public interest
ADVOCACY CENTRE

A Fairer NDIS

Improving outcomes under the
National Disability Insurance Scheme
for people with disability

Issues Paper

November 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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1. Introduction: A Fairer NDIS

In July 2019, PIAC commenced a legal advocacy project to deliver better outcomes under the National Disability Insurance Scheme (NDIS) for people with disability.

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 reported 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, to empower 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.

The scope of our project is confined to overarching, foundational issues in the NDIS that may have an impact on all participants and would-be participants, including the issues identified in this paper. Our project does not, at this stage, extend to considering specific types of supports or disabilities under the NDIS.

Over the course of July to early September 2019, PIAC engaged in extensive consultations with stakeholders across the disability sector to understand the concerns of the community in engaging with the National Disability Insurance Agency (NDIA) at key decision-making points.

This Issues Paper distils the key issues identified across the disability sector during the course of these consultations and suggests proposals for reform.

PIAC invites responses to this Issues Paper to inform our work, including our engagement with decision-makers within the NDIA, the Administrative Appeals Tribunal (AAT), and Members of Parliament.

2. Consultation purpose and methodology

PIAC has engaged widely with the disability sector, to understand the issues facing people with disability and their advocates, families and carers. We are very grateful for the time and effort that people have taken in communicating with us. We have also conducted our own research of published material. This has allowed us to:

- develop relationships with key disability advocates and organisations to ensure the project's goals are aligned with issues identified on the ground, and ensure referrals can be made to PIAC for future casework;
- understand issues facing people with disability that are relevant to the project, with a particular focus on marginalised groups including Indigenous people with disability, culturally and linguistically diverse (**CALD**) groups, people in rural and regional areas, and people with particular disadvantages, such as intellectual disabilities; and

- identify relevant case studies, so PIAC can better understand and explain how participants in the NDIS are affected by NDIA decision-making and appeals in practice.

Since July 2019, PIAC has consulted over 25 organisations in the disability sector, covering peak disability organisations, legal service providers and Legal Aid Commissions, general and specialised disability advocacy groups, including advocacy groups for CALD people with disability and Indigenous people with disability, academics, and the AAT. PIAC has also participated in multiple conferences and forums, extending our reach beyond the organisations we were able to consult individually.

The trends and issues identified through our consultations and research are explored below, broken down into policy issues and legal issues.

3. Policy issues

Our consultations identified a significant number of policy issues in relation to review and appeals processes – both internally at the NDIA and externally during conciliations and hearings at the AAT. These include:

- inconsistency in decision-making by the NDIA around plan approvals;
- poor communication with applicants and lengthy delays in the conduct of internal reviews by the NDIA;
- adversarial attitudes of NDIA representatives when defending AAT appeals;
- the formal and legalistic environment of the AAT, especially where applicants are not legally represented;
- failure by the NDIA to implement systemic changes to policies following settlements, AAT decisions and even Federal Court decisions;
- cases where individuals have received better outcomes by engaging their local Members of Parliament than by going through the review and appeals process; and
- accessibility and outreach issues, especially for people from CALD communities, Indigenous communities, rural and regional areas, and people with intellectual disabilities.

3.1 Inconsistency in decision-making

A common theme and frustration identified by stakeholders is inconsistency by the NDIA at various levels of decision-making and especially around plan approvals.

At the first stage, when preparing the 'statement of participant supports' *with* the participant, and approving that statement under section 33 of the Act, disability advocates consistently stated that decisions made by delegates appear to depend on:

- the ability of the participant, experts and medical professionals to articulate the person's goals and needs in the language of the NDIS, rather than in language that reflects their true needs;

- individual decision-makers and the approach taken in different offices of the NDIA, with advocates concerned about inconsistent decisions being 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 CALD and Indigenous people with disability. 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.

Advocates advised that these issues are especially apparent for people with multiple disabilities. In these cases, where funding is assessed based on the identification of a 'primary disability', planners are said to make decisions based on a need to fit a person's impairments into the right 'box', without appropriate consideration of how a person's multiple disabilities collectively impact their day-to-day life.

