Submission to the Department of Social Services on the Proposed NDIS legislative changes 2021

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Overview

Family Advocacy provides advice and support to families so they can advocate with or on behalf of their family member with developmental disability (hereinafter disability). Our goal is to advance and protect the rights of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians.

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. This includes making the most of emerging opportunities for self-directing supports and to use creative and innovative models of support through individualised funding.

In this way, we believe our purview lies in alignment with the overall objectives of the National Disability Insurance Scheme (NDIS) Act (1 July 2013), 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 arrangements and supports is a critical component of this.

Family Advocacy appreciates the opportunity to provide input to the Department of Social Services (DSS) on the proposed NDIS legislative changes 2021. 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

On the whole, there appears to be a number of good aspects of the proposed amendments that will enhance the effective operation of the NDIS and improve participant experiences, providing appropriate checks and balances are applied. We are particularly pleased to see what has been abandoned by the government and now not included: independent assessments, changes to the reasonable and necessary supports, and no new debt recovery powers.

At the outset, we want it to be noted on the record that the very tight timeframe of four weeks provided to respond to some 16 legislative changes have limited our capacity to review, analyse and comment. We note the Independent Advisory Council's recommendation of eight weeks. We provide what could be identified within the very short timeframe and should in no way be taken as an exhaustive list of all of our concerns with the draft legislation. 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. The NDIA has suffered reputational damage in 2021 with the "Independent Assessments" issue. With trust eroded, we see an opportunity for the NDIA to restore public confidence by working in genuine consultation, transparency, co-design and co-production with the disability community to address the concerns raised in the submissions it receives, including this one. On that note, we are aware of a number of other disability advocacy organisations making submissions and we expect the NDIA 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.

Concerns and areas for improvement

Overreliance on rules and discretionary powers

We are 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. 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.

Changes to Plan Management

We have serious concerns and this part of the legislation in relation to plan management needs to be removed. We appreciate that the NDIA is accountable to ensure that participants who seek to self-manage or appoint nominees to manage their plans are fit to do so. Checks and balances are important to ensure that vulnerable participants receive the maximum benefit from their plans and that they are not subject to financial abuse or exploitation.

The balance to this is that participants should be able to exercise choice and control in the supports and services they utilise and be afforded the dignity of risk. The capacity to self-manage or appoint a nominee is a fundamental aspect to this. We believe the balance is tipped too far in the NDIA's favour here. There appears to be an increasing focus from the NDIA on the participant being the problem. Why is the person with disability or family member as nominee not trusted? It is grossly unfair for every family doing the right thing to be penalised for the few bad apples that might be doing the wrong thing.

We are very concerned here as there are many advantages to the current set up for the person with disability to achieve the primary objectives of economic, social and community participation. Often, we hear of scenarios of self-management where the person with disability and their family member as a nominee choose plan management as it gives them the freedom to use unregistered providers for certain service types without the administrative burden of having manage all the bills.

Often, they are sole or small operators with an ABN and may have a few participant's only or run it part-time whilst working another job. This type of set up can be advantageous in many instances such as in rural and regional areas where markets are thin and/or because more flexibility is on offer and/or the support person can build a quality relationship with the person with disability as there is consistency (as opposed to large registered providers that have large rotating staff numbers that are always changing) and/or there is more loyalty and accountability due to the fact that a private support worker has a personal relationship with the person with disability and their family member as nominee. These factors such as relationship, really knowing the person with disability, consistency, loyalty and accountability are absolutely vital factors to providing a quality support service.

We understand there are “fraud” concerns behind the intent of these proposed changes but ironically, the families we hear from that do self-manage can negotiate much lower hourly rates than participants who use a registered service provider who charges the full rate in the price guide, regardless of their experience level. Also, they are often so scared about being audited or being incorrectly accused of fraud that they keep very good records, and pay tax/superannuation and workers compensation.

