

family

A D V O C A C Y

Submission to the Senate Standing Committees on Community Affairs on the Proposed NDIS Amendment (Participant Service Guarantee and Other Measures) Bill 2021

Cecile Sullivan Elder
Executive Officer, Family Advocacy
cecile@family-advocacy.com

Leanne Varga
Systemic Advocate
leanne@family-advocacy.com

Family Advocacy
(02) 9869 0866
Suite 704, 88-90 George Street,
Hornsby, NSW 2077, Australia

8 November 2021

Acknowledgement: Family Advocacy would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

Table of Contents

Overview	2
Introduction	2
Concerns and areas of improvement.....	3
<i>Lack of community engagement and the need to include people with disability in co-design.....</i>	<i>3</i>
<i>Concern over the scope of the Minister’s powers - Overreliance on rules and discretionary powers.....</i>	<i>3</i>
<i>Change the Category D rules in Sections 47A(6) and 48(5) to be Category A – The CEO must only be able to create Rules relating to decisions to vary or reassess participants’ plans with consent of the States and Territories.....</i>	<i>4</i>
<i>Expansion of CEO’s power to review, vary, or reassess a plan without consultation.....</i>	<i>4</i>
<i>Variations by the CEO need to be made with the consent of the participant</i>	<i>4</i>
<i>The range of matters that the CEO can consider when deciding to vary a plan need to be constrained and have clarity in their interpretation.....</i>	<i>5</i>
<i>The capacity for the CEO to decide to reassess a plan when a participant has only sought a variation remains highly problematic.....</i>	<i>5</i>
<i>Section 48(5) needs to expressly provide a sufficient prescription of the matters to be considered and their weighting.....</i>	<i>6</i>
<i>The decisions to reassess a participant’s plan by the CEO under their own initiative must be expressly included in the table of reviewable decisions.....</i>	<i>6</i>
<i>Providing reasons for decisions for an internal review should be automatic.....</i>	<i>6</i>
<i>Change the word “reassessment” to “scheduled plan meeting”.....</i>	<i>7</i>
Conclusion.....	7

Overview

Family Advocacy's aim is to advance and protect the rights and interests of people with developmental disability (hereinafter disability) across NSW so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. We do this by providing advice and support to families so they can advocate with or on behalf of their family member with disability.

Family Advocacy was founded and is governed by families of people with disability and is funded by the New South Wales (NSW) and Federal governments. One of our initiatives, Resourcing Inclusive Communities, aims to assist families to develop skills and confidence so that they can support their family member to have more choice and control over decisions and supports that facilitate individualised and normative lifestyles.

In this way, we believe our purview lies in alignment with the overall objectives of the NDIS Act with a similar aim to provide transformational benefits to the lives of people with a disability. Putting the person with disability at the centre of the decision making with regard to supports, is a critical component of this.

Family Advocacy appreciates the opportunity to provide input to the Senate Standing Committees on Community Affairs on the NDIS Amendment (Participant Service Guarantee and Other Measures) Bill 2021 (hereinafter "the Bill"). This submission is shaped by the accumulated knowledge of families' experience that spans over 30 years in advocating for supports, enhanced policies and practices that value the lives of people with disability.

Introduction

Family Advocacy provided a [submission](#) to the original draft Bill on 7 October 2021. We acknowledge a small number of our recommendations are reflected in the Bill. However, the majority of our recommendations have been overlooked or insufficiently addressed. In particular, the lack inclusion of people with a disability in the co-design of the NDIS reforms and the sense that this Bill is being rushed through before the years end, for convenience of a parliamentary timetable rather than getting the reforms right so as to the genuinely improving the lives of people with disability. Accordingly, we reiterate many of the points in our previous submission, which are outlined below.

The NDIA has suffered reputational damage in 2021 with the "Independent Assessments" issue. With trust eroded, we see an opportunity for the Committee to help restore public confidence in the NDIA by ensuring the NDIA is working in genuine consultation, transparency, co-design and co-production with the disability community to address the concerns raised in the submissions it received on 7 October, including this one. On that note, we are aware of a number of other disability advocacy organisations making submissions such as People with Disability Australia and the Physical Disability Council of NSW, and we endorse these submissions. We expect the Committee to take the range and diversity of concerns as evidence that a far more comprehensive consultation must occur before draft legislation is presented to Parliament. Accordingly, we ask the Committee stop this Bill being rushed through Parliament.

