

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL  
DISABILITY INSURANCE SCHEME AND THE PROVISION  
OF DISABILITY SERVICES IN NEW SOUTH WALES**

**Organisation:** Legal Aid NSW  
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## Inquiry into the implementation of the NDIS and the provision of disability services in NSW

Legal Aid NSW submission to  
Portfolio Committee No 2 Health  
and Community Services

*September 2018*

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## About Legal Aid NSW

The Legal Aid Commission of New South Wales (**Legal Aid NSW**) is an independent statutory body established under the *Legal Aid Commission Act 1979* (NSW). We provide legal services across New South Wales through a state-wide network of 24 offices and 221 regular outreach locations, with a particular focus on the needs of people who are socially and economically disadvantaged.

We assist with legal problems through a comprehensive suite of services across criminal, family and civil law. Our services range from legal information, education, advice, minor assistance, dispute resolution and duty services, through to an extensive litigation practice. We work in partnership with private lawyers who receive funding from Legal Aid NSW to represent legally aided clients.

We also work in close partnership with LawAccess NSW, community legal centres, the Aboriginal Legal Service (NSW/ACT) Limited and pro bono legal services. Our community partnerships include 29 Women's Domestic Violence Court Advocacy Services.

Legal Aid NSW is well placed to identify challenges that vulnerable people are facing in accessing the National Disability Insurance Scheme (**NDIS**) and

implementing NDIS plans. We receive federal funding to represent clients in appeals to the Administrative Appeals Tribunal (**AAT**) against decisions of the National Disability Insurance Agency (**NDIA**) that raise issues that are "complex or novel".

A significant proportion of our clients across all our practice areas have a disability.<sup>1</sup> We also offer a number of specialist services, which have contributed insights to our submission around the engagement of their clients with the NDIS. These services include the Mental Health Advocacy Service (**MHAS**), the Client Assessment and Referral Unit (**CARS**), the Family Law Early Intervention Unit, the Children's Civil Law Service, and the Prisoners Legal Service.

Legal Aid NSW welcomes the opportunity to make a submission to the Legislative Council's Inquiry into the implementation of the NDIS and the provision of disability services in NSW. Should you require any further information, please contact:

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<sup>1</sup> For example, from August 2017 to July 2018, 20.3% of all grants of legal aid for casework were to clients who identified as having a disability.

## Introduction

The introduction of the NDIS has set high expectations for improvement in supports and services for people with disability. The objects of the *National Disability Insurance Scheme Act 2013* (Cth) (**NDIS Act**) include giving effect to Australian's obligations under the Convention on the Rights of Persons with Disabilities.<sup>2</sup> The general principles contained in section 4 of the NDIS Act underline the rights-based approach that has been adopted for the NDIS. Those principles emphasise the agency of people with disability, their right to be live free from abuse, neglect and exploitation, their right to privacy and dignity and the role of advocacy in representing the interests of people with disability.<sup>3</sup>

Legal Aid NSW fully supports these principles and objects. We also acknowledge that the introduction of the NDIS provides opportunities to improve disability services and increase choice and control for people with disability. However, we are concerned that these goals are not being fully realised for some of our clients, due to a range of factors that have arisen following the implementation of the NDIS.

Those factors include:

- insufficient independent advocacy services for people with complex needs, including people with cognitive impairment, to help them access and navigate the NDIS
- barriers to accessing the NDIS and effective NDIS planning for people with complex needs
- challenges accessing adequate NDIS funded supports that are sufficiently coordinated with mainstream service systems
- thin or inadequate markets for services for people with complex needs, particularly for the provision of specialist disability accommodation (**SDA**)
- delays in reviews and withdrawal of supports when plans are under review, and
- delays and other issues in appeals to the AAT from NDIA decisions.

Our submission is based on the experiences of Legal Aid NSW clients engaging with the NDIS. Since the introduction of the NDIS across NSW, we have identified challenges experienced by some of our most vulnerable clients, such as children in out of home care (**OOHC**) and people with multiple diagnoses who are in contact with the criminal justice system, in gaining access to NDIS funded supports. The vulnerability of these clients is often heightened because of inadequate family and social supports, and their need for assistance with decision-making. While the experiences described in these case studies may not reflect the experiences of all participants in the NDIS, they illustrate the particular

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<sup>2</sup> Section 3(1)(a).

<sup>3</sup> This list does not reflect all of the General Principles that are contained in section 4.

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challenges faced by Legal Aid NSW clients, who will typically have multiple and complex needs in relation to the Scheme.

The structure of our submission reflects the journey that our clients take as they seek access to the NDIS, engage in NDIS planning, receive NDIS funded services and seek review of NDIA decisions. Through case studies drawn from our advice and casework services, our submission explores the challenges experienced by our clients as they navigate the NDIS system to:

- access the NDIS
- obtain a NDIS plan that will meet their needs and goals
- receive adequate supports and services
- seek review of NDIS plans, and
- appeal decisions of the NDIA about their plan.

The case studies have been de-identified to protect the privacy of our clients. For this reason, the case studies do not identify whether the client is Indigenous, has a particular racial or ethnic background, or whether the Public Guardian has decision making responsibility for the client. However, many of our clients facing challenges in connection with the NDIS are Indigenous, and the Public Guardian has decision making responsibility for a number of them, particularly for clients with complex needs who live in or need SDA. A significant number of our clients affected by the transition to the NDIS have cognitive impairment that limits their capacity to give consent to share their personal information. This means that many details cannot be provided in the case studies in this submission due to a risk they may be identified.

We understand that the issues highlighted in our submission are occurring during a period of transition from state based disability services to the full implementation of the NDIS in NSW, and that this might account for some of the service gaps that we identify in this submission.

Legal Aid NSW also acknowledges that the NDIA and NSW Government are working on a number of initiatives to address some of the issues that we highlight in our submission, including work by the NDIA to improve pathways to the NDIS for people with complex needs and by the NSW Government to ensure that mainstream services are inclusive of people with a disability. We believe that there needs to be a sustained effort, as well as additional services for some people, for these issues to be addressed.

Legal Aid NSW is committed to working with the NSW Government and the NDIA to ensure that these issues are addressed, and that the NDIS realises its goals of choice and control for all people with disability.

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## Challenges accessing the NDIS (TOR (a) (b) (c) and (i))

Legal Aid NSW acts for a number of clients who have faced challenges in accessing the NDIS. Barriers to access include:

- insufficient advocacy and support services for people who need help making an NDIS access request
- a lack of adequate planning for NDIS access when children are transitioning from OOHC, and
- difficulties faced by people with disabilities in prison accessing the NDIS.

These barriers are discussed further below.

### A significant service gap: insufficient advocacy and support for people trying to access the NDIS

In many cases, insufficient available advocacy services means that Legal Aid NSW is required to help clients apply for access, and navigate and overcome complexities in the application process. While we are able to help some of our clients in this way, it is likely that there are many vulnerable people who have no such support or advocacy, and are therefore unable to access the help they need through the NDIS. This can be seen in the case of Jodie.

#### **Case Study: Jodie**

Jodie is a 24-year-old woman with an intellectual disability and brain injury. Jodie lives with her mother who speaks very little English and is herself cognitively impaired. Jodie struggles with complex communication. Jodie was referred to Legal Aid NSW for assistance with her Disability Support Pension. We conducted a Legal Health Check, and advised Jodie that she was eligible for the NDIS.

Jodie was unable to fill in the necessary paperwork to apply for NDIS access without assistance. However, when we tried to refer Jodie to an organisation that could help her make an access request, it became clear that no such assistance was available. Support could only be offered *after* Jodie became a participant, not before. We spoke to several organisations, who agreed that there was a significant service gap in relation to clients who are unable to advocate for themselves or complete the necessary paperwork to apply for access.

Legal Aid NSW contacted the NDIS Local Area Coordinator (**LAC**) for assistance, however, the case worker from the LAC had never previously completed an application for access and was unable to provide guidance.

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In the end, Legal Aid NSW helped Jodie complete the access request form and submit the form and supporting material to the NDIA. Without our assistance, Jodie would not have been able to access the NDIS, despite her clear need for support.

Jodie's case highlights why people with complex needs require independent advocacy to gain access to the NDIS. Without that assistance, they may not be able to navigate the system, gather necessary evidence, and make an access application. People who may require such assistance include those with cognitive impairment, multiple diagnoses, substance abuse issues, or who are experiencing social isolation.

Legal Aid NSW supports the recent proposal of the NSW Law Reform Commission for a Public Advocate with new advocacy and investigative functions, including seeking help for people who need decision-making assistance from government agencies (including the NDIA), institutions, welfare organisations and service providers, and negotiating on their behalf to resolve issues.<sup>4</sup> The introduction of a Public Advocate could potentially meet some of the advocacy needs in this area.

