and disability stakeholders, to collaborate to develop training on the use of the CHAP tool that is suitable for GPs, practice nurses and disability support providers.
  4. PHNs explore options for promoting use of the CHAP tool through their Health Pathways program and other relevant activities.
  5. Department of Social Services, the NDIA and NDIS Commission to work with disability support providers on mechanisms for prompting people with intellectual disability, their families and carers to seek out and attend annual health assessments with their general practitioner or other care team.

### Medium Term (four to six years)

1. Commonwealth Department of Health to:
  - evaluate any measures put in place to increase the uptake of annual health assessments and the CHAP among GPs, with a view to implementing strategies to drive continuous improvement;
  - review existing MBS items that are relevant for people with intellectual disability and identify any possible modifications that could then be considered by government;
  - consider changes to primary health care funding models to support the extra time doctors need to provide appropriate person-centred care to people with intellectual disability.

## ***B3. Continuity of care, care coordination and integration within the health system***

### **Continuity of care**

Continuity of care is critically important for improving the health outcomes of people with intellectual disability. Strong relationships and partnerships between health professionals and people with intellectual disability, their families and carers can help health professionals better understand the unique needs of their patients, support them to deliver effective person-centred care, and coordinate multidisciplinary team-based approaches.

Health professionals also need to work with professionals in other key sectors that support people with intellectual disability (for example, disability and education).

The greater availability of telehealth services during the COVID-19 pandemic has allowed many people with intellectual disability to receive health care from home from their preferred practitioners. This supports continuity of care. However, face to face services remain a vital part of the service mix.

## Better care coordination and integration within the health system

In Australia, responsibilities for health are shared across the Commonwealth and state and territory governments. People with intellectual disability often need services from a wide range of health professionals, including GPs, medical specialists, nurses, oral health professionals, allied health professionals and pharmacists. This means the system is often complex to navigate, particularly for people with intellectual disability, but often also for their families, carers and support workers.

Most people with intellectual disability should be able to access mainstream health services. To improve the quality of care provided to people with intellectual disability, all health professionals involved in a person's care need to work as a multi-disciplinary team.

It is also important that care between specialist health services operating in some states and territories and mainstream services is well coordinated.

***‘In my experience the response of the health system to the care of people with [intellectual or developmental disability] remains patchy and fragmented, particularly in the context of adult health care... There is not yet systematic implementation of collaborative and integrated care, and other initiatives that can be expected to improve the health of people with [intellectual disability]...’***

Dr Jacqueline Small, Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 20 February 2020.

## Desired Outcomes

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

## Key Actions

### Short Term (one to three years)

1. Commonwealth Department of Health to:
  - promote voluntary patient registration to support people with intellectual disability registering with a general practice and nominating their preferred GP, and encourage continuity of care with that practice and GP. This would include the option for people to self-identify that they have an intellectual disability;
  - 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.



2. Commonwealth Department of Health to work with PHNs, states and territories and other relevant organisations to promote better use of My Health Record by clinicians, people with intellectual disability, their families and carers, including determining and implementing actions to ensure the My Health Record system is user friendly for people with intellectual disability.
3. State and territory governments to work with PHNs, researchers, advocates, and stakeholder organisations to develop tools for people with intellectual disability, their families, carers, support workers and health professionals, to support best practice clinical care pathways for people with intellectual disability.
4. PHNs to explore options for:
  - strengthening connections between primary health care providers, local hospital networks and other partner organisations to identify and implement ways of improving continuity and integration of care and health pathways for people with intellectual disability;
  - partnering with organisations and other stakeholders to incorporate mechanisms into referral pathways that alert receiving clinicians about reasonable adjustments for patients with intellectual disability ahead of time.

### Medium Term (four to six years)

1. Commonwealth Department of Health to work with states and territories, PHNs and other stakeholders to promote the uptake of case-conferencing technology that facilitates multidisciplinary team-based care for people with intellectual disability.

