



Roadmap Implementation Governance Group (RIGG)

Meeting Summary – 26 November 2021, 1:30 – 4:00 pm AEDT

Introduction

The Chair welcomed all members to the first meeting of the Roadmap Implementation Governance Group (RIGG).

The Chair thanked members for joining the RIGG and highlighted the importance of its role in overseeing implementation of the National Roadmap for Improving the Health of People with Intellectual Disability (Roadmap).

The Chair gave a verbal declaration, reminding members that discussions and meeting papers are confidential. Members were asked to declare whether they have any conflicts of interest. Members were advised that they could leave the meeting if they wished to do so, in view of any such conflicts. The Chair also asked that members make it clear when putting views forward, whether their views were as an individual expert, or as a representative of their organisation. It was noted that the Chair's verbal declaration would be documented in the meeting record, and that any conflicts declared would be documented by the Department.

Setting the scene

It was noted that the Roadmap was developed based on detailed stakeholder consultations, and that the Minister for Health and Aged Care, the Hon Greg Hunt MP, launched the Roadmap in August 2021. The Chair also emphasised that collectively, we are variously responsible for delivering many of the Roadmap actions and driving change. The Roadmap has also been a focus in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

People with lived experience were invited to discuss why actions under the Roadmap are important to them. They highlighted the need for:

- healthcare providers to better understand the needs of people with intellectual disability and improve communication with them
- people with intellectual disability to be involved in how we address changes to the health system to improve the health of people with intellectual disability
- the health system to respect the rights of people with intellectual disability
- increased access and availability of health information in Easy Read format
- longer appointment times, to help enable individualised health care
- a clear focus on outcomes, and evaluating the actions implemented under the Roadmap to assess whether they achieve genuine change in the health system

People with intellectual disability emphasised that they hoped implementing the Roadmap would allow them and their families to trust that the health system will provide quality care that meets their needs.

Other members also highlighted the importance of:

- combating discrimination against Aboriginal and Torres Strait Islander people with intellectual disability, particularly in remote communities
- identifying ways to monitor the number of Annual Health Assessments for people with intellectual disabilities
- the importance of having baseline data to enable monitoring and evaluation of the Roadmap
- vocational education curricula on intellectual disability health to be considered alongside higher education curricula.

RIGG Terms of Reference

The Chair noted that the RIGG is a newly created group with a role to oversee a broad and complex, 10-year program of work. Sitting under the RIGG are Expert Advisory Groups (EAGs) that have responsibility for implementation of particular projects or streams of work. Currently there are two EAGs:

- the National Centre of Excellence EAG
- the Education and Training EAG.

The Chair advised that the Department is also creating an Intellectual Disability Focus Group to help ensure appropriate and meaningful engagement with people with intellectual disability across all projects under the Roadmap. The Focus Group will be established in the first half of 2022.

Members discussed the draft Terms of Reference. It was agreed that the draft will be amended to reflect that:

- meeting communiques will be made publicly available (excluding any confidential information)
- the RIGG will report annually on progress with implementation of the Roadmap, including on outcomes, and that the annual reports will be publicly available
- at least one face-to-face RIGG meeting will be held each year once it is safe to do so.

Members also recommended that the RIGG annual report include baseline data and visual materials, with information separated by the Roadmap elements. This will help stakeholders focus on the aspects that are of particular interest or relevance to them and help generate broader interest in the work being done under the Roadmap.

Gap analysis and key actions under the Roadmap

Work is already underway to address the health needs of people with intellectual disability. The Chair advised that as a first step, we need to identify this work and who is leading it (for example, the Commonwealth, state and territory governments, statutory bodies, researchers, or consumer groups). This will allow the Department to identify work that still needs to be done. Members highlighted the importance of undertaking a gap analysis and identifying a list of priorities across sectors and jurisdictions.

The Department will circulate a template for members to identify and report on any work being done by their organisations that addresses actions under the Roadmap.

Members were asked to identify their top 3 priority actions under the Roadmap, to help identify key priorities for the RIGG to consider regarding the Roadmap implementation. It was noted that a template for this will be circulated to members out of session.

Update on current projects

The Department of Health provided updates on current projects under the Roadmap. A summary is included at **Attachment A**.

The Department of Social Services provided updates on current projects that align with the Roadmap. A summary is included at **Attachment B**.

