27 May 2026

The Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (NPRAG) met on Wednesday, 27 May 2026.

Focus of the meeting

The focus of the May 2026 meeting was:

- NDIA workforce capability and training.
- Feedback on draft support needs assessment resources for participants.
- Department of Health, Disability and Ageing (DHDA) update on reforms.
- Support needs assessment testing.

NDIA update

- The Government has announced a plan to Secure the NDIS for future generations
- The Department of Health, Disability and Ageing website has more information on these changes:
  - DHDA website – Securing the NDIS for future generations
  - Securing the NDIS for future generations factsheet .
- The NDIA has delayed the rollout of the new way of planning until April 2027. This change:
  - Was made after consulting with people with disability, families, carers and advocates.
  - Gives the NDIA more time to test and refine new framework planning processes, resources and service delivery systems directly with participants.
- The NDIS Quarterly Report for 1 January to 31 March 2026 is now available. The report shares data about the NDIS and stories from participants.

Member feedback included:

- Members said there have been recent impacts to funding in NDIS plans. This includes reduction in funding for therapy, social and community participation supports.

The NDIA confirmed:

- Parliament must pass the Bill before it becomes law.
- There have been no changes to NDIA processes for now.

Workforce capability and training

The NDIA gave an update on training frontline staff and new NDIA support needs assessors.

- There is a strong focus on working better with participants through all learning and training activities.
- NDIA would like to work with NPRAG members to understand training that help NDIA staff best understand participant needs.

Member feedback on frontline capability and training included:

- NDIA staff don’t always have a clear understanding of:
  - Rare and degenerative conditions.
  - The supports people need and what support they may need in the future.
- The Group would like to work with the NDIA to:
  - Strengthen training for NDIA frontline staff.
  - Support the NDIA to improve training for progressive conditions.
- The NDIA should support frontline staff to read and understand detailed reports from medical and therapeutic professionals.

Member feedback on training for NDIA support needs assessors included:

- It is important that support needs assessors have training to recognise warning signs that someone may be losing skills.
- The NDIA should implement a way to identify skills regression that happens even with allied health intervention.
- Staff need psychological safety and trauma informed training. Staff should understand that some participants have experienced years of not being taken seriously.
- The NDIA should put processes in place to make sure support needs assessors understand different diagnoses and support needs.

New Framework Planning – participant resources

The NDIA talked about work they are doing on resources to support participants through the support needs assessment. This is part of the new way of planning.

The NDIA shared 5 draft resources that will help participants understand what to expect before, during and after a support needs assessment.

The NDIA asked members for feedback to help make sure the resources:

- Meet the needs of all participants.
- Are clear and easy to understand.
- Are practical and easy to use.

The NDIA will use this feedback and feedback received from the support needs assessment testing to improve the draft resources.

Member feedback included:

- Concerns that the support needs assessment process might not work well for people with fluctuating or episodic conditions.
- Members said they were uncomfortable with reviewing the resources without consulting with their various lived experience advisory groups.
- The NDIA should provide more information to support participants to talk about themselves.
- The focus on strengths-based approach may be too strong. The NDIA might need to ask additional questions of participants with fluctuating needs:
  - Is it on a good day or a bad day?
  - What can you do every day?
- It might be a long time between when support needs have changed for a participant and when they may be ready to tell someone about the changes.
- People may feel like it is an assessment that they need to pass or fail.
- Some people may have the knowledge about what supports they need. It is therefore important that the support needs assessors listen to families and carers.
- Each person experiences their condition differently, with varying rates of progression or degeneration.
- Some of the language in the resources may be uncomfortable for people with palliative care needs or degenerative conditions, and for those supporting them.
- The need for a special pathway for people with neurodegenerative conditions.
- Many participants do not trust the NDIA or the recent changes.

The NDIA should focus on making sure participants are comfortable during the support needs assessment

Department of Health, Disability and Ageing (DHDA) update on reforms

The Government introduced the *National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026* on 14 May 2026.

DHDA talked about the NDIS Bill. This includes:

1. Returning the NDIS to its original intent.

2. Delivering genuine social and community participation.

3. Improving the quality of providers.

4. Tackling fraud and non-compliance.

Timelines for changes in the Bill are included in the reform timeline .

The update included:

- DHDA is setting up a Technical Advisory Group to provide advice to the government on an evidence-based assessment of functional capacity.
- NDIS plans will have an end date. Unspent funds will no longer be rolled over to a new plan.
- Stronger rules around unscheduled reassessments.
- Delaying the rollout of New Framework Planning to 1 April 2027. This will give more time for consultation and testing with participants.
- Improvements to pricing, and the design and delivery of plan management, support coordination and Supported Independent Living supports.
- Stronger rules to prevent fraud. This includes:
    - Providers must be registered with the NDIS Quality and Safeguards Commission if they deliver high risk supports.
    - Improved payment systems and record keeping requirements.
    - Stronger powers to investigate fraud.

The NDIS Quality and Safeguards Commission are working on mandatory registration reforms; more information can be found here NDIS regulatory reform page of the NDIS Quality and Safeguards Commission.

Member feedback included:

- Members represent participants with complex needs.
- Concerns that legislation changes may lead to poor outcomes for some participants.
- Neurological Alliance Australia and NPRAG members made a joint submission to the Senate Enquiry on the *NDIS (Securing the NDIS for Future Generations) Bill 2026.*

Other business

NPRAG members offered to work with the NDIA on the service design for support needs assessment and testing for the participant cohorts they represent.

The NDIA is developing a plan to work with NPRAG members.

The Group will talk about the service design at the next meeting.

The NDIA wants to test the new way of planning with participants. Information on how to take part is available on Engagement opportunities for the new way of planning on NDIS Engage. Participants will be paid to take part in testing.

Next meeting

The next NPRAG meeting is scheduled for Wednesday, 29 July 2026, 1:00pm – 4:00pm Australian Eastern Standard Time (AEST).

Related articles

Category

- Mental Health Sector Reference Group communique

National Mental Health Sector Reference Group Meeting June 2026

Date
10 June 2026
Category

- Neurodegenerative, Palliative Care and Rare Diseases Advisory Group communique

Neurodegenerative, Palliative Care and Rare Diseases Advisory Group meeting summary March 2026

Date
25 March 2026

Supported Decision Making Advisory Group meeting summary May 2026

Date
6 May 2026
Read more news