#### **Specialist Team for Intellectual Disability Sydney (STrIDeS) – Integrated Model of Care**

Sydney Local Health District has established a multidisciplinary team to enhance and extend its health care services for people with intellectual disability.

STrIDeS aims to better address the health needs of people with intellectual disability and improve their access to services through an integrated model of care.

STrIDeS provides:

- specialised advice, information and training to GP teams on management and care of a person with intellectual disability;
- information and advice on resources on intellectual disability;
- information for GP teams on health services;
- a multidisciplinary health assessment for eligible clients; and
- development of a Health Care Plan with recommendations for care by the clients GP or clinician.

STrIDeS was established as a result of a NSW State Government funding grant to expand specialised intellectual disability health services in New South Wales.



## **B4. Better coordination with other sectors**

The health and wellbeing of people with intellectual disability is influenced by a range of factors, including access to health care, disability support services, education, employment, and housing. Stronger coordination between sectors is needed to improve health outcomes for people with intellectual disability. In particular, health and disability providers need a better understanding of their respective roles, and more effective ways of communicating, to ensure people with intellectual disability achieve the best possible health outcomes. Disability liaison officers and nurse coordinators have been used at times to bridge the gaps between health and disability support services.

Disability service providers can play a key role in preventing ill health by promoting healthy lifestyles and initiating access to health services for people with intellectual disability. However, disability support workers do not always have the necessary health literacy or knowledge of the health system to support this approach. The disability sector also has a large proportion of casual workers, and some constraints on funding, that can make it difficult for disability support workers to facilitate access to health services on behalf of people with intellectual disability.

Many health professionals would benefit greatly from the expertise of people working in the disability sector, particularly on ways of communicating with and understanding the needs of people with intellectual disability.

Workers in both sectors need to collaborate to better understand, identify and respond to the causes of challenging behaviours, including physical or mental ill-health, in order to minimise the use of restrictive practices and better protect the human rights of people with intellectual disability.

***‘The disability support system [has a major role] in relation to supporting people to get the health care that they need, identifying early signs of health problems, promoting healthy lifestyles, supporting communication with the health professionals, supporting action on the health care professionals’ advice.’***

Jim Simpson, Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 20 February 2020.

## **Desired Outcomes**

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

# Key Actions

## Short Term (one to three years)

1. The Council for Intellectual Disability, PHNs and 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.
2. Commonwealth Department of Health to collaborate with:
  - key experts to develop resources and training that improves health literacy and health system literacy among disability service providers and disability support workers, and identify options for incorporating them into core modules of training programs (e.g. Certificate IV in Disability);
  - DSS, the NDIA, the NDIS Commission, state and territory governments, disability service provider and advocacy organisations, professional associations and people with intellectual disability, their families and carers to develop best practice guidelines and training for day-to-day preventive health supports for people with intellectual disability;
  - state and territory governments to ensure information on health services for people with intellectual disability is effectively shared throughout other key systems (e.g. justice and education systems);
  - states and territories, experts and stakeholders, to lead work on the development of minimum and best practice quality standards for medical practitioners prescribing psychotropic medication to people with intellectual disability, and actions to ensure these standards are met (including where medication is being used as a chemical restraint in NDIS funded disability services);
  - DSS to ensure nationally consistent language is used across the health and disability sectors. Clear definitions, including of roles and responsibilities, should be made available;
  - DSS, PHNs and other key partners to improve health professionals' knowledge of disability organisations that provide peer support and the important role they can play in providing informal support and information to people with intellectual disability.
3. 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;
  - include in its Workforce Capability Framework, a strong focus on the role of disability workforce in supporting healthy lifestyles and access to health services.

## Medium Term (four to six years)

1. Commonwealth to consider funding models and options for better supporting NDIS participants' access to health services.
2. NDIA to explore options for engaging NDIS Health Liaison Officers to support hospital admissions and for vulnerable people with intellectual disability.
3. Commonwealth and state and territory governments to explore the potential role of nurse coordinators to support people with disability and to liaise between health and disability services.
4. Commonwealth Department of Health to identify opportunities to embed reforms that enable better coordination between the health and disability sectors in the next National Health Reform Agreement with states and territories. This could include, for example, conducting a pilot study evaluating the impact of in-reach hospital services in supported accommodation, in reducing avoidable emergency department presentations and admissions.



