

Submission on the National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Amendments) Bill 2021.

Thank you for allowing me to make a submission regarding the exposure draft changes for the NDIS Act and related Rules legislation.

I am somewhat dismayed that the NDIS legislation becoming even more complex to follow with additional modifying Rules legislation documents to have to trace down. As a participant, it has already been difficult to find the actual rules relating to access and supports, and with additional new documents that is now becoming even more complex.

Can the NDIA please make an easily located page in the "Understanding the NDIS" area of the NDIS website that contains links to the NDIS Act legislation, and all of the NDIS Rules legislation documents so that participants and applicants can find the relevant legislation and read it themselves? If you don't know that a particular NDIS Rule document exists, it can be really hard to discover it - and missing some of the Rules makes it harder to understand how the NDIS is intended to operate. As an example - despite having read relevant sections the NDIS Act, NDIS Supports for Participant's Rules, and NDIS Restrictive Practices and Behaviour Support Rules, I was still completely unaware that the NDIS Becoming a Participant Rules, NDIS Plan Management Rules, NDIS Children Rules, NDIS Nominees Rules and NDIS Specialist Disability Accommodation Rules legislation documents existed until they were mentioned in the explanation of the legislation changes in this Amendment.

I do not feel that I have a good understanding of all the changes - with only 4 weeks to have read multiple Rules documents that I had not previously been aware of in addition to the new Rules documents, read the alterations to those Rules that existed previously, and actually write a submission in response, there has not been adequate time for me to investigate all of them fully.

I am disappointed that this consultation has been rushed after the IAC recommended a minimum 8 week consultation period for any NDIS legislation changes.

There are a few areas where the changes in the exposure draft cause me some concern.

NDIS Act Section 47: CEO initiated variations of a plan, without participant consultation.

As currently written, there are zero limitations or protections for the participant in the proposed amendment to allow the CEO to vary a plan without consultation. The Rules only set out a list of things to "consider" - but there is no requirement that any of those considerations actually have to affect/alter/determine the final decision.

When this power was proposed in the Tune Review, it was proposed to be available in specific circumstances only. The exposure draft is making it available in any and all circumstances, which is open to serious institutional abuse by the NDIA. The participant has no protection from circumstances such as finding a month after they received their plan that their funding has now been reduced by 1/3 because some delegate of the CEO decided that funding for a particular disability support was a "technical error" and "fixed it" by removing the funding from the participant's plan without consultation and without understanding why it had been approved in the first place. While

the delegate is required to consider whether their change would reduce the participant's plan, there are no legal limitations to prevent them deciding to make the variation anyway after considering it.

Being able to do an internal review of a decision from an NDIA delegate who made seemingly random changes to the participant's plan without consultation does not eliminate the significant potential for active harm to the participant due to the funding change during the time that they are waiting for the review to occur - and potentially extending to include during the time that they wait for AAT decisions afterwards if the internal review doesn't reverse such a decision.

Please refer back to the list of circumstances suggested in the Tune Review where such a power to vary a plan without consultation with the participant was reasonable, and add appropriate limitations to the circumstances where that power can be used to the legislation.

The powers provided to the CEO in this instance are too wide-spread/unlimited, leaving it open as an avenue for potential abuse by the NDIA.

NDIS Participant Service Guarantee Rules 2021 - Section 13: Reviewing decisions—period for giving reasons for a reviewable decision

If after an internal review (S100) of a reviewable decision the participant is still unhappy with the result of that review, they have the right to apply to the AAT within 28 days of receiving their result.

Part of an application to the AAT is the requirement to upload the NDIA's reasons for their decisions.

Having a 28 day period for the NDIA to respond to the participant requesting those reasons for the decisions made in the internal review (S100) has the potential to actively remove/block the participant's right to request an external AAT review of those decisions, particularly at times such as the present where there is a backlog on email processing resulting in many emails not being read/entered into the system for a month or more.

This is not a reasonable outcome, and I think it is likely an oversight with the exposure draft changes. As someone who has needed to take both their access and plan decisions made by the NDIA to the AAT (and won all cases during the initial mediation phase), having participants lose the right to an external review of an unfair/unreasonable decision through not receiving the reasons for that decision from the NDIA before the AAT application time has expired is extremely concerning.

