5 August 2025

# Meeting summary

The Neurodegenerative Palliative Care and Rare Diseases Advisory Group (NPRAG) met online on 5 August 2025.

# Focus of the meeting

The meeting covered:

- Impairment information
- Funding periods
- Pricing arrangements.

# Impairment information

The NDIA consulted with members on the early design of delivering impairment information to existing participants.

Although referred to as notice of impairment in the legislation, the NDIA has received significant feedback from participants, the sector, and Advisory Groups on the language and therefore, it is now being referred to as ‘impairment information’.

The design of impairment information for existing participants is still in development. The design is incorporating considerable feedback and input from participants and others in the community.

Member feedback included:

- Members emphasised the importance of ensuring the impairment categories information is clear, to avoid confusion and fear.
- Members suggested clearly outlining how a participant can change and/or add to the categories of impairment information.

# Feedback on impairment information letters

Given time limitations, the Group agreed to provide feedback on the impairment information letters out of session.

# Funding periods: Member position paper

Members presented a position paper which outlined a request for the NDIA to apply exemptions to people with neurological conditions and rare disease disabilities from short funding periods and instead for the NDIA to apply longer plan periods.

The NDIA has agreed to consider the points raised in the position paper.

## Funding periods: training and policy

The NDIA shared an update on how the NDIA delegates are trained in applying funding periods and a discussion on the funding periods policy.

Member feedback included:

- There seems to be a strong default to three-month funding periods and a strong resistance from the NDIA in deviating.
- Members would like further information regarding measuring outcomes and monitoring of performance of delegates undertaking conversations with participants.

## Navigators

The NDIA consulted with members on the early design of the new navigator role.

Member feedback included:

- Members enquired on the anticipated delivery method and emphasised the importance of meeting the needs of the participant, including options for face to face and phone meetings.
- Members suggested the need for a workforce strategy to meet and deliver the role of the Navigator, noting a shortage in professionals currently exists.

Members requested further consultation on the design of the Navigator role.

## Pricing arrangements

A discussion on the newly introduced pricing arrangements.

Member feedback included:

- Members expressed concerns that the latest pricing review did not consider the complexity of therapy supports that people with disability might require and enquired if there could be a consideration to a tiered pricing system for therapy supports, dependent on complexity.
- Members raised concerns that the impacts to travel pricing will reduce choice and control for the communities they support. Furthermore, there are few specialists that can support the

cohorts that members work with, given the complexity of the conditions.
- Members shared concerns around participant long-term wellbeing and health impacts for functional decline and increased needs over time, resulting from reduced ability to access vital therapy supports.

Further discussion to be held around pricing arrangements.

## NPRAG next meeting

The next meeting of the Neurodegenerative Palliative Care and Rare Diseases Advisory Group is on 24 September 2025.

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