Concerns and areas for improvement

Lack of community engagement and the need to include people with disability in co-design

At the outset, we want it to be noted by the Committee, we are very disappointed that, yet again, we are faced with very tight timeframes, having had only 7 working days on this current consultation. In the first round of consultations, the Department of Social Services only provided four weeks to respond to some 16 proposed legislative changes despite the fact that the Independent Advisory Council's recommendation was eight weeks. This severely limited our capacity to review, analyse and comment but it suggests an obvious disregard for genuine community participation.

We highlight Article 4(3) of the United Nations *Convention on the Rights of Persons with Disabilities* (UN CRPD), of which Australia is a signatory, which states that:

*In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties **shall** closely consult with and **actively involve** persons with disabilities, including children with disabilities, through their representative organizations [emphasis added].*

Family Advocacy commends the Australian Government as a state party to the UNCRPD for including in the Bill the planned insertion of a new section 4(9A) for the NDIS Act which states that '[p]eople with disability are central to the National Disability Insurance Scheme and should be included in a co-design capacity.'

However, the language should be strengthened by changing the word 'should' to 'must'. For too long, people with disability have been left out of decision-making processes that affect their lives. The word 'should' indicates that involvement would be optional. The word 'must' ensures involvement under the legislation, and therefore recognises the international human right under article 4(3) of the UNCRPD to be involved in the NDIS decision making processes.

Given the very short timeframe, this submission should in no way be taken as an exhaustive list of all of our concerns with the Bill. As such, we ask for the right to provide additional submissions should any glaring issues arise that have not been addressed. Despite these limitations, our main concerns are discussed below.

Concern over the scope of the Minister's powers - Overreliance on rules and discretionary powers

We continue to be concerned that this reform package relies too heavily on Rules rather than the Act for significant aspects of the NDIS, which we submit is poor legislative and administrative practice and should be avoided. As the Committee is well aware, Rules are delegated legislation and should not be used for substantive aspects of law-making. Rules do not come under the same Parliamentary scrutiny than does legislation. Laws which determine the eligibility of a person for access to the NDIS should be considered and made by Parliament, and not at the discretion of the Minister. Yet this proposed Bill includes the adoption of two new proposed Rules and a number of rule-making powers, including the broadening of the discretionary powers of the CEO and fundamental provisions which create the conditions for access to the Scheme. We submit these proposed changes are significant

and substantive and ought to be in the legislation rather than the Rules. Our concerns regarding these broad discretionary powers entrusted in the CEO are discussed below.

We are very concerned that the States and Territories will have no capacity to have direct input into rules made in relation to the power of the CEO to vary or reassess a participant's plan, especially in instances where the CEO acts on their own initiative. This is particularly worrisome given the fact that the list of factors to be considered by the CEO under Rule 10 of the Plan Management Rules is non-exhaustive and that the Rules could be theoretically amended within 30 days without parliamentary debate.

Change the Category D rules in Sections 47A(6) and 48(5) to be Category A - The CEO should must only be able to create Rules relating to decisions to vary or reassess participants' plans with consent of the States and Territories

We note that the capacity to make rules around plans and supports remain Category D rules. This means that while the Commonwealth is obligated to consult with the States and Territories, there is no need for the Minister to gain each state or territory's consent, or even to gain majority consent. There is also no definition of consultation.

Family Advocacy is significantly concerned the Category D rules in Section 47A(6) has the potential to alter the nature of the NDIS and fundamentally reshape or cut participant packages. Like the Melbourne Disability Institute, we agree that:

- 'the proposal to make the rules in sections 14, 47A(6) and 48(5) Category D rules [would give] the Commonwealth Minister almost complete control of the NDIS.'
- 'this proposal would completely undermine the shared governance of the NDIS.'
- 'Legislative provision must be made in section 48 to ensure participants have an opportunity to be heard during any reassessment which is initiated by the CEO. This is essential to ensure transparency and fairness and is consistent with accepted principles of natural justice.'

