

## Independent Advisory Council Home and Living Reference Group – Meeting Bulletin 5 October 2021

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The National Disability Insurance Scheme (NDIS) has an Independent Advisory Council (Council). Council gives independent advice to the National Disability Insurance Agency (NDIA) Board. This is a part of the NDIS Act 2013.

Council brings the participant's voice to the heart of the NDIS. It does this by using its four reference groups, to inform and improve its advice. Reference groups include members with expertise and experience in specific areas of disability.

The Home and Living Reference Group (Reference Group) gives advice to Council about 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.

This Bulletin summarises the 5 October 2021 Reference Group meeting, led by:

- Ms Robyn Kruk AO, Council Principal Member & Reference Group Co-Chair
- Dr Leighton Jay, Council Member & Reference Group Co-Chair.

The meeting included NDIA Representatives and Council Secretariat.

### From the Principal Member

Ms Kruk acknowledged the major changes to the NDIS, and work done by the NDIA and Council, since the [Reference Group's last meeting on 13 May 2021](#).

She thanked members who added to the Reference Group work plan. The plan outlines priority work the Reference Group will do over three years, and links to [Council's 2021-22 work plan](#). The plan aims to find solutions to home and living issues in the NDIS, and to inform Council's advice.

Ms Kruk acknowledged Reference Group members' involvement in co-design workshops with the NDIA, Council and the disability community. The workshops held in September 2021, fulfil outcomes from [July's Disability Reform Ministers' Meeting](#). The workshops aim to:

- strengthen relationships between identified stakeholders.
- identify projects that identified stakeholders can progress through co-design.

She also acknowledged members' earlier work:

- to develop Council's formal advice, '[Strengthening Scheme Reforms to Access and Planning](#)'.
- during the Scheme improvement forums, held throughout Q4 2020/21.

## From the Reference Group Co-Chair & Council's Independent Consultant

The Reference Group Co-Chair, Dr Jay, commended the NDIA's public consultation on Home and Living, which will inform its new policy. Council was involved in the consultation, which closed in September 2021.

Dr Jay noted that Council met with the Department of Social Services on the [NDIS legislation review and public consultation](#), which closed on 7 October 2021. He acknowledged DSS' genuine consultation efforts, but said the consultation period was too short.

Council's Independent Consultant, Ms Belinda Epstein-Frisch AM, said that Reference Group representatives had met with the NDIA CEO and senior staff to understand how they make decisions about home and living supports.

Ms Epstein-Frisch said that Council had refreshed its Home and Living Policy Sub-Group, previously called Home and Living Advisory Panel. The Sub-Group will:

- help the NDIA develop its home and living policy, guiding it through post-consultation.
- co-design work with the NDIA to improve its policy approach.

Ms Epstein-Frisch said the NDIA will study over 270 submissions to its consultation on Support for Decision Making. They will report to Council about its findings in November 2021. The results will help the NDIA co-design its Support for Decision Making policy with the disability community.

## Reference Group member reports

Reference Group members reported on matters for the Council's and Agency's attention, on behalf of people with disability in their communities. Members said:

- NDIS participants are having their plan budgets reduced, with funded supports reduced without explanation.
- There are reports of plan reductions:
  - for people who live in Specialist Disability Accommodation (SDA), or have supports for Individualised Living Options (ILO) and Supported Independent Living (SIL)
  - forcing people to consider other living options, like group homes, even when this is not suitable or sustainable
  - leaving people homeless or in other vulnerable settings, while having to appeal their plan decision
  - for people with psychosocial disability and/or behaviours of concern, which may increase safety risks for participants and providers
  - despite a rise in the burden of proof and evidence requested by the NDIA
  - and inconsistent decisions, being linked to 'Scheme sustainability'.
- The NDIA needs to make clear, consistent and timely plan decisions, driven by the values of control and choice, and social and economic participation.
- Delays in plan reviews mean that NDIS participants are running out of funds in vulnerable settings, like hospitals in COVID-19 hotspot areas.
  - The NDIA needs to address medium term accommodation.
- NDIS participants want to better understand:

- the evidence the NDIA uses to make reasonable and necessary decisions based on an individual's needs
- the appeals process, to save on time, trauma and costs
- who to contact when plan delays cause service disruptions, or they need other supports.
- Some NDIS participants lack supports to move out of group homes and institutions, like justice and/or health. The NDIA needs to work together with states and territories and health sectors on interface issues, while also stopping 'systemic abuse'.
- There is a need to educate people with disability and the NDIA about the cost-saving benefits of self-managing home and living supports, using case studies about NDIS participants.
- The NDIA should consider future care planning for people with disability, especially those with psychosocial disability and who are ageing. There are some reports that providers are removing services from participants with complex needs.
- Australians understand that the NDIA needs to deliver a financially sustainable Scheme, but say this should not undermine outcome values for participants.
- Some planners give NDIS participants incorrect information about ILO supports and guidelines, and flexible core supports available to those who self-manage or plan-manage.
- Co-design should cut horizontally across all NDIA business areas for shared understanding of the common goal, and intersectionality.
- The NDIA needs to review its definition of SIL, and help participants understand what SIL means for their life and independence, in the long-term.

## NDIA update on home and living work

NDIA Representatives updated the Reference Group on NDIA work underway on home and living, and work planned for next year. This includes the NDIA's recent Home and Living consultation and changes to operating guidelines, as well as known 'pain points' in the home and living space. They outlined decision-making processes, and the planned home and living demonstration projects and policy.

Reference Group members said:

- People with disability, families, and providers need support to understand SDA, SIL and ILO, and more generally, the home and living supports available to them.
- The NDIA Home and Living policy needs to help people with disability understand their options to live alone. It also needs a clear statement of values to guide the policy and its implementation and measure success.
- Reasonable and necessary decisions in home and living should use research around cost and benefit.
- The disconnection between SDA, SIL and ILO, presents gaps along the home and living pathway. For example, some people with complex needs and 24/7 supports do not want SIL, but fall out of ILO guidelines.
- They want to be part of the assessment of the [Home and Living demonstration projects](#).

## Changing NDIA's engagement on home and living

NDIA Representatives acknowledged the need to work and engage with the sector and participants in a better way to rebuild trust. They noted the work achieved to date through the co-design workshops. They updated the Reference Group on the NDIA's integrated approach to improving engagement on home and living issues in the short term, and co-designing future policy.

Reference Group members said:

- NDIA engagement should be inclusive and consider the needs of people with disability to meaningfully participate, understand the work and have their say.
- They want to use their experience to inform the NDIA's priority work, including helping the Agency have a clear proposition about its Home and Living policy.

## More information on the Reference Group

The Reference Group will keep working out of session to progress its work, before it formally meets again in 2022. You can find out more about Council meetings at the [Council's website meeting page \(external\)](#). You can access advice from the [Council's website advice page \(external\)](#).

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