



## **Response to Discussion Paper: Improving the NDIS Experience**

***Establishing a Participant Service Guarantee and removing legislative red tape***

## About Advocacy for Inclusion

Advocacy for Inclusion (AFI) provides independent individual, self and systemic advocacy for people with disabilities. We are a Disabled Peoples Organisation (DPO) which means most of our board, members and staff are people with disabilities. We represent all people with disabilities nationally from the ACT in our policy works.

Advocacy for Inclusion works within a human rights framework and acknowledges the United Nations Convention on the Rights of Persons with Disabilities and is signed onto the ACT Human Rights Act 2004.

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Prepared and written by:

Bonnie Millen, Senior Human Rights Policy Advisor

Molly Saunders, NDIS Appeals Officer

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Advocacy for Inclusion (AFI) can be found at:

2.02 Griffin Centre  
20 Genge Street  
Canberra City ACT 2601

Phone: 02 6257 4005

Email: [info@advocacyforinclusion.org](mailto:info@advocacyforinclusion.org)

ABN: 90 670 934 099



AFI acknowledges and pays respect to the Traditional Custodians of the lands across Australia on which our members live and work, and to their Elders, past, present and future. We pay respect to the Ngunnawal people as the Traditional Custodians of the land on which AFI's office stands.



AFI pay respects to those amongst the lesbian, gay, bisexual, trans, and intersex communities. We honour the elders in the diverse communities of which we are a part, and we celebrate the extraordinary diversity of people's bodies, genders, sexualities, and relationships that they represent.

## Table of Contents

<b>Executive Summary .....</b>	<b>5</b>
<b>The NDIS In the Australian Capital Territory (act).....</b>	<b>7</b>
<b>NDIS Plan Supports and Reviews.....</b>	<b>8</b>
Envisaging and articulating goals for NDIS plans .....	8
Organisation of services by informal supports .....	11
Planners and Local Area Coordination (LACs).....	12
NDIA's management of information and documentation in Plan Reviews.....	13
<b>Appealing Decisions by the NDIA: The Internal Review Process.....</b>	<b>16</b>
Ongoing Delays .....	16
Access to Information .....	20
Information management and communication .....	25
Financial resources.....	26
Choice, control, and equity of access .....	28
<b>Appealing Decisions By The NDIA: The External Review Process .....</b>	<b>29</b>
Adversarial conduct and the balance of power .....	29
(Re)traumatization.....	31
Management of non-legal issues.....	32
<b>Removing Red Tape from the NDIS .....</b>	<b>32</b>
Amending the Legislative Framework .....	32
<b>Other Key Gaps for the Guarantee to Plug .....</b>	<b>36</b>
Issue of Provider of Last Resort (POLR) .....	36
Thinning NDIS Workforce.....	40
Behavioural Management Support.....	42
Lack of Support Coordination .....	43
Supported Independent Living (SIL).....	45



# EXECUTIVE SUMMARY

AFI is a national systemic body representing people with disabilities in the ACT. AFI in this role undertakes systemic advocacy and provide expert policy advice on issues affecting people with disabilities through our individual advocacy client and membership base in the ACT. We are one of the two<sup>1</sup> individual advocacy organisations that are funded to provide NDIS Administrative Appeals Tribunal (AAT) support in the ACT.

Since the introduction of this additional funding on top of advocacy provided<sup>2</sup>, AFI has mapped a steady increase in the numbers of plan reviews that lead to AAT reviews over time. We also find that many of these cases are preventable and could be resolved at an easier pace under the new Participant Service Guarantee ('the Guarantee').

AFI welcomes the updated proposed principles. From an advocacy perspective, we have found they have not been practised from what has been promised and are often contradiction in delivery. The philosophy that underpins the NDIS has been based on trust that participants and their supports will use their packages to live fulfilling lives, build capacity and self-advocacy skills and be part of the broader community through participation and engagement. Instead, our clients have faced a system that is legalistic, incoherent, inconsistent and dysfunction in its operational functions at best. At best, the principles are to reach a standard where a majority of participants are happy with their plans, treatment in applying and being eligible for plans and their request for change. We welcome the proposed principles to be part of the Guarantee and believe they are all important for the NDIA to adhere to. In response to the key discussion questions, this section will list individually each proposed principle in response to how they are currently falling short.

Throughout this submission, we have indicated where possible change could match each proposed principle (i.e. 'Timely') and tied to the recommendations accordingly. Measurement can only be achieved through an extensive evaluation of how measurements are currently being collected and analysed. However, it can be agreed, by many that attended the consultations and have contributed via submissions, that the NDIA needs to become less bureaucratic, more people-centred and approachable to ensure that voices of people with disabilities, their families/carers and support networks (including advocates) are being measured correctly, transparently and openly.

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<sup>1</sup> ACT Disability Aged and Carer Advocacy Service (ADACAS)

<sup>2</sup> AFI provides individual case-by-case advocacy, self-advocacy development and systemic policy advocacy from the ACT.

This submission will also focus on the experiences, cases and issues of participants navigating the NDIS reviews process and the AAT process. It will also touch upon the additional gaps in which we hope the Guarantee will address in relation to 'thin/weak' markets<sup>3</sup>, particularly in relation to ongoing confusion of Provider of Last Resort (POLR), behaviour management support, support coordination and Supported Individual Living (SIL). We raise them in this submission in the trust of the Guarantee as a reform within the NDIA that will ensure those gaps are filled.<sup>4</sup>

We are concerned that participants of the NDIS are facing a disadvantage in the plan reviews and internal review processes due to:

- Lack of clear, concise and available information regarding 'feedback, complaints and reviews' for participants, their carers and support networks
- Lack of information regarding reasons for decisions made by the NDIA during plan reviews, i.e. to include or not include supports in the plan, or to not grant access
- Time delays of internal reviews, leading to formal complaints against the NDIA, frustration from the participant, which can contribute to hostility in AAT reviews.
- Lack of understanding and disability awareness among LACS, planners and call centre staff

The NDIS is a necessary social policy that has been a long-time coming and is beginning to look 'perfect'. However, as our clients and advocates have asserted to, the NDIS process and system is a bureaucracy. It was never meant to be this way, and it is becoming a complicated maze. AFI welcomes the implementation of the Participant Service Guarantee and what it promises for people with disabilities navigating the NDIS.

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<sup>3</sup> This echoes the views AFI put forward in our contribution to the *NDIS Thin Markets* consultations in June 2019.

<sup>4</sup> Australian Government Department of Social Services. (2019). *Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape*, Discussion Paper, p. 2

## The NDIS In the Australian Capital Territory (ACT)

In the ACT, planning and assistance regarding the NDIS have been the responsibility of Feros Care, an organisation funded and supported by NDIA to provide Local Area Coordination (LACs) to the ACT. However, there remains confusion and disparity as to the responsibility of the community organisations as to how much support we provide an individual unfunded before referring to Feros.

Currently, people with disabilities approaching AFI to seek support and assistance in navigating NDIS paperwork and requests is one of the most significant types of enquiries received.<sup>5</sup> However, AFI is not funded to provide this support adequately or separately from the NDIA or FerosCare in the ACT – yet there is an expectation that this is ‘advocacy’ and ‘support’.

To assist each individual with NDIS pre-planning or review paperwork has fundamentally cut into the time and capacity of the advocates' availability on low funding. Issues uncovered from advocates when agreeing to assist a client with their NDIS pre-planning or review assessment have varied from guardianship constraints which the individual would like to exercise their self-determination in their plan review, child protection and family support, justice interfaces, housing modifications or equipment to live independently but need to be negotiated and so forth. As a resolution, AFI assesses each case accordingly, prioritising internal and external review cases and whether there is the equivalent of a hidden iceberg of other issues lurking underneath and not identified in the initial intake.

There also remains concern how much choice and control are provided to NDIS participants in the ACT, that are not the prompting of disability service providers.<sup>6,7</sup> Initially, the NDIS promised to provide as much choice and control for the person with disabilities<sup>8</sup> and what requirements an individual may need to have ‘reasonable and necessary’ support in their daily lives.

In reflecting on the challenges that participants face in using and reviewing their NDIS plans, AFI is cognisant that the NDIS is an ambitious initiative that has been implemented in an accelerated

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<sup>5</sup> Echoes view of Commonwealth Ombudsman: “In several locations, we were concerned to find that many participants, and even key support organisations (like advocates, peak groups and peer support groups), were not aware of the availability of LACs to assist with pre-planning work, plan implementation and/or to provide referrals to mainstream services”, Submission by the Commonwealth Ombudsman (2017) *Response to Productivity Commission’s Issues Paper, ‘National Disability Insurance Scheme Costs’*, p.7

<sup>6</sup> ACTCOSS (2017) *Choice and Control: Strengthening human rights, power and inclusion for people with disabilities*, p. 16-17

<sup>7</sup> Productivity Commission (2011), *Disability Care and Support: Productivity Commission Inquiry Report*, p.2

<sup>8</sup> Australian Government (2013) *National Disability Insurance Scheme Act 2013*, p. 4

manner. As the NDIA becomes increasingly more bureaucratic and increase in power are provided to disability service providers, the message of 'choice and control' is becoming less certain among people with disabilities who feel choice and control are lacking. The Guarantee needs to remove the high bureaucracy that currently underpins the NDIS and makes it largely inaccessible and unfair.

## NDIS Plan Supports and Reviews

There are significant challenges which must be addressed in the ongoing operation of the Scheme from our standpoint in the ACT. These include challenges participants have in using the supports in their plans and in the plan review process. It is noted that the plan review process is separate from the internal review and external review processes. Similar terminology causes confusion and needs to be addressed.

