



## **Submission to the Joint Standing Committee on the NDIS**

### **Inquiry into General issues around the implementation and performance of the NDIS**

**13 July 2020**

## 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.

## Contact

Gudrun Dewey  
Public Interest Advocacy Centre  
Level 5, 175 Liverpool St  
Sydney NSW 2000

Chadwick Wong  
Public Interest Advocacy Centre  
Level 5, 175 Liverpool St  
Sydney NSW 2000

Website: [www.piac.asn.au](http://www.piac.asn.au)



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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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# **Recommendations**

## ***Recommendation 1 – Publication of settlement outcomes***

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*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 2 – Publication of typical support package guidelines***

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*If typical support packages are to be used by the NDIA as guidelines in creating participant plans, the NDIS legislative framework should require their publication and recognise that any guidelines published are guidelines only in the creation of plans that are person-centred and tailored to an individual’s goals.*

## ***Recommendation 3 – Publication of guidelines on financial sustainability***

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*The NDIA should publish guidelines on the manner in which it considers financial sustainability of the NDIS is relevant to planning decisions, and the way in which financial sustainability is determined. The NDIA’s guidelines should be informed by the following principles:*

- *the preparation and approval of a participant’s plan must take place through a participant-centric decision-making approach;*
- *the need to ensure the ‘financial sustainability’ of the Scheme is given effect through the application of the reasonable and necessary supports criteria under s 34, and is not a stand-alone ground on the basis of which the NDIA can refuse to fund a support;*
- *consideration of broader financial implications of funding a support in relation to other potential participants undermines the participant-centric approach and is not relevant to the assessment of ‘reasonable and necessary’ supports for an individual participant.*

## ***Recommendation 4 – Implementing systemic changes to reflect AAT and court decisions***

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*The NDIA should implement a transparent and accountable process to ensure that the NDIA’s advice and operational guidelines are updated to reflect relevant settlement outcomes and AAT and court decisions. The NDIA should report on any updates in its quarterly reports to the COAG Disability Reform Council.*

## ***Recommendation 5 – Clarify the meaning of available and appropriate treatment***

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*The NDIS Act and Rules 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 legislative framework 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.*

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***Recommendation 6 – Shift the burden of navigating NDIS and mainstream services gaps away from participants***

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*The NDIA should amend the Operational Guidelines to ensure that, where it 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, provided by that other service. In the absence of that support being provided by another service, the NDIA must not rely on s 34(1)(f) to determine that the support is not reasonable and necessary.*

***Recommendation 7 – Reimbursement to a participant following a successful review***

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*The NDIA should reimburse the participant, their family or their carer, as the case may be, for expenditure:*

- (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.*

## 1. Introduction

The Public Interest Advocacy Centre (**PIAC**) welcomes the opportunity to make a submission to the Joint Standing Committee's inquiry into general issues around the implementation and performance of the National Disability Insurance Scheme (**NDIS**).

PIAC has lengthy experience in tackling barriers to justice and fairness experienced by people with disability. As part of this work, in July 2019, PIAC commenced a legal advocacy project to deliver better outcomes under the NDIS for people with disability. PIAC's project, A Fairer NDIS, aims to support improvements to the effectiveness of the NDIS, and to create sustained impact in the interests of empowering the choice and control of people with disability.

This submission builds on PIAC's submission to the Joint Standing Committee's inquiry into NDIS Planning.<sup>1</sup> It focuses on two recurrent issues in the NDIS: the need to improve transparency in decision-making, and the need to strengthen the legal framework to help ensure fair decisions and just outcomes for people with disability.

Where relevant, we refer to findings and recommendations in the report of David Tune AO PSM's review of the NDIS Act (**Tune Review**) in December 2019. At the time of writing this submission, the Government response to the Tune Review report has not yet been released.

## 2. Improving transparency

A central purpose of the NDIS is to 'enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports'.<sup>2</sup> Transparency must be a cornerstone in the administration of the NDIS to ensure that the rights of people with disability are promoted and that people with disability are empowered to exercise informed choice and control in the planning and delivery of their supports.

A lack of transparency impairs the ability of participants, carers and advocates to understand the types and level of supports a participant can seek, the amount of funding that could be provided, and the reasons for decisions made in relation to their support needs.

