

Feedback to:

National Disability Insurance Agency (NDIA)

PO Box 6100 Parliament House, Canberra ACT 260022

SUBMISSION: Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility

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Consumers of Mental Health WA

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1. Preliminaries

About the Respondents

Consumers of Mental Health WA (CoMHWA) is Western Australia's peak body for and by mental health consumers (people with a past or present lived experience of mental health issues, psychological or emotional distress). We strengthen and advance the voice, leadership and expertise of people with lived experience of mental health issues. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery and wellbeing.

Language

CoMHWA uses the term 'mental health consumer' throughout this submission. Mental health consumers to refer to people who identify as having a past or present lived experience of psychological or emotional distress, irrespective of whether they have received a diagnosis of mental illness or accessed services. Other ways people may choose to describe themselves include "peer", "survivor", "person with a lived experience" and "expert by experience".

This definition is based on consumers' call for respect, dignity and choice in how we choose to individually identify.

2. Introduction

Impairments resulting from mental health conditions can be difficult to recognise and are less apparent than those who live with physical or intellectual disability. Systemic and cultural stigma in Australia has meant that many people with mental health conditions may try to manage or ignore any impairments. This can often exacerbate issues and cause the need for support for people with psychosocial disability to be overlooked¹.

¹ https://nmhccf.org.au/sites/default/files/docs/nmhccf_psychosocial_disability_booklet_web_version_27oct11.pdf

3. Consultation questions

1. How should a participant's plan be set out so it's easier to understand? How can we make it easy for participants to understand how their funding can be spent?

- Produce clearer print and digital information.
- Make the NDIS offices and employees more accessible to participants.
- Proactively offer and provide extra supports to those who request it.

Feedback from consumers indicates that there is no one single solution for this, given the complexity of the NDIS from the consumer perspective. We understand that in general, that it is very difficult for even the more experienced participants, to self-manage their plans. This indicates that there are foundational issues with the way participants understand the NDIS.

An NDIS participant with a psychosocial disability commented, "last year, suddenly I was left alone to manage my own transport plan. The money was put into my bank account, but I had to work out how to use it on my own. It was very difficult, and I had very little support."

In relation to the 2021 changes, she says, "it sounds like the changes are going to force people to manage their own plans, and I think people are scared of taking on the responsibility of managing a plan on their own."

Other feedback has indicated that people are confused about when and where they can spend their funding. We have received feedback from people who have received NDIS funding but were unclear on the details of expenditure and feared what would happen when the funding ran out for that year because they did not understand what to do when it got used.

Given the content of the feedback we have received regarding plan and funding management, there appears to be some fundamental issues with the way the information is communicated to participants.

Regarding communication, one consumer says, "Communication from the NDIS needs to be better. They gave me my plan and then sent me on my way, but I need help sometimes. The coordinator is supposed to help me but is inaccessible most of the time. The parking at the NDIS office near me is impossible, so most of the time, I can't park my car to go the their office. It would be very useful if the NDIS could meet me at my preferred meeting location."

Consumer feedback has also indicated that the language being used seems to be more-so directed at the NDIS staff members and delegates. Plans should be written for the participant to understand. As stated on page 6 of the discussion paper, ensure the same terminology is used across NDIS platforms so it is easier to understand.

Recognise that some individuals will require extra assistance regardless of their disability impact. Navigating the NDIS and related funding and services can be very difficult for some individuals regardless of their propensity to learn, existing informal supports, or having previous NDIS plans. There are many barriers that individuals can encounter to fully utilise their funding and at present, the NDIS should be more supportive in empowering individuals to overcome these barriers, by employing Peer Workers, or proactively support people on their journeys.

2. How can we support participants to prepare for a planning meeting? What might be needed to support participant decision-making?

Consumers and NDIS participants have indicated that they would like to be allowed to bring a support person with them to planning meetings.

"The best way to help people through this process is to ensure they are allowed to bring a support person with them in case they forget anything during the assessment."

Help before meetings is also essential, with some consumers mentioning that if it wasn't for some people stepping in to help, they would not be on the NDIS in the first place.

