

Submission to NDIS consultations:

Access and Eligibility Policy

Planning Policy

February 2021

About the Public Interest Advocacy Centre

The Public Interest Advocacy Centre (PIAC) is an independent, non-profit legal centre based in Sydney.

Established in 1982, PIAC tackles barriers to justice and fairness experienced by people who are vulnerable or facing disadvantage. We ensure basic rights are enjoyed across the community through legal assistance and strategic litigation, public policy development, communication and training.

Our work addresses issues such as:

- Reducing homelessness, through the Homeless Persons' Legal Service
- Access for people with disability to basic services like public transport, financial services, media and digital technologies
- Justice for Aboriginal and Torres Strait Islander people
- Access to affordable energy and water (the Energy and Water Consumers Advocacy Program)
- Fair use of police powers
- Rights of people in detention, including equal access to health care for asylum seekers (the Asylum Seeker Health Rights Project)
- Transitional justice
- Government accountability.

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1. Introduction

The Public Interest Advocacy Centre (**PIAC**) welcomes the opportunity to make this submission to the National Disability Insurance Agency's (**NDIA**) consultations into proposed changes to the NDIS. This submission addresses two consultation papers: the *Access and Eligibility Policy with independent assessments* paper (**Access Paper**) and the *Planning Policy for Personalised Budgets and Plan Flexibility* (**Planning Paper**).

PIAC has been involved in a number of consultations, both privately and publicly, with the NDIA and NDIS-related reviews, including in inquiries run by the Parliamentary Joint Standing Committee on the NDIS, the Australian National Audit Office and the Tune Review process. In each of these contributions, PIAC has consistently raised concerns regarding the lack of transparency and accountability in the NDIS, and issues concerning consistency around decision-making.

We are pleased to see the NDIA acknowledge, in both the Access Paper and Planning Paper, the issues raised concerning inconsistency and the need to work towards a future NDIS that is 'simpler and fairer'.

However, PIAC is concerned by the approach proposed by the NDIA. These concerns again relate to transparency, accountability and decision-making in the proposed reforms.

Respectfully, in our view, the proposed reforms do not address these issues that have been repeatedly raised and which have been the subject of recommendations by various inquiry bodies. Instead, there is a real risk that these proposed reforms may introduce further transparency, accountability and governance issues.

Our submission is set out in two parts, with a section addressing each of the Access Paper and the Planning Paper. Both sections provide our general feedback, before responding to selected questions posed by those Papers.

2. Access Paper

2.1 General comments

2.1.1 Independent assessments should not be mandatory

An overarching issue with the proposed reforms is that, while they seek to address the issue of inconsistent decision-making and inequitable access and planning decisions, the proposed solution of mandatory independent assessments will not resolve – and may entrench – those issues.

It is concerning that the NDIA has not consulted adequately with the disability sector ahead of the implementation of independent assessments. The consultation questions in the Access Paper do

not ask *whether* independent assessments should be implemented or mandatory, but are directed only at *how* mandatory independent assessments should be implemented.

To this end, we note the letter to the Minister dated 11 September 2020, endorsed by a number of Disabled Persons Organisations and Disability Representative Organisations, raising concerns about the lack of genuine and meaningful consultations, and the mandatory nature of independent assessments. We echo those concerns and emphasise the need for the NDIA to facilitate genuine consultations and co-design any independent assessment process with people with disability.

Notwithstanding our position that mandatory independent assessments should not go ahead, our submission nevertheless addresses the questions around implementation to minimise the harm that such an approach may cause if implemented.

2.1.2 Independent assessments and delegate's decision

We note that the Access Paper states the independent assessment will be used by delegates to 'determine where a person's functional capacity lies on a continuum in relation to the wider Australian population. This helps us understand if a person's support needs are best provided by the NDIS or other mainstream systems of support, such as the health system'.¹

This statement does not appear to be consistent with the access criteria under ss 21 and 24 of the NDIS Act. There is no requirement under the Act that a person's support needs are best provided by the NDIS before they are able to access the NDIS, or for their functional capacity to be compared against the wider Australian population. Decisions concerning whether a person's needs are best provided by the NDIS or another system are relevant only when considering early intervention (s 25(3)) and in relation to determining reasonable and necessary supports (s 34(1)(f)). If the Access Paper is suggesting that a further criterion be added to the existing access criteria, this must be clarified and an opportunity must be provided for the disability community to be consulted.

