

# Participant Reference Group

## Meeting summary – 13 and 14 May 2025

This is a summary of the Participant Reference Group's (PRG) recent meeting. The PRG is a key platform to make sure the participant voice is heard and understood by the National Disability Insurance Agency (NDIA). The NDIA uses feedback from meetings to keep improving our processes.

### Day 1 - Chairperson's welcome

Donna Purcell, Branch Manager, Office of the Participant Advocate welcomed members to the meeting.

### Session 1: Accountability statement

Nina Bendon, Assistant Director, Office of the Participant Advocate, spoke about the accountability statement. She said PRG members worked on it last year.

Nina asked PRG members to think about the accountability statement. She said there will be a breakout session tomorrow to talk about it. She asked PRG members to think about whether anything is missing or if there was anything they didn't agree with.

### Session 2: Strengthening Identity

#### Presentation summary

The NDIA is improving how we identify people to increase safety and privacy. We are making improvements to make sure the right person gets access to NDIS participant information.

We talked about the changes we have planned for the next few months:

- Participants and nominees can access the MyNDIS portal and mobile app through myGov

- Participants and nominees will need to have a link to a myGov service, such as Medicare, Centrelink or the ATO
- They will need to use myID digital identity
- We want to use SMS to send a code that will link the person to myGov
- Providers and their staff will need to use a myID account to prove who they are when they log into the NDIA provider portal

## **What we heard:**

PRG members raised issues around:

- The blind community doesn't have driver licences. The process to get their identity documents into the portal is not accessible
- Other disabilities may have challenges with identity documents
- The internet doesn't work well outside of major cities. Codes can take hours to come through
- There should be a dedicated phone number just for the codes. It should operate 24 hours a day 7 days a week
- The code message should be more formal, and it should say NDIS code
- Providers might also be participants – do they have to use their personal myID account in their provider role?
- If people think this is too hard, they may not do it and may lose access to the services they need

Breakout group online:

- Not everyone has a mobile or mobile coverage and people share phones
- Need to be able to access codes outside of business hours
- If someone didn't ask for a code and they have to call the call centre number, it can take a long time to get through. There should be a specific number to call. Banks have a fraud number
- People who are non-verbal will not call. An office could be hours away

#### Breakout group 1:

- Many people cannot afford to get a passport or be able to get a driver licence
- Some people may not need the taxation office or Centrelink
- An alternative to SMS is to send the code in an email
- There needs to be accessible information about why people need to do this
- The process may be complicated for people turning 18 and moving to new services
- There is a lot of fear about the change and how hard it will be to make the change
- A national free identity card that works with everything would be a good idea

#### Breakout group 2:

- Different phones get texts in different ways. Apple phones have a clear identifier that says the text is from the NDIS. Android phones do not always have that
- Can the 100-character limit be extended?
- Have a subject matter expert in a Centrelink office or a local NDIS office that people can talk to

#### Breakout group 3:

- Co-design the identity process and make it more accessible
- Have a special team in the call centre that can take direct enquiries
- Have a nationally recognised proof of age card that is at the same level as a driver licence

#### Breakout group 4:

- Have videos and Easy Read frequently asked questions
- Have a checklist of what identity documents are needed and what the alternative options are
- Set up children and teenagers to meet authentication requirements
- Instead of putting the NDIS call centre number, make it clear who the message is from and to use the known usual phone number

The NDIA has noted all the feedback provided during this session.

## Session 3: Debt Management

### Presentation summary

The NDIA talked to PRG about this topic in February 2025. We explained in this session what we did with your feedback from February.

In this session, the NDIA talked about a participant's capacity to repay a debt. We want to make sure our processes are fair, easy to follow and in line with the Fraud Fusion Taskforce ethical principles.

We gave some examples we have had for financial hardship requests. We talked about the supports we have in place when we need to talk to participants about a possible debt.

We said we are building systems and hiring people to help with prevention and education.

### What we heard:

- PRG members wanted to know how the NDIA decides there is a debt to pay
- Participants may lose NDIS supports if their funding is reduced to repay a debt
- Participants may be at a greater risk of abuse or losing informal supports
- Financial counselling is essential for participants who have a debt
- PRG members wanted to know if there was an opportunity to explain why they bought something before it becomes a debt
- There should be a clear list of supports that are not NDIS supports, and they will create a debt. And have a separate list of supports that might need extra evidence
- Participants should be able to ask for a review if the NDIA says they have a debt

Breakout group online:

- There needs to be a flexible framework to determine the debt
- There needs to be a consistent and case by case approach

- There should be one on one training and education. Some communities rely on plan managers, support coordinators or people in their community. The NDIA needs to engage and communicate with those people
- The NDIA needs to make sure they do not put the participant in a harder situation

#### Breakout group 1:

- Make sure the decision about the debt and how to pay it is not just focused on written documents
- Look at where the system allowed a duplicate payment request and why that wasn't picked up sooner
- Educate participants and NDIA staff on the rules, how to apply them and where to find them
- Version control on documents is important. A different version may have been used when the payment was made
- Think about the impact of this process on participants and their capacity to keep working
- Think about other examples – it is not always the participant getting it wrong