Concerns about poor decision-making at this initial stage are heightened by the lack of transparency around how decisions are made.

Stakeholders recognised that the NDIA uses typical support guidelines or reference packages to identify the level of funding to be provided to people with certain impairments.[1] It appears that these guidelines or packages are 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'.[2] On the other hand, despite their use, stakeholders were 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 reached through settlement.[3] The nature of settlements are private, confidential and non-binding on non-parties to the settlements.

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[1] The use of reference packages is also discussed in Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs* (Study Report, October 2017) 193-195.

[2] NDIS Act s 31(a).

[3] National Disability Insurance Agency, *COAG Disability Reform Council Quarterly Report* (Report, 30 September 2019) 102. The Report states that 1,908 cases out of 1,982 finalised cases had been resolved by settlement as at 30 September 2019.

Increasing the transparency in settlement outcomes will assist with addressing inconsistencies in decision-making, as it will allow some level of public accountability to ensure the NDIA makes decisions consistently with previous settlements. It will also improve the ability of participants to understand the types of supports that are funded, and assist participants to decide what types of supports they could seek.

All stakeholders consulted agreed that having access to de-identified settlement outcomes is highly desirable.

3.2 Internal reviews

Throughout our consultations, there were two primary issues identified relating to the internal review process. The first relates to delays in conducting internal reviews, and the second to the complexity of the process, which exacerbates delays.

3.2.1 Delays

As with the initial approval process, those who have applied for internal review are experiencing significant delays in receiving a decision. At the same time, there is limited information provided to individuals during 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 an internal review not completed within a 'reasonably practicable' timeframe is a deemed refusal which can be subject to an appeal to the AAT.

Stakeholders told us that in many instances – some suggested over 50% of the cases they assisted with – internal reviews were so delayed 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.

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, while risking exhausting all funds 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 us about the difficulties one 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 the removal of the child by the State, unless she could receive support for his disability. 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;[4] and

- disproportionate impacts on people requiring early intervention supports.

It was pointed out to PIAC that unlike with other forms of government administration, there is no clear basis for the back-payment or back-dating of funds for people who successfully challenge NDIA decisions at the AAT. 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. This means there is no financial disincentive for the NDIA to avoid delays in the review or appeals process and no compensation for people who have been disadvantaged by what may have been poor decision-making.

Stakeholders have also spoken of the inconsistency in the level of detail in reasons given for negative reviews. Some decision-makers give limited reasons for their review decisions, which makes it difficult for people with disability to decide whether they should file an appeal with the AAT, and on what basis such an appeal should be made.

Many of these issues were canvassed by the Commonwealth Ombudsman in its May 2018 report, *Administration of reviews under the National Disability Insurance Scheme Act 2013*. While the Commonwealth Ombudsman has noted that some of its recommendations have been implemented, the fact that stakeholders continue to see lengthy delays in the internal review process remains a serious concern.

3.2.2 Complexity

Related to the issue of delays is the complexity in the internal review process set out in the NDIS Act. Stakeholders identified that this complexity was leading to confusion not just from participants seeking to access the internal review process, but also from the NDIA in administering internal reviews.

Deputy President Forgie's comments in *LQTF and National Disability Insurance Agency* [2019] AATA 631 at [2]-[3] best summarise 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,

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

> 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 a review sought of 'a decision not to reassess a participant's plan' (a decision made under section 48(2)) and a review sought of a decision not to approve a statement of supports (a decision made under section 100(6), with regard to section 33(2)).

Under section 33(2) (combined with section 99), a participant can seek an internal review of a decision around the types of supports approved. Where that internal review, made under section 100(6), confirms the original decision, the participant can appeal the decision to the AAT under section 103.

In contrast, under section 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 can be challenged under section 100, but any appeal from that decision relates only to the decision to refuse the review. It does not involve a review of the substance of the supports approved.

