public interest
ADVOCACY CENTRE

Submission to the Review of the NDIS Act and the NDIS Participant Service Guarantee (Tune Review)

October 2019

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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, through our Indigenous Justice Project and Indigenous Child Protection Project
- 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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The Public Interest Advocacy Centre office is located on the land of the Gadigal of the Eora Nation.

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Executive Summary

The Public Interest Advocacy Centre (PIAC) is a community legal centre that works to tackle barriers to justice and fairness experienced by people who are marginalised or facing disadvantage. As part of this work, in July 2019, PIAC commenced a legal advocacy project to deliver better outcomes under the National Disability Insurance Scheme (NDIS) for people with disability.

Our submission identifies four key areas for law and policy reform that will improve the efficiency and fairness of the NDIS for all system users.

1. **Changes to the 'permanence' criterion in assessing the eligibility of would-be participants**

   In order for a person to be eligible for the NDIS, they must have an impairment that is, or is likely to be, 'permanent'. In the first instance, the language of 'permanence' in the eligibility criteria is inconsistent with the understanding of that term in disability policy and research, including with the language in the UN Convention on the Rights of Persons with Disabilities. This is especially the case for people with psychosocial disabilities, or people with chronic, recurring conditions.

   The second issue is that the definition of 'permanent' is too vague and restrictive. An impairment is defined as being 'permanent' or '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 of what 'available' and 'appropriate' means, and the concepts have been interpreted by the Administrative Appeals Tribunal (**AAT**) to mean treatment that is 'accessible', regardless of whether it is affordable, and provided that it does not impose a 'serious risk' to a person's health. This definition is not consistent with similar criteria for eligibility under the Disability Support Pension and imposes a high threshold for permanence.

2. **Improvements to the planning process, including reform needed to:**

   a. Improve the consistency of decision-making

   The experience of system users is that there is considerable inconsistency at various levels of decision-making by the National Disability Insurance Agency (**NDIA**). When preparing the statement of participant supports with the participant, and approving that statement, decisions made by the NDIA are inconsistent, and appear to depend on the ability of the participant and medical professionals to articulate their needs in the language of the NDIS Act, the particular NDIA office, the ability of the participant to advocate for the supports they consider reasonable and necessary, and whether their local MP advocates on their behalf. This has resulted in people with similar disabilities, in similar situations, receiving considerably different levels of support and funding. It has also resulted in people receiving inconsistent support decisions year-to-year.

This inconsistency is exacerbated by a lack of transparency in the planning and decision-making process. The NDIA determines the level of funding a participant receives with reference to 'typical support guidelines' or 'reference packages', which are not publicly available and the majority of appealed cases are settled confidentially. This lack of transparency makes it difficult to hold the NDIA accountable for its decisions.

b. Clarify the relevance of financial sustainability to individual planning decisions

As an insurance scheme, the financial sustainability of the Scheme is an important underlying principle of the NDIS. However, there is considerable uncertainty as to how the NDIA must 'have regard to' financial sustainability. Notably, although the NDIA is required to 'have regard to' financial sustainability in performing functions under the NDIS Act, 'financial sustainability' is not a separate criterion for the NDIA when it determines a person's reasonable and necessary supports.

There is no guidance on how the NDIA does or should consider financial sustainability in the context of individual support plans. Changes should be made to clarify the relevance of financial sustainability to individual planning decisions, and guidelines should be published to provide transparency around how this concept is relevant to NDIA decision-making.

c. Clarifying the interface between the NDIS and mainstream support services

Under the NDIS Act, a participant will not be granted supports if those supports are determined by the NDIA to be more appropriately funded through another system of service delivery, such as housing services, health services, corrective services or child protection and family support services. However, system users have identified and experienced gaps in the interface between the NDIS and these mainstream support services, where the NDIA considers that the support should be funded by another support system and refuses to fund the support, regardless of whether or not that other support system actually funds the requested support. Recent media reporting has highlighted this issue in relation to child protection and family support services.[1]

These interface issues represent policy challenges for the Commonwealth and State and Territory governments, but the burden should not fall on NDIS participants to navigate Commonwealth and State and Territory bureaucracies to determine where services might best be funded.

3. Improvements to the internal review process, including setting statutory deadlines and reducing the complexity of the process

The delays and complexities in the internal review process continue to be a significant source of stress for system users. It is well-reported that there are backlogs to the processing of internal review applications, and that as a result, the NDIA is taking up to nine months to complete reviews. These delays create a number of problems for participants, including

[1] Rick Morton, 'Exclusive: 500 children forfeited to state in NDIS standoff', *Saturday Paper* (online), 12 October 2019 <https://www.thesaturdaypaper.com.au/news/politics/2019/10/12/exclusive-500-children-forfeited-state-ndis-standoff/15707988008900>.

preventing people with disability from accessing the supports they need due to uncertainty over whether funding for those supports will be provided; disproportionate impact on people requiring early intervention support; and impact on the interface with other government departments. In relation to the latter, PIAC has been told that there are instances where a parent of a child with disability has been threatened with the removal of their child by the State, while waiting for the NDIA to conduct its review of supports for the child.

The complexity of the internal review process exacerbates these delays. The review process is so complex that both participants and NDIA staff have confused requests for 'plan reviews' and 'internal reviews'. This creates further delays through the double handling of reviews and clogs up AAT time with jurisdictional questions.

4. **Implementing a process for systemic policy changes to be made following Administrative Appeals Tribunal and Federal Court decisions and settlements**

   A key issue identified during PIAC's consultations with disability advocates is the failure by the NDIA to implement individual and systemic policy changes following decisions in the Tribunal and Court, or following settlements. In relation to individual changes, PIAC has been made aware of cases where a participant settles their dispute with the NDIA over funding for reasonable and necessary supports, only to face a cut in their level of funding at the next plan review, following which they are required to go through the appeals process again. This causes unnecessary stress for participants and is a waste of limited NDIA resources.

   In relation to systemic changes, the NDIA does not have an accountable process for the implementation of systemic changes to policies following settlements or decisions. The clearest example is the case of Mr Liam McGarrigle, who brought an appeal against the NDIA to the Federal Court. Both the Federal Court and the Full Federal Court on appeal decided against the NDIA in 2017. However, until recently, the NDIA's transport guidelines continued to refer to policy approaches which were determined to be incorrect interpretations of the legislation. After PIAC and other organisations raised the matter with the NDIA, the guidelines were finally amended on 10 October 2019. The failure to implement systemic changes undermines confidence in the NDIA and may waste resources by resulting in confusion and reviews and/or appeals on issues that should be considered settled.

PIAC makes a number of recommendations in this submission which address issues in these four areas. These recommendations are summarised in the next section.

PIAC supports incorporating the Participant Service Guarantee in the legislation, and broadly agrees with the proposed principles. In line with the issues identified in this submission, we also recommend including three further fundamental principles: transparency, commitment to service, and accountability.

Recommendations

Recommendation 1: Replacing the language of 'permanence'

The language of 'permanence' in relation to eligibility for the Scheme (at ss 24, 25 and 27 of the NDIS Act) should be replaced with alternative terms that reflect terms used within disability policy and research, such as 'long term', 'persistent', 'chronic' or 'enduring'.

