

Submissions to the

# Community Affairs Legislation Committee

*National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024*

May 2024

**CONTENT WARNING: THIS DOCUMENT CONTEMPLATES THE PREVENTABLE DEATHS OF PEOPLE WITH DISABILITY**

## About Us

Villamanta Disability Rights Legal Service Inc. (**Villamanta**) has been providing advocacy and legal services to people with disability since 1990. We are funded to provide advocacy under the National Disability Advocacy Program, NDIS Appeals and the National Legal Assistance Partnership Agreement.

Villamanta engages in the following activities which inform this submission:

- **Telephone Information Service** – our intake team receives around 2,000 contacts per year from people with disability seeking assistance.
- **Advice calls** – our legal team provide discrete advice to over 150 people with disability per year. Many of these are about NDIS Appeals, or else about their NDIS experience.
- **NDIS Appeals** – our representation of clients at the AAT provides us ongoing insights into how the current legislation and rules are working for different participants.

Villamanta have been providing NDIS Appeals support since 2017. In this time, we have assisted over 1,600 people with their NDIS concerns, representing 309 people at the Administrative Appeals Tribunal.

We were involved in the following AAT decisions:

- [Uthenwoldt single occupancy SDA](#) (successful appeal)
- [Mowjood access](#) (unsuccessful appeal)
- [Boicovitis Single occupant SDA](#) (successful appeal)
- [CYHY autism assistance animal](#) (successful appeal)
- [Ray Access and Independent Expert](#) (successful appeal)
- [Castledine supports and NDIA internal advice](#) (successful appeal)
- [KLMN and other service systems - prism glasses](#) (successful appeal)

We have made the following submissions related to the NDIS:

- [April 2024 NDIS Registration Taskforce Submissions](#)
- [May 2023 NDIS QS Framework Submission](#)
- [March 2023 Briefing Paper for NDIS Review and Access and Planning Under the NDIS](#)
- [October 2022 NDIS culture and capacity](#)
- [June 2022 - Model litigant obligations and NDIS Appeals](#)
- [August 2021 Unreasonable and unnecessary harms](#)
- [October 2021 - Proposed NDIS legislative improvements and Participant Service Guarantee](#)
- [November 2021 Joint Standing Committee on the NDIS - general issues around implementation and performance](#)
- [2021 General Issues around the implementation and performance of the NDIS](#)
- [July 2020 - NDIS Quality and Safeguards Commission](#)

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## Executive Summary

We thank the Community Affairs Legislation Committee for the opportunity to provide submissions on the *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024 (Bill)*.

We have serious concerns about participant safety should the Bill pass in its current form and if the Agency continues to administer the Scheme in the way that it does now.

People will die.

We are being asked to believe that this Bill is the “scaffolding” to progress key NDIS Review recommendations, and the work to follow will be co-designed with the disability community.

Yet the government has not responded to the NDIS Review, and there is no clarity on what the scaffolding is intended to achieve. The different visions being proffered make it clear that more detail is required before the Bill can be safely enacted.

We are asked to trust that co-design will occur but have seen no evidence that it has occurred to date. Rather, Disabled People’s Organisations were asked to sign Non-Disclosure Agreements and threatened with prosecution if they breached them.

Future design of the operation of the NDIS cannot be done safely without input from the users of the Scheme who have experienced the challenges of dealing with the Agency, and understand the risks, including:

- Failure to make reasonable adjustments in communicating or receiving information from participants;
- Document management processes that are not fit for purpose, resulting in repeated losses of materials;
- Removal of key escalation contacts for advocates to intercede in critical situations;
- Current extreme delays in processing requests from participants, including where funding has been depleted or their needs have changed; and
- Poor communication with participants and their supporters, resulting in bad outcomes which can take years to resolve.

The NDIA needs to clear their backlog, improve their processes, and conduct the essential co-design work, before the changes proposed by the Bill can be considered safe for participants.

## **Recommendations**

1. Do the co-design work and then come back to legislative change.
2. Open up the revocation process to co-design so it can be done safely and appropriately. The reasons for revocation must be included in the legislation and not delegated to the Rules. The Rules must include safeguards and appropriate measures to be taken including risk assessment, actual engagement with the participant, ensuring access to advocacy and decision-making supports as appropriate, and confirmation that alternative supports are engaged.
3. Be transparent about the proposed needs assessments and start the co-design process.
4. Be transparent about how the needs assessment informs the funding budget. Let people understand it, and identify where it doesn't work before trying to implement it.
5. Remove section 10.

## Contents

About Us .....	2
Executive Summary .....	3
Recommendations .....	4
Introduction.....	6
The scaffolding .....	7
What are they actually building? .....	7
The NDIS Review recommendations .....	9
Implementing reforms to ensure participants experience a smooth transition .....	11
Section 10 and “NDIS Supports” .....	15
Changes to access.....	17
Disability and Early Intervention.....	17
NDIS Supports .....	17
Revocation – the risk to participants .....	18
Isolated and unempowered .....	18
Information requests.....	18
Information management.....	20
Absence of case management.....	20
What does that look like to a participant? .....	21
What needs to change.....	22
Assessment tool and funding amount.....	23
New framework plans .....	24
Other factors .....	24
The obligations of participants.....	25

## Introduction

Our submissions in relation to the Bill are not purely the submissions of legal practitioners commenting on a legislative draft. Our submissions are also informed by our experience with the way the National Disability Insurance Agency (**NDIA**) has engaged with NDIS participants under the current legislation, rules, operational guidelines and internal policies, and the outcomes for our clients.

Our submissions are also rooted in the context that:

- The disability community and our clients engaged in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (**Royal Commission**) over four and a half years, culminating in a final report which was delivered to the Governor General on 28 September 2023. To date the federal government has not responded to the recommendations contained in this report.
- The disability community and our clients engaged in the NDIS Review, with its report being delivered on 7 December 2023. To date the federal government has not responded to the recommendations contained in this report.

While recommendations of the NDIS Review are being relied upon as a rationale for the Bill, there are problems with that position:

- The NDIS Review relied on foundational supports being in place. They are not.
- The Bill creates many risks for participants, without any mitigation or clarification of the obligations of the NDIA.
- There is no documented plan for how the implementation of the Bill, the government response to the NDIS review and the development of foundational supports will interact.