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. As 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.[5]

Ultimately this complexity in the NDIS Act requires reform to the legislation. In the meantime, concerted efforts should be made by the NDIA to reduce the complexity in administering the

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

different internal reviews, and to better assist users with identifying the type of review that they wish to undertake.

3.3 Adversarial nature of AAT appeals

A common complaint by stakeholders was the way in which the NDIA defended appeals before the AAT. All stakeholders who had engaged with the NDIA at the AAT level, including advocates, lawyers and academics, complained about a number of aspects of the NDIA's approach, and offered varying suggestions as to the underlying causes.

3.3.1 Concerns about the conduct of appeals

A number of common complaints were raised with PIAC concerning the conduct of appeals by the NDIA. These included:

- A failure to conduct appeals in accordance with the model litigant guidelines, including:
    - causing delays to the appeals process by failing to meet deadlines set by the AAT. Some stakeholders told us that they had cases that took 18 to 24 months, only to settle just before the hearing. These delays exacerbated the stress of seeking access to supports, particularly for people with psychosocial disabilities, and led to people withdrawing from the appeals process;
    - raising points of contention at the hearing which had been conceded earlier on, either during the internal review stage or at the start of the appeals process;
    - raising points of contention which were not truly in dispute. One stakeholder expressed concern that the NDIA's approach to evidence for proving permanence was overly combative and that, in some cases, those points could have been conceded without pressing for evidence; and
    - the making of arguments that were not legally supported, submissions that were misleading, settlement offers that appeared arbitrary, and assertions around financial sustainability which were unsupported by evidence.
- A lack of sensitivity to the experiences of people with disability, including instances where the NDIA's lawyers used language which was offensive to the applicant.
- An overly adversarial approach to evidence during AAT hearings, including a practice of issuing summonses for the applicant's entire medical record, even where those records were not relevant to their disability. Advocates spoke about the trauma that this can cause, especially where it leads to applicants re-living past trauma.
- Persistent requests for further evidence from expert reports, even where the evidence had already been provided at the internal review stage. In some cases this has resulted in people with disabilities, especially people in regional and rural areas, being forced to repeatedly travel long distances to seek expert opinion, causing both mental and physical stress.
- Frequent changes to the NDIA's approach to evidence and issues in a single matter, resulting from changes in NDIA personnel.
- Delays in NDIA's lawyers receiving instructions, leading to applicants having to present documents two weeks before a conciliation. Some stakeholders, including lawyers and

advocates, spoke of the fact that conciliations would often occur where the NDIA's instructors were not present or available, leading to settlements not being possible on the day.

- Late settlement in favour of the applicant just before the hearing, where no new evidence had been filed by the applicant. In these cases, applicants and advocates believe that the settlement could have occurred much earlier.

Delays at the AAT stage can lead to significant consequences. In addition to the consequences of delays to internal reviews, discussed above, delays may lead to difficulties in a person obtaining funding if their plan review comes up during the middle of an appeals process. For instance, if a participant's plan review date comes up in the middle of an appeals process, there is a question of whether the initial plan can be varied to provide continuity of funding while the appeals process is ongoing, or whether a new plan, potentially replete with the same issues as the plan under review, needs to be approved. This complex issue was recently considered by the AAT in *Williamson and National Disability Insurance Agency* [2019] AATA 2944.

Stakeholders speculated on a range of reasons for the underlying causes of these issues. It was suggested that NDIA panel lawyers coming from insurance law practices may have taken a particularly aggressive approach to defending claims. Criticism was levelled at certain panel firms, with numerous lawyers and advocates complaining about the attitudes and approach adopted by one firm in particular. In contrast, many lawyers and advocates noted the more positive and reasonable approach adopted by the Australian Government Solicitor.

Another common reason speculated by stakeholders was that the NDIA did not want its internal decision-making process to be exposed during the appeals process, or did not want precedents to be set or revisited. This was offered as a reason for the very high percentage of settlements, along with the constant requests for evidence while refusing to offer any evidence of its own. Advocates suggested that these settlements were especially common in transport, psychosocial disability, fibromyalgia and chronic fatigue syndrome-related cases.