**Preliminary recommendation: The NDIA should adopt new terminology for plan reviews to avoid this confusion. For example, plan reviews could be renamed 'plan evaluations' or 'plan appraisals.'**

### Envisaging and articulating goals for NDIS plans

Academic literature supports AFI's observation that participants may have difficulty in optimising their NDIS plans because of a reduced ability to "envisage and articulate their goals."<sup>9</sup> This is because people with disabilities may not be practised in making choices or envisaging options for themselves. Rather, people with disabilities are overly subjected to people making decisions for them or presenting them with limited options which they can choose between.<sup>10</sup> People with disabilities may be practised at saying yes or no, but "not necessarily saying, 'I don't like anything that you've got available for me, this is what I want 'cause that's what will make a difference to my quality of life'."<sup>11</sup> This is particularly pertinent in the context of the NDIS because many participants are unsure what types of supports the NDIS can provide. While access to online resources and disability advocates can mitigate the lack of awareness, one participant reported that if you weren't able to "identify available opportunities... [and] if you did not know the jargon you virtually got zilch."<sup>12</sup> Thus, participants may struggle to

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<sup>9</sup> Olney, S. and Dickinson, H. (2019). Australia's New National Disability Insurance Scheme: Implications for Policy and Practice, *Policy Design and Practice*, 2(3), p. 285.

<sup>10</sup> Olney, S. and Dickinson, H. (2019).

<sup>11</sup> Olney, S. and Dickinson, H. (2019), p. 284.

<sup>12</sup> Olney, S. and Dickinson, H. (2019), p. 284.



optimally utilize their plans because they have not been able to articulate their goals and support requests.

### **Case Study 1**

AFI has provided advocacy support to various clients with psychosocial disabilities. These clients tend to require additional support in the lead up to planning meetings, as they often become easily overwhelmed.

This case study concerns one client with bi-polar and anxiety, who was particularly distressed in the pre-planning process. They often stated that there was 'no point' requesting supports because they had 'tried everything'. They stated that there 'was nothing anyone could do' and that they 'didn't know where to begin' in trying to brainstorm what supports they could request from the NDIA. This client had not used many of the supports in their previous plan because they had not been granted support coordination and was not well enough to organise their own supports. Over several meetings with our organisation, the client was able to work through a pre-planning kit, identify what supports they would benefit from and even came up with ideas of their own.

The client required wrap-around support from the LAC, our advocacy organisation and two other community organisations to be able to both envisage and articulate their support needs.

Additionally, the lack of experience in envisaging options in decision-making processes can render the planning process particularly overwhelming. This is because it is a new process demanding that the participant use under-developed skills. AFI has observed that feelings of overwhelm are often heightened in circumstances where the participant has a psychosocial disability such as bi-polar or depression. Often people with these conditions feel that hope for improvement is beyond their reach, and so they find it difficult to conceptualize supports which may lead to improvement.

Additionally, participants who have experienced trauma may be acutely aware of power-relations and susceptible to influence. This may cause them to request different supports depending on whom they are talking to. In this way, participants may present inconsistent goals and support requests, and ultimately have their requests dismissed. This behaviour is not uncommon in the planning process and

can be a significant barrier to the articulation of goals and requests, particularly if the planner is not sensitive to the participant's behaviours and needs.

A client's advocates and support workers will be aware that a client provides different information to different people across various aspects of their life. NDIS Planners need to be aware of this behaviour and, where appropriate, ensure that the participant's support network is engaged in the planning process. Planners must ensure that they have a complete picture of the participant's life and are sensitive to any behaviours which need addressing in the planning process.

### **Case Study 2**

AFI met with an established client prior to their plan review meeting to discuss their support needs in their upcoming plan. The client outlined numerous gaps in their current NDIS plan. The client asked AFI to attend the planning meeting, however the NDIA and the planner were unable to arrange a suitable time for all parties. Consequently, AFI was unable to attend.

The planner reported that the client made no new requests during the planning meeting. They noted that the client said the most recent NDIS plan had been adequate.

**Recommendation 1: The Guarantee must ensure wrap-around supports for participants during the planning process. This may include advocacy support for people with disabilities, alongside training in supported-decision-making for NDIS Planners.**

**Recommendation 2: A single meeting is not necessarily sufficient to ensure that participants obtain an adequate NDIS Plan. This is particularly true where the participant's supports are not present, where they have a trauma-background and where they have complex communication or psychosocial barriers. The NDIA should encourage the development of an ongoing and collaborative relationship between the planner and participant in the planning process, to ensure that the planner has a complete understanding of the participant's behaviours and situation.**

**Recommendation 3: A long-term approach to developing the decision-making skills of people with disabilities. This will necessarily involve a cultural shift in the attitude towards the autonomy of people with disabilities. It should focus on the decision-making skills of children with disability in order to effect a generational change.**

## Organisation of services by informal supports

Participants may also be constrained in accessing their supports due to the significant administrative work and organisation required to access services. This work often falls on informal supports, such as families and carers, and places “additional pressure on people with disabilities and households that are already stretched in supporting family members with disabilities.”<sup>13</sup> The extensive administrative requirements of managing plans also have the practical effect of excluding people with disabilities from accessing their supports, if they don’t have the capacity or requisite assistance. AFI notes that there is the option for support coordination and plan-management.

AFI has witnessed instances in which participants are not granted support coordination, despite requesting and requiring it. They, therefore, are not able to utilise their supports. AFI has worked with clients who have been denied support coordination in their NDIS plans. In one instance, a client was unable to access the majority of the supports for six months, due to their difficulties in self-management. This caused additional administrative burdens in their subsequent plan review, as they were required to prove why they didn’t access all their funds.

It is also noted that the NDIA’s reliance on informal supports to manage the administrative requirements of the NDIS can constrain family members and carers from engaging fully in their own life. For example, parents may not be able to re-enter full-time employment due to the workload of NDIS plan management. AFI has also worked with adult clients whose families are unable to maintain full-time employment, due to the extensive administrative requirements of NDIS access applications and the planning process. In one instance, a mother reported that she no longer worked Mondays because that was her day for ‘NDIS work’.

**Recommendation 4: Training and guidelines for carers and informal supports should be provided to support them in navigating the administrative requirements of the NDIS.**

**Recommendation 5: The NDIA reconsider the role and extent of carer responsibilities in providing support in the application process, the development of the participant plan, the implementation of the support and the plan review process. AFI considers that the current expectation of informal supports is unreasonable.**

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<sup>13</sup> Olney, S. and Dickinson, H. (2019), p. 285.

**Recommendation 6: A possible solution to this problem involves LACs taking more responsibility for supporting people with disabilities throughout these processes. Creating more support for LACs to do this will match the proposed principles on 'Expert', 'Engaged' and 'Decisions made on merit'. This may mean that LACs require additional funding to ensure that their workloads are manageable.**

#### Planners and Local Area Coordination (LACs)

Advocates at AFI have raised concerns regarding the inconsistency of quality assuring plans for NDIS participants and the details of the plans themselves. A core value of the NDIS is that it promotes participants' choice and control. However, often people with disabilities are not in the driver's seat of their own plan, and they become confused and frustrated when the plan developed by the NDIA is not what they envisioned or asked for. Participants also report frustration where they are made aware of alternative support ideas after the planning process, only to be told there is a lengthy review process rather than a simple, quick modification to a plan.

Another concern held by AFI is that people with disabilities are placed on long waiting lists to access services. The supports are then removed from the plan if the participant does not access the funds or the service in time. The lack of accessibility of mainstream services and supports also means that even with specialist disability supports funded by the NDIS, people have still not able to receive all the support they need.

Other issues include the continued inaccessibility of information regarding planning processes, the lack of time to adequately confer and work through what information is required, the lack of time to consider equal access for people with different communication needs, being provided phone numbers only to access services without further assistance, and the control of plans by planners, LACs and service providers.<sup>14</sup>

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<sup>14</sup> Also noted in ACTCOSS, (2017). *Choice and Control: Strengthening the human rights, power and inclusion for people with disabilities*, p. 12.

### Case Study 3

AFI had a client who had been an NDIS participant through 2 plans. An advocate attended their third planning meeting to discover that this participant only had one disability listed on their NDIS file. The participant, in fact, had six diagnosed conditions causing functional impairment, but only one had been recognised and noted by previous planners. Unsurprisingly, the supports which had been requested made a lot more sense when NDIA realised the mistake – and supports which had been refused in the first two plans were finally approved in the third.

Participants have raised frustrations that NDIA planners and LACs fail to recognise that increased support and intervention must be ongoing and direct support is necessary. This is particularly prevalent in individual NDIS plans that are designed, but are not adequate for, accessing allied health supports around behavioural support, communication and SIL. Mistakes are inevitable but when they continuously occur where essential supports may be missed or not included, it is unfair to the participant.

The performance of a LAC or planner should be measured by the quality of their plans and the quality of their exchanges with participants. Participant satisfaction with their plans and their interaction with planners should also be monitored and evaluated through the ongoing NDIS evaluation framework. All planning meetings should be recorded to ensure that all evidence provided by participants, their carers or chosen supports are appropriately matched to a planner or LAC for quality-assurance purposes as part of any monitoring and evaluation process and the assistance in advocacy cases.

**Recommendation 7: Further breakdown of each funded component will assist people with disabilities to understand their plans and exercise choice and control with more ease to remove the confusion of what participants are actually funded for. This will match the proposed principles ‘Engaged’, ‘Valued’ and ‘Accessible’.**

### NDIA’s management of information and documentation in Plan Reviews

Complaints have been made by participants to AFI in regard to the NDIA’s management of documents. AFI has observed incidents where the NDIA has lost participant’s documentation due to the unintuitive and complex records management system and the NDIS Portal.

**Recommendation 8: The NDIA needs to continue to develop the portal in consultation with providers, participants and informal supports, to ensure that the site is user-centered and easily**

navigated. The NDIA must also ensure that their records management system is intuitive and organised.

Challenges regarding information management in scheduled and unscheduled plan reviews also include the complexity and volume of the information required by the NDIS to justify participants' requests for supports. The primary concerns highlighted by participants is that they are unable to make small changes to their plans without triggering an internal review and that they are unable to review draft plans. Therefore, the planning process is not collaborative. Additionally, the inability to see a draft plan means that it is unnecessarily difficult for plans to be amended in small ways. Rather, participants are instead immediately directed to the internal review process.

**Recommendation 9: The Guarantee needs to realise the potential for more flexibility where plans could be automatically rolled over. We recommend that participants could have the opportunity to roll over their plans in the following circumstances:**

1. Where there is no change of circumstances and the participant doesn't want a review;
2. If participants opt to roll over, options like a change of circumstances can continue to be an avenue to trigger a review, should the plan no longer be adequate at a later date;
3. Safeguarding mechanisms are required to be in place to make sure that participants do not avoid reviews due to the process being traumatic or stressful etc. (which, given the state of review process now, would not be implausible!).