Reasons for decisions that have been made *ought* to be provided as a standard part of providing the actual decision - not withheld until the participant requests them. The person doing the plan or review is in the process of actively making and recording those decisions - the reasons should be capable of being recorded for the participant at the same time as part of the same unit of work.

It is vital that the participant's right to an external review of a decision at the AAT is not impeded by the NDIA not having provided the required reasons for their decision in time for the participant to apply.

The Participant Service Guarantee should instead require that the reasons for a decision should be provided to the participant as part of providing the decision itself. Failing that, the time frame should be shortened to no more than 14 days (7 days preferred). These reasons are already recorded in the NDIA's planning system for plans when the NDIA delegate makes those decisions, so the

need to copy them into a letter/document to provide to the participant should not require a substantial period of time to assemble.

NDIS Act Section 45: Payment of amounts payable under the National Disability Insurance Scheme

Part 1 of section 45

Part 1a of section 45 states that payments for a participant's plan are to be paid "to the person determined by the CEO".

I have been informed by DSS that this change is supposed to be adding the ability to directly pay providers of disability supports for self-managed participants, and was not intended to remove the current methods of handling expenses.

Written as it is, it leaves scope for the complete removal of the existing payment request process used with self-management. This would be actively detrimental for many participants, and would likely have the unwanted consequences of removing participant choice of providers (if the provider needed to be registered in order to be paid directly), remove the participant's option for direct employment of their support staff (can't access the payroll expenses for the supports provided as there isn't an outside "provider" to pay, just direct employees), and remove the participant's ability to shop around for the best pricing available. There are many items that fit into the low-cost/low-risk category as assistive technology for people with a disability - common examples include jar openers and pickup/reach tools, which if purchased from mainstream vendors are typically substantially less expensive than when the exact same item is purchased from a "disability" store. Being unable to purchase these items if required due to the participant's disability and then claim reimbursement from the NDIS would result in the costs of these items being substantially higher (causing NDIS costs to rise for the same levels of support).

Please amend the language in clause 45.1.a to make it clear that the ability to pay "to the person determined by the CEO" is not intended to *remove* the existing payment options.

Part 2 of section 45

Part 2 of Section 45 discusses whether payments should be paid in installments or lump sums. During the year this year, the NDIA originally intended that NDIS plans would only permit access to one month or three months worth of funding at any one period of time.

This style of funding does *not* work for anyone whose support needs are not consistent on a monthly basis.

Anyone whose ability/functionality varies will find that they are unable to access the supports they have been approved for at the times when they actually require them. Typical examples include:

- Therapy/supports that run during school terms - spreading the budget over 12 individual months means that there would be inadequate funding for those supports during the school terms to be able to pay for those supports, and provision of funding during holiday periods for supports that cannot be accessed at those times.

- People whose condition is affected by weather changes - and who therefore have different support funding needs during winter compared to summer.
- People whose condition is unpredictable, e.g. conditions such as MS, where the user can go to sleep one day feeling ok, and wake the next day paralyzed or blind and need to be able to access immediate emergency support.
- People who need additional support during school holiday times, particularly within families with multiple people with a disability.

These people are *not* a minority of those who are on the NDIS - most people have a range of life reasons why they need different supports at different times. It concerns me that the purpose of this part of the legislation is specifically to pave the way for the same rationing of funding that the NDIA were seeking to implement at the beginning of the year, in ways that DO NOT actually work for the people being supported by the NDIS.

I am very strongly opposed to any reduction of access of funding to less than a one year period due to the variability of support needs for most people. It simply makes it harder for the participant to access the funding they *have* been allocated at the times of the year when they actually *need* it.

Submission Questions as specified by DSS

Schedule 1 (Participant Service Guarantee) and Schedule 2 (Flexibility Measures)

1. *Does the particular Schedule clearly set out the key changes being made to improve participant experiences with the NDIS?*

The schedule sets out the changes being made in broad terms, but in many cases the specifics of when particular rules or powers should be exercised is not adequately specified.

