



# Putting people first

## Removing barriers for people with disability to access NDIS supports

Submission to the Review of the NDIS Act and the new NDIS Participant Service Guarantee

4 November 2019



National Legal Aid Secretariat  
GPO Box 1422  
Hobart TAS 7001  
[nla@legalaid.tas.gov.au](mailto:nla@legalaid.tas.gov.au)  
03 6236 3813

## Table of Contents

<b>1. Executive summary</b>	<b>3</b>
<b>2. Summary of recommendations</b>	<b>5</b>
<b>3. Our work with Australians with disability</b>	<b>6</b>
3.1 About National Legal Aid and state and territory legal aid commissions	6
3.2 Free legal help for people with disability, their carers and families	6
<b>4. Participant Service Guarantee</b>	<b>8</b>
4.1 Timely and responsive decision making	10
4.2 Accessible for target groups	11
4.3 Targeted processes for access, planning and ensuring services for people in detention	14
4.4 Responsiveness and a service safety net	19
4.5 An accountability framework	23
<b>5. Access and eligibility</b>	<b>27</b>
5.1 Improved awareness of the NDIS	27
5.2 Reduced barriers to making an access request	27
5.3 Transparent and clear access decisions	30
<b>6. Creating a plan</b>	<b>32</b>
6.1 Reduced delays in planning	32
6.2 Pre-planning support	33
6.3 Accessible and effective planning meetings	34
6.4 Connection between planning meeting and NDIS plan	35
6.5 Plans that adequately meet people's needs	36
6.6 Improved access to specific supports	38
6.7 Consideration of relevant factors in decision making	39
6.8 Improved reasons for planning decisions	40
<b>7. Using a plan</b>	<b>43</b>
7.1 Understanding a plan	43
7.2 Choice and control for people in rural, regional and remote areas	43
7.3 The benefits of skilled support coordinators	46
<b>8. Reassessing and reviewing a plan</b>	<b>49</b>
8.1 Improved processes for scheduled plan reassessments	49
8.2 Maintaining service levels	51
8.3 Maintaining participant status following revocation	52
<b>9. Amending a plan</b>	<b>54</b>
<b>10. Appealing a decision by the NDIA</b>	<b>56</b>
10.1 Clear, timely internal reviews	56
10.2 Appealing a NDIA decision to the AAT	60
10.3 Reimbursement following successful review decision	68
<b>Annexure A: List of recommendations</b>	<b>71</b>

## 1. Executive summary

*Dealing with the NDIA has been a painful experience. I feel like I have been banging my head against a brick wall. Just when we think we have taken one step forward, we are forced two steps back. We will never stop fighting for our son but it shouldn't have to be this hard to get the help he needs and deserves. Marcus is now five years old and has so much potential. This process has taken two years now. Every day is crucial for early intervention and making gains in functioning.*

*We just want Marcus to have a bright future where he can function to the best of his ability. We feel deflated, extremely disappointed and disheartened. We are exhausted and just need help.*

The experience of five year old Marcus is all too commonly seen through the daily legal work of legal aid commissions across Australia.

We welcome this opportunity to inform reforms to the *National Disability Insurance Scheme Act 2013* (NDIS Act) and the proposed Participant Service Guarantee. This is an opportunity to address the delays and red tape facing people like Marcus and his family who are trying to access critical supports for themselves, the people they care for, or the people they love.

National Legal Aid brings together the practice experience of the eight Australian state and territory legal aid commissions. In the 2017-18 financial year, legal aid commissions provided over 2.3 million legal services to people across the country.<sup>1</sup>

We share the stories of 28 clients across Australia who were assisted by legal aid commissions to navigate the National Disability Insurance Scheme (NDIS).<sup>2</sup> The NDIS is the largest and most significant social reform in Australia since Medicare. It continues to be a source of hope and optimism for many people with disability, their carers and families. The NDIS has the potential to secure a brighter future for people with disability.

National Legal Aid and legal aid commissions strongly support the NDIS. This Review is an opportunity to identify and make improvements during the early implementation phase, which will safeguard the NDIS for decades into the future, and for many generations of Australians to come. Importantly, people with disability must remain at the centre of the NDIS and all considerations to improve how it operates for years to come.

Through our clients' experiences we see that when the NDIS doesn't work there can be serious consequences for people, their families and the communities around them. These include:

- deterioration in health, wellbeing and social engagement;
- lost opportunities for early childhood development interventions;

---

<sup>1</sup> National Legal Aid, 2017-2018 data, *National Legal Aid Statistics* <https://nla.legalaid.nsw.gov.au/nlareports/> Council of Australian Governments, *National Partnership Agreement on Legal Assistance Services 2015-2020*, 2017-18 data.

<sup>2</sup> Unless otherwise stated, this submission has removed identifying information from our client stories to protect our clients' confidentiality and anonymity.

- significant financial hardship for carers and family members;
- eviction and homelessness;
- extended detention in mental health services;
- long periods in custody without conviction;
- increased risk of offending or re-offending; and
- family breakdown, including entry into the child protection system.

The NDIS must work for people with different needs, including by providing culturally safe services, better regional access, expert planning, timely reviews and skilled support coordination.

In its current form, the NDIS is struggling to meet the needs of people with disability who most need support. This submission highlights consistent themes and systemic problems:

- The human cost of inefficiency, inaccessibility and delays across every stage of the NDIS, including significant impacts on people's health and wellbeing.
- The barriers to access to the NDIS for people with disability which can result in taking months, or even years, for people to secure essential supports.
- The cascading problems caused by inadequate plans which do not provide the levels of support needed for people to achieve their goals.
- Market failure preventing people from accessing the services they are funded to receive under their NDIS plan.
- The excessive delays and confusion for participants when the National Disability Insurance Agency (NDIA) makes a decision before a person can seek a review or appeal.
- Disproportionate harm caused by delays and red tape which are experienced most severely by people living in rural areas, Aboriginal and Torres Strait Islander people, people experiencing or at risk of homelessness, people experiencing family violence, families involved in the child protection system, young children needing time-critical early intervention and people detained in prisons or mental health facilities.

Informed by the legal aid commissions' direct work, and the experiences of clients, we make 46 recommendations for changes to the NDIS Act, Rules, operational guidelines and guiding principles for the Participant Service Guarantee to ensure the NDIS fulfils its objectives.<sup>3</sup> If National Legal Aid's recommendations for reform are accepted by the Review, we can provide more detailed recommendations on specific amendments to the NDIS Act, including potential drafting, on request.

---

<sup>3</sup> The Legal Services Commission of South Australia has made an additional submission to the Review, which sits alongside this national submission.

## 2. Summary of recommendations

For the NDIS to ensure people can receive the supports and services they need to live well and independently in the community, our recommendations focus on:

- The **Participant Service Guarantee**: Ensuring the service standards – in legislation, rules, policies and guidelines – set effective timeframes, improve accessibility for target groups and improve responsiveness where there is a serious risk of harm. This must include a service safety net that catches people with complex needs when the NDIS market fails, including an enforceable obligation to ensure the participant receives their funded supports and clear responsibility for coordinating, funding and providing services when the market fails.
- **Access and eligibility**: Changes to guidelines and practice to remove barriers to access, including relevant, accessible information and support to obtain documents or evidence when applying for a plan.
- **Creating a plan**: Changes to guidelines and practice to place people with disability at the centre of planning processes and ensure they receive tailored, appropriate plans that improve their lives and wellbeing, including building pathways out of restrictive mental health units and prisons.
- **Using a plan**: Changes that support people to use their plans, including resources that help people understand their plan and its potential, recognition of the role and importance of skilled support coordinators for people with complex needs, and measures to improve access to services in regional, rural and remote areas.
- **Reassessing and reviewing a plan**: System improvements to the reassessment and review processes, including shorter timeframes and creating a pathway for urgent reassessments and reviews to prevent serious harm.
- **Appealing NDIA decisions**: Technical legislative amendments to ensure that disputes resolve quickly and easily, without people being denied supports pending a review decision.

Our recommendations are set out in full in Annexure A.

## 3. Our work with Australians with disability

### 3.1 About National Legal Aid and state and territory legal aid commissions

Legal aid commissions are independent, statutory bodies established under state or territory legislation and funded by governments to provide legal assistance services to people who cannot afford a lawyer.

National Legal Aid represents the directors of the eight state and territory legal aid commissions in Australia.

National Legal Aid's purpose is to:

- Lead and encourage a national system of legal aid which allows people experiencing disadvantage to obtain access to justice.
- Provide a forum for engagement at a national level with governments, stakeholders, and the community, and for the individual legal aid commissions to engage with each other about best practice of delivering legal aid.

National Legal Aid aims to ensure that people's legal rights and interests are not prejudiced because they cannot:

- obtain access to independent legal advice;
- afford the appropriate cost of legal representation;
- obtain access to the federal and state and territory legal systems; or
- obtain adequate information about access to the law and the legal system.

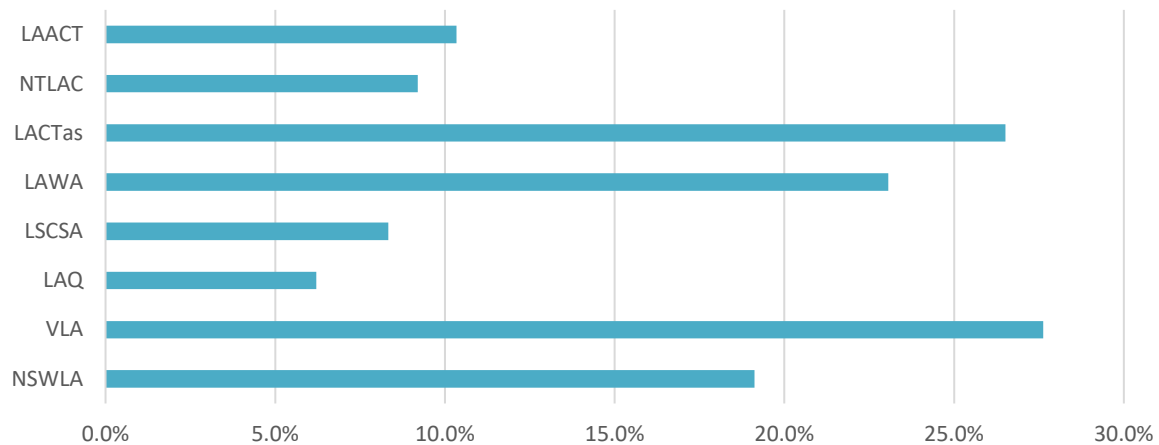
### 3.2 Free legal help for people with disability, their carers and families

Legal aid commissions are the largest provider of legal services to people with disability across Australia. Through this work we observe firsthand how the NDIS is not yet living up to its promise.

Legal aid commissions offer specialist legal advice and representation in courts, tribunals and mental health inpatient units for people with disability. In addition, legal aid commissions receive funding from the Department of Social Services to provide legal representation in NDIS matters on appeal before the Administrative Appeals Tribunal (AAT).

In the 2018-19 financial year, legal aid commissions provided 910,348 more intensive legal services to people.<sup>4</sup> 154,281 of these services were to people with a disability.<sup>5</sup>

Percentage of legal services to clients with a disability



Many of our clients are eligible for receiving services under the NDIS and have overlapping legal needs. Through this work we see how the NDIS functions for the most disadvantaged members of our communities. When the NDIS works, it provides vital supports for our clients to live well and safely. When the NDIS fails, it can lead to people struggling to get through each day, losing care of their children or being deprived of their liberty.

---

<sup>4</sup> Legal representation, duty lawyer services, legal task and legal advice.

<sup>5</sup> This figure will be an undercount as, in most cases, the data relies on the self-identification of the service user as a person with disability. Legal Aid NSW duty lawyer data is in-house only. LAQ does not collect demographic data in relation to Crime Duty Lawyer services or assigned duty lawyer data in general. LSCSA do not collect disability statistics for anonymous advice. Legal Aid WA data used a client's disability indicator from personal details for legal advice and legal tasks.

## 4. Participant Service Guarantee

The new Participant Service Guarantee is an important opportunity to legislate timeframes for NDIS decision making to reduce delays and introduce a set of minimum service standards to ensure the NDIS achieves its purpose. We welcome this commitment to ensure the NDIS realises its potential and to implement overarching principles about how the NDIA acts, views its role and connects with stakeholders.

The Participant Service Guarantee should apply across a range of regulatory and quality control aspects of the NDIS, including those identified in the Discussion Paper:

- an amended NDIS Act;
- quality frameworks designed to encourage good internal processes;
- statutory timeframes for responsiveness;
- service standards to set good practices; and
- statements of rights or charters intended to make it clear what users can expect.

The Participant Service Guarantee should provide a framework for enforceable minimum standards that decision makers can rely on to recognise their responsibilities, and participants, carers and families can use to understand their rights. A specific and enforceable framework would help to make sure the NDIS operates effectively. The Discussion Paper outlines the following possible principles, which we support in principle:

- **Timely:** The NDIS process will be easier to understand and use, enabling decisions about access, planning, reassessment and review to happen promptly.
- **Engaged:** The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.
- **Expert:**<sup>6</sup> NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability.
- **Connected:** The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.
- **Valued:** Participants, their families, carers and other support persons feel valued in their interaction with the NDIS and know where to go if they need further assistance.
- **Decisions are made on merit:** The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.

---

<sup>6</sup> We note concerns raised by disability support organisations about the use of the term "expert" as a principle, and the caution from people with disability that this may appear to place NDIA staff in the position of 'experts' about what it means to have a disability, rather than people with disability themselves. We recommend that this principle be changed to "skilled" to reflect the necessary skills and training which NDIA staff require to understand what supports are effective.



- **Accessible:** All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals.

In this part, we set out why these principles are so important. We also make recommendations about what these principles should look like in practice, and suggest “**Responsiveness**” and “**Accountability**” be added as crucial principles of the Participant Service Guarantee.

John’s story highlights the importance of the Participant Service Guarantee, including through showing the flow-on consequences of inadequate NDIS planning and supports, the need for statutory timeframes and binding principles in relation to scheduled and unscheduled plan reassessments, the importance of connection between the NDIA and mainstream services, and the critical need for a responsive service safety net when the services a person is funded to receive are not readily available in the NDIS market.

**Inadequate planning and services contribute to John’s offending and homelessness**

John has an ABI and schizophrenia. His disabilities have a significant impact on his everyday functioning and have contributed to past substance misuse, unemployment and limited community engagement.

John’s initial NDIS plan only included nine hours of core supports per week, which was largely absorbed by travel to and from appointments, without any support for daily activities of his choice or opportunities to be active and safe in the community.

Without the more intensive supports he needed, John committed further low-level offences and was taken into custody. John’s NDIS providers did not attend court to provide information about John’s needs or what services they provided to him.

John was released on bail and provided four nights’ accommodation at a motel. John spent weeks sleeping rough, in emergency departments or at his father’s house in breach of a current intervention order. John was taken into custody on remand for breaching his bail conditions. John remained in custody on remand for seven months, and applications for bail for John were adjourned and then withdrawn because of the absence of suitable accommodation in the context of his minimal supports.

John’s support coordinator requested a review of John’s plan to address his crisis and the inadequacy of his funded supports in meeting his needs. Victoria Legal Aid escalated John’s case to the Department of Health and Human Services (DHHS) Intensive Support Team in Victoria. The Intensive Support Team progressed accommodation and support options and effectively “stepped in” to provide a central, coordinating and solution-focussed role at the justice interface.

John’s plan was reviewed by a new specialist support coordinator with established expertise working with people with complex needs. This plan included a creative accommodation solution with a supported residential service.

With the support of the DHHS Intensive Support Team, John’s plan review was completed and his supports were increased to provide 24/7 support for him in shared accommodation.

John’s situation – including the NDIS plan reassessment and securing services and supports to build a sustainable post-release pathway – took 10 months to resolve. For the majority of this time, John was in custody.

John’s story could have been completely different. If NDIA staff had the skills and understanding of essential supports for people with complex needs, John would have been on a NDIS plan that supported him from the start, which would have reduced the likelihood of him losing his housing and entering prison. If the NDIA were required to deal with his plan reassessment in a timely way, and were connected with the state justice system, his exit from prison could have been much quicker and the damage to him minimised.

#### 4.1 Timely and responsive decision making

We support clear timeframes for decision making in the NDIS Act and Participant Service Guarantee to prevent serious harm for people with disability, their carers and families.

Timeframes which do not start until other actions take place (e.g. “once the NDIA has appropriate information”) are unlikely to reduce delays. In our practice experience, many people with disability, their carers and families experience difficulty obtaining the information requested by the NDIA for a range of reasons. These include difficulties understanding the nature of the requests or the level of detail the NDIA is seeking and obtaining medical reports without funding.

Embedding timeframes that require participants or prospective participants to provide information, including medical or allied health practitioner evidence, before a timeframe can commence would disproportionately affect people whose impairments affect their functional capacity in self-management and people experiencing socioeconomic disadvantage.

Timothy’s experience illustrates the difficulties faced by people with disability to obtain the information requested by the NDIA to determine a request for access or supports.

##### **Timothy denied access to NDIS supports due to onerous information requests**

Timothy lives in rural Queensland and has a significant intellectual disability.

The NDIA refused Timothy’s application to access the NDIS. There were no disability advocates in Timothy’s area who could help him to seek review of this decision and he could not afford specialist reports to support his application. A hospital social worker helped Timothy to apply for AAT review.

Legal Aid Queensland took on Timothy’s case, commissioned and covered the cost of expert reports and made legal submissions demonstrating that Timothy clearly met the legal requirements for accessing the NDIS.

As a result, the NDIA conceded that Timothy was eligible for the NDIS and created a plan to fund his support needs.

The NDIA should exercise their powers under the NDIS Act to support a participant or prospective participant to obtain the relevant information requested to prevent potential delays, assessed according to the person’s capabilities to obtain this information without support.<sup>7</sup>

## 4.2 Accessible for target groups

We support the “Accessible” service standard in the NDIS Guarantee which acknowledges the need for the NDIS to provide accessible information to meet the needs of target groups. This standard must operate alongside a “Skilled” service standard to ensure frontline staff have sufficient skills and training to provide accessible services.