It also impairs the ability of the community to hold the NDIA to account, to ensure that decision-making under the *National Disability Insurance Scheme Act 2013 (Act)* is consistent, accountable and in accordance with the law.

This was recognised in the Tune Review, which found that a lack of transparency 'is driving a lack of trust and confidence in the NDIA' and concluded that transparency and public accountability are likely to be 'the most effective tool to drive improved participant outcomes'.<sup>3</sup>

<sup>1</sup> PIAC, *Submission to the Joint Standing Committee on the NDIS in inquiry into NDIS planning*, 6 September 2019, available at <https://piac.asn.au/2019/09/06/submission-to-the-joint-standing-committee-on-the-ndis-planning-inquiry/>.

<sup>2</sup> *National Disability Insurance Scheme Act 2013 (Act)*, s 3(1)(a).

<sup>3</sup> David Tune AO PSM, *Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee*, 2 December 2019 (**Tune Review report**), [10.61].

The Tune Review report recommended that transparency be enshrined in the proposed Participant Service Guarantee as a key engagement principle and service standard to underpin the delivery of the NDIS.<sup>4</sup>

PIAC is particularly concerned about the lack of transparency in relation to: (1) settled outcomes of external appeals to the AAT, (2) the use of typical support packages as a guide in planning decisions, and (3) how the financial sustainability of the NDIS is considered in planning decisions. Publishing AAT settlement outcomes and typical support packages, and clarifying the role of financial sustainability considerations in planning decisions, are important steps the NDIA should take to improve transparency in its administration of the NDIS.

## 2.1 Publishing settlement outcomes

As at March 2020, of the 3,608 appeals that have been lodged at the AAT since the NDIS was rolled out, only 3 per cent of cases have gone to hearing and received a substantive decision.<sup>5</sup> 97 per cent of appeals have been settled before hearing, however there is presently no publicly available information on settlement outcomes.

As the Joint Standing Committee will recall, as part of the inquiry into NDIS planning, PIAC's recommendation to publish de-identified settlement outcomes was unanimously adopted by the Committee. In December 2019, the Committee strongly supported PIAC's recommendation in its NDIS Planning Interim Report 'as a means of increasing transparency and accountability for participants and planners',<sup>6</sup> and recommended that 'the NDIA publish settlement outcomes relating to external review by the AAT, in de-identified form.'<sup>7</sup>

The Government responded in February 2020 and raised concerns that publishing settlement outcomes would impose a burden on resources, create privacy issues, and create a misconception that the terms of individual agreements reached between the NDIA and an applicant could be generalised to other applicants with a similar disability.

PIAC remains of the view that publishing settlement outcomes is important to helping participants and planners better understand the types of supports that can be sought and funded under the NDIS and to improve consistency and fairness in planning decisions.

Regarding the Government's concerns, PIAC's view is that a settlement register would not be resource-intensive – because relevant information could be recorded on a database as a matter of business-as-usual file closure procedures – and could respect privacy through removing identifying details and seeking consent from individuals where necessary. We also do not agree that the publication of outcomes would create the misconception suggested by the Government – this is the same approach taken by the Australian Human Rights Commission to their Conciliation Register, with no suggestion that the Commission's Register could be generalised to other individuals.

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<sup>4</sup> Tune Review report, [10.12].

<sup>5</sup> NDIA, *Report to the COAG Disability Reform Council for Q3 of Y7 Full Report*, 117.

<sup>6</sup> Joint Standing Committee on the NDIS, *NDIS Planning Interim Report* (December 2019), [3.96].

<sup>7</sup> *Ibid*, Recommendation 6.

There continues to be a strong desire from the disability sector for this information to be made publicly available. In July 2020, over 20 disability organisations – including the peak bodies, Australian Federation of Disability Organisations and People with Disability Australia – endorsed an open letter to the Minister to express support for the recommendation. A copy of the open letter, which was copied to the Joint Standing Committee, is at **Attachment A**.

The NDIA's reluctance to publish settlement outcomes suggests that it is unwilling to publish information that it considers could encourage participants to seek higher levels of funding. Any such reluctance should be resisted. Participants should be empowered to seek the support they require; it is the role of the NDIA to approve the reasonable and necessary supports they are entitled to within the legislative framework.