2. *Could the proposed amendments in this particular Schedule lead to any misinterpretation or unintended consequences?*

a) The timeframe for the NDIA to provide the participant with the reasons for decision(s) made during an S100 review of a reviewable decision is too long, and could result in participants losing the right to make an application for external review with the AAT. The participant is required to submit those reasons from the NDIA as part of the AAT application, and the participant only has 28 days from receipt of the decision from the NDIA to submit an application to the AAT.

b) The lack of any safeguards for participants/limitations on when the CEO, and therefore any delegate of the CEO, can vary a participant's plan on their own initiative without consultation with the participant could be easily abused or misused, resulting in participants potentially being denied access to supports that had originally been approved in the plan. Being able to review those decisions doesn't stop the immediate loss of supports from causing harm during the time spent waiting for the review of a reviewable decision to occur.

3. *Are there any other changes which could improve the participant experience in the NDIS?*

Participants should be receiving the reasons for decisions being made at the same time as receiving those decisions. It shouldn't be something that the participant *has* to ask for - and further, to know in advance that it *needs* to be requested in order to receive them. My own experience with unfathomable decisions involved a week-and-a-half of being infuriated over one of my initial supports from the NDIS being 38.5% lower than the level of support I'd had from the local council prior to the NDIS even though no-one was supposed to be "worse off" on the NDIS, and it was only on receipt of the "Participant Information Access" request information a week and a half later that I discovered that the cut had been caused by the NDIA Planner having believed that the Council's supports would continue rather than being terminated. They'd believed that they were increasing my support instead of cutting it by 38.5%. *No* participant should have to go through that period of stress between being given an otherwise incomprehensible decision from the NDIA without the reason for why that decision was actually made, and then have to wait up to 28 days to find out why that decision was made.

NDIS Participant Service Guarantee

1. *Do the Rules provide clarity to participants on the timeframes that will apply to NDIA decision-making? (See Part 3 of the NDIS PSG Rules)*

The rules do specify timeframes on the NDIA's decision making, but do not specify *any* avenues of redress open to the participant when the NDIA fail to meet those timeframes. If the NDIA does not meet those timeframes, what options does a participant have to try to get the NDIA to actually start processing an application/quote/plan/etc? Is the participant just going to be left without support and ignored - as currently happens in many cases now? Is there an external complaints process that can be used when the NDIA are unwilling to do anything to help?

2. *Are the timeframes within which things must be done appropriate? Are they too long or too short?*

The timeframes for providing the reasons for a decision are *far* too long, and could result in the loss of the ability for a participant to request an external review of a reviewable decision at the AAT. Ideally, the reasons for a decision *should* be provided as part of providing the actual decision. Anything else creates a period of stress for the participant while waiting for the NDIA to reply with reasons for an otherwise incomprehensible decision. These reasons are already *required* to be captured into the NDIA's planning database for planning reasons (and I'd expect this to be the same for access decisions), so there should be no barrier to the decision maker providing those reasons to the participant at the same time as providing the decision itself.

Due to the requirement to submit those reasons as part of an AAT application and the AAT application being required to be submitted within 28 days of the participant receiving the decision, those reasons *must* be received by the participant no later than 14 days after the decision was made and preferably within 7 days to give the participant time to absorb the information and decide whether an AAT application is warranted, and to have adequate time to prepare an application if they felt one was warranted.

3. *Are the proposed engagement principles and service standards that will underpin how the NDIA works alongside people with disability in delivering the NDIS appropriate? Are there additional particular types of consultation or engagement important to consider? (See Part 2 of the NDIS PSG Rules)*

What options does the participant have when the service guarantee principles have been violated? My own experiences from the NDIA over the last few years have mostly been appalling, and frequently in violation of various subclauses under all of the principles in the Participant Service Guarantee. If the participant is bullied, belittled, ridiculed, has expert reports not read, decisions made solely through prejudice rather than submitted information, never has a stable point of contact, deals solely with people with little to no training in their disability and no comprehension of the impact of disability on their life - what redress is available to the participant?

What use is the Guarantee to the participant themselves when there is no way for it to be enforced, and no redress when the NDIA fail to meet this standard?

All of the above examples come from my own personal interactions with the NDIA over the last 3 years. Making complaints to the NDIA rarely achieves anything for the participant - it just gets passed on to the staff member's supervisor "for training purposes" while leaving any harm it caused to the participant still active.

4. *The Commonwealth Ombudsman will provide an annual report to Government on the NDIA's performance in delivering the Guarantee. The Rules set out what will be in that report. The Rules also set out the things the NDIA must report on in its quarterly report to Governments. Do the Rules clearly explain how both of those reports will ensure the NDIS delivers on the promises of the Guarantee? (See Part 4 of the NDIS PSG Rules) NDIS processes and the Participant Service Guarantee – proposed legislative improvements*

No.