Recommendation 2: Clarifying the meaning of 'available' and 'appropriate' treatment

The NDIS Act should be amended to clarify the meaning of impairments which 'are, or are likely to be, permanent'. Specifically, in line with the criteria for the Disability Support Pension, the Act or the Rules should be amended to clarify that 'available' and 'appropriate' treatment means 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

Recommendation 3: Improving transparency in the NDIA

If typical support guidelines are to be used by the NDIA in determining participant supports, the Rules should be amended to require publication of the guidelines. The Rules should recognise that any guidelines published are guidelines only, and that the decision must reflect the individual's circumstances and statement of goals.

Recommendation 4: Publication of AAT settlement outcomes

The NDIA should publish information around AAT settlement outcomes in a manner which balances confidentiality and privacy obligations with the need for transparency and accountability. In determining the information to be published, the NDIA should consult with participants and advocates, and should have regard to the information published in the Australian Human Rights Commission's Conciliation Register.

Recommendation 5: Clarifying 'financial sustainability' in the NDIS Act

Sections 21 and 34 of the NDIS Act should be amended to clarify that considerations of financial sustainability are not an additional or separate criterion to be considered in determining whether a person meets the access criteria or whether a support is 'reasonable and necessary'.

Recommendation 6: Publication of Guidelines on Financial Sustainability

The Rules should be amended to require the NDIA to publish guidelines on the manner in which it considers financial sustainability of the Scheme is relevant to individual eligibility and funding decisions, and the way in which financial sustainability is determined. The NDIA's guidelines should follow PIAC's interpretation of the legislative provisions.

Recommendation 7: Shifting the onus on service delivery between the NDIS and mainstream services

Section 34(f) of the NDIS Act should be amended to specify that where the NDIA determines that a support is more appropriately funded by some other system of service delivery, the NDIA must also be satisfied that the support is, or will be, in fact provided by that other service. The section should state that in the absence of that support being provided by another service, the NDIA must not rely on s 34(f) to determine that the support is not reasonable and necessary

Recommendation 8: Statutory timeframes for internal review

Section 100(6) of the NDIS Act should be amended to specify that the reviewer must make a decision within six weeks of the date that a request is made in accordance with s 100(3).

Recommendation 9: Deemed decision for failure to conduct review within specified timeframe

Section 103 of the NDIS Act should be amended to provide that if a review under s 100(6) is not conducted within six weeks of the date of the request, the reviewer is deemed to have made the original decision again.

Recommendation 10: Reimbursement of a participant's expenditure on supports or economic loss

The NDIS Act should be amended to insert a provision that:

(a) where a participant's statement of participant supports is varied or set aside and substituted on review or appeal, including during any settlement of a pending appeal, and

(b) the variation or substitution is to grant that participant funding for a requested support which was originally denied or only partially funded by the NDIA, and

(c) during the course of the review or appeal process, the participant, their family or carer paid for the support with funding outside of the NDIA, or otherwise suffered economic loss because of the denial of support by the NDIA, then

(d) the NDIA is to reimburse the participant, their family or their carer, as the case may be, for the expenditure.

Recommendation 11: Amend the NDIS Act to streamline reviews under ss 48 and 100

The NDIS Act should be amended to reduce the complexity between plan 'reassessments' under s 48, and internal 'reviews' under s 100. All requests under s 48 should be treated as both a request for 'reassessment' and internal 'review'.

Recommendation 12: The NDIA should implement systemic changes following appeals

The NDIA should implement a transparent and accountable process for ensuring that systemic changes to policies are made following settlement or decisions made in the AAT or Court. These changes should be reported in its Quarterly Report to ensure transparency and accountability.

Recommendation 13: The principles for the Participant Service Guarantee should be legislated

The principles for the Participant Service Guarantee should be inserted into the NDIS Act, alongside the general principles guiding action under ss 4 and 5 of the Act.

Recommendation 14: The principles for the Participant Service Guarantee should include accountability, transparency and commitment to service

In addition to the principles proposed in the Discussion Paper, separate principles should be adopted in relation to each of accountability, transparency and commitment to service.

1. Introduction

The Public Interest Advocacy Centre (**PIAC**) welcomes the opportunity to make this submission to the Tune Review into the *National Disability Insurance Scheme Act* (**NDIS Act**) and the Participant Service Guarantee.

The NDIS has the potential to provide choice and control for people with disability as well as early intervention services for many Australians who have never received assistance before. However, those who should be benefitting from the scheme have raised a range of concerns, particularly in relation to application and appeal processes.

PIAC's project, *A Fairer NDIS*, aims to support and improve efficiency and effectiveness in the rollout of the Scheme, and to create sustained impact in the interests of empowering the choice and control of people with disability. The initial focus of our work is on improving transparency and consistency around decision-making, and making the appeals process less adversarial and more user-friendly.

This submission draws on our consultations with people with disability, peak bodies, disability advocacy organisations, Legal Aid Commissions, academics and other stakeholders, as well as our experience advocating for people with disability more generally.

The submission broadly follows the structure of the Discussion Paper, and the process of NDIS decision-making itself, and addresses many of the issues raised in the Discussion Paper. The recommendations made focus on legislative reform, policy reform and the establishment of the Participant Service Guarantee.

2. Eligibility: The definition of 'permanent' impairments

A key barrier to access to the NDIS is the use of the term 'permanent' and the manner in which permanency has been defined. This section addresses questions 6, 26 and 27 of the Discussion Paper.

Under s 24(1)(b) of the NDIS Act, in order for a person to be eligible for the NDIS, they must have an impairment or impairments which 'are, or are likely to be, permanent'.

In the first instance, the use of 'permanence' in the eligibility criteria is inconsistent with the understanding of that term in disability policy and research. This is especially the case for people with psychosocial disabilities, or people with chronic, recurring conditions. The language of 'permanence' is not appropriate, especially for individuals with psychosocial disabilities, where an individual's impairments may be chronic, but fluctuating in severity.[2] This language contrasts, for instance, with the language used in the UN Convention on the Rights of Persons with Disabilities[3] (**CRPD**), which defines persons with disabilities as including those who have 'long-term' physical,

[2] For further discussion, see Jennifer Smith-Merry et al, *Mind the Gap: The National Disability Insurance Scheme and psychosocial disability – Final Report: Stakeholder identified gaps and solutions* (Report, 2018).

[3] *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).

mental, intellectual or sensory impairments.[4] There are also difficulties with National Disability Insurance Agency (**NDIA**) decision-makers, with little or no training on psychosocial disabilities, fitting people with psychosocial disabilities into this language of 'permanence'.

Second, the definition of 'permanence' is too vague and restrictive. The Act does not define 'permanent' or 'likely to be permanent'. Rather, paragraph 5.4 of the *National Disability Insurance Scheme (Becoming a Participant) Rules 2016* defines an impairment as being 'permanent' or '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'.

This has created issues in both the NDIA and the Administrative Appeal Tribunal's (**AAT**) interpretation of what treatment should be considered 'available' and 'appropriate' (see textbox 1 below).

