

Participant Reference Group

Meeting summary – 2 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 1

The NDIA said this is the first of 3 workshops. These workshops are about how the NDIA can support and help NDIS participants to understand information about impairments.

NDIS participants get a letter that says what their impairment categories are. The legislation calls this a notice of impairments. We have had feedback that we need to clearly explain what we mean by the categories in that letter. We also need to explain what it means for the participant receiving the letter.

Today's session is about before we send the letter. We want to make sure that the person who receives the letter understands what it means and why they got the letter. We want to make sure we have the right information and it is easy to find.

Our questions for the breakout groups today are:

- What should we be doing and telling participants before they get the letter?
- How can we make sure that our support is personalised to what participants need?
- What would participants like to see on our website about the letter?
- How else can we make this process as smooth as possible for participants?
- What support would participants like from us once they get the letter?

PRG members asked:

- What happens when a disability is put in one category, but it affects a participant in a different way? For example neurological and physical
- Some participants have secondary disabilities listed as the NDIA only allows one primary disability. At their planning meeting, they are finding out that some of those secondary disabilities have been revoked. Does this mean they have to go to the Tribunal to challenge that?
- The NDIA may not look outside of PACE for the latest information on a participant, but some participants are not on PACE. How can they make sure the NDIA is getting all their information?
- If there is a mistake in the letter, do participants have to go through a review process to get it fixed?
- What if a participant has impairments in more than one category? Together they can have a more severe rating than a single impairment might have.

What should we be doing and telling participants before they get the letter?

PRG members said:

- Getting information ahead of the changes will help participants get ready
- Be clear that this is not an eligibility reassessment
- Be clear that this will roll out over 5 years
- Make sure NDIA staff know about the changes
- Be clear about how the NDIA makes decisions about the changes. Where does the feedback come from? For example, PRG or focus groups, or the NDIA has made the decision without participant feedback

- Be clear about who has decided what a participant's impairment is. For example, was it a specialist or an NDIA staff member?
- Think about changing wording in the letter. It may not be a mistake but the participant may feel the decision does not cover all the impairments
- Think about participants who will not improve and what their NDIS journey will be like
- Think about literacy levels and whether someone has the capacity to advocate for themselves or their family member
- Have a pre-read type of document to prepare someone for the letter
- Think about staffing levels in the NDIA to make these changes. If there are not enough staff members, mistakes can happen

How can we make sure that our support is personalised to what participants need?

PRG members said:

- In the letter, refer to the reports participants have provided so participants can make sure the NDIA has the right reports
- Be clear about what the impairments mean
- Be clear about the impairment categories – what is mild, moderate or severe
- Be clear about what is in the law and what the NDIA can and cannot change. Say why the NDIA uses those terms and categories
- People are individuals. Similar symptoms do not mean the same impairments
- Have a direct person to contact who knows the participant's circumstances
- Think about how to make the letter more personal to the person receiving it
- Keep humanness, kindness and accessibility at the centre
- Use the participant's preferred communication method
- To make letters more personal, the NDIA staff member needs to understand the participant
- The NDIA needs to make sure the information in the letter is correct

- Participants should be able to talk to the delegate who makes the decisions. They should be able to give more information before the decision is final
- Participants need to know what information the NDIA has used to decide what impairments the participant has
- Contact the participant before sending the letter. Talk about the reports the NDIA has used to write the letter
- Participants should be able to book an appointment online to speak to an NDIA staff member

What would participants like to see on our website about the letter?

PRG members said:

- Make it easier to find information on the NDIA website, including the latest releases and news. Be aware that participants can get overloaded with information
- Say where to find relevant information on the website
- Include hot links for electronic letters. On those webpages have videos and diagrams to explain the participant pathway
- Have videos and podcasts that talk about the changes in different languages
- Use consistent language across all documents and the website. People don't know what words to use to search for information
- Update the terms across everything at the same time
- Have a public change policy that shows old terms and new terms
- Make sure information is consistent, and NDIA staff know where participants can get more information

How else can we make this process as smooth as possible for participants?

PRG members said:

- Be radically transparent
- Have information in different formats
- Have real examples and include secondary disabilities

- Have a dedicated phone number and team for participants to talk to about the letter
- Think about grouping certain disabilities. NDIA staff can learn about that disability and review those files before moving to another disability
- Staff should be trained to answer specific questions and have a trauma-informed approach
- Think about ways to communicate changes that will happen soon. For example, Facebook posts and radio ads. Indigenous, rural and diverse groups have their communities. Webinars and open forums let people ask questions
- The NDIA needs to be clear about the terms they use. For example, check-ins were meant to be a quick conversation. But they were also used to do plan reassessments
- Think about ways to communicate changes that will happen soon. For example, Facebook posts and radio ads. Indigenous, rural and diverse groups have their communities. Webinars and open forums let people ask questions

What support would participants like from us once they get the letter?

PRG members said:

- Think about the likely questions that the reader of the letter will have
- Think about the likely scenarios that will cause problems for participants. For example, after reading the letter what support will people need? What is the next step for them?
- Say where participants can get support if they want to talk to someone about their letter. The call centre is not helpful
- Participants may need to ask someone to explain the letter to them. For example, participants from non-English speaking backgrounds or with cognitive or intellectual disabilities
- Have a small group of NDIA staff who are the contact for a group of participants and who know their circumstances
- Tell participants who they should share their letter with, for example a support coordinator, and who they can say no to

Final comments and close

The NDIA thanked PRG members for their feedback. We said there will be another session about how we can support participants. It will also be about what information participants need if they want to change their letter.

There will be a third session about the evidence participants need to give to the NDIA.

Donna thanked PRG members for their time and contribution.

Next meeting

Wednesday 11 June 2025

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