



## **Housing Delayed and Denied**

# NDIA Decision-Making on Specialist Disability Accommodation Funding

May 2022

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The Housing Hub is an initiative of the Summer Foundation.

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#### **About the Public Interest Advocacy Centre**

The Public Interest Advocacy Centre (**PIAC**) is a leading social justice law and policy centre. Established in 1982, we are an independent, non-profit organisation that works with people and communities who are marginalised and facing disadvantage.

PIAC builds a fairer, stronger society by helping to change laws, policies and practices that cause injustice and inequality. Our work combines:

- Legal advice and representation, specialising in test cases and strategic casework
- Research, analysis and policy development
- Advocacy for systems change and public interest outcomes

#### Our priorities include:

- Reducing homelessness, through the Homeless Persons' Legal Service
- Access for people with disability to basic services like public transport, financial services, media and digital technologies
- Justice for First Nations people
- Access to sustainable and affordable energy and water (the Energy and Water Consumers' Advocacy Program)
- Fair use of police powers
- Rights of people in detention, including equal access to health care for asylum seekers (the Asylum Seeker Health Rights Project)
- Improving outcomes for people under the National Disability Insurance Scheme
- Truth-telling and government accountability
- Climate change and social justice



#### **About the Housing Hub**

The Housing Hub is an initiative of the Summer Foundation, and is an online community of people with disability and housing providers working together to create accessible housing options. The Housing Hub website – **www.housinghub.org.au** – lists properties for rent or sale that may be suitable for people with disability. With around 2,000 properties currently listed, the Housing Hub features all design categories of Specialist Disability Accommodation (**SDA**), as well as many other types of accessible housing.

The Housing Hub is not an SDA provider or a registered NDIS provider. The Housing Hub's Tenancy Matching Service (**TMS**) works with SDA providers to identify potential tenants for new SDA projects in the pipeline. The Housing Hub team began providing tenant matching services in 2017. To date, the team has supported over 600 people to access SDA funding and move into a new SDA home. The Housing Hub's TMS is a social enterprise that operates on a cost recovery basis.

The Housing Hub's position is that we want to see a whole range of dwelling types and housing options available, so that NDIS participants have a real choice. We do not have a vested interest in a particular dwelling type and promote the benefits of a diverse market with flexible support arrangements, tailored to the needs of individuals.

## **Acronyms**

**AAT** Administrative Appeals Tribunal

NDIA National Disability Insurance Agency

NDIS National Disability Insurance Scheme

PIAC Public Interest Advocacy Centre

**PSG** Participant Service Guarantee

RAC Residential Aged Care

SDA Specialist Disability Accommodation

**TMS** Tenancy Matching Service

**UNCRPD** United Nations Convention on the Rights of Persons with Disabilities

YPIRAC Younger Person in Residential Aged Care

### **Executive summary**

Suitable housing is essential for stability, dignity and quality of life. The National Disability Insurance Scheme (NDIS, Scheme) provides funding for people with disability and complex support needs who require housing specifically designed to maximise independence or improve the efficiency of the delivery of person-to-person support. This funding, which is intended to meet capital costs, is designed to provide access to housing called Specialist Disability Accommodation (SDA). Non-capital costs, such as day-to-day support and services are funded separately under the NDIS. Affordable and accessible housing is foundational to NDIS participants achieving their goals related to social and economic participation and independence. SDA funding enables people with disability to transition away from a range of living environments including group homes, hospital, Residential Aged Care (RAC) and living with ageing parents, to more contemporary models of housing.

In the past year, NDIS participants and providers have seen an increasing number of people who requested SDA funding from the National Disability Insurance Agency (**NDIA**, **Agency**) receive decisions that do not align with their needs and preferences. Agency decisions have become inconsistent with the NDIA's guidelines, and previous funding decisions for participants with similar functional capacity and support needs. The resulting uncertainty around eligibility criteria and opaque administrative processes causes stress and frustration for participants, their family and friends, and providers.

In order to understand and engage with the SDA decision-making and appeals process, the Housing Hub and the Public Interest Advocacy Centre (**PIAC**) commenced a collaborative project in mid-2021, providing legal help to participants seeking reviews of NDIA decisions about SDA funding at the Administrative Appeals Tribunal (**AAT**). This report presents early findings from this project, with the aims of:

- 1. Documenting decisions and processing times for requests for SDA funding made by participants to the NDIA, based on Housing Hub data
- 2. Exploring systemic problems within the NDIA's decision-making process that PIAC has identified during the project, and proposing solutions

The Housing Hub, through its Tenancy Matching Service (**TMS**), has supported over 600 participants along the SDA funding pathway. The TMS collects administrative data for many of the participants it supports to request SDA funding. The TMS have supported 41 participants to successfully review their initial funding decision, through either an internal or external review. Following lengthy delays, these participants received the SDA funding determination they had originally requested. This report presents data on outcomes and timeframes across requests for SDA funding, and reviews of SDA funding decisions (both internally by the NDIA, and externally by the AAT). Analysis of the data reveals the following:

- Initial funding decision For participants who had received an outcome as of March 2022, 26% received the funding they requested from the NDIA, and the median wait time was 96 days. For all 172 participants supported by the TMS at this stage, including participants for whom a decision was still pending, the median wait time was 97 days.
- Internal review For participants who had received an outcome as of March 2022, 25% received the funding they requested from the NDIA, and the median wait time was 76 days. For all 92 participants supported by the TMS at this stage, including participants for whom a decision was still pending, the median wait time was 99 days.

External review – For participants who had received an outcome as of March 2022, 92% received the funding they originally requested from the NDIA, and the median wait time for these decisions was 205 days. Of the 12 participants who had concluded the AAT process and reached an outcome, 11 participants ended up receiving the SDA funding decision that they had initially requested from the NDIA, after months (or years) of delay. This indicates that decision-makers – whether the NDIA's lawyers offering settlements, or the independent Tribunal members – are finding that participants' requests are reasonable and supported by evidence. It also raises questions as to why NDIA internal processes do not lead to similar conclusions.

Along with these findings from the TMS data, PIAC's work supporting a number of participants through the external review process at the AAT has identified a number of systemic problems with the NDIA's decision-making process. Key concerns identified by PIAC include:

- NDIA funding decisions that ignore the preferences of participants
- NDIA decision-making that is unfair, opaque and delayed
- NDIA making regular and significant errors in administering processes
- NDIA failing to meet obligations to participants when reviewing funding decisions

The Housing Hub and PIAC want to work constructively with the government to address the issues with decision-making on SDA funding for NDIS participants. Based on the findings of this report, recommendations to address concerns are listed below.



#### Recommendations

- 1. That Ministerial and Agency leaders direct NDIA planners and those on the Home and Living Panel to give greater weight to:
  - The importance of maintaining social connection and informal supports
  - The consequences of various SDA models for participant's health, wellbeing, lifetime care costs and social and economic participation, when making decisions about SDA funding for participants
- 2. That the SDA Rules be amended to establish rebuttable legal presumptions that a person who has very high support needs and/or extreme functional impairment should be funded for the kind of SDA that they request. This would include setting out in law that a person's preferred kind of SDA represents 'value for money' unless it can be shown through clear evidence that another kind of SDA would achieve the same goals for the person and would be significantly cheaper; and establishing that a person should only be funded for a kind of SDA that is not their preference in exceptional circumstances.
- 3. That the planned NDIS Rules implementing the Participant Service Guarantee be prepared and implemented as a matter of priority; and that they ensure the Guarantee operates effectively to:
  - Set specific standards for Home and Living Panel/SDA and housing-related support
    decisions, distinct from other types of plan. These standards should require urgent
    decisions (e.g. young people at risk of RAC, NDIS participants in hospital or living in
    precarious housing) to be made within 10 days of a participant's request, and all SDA
    and support decisions to be made in under 50 days
  - Assess the total time taken from the time a request for support was made by a
    participant, until the time a binding decision on that support was made and
    communicated to the participant
  - Provide clear avenues for individual participants to report their experience to the Commonwealth Ombudsman charged with overseeing the implementation of the Guarantee
- 4. That the NDIA urgently prioritise decisions relating to people seeking SDA who are in hospital awaiting discharge, living in RAC as a younger person, and/or facing homelessness. In these cases participant choice, needs, and the potential for SDA to maximise independence and create a pathway back to community living should be given even higher weight in decision-making.
- 5. That the NDIA ensures decision-makers review and consider all evidence provided by the applicant, in line with legal principles regarding administrative decisions. This should include preparation of appropriate policies, introducing review and quality-control mechanisms for decision-makers, and providing training and accountability processes for decision-makers who fail to meet minimum standards.
- 6. That the NDIA prepare and publish written guidelines regarding the specific evidence needed for a timely SDA decision, to enable stakeholders to assist the NDIA by providing concise and relevant information that is aligned with the NDIS legislation. Guidelines and FAQs could be developed for different stakeholders including NDIS participants, Support Coordinators, Occupational Therapists and other allied health and health professionals.