PIAC was not in a position to assess these claims, but records them here to reflect the concerns of system participants.

3.3.2 NDIA's response to concerns raised

NDIA is aware of many, if not all, of the concerns raised above relating to the conduct of appeals. A number of stakeholders recognised that the NDIA has made changes as a result of feedback it has received. A representative of the NDIA also responded to many of these issues at the Disability Advocacy Forum, held in Sydney on 20 August 2019.

PIAC understands that the changes made by the NDIA have included:

- establishing the AAT Applications and Decisions Division in October 2018, which manages all new AAT applications and focuses on early resolution of appeals. This Division includes the AAT Early Resolution Team and the AAT Legal Services Branch, with the former team engaging with applicants at an early stage of the appeals process, and the AAT Legal Services Branch taking over if the matter does not resolve in early conferences;
- making it a goal of the Division to meet model litigant obligations, including discussing model litigant obligations at frequent branch meetings; and

- increasing the number of in-house lawyers at the NDIA to ensure model litigant obligations are being met, and to avoid adversarial approaches being taken by panel firms.

The NDIA noted at the Forum that these processes are new and still evolving. These issues should therefore be closely monitored to ensure the concerns of stakeholders are resolved.

3.4 Legalistic nature of the AAT

Some concerns were also raised about the environment of the AAT in dealing with NDIS appeals. Advocates in particular noted the intimidating environment for people with disability, especially if they were not legally represented, but were facing the NDIA's barristers in conferences. There was often a significant power imbalance, exacerbated by some procedures adopted by the NDIA, and permitted by the AAT. For instance, several stakeholders noted that they had attended hearings with the applicant in person, where the NDIA's lawyers appeared over the phone. This created two issues. First, some people with hearing impairments struggled to hear and participate in the hearing. Second, some people found the process disrespectful in that the NDIA did not appear in person to address their concerns.

Several stakeholders also expressed concern that some Tribunal members may be 'desensitised' to the experiences of people with disability. Further training, especially for members without lived experience of disability, on engaging people with disability and understanding the need for reasonable adjustments would be valuable. This would assist in making the AAT process a more restorative, trauma-informed process, focused on the strengths of people rather than their perceived deficits.

3.5 Failure to implement systemic changes

Advocates have identified a number of instances where the NDIA has failed to implement systemic changes following settlement or decisions at the AAT or even at the Federal Court.

First, advocates noted 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. This is also the case for matters that have been determined by the AAT: 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 section 48(4) of the Act to review a participant's plan at any time.

Second, it appears that the NDIA has not always implemented systemic changes to its policies following settlements or decisions. For example, in the case of *McGarrigle*, the outcome of a Federal Court decision in 2017 was not reflected in the NDIA's transport policies until 10 October 2019. This change followed representations from PIAC and other organisations to the NDIA, including at a meeting between PIAC and the NDIA in early October at which this issue was pressed.

McGarrigle v NDIA [6]

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

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

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.[7] 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%.[8]

The Court decided 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 were 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.[9] 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.[10]

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.[11] The Guidelines were recently amended to delete this paragraph.

However, the newly amended Guidelines continue to maintain a three tiered system and emphasise 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.

[7] Ibid at [118].
[8] Ibid at [62].
[9] 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).
[10] 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).
[11] *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 instigate appeals on similar grounds as previous cases, simply to achieve a similar successful outcome in the individual case.

At the Disability Advocacy Forum, the NDIA stated that the 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 the Transport Guidelines remain inconsistent with the Federal Court's decision suggests that issues still remain in the implementation of systemic changes. In PIAC's view, the NDIA needs to 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.

3.6 Advocacy through local Members of Parliament

A number of advocates raised with PIAC the success that they have had in engaging in advocacy for their clients through their local MPs, as opposed to through the formal review and appeals system. The story of 'Anne'[12], as told to PIAC by an advocate, is set out in the box below.