The rules do not explain how reporting on those items will make any difference at all. The NDIA have already been reporting on items such as the percentage of decisions that properly applied reasonable and necessary criteria to the ANAO - those figures were in the low to mid 30% last year - but it doesn't appear to have had *any* effect on the NDIA's decision making. The NDIA were told by the ANAO to make sure that they referred back to legal reasoning from AAT cases - and nothing at all has changed, with the NDIA this year putting out information on their "would we fund it" site that directly violates the decisions and legal reasoning made by the AAT. An example of this is that the AAT declared that Gym membership was NOT an everyday cost of living - it was a discretionary cost that people without a disability could *choose* to pay or not - and provided a test that matched the examples from the legislation for determining if a cost was an everyday cost of living in the case "Millburn and NDIA [2018]" paragraphs 69-75, but this year the NDIA stated on their "would we fund it" website that gym membership wouldn't qualify for NDIS funding because in their opinion it was an everyday cost of living. Further, most of the examples of "everyday" costs on the NDIA's "would we fund it" website fail the test provided by the

AAT for determining an everyday cost. The NDIA also frequently forget that if the cost is solely attributable to the participant's disability support needs, the rule 5.1.d for not funding everyday costs does NOT apply and it falls into rule 5.2. If anything, the NDIA appears to have been getting worse this year, with the percentage of applications to the AAT doubling between January and June this year and reaching the highest percentage ever in the NDIS's recorded stats since 2018, despite reporting on this each quarter.

I fail to see how simply "reporting" on their performance will in any way affect the mindset within the NDIA when they have previously appeared to be unashamed of reporting on other failures of administration.

NDIS Plan Administration Rules

1. *Do the Rules clearly set out the circumstances in which a participant's plan can be varied, and the circumstances in which the NDIA would ordinarily first conduct a reassessment? (sections 10, 11 and 12 of the Rules)*

No.

Section 10.2 specifies some things that the CEO must "consider" when deciding to vary a participant's plan on their own initiative, but places no *actual* restrictions on when the CEO (and therefore any delegate of the CEO) may do so. This leaves this power unconstrained, and open to abuse.

2. *Do the Rules clearly explain the options a participant has to work with the NDIA to ensure their plan remains fit-for-purpose? (sections 10, 11 and 12 of the Rules)*

Mostly.

3. *Does the proposed alternative commissioning power clearly set out the circumstances under which the NDIA could support a participant to maximise choice and control? (section 5 of the Rules)*

No.

Like the things that the CEO needs to consider for varying a plan, the things that the CEO "must have a regard to" do not actually limit or specify when the NDIA may intervene by providing supports specifically for a person or region. There is nothing preventing the NDIA from using this to force a participant to use a provider that they have had previous disputes with.

I also had to read the Explainer document to properly understand this section of the legislation - it was not clear from the legislation alone.

4. *The Rules include details on the responsibilities of persons receiving NDIS funding to keep records about how those funds were spent. Is it clear what their responsibilities are? (section 9 of the Rules)*

No.

Section 9 completely excludes the situation where a self-managed participant is directly employing their support staff, and hence will have payroll, PAYG, Superannuation, Casual loading or Annual Leave Accruals records to be kept. The type of records in that case will not be invoices, won't have an ABN, will be paid to multiple people (e.g. staff, Tax Office, Superannuation clearing house) for usually the same claim, etc.

Further - is section 9.2.d stating that if a participant uses a support provider for 5 years, they must retain *all* invoices from that support provider for a minimum period of 5 years from the end day of support from that provider before they can discard *any* of those documents, or is it supposed to be 5 years from the last support listed on the invoice itself? In the first situation, that would mean that for some records a participant may need to keep them for 5 years, for others from service providers that they continue to use they may need to keep them for 10, 15, 20 years depending on how long the participant uses that provider for that support? It is currently confusing what "the last day on which the services are provided to the participant" means when it comes to a provider who continues to provide services to the participant. Suggested alteration: "from the last day on which the specific services listed on that record are provided to the participant".