- **7.** That the NDIA provide greater transparency around the operation of the Home and Living Panel by:
  - Publicising information on the NDIA's website about the Panel's existence and role, including its terms of reference/procedures and guidelines
  - Publishing information about the internal processes for SDA applications and the process for reviews to allow greater transparency
  - Directing representatives that Panel documents must be included in all document disclosures prepared by the NDIA for relevant AAT proceedings (known as 'T-documents')
  - Proactively engaging with applicants whose matters are set to be sent to the Panel, by informing them of this process and providing an opportunity to write to the Panel directly
- 8. That the NDIA urgently overhaul its internal processes and policies to eliminate critical administrative errors and the delivery of incorrect advice to participants. In doing so, it should consider conducting a top-down audit of processes, policies, and service delivery by staff at all levels.
- 9. That the NDIA adopt a policy of providing full and detailed reasons for reviewable decisions that comply with the requirements of s 28 of the Administrative Appeals Tribunal Act 1975 (Cth), to allow a participant to properly assess whether the information they provided with the NDIA has been considered and the strength of their argument that the funding provided is reasonable or otherwise.
- **10.** That the NDIA adopt policies regarding lawyers acting for the Agency in AAT matters, such that:
  - All external lawyers receive training regarding disability rights and awareness
  - Settlement offers are made as early as possible
  - Additional reports and evidence are only requested where they are clearly necessary and will not cause undue delay or stress to the applicant
  - T-documents are provided in a complete form and do not omit significant documents such as correspondence with the Panel or internal NDIA materials that are pertinent to the decision made
  - Compliance with model litigant obligations is proactively monitored by the Agency
- 11. That state and federal governments significantly increase funding to Legal Aid Commissions, in order to meet current and future growing demand for legal assistance and representation with NDIS participant appeals to the AAT.
- **12.** That the NDIA publish information around AAT settlement outcomes in a manner which balances confidentiality and privacy obligations with the need for transparency and accountability. In determining the information to be published, the NDIA should consult with participants and advocates, and should have regard to the information published in the Australian Human Rights Commissioner's Conciliation Register.

#### 1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) makes clear that people with disability should have the right to choose where and with whom they live. Australia has ratified the UNCRPD, and in doing so has committed to giving people with disability equal choices to others in society. Article 19 of the UNCRPD imposes obligations upon Australia to ensure that:

Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.<sup>1</sup>

One way that Australia implements this and other obligations it has under the UNCRPD is through the National Disability Insurance Scheme (**NDIS**, **Scheme**). The purpose of the Scheme is to change the lives of thousands of people with disability by increasing 'choice and control' in their lives through allocating funding in individual NDIS plans. For many participants in the Scheme, this includes funding for housing.

The National Disability Insurance Agency (**NDIA**, **Agency**) is a government agency set up to administer the NDIS in line with legislation and agreements set by the federal and state governments, under the oversight of the Minister for the NDIS.<sup>2</sup> The NDIA has said that it affirms the need for an 'ordinary life at home' for participants, including greater flexibility, independence and 'a sense of belonging, safety and security.'<sup>3</sup> Academic research supports these aims, showing that a well-designed home in the right location can facilitate independence, increase connections with community, and allow for more access to informal supports.<sup>4</sup>

Unfortunately, many people with disability still have limited control over their housing, including its location and layout, and even who they live with.<sup>5</sup> Furthermore, some people live in housing that was never intended for them, and fails to meet their needs, for extended periods of time. This may include residential aged care (**RAC**), large group homes, crisis accommodation, and even hospitals. One important response to the problems of NDIS participants living in inappropriate accommodation is SDA.<sup>6</sup>

<sup>&</sup>lt;sup>1</sup> Convention on the Rights of Persons with Disabilities, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 30 March 2008).

<sup>&</sup>lt;sup>2</sup> National Disability Insurance Scheme Act 2013 (Cth) s 3(1)(e).

<sup>&</sup>lt;sup>3</sup> NDIA (2021). 'Consultation Paper: An Ordinary Life at Home.' https://www.ndis.gov.au/media/3227/download?attachment

<sup>&</sup>lt;sup>4</sup> Douglas, J., Winkler, D., Oliver, S., Liddicoat, S., D'Cruz, K. (in press). 'Moving Into New Housing Designed for People with Disability: Preliminary Evaluation of Outcomes.' *Disability and Rehabilitation*; Oliver, S., Gosden-Kaye, E., Winkler, D., and Douglas, J. (2020). 'The Outcomes of Individualized Housing for People with Disability and Complex Needs: A Scoping Review.' *Disability and Rehabilitation*; Wiesel, I., Laragy, C., Gendera, S., Fisher, K., Jenkinson, S., Hill, T., Finch, K., Shaw, W. and Bridge, C. (2015). 'Moving to my Home: Housing Aspirations, Transitions and Outcomes of People with Disability,' *AHURI Final Report* No. 246, Australian Housing and Urban Research Institute Limited.

<sup>&</sup>lt;sup>5</sup> Oliver, S., Gosden-Kaye, E., Jarman, H., Winkler, D., and Douglas, J. (2020). 'A Scoping Review to Explore the Experiences and Outcomes of Younger People with Disabilities in Residential Aged Care Facilities.' *Brain Injury*, 34(11): 1446-1460.

<sup>&</sup>lt;sup>6</sup> Beer, A., Flanagan, K., Verdouw, J., Lowies, B., Hemphill, L. and Zappia, G. (2019). 'Understanding Specialist Disability Accommodation Funding,' *AHURI Final Report* No. 310, Australian Housing and Urban Research Institute Limited.

#### 1.1 Specialist Disability Accommodation

SDA is housing that has been specifically designed to meet the needs of people who have an extreme functional impairment and/or very high support needs resulting from their disability. SDA properties might include wider doorways and corridors, a hoist in the bedroom or bathroom, reinforced walls and windows, or integrated assistive technology.<sup>7</sup>

The NDIS provides funding to participants who need SDA, to live independently in a property that meets their needs and gives them access to the right supports. Funding for SDA is provided through participants' NDIS plans. This gives participants a budgeted sum of money which they can use to choose and pay for an SDA dwelling and support provider(s). The amount of money provided to each participant is determined by the Agency, applying the legal framework of the *National Disability Insurance Scheme Act 2013* (Cth) (*NDIS Act*) which sets out who is eligible for SDA funding and how much money they should be given. By 2025, the NDIA estimates that 30,000 participants will have SDA in their plans.<sup>8</sup> As of December 2021, however, only 16,972 were receiving SDA payments, suggesting issues with the rollout of appropriate SDA to participants.<sup>9</sup>

Even though SDA funding is designed to increase choice and control for NDIS participants, including providing for people to live alone or in the type of home they prefer, many people with high support needs find themselves funnelled into 'group homes' – dwellings with four or more people. This is concerning, as these homes are associated with poor outcomes for some people with disability. <sup>10</sup> Residents of group homes generally have limited say about who they live with, and there are few opportunities to grow more independent and reduce support needs over time. <sup>11</sup> Living in an environment that is not adaptable to the needs of people with disability diminishes choice and control, while potentially increasing support costs. <sup>12</sup>

Beyond concerns about independence, flexibility and choice, the Royal Commission on Disability found that people residing in group homes are vulnerable to violence, abuse and neglect.<sup>13</sup> Similarly, in assessing Australia's observance of the UNCRPD, the United Nations raised concerns about 'disability-specific residential institutions' that limit the autonomy of people with disability.<sup>14</sup>

Because of these issues, it is unsurprising that many NDIS participants have needs and preferences that are best met by a single occupant dwelling. Despite this, group homes remain the most common SDA option available for people with high support needs. NDIA data shows that over 60% of places in SDA are in dwellings for four or more people.<sup>15</sup>

<sup>&</sup>lt;sup>7</sup> NDIA (2022). 'SDA Design Standard.'

https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/specialist-disability-accommodation/sda-design-standard

<sup>&</sup>lt;sup>8</sup> Commonwealth (2021). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ21-000118.

<sup>&</sup>lt;sup>9</sup> NDIA (2022). 'NDIS Quarterly Report to Disability Ministers: Q2 2021-2022.'

https://www.ndis.gov.au/about-us/publications/quarterly-reports

<sup>&</sup>lt;sup>10</sup> Wiesel, I. (2011). 'Allocating Homes for People with Intellectual Disability: Needs, Mix and Choice.' *Social Policy & Administration*, 45(3), 280-298.

<sup>&</sup>lt;sup>11</sup> Clement, T., and Bigby, C. (2010). *Group homes for people with intellectual disabilities: Encouraging inclusion and participation.* Jessica Kingsley Publishers.

<sup>&</sup>lt;sup>12</sup> Wiesel, I. (2020). 'Living with Disability in Inaccessible Housing: Social, Health and Economic Impacts.' Melbourne: University of Melbourne. https://disability.unimelb.edu.au/\_\_data/assets/pdf\_file/0019/3522007/Accessible-Housing-FINALREPORT.pdf
<sup>13</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020). 'Public hearing 3: The Experience of Living in a Group Home for People with Disability.'

https://disability.royalcommission.gov.au/publications/report-public-hearing-3-experience-living-group-home-people-disability

14 United Nations Committee on the Rights of Persons with Disability (2019). 'Concluding Observations on the Combined Second and Third Periodic Reports of Australia.' UN Doc CRPD/C/AUS/CO/2-3.

<sup>&</sup>lt;sup>15</sup> NDIA (2021). 'SDA Enrolled Dwellings and NDIS Demand Data.' Appendix P, Tables P.6, P.9. https://data.ndis.gov.au/media/2770/download

#### 1.2 The Housing Hub and PIAC SDA project

The Housing Hub's TMS supports NDIS participants through the SDA pathway. It has extensive experience and understanding of the SDA eligibility criteria in line with the relevant legislation. How Working closely with participants, the TMS provides information on likely eligibility for SDA and advice to participants to assist in their application for SDA funding. The TMS employs a rigorous process to consider likely SDA eligibility for participants they work with. This helps to ensure that participants are applying for a level of SDA corresponding with their housing and support needs and preferences. The TMS also directs participants to other forms of housing if they are unlikely to be eligible for SDA funding.

In addition to supporting participants with their *initial request* for SDA funding, the TMS supports participants to request an *internal review* of the initial decision in cases where it does not align with the participants' needs and preferences. If the outcome of the internal review still does not fund participants for SDA in accordance with their needs and preferences, the TMS may offer to assist participants with an *external review* by the Administrative Appeals Tribunal (**AAT, Tribunal**).