Advocating for Anne

Anne has a congenital vision impairment which makes her very sensitive to glare, both indoors and outdoors. Glare causes significant safety, fatigue and pain issues for Anne, and renders her functionally blind. She wears dark polarised sunglasses outdoors to reduce glare, but requires dark tinting indoors to allow her to go about her daily activities.

With a recommendation from her treating professionals, Anne sought funding for window tinting at her home under the NDIS, at a cost of $860.

However, the NDIA rejected her statement of supports on the basis that window tinting was not a reasonable and necessary support. She lodged an internal review application, which, after a 14 month delay, again rejected the plan. She then lodged an appeal to the AAT.

At the AAT, it was discovered that the person who conducted the internal review was the same person who made the initial decision to reject her plan request. The internal review was therefore not properly conducted. Anne's matter was sent back to the NDIA to re-make the decision. Ahead of the second internal review, Anne obtained further medical reports to support her request.

The decision-maker at the NDIA rejected the plan again.

Anne appealed the decision to the AAT again, but ahead of the hearing, Anne's advocate emailed Anne's local MP to ask for assistance.

Within 48 hours, Anne's plan was approved.

[12] Not her real name.

No information or justification was provided as to why Anne's plan was suddenly approved. Anne's advocate asked the NDIA as to why the decision had suddenly changed, but they could not explain what the change was.

PIAC was advised by a stakeholder that advocacy by MPs on behalf of constituents is common enough for the NDIA to have a formal process for dealing with contact from local MPs. Local MPs who get a request from their constituents about issues with the NDIS can contact the Members and Senators Contact Officer at the NDIA (**MASCO**).

The MASCO triages the issue and determines the best pathway for a resolution such as:

- Referral to the Escalation team for a review
- Referral to the Finance team for approval of payments that are stuck
- Referral to the Complaints processes. An electorate officer might also make a complaint directly to the NDIS Quality and Safeguards Commission

While PIAC recognises the important role that MPs can play in advocating for their constituents and helping them navigate government services, stakeholders expressed concern that people with disability should not be required to rely on the intervention of their local MP to get better outcomes under the NDIS. Such a process also benefits people with higher levels of education, better networks and advocates, to the exclusion of marginalised groups such as Indigenous or CALD people with disability. Rather, the level of funding provided in support plans should reflect the actual needs and goals of participants.

We also note that success in individual cases where an MP or other advocate has been effective still leaves participants vulnerable to a cut in the next plan review.

3.7 Accessibility and outreach for marginalised groups

A key issue that became evident throughout PIAC's consultations was that people with disability from disadvantaged groups face particular obstacles with the NDIS decision-making process.

A concern common to CALD and Indigenous people with disability is that many in these communities feel intimidated by government representatives when advocating for themselves. Advocates told us that they have been essentially warned from filing reviews or appeals of their plan, because individuals had been told that they may receive less funding than they were initially approved for if they lodge reviews. Some stakeholders told us that although this may be true, the way it was framed by NDIA officers was often misleading and inappropriate, without consideration as to how the person would interpret the risk.

Both CALD and Indigenous people with disability also reported that there was a lack of advocacy services which understood and adequately represented them. This led to CALD and Indigneous people with disability falling behind in access to the Scheme. This was an issue both in that there were few CALD or Indigenous-dedicated advocacy organisations, as well as that few generalist advocacy organisations had an adequate understanding of and outreach to CALD or Indigenous communities to provide advocacy to those communities. This is a reflection on resourcing and capacity, rather than being a criticism of generalist services.

A significant issue identified by Indigenous, rural and regional stakeholders was the inconsistency in decision-making between offices. As indicated earlier in this paper, both groups identified that decision-making appeared to be based on local NDIA office interpretations of particular guidelines or policies, which were not referrable to the legislation. This resulted in high levels of variability and inequality in access and planning decisions depending on where an individual was located.

