

## Independent Advisory Council Intellectual Disability Reference Group Meeting Bulletin 5 April 2022

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This Bulletin summarises the recent meeting of the [Intellectual Disability Reference Group](#) (Reference Group). The Reference Group gives advice to the Independent Advisory Council (Council) to the National Disability Insurance Scheme (NDIS). Its advice aims to support people with intellectual disability:

- to live an ordinary life
- take part in their community
- have supports to make their own decisions.

### From Council's Principal Member

Leah Van Poppel, who is Council's Principal Member, led the meeting. Leah welcomed newly appointed Reference Group Co-Chair Sam Paior. She acknowledged Reference Group members' [work since their last meeting in October 2021](#), to progress priority work and advice.

### Update on Council & Reference Group work

Leah noted progress made by the Co-Design Advisory Group as part of the [next steps for co-design](#). She said the [NDIA recently released a new engagement framework](#). She noted productive meetings held with the co-design steering committees for the following projects:

- Information Gathering for Access and Planning
- Home and Living
- Support for Decision Making
- Participant Safety.

Reference Group Members said:

- Co-design should include people with intellectual disability and complex communications needs (CCN), ensuring projects are accessible for all.
- All NDIA co-design information and updates should be available in accessible formats. For example, Easy Read.
- Co-design principles should inform joint work. The NDIA should learn about co-design principles from organisations that do this work well.
- Frameworks for engagement should address gaps that exist in traditional engagement methods. Especially for people with CCN.

Council's Independent Consultant is Belinda Epstein-Frisch AM. Belinda noted progress made on Council's formal advice '*Equity in the NDIS: improving access and outcomes for diverse communities*'.

Reference Group members said:

- Council should include people with intellectual disability, who often face equity challenges, in its formal advice *'Equity in the NDIS: improving access and outcomes for diverse communities'*. This advice should also consider intersectionality.
- There should be regular progress reports on how the NDIA implements Council's formal advice.

## 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, including:

- Continued challenges with plan reviews and funding:
  - Reports of significant reductions in plans following a review, even after providing functional capacity assessment evidence.
  - The NDIA does not give some participants a copy of their plan.
  - Over-the-phone plan reviews do not always work for people with intellectual disability.
  - Increased delays in the completion of plan reviews and changes to existing plans without explanation or justification.
  - Some people with disability are in hospital waiting for NDIS plan approval.
- As states and territories live with COVID-19, there is still anxiety about the virus and a shortage of disability support workers in the community.
  - The NDIA's rapid antigen kit distribution to residential disability care settings works well.
- Increased reports that recent floods have affected supports for NDIS participants:
  - Reports of housing challenges, with many living in unsuitable short term accommodation.
  - The NDIA should strengthen its disaster management plans to best respond to participants' needs.
  - Challenges in accessing supports, when supports are already thin on ground. There is a need for trauma informed supports.
- Continued challenges around home and living:
  - Increased reports on funding reductions in home and living.
  - New Specialist Disability Accommodation (SDA) is not being built to robust standards.
  - The NDIA should share data on where participants live to assist state governments determine where community housing is required for future planning.
  - Reports of reducing supported independent living (SIL) funding without explanation or justification.
  - Reports that some people with SIL are exhausting funding because of COVID isolation supports.
  - Concerns that new accommodation being built is still focused heavily on shared / group housing.
- Reports that people with intellectual disability want to vote in the upcoming federal election. But they do not have access to information that helps them understand the election or supports that help them vote.

- A call for more open employment opportunities for people with intellectual disability, not only supported employment opportunities through Australian Disability Enterprises.
- Continued NDIS support challenges with the justice system:
  - Some people in the justice system find it hard to get NDIS supports.
  - There should be more NDIS support outreach to prisons.
  - 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.
- Reports that the [Administrative Appeals Tribunal](#) process is hard for those who cannot self-advocate. The information from the tribunal process is hard to understand.
- The NDIS Quality and Safeguards Commission needs stricter rules for providers that carry out and audit behaviour support plans.

## Update on Support for Decision Making

Anna Burke is Assistant Director of Agency Policy at the NDIA. Anna explained:

- Work underway to co-design a Support for Decision Making policy and implementation plan with the disability community, including the work of the Steering Committee.
- What the NDIA learnt from the [‘Supporting you to make your own decisions’](#) consultation.
- Ways the NDIA is putting public feedback into action.

Reference Group Members said:

- They want practical outcomes from the co-design project for people with disability.
- All NDIA co-designed policies, associated information and updates, should be available in accessible formats. For example, Easy Read.
- People with intellectual disability should be able to access stories that show how support for decision making works for different people.
- People with intellectual disability need the right supports, tools and adjustments to make their own decisions.
- There are ongoing challenges around nominees and guardians acting as decision makers for people with disability, rather than capacity builders.
- Support for decision making should consider the capacity building support needed for people with CCN to make their own decisions.
- Support for decision making work should always consider the voice of people with CCN.
- Some universities and organisations are doing important research about supported decision making and behaviour supports.
- 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.
- Concerns about the quality of some behaviour support plans and plans being developed before or in absence of a meeting with the person.

- The importance of knowing a person with disability well enough to assist with supported decision making. For example, a support worker may know a person with disability as well as family or friends.

### **More information on the Reference Group**

The Reference Group will next meet in mid-2022, and will keep progressing its work between meetings. Find out more about Reference Group meetings and bulletins at [Council's website](#). You can also access [Council's advice here](#).

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