

## Independent Advisory Council Intellectual Disability Reference Group Meeting Bulletin 22 June 2022

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This Bulletin summarises the recent meeting of the [Intellectual Disability Reference Group \(external\)](#) (Reference Group), held 22 June 2022. The Reference Group gives advice to the Independent Advisory Council (Council) to the NDIS. The Reference Group's 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.

### From Council's Principal Member & Reference Group Co-chair

Leah Van Poppel is Council's Principal Member and Reference Group Co-chair. Ms Van Poppel led the meeting acknowledging it was the first time the Reference Group has met face-to-face since the COVID-19 pandemic. In commitment to creating accessible meetings, Council provided Easy Read meeting packs with easier to understand information to allow members to follow discussion areas.

Ms Van Poppel discussed Council's work to progress its advice *'Equity in the NDIS: improving access and outcomes for diverse communities'* to the National Disability Insurance Agency (NDIA) Board. Members said that the advice should include all groups that face equity issues in the NDIS, not just Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD), and LGBTIQ+ communities.

### 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:

- Some specialist support coordinators give planners regular reports about a participant's progress and funding utilisation. This helps them make sound decisions about supporting the participant to use their plans.
- Continued challenges for NDIS participants seeking supported/open employment.
  - Advocacy and lobbying in Western Australia has resulted in a provider there being given support for a longer transition out of business. This will support those attending the Australian Disability Enterprise (ADE) to seek alternative employment. This situation has highlighted broader issues with how ADEs support NDIS participants.
- Reports that this year's floods continue to affect supports for NDIS participants.
  - Accessible and affordable housing challenges, with many living in unsuitable short-term accommodation.
  - Challenges connecting people who move from one home to another with supports, as well as issues for these people accessing supports in thin markets.
- Continued challenges with NDIS planning, plan reviews, and funding.
  - Reports of significant reductions in plans following a review.

- Perceived inconsistency around planning decisions for funded supports, including what is reasonable and necessary.
- COVID-19 has caused underutilisation of participants plans. Participants are concerned this may affect funding allocated at next plan review.
- Some are seeing disproportionate and significant reductions in capacity building supports, as compared to core supports.
- Suggestions the NDIA should update rules for using NDIS plans for smart phones, given some people with visual impairment need the latest technology to access online supports.
- People involved in the justice system want access to a NDIS planner/plan earlier, and a better understanding of what NDIS and justice can provide.
- Some people with complex disability and/or mental health issues find it harder to have a planning meeting and to plan for a planning meeting.
- Some people with disability still do not know the rules around accessing Rapid Antigen Tests in their NDIS plans.
- Self-managed participants need training on ways to organise their supports and maximise the value of their plans.
- Reports that some self-managers have had capacity building parts of their plan moved from self-managed to NDIA-managed without consent.
- Reports some providers find it hard to deliver planned supports because of funding gaps and pricing pressures.
- NDIS participants with intellectual disability need supports to expand their social connections, such as peer groups and other community-based networks, so do their parents.
- Greater cooperation needed between the NDIS Quality and Safeguards Commission and the NDIA to ensure participants get good and safe outcomes.
  - Some providers interact with people claiming to be someone's nominee/guardian when there is no evidence of those arrangements, which causes issues around privacy.
  - NDIS funding needs to make sure behaviour support plans are well supported and done properly.
  - Increased reports that people with intellectual disability are not being provided individualised supports, rather they are in segregated day programs that do not align to their goals.
- Continued focus on [Administrative Appeals Tribunal \(external\)](#) (AAT) cases and issues with the AAT process:
  - Reports that AAT works well for people who are well resourced or supported, and not so well for people who do not have supports.
  - Some states do not have access to funded advocacy services to support people with NDIS plan appeals. Other states have long waiting lists for advocacy services.
  - NDIA should look at moving to an earlier conciliation approach to save on time, money, and emotion associated with AAT reviews.
- Continued issues around workforce shortages.
  - Providers and people with disability face severe shortage of good support workers.
  - Increased reports the disability sector providers are competing for staff.
  - Shortage of quality behaviour support practitioners, with long waiting lists for their services.