2.1.3 Reviews of independent assessments

Decisions on exemptions

The Access Paper makes clear that a decision not to grant an exemption for an independent assessment will not be a reviewable decision.

The refusal of an exemption is a significant decision, given that an applicant will be deemed to have withdrawn their access request if they do not complete the independent assessment in the absence of an exemption.² In effect, a refusal to grant an exemption may be a final decision that prevents access to the NDIS, if a person feels genuinely unable to undergo an independent assessment.

² Access Paper, 21.

¹ Access Paper, 22.

No explanation is provided as to why these decisions should not be reviewable. The Access Paper acknowledges that circumstances which should give rise to exemptions are 'exceptional' in nature, and that individual circumstances need to be recognised.³ It also considers that exemptions may be granted where 'the process is likely to do more harm than benefit to the individual, and may pose a safety risk', or where there may be concerns about validity of the assessment.

In PIAC's view, the fact that exemptions will come down to individual circumstances and discretionary judgments about risk, safety and validity, combined with the significant impact of a refusal to grant an exemption, means it is important that these exemption decisions be subject to a review process. To do otherwise will lead to inconsistent decisions about exemptions that will differ depending on the exercise of discretion by individual delegates.

While we understand the NDIA may be seeking to limit reviews to reduce administrative burden and delays, we consider reviews of exemption decisions must be available to ensure good public administration.

No review of assessment results

The absence of a review process for independent assessment results and the inability to request a second assessment (except in very limited circumstances)⁴ is problematic. The independent assessments are to be used to determine key criteria for a person's access to the NDIS, as well as for the purposes of determing their budget and plan. In practice, they will have a determinative impact on whether a person is able to access the NDIS and the size of their funding – while it is the delegates who make access and planning decisions, rather than assessors, it is not realistic that a participant with a negative independent assessment outcome would ever be granted access to the NDIS.

This assessment, fundamental to a person's access and funding, is to be determined over just three hours, by an assessor who has never previously met the person.

The significant impact of the independent assessment requires that a process for review be available. We consider an appropriate procedure may be to provide funding for a second independent assessment, to be conducted by another assessor, and/or to allow participants to source their own functional capacity assessment. The delegate would then have alternative materials to weigh and consider. This process would reduce the number of access and planning decisions being appealed purely on the basis of the underlying independent assessment and ensure that a single three-hour assessment does not become the determinative basis for a person's journey through the NDIS.

2.2 Specific questions

In this section we respond to some of the specific questions posed in the Access Paper.

³ Access Paper, 20-21.

Access Paper, 23.

2.2.1 Question 3: How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long?

PIAC welcomes the indication from the Access Paper that clearer guidance will be provided on what defines a permanent disability requiring support under the NDIS.⁵ We have previously expressed concerns around two issues in relation to the permanence criteria to other inquiries.

First, when it comes to people with psychosocial disabilities, there remains confusion around how decision-makers determine whether a person's impairment is 'permanent'. The Tune Review reported that the permanence criteria are creating particular challenges for people with psychosocial disabilities 'given the episodic and fluctuating nature of severe and persistent mental health issues'. It recommended amendments to the Act and Rules to provide clearer guidance for the NDIA on the criteria that should apply, and the evidence that should be provided, in considering whether a psychosocial impairment is permanent. PIAC supports this need for clearer guidance when it comes to psychosocial disabilities.

Second, the NDIA's current interpretation of 'permanence' is too restrictive. Paragraph 5.4 of the *NDIS (Becoming a Participant) Rules 2016* provides that an impairment is, or is likely to be, permanent 'only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment'. There is no definition or clarification of what it means for treatment to be 'available' and 'appropriate' under the Rules.

