

Participant Reference Group

Meeting summary – 23 June 2025

The Participant Reference Group (PRG) makes sure the National Disability Insurance Agency (NDIA) hears and understands the participant voice. The PRG has 23 members from participant and carer organisations across Australia.

The NDIA uses feedback from PRG meetings to keep making the National Disability Insurance Scheme (NDIS) better. PRG members work on what the NDIA plans to do. They work on new and current policies, improving the systems we use, and how we deliver services.

Chairperson's welcome

Donna Purcell is the Branch Manager, Office of the Participant Advocate, and chair of the PRG. She welcomed members to the virtual PRG meeting.

Session – Impairment Information Workshop 3

This was the final session in a series of three NDIA focus groups on improving how participants understand information about impairments.

Awareness Campaign: NDIA will start a communications campaign to help participants better understand impairment categories.

Tailored Communication: Participants will get personalised letters based on their evidence status, with clear explanations and less legal jargon.

Supporting Materials: A factsheet will show how impairment decisions are made, and the NDIA website will be kept up to date.

Participant Support: NDIA will offer guidance on how to request changes or reviews and will meet with participants to explain new plans and assessments.

Feedback from PRG:

- All impairment-related information should be given in writing.

- The term “impairment” may need rewording.
- It’s important to know that impairments can sometimes change over time.

NDIA said there is a commitment to clear communication and ongoing support for participants throughout the change in process.

Our questions for the breakout groups today are:

- How should we support you when we need evidence of your impairment?
- How might we approach the conversation?
- How should we explain why we need to ask for more information
- How much time do you need if we need more information from you?

How should we support you when we need evidence of your impairment?

PRG members said:

- Timeframes alone are not enough – support is needed. Clear, direct communication channels, such as a phone number or email
- avoid repeating or re-telling
- the need to continually give evidence for lifelong or well-documented disabilities is frustrating
- we need to know that the NDIA would cover the cost
- there can be long delays in processing reviews or changes
- we need greater empathy, training, and accountability in how decisions are made and communicated.

How might we approach the conversation?

PRG members said:

- There is importance to having conversations with genuine humility, empathy, and care
- We want clear explanations about how decisions are made and what information is needed.
- The NDIA should offer multiple chances to review and respond to requests for information, especially in the early stages
- Some participants may misunderstand letters due to their needs or the large amount of communication they get. The NDIA should think about support for these people, such as follow-up calls or special help.

How should we explain why we need to ask for more information

PRG members said:

- be clear and specific about why more information is needed.
- the NDIA should see the frustration of repeated proof
- Use clear and accessible communication tailored to the participants needs
- Be upfront about which parts of legislation or guidelines are driving the request
- Participants with English as a second language need access to specialist interpreters familiar with NDIS language and wording.

How much time do you need if we need more information from you?

PRG members said:

- The time needed changes based on people's situations, such as those in remote or regional areas
- A minimum of 90 days is a good standard
- There is a lack of dedicated support within the NDIA to help participants with complex needs in getting the needed documentation
- The time needed often depends on how long it takes to get original reports from providers, which can change greatly
- We need individualised approaches instead of firm deadlines.

Final comments and close

The NDIA thanked PRG members for their feedback. Donna thanked PRG members for their time and contribution.

Next meeting

Wednesday 9 July 2025

End of document