

Independent Advisory Council Home and Living Reference Group Meeting Bulletin 17 May 2022

This Bulletin tells you about the recent meeting of the Home and Living Reference Group (Reference Group). The Reference Group met on 17 May 2022.

The Reference Group gives advice to the Independent Advisory Council (Council) to the National Disability Insurance Scheme (NDIS). Its advice focuses on home and living supports for people with disability to:

- live independently
- choose where they want to live
- do things for themselves in their homes
- be included in the community they live.

[Ms Leah Van Poppel, Council Principal Member \(external\)](#), and [Dr Leighton Jay, Council Member and Reference Group Co-chair \(external\)](#), led this meeting. The meeting included National Disability Insurance Agency (NDIA) Representatives and the Council Secretariat.

Updates from Council's Principal Member & Reference Group Co-chair

Ms Van Poppel acknowledged the traditional owners of the various lands people were meeting on, and the extensive knowledge that members bring to the Reference Group. She noted significant NDIS changes have occurred [since the last Reference Group meeting in October 2021 \(external\)](#), including a [focus on co-design \(external\)](#).

Dr Jay asked for members' feedback on ways the NDIA can empower participants to have greater choice and control over their supports and support delivery.

Update & discussion on co-design

Ms Van Poppel noted the [NDIA Engagement Framework \(DOCX 4.7MB\)](#) for [work on co-design \(external\)](#). She acknowledged the need for consistency, process, and evaluation, so that co-design is accessible and happens on good timelines.

Ms Van Poppel noted productive co-design meetings held, and that the Co-design Steering Committees provide strategic advice, governance, and oversight for the co-design and development of four key policies:

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

Members noted:

- There is community goodwill that the NDIA is genuinely focused on co-design. Including creating co-design processes that address community concerns while ensuring input from the widest variety of people.
- Co-design requires a balance of momentum and pace. The NDIA should maintain momentum on co-design outcomes while ensuring that the pace of work does not exclude people.
- While 'co-design' may be an over-used word its core principles are important. Especially that co-design is a continuous and iterative process of testing, adjusting, and engaging different people.
- Co-design should engage community participation at the start of the project design, research, and prototyping, or it runs the risk of losing trust with the community.
- Co-design does not stop at a certain point in the process, instead it carries on past the final product.
- Co-design work should include the [NDIS Quality and Safeguards Commission \(external\)](#).

Reference Group members' community reports

Reference Group members reported on matters for the NDIA's and Council's attention, on behalf of people with disability in their communities, including:

- Continued challenges with supports, funding and plan reviews for home and living.
- Increased reports about plan reductions for people who live in Specialist Disability Accommodation (SDA) or have supports for Individualised Living Options (ILO) and Supported Independent Living (SIL). This extends to capacity building supports.
- Inconsistencies with NDIS funding and decisions made by planners, and lack of planner training and/or awareness about ways to start conversations around home and living supports with a participant. The NDIA should get back to face-to-face planning for people with disability.
- Some participants do not understand their options for NDIS home and living supports and need more guidance and information that is easier to understand.
- Reports that the NDIA takes a long time to complete a review process, especially plans for SIL and SDA.
- Reports that a lack of robust SDA in some areas, leads participants to accept improved liveability SDA dwelling supports. When these participants need safety or assistive technology equipment installed related to their disability the SDA-provider cannot claim above the improved liveability standard.
- Reports that sometimes planners tell blind participants with guide dogs, who test their eligibility for SIL, that they can only get SDA supports.
- Increased reports the NDIA Home and Living Panel is reducing funding in higher-value plans, even if a participant has had previous plans. Reports that they cite lack of verifying information for their decision.
- Increased reports the NDIA is reducing larger plans without warning and/or a step-down approach for people with psychosocial disability who need dependable home and living supports. This also affects their families/carers, many of whom are ageing, who have long advocated for their child's home and living supports.
- Reports regarding inappropriate provider behaviour and practice, including an imbalance of power with service providers, confounding SDA and SIL issues. Participants should be in control of their services and only pay for services they get.

- Some people aged 65 years feel they get less options for housing. Also, concerns that people over 65 years old who are entering aged care for the first time lose their NDIS eligibility.
- NDIS online participant feedback methods seem overrun, because they do not appear to triage and respond to time-critical enquiries in a consistent or timely manner. For example, a participant waits for approval for essential equipment (power wheelchair) when they know another participant with a similar physical disability has had an outcome.
- People waiting for home and living supports or having their plans undergo appeal, are sometimes at risk or in vulnerable settings. The review and appeal processes are traumatising, time consuming and costly.
- The NDIA could consider using innovative ways to gain evidence and understanding about a participant, like daily video diaries that show their daily support needs, to make clear, consistent, and timely plan decisions.

NDIA's work on participant empowerment & greater choice and control

NDIA Representatives led discussions with Reference Group members about ways the Agency can increase participant empowerment with providers in the context of home and living supports. This included ways participants can build their capacity, for greater control, and have a greater say about how they get supports.

Members noted:

- Concerns around language in operational guidelines. Some people feel that a document marked 'plain English' could be condescending for some people for whom English is a second language.
- The NDIA should use real-life examples of best-practice relationships between SIL providers and participants to guide the direction of this work.
- Where participants have shared SIL supports, they should have the same choice and control to negotiate their service agreement as individuals do.
- The role of the provider in shared accommodation is not defined. It would be ideal if providers helped to both support participants set their home and living goals and put support workers in a place.
- Large and established providers need to recognise that participants can make their own decisions rather than providers making decisions in a participant's best interest.
- Service agreements need to be in plain English.
- The NDIA needs to understand a family's needs and ensure families are being listened to, especially those families caring for a person with psychosocial disability.
- Some people may not feel comfortable speaking in a working group with providers, especially if they feel there may be repercussions.
- Discussions on home and living should take place with participants and their families, and not providers. The conversation should move away from what the provider thinks, to how the participant would like to get their supports.
- There needs to be a reduction in stated supports and greater flexibility for participants.

NDIA's work on new home and living examples – 'Would we fund it?'

NDIA Representatives noted their work to develop new home and living examples. The examples or guides aim to inform participants about what the NDIA will fund around home and living supports. The NDIA invited feedback from members on the current four guides under development as well as suggestions for future 'Would we fund it?' guides.

Members noted:

- The guides show NDIA transparency around decision making.
- The need to include more 'Would we fund it?' examples for different home and living support options, including single living.
- Concern that planners may use the guides as prescriptive rules for funding when they should use them as examples only.
- The examples should link to [Article 19, Convention on the Rights of Persons with Disability: Living independently and being included in the community \(external\)](#).
- Concern the current examples focus on living in group homes, and do not encourage people to explore other home and living options.

More information on the Reference Group

The Reference Group will next meet in the first quarter of 2022-23 and keep progressing its work 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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