### ***Inclusive and accessible planning and services for target groups***

This service standard should require that planning and services are inclusive and culturally safe for people from culturally and linguistically diverse (**CALD**) backgrounds (e.g. facilitating access to interpreters), Aboriginal and Torres Strait Islander people (e.g. active consideration of kinship care arrangements) and LGBTQIA+ people (e.g. intake procedures are inclusive of gender diverse and non-binary people).

### ***Culturally safe planning and services for Aboriginal and Torres Strait Islander people***

Aboriginal and Torres Strait Islander people face specific barriers accessing culturally appropriate supports which ensure they are fully understood, respected and feel able to access supports free from discrimination.

The NDIS Act creates a broad obligation on the NDIA to communicate in language and terms that are appropriate for the people receiving the information.<sup>8</sup> This is consistent with Articles 9 and 21 of the UN Convention on the Rights of Persons with Disabilities.<sup>9</sup>

---

<sup>7</sup> *National Disability Insurance Scheme Act 2013* (Cth) ss 16 and 55.

<sup>8</sup> *National Disability Insurance Scheme Act 2013* (Cth) s 7.

<sup>9</sup> *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, [2008] ATS 12 (entered into force 3 May 2008).

The NDIS' Aboriginal and Torres Strait Islander Engagement Strategy recognises the importance of appropriate communication, including the need to engage with Aboriginal communities in "the 'proper way'".<sup>10</sup>

Northern Territory Legal Aid has seen little evidence that this strategy is being implemented in practice. In the Northern Territory, Aboriginal and Torres Strait Islander clients do not have access to information in language, or in appropriate formats, and many in remote communities do not have access to information at all. Mandatory forms – such as the access request form – require Aboriginal clients to identify a primary and secondary disability (a distinction not supported by the NDIS Act). The forms use confusing language and technical legal descriptions about consent and privacy which are inaccessible for most Aboriginal and Torres Strait Islander people with disability. In general, if people in remote communities do not have access to a lawyer (or an advocate, if one is available), they will not be able to access the NDIS.

Adam's story describes the implications of the NDIA engaging in planning without interpreters, family or legal supports.

#### **Adam's planning meeting conducted with his mum and without an interpreter**

Adam, a young person in detention, applied to access the NDIS with the help of his Northern Territory Legal Aid lawyer. Adam's family live in a remote community with limited access to services. They speak Yolgnu Matha.

Four months after submitting his access request, Adam received a letter from the NDIA requesting copies of "utility bills or home insurance policies" to confirm Adam's place of residence. The NDIA advised that if information was not received by the NDIA within 28 days, Adam's application would be refused. The NDIA identified a generic email address where information could be sent. When Adam's lawyer contacted the NDIA to explain that he was a child in detention without access to the requested information, they were informed that the NDIA did not recognise the standard client authority form used by Northern Territory Legal Aid. Following extensive efforts by Adam's lawyer, he was eventually accepted onto the NDIS.

The NDIA scheduled a planning meeting with Adam's mother without informing Adam or his lawyer. The meeting was scheduled over the phone without the use of an interpreter and the planner only provided one date and time for the meeting. Adam's mother later explained:

*I didn't know what [the NDIA] wanted. They said I had to go to this meeting at the government office. I had to get the bus. The lady asked me questions about Adam. I didn't know why.*

Adam's NDIS plan contains inaccurate information about his family and his life, and by the time that Adam's lawyer was aware that the meeting took place, the time limit for appealing the decision about the supports in the plan had expired.

---

<sup>10</sup> National Disability Insurance Agency, *Aboriginal and Torres Strait Islander Engagement Strategy* (2017) 9.

Unfortunately, many Aboriginal and Torres Strait Islander people's engagement with the NDIA is inflexible, inaccessible and not culturally safe. Engaging in "the 'proper way'" with Aboriginal and Torres Strait Islander participants requires respectful, sensitive and participant led relationships.

#### **Duane almost removed from his mother's care because of withdrawal of NDIS funding**

Duane, a young Aboriginal boy with high support needs, had an NDIS plan which included funding for part-time supported accommodation. Over the course of his NDIS plan, Duane was increasingly spending more time in supported accommodation because his mother had health issues that required her to travel to the hospital. Duane's mother also has a disability and an NDIS plan.

Prior to Duane's scheduled plan reassessment, the NDIA wrote to the child protection authority in the Northern Territory to advise that it intended to stop funding Duane's supported accommodation. The NDIA asked the child protection authority to take Duane into state care. The NDIA did not inform Duane's mother of this letter, and she was unaware that this had taken place.

The child protection authority responded to the NDIA's request by applying for a protection order for Duane. In child protection proceedings, it cited the withdrawal of funding by the NDIA and the need to ensure that Duane had supported accommodation to meet his needs. Duane's mother was highly distressed by the proceedings.

Northern Territory Legal Aid assisted Duane to appeal to the AAT for review of the NDIA decision to withdraw funding for supported accommodation. One day prior to the hearing, the NDIA settled the matter. Duane's mother worked hard to regain parental responsibility for him, but says she remains worried that he will be taken away from her again.

Communication from the NDIA must be accessible and meaningful for Aboriginal and Torres Strait Islander people the NDIS has been designed to support.

Duane's story also highlights the way in which the "Connected" principle – in this case the connection between the NDIA and child protection – can be unhelpful if not adopted in a skilled and culturally safe way. There must be a coordinated system between the NDIA and state and territory child protection and disability services and systems. In complex cases, communication between all parties is essential to support families to stay together. In no circumstances should a parent be advised or compelled to relinquish their child because of delays in accessing NDIS supports. This should be contemplated in designing and implementing the Participant Service Guarantee.

#### ***Referrals to disability advocates and for legal advice***

Where a participant requires support to understand and assert their rights, the NDIA should make appropriate referrals to independent external services with specialised expertise to support people with disability to uphold their rights under the NDIS.

### 4.3 Targeted processes for access, planning and ensuring services for people in detention

In our practice experience, legal aid commissions have witnessed the extreme levels of harm that failures of the NDIS can cause for our clients in detention. In the absence of proactive discharge and pre-release planning, discharge or release can be delayed. This means that people with disabilities are left in prisons and mental health facilities as a direct result of delays in accessing their NDIS plans.

In a submission to the NDIS Thin Markets Project in June 2019,<sup>11</sup> Victoria Legal Aid, Northern Territory Legal Aid and Legal Aid Queensland identified clients who remain in prison or inpatient units because of a failure to secure disability services.

Poor planning or subsequent market failure can mean that a person exits with inadequate supports and is more vulnerable to re-offending or readmission. People who remain in custody or mental health units because of a failure to secure disability services should be identified by the NDIA and state and territory governments as a matter of urgency. Clear processes for planning for a person's release before their sentence is complete or discharge is imminent should be systematically introduced so that supports are in place to facilitate successful discharge or release and reduce risk of reoffending or readmission. This may also require the funding of supports for transition prior to release.

The client stories we include here highlight the serious harm experienced by people in restrictive environments, which was caused by delays and system failure at each stage of the NDIS planning process.

Victoria Legal Aid's client, Francis, spent 180 days in jail because his NDIS funded accommodation and supports failed.

#### **Francis<sup>12</sup> held in custody due to lack of access to specialist disability supports needed for bail**

Francis is now 21. At the time he was remanded, Francis had no prior criminal convictions and had never been in custody before. He likes everything to do with Metro Trains, listening to music with oversized headphones and singing songs by Rihanna. Francis has a significant intellectual disability and autism. Before the NDIS, Francis was living in a Victorian Department of Health and Human Services (DHHS) house with DHHS-funded workers who provided live-in care to him 24 hours a day, seven days a week, as the complexities of his disabilities meant that he couldn't live independently.

When Francis was 19, he was remanded on assault charges. At that stage, he had been transitioned from Victorian DHHS supports to the NDIS. After Francis was remanded in

---

<sup>11</sup> Victoria Legal Aid, 'Ten Stories of NDIS Thin Markets: Reforming the NDIS to meet people's needs', *Submission to the Department of Social Services and the National Disability Insurance Agency's NDIS 'Thin Markets' Project* (June 2019).

<sup>12</sup> Consent has been obtained to use Francis's real name and circumstances for this submission.

custody, the agency contracted to provide services to him in his home quit, stating that they were withdrawing services because Francis posed a “business risk”.

In custody, Francis was detained in solitary confinement. He was subjected to an intensely restrictive regime, including being clothed in a canvas smock and handcuffed at all times when taken out of his cell.

There was no service provider able to provide him with services, even though the funding in his plan increased from about \$200,000 to \$1 million. The NDIA told Francis they were merely his insurer and “just a bank”. While a couple of service providers were interested in providing support, they lacked the relevant experience and expertise in working with people with complex needs in custody to be able to assist Francis.

After Francis had been in custody for two and a half months, the Victorian State Government intervened. DHHS collaborated with key service providers in Victoria to retain a service provider who would provide full-time supports. The Judge granted Francis bail, as there was now a support agency contracted to provide Francis with the disability supports he needed.

Unfortunately, on the day Francis was granted bail, he was charged with minor assault offences relating to two staff members when he arrived back at his former residence. Francis had previously been a victim of alleged sexual and physical abuse by former carers at this residence. The police did not want to re-arrest him and remand him in custody for these charges. However, the service provider refused to provide Francis with residential supports. As a result of having no supportive accommodation, Francis was again remanded in custody.

Francis’ wellbeing continued to deteriorate in custody. He remained very vulnerable and experienced the prison environment in an acutely harmful way because of his disabilities. For example, being subject to strip-searching and prolonged periods of solitary confinement had a negative impact on his mental health and wellbeing.

Again, Francis experienced extended delays in receiving appropriate disability supports. Eventually, structural modifications were made to his accommodation. However, he continued to experience problems accessing services to assist with his complex needs.

After being detained for six months, Francis was again released on bail.

In reviewing Francis’ situation, Justice Lasry said:

*He’s in 23-hour lockdown at Melbourne Assessment Prison. I can’t imagine a worse place for him. The longer he is there the more he will be damaged. Who knows what damage has been done already?*

Alex is another client with significant disability who is currently in prison not because of the seriousness of his offending, but because of failures in the disability service system.

**Alex stuck in prison because he had nowhere else to go**



Alex is a young person with a number of complex cognitive and developmental disorders. He was living with his parents and on a NDIS plan which provided staff to support his disability needs on a daily basis.

Alex was charged with non-violent offending and found unfit to plead. He was placed on a non-custodial supervision order and continued to live at home with his family.

Over the next few months, there were some incidents in which Alex put himself in danger and the police were called. Alex was brought before a judge who reluctantly decided there was an unacceptable risk that Alex might reoffend, or hurt a family member or himself. Consequently, he was placed on a custodial supervision order. At the time, the Court acknowledged that it was a difficult decision to have to send such a young person with Alex's disabilities to prison. However, there were no other options available for Alex.

There were no available placements in treatment facilities which could support Alex and his disability. Because there was nowhere for Alex to go, he was sent to prison. For almost a month he was held in 23-hour isolation, locked in a tiny cell in conditions which had a significant detrimental impact on his health and wellbeing.

Alex has now been in prison for months. He is acutely distressed and barely eating. His ability to communicate has been affected and he routinely engages in self-harming behaviour. The situation is very distressing for his parents, who are his strongest personal support but have been unable to visit him and have only been able to speak with him on the phone once.

Alex's doctors say his time in prison will harm him further and hinder any progress he has made from treatment.

Since he has been in prison, disability advocates and his NDIS support coordinator have tried to find suitable accommodation for Alex in the community. There have been delays caused because of the lack of available specialist disability accommodation for young adults like Alex as well as misunderstandings about Alex's eligibility for this accommodation under the NDIS. Although Alex is still young, he no longer qualifies for specialist accommodation services which supported him when he was a child. Alex's NDIS plan now includes funding for specialist disability accommodation, but there is no suitable specialist disability accommodation for him to live in.

Alex will continue to stay in harmful conditions in prison until a placement in a suitable specialist disability accommodation becomes available for him.

Laila's story also highlights the serious harm caused when pre-release planning cannot proceed until a release date has been set, which means that people may be released without NDIS supports in place.

#### **Delays in NDIS planning while Laila in prison**

Laila is a young woman with an intellectual disability and borderline personality disorder. Her home life was difficult as she was regularly beaten, physically abused by her parents and bullied by her siblings. She has self-harmed countless times and has had many hospital admissions. When she was 18, DHHS intervened and Laila has been supported to



live independently in short-term and supported residential accommodation for people with disabilities.

Laila recently completed a difficult and lengthy prison sentence. Victoria Legal Aid assisted her to appeal her sentence and met with various organisations to ensure she would have the best support in place for when she was released from prison on or around the date of her appeal.

Her post-release planning for NDIS supports could not properly take place while Laila was in prison pending a definite release date, which was uncertain until her appeal was heard. It was difficult to obtain confirmation of NDIS planning or funding prior to the appeal being heard by the Court – which made it impossible to secure permanent accommodation or ongoing support.

Laila has now been released and secured temporary accommodation not funded by the NDIS. Laila's NDIS plan has been approved and she is receiving community engagement and therapeutic supports, but is still waiting for NDIS-subsidised specialist disability accommodation for long-term stability.

In general, forensic patients will not be considered for conditional release unless accommodation and support services have been set up. NDIS plans must be completed and lodged by the NDIS representative, approved by the NDIA and implemented well before a notice of intention for conditional release is submitted. This does not happen in practice.

Legal aid commissions have previously highlighted the need to increase the number of specialised, trained planners working in institutional environments, including mental health inpatient settings.

### **Sam<sup>13</sup> held in acute psychiatric ward because he has no housing or services in the community**

Sam has spent over two years in an acute psychiatric ward of a public mental health service, despite not requiring inpatient treatment. Sam has Huntington's disease – a neurodegenerative disease which is terminal and can lead to complex support needs.

His successful discharge from the health service relies on a delicate balance of housing and supports, which span across NDIS and mainstream services. There are questions, for example, about whether Sam is eligible for specialist disability accommodation funding, and what packages of state-based and federal funding could be combined to build durable housing and support options for him.

For over two years Sam has been confined to a restrictive environment which is not designed for his care because he does not have housing, is not funded to receive specialist disability accommodation (meaning that neither State nor Federal options are realistically available), and has not been the subject of any overarching consideration of what supports could be provided across the NDIS/mainstream interface to create a pathway out of the psychiatric ward.

---

<sup>13</sup> Sam has given his consent to use his real name and circumstances for this submission.

Recently, VLA escalated Sam’s case to the DHHS Intensive Support Team. The Age reported that the Victorian Minister has “directed the department to prioritise finding suitable accommodation options” for Sam.<sup>14</sup> It was also reported that the NDIA reiterated that state and territory governments remain responsible for providing affordable and accessible housing to the community, including people with disability.

People experiencing mental health issues are often working with services focusing on recovery, as opposed to disabilities where the condition is permanent. The NDIS requires a more therapeutic and skilled understanding of psychosocial disability to ensure access to adequate supports. Mental health issues are often episodic rather than permanent, but where NDIS supports are removed this can have serious mental health implications. For example, some of our clients have been assessed as ineligible which makes it more difficult to access NDIS supports when their mental health later deteriorates due to a lack of appropriate supports.

Services for people with psychosocial disability need to be responsive to people’s actual needs to lead an ordinary life, including a recognition in NDIS plans of the importance of psychosocial and peer support for people experiencing mental health issues to re-engage in the community.

We welcome the recent COAG Disability Reform Council’s commitment to improve the interaction between the NDIS and clinical mental health services to remove barriers to people with mental health conditions from accessing NDIS supports, and the development of a new psychosocial disability recovery framework in consultation with state and territory governments.

For people who do not yet have a plan, access and planning is extremely difficult to navigate. For people who do have a plan, they often face market failure i.e. an inability to access funded supports for people with complex needs, or significant delays in plan reassessments. People in both these categories can spend unnecessarily protracted periods in prison or mental health inpatient units, in a way that does inestimable damage to their health and wellbeing.

### ***Justice Liaison Officers***

We welcome the recent Council of Australian Governments’ (COAG) Disability Reform Council commitment to introduce Justice Liaison Officers in every state and territory across Australia. The newly announced Justice Liaison Officers should play an expert role in ensuring that there is a coordinated approach to disability supports from the NDIA and state and territory justice systems. Ideally, Justice Liaison Officers will take responsibility for

---

<sup>14</sup> Miki Perkins, “We are drowning’, Sam doesn’t have mental illness, yet he’s living in a psych ward’, *The Age* (7 March 2019) <https://www.theage.com.au/national/victoria/we-are-drowning-sam-doesn-t-have-mental-illness-yet-he-s-living-in-a-psych-ward-20190306-p5128a.html>.

managing urgent cases or cases where there have been substantial delays due to interface issues between government agencies.

We recognise that implementation plans about how Justice Liaison Officers will operate in practice have not yet been released. The Justice Liaison Officer roles should be adequately funded by federal, state and territory governments and the roles expanded if needed to ensure there is adequate resourcing to respond in urgent, critical or complex cases where a person with disability faces a risk of serious harm, injustice or adverse impacts on their health and wellbeing.

There are other interface issues that would benefit from experts playing a coordination role, including between the NDIS and state and territory health, child protection or education systems. The COAG Disability Reform Council should consider introducing liaison officer roles or alternative methods of ensuring coordination with a single entry point for other interactions with state and territory agencies. We welcome the COAG Disability Reform Council's commitment to work together to improve the service experience of families with children unable to live at home because of their complex disability needs, and for child-focused arrangements to be in place in all states and territories by 31 August 2019.<sup>15</sup> Legal aid commissions will continue to monitor these arrangements to ensure they provide effective supported arrangements for children living outside the family home and early intervention support for families so children can stay at home where possible.

The role and success of the Justice Liaison Officers is also closely linked to the need for a service safety net to minimise the impact of market failure and make sure people with complex needs are able to access the services they are funded to receive.

#### **4.4 Responsiveness and a service safety net**

While the NDIS is working well for many people with disability, its reliance on market based support provision and coordination between different systems can result in its failure to work effectively for participants with more complex needs, putting them at risk of significant harm.