In the past year, NDIS participants and providers have seen an increasing number of people who submit requests for SDA funding receive decisions that do not align with their needs and preferences. Agency decisions are often inconsistent with the SDA Rules, with previous funding decisions for participants with similar functional capacity and support needs, and with the funding outcomes for participants who request an AAT review. This uncertainty around eligibility criteria, and opaque administrative processes, causes stress and frustration for participants, their family and friends, and providers.

In 2021, the Housing Hub engaged PIAC to provide legal support and representation to a number of NDIS participants through the AAT review process, to ensure they receive the SDA funding they need to live an ordinary life. Through this appeal process, PIAC and the Housing Hub are seeking to:

- Clarify the law
- Constructively engage with the practices of the NDIA in handling SDA funding requests
- Make sure that eligibility for participants is in line with the SDA legislation
- Ensure that the perspectives and needs of NDIS participants seeking SDA are represented and respected
- Support an efficient and effective process for SDA applications and approvals
- Identify systemic issues and the development and implementation of solutions

PIAC and the Housing Hub are committed to supporting the continued development of a well-functioning SDA market, where market contributors can rely on the system to operate in line with the intentions of the legislative scheme.

To date, the work of PIAC and findings from the TMS administrative data have revealed several systemic issues associated with the SDA funding approval process at the NDIA. This report provides an overview of these issues, as well as offering recommendations for how they might be addressed.

<sup>&</sup>lt;sup>16</sup> National Disability Insurance Scheme 2013 (Cth), National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2020 (Cth)

<sup>&</sup>lt;sup>17</sup> Winkler, D., Aimers, N., Rathbone, A., Douglas, J., Wellecke, C., Goodwin, I., Mulherin, P. (2021). 'Specialist Disability Accommodation Provider Experience Survey.' https://apo.org.au/node/316937

#### The report proceeds as follows:

- Decision-making process at the NDIA for funding requests from participants are discussed (Chapter 2)
- Findings are provided from an analysis of the TMS data about participants it has supported through the SDA funding process (Chapter 3). Key metrics considered are the outcomes of these requests, as well as the time it takes for a decision to be communicated back to participants
- Systemic issues with NDIA decision-making relating to SDA funding are considered, based on the experiences of PIAC in supporting participants since September 2021 (Chapter 4)
- A series of AAT case studies are presented, and issues identified (Chapter 5)
- Preliminary recommendations for addressing the issues identified in this report are provided (Chapter 6)



## 2. Decision-making structures for NDIS funding

Decisions about funding for housing and support are made under the *NDIS Act* and the *National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2020* (Cth) (*SDA Rules*). The *NDIS Act* enshrines the principles of autonomy and self-determination for people with disability. Principles of autonomy and self-determination include participants' preferences as to whom they live with and whether or not they live alone. These principles also underpin decisions relating to SDA funding.

#### 2.1 Reasonable and necessary: Funding criteria

Applying the above principles, all NDIS funding decisions – including requests for SDA – must consider if the support requested meets the requirements set out in section 34 of the *NDIS Act*. <sup>19</sup> This provision states that only 'reasonable and necessary supports' will be funded. To determine whether funding a type of SDA is reasonable and necessary, the *NDIS Act* and the *SDA Rules* set out eight criteria that the NDIA must consider. <sup>20</sup> All eight criteria must be satisfied for a person to be considered eligible for a given level of SDA funding. The eight criteria are:

- Assistance to pursue goals, objectives and aspirations<sup>21</sup>
- Assistance to undertake activities to facilitate social and economic participation<sup>22</sup>
- Value for money<sup>23</sup>

<sup>32</sup> Ibid, r 17.

- Effective and beneficial, with regard to current good practice<sup>24</sup>
- Account of reasonable expectations of families, networks and the community<sup>25</sup>
- Most appropriately funded through the NDIS<sup>26</sup>
- Either 'extreme functional impairment' or 'very high support needs'
- The 'SDA needs requirement'<sup>28</sup>

For participants assessed as eligible to receive support for SDA, the Agency must determine the SDA building type, SDA design category and the location factor of the SDA that is reasonable and necessary to support the participant.<sup>29</sup>

The appropriate 'building type' includes whether the SDA should be delivered in an apartment, villa/duplex/townhouse, or house, and how many bedrooms/other residents that SDA should have.<sup>30</sup> It is assessed by considering which building type would fit best with the participant's preference, the supports they require, their relationships and quality of life, and more.<sup>31</sup> The 'design category' relates to the features of the SDA that make it appropriate for meeting the participant's support needs.<sup>32</sup>

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18 National Disability Insurance Scheme Act 2013 (Cth) ss 4,17A.

19 Ibid, s 34(1).

20 National Disability Insurance Scheme Act 2013 (Cth) s 34; National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2020 (Cth).

21 National Disability Insurance Scheme Act 2013 (Cth) s 34(1)(a).

22 Ibid, s 34(1)(b).

23 Ibid, s 34(1)(c).

24 Ibid, s 34(1)(d).

25 Ibid, s 34(1)(e).

26 Ibid, s 34(1)(f).

27 National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2020 (Cth) rr 11-13.

28 Ibid, rr 11, 14.

29 Ibid, rr 15-18.

30 Ibid, r 16.

31 Ibid, r 16.
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Determining the best location of SDA is based on a number of factors.<sup>33</sup> Generally, this includes considering how the location will facilitate access to supports and amenities, including proximity to family and friends. Finally, participants need to show that their need for SDA is related to their disability.<sup>34</sup> The way this is determined depends on the particular circumstances of the participant, but often includes obtaining support letters from the participant's support team, including allied health professionals.

A central element of determining both the appropriate building type and location is considering the participant's preferences about where they would like to live.<sup>35</sup> This reflects a central principle of the overall Scheme, which is to give participants 'choice and control'.<sup>36</sup> As these preferences must be consistent with the participant's goals and aspirations, the legal framework does not accommodate whimsical or frivolous desires. Instead, the focus on preference highlights the fact that, generally, participants themselves are in the best position to know what is important to them and what will best suit their needs, lifestyle and human flourishing. It also reflects the central role that the home plays in a person's life, and the importance of suitable housing to a person being able to live the way they want to.

#### 2.2 Processes for requesting NDIS funding

The legal tests and framework set out above need to be considered every time a person requests NDIS funding for housing or support – including SDA – to be allocated in their plans. Broadly, the ways to request and review a funding decision are as follows:

- Initial funding decision Participants submit a request to the NDIA for funding for housing or support to be allocated in their NDIS plan and the NDIA makes a decision. The Agency's current Participant Service Guarantee (PSG, Guarantee) policy sets a target of 56 days to make an initial funding decision and communicate the outcome to the participant<sup>37</sup>
- 2. Internal review If participants believe the NDIA's initial decision is unreasonable, they may request an internal Agency review. The NDIA then needs to reconsider the original funding request, and make a decision to confirm, vary, or set aside and substitute the initial decision. Participants have three months from the time they receive a decision to request an internal review.<sup>38</sup> The PSG policy sets a target of 60 days for the Agency to conduct the review and communicate the outcome to the participant
- 3. **External review** If participants believe that the decision following the internal review is still unreasonable, they may apply for an external review by the AAT. Participants have 28 days in which to request an external review of the Agency's decision<sup>39</sup>

These three stages are depicted in Figure 1, with SDA funding as the example.

<sup>&</sup>lt;sup>33</sup> Ibid, r 18

<sup>&</sup>lt;sup>34</sup> National Disability Insurance Scheme (Supports for Participants) Rules 2013 (Cth) r 5.1(b).

<sup>&</sup>lt;sup>35</sup> National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2020 (Cth), rr 16(a), 18(a)

<sup>&</sup>lt;sup>36</sup> National Disability Insurance Scheme Act 2013 (Cth) s 4

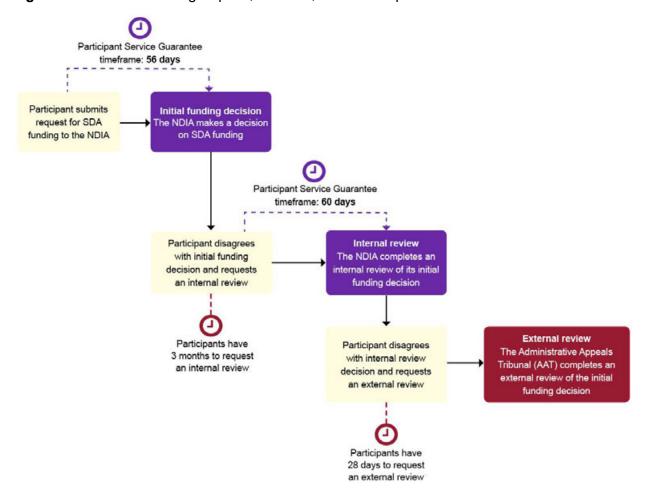
<sup>&</sup>lt;sup>37</sup> NDIA (2022). 'Participant Service Guarantee.'

https://www.ndis.gov.au/about-us/policies/service-charter/participant-service-guarantee

<sup>&</sup>lt;sup>38</sup> National Disability Insurance Scheme Act 2013 (Cth) s 100(2).

<sup>&</sup>lt;sup>39</sup> Administrative Appeals Tribunal Act 1975 (Cth) s 29(2).