As discussed below, the Bill proposes a significant shift in the power of the NDIA which creates negative consequences for participants, with no reciprocal rights being provided to the individuals affected.

## The scaffolding

According to the [DSS FAQs](#):

*The Government is introducing changes to the NDIS legislation to:*

- *create the scaffolding to progress key NDIS Review recommendations. Government will do this with people with disability and the disability community.*
- *clarify the intention of existing legislation. This will improve the delivery of the Scheme now.*

### WHAT ARE THEY ACTUALLY BUILDING?

The Bill and other relevant materials are not internally consistent or sensible, and their alleged enactment of recommendations of the NDIS Review is problematic. If the Bill is the scaffolding, what is being built?

The contradictions and confusion are highly problematic in the context of a Bill which is very light on detail, with the promise of co-design down the track. We are being asked to believe that although things aren't clear now, they will be in the future. If the government has not responded to the Royal Commission or the NDIS Review, how can we understand how this legislation is going to implement the changes the government says are necessary?

Given that the Bill content contradicts statements made by the Minister, and are at odds with the NDIS Review recommendations, we have no confidence in this approach. Furthermore, many proposed changes in the Bill are matters which have been in operation by the NDIA for years now<sup>1</sup> – there should be no reason the Agency does not have draft rules to accompany the Bill.

#### Example 1: CRPD and APTOS

The inclusion of selective parts of the Convention on the Rights of People with Disability at Section 10, and the reliance on the Applied Principles and Tables of Services (**APTOS**) at Section 124, bring about direct contradictions within the Bill itself:

- Section 10(a)(v) states that a rehabilitation service is an NDIS support.
- APTOS states that “Health systems are responsible for funding time-limited, recovery-oriented services and therapies (rehabilitation) aimed primarily at restoring the person’s health and improving the person’s functioning after a recent medical or surgical treatment intervention. This includes where treatment and rehabilitation is required episodically.”

Is this intended to shift a health service out of the column for the states, and into the column for the Commonwealth via the NDIS?

- Section 10 states that NDIS Supports includes “sickness benefits”, which would be understood by the average person to be Sickness Allowance - which ceased in September 2020. Sickness allowance was a welfare payment, administered by Services Australia, and recipients could spend it however they chose.
- The Explanatory Memorandum states that NDIS Supports are not for groceries or payment of utility bills.

If the funding under an NDIS plan is a sickness allowance, can participants use it to buy their groceries and utility bills, or not?

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<sup>1</sup> For example only funding supports related to certain impairments, reviewing and revoking access, limiting the use of Agency managed funds to registered providers (despite NDIS Review recommending revocation of this at 17.3), and the use of stated supports.

## Example 2: What is the Participant's Disability?

This has been an ongoing issue requiring clarification. While the Federal Court and Administrative Appeals Tribunal have interpreted the question in a fairly consistent way, the NDIA has taken an alternate view.

The Federal Court in *Mulligan* stated:

*The term “disability” is used in the Act ... as a descriptive concept for the overall effect of a person’s impairments on that person’s abilities to participate in all aspects of personal and community life.<sup>2</sup>*

The Agency, meanwhile, insists that “disability” means the impairment for which the participant met the access criteria. While it may not be immediately obvious how these two definitions are different, they are in practical terms polar opposites, due to the manner in which the process is conducted.

Upon a participant meeting the access requirements, a letter is sent to the participant informing them they have met access. Just that.<sup>3</sup> It does not say “on the basis of impairment A”, or “we have accepted impairment B, but not C”. It is not conditional, it is not partial, it just states that access has been met. This is consistent with the legislation and both Federal Court and AAT decisions, which are based on the “threshold” concept articulated in *Mulligan*,<sup>4</sup> whereby a person is either a participant, or they are not. There is no middle ground.

Meanwhile an entry is made into the Agency’s internal client management system stipulating a participant’s “primary disability”. The participant is not consulted or notified about this, and has no input into how it is decided. This categorisation of the nature of a person’s disabilities is carried out secretly, and as we have seen in the case of *VGCP*<sup>5</sup>, can even be changed subsequently with just as much secrecy.

The first time the participant becomes aware of this is when they are refused funding for a support because it is “not related to your disability”. Our previous submissions to both the Joint Standing Committee on the NDIS and the NDIS Review outlined the issues which compound:

- The Agency does not communicate which impairments they have accepted, and which they have not;
- This is not a decision under the NDIS Act, and therefore not reviewable;<sup>6</sup>
- The participant does not know this is happening until supports are rejected, and even that is not consistent; and
- There is no process to have this “decision” reconsidered.

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<sup>2</sup> *Mulligan v National Disability Insurance Agency* [2015] FCA 544 at [51]

<sup>3</sup> We note the Bill proposes to add a requirement that they are informed whether they have met access under disability or early intervention criteria, but does not propose a change in this hidden conditional access issue.

<sup>4</sup> *Mulligan v National Disability Insurance Agency* [2015] FCA 544 at [34].

<sup>5</sup> See [Briefing Paper for NDIS Review](#) and [Access and Planning under the NDIS](#) for background to this matter. We were advised by the Ombudsman that the changes in listed disability were an error and were rectified based on advice from Technical Advisory Branch, however a Freedom of Information request located no such advice.

<sup>6</sup> As confirmed in [Goodliff and the National Disability Insurance Agency \[2021\] AATA 5022](#) the AAT cannot review an Agency decision about what the “disability” is. “*This is because of the way in which the NDIS operates. There is essentially a two-step process. In the first instance an applicant must be accepted as a ‘participant’ and thereafter the participant and the Agency must agree upon a Participant Plan*” at [8]



### Case study

Jonathan has an appeal at the AAT over funding for assistive technology that he has been trialling for the past 12 months. The NDIA have funded the equipment trials, but are now declining to fund the purchase of the equipment itself.

After a year of conferencing at the AAT and Jonathan repeatedly seeking further recommendations and specifications about the equipment from his Occupational Therapist to satisfy the Agency's requests, he is informed that he only met access for his psycho-social disability and the equipment is not related to his disability.

This is the first he has heard of this, and in his view his physical disability impacts his functional capacity to a far greater extent than his psychosocial disability, but also the two are strongly connected. He is told he will now have to provide a suite of new reports justifying that his physical disability meets the access requirements.