To address this, the Participant Service Guarantee should ensure that the NDIA is responsive in time-critical and complex cases where urgent intervention is needed to prevent serious harm.

##### ***Strict timeframes where urgent intervention needed to prevent serious harm***

Our submission outlines clients' stories where urgent action is needed to secure NDIS supports to prevent serious harm to participants, prospective participants, their carers and

---

<sup>15</sup> COAG Disability Reform Council, *Communique* (28 June 2019)  
[https://www.dss.gov.au/sites/default/files/documents/07\\_2019/communique-drc-28-june-2019.pdf](https://www.dss.gov.au/sites/default/files/documents/07_2019/communique-drc-28-june-2019.pdf).

families. There are several **target groups** with complex and intersecting needs who are likely to require specialist responses for engagement, including:

- people at risk of or experiencing detention in restrictive environments, including:
  - people detained in prison and youth detention, particularly people who are potentially eligible for release soon where pre-release planning is essential to secure bail or parole;
  - people held in secure extended care units (SECU)<sup>16</sup> and hospitals, particularly people who would otherwise be living in the community but for the lack of NDIS supports; and
  - people who have recently been detained who need NDIS supports to assist their successful transition into the community and avoid being re-detained;
- people at risk of or experiencing interventions with the child protection system, particularly where children are at risk of going into or remaining in out of home care because adequate supports are not in place to keep their family together;
- people at risk of or experiencing homelessness; and
- people at risk of or experiencing family violence.

We recommend legislated timeframes to allow for certainty for participants through the introduction of urgent categories of people requiring NDIS supports, rather than a single timeframe. A shorter timeframe is justified for participants requiring a NDIS plan, a plan reassessment, or intervention to coordinate and provide funded services as a matter of urgency to avoid serious harm.

Where NDIS supports are required to avoid risk of serious harm, we recommend that the NDIA be responsive and implement the necessary supports through any stage of the NDIA process as soon as possible with an upper limit of 28 days, in recognition of the nature and gravity of the potential harms experienced.

### ***A service safety net***

It is inherent to the design of the NDIS that no one agency or worker is responsible for a person's supports and for navigating the system. Although the inevitability of thin markets and market failure was anticipated in planning for the NDIS, and there have been a series of calls for urgent measures to address thin markets and market failure,<sup>17</sup> there is still no

---

<sup>16</sup> Secure extended care units provide medium to long-term inpatient treatment and rehabilitation for people with unremitting and severe mental health symptoms.

<sup>17</sup> The Joint Standing Committee's 'Market Readiness Report' recommended that 'the NDIA publicly release the outcomes of the Maintaining Critical Supports project and its policy on provider of last resort (PLR) arrangements as a matter of urgency' (recommendation 24) in September 2018. This is the third time that Committee has highlighted that the publication and implementation of a PLR arrangement (or similar framework) is necessary. These remarks have been echoed by the Productivity Commission, the Australian National Audit Office and in the McKinsey & Company Independent Pricing Review. See Joint Standing Committee on the NDIS, *Report on Transition Arrangements for the NDIS* (2018) and *Report on Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*

enforceable obligation on any government body to ensure that an NDIS participant receives their funded support and no systematised way of avoiding and addressing thin markets and their consequences.

A market-based model of “supply and demand” cannot always be relied on to meet funded disability support needs, particularly when the participant has complex support needs or life circumstances. When the market fails, the government should step in to address the very real harm caused when people with disability are overlooked.

If a person has been found eligible for the NDIS and has a funded plan but cannot secure supports for reasons related to the market or the support provider withdrawing, the NDIA or other government agencies must intervene to ensure that the person with disability does not bear the burden of this system failure.

It must be clear (including to the public) who is responsible for arranging, funding and providing services in these situations.<sup>18</sup> This is essential to making sure people do not slip through the cracks and end up in prison, in the mental health system or separated from their families.

The COAG Disability Reform Council recently acknowledged this need for “an integrated and holistic framework for maintaining critical supports for participants” and requested that “implementation be expedited and that further refinement and consultation be undertaken”.<sup>19</sup> We support this important recognition of the need for intergovernmental cooperation to ensure that nobody is left to navigate the complexities of gaps in federal and state responsibility and the failures of the market on their own.

We support thoughtful research and consultation, but these can take time to explore and implement while the NDIS evolves. In the meantime, people with disability in Australia urgently need a reliable, systematised framework of accountability, coordination and response in place in every state and territory.

### ***Responsive service standard***

We recommend that Participant Service Guarantee include an additional service standard for responsiveness to reflect these cases, particularly for the target groups highlighted above. In determining its level of involvement, the NDIS system should assess a person’s

---

(2017); Productivity Commission, *National Disability Insurance Scheme – Costs* (2017) 36; Australian National Audit Office, *National Disability Insurance Scheme—Management of the Transition of the Disability Services Market* (2016–2017) 27; McKinsey & Company, *Independent Pricing Review*, Final Report (2018) (see especially 59 onwards).

<sup>18</sup> We recognise that the NDIA is not a service provider and that the appropriate model requires further consultation in terms of accountability for funding, overall responsibility and service delivery. Such models could also include collaboration between government and non-government organisations.

<sup>19</sup> Council of Australian Governments’ Disability Reform Council, ‘Meeting of the COAG Disability Reform Council’ (Communiqué, 9 October 2019) 1.

capability to navigate the system, particularly without supports, as a relevant factor in determining whether higher level of active coordination is required.

For example:

Principle	Description	Service Standard
Responsive	The NDIA is responsive to urgent and time critical requests for decision making.	The NDIA takes urgent action to assess a person’s eligibility, create a plan, reassess, amend or review a plan or ensure the provision of funded services where there is a risk of serious harm to a participant, prospective participant, or their family, carers or other support persons. In making its decision, the NDIA must take a coordinated, solution-focussed approach and must consider the complexity of the case, the participant’s lived experience and personal circumstances and gravity of the decision’s consequences for a participant, prospective participant, or their family, carers or other support persons.

***A model for responsiveness, coordination and accountability***

The Intensive Support Team run by Victoria’s DHHS has been largely successful when Victoria Legal Aid has escalated clients in acute crisis for response through this model.

**Victorian state-based Intensive Support Team provides pathway to escalate individual cases to expert coordination**

The DHHS Fact Sheet describes Victoria’s Intensive Support Team in this way:

*The Intensive Support Team (IST) is a team within the DHHS Disability and NDIS Branch established to provide time-limited intervention to current Victorian disability clients experiencing significant and critical issues with their transition to the NDIS.*

It identifies the target group of the IST as “current Victorian disability clients with complex needs or circumstances who are experiencing significant issues in their NDIS transition, where the risk of an adverse outcome for the person is high, and the need for intervention is time critical due to the impact of the issue”. Specific examples are listed:

- people who have been unsuccessful in resolving their concerns with the NDIA planning process and the lack of resolution is leading to a (potential) gap/loss of critical services and significant risk to the person (this includes situations where a support coordinator has been unable to resolve the issues);

- people who were in receipt of state funded supports that do not align with NDIA support types, requiring negotiation about how their reasonable and necessary disability needs can be met;
- people use a combination of disability related and mainstream supports and require coordinated planning across mainstream service systems such as health or justice.

Victoria's Intensive Support Team's role has included triage, coordination and problem-solving, most commonly for clients involved in the justice system, and is funded to June 2020.

This model provides a single point of contact and accountability for whole-of-government (state and NDIA) coordination in the system and enhances the skills of the multiple bodies engaging with the person. Prior to the creation of this team, clients and their lawyers were unsure what to do or where to go to resolve cases of crisis. The clear message from the Victorian government through this process is that there is support for vulnerable people who are reliant on disability support to live their lives.

The existence of the Intensive Support Team is time limited and its interventions are largely ad hoc in response to escalation, rather than addressing systemic problems on a broader scale. Its effectiveness does, however, provide guidance about the need to entrench and promote a systematic and efficient approach for people with complex needs at the interface NDIS and mainstream systems.

In New South Wales, the NSW Ministry of Health's Integrated Service Response (ISR) aims to resolve issues related to service coordination and "becomes involved when local services are unable to resolve a crisis or complex situation for a person with disability who has complex support needs".<sup>20</sup> The ISR aims to support local services to work together to resolve immediate issues for the client and put in place sustainable ongoing support arrangements. It also advises the NSW Government on systemic barriers to supporting people with disability with complex support needs. Similar to Victoria's Intensive Support Team, the Integrated Service Response is a time-limited initiative funded until December 2019.

#### 4.5 An accountability framework

For the Participant Service Guarantee to work in practice, the NDIA must be adequately resourced to meet its statutory obligations and respond appropriately to the needs of people with disability accessing or seeking to access the NDIS, including our clients.

We recognise the Government's commitment of \$2 million in additional funding:

---

<sup>20</sup> See summary available at <https://ndis.nsw.gov.au/integrated-service-response/>.

- for the Commonwealth Ombudsman to allow it to monitor the NDIA’s performance against the Guarantee timeframes; and
- to support NDIS participants pursuing complaints about the timeframes they have experienced.

We also support introducing clear standards under the Participant Service Guarantee, such as evaluation measures for the NDIA to report on as part of its existing quarterly reporting to the Disability Reform Council.

The Participant Service Guarantee must be accountable, transparent and effective for the duration of the NDIS, including when this allocated funding has been expended. Without a method for enforcing the service standards, there is a real risk that they will not be implemented, and the sector-wide changes needed to ensure the NDIS operates as intended will not be realised. For example, to ensure the Participant Service Guarantee functions as intended, the NDIA Act should include reporting and review timeframes within the legislation to improve the operation of statutory timeframes as needed.

In relation to a breach of the service standards or related instruments, the NDIA Act should provide for a timely and accessible complaints mechanism to address claims that the service standards have not been met. Where the service standards are found not to have been met, an individual should have recourse to escalate their complaint to an internal review. Accountability also includes ongoing funded access to advocacy and advice, and timely updates to guidance and training in response to emerging decisions.

We recommend that an “Accountable” principle be added to the Participant Service Guarantee principles. For example:

Principle	Description	Service Standard
Accountable	The NDIA is required to comply with the service standards.	The NDIA is transparent in its compliance with the service standards and is held to account for potential breaches which affect participants, prospective participants, their families and carers.

### Recommendations: Creating a Participant Service Guarantee that makes genuine improvements to the NDIS

1. **Timeframes:** The Participant Service Guarantee should introduce the following timeframes:
  - (a) In relation to an access request, if the participant has not provided requested information within 28 days, the NDIA supports the participant to obtain the requested information within 28 days.



- (b) Once the NDIA has obtained appropriate information, access request decisions are made in 28 days.
  - (c) Participants are offered a planning meeting within 14 days of receiving their access met decision.
  - (d) A NDIS plan for a child assessed as eligible for early intervention support is approved within 28 days of the access decision.
  - (e) First plan approvals take less than 28 days after their access decision.
  - (f) Plans are approved within 28 days of their final planning meeting, following the provision of all necessary evidence.
  - (g) If the participant has not provided necessary evidence within 28 days, the NDIA should support the participant or consult directly with identified service providers to obtain all necessary evidence within 28 days.
  - (h) Plan amendments are determined within 14 days of receiving the request.
  - (i) Plans involving specialist disability accommodation, home modifications or assistive technology requests are made within 28 days of the information being provided.
  - (j) Participants who request an internal review of a decision are contacted within 14 days of the request.
  - (k) An internal review of a decision is completed within 60 days of receiving the request.
  - (l) In urgent cases, the NDIA cooperates with relevant government and support agencies to streamline access to the NDIA to assess eligibility and approve a plan within 28 days.
  - (m) AAT orders are implemented within seven days.
2. **A “Responsive” standard:** The Participant Service Guarantee should include a “Responsive” service standard which requires decision makers and planners to take urgent action where there is a risk of serious harm if NDIS supports are not available.
  3. **Inclusive and culturally safe:** The Participant Service Guarantee should require the NDIA to provide inclusive and culturally safe planning and services to specialised groups, including CALD, LGBTQIA+ and Aboriginal and Torres Strait Islander people.
  4. **Culturally safe communication with Aboriginal and Torres Strait Islander people and communities:** The Participant Service Guarantee should require all communication with Aboriginal and Torres Strait Islander people to be culturally accessible through training, engagement and capacity building.
  5. **Referrals to disability advocates and legal services:** The Participant Service Guarantee should set out an early referral system and requires planners, Local Area Coordinators

and NDIA staff to make appropriate referrals to disability advocates or legal advice for support.<sup>21</sup>

6. **Urgent cases and serious harm:** The Participant Service Guarantee should require the NDIA to be responsive in time-critical cases where urgent intervention is needed to prevent the risk of serious harm, with a statutory timeframe of 28 days.
7. **Justice Liaison Officers:** The Participant Service Guarantee should set out minimum standards for the operation of Justice Liaison Officers to play an urgent intervention, escalation and coordination role between the NDIS, justice and mainstream service systems.
8. **Service safety net:** The NDIS Act and Participant Service Guarantee should introduce a service safety net that catches people with complex needs when the NDIS market fails, including an enforceable obligation to ensure the participant receives their funded supports and clear responsibility for coordinating, funding and providing services in these situations.
9. **An “Accountable” standard:** The Participant Service Guarantee should include an “Accountable” standard which ensures there are avenues to hold the NDIA to account for breaches of service standards.
10. **Complaints and escalation:** The NDIS Act should include a complaints mechanism for individuals to make complaints about a breach of the Participant Service Guarantee, and to escalate disputes to an internal review where a complaint is not resolved in a timely or satisfactory manner.
11. **Reporting and a five-year review:** The NDIS Act require the NDIA to provide annual reports evaluating the operation of the Participant Service Guarantee, with a scheduled legislative review of the effectiveness of the Guarantee in five years.

---

<sup>21</sup> Such an undertaking would give effect to general principles underlying the NDIS Act, specifically sub-section 4(13) of the NDIS Act, which provides:

*The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:*

- (a) promoting their independence and social and economic participation; and*
- (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and*
- (c) maximising independent lifestyles of people with disability and their full inclusion in the community.*

## 5. Access and eligibility

In our practice experience, we see the barriers our clients face in accessing the NDIS, both on an individual level in terms of making an access request and being assessed as eligible by the NDIA, and on a systemic level in terms of awareness of the NDIS and the importance of education, outreach and engagement.

### 5.1 Improved awareness of the NDIS

A precursor to applying for the NDIS is knowing that the NDIS exists and understanding that the NDIS could provide important supports. The roll-out of the NDIS is a large-scale undertaking which will take many years, with education about the NDIS, outreach into hard-to-reach communities and active community engagement being central to this. This should include flexible approaches to particular groups (e.g. Aboriginal and Torres Strait Islander people living in remote communities and people in restrictive environments such as mental health units and prisons). The Participant Service Guarantee should require the NDIA to engage in education, outreach and engagement activities to ensure people eligible for the NDIS are aware of the potential supports for them to achieve their goals.

### 5.2 Reduced barriers to making an access request

There are significant barriers which prevent some of our clients from making an access request, including issues with understanding how to make an access request and difficulties completing the form and obtaining supporting evidence. These barriers cause delays for months during which our clients do not receive the disability supports they deserve.

In our practice experience, we have identified the following common barriers:

- **Limited support** to make an access request, particularly support to obtain requested supporting evidence from their treating doctors, therapists and support people.
- **Lack of accessible, non-digital information** for people who do not use the internet or who cannot understand the information on the NDIS website.
- **Few instructions** on or accompanying the access request form to help people understand what information the NDIA typically requires to make an assessment.
- **Inadequate information for treating health practitioners and support people** about the level and type of detail the NDIA typically requires.

#### ***Understanding the form and NDIS process***

Jan's story highlights the need for further improvements to ensure the NDIS is accessible for people with disability seeking to make an access request as part of the Participant Service Guarantee.

**Jan denied access to the NDIS because of lack of understanding in completing the form**

Jan was assisted by a job network provider to fill out an access request form.

The form includes six boxes categorised by the areas of impairment as set out in the NDIS Act. In order to meet the access criteria, a person must have substantially reduced functional capacity in one of those areas.

In Jan's case, every one of the six boxes had been ticked "No, does not require assistance." Yet Jan suffers from severe depression and anxiety. At the time of application, she only left the house to attend work, needed regular support from another person to be in the workplace, could not manage self-management tasks in the home, and did not have any friendships.

The questions on the form, and lack of adequate written information provided with the form, resulted in Jan's treating doctor failing to understand how to demonstrate Jan's level of functional difficulties.

### ***Difficulty obtaining reports and providing further information***

As outlined above, obtaining requested reports and supporting evidence causes significant delays for our clients. Too often, our clients find themselves locked out of a system designed to help them, including supports which could assist them to access the NDIS in the first place. When a person is deemed ineligible for the NDIS, this can lead to significant hardship for months, or even years, during which they do not receive the supports they need.

#### **"I don't know why they couldn't have asked the OT for a report earlier"**

I applied for the NDIS in May 2017. I was 63 years old and live on my own. My disabilities mean that I have trouble moving around the house, looking after myself and going out. I get really breathless and have a lot of pain. Physically I can't move very well and sometimes I get stuck and can't move my legs. I was rejected from the NDIS in August 2017. I had help from my advocate to review the decision but was refused again. The advocate helped me apply to the AAT and for a legal aid lawyer. This was in December 2017.

The lawyer helped me get the evidence that the NDIA kept asking for because I couldn't afford to pay for the reports. I receive a pension from Centrelink and haven't been able to work for over 20 years. The NDIA kept saying they need more evidence and it wasn't enough. Finally, the NDIA paid for an assessment in April 2019 by an Occupational Therapist who already knew me. After they read this report, they accepted I should be on the NDIS. It was one week short of two years to the day that I applied for NDIS. It was such a battle and I don't know why they couldn't have asked the OT for a report earlier.