#### Breakout group 2:

- Look at the processes that other agencies or community organisations use
- Have different approaches depending on the intention. It might be deliberate, or it might be an honest mistake
- Make sure people are safe by putting safety into the process

#### Breakout group 3:

- Make sure information is in accessible formats, not just written documents
- Make sure it is clear how the debt was raised
- In the examples where a debt was being written off it did not feel fair and equitable
- Where a debt is reasonable there should be a discussion about what is fair to pay back
- Have a direct contact with a financial counsellor, not a generic agency

Breakout group 4:

- It should be clear who holds the debt. There may be other people involved in the claiming process
- Think about reasonable timeframes for each case

The NDIA has noted all the feedback provided during this session.

## **Session 4: Improving the eligibility reassessment experience**

### **Presentation summary**

The NDIA talked about feedback we have already received for this topic. For this session, we talked about the participant experience journey for eligibility reassessments.

In breakout sessions, we talked with PRG members about their experiences and the experiences of their communities. We also asked about the participant experience journey we explained in the presentation.

### **What we heard:**

- PRG members said it could be expensive to get re-diagnosed
- PRG members asked about an extension to the 90 days to gather evidence
- PRG members asked what happened to a person's supports if they were assessed as no longer eligible for the NDIS and asked for an internal review
- There may be a third option with Stage 6 where someone stays on the Scheme and their supports stay the same

Breakout group online:

- The eligibility reassessment process puts a lot of strain on families
- Someone with a permanent disability should not have to go through an eligibility process
- The NDIA needs to communicate more about why we are doing this
- The NDIA is vague about what they are asking for

- Participants have to make time for appointments and may have to use their funding to get more evidence

#### Breakout group 1:

- The NDIA needs to be clear about what they will ask for so people can prepare
- The NDIA needs to be clear about what is being assessed
- Providers may not say a disability is permanent because of changing technology, medical opinions or how the person functions at that time
- There is a lack of consistency with staff and their opinions so there needs to be consistency in the principles
- PRG members wanted to know how staff will be trained to make these decisions

#### Breakout group 2:

- The 90-day timeframe could be hard for rural and regional communities or where someone is on a long wait list
- The 28-day transition from the NDIS to foundational supports is not long enough. In many cases the foundational supports do not exist
- There are different rules in different locations. For example, in Far North Queensland service providers are not allowed in the school system
- The staff who will be doing this work need to be trained in a trauma informed approach
- This may impact very vulnerable people. For example, child protection or people in the justice system
- The burden for caregivers and families is high

#### Breakout group 3:

- Communication needs to be clear and accessible
- The communication needs to say what needs to be submitted, where to get it and who to get it from. It also needs to include what is being questioned
- The timeframes can be challenging due to long wait lists
- Leaving the Scheme could take longer than 28 days

- The tone of the letters can be confronting

#### Breakout group 4:

- PRG members wanted to know if there is a timeframe on the documents that participants have provided to the NDIA. For example, if the documents were provided in the last few years does the participant need to get more recent documents?
- Someone with a permanent disability should not have to keep proving it
- There is a lot of anxiety and fear when participants get a letter from the NDIA. A letter about eligibility would be traumatic

We then had a co-design activity for PRG members to design their ideal experience journey.

#### Breakout group online:

- There needs to be a dedicated phone number for this process
- The NDIA should contact the participant in their preferred way before sending a letter
- Communication needs to be clear. The NDIA needs to say what criterion they are questioning

#### Breakout group 1:

- Information about eligibility reassessments needs to be accessible and easy to find
- The timeframes need to be clear if those are business days or calendar days
- The timeframes should not start until the NDIA has confirmed that the person has received the documents and understands them

#### Breakout group 2:

- The letter needs to be clear. It needs to say what documents the NDIA already has. Participants should be able to get a transcript of previous conversations with the NDIA

- PRG members suggested an advocacy service to support participants through the process
- PRG members suggested case management support to help participants connect with foundational supports
- Lived experience of going through the eligibility process is valuable and should be included in the co-design process

#### Breakout group 3:

- Communication needs to be clear. It needs to say if information is missing, or the participant needs to get a functional capacity assessment
- PRG members said the 28-day timeline should be revoked and participants should have 6 to 9 months to find other supports
- The terminology is confusing. For example, early intervention for adults versus early intervention for children

#### Breakout group 4:

- Participants need clear instructions about the reports and evidence they need to get
- Face to face meetings would be helpful for some people
- Letters should have an Easy Read option
- The NDIA should check the evidence they already have before asking for more reports
- The NDIA should cover the costs of getting more reports

The NDIA said we are talking to different groups, including participants, carers and nominees.

The NDIA has noted all the feedback provided during this session.