Rules relating to participant plans have the capacity to directly impact States and Territories, particularly if changes result in a participant having to rely on state-based services. Hence, checks and balances must be put in place. We previously called for rules relating to the CEO modifying participant plans and supports to be Category A rules, and we continue to make this recommendation.

Expansion of CEO's power to review, vary, or reassess a plan without consultation

We are concerned about the scope of decision-making vested in the CEO or their delegate to initiate a plan variation or reassessment, without request, consultation or consent from the participant. There are several improvements that should be made to better align these provisions with natural justice principles.

Sections 47A and 48 need refinement. Our comments regarding these sections are discussed below.

Variations by the CEO need to be made with the consent of the participant

Family Advocacy remains concerned about the plan variation power that is proposed to be given to the agency's CEO under the Bill's new section 47A for the Act, which is a power to vary plans at the CEO's own initiative. Section 47A(1) states that 'each variation must be prepared with the participant'. However, this does not guarantee that the participant consents to the changes. We are also concerned about the proposed new section 47A's clause (9) which states that where a participant

requests a variation, the CEO can make a variation that differs to the one requested. This is only appropriate if the variation is made with the consent of the participant. However, again, this is not guaranteed by new section 47A(1). To ensure people with disability enjoy choice and control, we therefore recommend that proposed section 47A(1) be amended to require that variations are to be prepared with and consented to by participants.

The range of matters that the CEO can consider when deciding to vary a plan need to be constrained and have clarity in their interpretation

We note that section 47A of the Bill now provides that variations must be prepared with the participant but the CEO can still decide to vary a participant's plan without the participant's consent or providing any basis for the decision.

We are pleased that our recommendation was adopted with the inclusion of the range of matters that the CEO must consider when deciding to vary a participant's plan included within the Bill itself (section 47(A)(3)). We note however, that the list of matters which the CEO should have regard to is not limited and that several of the matters for consideration are drafted loosely.

The term "have regard to" is vague and unhelpful. There is no hierarchy in terms of which matters should be given the greatest consideration, or any prescription on what "having regard to" might mean in practice. We are concerned situations could arise for a participant where certain aspects of a plan such as the cost of services, are weighted more highly than a patient's goals and aspirations or assessments.

The capacity for the CEO to decide to reassess a plan when a participant has only sought a variation remains highly problematic

We had previously sought removal of the provision which allows the CEO to decide to reassess the participant's plan under section 48 in response to a request by the participant to vary their plan.

We are now also seeing the addition of a new provision – section 47(A)(9) allowing the CEO to make variations that are different to those requested by the participant, and section 48(3)(a) which allows a CEO to decide to vary a plan, rather than reassess it, when a participant explicitly asks for a reassessment.

This represents a serious imbalance of power and blatant disregard to the concept of choice and control which underpins the NDIS. We are concerned from a procedural fairness perspective, that the current drafting allows the CEO to do something entirely different to what has been formally requested – especially if this decision can be made without the consent of the participant.

On a practical level, varying a plan is a complicated, often time-consuming, and stressful process where participants invest substantial time and effort in working with the NDIS to create plans that best reflect their needs. Having a request for variation potentially gives the CEO the ability to reassess a plan altogether which will make participants hesitant to request variations in the first instance, and potentially result in supports and services not being used, or being unsuitable. People with disability will effectively be forced to accept a plan that is less than ideal for fear that they will lose everything.

This is inherently different to the plan flexibility envisaged in the Tune Review, which was expected to improve participant experiences:

The inability to amend a plan is one of the key frustrations for participants and one of the biggest weaknesses of the NDIS Act. Allowing a plan to be amended, in appropriate

circumstances, would be one of the most effective levers to improve the participant experience. This would allow small changes to plans to be made quickly with a low administrative burden, such as adding capital or equipment supports after obtaining quotes, fixing obvious errors or enabling a fast response in crises. It would also help to resolve current jurisdictional issues between the NDIA and the Administrative Appeals Tribunal¹

For the concerns raised above, we recommend Sections 47(A)(4)(c), 47(A)(9) and 48(3)(A) should be removed.