In our practice experience, medical practitioners often complete the access request form with sufficient information for the NDIA to determine whether the person should access specific supports (e.g. [Client] requires help from others with all self-care tasks including showering, dressing and preparing meals). Despite providing the necessary information required to satisfy the criteria under the NDIS Act, the NDIA commonly requests further, more detailed reports from the same medical practitioners. As one client asked Legal Aid Queensland: "If the NDIA decided there is insufficient evidence for them to make the necessary assessments about the impact of my daughter's impairments, then why is the

form like this, and why didn't they contact my daughter's doctors to get more information?" Requiring people with disability to obtain new medical documentation when existing reports are sufficient, or requiring specific language to be used by their clinicians (often at the person's own cost), excludes people who would and should otherwise be eligible for NDIS supports. In addition, our clients are often asked to provide highly detailed information about their disability from their clinicians which is not required to satisfy the legal tests for eligibility under the NDIS Act.

Where a person does not respond to the NDIA's request for further information within the statutory timeframe, their access request can be taken to have been withdrawn, unless the CEO is satisfied that it was reasonable for the prospective participant not to have complied.

Requests for further information and the extension of time for a decision should only be exercised where strictly necessary and must be consistent with the eligibility criteria under the NDIS Act. The NDIA should not impose a higher bar or request more information than is required by law, particularly where these types of requests are unduly barring access to the NDIS.

### ***Facilitating supporting evidence and funding for reports***

Many of our clients struggle with the everyday reality of living in poverty and cannot afford to pay for the detailed reports and supporting evidence the NDIA typically requests. Where a person is unable to self-fund the type of detailed specialist assessments the NDIA typically requires, people with disability face long delays in gaining access, significant stress and financial hardship. This imposes an increased burden on the resources of other agencies, including legal aid commissions, service providers, disability advocates and the AAT.

The NDIA has the power to fund and obtain these reports directly from treating medical practitioners or other supporting people,<sup>22</sup> and should exercise this power with the consent of the prospective applicant. This would also assist decision makers to make more informed and accurate decisions in the first instance, thus reducing the number of reassessments and reviews. In addition to the NDIA's discretionary power to fund and obtain reports, the NDIS Act should include a provision for applicants to obtain funding for reports. In seeking reports for clients, legal aid commissions have often found the NDIA unwilling to consider requests to fund medical reports unless the matter has been appealed to the AAT.

There are some practical improvements to improve access, save substantial time and resources and remove delays. For example:

- Ensuring accessible information booklets explaining the eligibility criteria are provided to prospective participants and their treating health practitioners, together with the access request form or forms requesting supporting evidence or additional information.

---

<sup>22</sup> *National Disability Insurance Scheme Act 2013* (Cth) s 55.

- Supporting participants to complete required forms and obtain requested supporting information (e.g. additional funding for Local Area Coordinators to provide this level of support).
- Online and telephone support for people completing the form to speak or webchat with a NDIA representative in a reasonable amount of time.
- Providing useful resources developed by support organisations (e.g. the Self Advocacy for the NDIS (Mental Health) resource booklet developed by Victoria Legal Aid's Independent Mental Health Advocacy service in partnership with consumers).<sup>23</sup>
- Consulting with the prospective participant directly, or their carer or family members or treating health practitioners provided the person consents, to better understand the impact of a person's impairments.

### 5.3 Transparent and clear access decisions

Correspondence from the NDIA outlining reasons for access decisions are generally brief and do not provide sufficient information about how a decision was made or on what basis. This means that people refused access to the NDIS do not know on what basis access has been refused, and can be frustrated or confused as a result.

As part of the Participant Service Guarantee service standards on accessibility, and to improve transparency, refusal letters should explain the decision maker's reasoning, including the evidence considered and why the person does not meet the legislative criteria for access.

---

<sup>23</sup> Independent Mental Health Advocacy, *Self-Advocacy for the NDIS (Mental Health)* (August 2019) <https://www.imha.vic.gov.au/about-us/news/support-for-people-with-mental-health-conditions-to-access-ndis>.

## Recommendations: Improving access and supporting eligibility

12. **Outreach, education and engagement:** The Participant Service Guarantee should require the NDIA to engage in education, outreach and engagement activities to support access through improving awareness of the NDIS and how and why to access it.
13. **Assistance with access requests:** The Participant Service Guarantee should require the NDIA to provide accessible, timely practical assistance for people completing the access request including more specific guidance accompanying the access request forms and requests for supporting evidence.
14. **Requests for further information:** The Participant Service Guarantee should ensure that requests for further information are only made when strictly necessary to obtain information required to establish the eligibility criteria under the NDIS Act.
15. **Facilitating access and assistance with reports:** The Participant Service Guarantee should facilitate access to the NDIS by helping people to provide evidence of their disability, including contacting treating health practitioners or other support people provided the person consents, and including criteria for when funding will be provided for necessary reports.
16. **Reasons for refusing access:** The NDIA should ensure that letters refusing an access request provide a person with reasons for the decision, refer to the evidence considered in making the decision, provide information on all their options, and provide information on disability advocates and legal advice.

## 6. Creating a plan

Ensuring a person has a NDIS plan with the right supports in the time they need for it to make an impact is central to the promise of the NDIS. Where there are excessive delays or plans do not cover the types or level of supports needed for a person to achieve their goals, this undermines the effectiveness of the NDIS and can leave a person in a precarious situation without the essential supports needed to live their lives.

### 6.1 Reduced delays in planning

For legal aid commission clients, delays in the planning process continue to be a major area of concern.

Julia's story highlights the significant impact of delays in getting a plan during critical periods in a child's life when access to specialist therapy can have long-term consequences for a child's social and educational outcomes for the future.



### **Planning delays affected opportunities for Julia’s early childhood development**

When Julia was a toddler, she wouldn’t respond to her own name. Julia’s mum Lisa and dad James finally understood why when she was diagnosed with autism when she was two years old. Lisa and James did everything in their power to give Julia access to effective early intervention, trying a range of different therapies. But Julia didn’t make progress. It was heartbreaking for her parents to learn that other children would tease Julia in childcare because she was different.

When Julia started a new, more expensive program, she started to make incredible progress. Julia had never called Lisa “mum” before. Within one month of starting the program she was calling Lisa “mum” regularly. She also started to respond to her own name. There was still a lot of room for her to grow, but her mum said that the difference in Julia’s development with other people after a year in the program was like a “before” and “after” advertisement.

Julia was accepted onto the NDIS when she started the program. Despite urgent requests for NDIS funding, Lisa and James waited six months for Julia’s first NDIS plan. In the meantime, they had to personally fund this program. They sold a property and spent their entire savings to keep Julia in the program for as long as they could, but eventually they ran out of money. They had to pull Julia out of the program. Julia started to go backwards. While they waited for NDIS support, they knew that every day was a passing window for successful early intervention for Julia’s developmental milestones.

When Julia finally received her NDIS plan it did not cover the cost of the program. Victoria Legal Aid represented Julia in the Administrative Appeals Tribunal and helped her to secure funding for the program. Julia finally had the support she needed to resume the program and has made great progress since then. However, the NDIA would not retrospectively cover the cost of the program during the six month period when Julia was waiting for a plan.

Lisa and James are overjoyed about Julia’s progress and have been told she will be ready for school. This was their dream for Julia. Lisa says that these days Julia is a completely changed child. However, Lisa and James are still experiencing significant financial hardship and have lost their financial safety net due to the delays experienced waiting for Julia’s NDIS plan.

Once a child is assessed as eligible for NDIS early intervention support, their NDIS plan should be created as soon as possible.

## **6.2 Pre-planning support**

In our experience, many participants need support to plan for a planning meeting. Local Area Coordinators and Early Childhood Early Intervention (ECEI) partners are funded to provide some pre-planning support. However, our experience is that Local Area Coordinators do not often engage in comprehensive pre-planning.

Our clients generally do not understand the significance of considering what their goals are under their plan and what supports they will need to meet those goals. Specificity in goals is

important because it ensures people receive the right kinds of supports, but many NDIS plans contain generalised, non-individualised goals which can lead to inadequate NDIS plans.

In practice, lack of systematic and consistent pre-planning support is contributing to a two-tiered system where people who have access to supports (either through funded services, family members or support people) obtain more relevant plans, while people who are unsupported and more likely to be socially isolated are more likely to receive inadequate plans.

### 6.3 Accessible and effective planning meetings

A person's NDIS plan should set them up properly from the start.

Some of our clients report that inadequate time is given to planning meetings about creating their NDIS plans. Many participants, especially those with complex needs, require support in planning meetings to communicate their goals, preferences and support needs. They need to provide a significant amount of information regarding their support needs, which is beyond the capacity of many people with cognitive impairments or complex needs.

Participants should also be able to choose how planning meetings are held, whether that is face to face, over the telephone, using assisted communication facilities, web chat, with support people or on the papers. This method of engagement should be flexible to ensure it is the most useful and relevant for the participant at that point in time.

Jimmy's story highlights the significant unfairness and difficulty that can result from a planning meeting being held without involving a person's family members or nominated support people.

#### **Family and vital support people excluded from NDIS planning meeting**

Jimmy has an intellectual disability and significant mental health issues. He is a forensic patient in custody in NSW. His disability support needs are not being met in custody and his father and legal representatives are trying to assist him to move to supported accommodation. He also has a public guardian.

The NDIA conducted a planning process with Jimmy alone, without consulting his legal representatives, his father or the guardian. Because of his intellectual disability, Jimmy would have had difficulty communicating his needs and his plans on his own. His informal support network doesn't know what assessments have been conducted, what goals are recorded in his plan or what supports are included in his plan.

A support person can assist the participant to outline their goals and preferences, and to recall all their support needs. A support person is particularly important for people with no experience of disability supports, or who were not previously connected with funded disability supports. They will often have limited knowledge of what supports are possible and available.

## 6.4 Connection between planning meeting and NDIS plan

Clients report that the personal information and goals set out in their plans do not always reflect their own experience or preferences. As a result, funding is not always provided for the supports they need to meet their actual goals. In some cases, several planning meetings may need to be held before a plan is approved by the NDIA.

Legal aid commission clients frequently report that what they told their planner in the planning meeting is not reflected in their plans, including:

- failing to identify the person’s current supports and their goals and aspirations; and
- not including in the final written plan what they were orally told would be funded in their plan.

Once a NDIS plan is created, it cannot be changed except by an internal review of the statement of participant supports or an unscheduled plan reassessment, even if it contains clear errors.<sup>24</sup> This sometimes results in participants facing delays of months, if not years.

After a planning meeting, planners should actively seek further information to determine appropriate supports for a NDIS plan with the participant’s consent.

### **“She just substituted her own idea about what is best for our son”**

My youngest child has Autism Spectrum Disorder Level 2. He is nearly five years old and was diagnosed less than a year ago. He has real social, emotional and communicative problems and he needs intensive Applied Behaviour Analysis (ABA) therapy before he starts school.

My partner and I wanted to be prepared for the planning meeting, so we asked a psychologist who was very experienced in ABA to attend the meeting with us. She was great to have. She helped us get the planner to write down the goals our son needs to achieve so that he can start school. During our discussion, the planner told us about a new three-month trial plan where our son could get 20 hours each week of intensive ABA, probably with the provider of our choice. The purpose of the plan was to gather evidence to see if ABA would work for our son. The planner confirmed that it was “a given” that we would get three months’ worth of 20 hours per week of intensive ABA on this trial plan.

After our planning meeting in February, we didn’t hear back from our planner for ages. I chased her so many times. She did respond to emails, but they didn’t tell us anything about the drastic plan changes that were underway.

Three months after the planning meeting we received my son’s plan, but it bore no resemblance to the plan that my husband and I and the psychologist discussed with the planner.

---

<sup>24</sup> As noted below, National Legal Aid supports the creation of a plan amendment power if it is carefully crafted and implemented. Even after the introduction of such a power, it will be important to have planning processes which are careful and reduce the incidence of errors.

First, it was a 12-month plan. Second, it contained nothing like what we had asked for - no intensive therapy, nothing. I wanted to see what our planner had done so I did an FOI request. I saw from the documents I got back that unbeknownst to us, our planner had discovered that our son wasn't eligible for the "trial" plan because as soon as our son was diagnosed we had self-funded a course of parent training with our ABA provider which also went for three months, and we had started self-funding our son to have two hours of ABA each week (which was the most we could afford).

Without consulting us, she put a completely different plan forward to the NDIA. It was like the planning meeting and what we asked for didn't happen. She just substituted her own idea about what is best for our son without regard for our opinions based on our lived experience as parents.

Greater transparency in planning decisions is required. Before a statement of participant supports is approved a participant should be provided with a draft and informed of:

- what supports will and will not be included in their plan;
- what decision will be made about the management of funding under their plan;
- at what rate the NDIS amounts in their plans will be calculated; and
- reasons for the draft NDIS plan.

This would allow certainty for participants about the supports they will receive and make it possible to correct errors quickly before a plan is finalised without having to rely on drawn-out review processes.

In addition, we do not support a more exhaustive definition of "reasonable and necessary" supports under section 34 of the NDIS Act.<sup>25</sup> A more exhaustive definition could have the unintended consequence of further restricting participants' entitlements to disability supports.

## 6.5 Plans that adequately meet people's needs

In a number of our clients' cases, a lack of appropriate planning at the outset of their participation in the NDIS meant they were not set up with the supports they needed to live well and independently. Their disability needs were not well met, and the intensive core supports they needed were not funded, which put pressure on the services that were funded and created a risk of those services withdrawing.

Brian's story illustrates the impact of people receiving inadequate NDIS plans that do not provide the level of support they need to fully participate in the community and to meaningfully engage in study, work or social activities. If the Victorian DHHS Intensive Support Team had not intervened in his individual case, it is likely Brian would have been held in custody unnecessarily for even longer, due to delays in having his NDIS plan reviewed.

---

<sup>25</sup> See Discussion Paper, question 27(d).

### **Magistrate recommends increased NDIS supports so Brian can live in the community**

Brian is 19 years old. He is friendly and sociable, and loves being around people, especially people his age. He has an intellectual disability, Autism Spectrum Disorder, and anxiety. Like many teenagers, he likes swimming at the pool, and going to the movies.

Due to his complex disability, Brian has trouble managing his impulses, and he needs ongoing support to work on regulating emotions like frustration and anger. When Victoria Legal Aid first met Brian, in mid-2018, he was referred by the Children's Court to a program where he could access a range of local health, education, employment and recreational supports. Brian was progressing well and his behaviours of concern had lessened, but the funding for that program stopped once Brian's court case finished.

When the NDIA rolled out where he lived Brian received an NDIS plan. Despite his complex needs, previous behaviours and the clear success of more structured supports, Brian's NDIS plan only provided modest supports with no significant outreach or specialist support coordination. Within six months, Brian was spending much of his time at home, away from peers and disengaged from positive community supports.

Earlier this year Brian seriously injured his younger sibling and he was arrested and remanded in adult custody. Brian was seriously distressed in prison and told his lawyer repeatedly that he wanted to go home. Given the change in circumstances, an urgent review of his NDIS plan was needed. He needed to access alternative supported accommodation and an increase in the level of funded supports. Victoria Legal Aid immediately requested that his Disability Justice worker facilitate an NDIS plan review. The NDIA responded that it would take several months, and nothing could be done to hurry up the review.

Victoria Legal Aid continued to advocate to Brian's Disability Justice worker for urgent assistance and escalated the case to the state-based DHHS Intensive Support Team. An application for bail was made for Brian to be released from custody. At his bail hearing, the Magistrate insisted that more be done to increase funding to allow for greater outreach support for Brian in the community.

Brian spent nearly three months in prison on remand before he had access to the disability supports he needed to be released on bail. The delay in reviewing his plan was the difference between being held in custody and being supported to live in the community. In terms of its impact, the prolonged time he spent in custody took a significant toll on Brian's health, wellbeing and sense of safety.

Brian is now receiving the levels of NDIS support he needs to achieve his goals. He has access to specialist support coordination and a skilled outreach worker who helps him with his behaviour and takes him to participate in recreational activities. Brian's specialist support coordinator plays a crucial role in bringing together the various agencies and workers involved in supporting him to live well and safely.

Brian's story highlights how poor planning can contribute to offending and how delays in plan reassessments can contribute to imprisonment and harm. It demonstrates the important role of the Intensive Support Team in service coordination and the positive outcome when the NDIS does work to make a real difference to people's lives.

## 6.6 Improved access to specific supports

### ***Greater transparency about Supported Independent Living funding***

Supported Independent Living funding is funding for assistance with daily tasks, delivered in the home on a shared or individual basis. In 2018, the NDIA removed Supported Independent Living prices from the Price Guide. Supported Independent Living providers were directed to instead submit quotes. While this measure was designed to increase individualisation of funding, for many participants this process is not transparent. Supported Independent Living funding amounts do not appear in the participant's plan. If the funding for approved independent living is lower than what was requested, the participant is reliant on the provider to assist them to challenge the decision.

In some cases, the absence of information about how much funding has been provided, and what activities or tasks the Supported Independent Living funding is expected to fund, results in participants finding themselves in a dispute with their Supported Independent Living provider about what supports or services they are funded to receive under their NDIS plan. For example, a Supported Independent Living provider may advise the participant that the funding does not cover a support the participant wants delivered, and the participant does not know whether this is accurate or not.

#### **Ian socially isolated due to insufficient Supported Independent Living funding information in his NDIS plan**

Ian is a participant in the NDIS with an intellectual disability and has in the past had contact with the criminal justice system. He lives in shared accommodation with Supported Independent Living (SIL) funding.

Ian is subject to a guardianship and a financial management order and has no family support. Ian's SIL provider put in a quote for his care needs, but the SIL funding he received was much lower than the quote. The provider used the funding for Ian's basic needs, but couldn't accommodate his need to go out into the community for social interaction, so he spent every day in his room.

Ian didn't know why he couldn't access the community. He thought he was being punished. When he sought assistance from Legal Aid NSW, the SIL funding amount was not specified in his plan – the amount of funding and the use of it was entirely at his provider's discretion. This made it much more difficult for him to have control of his supports and to access legal assistance.

### ***Assistive technology, home modifications and specialist disability accommodation***

Some participants request home modifications, assistive technology items and specialist disability accommodation at a planning meeting. In these situations, planners generally request further information and/or assessments. However, there is no timeframe for when a decision will be made about the appropriateness of the support and the funding amount that should be included.