#### ***Recommendation 1 – Publication of settlement outcomes***

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*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.*

## **2.2 Guidance on typical support packages**

There remains an unreasonable lack of transparency around the use of typical support packages in the planning process.

In response to questions on notice during estimates hearings in March 2020, the NDIA described typical support packages as the 'baseline amount of funding based on the participant's disability, individual support needs and characteristics', which are used by NDIS planners 'to understand if a participant's funded supports are within the expected range and to make sure they are using an evidence based and nationally consistent approach to planning'.<sup>8</sup> The NDIA said that there are around 15,000 typical support packages considering all the combinations of disability, age, level of function, and other adjustment factors. It said that these serve as a 'guide for planners' when making decisions about the funded supports to include in a participant's plan and a 'monitoring tool' for management to 'understand differences from expected'.

However, despite typical support packages being used as an essential tool in decisions as to whether certain supports will be funded, the NDIA has refused to publish details of typical support packages, examples of such packages, or to make them available in individual planning processes. On the one hand, this raises concerns that they may be applied contrary to the requirement that plans be individualised and with the result that participants receive inadequate, or insufficiently tailored, supports under their plan. On the other hand, despite their use, participants have complained about a lack of consistency in decision-making across people with apparently similar needs.

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<sup>8</sup> Senate Community Affairs Legislation Committee, *Additional Estimates – 5 March 2020, Answer to Question on Notice to the National Disability Insurance Agency*, Question reference number: NDIA SQ20-0000146.

If typical support packages are to be used as guidelines in NDIA decisions about participant supports, they should be published and planners should clearly explain to participants how they are used.

The NDIA has previously stated that it does not proactively publish typical support packages as part of its publication of operational information<sup>9</sup> because ‘releasing the data could risk manipulation of responses to questions on participant circumstances in order to receive higher funding amounts.’<sup>10</sup>

PIAC considers this is not a sufficient basis to exclude typical support packages from publication. There is no basis for the assertion that releasing typical support packages could risk participants using the information to manipulate the planning process for a desired outcome. The Act mandates an individualised planning approach and the stringent criteria in the Act and Rules require NDIA decision-makers to consider evidence in order to be satisfied that a person is eligible for support and the support is reasonable and necessary.

This is all the more so when it comes to explaining how typical support packages are used, or publishing examples of the ‘15,000’ typical support packages.

As with the NDIA’s reluctance to publish settlement outcomes, the NDIA’s unwillingness to publish typical support packages suggests an unwillingness to publish information that could encourage participants to seek higher levels of funding. This approach should be resisted for the same reasons. People with disability should be empowered to seek the support they require and it is the role of the NDIA to approve the supports to which they are entitled in accordance with the legislative framework.

The Tune Review highlighted that many participants do not understand how the planning process works or the sorts of things that might be included in their plan. Any risk that publishing typical support packages could encourage people to manipulate responses about their circumstances (which in itself is a proposition made by the NDIA unsupported by any evidence) is outweighed by the benefits such transparency would have on improving participants’ understanding of the planning process.

### ***Recommendation 2 – Publication of typical support package guidelines***

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*If typical support packages are to be used by the NDIA as guidelines in creating participant plans, the NDIS legislative framework should require their publication and recognise that any guidelines published are guidelines only in the creation of plans that are person-centred and tailored to an individual’s goals.*

<sup>9</sup> Under s 8(2) of the *Freedom of Information Act 1982*, the NDIA must publish its operational information, defined in s 8A as ‘information held by the agency to assist the agency to perform or exercise the agency’s functions or powers in making decisions or recommendations affecting members of the public (or any particular person or entity, or class of persons or entities). Example: The agency’s rules, guidelines, practices and precedents relating to those decisions and recommendations.’

<sup>10</sup> Senate Community Affairs Legislation Committee, *Additional Estimates – 5 March 2020, Answer to Question on Notice to the National Disability Insurance Agency* (NDIA SQ20-0000146).

## **2.3 Guidance on financial sustainability considerations**

PIAC remains concerned about the NDIA's approach to applying financial sustainability considerations when making decisions about an individual participant's supports.