It is clear to us that this "primary disability" is a category which determines funding, and a process which the NDIA have been trialling and implementing for some time. It is also a breach of procedural fairness because it is not a decision made in accordance with the legislation, is not reviewable, and withholds crucial information from the person affected by it.

There is a large gap between what the Bill purports to propose in terms of treating a participant as a whole person and what it actually contains. On the one hand, stating that participants are seen as a whole person:

- The Hon Bill Shorten MP, whose Second Reading Speech states "Your needs assessment will look at your support needs as a whole – and we won't distinguish between primary and secondary disabilities any longer."
- The NDIS Review, which this Bill claims to give effect to, recommends that the "budget should be based primarily on support needs and intensity, rather than functional impairments"; and
- The recommendations of the Joint Standing Committee on the NDIS are "that the National Disability Insurance Agency assess people according to the totality of their disabilities and no longer require participants to nominate a 'primary disability' and 'secondary disability'".

That is not what the Bill does, nor what the Department of Social Services contemplates:

- Section 32L states "The assessment must assess the participant's need for supports only in respect of impairments in respect of which the participant meets the disability requirements or the early intervention requirements."
- Section 34(1)(aa) includes "the support is necessary to address needs of the participant arising from an impairment in relation to which the participant meets the disability requirements (see section 24) or the early intervention requirements (see section 25)";
- The Explanatory Memorandum notes that "(t)he method will only take into account ... impairments that meet the disability requirements or early intervention requirements." It also clarifies the view that this "amendment clarifies that the NDIS only funds supports for impairments that meet the disability or early intervention requirements, as per the Scheme's original intent."
- The [DSS FAQs](#) note that "NDIS supports in a plan relate to the impairment(s) that meet the access requirements."

### THE NDIS REVIEW RECOMMENDATIONS

According to the [Explanatory Memorandum](#):

*"The amendments in this Bill give effect to NDIS Review recommendation 3 and interconnected*

*elements in recommendations 5, 6, and 7. The amendments also support the partial implementation of recommendation 17.”*

Let’s take a look at what those are and how they interact with the Bill.

**Recommendation 3: Provide a fairer and more consistent participant pathway**

*Actions for recommendation 3*

- 3.1 *The NDIA should introduce a more consistent and robust approach to determining eligibility for access to the NDIS based on transparent methods for assessing functional capacity.*
- 3.2 *The NDIA should introduce a new Access Request and Supporting Evidence Form and accompanying guidance to make the process of applying for NDIS access more transparent and simple.*
- 3.3 *The NDIA should change the basis for setting a budget to a whole-of-person level, rather than for individual support items.*
- 3.4 *The NDIA should introduce new needs assessment processes to more consistently determine the level of need for each participant and set budgets on this basis.*
- 3.5 *The NDIA should allow greater flexibility in how participants can spend their budget, with minimal exceptions.*
- 3.6 *The NDIA should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support.*
- 3.7 *The NDIA should reform the NDIS early intervention pathway to provide supports to individuals where there is good evidence the intervention is safe, cost effective and significantly improves outcomes.*
- 3.8 *The NDIA should implement reforms to the participant pathway using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.*
- 3.9 *The Australian Government should update and clarify legislation to support a more effective approach to determining access.*

We note that there has been no government response to the first eight items. In our view, these are the steps that should be occurring with the involvement and co-design of the disability community.

Absent this work, and the consequent lack of trust in the co-design process, the legislation is premature. There is no need for legislative change to provide for needs assessments, whole of person budgets, and flexibility in budgets, because they don’t yet exist.

We note recommendation 3.6 refers to a trust based approach to oversight of how participants spend their budget. The Bill does the exact opposite of this by:

- Introducing a definition of “NDIS supports” that not even experienced NDIS lawyers understand, much less the average NDIS participant; and
- Linking that definition to key decisions about access, planning, budgets and use of funding; and
- Threatening participants with the following outcomes if they get it wrong:
  - Changing the management of funding in the plan; and/or
  - Changing the duration of funding periods in the plan; and/or
  - Incurring a debt to the NDIA.

Nonetheless, the [Explanatory Memorandum](#) insists that “These changes will support the NDIS Review’s recommendations to provide more guidance to participants about how to spend their NDIS funding.”

Let us then turn to recommendation 5 of the NDIS Review.

**Recommendation 5: Provide better support for people with disability to make decisions about their lives**

*Actions for recommendation 5*

- 5.1 *The NDIA should ensure participants receive accessible information and tailored advice to support informed decision-making.*
- 5.2 *The Department of Social Services and NDIA should both ensure those with cognitive disability or complex communication support needs are connected with capacity building support and other lifelong opportunities to build decision-making skills and experience.*
- 5.3 *The NDIA should include an assessment of participants' need for independent decision-making support as part of budget setting and ensure participants can use their NDIS budgets to access independent decision-making supports.*
- 5.4 *The Department of Social Services, the new National Disability Supports Quality and Safeguards Commission and NDIA should ensure decision-supporters have access to information, training and resources to assist them in providing best-practice support for decision-making.*
- 5.5 *The NDIA should reform the approach to appointing nominees, provide improved training and information to nominees, and increase oversight of nominee decisions.*

It is unclear how any of the actions in this recommendation have been given effect by the Bill, although we do note that:

- Section 10 is not accessible information; and
- The reliance on “impairments that meet the disability requirements” has a significant impact on whether the NDIA even records cognitive impairment. If a participant is blind, has a physical disability and has a cognitive impairment, who is to say how the NDIA will record this? If the person’s primary disability is listed as vision impairment, how will they be identified as having a cognitive disability that is connected to the capacity building support under 5.2?
- The assessment process (discussed below) does not consider the need for independent decision making supports as envisaged at 5.3, despite there being a significant risk of being removed from the Scheme (as discussed below) for this population.

At this point, it is clear we should not take seriously the statement about what the Bill achieves in terms of NDIS Review recommendations.

**IMPLEMENTING REFORMS TO ENSURE PARTICIPANTS EXPERIENCE A SMOOTH TRANSITION**

By far the biggest immediate risk to participants in the Bill is the expansion of revocation powers, linked closely to requests for information. Within these provisions, there are clear assumptions that:

- The NDIA will only ask for relevant information that it needs to make a relevant decision; and
- The NDIA will communicate clearly with the participant, and in a way that supports the participant’s understanding and involvement in any process affecting their rights; and
- The NDIA will comply with their own obligations.