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

The Disability Royal Commission, established in April 2019, heard evidence that health professionals lack the knowledge, skills and appropriate attitudes required to address the health needs of people with intellectual disability. Many health professionals have minimal training in intellectual disability health care (an average of 2.6 hours in medical degrees), and the amount and content in nursing degrees varies considerably.<sup>11</sup>

It is vital that health professionals – both students and qualified practitioners – are better educated about the inequities in health outcomes and the barriers to care that people with intellectual disability face. Health providers also need education on the importance of having positive attitudes towards people with intellectual disability, and to gain the knowledge and skills needed to provide this population group with high quality health care.

***‘It’s training around intellectual disability. It’s training around respecting the word of advocates, so if a parent is saying ‘you need to stop, you need to slow down’, then stop and slow down, and listen.’***

Dr Rebecca Kelly, Our Health Counts campaign 1 April 2019

<sup>11</sup> Trollor, J. N., Eagleson, C., Ruffell, B., Tracy, J., Torr, J. J., Durvasula, S., ... & Lennox, N. (2020). Has teaching about intellectual disability healthcare in Australian medical schools improved? A 20-year comparison of curricula audits. *BMC Medical Education*, 20(1), 1-10.

## Desired Outcomes

1. 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.
2. 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.
3. Improved access to appropriately trained and culturally sensitive health care professionals for people with intellectual disability, including Aboriginal and Torres Strait Islander people, and people from CALD and LGBTI backgrounds.

## Key Actions

### Short Term (one to three years)

#### *Primary Care Enhancement Program (PCEP)*

1. The Commonwealth Department of Health continue to:
  - support the roll out of the PCEP, which supports General Practitioners (GPs) and other primary health care professionals to provide more effective care to people with intellectual disability, and gives people with intellectual disability better access to appropriate, quality health services;
  - work with PHNs, the Council for Intellectual Disability, and other experts, to evaluate the initial rollout of the PCEP;
  - further develop the PCEP with a view to national rollout.

#### *State and territory health services*

2. States and territories to consider implementing measures that make public hospital and community health services accessible, trusted and safe for people with intellectual disability. This could include guidance along the lines of 'The Essentials' produced by the Intellectual Disability Network of the NSW Agency for Clinical Innovation.

#### *Curriculum development in intellectual disability health*

3. The Commonwealth Department of Health to lead work with professional organisations, health professional accrediting bodies, deans of medical and health professional schools, researchers, intellectual disability organisations, and people with intellectual disability and their families to ensure intellectual disability competencies, curricula content, and tools:
  - instil positive, respectful attitudes towards people with intellectual disability and their families and carers;
  - develop health professionals' knowledge of intellectual disability, including the causes, types, impacts, and co-occurring health conditions, and awareness of and skills in identifying trauma among people with intellectual disability;
  - deliver values based training based on a human rights approach;
  - develop health professionals' skills in communicating effectively with people with intellectual disability (including awareness of the importance of nonverbal communication methods), as well as their families and carers;
  - incorporate clinical case studies on diagnosing and treating people with intellectual disability throughout relevant components of health professional curricula;
  - build health professionals' capacity to make reasonable adjustments in delivering quality health care for people with intellectual disability, including appreciating the importance of working in flexible and respectful ways.

***‘Health care isn’t always good. People with intellectual disability might have speech impairment or need time to put sentences together and think. Doctors can ask things but you can’t answer quickly. They should give more time and be patient with us.’***

Laura Naing, Targeted Group Discussion 9 February 2021

### *Education, training and continuing professional development for health professionals*

4. Professional associations, regulating bodies and other key partners to encourage the inclusion of:
  - competencies relating to the provision of health care to people with intellectual disability in registration standards and practice standards;
  - obligations relating to the provision of health care to people with intellectual disability in practice conduct codes, acknowledging their right to the enjoyment of the highest attainable standard of health, without discrimination.