The importance of ensuring the financial sustainability of the NDIS is reflected in the Act and the *NDIS (Supports for Participants) Rules 2013*. They require the NDIA to 'have regard to' 'the need to ensure the financial sustainability of the NDIS' in giving effect to the objects of the Act, when acting in accordance with the general principles that guide actions under the Act, and in administering the NDIS and approving each plan.<sup>11</sup>

However, there is a lack of clarity as to how the NDIA must 'have regard to' financial sustainability. Notably, s 34 of the Act, which sets out the considerations for determining 'reasonable and necessary supports', does not refer to financial sustainability.

There are two aspects to this problem. First, there is a lack of transparency around how the NDIA is applying this consideration in practice. From the conduct of the NDIA in a number of AAT and Federal Court matters, there are concerns that the NDIA's approach is not correct.

Second, there is a need to identify 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.

### ***Approach of the NDIA to financial sustainability considerations***

First, there is no guidance from the NDIA on how it, in practice, has 'regard to' financial sustainability when making decisions about an individual participant's plan. It is not possible to ascertain whether the NDIA applies financial sustainability considerations in accordance with the requirements of the NDIS Act.

Based on the NDIA's approach to AAT and Federal Court matters, the NDIA appears to be inappropriately relying on broad-based actuarial evidence as a basis to determine that supports, which are otherwise reasonable and necessary for an individual, are not funded due to financial sustainability considerations for the whole of the NDIS.

For example, in *WRMF and NDIA [2019] AATA 1771*, the NDIA relied on actuarial evidence 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.'<sup>12</sup> The evidence did not refer to data as to the extent to which people with multiple sclerosis or other disabilities might wish to use a sex worker, the frequency with which such requests would otherwise meet the criteria for 'reasonable and necessary support' under the NDIS Act, and the actuarial report did not consider what the cost might be if calculated on the assumption that the support claimed was the more specialised support sought by WRMF. The AAT found that the NDIA's actuarial evidence 'shed little or no light on the financial sustainability of the NDIS', and the Full Court of the Federal Court, which dismissed the NDIA's appeal, upheld that finding.<sup>13</sup>

<sup>11</sup> *NDIS Act 2013*, ss 3(3) and 4(17); *NDIS (Supports for Participants) Rules 2013*, paras 1.3 and 2.5.

<sup>12</sup> At [42].

<sup>13</sup> *NDIA v WRMF [2020] FCAFC 79*, [114].

A similar 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’.<sup>14</sup> This approach undermines the choice and control of people with disability, by assuming that all participants with the same disability in similar circumstances will seek the same supports. It also does not provide a sufficient evidentiary basis for rejecting a support that would otherwise satisfy the requirements for ‘reasonable and necessary’.

More recently, the NDIA appears to be making a new argument that it has ‘residual discretion’ to refuse funding on the basis of, among other things, the need to ensure the financial sustainability of the NDIS. In *NDIA v WRMF* [2020] FCAFC 79, the NDIA argued that it has a residual discretion not to fund a support in a participant’s plan even where the support satisfies the reasonable and necessary criteria in s 34, on the basis that it would jeopardise the financial sustainability of the NDIS.<sup>15</sup>

This approach would mean that the NDIA could decide to refuse to fund supports, which were otherwise determined to be reasonable and necessary in accordance with the Act, based on grounds that are not made clear to participants. As observed by the Full Court of the Federal Court, this would be a ‘somewhat substantial revision’ to how the NDIS is currently understood to work.<sup>16</sup> This approach would make NDIA decisions even more opaque and less accountable than is already the case.

### ***Clarity needed***

The manner in which the NDIA takes the financial sustainability of the NDIS into account in individual planning decisions requires increased transparency and clarification.

In PIAC’s view, the need to ensure financial sustainability of the NDIS (as expressed in the objects (s 3(3)) and principles (s 4(17)) provisions of the Act) does not constitute a stand-alone consideration that would allow the NDIA to refuse to fund a support on the basis that it would threaten the financial sustainability of the NDIS, where that support otherwise meets the criteria in s 34(1) of the Act as being reasonable and necessary.