## Day 2 – Chairperson’s welcome

Donna Purcell, NDIA Branch Manager, Office of the Participant Advocate, thanked everyone for their contribution on day 1.

## Session 5: Participant journey for the new way of planning

### Presentation summary

We talked about the new way of planning. It aims to make the steps to get a plan fairer, clearer and better aligned to the needs of participants. We wanted to hear from PRG members about our approach to this change.

### What we heard:

PRG members said the support needs assessors need to be properly trained. They need to understand the needs of the participants they are working with. PRG members said sharing personal information repeatedly is exhausting.

PRG members said it was good that the assessors would read and be prepared for the meeting. But they said this might also mean the assessors judge the participant before meeting them.

PRG members said planners put too many supports as stated when they should be flexible. PRG members said it would be helpful to be able to get a copy of the transcript during the assessment. They said that would make it easier to check for errors.

The NDIA encouraged PRG members to send their comments and questions to the PRG secretariat team. These will be passed on to the business team.

## Session 6: Deputy Chief Executive Officer Corri McKenzie – update

### Presentation summary

Corri said the NDIA now has a specialised services team to support participants with complex support needs. This includes participants who are also part of other systems, like justice or hospital. It also includes a children's pathway.

### What we heard:

- PRG members asked about audits in Supported Independent Living homes

- PRG members also asked about large providers who cover all supports in Supported Independent Living homes
- PRG members asked if there will be a pilot for the new needs assessment process

The NDIA collected other questions and will work with Corri's office to get answers.

## Session 7: Accountability Statement continued

### What we heard:

Feedback from online group:

- If there is a lot of discussion about a topic, let this continue and adjust the agenda
- Have an out of session meeting for topics that need more time
- Check the language – assigning blame is negative, can it be changed to a more positive statement?
- Presenters need to understand what co-design is
- Presenters need to tell PRG members at the start of that session if they want to inform, consult, involve, collaborate or empower PRG members
- PRG members want to know what happens if the statements are not met
- Documents for a 2-day PRG meeting should be sent 10 days in advance
- Help PRG members talk to their network or community about what was talked about in the meeting

Feedback from the in-person room:

- PRG members suggested adding a commitment to read all the material and do the preparation to be an accountable and responsible PRG member
- Focus on the solution rather than the problem or situation
- Rank feedback based on must have or like to have
- Make sure everyone gets a turn to have their say. Look at different ways people can do that

- The colour cards work for some people but not others. Think about other ways for PRG members to be part of the conversation

The NDIA has collected all feedback. We will come back to PRG members with proposed changes to the accountability statement.

## Session 8: A new way of planning

### Presentation summary

The NDIA said we want to talk about communication. We know the way we communicate is not always the best way. We want to do better with the new way of planning.

### What we heard:

PRG members asked if there were similar models that the NDIA could learn from. They said nobody should have to go through more than one negative experience because the NDIA didn't take the time to learn. The NDIA said we are looking across Australia and other countries to find best practice.

PRG members asked who decides the order of the groups to move to the new way of planning. The NDIA said the Department of Social Services, and soon to be the Department of Health, Aging and Disability, is still working through the legislation changes.

PRG members asked about the impairment categories. They asked where the information for them came from. They said a lot of participants have disabilities that go across multiple categories. The NDIA said we have a policy to manage those participants.

Breakout group online:

- Clear communication and transparency, and human contact
- Have time between each step to think about what is happening and think about questions
- Support to ask questions and get clear and consistent answers

- Training for NDIA staff and providers, so participants get consistent answers

#### Breakout group 1:

- There needs to be clarity around the categories of impairment. Some people's disability might fall into a couple of categories
- There needs to be clarity around when things are happening. Documents need version control on them
- NDIA staff, local area coordinators and other providers need to be educated about the new policies
- There should be an interactive session and something to show the person has learned and applied the information
- The decision makers should be local where possible. Families should have one person managing the whole family
- Consider having people who know about the disability of the participants they are working with

#### Breakout group 2:

- Build the capacity of people through education
- Make sure past learnings are part of the process of transition
- Face to face relationships and appointments for those who want that
- Have collaborative problem solving that responds to problems

#### Breakout group 3:

- Give basic information and say where to go to get more information if you want it
- Empower and respect people
- Make sure the messaging is not condescending
- Have a current status bar on the portal that shows where the participant is now and where the assessment will be

#### Breakout group 4:

- Make sure the information empowers the participant

- Build trust through empowering the participant and being transparent
- Information needs to be up to date and relevant
- Information in different formats needs to be available at the same time

The NDIA has noted all the feedback provided during this session.

## **Session 9: PRG Induction Survey feedback**

This session did not go ahead. The NDIA will send this information to PRG members separately.

## **Final comments and close**

PRG secretariat took questions on notice during the meeting. We will get answers to these and send them out to PRG members.

Donna thanked PRG members for their time, commitment, and for travelling to the meeting or working online to give their valuable feedback.

## **Next meeting**

Wednesday, 11 June 2025

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