This definition of permanence contrasts with the definition used for the assessment of eligibility for the Disability Support Pension (**DSP**). 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.[5] 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.[6]

This approach to assessing whether treatment is appropriate for an individual recognises the context in which a person with disability decides whether or not to undergo particular treatment. This is not the approach currently taken by the NDIA. The following decision by the AAT illustrates how strictly 'available and appropriate' treatment is interpreted when determining whether a person has a permanent disability.

Textbox 1

Schwass and NDIA [7]

Mr Schwass was a 64 year old man with morbid obesity and osteoarthritis, and sought to become a participant in the NDIS. The NDIA had decided that he was ineligible because his impairments were not permanent. A key question for the Tribunal was whether Mr Schwass' impairments were 'permanent'.

[4] Ibid art 1.
[5] *Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011* (Cth), s 6(4).
[6] Ibid s 6(7)(a)-(f).
[7] *Schwass and National Disability Insurance Agency* [2019] AATA 28.

In deciding that Mr Schwass did not have a 'permanent' impairment, the Tribunal held that 'available' treatment meant 'accessible or within reach', and that affordability was not a relevant consideration. Deputy President Humphries considered that treatment which might 'impose a serious risk to a person's health' is not treatment that would be required.

This decision outlines the difference in approach to 'permanence' between the NDIS and the DSP, predominantly on the basis that the DSP legislation sets out clearly how 'permanence' and 'reasonable treatment' should be defined, while the NDIS Act does not. It is also notable that Deputy President Humphries considered that treatment might not be available or appropriate if it imposes a 'serious risk' to a person's health, in contrast to the lower threshold under the DSP of the treatment carrying a 'low risk'.

In another example, a stakeholder told PIAC of a client, 'Emma' who was denied entry to the NDIS, in part on the basis that her impairment was not permanent. The reason for this was that the NDIA considered that medical treatment, being brain surgery, remained an option. Emma advised the NDIA that she had made an informed decision, based on advice from all medical specialists she consulted, that surgery was not suitable for her. Despite this, the NDIA defended its decision to refuse access through the AAT. The NDIA stated in its internal review decision that because she had 'declined surgery as an option', she did not meet the permanence requirements because 'all treatment options have not been explored'. The matter was ultimately settled, with the NDIA accepting her into the Scheme, but only after a second neurosurgeon's report was provided, which clearly stated that surgery was not suitable. Emma was granted entry into the Scheme some 1,120 days after she initially put in the request for access.

The decision in *Schwass* and Emma's case study show the need for further clarity around what 'permanence' requires, and in particular, what treatments might be considered 'available' and 'appropriate'.

PIAC notes that some organisations have expressed concerns around the DSP criteria, and have called for amendments to those criteria. However, while the DSP criteria remain operative, it serves as a useful baseline for the determination of permanent impairment. It should not be the case that, in order to access the NDIS, a person must be willing to accept treatments which carry a higher risk to their health as compared to the DSP requirements. While the DSP and NDIS serve different purposes, it would be unreasonable to expect people seeking access to the NDIS to take on a higher risk of complications from treatment as compared to the DSP. Such a requirement would undermine one of the primary principles of the NDIS Act: 'people with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives…'.[8]

[8] NDIS Act s 4(8).

Recommendation 1: Replacing the language of 'permanence'

The language of 'permanence' in relation to eligibility for the Scheme (at ss 24, 25 and 27 of the NDIS Act) should be replaced with alternative terms which reflect terms used within disability policy and research, such as 'long term', 'persistent', 'chronic' or 'enduring'.

Recommendation 2: Clarifying the meaning of 'available' and 'appropriate' treatment

The NDIS Act should be amended to clarify the meaning of impairments which 'are, or are likely to be, permanent'. Specifically, in line with the criteria for the Disability Support Pension, the Act or the Rules should be amended to clarify that 'available' and 'appropriate' treatment means treatment that:

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(e) has a high success rate; and
(f) carries a low risk to the person

3. Planning processes: improving decision-making

3.1 Addressing inconsistency in planning processes

An overarching issue facing the NDIA is the inconsistency at various levels of decision-making by the NDIA, especially at the planning stage. This section addresses questions 13 and 14 of the Discussion Paper.

When preparing the 'statement of participant supports' *with* the participant, and approving that statement under s 33 of the Act, system users have raised concerns that decisions made by the NDIA appear inconsistent and depend on:

- the ability of the participant and their medical professionals to articulate their goals and needs in the language of the NDIS, rather than in language that reflects their true needs;
- the participant's geographic location, with advocates stating that their experience shows inconsistent decisions made depending on the planner in different locations;
- the determination and endurance of the participant, their family and their advocates in pushing for the supports they consider necessary. This has a disproportionate effect on culturally and linguistically diverse (**CALD**) and Indigenous people with disabilities. Advocates advised that many such applicants found it difficult to advocate for themselves against government decision-makers;
- whether a person's local MP is involved and advocating on their behalf; and
- in some cases, even the profile of the participant. There is a concern held by some in the disability sector that participants with higher profiles may be more likely to get the supports they seek. Conversely, concerns have also been raised that people in marginalised and poorer communities receive lower levels of funding and support.

Throughout our consultations, PIAC has been given a considerable number of examples of a lack of consistency in decision-making. The types of inconsistencies include:

- inconsistency in the funding of support plans for people with similar disabilities in similar situations. Advocates have advised that the planning outcomes between people in similar situations vary considerably depending on the level of advocacy support received, the determination and endurance of the participants and their carers to press for what they consider is an appropriate level of funding, and the location of the participant (especially whether the participant is located in a regional or metropolitan area); and
- inconsistency in the funding of support plans for the same person at the next plan review following an AAT decision or settlement of their appeal. We have been informed that there have been many cases where a participant settles their dispute with the NDIA over funding for reasonable and necessary supports, only to face a cut in their level of funding at the next plan review, following which they are required to go through the appeals process again.

These inconsistencies are well-reported, including by the Joint Standing Committee on the NDIS.[9]

Poor decision-making is exacerbated by the lack of transparency around how decisions are made. It is understood that the NDIA uses typical support guidelines or reference packages to identify the level of funding to be provided to people with certain impairments.[10] It appears that these guidelines or packages are developed and applied using a computer program. PIAC understands that access to these guidelines has been sought by numerous organisations but the NDIA has not provided access.

Greater understanding of typical support guidelines and how they are used is important to ensure confidence in the administration of the NDIS. On the one hand, their use may fail to give effect to the requirement that participants' plans be 'individualised'.[11] On the other hand, despite their use, stakeholders are concerned about a lack of consistency in decision-making across people with apparently similar needs.