Financial sustainability considerations are already factored into the reasonable and necessary criteria in s 34(1)(a)-(f), which assist the decision-maker to form a state of satisfaction about whether a support is reasonable and necessary. In fact, certain criteria – such as s 34(1)(c) (that the support represents value for money) and s 34(1)(f) (that the support is most appropriately funded or provided through the NDIS) – ‘expressly incorporate’ the financial sustainability consideration into the determination of whether a support is reasonable and necessary under s 34(1).<sup>17</sup> Consistent with the participant-centric approach required under the Act, the financial sustainability of the NDIS and any associated actuarial evidence is appropriately given effect through the application of the reasonable and necessary supports criteria.

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<sup>14</sup> *McPherson and NDIA* [2018] AATA 4303, [42].

<sup>15</sup> *NDIA v WRMF* [2020] FCAFC 79, [158]-[167].

<sup>16</sup> At [167].

<sup>17</sup> *McGarrigle v NDIA* [2017] FCA 308, [109].

PIAC recommends that the NDIA publish guidelines to clarify how it considers the financial sustainability of the NDIS is relevant to individual eligibility and funding decisions, and how financial sustainability is determined. Such guidance should clarify that ‘the need to ensure the financial sustainability of the NDIS’ is given effect through the application of the reasonable and necessary supports criteria under s 34, and is not an additional criterion on the basis of which the NDIA has a residual discretion to refuse to fund a support. Any guidance should be regularly reviewed and updated to incorporate developments in case law and to ensure consistency with the legislative criteria.

#### ***Recommendation 3 – Publication of guidelines on financial sustainability***

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*The NDIA should publish guidelines on the manner in which it considers financial sustainability of the NDIS is relevant to planning decisions, and the way in which financial sustainability is determined. The NDIA’s guidelines should be informed by the following principles:*

- *the preparation and approval of a participant’s plan must take place through a participant-centric decision-making approach;*
- *the need to ensure the ‘financial sustainability’ of the Scheme is given effect through the application of the reasonable and necessary supports criteria under s 34, and is not a stand-alone ground on the basis of which the NDIA can refuse to fund a support;*
- *consideration of broader financial implications of funding a support in relation to other potential participants undermines the participant-centric approach and is not relevant to the assessment of ‘reasonable and necessary’ supports for an individual participant.*

### **3. Strengthening the legal framework**

In addition to the need to improve transparency and accountability in NDIA decision-making, the legal framework for decision-making also requires strengthening in certain areas to better support fair and just outcomes.

Key current issues relating to the legal framework, which can result in people being unfairly excluded from the NDIS or denied reasonable and necessary supports, are: where NDIA policies and decisions are inconsistent with AAT and court outcomes; ambiguity in the application of the Act’s permanence criteria; unresolved gaps between the NDIS and mainstream service systems; and uncertainty as to whether the NDIA will reimburse a participant where a decision not to fund a support is overturned on review.

Our recommended reforms to address these issues includes amendments to the legislative framework, but also changes in the approach of the NDIA to decisions made at the AAT and Federal Court.

#### **3.1 Implementing systemic changes to reflect AAT and court decisions**

There are a number of instances where the NDIA has failed to implement, or unreasonably delayed implementation of, changes to policies and practices following settlement or decisions at the AAT or even at the Federal Court of Australia. This is a key issue, as 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.

It also means the oversight mechanism is ineffective, if policies which are deemed inconsistent with the NDIS Act (and thereby unlawful) continue to be applied by the NDIA.

The NDIA has so far failed to implement a mechanism to ensure that policies and operational guidelines are updated to reflect AAT and court decisions.

For example, in 2017 the Federal Court clarified the approach to decision-making about transport supports in *McGarrigle v NDIA* [2017] FCA 308, finding that once a support is found to meet the reasonable and necessary criteria it should be fully, rather than partially, funded. However this outcome was not reflected in the NDIA's operational guidelines until October 2019, and the change was only made following representations by PIAC and other organisations to the NDIA.

This delay is unacceptable. Court decisions that directly contradict NDIA policies and practices are binding and must be implemented systemically at the first opportunity. The failure to implement decisions swiftly undermines the oversight mechanism of the appeals process, and wastes resources by resulting in confusion and appeals on issues that should be considered settled.