This begs the question: Why is the focus on the participant being the problem when it comes to concerns regarding fraud? What regulatory controls are being put on service providers to ensure they are providing services that are legitimate and in the best interests of the participant ? We do hear of large organisations that are allowed, despite the massive conflict of interest, to provide supports, support coordination and plan management all under the one roof, and that charge the same regular supports each week from Plans even though the service is not being provided in part or at all, where people with a disability are missing out on vital care and assistance. Often, the person with disability or their family member as nominee have no idea what they are being charged, and whether that service was actually provided. Clear weekly invoices are often not provided, despite being requested. The NDIA ought to be focussing its energy on assessing the unreasonable risk these types of service providers pose to cost saving and reducing fraud rather than placing these potential restrictions on a person with disability which reduces their option to choose how they manage their plans.

Our reading of these proposed changes is that small business or sole operators would then need to be NDIS registered providers. That is, plan managed participants would only be able to use NDIS registered providers. These smaller operators could not justify the cost of becoming a registered provider and people with disability will lose their invaluable supports that often take a long time to find and are difficult to replace. Could you please clarify, will the proposed changes require plan managed participants to only use NDIS registered providers? If this is the case, we vehemently oppose this and submit that it should be removed as it reduces choice and control.

In addition, there does not appear to be any capacity for a person with disability and/or their family member to appeal the decision of the CEO where there is disagreement over the calculation of unreasonable risk. If the CEO has unfettered power to force a person with disability to be Agency managed, we are going backwards in time where choice and control did not exist. A clause needs to be added to this effect to allow for an appeal for the CEO’s decision.

As an aside, the NDIA are known to struggle to make timely payments. Yet this new legislation will put more pressure on the system. How will the NDIA ensure bills will be paid in a timely fashion?

Should these changes go ahead and disregard our concerns expressed here, it is critical that transparency is provided on what the NDIA would consider to be ‘unreasonable risk’ to a participant. If there is an unreasonable risk, what is it? How is this defined? What is the role of the Quality and Safeguards Commission here where risk is being assessed?

We also make the point that system navigators were supposed to help build the capacity of a person with disability and/or their family member learn how to manage their plans. There ought to be an addition to the Rules that capacity building be built into NDIS Plans.

Payment of supports

We do not oppose, in principle, the proposed amendments under s 45 of the Act to enable the NDIA to pay service providers directly on behalf of participants through a new payment platform. Our understanding is that it is not the intention to make this mandatory but rather to provide this as an option for participants, including those who self-manage. We want to make sure that clarity is provided that the intention of this change is to allow participants to continue to be empowered to choose to pay the service provider in a manner that suits them.

Reassessments and variations

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

We are generally satisfied with the changes to plans which now allow for plans to be varied without triggering a complete reassessment. This will greatly enhance the capacity for participants to modify their plans to suit changes in supports and services needed.

We also see great benefit in the new provisions allowing for variations which occur to a plan whilst the plan is under review to be considered under the scope of the review, as opposed to a participant having to request a new review. This provides much greater capacity for participants to make necessary adjustments to their plans, which in turn facilitates greater choice and control, as well as and less time wasting and delays.

However, 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.

Participants need to be notified of decisions to vary or reassess their plans

We see no reason why the CEO should be able to unilaterally decide either to vary or reassess a plan without consultation or consent from the participant (except in very rare cases). Currently, under the proposed changes, it is possible for the CEO to vary a plan where the participant can be unaware until 7 days after the variation has taken effect or a new plan is about to be prepared.

It is vitally important that participants are notified of an intention to vary or reassess their plan and given a reasonable timeframe in which to adjust to the variation or reassessment. Firstly, it is necessary that a participant is aware of the intention to vary or reassess a plan so that they can seek a review of the decision if they believe that the decision is incorrect.

Secondly, notification of the intention to change aspects of a participant's plan is necessary for the participant to adjust to the changes - if supports are being withdrawn, for instance, the participant may be contractually obligated to provide notice to service providers or may need to make alternative arrangements for the support or funding.

The other concern is that the CEO's power to review, vary or reassess plans is significant as it is not constrained. We acknowledge there is a non- exhaustive list of matters the CEO must consider when deciding to vary a plan on their own initiative, but these matters do not limit the CEO's power. This means a participant could have variations made to their plan in relation to funding amounts or how funding could be used, without any consultation. Again, the balance is tipped too far in favour of the CEO and this proposed change 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.