**Recommendation 10: Requests for small amendments or additions to plans should be able to occur without triggering an entire plan review. AFI notes that 'light touch' reviews are being implemented. However, the process is opaque, dependent upon the individual planner's knowledge and discrepant across jurisdictions. The importance of establishing a formal mechanism for light touch reviews is essential.**

**Recommendation 11: That "requests for funds under a certain amount, or requests for equipment where the need is clearly self-evident, [should] be approved without involving intermediary professionals." For example, amendments or additional requests for assistive technology which cost under a certain monetary amount should not require a plan review or change of circumstances form.**

**Recommendation 12: For cheaper requests, or requests that are self-evident, there should be a lower standard of supporting evidence required. AFI believes these measures will reduce the**

**complexity of plan reviews and the number of internal review applications. It also builds the NDIS's capacity to respond to smaller unexpected support needs, without compromising the Scheme's integrity.**

Participants also report gaps in their NDIS supports, where the review process is delayed, and their original plan expires before the new plan is in place.

**Recommendation 13: Participant plans should automatically rollover on a pro-rata rate until a review is conducted and a new plan decision is reached. This will ensure that participants are not stressed that they are going to be left without funding. It will also remove issues around backdating and refunding of participant supports which were incurred during the gap.**

# Appealing Decisions by the NDIA: The Internal Review Process

This part of the submission highlights the significant challenges faced by NDIS participants in the Agency's internal review process. The discussion will also explore the challenges faced by non-NDIS participants appealing access decisions at first instance.

The challenges provide a complex overview of the reasons why an NDIS participant, or a person with a disability seeking to access the NDIS, may not engage effectively in the internal review process. This submission will discuss the barriers in ongoing delays, access to information, the prevalence of misinformation, and the burdens on financial and personal resources. The challenges across these domains contribute to broad concerns regarding the choice and control of participants in the internal review process, alongside the equity of access to review.

## Ongoing Delays

The NDIA is aware of the significant delays faced by people with disabilities throughout the internal review process.<sup>15</sup> AFI welcomes the NDIA's commitment to introduce better 'Timely' responses for internal review decisions. We would further encourage the NDIA to extend statutory timeframes through-out the entire internal review process to match the principles of 'Timely', 'Engaged' and 'Decisions made on merit'.

To address and measure ongoing delays and challenges in accessing information, we encourage the NDIA to extend statutory timeframes through-out the entire internal review process. Imposing legislative accountability for timeliness will ensure that applicants are notified that the review has been received, are consulted if their applications would benefit from providing more supporting evidence and know when to expect an internal review decision.

This framework may involve imposing a specified number of calendar days on the Agency for various parts of the review process. Possible provisions could include:

- The Agency will acknowledge the request for an internal review within 7 calendar days;

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<sup>15</sup> Commonwealth Ombudsman, (2018). Administration of reviews under the National Disability Insurance Scheme Act 2013: Report on the National Disability Insurance Agency's Handling of Review (Report No. 03/2018).



- The Agency will decide about the request and provide reasons for that decision within 30 calendar days of receiving the request for an internal review;
- If the Agency needs to consult with the applicant, for example, to obtain more supporting evidence, the clock may be paused for the consultation period. The consultation will last maximum 30 days unless an extension is expressly agreed to by the applicant;
- At any point, the applicant may voluntarily grant the Agency an extension of time to decide about their request;
- If the Agency does not decide in the defined time limit, the applicant may appeal to the AAT for a review of a decision on the basis that the NDIA is deemed to have made an internal review decision.

Other commonwealth instruments, such as the *Freedom of Information Act 1982* (Cth), impose similar time-limits throughout their internal administrative decision-making processes. It ensures accountability and timeliness in the decision-making process, and consequently, AFI encourages the NDIA to adopt a similar framework.

**Recommendation 14: An internal review decision should be provided within 30 calendar days of receiving the request unless the consultation period is entered or consent for an extension is obtained.**

**Recommendation 15: NDIA should consider and incorporate similar models such as the *Freedom of Information Act 1982* (Cth) to impose similar time-limits throughout their internal administrative decision-making processes. It will ensure accountability and timeliness in the decision-making process, matching the principles of ‘Timely’, ‘Engaged’ and ‘Decisions made on merit’.**

Ongoing delays may also be reduced through a reformed planning process which reduces the number of applications for internal review. There are various intervention points for reform, including where a participant receives their NDIS plan and is unsatisfied that a support has not been included. Firstly, the participant could be presented with a draft NDIS plan before the final version. Then, in instances involving simple additions or alterations, the participant could ‘request to add support to plan’; as opposed to applying for internal review. This would encourage the collaborative production of an NDIS plan, including more dialogue regarding the reasons for a support’s inclusion or exclusion. Moreover, it will allow for small changes to plans without applicant’s having to engage in the internal review process. If the applicant remains unhappy with the plan after this dialogue, they can still appeal for an

**Recommendation 16: Participants should be able to review a draft NDIS plan before the final version is implemented. This is to encourage a more ‘Connected’ approach to the development of NDIS plans and to ultimately ensure the participants’ support needs are met through effective communication and active listening. AFI anticipates that this will also reduce the number of plans escalating to the internal review process.**

Applicants have also reported that the NDIA has encouraged them to withdraw their internal review application, where they have an upcoming scheduled plan review. This has occurred in situations where there have been significant delays in obtaining an internal review decision, and therefore the applicant’s plan is due to expire. AFI considers this behaviour troublesome because it discourages applicants from fully accessing their review rights, including their external review rights. Moreover, it risks subjecting the applicant to another lengthy internal review process, in instances where the applicant relinquishes their review rights in favour of the plan review and are denied their requested supports again.

#### **Case Study 4**

One client experienced a six-month delay in processing their request for internal review. They managed to obtain a response by filing a complaint. The response occurred when the applicant’s plan was due for a scheduled review. The NDIA contacted the client stating:

*“There are 3 possible decisions that we would make as a result of a S100 review. These are: 1. Confirm the reviewable decision, which means no changes will be made to your current plan. 2. Vary the reviewable decision which means either all of the review requests will be approved or only part of the review requests will be approved based on the evidence provided.*

*3. Set aside the reviewable decision and substitute a new decision which means all areas of your current plan will be relooked at based on the evidence provided.*

*The implication of conducting a S100 review is that if the review decision is to vary or set aside the reviewable decision, a new plan will be generated at the time of approval and you will not be entitled to a schedule review until close to the 100 days period before the newly approved plan expires.*

#### Case Study 4 - Continued

*Due to the unexpected delay to address your S100 review request, you are now approaching the schedule review period for your current plan.*

*Hence, we need your confirmation and instruction regarding what you would like us to proceed with the S100 review request at this point in time.*

*The difference between a S100 review and a full schedule review is that in the S100 review, most often, we would only address part of the plan based on what you have requested while a full schedule review will rebuild a new plan based on your previous plan outcome/gap and your expected needs and goals in the coming year.*

*Please let us know how you would like us to proceed by a return email..."*

This email notifies the client of the potential outcomes of the s100 (internal) review.

The above case study is problematic as the email is complete with legalese and is not accessible or easily understandable for someone without a legal background.

Notably, in this case, for example, NDIA omits that if the participant proceeds to the full scheduled review, they may not be granted the supports that they are requesting in the internal review. They also fail to advise the participant that choosing the scheduled review will sacrifice their review rights, such that they will have to begin the entire process again if they don't get their requested supports. In this way, the email worryingly omits important information regarding the applicant's review rights. AFI considers that it is implicitly geared to encouraging the participant to build a new plan.

**Recommendation 17: AFI encourages the NDIA to refrain from this practice. If the participant is due for a scheduled plan review, it is essential that the NDIA informs participants of all the relevant information, including the consequences on their review rights if they opt for the scheduled plan review.**

Finally, applicants have reported that the delays in the internal review process can cause the review process to extend past the expiration date of their NDIS plan. This can leave the applicant without an ability to pay for their supports, and ultimately lead to their support services being temporarily

suspended. This ultimately goes against the proposed principles of 'Timely', 'Connected' and, at best, 'Valued'.

**Recommendation 18: If the plan expires during the review process, there should be a system whereby the plan automatically extends, at a pro-rate rate, to ensure people retain access to their supports.**

**Recommendation 19: AFI supports the implementation of a formal triage and escalation process for internal review matters. This will mitigate the negative impacts of ongoing delays for urgent matters. It will also help ensure that unaddressed requests can be smoothly brought to the NDIA's attention. Currently, such requests can only be escalated through the NDIA's complaints mechanism. This needs to be improved to be measured effectively.**

### Access to Information

Another challenge faced by people with disabilities engaging in the internal review process is regarding access to information.<sup>16</sup> There are three key aspects to this. First, there are issues with information sharing between the NDIA, participants and advocates. Second, it is not uncommon for applicants to report that they have been unable to obtain an acknowledgement of receipt regarding their application for review of a reviewable decision. Third, applicants report difficulty in obtaining information regarding the status of their internal review. Finally, applicants often have limited knowledge and understanding of the review process, their legal rights and the reasons for the original decision. Ultimately, this means that the effectiveness of the internal review process often depends on the applicant's access to informal and formal supports; rather than the integrity of the process itself.<sup>17</sup>

First, AFI has been involved in a confusing information sharing debacle that impacted both time and the ability for advocates to communicate with NDIA staff, including planners, regarding their client's matters. While the issue has been resolved with a positive outcome that led to NDIA tightening their policies and procedures on information sharing between NDIA staff and advocacy organisations, it is an example of how unclear information can cause delays, anxiety and frustration for all parties involved in the review process.

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<sup>16</sup> Olney, S. and Dickinson, H. (2019).

<sup>17</sup> Carey, G. Malbon, E. Olney, S, and Reeders, D. (2018). The personalisation agenda: the case of the Australian National Disability Insurance Scheme, *International Review of Sociology*, 28(1), p. 7.