Participants often wait months for the deferred decision about funding to be made, after providing the assessment and/or quote. Many participants are confused about how the funding can be provided without an internal review of the plan.

Once the quote or assessment has been provided and the NDIA approves the quote provided in the assessment and decides to fund the support, there is no clear mechanism for including the support in the plan.

A participant may experience difficulty seeking an internal review if the NDIA refuses a request for assistive technology, home modifications or specialist disability accommodation following the provision of a quote. Participants should be able to seek an internal review of a relevant decision under section 100 of the NDIS Act and, ultimately, AAT review if they disagree with the outcome.

## 6.7 Consideration of relevant factors in decision making

### ***Incorrect reliance on “primary disability”***

Our clients have reported that planners refer to a “primary disability”, or a disability that most impacts upon them. In some instances, planners have refused to include supports in a plan that relate to a “secondary disability”.

This approach has no legislative basis. The NDIS Act contains no reference to primary or secondary disabilities. Multiple disabilities can compound the difficulties for participants in accessing supports. NDIS supports should not be limited to a single impairment and appropriate supports denied to people with multiple disabilities.

### ***Over-reliance on “typical support packages”***

The NDIA has developed several typical support packages (TSPs). TSPs play an important role as guidelines to enable the NDIA scheme actuaries to monitor scheme spend as a guarantee of sustainability for people with disability into the future, and for national consistency. TSPs are used as a reference for planners to compare total dollar value of a plan they have built for a participant against a benchmark.

The NDIS Act requires plans to be person-centred, self-directed and individualised.<sup>26</sup> The first principle of the NDIS Act states that the CEO must take individualisation into account when making and approving plans.<sup>27</sup>

**Greg received inadequate supports due to incorrect application of “typical support plan”**

---

<sup>26</sup> See also, Revised Explanatory Memoranda, National Disability Insurance Scheme Bill 2013 (Cth) 1.

<sup>27</sup> *National Disability Insurance Scheme Act 2013* (Cth) s 31(a).



Greg is 60 years old, has an acquired brain injury and has been living independently for seven years after the injury. He needs a high level of assistance each day to access the community, make decisions and maintain his health and wellbeing.

Each year when his plan was reviewed Greg received a lower and lower level of support. For his most recent plan, Greg's providers said they were concerned that they could not provide enough care and with the assistance of his family, he appealed the decision to approve the supports in his plan. When his plan was reviewed by the NDIA, funding was increased but not to the level he needed, and he sought further review by the AAT.

When Legal Aid NSW came on board at the AAT, documents from Greg's NDIA file were provided that revealed that the planner who met with Greg had decided a much higher level of support was needed. Because the plan exceeded the typical support package used as a reference for Greg's disability, it was sent to another planner for review and reduced by close to a third. In the AAT, the result of Greg's matter was that he received support close to what was originally recommended.

TSPs are not made available to participants and there is concern among legal aid commissions that they are misused during planning. They are not intended to be binding or determinative, or to restrict the possible supports which a participant should receive under their NDIS plan.

Where TSPs are misused this poses risks to the integrity and operation of the NDIS. For example, as Greg's story above shows, there have been instances where a participant's file reveals that planners have been directed to adjust their funding decision to be within 10 per cent of the typical support package, despite clear evidence demonstrating the greater support needs of a client. Using TSPs to deny access to specific supports is not consistent with the principles and purpose set out in the NDIS Act. In particular, TSPs should not skew decision making towards a range. NDIS plans should always be tailored to an individual's goals.

NDIS planners should always place the participant at the centre of the decision making process and determine reasonable and necessary supports for an individual as required by the NDIS Act.

Where a plan is being considered or benchmarked against a TSP, this reliance should be disclosed in the written decision and a copy provided to the participant and nominated support person.

## 6.8 Improved reasons for planning decisions

Many participants do not understand how decisions are made about the supports in their plan. For example, they have heard the phrases "reasonable and necessary" and "choice and control", but do not understand how these words do, or do not, shape decisions about specific supports.



The following story describes the confusion and frustration for parents when they receive a letter which refuses the essential supports their child needs, without any reasoning about how that decision was made.

**“I don’t know why the supports were not funded originally”**

I have a nine-year-old son who has been diagnosed with Autism Spectrum Disorder, Attention Deficit and Hyperactivity Disorder and Oppositional Defiant Disorder, among some other diagnoses. My son faces significant barriers to learning and every day with him is a struggle.

We really needed funding for ongoing psychology and a behaviour support plan. These supports have been recommended by nearly every therapist and person we have spoken to. At our planning meeting we asked for these supports and provided evidence to back up our son’s need for them. We got a plan back that did not have these supports and didn’t even have the goals that we asked for. I asked why this was, but no-one could tell me. I asked for an internal review straight away. The internal review decision just said that my son could not have his plan reviewed as his circumstances had not changed (even though I had asked for a review because the original plan was inadequate).

I made an application to the AAT and was represented in the proceedings by Legal Aid NSW. Shortly after I filed the application, the NDIA agreed to fund my son’s supports. I don’t know why the supports were not funded originally and I don’t know why the NDIA changed its mind five months later.

The NDIA has worked with the Commonwealth Ombudsman to improve internal review decisions. We acknowledge the improvements made to internal review decision letters with participants being provided with statements of reasoning for a decision. Despite these improvements, the NDIA should improve the quality and amount of information contained in original decision letters.

## Recommendations: Creating a plan that sets a person up to meet their goals

17. **Timeframe for early childhood intervention:** The NDIS Act should be amended to ensure that a NDIS plan for a child assessed as eligible for early intervention support is created within 28 days of the access decision.
18. **Draft NDIS plans and reasons:** The NDIS Act should require that a planner provide a proposed NDIS plan with reasons for decision-making to the participant and their nominated support people and allow for discussion of the NDIS plan before it is finalised.
19. **Skilled planners:** The Participant Service Guarantee should ensure that planners receive adequate training and guidance to ensure that people receive adequate plans individually tailored to support their needs and achieve their goals.
20. **Supported Independent Living prices:** The NDIA should ensure participants understand and have access to information about what services, activities and tasks are included under Supported Independent Living funding in their NDIS plan.
21. **Requests for home modifications, assistive technology and specialist disability accommodation:** The NDIS Act should be amended to establish a clear and responsive approach for the NDIA to consider requests for home modifications, assistive technology items and specialist disability accommodation. Decisions about home modifications, assistive technology items and specialist disability accommodation should be included as specific 'reviewable decisions' in s 99 of the NDIS Act.
22. **Timeframe after a quote provided:** The NDIS Act should require the NDIA to make a decision about a request within 28 days after a quote is provided, if the plan provided for a support to be funded subject to a quoting process, and allowing internal review of a decision if the timeframe is not complied with.
23. **Remove references to 'primary disability':** The NDIS guidelines, forms and practice should be changed to no longer rely on the concept of a person's 'primary disability'.
24. **Typical support packages:** The Participant Service Guarantee should ensure that the NDIA does not misuse 'typical support packages' to create NDIS plans which are not person-centred or tailored for an individual's goals.

## 7. Using a plan

People with disability are often denied the disability supports they need because they are not available where they live or because they cannot access them. This submission shares stories from clients in rural and regional parts of Australia and clients with complex support needs and highlights the damage caused by the lack of a service safety net to ensure access to crucial NDIS supports.<sup>28</sup>

### 7.1 Understanding a plan

A lack of understanding of what the funding in plans can be used for can result in under-utilisation of NDIS funding. Participants are given a statement of supports that sets out lump sum figures in different categories covering core supports, improved daily living supports, and supports for social and community participation. Sometimes those categories are so broadly described, that the participant doesn't understand what supports they have been funded for. Our clients report that when participants seek further information from their planner about what they can use the funding for, often emails are left unanswered and phone calls are not returned.

Legal aid commissions support the NDIA's approach to allowing participants to flexibly use funding in the plan, within the constraint of broad categories of support. However, greater guidance should be given to participants about how to use their NDIS plan and how they can choose to use their funding.

### 7.2 Choice and control for people in rural, regional and remote areas

People with disability in rural, regional and remote areas continue to be disadvantaged in the roll-out of the NDIS because the available services they need for their disability do not exist close to where they live, or they are denied accessing suitable services. These difficulties are exacerbated for people with disability with complex needs and a lack of social supports.

In rural, regional and remote areas, participants generally have less choice of service providers. Larger service providers with branches or franchises in small towns are often the only service providers and dominate regional markets meaning price is not competitive, and there is little to no flexibility for participants to make the most out of their NDIS funding.

#### **Four-year-old Zachary missing out on services in remote Queensland**

Zachary is four years old. He has a rare genetic disorder that manifests in both physical and intellectual impairments. Due to his age, the provision of early childhood intervention, physiotherapy, occupational therapy, psychology and support in the home and community is critical.

---

<sup>28</sup> Part 4 above discusses market failure and the need for a service safety net in more detail.

Zachary lives in a remote community in Queensland, and his mother is required to travel over 800km each week to take Zachary to the closest regional town, city and metropolitan city for medical appointments, assessments and therapy services. The funding in Zachary's current NDIS plan does not include any allowance for travel time or for the provision of support workers to assist Zachary at home.

Zachary's parents are physically and emotionally exhausted and this current arrangement is unsustainable. They have commenced a review in the AAT regarding the adequacy of the supports in Zachary's plan, but even with the support of a disability advocate and a Legal Aid Queensland lawyer, it is anticipated that securing funding for travel time or for support workers to assist Zachary at home will be a challenge.

Northern Territory Legal Aid recently assisted young people detained in the Alice Springs Youth Detention Centre and Don Dale Youth Detention Centre with their NDIS claims. Significant difficulties in gaining access to the necessary specialist assessment services as a detainee caused lengthy delays in progressing the status of these claims. This delay often meant that the young person cycled out of detention and back into the community without any decisions being made about their claim. Once the young people did have a plan, as Joseph's story shows, lack of access to services severely undermines the ability of the NDIS to support young people with disability to live their lives in their communities.

#### **Joseph cycled in and out of youth detention without NDIS supports**

Joseph is a young person who was detained in Alice Springs Youth Detention Centre and who has been diagnosed with Foetal Alcohol Spectrum Disorder and an intellectual disability. Joseph lives in a remote area of the Northern Territory. He was not diagnosed or formally assessed prior to entering detention, despite several interactions with the justice system.

When Joseph entered detention Northern Territory Legal Aid arranged for him to undergo diagnostic assessment from the only service provider who can provide assessments in Alice Springs. As a result, Joseph was granted access to the NDIS.

Joseph's diagnostic assessment recommended a number of specialised supports, but these supports do not exist in Alice Springs. This has caused significant delays in establishing his NDIS plan, as any supports provided to Joseph in detention will need to be delivered by visiting interstate service providers.

In that time, Joseph was released and subsequently detained again due to re-offending resulting from a lack of necessary supports.

For regional clients the concepts of choice, control and flexibility are severely constrained by the market and do not exist in reality.

### **Absence of NDIS service providers contributes to Jade's entry to the justice system**

Jade is a young child who was assisted by Northern Territory Legal Aid in proceedings before the Administrative Appeals Tribunal. Jade lives in a highly remote area in the Northern Territory and has significant disability support needs.

Due to there being no service providers in the region, the allocated funding in Jade's first NDIS plan was not fully utilised. On this basis, the funding approved in Jade's subsequent plans was reduced significantly, leading to the cessation of necessary behavioural supports. Without these supports, Jade had encounters with the criminal justice system.

While Northern Territory Legal Aid's advocacy led to an overall increase in funding for Jade, it was not to the level provided in Jade's first plan, or to the level arguably required to provide adequate support. A lack of available services had already led to poor legal outcomes for a child.

Jade's story highlights the heavy toll on people with disability and their families in regional and remote communities and the flow-on consequences for individuals, communities and the system. These difficulties using or accessing supports for participants in regional and remote communities represents a weakness in the NDIS that was predicted, and which has been allowed to continue, unaddressed, to cause severe harm and disadvantage. People with disability living in remote Aboriginal and Torres Strait Islander communities are more acutely affected by the fact that they cannot implement their NDIS plan in practice to access the funded supports they need.

Isaac's case highlights the way in which thin markets can result in serious harm for entire families as a result of a lack of adequate NDIS funded supports in parts of country Australia.

### **Isaac removed from his family due to inadequate supports in regional area**

Isaac is 16 years old and lives with his family in a regional area. Isaac's mother and stepfather also have five younger children, and he does not have a relationship with his biological father. Isaac has autism, and his family needs support – particularly respite – to manage his behaviours and minimise the impact on his siblings.

Isaac previously had access to weekend respite care supports and would participate in group activities such as fishing and camping with carers and other children. His mother says that this worked well. However, when Isaac transitioned to the NDIS these supports ceased as his NDIS plan specified 1:1 respite care, and the service provider was only able to provide this on weekdays.

To access this service, Isaac's family was required to drive long distances between regional centres every day of the week – picking him up after school, dropping him off overnight, and then returning to collect him before school the next morning. Isaac's family explained that this was unmanageable, but the service provider said they were required to comply with the NDIS support plan.

Without appropriate supports, Isaac's behaviour became increasingly difficult and his mother and stepfather were concerned about the impact on their other children. His

family instead attempted to manage the situation themselves by arranging for Isaac to live with his grandmother, and subsequently by renting a property so that Isaac and his stepfather could live there separately.

These arrangements were unsustainable and ultimately the family contacted DHHS seeking respite or shared care as Isaac's behaviours became too difficult to manage without appropriate supports. In response, DHHS issued a protection application and sought a Family Reunification Order, which was granted in 2018. Isaac was initially placed with his biological father, but when this arrangement broke down, he was placed in a residential unit.

Isaac has formally been in a residential care unit since July 2018. During this time, he has stopped attending school, no longer works in his part-time job umpiring football and his mother states that he has experienced bullying by other residents. Over the last few months, Isaac has spent a considerable amount of time at home with his family, at one time spending 12 out of 14 nights in a fortnight with his family.

Despite this, DHHS has made an application for a Care by Secretary Order. Isaac's mother sought an internal review of the case plan and successfully negotiated for DHHS to change their case plan to reunification. Victoria Legal Aid has referred Isaac's case to the DHHS Intensive Support Team for consideration and will continue to monitor his matter to try to ensure that Isaac receives appropriate services and supports in accordance with his NDIS plan.

In this case, Isaac, his family, the service provider and the child protection system are all worse off as a result of the NDIS market's failure. There are compelling policy reasons for building a system that avoids these outcomes.

### **7.3 The benefits of skilled support coordinators**

Where the complexity of an NDIS participant's support needs presents an impediment to implementing their plan, funding for skilled support coordination is essential. Ongoing access to innovative and skilled support coordinators is an essential part of the NDIS regime for clients with complex needs. The position that support coordination is only an initial or introductory requirement is not accurate across the board. For people with complex needs, who face significant barriers to navigating the devolved nature of the NDIS, skilled support coordination will be a necessary ongoing feature of their plan and the foundation that keeps other supports in place.

In this context, we are concerned to learn of cases where support coordination is being reduced or removed for clients at plan reassessments, including those with complex needs. Skilled and experienced support coordinators can assist participants to:

- prepare for a planning meeting by considering their support needs and obtaining evidence;
- find alternative supports; and
- think creatively about existing or future supports.

Support coordination provides essential assistance for a participant to properly engage NDIS funded services and achieve the most out of their funding. Support coordinators help decipher the lump sum funding provided under the NDIS and advise participants of therapies, equipment, and supports they can access for the life of the plan. They will engage services, explain service agreements and manage schedules. In many cases this coordination is vital for participants. Unfortunately, we see many participants who are not given funding for a support coordinator and as a result are unable to fully use their NDIS funding and miss out on essential supports required to live a full and meaningful life.

In our experience, the NDIS functions well for participants where there is skilled coordination by someone with a strong knowledge of the system. To best prepare and equip participants to use their NDIS plans, skilled and experienced support coordinators must be a systematised and ongoing part of the scheme for people with complex needs (not just as an introductory requirement). Support coordinators can assist to problem-solve issues, navigate systems and think creatively about supports. As outlined above, support coordinators also play a role in minimising the risk and impact of market failure, by providing practical assistance to participants with complex needs to help them to navigate and advocate for access to services. This is a key foundation for keeping other supports in place like informal support provided by family or friends.

This Review presents an opportunity to more clearly define roles for Local Area Coordinators, Support Coordinators and Specialist Support Coordinators to ensure there is a clear understanding of roles and responsibilities, and to ensure that participants are connected to the appropriate person to assist them in their engagement with the NDIS.

## Recommendations: Making sure people can use their plan

25. **Skilled and ongoing support coordination:** The “Connected” service standards in the Participant Service Guarantee should recognise that skilled and experienced support coordinators must play a systematic and ongoing role for people with complex needs to problem-solve issues, navigate systems and think creatively about supports.
26. **Guidance about using a plan:** The Participant Service Guarantee should ensure that participants and their nominated support people are provided with adequate and accessible information about how to use their NDIS plan, including guidance, detailed information about the implications of self-management, plan management and agency management of support categories in their NDIS plans.
27. **Rural, regional and remote services:** The NDIS Act and operational guidelines should make changes to pricing in relation to travel for providers and participants and directly purchase services on behalf of participants if needed to ensure the promise of the NDIS can be fulfilled outside cities.



## 8. Reassessing and reviewing a plan

There are a number of barriers in how reassessment and review processes operate under the NDIS Act.

There is confusion between:

- **Scheduled plan reassessment:** A scheduled reassessment of a participant's plan before the set date under s 48(5) of the NDIS Act;
- **Unscheduled plan reassessment:** An unscheduled reassessment of a participant's plan under ss 48(2) of the NDIS Act which can be conducted at any time, including to reflect a change in a participant's goals and aspirations or a change in their circumstances which require their NDIS plan to be reassessed; and
- **Internal review:** A merits review of the decision relating to a statement of participant supports in a participant's plan under s 100 of the NDIS Act.<sup>29</sup>

Part 8 of this submission deals with scheduled and unscheduled plan reassessments, and part 10 covers internal review and appeals to the AAT.