We also welcome the recent announcement of the NSW Government of funding for disability advocacy organisations until 2020, to support the transition to the NDIS. However, we believe that the promise of the NDIS cannot be fully realised without a sustained commitment to fund advocacy services to meet the needs of vulnerable people who lack the capacity to advocate on their own behalf, both with the NDIA and with mainstream systems. The NDIS is a complex legislative and administrative scheme, and some people with disability need independent and client-centred advocacy services to ensure they can navigate the scheme with success. While the NDIA funds support for people to apply to the NDIA through the Information, Linkages and Capacity Building (ILC) programme, such support does not extend to individual or systemic advocacy.<sup>5</sup> Nor is that role fulfilled by the Scheme's Local Area Coordinators or by Legal Aid NSW. We are not directly funded to assist people to access the NDIA, but would welcome funding to do so.

In addition to independent advocacy, we believe that the NDIA could provide specifically targeted assistance to people who are likely to face challenges in gathering the information required to support an access request. The NDIS Act provides the NDIA with the capacity to provide such assistance:

- Section 6 provides that the NDIA has a role to 'provide support and assistance (including financial assistance) to prospective participants and participants in relation to doing things or meeting obligations under, or for the purposes of this Act.'

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<sup>4</sup> NSW Law Reform Commission *Report 145 Review of the Guardianship Act* May 2018 Recommendation 13.1.

<sup>5</sup> The ILC Commissioning Framework states that "We will not fund individual or systemic advocacy in ILC (Page 21).



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- Section 26 gives the Chief Executive Officer (**CEO**) the power to request a prospective participant to undergo a medical, psychiatric or other examination. This provision could be used to help prospective participants who do not have the means or opportunity to undergo assessments for the purpose of accessing the NDIS.

We suggest that the NDIA provide further guidance and additional proactive assistance to advocates and LACs to assist prospective participants to undergo relevant assessments to support an access application.

### Children at risk: inadequate planning for children leaving care

We are concerned that children in OOHC may be missing out on supports under the NDIS. The fragmentation in care received by such children means that there is often, in our experience, a lack of clear responsibility for pursuing NDIS access on a child's behalf. This was the case for Elijah:

#### ***Case Study: Elijah***

Elijah has a mild intellectual disability and a congenital physical condition. He faces challenges due to trauma he experienced as a child. He does not have adequate living skills and is having ongoing contact with the criminal justice system. He was in OOHC until he turned 18 years.

His intellectual disability was identified at age 12 when his case was managed by a non-government organisation. However, information regarding his intellectual disability was not communicated to FACS. As a consequence, this disability was not noted in his leaving care plan. The plan did refer to Elijah's physical disability. Elijah was very transient during his last few years in care and his whereabouts were often unknown.

After Elijah left care, and while he was in custody, Juvenile Justice (at Legal Aid NSW's request), ascertained that no NDIS access application had ever been made for Elijah. Legal Aid NSW worked with Juvenile Justice to gather information in support of an application, however the application was not successful because the evidence provided did not show that his intellectual disability was current or ongoing, and did not outline the impact of his physical disability on his ability to carry out day to day activities. As is often the case, it was difficult to obtain sufficient evidence while Elijah was in custody, so his NDIS access request could not be progressed.

Elijah spent a number of months in adult custody serving a sentence. Following his release from prison, Legal Aid NSW now intends to seek Aftercare funding from FACS to fund an adaptive assessment to support his NDIS application.

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Elijah's case demonstrates how better planning while a child is in care might avoid later difficulties accessing the NDIS. In Elijah's case, FACS did not have a full picture of his disability, and no one responsible for his care took the initiative to make an NDIS access request on his behalf. Assessments and information that may have readily been available in the community could not be accessed while Elijah was in custody. Once a person is in custody, it is difficult to establish how a disability impacts their ability to undertake day-to-day activities which is a requirement to obtain access to the NDIS.<sup>6</sup> Despite having long-standing disabilities, Elijah is still waiting to access the NDIS.

Children in OOHC may move between temporary care arrangements as well as be case managed by FACS and non-government organisations. They also transition from temporary care to a permanent care arrangement. This creates a number of opportunities for information about a child's disability to be lost or overlooked, and creates confusion about who should be responsible for making an access request to the NDIS. The risk that an access request is not made or overlooked is heightened for older children in OOHC who are transient or disengaged from their caseworker. The lack of coordination and information sharing between care providers and FACS that occurred in Elijah's case meant that crucial information about his disability was not part of his leaving care plan. Legal Aid NSW is not aware of the extent of this issue across the sector. However, we are concerned that without such coordination and information-sharing, there is an increased risk that an application for NDIS access may not be made before a child transitions from temporary care arrangements to permanent arrangements or to independence.

If an access application to the NDIS is not made by FACS or the NGO with casework responsibility for the child, this responsibility may then shift to family carers, such as grandparents, who may struggle with making an application for access, particularly if they do not have the required information to make an application.

We acknowledge that FACS is working to improve the capacity of case managers to understand and assist children in OOHC to obtain access to the NDIS, and to ensure that NDIS issues are addressed in leaving care plans. In order to enhance these efforts we suggest that FACS consider better education and support for caseworkers to make NDIS access requests for eligible children with a disability who are in OOHC. If a young person transitions from OOHC after turning 18 years, without arrangements being made for access to the NDIS, we suggest that FACS or the NGO responsible for case management for the young person remain responsible for ensuring that the young person has adequate support and information required to make an access application and negotiate a plan (if eligible) until the young person is 25 years old. This would be consistent with the age that a young person can access leaving care entitlements in their leaving care package.

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<sup>6</sup> To meet the access requirements for the NDIS a person must have a disability attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or one or more impairments attributable to a psychiatric condition that is/are permanent or likely to be permanent and that result in a substantially reduced functional capacity in the areas of: communication, social interaction, learning, mobility, self-care or self-management: *National Disability Insurance Scheme Act 2013* (Cth) sections 21 and 24.

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FACS might also consider ways to improve information sharing and coordination with NGOs who manage OOHC, so as to ensure that all eligible children with disability in OOHC can gain access to the NDIS.

### Transitioning without support: access difficulties for prisoners

People with disability are at particular risk when they are in prison. For example, we know that prison can have serious detrimental consequences for people with cognitive impairment, including:

- entrenchment in a culture of criminality because of a desire to be accepted by peers
- vulnerability to assault and mistreatment
- significant trauma experienced by the use of segregation and isolation as behaviour management tools, and
- post-release readjustment problems because of impaired adaptive skills.<sup>7</sup>

In our experience, these problems can be exacerbated further by failures to gain access to the NDIS. For example, eligible people with disability who are released without an adequate NDIS plan in place may find themselves homeless, and without the support they need to transition to and live successfully in the community. This can lead to increased interaction with the criminal justice system, and repeated incarceration of extremely vulnerable individuals.

Difficulties with gaining access to the NDIS for eligible prisoners are demonstrated by the case of Fred:

#### **Case Study: Fred**

Fred has a cognitive impairment, schizophrenia and substance abuse issues. Following his arrest, Fred was remanded in custody, partly because of the lack of appropriate alternative accommodation. Some of his time in prison was spent in a mental health unit. He spent 20 months on remand before the charges against him were withdrawn because he was unfit to plead.

Because of the complexity of Fred's impairments, and his serious mental illness, the full extent of his disability was not diagnosed while he was in custody. He was not provided with any support to make an NDIS access request. As a result, he was released without any disability supports or accommodation in place.

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<sup>7</sup> Baldry E., Dowse L. & Clarence M. (2012) *People with intellectual and other cognitive disability in the criminal justice system*. Sydney, University of NSW 4, 34.

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In the following case, Michael did obtain access to the NDIS while in prison. However we believe that the support provided by Legal Aid NSW in making the application was an important factor in him being able to do so.

### ***Case Study: Michael***

Michael is a young man who is in custody after being charged with offences and breaching an Apprehended Violence Order. Michael has a significant intellectual disability that is compounded by the impact of childhood abuse and substance abuse. He has previously been charged with offences and discharged under section 32 of the *Mental Health (Forensic Provisions) Act (MHFP Act)*.

Michael does not have the capacity to advocate for his own needs, and has no friends or family who can advocate for him. He has been homeless for significant periods.

Michael was referred to the Client Assessment and Referral Service (**CARS**) within Legal Aid NSW because he needed accommodation after leaving prison.

Prior to entering prison Michael had not requested access to the NDIS. Corrective Services NSW and CARS facilitated Michael's NDIS access request. It took six months for Michael's access request to be determined by the NDIS, and a further three months for an NDIA planner to meet with Michael. CARS has monitored Michael's request and provided information to the NDIA as required.

CARS has ongoing concerns about the adequacy of supports that will be provided under Michael's plan, in particular, the inappropriateness of group housing given the circumstances of Michael's childhood trauma. If Michael does not obtain funding for supported independent living (**SIL**), it is likely he will become homeless again on leaving prison.

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People who are in prison face a number of barriers in gaining access to the NDIS, including a lack of advocacy services, lack of requisite information or formal diagnosis to support an application to the NDIS, and lack of expertise within LACs in working with prisoners. In our experience, people with cognitive impairment who are on remand are most likely to face significant barriers in accessing the NDIS.