"Many people access the NDIS by word of mouth. I was told about it 3 or 4 years ago by someone from Neami National, I was lucky because they helped me with accessing the NDIS and went with me to NDIS appointments to support."

"For people accessing the NDIS, especially for the first time, having someone there to walk through it with them is one of the simplest and most useful things to do."

This feedback suggests that without having someone there who knew about the system, the participants would never have known about the NDIS, and would never have been able to navigate to a successful outcome.

Information needs to be easier to comprehend and created **for** consumers / participants. Employ mental health peer workers to help participants fully understand processes and expectations.

Supported decision making by independent Mental Health Peer Support Workers builds the decision-making skills of the individuals that are transferable to various situations. Peer Support helps to establish trust and understanding and engages hope for the participant.

- Enable participants/applicants to bring a support person to the planning meeting.
- Conduct walkthroughs with participants about what the process is to decrease anxiety and increase their understanding and participation in the process.
- Employ Mental Health Peer Support Workers to help people understand the process if they are unable to bring a support person with them to the planning meeting.

3. Which supports should always be in the fixed budget? What principles should apply in determining when supports should be included in the fixed budget?

Supports with a fixed budget should be those supports that are a permanent feature on the participant's calendar such as regularly occurring therapies, and other supports that do not change in their cost.

Fixed budgets are not appropriate for things such as transportation; costs that can change rapidly from day to day, for example.

4. How can we assure participants that their plan budgets are at the right level? (e.g. Panels of the Independent Advisory Council that meet every six-months to review learnings and suggest improvements)

Develop this with participants by asking how they can be assured that their plans are at the right level. Decision-making on planning of budgets should be made in partnership with participants and (their support people).

5. What new tools and resources should we provide to support people using their plan and new plan flexibilities?

Psychosocial stream participants are concerned with having their access to face-to-face supports being taken away. Rather than 'new tools and resources', some psychosocial participants would rather there be improvements to access and communications with face-to-face NDIS supports.

A solution would be to tailor communication preferences to each participant, asking their preferred methods of communication, and their preferred frequency of communication. An NDIS participant we spoke to for example, stated that they would prefer to meet their NDIS planning contact in the local library, and on a more regular basis. Everything needs to be customisable and tailored to the individuals.

6. What do we need to consider for children aged 7 and above in the new planning process?

n/a

7. What ideas do you have for how people can use their plan more innovatively?

n/a

8. How best to handle the timing of the release of funds into plans and rollover of unused funds?

Consumer feedback suggests that unused funds should be rolled over into the next year / month. Unused funds are not as 'black and white' as the participant not 'needing' the funds. It may be a case of the participant simply being unsure of how to use funds properly.

The NDIS should consult with the participant to ensure the individual's requirements are met and their plan is flexible enough to accommodate their needs.

9. How should check-ins be undertaken? Under what circumstances is a check-in needed? Who should be involved in a check-in?

Consumer feedback suggests that this process should be customised to suit the individual participant because everyone's needs are different.

10. How often should we check-in with participants in different circumstances?

According to NDIS participant feedback, this should be conducted according to participant preferences. This needs to be tailored to each participant.

Appropriate funding and additional supports to understand and utilise their plans may be a better use, rather than discussing the frequency of check-ins.

11. How can the NDIS ensure positive relationships between participants and planners?

Participants would like to see more continuity in relationships with NDIS Planners. This will enable more meaningful communication and support for participants.

An NDIS Participant stated, "it would be good if they called me once or twice per month, or if I could call my planner so I can clarify things instead of waiting for meetings."

12. How can we best support participants to transition to this new planning model?

Feedback from consumers and NDIS participants suggests that people can't just be left alone to wait for things to go wrong before the NDIS steps in to help.

Feedback suggests that some participants need to be guided through transition processes and investment needs to be made to ensure people are available via phone, or in-person to help with any issues that may arise at any time.

Some general points

- The policies tend to blame consumers for not using plans in an effective and valuable way as oppose to acknowledging the difficulty individuals have in navigating the NDIS
- There is a continual focus on connecting individuals with community and mainstream supports despite many of these groups having not having continual funding to provide services or supports.
- How do these proposed/current changes impact individuals who are under a guardianship or public trustee?