Instead, the definition of 'available' and 'appropriate' treatment is up to the NDIA's discretion, and has been very narrowly construed by the AAT. Of most concern is that the NDIA and AAT have considered treatment to be 'available' and 'appropriate' even where there is a risk to a person's health in undergoing that treatment. The AAT has said that treatment which might 'impose a serious risk to a person's health' is not required to be undertaken, but suggests that anything short of a 'serious risk' could be required – including surgery.⁸

In one case raised with PIAC by a stakeholder, 'Emma' was denied entry to the NDIS in part because her impairment was not permanent. The NDIA considered there was 'available and appropriate' treatment for the impairment, being brain surgery. Emma advised the NDIA that she had made an informed decision, based on specialists' advice, that surgery was not suitable for her. Despite this, the NDIA defended its decision. The NDIA stated in its internal review decision that, because Emma had 'declined surgery as an option', Emma did not meet the permanence requirements because 'all treatment options have not been explored'. The matter was ultimately settled and Emma was granted access to the NDIS, but only after a second neurosurgeon's report was provided to clearly state that surgery was not suitable. Emma was granted access to the NDIS some 1,120 days after her initial request for access.

Tune Review Report, 72. See also, Jennifer Smith-Merry et al, *Mind the Gap: The NDIS and psychosocial disability – Final Report: Stakeholder identified gaps* (Report, 2018).

8 Schwass and NDIA [2019] AATA 28.

⁵ Access Paper, 8.

Tune Review Report, Recommendation 8. At 75: this further and more specific clarification 'should align with emerging bodies of evidence and best practice mental health care approaches which emphasise the language of empowerment and capacity building, recovery and ability over that of disability, impairment and illness.'

PIAC considers that the definition of 'permanent' must be clarified. To require would-be participants to undergo treatment, including surgery, which may pose a risk to their health undermines the choice and control of people with disability and takes away their ability to make informed decisions about their life.

In contrast, the definition of permanence used for the assessment of eligibility for the Disability Support Pension (DSP) is much clearer. Under the DSP criteria, a condition will be recognised as being permanent if the condition has been 'fully diagnosed', 'fully treated', has 'fully stabilised', and is more likely than not to persist for more than 2 years. 9 In determining whether the condition has 'fully stabilised', reference is made to whether 'reasonable treatment' is possible. The DSP defines 'reasonable treatment' as treatment that: (a) is available at a location reasonably accessible to the person; (b) is at a reasonable cost; (c) can reliably be expected to result in a substantial improvement in functional capacity; (d) is regularly undertaken or performed; (e) has a high success rate; and (f) carries a low risk to the person.¹⁰

PIAC notes that some organisations have expressed concerns around the DSP criteria and have recommended amendments to them. However, while the DSP criteria remain operative, their definition of 'reasonable treatment' provides a useful baseline for what could be considered 'available and appropriate' treatment in applying paragraph 5.4 of the NDIS (Becoming a Participant) Rules 2016. It should not be the case that in order to access the NDIS, a person must be willing to accept treatments that carry a higher risk to their health as compared to the DSP.

In its General Issues report of December 2020, the Joint Standing Committee on the NDIS stated that it 'encourages the Government to consider whether the NDIS Act and Rules should also be amended to align the meaning of 'available and appropriate' treatment with the criteria which apply to the DSP'. 11 We consider this to be an opportune time to re-examine the permanence criteria.

2.2.2 Question 4: How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

We do not seek to address the specifics of how to make this distinction clearer. We acknowledge there are difficulties in clarifying the distinction between disability supports which should be provided by the NDIS, and other related supports which should be provided by health, or other support systems.

However, this question raises a broader issue concerning the interface between the NDIS and mainstream support systems. As the Tune Review has stated, the lack of clarity at an operational level about the lines of responsibility between the NDIS and mainstream service systems, 'result[s] in boundary issues and funding disputes, service gaps and confusion for NDIS participants, poor quality planning and inconsistent decisions about when a support is reasonable and necessary.'12

11 Joint Standing Committee on the NDIS, General Issues (Report, December 2020) [6.22]

Tune Review report, [6.26].

⁹ Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011 (Cth), s 6(4).

¹⁰ Ibid, s 6(7)(a)-(f).

While these interface issues are being clarified, NDIS participants should not carry the burden of navigating these gaps between the NDIS and mainstream support systems. The AAT considered this in *Burchell and NDIA* [2019] AATA 1256, where the Tribunal held that, for the NDIA to deny funding on the basis that the support is more appropriately funded by some other service delivery system, the support must *in fact* be provided by that other system. It is not for the NDIA to evaluate what supports *should* be provided by other service providers.