It is also important to provide guidance on when it might be appropriate to decide to do each of the three options.

Providing reasons for decisions should be automatic not by request

Whilst it is a welcome change to allow a participant to request reasons for decisions made by the NDIA, prior to any internal review application, we submit it does not go far enough. The provision of reasons should not come only if a participant requests it. Yet again, this places too much onus on the participant to request something that should be given automatically.

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 must be accompanied by a statement of reasons.

The removal of a participant's right to seek a review of their plan

Section 48 of the *National Disability Insurance Scheme Act 2013* (Cth) ('the NDIS Act') currently provides that a participant may request that the CEO conduct a review of their plan at any time. Our interpretation is that Section 23 of the Exposure Draft of the National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Amendments) Bill 2021 ('the NDIS Amendment Bill') repeals section 48 of the NDIS Act and creates a new section 48.

The new section changes the language from 'review' to 'reassessment' and it allows for the CEO to conduct a reassessment of a participant's plan on the CEO's own initiative at any time. Importantly, the amendments do not provide any basis for the participant to be able to request that the CEO conduct a reassessment of the participant's plan. A right that previously existed has been taken away.

The NDIS Amendment Bill does allow for a participant to request a variation of their plan (*NDIS Amendment Bill, Schedule 1, s 22*), however, it appears that a CEO may only decide to vary a plan in certain circumstances and, as discussed below, even these circumstances are uncertain. Whilst we support changing the legislation to enable a participant to seek a variation of their plan, a participant should still be able to request a reassessment of their plan at any time.

It follows that a decision by the CEO to not conduct a reassessment of a participant's plan should then also be listed as a reviewable decision under section 99 of the NDIS Act in the table of reviewable decisions.

Clarity needed over what CEO must consider when deciding to vary a plan or conduct a reassessment

Given the point we have just raised regarding the removal of the participant's right to seek a reassessment, we submit more certainty is required for participants in terms of providing clear guidelines about what the CEO needs to consider when deciding whether to vary or reassess a plan. We would argue that it is not clear what circumstances will and importantly, what circumstances will not, warrant a variation or a reassessment of a plan.

Certainly, we acknowledge some guidance exists as set out in section 10(2) of the Exposure Draft of the National Disability Insurance Scheme (Plan Administration) Rules 2021 (hereinafter, The Proposed Admin Rules). The CEO must also have regard to the matters listed in section 10(2) in deciding to not vary or reassess a plan, or to not vary but to reassess a plan (*Proposed Plan Admin Rules s 11(3)*).

However, we provide an example to illustrate our concern. The matter at section 10(2)(c) of the proposed Plan Admin Rules is simply '*whether the variation is of the reassessment date of the participant's plan*'. It does not make it clear whether this is intended to mean that a CEO should or should not vary a plan because the variation is of the reassessment date. The same uncertainty arises from the matter listed at section 10(2)(a), which is '*whether the variation is minor or technical'*.

Not only is it unclear whether this is intended to mean that only variations of a minor or technical nature should be made, but there is also no explanation or definition provided regarding what is to be considered a minor or a technical variation.

The same concerns apply to the additional considerations that the CEO must have regard to in deciding whether to conduct a reassessment of a participant's plan (set out at section 11(4) of the proposed Plan Admin Rules). The wording makes it uncertain as to whether one or more must be present in order for the CEO to decide to conduct a reassessment.

We recommend clarity and certainty be provided in this regard and this ought to be done as a co-design process with the disability community.

Concern over the scope of the Minister's powers

We note that the Rules for the purposes of provisions 47A(6) and 48 (2) have been identified as 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. Likewise, there is no definition of consultation.

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.

Participants right to appeal CEO's decisions

Our reading of the draft Bill introduces two new reviewable decisions into the current table located at section 99(1) of the NDIS Act - the decision to vary a participant's plan under the new section 47A(1), and a decision not to vary a participant's plan and not to reassess the plan under the new section 47A(3)(b).