### *National Centre of Excellence in Intellectual Disability Health*

5. Commonwealth Department of Health 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;
  - Work towards establishing a central repository for intellectual disability health content and resources for people with intellectual disability, their families and support providers, health students, professionals and their educators, including shared language and concepts around human rights, communication and consent and decision making.

## **Medium Term (four to six years)**

### *Education, training and continuing professional development for health professionals*

The Commonwealth Department of Health will work with professional organisations, health professional accrediting bodies, deans of medical and health professional schools, researchers, intellectual disability organisations, and people with intellectual disability and their families, to build on and expand short term curriculum development actions set out above by:

1. embedding training and continuing professional development within all specialist training programs, including working with the medical colleges, professional accreditation bodies and other key organisations to develop curriculum for sub-specialties in intellectual disability physical and mental health;
2. embedding training and continuing professional development within all nursing and midwifery, allied health, oral health, and pharmacy training programs, including working with their professional colleges and accrediting bodies;

3. developing training and continuing professional development modules for health professionals that focus on:
  - non-verbal communication (including the use of augmentative and alternate communication aids) and the use of simple language to support better communication with people with intellectual disability about health issues and treatments;
  - consent and supported decision-making by people with intellectual disability in their own health care;
  - identifying and responding to suspected violence and abuse against people with disability;
  - responding to complex behaviours and behaviours of concern;
4. supporting health service providers to use multidisciplinary models of team based care;
5. supporting existing and emerging 'champions' within medical, nursing, dentistry and oral health, and allied health schools to promote the importance of better care for people with intellectual disability;
6. drawing upon the knowledge and experience of health professionals with expertise in intellectual disability, to better educate and train nurses in caring for people with intellectual disability, across health care settings;
7. exploring options for introducing student placements across health disciplines in disability settings.

#### *Network of specialised intellectual disability health services*

8. Commonwealth Department of Health to work with states and territories and build on the proposed establishment of a National Centre of Excellence by further developing a national network of specialised intellectual disability health services. The network will facilitate the delivery of clinical services in collaboration/consultation with existing services and enable access to care for people with intellectual disability with multiple and complex needs.

### **Long Term (seven to ten years)**

#### *Network of specialised intellectual disability health services*

9. Commonwealth Department of Health to work with states and territories to expand the national network of specialised intellectual disability health services to ensure it supports people with intellectual disability living in every state and territory, including rural and remote areas.





## D. Improving oral health for people with intellectual disability

Oral health is central to overall wellbeing. Good oral health supports are required in order for people with intellectual disability to experience good general health, participate in their communities, and function to the best of their abilities.

Studies have shown that people with intellectual disability have poorer oral hygiene and greater prevalence and severity of periodontal disease than the general population. The consequences of neglecting oral health are serious and include pain, infection and loss of teeth, leading to functional difficulties with diet, speech and behaviour, as well as severe systemic health issues.<sup>12</sup>

***‘The dental needs of patients with disability are, in many cases, greater than other patients in the general community. In addition to their cognitive impairment, people with ID often have associated medical conditions, physical disabilities and psychiatric conditions which impact on their ability to clean their teeth, maintain a healthy diet, and cooperate with dental care.’***

Disability and Oral Health Collaboration, Your Dental Health and Australasian Academy of Paediatric Dentistry Joint Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 24 February 2020.

<sup>12</sup> Joint submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability from Disability and Oral Health Collaboration, Your Dental Health project team and the Australasian Academy of Paediatric Dentistry.



The majority of people with intellectual disability face barriers, such as cost and access to specialist dentist services. Some people with intellectual disability need to attend hospital for dental care as they cannot tolerate dental interventions without general anaesthetic.

A lack of dentists with adequate skills in treating people with disability is the most frequently reported problem in obtaining dental care, followed by cost.