Likewise, the lack of transparency around settlement outcomes at the AAT impairs consistent decision-making and makes it difficult for participants to understand the types of supports they could seek. Based on the most recent Quarterly Report published by the NDIA, approximately 96% of all finalised cases before the AAT were finalised through settlement.[12] The nature of settlements are private, confidential and non-binding on non-parties to the settlements. Increasing the transparency in settlement outcomes will assist with addressing inconsistencies in decision-making, as it will allow some level of public accountability in ensuring the NDIA makes decisions consistently with matters that it has settled. It will also improve the ability of participants

[9] Joint Standing Committee on the National Disability Insurance Scheme, *Progress Report* (Report, March 2019) 20-21.
[10] The use of reference packages is also discussed in Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs* (Study Report, October 2017) 193-195.
[11] NDIS Act s 31(a).
[12] National Disability Insurance Agency, *COAG Disability Reform Council Quarterly Report* (Report, 30 June 2019) 96. The Report states that 1,522 cases out of 1,576 finalised cases had been resolved by settlement as at 30 June 2019.

to understand the types of supports that are funded, and assist participants to decide what types of supports they could seek.

Recommendation 3: Improving transparency in the NDIA

If typical support guidelines are to be used by the NDIA in determining participant supports, the Rules should be amended to require publication of the guidelines. The Rules should recognise that any guidelines published are guidelines only, and that the decision must reflect the individual's circumstances and statement of goals.

Recommendation 4: Publication of AAT settlement outcomes

The NDIA should publish information around AAT settlement outcomes in a manner which balances confidentiality and privacy obligations with the need for transparency and accountability. In determining the information to be published, the NDIA should consult with participants and advocates, and should have regard to the information published in the Australian Human Rights Commission's Conciliation Register.

3.2 Financial sustainability and 'reasonable and necessary supports'

Financial sustainability of the NDIS is another area in which decision-making by the NDIA remains opaque and vague. This section addresses questions 13, 14, 26 and 27 of the Discussion Paper.

As an insurance scheme, ensuring the financial sustainability of the Scheme is an important underlying principle of the NDIS. This is clearly stated in the legislation and the rules. Section 3(3)(b) of the NDIS Act provides that, in giving effect to the objects of the Act, regard is to be had to 'the need to ensure the financial sustainability' of the NDIS. Section 4(17)(b) of the Act also specifies that it is the intention of Parliament that in performing functions and exercising powers under the NDIS Act, the NDIA CEO and Board (among others) must again have regard to 'the need to ensure the financial sustainability' of the NDIS. The *NDIS (Supports for Participants) Rules 2013* states at paragraph 2.5 that in administering the NDIS and in approving each NDIS plan, the CEO 'must have regard to objects and principles of the Act including the need to ensure the financial sustainability of the NDIS…'.

There, is, however, a lack of clarity as to what it means in practice to 'have regard to' the financial sustainability of the Scheme. Notably, s 34 of the Act, which sets out the considerations for determing 'reasonable and necessary supports', does not refer to financial sustainability.

There are two aspects to this problem. First, understanding how the NDIA is applying this consideration in practice, and second, identifying how, in fact, the financial sustainability of the Scheme *should* be taken into account in decision-making and the performance of the NDIA of its functions.

3.2.1 Financial sustainability in practice

PIAC understands the NDIA has refused to fund supports on the ground that it would threaten the financial sustainability of the NDIS, but there are limited ways in which the participant could understand the basis for the decision. One stakeholder reported that some participants felt the onus was on them to prove that their support would not lead to financial unsustainability of the

Scheme. It was reported to us that some participants, especially people with psychosocial disability, were so concerned about financial sustainability that they were worried about using the funding they had been allocated because of the fear that they would be a burden on society. Another stakeholder also reported similar concerns raised by CALD people with disability.

The manner in which financial sustainability is raised by the NDIA appears to assume that all participants with the same disability in similar circumstances will seek the same supports when drafting their plans, which undermines the choice and control enjoyed by each individual. This approach is demonstrated by the NDIA's approach to the matter in *WRMF and NDIA* [2019] AATA 1771, where evidence from the Scheme Actuary was given to show the 'worst case scenario' where 'every person, male or female, married or unmarried, who suffered from multiple sclerosis, and certain other disabling diseases, sought a sex worker'.[13] A similar broadbrush approach was taken by the NDIA in *McPherson and NDIA* [2018] AATA 4303, in relation to the cost of providing a motor vehicle 'for all participants with muscular dystrophy'.[14]

The ambiguity of the phrase 'have regard to… the need to ensure the financial sustainability of the NDIS' is reflected in the lack of authoritative decisions on the matter, whether at the AAT or at the Federal Court. In *McGarrigle*, the Court expressly declined to decide on the role of considerations of financial sustainability in the NDIS, noting that it 'is an important issue which should await determination in an appropriate case'.[15]

Decisions at the AAT on financial sustainability provide only limited guidance on the matter. More recent decisions tend to suggest that evidence from the Scheme Actuary would be required to raise financial sustainability as an issue before the Tribunal, and that the evidence must be specific and relevant.[16] Deputy President Humphries in *BIJD* reasoned that financial sustainability entails the making of value judgments balancing, on the one hand, the cost of widening the NDIS's scope, and on the other, the benefits conferred. Thus, if the benefits conferred by the requested support are significant, then a significant additional cost may be justified.[17] Given the need for value judgment, it is clear from this decision that actuarial analysis can only be an advisory tool to assist with determining the effect on costs to the Scheme, and not a determinative tool in deciding whether a person's supports should be funded.

The ambiguity has also led to the consideration of financial sustainability in relation to eligibility and access to the Scheme. In *YPRM and National Disability Insurance Agency* [2016] AATA 1023, the NDIA argued that the financial sustainability of the Scheme was relevant in determining whether a child was eligible to be a participant under the early intervention pathway. It is difficult to see how the financial sustainability of the Scheme should be relevant to determining whether a person meets the eligibility criteria set out in the legislation.

[13] At [37].
[14] At [42].
[15] *McGarrigle v National Disability Insurance Agency* [2017] FCA 308, [117].
[16] See, for example, *WRMF and NDIA* [2019] AATA 1771; *WKZQ and NDIA* [2019] AATA 1480 and *FRCT and NDIA* [2019] AATA 1478; *McPherson and NDIA* [2018] AATA 4303; *BIJD and NDIA* [2018] AATA 2971; *Mazy and NDIA* [2018] AATA 3099.
[17] *BIJD and NDIA* [2018] AATA 2971, [68].

The ambiguity in the application of the concept of 'financial sustainability' to individual support plans combined with the lack of transparency in the manner in which the NDIA incorporates 'financial sustainability' in its decision-making requires clarification and/or reform.

3.2.2 How should financial sustainability be taken into account?

In PIAC's view, considerations of financial sustainability are not in fact (and should not be) relevant to determining whether supports are 'reasonable and necessary' under s 34.

Section 34 of the NDIS Act lists the criteria of which the CEO must be satisfied when determining the reasonable and necessary supports that will be funded. In PIAC's view, the financial sustainability of the Scheme is not, in fact, relevant to any of the specific factors and should not play a role in deciding individual participant supports under that section.

While the criterion relating to 'value for money' may suggest financial sustainability can and should be taken into account, in fact that criterion is narrow and individualised in its scope. The section requires the CEO to consider whether 'each support' being considered for a participant 'represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support'.

In PIAC's view, this requires an individualised assessment and cannot meaningfully take into account the broader financial sustainability of the Scheme. Any 'benefits achieved' will necessarily be different for each participant, as will the cost of alternative support.