Likewise, Indigenous, rural and regional stakeholders raised issues with the reference packages that were provided to participants. Both groups of stakeholders advised that their clients often received standard packages which provided funding for services that were not accessible or available to people in regional areas, leading to low utilisation rates of their funded supports. For example, in some cases, packages were provided to the participant for occupational therapy at the standard per hour rate. However, the funding did not take into account the unavailability of occupational therapy services in those regions, and that the standard rate was not sufficient to cover the transport costs for professionals travelling to the participant.

4. Legal issues

Stakeholders also raised issues with the drafting and interpretation of the NDIS Act. At the outset, it is important to recall that a key object of the NDIS is to give effect to Australia's international human rights obligations under a plethora of international human rights instruments. Most important of these for the Scheme is the Convention on the Rights of Persons with Disabilities (**CRPD**).[13] However, the objects section of the NDIS Act makes clear in section 3(1) that, in addition to the CRPD, it must also give effect to certain obligations stated in each of these instruments:

- the International Covenant on Civil and Political Rights[14]
- the International Covenant on Economic, Social and Cultural Rights[15]
- the Convention on the Rights of the Child[16]
- the Convention on the Elimination of All Forms of Discrimination Against Women[17]
- the International Convention on the Elimination of All Forms of Racial Discrimination[18]

The NDIS Act should accordingly be interpreted with these international human rights instruments in mind.

This section summarises some of the legal issues which stakeholders have raised during consultations.

[13] Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).
[14] Opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976).
[15] Opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976).
[16] Opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990).
[17] Opened for signature 18 December 1979, 1249 UNTS 1 (entered into force 3 September 1981).
[18] Opened for signature 7 March 1966, 660 UNTS 1 (entered into force 4 January 1969).

4.1 Interface between NDIS and mainstream services

A key issue noted by stakeholders was the gaps between the NDIS and other mainstream services provided by Commonwealth or State and Territory governments. Under the NDIS Act, there are two critical interface points between the NDIS and mainstream services. The first is in relation to eligibility. Under section 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 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 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 section 34(1)(f), the NDIA must be satisfied that the support is most appropriately funded or provided through the National Disability Insurance Scheme, and, as with section 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.

Stakeholders have advised that there are gaps between services, where the NDIA refuses to fund a support on the basis that it considers that that support is more appropriately funded through other services, but where that other support service does not provide funding. Stakeholders suggested that these gaps commonly existed 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.[19]

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.[20] The 'Health related supports' fact sheet clarifies 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, stakeholders have commented that several interfacing issues remain in the actual mechanics of the NDIS, particularly with State and Territory services. In particular, gaps in relation to housing services and corrective services were frequently raised by stakeholders.

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, and there are high eligibility thresholds for access to the initiative.

Clearly, interfacing between the NDIS and mainstream support services continues to be an issue, and will require both policy and legal changes to stop people with disability falling between the gaps of Commonwealth and State and Territory service provision.

4.2 Financial sustainability

As an insurance scheme, 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 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…'.

[19] *Burchell and National Disability Insurance Agency* [2019] AATA 1256, [36].
[20] 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.

However, stakeholders have identified that 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 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.

4.2.1 Financial sustainability in practice

Stakeholders reported that the NDIA has refused to fund supports on the ground that it would threaten the financial sustainability of the NDIS, but the lack of transparency in the NDIA's decision-making means that a participant is limited in their understanding of and their ability to challenge that 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 also reported 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.

Some stakeholders noted that the manner in which financial sustainability was raised by the NDIA assumes 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 that should be 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 by 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.'[21] 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'.[22]

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'.[23]

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

[21] At [37].
[22] At [42].
[23] *McGarrigle v National Disability Insurance Agency* [2017] FCA 308, [117].

specific and relevant.[24] Deputy President Humphries in *BIJD* reasoned that financial sustainability involves 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.[25] 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.

Within this context of legal ambiguity and value judgment, stakeholders were firm in identifying financial sustainability as an issue that required clarity – both in its operation within the NDIS Act, and in how the NDIA applies financial sustainability considerations in its decision-making.

