24 January 2025

This is a summary of the Participant Reference Group's (PRG) meeting.

The Participant Reference Group (PRG) makes sure the 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 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 a face-to-face meeting to talk about:

- the Section 10 Substitution documents
- the NDIA Integrity update
- the Chief Executive Officer, Rebecca Falkingham's update
- the NDIA and Services Australia information sharing pilot
- the NDIA Board.

Session 0: Section 10 Substitution draft process

Presentation summary

We are working on the substitution, or replacement, process. There are 3 parts of the substitution process – getting ready to apply, doing the application, and hearing back from the NDIA.

What we heard:

- Asking for more information during the process might confuse people – it's not expected as it's not part of the process.
- Participants may not want the NDIA to help them to apply – other people, like support coordinators and the National Contact Centre (NCC), should be able to help.
- Keep an anonymous record of what substitutions were requested. When reviewing the lists, there may be a support that has been requested a lot and that support should be reconsidered.
- These decisions are open to interpretation – there should be a step in the process for the NDIA to go back to the participant before the application is denied. There might be something the NDIA doesn't understand, or the participant might have more evidence.

- Communication is important in the claiming process, not just the approval process.

Breakout group 1 – How do we make it quick and simple to apply? What information and support are needed to apply?

- There needs to be a few ways to apply. Have a specialist dedicated team with a dedicated phone line, not the 1800 number. Make it clear what is in and out of plans. Staff need to be better trained in disability and accessibility.
- Ask the person if they need a support person. Tell the person what information they need to provide to apply. Contact the person to find out more information before making the final decision.
- People need to know what the process is and what to expect.

Breakout group 2 – List of things to help understand substitute supports. Is the list right? What should the NDIA include?

- Staff training should be number one – make sure the application process and the advice that participants get are the same for everyone.
- Replacement is a better word than substitute.
- Give participants the lists of in and out when they need it, not when the NDIA is ready to send them out.

Breakout group 3 – What is the easiest way to tell the NDIA about the substitution item? Should the NDIA work out the cost of the support it would replace? How would the participant show the substitution gives the same or better outcomes?

- The NDIA should work out the cost of the support. Make sure the participant understands what it means when they apply for a substitution and what the process is to apply.
- As the process can’t be reviewed, there should be a list of questions that the participant can get before the conversation. The conversation should be simple, based on common sense and at a level the participant can understand.
- There should be at least 2 delegates looking at the application. The delegates should look at it separately and then make a decision together. If the delegates can’t agree, then the participant could be asked for more information.

Breakout group 4 – Overall process and support to help a participant to apply.

- Participants should be able to apply over the phone, with an email or in a form. They should be able to talk to someone about the application if they want to.
- Participants should be able to talk to someone about the decision. There should be support to find something that works for the participant.
- There could be a self-serve option. Participants could use their lived experience, talk about their life, and show how they can use a substitute support. The NDIA could follow up with spot

checks or spot audits.
- There should be a resource like the self-management Can I Buy It guide.
- Remove the burden from participants to provide all the evidence. Don’t create a process that takes too long and causes backlogs and delays.
- Build capacity to support participants with all the changes.

PRG members gave more feedback during the breakout sessions. We will use this to continue work on the substitution process.

Session 1: Integrity update

A PRG member who is also a member of the Integrity working group had a question and answer session with the NDIA’s Co-Design and Stakeholder Engagement director.

- NDIA: integrity is about keeping NDIS funds safe and secure so people with disability can be safe and get the supports they need.
- NDIA: we need to deal with fraud that has already happened and also prevent it happening again. We said the Integrity working group looks at the impact on participants.
- PRG member:
  - Participants can’t always get everything they want.
  - The NDIA can forget steps in the middle of a process.
- NDIA: we have learned to check the meaning and messaging behind the words.
- NDIA:
  - There are times when we may not be able to achieve an ideal outcome.
  - The working group understands that may happen but wants to know why.
- PRG member: if the NDIA says no, they need to explain it.

What we heard:

- The ethics and human oversight framework needs to be made public.
- On the NDIS website, it says the task force is governed by the framework. The wider community needs to be able to hold the task force accountable to the framework.

The NDIA provided an update on the Fraud Fusion Taskforce and the Crack Down on Fraud Program.

What we heard:

- Participants need to hear that their NDIS funding is protected. They need to know fraud reporting is working.
- In the past, PRG members have spoken about an induction video for participants. It should include rights and information about fraud.

- It’s hard to tell if it’s a task force problem, or an NDIS Commission problem or an ACCC problem. It’s hard to sort through the consumer guarantee issues.
- Some practices may be allowed as part of the NDIS Rules but are close to fraud.
- Some providers may overcharge but if a participant reports them, that participant may lose their provider.
- Self-managed participants seem to be a focus of the crack down on fraud – PRG members thought there would be bigger areas to focus on.
- PRG members asked if the NDIA will have the same requirements for evidence from providers that they have for self-managed participants.
- PRG members said this was the first time they had heard about the changes to claiming. They said there will be questions from the community.
- PRG members noted there needs to be more discussion with participants around the changes.

The NDIA noted these issues. We have teams who look at these issues and do risk assessments to ensure participants continue to receive supports.

PRG members gave more feedback during the session. We will use this to continue work on integrity and fraud.

Session 2: CEO update

The NDIA CEO, Rebecca Falkingham, gave an update on the work the NDIA is doing to make changes to the NDIS, in line with the new legislation.