A further example is in relation to gym memberships. The AAT has consistently stated, since the 2018 decision of *Milburn and NDIA* [2018] AATA 4928, that gym memberships can be funded by the NDIS in certain circumstances. The reasoning in that decision has been accepted in two subsequent AAT decisions and raised by the NDIA itself in one of those decisions.<sup>18</sup> Despite this, the NDIA website continues to advise that the NDIS does not fund gym memberships.<sup>19</sup>

In relation to AAT decisions, in discussions with PIAC, the NDIA has taken the position that AAT decisions provide non-binding interpretations of law and policy, and therefore do not necessarily need to be implemented by the NDIA. While this may be technically correct, it results in an ineffective oversight mechanism, especially where the AAT has made consistent decisions on a particular policy issue or on the application of the law.

The NDIA should implement a mechanism to ensure that its operational guidelines and policies are up to date in reflecting relevant AAT and Court decisions. These documents should also reflect settlement outcomes that have an impact beyond the individual case. The NDIA should report on such updates in its Quarterly Report to the COAG Disability Reform Council to ensure transparency and accountability.

It may be that not all AAT or Court decisions require changes to policies. But where they do, as in *McGarrigle*, it should not take over two years for the changes to be (partially) implemented.

#### **Recommendation 4 – Implementing systemic changes to reflect AAT and court decisions**

*The NDIA should implement a transparent and accountable process to ensure that the NDIA's advice and operational guidelines are updated to reflect relevant settlement outcomes and AAT*

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<sup>18</sup> *McKenzie and NDIA* [2019] AATA 3275, [79] and *Hoolachan and NDIA* [2019] AATA 4798, [56]-[57]. The NDIA raised it in *Hoolachan and NDIA* at [56].

<sup>19</sup> NDIA, *Support budgets in your plan*, <https://www.ndis.gov.au/participants/using-your-plan/managing-your-plan/support-budgets-your-plan> (accessed on 1 July 2020).

*and court decisions. The NDIA should report on any updates in its quarterly reports to the COAG Disability Reform Council.*

### **3.2 Clarifying the definition of ‘permanence’**

Under 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’ (s 24(1)(b)). The *NDIS (Becoming a Participant) Rules 2016* provide guidance on when an impairment is permanent or likely to be permanent (paragraphs 5.4 to 5.7).

However, PIAC is aware of two issues in relation to this permanence criteria.

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’.<sup>20</sup> 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.<sup>21</sup> PIAC supports this need for clearer guidance when it comes to psychosocial disabilities.

Second, the NDIA’s 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.<sup>22</sup>

In a practical example, one stakeholder told PIAC of a client – ‘Emma’ – who 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

<sup>20</sup> 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).

<sup>21</sup> 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.’

<sup>22</sup> Schwass and NDIA [2019] AATA 28.

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.

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.<sup>23</sup> 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.<sup>24</sup>

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.

#### ***Recommendation 5 – Clarify the meaning of available and appropriate treatment***

*The NDIS Act and Rules 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 legislative framework 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.*

### **3.3 Resolving gaps between the NDIS and mainstream service systems**

The Tune Review heard that there is a lack of clarity at an operational level about the lines of responsibility between the NDIS and mainstream service systems, 'resulting in boundary issues and funding disputes, service gaps and confusion for NDIS participants, poor quality planning and

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<sup>23</sup> Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011 (Cth), s 6(4).

<sup>24</sup> Ibid, s 6(7)(a)-(f).

inconsistent decisions about when a support is reasonable and necessary.<sup>25</sup> These gaps between the NDIA and mainstream service systems create situations where people with disability are either unable to get the support they need from the appropriate system, or unable to navigate the process to determine which system ought to provide the support.

These gaps have commonly existed between the NDIS and education services, health services, corrective services, justice services, housing services and child protection and family support services.

Under the legislative framework, these gaps arise in two instances. The first is in relation to eligibility. Under section 21 of the Act, a person meets the criteria for access to the NDIS if they satisfy the age requirements, residence requirements, and either the disability or early intervention requirements. However, under section 25(3), even if a person would otherwise satisfy the early intervention requirement, they would not be able to access the NDIS if the support is ‘not most appropriately funded or provided’ through the NDIS, and is more appropriately funded by another system of service delivery.