The principle established in *Burchell* however, has not been adopted by the NDIA more broadly. To remedy this issue, the Joint Standing Committee in its recent Planning Final Report made three recommendations addressing this issue: recommendations 11, 12, and 13.

PIAC supports these recommendations being adopted to ensure that participants do not fall through the interface gaps. These recommendations are reproduced in their entirety below.

Recommendation 11 of the Joint Standing Committee on the NDIS' Planning Final Report

The committee recommends that the National Disability Insurance Agency require planners to provide, in planning meetings, personalised material that outlines how the participant could access supports that the National Disability Insurance Scheme will not fund on the basis that the support is available in another service system.

Recommendation 12 of the Joint Standing Committee on the NDIS' Planning Final Report

The committee recommends that the Australian Government amend the National Disability Insurance Scheme Act 2013 to clarify that where the CEO of the National Disability Insurance Agency (or their delegate) considers that a support would be more appropriately funded or provided through another system of service delivery or support services, the CEO must be satisfied that this support is in fact available to the participant and that they are likely to be eligible and able to access it.

Recommendation 13 of the Joint Standing Committee on the NDIS' Planning Final Report

The committee recommends that where the CEO of the National Disability Insurance Agency (or their delegate) is satisfied that a support is more appropriately funded or provided by another system of service delivery or support services, the National Disability Insurance Agency be required to provide written reasons for this view (and also in an alternative format where appropriate).

2.2.3 Question 10: How should we provide the assessment results to the person applying for the NDIS?

The Access Paper indicates that only a 'summary of their independent assessment results and an explanation of the access decision' will be provided, along with guidance to help applicants understand the results.

It is not clear why an applicant should not be provided with their full independent assessment results. Provision of the full independent assessment would better fulfil the objects and general principles of the NDIS Act, including in enabling people with disability to exercise 'choice and

control' in the pursuit of their goals, to ensure people with disability have the same rights to pursue any grievance, and to determine their own best interests in decisions that will affect their lives.

Provision of the full independent assessment empowers applicants in a number of ways, including by:

- allowing the applicant to ensure the assessor has understood and considered all relevant issues:
- ensuring the applicant has all relevant information if they wish to appeal a decision to refuse access. Given the independent assessment forms a crucial part of the access process, and that access decisions are reviewable, it is important that applicants have the full assessment;
- allowing the applicant to have the benefit of the functional capacity assessment that has been conducted, to use as they wish, for instance to provide to other health care providers, service providers, or employers; and
- most importantly, giving applicants information which is about them. This in itself should be sufficient reason for providing the applicant with the full assessment report.

In any case, we note that applicants would likely have the right to access their full independent assessment under the *Privacy Act 1988* (Cth), given the information is personal information. The NDIA should simply provide applicants with their full assessment, rather than requiring them to go through another process.

3. Planning Paper

3.1 General comments

3.1.1 Total reasonable and necessary level of funding

Our overriding concern with the Planning Paper is the proposed shift from plans based on 'reasonable and necessary supports' to a 'total reasonable and necessary level of funding for each participant'.¹³

This proposed shift marks a significant and substantive change from how the NDIS Act currently operates, including as interpreted by the Federal Court. The Planning Paper provides little to no explanation as to how this change is proposed to be implemented and what this means from a practical and legal standpoint. In these circumstances, it is difficult to provide feedback on the substance of the change. Given the apparent significance of this change, the NDIA must publish further consultation papers to explain this proposed shift and allow for a period of consultation.

In particular, the proposed shift raises at least the following questions which are not addressed in the Planning Paper:

Planning Paper, 4.	13	Planning Paper, 4.	
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- Will the criteria set out at s 34 of the NDIS Act, concerning the determination of 'reasonable and necessary supports' remain in place, or will the criteria be replaced?
- If the s 34 criteria remain in place, how does this interact with the proposed shift to 'reasonable and necessary level of funding'? Does this mean participants will need to have each proposed support assessed under the existing criteria, and then for a further decision to be made that the total amount of funding is 'reasonable and necessary'? The Planning Paper appears to suggest this will not be the case, 14 but it is difficult to see how a funding figure can be arrived at without reference to what the funding is intended to cover.
- If the s 34 criteria is to be replaced, what will they be replaced by? How will 'total reasonable and necessary level of funding' be determined? This is a significant question that goes to governance, accountability and transparency of the NDIS. The Full Federal Court has observed the difficulties of determining the contents or limits of the phrase 'reasonable and necessary supports'. This will be all the more so if funding is determined not by reference to specific supports, but at a global level. The Planning Paper explains that the level of funding will be determined as follows:

