

Submission to the Senate Standing Committee on Community Affairs

National Disability Insurance Scheme (NDIS) Bill 2021



About Disability Advocacy NSW (DANSW)

DANSW has over 35 years of experience providing individual advocacy to people with disability (PWD) of any age and disability. The organisation services over two thirds of NSW, making it the largest individual advocacy disability organisation within NSW.

While DANSW has a presence in Sydney, it has a strong commitment to regional, rural and remote (RRR) areas in NSW. With local disability advocates – on the ground - in Armidale, Bathurst, Broken Hill, the Blue Mountains, Coffs Harbour, Dubbo, Newcastle, Central Coast, Upper Hunter, Port Macquarie, Tamworth and Taree – DANSW has firsthand insights and observations of the lived experiences of PWD and their families living in these areas.

DANSW's systemic advocacy draws on coalface information from clients, disability advocates, and the disability sector more broadly to identify and address emerging policy issues. We embrace the saying, 'nothing about us, without us', ensuring that the voices of PWD are central to informing our systemic advocacy. In this submission, we focus on how some of the Bill's amendments may affect people with the disability living in RRR areas. In addition to this submission, we invite committee members to conduct site visits to our RRR offices alongside our policy officer (contact details below) to hear more about the experiences of PWD living in RRR areas.

Contact

Dr. Cherry Baylosis
Policy Officer at DANSW

Introduction

To contribute to this inquiry, this submission identifies potential impacts that the NDIS Act may have on PWD living RRR areas. We draw on consultations conducted with DANSW advocates and research conducted by DANSW that investigated PWD's experience of the NDIS in both metropolitan and RRR areas¹. In doing this, we wish to highlight the elevated disadvantage PWD face when they live in RRR areas.

As a general comment, DANSW is supportive of changes that address issues relating to:

- Improved access pathways for people with psychosocial disability
- Increased powers for the NDIA to engage in market stewardship in thin markets
- Greater flexibility for the NDIA to vary plans
- Participants empowered to request reasons for decisions

However, within many of these amendments, we are concerned about an over reliance on rules and unconfined discretionary powers of the CEO. Many of the Rules require further clarification to minimise the likelihood of inconsistent and subjective interpretations that may lead to unfair outcomes for PWD. Moreover, we question why much of the critical information and details are relegated to the Rules, and not in the Act.

Concerningly, we view that the NDIS Act is moving away from the scheme's original principles of accessibility, equitability, and transparency, which first and foremost is driven by the needs and best interests of PWD. Such a philosophy demands meaningful engagements with PWD and the disability community. Yet, community consultation around the Bill has often imposed short time frames to provide feedback. Our concern is that this has not only led to a diminished capacity within the disability sector and community to meaningfully engage with amendments, but it has also minimised opportunities for participation to allow PWD to have their say.

We are appreciative of the opportunity to participate in this inquiry. It has been a trying task to examine the numerous complex materials in a short-time frame. However, our submission hopes to highlight some of the key areas of concern for our clients and advocates, while proposing recommendations (summarised next page) to better align the Act with its original intent and purpose – to empower PWD to have choice and control. These recommendations are discussed in further detail in the remainder of this submission.

¹ For information of research, see page 5, 'Research Process' of the DANSW's submission to [NDIS Joint Standing Committee's Inquiry into NDIS' Implementation and Performance](#) (submission number 79).

Summary of recommendations	
Becoming a participant	
<i>Improved eligibility and access pathways for people with psychosocial disability and for early intervention</i>	
Recommendation 1	Clearer definitions are developed for eligibility criteria in consultation with PWD and their treating specialists.
Recommendation 2	Provisions are included in the rules that require The Agency to consider barriers that may hinder a participant's capacity to gather evidence and engage in 'appropriate treatment' over a 'reasonable period of time'.
Plan Administration	
<i>Thin market intervention</i>	
Recommendation 3	The Act enables the NDIA to develop targeted ILC programs that supports the development of markets and ensures that PWD are given effective support and information to access other service systems.
<i>Plan variations and reassessments</i>	
Recommendation 4	The NDIS Act includes provisions that enable participants to request reassessments, and not only plan variations.
Recommendation 5	The NDIS Act clearly lists The CEO's decisions regarding the particulars of plan variations and reassessments as a reviewable decision.
Recommendation 6	Rules specify clear criteria that describe when a plan will be varied, reassessed, or have no action taken.
Plan Management	
<i>Risk assessment for plan-managed plans</i>	
Recommendation 7	Rules clearly define 'unreasonable risk' in relation to plan-management providers.
Participant service guarantee	
<i>Request for explanation of decisions</i>	
Recommendation 8	The Act requires the NDIA to provide a detailed statement of reasons for <i>all</i> decisions made by NDIA planners.
Recommendation 9	The Act mandates the NDIA to provide a detailed letter that particularises a participant's plan, explaining the intention of funding.

