17 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 legislation reforms to NDIS supports and plan use.

Draft rules

The NDIA is working with the Department of Social Services (DSS) on rules that will become official if the legislation passes. We are talking about the rules with groups who have an interest. We want to hear feedback before the rules are made and before they would start to apply to NDIS participants.

If the legislation doesn't pass, then there is no need for the rules, and they can't be made. If there are changes to the legislation before it is passed, we have to change the work we are doing.

PRG members noted the negative way the disability community is being seen in the media. NDIS participants are afraid they will be thrown off the NDIS.

PRG members noted the general view that the NDIS problem is due to participants and how much funding is in their plans. They said this was because the NDIA has said most problems come from some providers and NDIS practices on price guidelines.

The NDIA will keep talking with the disability community. DSS will also provide opportunities to consult from August 2024.

NDIS Supports – what you can and can’t spend your NDIS funding on

The proposed legislation introduces a new section 10 (s10) of the NDIS Act that describes what is and is not an NDIS support. It is a Category A Rule. This means it can only be made into a rule if the states and territories and the Commonwealth all agree.

Our current legislation has a rule about supports for participants. This information is in different places and written in different ways. We want to make a rule to put all the information in one place for the first time.

There is a lot of confusion and different views on what’s in and what’s out now. Some participants may need an item because of their disability, but it may not be seen as something the NDIS should fund.

The NDIA has agreed to working with people with disability on the proposed Category A rule.

PRG members noted value for money sometimes fights against choice and control. NDIS participants want to get the most out of their plan because the funds are limited.

The NDIA knows that currently the rules are very confusing and unclear. They say an NDIS participant can’t spend their funding on things that are not value for money. Under the new section, the NDIA will have a list.

PRG members noted the NDIA needs to think about the whole family, not just the participant. They also noted the NDIA is trying to save money to help the people who need it. They said a checklist for what the NDIS can fund can’t just be black and white. It needs to allow for shades of grey.

PRG members noted the statement that says some supports should be funded by a mainstream service system such as health or education, instead of by the NDIS. They said those systems need reform. Even with the Disability Discrimination Act in place they don’t think they have to provide support to someone with a disability.

PRG members said sometimes an NDIS support is needed to access mainstream services. Without that NDIS support, some people can’t attend university.

The NDIA said the draft rule is much more specific. There are things that Parliament didn’t mean for the NDIS to fund.

Things that are NDIS supports are in broad categories so participants can spend money on disability-related supports. Things that are not NDIS supports are very specific, so we are clear on what is not allowed. This will give participants flexibility to spend their NDIS money.

PRG members suggested making sure the words are very clear. For example, if it's not on the very specific out list, then it must be in.

The NDIA is keen to hear feedback from PRG members.

Discussion

PRG members noted they talk with their communities and pass along information. They said they need the NDIA to give them more information. The information needs to be clear. We need to use a range of formats.

They said people are worried about the changes. The NDIA noted there are a lot of changes coming in, including the new computer system PACE and the legislation changes.

PRG members said to be aware that words have meaning, and that it takes time for people to understand all the changes and new words. They said timelines are helpful.

PRG members said there had been a clear set of guiding principles when the NDIS first started. These principles seem to have been lost. They said there are a lot of staff changes, and a lot of new NCC staff and local area coordinators. The NCC staff and local area coordinators often have the wrong information.

PRG members noted the Changes to NDIS Supports letter isn't clear. They offered to send through some feedback. The NDIA said sometimes we have to use certain words and we need to explain them better.

PRG members said if the NDIA is changing the words we use, we need to explain and be clear about those changes.

PRG members said people are worried about having to pay money back. The rules aren't clear. They said people don't understand the changes.

PRG members noted some NDIA staff use the scripts and some don't. They said some staff make their own decisions. They said that people should hear the same decision from all the people they contact.

PRG members said it was important for them to feel heard. They said they are told to call the local area coordinator or the NCC. They said nobody wants to call those people because they may not get the correct information.

PRG members said the NDIA must be honest if it wants to build trust. They noted that sometimes the Minister and the Department of Social Services say different things. They said that is confusing and doesn't help to build trust.

The NDIA said the CEO will be the only person who can issue a debt or waive a debt. PRG members said that should be communicated because there's so much fear about doing the wrong thing and having to pay money back. They said it's good to know the CEO will have that oversight.

PRG members noted the changes will affect people in different ways. They said NDIA staff need to be sensitive when talking to people.

PRG members said the NDIA needs to understand how the changes will impact different groups. They said people in rural and remote areas will have extra challenges. They said the NDIA needs to make sure participants don't lose their voice.

PRG members said people want to know how the changes affect their personal situation.

Final comments and close

Donna thanked PRG members for their time and contribution.

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