4.2.2 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

[24] 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.

[25] *BIJD and NDIA* [2018] AATA 2971, [68].

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' who performs functions or exercises powers under the Act. 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.

4.3 Meaning of 'permanent' disability

Stakeholders also raised concerns about the use of the term 'permanent' and the manner in which permanency has been defined. Under section 24(1)(b) of the 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, a number of academics indicated that the use of 'permanence' in the eligibility criteria was inconsistent with the understanding of that term in disability policy and research. This was especially the case for people with psychosocial disabilities, or people with 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.[26] This language contrasts, for instance, with the language used in the UN Convention on the Rights of Persons with Disabilities[27] (**CRPD**), which defines persons with disabilities as including those who have 'long-term' physical, mental, intellectual or sensory impairments.[28] There are also difficulties with NDIA decision-makers, with little or no training on psychosocial disabilities, fitting people with psychosocial disabilities into the language of 'permanence'.

[26] 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).
[27] *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).
[28] Ibid art 1.

Second, stakeholders also complained that the interpretation of 'permanence' was too restrictive. Under paragraph 5.4 of the *National Disability Insurance Scheme (Becoming a Participant) Rules 2016*, permanence is defined to mean, relevantly, that 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 definition of permanence contrasts with the definition used for 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.[29] 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.[30]

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 case study illustrates how strictly 'available' and 'appropriate' treatment is interpreted when determining whether a person has a permanent disability.

Schwass and NDIA [31]

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.

In considering whether Mr Schwass' impairments were permanent, the Tribunal held that Mr Schwass should have further explored bariatric surgery. The Tribunal held that 'available' treatment meant 'accessible or within reach', and that affordability was not a relevant consideration. This is the case even where the treatment is not funded in the public health system. Deputy President Humphries considered that treatment which might 'impose a serious risk to a person's health' is not treatment that would be required. There being no evidence that bariatric surgery would impose a serious risk to Mr Schwass' health, bariatric surgery remained open to Mr Schwass.

The implication in this decision is that a person is required to undertake any treatment, including any surgery, which is able to be accessed by the person, provided it does not impose a 'serious risk' to their health. None of the other factors considered under the DSP are relevant to the requirement

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

under the NDIS. It is not relevant whether the surgery comes at a reasonable cost or is affordable to the person involved, or whether the surgery can be expected to result in a substantial improvement in functional capacity, or whether it has a high success rate, or even whether it carries a *low* risk to the person (as opposed to anything less than a 'serious risk'). The fact that these considerations have been determined to be irrelevant under the NDIS legislation takes away the agency of a person in determining whether surgery or treatment is right for them.

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'. If it is 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, then that ought to be clearly specified and explained.

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. 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…*'[32]

5. Proposals for change

The concerns raised in this Issues Paper highlight some of the overarching challenges identified by users of the NDIS, some of which could be addressed reasonably easily while others will require legislative reform. This section makes proposals for reform, which PIAC will take up as part of our work – including through further consultation with stakeholders. These proposals should not be considered exhaustive and we welcome feedback on them.

[32] NDIS Act, s 4(8).

5.1 Proposals for practice reform

Proposal 1: Publication of AAT settlement outcomes

The publication of AAT settlement outcomes is a key initiative that *A Fairer NDIS* hopes to advance. We consider that the publication of AAT settlement outcomes will improve decision-making in at least two ways. First, it will improve the consistency of decision-making by allowing a greater level of public accountability in ensuring the NDIA makes decisions consistently with matters that it has settled. Second, it will improve the ability of participants to understand the types of supports that are funded, and assist participants to decide what types of supports they could seek.

Proposal 2: Training of NDIA staff on disability inclusion, including specifically in relation to Indigenous and CALD people with disability

As identified above, stakeholders have raised concerns regarding the NDIA's understanding of the lived experience of people with disability, which affects both its decision-making and its communication. In relation to Indigenous and CALD people with disability, there are further concerns regarding culturally sensitive communication. Stakeholders identified that increased training is critical in improving the engagement of the NDIA with people with disability.