Figure 1 – The SDA funding request, decision, and review process

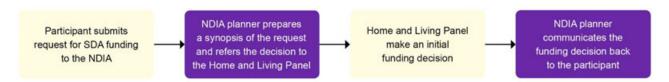


Within the NDIA, initial requests for SDA funding and internal reviews of SDA funding are not determined by an ordinary planner in conversation with the participant, but are instead escalated to the NDIA's Home and Living Panel (**the Panel**). Requests for SDA funding generally require the participant to provide the following evidence, at a minimum, to support their request:

- A housing goal in their NDIS plan
- A Participant Housing Statement
- A Home and Living Request Form
- A functional capacity assessment by a suitable allied health professional
- Additional assessments to support the application if needed

The Panel makes a decision on the participant's eligibility for SDA funding, including the design category, building type, location and supports. This decision is then communicated back to the participant by their planner – see Figure 2.

Figure 2 – Requests for SDA funding and NDIA initial decision-making process



The Panel process is not publicised by the Agency. Participants are often not informed that their request will be decided by the Panel, nor are they told how the Panel will consider their case.

During this project, PIAC has filed a number of requests under the *Freedom of Information Act* 1982 (Cth) (**FOI request(s)**), seeking to learn more about how the Panel operates. Many of these FOI requests were resisted by the NDIA, and the Agency refused to produce some documents PIAC asked for. However, as a result of successful FOI requests, PIAC and the TMS have learned that while the Panel used to produce 'recommendations' for planners to consider, in late 2021 it began making legally binding decisions on SDA requests.<sup>40</sup>

The NDIA says that Panel staff do not receive any specialised training for their role on the Panel, and do not apply any Panel-specific policies.<sup>41</sup> Instead, the Panel is composed of staff who are generally more senior than those making ordinary planning decisions, who are delegated with the power to approve SDA funding.<sup>42</sup> PIAC understands that currently, 5 Home and Living panels are scheduled each week which run from 1 hour to 1.5 hours each.<sup>43</sup> Between 5 to 15 participant decisions are completed per panel, depending on the complexity of each participant's support needs and current or proposed living situation.<sup>44</sup> The Panel makes approximately 130 decisions per week, or about 520 decisions per month.<sup>45</sup> As discussed below at 4.2.4, many elements of the Panel's operations are problematic. Concerns raised by participants and stakeholders in the NDIS about the Panel are exacerbated by the lack of transparency around the Panel.

#### 2.3 Reviewing and appealing NDIA funding decisions

Decisions made by the NDIA about funding SDA are 'reviewable decisions' under the *NDIS Act*. If the Home and Living Panel rejects the participant's application for funding, or chooses to fund a different type of SDA than what has been requested, the participant may ask for that decision to be reviewed. In order to have a decision reviewed, it is very important that participants receive information about the NDIA's funding decisions in writing.

The process for an internal review is governed by Section 100 of the *NDIS Act*.<sup>46</sup> Section 100 sets out that the person must request the review within three months after receiving the notice of the funding decision.<sup>47</sup> The request for a review may be made in writing, in person, or on the phone. If the participant disagrees with the outcome of the internal review, then they may appeal to the AAT.<sup>48</sup>

In the first 6 months of 2021, 452 requests for an internal review were made which related at least in part to SDA funding.<sup>49</sup> In terms of all requests and funding categories, between 1 January and 31 December 2021, there were 47,677 requests for an internal review.<sup>50</sup> PIAC and the Housing Hub understand that internal review decisions about SDA are also made by the Home and Living Panel. It is believed that SDA reviews follow the same Panel processes, and are included within the same decision statistics. As outlined above, if a participant disagrees with an NDIA internal review decision, they can apply for an external review by the AAT.

<sup>&</sup>lt;sup>40</sup> FOI decision released pursuant to request reference NDIA 21.22-0422 and associated materials.

<sup>&</sup>lt;sup>41</sup> Ihid

<sup>&</sup>lt;sup>42</sup> Commonwealth (2021). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ21-000175. Decision on FOI release NDIA 21.22-0422.

ADIA Executive Brief ref EC21-000663 (13 September 2021), p1 - released pursuant to FOI request NDIA 21.22-0422
 Ibid.

<sup>&</sup>lt;sup>45</sup> Ibid, p 2.

<sup>&</sup>lt;sup>46</sup> National Disability Insurance Scheme Act 2013 (Cth) s 100.

<sup>&</sup>lt;sup>47</sup> Ibid, s 100(2).

<sup>&</sup>lt;sup>48</sup> National Disability Insurance Scheme Act 2013 (Cth) s 103.

<sup>&</sup>lt;sup>49</sup> Commonwealth (2021). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ21-000119.

<sup>&</sup>lt;sup>50</sup> NDIA (2022). 'NDIS Quarterly Report to Disability Ministers: Q2 2021-2022,' p. 61.

The AAT is an independent body, with some of its processes similar to those of a court. However, while most courts are only able to consider whether a government agency has acted legally, the AAT is able to consider whether the Agency's decision was correct and preferable. This is sometimes summarised as the AAT 'standing in the shoes of the original decision-maker'. In the case of an SDA funding decision, the Tribunal will look at all the evidence in front of it and make up its own mind about the kind of SDA that a person should be funded for. While the AAT is designed to be more accessible and less formal than a court, it can still be very complex and intimidating for participants to challenge decisions.

AAT cases can also take a long time to be considered and decided, during which time the NDIA's initial decision will stand. Despite this, many more NDIS participants have recently been challenging NDIA decisions at the AAT. Between 1 January and 31 December 2021, there were 4,480 AAT cases brought by NDIS participants relating to NDIA funding decisions – more than three times the number of cases in the previous 12 months.<sup>51</sup>

#### 2.4 Existing legal support for appeals

In the course of this project, PIAC has mapped the legal services, firms and lawyers who provide legal support to people appealing NDIA funding decisions, including about SDA, to the AAT. Unfortunately, despite the complex and technical nature of AAT cases, the findings showed that it is often difficult for participants to get legal advice and representation.

The main organisations providing help to applicants challenging NDIS decisions at the AAT were the Legal Aid commissions of each state and territory. However, the level of help available through Legal Aid varied greatly from state to state. As the most populous states, New South Wales and Victoria have the largest NDIS Legal Aid teams, while other smaller teams may have only one or two lawyers responsible for assisting with NDIS cases across the whole state or territory. In all cases, Legal Aid cannot represent everybody who asks for help; as a result of limited resources, many applicants will only be offered one-off advice, or perhaps help with a specific stage of their application.

Beyond Legal Aid, there are limited options for an NDIS participant to get legal help with their AAT case. There were only a small number of private law firms with experience in these kinds of appeals, which means that few lawyers could agree to take on these cases pro bono. This also means that even participants that can afford to pay for representation only have a few choices of firms that they can hire. Legal fees for these cases could be expensive, as the law in this area is complex and specialised, meaning that a case requires many hours of lawyer-time to run.

The strain on Legal Aid commissions, and the parts of the legal sector who are able to assist with these cases, is increasing as the number of AAT appeals has grown. While some targeted government funding for advocates and lawyers has been provided by the Australian Government, the grants provided are largely piecemeal and have not kept pace with huge increases in demand. <sup>52</sup> Without reform, it is likely that more and more NDIS participants will struggle to get the legal support they need to challenge decisions at the AAT.

<sup>&</sup>lt;sup>51</sup> NDIA (2022). 'NDIS Quarterly Report to Disability Ministers: Q2 2021-2022,' p. 61.

<sup>&</sup>lt;sup>52</sup> Disability Support Guide (2022). 'Demand for Disability Advocates Recognised but not Matched by Funding.' April 11. https://www.disabilitysupportguide.com.au/talking-disability/demand-for-disability-advocates-recognised-but-not-matched-by-funding

## 3. Outcomes and wait times for SDA funding decisions

Since mid-2017, the Housing Hub's TMS has supported over 600 NDIS participants to pursue a request for SDA funding at one or more of the three stages: initial funding decision by the NDIA; internal NDIA review of the initial funding decision; and external AAT review of the initial funding decision. The TMS has supported 41 participants to successfully review their initial funding decision. Following either an internal or external review, and lengthy delays, these participants received the SDA funding determination they had originally requested.

This report includes statistics on 357 participants for whom administrative data was collected. Of the 357 participants in the total dataset, 172 participants were supported by the TMS for the initial funding request, 92 participants for an internal review, and 48 participants for an external review – Table 1. Some participants worked with the TMS from the initial funding decision stage, while others only began working with the TMS for the internal or external review stage. Therefore, each stage will be explored as a discrete sample within the larger dataset.

**Table 1** – Number of participants for each stage of the SDA funding request pathway

Stage	n
Initial funding decision	172
Internal review	92
External review	48

Note: The number of participants in the total dataset (357) is higher than the sum of participants in each of the three stages (312) due to different exclusion criteria. For the three individual stages, participants needed to have a final date recorded in order to calculate median wait times. Since wait times are not calculated for the total dataset, participants without a final date recorded were also included in order to provide demographic information on a larger sample of participants supported by the TMS.

As shown in Table 2 below, the entire process from submitting an initial SDA request to receiving the level of funding requested can take many months. For a participant who requests both an internal and external review of an initial funding decision, the entire process could take over 400 days (13 months), based on median wait times at each stage.

**Table 2** – Median wait times for SDA funding request stages

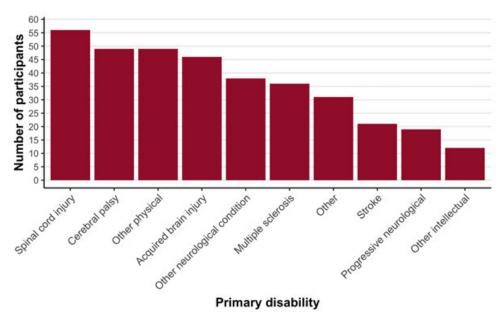
	Initial funding decision	Internal review	External review	Possible total wait time
Median wait time (range)	97 days (6-624)	99 days (6-396)	205 days (103-513)	401 days
Participant Service Guarantee	56 days	60 days	-	-

Note: Wait times for initial funding decisions and internal reviews are calculated based on all outcomes, including decisions 'pending', while wait times for external reviews are calculated based on the outcomes 'decision varied or set aside by consent', and 'matter determined by AAT'. It should also be noted that requests for SDA funding are often treated as a 'complex change' to an existing plan, for which the PSG is 50 days.