Instead, PIAC considers that the requirement to have regard to the financial sustainability of the Scheme operates as follows, in respect of determining reasonable and necessary supports:

1. The CEO, or his delegate, must be satisfied that a proposed support meets the criteria specified in s 34, and must consider all other factors listed in s 33(5). Once the CEO or his delegate is satisfied that those factors are met, the CEO must approve the statement of participant supports under s 33(2).
2. In the course of making that decision, the CEO or his delegate must keep in mind (or 'have regard to') the financial sustainability of the Scheme. However, it is not for the CEO or his delegate to determine that risks to the financial sustainability of the Scheme prevent the approval of the proposed support in accordance with ss 33(2), 33(5) and 34. If the CEO or his delegate is satisfied that all criteria under those provisions are met, the statement of participant supports must be approved, notwithstanding any concerns about financial sustainability.
3. In the event that concerns about financial sustainability are raised, the CEO or his delegate must consider the need to ensure the financial sustainability of the Scheme, *following* the approval of the statement of participant supports. This is a role which, as per s 4(17)(b), may involve the Ministerial Council, the Minister, the NDIA Board, the CEO, the Commissioner of the NDIS Quality and Safeguards Commission, and 'any other person or body'. In practice, this may mean the following steps could be taken:
    a. The CEO or his delegate may raise concerns regarding financial sustainability issues arising from a reasonable and necessary support to the Scheme Actuary for advice, and for the purposes of the Scheme Actuary's duties under s 180B;

b. If 'significant' actuarial advice or a report is received, the CEO must provide that report to the Board under s 159(7);
c. If the Board considers it to be relevant actuarial analysis and advice under s 125A, it must have regard to that information, and it may determine objectives, strategies and policies for the NDIA to ensure that the need to ensure financial sustainability is met. The Board may consider it necessary to give written directions to the CEO under s 159(4) in the performance of his duties, to ensure financial sustainability is maintained. The CEO would then need to act on those directions (s 159(5)); and
d. The CEO may also act on the advice of the Scheme Actuary in connection with the performance of his duties under s 159(2) – for example by bringing issues to the attention of government or other stakeholders.

PIAC makes two recommendations in relation to this interpretation. First, the NDIS Act should be amended to clarify that 'financial sustainability' is not an additional or separate criterion to be considered under s 21 in relation to eligibility, or s 34, in determining what support is 'reasonable and necessary'. Requiring considerations of financial sustainability in each individual case would otherwise create an implicit onus on an individual to prove that their requested support would not cause the Scheme to be financially unsustainable.

Second, the NDIA should publish guidelines on the manner in which it considers financial sustainability of the Scheme is relevant to individual eligibility and funding decisions, and the way in which financial sustainability is determined. PIAC recommends that these guidelines follow our interpretation of the legislative provisions above.

Recommendation 5: Clarifying 'financial sustainability' in the NDIS Act

Sections 21 and 34 of the NDIS Act should be amended to clarify that considerations of financial sustainability are not an additional or separate criterion to be considered in determining whether a person meets the access criteria or whether a support is 'reasonable and necessary'.

Recommendation 6: Publication of Guidelines on Financial Sustainability

The Rules should be amended to require the NDIA to publish guidelines on the manner in which it considers financial sustainability of the Scheme is relevant to individual eligibility and funding decisions, and the way in which financial sustainability is determined. The NDIA's guidelines should follow PIAC's interpretation of the legislative provisions.

3.3 Interface between NDIS and mainstream services

A key area of ambiguity within the NDIS Act is the interface between the NDIS and mainstream services. This ambiguity has led to participants falling in the gaps between the NDIS and other mainstream services provided by Commonwealth or State and Territory governments. This section addresses questions 10(2), 26 and 27(g) of the Discussion Paper.

Under the NDIS Act, there are two critical interface points between the NDIS and mainstream services. The first is in relation to eligibility. Under s 21 of the Act, a person meets the criteria for access to the Scheme if they satisfy the age requirements, residence requirements, and either the disability or early intervention requirements. However, under s 25(3), even if a person would otherwise satisfy the early intervention requirement, they would not be able to access the NDIS if:

> the CEO is satisfied that early intervention support for the person is not *most appropriately funded or provided through the National Disability Insurance Scheme*, and is *more appropriately funded or provided through other general systems* of service delivery or support services offered by a person, agency or body, or through systems of service delivery or support services offered:
>
> (a) as part of a universal service obligation; or
>
> (b) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability. [Emphasis added.]

The second interface is in relation to reasonable and necessary supports. Under s 34(1)(f), the NDIA must be satisfied that the support is most appropriately funded or provided through the NDIS, and, as with s 25(3):

> is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:
>
> (i) as part of a universal service obligation; or
>
> (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

In the recent AAT decision of *Burchell and National Disability Insurance Agency* [2019] AATA 1256, Deputy President Rayment considered that there are two 'limbs' of which the CEO of the NDIA must be satisfied. First, that the support is most appropriately funded or provided by the NDIS. Second, that it is not more appropriately funded by some other system of service delivery, such as a health department.

The cases show that there are gaps between services, where the NDIA refuses to fund a support on the basis that it considers that the support is more appropriately funded through other services, but where that other support service does not provide funding. Gaps commonly exist between the NDIS and:

- education services;
- health services;
- corrective services;
- justice services;
- housing services; and
- child protection and family support services.

In *Burchell*, Deputy President Rayment held that, for the NDIA to deny funding on the basis of the second limb – that is, that the support is more appropriately funded by some other system of service delivery – that support must in fact be provided by another health authority. It is not for the NDIA to evaluate what supports should be provided by other service providers. In other words, the NDIA cannot determine that another service provider should provide a support even if they do not.[18]

[18] *Burchell and National Disability Insurance Agency* [2019] AATA 1256, [36].

After the *Burchell* decision was handed down, the COAG Disability Reform Council further clarified the interface between the NDIS and the health system following its meeting on 28 June 2019, through the publication of a fact sheet.[19] The 'Health related supports' fact sheet clarifies that the NDIS will fund disability-related health supports 'where the supports are a regular part of the participant's daily life, and result from the participant's disability,' and provides a non-exhaustive list of such supports.

However, despite these principles and further agreements, several interfacing issues remain in the actual mechanics of the NDIS, particularly with State and Territory services.

The NSW Government has acknowledged gaps in these interfaces, and has set up the Integrated Service Response initiative. This initiative coordinates support for an individual with support needs that require multiple mainstream and disability support services to work together, and provides coordination between different NSW Government agencies to ensure that the support is provided. There are, however, limitations to this initiative. It only has capacity for 15 referrals per month, there are high eligibility thresholds for access to the initiative, and it is only funded until December 2019.

These interfacing issues require COAG to agree clearer boundaries as to the funding of services between the NDIS and other mainstream service providers. PIAC notes the recommendations made by the Productivity Commission in its January 2019 Review of the National Disability Agreement, concerning the need for a new National Disability Agreement (**NDA**) between the Australian, State and Territory Governments, and the need for the NDA to better clarify the responsibilities between each level of government and the relationship between the NDA, NDIS and the National Disability Strategy.