## Case Study 5

A client approached AFI for assistance with getting information from NDIA. She said her caseworker and herself were 'hitting the same brick walls' when trying to communicate with NDIA. The client had appealed access request rejections for both her and one son, as well as having appealed her other son's plan. The client said she had no response from NDIS, and when she contacted them, they denied receiving information from her despite evidence of an NDIA email acknowledgements/stamped hard copies as proof of her contact. The client also said that she had been told by them that there was a note on her file saying not to give out any information regarding the matter.

An AFI advocate called NDIA and asked what was needed to provide to be able to discuss any clients with them. They said to email proof of clients' consent to the NDIS enquiries email. The advocate then emailed the client's completed consent to share and authority to act as advocate forms to the NDIS enquiries email and received the following email in response:

*Thank you for your recent enquiry to the National Disability Insurance Agency (NDIA).*

*The information we require to complete your enquiry includes three points of identification for the participant/child representative (e.g. date of birth, phone number).*

*If you could please provide this information at your earliest convenience, we will be able to progress your enquiry.*

*Alternatively, you can call us on 1800 800 110 between 8am and 8 pm.*

*Thank you again for your enquiry.*



*National Disability Insurance Agency*

*T 1800 800 110*

*Please note responses received by this mailbox will not be responded to.*

## Case Study 5 – Continued

Four weeks later, the advocate called the NDIA to provide the 3 points of identification. They said she was not listed on the participant's account. The advocate then verified she had sent the consent to share information and authority to act as advocate to the NDIS email as requested. NDIA said they had not received the email.

The advocate confirmed that she had received the response confirming receipt of the email and requesting three points of identification. The NDIA staff member asked if the participant was with the advocate then, and when she responded no, they said the participant, or their parent had to give the ID. The advocate queried why she needed to provide further ID when she had provided consent forms. The NDIA staff member placed the advocate on hold to search for the consent forms, then returned and said it takes some time to read the emails and transfer the information to the participant's account. The staff member requested the advocate call in a week.

After negotiation of consent agreement, the NDIA staff member agreed on the phone to add the advocate to the participant's file as she was rejected from NDIS so did not have a current plan in place at the time. The NDIA staff member requested advocate's birth date, phone number and business address. In contrast, on the day the advocate originally emailed the consent to share to the NDIA, she had also separately emailed another client's consent to share. The advocate received no reply to it, and 3 days later phoned NDIS and was able to access her client's information as the consent to share had been received and found she had been added to their file.

In a period of six months, an outcome had been reached. It was found other advocacy organisations had faced similar issues with consent, identification and miscommunication of policies on the NDIA's side. All advocacy organisations received an email of 'Interim Escalation Process for NDIA Matters' stating:

*"Consent is not required to be provided on an NDIA specific consent form. It can be provided on any form that covers the requirements for express consent. For escalations regarding plan reviews, email -----, Branch Manager of the Review Team. For other crisis escalations, email the relevant State/Territory Contact"*

The case study is an example of why clearer information-sharing protocols are necessary for people with disabilities to understand why their review has been unsuccessful or if more information is required or needed. Often, AFI advocates have untangled what has been the mistakes and medicalised (not socialised) language of medical practitioners, allied health professionals and other supports to make an individual's case for NDIS funding or review in the request for further equipment validated to the social model of disability. This case study demonstrates the inconsistency of proposed principles, 'Timely', 'Expert', 'Connected' and for our advocacy expertise and trust from clients, 'Valued'.

#### **Case Study 6**

An NDIS participant and AFI client had appealed the decline of her original NDIS application and the original decision was overturned under internal review as an outcome. However, this process took over 1 year (May 2018 – later May 2019), during which the client received no communication from NDIA, except from an automatic reply acknowledging receipt of the letter she sent appealing the decision.

The client contacted AFI because she was not being told any information when contacting NDIS and the information she was being told was conflicting, confusing and creating anxiety. She did not even know whether a review was underway. After a lengthy time, delay, the advocate was told that the client's review was being processed. That was all the client and the advocate heard until the day the client was directly informed that the decision had been overturned and she was granted access.

Second, Applicants often report that they have been unable to obtain an acknowledgement of receipt regarding their application for review of a reviewable decision. This is most prevalent where the application for review of a reviewable decision is sent via email. The NDIA must ensure that staff are adhering to the relevant communications policy and acknowledging the applications in an appropriate timeframe.

**Recommendation 20: AFI notes that the NDIA does not have a separate email address for applications for internal reviews. It is suggested that a separate email address may facilitate a timelier acknowledgement of applications. This is as it will contribute to a streamlined review process and effectively ongoing measurements.**

Thirdly, after submitting their applications for review, applicants report that they often have difficulty in obtaining information regarding the status of their internal review. This includes, but is not limited to, information regarding whether the review has been allocated to a decision-maker, when the review will be allocated to a decision-maker and when an internal review decision will be handed down.

The NDIA could match the commitment of legislated timeframes by enabling people with disabilities, their carers/families and support networks to visually see where their process is up to on the portal. Whether a person is waiting for an outcome on their initial access application, their plan reviews or on a complains resolution; the portal could be an effective tool that tackles timeliness to 'reassure' participants of their inquiries.

Having a visual tracking option at the beginning of the portal page could improve communication between the Agency and participants, their carers/families and support networks (including advocates). This will also reduce the time they spend calling the NDIA directly. In effect, a tracking system seen by participants would also be a quality measurement of the NDIA's compliance with their service delivery, as well as the quality of each of the proposed principles.

**Recommendation 21: NDIA to consider placing a 'tracking' mechanism on the portal or online correspondence for plan reviews and internal reviews. Participants cannot track their planning applications, their reviews or correspondence. This would be a useful process for a person with disability who would prefer to be updated 'visually'. The benefit of having a visual tracking system will a) lower the calls to NDIA requesting updated information, and b) reduce the requests for advocacy to navigate the NDIS internal reviews process.**

**Recommendation 22: AFI relates back to the time frames identified in 'Ongoing Delays' in order to address issues around access to information throughout the internal review process. Most relevantly for access for information, the NDIA Act should contain a provision stating that the Agency must acknowledge the request for a review of a reviewable decision within 7 calendar days.**

Finally, applicants may experience challenges in the internal review process due to the limited knowledge and understanding of the review procedure and their legal rights. There is also often a lack of understanding regarding the reasons for the original decision and the corresponding gaps in their supporting evidence. This is particularly the case regarding the issue of substantially reduced functional capacity (*NDIS Act*, s 24(1)(c)). Ultimately, this means that applicants can find it challenging



to collect the appropriate supplementary evidence. This can compromise procedural fairness and increase the number of external review applications.

**Recommendation 23: It is recommended that the NDIA should have a legislative duty to take reasonable steps to assist a person with disabilities to understand the reasons for the original decision and to take reasonable steps to assist the person to understand what supporting evidence they require for a favourable outcome in the internal review process. This may involve the NDIA requesting specific evidence, such as a report from an Occupational Therapist regarding functional capacity and providing detailed guidance to practitioners regarding the issues that need addressing. The Agency has performed this service for non-medico-legal and medico-legal professionals, in the external review process. AFI would endorse the adoption of this practice in the internal review process and believes that it may lead to fewer external merits' reviews.**

#### Information management and communication

A common complaint has been that participants receive incorrect or erratic information from the NDIA regarding their internal review process. For example, applicants have reported receiving letters from the NDIA requesting more evidence a day before, on the day of, or even after, the original decision letter. Additionally, applicants have experienced situations in which NDIA staff have been unable to locate documentation on their records management system, despite having received confirmation of their receipt. These experiences may cause applicants to feel that they have been denied a fair opportunity to present their evidence, whilst also fostering feelings of resentment and frustration in the internal review process.

**Recommendation 24: It is imperative that the NDIA implement responses to reduce disorganised and inflexible decision-making. This may involve developing an improved records management system, implementing better training for the call-centre staff on NDIS operations, and increasing the accountability of staff who consistently deliver incorrect information.**

AFI has observed that clients usually understand that large organisations, such as the NDIA, are vulnerable to issues with consistency and miscommunication. However, they still expect accountability for mistakes and quality of service. The complaints mechanism offers one form of redress, however often the NDIA's response is inadequate and does not accept responsibility, nor offer an apology. As noted, this leads to feelings of frustration and resentment. Restorative practice

seeks to repair damaged relationships and will foster a more equal and harmonious relationship between the NDIA and participants, matching proposed principles 'Engaged' and 'Valued'.

**Recommendation 25: The NDIA to adopt a restorative approach to handling issues regarding miscommunication and inconsistent information. Restorative practice seeks to repair damaged relationships and will foster a more equal and harmonious relationship between the Agency and participants.**

There are also instances in which internal review decision-makers have demonstrated a reluctance to adapt and change in response to new information, whilst following opaque decision-making processes. For example, one internal review decision-maker indicated that they agreed the applicant's requested supports were necessary but that they were required to follow the NDIS's Technical Advisory Team's advice and deny the support. This is concerning because there is a dearth of information regarding the weight of TAT advice, in addition to the criteria and processes used by the Team. Moreover, the applicant is unable to access the advice and are therefore denied a fair opportunity to know the case against them. Thus, while the Scheme promises choice and control, participant's preferences and requests are subject to discretionary approval on the part of the Scheme's planners and decision-makers.

**Recommendation 26: The NDIA must be more transparent in its decision-making processes, including by releasing its operational blueprints and information regarding the role of the Technical Advisory Team. Where TAT advice is used in relation to requested support, the participant should be notified and granted access to the advice upon request. This would help satisfy the NDIA's obligation to provide reasons for decisions.**

### Financial resources

The burden on applicants to collect medical reports evidencing their impairments can be significant and can be financially crippling if bulk-billing is not a viable alternative (i.e. as it may be for people with disabilities who are reliant on the Disability Support Pension (DSP) or Newstart). For low-income households, this presents a significant challenge in both accessing and appealing an NDIA decision. Some medical professionals are completing supplementary reports in their own time, and at their own expense. However, this is not sustainable and transfers the financial burden to professionals such as speech pathologists, occupational therapists and psychologists. These professions are comprised of a

predominately female workforce, and thus this transfer risks gendered financial impacts for the Scheme.