## Desired Outcomes

1. People with intellectual disability are supported to maintain dental/oral hygiene as a vital preventive health measure.
2. Oral health care is integrated into general health care.
3. Establishment of an oral health data collection on people with disability, including intellectual disability.
4. More oral health promotion done in the disability sector.
5. 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.
6. Better access to dental services for people with intellectual disability in the private and public sectors.
7. A national approach to dental care for people with intellectual disability is developed and linked to a National Oral Health Plan.

## Key Actions

### Short Term (one to three years)

#### *Increasing the volume of services*

1. Commonwealth Department of Health to:
  - work with the Australian Dental Association to promote the Child Dental Benefits Schedule (CDBS) to people with intellectual disability;
  - investigate the uptake of the CDBS by particular cohorts, including children with intellectual disability, to help inform the development of appropriate models of care;
  - explore the feasibility of financing a dental schedule under the Dental Benefits Act 2008 and other options for people with disability that better support complex and difficult services, such as in hospital services under general anaesthetic;
  - lead work with states and territories, peak oral health organisations and PHNs, including in the context of the proposed National Centre of Excellence in Intellectual Disability Health, to support the implementation of 'hub and spoke' models of care that facilitate upskilling, communication, and appropriate referral between centralised special needs dentists and community dental clinics.
2. PHNs to consider including oral health of people with intellectual disability, in their activities targeted at (non-dental) health professionals, acknowledging the role that primary health care professionals play in oral health interventions.

## **Your Dental Health: A Guide for People with a Disability, Their Family Carers, Friends and Advocates**

(Inclusion Melbourne – Oral Health Models of Care/Community of Practice)

Endorsed by the Australian Dental Association (ADA) and Australian Society of Special Care in Dentistry (ASSCID), this 16 page guide bridges the dentistry and disability support sectors. It outlines treatment pathways, information about communication and consent, and strategies for achieving better long term oral health outcomes for people with intellectual disability.

### *Expanding workforce training*

**3.** Commonwealth Department of Health to:

- work with deans of dental schools on courses for dentists, dental therapists and hygienists to specialise in oral health care for people with disability;
- work with the Australian Dental Association to develop continuing professional development modules.

### *Expanding oral health promotion*

- 4.** The Commonwealth to work with the disability sector to identify ways of implementing training in oral health as compulsory for disability support workers (Certificate IV), noting that it currently only contains elective content on this issue.
- 5.** State and territory governments to develop options for expanding access to oral health coaches (i.e. dental assistants that have training in providing services for people with intellectual disability) who work with people with intellectual disability and their families, including people living in supported accommodation services.
- 6.** The Commonwealth Department of Health to:
- consider options for supporting a national digital platform that enables general dentists and other oral health professionals to access special needs dentistry support and advice;
  - work with peak oral health groups to consider ways of including key performance indicators on the oral health of people with disability in the current National Oral Health Plan 2015-2024.
- 7.** PHNs participating in the PCEP to work with the states and territories on oral health promotion for people with intellectual disability and their carers. States and territories have targeted oral health strategies that could be linked with emerging PHN activities, for example, the Dental Health Services Victoria video, '[Sally's visit to the dentist – Preparing for positive dental visits](#)'.

## **Medium Term (four to six years)**

### *Improving oral health data collection*

**1.** The Commonwealth Department of Health to:

- consider options for establishing an oral health data collection related to people with disability, including intellectual disability. For example, the National Adult Oral Health and the National Child Oral Health Surveys could be expanded to collect this data;
- work with peak oral health groups and states and territories to develop the National Oral Health Plan 2025-2035, with stronger data sharing arrangements that enable all jurisdictions to monitor service provision and access to oral health services including for people with intellectual disability.



## E. Research, data and measurement to support continuing improvement

Research, data and measurement are fundamental to monitoring health outcomes of people with intellectual disability, and assessing the effectiveness of initiatives designed to improve outcomes. Currently, there is no routine data collection or reporting on health outcomes for people with intellectual disability at a national level (and limited data collection and reporting from states and territories). The evidence that is available suggests that people with intellectual disability experience some of the greatest health disadvantages of any population group in Australia.<sup>13</sup>

Because of the paucity of national data, governments rely on research data to monitor health outcomes in this population. However, securing long-term research funding in the field of intellectual disability health can be difficult.