The NSW Operational Guidance for NSW Mainstream Services on the Interface with the National Disability Insurance Scheme (**NSW NDIS Operational Guidance for Mainstream Services**) indicates that:

*Adults and juvenile correctional centres will clinically assess whether an offender has a disability upon admission and determine whether they are an existing NDIS participant, where appropriate.<sup>8</sup>*

Consistent with that guideline, Corrective Services NSW's (**CSNSW**) policy on Inmates with disabilities provides for the screening and referral of inmates with disability to the Statewide Disability Service (**SDS**). Under the policy, SDS can provide assistance with accessing the NDIS.<sup>9</sup>

However, the above cases, and Legal Aid NSW's practice experience more generally, suggests that despite systematic screening for disability, subsequent access of prisoners (particularly remanded prisoners) to the NDIS is not always prioritised. It is also unclear whether, and how, inmates who may be eligible for the NDIS, or who have met the access requirements for the NDIS and are waiting to develop a plan, are prioritised by the NDIA. A further problem can arise if a family member or advocate arranges for a specialist to assess an inmate to support an NDIS access request. In our experience, visiting experts often have insufficient time with an inmate to undertake an assessment.

Addressing these issues is particularly important for inmates who are on remand or approaching parole, and who would be eligible for release if they had access to NDIS funded supports such as SDA and SIL.

For these individuals, delays in organising necessary eligibility assessments and planning are likely to increase the time that they spend in prison. Where inmates have not had a prior association with the former Ageing Disability and Home Care (**ADHC**) or who lack family support, the role of an independent advocate is crucial. We therefore suggest that advocacy services be adequately funded to encompass specialist expertise for people in secure environments, such as prisons and mental health facilities. These services should also have the capacity to actively follow up with potential NDIA participants/participants if their status changes, for example, if they enter or leave custody, and to obtain evidence on behalf of the prospective participant in support of an NDIS access request. The NDIA should also develop specialist services to help people in prisons and mental health facilities make access applications to the NDIS.

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<sup>8</sup> NSW Operational Guidance for NSW Mainstream Services on the Interface with the National Disability Insurance Scheme November 2016 page 67.

<sup>9</sup> Corrective Services NSW (2017) *Custodial Operations Policy and Procedures*, 6.9 Inmates with disabilities.

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Collecting and publishing data concerning the length of time between the initial disability screening of an inmate entering custody in NSW, their application to the NDIA and granting of their NDIA funding would assist in scoping the concerns identified by our experience and case studies.

## Restrictions on eligibility

In Legal Aid NSW's experience, there are a number of critical gaps in eligibility for the NDIS, which are resulting in people not receiving the supports they need to live in the community. In our view, the failure to fund supports for these clients may result in significant additional long-term costs, both to the NDIS and to the health system.

The following section sets out our concerns in relation to limited eligibility for:

- children with mental health impairments which have not been assessed as being permanent, and
- people who received supports under programs and funding streams that will cease as a result of full rollout of the NDIS.

## Limitations on early intervention for vulnerable children

Based on our casework experience, we have observed that the NDIA commonly refuses access to supports for children who have conditions such as attention deficit disorder or post-traumatic stress disorder, on the basis that the conditions are not permanent or likely to be permanent.

Understandably, there is a reluctance on the part of treating professionals to conclude that young people with these conditions are likely to have them permanently. However access to early intervention supports may result in an improvement to the child's condition, prevent the condition persisting permanently, and reduce the long-term costs to the scheme. In our view, the NDIA should take a more expansive view of eligibility for children with psychosocial disability.

## Gaps in services for some mental health consumers due to transition of Commonwealth funded mental health services into the NDIS

Legal Aid NSW is aware of a cohort of people who do not meet the access criteria for the NDIS but who still require services. Unfortunately, under the current arrangements, some clients have experienced a reduction in some of the supports they previously received.

These include mental health services provided by Partners in Recovery (**PIR**), or Personal Helpers and Mentors (**PHaMS**), which provided case management services. We understand that funding for these services has been extended by the Commonwealth Government to June 2019 to support the transition to the NDIS.

In our experience, some PIR and PHAMS clients with mental health conditions may not get access to the NDIS, as the NDIA does not consider their condition is permanent. Our

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concern is that some people with serious mental health conditions, who were successfully supported by PIR or PHaMS to remain living in the community, may not be able to successfully transition to the NDIS. This gap in services is also likely to have an impact on the demand for hospital and mental health services.

Another example concerns people with complex and multiple health conditions (such as osteoarthritis, back and knee conditions, fibromyalgia, chronic pain, obesity, and chronic obstructive pulmonary disease). Prior to NSW transitioning to the NDIS, many of these people were able to access assistance from NSW state-funded services for house cleaning, gardening and shopping, but now they do not meet the eligibility criteria for the NDIS. In our experience, the basis for the NDIA refusing a person access is that they suffer from 'medical conditions'. The NDIA argues that the health system is best placed to provide supports, rather than the NDIS. Without supports there is a risk that the health of people in this situation will worsen, and increase the burden on the health system.

## Problems with NDIS planning (TOR (a) (b) and (i))

Legal Aid NSW recognises and supports the positive steps that the NDIA is taking to improve participant pathways.

In our view, significant work still needs to be done to improve the timeliness and quality of planning, and communication between the NDIA and LACs. Particular attention should be given to improving planning processes for prisoners.

These issues are addressed in further detail below.

### Unacceptable planning delays for early intervention supports

For Legal Aid NSW clients, delays in planning continue to be a major area of concern in relation to the NDIS.

For example, some of our clients have experienced delays in planning when seeking support for children, in particular, those with autism. In one case, a family waited 10 months to obtain a plan with early intervention supports for their child. Unfortunately, the funding in the plan was inadequate, and the family had to go through a review process that took a further 8 months in order to obtain the right kind of support for their child. In at least three other cases, families waited between 9 and 10 months for a plan with funded supports after their child was accepted into the NDIS.

Some families can self-fund early intervention supports during these periods of delay, but other families cannot afford to do this. For these families, children miss out on time-sensitive early intervention supports. For families that have self-funded supports, the NDIA refuses to reimburse those costs when supports are finally approved for their child.



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## Problems with the quality of the planning process

For most participants a LAC is their main contact with the NDIS. In our experience, many clients who meet with an outsourced planner from a LAC are confused about how the information obtained by the LAC is then communicated to the NDIA, which then makes the decision about whether to approve funding in a plan. This lack of transparency, and planning at 'arm's length' from the participant, can give rise to diminished confidence in the system. This is particularly where people see inaccurate information in their plan, such as inaccurate 'goals and aspirations' which are meant to be nominated by the participant.

Some of our clients have reported that inadequate time is given to the planning conversation that leads to the creation of the NDIS plan. Nick's case study illustrates the impact that these problems have on the planning process.

### ***Case Study: Nick***

Nick has a cognitive impairment and is a participant in the NDIS. Due to his impairment he knew that he would find it difficult to answer questions on the spot during his NDIS planning meeting. Prior to the planning meeting he asked his LAC for information about the questions that he would be asked, and what information the LAC needed to gather for the planning meeting. However, the LAC refused to give him the information he requested. He said that the planning meeting was held very quickly, and as a result he could not fully participate in the process. The personal information and the goals contained in Nick's plan did not reflect his own experience or preferences. As a result, the funding for supports contained in his plan does not reflect his disability support needs.

The lack of independent advocacy services, which we have noted may limit initial access to the scheme, also has significant ramifications during the planning phase. Participants who are engaged in developing a NDIS plan are required to submit a significant amount of information regarding their support needs, which would be beyond the capacity of many people with cognitive impairment, or complex needs. Those who are unable to strongly advocate for the supports they need may end up with inadequate funding packages. People with no experience of disability supports, who were not previously connected with NSW funded disability supports, will also be disadvantaged in this process, because they often have limited knowledge of what supports are possible and available.

Matthew's case study demonstrates the consequences of lack of advocacy in the planning phase, and the barriers faced by people who are not literate but who are required to use the NDIS portal to manage their plan.



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### **Case Study: Matthew**

Matthew has a mild intellectual disability and has also been diagnosed with post-traumatic stress disorder.

After Matthew gained access to the NDIS he was not involved in a pre-plan meeting with NDIS; he does not understand his NDIS plan and does not know how to access his NDIS funds. Further, the plan does not take into account his accommodation or employment needs. He participates in a supported work program, but this is not linked to his NDIS plan. Matthew does not have the ability to coordinate his NDIS plan, is unable to source supports for himself and requires assistance to follow through and engage with supports. The plan directs him to access his NDIS funding by using an online portal and to contact the NDIS if he has any further enquiries. Matthew has limited literacy skills and does not understand how to access this assistance online.