State and territory representatives provided updates on current projects that align with the Roadmap. A summary is included at **Attachment C**.

Next Steps

The Department of Health will:

- update and circulate the Terms of Reference, with the final version to be confirmed by the Chair by the next meeting, and
- email RIGG members templates for completion regarding gap analysis and top priorities under the Roadmap.

Attachments

Attachment A: Department of Health Roadmap Project Updates – Summary

Attachment B: Department of Social Services Project Updates – Summary

Attachment C: State and Territories Project Updates – Summary

Attachment A: Department of Health Project Updates – Summary

National Roadmap for Improving the Health of People with Intellectual Disability

The Government has provided **\$19.26 million** in initial funding to support four key projects under the Roadmap.

This includes:

- **\$1.4 million** to scope and co-design a National Centre of Excellence in Intellectual Disability Health
- **\$4.7 million** for curriculum development in intellectual disability health
- **\$6.6 million** to develop a Primary Care Enhancement Program for people with intellectual disability
- **\$6.7 million** to improve the uptake and implementation of Annual Health Assessments.

National Centre of Excellence

Government funding has been provided for the Department of Health to scope and co-design a National Centre of Excellence in Intellectual Disability Health.

This means working out a draft plan for what a Centre could look like.

Working out a draft plan for the Centre is a key short-term action under the Roadmap.

This is because a National Centre of Excellence in Intellectual Disability Health is important for many other actions under the Roadmap.

The draft plan will help the Department to give advice to the Government about setting up the Centre.

We have asked a company called Nous Group to help us draft the plan for the Centre.

We also have an expert advisory group helping us to draft the plan for the Centre.

- The advisory group is giving us ideas about what work the Centre should do, and how the Centre should be run.
- The advisory group includes people with intellectual disability, plus advocates and other experts who know about intellectual disability health.
- Some members of this expert group are also members of the Roadmap Implementation Governance Group (RIGG).

Based on their ideas so far, we have prepared a first draft of the plan. It outlines:

- What we think the Centre's mission should be - to help people with intellectual disability to have better health.
- That people with intellectual disability will be at the heart of the Centre.

In summary, we think that the Centre will do four main things:

- Be a leader in intellectual disability health. For example, working with intellectual disability health services, health workers, researchers, and advocacy groups; and working with existing advocacy organisations to help make change happen.

- Make health services better for people with intellectual disability. For example, helping health workers to understand and respect people with intellectual disability and their families; and giving information and training to health workers.
- Provide support. For example, to help people with intellectual disability and their families to find the right health services.
- Lead research in intellectual disability health including, for example, helping get research done so governments and the health system know how to give better care for people with intellectual disability.

Intellectual Disability Health Curriculum Development

The Disability Royal Commission found that health workers have often not been trained in how to provide health services for people with intellectual disability.

The main aim of the curriculum development project is to develop an intellectual disability health competency framework which will outline the key knowledge, skills and attitudes health workers need to provide safe and effective health care to people with intellectual disability.

The competency framework will support universities to develop and deliver undergraduate content and will also be used to update the accreditation standards for health courses.

Accreditation standards are used to guide universities about what they need to include in their courses.

Work on this project is just starting and the Department of Health is setting up an Education and Training Expert Advisory Group (Advisory Group) to provide advice and guidance on education and training related actions under the Roadmap.

The Department of Health will also be looking at what resources might be needed by universities to teach students about people with intellectual disability.

The resources will be put online so they can be used by universities, health workers and people with intellectual disability their families and carers.

Primary Care Enhancement Program (PCEP)

The PCEP will help General Practitioners and other health professionals to provide better care to people with intellectual disability and give people with intellectual disability improved access to appropriate, quality health services that meet their needs.

The PCEP is a pilot within 4 Primary Health Networks (PHNs): Central and Eastern Sydney; Central Queensland, Wide Bay and Sunshine Coast; Tasmania; and Western Victoria.

This project involves the Council for Intellectual Disability creating resources and training materials. These include:

- a training module for delivery to health professionals by PHNs expected between March and December 2022
- resources for General Practitioners (GPs) and other primary care professionals, including information about the National Disability Insurance Scheme
- health promotion materials in Easy Read format for people with intellectual disability and their families.

