Participant Reference Group Meeting Summary – 14 and 15 November 2023

9 April 2024

This is a summary of the Participant Reference Group's (PRG) recent meeting. The PRG consists of 23 participant and carer representatives across Australia. The PRG is a key platform to ensure 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.

Chairperson's welcome

Debbie Irvine, NDIA Director, Participant First, welcomed members to the tenth meeting for 2023. This meeting was a live event held over 2 days in Melbourne, Victoria. Debbie thanked PRG members for travelling to Melbourne. She also thanked those who could not make it but joined online.

Donna Purcell, the NDIA Disability Champion and Branch Manager of the Office of the Participant Advocate also welcomed PRG members to the meeting and discussed what will be covered over the two days.

Day one. Tuesday, 14 November 2023

2023-24 Annual Pricing Review

Mary Hampton from the NDIA Economics and Pricing Branch spoke to the group about the 2023-24 Annual Pricing Review and the Participant consultation paper.

A very early draft Annual Pricing Review Participant Consultation paper was shared with the PRG. We talked about:

- What an Annual Pricing Review is.
- The purpose of the Annual Pricing Review Participant Consultation paper.
- How we can make the Participant consultation paper easy to understand.
- Ways we can encourage participants to make a submission.

We heard:

- The Participant consultation paper is not clear or easy to understand.
- We need to explain the benefits to participants for completing a submission and how their input into the Pricing Review will be used.
- Don't ask too many open-ended questions, as that can be overwhelming for participants.
- Offer the option to submit a simple yes or no response, allowing those that want to say more the opportunity to elaborate.

- Using terms like 'value for money' can be interpreted differently by participants. Be specific where possible.
- Participants need multiple options to provide input. A simple survey or focus groups were raised as ways to optimise the participant response.
- Participants are often told by providers that the NDIS sets the price they charge.
- Participants do not feel empowered to negotiate price and are often charged at higher rates than non-NDIS participants.

Suggestions:

- Make the consultation paper easier for participants to understand. Provide information in plain English, Easy Read, and languages other than English.
- During the consultation period, talk about the Participant consultation paper during planning meetings.
- Promote the Participant consultation paper to participants through many different channels, like direct emails, on the participant portal, Local Area Coordinators, plan managers, providers, and Peak bodies
- Have clear directions in the opening section of the Participant consultation paper so participants understand how to complete a submission.
- Make it easier for participants to contribute – simple surveys, reduce the number of questions.
- Promote the Participant consultation paper in a way that encourages participants to make a submission.
- Highlight how their submission can have a direct impact on how a plan is used.

Participant readiness for PACE

National rollout of the new computer system (PACE) commenced on 30 October 2023. Paul Rawson, from the Office of the Participant Advocate, gave an update on the work done to support participants to move to the new system.

We have worked with participants to create resources and materials to support participants as the new system is rolled out over the next 18 months.

These will be continuously improved as feedback from the roll out of PACE is received.

Please visit the NDIS Improvement website for more information.

Changes to the Participant Reference Group Terms of Reference

Debbie Irvine spoke about changes to the Terms of Reference for this group in 2024. PRG members approved the following changes:

- Allow members to express an interest in extending their membership term for up to 2 years.
- Payments to members will increase to match other recognised reference groups.
- Some minor changes to language.

Participant Reference Group meetings for 2024

Debbie Irvine asked members if the current meeting structure still suited most members. Members agreed to move meetings to the second Wednesday of each month in 2024. The meeting times will stay the same.

Day two. Wednesday, 15 November 2023

Plan and plan approval letter

Carolyn Tetaz, from Service Guidance and Practice, spoke to the group about improving the plan and plan approval letter. An NDIS plan is one of the most important documents participants get from us.

We want to make the plan easier to use. We want to make sure participants can understand their plan and plan approval letter and be clear on any actions they need to take and when.

We asked PRG members to give us feedback on how we can improve the look and layout of the NDIS plan and plan approval letter. We also asked what information should be included in the plan and how we can make it accessible for all participants.

We heard:

- Having a summary of supports is good but it is helpful to have the funding listed first on the plan.
- Language and terms can be confusing in the plan and letter. Content needs to be in plain English and languages other than English.
- Participants want to access this information in different ways. Some like emails but others prefer a letter, or to find the information on the NDIS app or portal and be able to print from the portal.
- Extra information about what core supports and capacity supports are don't need to be included in the plan. These could be an attachment or provided in a booklet format.
- Participants don't always want to share all the information in their plan. It would be good to have a cover letter and summary and be able to pull out sections of the plan to share as needed.

