



Roadmap Implementation Governance Group (RIGG)

Meeting Summary – 16 March 2022

Introduction

The theme of the meeting was primary health care for people with intellectual disability.

The Chair welcomed all members to the second Roadmap Implementation Governance Group (RIGG) meeting and gave an Acknowledgement of Country.

The Chair gave a verbal declaration about confidentiality and conflicts of interest. Members were asked to declare any conflicts of interest that were not declared at the previous meeting. One member declared a conflict of interest to the Secretariat. No additional measures were required to manage this conflict.

The Chair also asked members to clarify when sharing views, whether their views were as an individual expert, or as a representative of their organisation.

Setting the scene – experiences in the primary care setting

People with lived experience were invited to share some of their experiences of primary health care. Issues raised included:

- health workers with poor communication skills
- not feeling heard
- not being understood
- health workers appearing not to know that the person has intellectual disability
- having to repeat information to the health worker
- health workers speaking to the person's carer instead of them
- health workers showing a lack of respect for the person
- health workers being dismissive of the person's concerns
- health workers not explaining what will happen in an appointment or hospital visit
- not having enough time for a person to explain their health issues
- difficulty navigating the health system without support, especially for people who are not eligible for the NDIS.

People with intellectual disability had good experiences when they were treated with respect and were acknowledged as a person. People with intellectual disability emphasised the importance of having a primary care worker who understands their needs. It was suggested that primary health care workers should have software that identifies a person with intellectual disability.

The Primary Care Enhancement Program (PCEP)

The PCEP addresses part of Elements A and C under the Roadmap. The PCEP is a pilot project operating in four Primary Health Networks (PHNs).

Each PHN will recruit relevant health professionals and a person with intellectual disability to deliver the training together. Training will start mid-year. It includes technical information and stories of

people's lived experience (case studies) so health care workers can better understand the difficulties faced by people with intellectual disability. Training resources have also been co-designed with people with intellectual disability. Easy Read versions will be available.

RIGG members were asked for ideas on how to promote the PCEP training and resources. They suggested:

- social media
- professional colleges and university programs
- Local Health District educators
- specialised intellectual disability health service education initiatives
- champion intellectual disability health professionals
- sharing with advocacy organisations
- including in Participant First newsletter
- people with lived experience to promote with their own primary health care contacts
- ensuring the training attracts points for continuing professional development
- consider ways to tailor and promote training to nurses, potentially through the Australian Primary Nurses Federation
- having questions about the content included in exams for health students.

Members noted it is important to ensure training is available to all primary care services, not just GPs, and should include practice reception and administration staff.

Roadmap gap analysis and top priorities

An overview of the Roadmap gap analysis and top priorities activity from the 26 November 2021 meeting was provided. The Department of Health (the Department) created a Dashboard to visually demonstrate how much activity was occurring that aligned with Roadmap actions, using different colours for different levels of activity over the short, medium and long-term. The methodology and findings were discussed.

Members supported the approach taken to draft the Dashboard but noted gaps in the information. In particular it was noted that some jurisdictions had not provided responses.

Members suggested:

- creating additional dashboards for each jurisdiction
- the Department reach out to peak professional bodies, representative organisations, and other external stakeholders to add more information to the Dashboard
- ensuring activities being carried out in regional and rural areas are included
- seeking advice from an implementation specialist
- allocating a lead from the RIGG to each of the element areas in the Roadmap.

Going forward, members agreed that the Dashboard was a useful reporting format and should be updated once a year. The Dashboard will form part of the annual progress report on implementation of the Roadmap. The annual progress report will be published, so input from all members is important.

The Department will seek to provide the Dashboard in Easy Read.

Members discussed how to prioritise actions for implementation. It was agreed that a balanced approach considering many factors is needed when deciding which areas of the Roadmap to prioritise.

It was noted there is a need to look at duplication of effort and scaling up existing activities where they are working well. It was noted that many resources already exist, and the challenge is in promoting and implementing them.

The Department will compile guiding principles to help the RIGG consider which elements and actions to prioritise.

Members also considered the need for monitoring and evaluation of the Roadmap. Measures could include:

- life expectancy and quality of life
- avoidable deaths and comparative morbidity
- contribution to society (good health is vital to a person being able to contribute).

There may be opportunity to establish outcome measures using the National Disability Data Asset. A noted risk was difficulty in extracting data for intellectual disability from datasets. Monitoring and evaluation will be discussed in more detail at the next meeting.

Australia's Disability Strategy 2021-2031 and how it relates to the Roadmap

The Department of Social Services (DSS) presented an overview of Australia's Disability Strategy and its relation to the Roadmap, including:

- the need for cross-government leadership
- more outcomes-focused programs
- more focus on making life easier for people with intellectual disability including employment and financial security.

DSS also discussed a project that addresses Element C of the Roadmap. This project will develop a Disability Best Practice Guide and Action Plan for training workers in government services that are accessed by people with disability. The desired outcome is for people with disability to have better services and supports when they access health, education, justice, and social services.

Updates from states and territories

Queensland Health

- The Julian's Key project has been evaluated. A fact sheet on the evaluation is available: [Julian-s-Key-Evaluation-Factsheet.pdf \(health.qld.gov.au\)](https://health.qld.gov.au)
- Disability awareness training for health practitioners is being provided by Check Up. Queensland Health is investigating making the training mandatory.
- Queensland Health is partnering with the Department of Developmental Disability Neuropsychiatry on research for preventative health for people with intellectual disability.

Northern Territory Department of Health (NT Health) noted their contribution to the Roadmap gap analysis task.

South Australia Department for Health and Wellbeing (SA Health)

- The SAIDHS website has been launched. This was co-designed with people with intellectual disability, families, carers and clinicians. See: [SA Intellectual Disability Health Service | SA Health](#)
- A COVID vaccination clinic has been established for people with intellectual disability and complex needs.
- Poor data to identify patients with intellectual disability presenting to emergency departments makes it difficult to identify service gaps.

The other states and territories will have an opportunity to provide updates at the next meeting.

Meeting close

The Chair reminded participants that meeting papers are due four weeks in advance of the next meeting to allow for appropriate preparation and Easy Ready translations.

The next meeting will be on Wednesday 20 July 2022.

Next Steps

RIGG members will:

- email RIGG.Secretariat@health.gov.au with any further feedback concerning the Dashboard
- be asked to provide input to update the Dashboard for annual publication on the Department's website in the second half of 2022.