29 July 2026

The Neurodegenerative Palliative Care and Rare Diseases Advisory Group (NPRAG) met on 29 July 2026. The meeting was held online.

Focus of the meeting

The focus of the July meeting was:

- Testing the new way of planning.
- Aged care and hospital interface with the NDIS.

Testing the new way of planning

The NDIA's Engagement Branch gave an update on the testing for the new way of planning and the support needs assessment (SNA).

- Testing has of the SNA has increased since October 2025.
- The NDIA is running 2 activities to help test the new way of planning:
  - Activity one: Testing the SNA.
  - Activity 2: Helping NDIA staff become accredited assessors.
- Participants will complete a simulated SNA to support training and testing.
- The NDIA will not:
  - Record the results of the simulated SNA on the participant's record.
  - Use it to change the participant's plan.
  - Use it in future planning discussions.
- The NDIA wants to test the participant experience with people who have different disability types and support needs. This includes participants:
  - With different disabilities, including complex disabilities and intellectual disabilities.
  - Who are First Nations participants.
  - From Culturally and Linguistically Diverse communities.
  - From LGBTIQA+ communities.
  - Who need interpreters.
  - Living in regional, remote and very remote locations.
  - Who use assistive technology
  - Who live in specialist disability accommodation (SDA).
  - Aged between 18 to 25 years old.
  - With an NDIS plan of more than $150,000.
- Please visit NDIS Engage to find out more or sign up to take part in testing.

Member feedback included:

- People in the community have reported low trust in the NDIA.
- NPRAG members want to work with the NDIA to support the participants they represent.
- Members suggested the NDIA include people who are new to using assistive technology in testing activities. This will help make sure testing is accessible for people with different levels of experience.

Aged Care and Hospital Interface

The NDIA's Specialised Service Delivery Division discussed the NDIS and hospital interface.

The NDIA discussed the hospital discharge process with members, including:

- Key steps in the hospital discharge process.
- How the NDIA and health services work together for:
    - Existing participants.
    - Potential participants.

The NDIA created the Hospital Interface Team in 2022. This team works with hospital staff and patients to coordinate safe and timely discharges for NDIS participants.

The team provides a dedicated link between state and territory hospitals, participants, families, providers and the NDIA planning teams, when:

- A participant enters hospital.
- A participant's disability support needs change during a hospital stay.
- A participant leaves hospital.

The NDIA has Hospital Liaison Officers (HLO's) who work directly with the health system, including hospitals.

Member feedback included:

- Some hospital processes can make it harder to access to HLO support and NDIS access.
- HLO's generally work in public hospitals. This creates a gap for people in private hospitals.

The NDIA also discussed NDIS concurrent supports in hospitals.

- In some circumstances, the NDIS may fund supports while a participant is in hospital or accessing health services if they have complex communication needs or behaviours of concern.
- Participants can continue to access support coordination or recovery coaching while they are in hospital.
- Hospitals are responsible for providing personal care and medication support.
- Health services should adjust their care to meet disability-related support needs during a hospital stay.

- Participants should ask the hospital about reasonable adjustments and use NDIS funding in line with NDIS rules and regulations.
- The NDIA works with hospitals and states and territory governments to strengthen hospital interface arrangements.

Member feedback included:

- Hospitals cannot always provided reasonable adjustments for participants with complex support needs. This can mean participant's experience:
  - Their health getting worse.
  - Loss of independence.
  - Increased support needs in the future.
- Asking participants to request reasonable adjustments places an extra burden on people who are already unwell and their family members.
- Long hospital stays can cause participants to lose their specialist community support teams. This workforce is hard to replace.
- Better coordination between the NDIA and health services could:
  - Support continuity of care.
  - Improves outcomes in hospital and at home.

Other business

- Members raised concerns that NDIA planners are holding planning meetings with participants without giving notice. This sometimes happens during check in calls.
- Members raised concerns about funding reductions or caps for social and community participation supports.
- The NDIA confirmed it has not changed any policy, processes or decision making guidance while waiting for the
- National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill to become law.

Next meeting

The next Neurodegenerative Palliative Care and Rare Diseases Advisory Group meeting is scheduled for 30 September 2026.

Related articles

Category

- Neurodegenerative, Palliative Care and Rare Diseases Advisory Group communique

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

Date
27 May 2026
Category

- Neurodegenerative, Palliative Care and Rare Diseases Advisory Group communique

Neurodegenerative, Palliative Care and Rare Diseases Advisory Group meeting February 2026

Date
4 February 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
Read more news