<sup>&</sup>lt;sup>53</sup> 31 of the 41 participants who successfully reviewed their decision are included in the 357, but due to changes in data collection methods in mid-2019, and exclusion criteria for the final dataset (submission and determination dates needing to be recorded), data for 10 participants could not be included in the dataset.

#### 3.1 Demographics of participants requesting SDA

Demographic characteristics of the entire dataset of 357 participants are provided below, after duplicates have been accounted for. The average age of participants was 47 (range 18-70), and over half (54.1%) were males. The most common primary disability types for the cohort were: spinal cord injury (15.7%), other physical (13.7%), cerebral palsy (13.7%) and acquired brain injury (12.9%) – see Figure 3. These reflect the types of disabilities that may lead to a person needing SDA. This cohort differs from the majority of NDIS participants currently receiving SDA funding, where 45.0% have an intellectual disability.54



**Figure 3** – Primary disability types of participants (n = 357)

Participants requesting SDA lived in all Australian states and territories other than Tasmania or the Northern Territory, including a majority from the most populous states of New South Wales (33.1%) and Victoria (29.1%). At the time of making a request for SDA funding to the NDIA, the most common living arrangements for participants were private homes (58.0%), supported accommodation (10.6%), residential aged care (9.5%), and hospital (8.4%) – see Figure 4.



**Figure 4** – Participant living arrangements (n = 357)

Number of participants 60 40 20 Crisis and Supported Other Hospital transitional accommodation housing Living arrangements

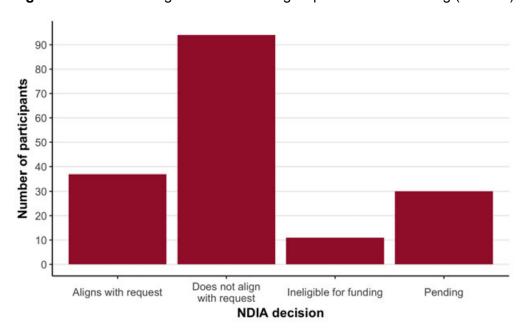
<sup>&</sup>lt;sup>54</sup> NDIA (2022). 'NDIS Specialist Disability Accommodation 2021-22 Quarter 2 Report.' https://data.ndis.gov.au/reports-and-analyses/market-monitoring#specialist-disability-accommodation-sda-quarterly-report

#### 3.2 Initial funding decision

The Housing Hub's TMS tracks participants' initial requests for SDA funding and categorises outcomes and decisions by the NDIA according to the following criteria:

- Aligns with participant's requested SDA the Agency decides to fund the participant for the design category, building type and occupancy they have requested
- **Does not align with participant's requested SDA** the Agency decides not to fund the participant for the design category, building type and occupancy they have requested
- Ineligible for funding the Agency decides that the participant is ineligible for any SDA funding
- Pending the Agency has not yet communicated a decision to the participant

For the 172 participants, only 37 (21.5%) received a decision from the Agency that aligned with their request for SDA funding. For 94 participants (54.7%) the NDIA made a decision that did not align with the participants' request and their submitted evidence. In total, 11 participants (6.4%) received a decision that they were ineligible for funding, while 30 participants (17.4%) had a funding decision from the NDIA still pending as of March 2022 – see Figure 5.



**Figure 5** – Initial funding decision following request for SDA funding (n = 172)

The NDIA's PSG policy states that participants' plans should be approved within 56 days. <sup>55</sup> However, for the 172 participants that the TMS has supported to apply for initial SDA funding, the median wait time was 97 days (range 6-624). This includes participants who have received a decision, and those still awaiting one – see Figure 6.

When broken down by individual outcomes, the median wait time for every outcome was still considerably longer than the Agency's own target. For decisions that aligned with the participant's requested SDA, the median wait time was 96 days, while for decisions that did not align with participant's requested SDA the median wait was 92 days. Participants who received an 'ineligible for funding' decision from the NDIA had a median wait time of 99 days, while for those with a decision pending the median wait was 99.5 days as of March 2022.

<sup>&</sup>lt;sup>55</sup> NDIA (2022). 'Participant Service Guarantee.' If requests for SDA funding are treated as a 'complex change' to an existing plan, the PSG is 50 days.

Aligns with request Does not align Ineligible for funding Pending

**Figure 6** – Wait times for initial funding decision following request for SDA funding (n = 172)

The median number of days awaiting a decision from the NDIA were further broken down by participants' living arrangements. For those living in private homes it was 106 days, for those in hospital 49.5 days, for those in aged care 54 days – see Appendix A.

**NDIA** decision

#### 3.3 Internal review of the initial funding decision

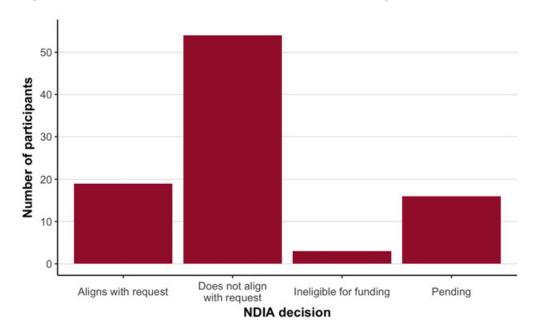
with request

For requests made for an internal review, the Housing Hub's TMS also tracks participants' requests and records outcomes according to the following criteria:

- Aligns with participant's requested SDA the Agency decides to set aside or substitute
  its initial decision, and fund the participant for the design category, building type and
  occupancy they have requested
- Does not align with participant's requested SDA the Agency decides to confirm its initial decision, and not fund the participant for the design category, building type and occupancy they have requested
- **Ineligible for funding** the Agency decides that the participant is ineligible for SDA funding
- **Pending** the Agency has not yet communicated a decision to the participant

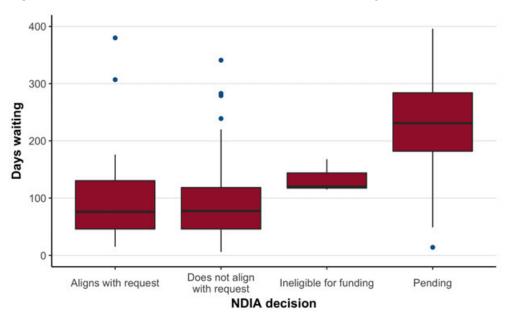
Of the 92 participants who requested an internal review, 19 (20.7%) received a decision that overturned the initial NDIA decision and funded participants for their requested SDA. However, 54 (58.7%) received a decision that did not align with their requested SDA. Only three participants (3.3%) were found to be ineligible for funding, while for 16 participants (17.4%) a decision following the internal review was still pending as of March 2022 – see Figure 7.

**Figure 7** – Outcomes for internal reviews of initial funding decision (n = 92)



The current PSG policy commits the NDIA to complete internal reviews within 60 days. <sup>56</sup> Despite this target, the median wait time for the 92 participants supported by the TMS to request an internal review was 99 days (range 6-396). The wait time for individual outcomes was again considerably higher than the Agency's own guarantee. For both 'aligns with request' and 'does not align with request' outcomes, the median wait time was 76 days – see Figure 8. For those deemed ineligible, the median wait time was 120 days (though this outcome was only listed for three participants). For the 16 participants still awaiting an outcome of their internal review, the median wait time was 231 days as of March 2022.

**Figure 8** – Wait times for internal reviews of initial funding decision (n = 92)



The median number of days awaiting a decision following an internal review from the NDIA was further broken down by participants' living arrangements. For those living in private homes it was 110.5 days, for those in hospital 61 days, for those in aged care it was 63 days – see Appendix A.

<sup>&</sup>lt;sup>56</sup> NDIA (2022). 'Participant Service Guarantee.'

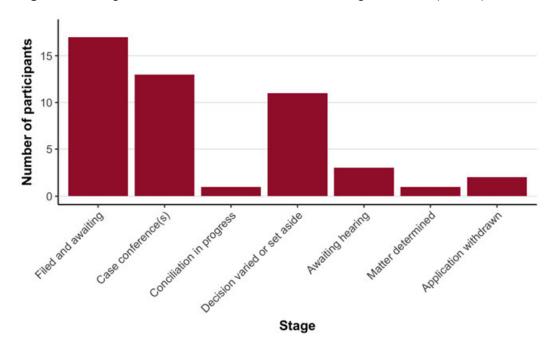
#### 3.4 External review of the initial funding decision

For requests made for an external review by the AAT, the TMS tracks participants' requests and records outcomes and steps in the process according to the following criteria:

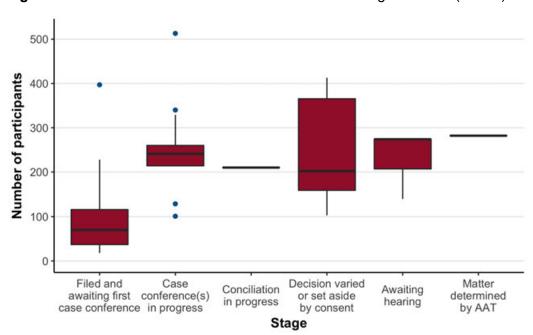
- Filed and awaiting first case conference participants who have filed their forms and are commencing the AAT process
- Case conference(s) in progress participants who are negotiating with the NDIA about the timetable of the AAT case, and what evidence needs to be provided
- Conciliation in progress participants who are in negotiations with the NDIA about whether their case can be settled by agreement, without going to an AAT hearing
- Decision varied or set aside by consent participants who have ended/settled their AAT
  case after reaching an agreement with the NDIA regarding SDA funding. This agreement
  may be what the participant requested in their initial SDA request, or a variation of it
- Awaiting hearing participants who have not reached an agreement to settle the case with the NDIA and are waiting for the AAT to hold a final hearing to decide their case
- Matter determined by AAT participants whose case has gone to a hearing before the AAT, and the AAT has made a final decision on their case
- Application withdrawn by applicant participants who have decided not to continue with their AAT case

Of the 48 participants pursuing an AAT review of the NDIA's decision on SDA funding as of March 2022, only one had been determined by the AAT – see Figure 9. For 11 participants, the NDIA's internal review decision was varied or set aside with the consent of the Agency and the participant. A total of 34 participants (70.8%) had begun proceedings at the AAT, including 17 who had filed an appeal, 13 with a case conference in progress, one with conciliation in progress, and three awaiting a final hearing. It is also noteworthy that two participants filed with the AAT, began the Tribunal process, but then later decided to withdraw their cases. In each of these cases, the TMS understands that the decision to withdraw was based on the participant feeling exhausted and disillusioned with the drawn-out and intimidating nature of the process.

**Figure 9** – Stages for external review of initial funding decisions (n = 48)



Of the 48 participants at various stages of the external review process, the median number of days waiting for a decision to be varied or set aside by consent was 202 days (range 103-413) – see Figure 10. The median wait time was 70 days for those who had filed their appeal and were awaiting their first case conference, 241 days for case conferences in progress, and 210 days for conciliation in progress.<sup>57</sup> For the single case where the matter had been determined by the AAT, it took 282 days – approximately nine months – for the participant to receive the SDA determination they had initially requested from the NDIA.



**Figure 10** – Wait times for external review of initial funding decisions (n = 48)

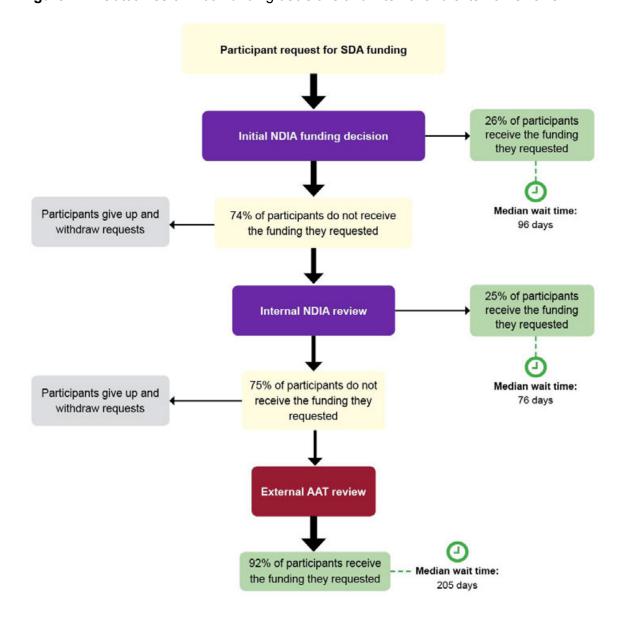
#### 3.5 Accuracy and outcomes of SDA funding decisions

Analysis of the TMS data reveals that, alongside lengthy median wait times for NDIA decisions at the initial funding decision and internal review stages, a majority of these decisions do not align with participants' requests.

Figure 11 summarises the outcomes for participants included in the TMS dataset who requested SDA funding, and/or requested an internal or external review of the initial funding decision. In each case, participants requested SDA that the TMS team considered was appropriate, supported by expert evidence and reports, and aligned with the legislative framework and previous NDIA decisions for participants with a similar level of function and support needs. Despite this, and excluding participants for whom a decision was still pending, only 26% of initial SDA decisions made by the Home and Living Panel aligned with participants' requested SDA. Many participants give up and do not proceed with an internal review of the initial funding decision. But of those that do, in the TMS dataset only 25% received an outcome from an internal review that aligned with their requested SDA. Due to the complexities, delays, frustrations and stress associated with requesting an internal review, many NDIS participants give up and do not request an external review.

<sup>&</sup>lt;sup>57</sup> Days waiting are cumulative, rather than for each stage. For stages with small sample sizes, statistics on days of wait should be interpreted with caution.

Figure 11 – Outcomes of initial funding decisions and internal and external reviews



The TMS supported 12 participants to reach a final outcome following an AAT review. After lengthy delays, 11 participants (92%) received the SDA funding determination that they had originally requested. Of these 11 participants, 10 received a favourable outcome prior to the actual AAT hearing, while only one person had the matter determined by the AAT. For these 10 participants, the median wait time was 552 days (range 329-735) to get the SDA funding they had originally requested. In other words, it took over a year and a half from the initial SDA funding request to the outcome of the external review. In several of these cases, participants received last minute settlement offers from the NDIA's lawyers just days prior to their scheduled AAT hearing.

Based on the outcomes for these 11 participants, it is evident that for participants whose request is consistent with legislation and previous SDA decisions, those who are willing and able to request an AAT review of the initial NDIA funding decision have a good chance of having the decision varied in their favour. Furthermore, a fair approach to these cases would see the NDIA conclude matters as soon as possible, rather than dragging the process out and settling the case just prior to an AAT hearing.

## 4. Systemic problems with NDIA decision-making

This chapter explores problems with NDIA decision-making with regards to SDA funding, derived from the experiences of PIAC in supporting participants to pursue an external review at the AAT. Broadly, these problems fall into four categories:

- NDIA funding decisions that ignore the preferences of participants
- NDIA decision-making that is unfair, opaque and delayed
- NDIA making regular and significant errors in administering processes
- NDIA failing to meet obligations to participants when reviewing funding decisions

These problems are explored in detail here, including with reference to anonymised TMS and PIAC case studies from NDIS participants who have requested SDA funding.

## 4.1 The NDIA regularly makes funding decisions that ignore the preferences of participants

As discussed above, one of the foundational principles of the NDIS is that people with disability should have choice and control over their lives and how they are supported. This principle is reflected in a number of places in the *NDIS Act*, and needs to be taken into consideration by the NDIA at every stage of the SDA decision-making process. <sup>58</sup> This should mean that people with disability are not forced to accept SDA homes they do not want, or live in a place where they do not feel safe, comfortable and free.

Unfortunately, TMS data demonstrates that this often does not happen in practice. It is common for NDIS participants to request funding to live in a particular kind of SDA home, but for the Agency to instead decide to only fund them for a less expensive type of SDA.

As can be seen from the TMS data above, out of 131 participants who were given funding for SDA at the initial stage, 94 (71.8%) were funded at a level that did not reflect the SDA they had requested based on their needs and their submitted evidence. Furthermore, of the 92 who asked for an internal review of the initial funding decision, only 19 (20.7%) were able to overturn the initial decision. Whereas in 54 (58.7%) cases the NDIA confirmed its initial decision to only fund the participant for less expensive SDA. This leaves most participants having to apply to the AAT for an external review, where they face a long and complex legal fight against the NDIA, or else resigning themselves to living in a home that does not give them choice and control over how and where they live.

#### 4.1.1 Denying people the right to live with who they want

The most common type of SDA decision that ignores individual needs involves funding people who want to live on their own, or with their family, to instead live with other people who need SDA – either in a group home, or with housemates they do not know and have not chosen.

This often happens even where the participant has very good reasons for not wanting to live in a shared home. For instance, people with serious mental health concerns have in some cases been told they will only be funded to live in shared accommodation – despite mental health professionals providing evidence to the NDIA that the person is at risk of serious harm or even suicide if they cannot live in a house of their own – see Case Study 1.

<sup>&</sup>lt;sup>58</sup> National Disability Insurance Scheme Act 2013 (Cth) ss 3, 4, 33(5), 34; National Disability Insurance Scheme (Supports for Participants) Rules 2013 (Cth) rr 1.2; National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2020 (Cth) rr 16(a), 18(a).

#### Case Study 1: Example of the AAT overturning an NDIA decision – LWVR v NDIA 59

An NDIS participant, known as 'LWVR' to protect her anonymity, asked to live in single occupant SDA. Among the reasons that she gave for wanting to live alone was her mental health. This was supported by a number of reports from psychological experts. The NDIA nonetheless refused to fund her for SDA to live alone.

When LWVR's case went to the AAT, the NDIA agreed that only funding her to live with other people would 'likely exacerbate her depressive and anxious symptoms', and that there was a '...real possibility that [LWVR] may take her own life if she faced the prospect of sharing SDA...' Despite this, the NDIA still argued that LWVR should only be funded to live in a shared accommodation, since this might be cheaper for the NDIS to fund.

In November 2021, the AAT ultimately decided that LWVR should be given funding for SDA where she could live alone, because the risks to her mental health were 'sufficiently severe' to justify the additional costs in providing single occupant SDA. However, this result was only reached after a lengthy review process.

