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# Reference Group meeting bulletin – 22-23 November 2023

## Intellectual Disability Reference Group

The [Intellectual Disability Reference Group](#) (Reference Group) met recently. This bulletin summarises the meeting that took place in Melbourne on 22-23 November 2023.

The Reference Group advise the Independent Advisory Council (IAC) on issues affecting people with intellectual disability. This informs the IAC's advice to the National Disability Insurance Agency (NDIA) Board on how to improve the National Disability Insurance Scheme (NDIS).

[Ms Leah van Poppel, IAC Principal Member and Reference Group Co-chair](#), led the meeting.

### From the Reference Group Co-chair

Ms van Poppel highlighted work the Reference Group have done since their last meeting on [16-17 August 2023 \(DOCX 95KB\)](#). This includes their work to determine what they will focus on for 2024.

Ms van Poppel welcomed Ms Samantha Jenkinson, the IAC's new Senior Independent Advisor. She will be responsible for supporting the work of the IAC, including development of the IAC's advice for the NDIA Board.

### What Members have heard in their community

Reference Group Members reported on matters for the NDIA's attention, relating to:

#### NDIS access and planning

- Concern that some people with disability are not gaining access to the NDIS because they incorrectly filled in their [Access Request Form](#).
- Calls for face to face planning meetings, particularly for participants who may be at risk.
- Reports of young people finding it difficult to access the NDIS because they lack personal identification.



## NDIS service and supports

- Reports some participants find it hard to contact the NDIA and let them know about a change in their circumstances.
- Concern that some participants with intellectual disability have limited choice and control over how and where they receive supports, such as at home or via a day program.
- Reports some people with disability are not using their NDIS funding. This is because they cannot find quality support workers.
- Calls for support workers to have better training on how to implement behaviour support plans.
- Calls for the NDIA to rethink [Capacity building supports budgets](#) and how they categorise therapy in NDIS plans.
- Calls for the NDIA to educate providers about quality home and living supports for people with disability.

## Providers and disability organisations

- Concern in the community that it is sometimes difficult to make a complaint about a provider. This makes it hard if providers are doing the wrong thing.
- Reports that some providers are not supporting ageing in place. Instead, they encourage participants with intellectual disability and age-related illnesses to move into aged care, even if they are not over 65 years old.
- Some providers are building Specialist Disability Accommodation (SDA) close together. This may isolate people with disability from their community.
- Most participants in contact with the justice system find it hard to find providers to support them.
- Issues around the quality of service delivered by some support workers. There is concern that some see their job as 'watching over' the person with disability rather than genuinely engaging with them.
- Reports that some providers seek guardianship orders for young participants. This is when they have taken control of their NDIS plan. This mostly happens to those who have few informal supports.
- Calls for long-term funding for peer and self-advocacy organisations so they can better help participants with supported decision making.

## Reform for outcomes, NDIA's co-design projects

IAC representatives shared their work on the NDIA's [Reform for outcomes co-design activities](#).

Members discussed co-design work on better planning in a session led by Mr Gavin Burner, Intellectual Disability Reference Group Member. General feedback advocated for more in person planning meetings and better training for planners. Members also highlighted that NDIS plans should provide supports based on a participant's needs and not if the participant uses their supports or not.

Mr James Manders, IAC Member, led a discussion with Reference Group members about the co-design work on fraud. Members shared that there needs to be more education and support for participants to



understand fraud. There were also calls for compulsory registration of support coordinators and harsher consequences for providers who do the wrong thing.

Members discussed the co-design work on evidence-based supports in a session led by Ms van Poppel, the IAC Principal Member. Members advocated for a simplified NDIS website and more information on how to find good providers. They also discussed the importance collecting evidence to measure if participants are meeting their goals.

Ms Sylvana Mahmic, IAC Member, led a discussion on co-design work to improve the NDIA's workforce capability. Members advocated for more NDIS planners and for planners to receive more training. They also discussed how NDIS planners can support decision making and help build a participant's capacity.

Members discussed co-design work on independent living in a session led by Dr George Taleporos, IAC Member. They highlighted what people with intellectual disability need to live independently and the challenges they face.

Members discussed co-design work on plan flexibility and reflected that many participants have trouble understanding how the NDIS funds supports. Members also advocated for emergency funding participants could access within 24 hours and more support for participants waiting for plan reassessments.

## Update on Easy Read NDIS plans

The NDIA shared an update on the work they are doing to offer participants NDIS plans in Easy Read. Members explained that the structure of NDIS plans needs to change to suit people with intellectual disability. The Reference Group also advocated for a toolkit of options for presenting NDIS plans. They recommended the NDIA consider the tools and information some community groups have created. These resources have been successfully used to engage vulnerable people in NDIS planning.

## Work on the Engagement Guide

The Reference Group discussed their current Engagement Guide. The guide explains how they run meetings. Members suggested ways the NDIA can make it easier for people with intellectual disability to take part in meetings:

- Give everyone at the meeting the Easy Read version of the meeting papers. This version should only include information the members need to know.
- Make sure meetings are culturally safe and support people to have a say.
- Make sure everyone talks slowly and does not use big words.
- Include more breaks and time for people to talk about ideas in smaller groups.
- Make sure people have enough support to get to and take part in meetings.



## More information on the Reference Group

The Intellectual Disability Reference Group will next meet in 2024. Find out more about Reference Group meetings and bulletins at [the IAC website](#). You can also access [IAC advice here](#).

**The IAC publishes an Easy Read version Bulletin. This is part of its commitment to accessibility.**