Section 48(5) needs to expressly provide a sufficient prescription of the matters to be considered and their weighting

Section 48(5), in contrast to section 47(A)(3), does not set out the range of matters which need to be considered when deciding to reassess a plan. It is our view that the reassessment of a plan is significantly more concerning than a variation – since it could result in sizable changes to supports and funding, or even potentially in a decision that the participant is no longer eligible for the Scheme.

Accordingly, the matters that the CEO should consider under section 48(5) need to be expressly provided within the Act and prescription given in terms of the weighting to be given across the different matters.

The decisions to reassess a participant's plan by the CEO under their own initiative must be expressly included in the table of reviewable decisions

In our previous submission, we called for a decision of the CEO to reassess a participant's plan without their consent be expressly provided in the list of reviewable decisions, in order to have the right of appeal. This type of decision is, by far, most likely to have significant impact on a participant, and would be the type of decision that participants would most likely seek to challenge.

In the interests of procedural fairness, it is necessary for participants to be able to challenge the necessity of a plan reassessment and the results of such action. Part of such a process would involve an assessment of whether the CEO had had regard to all prescribed matters when making the determination.

Therefore, we recommend section 48(2) should be expressly provided as a reviewable decision in section 99(1).

Providing reasons for decisions for an internal review should be automatic

Whilst it is a welcome change for the planned amendment to section 100(1) requiring the NDIA to automatically provide reasons for reviewable decisions, we submit it does not go far enough. This requirement should extend to NDIS internal review decisions. Giving reasons for decisions is consistent with good administrative decision-making principles as well as the intentions of the Tune Review, which states it should be a “routine operational process for the NDIA when making access, planning and plan review decisions”. A provision should be inserted to make it a legislated requirement that every decision made by an NDIA reviewer for reviewable decisions as well as internal review decisions must be accompanied by a statement of reasons.

¹ Tune, D, *Review of the National Disability Insurance Scheme Act 2013, Removing Red Tape and Implementing the NDIS Participant Service Guarantee*, December 2019 <NDIS Act Review - final - with accessibility and prepared for publishing¹ (dss.gov.au)> accessed 8 November 2021.

Change the word “reassessment” to “scheduled plan meeting”

The renaming of the annual review to reassessment causes us concern. We have long advocated that the NDIA clearly distinguish between the many different reviews undertaken and so consider this to be positive in principle. However, any names used in the renaming initiative have to be readily understood by the population at large, non-triggering and agreed to by the disability community.

Through its Independent Assessment initiative, the NDIA induced great anxiety in the disability community. The proposed renaming of the annual Plan Review to ‘reassessment’ is reminiscent of the Independent Assessment initiative. The fear and anxiety each participant experiences coming up to their annual review will not be allayed by calling this review a ‘reassessment’.

This word implies that it is the NDIS planner who does the ‘reassessment’, and is able to do this with complete disregard for any supporting reports and letters provided by the participant at this review. Using this term does not assist the NDIA in rebuilding the trust of the disability community. To help allay any anxiety, avoid confusion and provide a feeling of certainty in funding levels going forward for participants, we recommend this annual review of participant plans (whether it be 12 months or 24 months) should be simply called ‘scheduled plan meeting’. The meaning of this term is easily understood by everyone.

Conclusion

As previously stated, we feel the government is paying ‘lip service’ to the meaning of consultation. The narrow timeframe has made it difficult to respond exhaustively and is seen as a missed opportunity to rebuild the trust that has been eroded in the disability community. The disregard that continues to be shown for genuine community engagement is damaging the reputation of the NDIS and only feeds into the mistrust felt by the disability community.

On the whole with the proposed amendments, the balance of power is tipped too far in favour of the CEO and these proposed changes must not be allowed. It is important that there are strong statutory safeguards around the types of matters a CEO might consider when determining whether to exercise these powers.

In relation to the concerns we have raised, we seek to engage with the Senate Standing Committees on Community Affairs and the NDIA in a constructive manner to address these concerns through co-design in the spirit of rebuilding trust.