To develop targeted, evidence-based interventions that improve the health of people with intellectual disability, national leadership is needed to improve data collection and reporting.

***‘It is recommended that population health outcomes for people with intellectual and other developmental disabilities including health status, health service utilisation and health outcomes are routinely analysed and reported.’***

Professor Julian Trollor, Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 20 February 2020

<sup>13</sup> Trollor, J. (2020). Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, dated 11 February 2020. Available at: <https://disability.royalcommission.gov.au/system/files/exhibit/STAT.0049.0001.0001.pdf>

## Desired outcomes

1. 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.
2. Experiences of people with intellectual disability are captured throughout the patient journey.
3. 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.
4. Research includes people with intellectual disability during design and implementation.

## Key Actions

### Short Term (one to three years)

1. Commonwealth Department of Health to:
  - work with the Australian Institute of Health and Welfare (AIHW) and other relevant agencies to examine options for intellectual disability identifiers to be used that generate new data sets and can be linked with existing data sets and the proposed National Disability Data Asset (NDDA);<sup>14</sup>
  - develop options for targeted national research that builds the evidence base on strategies to improve health outcomes for people with intellectual disability (for example, through the NHMRC targeted call for research on intellectual disability health, and research into the social and economic impacts of poor oral health care);
2. Commonwealth Department of Health to work with states and territories, other relevant agencies and service provider organisations, to improve data collection on the prevalence and impact of communicable diseases on people with intellectual disability (e.g. COVID-19).
3. Commonwealth agencies (AIHW, the Australian Bureau of Statistics (ABS), the NDIS Commission, NDIA, and the Department of Health) to work with states and territories, advocacy organisations, NDIS and non-NDIS registered providers, to enable nationally consistent mortality reviews for people with intellectual disability. Reviews should identify any failings in health care, disability support and by other people with a view to recommendations to improve health and avoid unnecessary deaths.

### Medium Term (four to six years)

1. AIHW to work with the ABS, Commonwealth Department of Health and DSS, states and territories and other partner organisations to:
  - develop a national data asset that captures, and routinely reports on progress in improving, the health outcomes of people with intellectual disability;
  - find better ways of identifying people with intellectual disability in population level health surveys.
2. Commonwealth and state and territory governments to work with health care providers to adapt existing patient experience surveys so they capture the experiences of patients with intellectual disability throughout the patient journey, for example:
  - ABS and AIHW primary care and patient experience surveys;
  - hospital patient experience surveys.

### Long Term (seven to ten years)

1. Commonwealth agencies to maintain investment and focus on national, population based data collection on the health of people with disability, to inform continuous improvement and further policy refinement and development to improve health outcomes for people with intellectual disability.

<sup>14</sup> The Commonwealth has invested in the pilot national disability data asset (NDDA) to test how to best link data to understand a range of outcomes of people with disability. The establishment of the NDDA as an enduring asset is subject to the decisions of government.



## F. Emergency preparedness and response

Thorough preparedness for and timely responses to public health emergencies can significantly reduce their impact on populations. Emergency preparedness must include people with intellectual disability, and it must be responsive to their needs.

***‘When COVID-19 happened, I got most of the information from the news... Too much information was given at one time. Every day they were changing the rules. I was confused. Who do you believe?’***

Anthony Mulholland, Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 19 August 2020

The COVID-19 pandemic has highlighted the need for specific consideration of people with disability, including people with intellectual disability, in Commonwealth, state and territory and local emergency responses. Throughout the pandemic, people with intellectual disability and their supporters have faced challenges in accessing:

- clear public health guidance in formats suitable to their needs;
- COVID-19 testing;
- personal protective equipment (PPE);
- regular (non-COVID-19 related) health services; and
- disability supports.



