

## Independent Advisory Council Intellectual Disability Reference Group Meeting Bulletin 17 May 2021

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The National Disability Insurance Scheme (NDIS) has an Independent Advisory Council (Council). Council gives independent advice to the National Disability Insurance Agency (NDIA) Board. This is a part of the NDIS Act 2013.

Council brings the participant's voice to the heart of the NDIS. It does this by using its four reference groups, to inform and improve its advice. Reference groups include members with expertise and experience in specific areas of disability.

The Intellectual Disability Reference Group (Reference Group) gives advice to the Council about ways to support people with intellectual disability to:

- live an ordinary life
- take part in their community
- be supported to make or contribute to making their own decisions

This Bulletin summarises the 17 May 2021 Reference Group meeting, led by:

- Ms Robyn Kruk AO, Council Principal Member and Reference Group Co-Chair
- Ms Leah Van Poppel, Council Deputy Chair and Reference Group Co-Chair
- NDIA Representatives and Council Secretariat.

### From the Reference Group Co-Chairs

Ms Kruk said the Reference Group will help people with intellectual disability access the NDIS, and reach their full potential just like everyone else. The Reference Group gives:

- Members the opportunity to influence NDIA policy and practice for people with intellectual disability
- NDIA staff access to people with disability and expertise in intellectual disability.

She noted the 2021-22 federal budget's investment to [improve the health and care of people with intellectual disability](#), will give a national plan for more consistent preventive health care for people with intellectual disability.

Ms Van Poppel spoke about the role the Reference Group plays to:

- progress matters on intellectual disability to the Council and other stakeholders
- inform Council advice to help people with intellectual disability in the NDIS.

## Reference Group member reports

Reference Group members reported on concerns they've heard from people with disability in their communities.

They said they've heard about:

- Issues with Independent Assessments (IAs). Some people with intellectual disability:
  - don't know enough about IAs and how they work.
  - have not been properly informed about participating in the IA pilot. Unclear communications from pilot assessors has left some NDIS participants, who are already in vulnerable situations, with limited supports, feeling unsafe or that they've done something wrong.
  - are impacted by having to re-tell their stories.
  - think that assessors should have more training, because they don't understand their disability, or how their disability links to the other things in their lives.
  - want the NDIA to do more work on reasonable and necessary supports in the context of IAs.
- The low COVID-19 vaccination numbers amongst people with disability, especially those living in residential disability homes.
- Shortages of safe and accessible Specialist Disability Accommodation (SDA) or Supported Independent Living (SIL) housing options for people with disability.
- Those people with disability who are in hospital and jail, need assistance to better understand NDIS funded supports that will help them when they move out of these settings.
  - There are concerns about the end of the [NSW Government's Cognitive Impairment Diversion Program](#), which aimed to divert people from the criminal justice system and connect them to the NDIS.
- Issues for NDIS participants around planning. With concerns that:
  - participants are getting less funding in their plans at review, with some plans rolling over.
  - the NDIS does not clearly communicate with participants at plan reviews.
  - participants need to regularly give proof of identity and evidence about their disability.
- The importance of a circles of support and/or micro boards.
- Concerns that some people with disability don't now know how to give feedback and complaints about service standards from a service provider or support coordinator.

## Update of NDIA work for intellectual disability

Mr Daniel Leighton is a Strategic Adviser at the NDIA. His work focuses on people with intellectual disability.

Mr Leighton noted that the [Information, Linkages and Capacity Building \(ILC\) program](#) has moved to the Department of Social Services (DSS). DSS is leading a review and is consulting broadly on future directions for ILC.

Mr Leighton said that the NDIA is focused on:

- Doing work to help participants make their own decisions. The NDIA is finishing its work on a Support for Decision Making Consultation Paper, which will be released soon.
- Doing work on IAs to make sure people with intellectual disability:
  - can answer the questions in the assessments
  - get help to answer the questions if they need it
  - not have other people answer the questions for them
  - only need to do the assessment once.
- Making Participant Decision Guides to give people with a disability information about supports they can use. These guides will:
  - tell people how to use supports and what they might cost to buy
  - help people talk about different supports at a planning meeting.

Ms Belinda Epstein-Frisch AM is Council's Independent Consultant. She said that:

- It is important for the NDIA to connect to the work DSS is doing for ILC.
- The NDIA work on support for decision making results from Council's 2019 advice to the Board '[Support for Decision Making in the NDIS](#)'.
- The Council has provided feedback on the Participant Decision Guides.

Reference Group members gave feedback on:

- The importance of the work on support for decision making to be properly implemented in the NDIS.
- The importance of accessible NDIS communications and engagement, including plain English, Easy Read, and alternative formats like video or animation.
- The need for people with intellectual disability to:
  - have more control and authority over their lives and support needs.
  - understand and access the services they need.
  - understand what good service is.
  - have family and friends around them who trust the decisions they make about their life.
  - be heard by NDIS staff (in some instances a carer is listened to over the person with disability).

## Reference Group priorities

Ms Van Poppel led discussions on priorities for the Reference Group. This includes advisory work it will complete in its three-year term, until June 2023. The priorities aim to provide solutions to home and living issues in the NDIS.

The Reference Group will finalise its priorities out of session. The priorities will align with Council's Work Plan and advice, and the NDIA Corporate Plan.

## More information on the Reference Group

The Reference Group will next meet in the second half of 2021. You can find out more about Council meetings at the [Council's website meeting page \(external\)](#). You can access advice from the [Council's website advice page \(external\)](#).

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