5.2 Proposals for policy reform

Proposal 3: Publication of financial sustainability guidelines and typical support guidelines

This Issues Paper has identified the complexities in the meaning and relevance of financial sustainability for individual planning decisions, as well as the inconsistency in the application of typical support guidelines. The publication of these guidelines will ensure participants have more information on the factors critical to the NDIA's decision-making, and again improve the consistency of decision-making. PIAC considers that the NDIA's guidelines on financial sustainability should follow PIAC's interpretation of the legislative provisions, as discussed above.

Proposal 4: Increased funding for disability advocates, including for CALD and Indigenous specific advocates

The complexities of the NDIS set out in this Paper clearly identify the need for strong advocacy for people with disability. Increased funding for advocates is critical to improve the operation of the NDIS, especially for specialist advocacy services dedicated to CALD and Indigenous outreach.

Proposal 5: Implementation of systemic changes following appeals and settlements

A key issue identified above is the failure of the NDIA to implement systemic changes following adverse AAT and Court decisions, as well as settlements. It is important that the NDIA implements a transparent and accountable process for ensuring that systemic changes to policies are made following settlement or decisions. These changes should be reported in its Quarterly Report to ensure transparency and accountability.

5.3 Proposals for law reform

Proposal 6: Replacing the language of 'permanence'

The language of 'permanence' in relation to eligibility for the Scheme (at sections 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 'persistent', 'chronic' or 'enduring'.

Proposal 7: 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.

Proposal 8: Clarifying 'financial sustainability' in the NDIS Act

The reference to 'having regard to' financial sustainability in 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'.

Proposal 9: Shifting the onus on service delivery between the NDIS and mainstream services

This Paper has identified that there is a need for policy and legal change to ensure that users of the NDIS are not falling in the gaps between the NDIS and mainstream services. These gaps are policy matters that the Federal and State and Territory governments need to decide. In the meantime however, it should not be up to the person with disability to navigate the gap and work out which system will provide the support to which they are entitled.

Section 34(1)(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 be 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 section 34(1)(f) to determine that the support is not reasonable and necessary.

Proposal 10: 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 section 100(3).

Proposal 11: Deemed decision for failure to conduct review within specified timeframe

The failure of the NDIA to determine internal reviews within a 'reasonably practicable' timeframe does not currently allow the individual to take their appeal to the AAT. To address this, and to remove the bottleneck of internal reviews, section 103 of the NDIS Act should be amended to

provide that if a review under section 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.

Proposal 12: Reimbursement of a participant's expenditure on supports

Due to the lack of a back-payment or reimbursement scheme under the NDIS, the NDIA is not currently subject to any financial disincentive to avoid delays in the review or appeals process. People who have been disadvantaged by what may have been poor decision-making are not subject to any compensation or reimbursement. This is unfair, especially where an NDIA decision is overturned or settlement agreed, and puts the onus on the person with disability to fund their support during the interim period. To address this, 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.

We consider that such a provision strikes the right balance between ensuring that the NDIA remains responsible for providing funding if a planning decision is overturned, while also ensuring that the NDIA is not responsible for funding supports that are not ultimately approved at the AAT stage.

Proposal 13: Amend the NDIS Act to streamline reviews under sections 48 and 100

There is considerable complexity in the NDIS Act regarding the difference between plan reviews (or 'reassessments') under section 48 and internal reviews under section 100. The NDIS Act should be amended to reduce this complexity.

One option would be to amend the Act to provide that all requests under section 48 are treated as both a request for 'plan reassessment' and internal 'review'. Practically, there is little reason to separate internal reviews from reassessments. A decision refusing a reassessment (under section 48) 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 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 section 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.

6. 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 Issues Paper 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. It is hoped that this Issues Paper can contribute to the conversation already happening in the disability sector and lay down a foundation for key issues arising in the decision-making, review and appeals processes.