The funding provided in a personalised budget will be informed by the participant's individual circumstances, such as their age and where they live, and their functional capacity, including any relevant environmental factors, such as available informal supports. The outcomes of the participant's independent assessment will inform their personalised budget.¹⁶

This does not provide sufficient information to explain how exactly a person's reasonable and necessary level of funding will be determined. For instance, we would be concerned if the reference to a participant's 'individual circumstances' were to include their income as a factor.

 How will participants know whether their funding package is suitable – or 'reasonable and necessary' – for them? A participant would still have to identify each support they require, in order to ascertain whether the total amount will cover their needs. The determination of a single figure of funding, untied to any particular support, will make it harder for participants to understand whether their funding is sufficient for their needs. The Planning Paper states:

The personalised budget, informed by the independent assessment, will mean that planning will no longer need to focus on the negotiation and agreement of each individual support.¹⁷

The change from discussing and agreeing each individual support with the participant, to determining funding based on an independent assessment, shifts choice and control away from participants and gives it to the independent assessor. The independent assessor should not be used to determine the supports that a participant chooses for themselves.

¹⁴ Planning Paper, 11.

National Disability Insurance Agency v WRMF [2020] FCAFC 79, [252].

Planning Paper, 11.

Planning Paper, 14.

Providing this information is all the more important given that the change in methodology for determining budgets will raise questions as to the relevance of existing judicial guidance on s 34.

PIAC continues to call for the publication of AAT settlement outcomes: a recommendation which has been adopted twice by the Joint Standing Committee on the NDIS.¹⁸ This publication will be all the more important in any shift to 'reasonable and necessary level of funding'. One of the aims of shifting to this new method is to address the 'inconsistent decision-making and high volume of reviews', where participants 'with similar levels of functional capacity and environments may have very different levels of funding.¹⁹ Transparency of settlement outcomes is the only way to ensure this does not continue to happen.

3.1.2 Draft budgets

The indication from the Planning Paper that the NDIA will provide draft budgets and plans to the participant is welcome. However, the Paper then goes on to state the limited circumstances in which a draft budget will be changed, being only where a participant has 'extensive and/or complex support needs' or where there are 'additional high-cost supports required that are not accounted for in the independent assessment'.²⁰

This defeats the purpose of having a draft budget.

The Joint Standing Committee, in its Planning report, set out why it recommended draft budgets and plans be provided to participants:

The recent announcement that draft plans will include budgets, with participants able to use most funds flexibly, is especially welcome.

While these reforms are needed, the committee reiterates its recommendation that participants be given a copy of fully-costed plans at least a week before a joint planning meeting so that they are able to consult with experts and reflect before the decision is made. As outlined in Chapter 6 of this report, the committee was informed that in many instances planners may be funding different supports to what experts have recommended in reports. Providing participants with fully costed plans a week before a joint planning meeting would allow participants, their families, carers or nominees the opportunity to ask the experts who made these recommendations whether these revised or new supports would be appropriate for the participant, given their individual circumstances.²¹

While it may be appropriate to provide examples of when a draft budget or plan may need to be amended, the default position should *not* be that changes are only made in those specific circumstances.

Participants should be given an opportunity to discuss their draft budgets and plans with the delegate, to ensure the final budget and plan is suitable and appropriate. The planning meeting with the delegate should not simply be a discussion about how to use an already-decided budget.

²⁰ Planning Paper, 13.

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Joint Standing Committee on the NDIS, *Planning* (Final Report, December 2020), Recommendations 34 and 35; Joint Standing Committee on the NDIS, *Planning* (Interim Report, December 2019), Recommendation 6.

Planning Paper, 5.

²¹ Planning Final Report, [2.96].

