23 July 2024

Meeting Summary

The Neurodegenerative Palliative Care and Rare Diseases Advisory Group (NPRAG) met for the second time on 23 July 2024. The meeting was held online and chaired by Prue Coroneos, General Manager, Policy Evidence and Practice Leadership at the National Disability Insurance Agency (NDIA).

Focus of the meeting

The meeting covered:

- Terms of Reference and proposed work plan
- Early Intervention

Early Intervention

Members of the NDIA's Scheme Eligibility Branch gave a presentation to the group regarding early intervention. This included the current approaches and processes in place to support people with neurodegenerative and rare diseases and those experiencing palliative care.

Following the presentation, members discussed:

- What early intervention means for people with neurodegenerative and rare diseases and those experiencing palliative care.
- The main issues NDIS planners need to know about.
- The experience and support people need from the NDIS.

Members provided advice regarding the ways the NDIA requests and considers evidence to support access and planning decisions. This included considerations for:

- Priority access pathways.
- The issues people with fluctuating conditions experience when engaging with the NDIS related to criteria and rules.
- The need to further clarify what early intervention means for people with certain conditions.
- The additional considerations and sensitivities required to understand children with degenerative conditions.

NPRAG Next Meeting

The next meeting of the Neurodegenerative Palliative Care and Rare Diseases Advisory Group is on 24 September 2024.

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