The second instance is in relation to reasonable and necessary supports in a participant’s plan. Before approving such a support, the NDIA must be satisfied of the reasonable and necessary criteria in s 34(1) including that the support is most appropriately funded or provided through the NDIS, and is not more appropriately funded or provided through other service systems (s 34(1)(f)).

In *Burchell and NDIA* [2019] AATA 1256, the AAT 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. In other words, the NDIA cannot determine that another service provider should provide a support even if they do not.

After the decision in *Burchell* was handed down, the COAG Disability Reform Council (**DRC**) provided further clarity on the interaction between key interface areas, particularly in health services, housing and child protection areas.

The principle established in *Burchell* however, does not appear to have been adopted by the NDIA more broadly. While the boundaries between the NDIS and other service systems continue to be clarified, the burden must not fall on NDIS participants to navigate the gaps between the NDIS and mainstream services and ending up worse off or without the support they need.

The NDIA should update its operational guidelines to ensure that decisions are consistent with the approach in *Burchell*. That is, where the NDIA determines that a support is more appropriately funded by another service system, it must in fact be funded by that system. In the absence of the support being funded by another service, the NDIA must not rely on s 34(1)(f) to determine that the support is not reasonable and necessary.

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<sup>25</sup> Tunc Review report, [6.26].

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***Recommendation 6 – Shift the burden of navigating NDIS and mainstream services gaps away from participants***

*The NDIA should amend the Operational Guidelines to ensure that, where it 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, provided by that other service. In the absence of that support being provided by another service, the NDIA must not rely on s 34(1)(f) to determine that the support is not reasonable and necessary.*

### **3.4 Reimbursing participants following successful review**

NDIS participants presently bear the financial burden for the period of time they did not have funding for reasonable and necessary supports as the result of an incorrect decision. This burden can be significant, particularly in circumstances where there is delay in the conduct of internal reviews.

The recent case of *XXWC by his mother and NDIA* [2020] AATA 923 demonstrates the unfairness that can result. XXWC is a three year old boy, diagnosed with Autism Spectrum Disorder when he was 18 months old. His parents sought review of the funding decision in his original NDIS plan, seeking funding for a further 18 hours of early intensive behavioural intervention each week. By the time of the review, the NDIA had agreed that the plan budget should be varied to provide for this, however – having personally shouldered the costs for the additional hours up until the plan’s variation – XXWC’s parents sought to be reimbursed for the personal expenditure that had resulted from the initial decision. The AAT considered it did not have the power to make an order for reimbursement, but noted that this is not to say that the NDIA does not have the power to reimburse monies spent.<sup>26</sup>

Reimbursing participants for expenditure that should not have been incurred is distinct from imposing a financial penalty on the NDIA. The Tune Review considered that a financial penalty should not be a consequence where the NDIA fails to comply with timeframes in the proposed Participant Service Guarantee, noting that this ‘could create perverse incentives as it could drive the NDIA to make quick but poor quality decisions in favour of avoiding the financial impact of paying the penalty.’<sup>27</sup> However the Tune Review did not consider the issue of whether the NDIA should reimburse participants for out-of-pocket expenditure following a successful review.

PIAC considers that the NDIA should reimburse participants for expenditure on supports in instances where the NDIA’s decision not to fund that support is overturned on internal or external review. This will help to address the disadvantage to participants caused by incorrect decision-making.

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***Recommendation 7 – Reimbursement to a participant following a successful review***

*The NDIA should reimburse the participant, their family or their carer, as the case may be, for expenditure:*

*(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*

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<sup>26</sup> At [119]-[124].

<sup>27</sup> Tune Review report, [10.60].

- (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.

## 4. Conclusion

The NDIS 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.

Our submission highlights that there are recurring issues with particular aspects of the administration of the NDIS, which ought to be addressed to ensure the NDIS works as intended.

The reforms we have recommended would contribute to much needed increased transparency in decision-making and strengthen the legal framework to address issues that have led to reasonable and necessary supports being unfairly denied. In doing so, they would help to improve the performance of the NDIA to deliver fair and just outcomes for people with disability.