These are extraordinary assumptions, given the current extraordinary delays within the NDIA, and their poor track record of process change and communication with participants and prospective participants.

**Case Study 1: The Agency will only ask for relevant information that it needs to make relevant decisions**

Our client applied for NDIS Access on 14 October 2022. Following rejection of the application and internal review, an application to the AAT was made on 31 December 2022.

On 17 March 2023 the NDIA Technical Advisory Team stated that our client met the eligibility requirements. This was not shared with our client, or us as his representatives, until May 2024.

For 16 months this matter had been conferenced at the AAT, and a great deal of time and effort expended in preparing it for hearing, when the NDIA had formed a view that should have resolved the matter. The client experienced great stress and intrusion. The NDIA continued to insist that further evidence was required in the form of independent medical examination and further questions to be answered by their medical professionals. Meanwhile the client was required to attend alternative dispute resolution through the AAT, which they found overwhelming due to the condescending attitude of the NDIA representatives.

All of this was entirely unnecessary: the Agency did not need any further information and should never have subjected our client to this extraordinary ordeal.

### **Case Study 2: The NDIA will communicate clearly with the participant and comply with their own obligations**

In November 2023, advocates became aware of a sudden change in the process by which individuals seek to become a participant of the NDIS. Where applications had previously been submitted directly to the National Access Team (**NAT**), now they would be diverted to Local Area Co-ordinators (**LACs**) who would seek to divert people to “community connections” programs if they formed a view that the individual did not meet the access criteria. We were hearing stories of people believing their application had been declined, when in fact it had not even been made.

On 6 December 2023 Villamanta made an access request on behalf of a client, by email directly to the NAT in the same way we have done for over a hundred other clients.

On 20 December 2023 we followed this matter up and were told that it needed to be sent to the LAC. We stated that all the necessary materials had been provided and were advised the matter would be sent through to the NAT.

When the legislated 21 days had passed, we asked for an internal review of the deemed decision to refuse access. We were told this happens automatically. Throughout January, we were told repeatedly that it was sitting with the NAT and no decision had been made.

On 8 February 2024 we made a complaint to the NDIA about the failure to respond.

On 14 February 2024 the question was asked in [Senate Estimates](#), with CEO Rebecca Falkingham stating:

*Ms Falkingham: We will take it on notice and we will put out communications to all of our partners to say it is not a requirement for access and remind people how the access process works. As you know, those plans have been in place for a long time for people to participate in those if they would like. **There's been no change at all from the agency, so we will try and understand why that was happening in those instances and I'm very happy if you want to provide me the Victorian details so we will follow up. But I think it's a good call out and we will get out communications to all of our partners.***

*Senator STEELE-JOHN: What work have you done to identify exactly how the partners in community ended up with the impression that you were not able to apply for the NDIS until you'd gone through this process?*

*Ms McKenzie: There have been a number of access issues we've been made aware of where the access process hasn't been working for people seeking access to the scheme, particularly for children and their families. So we've been undertaking over the last, particularly couple of months now, quite a detailed root cause analysis of understanding some component parts to that. The issue you've raised around community connection plans and the misconception that it's a requirement prior to access is one component of that. Also,*

*we've just been wanting to understand, across that experience, what the kind of causes might be. As you're aware, 30 October was the commencement date for the national expansion of our new computer system—PACE. I don't want to underestimate the significance of the change process that's happened around that. Partners and our staff and participants and providers are learning to transition to this new system and that's a significant change process. **I think the misconception has arisen as a result of those change pieces. We're still in a hypercare period at the moment and will be for some time, and one of the things we're doing in that is trying to understand what has happened. We'll continue to improve communications and improve change resources to make sure that we are simplifying things where we can in our advice and guidance to staff and our partners, particularly, as well as addressing issues in the system if they're occurring, so it's an ongoing process of continually improving that experience.***<sup>7</sup> (emphasis added)

On 28 February 2024 we were still trying to determine the state of our access request, and the NDIA would not even speak to us about the matter, stating they did not have the client's consent. We escalated a complaint to the head of the contact centre. On 29 February we received an apology for the confusion the day before and were told the matter is with the right person and there is no outcome yet.

On 14 March 2024 we were told there was no pending access request and that the process was to refer this to a LAC. We again stated there was no need for this as the application had been completed and was awaiting a decision. We were told there is no choice, this is the policy, and it must be actioned this way.

On 15 March 2024 we received an email about arranging a meeting with the client, and when we asked what this is about, we were advised that our client must attend a 1-2 hour meeting for information-gathering purposes, confirming their diagnoses meet the NDIS criteria and creating goals. We asked for an explanation of why goals were being discussed pre-access, rather than at a planning meeting. The NDIA responded that the purpose was to identify non-NDIS supports that could assist if NDIS was not successful or appropriate. They stated that this change was implemented in November 2023.

We again pushed back, stating that we had provided all the materials and were seeking a decision, not a diversion by a LAC; also our client does not have the ability to engage in such a discussion.

On 18 March 2024 we were advised by the LAC that the matter was to be sent back to the Agency for a decision.

On 20 March 2024 we sent a formal complaint to Corri McKenzie and Rebecca Falkingham about this matter.

On 8 April 2024 we finally had contact from the NAT who noted the materials had been loaded onto the system multiple times, and it was not clear why this had taken so long. They now needed identification documents in order to proceed, a new requirement that had not been communicated to us.

On 19 April 2024 we were advised our client had not met access criteria because they were over 65 years of age. They turned 65 in February.

We have not received a response to our complaints.

In summary, the NDIA claimed there was no change in their process, but changed the process. They did not communicate what individuals needed to do, and there were significant delays with the potential for very real detriment to participants. There were clearly issues with their document management, with some staff stating documents did not exist on the system, and others saying they were there in multiple locations. The communication was non-existent, with concerted advocacy required to continue

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<sup>7</sup> Page 54

following this matter up, and even so, the initial decision was that the administrative failures of the Agency would prevent access to the NDIS for this individual.

We did seek an internal review, and the individual is now a participant, but this level of advocacy is not available to everybody who experiences these types of barriers from the NDIA.

