16 October 2024

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

The PRG consists of 22 participant and carer representatives across Australia. The PRG is a key platform to make sure the participant voice is heard and understood by the National Disability Insurance Agency (NDIA).

Feedback from meetings is used to inform strategy, policy development, system and service delivery development and review, to support continuous improvement.

Day 1 – Chairperson's welcome

Donna Purcell, Branch Manager, Office of the Participant Advocate welcomed members to the seventh PRG meeting for 2024.

Donna introduced Corri McKenzie, NDIA Deputy Chief Executive Officer (CEO), Service Design and Improvement, for Session 1.

Session 1: Deputy CEO Round Table discussion

Corri provided the following updates:

- We know there are long wait times for plan reassessments. We are currently working through the backlog. We are also managing urgent plan reassessments.
- Plan reassessment is about understanding support needs. It isn't about getting access to the National Disability Insurance Scheme (NDIS, Scheme).
- Eligibility assessment is different. It focuses on young children and those who may no longer need the Scheme.
- Changes to legislation – the Draft Bill is in the Senate, with the second report due by 5 August 2024. We have made some changes based on feedback. These have been accepted by the government.
- We are starting some projects to improve how we support people with psychosocial disability.
- We are working to make the review process clearer.
- We are training Planning staff, so they have the right skills for good planning conversations.
- Our new computer system will support how participants want us to communicate with them.
- We are working with planners to help them communicate with participants in their preferred method, including more face-to-face meetings.
- We talked about draft plans and how they could be used to avoid full plan reviews. We have not done this before for many reasons, including limits on the number of staff we can have in the

Agency.

- As a result of the Plan and Plan Approval Letter co-design project, there will be an Easy Read version, and it will have less pages.

Next steps:

On Wednesday, 24 July 2024, PRG will have an out of session meeting with Corri McKenzie. The topic will be Legislation Reforms.

Session 2: Informed and Empowered Consumers Strategy

Presentation summary

We are working on the Informed and Empowered Consumers Strategy. This strategy works with the Supported Decision Making Policy and the Participant Safeguarding Policy.

The strategy and policies will help participants to use their disability supports in the way that works best for them.

What we heard:

What you think the strategy should include

- Tell participants about their consumer rights and consumer law.
- Help participants understand service agreements. Include how to end the agreement, what should be in the agreement, and what it means when you sign the agreement.
- Make sure contracts and service agreements meet the needs of participants.
- Include an understanding of trauma in training and how we talk with participants.
- Focus on making goals personal, to make it easier to get supports.
- Allow exceptions to rules, and let participants change providers.
- Set up peer support groups to help participants write their goals.
- Help participants build their capacity to choose who gives them support.
- Fix the issues in creating plans.
- Develop a focused program to teach young people (ages 14-24) about how to manage their funding.

What are the barriers to choice and control?

- Lack of ongoing, face-to-face support from someone other than planners.
- Hard to find information on the NDIS website and the call centre doesn't help.
- Planners don't understand disabilities and some of the plan sections can't be changed.
- Service providers don't have training or are not qualified, leading to poor service.
- No supported decision-making, leading to the participant being unable to make their own decisions
- Confusion about options and support categories.
- Limited provider options and long wait times for services.
- Issues with getting proper funding, and planners don't believe reports on functional capacity.
- Providers overcharge, and the NDIS doesn't make sure providers charge standard pricing.
- It can be hard to find the right provider.

Session 3: Management of funding for supports

Presentation summary

We want to improve how planners make decisions about how the participant manages their supports in their plan. We also want to improve how participants (and/or their representatives) are supported to manage their funding.

To do this, we want to identify risks that could cause harm and use the right safeguards to support participants and the NDIS.

What we heard:

When should a participant's request to self-manage not be approved?