Many people with intellectual disability have also experienced poor mental health outcomes throughout the COVID-19 pandemic due to extended periods of isolation and disruptions to their usual routines.

Disability providers have also faced significant challenges, including:

- maintaining workforce supply;
- accessing PPE;
- accessing and providing infection control and prevention training for their staff.

These issues made it difficult for disability service providers to give the best possible support to people with intellectual disability during the pandemic. This Roadmap includes some short-term actions in response to the COVID-19 pandemic. Planning for future emergencies will be refined during the medium and long term.

## Desired Outcomes

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

## Key Actions

### Short Term (one to three years)

1. Commonwealth, state and territory and local governments, and providers, to consider the needs of people with intellectual disability in their emergency preparedness planning. Planning for future health emergencies should include focus on:
  - inclusive communication;
  - continuity of access to health, mental health supports and disability support services;
  - supported accommodation settings and ready access to appropriate PPE and flexible testing and vaccination arrangements.
2. Commonwealth Department of Health and DSS to continue to consult with disability sector stakeholders including people with intellectual disability, their families and carers, and disability representative organisations during the COVID-19 pandemic, and maintain an ongoing consultative mechanism that can be stood up in response to any future national emergency.
3. Commonwealth Department of Health, in coordination with states and territories, to continue work to ensure that disability support workers have priority access to PPE, appropriate testing procedures, and infection prevention and control training during the COVID-19 pandemic and any future widespread communicable disease outbreaks.

4. Commonwealth Department of Health to:
  - examine where tailored national guidance for people with intellectual disability and their supporters is needed, and develop this where appropriate during the COVID-19 pandemic and any future national emergency;
  - review Australia's COVID-19 response for people with disability and incorporate learnings into emergency planning and future emergency responses;
  - promote the use of health passports, My Health Record, and person-centred emergency planning resources, such as the Person-Centred Emergency Preparedness Planning for COVID-19 tool to people with intellectual disability, their families, carers, disability support providers and support workers.
5. Commonwealth, state and territory governments to recognise the disability workforce as an 'essential workforce' in the context of public health emergencies and in public health emergency planning.
6. Commonwealth to work with state and territory governments to provide greater clarity on agency roles and responsibilities for responding to health emergencies for people with disability and the disability sector.





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

The actions prioritised in this Roadmap lay out an ambitious but necessary agenda for improving the health of people with intellectual disability. Implementing many of these actions will require significant commitment and cooperation from the Commonwealth, state and territory governments, educational institutions, health care providers and professionals, and other stakeholders. Importantly, it will require engagement directly with people with intellectual disability, their families and carers.

To ensure that governments and other stakeholders are accountable for implementing actions outlined in this Roadmap, robust, transparent and inclusive oversight and monitoring arrangements are needed. These governance arrangements will also be critical to ensuring that the Roadmap achieves the desired outcomes.

***‘Hear us, support us, and value our opinion.’***

Jack Kelly, Targeted Group Discussion  
24 February 2021

In light of this, the Commonwealth Department of Health will establish a governance group that includes health and disability sector stakeholders to:

- oversee the implementation of the Roadmap (throughout its lifespan);
- provide advice on implementation.

## Desired Outcomes

1. 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.
2. Implementation of the Roadmap is conducted in an inclusive and transparent manner.

## Key Actions

1. The Commonwealth Department of Health to:
  - establish a governance group to provide oversight and monitor the implementation of the Roadmap;
  - ensure information about the Roadmap and implementation progress updates are made publicly available, and made accessible to people with intellectual disability. This will include yearly public reporting on implementation progress.
2. The Commonwealth Department of Health and other relevant agencies will consult with people with intellectual disability and their families and carers, through the governance group in:
  - planning and evaluating specific actions under the Roadmap;
  - designing and undertaking a broader evaluation of the Roadmap and its implementation at the three, six and 10 year points;
  - considering future reviews and updates to the Roadmap, to help ensure continuing focus on the health of people with intellectual disability in the design and delivery of health policies and programs.