This will help ensure that the participant is being provided the right level of funding, and that both the NDIA and the participant are satisfied with the plan.

Getting the plan right at this stage will reduce the number of internal reviews and appeals to the AAT, and ultimately lead to a more efficiently administered NDIS.

3.2 Specific questions

In this section we respond to some of the specific questions posed in the Planning Paper.

3.2.1 Question 4: How can we assure participants that their plan budgets are at the right level? (e.g.panels of the Independent Advisory Council that meet every six-months to review learnings and suggest improvements)

First, this is not how this question should be framed. Rather than 'assuring' participants that their plan budgets are at the right level, the NDIA should focus on how to *ensure* participants get the budgets right in the first planning stage. There is no point assuring participants that their plans are at the right level if they are not.

Second, we repeat our recommendation above, that further information and guidance be published on how 'total reasonable and necessary level of funding' is to be determined. In the absence of clear guidance, participants will find it difficult to understand how delegates have reduced their needs to a single funding figure.

Third, we reiterate the need for transparency around AAT settlement outcomes. The publication of these outcomes will serve two purposes. The first is it will provide greater information to participants about the amounts funding that others in similar circumstances receive. Where this is consistent with their funding, this will help 'assure' them that the funding is correct. Given that planning decisions are no longer framed around individual supports, but rather around a single budgetary figure that will 'reflect the expected costs of providing a reasonable and necessary package of supports for a participant with a similar level of functional capacity, support need and environmental context'²², the publication of these outcomes should not be controversial.

The second purpose of publishing settlement outcomes is that it will inform delegates of the amounts of funding that are ultimately approved. There must be a feedback loop to ensure that delegates at the initial planning stage know whether the plans they (and their colleagues) have approved are ultimately amended, whether by settlement or by an AAT decision, to ensure better planning decisions in future.

Finally, the NDIA must implement a mechanism to consider whether settlement outcomes or AAT decisions require changes to policies or practices. Again, this is a matter PIAC has raised in a number of forums, and which has been adopted in different inquiries. The Australian National Audit Office has recommended that:

The National Disability Insurance Agency establishes mechanisms to track and analyse (at the enterprise level) issues arising from review mechanisms to inform continuous improvement in reasonable and necessary decision-making, including:

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Planning Paper, 13.

 using outcomes data from internal reviews and AAT reviews, including early resolution outcomes, to inform continuous improvement in reasonable and necessary decisionmaking...²³

The NDIA agreed to this recommendation, but it does not appear such a mechanism has been established. Establishing such a mechanism, and publishing any policy or practice changes arising in its Quarterly Report, will help improve the quality of decision-making while also improving public trust in those decisions.

3.2.2 Question 8: How best to handle the timing of the release of funds into plans and rollover of un-used funds?

We do not understand the premise of 'timing' the release of funds into plans, when the current proposal is for a total funding package to be approved, untied to specific supports (unless there is a fixed budget component), and which is intended to be used flexibly. The stated principles of this new process include to 'recognise participants as experts in their own lives and maximise flexibility and participant control over their personalised plan budget'; 'recognise the participant's autonomy and independence in decision making processes that affect them, and support them to make decisions for themselves', and 'recognise the dignity of risk'. ²⁴

In these circumstances, it is not necessary that the release of funds be timed. Participants will have already been approved for the level of funding, with a discussion having been had with the delegate as to how the funding supports the person's goals. The participant should be entitled to access the funds as they wish, over the period of the plan. To do otherwise runs counter to the choice and control of participants, and to the stated principles. Timed release should only be provided in specific circumstances, such as where the participant makes such a request.

4. Conclusion

The proposed reforms do not address the existing transparency, accountability and governance issues that have been repeatedly raised and which have been the subject of recommendations by various inquiry bodies. These proposed reforms, particularly in relation to mandatory independent assessments, have been introduced without proper consultation, and carry the risk of perpetuating existing public administration issues.

Notwithstanding this, in the event the proposals are implemented, we have raised a number of issues requiring further consideration and action by the NDIA. We are available to discuss our submission further should that be of assistance.

Australian National Audit Office, *Decision-making Controls for NDIS Participant Plans* (Auditor-General's Report, 2020-21), Recommendation 2.

Planning Paper, 10.