

Participant Reference Group

Meeting summary – 11 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 2

The NDIA said this is the second 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.

Today's session is about changing your impairment information. We will talk about how we support participants who want to change the information in their letter.

Our questions for the breakout groups today are:

- What are the different ways we can explain how you can ask to change your impairment information?
- How would you like to request a change to your impairment information?

- How should we tell you if we have or haven't changed your impairment information?
- How should we support you if you want to change your impairment information?

PRG members said:

- The NDIA needs to talk to participants before sending the letter. It is not fair that the participant has to ask for a review to fix errors in the letter
- Having the letter doesn't mean the participant is now prepared for a support needs assessment
- Examples need to be realistic
- NDIA staff need to be willing to learn about how a disability may affect a participant's life

What are the different ways we can explain how you can ask to change your impairment information?

PRG members said:

- It may not be a change; it may be correcting wrong information. It may also be an update to a participant's disability
- Make it easy to read. Use tables or columns and do not have too much information on the page
- Use different formats for information. For example, the newsletter, on the website, videos, social media. Also have Braille and Easy English
- Have a flow chart that shows where the participant is up to in the process
- Think of different ways to record information other than writing it down. For participants who are not able to type or write, think about voice recordings and transcripts
- Think about YouTube videos. Remove the old videos and have ones that are about the new processes
- Update the website. Remove old information and make sure what is on the website is the latest information. Have links to the information participants will want when they get their letter

How would you like to request a change to your impairment information?

PRG members said:

- Think about a direct phone line or a pop-up chat box for participants using the portal
- Think about a simple form that the participant can fill in with their details, what information they want to change and why
- Participants should be able to use this form to let the NDIA know the participant wants to be contacted about their letter. This shifts the administrative burden from the participant to the NDIA
- The NDIA should say what evidence they need to make a decision. There should be a standard list of evidence that all NDIA staff use. It should be publicly available
- The participant should get a notification that their request has been received
- If a participant has put in a change request, they should be able to see where it is up to in the portal or app
- Make sure the letter has links to the evidence used for each decision. Participants can then see if the NDIA is missing information
- Make sure the letter is simple and all different communities can understand it
- Include next steps. Tell the participant what they need to do
- Include a link to a dedicated web page to help participants if they need to do something or have questions
- Think about the language. Is it a change because the NDIA made a mistake with the information they have? Or is it a change because the participant is adding a new diagnosis or a new report?
- Think about contacting the participant to talk about what will go in the letter before it is written. The participant can make sure the NDIA has all the information about them
- If the NDIA has made a mistake, the participant should not have to go through a review to get it fixed

- Participants need to know how the impairment categories link to the support needs assessment. If they do not fit an impairment category, does this mean they will not be considered for some supports?

How should we tell you if we have or haven't changed your impairment information?

PRG members said:

- This needs to be handled carefully. There can be big impacts on a participant
- This may be a change, an update or a correction
- The NDIA must make sure they give clear information. Use bullet points and do not have stories. Have the main information at the start
- Be clear about the decisions the NDIA makes. Tell participants why an impairment is not added to their file, or why a change is or is not made. Tell participants what evidence was used to make a decision.
- The NDIA should not be able to change the impairment information without notice. There needs to be procedural fairness
- The NDIA should do a risk assessment if they are taking away supports. They need to think about what it will mean for the participant. They should phone the participant before sending the letter if they think there is a risk
- If the participant says there is a mistake in their letter, the NDIA should say what they have looked at, what their new decision is and send a new notice if there are changes. The NDIA should be able to fix it straight away
- Tell participants what they can do next. If they think there is still a mistake, what can they do? If they think it is right, what do they do next?
- Tell participants what information the NDIA has about them. If this needs to be done through a Freedom of Information request, tell participants how to do this
- Use real examples. Show secondary disabilities. Show where a disability may not be accepted. Show the process where someone requested a change and it was not approved

How should we support you if you want to change your impairment information?

PRG members said:

- Participants need help to feel empowered to advocate for themselves
- Participants may need a longer timeframe to understand the letter
- Rushing the process can be dangerous and harmful for participants
- Give participants options about how to be contacted. Use their preferred communication method but have other options too
- The NDIA should say what the timeframe is to ask for changes
- If a participant asks the NDIA to add another impairment, does that mean all the impairment information is looked at again? That needs to be clear
- Tell participants where they can get support outside of the NDIA. Give local area coordinators the information they need to support participants
- Give support coordinators good information to support participants
- Make sure NDIA staff know how to answer questions participants may have about their letter
- Have a dedicated 24-hour phone line or a contact person who can support the participant and answer their questions. Make sure they are well trained to understand the individual needs of participants.
- Think about getting participants to help with the training
- Have step by step instructions in clear language
- Think about pop up booths in areas where there is no NDIS office
- When the NDIA makes a mistake, they should say that. It will help the participant feel like the NDIA is listening to them
- The NDIA should work with participants on the new legislation and new framework.

Final comments and close

The NDIA thanked PRG members for their feedback. We said 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

Monday 23 June 2025 – out of session

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