However, until these boundaries are clarified, the burden should not fall to NDIS participants to navigate Commonwealth and State and Territory bureaucracies to determine where services might best be funded.

The legislation should be amended in line with the *Burchell* decision, to specify that where the NDIA determines that a support is more appropriately funded by some other system of service delivery, that support must in fact be provided by that other service. In the absence of that support being provided by another service, the NDIA must not rely on s 34(f) to determine that the support is not reasonable and necessary.

Recommendation 7: Shifting the onus on service delivery between the NDIS and mainstream services

Section 34(f) of the NDIS Act should be amended to specify that where the NDIA determines that a support is more appropriately funded by some other system of service delivery, the NDIA must also be satisfied that the support is, or will be, in fact provided by that other service. The section should state that in the absence of that support being provided by another service, the NDIA must not rely on s 34(f) to determine that the support is not reasonable and necessary.

[19] COAG Disability Reform Council, 'Meeting of the COAG Disability Reform Council: Communiqué', 28 June 2019; COAG Disability Reform Council, 'Health related supports fact sheet', 28 June 2019.

4. Internal merit reviews

There are two related issues in respect of internal reviews that warrant attention. The first is delays in the internal review process, and the second is the complexity in the internal review process, which exacerbates delays. This section addresses questions 19, 20, 21, 26 and 27(f) of the Discussion Paper.

4.1 Delays in internal review

Significant delays in the internal reviews process are well-known. The Commonwealth Ombudsman in its May 2018 report, *Administration of reviews under the National Disability Insurance Scheme Act 2013*, noted that the NDIA has acknowledged some reviews taking 'up to nine months' to be completed.[20]

Some advocates have told PIAC that in as many as 50% of the cases they worked on, internal reviews took so long that the participant's plan would come up for its 12-month review before the internal reviews had been conducted. In these cases, the NDIA would suggest to the participant that they withdraw their request for internal review and resolve any issues through the plan review. However, if the plan review failed to address their concerns, the participant would then have to lodge another internal review, restarting the whole process.

During these delays, there is limited information provided to individuals about the internal review process, adding to the uncertainty during the lengthy process.

Delays in the internal review process further impact the ability of individuals to appeal to the AAT, as the legal position remains unclear as to whether internal reviews not completed within a 'reasonably practicable' timeframe is a deemed refusal which can be subject to an appeal to the AAT.

These delays have a number of impacts on people with disability, including:

- preventing people with disability from accessing the supports that they need due to a lack of certainty in whether the funding for those supports will be provided;
- requiring people with disability to decide between spending the funding provided in the manner in which they need it, but risking that those funds are exhausted before the review takes place, or limiting their spending of the funding to ensure the funding lasts but not getting the full support that they need;
- impacts on the interface with other government departments. One advocate told PIAC about the difficulties a participant had between managing the interface between the NDIA and the then NSW Department of Family and Community Services. The client was waiting for the NDIA to conduct its internal review of supports for her child, while at the same time being threatened with his removal by the State, unless she could receive support for his disability.

[20] Commonwealth Ombudsman, *Administration of reviews under the National Disability Insurance Scheme Act 2013* (Report, May 2018) 3.

In these situations, delays in internal review can impact the provision of supports by other government agencies. Recent media reporting has further highlighted this issue[21]; and

- disproportionate impacts on people requiring early intervention supports.

There is also no financial pressure or disincentive for the NDIA to avoid delays in the internal review (or subsequent appeal process). Unlike with other forms of government administration, there is no clear basis for the back-payment or back-dating of funds for people who are successful at the internal review or appeals stage. Neither the Scheme for Compensation for Detriment caused by Defective Administration (**CDDA**) nor the Act of Grace payment generally applies to the NDIA. There is no legislative basis to account for time without funding in the period before a decision or a settlement.

These delays should be addressed through legislative reform. The legislation does not currently specify a timeframe for internal reviews to be conducted, only that it must be conducted 'as soon as reasonably practicable'. There are also conflicting decisions at the AAT as to whether the AAT has jurisdiction to hear appeals where internal reviews have not been conducted within a reasonably practicable timeframe. The NDIS Act must be amended to:

- specify a timeframe for internal review;
- provide for jurisdiction to the AAT to hear appeals if the timeframe is not met; and
- provide for reimbursement of a participant's expenditure on supports and compensation for any economic loss if the NDIA's refusal to fund that support is ultimately overturned at internal review or on appeal. This will create a financial disincentive for the NDIA to avoid delays, while also ensuring participants do not carry the burden of delayed reviews.

Notwithstanding the recommendation to provide the AAT with jurisdiction to hear appeals if the timeframe is not met, the NDIA should ensure that it continues to improve the efficiency and timeliness of internal reviews. It should not allow internal review timeframes to lapse and effectively require participants to take the matter to the AAT.

Recommendation 8: Statutory timeframes for internal review

Section 100(6) of the NDIS Act should be amended to specify that the reviewer must make a decision within six weeks of the date that a request is made in accordance with s 100(3).

Recommendation 9: Deemed decision for failure to conduct review within specified timeframe

Section 103 of the NDIS Act should be amended to provide that if a review under s 100(6) is not conducted within six weeks of the date of the request, the reviewer is deemed to have made the original decision again.

Recommendation 10: Reimbursement of a participant's expenditure on supports or economic loss

The NDIS Act should be amended to insert a provision that:

[21] Rick Morton, 'Exclusive: 500 children forfeited to state in NDIS standoff', *Saturday Paper* (online), 12 October 2019 <https://www.thesaturdaypaper.com.au/news/politics/2019/10/12/exclusive-500-children-forfeited-state-ndis-standoff/15707988008900>.

(a) where a participant's statement of participant supports is varied or set aside and substituted on review or appeal, including during any settlement of a pending appeal, and

(b) the variation or substitution is to grant that participant funding for a requested support which was originally denied or only partially funded by the NDIA, and

(c) during the course of the review or appeal process, the participant, their family or carer paid for the support with funding outside of the NDIA or otherwise suffered economic loss because of the denial of support by the NDIA, then

(d) the NDIA is to reimburse the participant, their family or their carer, as the case may be, for the expenditure.

4.2 Complexity in internal review process

Related to the issue of delays is the complexity in the internal review process set out in the NDIS Act. Deputy President Forgie's comments in *LQTF and National Disability Insurance Agency* [2019] AATA 631 at [2]-[3] describe the complexities inherent in the process:

> In giving these reasons, I have set out the steps that must be followed in seeking review of a statement of participant supports and review of a participant's plan. I have done so in order to illustrate the complexity of the review process provided for in the NDIS Act. It is a process that I respectfully suggest is often too complex for a participant to navigate with any ease, let alone with any confidence, and that is not conducive to the NDIA's being able to respond quickly to the needs of participants. It is a process that may leave both the participant the NDIA disagreeing about the proper characterisation of the decision that has been made.
>
> It is important that the NDIA's decision be characterised for it is apparent from what I have said below that the review may take a very different course depending on whether a decision is characterised as, for example, a decision not to reassess a participant's plan, a decision to review a participant's plan or a decision to review a statement of supports. A request may be made for review of the first and the third but not of the second. Review of the third will address what are reasonable and necessary supports. Review of the first, however, will not for it is limited to whether or not the plan should be reassessed. It may consider whether the statement of participant supports is adequate but only in the limited context of deciding whether or not to reassess the plan. If the review leads to a decision setting aside the initial decision not to reassess a participant's plan, the practical result will be that the NDIA must review the plan. Only when the plan has been approved, will a participant be able to request review by a reviewer within the NDIA of the statement of supports that the Chief Executive Officer (CEO) of the NDIA has approved in making the plan. [Footnote omitted.]