If the organisational effectiveness we have been experiencing is assumed while reading the Bill, the focus on information and revocation powers is alarming, and the potential for this to go horribly wrong for participants is clear.

We turn now to the details of the Bill itself.

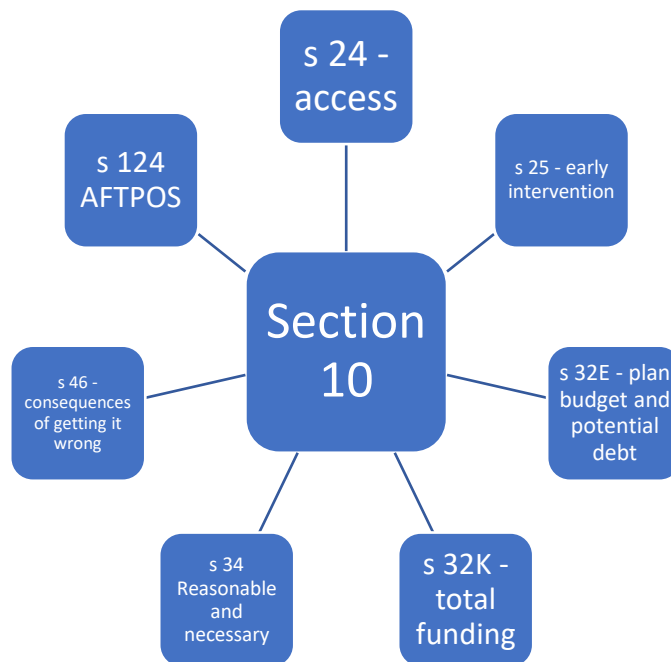
## Section 10 and “NDIS Supports”

Section 10 is like changing the recipe for BBQ Shapes.

Nobody asked for it, nobody wants it, and it doesn't achieve anything useful.

Section 10, as proposed by the Bill, defines what is an “NDIS support”.

The references to constitutionality, as imported by the CRPD segments and reference to “sickness benefits”, suggest that the main purpose of this section is to delineate state and Commonwealth responsibilities.



It fails to do that effectively, but then it goes on to cause problems in other areas of the Act

- It is imported into the access decision, limiting access to those who will need NDIS supports, rather than just support;
- It is imported into sections on funding to threaten participants with debts if they don't spend their funding according to this definition; and
- It effectively overrides the s 34 reasonable and necessary criteria

The missing detail is to be provided in the Rules, which do not yet exist. Meanwhile, APTOS is brought into the Bill to fill the gaps.

In our view, this is entirely unnecessary, as the current wording of s 34 of the NDIS Act allows for the exclusion of supports that are the responsibility of other systems.

A proper co-design process to begin with APTOS and carefully define the federal/state responsibilities could occur alongside the development and implementation of the Foundational supports envisaged by the NDIS Review and a key component of their recommendations.

The importance of co-design is underscored by the clumsiness of this section. What are the difficult federal/state questions to be answered? What challenges with these interactions have been experienced in the past ten years of the Scheme that need to be resolved? How have participants been negatively impacted by the gaps left between federal and state systems and what can we learn from



that? These issues cannot be resolved by legislation until the work has been done to co-design the solutions.

Then there is the messaging to participants. The [Explanatory Memorandum](#) contains this unhelpful commentary:

*“things such as holidays, groceries, payment of utility bills, online gambling, perfume, cosmetics, standard household appliances and whitegoods will not qualify as NDIS supports.”*

Besides the patronising statement that conflates everyday expenses with online gambling, the statement about household appliances and whitegoods is misleading and problematic.

There are circumstances where the assistive technology solution to a problem is more easily sourced, and more cost effective, by relying on standard household items. Insisting that these solutions be sourced from disability specific sources returns us to the stigma and over-pricing of hospital style homewares and devices, and equipment that costs a lot more.

The participant experience in relation to threats of being required to return funding to the NDIS is unpleasant and distressing. While not universal, there certainly have been a proportion of participants who have had planners, LACs, plan managers and support co-ordinators give misleading information about what is an appropriate use of funding, and what the potential consequences are of getting this wrong.

The inclusion of a confusing definition, and multiple linkages to threats of potential debts to the Agency, is not in any way consistent with the NDIS Review recommendations about support for participants to understand how they might use their funding. It certainly is not consistent with a trust-based approach to oversight of spending with a focus on providing guidance and support.

Finally, the interpretation of this section will impact participants at the point of a decision by a delegate. Given the inconsistency we have seen in these decisions, and the bizarre and random statements included in decision letters, it is anyone’s guess what they would read into this section and how they would use it in their decision making.

For example, the definition stipulates that the support “needs to be necessary to prevent segregation and isolation.” If interpreted narrowly, this has the potential to have significant implications for participants.

### **Case Study**

John lives in a group home with 4 other residents. He has experienced violence in the group home and as a result doesn’t participate in activities with other residents. He mostly stays in his room and his only time to engage in activities is when he has 1:1 support to leave the house.

It is not difficult to imagine a delegate coming to the conclusion that John is not isolated or segregated because he lives with others, but in reality he is afraid to leave his own room and the removal of 1:1 supports would have a profound effect on his mental and physical health.



## Changes to access

The Bill proposes three main changes to the access decision:

- A requirement to make and communicate a distinct decision about whether the person meets the disability requirements, or the early intervention requirements, or both.
- A significant expansion of the Rule making powers in relation to the decision-making processes involved in an access decision.
- A requirement that the supports the person needs come under the definition of “NDIS supports.”

### **DISABILITY AND EARLY INTERVENTION**

Clarity around the access decision being made is useful, but we do not see it is a critical change that could not be implemented by the Agency without legislative amendment. In our view a better process would be the co-design development of draft Rules that demonstrate the need for the broader powers proposed in the Bill.

### **NDIS SUPPORTS**

As noted above, section 10 is extremely problematic, and that then flows through into the access decision.

The NDIS Act presently states that in order to be granted access, the individual must satisfy the requirement that they will likely require support under the NDIS for their lifetime. There is no requirement for the individual to specify the exact supports they would seek under the NDIS, nor address the reasonable and necessary criteria for such supports. These matters are addressed at the planning stage if the individual meets NDIS access.