NDIS Plan Management Rules

1. *Do the Rules clearly set out the circumstances in which a support must be specifically identified in a plan? (section 6 of the Rules)*

The rules for when a support must be specifically identified in a plan appear to be completely unconstrained, in the same manner as several other issues with the rules. While the CEO "must have regard to" some matters, there is nothing restricting them from considering and discarding all of the various matters.

This rule is open to abuse by the NDIA, and provides the participant no protection from that abuse.

2. *Do the Rules clearly set out the things the NDIA will consider in protecting participants from provider conflicts of interest and help them maximise the benefits of their NDIS funding? (Section 8 of the Rules)*

Section 8 of the Rules is again unconstrained. The CEO must "consider" some things, but is not limited by those considerations.

This rule is open to abuse by the NDIA, and provides the participant no protection from that abuse.

3. *The Rules set out the considerations taken into account when a participant or their representative request to self-manage their NDIS funding, or use the support of a registered plan management provider. Is it clear how these considerations are designed to protect participants from unreasonable risk or harm? (sections 9 and 10 of the Rules)*

It is not clear why the participant receiving supports from a person or entity who is not registered is automatically considered a risk. Isn't this what plan and self management are meant to provide the ability to do? Where does the participant's choices come into this rule?

Becoming a Participant Rules

1. *Do the Rules clearly set out the circumstances under which psychosocial disability may be considered permanent? (section 8 and section 12 of the Rules)*

No.

For the purposes of these rules, what do the terms "known", "available", "appropriate", "other treatments", "reasonably available" mean?

Is a treatment considered "known" and "available" if the participant has to leave Australia to access it?

Is it considered "available" if it would cost the participant \$100,000 to access the treatment?

Is it considered "appropriate" if there is substantial risk involved to the participant by that treatment?

Where does the participant's rights to refuse treatment that they consider "too risky" fit?

Where does the participant's rights to individual autonomy fit?

If the participant has other conditions that make a treatment that is regularly used contra-indicated for themselves, would that qualify as an "inappropriate" treatment or would it still be required?

What sort treatments that are not clinical or medical are intended to be part of "other treatments"?

2. *Do the Rules clearly set out when an impairment attributable to a psychosocial disability may be considered to result in substantially reduced functional capacity of the person to undertake an activity in communication, social interaction, learning, mobility, self-care, and/or self-management? (section 10 of the Rules)*

Section 10.2.b: "the person is unable to participate in the activity or to perform tasks or actions required to undertake or participate in the activity, **even with** assistive technology, equipment, home modifications or assistance from another person"

Why are psychosocial participants excluded from "substantially reduced functionality" due to the use of assistive technology/home modifications, when participants for other disabilities are not? Section 9.2.a.i allows people with all other disabilities that require assistive technology or home modifications due to their disability to qualify for the NDIS, but there is no such clause for psychosocial participants.

Isn't access to funding for assistive technology/home modifications one of the major reasons that someone may need NDIS funding? Where is a person who has a psychosocial disability that requires specific disability supports meant to go in order to access those supports, if by accessing those supports they then no longer qualify for NDIS access due to being able to do

an activity with assistive technology/home modifications?

If a person requires a specific support - e.g. an assistance dog - in order to be able to leave the home/go into the community, the psychosocial "substantially reduced functional capacity" rule currently says that because they would be able to go into the community if an assistance dog were to be provided they would not qualify for NDIS support. The costs for a trained assistance dog typically start from around \$30,000, plus yearly insurance/vet bills/equipment/food costs, which with no ability to receive funding support from the NDIS in most cases the person with a psychosocial disability could not afford to obtain the assistance dog support that they needed and could not receive funding from anywhere.

The end result being that the person with a psychosocial disability is disqualified from NDIS access on the basis that the use of assistive technology that they do not yet have and could never afford to get would permit them to carry out some activities. *Every* other type of disability would have qualified for the NDIS and received funding assistance in order to obtain the required assistive technology. Why is there any difference at all for people with a psychosocial disability on this point?!

This is a **ludicrous** level of discrimination against people with a psychosocial disability and must NOT be written into our legal system in its current form. It violates the intent of the NDIS where people with severe disability are supposed to receive the supports that they require to be able to function in the community. Denying access to essential assistive technology/home modifications to people with severe psychosocial disabilities is a very cruel and disgusting proposal.