



# Roadmap Implementation Governance Group (RIGG)

## Meeting summary – 21 August 2023

### Introduction

Prof Nick Lennox, Senior Medical Advisor for Disability and Health in the Department's Primary Care Division chaired the meeting.

The Chair welcomed all members to the sixth meeting of the Roadmap Implementation Governance Group (RIGG), gave an Acknowledgement of Country and acknowledged intellectual disability self-advocates.

The Chair gave a verbal declaration about confidentiality and conflicts of interest. Members were asked to declare any new conflicts of interest. No new conflicts of interest were declared.

### National Centre of Excellence in Intellectual Disability Health

#### People with intellectual disability on what the National Centre of Excellence means to them

The Chair asked RIGG members with intellectual disability to outline what the establishment of the National Centre of Excellence (the Centre) meant to them. Members said the Centre would improve health outcomes for people with intellectual disability by:

- recognising that everyone has the right to quality health care
- sharing research and data
- improving health providers' knowledge about people with intellectual disability
- improving the health literacy of people with intellectual disability, and
- including and providing job opportunities for people with intellectual disability.

### Presentation from the successful consortium

Prof Julian Trollor, Interim Director of the Centre, spoke to the RIGG about the consortium selected to set up and run the Centre. The focus of the Centre is to identify how to improve the health of people with intellectual disability.

The Centre's board will include people with intellectual disability and their families and First Nations people. A person with intellectual disability will be a co-chair of the board. Roles within the organisation will be advertised soon. Prof Trollor encouraged members to sign up to the Centre email list to receive updates.

Members expressed their support for the work undertaken so far, and advised the following cohorts should be engaged and considered in the work of the Centre:

- people in rural and remote areas,
- First Nations people with intellectual disability and their families, and
- disability support workers.

## May 2023-24 Budget: Overview of primary care measures

In the May 2023-24 Budget the Australian Government announced \$6.1 billion worth of investments to build a stronger Medicare. The Chair provided a brief outline of the primary care measures that were announced, including:

- MyMedicare
- Digital Health
- Consumer engagement in Primary Care reform.

RIGG members impressed the importance of early and meaningful consultation to ensure that measures benefit people with intellectual disability. Some members highlighted the importance of communicating information to people with intellectual disability in person or by printed materials. This is because many people with intellectual disability have low computer literacy and or would need better access to digital devices and support to use them.

The Department committed to passing on this feedback to the teams implementing the measures, and to updating members of the RIGG when there are opportunities to engage.

## Discussion on Roadmap action: Information available to parents during the pre-and post-natal period

### Presentation from Down Syndrome Australia

Element A of the National Roadmap for Improving the Health of People with Intellectual Disability includes an action for the Department to work with PHNs, professional colleges and disability advocacy organisations to ensure balanced, evidenced-based information about intellectual disability and related diagnoses, such as Down syndrome, is available to parents during the pre- and post-natal periods.

Down Syndrome Australia (DSA) nominated this issue for discussion. DSA representatives, Natalie Graham, Health Program Manager, and Lizzie Callinan, Advisor – prenatal screening, presented to the RIGG on information available to parents in the pre-and post-natal periods. Their presentation focused on:

- misunderstandings about Downs syndrome screening, for example, that it is voluntary and it is not a diagnostic test
- screenings being performed earlier in pregnancy due to advancements of technology and results being discussed with GPs who may not have the appropriate knowledge or expertise
- Down Syndrome Queensland's Prenatal Screening website and its featured resources for parents and health professionals
- DSA's work with Queensland Health to develop clinical screening guidelines, and
- recent survey results which indicated issues of informed consent for screening.

## Facilitated discussion: Opportunities to implement actions that meet Roadmap objectives

RIGG members with intellectual disability spoke about:

- how people with intellectual disability can live happy and fulfilling lives with the love and support of their families
- what they would tell parents about Down syndrome and intellectual disability, and
- what they thought doctors should communicate when speaking to parents about Down syndrome and intellectual disability.

RIGG members with intellectual disability suggested:

- people shouldn't judge people with Down syndrome before meeting them, and
- parents should know they have choices and have access to support and resources to help them.

Members discussed actions that could:

- increase use of neutral wording suggested in guidelines for health professionals, such as 'chance' instead of 'risk'
- improve parents' and health professionals' timely access to up-to-date resources about intellectual disability, including Down syndrome, in the pre and post-natal periods
- improve information and training on non-invasive pregnancy testing available to general practitioners
- improve access to genetic counselling services for parents.

The Department committed to summarising the discussion and circulating to the RIGG members for their review.

## Meeting close

The Chair noted the secretariat would email members about:

- input for the 2023 Annual Progress Report, and
- the next meeting date.

The next RIGG meeting will focus on annual health assessments.

## Next Steps

The Department will:

- circulate the RIGG's new terms of reference to members. The updated terms of reference extended members' terms from two to three years.
- circulate the slides Prof Julian Trollor presented on the Centre
- circulate a summary of the discussion on information available to parents in the pre- and post-natal period and providing to RIGG members for their review
- provide members' feedback on the primary care measures in the 2023-24 Budget to the teams implementing those measures, and
- host a roundtable for interested members of the RIGG to provide more information on primary care measures announced in the 2023-24 Budget and opportunity for members to provide further feedback on these.