The confusion resulting from calling all processes a 'review' often results in participants who want an internal review of their statement of supports going through an unscheduled reassessment process.<sup>30</sup> There are a number of reported AAT decisions where the NDIA has either incorrectly advised or failed to appropriately advise and direct a participant regarding their internal review and appeal rights.<sup>31</sup>

We support technical amendments including new language which makes a clear distinction between a scheduled plan reassessment, an unscheduled plan reassessment and internal review of a statement of participant supports.

### 8.1 Improved processes for scheduled plan reassessments

The conduct of scheduled plan reassessments is a cause for stress and anxiety for many of our clients, where NDIS plans can be reduced following a scheduled plan reassessment for a range of reasons outside the participants' control (e.g. market failure causing a lack of access to funded supports and leading to under-utilisation).

Our clients report that they often receive a lower level of funding for their supports in each

---

<sup>29</sup> An internal review of the decision to approve a statement of participant supports allows decision makers to consider the substance of an NDIS participant's request for supports. An unscheduled plan reassessment only allows decision makers to consider whether a plan should have been reviewed.

<sup>30</sup> This submission uses the terms "scheduled plan reassessment" and "unscheduled plan reassessment" for clarity. We note that the term 'review' is currently used in the NDIS Act for these processes.

<sup>31</sup> See for example: *ZKTN and National Disability Insurance Agency* [2017] AATA 744; *Simpson and National Disability Insurance Agency* [2018] AATA 1326; *BSLR and National Disability Insurance Agency* [2018] AATA 1282; *Hassett and National Disability Insurance Agency* [2018] AATA 4; 74 AAR 112; *Eccles and National Disability Insurance Agency* [2017] AATA 1457; 72 AAR 565; *Nairn and National Disability Insurance Agency* [2017] AATA 242; 71 AAR 439.

subsequent plan without clear explanations and without a change in their circumstances. This can be extremely distressing, with severe consequences for participants' health, wellbeing, access to secure housing and access to the community. There have been instances of participants or their family members challenging planning decisions at the AAT and successfully increasing the level of support they receive, only to have that support reduced again at the next scheduled plan reassessment.

As the story below shows, delays in the scheduled plan reassessment process – even where existing plans are inadequate – can have significant financial and personal consequences for participants.

**“I now owe a debt to my service providers ... I can't afford to pay them”**

I am 31 years old and received disability supports through the NSW Government prior to the NDIS. Since moving onto the NDIS I have been underfunded. Last year I was contacted by a Local Area Coordinator three months before my scheduled review date because I was going to run out of money.

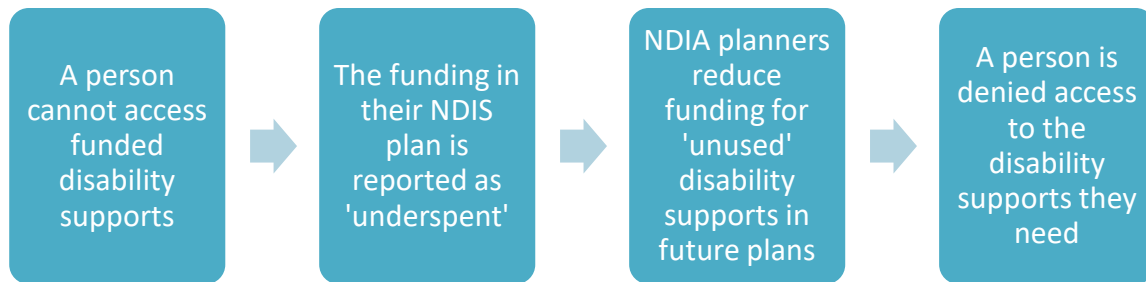
At the planning meeting the Local Area Coordinator assured my family and plan manager that he would be the person building the plan, that he had taken on board all the information about my support needs and would make sure that my needs were met. The Local Area Coordinator also said that the NDIA would start my new plan early so that I wouldn't run out of money – my scheduled review date wasn't for another three months.

My plan manager followed up weekly highlighting the need to release my new NDIS plan. The Local Area Coordinator eventually replied saying that he wasn't building the plan and that it was being done by a planner at the NDIA. My plan manager contacted the NDIA and was told that my new plan would only commence on the scheduled review date. The new plan did give me increased funding but it didn't fix up the three-month period when my funding ran out. I now owe a debt to my service providers for the services they provided me. I can't afford to pay them. The NDIA told them to take legal action against me.

It's really unfair because the NDIA have already agreed that my plan was funded too low and I needed more supports.

***Reduction of planned supports due to “under-spending”***

The lack of availability of specialist disability supports also affects people's long-term access to disability supports through a troubling cycle of service reduction.



Participants report that if they have underspent their funding, their funding is often reduced in subsequent plans. The assumption appears to be that an underspend means the participant was previously provided too much funding. The NDIA must properly fund reasonable and necessary supports. Legal aid commissions recommend that planners are instructed to carefully inquire as to the reasons for the underspend. If the level of funding is still considered “reasonable and necessary” it should be maintained in the subsequent plan, and possibly additional funding provided for a support coordinator to assist the person to use the funds on supports.

***Critical role of skilled and experienced support coordinators***

Support coordination can also be reduced or removed from a plan at a plan reassessment, including for participants with complex needs. As outlined above, support coordination should not be seen as only an initial or introductory requirement for those with complex needs but should be recognised as the foundation that keeps other supports in place, either until they are clearly established, or ongoing. In addition, support coordinators play a crucial role in supporting participants to prepare for scheduled plan reassessments to ensure the plan reassessment process is more efficient, tailored to the individual and more likely to result in sufficient practical supports.

**8.2 Maintaining service levels**

The NDIS Act should clarify a plan’s status between when a plan reassessment date passes and the reassessment is completed and the plan is replaced. This appears to be reflected in NDIA policy, but not in legislation.<sup>32</sup>

When a plan is reassessed, the previous level of support must be taken as a benchmark for the participant’s next plan, unless there is a demonstrated change in the participant’s circumstances and an evidence-based change to the participant’s needs (e.g. where a person has an inadequate plan and is experiencing significant harm).

Participants should be given warning of the future change, be provided with the draft plan, and be provided with adequate time and support to respond to the draft plan. While this

---

<sup>32</sup> National Disability Insurance Agency, ‘Paying providers when there is a gap in-between plans – NDIS’ (Frequently Asked Questions Sheet, 15 October 2019) <<https://www.ndis.gov.au/media/1440/download>>.

reassessment process takes place, funding should be maintained at the previous level.

### 8.3 Maintaining participant status following revocation

#### ***Access to supports throughout a review if a person's access to the NDIS is revoked***

The NDIS Act allows the NDIA to revoke the status of a participant at any time if the CEO is not satisfied that the person meets the disability or early intervention criteria.<sup>33</sup> If a person's status is revoked and they seek an internal review or appeal to the AAT, they have no access to supports throughout that review process. This places significant pressure on applicants to pursue their appeal rights without support. If the decision is later reversed, their mechanism to seek reimbursement for supports they otherwise would have been entitled to is unclear. The NDIS Act should be amended to include a provision under which payment for supports would continue pending a review, similar to section 131 of the *Social Security (Administration) Act 1999* (Cth).

#### **Martha denied access to personal care, transport and therapy for two years while waiting for review**

Martha is a 62 year old living in regional NSW who has complex trauma and multiple physical disabilities.

She was a participant on the NDIS for two years before her status was revoked. With the assistance of Legal Aid NSW, she appealed the decision to the Administrative Appeals Tribunal. After close to two years, the NDIA accepted that its decision about Martha's access to the NDIS was incorrect and reinstated her to the NDIS.

For two years while the review process went on, she had no access to funding for personal care, transport or therapies.

---

<sup>33</sup> *National Disability Insurance Act 2013* (Cth) s 30.

## Recommendations: Ensuring clear, accessible and efficient reassessment and review processes

28. **Clear terminology regarding reassessments and reviews:** The NDIA Act should be amended to clarify the differences between a scheduled plan reassessment, an unscheduled plan reassessment and an internal review. Following changes to terminology, new review and assessment forms should be created that clearly distinguish between the different processes.
29. **Role for support coordinators in scheduled plan reassessments:** The NDIA should provide adequate funding for support coordinators to support participants to meaningfully engage in scheduled plan reassessments.
30. **Communication and support in the reassessment process:** The NDIS Act should require a person conducting a scheduled or unscheduled plan reassessment to communicate with the participant before completing the reassessment, and the Participant Service Guarantee should require a person conducting a review to provide support and assistance to participants to obtain evidence in relation to a support.
31. **Maintaining service levels during reassessment process:** The NDIS Act should provide that a person maintains their current level of services between plan reassessments (i.e. when a review date passes and the review is completed and the plan is replaced).
32. **Access to supports pending internal review or AAT appeals:** We recommend that the NDIS Act and Participant Service Guarantee should allow for payment for supports pending an internal review or AAT appeals.

## 9. Amending a plan

There is a clear need to improve how plans are created, reassessed, reviewed, changed, appealed and updated. Current processes are confusing, slow and ineffective.

The Discussion Paper proposes a “plan amendment” when a participant’s goals and outcomes do not need to be changed, but minor changes are needed to ensure it remains fit for service. A plan amendment may improve processes by speeding up NDIA processes, including for adding assistive technologies, home modifications and specialist disability accommodation later when supporting material is made available.

If the NDIS system was operating as intended, a plan amendment power should not be necessary. It is important that a plan amendment power is not used as a substitute for resolving current implementation issues which legal aid commissions are seeing in our daily casework.

Under the current NDIS model, there is no funding provided for contingencies. Where a person’s circumstances change, the only avenue to change the level or types of supports provided is to undergo a long and difficult reassessment or review process, during which these supports are not available.

We support measures which reduce delays and improve NDIA processes, provided any amendments do not diminish the rights of NDIS participants. Without further information about the proposed plan amendment power, we can only provide the high-level comments below on the its potential usefulness or the risks it might pose. We encourage careful consultation on the specific content and statutory framing of a plan amendment power. Importantly, a plan amendment power should not act as a barrier to the exercise of internal and external review rights.

A key challenge is finding a mechanism that achieves all the following objectives:

- **flexibility** where additional supports are required due to a change in circumstances;
- **clear and easy to access**, so that participants are easily able to identify and access the appropriate pathway based on the outcome they seek;
- **prompt** to allow participants to implement supports as soon as they are assessed as reasonable and necessary;
- **certainty** so that a participant can rely on the supports being provided for the period set out in the plan; and
- capable of **effective and timely merits review** so that disputes about important supports that cannot be resolved can proceed through an effective merits review process quickly.

For a plan amendment power to achieve these objectives it would need to:

- sit within a clear, deliberate and effective framework for adding supports to plans that is understood and accessible by participants and the NDIA;
- prioritise ensuring participants get the supports they need as soon as possible;
- be structured in such a way so it does not delay or inhibit any other review or appeal processes that are on foot in relation to other supports;
- have fixed and swift timelines to review a decision and avoid delay;
- ensure it does not increase the amount of evidence required for decisions to be made by the NDIA; and
- allow any refusal decision to be coupled with any other review decisions that are currently on foot, so that multiple appeals are not required.

If a plan amendment power is introduced into the legislation it is crucial that safeguards are in place to ensure that this power does not disadvantage participants or permit a reduction in supports.

The inclusion of a plan amendment power would effectively mean that there are three methods of changing a plan.<sup>34</sup> The AAT has been required to grapple with the different statutory foundations of NDIA decision making in a number of cases.<sup>35</sup> The inclusion of a plan amendment power might mean that the AAT is required to determine whether the NDIA has made a decision to amend a plan, reassess a plan, or review a statement of participant supports, as a threshold question before considering an NDIS participant's substantive claim.

### Recommendations: Allowing for quick, accessible, reviewable amendment of plans

**33. Amendment power:** Subject to further consultation on its form and proposed operation, the NDIS Act should include a plan amendment power which is prompt, clear and easy to access to increase or adapt supports for participants but which does not result in a participant being disadvantaged or having their supports reduced, and can be subject to effective and timely merits review.

---

<sup>34</sup> Section 48 of the NDIS Act provides for plan reassessments and sections 99 and 100 of the NDIS Act provide for reviews of statements of participant supports.

<sup>35</sup> See for example: *ZKTN and National Disability Insurance Agency* [2017] AATA 744; *Simpson and National Disability Insurance Agency* [2018] AATA 1326; *BSLR and National Disability Insurance Agency* [2018] AATA 1282; *Hassett and National Disability Insurance Agency* [2018] AATA 4; 74 AAR 112; *Eccles and National Disability Insurance Agency* [2017] AATA 1457; 72 AAR 565; *Nairn and National Disability Insurance Agency* [2017] AATA 242; 71 AAR 439.

## 10. Appealing a decision by the NDIA

People with disabilities continue to shoulder the burden of navigating complex, lengthy and emotionally taxing internal reviews and AAT reviews.

Our clients frequently experience prolonged delays in obtaining internal review decisions. Internal review decision makers continue to apply policy that is inconsistent with the legislation and case law, thereby necessitating further external review in the AAT.

Before considering the substance of a participant's application, the AAT must often determine complex legal questions regarding the extent of its jurisdiction, powers and how the participant can continue to access supports once their plan reassessment date has passed.

Once these jurisdictional or procedural issues have been determined, the conduct of the NDIA itself presents obstacles to obtaining funding for supports that meet the "reasonable and necessary" legal criteria. These obstacles include the application of policies that are inconsistent with the legal criteria and ongoing delays.

This Review provides an opportunity to clarify technical questions around jurisdiction and procedure to reduce delays, to ensure the Participant Service Guarantee requires the NDIA to provide avenues for review and appeal established under the NDIS Act and to resolve disputes quickly and easily for participants, their carers and families.

### 10.1 Clear, timely internal reviews

#### *Misunderstanding internal review requests*

As outlined above, requests for internal reviews of statements of participant supports are routinely mischaracterised by the NDIA as requests for unscheduled plan reassessments. This places NDIS participants in an ongoing cycle of internal review and introduces barriers to external review in the AAT.

Christina's story demonstrates the confusion this causes for NDIS participants and their representatives or nominees.

#### **Christina's mum left confused and trapped in a "review loop"**

I wanted to review the supports in my daughter Christina's NDIS plan. I applied for AAT review before an internal review decision was made.

I didn't realise that I needed to have an internal review decision before applying to the AAT. Legal Aid Queensland helped me to withdraw Christina's AAT application and advised me to get an internal review decision. NDIA staff told me to withdraw the internal review request and instead seek a "plan review" based on a change in circumstances.



The NDIA are now doing a plan review. I've been told that if the new plan does not meet Christina's support needs, I will have to seek further internal review before the AAT can review Christina's supports.

### ***Internal review delays***

The NDIS Act does not set a timeframe for a decision to be made on internal review beyond "as soon as reasonably practicable". Participants can wait the entire length of their plan (and beyond) before they receive an outcome.

The Commonwealth Ombudsman's 2018 report in relation to NDIS decision making delays found that the NDIA was at the time receiving over 600 requests for review each week, and that reviews were taking up to nine months to be completed.<sup>36</sup>

Despite efforts to expedite reviews, delays are still extremely common. For the Legal Services Commission of South Australia, 34 of the 117 applications for legal assistance with NDIS appeals received to date involved a situation where the NDIA had failed to make an internal review decision.

An internal review decision is a necessary precondition to an AAT appeal. In Christina's matter, the NDIA's conduct delayed the resolution of her matter, including her access to external review of the supports in her plan by an independent decision maker.

The AAT previously found that an internal review decision could be "deemed" to have been made depending on the circumstances.<sup>37</sup> However, the availability of this mechanism is now unclear.<sup>38</sup>

In Carmen's case, delays in the review process and a failure to consider evidence meant that she was unable to leave hospital for two years.

### **"I was stuck in hospital for two years after I was cleared for discharge"**

While I was medically cleared for discharge from hospital, my disabilities meant that I couldn't look after myself independently in my home. My home needed modifications before I could be discharged and I asked the NDIA to fund this. They refused to do so.

I asked for internal review of this decision. The decision maker did not read reports and assessments that my allied health practitioner gave to the NDIA. My internal review request was unsuccessful and I applied for further review in the AAT. Legal Aid Queensland then took on my case and they thought that my allied health practitioner's reports and assessments clearly demonstrated that the home modifications should be

---

<sup>36</sup> Commonwealth Ombudsman, *Administration of Reviews under the National Disability Insurance Scheme Act 2013* (Report No 3, May 2018) 3.

<sup>37</sup> *FJKH and National Disability Insurance Agency* [2018] AATA 1294.

<sup>38</sup> See for example: *KRBG and National Disability Insurance Agency* [2019] AATA 144.

funded. Despite this, Legal Aid Queensland helped me get further evidence and reports requested by the NDIA's lawyers.

My case was progressing towards an AAT hearing. An informal meeting was scheduled with my lawyer, my allied health practitioner, the NDIA's lawyer and the NDIA's instructor. The instructor said that the internal review decision maker had not read my allied health practitioner's original reports and assessments. The NDIA then agreed to fund the home modifications.

While this was a good result in the end, I was stuck in hospital for two years after I was cleared for discharge. If the internal reviewer had considered the evidence or made a decision earlier I could have been discharged from hospital and back at home sooner. This affected my health, wellbeing and family and social relationships.

Had Carmen's internal review request been finalised within a time limit, she would have been able to be discharged from hospital years earlier. If it was an unfavourable decision, she would have been able to access AAT review sooner and the deficiencies in the internal review process could have been detected earlier. Instead, Carmen suffered consequences that were detrimental to her health and wellbeing.

Awaiting an internal review decision can have devastating consequences for participants and prospective participants. Where a participant is seeking review because they need more daily living assistance, they may need to go without showers or meals or transportation while seeking additional funding. Where a family seeks review of a child's early intervention supports, they may need to take out a personal loan to fund the therapy to ensure the child receives the therapy at developmentally critical time.

#### **"I was struggling to get my kids to school"**

I can't remember exactly when I applied, but it took almost three years to get through the appeals process (with the help of Legal Aid NSW and an advocate) and get onto the NDIS.