The financial burden on the applicant is evident when considering the confusion regarding what information needs to be collected. Currently, an applicant will produce medical evidence in the original application. Where the NDIA deems it insufficient, the applicant will often request further medical evidence for the internal review process. Confusion about the reasons for the original decision and the operation of the s24 and s34 criteria may mean these documents are not correctly tailored to the issues identified by the NDIA. The appeal may then proceed to the AAT. Here, the applicant may be requested by the NDIA to produce specific reports by particular practitioners, at their own cost. By this stage of the process, the clarity of the request for information is usually adequate. However, it may be the third round of appointments for gathering supporting evidence, and as such the third round of significant medical fees.

People with disability are much more at risk of poverty than the general Australian population,<sup>18</sup> meaning that the impact of these fees is highly likely to be burdensome for applicants and their families. This is at odds to the original purpose of the NDIS, which is to create a societal shift from the medical model of disability towards the social model of disability.

**Recommendation 27: As discussed above, the NDIA should have a legislative duty to take reasonable steps to assist a person with disabilities to understand what supporting evidence they require for a favourable outcome in the internal review process.**

**Recommendation 28: The NDIA should provide more comprehensive training for medical professionals on the application of the access and planning criteria in the NDIS Act. This training should address how to prepare supporting evidence.**

**Recommendation 29: The NDIA should also provide tailored individual support to treating professionals preparing supporting evidence. The Agency has performed this service for non-medico-legal professionals, in addition to medico-legal professionals, in the external review process. This will ensure that the applicant does not spend unnecessary time, energy and money collecting irrelevant or poorly worded evidence.**

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<sup>18</sup> PricewaterhouseCoopers. (2011). Disability expectations: Investing in a better life, a stronger Australia, p. 9. Retrieved from <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>.

## Choice, control, and equity of access

The cumulative effect of these issues causes concern regarding the choice and control of people with disabilities in the internal review process, alongside the equity of access to review.<sup>19</sup> This is because the extent to which these issues can be overcome often depends upon the personal resources of the people with disabilities, including their advocacy and support networks.<sup>20</sup> This creates notable issues for:

- People with disabilities who are homeless
- People with disabilities in the prison system or in remand
- People living in rural and remote communities
- People with behavioural problems, including mental health issues, which isolate them from supports
- Other marginalised communities

These observations are supported by global research regarding the impact of market-based reforms on marginalized communities. Specifically, research in the United Kingdom has found that individuals with significant financial and interpersonal supports in place prior to the reform are more likely to benefit than those who do not. Recent Australian research has concluded that this “suggests that those who are already marginalized or of low socioeconomic status may benefit least from the NDIS.”<sup>21</sup> AFI contends that this phenomenon manifests itself in the appeals process.

**Recommendation 30: To address concerns regarding the equity of access, it is imperative that the identified issues are addressed upfront as part of the Guarantee. This includes addressing the barriers in access to information, the prevalence of misinformation, ongoing delays, the triage and escalation processes, and the burdens on financial and personal resources. In remedying these issues, the NDIA must build an internal review process which is built around the needs of applicants and participants, rather than to accommodate the staff of the NDIA.**

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<sup>19</sup> Olney, S. and Dickinson, H. (2019), p. 283.

<sup>20</sup> Carey, G. Malbon, E. Olney, S, and Reeders, D. (2018).

<sup>21</sup> Carey, G. Malbon, E. Olney, S, and Reeders, D. (2018), p. 5.

# Appealing Decisions By The NDIA: The External Review Process

In addition to the barriers identified in the internal review process, there are various issues and challenges which occur in the external review process. This section will discuss the adversarial nature of external merits review, the balance of power, potential (re) traumatisation and the management of non-legal issues.

## Adversarial conduct and the balance of power

The NDIA external merits review process “is designed to be accessible and as non-adversarial as possible for people with disabilities.”<sup>22</sup> AFI welcomes this effort, including complimentary measures such as fee-waiving and a designated section of the AAT for NDIS matters. However, AFI considers that aspects of the NDIA’s approach to AAT conciliation conferences and hearings are unnecessarily adversarial and insensitive to the power imbalance between applicants and the NDIA. Specifically, AFI considers the following conduct to contribute to an adversarial culture in external merits review.

First, AFI considers that some NDIA staff and contractors have demonstrated a limited ability to empathise and work collaboratively with applicants. Rather, during conciliations, the NDIA has manifested hostility and become subject to speculation that they are making personality-based decisions. This is most notable in conciliations involving applicants who have behavioural difficulties, including inappropriate social interaction and rapport-building. Rapport-promoting behaviour, such as eye-contact and mimicry, is vital for successful negotiation and conflict management as it builds trust and acts as a ‘social tranquilizer’.<sup>23</sup> A lack of rapport can lead to emotional and rational biases in negotiations and decision-making. The NDIA interacts with many people with disabilities who have a reduced capacity to engage in rapport-promoting behaviour. Therefore, the NDIA staff work in situations which render them susceptible to significant bias. AFI has noticed this bias within the external review process and considers that it results in increased hostilities and adversarial behaviour. As discussed, this is likely because they lack rapport limits the ability of NDIA staff to empathise and work collaboratively with applicants who have behavioural issues.

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<sup>22</sup> Australian Government Department of Social Services. (2017). Operational Guidelines NDIS Appeals, p 4. Retrieved from [https://www.dss.gov.au/sites/default/files/documents/03\\_2017/ndis\\_appeals\\_factsheet.pdf](https://www.dss.gov.au/sites/default/files/documents/03_2017/ndis_appeals_factsheet.pdf).

<sup>23</sup> Harvard Law School Program on Negotiation. (2012). Dispute Resolution: Working Together Toward Conflict Resolution on the Job and at Home. (Negotiation Special Report #9).

**Recommendation 31: The NDIA must address unconscious bias to ensure that they are not making ‘personality-based’ decisions. This may include providing staff training in communicating with people with behavioural difficulties, addressing unconscious bias, general conflict management training and constructive negation.**

Second, AAT conciliation conferences typically involve three NDIA representatives, comprising an in-house lawyer, an external lawyer and a non-legal instructor. This is an issue because many applicants consider it to be a deliberate intimidation tactic. They perceive the NDIA as a powerful body with significant influence over their social and economic wellbeing, alongside an unobtainable knowledge of the merits review process and NDIS legislative and policy framework. In contrast, applicants often have no experience with the AAT and find the external merits review process nerve-wracking and confusing. They typically enter conciliation conferences with maximum one lawyer and one advocate, and a perception that they are coming ‘up against the system’. Consequently, for many applicants, facing three NDIA staff members in conciliation seems overtly insensitive to the imbalance of power, knowledge and resources between them and the NDIA.

Furthermore, “over 90 per cent of the cases [in the external review process] may be subject to undue influence by the NDIA.”<sup>24</sup> This is because the NDIA negotiates most of the external review appeals with the applicant; in 2018/19, only 3% of matters went to a hearing.<sup>25</sup> This may be positive as it avoids a lengthy and intimidating legal process. However, where the imbalance of power, knowledge and resources is inadequately mitigated, the applicant may be subject to undue influence and intimidation. This may lead to the applicants settling for decisions which are less than what they are entitled to.

**Recommendation 32: The NDIA and AAT must establish additional mechanisms to address the imbalance of power, knowledge and resources between the applicant and the NDIA. This may include refraining from using lawyers in negotiations, or conversely ensuring that applicants have obtained legal support before entering negotiations. AFI notes that “it is not enough to simply remove barriers to (equal) participation.”<sup>26</sup> The NDIA must also empower people with disabilities**

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<sup>24</sup> Southwell, G. (2019). The Administrative Appeals Tribunal affirms less than 2% of NDIS decisions appealed by participants. Retrieved from: [https://probonoaustralia.com.au/news/2019/10/the-administrative-appeals-tribunal-affirms-less-than-2-of-ndis-decisions-appealed-by-participants/?utm\\_source=Pro+Bono+Australia+-+email+updates&utm\\_campaign=214e17324d-](https://probonoaustralia.com.au/news/2019/10/the-administrative-appeals-tribunal-affirms-less-than-2-of-ndis-decisions-appealed-by-participants/?utm_source=Pro+Bono+Australia+-+email+updates&utm_campaign=214e17324d-)

<sup>25</sup> Southwell, G. (2019).

<sup>26</sup> Carey, G. Dickinson, H. and Olney, S. (2019) What can feminist theory offer policy implementation challenges? *Evidence & Policy: A Journal of Research, Debate and Practice*, 15(1), p. 152.

**through education, including in self-advocacy, and encourage cultural shifts in the perception of the autonomy of people with disabilities.**

### (Re)traumatization

The external merits review process may be challenging for applicants due to its emotional toll. First, as discussed previously, the face-to-face confrontation with three NDIA representatives can feel threatening, and thus be triggering and emotionally charged. This is particularly pertinent for applicants who have psychosocial conditions. AFI has worked with various clients who have reported an exacerbation in their mental health conditions due to their engagement with the external review process.

Second, the conversation within the conferences and hearing may be challenging for the applicants. This is because they are privy to discussion and comments regarding the permanence of their condition/s, the substantiality of their difficulties and the legitimacy of their support needs. This may feel invalidating, incorrect and/or dismissive. For example, one applicant reported feeling like they were being told that their child 'did not have needs', despite their lived experience that they required intensive familial support. AFI understands that the criteria in section 24 and 34 require such assessments. However, it is noted that in other civil matters, such as personal injury compensation cases, the applicant will not be present in the negotiations regarding the validity and extent of their conditions. This is due to a general acceptance that such discussion can be incredibly upsetting for applicants who have experienced any physical and mental health difficulties. Akin to other civil matters, NDIS applicants engaged in external merits review can find discussion of the extent and nature of their conditions and needs to be challenging. This can be mitigated by the applicant's support network; however, where the applicant does not have a robust network, the NDIA must be particularly cognizant of the significant emotional impact of external merits review.

