8 August 2024

The Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (NPR) met online on 23 May 2024.

The Chairperson, Aaron Verlin, General Manager, Co-design and Engagement, National Disability Insurance Agency (NDIA), welcomed everyone to the meeting and highlighted the importance of this group in supporting the NDIA to hear the voices, perspectives and gain a better understanding of the unique challenges NDIS participants with neurodegenerative conditions, in palliative care and have rare diseases face. /p>

Focus of the meeting

The meeting covered:

- Terms of Reference.
- Key issues from members.
- Opportunities.

Terms of Reference

NPR discussed the draft Terms of Reference (ToR) and discussed:

- Strengthening an agreed understanding of “strategic advice”.
- The group’s expertise as a significant touch point to work through relevant NDIS Review recommendations once Government releases their official response.
- That current challenges that often span and reflect a person’s range of supports, that the NDIA can work with this group to understand gaps and interconnections in service systems.

The group adopted the ToR, including a determination to rename the group, from Neurodegenerative Disorders and Palliative Care Working Group to Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (NPR).

Current Key Issues

Members discussed the following key issues:

- Proposed changes to assessments rather than a diagnosis is positive.
- Further information is required on the training of assessors. There is an opportunity to co-design both the training and the process.

- Degenerative conditions require timely reassessments, they often occur too late. This can lead to inequity with funding in plans.
- Current NDIA delays mean change of circumstances reviews are taking too long for people whose condition is declining. There was a suggestion for the need for a rapid response team for change of circumstances, and a mechanism that allows for predictable changes.
- Feedback received that people must prove they are not palliative at the point of access. This presents issues in the definition of the term ‘palliative’. Palliative care definition needs to separate out end of life, people can be palliative for years.
- The NDIA should use the data and learning spanning over 10 years to assist decision making.

Opportunities

The group discussed the key areas where they may be able to provide expertise and advice to inform co-design:

- Functional assessment
- Support needs assessments.
- Navigators
- Changes of circumstances
- Pre-access and priority pathways
- Training and capability of planners

NPR Next Meeting

The next NPR meeting is on 23 July 2024.

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