16 October 2024

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

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 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 an out of session meeting to talk about feedback from the Section 10 legislation changes and the substitution rule.

Feedback from the Section 10 legislation changes

The NDIA and the Department of Social Services (DSS) talked to the Disability Representative and Carers Organisation (DRCO) and the Independent Advisory Council (IAC). We also ran focus groups. We collected information from these meetings.

The NDIA is writing a report. DSS will also write a report. These 2 reports may both be included in a final report, or they may stay as 2 reports. We have provided a draft copy of the NDIA's report to PRG members.

DSS said sorry for the process being rushed and not accessible. PRG members noted the low response from participants. They said it shows how hard it was to respond to the survey.

DSS noted they have feedback on what they should do better. They are working on making their communications more accessible and easier.

DSS talked about the survey question about the draft list of supports and if it covered what people thought should be included. DSS noted that two thirds of people who did the survey said no and one third said yes.

PRG members said it would be interesting to know how many of those who said yes were participants

or carers.

DSS has free text responses from the survey. They are reading those, and they will do a report. PRG members asked if the submissions would be included in the report. DSS said they will ask everyone who put in a submission if they consent to it being released.

PRG members noted concerns about the impact of power outages on disability needs.

PRG members asked about consistency in decision making and how that impacts participants with unique disability needs. They also asked about how debts will be managed and whether they should exist in the first place.

PRG members noted the NDIS needs to work for everyone. They said foundational supports seem to only be for young children. Having some support would make a difference to people who aren't NDIS participants

PRG members asked about the change to carve outs. The NDIA said we heard carve outs were confusing. We are working on making the list clearer about what is included and what is not included.

PRG members asked if the lists would mean mainstream providers had to become registered providers. DSS said they were working with the NDIS Commission to make sure there are no unintended changes to registration.

PRG members noted the length and number of meetings. They said there was an impact on mental health. The NDIA said we were aware and were working on providing support. We said we would share details shortly.

Substitution rule

The NDIA heard that we need a way for people to apply for an item that is not on the list. They need to be able to do that without a legal process or getting reports.

PRG members noted that regional areas and areas with thin markets may not be able to get a substituted support for the same price.

PRG members asked if a substituted support was included in their plan, do they have to keep asking for it at future planning meetings? The NDIA said we were looking at how to make the substitution process easy. This would mean it isn't hard to get the substitution support in future plans.

PRG members said they weren't confident that the substitution would be accepted for future plans.

They said participants won't trust the delegate to make a fair decision. They said if the substitution wasn't included in their next plan, it could have unintended consequences that could cause harm.

The NDIA noted the PRG's concerns. We said we are working on getting the process right. We said the PRG's feedback would be part of that work.

PRG members also noted that the focus is on the substitution not costing more, instead of safety or trauma. The NDIA said one of the criteria for the substitution was that it needed to cost the same or less. Another of the criteria was that it provides the same or a better outcome for the participant.

PRG members said that if the NDIA is moving to more flexible funding, plans won't include everything a participant may need. They said if they must put in a change request, that would add to the NDIA's workload.

PRG members noted that National Contact Centre (NCC) staff give different answers. They said NCC staff aren't following the guidelines now, so they probably won't follow them after the changes are made.

PRG members said fraudulent providers could offer services not on the list but call them something different. They said there is a lot of anxiety among participants. They said participants are worried about doing the wrong thing.

PRG members asked about informal supports as part of substitution. They noted that there were some examples where family members were paid for providing supports. They said that needs to be part of the process discussion. The NDIA agreed.

PRG members said the key principles should be based on the self-management questions. The NDIA said we would look at those questions and the four substitution criteria.

PRG members asked if the lists were to help the Fraud Fusion Task Force. They noted that every participant is likely to have at least one substitution. They said this would increase the NDIA's workload. They said the legislation has principles, not a support list.

DSS noted that some participants have said they are confused about how to use their funding. They said this is the pathway to flexible budgets. They noted the need for engagement and good communications.

The NDIA said they want to make the out list as tight as possible. That would mean people wouldn't need to use the substitution rule very often.

PRG members noted there needs to be very clear definitions of what services are and are not. They discussed sexual therapy and sex services.

DSS said they would continue to work with PRG members to get appropriate guidance in place.

Final comments and close

Donna thanked PRG members for their time and contribution.

Next meeting

Out of session: Thursday 12 September 2024

Planned: Tuesday 17 to Wednesday 18 September 2024

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