25 November 2024

The Neurodegenerative, Palliative Care and Rare Diseases Advisory Group ((NPRAG) met online on 25 November 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 thanked the group for supporting the NDIA to hear the voices, perspectives and gain a better understand of the unique challenges of people living with neurodegenerative, palliative care needs and rare diseases.

Focus of the meeting

The meeting covered:

- Legislation Implementation – plan management, reassessments, and variations.
- The proposed 2025 Workplan including ongoing data reporting for the group.

Legislative Implementation

NDIA shared an overview of three new NDIS rules under legislation changes that came into effect from 3 October 2024. Members were advised there will be continued work occurring on the development of associated rules and policies to support change implementation.

The rules covered in the meeting related to plan management, plan variations and plan reassessments

Members are interested to hear more from the NDIA on:

- The impact of change on providers.
- How the changes are being communicated to participants.
- When and how people can move between different plan management arrangements.
- Considerations for episodic changes and ability to structure flexibly or predict the fluctuating needs of some participants.
- The difference between plan variations and a change of circumstances.
  When other forms of evidence may be considered, such as the WHODAS or PEDICAT, and if these could be conducted by LACS, nurses, or other allied health professionals.

Members were concerned about:

- Potential impacts for regional areas particularly those with thin markets.
- Current cost and wait times to re-obtain evidence, particularly from Occupational Therapists.
- Current wait times when people need changes to their plan.

Planned 2025 Workplan

The meeting discussed a draft workplan for 2025 which maps out the advice and input that will be sought from the group. There is a strong focus on Scheme reforms.

NDIA shared their support for ongoing and specific data sharing to the group in 2025.

NPRAG Next Meeting;

The NPRAG will meet online again on 29 January 2025.

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