- There is evidence of fraud or not using funds the right way. The NDIA should talk with the participant before making a final decision.
- Participants in prison should not be allowed to self-manage.
- There are signs of funding not being used the right way or financial abuse, such as overspending or providers taking too much.
- The planner finds red flags during meetings.
- The participant heavily relies on intermediaries for managing their funds.

- A participant self-managing part of their plan for a trial period showed poor results or big problems.

When should a participant's request to self-manage be approved?

- Participants have a good history of managing money.
- Participants show they can manage funds, possibly by doing lessons and tests.
- There is a low risk of people taking advantage of the participant financially.
- Participants find managing their own funds can be empowering, even if they have been abused in the past.
- Planners should think about the participant's view and circumstances with empathy.
- Participants should be able to learn how to manage funds and use the NDIS system and be able to fix mistakes, before the NDIS changes how they manage their plan.

How can we measure a participant's ability to self-manage?

- Put in place a 2-hour lesson followed by a test, like universities use.
- There are guides on how to screen support workers – these can be used to check if a participant is able to self-manage. Include ratings on how well the participant answers the questions. Give participants the chance to learn more and take the test again.
- Make sure participants know how to use a budget to manage their funds.
- Past abuse should not mean participants can't self-manage; managing their own funds can be empowering.
- Provide education programs on how the NDIS works, with lessons, supervision, and the chance to show they understand and can self-manage.

What safeguards do you think would help the NDIA manage risks, regardless of the plan management type?

- Set up clear guidelines on what participants can buy and use the same method to make funding decisions for all participants.
- Carry out audits on providers to make sure they don't charge NDIS participants more, to reduce the risk of unfair pricing.
- Give participants information on what they can and can't buy and make sure they provide receipts for claims.
- Limit the amount of plan funds that participants can access, so they don't get all their funding at one time. Provide options to ask for more funding from their plan if needed.

- Provide flexible options for how new participants can access their funding while they get used to managing their plan.
- Offer mentors or buddies to help with keeping records. Run workshops to help participants with invoices, using the app and portal, claims, and keeping documents.
- Have regular check-ins to support participants, using templates, guides, and communication resources to make sure they are on the right track.

When should a participant's plan management type be changed from self-managed to NDIA-managed?

- If the participant doesn't put in claims regularly, and they are at risk of losing supports.
- If the participant is at high risk of harm or financial abuse, especially if they have previously been financially abused by a manager or helper.
- Where there has been fraud, the participant has deliberately done the wrong thing, or has used funds the wrong way.
- Where informal or guardian supports are not available, such as after the death of a close family member.
- If the participant has shown they can't manage funds, for example if they have an addiction.
- Life-changing situations like moving from residential care to Supported Independent Living (SIL) without the right support.

What would help a participant to spend their funds in line with their plan?

- Make sure the plan meets the participant's needs and provide advice on products and services that suit the participant.
- Help participants understand their rights and how to use their funds. This includes how to get training on keeping records and self-management.
- Offer regular check-ins with Local Area Coordinators (LACs) or the Agency to make sure spending is in line with the plan. Provide support in making claims.
- Provide clear information on what can and can't be claimed. Include real examples and videos.
- Help participants find good plan managers and support coordinators, especially for participants with complex needs or those new to the Scheme.
- Develop tools like self-management templates, guides, and workshops to help participants understand and manage their budgets well.

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: Meeting videos – presentation

Presentation summary

In January 2024, we completed a project to learn how we can better prepare and support participants to take part in engagement activities.

We met with participants who have been part of recent long-term engagement activities. For example, Participant Reference Group (PRG) members and Reform for Outcomes (RFO) and PACE working group members.

We are now working on some of the suggestions that participants shared with us.

One of the suggestions was to create some short videos.The videos will help participants who haven’t been part of long-term engagement activities. They will explain what the participants can expect and will be part of the participant induction. Each video will have a different topic.

We want to know if the topics are right and what the videos should be about.

