26 March 2025

The Neurodegenerative, Palliative Care and Rare Diseases (NPR) Advisory Group met online on 26 March 2025.

The Chair, Ms. Prue Coroneos, General Manager, Policy, Evidence and Practice Leadership, National Disability Insurance Agency (NDIA), welcomed everyone to the meeting.

Ms. Coroneos formally welcomed Ms. Olivia Nassaris, CEO Parkinson's Australia as co-chair of the group, and thanked Ms. Nassaris for undertaking the role. Co-chairing will ensure that the meetings are meaningful for everyone.

Focus of the meeting

The meeting covered:

- Member reporting – discussion of issues raised by members.
- Practice Improvement – Technical Advice and Practice Improvement Branch provided an update to the group on progress of disability snapshots
- Modifications to the assessment and budgeting approach – Assessment and Budgeting Initiative team provided an update to members.

Member reporting

The newly implemented members reporting document was discussed. This document is updated prior to every meeting and invites members to table issues on behalf of their communities and members. Issues are logged for future meeting agendas and inform updates to the work plan. Forward agenda items include priority access processes, evidence requirements, and early onset dementia.

Practice improvements

The NDIA Technical Advice and Practice Improvement Branch shared an update on disability snapshots that are used by staff to help inform the way they work with participants.

The team are updating current snapshots and are developing a range of new snapshots. They asked to work with members to review existing snapshots and provide input into new snapshots.

Assessment and Budgeting Approach

The NDIA Assessment and Budgeting Initiative team shared information about how the Agency will modify the new approach to delivering support needs assessments and more flexible budgets to better support participants with rapidly changing support needs.

Members shared their expertise, including considering further consultation with peak bodies that hold expertise and knowledge, to ensure the assessment process is appropriate for participants with degenerative conditions. Members recommended that assessments be held in person and be as personalised as much as the participant would like it to be. They also emphasised the importance of ensuring the same level of skilled workforce is able to service remote locations. Members also discussed the need for participants to be able to unlock additional funding or supports as needed, and better ways to streamline the process including the need for a rapid plan approval to be flagged at access.

NPRAG Next Meeting;

The NPRAG will meet online again on 28 May 2025.

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