### Additional planning difficulties for prisoners

Prisoners are particularly disadvantaged during the NDIS planning process. This is because, in our experience:

- LACs and/or NDIA planners are not able to carry out functional assessments for prisoners, which means that decisions about reasonable and necessary supports cannot be made. This can be particularly problematic for those inmates who have had no prior interaction with state disability agencies or who have not had a formal diagnosis prior to entering custody.
- The NSW NDIS Operational Guidance for Mainstream Services indicate that assistance with plan reviews will be provided six months prior to a person's earliest release date.<sup>10</sup> For many prisoners, there is only a short period between the imposition of a sentence and their final release date, once time spent on remand is taken into account. Forensic patients found not guilty on the grounds of mental illness may be particularly disadvantaged because they do not have a release date until the Mental Health Review Tribunal determines that they can be released.

These limitations on planning support for prisoners mean that it is often difficult or impossible to adequately plan for a prisoner's transition from custody. This is particularly problematic when a person requires accommodation supports to be in place before they can be released.

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<sup>10</sup> NSW Operational Guidance for NSW Mainstream Services on the Interface with the National Disability Insurance Scheme November 2016 page 69.

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The first three months following release from custody are a high-risk period for reoffending, homelessness and death.<sup>11</sup> Legal Aid NSW considers that much more needs to be done to ensure that prisoners who require disability supports have those supports in place before they are released, and that planning delays do not result in additional periods of incarceration. We suggest the NDIA and CSNSW work together to develop priority pathways for people in prison who require NDIS funded accommodation supports on release from prison. The NDIA and LACs should also develop expertise in planning for NDIS participants in prisons.

## Limits on supports and services (TOR (a) (b) (d) (e) (f) (i) and (j))

Legal Aid NSW clients who have obtained an approved NDIS plan have encountered a range of issues, which affect their ability to realise the benefits of the NDIS. The particular issues addressed in this submission relate to:

- inadequate funding of supports
- a lack of clarity around what activities are funded under a plan
- conflicts of interest where multiple supports are provided by the same service provider, and
- adequacy of supports for people in specialist disability accommodation

### Inadequate funding of supports

The NDIA has stated that no participant will be worse off under the NDIS.<sup>12</sup> However, some Legal Aid NSW clients have been adversely affected as a result of transitioning to the NDIS.

As we have noted throughout this submission, the lack of independent advocacy services means that the funded supports in an NDIS plan may be inadequate.

We regularly encounter clients who previously received a range of ADHC funded supports, such as day programs, weekend activities, and respite care, but whose NDIS package is insufficient to cover these supports. Participants have to choose what supports they will give up, and their quality of life is diminished as a result. Richard's case demonstrates this problem.

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<sup>11</sup> NSW Mental Health Commission, Submission to the NDIS Joint Standing Committee Inquiry into provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition (February 2017).

<sup>12</sup> For example, see Frequently Asked Questions at <http://ndismiway.org.au/ndis-frequently-asked-questions/>.

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### ***Case Study: Richard***

Richard is a 40 year old man who suffers from epilepsy, severe developmental delay and cerebral palsy. He has limited verbal capacities, needs help with all activities of daily life such as toileting, dressing and showering, and experiences regular seizures. He lives with his elderly parents in a rural location. He needs one on one support at all times.

Prior to the commencement of the NDIS, Richard attended a day program 5 days per week and respite every second weekend at a respite centre. This had been his routine for over 15 years. When he transitioned to the NDIS, his funding was insufficient to allow him to continue with these activities. The options for his elderly parents were to cut back on his day program (which was an important activity that Richard looked forward to), or to cut back on respite (which provided a great opportunity for Richard to be independent of his parents and gave his parents a chance to rest). The NDIA failed to give clear reasons as to why Richard should receive less supports and services under the NDIS than he previously did under state funded services.

While the problem of inadequate funding packages has been experienced by many NDIS participants Legal Aid NSW has contact with, we would like to specifically raise three scenarios where the impact of inadequate supports is particularly concerning.

#### *Coordination of supports for changes in accommodation*

In our experience people with complex needs are often only allocated a small number of support coordinator hours to assist with the initial planning and implementation of their NDIS plan. This limited allocation does not take into account additional coordination that may be required in the future. This is a particular issue when SDA arrangements break down and new accommodation needs to be arranged, such as where an SDA provider cannot provide adequate support for a participant's complex needs. We suggest that additional hours for support coordination should be allocated to clients on an urgent and ad-hoc basis where a participant is required to find new accommodation.

#### *Inadequate supports for people in contact with the criminal justice system*

NDIS packages that provide inadequate supports to people in contact with the criminal justice system or a history of offending can have a significant impact on the justice system. This is demonstrated by the cases of Geoff and Troy.

### ***Case Study: Geoff***

Geoff has an intellectual disability. He is an NDIS participant, however in the transition from ADHC to the NDIS, his funded support was reduced from intensive support, which

included specialist accommodation and 24 hour supervision, to one hour's support per day.

Geoff has been in and out of custody on numerous occasions. Because his NDIS plan does not fund supported accommodation, he has stayed in boarding houses and hotels when he has not been in custody. All of Geoff's treatment providers agree this is inappropriate and that Geoff requires a greater level of support. Without the intensive support he requires, Geoff continues to cycle in and out of prison.

### ***Case Study: Troy***

Troy is a young man with a significant cognitive impairment, mental ill health and substance abuse problems. Troy has high needs and is currently in an Additional Support Unit in prison.

Troy went into custody after being charged with offences. He does not have capacity to plead to the charges. The prosecution has agreed to support a bail application by Troy if suitable accommodation can be found, and Troy agrees to certain conditions.

SDS and Legal Aid NSW helped Troy access NDIS funding. A support coordinator started to work with Troy after he had been in custody for six months, but they were unable to find appropriate accommodation for him that met the approval of the NDIA. The NDIA has engaged a specialist support coordinator, but they have also been unable to identify suitable accommodation for Troy.

Although Troy has very high needs, his NDIS plan does not include adequate funding to meet his accommodation and support needs. . Legal Aid NSW is concerned that Troy's allocated funding is being exhausted by support coordination that is not meeting his needs, and that his support coordinators are not addressing the issue of the inadequacy of his plan. Legal Aid NSW is also concerned that poor communication between the NDIA planner and the support coordinators is contributing to delays in reaching a solution for Troy.

Until appropriate accommodation can be found, Troy remains in custody.

These cases highlight how vulnerable people can end up being held in custody, because alternative accommodation is not available in the market, or has not been adequately provided for in a participant's NDIS plan. The case of Troy also illustrates the need of people with complex needs for skilled support coordination.

This can have a significant impact on the justice system, both through the increased costs of incarceration, and through the increased workload on Legal Aid NSW practitioners, who

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find that they spend considerable time advocating on behalf of their clients with LACs, the NDIA and other service providers. Of greatest concern is the impact of incarceration on individuals who are inherently vulnerable.

### *Inadequate supports for children*

Legal Aid NSW is concerned that inadequate NDIA funding of supports for children with disability has created significant difficulties for some families, who have in turn sought support from FACS.

According to the NSW Operational Guidance for Mainstream Services, the NDIS is responsible for:

*support for children, young people, families and carers required as a direct result of the child's or parent's disability, including supports that enable families and carers to sustainably maintain their caring role.*<sup>13</sup>

The NDIS Applied Principles note that this support includes 'community participation, therapeutic and behavioural supports, additional respite, aids and equipment'. However, we understand from discussions with FACS that the NDIA assumes that a child with a disability will live with their family until they reach the age of 18 years. In circumstances where a child has complex needs and requires a high level of support, and it is not sustainable for the child to live in the family home, families have to seek support from FACS.

While we are not aware of the extent of this problem, we are aware of two cases where families have had to consider relinquishing their child to the care of the state under the *Children and Young Persons (Care and Protection) Act 1998 (CYPCP Act)* in order to obtain adequate supports for their child.

Orders under the CYPCP Act are generally made where there are concerns about the ability of the parents to provide adequate care for a child, and where a court is satisfied that the child is in need of care and protection. However, in the case of Rochelle below, section 38 of the CYPCP Act, which allows a court to make orders to give effect to a care plan without being satisfied that the child is in need of care and protection, was used to address inadequacies in NDIS funding for a child with a disability.

#### ***Case Study: Rochelle***

Rochelle is 16 years old and has a significant intellectual disability. She has been cared for by her parents for her entire life, spending some periods in respite care. Rochelle has an NDIS package, but it contains insufficient funding for respite care.

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<sup>13</sup> NSW Operational Guidance for NSW Mainstream Services on the Interface with the National Disability Insurance Scheme November 2016 page 34.

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Rochelle's parents sought assistance from FACS, as they were unable to care for her on a full time basis and also provide a safe environment for their other children. FACS supported Rochelle's family in requesting that the NDIA increase funding to cover the costs of respite care, but this was not successful. We understand that the NDIA considered that the funding was directed at child protection concerns, rather than disability concerns.