What I have is fibromyalgia and the stress that was attached to the appeal was making the fibromyalgia worse. It got to the point where I was even suicidal.

I was struggling to get my kids to school. It got to the point where the school notified Family and Community Services that I was struggling and that I wasn't taking my kids to school.

Knowing that I had a disability and getting knocked back even though I was after so much help was really hard on me. Since getting the help I am in such a different place, in such a good place. The kids have a better person as a mum. During the winter period I have had a support worker take my daughter to school. Thanks to the support worker I can get up a lot more slowly which my condition requires. Now that we have support with a dietician and I'm also able to better able to manage food for the family.

Last weekend, I took the kids to ice skating, I have a scooter now, so we even managed to go for a walk after it. Me on the scooter, the kids on their feet. That only happens now because I have the support from the NDIS to do these kinds of things.

Since being on the NDIS I have been really happy. I have supports that are really helping. Everything is going all well and good.

Other examples of hardship from legal aid commission casework includes:

- Participants with complex needs experiencing increases in hospitalisation or bouts of sickness, infection or other health complications when there has been a decrease in services.
- A participant's family increasing the informal care they provide at the expense of their paid employment.
- Participants using their supports at an unsustainable rate leading to a crisis point or a debt to service providers when the budget is exhausted.
- Interruption to therapy interventions due to a lack of funding, which often results in reversals of a participant's skill attainment or loss of the benefits previously achieved by the intervention.
- Early intervention for young children to maximise long term outcomes for children and their families<sup>39</sup> is denied at a critical time. Many families cannot bear the cost for early intervention, and many fund it privately to the point of extreme debt and significant financial hardship to avoid the serious long-term consequences of delayed, intermittent or reduced intervention on their child's development.

An internal review should be a cheap, accessible and informal mechanism for a participant to challenge a decision about their supports. For it to work effectively, decisions must be made quickly, with full consideration of the participant's circumstances, an opportunity for the participant to present their case and detailed, considered and consistent reasons.

A time limit for internal reviews will reduce delays, allow participants the benefit of the deemed decision making provisions should the NDIA fail to make a decision, provide participants with a clear path forward to AAT appeal and reduce the strain caused by uncertainty about supports.

### ***Direct communication with participants***

Internal reviews could be enhanced by requiring a reviewer to:

- communicate with the participant before completing the review;

---

<sup>39</sup> Early Childhood Intervention Australia, *National Guidelines: Best Practice in Early Childhood Intervention* (February 2016) 4.

- consider the general power under section 6 the NDIS Act to provide support and assistance (including financial assistance) to participants in relation to doing things under the Act; and
- consider the power under section 55 of the NDIS Act to obtain information relevant to whether a prospective participant meets the access criteria and decisions relating to funded supports.

If the reviewer is not satisfied that there is sufficient evidence in relation to a support, they should support the participant (financially or otherwise) to obtain that evidence.

### ***Allowances for participants to adjust services without experiencing hardship post review***

The NDIS Act should also include allowances to ensure participants are not adversely affected immediately following a review if the decision is either confirmed, varied or set aside. For example, where supports are removed following a review.

If it is determined that the decision be varied or set aside on the basis that the supports in issue are reasonable and necessary such a timeframe ensures that the consequences of not receiving that support are minimised.

Similarly, if the determination confirms the decision then the participant has time ahead of the scheduled review to adjust their services accordingly and prepare for the scheduled review.

### ***Adequate written reasons***

There are significant difficulties when internal review decisions do not contain sufficient reasoning about how the legislative tests in the NDIS Act have been considered and applied, which often causes further delays.

## **10.2 Appealing a NDIA decision to the AAT**

Appealing a NDIA decision to the AAT involves extensive delays and causes stress and difficulty for participants, their carers and families. Significant resources have been required to determine complex procedural and jurisdictional issues before the AAT can consider whether a participant's request for supports should be funded. People's support needs are effectively sidelined pending resolution of complex legal issues around the operation of the NDIS Act. These processes can demonstrate a stark power imbalance where a participant is self-representing and the NDIA is legally represented.

The key procedural or jurisdictional issues include:

- whether the decision before the AAT is an internal review decision to approve the statement of participant supports in a plan (sub-section 33(2)) or a decision not to conduct an unscheduled plan reassessment (sub-section 48(2));<sup>40</sup>
- whether the AAT has jurisdiction and if so, over which plan;
- what happens to a plan when the review date occurs during the AAT process; and
- does the AAT's jurisdiction continue after plans are issued following an internal review decision.<sup>41</sup>

### ***Nature of decision under review***

The AAT has often been required to determine the nature of review that the NDIA has conducted (i.e. an internal review or an unscheduled plan reassessment) as a threshold issue before the participant's support needs can be considered.

#### **“It’s been three years. I am still waiting for NDIA to understand my needs.”**

Having appropriate and stable accommodation that meets my needs is important to me. I am in my 40s and have an intellectual disability and psycho-social impairments. I have never had a permanent residence where I have felt secure and part of a family. I was in State care from a very young age. I have experienced periods of homelessness. I live in an aged care facility.

I became an NDIS participant in 2016. I received my first plan in late-2017, but it did not meet my support needs. My support coordinator helped me to ask for internal review for more core supports funding. I wanted funding for appropriate accommodation and increased disability support worker hours. The NDIA told me to ask for this funding once I found appropriate accommodation. They told me to find the accommodation on my own and come back to them. The NDIA promised they would consider my request for accommodation at that time. Five months passed and I still hadn't heard anything about my internal review. Around the same time, I found a group home that I wanted to live in and accepted an accommodation offer. I wanted to live in that house to feel secure and be part of a family where I had the option of having someone available to support me if needed. I spoke to NDIA and they said 'no'. They told me that I did not satisfy the legal requirements for SDA. I didn't know it at the time, but the group home that I wanted to live in was not SDA. The NDIA told me to ask for a plan review in relation to my accommodation needs and I did so.

Eight months after I asked for internal review I received a letter that said that my internal review was unsuccessful. The letter didn't say anything about my plan review. I didn't understand the process – no one explained to me the difference between an internal review and plan review.

<sup>40</sup> See for example: *ZKTN and National Disability Insurance Agency* [2017] AATA 744; *Simpson and National Disability Insurance Agency* [2018] AATA 1326; *BSLR and National Disability Insurance Agency* [2018] AATA 1282; *Hassett and National Disability Insurance Agency* [2018] AATA 4; 74 AAR 112; *Eccles and National Disability Insurance Agency* [2017] AATA 1457; 72 AAR 565; *Nairn and National Disability Insurance Agency* [2017] AATA 242; 71 AAR 439.

<sup>41</sup> See for example: *SHGH and National Disability Insurance Agency* [2018] AATA 674; *FFVQ and National Disability Insurance Agency* [2018] AATA 1968; *Williamson and National Disability Insurance Agency* [2019] AATA 2944.

My disability advocate helped me to apply for AAT review. I wanted the AAT to assess my support needs. Victoria Legal Aid then took on my case. Months into the AAT proceedings the NDIA's lawyer said that the AAT did not have the power to consider my support needs. They made legal submissions that the NDIA could only consider whether a plan review should have been done. This was really upsetting, because the NDIA knew about my situation and what supports I needed. It felt like they weren't listening.

A few months ago, the AAT decided it had the power to review my support needs. The NDIA refused to accept this until the AAT told them so. It has taken the NDIA 18 months to acknowledge the supports I have been asking for. So much time and resources have been involved going through this process. The NDIA agreed to increase my disability support worker hours.

It felt like the NDIA did not consider my support needs at any stage. If they had done so maybe they would have worked out earlier that I was not asking for SDA – that I was asking for accommodation in a group home. It is possible my matter would not have gone to the AAT. I ended up losing the offer to live in the group home and am still stuck in an aged care facility. I still don't have accommodation where I feel secure and part of a family.

It's been three years since I joined the NDIS. I am still waiting for the NDIA to understand my needs. While the NDIA have increased funding for disability support worker hours, they are not helping me to find the right accommodation.

AAT determination of the nature of the NDIA's decision making is a confusing and unnecessary step for participants who simply want a decision about their support needs.

In a recent AAT case Deputy President Forgie commented on the resources required and confusion involved in determining similar matters (emphasis added):<sup>42</sup>

*In this case, I have set out the steps that the NDIA has taken to illustrate the confusion that would seem to permeate the process of review. To a large extent, the confusion would seem to arise from the structure of the NDIS Act... To distinguish between decisions regarding the plan and its reassessment and decisions regarding the substance of what it is to which a participant is entitled and which is set out in a statement of participant supports in his or her plan, seems an unnecessary distinction. It is a distinction that leads to cases such as this in which time must be spent to work out what has been decided rather than to work out what it is to which a participant is entitled.*

### **Clarification of scope of AAT power to review a decision when a plan has been replaced**

There is uncertainty about the scope of the AAT's jurisdiction to review a decision where a plan has been replaced. There are many instances where plans are replaced before the AAT makes a decision, as even minor changes to supports or goals results in a new plan. Not only

---

<sup>42</sup> LQTF and National Disability Insurance Agency [2019] AATA 631, [4].

are there questions about the efficacy of the AAT review process, but the continuing lack of clarity causes delays, difficulties advising clients and acts as a barrier to NDIS participants without legal representation.

AAT members have adopted the following inconsistent approaches:

- making orders only in relation to reimbursement for the duration of the plan under review only;
- making orders for prospective supports (e.g. by making its decision take effect from the date of its review rather than the date the original plan was approved);<sup>43</sup>
- creating a new plan (e.g. starting from the date the plan commenced until the AAT decision);<sup>44</sup> and
- varying the unscheduled plan reassessment date so the plan has not been replaced before the AAT decision (either by agreement between the parties<sup>45</sup> or remitting the matter to the decision maker by consent).<sup>46</sup>

There is no uniform approach to preserving the AAT's jurisdiction when a plan has been replaced and the case law remains confusing and inconsistent.

Legislative amendment is needed to clarify the scope of the AAT's power when reviewing plans that have been replaced. The ability of the AAT to vary or create plans spanning beyond the effective period of initial plans should also be reflected in the NDIS Act.

These changes should reflect the intent of merits review to provide reviewers with a wide remit to give effect to the correct or preferable outcome. It should not restrict the AAT to reviewing individual plans in individual applications for review. It should also not require individual plans to be individually reviewed and then joined at the AAT level, given the additional resources that this would require of NDIS participants, the NDIA and AAT.

We recommend that the NDIS Act clarify the AAT's jurisdiction including the following:

- The AAT's jurisdiction to determine the statement of participant supports from the time the original statement of participant supports (the one under review) was approved by the CEO.
- The AAT's jurisdiction to approve the statement of participant supports under sub-section 33(2) of the NDIS Act, which should result in a new plan under sub-section 37(1) of the NDIS Act.

---

<sup>43</sup> See for example: *Re PNMJ and National Disability Insurance Agency* [2015] AATA 866, [23]-[26], [106].

<sup>44</sup> *Re QZHH and National Disability Insurance Agency* [2018] AATA 1465, [47]-[65] (Member Parker); *Re Ewin and National Disability Insurance Agency* [2018] AATA 4726, [280]-[318] (Member Parker).

<sup>45</sup> *Re SHGH and National Disability Insurance Agency* [2018] AATA 674, [30]-[32] (Deputy President Constance).

<sup>46</sup> *Re Williamson and National Disability Insurance Agency* [2019] AATA 2944 (Deputy President Forgie).

- The statement of participant supports decision should be effective from the time the original statement of participants supports was approved by the CEO or a later date to be determined by the AAT.
- The AAT should determine the date by which or the circumstances in which the NDIA must review the plan as required under sub-section 33(2)(c) of the NDIS Act.

***Operational guidelines should be consistently reviewed and reflect court decisions***

The application of the NDIA’s operational guidelines in both internal review decision making and in the course of AAT review continues to present a barrier to NDIS participants realising their entitlements to “reasonable and necessary” supports.

The case of *McGarrigle v National Disability Insurance Agency* [2017] FCA 308 (*McGarrigle*) clarified how decision making about supports, and particularly transport supports, should be conducted. This decision stands for the broader proposition that once a support is found to meet the reasonable and necessary criteria it should be fully, rather than partially, funded.

The operational guideline on transport (Transport Guideline)<sup>47</sup> which decision makers rely on, sets out caps, or limits, on transport funding, and continued to contain references to the overturned original decision of the AAT in *McGarrigle* until October 2019, including relying on an approach that was expressly rejected by the Federal Court in 2017.<sup>48</sup>

There must be a mechanism to ensure that court decisions are implemented in a timely manner to improve the operation of the NDIS.

The Transport Guideline was updated in October 2019, and now contains no mention of *McGarrigle*, despite it being the key decision in relation to transport funding. Neither the effect of *McGarrigle*, or subsequent decisions of the AAT are reflected in the Transport Guideline.

***NDIA must uphold model litigant policy***

In mid-2018, Legal Aid NSW raised the following concerns with the NDIA regarding its conduct of AAT reviews and compliance with its obligation to act as a model litigant in AAT proceedings:<sup>49</sup>

- **extensive delays** across all aspects of the AAT review process, including seeking expert reports, filing documents, returning correspondence and signing agreements;

---

<sup>47</sup> National Disability Insurance Agency, ‘12. Transport’, *Including Specific Types of Supports in Plans Operational Guideline – Transport* (Web Page, 10 October 2019) <<https://www.ndis.gov.au/about-us/operational-guidelines/including-specific-types-supports-plans-operational-guideline/including-specific-types-supports-plans-operational-guideline-transport>>.

<sup>48</sup> Prior to October 2019, the Transport guideline stated “if the criteria relevant to including supports in a participant’s plan are satisfied, this does not mean that the full cost of the support should be funded as it may be reasonable for a participant’s family members, carers, informal networks and/or the community to provide some of this support (see *McGarrigle and NDIA* [2016] AATA 498 at [36])”.

<sup>49</sup> *Legal Services Direction 2017*, Appendix B - Directions on *The Commonwealth’s Obligation to Act as a Model Litigant*.



- the NDIA’s approach to conceding appeals led to **untimely resolution of disputes**;
- resource implications and the impact on applicants by the NDIA not participating fully and effectively in alternative dispute resolution mechanisms;
- the NDIA’s **overly broad summoning practice** from all medical practitioners, not limiting the scope of summons to information relevant before the AAT;
- **non-compliance with AAT directions**, leading to delays in proceedings, additional time and cost for both parties and the AAT, and further work demands on Legal Aid solicitors;
- the NDIA **putting applicants to proof unnecessarily** for matters which the agency knows to be true; and
- the NDIA **failing to assist the AAT** to reach the correct and preferable decision.

We commend the NDIA’s efforts to date in amending its conduct of AAT reviews, including:

- ongoing efforts to facilitate early resolution for people with disabilities to achieve their reasonable and necessary support needs;
- appointing an early resolution team for early assessment of merits to resolve claims promptly and without delay;
- no longer requiring confidential settlements to ensure transparency and help applicants understand why decisions are made;
- improved responsiveness;
- improved use of alternative dispute resolution mechanisms to concede matters before a hearing; and
- improved case management of AAT matters.

However, we highlight the following NDIA obligations which should be addressed to ensure the NDIA conducts itself as a model litigant:

- **Assisting the AAT to arrive at the correct or preferable decision:** The NDIA has an obligation to avoid, prevent and limit the scope of litigation. For example, the NDIA has expanded the scope of issues in dispute by raising matters at hearing which were not previously raised during alternative dispute resolution. The NDIA has put participants to proof unnecessarily for issues not in dispute. In addition, the NDIA has challenged the AAT’s jurisdiction, incorrectly characterised the decision under review, and obstructed rights to review by attempting to undertake local office plan unscheduled reassessments instead of an internal review of the statement of participant supports. The NDIA should assist the AAT and avoid actions which unnecessarily cause delays and draw out litigation.
- **Inconsistency:** The NDIA has an obligation to act consistently in the handling of claims and litigation. For example, the NDIA takes a blanket position in some cases that it does not fund a particular type of support yet concedes funding that support for other participants, rather than tying funding of that support to “reasonable and

necessary” criteria. This leads to inconsistencies in the handling of claims. These inconsistencies leave applicants with no understanding of why decisions are made, how matters are approached by the NDIA and how future matters will be handled.

- **Summoning practice:** The NDIA has an obligation to make information easily available to the AAT and to present new material that is relevant and may assist the AAT. The NDIA’s ongoing practice of seeking an excessive number of summonses that are unlimited in scope often results in participants being required to provide a large volume of irrelevant material. This practice also imposes heavy work demands on legal aid commission solicitors in reviewing copious records, and limits the number of clients we can assist.
- **Implementation of decisions:** The NDIA has an obligation to minimise delay and act in good faith in implementing decisions of the AAT. The NDIA must act honestly, fairly and promptly in all its dealings. Legal aid commissions have consistently seen delay of months in the NDIA complying with AAT settlements to provide reimbursements to our clients.

Marcus’ story highlights the way in which non-compliance with model litigant obligations can result in protracted litigation and have a devastating impact on NDIS participants and place strain on family relationships and informal support arrangements.

#### **Fighting an endless battle for the NDIA to deliver on its promise to my son Marcus**

For two years my husband and I have fought what feels like an endless battle for our son, Marcus. When Marcus was almost three the NDIS took him on as a participant. Marcus has Autism Spectrum Disorder. His first plan did not have enough funding for the early intervention he needed.

I applied for review of Marcus’ statement of participant supports just after his third birthday in late-2017. The NDIA did not conduct this review. I felt that they had completely disregarded the application and Marcus was not being heard. I didn’t know what to do.

It was only when a disability advocate assisted us a year later that the NDIA acknowledged our review request. In the meantime, our family were out-of-pocket covering much of the cost of Marcus’ early intervention needs.

Once an internal review decision was made a year after we asked for review our advocate helped us to apply for AAT review and then Victoria Legal Aid took our case on.

Several case conferences were held over months. There was so much back and forth, with the NDIA requesting reports, statements, weekly schedules and assessments from us. And then the waiting, waiting, waiting, endless waiting. This drawn-out process caused so much stress within our home, our concern for our son and the unknown tested the strength of our relationships and our family. We questioned ourselves as if we had done something wrong or something terrible to deserve this.