In addition, the 4 PHNs are undertaking several key intellectual disability health activities through the PCEP in their regions, including:

- recruiting project officers and setting up local expert advisory groups
- improving ways to share information with health professionals who have patients with intellectual disability
- preparing Continuing Professional Development (CPD) training for health professionals in oral health for people with intellectual disability
- telling NDIS liaison officers and people from different cultures about resources and services for people with intellectual disability
- reviewing, updating and developing local intellectual disability health pathways
- creating a list of local intellectual disability health services and specialists.

The Department of Health will measure the changes that occur because of the PCEP in the four Primary Health Networks. This evaluation will be important information for the Government to decide whether to extend the pilot nationally.

Implementation of Annual Health Assessments

Annual health assessments are health checks people with intellectual disability can have every year. These checks help doctors find health issues before they get serious.

The government pays GPs for each annual health assessment they do.

Increased use of annual health assessments is an important outcome under the Roadmap. The Australian Government has given us \$6.7 million to help more people with intellectual disability have annual health assessments.

There is a special form that GPs can use to do annual health assessments. We want to make this form free and easier to use for GPs, people with intellectual disability, and their family and carers.

We are talking to groups like software developers about how the form could become a part of GP software (engaging with people who make GP software, RACGP, Digital Health Agency etc.).

We will ask our stakeholders (people with intellectual disability, families, disability service providers, and consumer organisations) about:

- how to make the tool easier for consumers to access and use, and
- how best to tell people with intellectual disability and their supporters about annual health assessments.

Attachment B: Department of Social Services Project Updates – Summary

Disability Strategy

- Australia’s Disability Strategy 2021–2031 starts on 3 December.
- We call it the Strategy.
- It is a plan to make life better for people with disability.
- The Strategy will last for 10 years.
- It was developed over two years.
- We spoke to lots of people about what they wanted to see in a Strategy. We spoke to:
 - Australian, state, territory and local governments
 - people with disability, their families and carers.
- The Strategy talks about what we can do so everyone can take part in everything that happens in Australia.
- It also talks about how we must treat people with disability as equals and with respect.

Information, Linkages and Capacity Building (ILC) program

Background

- The ILC program provides funding to organisations for community projects that benefit Australians with disability, their carers and families.
- The ILC program goals are:
 - create, support and promote connections between people with disability and the communities in which they live
 - build the knowledge, skills and confidence of people with disability, and improve their access to community and mainstream services.
- The ILC program moved from the National Disability Insurance Agency (NDIA) to the Department of Social Services (the department) in October 2020.

ILC review

- The department has been looking at the ILC program to better understand the program, including the local area coordinator (LAC) role. (The LACs help connect people with disability to the ILC grants. The LACs are managed by the NDIA).
- We are working to build evidence about progress and outcomes achieved by the ILC grants, noting many have been affected by COVID-19.
- State and territory governments, the NDIA and sector representatives have been consulted to identify issues and high-level themes.
- A research project carried out by Swinburne University of Technology is a key part of the ILC review. The research project will assist the department to understand where there are gaps and unmet needs within the current ILC program.
- A final report is due before the end of this year.
- The department will consult with people with disability, the disability sector and state and territory governments on developing a future strategy for the ILC program.

- Any changes to the ILC program will match up with Australia’s Disability Strategy 2021-2031.

Timing of funding rounds

- We will open a grant round in future. We don’t know exactly when yet but we will put the information on the [Community Grants Hub](#) and [Grant Connect](#) websites, when we know.

Examples of current ILC grants which support improving the health of people with intellectual disability are:

Organisation	Description	Funding
Inclusion Australia	<p>The Making Decision Real project aims to build the decision making skills and experience of people with intellectual disability.</p> <p>The project will:</p> <ul style="list-style-type: none"> • develop new resources and training • test existing resources by people with intellectual disability • make all resources available across Australia for people with intellectual disability, their families and trusted supporters. 	\$1,254,600
New South Wales Council for Intellectual Disability	<p>This project aims to develop accessible and relevant resources for people with intellectual disability and their supporters to keep them informed about COVID-19.</p> <p>Resources will include information sheets, podcast and videos.</p>	\$24,160
University of NSW partnering with the New South Wales Council of Intellectual Disability	<p>This project aims to deliver and evaluate an interactive mental health service pathway web tool for people with intellectual disability.</p> <p>The project aims to enhance the capacity of the mainstream mental health sector in NSW to meet the mental health needs of people with intellectual disability by linking mental health staff and people with intellectual disability to the resources they need to better support their mental health journey.</p>	\$1,243,523
Gippsland Centre Against Sexual Assault	<p>The project works with sector professionals to reduce violence and abuse of people with intellectual disability.</p> <p>The project aims to reduce the risk of violence and sexual violence, and to improve reporting, by providing information and services to people with intellectual</p>	\$450,000

