

# Neurodegenerative Disorders and Palliative Care Working Group Terms of Reference

May 2024

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## Neurodegenerative Disorders ad Palliative Care Working Group

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## 1. Purpose

The purpose of the Neurodegenerative Disorders and Palliative Care Working Group (N&PWG) is to provide strategic advice to the National Disability Insurance Agency (NDIA) on a set of defined issues relating to Neurodegenerative and Neuromuscular or rare conditions or those requiring palliative care.

The defined issues include:

- challenges to accessing the Scheme relating to the assessment of NDIS eligibility and specifically the timeframes for decision making for a cohort where the functional impairment can progress rapidly.
- NDIA staff, Local Area Coordinators and Planners having insufficient knowledge of neuromuscular conditions or disorders, particularly in the context of rapid deterioration.
- Synchronisation of planning with families where multiple family members have the same condition.
- Reflecting a person's range of supports in their engagement with the NDIS, including health related supports and informal support networks.

Where the NDIS Review makes recommendations about changes to the NDIS experience that are likely to address these issues, the Agency will use the N&PWG as a consultative mechanism for considering the needs of this cohort on any specific recommendations that address these issues.

The activities of this Working Group are intended to complement the Agency's co-design activities, which include people with these conditions.

## 2. Outcomes

The N&PWG advice will assist the NDIS to deliver the following outcomes to support implementation of reform initiatives:

- a) National Disability Insurance Scheme (NDIS) policy, practice and processes will better address the specific needs of people with neurodegenerative disorders, rare conditions or those requiring palliative care and their families and carers through feedback from N&PWG members, and their organisational networks, including through participant experience and sector insights.
- b) People with neurodegenerative disorders, rare conditions or those requiring palliative care and their families and carers are well informed about the NDIS, and the supports it provides; and
- c) The NDIA is well informed about emerging issues and concerns, and opportunities for improvement and solutions in the delivery of the NDIS for people with neurodegenerative disorders, rare conditions or those requiring palliative care to consider in the context of the reform agenda.

The advice of the working group will support design and implementation of the current reform initiatives, particularly strategies to improve planning practice, flexibility in plans and the capability for front line Agency staff working with people with disability.

### 3. Outputs

As a time-limited Working Group, the outputs of the group are expected to be identifiable and tangible, and in a form that the Agency is able to practically apply in delivery of its functions. They will be solution focussed. The outputs of the Working Group include:

- a. Provide targeted expert advice to the NDIA on specific strategies to deliver improved experiences for people with neurodegenerative disorders or rare conditions or those requiring palliative care, with a particular focus building the capability of Agency front line staff.
- b. Examination of defined issues and concerns in relation to engagement of participants with these conditions through the NDIS access and planning processes, and collaborate with the NDIA to identify potential solutions to improve the participant pathway in this regard.
- c. Assist the NDIA to provide clear and consistent communications to people with neurodegenerative disorders, rare conditions or those requiring palliative care and their families about the NDIS, with a focus on plan implementation; and
- d. Identification of solutions that the Agency can consider and practically apply to address the defined set of issues outlined in section one to be fed into the reform work programs for future consideration.

### 4. Membership

Membership to the group is intended to reflect the diversity of the neurodegenerative disorder and palliative care communities with a view to geographic and gender diversity, as well as having a minimum of two people with neurodegenerative disorders as members of the group. Membership will also extend to Rare Voices Australia, a national peak organisation, to ensure the experience of participants with rare conditions are included, due to similar issues being raised by this group about the experience of people with rare conditions interacting with the NDIS.

Membership includes:

- seven (7) nominated representatives from the Neurological Alliance Australia (NAA)
- one (1) nominated representative from Rare Voices Australia
- one (1) nominated representative from Palliative Care Australia
- one (1) nominated representative from Younger People in Nursing Homes (early onset dementia focus)
- NDIA staff from Service Delivery, Policy, Service Design, and Engagement.

The membership will include people with disability. Additional attendees may be invited as required depending on agenda items.

### 5. Processes

#### a) Conflicts of Interest

All Members will be required to complete a Conflict-of-Interest declaration and Confidentiality Deed. Members should also declare any perceived or actual conflicts of interest before any meeting.

The NDIA is responsible for determining the appropriate course of action for dealing with specific conflicts of interest. Depending on the conflict involved, the NDIA may excuse the Member from the meeting for the relevant agenda item or may take other action as appropriate.

**b) Meeting agenda and papers**

Agenda items for discussion will be developed and distributed by the NDIA with input from the Working Group members prior to each meeting.

Any actions arising will be added to the next meeting agenda to ensure feedback is delivered and able to inform discussions. Meeting papers will be provided to members prior to the meeting.

**c) Frequency and timing of meetings**

The NDWG will meet bi-monthly from May 2024 – May 2025. Meetings will be held online via MS teams and will be between one and two hours in duration.

**d) Records management**

The NDIA will provide Secretariat support to coordinate meetings and will advise members in advance of meeting dates and times.

The Secretariat will provide ongoing coordination, record keeping and liaison with members for all matters relating to the operations of the group.

**e) Accessibility**

The NDIA will ensure appropriate adjustments are made so that meetings are accessible to all participants based on their identified communication and access needs and is committed to providing fully accessible documentation in plain English. To ensure accessibility requirements are met, a meeting may be postponed until appropriate adjustment can be made.