**Recommendation 33: AAT and NDIA must increase their expertise in trauma-informed work. AFI also encourages the AAT and NDIA to contemplate high-level reforms to the adversarial and hierarchical political-administrative system, in favour of restorative and relational decision-making mechanisms widely discussed in critical literature.<sup>27</sup>**

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<sup>27</sup> Carey, G. Dickinson, H. and Olney, S. (2019), p. 152

## Management of non-legal issues

Finally, AFI has observed that applicants can find it hard to focus on the legal issues identified for the external review process. As discussed, applicants have often experienced miscommunication, misinformation and extensive delays in the internal review processes. Consequently, they often want to discuss these issues in the AAT conferences and obtain an acknowledgment from the NDIA that the process has been frustrating, confusing and inadequate. Registrars and the NDIA may remind the applicants that the AAT is not the appropriate forum for these grievances; however, this may cause the applicant to feel unheard, disrespected and increasingly angry. This contributes to an overall frustration with the appeals process and participant dissatisfaction.

**Recommendation 34: The NDIA may find it useful to establish a process for acknowledging non-legal complaints for applicants who are engaged in external merits review. AFI encourages the NDIA to adopt restorative practice in the management of these issues as emphasised in the recommendations made for internal reviews. For example, the NDIA could refer non-legal issues raised in AAT conferences to a dedicated team in their Complaints Branch. This will support applicants to feel heard and respected, whilst also allowing them to focus on the legal issues in AAT conferences and hearings. Ideally, this will increase the applicants' wellbeing, understanding, satisfaction and make them more accepting of the AAT's final decision.**

## Removing Red Tape from the NDIS

### Amending the Legislative Framework

AFI notes that the NDIS is an inter-organisational and complex system, which is governed by a plurality of laws, policies, processes, and actors. The NDIS Act and Rules operate at a high-level and have a limited sphere of influence in the overall operation of the Scheme. However, various elements of their design and implementation cause difficulties for people interacting with the NDIS. These are identified below and are proceeded by recommended changes to the legislation to facilitate easier engagement by the community with the NDIS.

First, AFI considers that the language of the Rules and Act are inaccessible and are not tailored to the plurality of individuals interacting with the Scheme. This is supported by recent academic literature which found that “many participants described lack of clarity in the process of planning their care, particularly surrounding their level of choice and control and what constitutes ‘reasonable and



necessary support.’’<sup>28</sup> It is also demonstrated by the under-representation of women, indigenous people, CALD people and people with a psychosocial disability, in the NDIS.<sup>29</sup> There is a dearth of research into the causes of this underrepresentation. However, it is clearly representative of some deficit in the NDIA’s ability to render the Scheme accessible and appropriate for marginalised groups. Ensuring that both the access criteria and the reasonable and necessary criteria are appropriate across a diversity of backgrounds may minimise the difficulties people have when interacting with the NDIS.

**Recommendation 35: The NDIA should adopt innovative approaches to ensuring that legislation is accessible and understandable. As a priority, the NDIA must ensure that people with disabilities can understand the criteria under sections 24 and 34. AFI notes that there have been innovative approaches to legislative drafting and communication across the globe, including through the development of pictorial legislative instruments. Pursuing new modes of legal communication may encourage accessibility and understanding of the NDIS Act.**

**Recommendation 36: AFI encourages the NDIA to make space for differences in language and a plurality of experiences. This will contribute to the de-mystification of the law and allow the NDIS Act to become consciously embedded in participants’ daily life. Moreover, AFI considers that the expansion of language and understanding will develop the flexibility, inclusivity and cultural appropriateness of the Scheme.**

**Recommendation 37: The NDIA must conduct, or finance, research into the causes of under-representation of marginalised groups within the Scheme.**

**Recommendation 38: The NDIA must better work with Indigenous People to ensure the Scheme and the NDIS Act are culturally appropriate, including regarding different cultural understandings of disability.**

Second, the NDIS Act and Rules do not provide equal opportunities for older persons with disabilities. This was highlighted in the UN’s report on Australia’s Review of the CRPD.<sup>30</sup> This constrains a significant cohort of Australians with disabilities from accessing individual, enduring and well-resourced support.

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<sup>28</sup> Olney and Dickinson (2019), p. 281.

<sup>29</sup> Standing Committee on Health, Ageing and Community Service. (2018). *Inquiry into the Implementation, Performance and Governance of the National Disability Insurance Scheme in the Act*, p. vii.

<sup>30</sup> Civil Society. (2019). *Disability Rights Now: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review*.

**Recommendation 39: AFI recommends that the age requirements (of 65 years or younger) be removed; or, that the Government increase funding for aged-care services to ensure that older people with disabilities have their human rights upheld and protected.**

Third, the NDIS Act consists of numerous interpretive silences. Some of these silences are addressed in the policy. For example, the NDIA has increasingly made attempts to clarify the delineative ambiguities between Health and Disability. However, there remains a problematic dearth of definitions in the NDIS Act, including for core terms such as ‘conditions’ and ‘impairment’. Furthermore, the NDIS Act does not provide criteria for determining the severity of a person’s ‘reduced functional capacity’, nor whether an impairment is ‘likely to be permanent’.

The lack of clarity regarding the meaning and assessment criteria for ‘substantially reduced functional capacity’ is particularly concerning for people whose impairments fluctuate. This is because, while the NDIS Act provides that impairments “that vary in intensity may be permanent” and that persons with such impairments “are likely to require support” for their lifetime (s24(2)), it does not address the impact of such variations on the assessment of functional capacity. Rather, the *NDIS (Becoming a Participant Rules) 2013*, rule 5.8, considers the person’s functional capacity with regard to their ability to perform day to day tasks. This is concerning for people with fluctuating conditions because the NDIA is often uninterested in hearing about applicant’s “bad days.”<sup>31</sup>

Specifically, AFI has observed that applicants with fluctuating capacity are often told that their support needs are not substantial enough. For example, an NDIS participant with fluctuating neurological conditions was told by a LAC that their needs were not ‘severe enough, compared with other NDIS participants’, despite being unable to walk on their ‘bad days’. Another applicant who experiences fluctuating mental health conditions was told that they did not have a substantially reduced functional capacity, despite requiring intensive support from their parents to undertake self-care and self-management on an ongoing basis. This applicant could complete tasks such as socialising, dressing, eating and showering on their ‘good days’. However, the cyclical state of their mental illness meant that they were not able to take responsibility for themselves on an on-going basis. Rather, their parents were required to continually manage their financial and medical affairs and be constantly alert early warning signs.<sup>32</sup> The periodic loss during regular acute episodes of their capacity to “manage finances” or “take responsibility for oneself” – specifically listed as examples in the Agency policy –

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<sup>31</sup> O’Donovan, D. (2018). Renewing the NDIS: Refocusing the Eligibility Debate. Retrieved from: <https://auspublaw.org/2018/07/renewing-the-ndis-refocusing-the-eligibility-debate/>

<sup>32</sup> O’Donovan, D. (2018).

can have the most serious consequences for life outcomes, such as interactions with the justice system or extreme poverty.”<sup>33</sup> AFI remains concerned that the ambiguity and interpretation of ‘substantially reduced functional capacity’ cause significant difficulties for people with fluctuating conditions.

**Recommendation 40: The NDIA should develop a separate access pathway for people with fluctuating conditions, such as psychosocial conditions. This may include distinct Rules for the application of section 24 to psychosocial disabilities. It is particularly important that the NDIA reconsidered the application of section 24(1)(c) to fluctuating conditions and ensures that activities such as self-management and self-care are assessed over weeks or months, as opposed to on a daily basis.**

The NDIS Act also fails to provide a standard of proof for sections 24 and 34. This has raised particular issues with regards to the determination of whether an impairment is ‘likely to be permanent’. AFI notes that the *NDIS (Supports for participants) Rules 2016*, rule 5.1, provides that permanence arises where there is no “known, available and appropriate treatment which is likely to remedy the impairment.” However, practically, the quantity and quality of evidence required for this appear discretionary, depending on the nature of the condition, the decision-makers preferences and their medical expertise. At times, applicants are required to provide a significant amount of supporting evidence in their application. AFI considers that the variable and, at times unreasonable, standard of proof prejudices marginalized people, including those who have a lower socioeconomic status or live regionally.<sup>34</sup>

**Recommendation 41: The NDIA must identify the standard of proof required for applicants. This is particularly important in decision-making guidelines for section 24(1)(b). The NDIA must also increase the transparency of their decision-making to minimize the haphazard and discretionary nature of their decision-making processes.**

Additionally, the NDIS Act does not codify necessary protective processes such as the Government’s ability to regulate the market through price-setting or the human rights of people with disabilities. This can make it harder for people with disabilities to exercise choice and control because of the competing conceptions of rights, autonomy and agency in the lives of people with disabilities across Australia. Most pertinently, there are areas of law, policy and society in which the autonomy of people with disabilities is ignored or inconsistent with the human-rights framework of the NDIS. This means

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<sup>33</sup> O’Donovan, D. (2018).

<sup>34</sup> O’Donovan, D. (2018).

that the autonomy of people with disabilities to exercise choice and control cannot be fully realised within the NDIS. AFI notes that the *Disability Discrimination Act (1992)* has been an important step in protecting people with disabilities. However, it is insufficient in promoting the positive rights of people with disabilities.

**Recommendation 42: It is essential for Australia to have an entrenched Human Rights Act, in order to ensure that the autonomy and agency of people with disabilities are consistently upheld in a manner congruent with the aims of the NDIS Act.**

## Other Key Gaps for the Guarantee to Plug

### Issue of Provider of Last Resort (POLR)<sup>35</sup>

There remains confusion of what constitutes as a ‘Provider of Last Resort’ (POLR).<sup>36 37</sup> As an advocacy organisation, we have faced confusion as to whether we are acting as a source of ‘last resort’ is urgently advocating on behalf of a consumer to be supplied adequate care and accommodation. At best, providing advocacy where crisis support is required, is difficult when the NDIA is seen as a giant boulder in the path of progress for an individual in need. In our experience, we often have participants being denied services and care due to funding disputes between the NDIA and other government services, including:

- NDIS participants, with plans providing for intensive supports including 24/7 care to support their independent living;
- Trapped in a constant cycle of recidivism due to lack of supports to aid people with disabilities and mental health in the criminal justice system
- cannot get bail from the court because they cannot safely return home without residential care supports in place;

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<sup>35</sup> Section taken and applied from Advocacy for Inclusion (2019) *Submission in response to the NDIS Thin Markets Project Discussion Paper*, DSS Consultation with Ernst & Young pp. 7-12.