Part 1: PRG members talked about video topics. The final list included:

- What are long-term engagement activities?
- What can I expect in a working group or a co-design group?
- How can I prepare?
- How can I share my feedback?
- Helpful tips
- What a good meeting looks like.
- Meeting etiquette
- Safety during a meeting – content warning and having someone to contact
- Handling disputes
- Positive messages

PRG members also said the videos should be audio described and there should be other ways to access the videos.

Part 2: We asked PRG members what they thought the videos should be about.

What we heard:

Topic 2: What can I expect in a working group or co-design group?

- Explain what working groups, PRG and co-design groups are.
- How to prepare for a meeting.
- Explain how much time is needed. For example, how long the meetings or groups are, pre-reading, travel needs or option to participate online.
- Make it clear that participants will be paid for their time with no out-of-pocket expenses, and specific needs will be met.

Topic 3: How can I prepare?

- Explain what a conflict of interest is.
- Explain what can be shared and what can’t be shared.
- Use a social story to describe what will happen.
- How to collect your ideas and questions to prepare for the meeting.

Topic 4: How can I share my feedback?

- Explain that you can follow up with an email if you have more you want to say.
- Talk about ways to prepare. For example, make notes from pre-reading or write down any questions.
- Talk about how to get feedback from your community.
- Explain how you can share your feedback. For example, online meeting chat.
- The video could show examples of people using assistive technology. It could also show interpreters or live captions.

Topic 5: Helpful Tips

The heading for the topics under Helpful Tips should be changed to Meeting Etiquette. The meeting etiquette video should also include:

- Real life examples and how the meeting might look.
- Explain why documents are confidential and can’t be shared.

There should be another video for Helpful Tips that includes things like:

- MS Teams tips (for example, the shortcut for hand up)

- speaking in turn online or making sure everyone has their turn to ask questions in the room
- saying your name before you speak

The videos should try to show the energy of the PRG and how everyone supports each other in a positive way. There should be images of people taking part in person and online.

Topic 6: What a good meeting looks like

- Video examples to show what a meeting looks like. Online, face to face and a mix of both.
- Give examples of how to give positive or negative feedback in a respectful way.
- Give examples of how a meeting usually takes place.
- Give examples of how people share their experiences.
- Add in a quiz to check if you understand the video.
- Explain what happens in a breakout discussion.
- What to do if you don’t understand the topic or need support.

Session 6: Proposed Buddy system

Presentation summary

This project also suggested setting up a buddy system. A buddy system can prepare and support participants to take part in engagement activities.
We want to understand your ideas about how a buddy system could work.

What we heard:

A buddy system or mentor program would help participants joining PRG or a working group.
Participants can find out how meetings work, how to prepare and what to do in meetings.
The buddy system should be for:

- Someone who is new to working groups. A current group member can help the new group member be more comfortable and take part at the meetings.
- Anyone who wants to talk to a current PRG member about how PRG or similar groups work. The current member can give tips on how to make great contributions during meetings. If someone has already been to one of the meetings, they should still be able to use this program.

What does it look like?

- It should be informal, but the mentor's role needs to have clear guidelines on what the mentor needs to do.
- There should be a system to support mentors. This should include suggestions on how often the 2 people meet, which both should agree to.
- People shouldn't have to take part. The NDIA should think about whether people will be paid to take part.
- Face-to-face meetings at the start can help to build relationships. Online meetings should also be available to those who prefer this.
- There should be a way to report issues if something goes wrong.
- Buddies should have an information pack.

Describe the role: what would a buddy or mentor do?

The buddy should make new members feel comfortable and able to take part in meetings. The buddy can talk about the meeting structure and provide support.

A buddy should help new members understand:

- how the sessions work
- when and how to share experiences and give feedback
- how to answer questions about the PRG or working group
- roles in the working group or PRG
- how to provide tips on respectful communication.

Final comments and close

Donna thanked PRG members for their time, commitment, and for travelling to the meeting or working online over two very busy days.
Next meeting

Next meeting

Out of session: Wednesday 24 July 2024

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