In other cases, couples and families – including families with young children – have been given funding decisions from the Agency that say they should live in a group home setting, despite the impact this can have on family relationships and children's development. There have been many other examples of people with good reasons to want to live in single occupant SDA, and which have been ignored by the NDIA, including:

- Immunocompromised people who are concerned that living with housemates would endanger their health
- People who need space and privacy so they can participate in home-based rehabilitation and recreation that is critical to maintaining their health, wellbeing and level of function, or take part in their hobbies
- People who work from home and would not have any space for a quiet workstation if they lived in a shared home
- People from Culturally and Linguistically Diverse (CALD) backgrounds, who cannot communicate with other residents and support staff in a shared residence because of language barriers, or for whom a shared residence is culturally inappropriate

<sup>&</sup>lt;sup>59</sup> LWVR and National Disability Insurance Agency [2021] AATA 4822.
A full copy of this decision can be viewed online at http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2021/4822.html

#### Case Study 2: Example of the NDIA overlooking needs and preferences – Katrina\*

Katrina is a woman in her early 40s who is an NDIS participant. She applied for SDA, and requested to live alone for a number of reasons.

As Katrina is immunocompromised, living with other people (particularly with COVID-19 circulating in the community) would place her at serious risk of catching a life-threatening disease. Katrina has experienced anxiety and poor mental health when she is forced to constantly worry about exposure to disease, such as in a shared home where another person's visitors and care staff are circulating regularly. Katrina also works from home as a creative professional, and would like a quiet workspace rather than needing to try and cram a desk into her bedroom. Finally, Katrina also values her privacy and independence, and is at a stage of life where she would like her own space and home.

Katrina provided all of the above information to the NDIA, along with expert reports and other evidence to support her reasons for her request. The Agency agreed that Katrina required SDA, but would only agree to fund her for shared SDA with another person.

Katrina has faced a series of rejections by the NDIA since first requesting single occupant SDA in 2020, and has recently applied to the AAT for external review of this decision.

\*Name has been changed.

Generally, these decisions are made on the basis that, in the NDIA's view, it would be cheaper to fund a person to live in a shared dwelling rather than a co-located single occupant dwelling with shared support. These assessments are often short-sighted, ignoring the longer-term benefits and efficiencies of funding a person for a home that suits their preferences and needs.

A recent review of existing academic research into the benefits of individualised housing for people with disability found that providing people with their own home helped develop autonomy, greater skills and independence, better social relationships, and improved mental health and overall wellbeing. Furthermore, new evidence from a national longitudinal study from La Trobe University and the Summer Foundation shows that single occupant SDA built with tenant outcomes in mind will improve independence, quality of life, wellbeing, and community integration. NDIA data also shows that the cost of Core supports for participants living in single occupant SDA are lower than when two or three participants live together in an SDA house. These are clear benefits to individualised housing that improve the lives of people with disability, and may even be more cost-effective in the long run by reducing the need to fund other supports. At the same time, a number of independent bodies have made clear that forcing people to live in shared accommodation and/or group homes increases the risks of abuse and neglect, disempowers the people involved, and potentially breaches Australia's obligations under the UNCRPD.

<sup>&</sup>lt;sup>60</sup> Oliver, S., Gosden-Kaye, E., Winkler, D., and Douglas, J. (2020). 'The Outcomes of Individualized Housing for People with Disability and Complex Needs: A Scoping Review.' *Disability and Rehabilitation*.

<sup>&</sup>lt;sup>61</sup> Douglas, J., Winkler, D., Oliver, S., Liddicoat, S., D'Cruz, K. (in press). 'Moving into new Housing Designed for People with Disability: Preliminary Evaluation of Outcomes.' *Disability and Rehabilitation*.

<sup>&</sup>lt;sup>62</sup> Commonwealth (2022). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ22-000021.

<sup>&</sup>lt;sup>63</sup> See Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020). 'Overview of Responses to the Group Homes Issues Paper'; Australian Human Rights Commission (2019). 'Information Concerning Australia's Compliance with the Convention on the Rights of Persons with Disabilities: Submission to the United Nations Committee on the Rights of Persons with Disabilities,' 25 July, pp. 81-85; Independent Advisory Council (2019). 'Challenges in Housing and Support Under the NDIS.' November, pp. 4, 9.

In figures provided to Senate Estimates, the NDIA confirmed that in the 2020-2021 financial year 3,507 people were given SDA funding for the first time, but only 567 of them were funded to live in single occupant SDA. <sup>64</sup> It should be noted that not all of these participants would have requested single occupant SDA and some may prefer sharing a dwelling, and the NDIA states that it does not keep statistics about SDA preferences. <sup>65</sup> Without evidence to the contrary, however, it appears that most people who ask the NDIA for funding to live alone in SDA are refused. When considered together with TMS data, this suggests that the NDIA regularly overlooks the needs and preferences of people seeking SDA funding, and disregards their right to choice and control.

In other apparent efforts to rein in costs, in addition to funding participants for shared rather than single-occupant SDA, the NDIA is making decisions to fund SDA that:

- Is located in an area where the person does not want to live, but where housing is cheaper
   see Detailed Case Study 1
- Provides a lower level of supportive features than the person requires (e.g. lacking a ceiling hoist to transfer in and out of a wheelchair, or a breakout room for the person to manage mental health episodes)
- Is in a different kind of building than the person requests (e.g. a villa rather than an apartment)

It is not clear why the NDIA appears to be concerned that the costs of funding SDA will endanger the financial sustainability of the NDIS. The federal government expects SDA funding to reach \$700 million per year, <sup>66</sup> but is currently only spending 33% of that amount. <sup>67</sup> This means that nearly \$500 million has been set aside to pay for SDA for participants that is not being spent. Given this, it is unclear why funding participants for their required SDA would be unsustainable for the Scheme. Such an approach also ignores the costs of denying participants the benefits of SDA identified above – namely independence, quality of life, wellbeing and community integration.

Because of this, PIAC and the Housing Hub believe that the focus on cost by NDIA decision-makers is disproportionate and unhelpful. Instead, Agency leaders should issue directives that all NDIA staff give greater weight and consideration to the many ways in which appropriate housing can improve the lives and outcomes of participants. This would reflect the underlying intention of the NDIS, and its legislation, to provide individual solutions to improve the lives for each person with disability under the Scheme.

While such a reorientation in focus by the NDIA would be helpful, PIAC and the Housing Hub also contend that the legal framework for SDA could be made clearer to provide less scope for misunderstanding and reinforce the central NDIS principles of choice and control. An effective way to do this would be by amending the *SDA Rules* so that a decision-maker must start by considering the type of SDA a participant has requested, and only fund a different type of SDA if there are good reasons that clearly show that this is the more appropriate option.

#### Recommendation 1

That Ministerial and Agency leaders direct NDIA planners and those on the Home and Living Panel to give greater weight to:

- The importance of maintaining social connection and informal supports
- The consequences of various SDA models for participant's health, wellbeing, lifetime care costs and social and economic participation, when making decisions about SDA funding for participants
- A participant's preferences, as described by the legislation

<sup>&</sup>lt;sup>64</sup> Commonwealth (2021). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ21-000167.

<sup>&</sup>lt;sup>65</sup> Commonwealth (2021). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ21-000114, Q4b.

<sup>&</sup>lt;sup>66</sup> NDIA (2018). 'SDA Provider and Investor Brief.'

<sup>&</sup>lt;sup>67</sup> NDIA (2022). 'NDIS Quarterly Report to Disability Ministers: Q2 2021-2022.'

#### **Recommendation 2**

That the SDA Rules be amended to establish rebuttable legal presumptions that a person who has very high support needs and/or extreme functional impairment should be funded for the kind of SDA that they request. This would include setting out in law that a person's preferred kind of SDA represents 'value for money' unless it can be shown through clear evidence that another kind of SDA would achieve the same goals for the person and would be significantly cheaper; and establishing that a person should only be funded for a kind of SDA that is not their preference in exceptional circumstances.

#### 4.2 The NDIA's decision-making is often unfair, opaque, and delayed

In addition to making SDA funding decisions which seem to overlook the needs and preferences of participants, the NDIA's *process* of making decisions is also unfair and lacks transparency. In turn, this leads to added frustration and stress for people requesting SDA.

#### 4.2.1 Delays in decision-making

A major issue is the delays that happen after a person requests SDA. As discussed earlier, the NDIS includes a PSG, which promises that service by the NDIA will meet certain standards, including the making of decisions in a timely way. The Agency's website says that it meets its standards for approving participant's plans and conducting internal reviews in 86% and 85% of cases respectively.<sup>68</sup>

Despite these overall figures, in the case of decisions about SDA, participants supported by the TMS waited a median of 97 days for their plans to be created (instead of the maximum of 56 days that the PSG promises), and a median of 99 days for an internal review to be finalised (instead of the 60 day maximum promised by the PSG) – see Table 2. This would mean that the average participant in this dataset who requests SDA, and is given an SDA funding decision which they choose to review, would need to wait 196 days for the NDIA to fully consider their request.

While decisions about SDA can be complex, involving a lot of issues and documents, these delays are extreme. At a minimum, participants awaiting an SDA decision will be frustrated and disillusioned by these extensive waiting times. However, in many cases the consequences are more serious, where participants are left living in sub-par situations that can result in a loss of skills and social connection or can even pose dangers to their wellbeing and health.

Until recently, the PSG was only a policy, which meant if the Guarantee was not being satisfactorily delivered, a participant was limited to complaining to the NDIA. Recently, by amendments to the *NDIS Act*, the PSG was legislated. The exact way the PSG will be implemented will be contingent on *NDIS Rules* yet to be developed. When the Guarantee is fully legislated, it is essential it is implemented by the NDIA in consultation with the disability sector, and that the NDIA is made accountable for doing so.

<sup>&</sup>lt;sup>68</sup> NDIA (2022). 'Participant Service Guarantee.'

The current form of the legislated Guarantee fails to set standards specifically for SDA decisions and allow these to be reported on clearly. Because housing and SDA are such important supports for people who need them, these standards should hold the NDIA to a higher standard than for other decisions – when a person requests SDA, PIAC and the Housing Hub contend that the NDIA should make a decision about whether to fund that SDA within 10 days, and finalise the plan to provide the person's funding within 28 days. This should then be tracked and reported on separately to the overall statistics for plan decisions.