We notice a glaring omission. It does not provide a participant with the right to appeal a decision made by the CEO to conduct a reassessment, or to appeal a decision by the CEO to prepare a new plan. We submit both should constitute reviewable decisions, particularly in circumstances where the CEO may conduct a reassessment without notifying or consulting the participant prior.

All decisions by the CEO to vary or reassess a plan should be appealable. We would recommend that a decision by the CEO under their own initiative, to reassess a participant's plan under s.48, should be expressly provided in the list of reviewable decisions in s.99. Alternatively, we would suggest that 103(2)(d) be redrafted to refer both to the decision to make a new plan and approve the statement of participant supports in the new plan.

We also note that, under the NDIS Amendment Bill, the default position for when the CEO fails to respond to a participant's request for a variation within the time period stipulated is that the CEO is taken to have decided to reassess the plan. While we support the principle here of assuming that the participant's initial request for plan changes should be granted, this does also present the risk of plans being reassessed in situations where it may not be necessary. For example, it is currently common for participants to submit a Change of Circumstances request to change their plan funding when the existing funds can be used flexibly to accommodate their needs. Defaulting to a full reassessment in these cases would cause significant administrative delays, and risk introducing errors where none exist, when the participant could instead have been supported immediately to understand their options for flexible plan use. Further consultation is needed on this matter.

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’. This meaning of this term is easily understood by everyone.

‘Becoming a Participant’ Rules

We support the changes to the Becoming a Participant Rules where they enhance the capacity for people with psychosocial disabilities who experience impairments that are episodic or fluctuating to access the Scheme. We also support the inclusion of s.31(c)(ca) which recognises the importance of the relationship between participants, their families, and carers. We submit this flexibility should also be expanded to persons with chronic illnesses/disease.

Lack of definition around key influential terms

Rule 8 of the Becoming a Participant Rules states that, to access the NDIS, a person must be undergoing or have undergone ‘appropriate treatment’ for the purposes of ‘managing’ their condition, and that the treatment has not led to a ‘substantial improvement’ in their functional capacity after a reasonable period of time or that no ‘appropriate treatment’ is ‘reasonably available’ to the person.

It is important that prescription is provided around what will be covered under ’*appropriate treatment*’ and that ‘*managing*’, ’*substantial improvement’* and ‘*reasonably available*’ should be defined. Particularly, as these sections have a direct impact on if/what support a person receives.

It is particularly important when defining ‘*appropriate treatment’* to allow people with disability to choose how best to manage their own condition from as broad a range of evidence-based treatment options as possible. This term “appropriate” is vague and should include respect for bodily autonomy. People with disability should have the right to personal choice around what treatments work for them.

Likewise, when determining whether a treatment is ‘*reasonably available*’, the CEO or their delegate should consider a range of factors including where a person lives, the effort involved in accessing treatment, the capacity of the individual to afford the treatment etc.

People seeking to access the NDIS also need to understand what is meant by ‘*substantial improvement*’ and how long they would be expected to have sought appropriate treatment before they would be eligible for the NDIS.

While we appreciate that there will always be an element of subjectivity in determining whether a treatment has ‘substantially improved’ an individual’s functional capacity, we would expect that the NDIA would commit to co-design with the disability community in establishing the class of persons who would be qualified to make such an assessment and the range of tools they might use to do so.

Applicants also need to understand what sorts of specific requirements might be required to satisfy the NDIA that an impairment is permanent or likely to be permanent, for example, whether it is sufficient to provide documentation from their treating health professional, whether the NDIA might require an independent health professional to assess them, whether they may need to undergo an assessment – again, we would expect to see a genuine commitment to broad consultation and co-design in relation to determining who would be the most appropriate person/or persons to make such a judgement and what evidence they would use to support their view.

CEO's discretion is too wide

We are also concerned with the breadth of power given to the CEO in Section 13(2), which sets out the matters the CEO must have regard to in assessing whether provision of early intervention support is likely to benefit a person. Section 13(2)(d) is 'any expert opinion that the CEO considers relevant'. We submit this discretion is too wide.