- We will work with participants and the disability community.
- We will be clear on what is changing, how participants are affected and when the changes will take effect.
- We will talk to NDIS participants, advocacy groups and providers.
- We regularly update the NDIS website’s legislation page.
- We are reviewing the feedback on the Section 10 changes.
- Where someone has purchased something and they didn’t know that it isn’t approved, the NDIA has greater ability to prevent and waive debts.
- The CEO makes the final decision on whether to pursue a debt.
- The NDIA is working on changes recommended by the NDIS Review.

What we heard:

PRG members raised issues around:

- review rights
- Robodebt

- lack of communication on app updates and the CEO saying we will communicate changes
- Disability Representative and Carers Organisation (DRCO) messaging
- psychosocial disability and multiple disabilities
- short-term accommodation/ respite
- supported independent living

The NDIA suggested having a separate meeting to talk about the legislation and the new planning framework

Session 3: NDIA and Services Australia Information Sharing Pilot

Presentation summary

Services Australia and the NDIA are working together to make the claim process easier for the Disability Support Pension and the application process for the NDIS.

Services Australia and the NDIA are testing how to securely share medical information between the 2 agencies.

What we heard:

- People need to be able to withdraw their consent.
- Be clear about how consent will work. What does it cover? Will there be limits to the consent? How much information is shared?
- Think about people who are non-verbal and unable to write, and how they can give consent.
- The Australian Privacy Commission should be involved in the project.
- How old is the information held by the agencies? If it is too old, the consent process may hold up an application longer than needed.
- Can the requestor see the information that was provided to the requesting agency?
- Be clear about the separate application processes, and what information can be shared to make the application process easier.

Breakout group 1:

- What part of the file is required? Is there a need to give access to everything? How long is the consent valid for?
- Information and documents need to be in plain language. They need to be in a format and language that is accessible for all audiences.
- Know what the agencies do with the information that is collected and how they will share it.

- People may not be aware or remember what information is stored by each agency.

Breakout group 2:

- Need to be able to say what documents can be shared. There should not be free access by either agency.
- The 2 agencies have different focuses. Could one be used against someone so they can't access something or something is taken away?
- What are you consenting to at the start? You may not know all the documents that one agency has about you. Can you select which documents to share?

Breakout group 3:

- Make sure the rural and remote communities can understand the information and the pilot process.
- If you bring the people along as you develop the process, they can promote it in their community.

Breakout group 4:

- The people that these communities trust should be the ones who communicate this process.
- The pilot should include translators, so everyone understands the process.
- There should be many consultations during the pilot, and updates with the feedback that is provided.

The NDIA has noted all the feedback provided during this session, and will share it with Services Australia.

Session 4: NDIA Board – round table panel discussion

Topic 1 – Co-design

PRG members said the Co-design branch spoke to PRG in April about the draft approach to co-design.

PRG members said there needs to be more detail about accountability and how the approach will be put into action.

PRG members asked the Board how they will make sure participants are heard and consulted in the co-design of all the changes and reforms.

The Board said:

- we need to co-design with community for changes to be effective
- we will advocate for changes within the Scheme

- we will advocate for as much time as possible to ensure co-design
- we have Board members who go to the Independent Advisory Council (IAC) meetings
- the chair of the IAC is also a Board member, and is part of all co-design working groups
- government and Members of Parliament managed the legislative process so we can't control that. The processes we are starting now are controlled by the NDIA so we can make sure they are co-designed.

Topic 2 – rebuilding trust in the NDIA

PRG members asked how the Board will:

- support the disability community to rebuild trust in the NDIA, and
- support the culture of change.

PRG members asked how to get the message to those who need the NDIS, so they know they will be supported. They asked how the Board knows that participants aren't experiencing harm out of change.

The Board said:

- We need to continue the real work with people with disability.
- We can sort out misinformation in the community by doing and living what we say.
- We need to be an agency that genuinely values people with disability.
- We need to make sure the NDIA is more comfortable, confident, and better at talking to people with disability.
- We are committed to listening to people with disability.
- At IAC meetings we hear about issues in the community. We have either the CEO or Deputy CEO at those meetings. They talk to us about what they will do to address those issues.
- We get reports and information. These tell us about participants having choice and control, accessing the community, having a say in their lives.

Topic 3 – informed and empowered consumers

PRG members said the informed and empowered consumers strategy works with the supported decision-making policy and the participants safeguarding policy.

PRG members asked about choice and control for families who need to register as NDIS providers.

This includes families who need to register for restrictive practices and employing staff. These families will be put in the high registration category. For some families this is the only way to safeguard a loved one.

PRG members asked about support for these families to meet registration and regulatory requirements.

The Board said:

- we will take the questions on notice and get answers for PRG members.
- the NDIS Review looked at the registration process. It recommended increasing registration in line with the level of risk.

The Board asked PRG members what they thought about the NDIS Review recommendation.

PRG members said:

- when positive behaviour supports are in a plan, that goes straight to the high category.
- it depends on the individual. Some may like the additional structure, and some may prefer less regulation in their life.
- they appreciate the recognition that they are the expert in their lives.

Session 5: NDIA Board – small group discussions

PRG members sat with Board members to talk through a range of issues.

Final comments and close

Donna thanked PRG members for their time and contribution.

Next meeting

Tuesday 24 September 2024

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