In short, there is confusion between an internal review sought of 'a decision not to reassess a participant's plan' (that is, a decision made under s 48(2)) and an internal review sought of a decision not to approve a statement of supports (that is, a decision made under s 100(6), with regard to s 33(2)).

Under s 33(2) (combined with ss 99 and 100(6)), a participant can seek an internal review of a decision around the types of supports approved within three months of the decision being made. Where that internal review, made under s 100(6), confirms the original decision, the participant can appeal the decision to the AAT under s 103. The AAT can then consider the reasonable and necessary supports being requested by the participant.

In contrast, under s 48, a participant can request a review of their plan at any time. This could be for a range of reasons, such as for changes in the participant's circumstances or if the plan is not working as envisaged for the participant. Section 48(2) only requires the CEO to decide whether or not to conduct a review of the plan. A decision to refuse to conduct a review of the plan must be automatically reviewed internally under s 100(5), however any appeal from that decision to the AAT relates only to the decision to refuse the review. It does not involve a review of the substance of the supports approved.

If the AAT decides that the participant's plan should have been reviewed, the plan will go back to the CEO to conduct that review under s 48. If the CEO approves a new plan which the participant does not agree with, the participant will have to go through the ss 33(2) and 99 process outlined above, and potentially end up in the AAT a second time.

As the Commonwealth Ombudsman described in its report, notwithstanding the guidance provided to NDIA staff, there are situations where participants who have requested a review of their statement of supports have instead been subjected to a plan review. The Ombudsman stated:

> The inaccurate classification of review requests creates issues for participants—who are required to await the outcome of two processes (rather than one) before they can access their right to external merits review; and the NDIA—which unnecessarily expends time and staff resources on additional review processes. As highlighted in our submission to the Productivity Commission's inquiry into NDIS costs, 'double handling' of reviews will likely also drive additional complaints to the NDIA, which are a further drain on resources.[22]

There are also examples of the opposite situation – where a request for an unscheduled plan review under s 48 is misinterpreted by the NDIA as a request for review of the statement of participant supports. See, for instance, *LQTF* at [13].

While the Ombudsman recommended that the NDIA update its Operational Guidelines and decision letter templates to clarify the distinction between an 'internal review' of a decision or a 'plan reassessment', we consider that this terminology remains apt to mislead. The semantic distinction between an 'internal review' of a participant's plan and a 'reassessment' is not useful for people navigating the NDIS system.

Instead, we recommend amendments to the NDIS Act to reduce the complexity – and the bureaucratic red tape – in distinguishing between 'internal reviews' and 'reassessments'. One manner in which this could be streamlined is to treat all s 48 requests as requests both for a 'reassessment' of the plan and for a review of the statement of participant supports.

Practically, there is no reason to separate internal reviews from reassessments – a decision refusing a reassessment is, in reality, a decision that the existing statement of supports is appropriate. A decision to reassess in turn, implicitly accepts that the existing statement of

[22] Commonwealth Ombudsman, *Administration of reviews under the National Disability Insurance Scheme Act 2013* (Report, May 2018), paragraph 3.14.

supports is either no longer appropriate, or was not appropriate from the start, and involves a decision to review the supports. Any decision in respect of an internal review from a decision under s 48 should enable the participant to appeal to the AAT to review the approved statement of participant supports.

There is unlikely to be any considerable increase in the number of AAT appeals, given that, first, internal review decisions following decisions made under s 48 can already be subject to appeal, and second, the AAT would still need to determine that a review of the plan is warranted under s 48, before deciding what the new plan should be. This legislative change would reduce the duplication of processes highlighted by the Ombudsman, simplify the appeal process, and eliminate appeals to the AAT raising jurisdictional issues regarding the distinction between ss 48 and 100.

Recommendation 11: Amend the NDIS Act to streamline reviews under ss 48 and 100

The NDIS Act should be amended to reduce the complexity between plan 'reassessments' under s 48, and internal 'reviews' under s 100. All requests under s 48 should be treated as both a request for 'reassessment' and internal 'review'.

5. Implementing systemic changes following appeals

There are a number of instances where the NDIA has failed to implement, or unreasonably delayed implementation of, changes following settlement or decisions at the AAT or even at the Federal Court of Australia. This section addresses, in part, questions 23 and 24 of the Discussion Paper. The key issue is that the failure to implement systemic changes following successful challenges results in inefficiencies in decision-making, and unfairness to people unwilling or unable to go through the appeals system.

First, PIAC has been made aware of cases where a participant settles their dispute with the NDIA over funding for reasonable and necessary supports, only to face a cut in their level of funding at the next plan review, following which they are required to go through the appeals process again. This is also the case for matters that have been determined by the AAT. As the AAT's decisions in relation to plans generally last for only 12 months, once the plan comes up for review, the NDIA retains the discretion to alter the plan. Notably, even after a decision from the AAT, the CEO also maintains discretionary power under s 48(4) of the Act to review a participant's plan at any time.

Second, it appears that the NDIA has not always implemented, in a timely way, systemic changes to its policies following settlements or decisions. For example, in the case of Mr Liam McGarrigle, the outcome of a Federal Court decision in 2017 was not reflected in the NDIA's policies until October 2019. This change was only made following representations by PIAC and other organisations to the NDIA. The box below describes Mr McGarrigle's case.

Textbox 2
McGarrigle v NDIA [23]

[23] *McGarrigle v National Disability Insurance Agency* [2017] FCA 308.

Liam McGarrigle, a 21 year old man with autism spectrum disorder and an intellectual disability, sought to have his travel expenses to go to and from his home to a disability group program, his work and the gym, funded through the NDIS. The total cost was $15,850. The NDIA's policy on transport funding was based on a three tier system, in which the NDIA would fund up to $6,000 per year only in exceptional circumstances.[24] The NDIA acknowledged that the travel expenses for Mr McGarrigle was a reasonable and necessary support, but decided that it would grant funding for 75% of these expenses ($11,850). This decision was affirmed by the AAT. By only funding 75% of the travel expenses, it was implied that it was reasonable for Mr McGarrigle's family and informal support networks to contribute 25%.[25]

The Court decided that the NDIA should fund all of Mr McGarrigle's travel expenses which were determined to be a 'reasonable and necessary support'. The Court held that if the NDIA found that a participant's support was a reasonable and necessary support, it would need to fully fund the total expense, even if it exceeded the levels set by NDIA guidelines. This decision was handed down in March 2017, and was upheld on appeal to the Full Federal Court in August 2017.