Participant Service Guarantee (PSG)

Enforcement mechanism required

The proposed changes provide timeframes for key NDIS processes as well as setting out engagement principles and reporting requirements for the NDIA. The PSG has emerged due to the consistent participant feedback of extensive wait times with the NDIA and inability to do anything about this. However, we see one large oversight. There are no enforcement provisions to hold the NDIA to account. There certainly appears to be no remedies available where the CEO or NDIA have failed to meet any of the PSG requirements. Without it, we are concerned the PSG will be simply an aspirational statement, a blunt tool without any "teeth". Therefore, we recommend some mechanism for enforcement be introduced as part of the PSG.

Reporting to the Commonwealth Ombudsman needs clarification

From an accountability perspective, we welcome the requirement of annual reporting by the Commonwealth Ombudsman to review the NDIA's performance against the PSG as well as in relation to the participant's experience. However, we have concerns over the wording in the NDIS Act that requires the Commonwealth Ombudsman to *'prepare and give to the Minister a report about some or all of the matters prescribed by the National Disability Insurance Scheme rules for the purposes of this subsection' (Section 204A in the NDIS Amendment Act)* as it enables the Commonwealth Ombudsman to choose to report on only some of the matters listed.

The matters about which the Commonwealth Ombudsman may report have been prescribed in section 16 of the proposed National Disability Insurance Scheme (Participant Service Guarantee) Rules 2021 ('the PSG Rules'), and are as follows -

> *(a) collective performance in the financial year against one or more of the engagement principles and service standards set out in section 5 of this instrument;*
>
> *(b) performance against one or more of the timeframes that:*
>
> > *(i) apply to the Agency or CEO under the Act or this instrument; and*
> >
> > *(ii) end in the financial year;*
>
> *(c) other matters relating to the experience of participants, or prospective participants, relating to decisions by the Agency or CEO under the Act or this instrument in the financial year.*

The use of the wording 'one or more' and 'other matters' provides even less direction to the Commonwealth Ombudsman about what they are to report on. We consider it to be highly unlikely that the Commonwealth Ombudsman would voluntarily choose to report on all the matters mentioned, particularly as it is the overwhelming experience of people with disability that when they do take a matter to the Commonwealth Ombudsman they are being told that the Ombudsman already does not have enough funding to fulfil its core obligations in a timely manner.

There is a real danger that the reporting requirement becomes a meaningless process of box ticking rather than it being used as a diagnostic tool to see where the problems/barriers lie within the NDIA in order that they may be improved.

We submit that all relevant matters (which should include all timeframes and all standards) should be reported on. This is particularly important in circumstances where (as discussed above) there are already no enforcement mechanisms or remedies available to participant's where the PSG timeframes are not met, and where it appears public accountability will be the sole mechanism for monitoring performance of the PSG.

We also note that it is unlikely that people with a disability will be satisfied with the Ombudsman being the sole reporting mechanism, as they are already reluctant to pursue the option of complaint to the Ombudsman due to the perception that it is a pointless exercise. People with disability report this perception is based on beliefs that the Ombudsman is "toothless" and experiences of the Ombudsman's long wait times and lack of resources necessary to meet its current obligations.

Providing draft plans

We have long advocated for the automatic provision of a draft plan. Section 5 of the PSG Rules sets out engagement principles and service standards for the NDIA, CEO and other responsible persons. Item 4 is about empowerment and, amongst other things, provides that the responsible persons must collectively empower participants to request to see a draft plan in advance of final planning decisions and in advance of the approval of the statement of participant supports to be included in the plan.

We submit that merely empowering participants to request to see a draft plan is not enough. All participants should be offered to see a complete draft of their plan prior to any final planning decisions and in advance of the approval of the statement of participant supports. Furthermore, participants should be given the opportunity to provide feedback or have a follow up meeting if they have any questions or concerns about the contents of their plan.

Conclusion

Family Advocacy supports a number of the proposed amendments. As previously stated, the release of a large number of documents for consultation in a very short timeframe has limited our ability to respond exhaustively and is seen as a missed opportunity to rebuild the trust that has been eroded in the disability community. In relation to the concerns we have raised, we seek to engage with the government and the NDIA in a constructive manner to address these concerns through co-design in the spirit of rebuilding trust.