24 September 2024

The Neurodegenerative, Palliative Care and Rare Diseases (NPR) Advisory Group met online on 24 September 2024.

The Chair, Ms Prue Coroneos, General Manager, Policy, Evidence and Practice Leadership, National Disability Insurance Agency (NDIA), welcomed everyone to the meeting. Ms Coroneos highlighted the importance of this group in supporting the NDIA to hear the voices, perspectives and gain a better understand of the unique challenges people living with neurodegenerative, palliative care needs and rare diseases face.

Focus of the meeting

The meeting covered:

- Changes to the NDIS Act.
- Planned reforms to NDIS assessment and budgeting processes.

Changes to the NDIS Act

The NDIA provided an overview of recent legislative changes and work the NDIA is undertaking in preparation for the amended NDIS Act to take effect from 3 October 2024. Members were advised there will be further work occurring on the development of associated rules and policies to support the implementation of the changes.

The NDIA confirmed there are no changes to the current access decision process. Members were advised that legislative changes mean that some people will now receive an access decision under different sections of the NDIS Act.

Members sought further clarity from the NDIA on:

- Plan roll overs and associated unintended consequences they are seeing.
- Communications products the NDIA are developing to explain the changes.
- Length of time for change of circumstances applications to be processed.
- If the legislative changes will enable a more holistic view of participant’s functions and needs.
- How the planning processes will consider fluctuating needs or rapid deterioration.

Assessment and Budgeting

The NDIA provided an overview of ongoing work to design new assessment and budgeting approaches.

The NDIA recognised the value of the advice that the NPR Advisory Group and other advisory groups can provide to help inform future Scheme reforms. The NDIA will also draw on other mechanisms such as dedicated co-design groups and direct engagement with participants, their families and carers. Advice provided through engagement, consultation and co-design will guide the NDIA on what to consider for assessment approaches and tools particularly in considering the needs of participants with complex support needs.

Members will have future opportunities to provide advice on a range of tools, process, participant pathway experience and workforce capability for the NDIA to consider.

Some initial feedback from members included:

- The need for inbuild flexibility within the budgeting approach that considers fluctuating needs, degeneration and rapid changes.
- Limiting the need for people to retell their story multiple times.
- Consider longer term plans.
- The need for trauma informed practice.

NPRAG Next Meeting

The NPRAG will meet online again on 26 November 2024.

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