Improved eligibility and pathways psychosocial disability

DANSW is supportive of amendments that can improve access pathways to NDIS for people with psychosocial disability (PWPD). However, we wish to highlight that some of the changes may contribute to the already blurry boundaries between health systems and the NDIS. This may leave the most vulnerable at risk of falling through service gaps, particularly if they have psychosocial disability and live in RRR areas.

Barriers to access

The proposed changes suggest that PWPD are expected to engage with mainstream health services prior to seeking NDIS access. They must undergo ‘appropriate treatment’ to ‘manage’ their condition and have had no ‘substantial improvement’ within a ‘reasonable period of time’.

However, DANSW implores the committee to consider that there are multiple barriers to accessing often under resourced medical and mental health services in RRR areas. These can include the need to travel across vast geographical distances, alongside unreliable and/or inaccessible transport, a scarcity of services and specialist health professionals, and prohibitive costs. This is exacerbated when people are unable to receive appropriate support that they may require to access treatment and attend appointments. This is demonstrated by following quotes below²:

Mental health care could be a bit better, especially access to clinical psychiatrists, [in] Bathurst it cost about \$800 for a 1-hour appointment and then you must wait weeks for the report to be done (regional survey participant)

Regional areas need more health services and specialists in their regions. Getting help takes forever because waiting lists for everything are so long, especially in the public sector (regional survey participant).

Such barriers, as reflected in these quotes above, can hinder people’s ability to demonstrate their eligibility in accordance with criteria listed in Rule 8 (see next page) because it hinders engagement with medical and health services.

To improve access pathways, we recommend that the Rules permit greater flexibility for participants to produce evidence to support their access request. For instance, the NDIA has capacity to accept assessments made by the applicants’ treating specialist(s), and/or

² Quotes on this page are from the 2021 DANSW survey for people with disability and their families

supports, as well as other documentation relevant to applicants' psychosocial disability such as hospital discharge summaries.

Terms require clarification

Rule 8 of Becoming a Participant has several criteria that lack clarity and definition, making them susceptible to inconsistent and subjective interpretations and decision-making. These are listed below:

- Appropriate treatment
- Substantially reduced capacity
- Fluctuating conditions
- Manage a condition
- Treatment
- Substantial improvement
- Exit point

We recommend these criteria are developed in consultation with PWD and/or are informed by participants treating specialist(s) who know and understand the participants' conditions and treatment history.

Thin market intervention

DANSW supports provisions that provide the NDIA with more definitive powers to engage in market stewardship in thin markets. The proposed new Section 5 provides a non-exhaustive list of matters that the NDIA must consider in deciding whether to provide funding to a person or entity under the new subsection 14(2). This includes:

- The urgency of supports
- Participants' ability exercise choice and control
- Funding promotes diversity and sustainability of the NDIS market
- Participants' cultural background
- Regional and remote locations – whether participants/entity take best-practice and evidence-based approach in a given location
- Provision of funding can deliver improved outcomes for other participants
- Opportunity to deliver improved outcomes for other participants in the location

Restrictive considerations

In practice, these criteria may be used to restrict The Agency's capacity to fund supports and services in thin markets. For instance, assessing whether individual funding will benefit others in the participants' area, in conjunction with the urgency of a given support, may provide the basis to deny funding if a participant requires support that does not mirror the needs of others in their area and if it not considered urgent.

There should be no reason that PWD miss out on reasonable and necessary supports and services due to their location, and because the type of support they need may not be a benefit to others in their area. These criteria require further consideration to minimise the disadvantage PWD face living in RRR area. We recommend a greater emphasis on stimulating markets outside of funding plans is needed.

Targeted ILC programs in thin markets

Importantly, as we have addressed in detail in a previous submissions (see aph.gov.au, submission number 79) the focus on funding plans is only one component of market stewardship. While it may provide more financial resources for people to access services and supports, it will not necessarily stimulate market growth.

We support Information Linkages and Capacity Building (ILC) that are designed to ensure that PWD can access and connect with mainstream supports, to build community capacity and support market innovation and competition. These can play a significant role in supporting market development. Importantly, such programs are crucial to ensuring that PWD can access other service systems if they are unable to access the NDIS.

However, the benefits of ILC programs have not been realised in many RRR areas with many clients reporting that there is a lack of services, and little support and information to access mainstream services³. Put simply, many PWD living in RRR areas are left to go without vital services and supports. Therefore, we recommend that the NDIS Act mandates the Agency to ensure that targeted ILC programs are developed to address systemic issues related to thin markets, particularly those in regional and rural areas.

Plan variations and reassessments

Section 47A allows plan variations without the need for a reassessment (previously termed 'plan review'). This is a positive change that should enable to The Agency to make minor changes to participants' plans – at their request - more simply and quickly with less red tape.