As a result, Rochelle's family felt they had no option but to relinquish their parental responsibility to FACS, in order to secure adequate accommodation support for Rochelle. FACS sought orders under section 38(3) of the CYPCP Act for parental responsibility to be allocated to the Minister, with her parents having unlimited access and engagement in Rochelle's life. The Children's Court made a direction for a child's representative to be appointed for Rochelle. The experience of going through the Children's Court process was traumatic for Rochelle's family because there were no child protection issues.

In the case study below, the parent, Trudi, was also advised by FACS to consider relinquishment. However as a result of effective advocacy, assistance was provided without any orders being sought or made under section 38 of the CYPCP Act.

#### ***Case Study: Trudi***

Trudi is the mother of three children: April, aged 12 who has a diagnosis of Asperger's Syndrome; David, aged 8 who has a diagnosis of autism and severe intellectual disability and is non-verbal; and the youngest, Ben. Trudi and her family were struggling to care for David as his behaviour has increasingly become more difficult to manage, to the point where he frequently hurts himself by slapping himself in the head and slamming himself on the ground. David also lashes out at those around him and is a danger to his family, particularly his siblings.

David transitioned to the NDIS at the end of 2015 and Trudi is receiving support from paid care workers in addition to informal supports from her mother and her husband. The coordinator of supports for David became concerned about the circumstances that Trudi and her family are living with at home with David. She made numerous reports to FACS concerning David as the situation became worse. In January 2018, when Trudi spoke to FACS, she was told that her case was a "low priority" as David is still living at home.

The difficulties with David reached a point where he was admitted to hospital to try to address his self-harming behaviour. When the hospital said that David could be released, Trudi could not be satisfied that her family or David would be safe with him back in the family home and she was forced to refuse to take David home. David was then released into voluntary full-time OOHC provided by a specialist accommodation service and funded through David's NDIS plan. However, there was only 4 weeks' worth

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of funding left to cover this arrangement. Trudi was struggling with the NDIS as she had been through a review the previous year which took 14 months and had not resolved her situation. She was told that FACS could only step in to help if Trudi “relinquished care of David”.

Trudi knew that she needed more support to manage the competing needs of her family. She thought that the best arrangement for her family would be to set up a second house where David could live and be cared for by Trudi and paid care workers. The only problem was that she could not afford to pay the mortgage on the family home as well as the rent for David’s accommodation, and she was told by the NDIA that they could not fund accommodation or pay rent for a second house for David.

Trudi approached a family lawyer from Legal Aid NSW. Trudi was very concerned at the prospect that she may have to give up care for David in order to obtain support. With Legal Aid NSW’s help, Trudi wrote to her federal and state Members of Parliament asking for the NDIS and FACS to work together to support Trudi’s family staying together, while also giving David the support he needs. As a result of this advocacy, the NDIA and FACS have worked out a funding arrangement to enable Trudi and David to live in a private (rented) residence separate to the family home. However, this arrangement is short-term and Trudi remains concerned about the future.

We understand from internal discussions with FACS that NSW and the NDIA have recently made an agreement that NSW will pay for ‘board and lodging’ for children who have a significant disability but who cannot live at home. It is hoped that this agreement may prevent relinquishment of parental responsibility in cases such as Trudi and Rochelle’s. Legal Aid NSW welcomes this development.

To address the above issues, we also suggest that the NDIA and FACS develop a clear mechanism for reviewing matters where a question is raised as to the ability of parents to maintain care of a child with a disability without additional supports. Such a mechanism could include expedited internal review.

We understand that the NDIA and FACS are working together to support family preservation and restoration in these circumstances, and that the intention is to develop an operational framework to formalise the mechanisms for doing this. This will be an important development in addressing the concerns raised above.

### Lack of clarity in NDIS plans

NDIS plans can be difficult to understand and they commonly use vague descriptions, such as ‘core supports’ to describe the supports that have been approved. In our experience, when participants seek further guidance about how they might use their funding they may either receive conflicting advice from the NDIA, or simply be advised that the funding can be used ‘flexibly’.



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While we support flexibility for participants, the lack of clarity around funded supports makes it difficult for participants to assess whether their package meets all of their reasonable and necessary supports. Participants encounter difficulties when they try to use their funding for certain activities, which they believe are funded, and are told that they are unable to do so. In these circumstances participants are forced to seek a review of their plan in order to gain sufficient guidance about how they may use the funding that has been approved. This can be seen in the case of Claire.

### **Case Study: Claire**

Claire is a 28 year old woman with severe autism spectrum disorder, anxiety, epilepsy and an intellectual disability. Under her previous package of funding from the ADHC, Claire was able to participate in social and economic activities that were important and of interest to her. Since becoming a NDIS participant, she has been told that she cannot use her NDIS funding to do the same activities. The restrictions on her choice impact on her mental health, increase her anxiety and make her feel more isolated. Claire tells us:

*“It has been very confusing with different information and messages [from the NDIA]. At the moment there is no middle ground. The NDIA say ‘you can use the funding for what we fund or you don’t use it at all.’....At the moment my current plan is not working. I am not happy with it, it doesn’t give me the flexibility, choice and control that I am looking for, everything is limited on what I can use my funding for, barriers and challenges are placed in front of me that is not allowing me to do what I did before transitioning to the NDIS.*

*I feel at the moment like the service providers are pushing me to the side and my power has been taken away from me. Instead of me being supported to achieve what I want to achieve and participate in the community in what interests me, it is like I have no choice. If it worked correctly and smoothly I should have been able to maintain the same economic participation in the community like what I did when I was state funded. Instead of everything transferring across smoothly I have gone from having a plan that is holistic with voice, choice and control to a plan that is not holistic, no voice, choice, control and no options to choose from. I have gone from a package with no barriers, challenges or restrictions put in front of me to a package with barriers, challenges and restrictions that doesn’t reflect my goals, passions, interests and aspirations”.*

We suggest that participants be given information in plain English and/or in a format appropriate to the particular communication needs of the participant clearly setting out what supports the NDIA accepts are reasonable and necessary and have been funded in the plan.



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## Conflicts of Interest

One of the strengths of the NDIS is that it provides funding for a range of different supports depending on the person's needs. However, for many of our clients, choice and control are undermined where the same service provides many or all of the funded supports. This issue is of particular concern for people with complex needs who live in SDA, where the participant does not have the capacity to engage alternative service providers and does not have access to independent advocacy. It is also a concern where the SDA service provider withdraws services with little or no notice to the participant, leaving the person with no support to find alternative accommodation.

The NDIS provides some broad rules around conflict of interest. However, they only apply where services provide plan management along with other supports. They do not cover the situation where a service provider provides a range of other services to a participant, such as SIL and SDA<sup>14</sup>.

Conflicts of interest also arise where a service provider that is providing supports, such as SIL and SDA, is a complainant in a criminal matter against the participant, or an employee of the service provider is a protected person in an Apprehended Violence Order against the participant. In our experience this commonly arises for participants who live in SDA who exhibit challenging behaviour arising from their disability.

To address conflicts of interest, we suggest that NDIS participants with a cognitive impairment should always be provided with a specialist support coordinator,<sup>15</sup> or have access to a specialist LAC. In our experience, providing intensive case management for people with disability who have complex needs is likely to result in positive legal and clinical outcomes, and we consider that providing NDIS participants with a cognitive impairment with specialist support coordination will also result in improved outcomes. We also suggest that support coordinators for people living in SDA should not be employed by the provider of SDA.

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<sup>14</sup> National Disability Insurance Scheme (Registered Providers of Supports) Rules 2013 and NDIS Operational Guidelines. Providers are required to have mechanisms in place for dealing with conflicts of interest, rule 3.15. The NDIA also offers a general 'NDIS and Conflict of Interest Policy and Procedures' template for service providers to use when registering for both plan management and other service provision.

<sup>15</sup> The NDIS funds capacity building (also known as support coordination) at three levels: support connection, coordination of supports and specialist support coordination. The highest level, specialist support coordination, is provided by a qualified and experienced practitioner such as a social worker or mental health nurse, to reduce complexity and barriers to services. A specialist support coordinator can also develop an intervention plan to be put in place by disability support workers: NDIS Price Guide Victoria, New South Wales, Queensland, Tasmania 1 July 2018 pages 44 to 47. <https://www.ndis.gov.au/providers/pricing-and-payment.html>.

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## Issues of concern in relation to Specialist Disability Accommodation

People who require SDA are some of the most vulnerable people in our society. Many of them have complex needs arising from the interplay of their disability with mental and physical health problems, the impact of childhood trauma, poverty, difficulty in accessing mainstream services, periods of homelessness and social isolation. They are also likely to engage in challenging behaviour and require specialist behavioural support, including support to reduce the risk of committing offences.

Legal Aid NSW has a number of concerns about the current operation of SDA, including:

- the failure of the market to provide appropriate accommodation for people with complex needs
- inadequate protections for SDA residents and
- the use of inappropriate behaviour management techniques by SDA providers.