Organisation	Description	Funding
	disability, Acquired Brain Injuries and complex communication needs.	
Developmental Disability Council of Western Australia	The How to make and keep friends - Video Series and Communication Support Resources project aims to address depression and anxiety in young people with intellectual disability by assisting them to develop the skills and understanding necessary for real friendships and relationships.	\$209,000
La Trobe University	The Think Smarter, Nor Harder project is developing and trialling multimedia training for hospital staff and other stakeholders to improve hospital experiences and outcomes for adults with cognitive disability, intellectual disability and traumatic brain injury.	\$1,198,372.4

Additional Information

ILC program

- The department's website provides information on the [ILC program](#).

La Trobe University ILC project

- The La Trobe University ILC project aims to build the capacity of hospitals in Victoria to improve experiences and outcomes for adults with cognitive disability, including people with Acquired Brain Injury, Autism, Cerebral Palsy and Intellectual Disability.
- The project will use multi-media training to focus on communication processes among hospital staff, disability support workers, family members and people with disability to deliver support, information, collaboration and knowledge.
- The project will develop, trial and evaluate multi-media training tailored to each stakeholder group with acting and co-design support from people with disability.
- Training trialled during the project will be available to hospital and disability networks on an open-access online platform.
- In collaboration with hospital and disability service partners the project builds on a 2015 study funded by National Disability Research Agenda.
- The three year project is due to end in February 2023.

Attachment C: State and Territory Project Updates - Summary

Victoria highlighted a number of health initiatives for people with intellectual disability. This included:

- Victoria's Disability Liaison Officer COVID-19 initiative, which is supporting people with intellectual disability to connect to health services during the pandemic. An evaluation is currently being considered to inform continuation of the initiative beyond the pandemic.
- Dental health service vans that visit special schools within Victoria and assess the oral health of people with a range of disabilities. It was also noted there is ongoing work to improve accessibility and care for people with intellectual disability in mainstream dental clinics.
- The Centre of Research Excellence in Disability and Health (CRE-DH), which aims to guide social and health policy reform for people with disabilities in Australia.

Victoria also noted the Disability Royal Commission had requested a report on Victoria's health programs for people with intellectual disability. Victoria agreed to share a summary of this report with the group.

New South Wales highlighted a number of health initiatives underway for people with intellectual disability. These were:

- The Intellectual Disability Health Service, which aims to improve access to the health care system and mainstream primary care services for people with intellectual disability. An evaluation of this program is underway.
- The Intellectual Disability Mental Health Hubs. There are two hubs, one for children and one for adults. The Hubs also provide the training for staff from health and disability services. An evaluation of this program is also underway.
- [17 Easy Read resources](#) that describe and provide accessible information about mental health services, for people with cognitive disability and their families and carers, have also been released.

South Australia highlighted the South Australian Intellectual Disability Health Service Model of Care that is currently being implemented. The Model of care was developed to improve healthcare accessibility for people with intellectual disability with the goal of improving health outcomes and experience. The recommendations within the Model of care have significant overlap with the national roadmap and some of these include establishment of a specialised intellectual disability health service that provides multidisciplinary health assessment and advice; promotion of annual health assessments; development of a range of patient/carer and clinician resources including a 'hospital passport'; development of intellectual disability specific Health Pathways for General Practitioners; and highlighting the role of Disability Liaison Officer positions within hospitals as a key integration point.

Queensland Health provided an update on the evaluation of a trial initiative called *Julian's Key Health Passport*. The passport tool was designed to help people with disabilities receive person centred care, and is available as a downloadable PDF and phone application. The project was trialled in two Queensland hospitals. Overall, the evaluation found that stakeholders considered the tool to be effective.