

Independent Advisory Council Intellectual Disability Reference Group Meeting Bulletin 28 October 2021

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 Council and the NDIA about ways to support people with intellectual disability to:

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

This Bulletin summarises the 28 October 2021 Reference Group meeting, led by:

- Ms Leah Van Poppel, Council Deputy Chair & Reference Group Co-Chair
- Dr Leighton Jay, Council Member.

The meeting included NDIA Representatives and Council Secretariat.

From Council's Deputy Chair & Reference Group Co-Chair

Ms Van Poppel acknowledged changes to the NDIS, and work done by the NDIA and Council, since the [Reference Group's last meeting on 17 May 2021](#).

Council made an Engagement Guide with rules to ensure that Reference Group meetings are inclusive and accessible for people with intellectual disability. Council will improve the Guide, based on feedback from members.

The Deputy Chair thanked members who added to the Reference Group work plan. The plan outlines priority work the Reference Group will do over three years, and links to [Council's 2021-22 work plan](#). The plan aims to find solutions to issues that affect people with intellectual disability in the NDIS, and to inform Council's advice.

Ms Van Poppel acknowledged members' earlier work [to develop Council's formal advice](#), during the Scheme improvement forums, held during June and July 2021.

Update on Council & Reference Group work

Council's Independent Consultant, Ms Belinda Epstein-Frisch AM, noted Council's [submission](#) to the Department of Social Services (DSS) on the [NDIS legislation review and public consultation](#). The Minister for the NDIS welcomed Council's further input to the proposed Bill at the [18 October Council meeting](#).

Ms Epstein-Frisch thanked Council and Reference Group members who helped give advice to DSS about improving the [Information Linkages and Capacity Building \(ILC\) Program](#). Council will keep working with DSS to make the ILC Program better.

Ms Epstein-Frisch noted the Reference Group will assist Council develop the following priority formal advice in 2022:

- 'Enhancing the effectiveness of behaviour support'
- 'Participants who are ageing'.

Reference Group Members said:

- Reference Group meeting documents and the Engagement Guide should be simplified made available in other accessible formats, like Easy Read.
- Pre-meetings help Reference Group members understand what the meeting will be about and plan ways to have a say.

Reference Group member reports

Reference Group members reported on matters for Council's and the Agency's attention, on behalf of people with disability in their communities. Members said:

- COVID-19 pandemic lockdowns and easing restrictions have positive and negative impacts on health, safety, mental health and social participation for people with disability.
- Using trusted disability workers may improve COVID-19 vaccination rates. Especially for people with intellectual disability and their carers, and among Aboriginal and Torres Strait Islander peoples.
- Some people with intellectual disability have had their NDIS plans reduced. This affects supports to manage health conditions and early intervention, as well as psychology, education, speech and support coordination.
- There are reports that functional capacity assessments for plan reviews need more proof and evidence.
- Some people with intellectual disability and combined disabilities experience an increase in plan reviews, automatic plan rollovers and delays in plan reviews.
- Some participants who use the [Administrative Appeals Tribunal](#) to review NDIA decisions find it hard to access advocates to support them. They also say information from the tribunal process is hard to understand.
- Some people in regional areas cannot access local area coordinators (LAC), which makes it harder to understand and access the NDIS.
- While technology enables supports and social participation, some people with intellectual disability cannot access technology, or find it hard use and get information online.
- Australian Disability Enterprisers should improve capacity-building supports that ensure economic participation and open employment, not only supported employment opportunities.
- There are delays with planning once a person with disability gets NDIS access.
- NDIS planners, state and territory governments, LAC and other service providers should have training to better understand intellectual disability, fetal alcohol spectrum disorder and acquired brain injuries.

- Supports and services from the NDIS and state governments should treat people with disability like they matter, and work together to help people move out of justice and hospital settings.
- People with intellectual disability want clear and consistent NDIS plans that include psychological supports.
- The NDIS Quality and Safeguards Commission needs stricter rules for providers that carry out and audit behaviour support plans.
- People with complex mental health issues and intellectual disability cannot find advocacy organisations to support their rights.
- People with intellectual disability who live in institutions with whole-of-life supports need additional supports to understand home and living options in the NDIS.
- Some parents with children with intellectual disability find it difficult to self-manage NDIS plans.

Update on NDIA's co-design work

Ms Jamie Lowe, Communications and Engagement General Manager, NDIA, outlined the [next steps for the NDIA's co-design work](#). She said the NDIA, Council and disability and carer representative organisations (DCROs) will form a co-design advisory group and confirm priority work for co-design.

She said that while co-design means different things to different people, it will ensure that the NDIA uses the experience of people in the disability community when they make improvements to the Scheme.

She thanked Reference Group members for their work at two virtual co-design workshops in September. This has helped the NDIA shape its co-design approach.

NDIA representatives and Council members encouraged further feedback from the Reference Group. Reference Group Members said:

- Co-design principles are needed to inform joint work. The NDIA should learn about co-design principles from organisations that do this work well.
- While co-design aims to engage all people with disability, there will be gaps. For example, people with acquired brain injuries, who are nonverbal and do not have access to phone, internet and email, would find it hard to help the NDIA with co-design work.
- The NDIA should release a schedule for its future co-design work priorities. This will ensure that the subject matter experts can plan to be engaged in the work.
- The NDIA needs to make sure it is transparent and informs the disability community of co-design topics and progress, and when wider consultation is needed.
- All NDIA co-design information and updates should be available in accessible formats. While the NDIS website is a great information hub, not every person with disability accesses information from websites.

Update on NDIA's consultations

Dr Sam Bennett, General Manager of Policy, Advice and Research, NDIA, explained work underway and planned as part of the consultations for:

- home and living, or [‘An ordinary life at home’](#).

- support for decision making, or [‘Supporting you to make your own decisions’](#).

Dr Bennett noted that the NDIA will publish post-consultation reports after all submissions are reviewed. The feedback from the submissions will help the NDIA co-design policies for home and living and support for decision making with the disability community.

Reference Group Members said:

- There are issues around housing affordability for people with disability.
- They want to be involved in future home and living consultations.
- People with disability need support for capacity building for home and living supports. For example, learning about how to raise issues with real estate agents.
- People with disability want to reduce their reliance on traditional models of home and living support, used over a long period of time.
- People with intellectual disability, who are in and out of the criminal justice system, do not have stable housing and are at risk of neglect and abuse.
- There needs to be safeguards around behaviour support plans. Especially when there is a transition in supports or when experts like psychologists, support coordinators, service providers or planners change roles.
- Support for decision making should consider the supports for people with complex communication access needs, and help these people to build capability and capacity to make, act and honour their decisions.

More information on the Reference Group

The Reference Group will keep working out of session to progress its work, before it formally meets again in 2022. 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 \(external\)](#).

Council publishes an Easy Read version Bulletin. This is part of its commitment to accessibility.