### *SDA market failure for people with complex needs*

In our experience, the SDA market is struggling to provide sufficient, reliable and appropriate accommodation for people with complex needs, particularly those who have contact with the criminal justice system.

Compounding this problem is the lack of an SDA provider of last resort to step in when the market fails. These problems mean that our clients are more likely to become homeless, come into contact with the criminal justice system, and spend longer in prison than necessary.

The provision of adequate SDA to meet demand was acknowledged as a major challenge by the NDIA in its submission to the Inquiry by the Joint Standing Committee on the NDIS into market readiness for provision of services under the NDIS.<sup>16</sup> The NDIA also indicated in its submission that it would be developing a “Market Insight into SDA” in collaboration with other stakeholders, to be released in early 2018.<sup>17</sup> Legal Aid NSW also made a submission to that Inquiry in which we highlighted challenges for our clients in gaining access to SDA.<sup>18</sup>

In our view, the shortage of SDA is one of a number of contributing factors to clients spending significant periods of time in custody that requires an urgent response. As a starting point, and to clearly scope this problem, we suggest that the volume of NDIS participants who remain in custody because of a failure to secure disability services should be assessed by the NDIA as a matter of urgency.

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<sup>16</sup>[https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/MarketReadiness/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MarketReadiness/Submissions) at page 19.

<sup>17</sup> The NDIS website indicates that this work has not yet been released. We also note that this work will be directed at potential market providers of SDA.

<sup>18</sup> Legal Aid NSW submission to the Joint Standing Committee on the NDIS *Inquiry into market readiness for provision of services under the NDIS*  
[https://www.legalaid.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0003/28650/Sub-93.pdf](https://www.legalaid.nsw.gov.au/__data/assets/pdf_file/0003/28650/Sub-93.pdf)

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We are aware that the NDIA has recently taken steps to address crisis situations and maintain critical supports for NDIS participants whose supports have failed or been withdrawn. However, this response, which includes after-hours telephone assistance and access to a panel of providers, is currently only available to health and emergency services and Legal Aid NSW cannot access it for our clients. We suggest that this service be available more broadly.

Legal Aid NSW is also a referring agency to the Integrated Service Response, (**ISR**) a specialist short term service operated by the Ministry for Health for NDIS participants whose needs are not being met by services, which can assist with finding appropriate accommodation for NDIS participants with complex needs. While our experience to date has been positive, the assistance provided by the ISR is short term in nature, and does not include on-going case management.

In our view, neither of these crisis responses address the underlying issue of insufficient accommodation and ongoing holistic case management for NDIS participants with complex needs. Nor do these responses provide last resort accommodation where accommodation in the NDIS private market is unavailable or fails. We consider that there is a need for such support. Last resort accommodation should not be limited to people who are in crisis, but be available before the person reaches crisis point: that is, in cases where a service cannot meet the needs of a resident and there is an emerging risk that the service will be withdrawn. Further, we are concerned about the extent to which the NDIA has been able to provide last resort accommodation in NSW. This is based on our observations in a number of cases to date, and should be a concern for both federal and state governments.

#### *Improving protections for SDA residents*

The transition of the SDA sector to market based individual service provision has highlighted the need for improved legal protections for SDA residents.

People with complex needs, particularly those with a cognitive or mental health impairment, may not have capacity to negotiate an SDA agreement with a service provider without assistance from an advocate.

SDA residents also have limited legal remedies for breach of an SDA agreement. They are also vulnerable to having their SDA agreement terminated, as in the case of Maxine:

#### ***Case Study: Maxine***

Legal Aid NSW assisted Maxine with some legal issues. She had a service agreement for SDA that provided for termination of the agreement after 28 days, but the notice period did not apply where “either party seriously breaches this Agreement.” Maxine, who is profoundly disabled and has challenging behaviours, was given the agreement for one year. The care provider said that they could provide the care that she needed but Maxine’s guardian became concerned about the measures that the service used to

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manage her behaviour, including calling the police. The service provider gave notice that they would no longer provide Maxine with accommodation services. Legal Aid NSW negotiated a short extension to the SDA agreement, after which she had to enter short-term accommodation which is having an adverse impact on her wellbeing.

The NDIA Terms of Business (**TOB**) for registered providers require that service agreements provide a minimum of 90 days' notice to vacate premises, unless a shorter term is necessary to address the risk of harm to the participant or others. The standard accommodation agreement provided by the NDIA requires only 30 days' notice if the provider considers a resident poses a serious risk of harm. In our experience, the 'risk of harm' term is often used as a basis for terminating agreements with short notice when residents display complex and challenging behaviour. This is an inappropriate response to such behaviours, when those behaviours (and the disabilities that underlie them) constitute the very basis for the person receiving SDA. Additional protections are required to ensure that participants receive the support they need to manage behaviour and remain in stable accommodation.

As in Maxine's case, it has been our experience that service providers do withdraw services within two years. It appears that providers are frequently confused about their obligations around termination of accommodation support.

Legal Aid NSW understands that the NSW Government is currently considering options for improving legislative protections for people living in group homes.<sup>19</sup> One of the options canvassed by the NSW Government has been for legislation that would permit termination of SDA agreements on 30 days' notice where the resident cannot be supported at the property without risk of harm to other residents or staff. We do not support that proposal because SDA providers are fully aware of the needs and any challenging behaviour of the client prior to entering into an agreement with a participant. External scrutiny of the decision to terminate a SDA agreement is desirable, and we suggest that a SDA service provider should be required to apply to the NSW Civil and Administrative Tribunal (**NCAT**) for termination of the agreement.

We are also concerned that some SDA service providers are seeking to include terms about the behaviour of a resident into SDA agreements. For example, a service provider may seek to include a term that the resident is not to intentionally damage property while living at the group home. Challenging behaviour should be managed by appropriate behaviour management approaches, not through punitive clauses in SDA agreements. Legal Aid NSW is also aware of cases where a participant's representative has objected to clauses of this nature, resulting in the service provider refusing to provide accommodation. We suggest that a standard SDA agreement be developed in

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<sup>19</sup> FACS released a *Technical Issues Paper Protections for Residents of Long Term Group Accommodation* in January 2018, which indicated that a further report on the consultation would be released later in 2018.

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consultation with disability advocates and other relevant stakeholders. The standard agreement should not permit the use of additional behaviour clauses.

*Inappropriate SDA provider responses to challenging behaviour*

Legal Aid NSW has repeatedly observed SDA providers taking a punitive approach towards a resident's challenging behaviour. In some cases, providers have openly expressed their view that the criminal justice system is a viable and effective response to challenging behaviour for people with a significant disability.

This type of approach is evident in the cases of Brett, Jason and Paul.

**Case Study: Brett**

Brett has an intellectual disability and schizophrenia. He has NDIS funded accommodation. He has a lengthy history of dismissal of charges under the MHFP Act. As such, he is well known to police and to services as at risk of prison.

Brett was charged with damaging property and released on bail, on condition that he live at one of the service provider's residential homes. Brett damaged property while at the home and was arrested and charged with a further offence. The Senior Manager of the service provider wrote to Legal Aid NSW "[recommending] that bail be declined" for the "safety of [the client] as well as the other residents".

At court, the service provider told Brett's Legal Aid NSW lawyer they would ask the court to refuse to give bail to Brett. Brett was refused bail because of the attitude of the service provider, and the lack of any alternative accommodation. The Magistrate requested that the service provider follow up alternative accommodation options within one week. This did not occur.

Several weeks later, Brett was granted conditional bail to reside at an alternative address under the care of another service provider.

Several days later Brett self-harmed and was found in possession of a lighter and a knife. The new service provider called the police, and Brett was charged with fresh offences and refused bail. The service provider wrote to the Court requesting that Brett stay in custody for at least 2 weeks to enable additional staff training, and the refinement of risk management strategies and support plans.

The Magistrate indicated on record that the court would have been prepared to continue bail but for this letter. The prosecution also indicated they would not oppose bail if Brett's accommodation could be confirmed. Several weeks passed until the service provider advised the court that necessary training and renovations were complete. Brett was then granted bail. Apart from a brief period, Brett had been remanded in custody for over two months.

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### ***Case Study: Jason***

Jason has an intellectual disability, mental health issues, and a history of childhood trauma and abuse. As a result, he exhibits challenging and occasionally violent behaviour.

Since he began living in SDA he has had regular contact with the criminal justice system. Following his interaction with the criminal justice system, service providers have withdrawn services from Jason on a number of occasions, resulting in him being unable to be bailed, and cycling in and out of prison. His SDA providers have used isolation and segregation to manage his behaviours.

On one occasion following Jason's arrest, his SDA provider requested that the court refuse bail, and that Jason be detained in prison until new accommodation was found for him. The Magistrate was reluctant to do so, but was left with no option when the service provider refused to provide support. On this occasion, Jason remained in custody for four weeks before alternative accommodation could be found.