The change which the Bill makes to the wording in section 24(1)(e) and section 25(1)(d) which imports the section 10 definition of “NDIS supports”, puts the obligation on the person making the application to understand the meaning of “NDIS supports” and how it would apply to an individual. This creates another barrier for individuals seeking access.

We have seen many supporting evidence forms from treating practitioners that reflect a lack of knowledge of the information the NDIA needs when assessing an access application. We have received forms from General Practitioners who, despite verbally communicating that their patient desperately requires NDIS supports, state on the form that the disability may not be permanent or that the functional impact was that the person could “use some help with gardening”. There is also a common reluctance from health professionals to complete NDIS-related forms as the language is foreign to the medical concepts they know, and the level of everyday functional capacity the NDIA asks for is outside of their knowledge of the patient.

The Bill would result in the necessity for each health professional to understand the disability requirements of s 24, early intervention requirements of section 25, and the definition of NDIS supports under section 10. Only the professionals whose core business is in supporting NDIS participants, such as occupational therapists, would be likely to understand the term “NDIS supports”. However, a detailed functional assessment with an experienced occupational therapist is often only available if individuals can privately fund, and can cost over \$2,000.

This change also affects the potential for revocation, which we discuss in the next section.

## Revocation – the risk to participants

There are four reasons we see considerable risk to participants in relation to revocation and plan suspension.

- There are still too many participants whose only contact with others is through paid supports.
- The NDIA repeatedly does not make their communication accessible to participants and does not make it easy for participants to communicate with the NDIA.
- The NDIA does not have reliable information management.
- There is no requirement for this process to be proactively case managed.

### **ISOLATED AND UNEMPOWERED**

The participants we consider to be at high risk in relation to the proposed changes are not living with friends or family<sup>8</sup>. Despite being on the NDIS, the work has not been done to connect them to their communities and they don't have people in their lives aside from paid supports. If those cease, they have nobody. These are people who are just getting by, and even small changes in their environment can be extremely destabilising.

Or they are people who are already destabilised; they are homeless, detained, hospitalised or receiving compulsory treatment.

Then there are the participants who are actively being exploited for their NDIS funding in settings such as the so-called "SIL houses" and in some supported residential services. As soon as the funding ceases, these individuals are guaranteed to lose all supports.

Lastly, there are those who cannot understand the written communications of the NDIA for various reasons.

The NDIA has demonstrated they do not have a relationship with participants to the effect that they could possibly identify any risks associated with:

- An unexpected request for information;
- A demand that this information is provided within a specific timeframe;
- A threat of negative consequences if they do not; and
- No personal interaction to assist the person to understand how to respond to this change.

### **INFORMATION REQUESTS**

The Bill empowers NDIA to request any "information" from any person, as long as the NDIA believes it is reasonably necessary to make a decision regarding whether or not to revoke participant status. If participants do not provide the requested information within 90 days, the NDIA may revoke the participant's status.

This all sounds reasonable from a legal perspective: a request is made, the participant has time to respond, and they can discuss their circumstances if there are challenges with complying with the request.

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<sup>8</sup> This is not intended to suggest there is no risk for other participants. We are describing the participants that we have seen become destabilised when change happens unexpectedly.

In practice, our experience tells us that any such request has a high probability of being made without any regard for the communication needs of the participant.

### **Case study**

Villamanta assisted a client to access the NDIS, and as a result were contacted to arrange the planning meeting. We advised that our involvement had ended, but explained the communication needs of the client, who has a cognitive impairment. This included simple requests like confirming things in writing.

The LAC replied that this is not a service they can offer.

We have had numerous reports of the NDIA failing to acknowledge the communication needs of participants, for example:

- Calling D/deaf participants on the phone and leaving a voicemail;
- Sending hard copy letters to blind participants when they have been asked to communicate by email;
- Calling participants who have experienced violence and trauma from a private number without first texting as requested;
- Refusing to meet in person despite advice that the participant will only appear to understand a phone conversation, even though they do not;
- Calling participants without notice, despite having been informed they need to have support to understand the conversation (such as translators or other supports); and
- Requiring all participants to access their contact centre by telephone, despite this being inaccessible for many.

While the NDIS Review recommended the NDIA ensure participants receive accessible information and tailored advice to inform decision-making, the Bill does not in any way ensure that this occurs. In fact, the default “written notice” is generally the least accessible form of information – a hard copy letter sent by post.

Where the NDIA previously had contacts available for funded disability advocates to escalate issues where participants were at risk, these escalation points have now been ceased. In situations where a nominee was no longer available, or other communication channels had been disrupted, this formed a useful safeguard for participant. Communication with the Agency has become more difficult in the past 12 months.

Likewise, it will likely be impossible for the participant to speak to anybody who can help them comply with the request. When our clients have had these types of requests, they have found that:

- The request itself is broad and does not clearly specify what is required;
- They are not provided with a specific contact, and the contact centre only know what is contained in the letter;
- While they can ask for an extension from the contact centre (if they are able or supported to do so), this does not actually help if they still don’t know what they are being asked to do;
- There is no assistance or clarification available from the NDIA in order to comply with the request; and/or
- The participant is experiencing a highly anxious state, given the threatened removal of all supports if they do not comply with the request.

## **INFORMATION MANAGEMENT**

We do not have confidence that the information management systems of the NDIA are fit for purpose, given our ongoing experience of:

- Materials sent by email not being available to some NDIA staff;
- Materials held by the NDIA not being shared or disclosed even when they are directly relevant to the issue at hand;
- Materials not being sent to the team who are responsible for the decision to be made; and
- The ongoing issue of materials provided at the AAT not being available to the planners and delegates making decisions post-AAT decision.

In our view there is a very real risk that participants will be asked for information the NDIA already has or will provide information that does not find its way to the person making the decision.

Likewise, if information has been provided to the NDIA during the course of an AAT review, and it is directly relevant to the question at hand, it will not be available to the decision-maker considering revocation.

All of which is not apparent to the participant, whose only option is to call the contact centre (if they can) and try to discuss the situation. As noted above, this is a fairly hit and miss endeavour, and unlikely to actually resolve the matter.

## **ABSENCE OF CASE MANAGEMENT**

All of these factors enhance the likelihood of certain participants having their access to the scheme revoked inappropriately and without notice.