³ See findings in DANSW's submission to [NDIS Joint Standing Committee's Inquiry into NDIS' Implementation and Performance](#) (submission number 79).

Impacts on the review process

DANSW is concerned about the CEO's power to decide on the particulars of plan variations. They may determine a plan variation is reasonable and necessary, and they have the authority to limit funding to cheaper and inferior alternatives that differs to the participants' specialists' recommendations.

Concerningly, under the proposed changes to Section 47A and Section 99, it is unclear if participants can request a review of the CEO's decisions relating to the particulars of plan variations. Clearer criteria are needed for deciding *when* and *how* a plan will be varied, or have no action taken. Additionally, clear provisions are needed for participants to be empowered to request a review of the CEO's decision regarding the particulars of plan variations. Without such provisions, there is a risk that participants who request a plan variation, may receive unwanted amendments, or no changes to their plan and have minimal avenues to appeal The Agency's decision.

Concerns regarding CEO's power to reassess plans without consultation

For major changes to plans, participants are unable to request a reassessment. This can only be initiated under the CEO's discretion. This raises two concerns that should be addressed:

- 1.) *DANSW sees no reason why participants should not be able to request a reassessment of their plan.* There is a risk that participants who require significant adjustments to their plan, may only receive minimal, or no, changes to their plan.
- 2.) *The CEO has power to amend plans without consultation.* The CEO has uncontained powers to change and restrict funding without the need to consult with participants first.

Naturally, this is a source of concern for disability advocates who foresee that there will be an influx of AAT matters without clear criteria to vary and conduct reassessments and plan variations. Therefore, we strongly recommend that there are clearer parameters that confine the CEO's power to initiate reassessments and amend plans. The Tune Review provided a useful list of limitations that can be integrated into the Act.

Risk assessment for plan-management

Defining unreasonable risk

New safeguards have been proposed under the Section 9, which require plan-managed plans to undergo a similar risk assessment as self-managed plans. This, in effect, should minimise

the risk associated with using unregistered providers accessed through registered plan-management providers. However, there is a risk that these measures may limit the participants' choice and control because they can prevent access to reputable and safe unregistered providers. There seems to be an inherent assumption that unregistered providers are inferior and unsafe. While they may not have similar safeguards as registered providers, they can provide greater choice and control for participants. This is particularly important for those who live in RRR areas where choice can be limited.

We recommend that more clarity is provided in defining 'unreasonable risk'. This is described in Section 10, however some further detail on how this will be applicable to plan-management providers is needed.

Request for explanation of decisions

Reasons for decisions as requirement, not a request

Participants will be empowered to request reasons for decisions made by the NDIA under Section 100(1B) and (C). This is a welcomed change that may equip participants with important information to understand initial decisions about access or plans. However, the proposed changes place the responsibility on participants to initiate the process of obtaining reasons. Ideally, the onus of responsibility should be placed on The Agency.

Thus, to remain consistent with Tune Review, we recommend that there be a legislative provision under which the NDIA is required to provide a statement of reasons for *all* decisions made by NDIA reviewers. Having a such a requirement will enhance transparency and promote accountability in decision-making processes.

Quality of information and details

To ensure that participants are provided with useful information, we recommend that reasons provided not only outline reasons for access issues, but clearly outline actions that the participant can take.

Additionally, following on from the discussion regarding plan variations and reassessments, there is no requirement to provide an explanation for decisions around plan variations and reassessments. As noted above, an improvement can be made by mandating an explanation for decisions as a *requirement* rather than rely on the participants' *requests*. Some of whom may lack the capacity to initiate the process of requesting reasons, which places them at an unfair disadvantage.

Similarly, to improve the participants' experience, we recommend that not only is a statement of reasons provided, but a breakdown of a participant's plan is provided. The current

provisions are unclear for NDIS participants, leading to confusion about how to spend their funding as reflected in the following statements⁴:

[W]hen I ask the answer from plan manager or NDIA LAC is usually 'we can't say for sure. why don't you pay for the service with your own pension and then afterwards we can see if you get your money back' (no thanks, I'll save what little real money I get for food and bills). (Rural participant).

I am still very unsure about what services they provide or how I use the funds available to me (Rural participant).

The lack of information regarding funding limits the participants' capacity to exercise choice and controls. They are not often equipped with sufficient knowledge to understand what is available to them or how they can use their funds. Therefore, providing information that equips them with knowledge can better enable them to access reasonable and necessary supports and services.

Conclusion

The NDIS Bill responds to many issues that have been raised within the disability community. We strongly view this as a positive step in the right direction. To improve, we hope that this consultation process will continue to incorporate concerns that are raised. By taking on board such recommendations made within the disability community and the sector, we hope to see an amended NDIS Act that better supports people with disability to lead a life where they have meaningful choice and control.

⁴ Quotes from the 2021 DANSW survey for people with disability and their families