On another occasion, after Jason damaged property during an incident at his home, his new SDA provider requested that Jason be detained in prison until his mental health condition had stabilised. Unsurprisingly, his condition deteriorated in prison. After significant effort on the part of justice agencies, Jason obtained a full psychiatric assessment and treatment plan and was released. On this occasion, Jason remained in custody for 2 months.

Shortly afterwards, Jason was involved in a further incident at the group home and was again arrested and remanded in custody. During this period in custody he has self-harmed and been the victim of assault.

The people involved in Jason's care should have used a therapeutic response to his behaviour, and developed positive behaviour support strategies to reduce the frequency and severity of his challenging behaviours. Instead, they have used isolation, exclusion from accommodation and police intervention as their first line of response. As a result, Jason has spent repeated periods in custody, and has suffered significant harm.

### ***Case Study: Paul***

Paul is a young man who suffers from significant physical and intellectual disabilities that make him extremely vulnerable and hypervigilant. He lives in 24 hour supported accommodation provided by a service provider that is funded from his NDIS package. He was in out of home care when he was a child.



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Paul was arrested in relation to an incident at his residence involving another co-resident. Paul was remanded in custody because there was no staff member from the service provider at court when his case was considered. Paul was granted bail seven days later but the alternative accommodation was deemed unsuitable almost immediately based on the client mix.

Paul was transferred to another residence run by a different service provider. Paul later attended the Local Court with a representative of the second provider who refused to provide Paul with ongoing assurances of accommodation unless further bail restrictions were imposed on Paul preventing him from participating in any form of gambling or threatening staff. The court declined to make these restrictions. This was conveyed to the service provider, along with concern that the service provider was seeking to coerce the court to impose what were essentially behaviour management conditions. Following a further incident involving threats towards staff, Paul was again arrested and charged. Paul was eventually granted bail back into the care of the same service provider.

Following a subsequent incident of behavioural disturbance whilst in the care of the second accommodation provider, Paul was again charged with further offences and arrested. He was released after a number of days back into the care of the same care provider. Legal Aid NSW was advised by Paul's mother that shortly prior to his release, he was assaulted by several inmates, requiring hospitalisation for injuries.

Prior to finalisation of his court matters, Paul was again arrested and charged. The service provider refused to allow him to return to the accommodation. The service provider approached a member of Paul's family requesting, instead, that they provide accommodation. The family member was unable to do so.

Paul remained in custody for a period of time before again being granted bail back into the care of the same service provider. Ultimately, all of Paul's charges were dealt with under section 32 of the MHFPA.

The NGO (and NDIS service provider) that repeatedly argued for coercive bail conditions and refused on a number of occasions to accommodate Paul's immediate return remains responsible for the provision of his care and treatment.

In the above cases, our clients were further disadvantaged because the SDA service provider also provided SIL services to the client, so all supports were withdrawn when the SDA was terminated. Withdrawal or refusal of service for people with complex needs has a significant impact on the justice system and agencies such as Legal Aid NSW and leads to repeated adjournments, and clients spending longer in prison than necessary. Clients who would be suitable for diversion under the MHFP Act, or who are charged with relatively minor offences that would not result in a sentence of imprisonment, are particularly disadvantaged when accommodation supports are withdrawn or terminated.

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Delays in finding alternative accommodation result in the person being detained in custody where this would not otherwise be the case.

According to the Applied Principles, the NDIS will fund:

*supports to address behaviours of concern (offence related causes) and reduce the risk of offending and reoffending such as social, communication and self-regulation skills, where these are additional to the needs of the general population and are **required due to the impact of the person's impairment on their functional capacity and are additional to reasonable adjustment** (our emphasis).*<sup>20</sup>

We are concerned that the NDIA and LACs involved in NDIS planning for people like Brett, Jason and Paul may not be fully adhering to this principle, and that this is having an adverse impact on the responses of some services to challenging behaviour.

We consider that these issues could be addressed by:

- Providing NDIS participants with cognitive impairment with funding for a specialist support coordinator. This could also improve the capacity of services to respond more appropriately to challenging behaviour.
- A strategy to support SDA providers in developing appropriate responses to behaviours of concern, and ensuring that criminal justice responses are only used in exceptional circumstances.
- Improved oversight of planners and LACs to ensure consistent compliance with the Applied Principles relating to the funding of supports to address behaviours of concern.

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<sup>20</sup> COAG Principles to Determine the Responsibilities of the NDIS and Other Service Systems page 23.  
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## Review of NDIA decisions (TOR (a) and (b))

NDIA decisions regarding access to the scheme, and the approval of statements of supports, can be internally reviewed at the instigation of the participant or the CEO of the NDIA.<sup>21</sup> Legal Aid NSW is concerned that some participants may be disadvantaged in the NDIA review process because of:

- a lack of adequate information and support for participants regarding review
- withdrawal of supports without notice while a plan is under review
- restrictions on the availability of legal assistance for review of NDIA decisions and
- extensive delays with internal reviews.

Effective and efficient internal review of NDIA decisions is particularly important because, in our experience, there can be significant variations in NDIA funding decisions, and because of the lack of clarity for participants around how they may spend their approved funds (as noted on page 20, above). Flexibility in responding to the circumstances of individual participants should be balanced with fairness, equity and transparency in decision-making. This can be achieved through a robust and accessible system of review of NDIA decisions.

We detail our concerns about the NDIA review process in the following section.

### Poor visibility of information about review rights

We are concerned that the NDIS website does not currently provide clear information about review and appeal rights. Currently, this information is located by going to the “About us” section of the website, and selecting ‘Contact us’ where information at the bottom of that page can be found under the heading ‘Feedback, complaints and reviews.’ We suggest that information about review and appeal rights needs to be more prominent in public information provided by the NDIA.

### Withdrawal of funding for supports

In our experience, funding for supports has been withdrawn from participants without notice when a plan is under review. Sudden cessation of funding is extremely distressing for participants and can also have dangerous consequences for some people. This is demonstrated in Kim’s case.

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<sup>21</sup> Section 99 of the NDIS Act identifies reviewable decisions, which include access decisions and decisions to approve the statement of participant supports in a participant’s plan.

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### **Case Study: Kim**

Kim lives in a group home and has multiple complex disabilities including insulin dependent diabetes. She has been in the same group home for 20 years and receives 24/7 care.

Prior to the NDIS, a nurse visited Kim's home three times a day to deliver insulin injections, as Kim was unable to administer them herself due to her disabilities. ADHC funded this support. The NDIA refused to continue paying for this support. Her carers sought review of this decision and asked the NDIA to prioritise the review because of Kim's circumstances. The NDIA took five months to make a decision. It maintained that it was not responsible for funding this support. The NDIA did not assist in finding an alternative way to fund the support. Fortunately the service provider carried the cost of continuing with the support because of the risk to Kim's life if it did not continue.

The matter was taken to the AAT where NDIA argued that NSW Health should pay for administering of insulin. This argument was not accepted by the AAT. The AAT held that administering of insulin by a registered nurse was a support that the NDIS should fund.

We propose that where the NDIA decides to cease funding a support, and the person seeks review of the decision, interim funding for the second support should continue pending outcome of that review.

### **Internal review delays**

Lengthy delays in the NDIA undertaking internal reviews can cause significant disadvantage for participants. In our experience it is common for a person to wait 5 to 6 months to receive an internal review decision from the NDIA. During this time, the person may be without any supports. Delays in undertaking internal review have been canvassed by the Commonwealth Ombudsman.<sup>22</sup> In our experience, these extensive delays are continuing.

### **Revocation (TOR (a) and (b))**

The NDIA has the power to revoke a person's status as a participant at any time if the CEO is not satisfied that the person meets the disability requirements or early intervention requirements for access. We are concerned about how this power is being implemented, particularly where the NDIA does not give the participant any warning that their access status is being reconsidered. Instead, in our experience a participant is not given any

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<sup>22</sup> In his report on the National Disability Insurance Agency's Handling of Review, *Administration of Reviews under the National Disability Insurance Scheme Act 2013*, Report No. 3 of 2018, May 2018.

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notice that their status of a participant is being re-considered by the NDIA until they receive the written notice that their status has been revoked.

### ***Case Study: Cath***

Cath has a condition that affects the nerves on her spine which results in reduced movement, pain and bladder problems. These affect her mobility and ability to self-care. She used her initial NDIS funding to pay for assistance with domestic tasks, personal care such as showering and dressing, transport assistance and support to transition to employment. Her second NDIS Plan had significantly less funding and so she sought internal review of that plan. Without any warning Cath received a notice telling her that her status as a NDIS participant was revoked with immediate effect. This left her without funding for ongoing assistance, and owing a bill to her carers for the domestic support that they had provided to her in the previous months. She had to cover those costs herself.

Cath sought internal review and then review by the AAT of the NDIA's revocation decision. During this time she had no assistance to undertake her daily activities. One year after the revocation decision, the NDIA conceded that she met the requirements for the NDIS. It took a further three months for the NDIA to implement a new plan with funded supports for Cath.