<sup>36</sup> NDIA (National Disability Insurance Agency) (2016), *NDIS Market Approach: Statement of Opportunity and Intent*, Geelong, p. 15.

<sup>37</sup> Ibid. The NDIA’S current ‘market intervention framework’ highlights the presence of ‘weak/thin markets’ as well as describing the authorisation of a POLR by the NDIA where “provision of goods and services in order to ensure supply” is commissioned. The confusion lies in the line that “even in a mature NDIS marketplace, insufficient local demand, limited-service delivery, workforce shortages, and lack of infrastructure will produce “weak” or “thin” markets” – providing no reassurance that even at a crisis intervention point, support and supply will be provided under the NDIA.

- cannot attract service providers to give them the necessary support or attract providers to coordinate their in-home supports as they are deemed too complex and challenging.

The issue of the interface between the NDIS and mainstream services have become more complex and the roles of each need to become well-defined in a policy framework to differ to avoid conflict of interest.

**Recommendation 43: NDIA act and review via a formal mechanism between Commonwealth and State and Territory jurisdictions to delineate the roles and responsibilities of the NDIA and mainstream services regardless of progress level. This should be focused on the delivery of services, plugging gaps in the event of funding disputes and disagreements of responsibility. The participant is and should remain a priority.**

People with a disability with complex needs or unpredicted circumstances, ending up in public aged care facilities, hospitals or institutional care such a prison, mental health wards and group homes is concerning. The lack of resolution surrounding how jurisdictions, including the ACT, can settle for a framework that identifies key service providers or settings of last resort to maintain critical supports that are ongoing.

In our experience, when people with high and complex needs rely on support to eat and drink are admitted to hospital are often left unsupported as it becomes a health vs NDIS interface issue. Arguments seem to arise from Supported Independence Living (SIL) providers that this support is not covered in their SIL quote if the participant is not present in the home and when the quote covers daily living matters. Instead, such support seems to then appear from their social support funding. It then becomes left for an advocacy organisation to organise such independent living support as it is overlooked in by the SIL provider.

We also see alarming cases of people being admitted to hospital, healthcare or aged care facilities and not being released (or placed under guardianship arrangements) due to lack of support staff available to assist daily. Within these practices, AFI can attest to handover processes lacking or unprovided, compromising the care and support of the individual. Despite participants being eligible and have access to NDIS, the question of what happens when sudden care changes occur, and they cannot be cared for in their own homes. Without the NDIS and limited care options available in the community

for family or providers, there has been no choice but to admit them to a hospital or an institutional setting arrangement.

It is unfair to assume the individual should have funding to cover any critical incidents that may occur outside of that the NDIS would traditionally fund. The confusion of how last-resort support will be addressed, who provides support and how quickly falls to the NDIS and should not fall to the person with adequate support measures put in place. *This is not the role of an advocate and nor should it be if the NDIA claims to be a PORL provider. It places extra strain on advocacy organisations to pick up the pieces for individuals in PORL situations.*

**Recommendation 44: Safety of individuals is essential, and thus should alternative accommodations, or care settings arise at short notice, the NDIS should make provisions to address urgent and critical situations without delay nor question.**

**Recommendations 45: NDIA further funds and supplies additional resources and funding to advocacy organisations if advocates are picking up the pieces when it comes to POLR situations.**

People with disability and psychosocial disability have been provided wrong supports as an option by staff whom are ill-trained or equipped to support them, be retained in a custodial environment, hospitals or institutional settings as there is nowhere for them to go and forced to remain in their homes without additional support for their families or carers. If there are no complex services to support individuals 'to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life'<sup>38</sup>, then it enters a thin market domain. This is evident where there is no market and no accessibility to alternative options.

**Recommendation 46: NDIA to develop and operate a triage system to prioritise people who require urgent assistance. The individual themselves should be supported by their provider, advocacy organisation or support networks without further barriers in place.**

**Recommendation 47: NDIA needs to place transparent Provider of Last Resort arrangements in place as the absence of such arrangements are putting people at risk of not accessing any supports, resulting in admission to hospital, aged care facilities or jail.**

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<sup>38</sup> UN CRPD Article 26 – Rehabilitation and habilitation, s.18(a).

**Recommendation 48: NDIA to reevaluate what ‘last resort’ means and how it has been problematic in the past. If there is no market, one needs to be created to provide basic crisis intervention and basic services and supports alongside advocacy organisations in each jurisdiction.**

Existing state and territory government processes that arise in crisis and emergencies that will cease despite the absence of formal arrangements under the NDIS is a concern.<sup>39</sup> Without key services that can respond to emergency crises and have expertise in linking people with complex needs to providers and services, there will be consequences where people continue to be placed in environments in which they will be stuck. The NDIA has not placed triaging systems in place to address urgent cases. From an advocacy perspective, there appears to have been no process to ensure the provision of adequate, equipped services that manage crisis intervention and emergency service as there is no direct market and the system ultimately relies on state and territory governments.

The COAG document *Principles to determine the responsibilities of the NDIS and other service systems* lacks clarity and are open to misinterpretation. The lack of funding, roles and responsibility between the NDIA and mainstream services has created an emerging gap of its own where the fault is not of the participant. The impact on access to services for both eligible and non-eligible people with disabilities is great, particularly in the areas of justice, health, transport and crisis accommodation.

The focus should largely be on addressing boundary issues with mainstream services, the health interface and supported living accommodation settings. The slow delivery and promise of the *Maintaining Critical Supports* pilot framework remain unignored by the advocacy sector – as advocacy organisations are often called to address and hopefully plug the gaps involving participants with short-term solutions. We recognise and welcome the introduction of the *NDIS Complex Needs Pathway*. However, crisis intervention is a priority. The lack of information and approach by the NDIA is troubling – particularly when it is blatantly obvious that the issue is ignored and hidden behind a bureaucratic response.

**Recommendation 49: The NDIA to review the *Principles to determine the responsibilities of the NDIS and other service systems* between Commonwealth and State and Territory jurisdictions to**

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<sup>39</sup> Transitional arrangements for the NDIS and the Market readiness for provision of services under the NDIS reports.

**determine responsibilities, roles and appropriate funding, budgeting and elimination of gap issues for participants caught in a complex systematic web that is not their fault.**

**Recommendation 50: The *Maintaining Critical Supports* policy needs to be evaluated and must commit to providing services in areas of crisis accommodation and emergency intervention.**

**Recommendation 51: The NDIA steps up to acknowledge the priority of addressing Provider of Last Resort as a thin market. The NDIA needs to create a funding framework for continued provisions of disability services where the need for crisis accommodation and emergency intervention.**

### Thinning NDIS Workforce

In our experience working with clients of high and complex needs, the lack of progress to address gaps where scarce services are available or exist has been highlighted continuously. We also note NDIA's reluctance to consider any service delivery model that is not based on the individualised and broadly-rolling-out of fee-for-service models. It is also a gap when continuity of supports lessens, and the participants lose their chosen provider and are required to redevelop a rapport or support system with a new provider or support staff who may be less experienced in working with high and complex needs. This is clear where the allied health workforce is thin within the NDIS: OTs, psychologists, speech and language therapy and behavioural therapists are all in demand.

Case studies highlight a significant gap where disability support workers are low in numbers and reliant on casual contracts due to low support staff available. We regularly receive requests for advocacy for people being put to bed at 8 pm and not provided choice and control in their own group home accommodation due to lack of support staff available to monitor and support during the night. Equally, people have been left in bed until 11 am to be provided breakfast, showered and dressed or released into the community due to staff unable to commit to early morning availabilities.<sup>40</sup>

We argue that there is currently an immature market framework under the NDIS – that is already well known, acknowledged and possibly burnt to a crisp where awareness is concerned. The NDIA also appears to be working in isolation and not building on existing service delivery models, which in turn, falls back into the disability advocacy organisations where capacity is overflowing, and the availability

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<sup>40</sup> Also refer to Advocacy for Inclusion (2014) *I Make My Own Decisions* paper.



individual advocacy is narrow and based on the severity of individual cases.<sup>41</sup> A thin market, except in a different context. This is not surprising where the Joint Standing Committee has pointed out “there is currently no clear national strategy to grow the workforce despite the need for an additional 70 000 disability workers by 2020”.<sup>42</sup>

Through the AAT process, AFI has found that Local Area Coordinators (LACS) and NDIS Planners do not have the training, skills or direct experience to support people with complex and high support needs. The high reliance on the diagnosis of psychiatrists and GP letters in which is influencing whether people are supported or provided the level of support required.

Accountability remains key. To promote and actively drive a market that is unable to deliver, and the workforce is unable to supply, there is an assumption that providers and advocacy organisations will assist to plug those gaps. Ideologically, this is possible as AFI cannot effectively deny advocacy and the increase in AAT has proven that.

**Recommendation 52: The need for the NDIS workforce to grow is paramount and the number of NDIS providers will need to increase to create balance and support choice, control and individualisation of services. NDIA needs to create a national strategy between Commonwealth and State and Territory governments in addressing and improving the disability services workforce.**

There is also a need to begin addressing the potential growth in a growing aged population of people with disabilities over 55 where the NDIS age cap and participants are then reliant on the aged care system for system. Effectively and realistically, both sectors and service provisions are requiring growth in support and specialised staff. This is going to place additional strain on the current thin/weak market structure where NDIS funding for the participant is supplied, but the aged care sector and those ineligible for the NDIS may potentially require just as frequently and urgently.

**Recommendation 53: By identifying where innovation is currently occurring in the disability services and the overall service provisions, it is necessary the NDIA effectively work with providers and community organisations to match demand and plug future gaps.**

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<sup>41</sup> Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, p. 34

<sup>42</sup> Joint Standing Committee on the National Disability Insurance Scheme (2018) *Market readiness for provision of services under the NDIS*.

