

24 September 2025

Meeting summary

The Neurodegenerative, Palliative Care and Rare Diseases (NPRAG) Advisory Group met on 24 September 2025 for the fifth meeting of the year. The meeting was held online.

Focus of the meeting

The meeting covered:

- Data update
- Scheme Eligibility Branch update
- Common challenges at the NDIS/palliative care interface.

Data update

The NDIA presented data about the participant cohorts represented by member organisations.

Members also heard from the NDIA about key considerations when addressing the data distribution guidelines.

Scheme Eligibility Branch update

The NDIA shared an update on:

- A high-level overview on the eligibility reassessment process including referrals, outcomes, and timeframes
- The recent change to legislation resulting in the NDIS being able to assess access decisions on both section 24, disability criteria and section 25, early intervention criteria
- Access decisions and timeframes, priority pathways, and workforce development
- Impairment information, including requests for variation for the impairment information, which can be lodged at any time.

Members provided the following feedback:

- The information outlined about the priority pathways is not easily found in the guideline (page 48)
- Suggestions for clear and accessible communications to advise how to update disability information and request plan variations
- The importance of having correct data pertaining to diagnosis and impairments.

Common challenges at the NDIS/palliative care interface

Members shared common challenges at the NDIS/palliative care interface which included four key issues:

- NDIS fundamentals
- NDIA understanding of the palliative care system
- Withdrawal of supports
- Communication blockages and associated delays.

Members provided the following feedback:

- Acknowledgement that there has been a significant improvement noted since the implementation of the priority pathway
- Concerns that the information outlined in the guideline (Page 48) where terminal conditions are briefly outlined, is not sufficient and not easily found resulting in a communication gap for community and sectors in supporting people to access the pathway
- There is a community perception that those with terminal conditions, will be found ineligible for the NDIS.

Next meeting

The Neurodegenerative Palliative Care and Rare Disease Advisory Group's next meeting is 26 November 2025.

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