As a matter of procedural fairness, and to avoid potentially harsh consequences to a person with a disability in need of funded supports, we suggest that the NDIA should provide notice to a participant that their status is under consideration. Such participants would then have an opportunity to provide further information to the NDIA about how they do meet the access requirements. Alternatively they could seek to put in place alternative supports.

## **Legal assistance for review of NDIA decisions (TOR (a) and (b))**

Legal assistance is not available for internal review of NDIA decisions and is only available in limited circumstances for external review of NDIA decisions by the AAT.

Applications may be made to the AAT for review of certain NDIA decisions, including those about access and funding for supports.<sup>23</sup> Since the NDIS pilot began on 1 July 2013, Legal Aid NSW has been funded by the Commonwealth Department of Social Services to provide legal representation services for applicants before the AAT whose NDIS matters raise a complex or novel issue. As indicated in Figure 1 below, this work has increased significantly since that time.

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<sup>23</sup> NDIS Act section 103. Section 99 identifies decisions that are reviewable by the AAT.

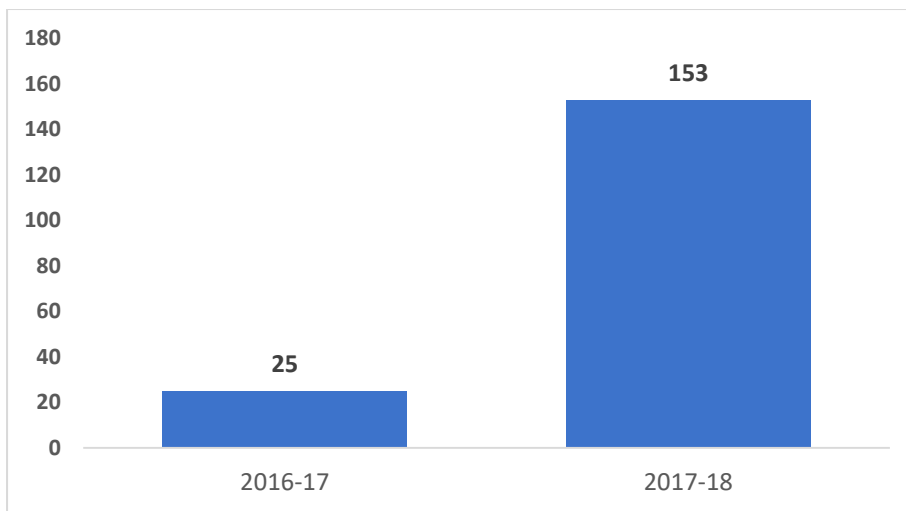


Figure 1: Grant of Legal Aid to represent clients in NDIS matters in the AAT.

We are concerned that the current restrictions on access to legal assistance means that vulnerable applicants with complex needs are not appropriately supported in the appeal process. For similar reasons, vulnerable participants seeking internal review of NDIA decisions would benefit from having legal representation during the internal review process.

Without legal assistance, such individuals may miss out on the opportunity to achieve a plan that meets their disability needs. The need for legal assistance for vulnerable people seeking a review in the AAT is underlined by the adversarial approach taken by the NDIA and its representatives in many cases.

## Conduct of appeals in the AAT (TOR (a) and (b))

Our extensive experience in the AAT appeal processes has highlighted a number of concerns about the efficiency and fairness of dispute resolution in the AAT between the NDIA and participants. We consider that in some cases, this reflects a lack of adherence by the NDIA and its representatives to the Commonwealth's model litigant policy,<sup>24</sup> such as:

- extensive delays caused by the NDIA throughout the AAT appeals process
- the NDIA's participation in the AAT's alternative dispute resolution mechanisms and
- the NDIA's approach to conceding appeals.

## Extensive delays

We are concerned about extensive delays in AAT proceedings as a result of:

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<sup>24</sup> *The Commonwealth's Obligation to Act as a Model Litigant*, Appendix B Legal Services Direction 2017, issued by the Attorney-General pursuant to section 55ZF of the *Judiciary Act* 1903.

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- delays in seeking expert reports to support the NDIA's position
  - delays in filing documents including the NDIA's Statement of Position outlining their position, so that the appellant and their lawyer are able to identify what issues are in dispute, or whether they are any areas where an agreement might be reached before the hearing of the appeal
  - delays in instructions being communicated by the NDIA to their lawyers, and
  - delays in signing terms of agreement.

Some of these issues are illustrated by the following case study.

***Case Study: Non-compliance with AAT Directions***

Legal Aid NSW assisted an applicant in a NDIA matter in the AAT where the applicant filed a considerable amount of evidence in support of her appeal. The NDIA's internal review decision did not provide adequate information, and predated the new evidence filed by the applicant.

The AAT conference registrar issued directions, including that the NDIA was to file and serve any evidence it intended to rely on, and/or a Statement of Position. On the date that the material was required to be filed, the NDIA's legal representative wrote to the AAT and Legal Aid NSW and advised that they did not intend to provide any further evidence or wish to provide a Statement of Position.

The efficiency of AAT proceedings is undermined when the applicant does not understand what the issues in dispute are, resulting in increasing costs for both parties.

In another recent matter, the NDIA issued a summons to produce the appellant's entire medical files. At the time, the appellant was not legally represented. The files summonsed included sensitive records about sexual assault which are not protected by the sexual assault communications privilege (as they would be in criminal proceedings). This action caused the appellant significant distress.

### The NDIA's participation in the AAT's alternative dispute resolution processes

Conciliation conferences in the AAT offer parties the opportunity to resolve cases without the time and expense required for a full hearing. In our experience the NDIA does not always directly participate in conciliation conferences at the AAT, leaving only its lawyer to participate in those processes, which can contribute to delay and increased costs. On a few occasions the NDIA's legal representative has attended a conciliation conference with our client and advised that they have no instructions to conciliate. Instead, in some cases (following a half or full day of evidence at a hearing), the NDIA has advised that it was prepared to offer a settlement, after having heard the evidence. In these cases, if the

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NDIA had sent a representative to the conciliation conference they would have had an opportunity to consider the case well before the hearing.

### Late concessions

Legal Aid NSW has assisted clients in a number of matters that have been through extensive pre-hearing processes with the AAT, where the evidence has been provided weeks in advance of the hearing, and where the NDIA has conceded the appeal in the days or sometimes just hours prior to the hearing. For example, in one recent appeal concerning 'reasonable and necessary supports' where eight supports were in dispute, the NDIA lawyer advised for the first time in opening submissions at the hearing that the NDIA was conceding four of the eight supports in dispute.

As evidenced in the following two cases, delays on the part of the NDIA in making reasonable concessions in the course of an AAT appeal can cause unnecessary distress to our clients and inefficiencies for all parties.

#### ***Case Study: Nicky***

Nicky is two years old and has profound and complex disabilities, including severe brain injury, which mean she needs constant care and supervision.

In Nicky's second NDIS plan, the level of funding provided for support coordination and core supports were reduced because the funding for those supports had not all been spent in her first plan. This was partly because Nicky's parents had taken significant leave from work in the first year of her life as it was unclear how long Nicky might live after her birth.

The NDIA declined a request for additional funding because they were not satisfied that the supports represented value for money, and that the personal care supports requested could reasonably be expected to be provided by friends and family.

Nicky's family sought review of the decision in the AAT. At conciliation the NDIA agreed to increase the additional support coordination hours sought by the family. However, it argued that the personal care supports sought by the family were appropriately funded by other general systems or service delivery. The matter proceeded to hearing, where evidence was given by Nicky's parents, specialist doctor and carer. The NDIA conceded on the second day that Nicky's personal care supports should be increased, and the AAT ultimately agreed to almost all of the increases in supports that had been sought by the family.

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### ***Case Study: Felix***

Felix is a young man with severe uncontrolled epilepsy and global developmental delay. He attends a day program and lives in his own home. Felix needs 24/7 one on one support due to the risk of his frequent and long seizures. The NDIA would not agree to provide sufficient funding to allow Felix to remain in his home with one on one personal care. The NDIA argued it was not value for money and that he should move into a group home instead.

Felix appealed to the AAT seeking funding for individualised 24/7 personal care so he could remain in his home. A week prior to the AAT hearing the NDIA agreed to fund this support so Felix could remain in his home.

Legal Aid NSW suggests that the current review system in the AAT could be improved by the introduction of an additional tier for NDIS appeals. Such a structure would be similar to the merits appeal process that is currently in place for social security appeals where the Social Services and Child Support Division of the AAT acts as the first tier review for social security decisions, and the General Division of the AAT acts as a second tier for reviews.

This reform would address the problem of the volume of merits appeals to the AAT about NDIS decisions, resulting in long waiting time and frustration for participants. The first tier could deal with most of the NDIS appeals with less formality which is not required for less complex cases, and provide a quick, informal and efficient level of review. Second tier review by the General Division of the AAT would allow for more complex legal issues, or complex factual situations, to be considered properly. Second tier decisions would be published and would provide an important role in setting precedents and guiding internal decision making for the NDIA.