It was not until 10 October 2019 that the NDIA's Operational Guidelines on transport were updated to (partially) reflect this decision.[26] Up until that date, the Guidelines cited the AAT's overturned decision for the proposition that:

When considering transport as a funded support, if the criteria relevant to including supports in a participant's plan are satisfied, this does not mean that the full cost of the support should be funded as it may be reasonable for a participant's family members, carers, informal networks and/or the community to provide some of this support.[27]

The Federal Court, however, made clear that the full cost of the support must be funded if the transport is determined to be a reasonable and necessary support. Consideration of supports by family members, carers, informal networks and/or the community are only relevant to the 'activity or assistance' that could be provided by those networks, and not to financial contributions.[28] The Guidelines were recently amended to delete this paragraph.

However, the newly amended Guidelines continue to maintain a three tiered system and emphasises that the NDIS 'will provide *up to*' a certain amount. The three tiers also continue to be linked to generic categories of whether a person is working, studying or attending day programs, rather than being based on an individual's goals and needs. The Guidelines state that the amount could be higher only in 'exceptional circumstances' where a participant needs that support 'for their participation in employment'. It still does not make clear that where a person's transport supports are determined to be reasonable and necessary, and they exceed the capped amount, the full amount of that transport support will (indeed, must) be funded.

[24] Ibid [118].
[25] Ibid [62].
[26] See National Disability Insurance Scheme, 'Including Specific Types of Supports in Plans Operational Guideline – Transport', 10 October 2019, https://www.ndis.gov.au/about-us/operational-guidelines/including-specific-types-supports-plans-operational-guideline/including-specific-types-supports-plans-operational-guideline-transport#12 (accessed 16 October 2019).
[27] See National Disability Insurance Scheme, 'Including Specific Types of Supports in Plans Operational Guideline – Transport', 18 July 2019, https://www.ndis.gov.au/about-us/operational-guidelines/including-specific-types-supports-plans-operational-guideline/including-specific-types-supports-plans-operational-guideline-transport#12 (last accessed 16 August 2019, not currently available on the website).
[28] *McGarrigle* [2017] FCA 308, [97].

This failure to make systemic changes to policy following Court and AAT decisions means that participants will be forced to initiate appeals on similar grounds as previous cases, simply to achieve a similar successful outcome in the individual case.

The NDIA has stated at public forums that the newly established AAT Applications and Decisions Division will now aim to provide feedback to the NDIA on systemic issues arising from AAT appeals. It stated that following resolution of a matter, it will do a handover of information to the relevant region, and to implement a feedback loop to other parts of the decision-making process.

However, the fact that until recently the Transport Guidelines remained inconsistent with the Federal Court's decision suggests that issues still remain in the implementation of systemic changes. The NDIA should be transparent and accountable in implementing systemic changes to policies. This should occur not only following AAT and Federal Court decisions, but also where settlement outcomes are identified to have a systemic impact beyond the individual case being settled.

Recommendation 12: The NDIA should implement systemic changes following appeals

The NDIA should implement a transparent and accountable process for ensuring that systemic changes to policies are made following settlement or decisions made in the AAT or Court. These changes should be reported in its Quarterly Report to ensure transparency and accountability.

6. Principles for the Participant Service Guarantee

Taking into account the issues raised above, PIAC supports the legislation of principles for the NDIS Participant Service Guarantee. The NDIS Act contains a set of general principles which are important acknowledgments of the rights of people with disability underlying any action taken under the Act. It is important that the principles which guide the actions of the NDIA are similarly legislated and binding, so that they are seen to be front of mind when the NDIA performs its legislative functions.

PIAC generally supports the principles proposed in the Discussion Paper. PIAC recommends however that three further principles are added, or given greater visibility: transparent, commited to service, and accountable.

First, transparency should be an independent principle. The Discussion Paper proposes to include transparency as part of the principle that 'decisions are made on merit'. However, PIAC considers that transparency should be an underlying principle guiding all NDIA action, beyond decision-making in respect of participants. For instance, the NDIA should be transparent in providing information on the performance of the NDIS, to allow for scrutiny over whether it is achieving the objectives of the NDIS Act. It should be transparent in providing information on the financial sustainability of the Scheme. Having transparency as a standalone principle reinforces the standard that, to the greatest extent possible, the administration of the NDIS should be visible to the public.

Second, it is important that commitment to service be a key principle. The principles should recognise that the NDIS comprises 'the provision of services or activities'[29] to people with disability, and that the NDIA, first and foremost, is an agency established to 'deliver'[30] the NDIS. It is crucial that the NDIA recognises that the provision of high quality and professional services is central to its role. The *Public Service Act 1999* (Cth) contains a similar value in respect of the Australian public service.[31]

Finally, accountability must be a core principle in the Participant Service Guarantee. The NDIA should be held to account, and should strive to be accountable in its delivery of the NDIS. Some of the key issues outlined in this submission relate to the difficulties with holding the NDIA accountable: for instance, its failure to implement systemic changes to policies following adverse AAT or Court decisions, or the inability to hold the NDIA accountable for delays to internal review processes. It must be clear in the Guarantee that the objectives of the NDIS Act and the principles in the Guarantee are not stretch targets; rather they are tangible and achievable goals that the NDIA will be held accountable for failing to meet.

Recommendation 13: The principles for the Participant Service Guarantee should be legislated

The principles for the Participant Service Guarantee should be inserted into the NDIS Act, alongside the general principles guiding action under ss 4 and 5 of the Act.

Recommendation 14: The principles for the Participant Service Guarantee should include accountability, transparency and commitment to service

In addition to the principles proposed in the Discussion Paper, separate principles should be adopted in relation to each of accountability, transparency and commitment to service.

7. Other legislative reform

In addition to the recommendations made above to legislative reform on specific issues, PIAC makes the following specific recommendations on legislative changes to the NDIS Act. The following table provides comments on the COAG agreed amendments from the 2015 NDIS Act Review. Where no comments are provided on particular amendments previously agreed by COAG, PIAC expresses no views on the matter.

Section to be amended	Description of recommended change
Sections 4(2), 4(8), 4(9)(a), 5(d), 17A, 209(3)	PIAC supports the COAG agreed amendments to these provisions.
Sections 9, 31, 33, 36, 37, 41, 47, 48, 49, 50, 55, 78, 79, 96, 99 and 104	As noted in this submission, PIAC does not consider the change to terminology from 'plan review' to 'plan reassessment', as distinct from 'review of decisions', to be sufficient to clarify confusion between s 48 and s 100 reviews. PIAC recommends the changes referred to at Recommendation 11.

[29] NDIS Act s 8.
[30] NDIS Act s 118(1)(a).
[31] *Public Service Act 1999* (Cth) s 10(1).

8. Conclusions: Improving choice and control for all Australians

The NDIS is a major piece of social reform which has the potential to revolutionise the way in which people with disability are supported to participate fully in the Australian community. The rollout of the NDIS represents a major challenge, and the community is committed to ensuring the Scheme works as it should: to improve choice and control for all Australians.

This submission has highlighted that there are many improvements that can be made to the decision-making, review and appeals processes. Creating systemic change to improve these processes will provide greater transparency, consistency, accountability and equity across the entire Scheme.