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 virtual meeting to talk with the Department of Social Services (DSS).

DSS is working on new rules about plan management, plan variations and plan reassessments.

New rule – plan management

The NDIA has a process to manage risks that could cause harm to a participant who self-manages their plan. This new rule will extend that process. It will include participants who use a plan manager.

DSS asked PRG members if there were things the CEO should think about when assessing risk to a participant. DSS also asked what information participants will need to understand this rule.

PRG members asked if the new rule will also cover NDIA-managed plans. DSS said no, that isn't part of this new rule. PRG members said there can be risks to participants who are NDIA-managed.

DSS noted the CEO should not consider the participant's impairment or the size of their plan. PRG members said people with a bigger plan may be a target by someone doing the wrong thing.

PRG members said there are pros and cons for each level of plan management. They said if someone is NDIA-managed, that will restrict their access to services. They will have less flexibility and will pay more.

PRG members said the CEO needs to think about flow on effects from changing how a plan is managed. They said the CEO needs to think about where the risk is. They said participants need dignity of risk.

PRG members said participants should be contacted before there is a change to how their plan is managed. They said the NDIA may not know all the benefits the participant gets from how they manage their plan. They said there might be unintended consequences that the NDIA needs to

consider.

PRG members said at the September meeting, the NDIA said if a participant had been financially abused, they would not be able to manage their own funding. PRG members said the fact they had been abused shouldn't be a reason to change their funding.

They said the NDIA should look at the factors that made the participant vulnerable instead. They said improved safeguards could help reduce the risk.

PRG members said there needs to be clear communication about the different types of plan management. They said participants may not understand why they have been moved to a different type of plan management. They said participants need to know what the ongoing impacts will be.

They said participants should be able to talk to the person who decides to change the way their plan is managed.

PRG members said there should be training and support for participants to self-manage. They said these should be in accessible formats.

New rule – plan variations

DSS said this new rule will explain what a plan variation can do. They said the legislation doesn't give a definition of what a minor variation is.

PRG members said it should include fixing a wrong decision about a participant's plan. They asked if a variation can be used to shorten plans or cut funding. DSS said they didn't know.

PRG members said they haven't heard of a case where emergency funds or light touch changes have been implemented.

PRG members used two examples. One was a primary caregiver passing away. Another was someone with high needs losing their provider. They said a plan variation for emergency funding would cover the immediate need.

They asked if a process could be included where the NDIA also starts a plan reassessment.

PRG members said there is no timeframe for how long it will take to get emergency funding. DSS said the rule won't have timeframes, that's part of the NDIA process for starting a plan variation.

PRG members said an emergency crisis is different for everyone. They said people may have setbacks in their progress.

PRG members said the plan variation system needs to think about all types of emergencies, for example bushfire evacuations. They said NDIS participants may have special needs, for example a

relative's house may not be accessible for them.

PRG members said a crisis situation is where an NDIS participant is at risk of neglect or harm, or where they have lost someone who supports them.

PRG members said it needs to be clear when a plan variation can be done and when a plan assessment needs to be done.

New rule – plan reassessments

DSS said this new rule will explain what the CEO and delegate must think about when they decide if they will do a plan reassessment.

PRG members said there is no clear advice about what evidence is needed for a plan assessment to happen. They said the NDIA needs to only use the evidence provided for that process and not use evidence that was provided for something else.

PRG members said a lot of participants have had plan reassessments. They said there's a lot of anxiety and not much understanding about why they had plan reassessments.

PRG members said there needs to be a balance for participants between proving a change of circumstances and not having to prove they still have a disability.

PRG members said the examples given for deciding to do a plan reassessment sound good. But they also sound too easy. PRG members said it can be hard to get enough evidence to prove a change of circumstances. They said transitions need to consider what is stopping as well as what will be starting.

PRG members said since the new rules have come out, there have been a lot of plan reassessments. They said these feel more like cuts to plan funding.

PRG members said they don't have a good understanding of the rules yet. They said it's hard to think about what information someone needs.

DSS said they are getting feedback from a lot of different groups. They said the timing is not good but is out of their control.

PRG members said a change in circumstances could be the loss of a carer or family member. They said a participant's capacity can decrease during that time and they may need more support. They said a participant moving out of home may need more support for a couple of years.

DSS noted the discussion covered 2 broad categories. One is changes in impairments and functioning. Two is changes in personal circumstances. PRG members agreed these are good categories. PRG members said a third category could be a change in context, like a pandemic.

DSS asked what information participants will need to understand the rule and how it might impact them. PRG members said participants need to know:

- what evidence they need to get
- the timeframe for the process
- where to get accurate information
- their rights and how to appeal.

PRG members said they like to get information by email or from the NDIS website. They said they like to talk to someone, but the call centre gives different information.

Final comments and close

DSS said they will use the feedback from PRG members along with other feedback from disability ministers in the states and territories.

Donna thanked PRG members for their time and contribution.

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