- Continued challenges around home and living.
  - Increased reports of funding reductions in home and living for people with intellectual disability.
  - Some plans have reportedly had supported independent living (SIL) funding reduced without explanation or justification.
  - Workforce shortages in the SIL and the accommodation environment.

## Behaviour supports update and feedback session

The Reference Group heard about Council's advice on behaviour supports, which is currently under development. Members gave their feedback about solutions to systemic issues with behaviour supports, quality factors for positive behaviour support (PBS) plans, and PBS practitioners, and ways behaviour supports work with the justice system.

Reference Group Members noted:

- The NDIA should coordinate and implement PBS plans, and the NDIS Quality and Safeguards Commission should monitor and review the quality of PBS plans.
- Cooperation needed between systems for better support coordination and evidence of efficacy of PBS. For example, the NDIA, Australian Health Practitioner Regulation Agency (Ahpra), and other services.
- Opportunities for the NDIA to use NDIS Pricing Arrangements and Price Limits to influence sector change around PBS plans, rewarding providers for best practice.
- People with restrictive practices in their PBS plans should have funding for a specialist support coordinator. This will support better outcomes.
- The NDIA should recognise the important role specialist support coordinators play in ensuring outcomes from PBS plans.
- Providers should not claim funding when they have not worked on a PBS plan or worked as part of a clinical team to achieve outcomes for a participant.
- Some providers/practitioners use PBS plan funding for basic systems of support in their accommodation settings, which exhausts a participant's funding for PBS.
- The need to define behaviours of concern and inform people with disability about which behaviours need supports, and the benefits supports give.
- The need for informed selection of PBS practitioners and raising awareness about what makes a quality practitioner.
- PBS practitioners should have set qualifications/training standards.
- PBS plans with restrictive practice and guardianship, should use strength-based models to implement supports for a limited time and with minimal restrictions.
- Revisiting past work done by states and territories, before transition to the NDIS, on strength-based models of PBS may provide solutions to current issues.
- People with intellectual disability need to be at the centre of a PBS plan. They need genuine choice and control and supported decision-making processes.
- The NDIA should consider the funding and education required to implement PBS plans, including the time needed to train workers and families.
- The need to look at environments that contribute to behaviours of concern.
- The NDIA should look at ways to provide culturally informed practices as part of PBS plans for Aboriginal and Torres Strait Islander people and communities where there are no registered providers.
- There are some examples of the criminal justice and other systems working well together, for example justice advocacy and community safety programs.
- The NDIS should support people in the justice system and consider that they are often a part of transient populations that cannot access supports.

## Co-design update and feedback session

Leah Van Poppel discussed the progress and milestones of the NDIA's [co-design activities and projects \(external\)](#) for:

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

Ms Van Poppel invited Reference Group members to give feedback about who to involve in co-design and how to best engage people with intellectual disability. Members said:

- People with intellectual disability and complex communications, access, and support needs, should lead and be a part of co-design work and processes. Co-design work should consider including the support networks/informal supports around these people.
- Evaluation of Information Linkages and Capacity Building programs about support for decision-making can inform evidence-base and practice knowledge.
- The NDIA should consider those people with intellectual disability who do not use the internet, email etc., and use different ways to connect with these people.
- The NDIA should clearly communicate where work is already underway and part of its co-design work in home and living, like the demonstration pilot project.
- All NDIA co-design information and updates should be available in accessible formats. For example, Easy Read and video case studies that give real-life examples of support options.
- The NDIA's co-design work in home and living should look at:
  - ways to always include people with intellectual disability.
  - ways to have discussions to understand where a person with disability wants to live rather than finding people to fill spots in houses.
  - ways to continue funding services and supports for people who regularly move from place to place.
  - central housing services, advisory or advocacy groups, where people with disability can go and get information they need.
  - ways to minimise a participant's need to repeatedly tell their story or complete paperwork for NDIS.
  - providing options that are person-centred, built around supported decision-making principles and are accessible.
  - including those people/organisations that give trusted independent information to people with intellectual disability about home and living supports.

## More information on the Reference Group

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

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