- It is not always clear who to contact if participants have questions or problems with their plan. A consistent contact point in the NDIA would be helpful.
- There is still fear around the planning process and the funding participants receive.
- It is important for the plan to reflect the participant's goals. Sometimes the goals in the plan don't match the goals the participant shared with their planner. Participants also need to be able to change their goals as needed.

Suggestions:

- Reorder the content so the funding is at the front.
- Clearly explain any changes from the previous plan.
- Provide information about why a decision has been made to decline or approve something in a plan.
- Add a table of contents so you can easily move to the section you want.
- Have clear headings for personal information, funding, definitions, a summary, and information you provide to others.
- Develop a tool kit to help participants use their plan and, if needed, appeal a decision made in their plan.
- Have a summary of the plan that you can share with providers that shows the hours funded, not the funding amount, so that support is based on hours, not maximum price guide rates.
- Make language consistent and easy to read. Provide an Easy Read version for participants who need it.
- Make sure the plan and plan approval letter are accessible for each participant's individual needs.
- Allow National Contact Centre staff access to plans so they can answer questions faster.

PRG celebrations and achievement for 2023

Debbie Irvine shared a presentation about the amazing achievements of our PRG members during the year. Some members were appointed as committee or board members or took part in international sporting events. Everyone had a chance to talk about what they had accomplished for the year or were proud of achieving.
We also spoke about the topics we covered in our meetings during the year and how the groups input has been used on some significant improvements.

Corri McKenzie update

Corri McKenzie, the Deputy Chief Executive Officer (DCEO), Service Design and Improvement, thanked PRG members for their valuable contribution to the work the NDIA is doing.

Corri spoke about using the PRG to strengthen the voice of participants within the Scheme and involve more participants in co-design. Corri also answered questions about creating a PRG page on the NDIA website, improving communication between different NDIA departments and providing employment opportunities within the NDIA for members of committees and groups like the PRG.

Participant resources for long-term working groups

The NDIA has committed to having more participants involved in in helping us improve the way we work. The NDIA sometimes sets up long-term working groups or committees about a specific topic or project. We asked PRG members to help us improve the way we support participants who are selected for long-term working groups to set them up for success.

We talked about our current documents and how these could be improved for all new working groups. We also spoke about what information was missing and other resources we could create.

We heard:

- PRG members said other working groups need to see how well PRG meetings are held. It is an excellent example of how to build trust and respect with each other.
  - Members of the PRG know what to expect at every meeting and they are prepared with meeting documents well in advance. Any changes are advised with plenty of notice and accessibility needs are taken care of.
- Sometimes it feels like decisions about the project or process have already been made and members are talked into agreeing with the outcome. People's lived experience must be considered and respected by everyone.
- All members felt they could contribute to creating resources for both other participants, and business teams.

Suggestions:

- Create a buddy program where PRG members can work with members of new working groups to talk about their experience being involved in a long-term group.
- Help new members feel comfortable to share their experiences and what they bring to the group. People might feel intimidated if they aren't a part of lots of advocacy groups, but their experiences are still valid and important.
- Stress there are no wrong answers. All feedback is valuable, and this creates trust within the groups. Participants appreciate when a facilitator encourages new members to share their ideas with the group.
- Run induction sessions for new members as well as staff. This will help members know what to expect in meetings, and staff become more comfortable working with group members.
- Create videos, and other documents showing how a good meeting should be run.

- An accountability statement is helpful, so members and staff know what everyone's role is and what to expect from each other
- Make sure business teams have a consistent meeting structure. Pre-reading should be sent on time, sessions should stay as scheduled and when changes can't be avoided, must be notified with plenty of time.
- Provide contact information for staff managing the working group. This makes things more personal, and people know who to contact if needed. Emails get lost and not always responded to quickly.
- Have 'housekeeping' rules at the start of each meeting. Let people know how to use digital meeting functions like chat and hands up and that they can leave the meeting at any time.
- Create a resource around safe story telling.
- Collaborate with other organisations who have developed resources.

Final comments and close

The Chairperson thanked PRG members and NDIA staff for taking part in the meeting. It is always wonderful when we can meet in person to get to know each other better and build trust and respect. It was a wonderful two days, and we heard such valuable feedback on the topics we discussed. The commitment from our PRG members is greatly appreciated.

Next meeting

Wednesday, 13 December 2023

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