A conciliation was finally scheduled in June 2019 – almost two years after we asked for the review. We were hopeful that the case would resolve. There was so much anxiety

leading up to the conciliation, sleepless nights, stress, tears, worry, fear and questions. How will we cope if we don't get a good outcome? What will we do? What does the future hold for our son if we can't get help?

Despite the constant disappointment we had experienced in dealing with the NDIA, we still had hope.

The morning we arrived for our conciliation, our lawyer advised us that the NDIA lawyers had emailed them on the business day before the conciliation at 6pm that there were some legal technicalities that meant that a decision could not be made in Marcus' case. We were in absolute disbelief. We had already experienced an emotional roller-coaster and this just added to our stress and anxiety. When the conciliation started, we were told that the NDIA would act in good faith and proceed to make a decision, if agreement could be reached, regardless of this technicality.

At the conciliation my husband and I were given the opportunity to speak. It was such an emotional build-up to this point. This day was a day that could change our lives and finally give our son the help he needs and deserves. We spoke about the stress, the financial pressure, the strained relationships, depression, the debt we incurred in order to help our son, the lack of support from the NDIA, the frustration, ongoing worry and heartache. The Special Adviser who attended the conciliation on behalf of the NDIA acknowledged that Marcus' plan did not meet his early intervention needs. The NDIA and their legal team left the room to deliberate. They returned after 15 minutes and advised us that they would like to make an offer, which they did and we agreed to. They advised us that consent orders would need to be written and signed which would take approximately three weeks. We were elated, we had finally resolved this, we felt a sense of relief, we felt so many emotions, a weight lifted from our shoulders that in three weeks we would have the funding to continue Marcus' therapy. We were in disbelief, it was over. At least this was what we thought.

Three and a half months later and we are still waiting. I ask myself the question - how are we still waiting? They promised us this funding to help our son. We are in such a difficult situation trying to scrape the bottom of the barrel to pay therapy bills when our conciliation was held months ago. We came to an agreement with the NDIA and in good faith we trusted them. We trusted that they would keep their word and finally help our son.

The NDIA asked us to create goals for Marcus's new plan, we did that. They have asked us for documents they already had, we have sent them again. We continue to follow up the status of the consent orders that were agreed to and continue to get bounced around to different people from different departments in the NDIA. Communication is poor, we don't know who is overseeing Marcus's case, we don't know who is responsible, we don't know who to contact and we don't know when or if we will get what has been promised.

Dealing with the NDIA has been a painful experience. I feel like I have been banging my head against a brick wall. Just when we think we have taken one step forward, we are forced two steps back. We will never stop fighting for our son but it shouldn't have to be this hard to get the help he needs and deserves. Marcus is now five-years-old and has so

much potential. This process has taken two years now. Every day is crucial for early intervention and making gains in functioning.

We just want Marcus to have a bright future where he can function to the best of his ability. We feel deflated, extremely disappointed and disheartened. We are exhausted and just need help.

Our committed advocate and lawyer have stuck by our side throughout this and sent endless emails and made countless phone calls on our behalf. They continue to pursue this with us and will do so until the NDIA fulfil the promises they have made.

I am extremely concerned about those who do not have such support or do not have the capacity to pursue the NDIA. The ability to navigate through this system so difficult that it is so easy to just become so disheartened and give up. People need to be able to access support and be heard if the NDIA wants us to “see how the NDIS is making a difference”.

### 10.3 Reimbursement following successful review decision

In cases where our clients have experienced hardship, they continue to bear the significant financial burden for the period of time during which they did not have access to NDIS supports as a result of an incorrect decision by the NDIA.

Where a decision is made that a support is reasonable and necessary and that support had previously been provided at a cost to the NDIS participant, the cost of the support should be reimbursed to the participant.

NDIS participants should be able to seek compensation where they have experienced detriment as a result of a defective action or inaction of the NDIA. The NDIA should be able to make payments to NDIS participants where appropriate.

## Recommendations: Appealing and resolving disputes quickly, easily and fairly

34. **Access to merits review of NDIA decisions:** The Participant Service Guarantee should: (a) recognise the right to internal review and AAT review of all reviewable decisions and undertake to support and facilitate access to these review processes; and (b) ensure that any review process will be conducted with a view to preserving a person's right to AAT review.
35. **Avoiding confusion between reassessment and review:** The NDIS Act should be amended to clarify the difference between reassessment and review, and require that any request for review made within three months of a statement of participant supports be received be treated as a request for internal review.
36. **Communication about internal review:** The NDIS Act and the Participant Service Guarantee should require decision makers to confirm in writing that a person's internal review request has been received within 14 days of receiving the request, inform participants that their request will be actioned within 60 days and outline what action can be taken if the time limit is exceeded.
37. **Timeframes for internal review:** The NDIS Act should be amended to require an internal review to be completed within 60 days of receiving the request and providing that a failure to take relevant action within the prescribed time limits gives rise to a participant's right to seek AAT review.
38. **Transitional provisions:** The NDIS Act should include transitional provisions following a review for the participants to seek alternative interim supports or adjust their services to ensure participants are not adversely affected immediately following a review decision.
39. **Reasons for internal review decisions:** The Participant Service Guarantee should provide clear guidance to the NDIA on providing internal review decisions that contain written reasons outlining their legislative and factual basis and acknowledge that all information provided by the participant or prospective participant has been considered by the decision maker.
40. **Clarify the AAT's jurisdiction:** The NDIS Act should be amended to clarify the scope of the AAT's jurisdiction once a plan has been replaced to determine the statement of participant supports and ensure the AAT's decision is effective from an earlier date as determined by the AAT.

41. **Updated operational guidelines:** The NDIA's operational guidelines should be regularly reviewed to incorporate developments in case law and ensure their consistency with the legislative criteria under the NDIS Act.
42. **Transport guideline:** The NDIA's operational guideline on transport should be updated to give effect to the principle of fully funding support in the Federal Court decision in *McGarrigle v National Disability Insurance Agency* [2017] FCA 208.
43. **COAG agreed 2015 amendments:** The NDIS Act should be amended to incorporate the COAG agreed amendments from the 2015 NDIS Act Review, subject to further updates and amendments recommended in this submission.
44. **Timeframe for implementing AAT orders:** The Participant Service Guarantee should include a timeframe for implementing AAT orders within seven days.
45. **Reimbursements for participants:** The NDIS Act should be amended to provide that where a decision is made that a support was a reasonable and necessary support and that support was provided at a cost to a participant, that amount is to be reimbursed to the participant.
46. **Compensation for participants:** The NDIA should be subject to the Commonwealth scheme for compensation for detriment caused by defective administration and the act of grace provisions in section 65 of the *Public Governance, Performance and Accountability Act 2013* (Cth).

## Annexure A: List of recommendations

### Creating a Participant Service Guarantee that makes genuine improvements to the NDIS

1. **Timeframes:** The Participant Service Guarantee should introduce the following timeframes:
  - a. In relation to an access request, if the participant has not provided requested information within 28 days, the NDIA supports the participant to obtain the requested information within 28 days.
  - b. Once the NDIA has obtained appropriate information, access request decisions are made in 28 days.
  - c. Participants are offered a planning meeting within 14 days of receiving their access met decision.
  - d. A NDIS plan for a child assessed as eligible for early intervention support is approved within 28 days of the access decision.
  - e. First plan approvals take less than 28 days after their access decision.
  - f. Plans are approved within 28 days of their final planning meeting, following the provision of all necessary evidence.
  - g. If the participant has not provided necessary evidence within 28 days, the NDIA should support the participant or consult directly with identified service providers to obtain all necessary evidence within 28 days.
  - h. Plan amendments are determined within 14 days of receiving the request.
  - i. Plans involving specialist disability accommodation, home modifications or assistive technology requests are made within 28 days of the information being provided.
  - j. Participants who request an internal review of a decision are contacted within 14 days of the request.
  - k. An internal review of a decision is completed within 60 days of receiving the request.
  - l. In urgent cases, the NDIA cooperates with relevant government and support agencies to streamline access to the NDIA to assess eligibility and approve a plan within 28 days.
  - m. AAT orders are implemented within seven days.
2. **A “Responsive” standard:** The Participant Service Guarantee should include a “Responsive” service standard which requires decision makers and planners to take urgent action where there is a risk of serious harm if NDIS supports are not available.
3. **Inclusive and culturally safe:** The Participant Service Guarantee should require the NDIA to provide inclusive and culturally safe planning and services to specialised groups, including CALD, LGBTQIA+ and Aboriginal and Torres Strait Islander people.
4. **Culturally safe communication with Aboriginal and Torres Strait Islander people and communities:** The Participant Service Guarantee should require all

communication with Aboriginal and Torres Strait Islander people to be culturally accessible through training, engagement and capacity building.

5. **Referrals to disability advocates and legal services:** The Participant Service Guarantee should set out an early referral system and requires planners, Local Area Coordinators and NDIA staff to make appropriate referrals to disability advocates or legal advice for support.<sup>50</sup>
6. **Urgent cases and serious harm:** The Participant Service Guarantee should require the NDIA to be responsive in time-critical cases where urgent intervention is needed to prevent the risk of serious harm, with a statutory timeframe of 28 days.
7. **Justice Liaison Officers:** The Participant Service Guarantee should set out minimum standards for the operation of Justice Liaison Officers to play an urgent intervention, escalation and coordination role between the NDIS, justice and mainstream service systems.
8. **Service safety net:** The NDIS Act and Participant Service Guarantee should introduce a service safety net that catches people with complex needs when the NDIS market fails, including an enforceable obligation to ensure the participant receives their funded supports and clear responsibility for coordinating, funding and providing services in these situations.
9. **An “Accountable” standard:** The Participant Service Guarantee should include an “Accountable” standard which ensures there are avenues to hold the NDIA to account for breaches of service standards.
10. **Complaints and escalation:** The NDIS Act should include a complaints mechanism for individuals to make complaints about a breach of the Participant Service Guarantee, and to escalate disputes to an internal review where a complaint is not resolved in a timely or satisfactory manner.
11. **Reporting and a five-year review:** The NDIS Act require the NDIA to provide annual reports evaluating the operation of the Participant Service Guarantee, with a scheduled legislative review of the effectiveness of the Guarantee in five years.

## Improving access and supporting eligibility

12. **Outreach, education and engagement:** The Participant Service Guarantee should require the NDIA to engage in education, outreach and engagement activities to support access through improving awareness of the NDIS and how and why to access it.

---

<sup>50</sup> Such an undertaking would give effect to general principles underlying the NDIS Act, specifically sub-section 4(13) of the NDIS Act, which provides:

*The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:*

- (a) promoting their independence and social and economic participation; and*
- (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and*
- (c) maximising independent lifestyles of people with disability and their full inclusion in the community.*



13. **Assistance with access requests:** The Participant Service Guarantee should require the NDIA to provide accessible, timely practical assistance for people completing the access request including more specific guidance accompanying the access request forms and requests for supporting evidence.
14. **Requests for further information:** The Participant Service Guarantee should ensure that requests for further information are only made when strictly necessary to obtain information required to establish the eligibility criteria under the NDIS Act.
15. **Facilitating access and assistance with reports:** The Participant Service Guarantee should facilitate access to the NDIS by helping people to provide evidence of their disability, including contacting treating health practitioners or other support people provided the person consents, and including criteria for when funding will be provided for necessary reports.
16. **Reasons for refusing access:** The NDIA should ensure that letters refusing an access request provide a person with reasons for the decision, refer to the evidence considered in making the decision, provide information on all their options, and provide information on disability advocates and legal advice.

### Creating a plan that sets a person up to meet their goals

17. **Timeframe for early childhood intervention:** The NDIS Act should be amended to ensure that a NDIS plan for a child assessed as eligible for early intervention support is created within 28 days of the access decision.
18. **Draft NDIS plans and reasons:** The NDIS Act should require that a planner provide a proposed NDIS plan with reasons for decision-making to the participant and their nominated support people and allow for discussion of the NDIS plan before it is finalised.
19. **Skilled planners:** The Participant Service Guarantee should ensure that planners receive adequate training and guidance to ensure that people receive adequate plans individually tailored to support their needs and achieve their goals.
20. **Supported Independent Living prices:** The NDIA should ensure participants understand and have access to information about what services, activities and tasks are included under Supported Independent Living funding in their NDIS plan.
21. **Requests for home modifications, assistive technology and specialist disability accommodation:** The NDIS Act should be amended to establish a clear and responsive approach for the NDIA to consider requests for home modifications, assistive technology items and specialist disability accommodation. Decisions about home modifications, assistive technology items and specialist disability accommodation should be included as specific 'reviewable decisions' in section 99 of the NDIS Act.
22. **Timeframe after a quote provided:** The NDIS Act should require the NDIA to make a decision about a request within 28 days after a quote is provided, if the plan provided for a support to be funded subject to a quoting process, and allowing an internal review of a decision if the timeframe is not complied with.

23. **Remove references to 'primary disability':** The NDIS guidelines, forms and practice should be changed to no longer rely on the concept of a person's 'primary disability'.
24. **Typical support packages:** The Participant Service Guarantee should ensure that the NDIA does not misuse 'typical support packages' to create NDIS plans which are not person-centred or tailored for an individual's goals.

### Making sure people can use their plan

25. **Skilled and ongoing support coordination:** The "Connected" service standards in the Participant Service Guarantee should recognise that skilled and experienced support coordinators must play a systematic and ongoing role for people with complex needs to problem-solve issues, navigate systems and think creatively about supports.
26. **Guidance about using a plan:** The Participant Service Guarantee should ensure that participants and their nominated support people are provided with adequate and accessible information about how to use their NDIS plan, including guidance, detailed information about the implications of self-management, plan management and agency management of support categories in their NDIS plans.
27. **Rural, regional and remote services:** The NDIS Act and operational guidelines should make changes to pricing in relation to travel for providers and participants and directly purchase services on behalf of participants if needed to ensure the promise of the NDIS can be fulfilled outside cities.

### Ensuring clear, accessible and efficient reassessment and review processes

28. **Clear terminology regarding reassessments and reviews:** The NDIA Act should be amended to clarify the differences between a scheduled plan reassessment, an unscheduled plan reassessment and an internal review. Following changes to terminology, new review and assessment forms should be created that clearly distinguish between the different processes.
29. **Role for support coordinators in scheduled plan reassessments:** The NDIA should provide adequate funding for support coordinators to support participants to meaningfully engage in scheduled plan reassessments.
30. **Communication and support in the reassessment process:** The NDIS Act should require a person conducting a scheduled or unscheduled plan reassessment to communicate with the participant before completing the reassessment, and the Participant Service Guarantee should require a person conducting a reassessment to provide support and assistance to participants to obtain evidence in relation to a support.
31. **Maintaining service levels during the review process:** The NDIS Act should provide that a person maintains their current level of services between when a review date passes and the review is completed and the plan is replaced.

32. **Access to supports pending internal review or AAT appeals:** We recommend that the NDIS Act and Participant Service Guarantee should allow for payment for supports pending an internal review or AAT appeals.

### Allowing for quick, accessible, reviewable amendment of plans

33. **Amendment power:** Subject to further consultation on its form and proposed operation, the NDIS Act should include a plan amendment power which is prompt, clear and easy to access to increase or adapt supports for participants but which does not result in a participant being disadvantaged or having their supports reduced, and can be subject to effective and timely merits review.

### Appealing and resolving disputes quickly, easily and fairly

34. **Access to merits review of NDIA decisions:** The Participant Service Guarantee should: (a) recognise the right to internal review and AAT review of all reviewable decisions and undertake to support and facilitate access to these review processes; and (b) ensure that any review process will be conducted with a view to preserving a person's right to AAT review.
35. **Avoiding confusion between reassessment and review:** The NDIS Act should be amended to clarify the difference between reassessment and review, and require that any request for review made within three months of a statement of participant supports be received be treated as a request for internal review.
36. **Communication about internal review:** The NDIS Act and the Participant Service Guarantee should require decision makers to confirm in writing that a person's internal review request has been received within 14 days of receiving the request, inform participants that their request will be actioned within 60 days and outline what action can be taken if the time limit is exceeded.
37. **Timeframes for internal review:** The NDIS Act should be amended to require an internal review to be completed within 60 days of receiving the request and providing that a failure to take relevant action within the prescribed time limits gives rise to a participant's right to seek AAT review.
38. **Transitional provisions:** The NDIS Act should include transitional provisions following a review for the participants to seek alternative interim supports or adjust their services to ensure participants are not adversely affected immediately following a review decision.
39. **Reasons for internal review decisions:** The Participant Service Guarantee should provide clear guidance to the NDIA on providing internal review decisions that contain written reasons outlining their legislative and factual basis and acknowledge that all information provided by the participant or prospective participant has been considered by the decision maker.
40. **Clarify the AAT's jurisdiction:** The NDIS Act should be amended to clarify the scope of the AAT's jurisdiction once a plan has been replaced to determine the statement

of participant supports and ensure the AAT's decision is effective from an earlier date as determined by the AAT.

41. **Updated operational guidelines:** The NDIA's operational guidelines should be regularly reviewed to incorporate developments in case law and ensure their consistency with the legislative criteria under the NDIS Act.
42. **Transport guideline:** The NDIA's operational guideline on transport should be updated to give effect to the principle of fully funding support in the Federal Court decision in *McGarrigle v National Disability Insurance Agency* [2017] FCA 208.
43. **COAG agreed 2015 amendments:** The NDIS Act should be amended to incorporate the COAG agreed amendments from the 2015 NDIS Act Review, subject to further updates and amendments recommended in this submission.
44. **Timeframe for implementing AAT orders:** The Participant Service Guarantee should include a timeframe for implementing AAT orders within seven days.
45. **Reimbursements for participants:** The NDIS Act should be amended to provide that where a decision is made that a support was a reasonable and necessary support and that support was provided at a cost to a participant, that amount is to be reimbursed to the participant.
46. **Compensation for participants:** The NDIA should be subject to the Commonwealth scheme for compensation for detriment caused by defective administration and the act of grace provisions in section 65 of the *Public Governance, Performance and Accountability Act 2013* (Cth).