On the flip side, there is a necessity to reconsider the staffing cap of the NDIA staffing ratios. Adjusting the issue of the 'thin markets' requires monitoring, increasing the quality and safeguarding and transparency to allow providers and participants to have increased capacity. The lack of capacity of NDIA staff is becoming extremely problematic, particularly as more participants enter the Scheme. The NDIA staffing cap has been a notable criticism<sup>43 44</sup> as to whether capacity and current resources allow for the NDIA to address the issue of 'thin markets' effectively across a number of issues. The management of the issue needs to be balanced with ensuring that providers and specialists have support to deliver the support required under the NDIS without additional and unnecessary constraint.

**Recommendation 54: The NDIA to reconsider the staffing cap to have the capacity to address and implement changes to plugging thin market gaps for participants.**

### Behavioural Management Support

The severe lack of behavioural management support in the ACT has been a highlighted issue for our clients. There is a Catch-22 within the ACT where (1) NDIS participants cannot receive funding to support them to receive Behavioural Management Support, creating difficulty to find services that fit their needs whilst also liaising with education and health outside of NDIS remit and, (2) there are extremely limited capacity of behavioural support specialists to sign and support further behavioural management support in line with the current and new *Senior Practitioner Act 2018*. In the ACT, this has created a stalling of supports as they toe the line with education and health.

In the ACT, there is a severe shortage of NDIS behavioural support planning available, and it falls to the requirement of the provider who must be registered creating backlog and urgency where qualified behaviour specialists are available. This, in turn, must be provided to the NDIS Quality and Safeguards Commission for quality assessment, monitoring and recording

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<sup>43</sup> Australian National Auditing Office (2017) Decision-making Controls for Sustainability: National Disability Insurance Scheme.

<sup>44</sup> Joint Standing Committee on the NDIS (2018) Market readiness for provision of services under the NDIS: Final Report.

## Lack of Support Coordination

At 31 December 2018, 40 per cent of NDIS participants had support coordination in their plans and many more require it due to the complexity of sourcing appropriate supports.<sup>45</sup> However, there is a confusing mythical misunderstanding of what support coordination is, who should receive it and why, and why people who would benefit from support coordination miss out.

In our experience, we continuously find people with complex support needs are falling through the gaps and are facing a significant risk of homelessness, reoffending and without continuous supports due to the lack of support coordination. We have questioned the previous 76 hours<sup>46</sup> of support coordination in NDIS plans was considered as significant for those with core supports, it remains from enough for people with high complex support needs particularly when dual psychosocial and mental health is also a factor. Under the current market economy,<sup>47 48</sup> support coordination has an impact on people gaining services and support they require. In the mental health space, there is a lack of service providers which offer support coordination for people who have a large core funding amount in their packages.

People have required assistance in setting up for the right supports and services outside of our advocacy capacity; however, support coordinators have a tougher job when services, supports and programs, needed, based on a participant's goals, pre-existing supports (informal, mainstream and/or community supports), within the plan period – are non-existent and there is a risk of services closing down or are unequipped and trained in providing services to people with high and complex needs.

AFI has experienced questions of confusion from participants as to what and how Support coordination is supplied, regulated and managed as an NDIS funded requirement. There is confusion of from participants of what constitutes support coordination and how it differs the role of advocacy. Advocacy for Inclusion acknowledges that 'advocacy' is separate support and cannot be meddled with the roles of support coordination or even case management.

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<sup>45</sup> Ibid.

<sup>46</sup> Previous NDIS Price Guide 2018-2019.

<sup>47</sup> Joint Standing Committee on the National Disability Insurance Scheme (2018) *Market readiness for provision of services under the NDIS*.

<sup>48</sup> Ibid, p. 32.

We have also experienced instances where people with disabilities are not been properly accommodated by support coordinators, who appear to operate on an ad-hoc basis in the community and with limited oversight of the NDIA itself. Despite the concept of support coordination is a necessary component for people with high and complex needs, participants have equally complained to AFI that support coordinators are not skilled or funded adequately to deliver a holistic service for people with disabilities nor knowledgeable in finding the services they require, instead pocketing funding despite being required for a specific purpose. Support coordinators should not be funded to service providers that also provide advocacy services under Government funding. It is a high conflict of interest, blurs the understanding between support coordination and advocacy, and is not an oversight and regulated by the NDIA or DSS if both advocacy and support coordination is provided.<sup>49</sup> Organisations should not receive funding for a free service (advocacy) and another bucket for providing a service (support coordination).

We argue that the high conflict of interest present can create bias from an advocate that may be present in both 'services', and clients may be referred indirectly to the services of support coordination offered by advocacy organisations that have a support coordination service attached. Organisations may insist that a free service (advocacy) and support coordination (funded via participant plans) are mutually separate. However, in a current debate of the difference between the roles, they are easily blurred.<sup>50</sup>

The premise of a service provision side of an NDAP funded individual advocacy (i.e. AFI) remain completely independently operated by the advocacy organisation.<sup>51</sup> Non-bias and protection of

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<sup>49</sup> NDAP Code of Conduct for advocacy specifically state that:

1. Disability Advocates are concerned with issues of social justice and equity for people with disabilities including access to quality services.
2. An advocacy service must remain independent of government and service provision so to ensure all conflicts of interests are minimised.

<sup>50</sup> Ibid. "A client/Advocate relationship is unique. The advocates role carries with its specific responsibilities that arise out of this relationship to;

- Act independently;
- Promoting the autonomy and best interests of the person with a disability;
- Respecting the privacy, dignity and confidentiality of the person with a disability;
- Maximising the safeguards of the person with a disability from possible exploitation, abuse and/or neglect;
- Supporting people with disabilities to make informed choices."

<sup>51</sup> NDAP Code of Conduct for advocacy specifically state that:"Disability Advocates must:

- Minimise conflicts of interest;
- Promote Decision making and choice free from bias
- Support options are planned, developed, implemented and reviewed in a manner that is responsive to the decisions, choices, and aspirations of individuals.

privacy and confidentiality cannot be guaranteed under two models if they are responsible for both a paid and unpaid provision, both similar in nature and approach to assisting the participant to access their NDIS packages successfully.

**Recommendation 55: The Service Participant Guarantee needs to track, monitor and evaluation the position of support coordination, particularly against the confusion of where advocacy can overlap. This evident to ensure that bias and advocacy independence is assured under the Guarantee on behalf of participants as a safeguarding mechanism.**

**Recommendation 56: The NDIA, under tightening red tape and processes, to provide oversight and evaluation mechanisms placed to support coordinators in purpose of KPIs to ensure that support coordination is provided correctly, participant funds are being used wisely, and services are provided adequately under the Guarantee standards.**

### Supported Independent Living (SIL)

SIL is not provided in any NDIS plans and instead is listed by NDIS as 'SIL quote required'. AFI advocates never receive SIL quotes (they are lodged directly to NDIA for approval), or an indication that the SIL quote has been approved. AFI is only made aware when we receive SIL agreements to consent to by the participant and is often muddled with social supports.

At best, the quoting for and negotiating on SIL services, within SDA or living in a congregate setting is hidden from participants and in the control of providers. It is hidden by the service provider and the NDIA under the guise of 'privacy' despite participants requesting advocacy support to understand and negotiate their living circumstances. This prevents participants from having the promised choice and control and negates the ability for the participant's nominee, family support or chosen advocate, to monitor the provision of extra or reduced support hours' where relevant.

The provisions of SIL is both confusing for the participant and the advocate to understand. To remove the 'red tape' around participants understanding SIL as part of their NDIS plan, it should be discussed at the participant review. In one example, AFI had a client had limited SIL funding and therefore was

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- Maintain Privacy, dignity and confidentiality"

not provided support to do her grocery shopping or meal preparation, so she was just buying frozen meals to compensate the lack of support. She was not aware of what she can access, and the service provider was not forthcoming as they handled only the 'accommodation aspect' and not the social supports. Participants are the ones who know what support they would like to receive in regard to daily supports and not be provided supports that the service provider determines.

This is where our advocates see gaps, and neglect in support and care – unless reflected in the participants' plans that is both transparent (to all parties the participant choose to have involved) and easy to understand.

**Recommendation 57: The NDIA to review quoting for and negotiating on Supported Independent Living (SIL) services, within Specialist Disability Accommodation (SDA) is hidden from Participants. It is hidden by both the NDIA and the Service Provider and is an issue to be addressed. Addressing this will match proposed principles of 'Connected' and 'Engaged'.**

## Conclusion

In conclusion, AFI welcomes the current efforts of the NDIA to improve delivery for all NDIS participants. This cannot be done without flexibility in response to circumstances of individual participants and should be balanced with equity and transparency in all levels of decision-making. With a robust, clear and accessible system of internal reviews and external processes available to participants, their carers and support networks, the NDIA is heading in the right direction. We will continue to work positively with the NDIA, and we look forward to continuing future collaboration following this submission.

In response to how the NDIA can measure how well the NDIA has delivered on each of the seven proposed principles<sup>52</sup>, the question of how to measure how well the NDIA has delivered on each principle can be done through implementing the purpose behind the principles in themselves. The measurement from participants as well as disability representative groups needs to be measured in how often engagement occurs and additional submission consultancy is not a recommended approach to this. Instead, regular targeted face-to-face consultation in collaboration with each State and Territory government to deliver is key to success.

We anticipate that not only will people be able to be better prepared and provide better evidence etc, but also a better understanding of reasons may lead some people to accept the outcome (not from resignation, but simply understanding what the NDIS provides/who it does/doesn't give access to etc.) which will lead to more organisation trust and less disgruntled participants. Current reasoning of decisions made by the NDIA is either non-existent, inadequate, or full of jargon and pulled from a template which doesn't actually explain properly (or in Plain or Easy English format) as to why someone didn't get access to the NDIS or requested support.

It is the strong belief of AFI that the NDIA Service Standards should be focused on increasing meaningful and tangible support for people with disabilities to exercise self-determination, tied with vigorous accountability, transparency and monitoring systems. Importantly, people with disabilities must continue to be engaged as designers and co-designers in all NDIS and disability-related systems, to enable real self-determination for people with disabilities – as originally intended.

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<sup>52</sup> Discussion Paper, Introduction: Key Discussion Question 5, p. 6.