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Reference Group meeting bulletin – 12 October 2022

Intellectual Disability Reference Group

This Bulletin summarises the recent meeting of the Intellectual Disability Reference Group (Reference Group). The Reference Group met on 12 October 2022.

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

[Ms Leah van Poppel, Council Principal Member and Reference Group Co-chair](#), led the meeting. Ms Sam Pairor, Council Member and Reference Group Co-chair helped Ms van Poppel run the meeting.

From Council's Principal Member and Reference Group Co-chair

Ms van Poppel acknowledged the work the Reference Group has done to progress advice [since they last met](#). This includes work to develop advice for the National Disability Insurance Agency (NDIA) Board. This advice aims to improve positive behaviour supports in the NDIS and is still in development.

She noted that the NDIA will soon welcome Ms Rebecca Falkingham, as Chief Executive Officer. She added that Mr Kurt Fearnley, the incoming NDIA Board Chairperson, has expressed enthusiasm to attend Council and Reference Groups meetings.

The Reference Group welcomed representatives from Inclusion Australia. They are helping the NDIA co-design some of its policies.

Update on NDIA supported decision making policy

The NDIA updated the Reference Group about its work on the supported decision making policy. Reference Group Members noted:

- The NDIA is on the right track with its work but stressed the policy needs to work well in practice.

- The policy should reflect the needs of participants with intellectual disability. It should also reflect the population of participants who need support for decision making at some point in their lives.
- The NDIA should ensure information about the policy includes people with intellectual disability. The information should also include their families and people from diverse backgrounds, for cultural safety.
- The NDIA should directly communicate with people with intellectual disability and consider a person's complex communications needs.
- The NDIA should consider how the policy works with other systems and supports. They should work with other government organisations to improve supported decision making.
- The policy should balance the need for capacity building supports and dignity of risk for people with intellectual disability.
- The policy should consider the rights of children and young people. It should also think about supports young people with intellectual disability and their families need.
- It would be ideal if the NDIA staff with intellectual disability were a part of the policy implementation.

Update on the NDIA home and living policy

- The NDIA updated the Reference Group on its work on the home and living policy. The policy should clearly define the role and responsibility of a 'home and living partner.'
- There is a need for a trusted person to support participants with their home and living supports.
- The policy should highlight options for home and living supports that support independence. The policy should give people with intellectual disability time to understand their options.
- Rules for home and living should promote choice and control for participant.
- The policy should allow for a flexible approach to home and living supports.
- The NDIA should consider the role of Australia's Disability Strategy as part of its policy.
- The policy should consider participant safety and people with positive behaviour supports.
- Home and living supports should consider people in the justice system and crisis situations.
- There is a need to build peer led organisation's capacity to support people with disability who are exploring their home and living options.

Inclusion Australia asked for feedback about policies release dates. Members agreed the NDIA should release the policies as soon as possible and regularly update them as things change.

Reference Group Members' community reports

Reference Group Members reported on matters for the NDIA's attention. Members provide these reports on behalf of people with disability in their communities. The reports give the NDIA CEO and staff understanding about issues from the ground. They also give the NDIA the opportunity to respond to themes, concerns, and opportunities raised by Members.

Key matters Members noted related to access and planning, service and supports, providers and the disability network:

NDIS access and planning

- General concern about the NDIS planning process and plan reductions after review. Specific issues around automatic plan extensions without participant knowledge. Also, issues with marginalised/diverse groups who find it hard to access the NDIS.
- Some people with intellectual disability experience lengthy Administrative Appeals Tribunal AAT processes. Concerns that some people using AAT process find it hard to access advocacy services. In some states, there are no advocacy services.
- Concerns around the way that some organisations put in place positive behaviour support plans.

NDIS service and supports

- General concern about home and living supports. There is a lack of understanding about supports for specialist disability accommodation (SDA) and supported independent living (SIL). There is also concern around how providers use SDA to improve business returns.
- The availability of suitable public housing should improve.
- General concern about how the NDIS works alongside other services that support Australians. For example, health, education, housing, justice, child protection, family, and domestic violence. Reports that people with intellectual disability and other disabilities are falling 'between the cracks' of systems.
- Concern that some people with intellectual disability do not have trusted supports in their life. These people say it is hard to find trusted providers and support people.
- Concern that some planners do not promote school leaver employment supports funding. This NDIS support aims to build a participant's ability and confidence to enter the workforce.
- Reports of limited access to speech pathologists who assist with augmentative and alternative communication (AAC) devices.
- The NDIS should look at packaging individual NDIS funds for First Nations communities. This may allow collective choice and control and use of NDIS plans despite thin markets.
- Concerns that some ageing parents are in unsustainable caring arrangements. These parents want to know how the NDIS will help their adult child with disability in the future. Especially if the parent can no longer give care because of old age or declining health.

Providers

- There needs to be greater accountability and auditing of some providers.
- Sometimes providers lock participants into supports over a period. For example, they agree to give supports over 12 weeks. This leads to rapid spending of participant plans.

Disability community

- The NDIA should improve the way it communicates and shares information with the disability community. Especially, people with complex communications needs. These people are unable to use speech to meet all their communication requirements.
- General feedback about challenges with support workers. People with disability want quality and stable supports in their life. They also want to be able to access supports wherever they live, for example rural and remote areas.
- People with intellectual disability want inclusive employment opportunities. They also want to learn more about their job options. The NDIA should be a role model by employing more people with intellectual disability.
- There should be more supports to promote the importance of oral health for people with intellectual disability. People with intellectual disability have more oral health issues.
- The importance of programs like the Up the Hill Project. This project allows people with intellectual disability to experience university life.
- Concern about the future of Western Australian Individualised Services (WAIIS). WAIIS has indicated they will close by the end of June 2023 due to funding issues.

More information about the Reference Group

The Reference Group will next meet in 2023. They will keep developing their advice between meetings. Find out more about Reference Group meetings and bulletins at [Council's website](#). You can also access [Council's advice here](#).

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