This is the worst possible way for a person to exit the scheme and leaves them at risk, as discussed below.

Any increased powers given to the NDIA to request information that will be used to consider revocation must be accompanied by positive obligations to ensure the participant is appropriately supported to engage with such a process. There must be active case management to ensure there is a nominated contact who can take responsibility for ensuring the participant has been appropriately supported to understand and comply with the request.

Someone must have actually been in real communication with the person, and have an understanding of their current situation. Sending a letter to a participant who is on remand, and then revoking their access 90days later, is not an appropriate or fair process.

Section 30 was previously a reviewable decision in its entirety. Now it is reviewable only to the extent of the revocation decisions. The information requests are not reviewable. This means the CEO can ask for entirely irrelevant or inappropriate information, and the participant has no recourse until their access is revoked.

There is a significant level of distrust with the NDIA's information gathering history. In our experience of the conduct of the NDIA at the AAT, there has been a practice of violating participants' right to privacy with no proper basis. We see the NDIA ardently pressing that without turning over every stone, they could never be satisfied that there was no further information. As described above, this intrusion has occurred even when the NDIA had access to their own determination that the matter was resolved and no further information was necessary.

The scope of the NDIA's information gathering powers should be clearly stated, including an explanation as to what could be considered "reasonably necessary" to make revocation decisions. A participant's right to a review of any information request must be available, not just a right to review when revocation has already occurred and supports have therefore ceased.

We note the very low rate of NDIA decisions being upheld at the AAT and the 18% acceptance rate in the context of the Independent Expert Review Pilot for AAT appeals in 2023<sup>9</sup>. Bad decisions are made, and they can have negative consequences. Revocation of access is a high-risk decision due to the consequential loss of supports and must be handled carefully.

### **WHAT DOES THAT LOOK LIKE TO A PARTICIPANT?**

To a participant, this likely looks like a downward spiral they have no way of stopping.

Below are scenarios that are foreseeable based on our experience with NDIS participants.

#### **Something changed**

Petro lives with his mum. She helps him with his paperwork and organising things. He has some NDIS support in the home, and some community access. He goes to a group activity twice a week, and occasionally has a trip away with the provider that runs the group activities.

His mum has a fall and needs to have surgery. She is in hospital for a while, and then the doctors tell Petro she can't come home and needs to go to aged care. She doesn't want to do this, and Petro thinks that means she will come home. She doesn't.

Petro doesn't know that just before her accident, his mum had received a letter from the NDIA asking for information about Petro's disability. It hasn't been replied to, and the only phone number on record is the home phone. It is unclear whether they called, but Petro has been at the hospital, aged care, or his activities.

The first thing Petro knows about the process that is occurring is when there is no prepared food in the house. He can't remember what day it is, because he normally knows it by which support worker comes to the house. They haven't been coming. He hasn't been to his group activities because he hasn't had support to organise himself, and he has no clean clothes. His medications are running low, so he has started taking them every second day. He doesn't know what to do.

Any number of things could go horribly wrong for Petro if he doesn't find someone to help; he tries to cook by himself, which he has never done before, and has no safety skills about knives or fire. He has a medical episode because of the reduction in medication, and does not recognise the need to call an ambulance or he attempts to navigate the community but becomes overwhelmed and runs into traffic.

#### **It's all about the money**

Sarah was living in a supported residential service (**SRS**). It was not very nice, but better than the one she was in before.

One day she is at the shops and the proprietor of her former SRS approaches her and tells her he has set up a new place. It's a new house, has lots of space and a big TV. The residents go out on fun activities and they have pizza for dinner. Sarah agrees to go take a look, and the proprietor takes her there by car, saying he will pick up her things from the other SRS.

At first it is really good: she has a lot more support, and she gets to go to new places and do fun things. She has signed some forms she didn't understand, but it means she can have 1:1 support organised by the SRS.

Meanwhile the NDIA has written to her and asked for information. They called her mobile number, but that was disconnected when she got a new phone from the SRS owner. They sent a letter to the old SRS, but that was thrown in the bin.

The first Sarah knows about any of this is when the SRS owner tells her she owes him \$15,000 and she needs to move out. Her NDIS access was revoked and her plan ended, and by the time the plan

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<sup>9</sup> Independent Expert Review (IER) evaluation report October 2023.

manager stopped paying invoices, \$15,000 worth of services had been provided without funding to pay for them. He says if she doesn't leave, he will call the police and have her arrested.

Sarah has nowhere to go and no money. She has no idea what to do and her mental health declines rapidly. An underlying medical condition begins to flare up. It is treatable but needs medical attention. She is afraid to ask for help because she believes the police will be called.

### **Tried to comply**

Geoff lives independently and he's very proud of that. His family expected him to live in a group home, or move into aged care with his mother, but he did not want to. With NDIS supports, he can live in the community and live a life based on his own choices and preferences.

He receives a letter asking for more information. His support worker reads it to him and helps him call the NDIA to ask for help.

They explain what they need, and with his support worker's help, he explains he already did that last year when he was at the AAT. His doctor wrote a letter, and he gave it to them. That doctor has retired now and he has a new one, but that doesn't matter because they already have the letter.

Geoff forgets all about the letter because he has explained to them. Ninety days later, he gets a letter saying they are revoking his access.

Geoff holds onto the letter, waiting for his support worker to come and help him again. He doesn't understand the letter and can't call the contact centre by himself.

The support worker doesn't come.

Geoff goes to his neighbour, who explains that he doesn't have NDIS anymore. He doesn't know what to do about that, but he knows the disability advocates who helped him at the AAT. So his neighbour helps him call them.

The advocates help him seek an internal review of the revocation.

Meanwhile Geoff is trying to manage without supports. He is too embarrassed to tell his family what has happened because they will tell him he should be in a group home, so he tries to manage by himself. One night he slips in the shower and falls. He is unable to get up.

Nobody comes the next day, so nobody knows he has fallen. Nobody calls for help.

### **WHAT NEEDS TO CHANGE**

The reasons for revocation must be included in the legislation and not delegated to the Rules.

The Rules must include safeguards and appropriate measures to be taken including risk assessment, actual engagement with the participant, ensuring access to advocacy and decision-making supports as appropriate, and confirmation that alternative supports are engaged.

## Assessment tool and funding amount

This is the NDIS equivalent of Robo-debt.

While we haven't seen what is proposed because it apparently has not been developed yet, and will be co-designed, we do know the following:

- The Bill focuses on people having a single impairment
- The Bill includes numerous mentions of “classes” of participants
- The Agency already relies on primary impairment to create the Typical Support Package
- There is no mention of the information to be provided to the assessor
- There is no mention of the involvement of the participant in the assessment
- There is no mention of the participant having access to a copy of the assessment
- There is provision for the Agency to request a replacement assessment, but not the participant

Collectively, this raises the very real possibility that the intended assessment is simply using the category of disability recorded in the Agency's database (assigned by the Agency at access, but never disclosed to the participant), entering it into a formula, and generating the funding budget.

While our observations suggest this is likely already happening, there are key differences between current practice and the proposal suggested by the Bill:

- The reviewable decision is currently based on whether supports are “reasonable and necessary”. Under the Bill, it would be whether the legislative instruments have been followed in applying the assessment to calculate the budget.
- The reasonable and necessary criteria require a human being to make a decision. The use of an assessment tool automating the process does not.
- The AAT would be unable to consider and review the merits of such a decision.

We recognise the efficacy and time saving of tools, formulas and algorithms. However administrative decision making must also ensure there is actually a decision being made. It cannot outsource the decision to a tool, no matter how good that tool is.

We haven't seen the tool, so we don't know whether it works. We don't know who it works for, and who it doesn't work for.

We don't know who is going to experience very adverse outcomes from the tool with no recourse to appeal rights.

It is premature to seek to enact Agency practice into the legislation without having engaged in the promised co-design work that ensures this is done properly and the outcomes are safe and can be relied upon. Any reliance on a tool must also include the discretion for a delegate to vary the outcome if it is not appropriate in the circumstances. There must be an actual decision being made which can in turn be reviewed or appealed.

## New framework plans

We support the removal of funding categories and replacement with an overall budget, providing the kind of flexibility proposed by the NDIS Review.

In a move only a non-participant could contemplate, the flexibility is then undermined by overly complex arrangements around total funding, funding periods, stated and flexible supports.

What results is the possibility of flexibility, but the potential for delegates to create such complex and limited plans that participants have effectively no choice at all. There is no mention of participant input.

There is also the potential for the Agency to complete standard plans for classes of participants; without Rules around when and how this is allowable this could be used in highly problematic ways.

This entire section should be co-designed before any attempt at enacting legislation around it. Only someone who has seen what an NDIS delegate on a mission to limit the choice and control of a participant can do to a plan can explain where the risks lie in this space.

The Agency has used “Stated Supports” almost since the Scheme’s inception, so the absence of draft Rules around this is troubling. There must be limits on how a delegate can undermine the flexibility intended.

### **OTHER FACTORS**

#### **Section 10 strikes again**

While the total budget approach is in line with the recommendation of the NDIS Review, the insertion of s 10, and the requirement to spend funding accordingly, arguably pushes a significant responsibility onto the participant to know what will be considered appropriate use of funding, and how to use the overall budget to meet their specific needs.

Coupled with the potential complexity of plans, with different funding types (flexible and stated), different durations (funding periods for flexible and funding periods for stated) and the bewildering section 10 requirements, there is likely to be extreme uncertainty about how participants can actually use their funding without negative consequences.



## The obligations of participants

Overall, the Bill paves the way for significant changes to the way the NDIS works but provides detail only in relation to the obligations of participants. The Bill proposes a range of powers for the CEO which are hazy and reliant on non-existent Rules. The participant however is now subject to more requirements than ever to comply with, and a more direct line to negative consequences of failing to understand and comply.

The outcomes of the NDIS Review that would benefit participants, such as flexible funding and longer plans, are not available because the work is yet to be done.

The only thing the Bill does, if enacted now, is open the door for punitive action to be taken against participants who were unable to comply with the demands of the Agency, whether or not they even knew about them.

The Bill contains 17 new references to Section 46, which deals with how funding has been spent. The combination of the new definition of NDIS supports and the focus on how funding has been spent (or will be spent) is inconsistent with the NDIS Review recommendation that they “should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support.”

As above, the interpretation of the proposed section 10 and definition of “NDIS Supports” is fraught. It can be guaranteed that participants, support coordinators, plan managers and NDIA planners will come to different interpretations of what can be considered an NDIS Support.

Note: The following case study uses scenarios we are familiar with and suggests likely outcomes under the proposed changes to the legislation.

### **Case study**

*Tony is an NDIS participant who is being evicted from his home. Tony’s NDIS support coordinator said that he could use some of his flexible NDIS funding for removalists.*

*The support coordinator engaged ABC Company, who say on their website that they are a registered NDIS provider. The support coordinator signed the service agreement, and ABC directly invoiced the support coordinator who passed it into the plan manager who paid without question.*

*After payment, Tony was told that ABC had invoiced almost double the quoted amount and charged for support work, on top of the removalist charges. Tony now has very little funding to last for the next six months of his plan.*

*His support co-ordinator submits a change of circumstances to the NDIA, and a month later he is contacted by the NDIA who say they are raising a debt. They say that removals is not an “NDIS Support” and that he will need to refund the money paid.*

*Tony is overwhelmed at this news. Tony relies on a Disability Support Pension and has no savings to repay such a debt.*

*They also suggest that his plan will be reviewed and his funding will now be Agency Managed. This means that Tony’s independent support workers who know him and have worked with him for years would be ceased, because they’re not NDIS registered.*

*Worse, his plan could be suspended, resulting in him being abruptly cut off from all NDIS supports, which includes support workers for daily living, community access and capacity building supports including his psychologist. Without any support, Tony’s mental health would dramatically decline and he would have no support to link him with people who may be able to work through the situation. Tony’s situation could quickly snowball into very poor outcomes.*

Entirely replacing the current NDIS Supports regime, while also introducing harsh consequences for participants if they, or their paid NDIS supports, get it wrong, is going to create unsafe situations for

participants. Further, adding further levels of bureaucracy to NDIS processes will only compound the significant backlog and delays across the NDIA.

There will be genuine mistakes and misunderstandings about how NDIS funding can be used. There must be a requirement in the Bill for the NDIA to proactively support the participant to build their capacity to understand the identified misuse and how that can be avoided in the future.