The legislative amendments require the Commonwealth Ombudsman to report on this process; there must be clear and accessible avenues for participants to share their accounts with the Ombudsman and the resulting reports must be detailed and reflect these participant's experiences. As explained above, when only general statistics on NDIA decisions for all plans are reported, this can mask the fact that while the NDIA might meet the Guarantee's standards for many kinds of participant requests, it regularly fails to handle SDA requests in a timely way.

It is important that the standards and statistics for SDA decisions consider the total wait time for a participant of all of the steps involved in their request for SDA, so that they take into account the total time that a person is left waiting for a fair decision about where they are to live. For instance, the NDIA reports that on average, the Home and Living Panel takes 32 days to make a funding decision. However, the Agency also notes that this is how long it takes for just one of several internal steps in the 'end to end planning process' of requesting SDA funding. It seems likely that the time taken by NDIA planners to communicate a participant's request to the Panel, and then communicate a decision from the Panel back to the participant, is not accounted for in the 32 days, nor publicly reported.

Unfortunately, the Guarantee legislation does not prescribe time limits for the NDIA to consider and decide most requests for SDA. It does not contain specific provisions for SDA, and it is understood that decisions on SDA may even be excluded from this general framework – meaning that the NDIA could continue to make decisions on requests for SDA very slowly without being held accountable. The Guarantee would therefore hold the NDIA to a *lower* standard for SDA than for other decisions. This would not address the issues identified in this report, or meet the needs of participants for timely decisions.

The government could fix many of the above problems by crafting the right *NDIS Rules* to finish implementing the Guarantee. As the government drafts these *Rules*, they must take into account the experiences of participants dealing with delays for SDA decisions, and introduce clearer standards and accountability mechanisms.



<sup>&</sup>lt;sup>69</sup> Commonwealth (2022). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ22-000020.

#### **Recommendation 3**

That the planned NDIS Rules implementing the Participant Service Guarantee be prepared and implemented as a matter of priority; and that they ensure the Guarantee operates effectively to:

- Set specific standards for Home and Living Panel/SDA and housing-related support
  decisions, distinct from other types of plan. These standards should require urgent
  decisions (e.g. young people at risk of RAC, NDIS participants in hospital or living in
  precarious housing) to be made within 10 days of a participant's request, and all SDA
  and support decisions to be made in under 50 days
- Assess the total time taken from the time a request for support was made by a
  participant, until the time a binding decision on that support was made and
  communicated to the participant
- Provide clear avenues for individual participants to report their experience to the Commonwealth Ombudsman charged with overseeing the implementation of the Guarantee

#### 4.2.2 Failure to prioritise particularly urgent groups of cases

Within the general context of slow decision-making and delays, even many acutely urgent cases are held up for months. These cases have serious knock-on effects for the participants affected, and on wider family, friends and social networks. In particular, there are several specific groups of people whose SDA applications should be prioritised, but who often face long waiting times and serious consequences.

#### People in hospital who cannot be discharged

It is common for people with disability to be admitted to hospital for treatment, particularly if their level of disability increases or they experience related health issues. In addition to this, there is the cohort of people who are admitted to hospital as a result of acquiring their disability (e.g. spinal cord injury, traumatic brain injury, stroke, etc). The person's disability and health conditions may mean that they cannot return to their former home, and instead require an SDA home to meet their support needs.

Over 9% of participants requesting SDA who were assisted by the TMS were in hospital when they requested SDA funding – see Appendix A. Without suitable alternative housing as they wait for an SDA funding decision to be made, many are forced to remain in hospital. The result is that a person who is clinically ready for discharge is left occupying a hospital bed, living in an institutional hospital setting (with associated limitations on freedom, visitors, etc), and is unable to begin re-establishing themselves in their home and in the community.

As at November 2021, NDIA data showed that there were 1,140 NDIS participants who were waiting on a plan to be approved so that they could be discharged from hospital.<sup>70</sup> This delayed discharge not only affects participants and their families, but also may be costing taxpayers over \$800m per year.<sup>71</sup> While not all of these people will necessarily require SDA, the TMS data suggests that many of them do, and each one represents a person left occupying a hospital bed as they await an NDIA decision.

<sup>&</sup>lt;sup>70</sup> Commonwealth (2021). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ21-000226.

<sup>&</sup>lt;sup>71</sup> Summer Foundation (2022). 'Pre-Budget Submission.'

## Case Study 3: Example of NDIA decision-making delays and their consequences – Gregory\*

Gregory is a man in his early 60s, who was admitted to hospital with a sudden and very severe illness at the end of 2019. After a lengthy period of treatment, Gregory was ready to be discharged from hospital by the start of 2021. However, his illness left him with a severe and ongoing physical disability that meant he could not move back into his previous home, and would instead need an accessible SDA property. He prepared and submitted a detailed SDA application in March 2021, asking to live in single occupant SDA with shared onsite support.

Gregory was nervous about sharing a home with others as he feels sharing a home would make it difficult to continue his rehabilitation, and play music in a band. He also needs a private space where he can spend quality time with his partner and adult children; as their homes are not accessible, he will only be able to spend private time with them one-on-one if he lives alone.

It took six months from the time that Gregory requested SDA for the NDIA to finish considering his plan and his internal review request – at the end of which, the NDIA refused to fund him for single occupant SDA. For the whole of that six months, Gregory was left waiting in hospital.

Gregory's case is now before the AAT. Gregory has recently moved from hospital into temporary transitional accommodation, which remains unsuitable for his needs. Without his own home to welcome guests, several months after his first grandson's birth Gregory had only been able to meet him briefly – outside, on his daughter's front lawn.

\*Name has been changed.

#### Younger People in Residential Aged Care

Under past and present systems of disability housing in Australia, younger people with high support needs have often found themselves forced into residential aged care (**RAC**). In RAC, younger people often lose skills and the gains they made in rehabilitation, lose social connection and lose hope.

This is detrimental to the individual's wellbeing, and often results in an inefficient mismatch between the RAC system and the support needs of the younger person. Unfortunately, this means younger people may end up 'falling through the cracks' of other government systems, such as disability care services, so that the only setting that can provide the necessary institutional care is in RAC.

Australian state and federal governments have repeatedly said that reducing the number of Younger People in Residential Aged Care (**YPIRAC**) should be a priority. However, many YPIRAC are NDIS participants who have been unable to obtain the SDA that they need in a timely manner. At 31 June 2021, 886 YPIRAC were NDIS participants who had said that they wanted to leave RAC.<sup>72</sup> On that same date, 19 of these people had applied for SDA funding but were still waiting on the NDIA to make a decision.<sup>73</sup> Over 7% of the participants helped by the TMS were living in RAC when they requested SDA – see Appendix A. Unfortunately, many of them have stories like Mark's.

<sup>&</sup>lt;sup>72</sup> DSS (2022). 'Younger People in Residential Aged Care Strategy 2020-2025: Annual Report.' <a href="https://www.dss.gov.au/sites/default/files/documents/12\_2021/younger\_people\_in\_residential\_aged\_care\_strategy\_2025\_-\_annual\_report.pdf">https://www.dss.gov.au/sites/default/files/documents/12\_2021/younger\_people\_in\_residential\_aged\_care\_strategy\_2025\_-\_annual\_report.pdf</a>

<sup>&</sup>lt;sup>73</sup> Commonwealth (2021). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ21-000183.

#### Case Study 4: Example of NDIA delays for participants living in RAC - Mark\*

Mark is 57 years old. In 2016, he acquired a serious infection from antibiotic-resistant bacteria, which damaged his nervous system and left him unable to walk or use his right arm and requiring a high level of support and assistance. Mark still has this bacterial infection, which means that everybody who deals with him needs to be extremely careful and use full protective equipment, as well as disinfecting everything that he touches.

Mark spent a number of years in hospital, but in 2019 was ready to be discharged. He was discharged into an aged care facility, where he has been completely confined to his room due to the risk his infection would pose to other residents.

Mark wants to live in SDA, and requested SDA on 7 June 2020. It took five months, until 7 December 2020, for the NDIA to make a decision on his request. In that decision, the NDIA only agreed to fund him for SDA shared with another person – which Mark and his team believed would be impossible for Mark to live in, as Mark's infection would cause huge risks to any housemate(s) he had.

Mark requested an internal review of this decision. The internal review was decided on 18 August 2021, when the NDIA decided not to change their initial decision. Mark has applied to the AAT for a review of this decision; his case is ongoing at the AAT.

More than 18 months after he initially requested SDA, Mark remains in Residential Aged Care. \*Name has been changed.



#### People at risk of or experiencing homelessness

The most troubling group of people left waiting for an SDA decision are those who are left homeless in the meantime. All Australians would agree that people with disability – particularly those with the kinds of high support needs that require an SDA home – should not be left homeless by delays and failures in government systems that are supposed to provide for them. Tragically, in many cases we have heard stories of people left without a stable home, couch-surfing or sleeping rough, while they wait for extended periods for a decision on their request for SDA. It is extremely difficult to gather statistics about these cases, which means that the scale of this problem is hard to measure; but the serious risks of being homeless and having a disability that requires very high support needs mean that it must be addressed immediately. While the NDIS is not designed to fix the broader problem of homelessness in Australia, the NDIA must ensure that poor administration and delays do not make the problem worse.

#### Case Study 5: Example of NDIA delays and lack of written decisions – Penny\*

Penny is 53. In 2017, she was diagnosed with Cerebellar Ataxia, a condition that affects her ability to balance, walk, and co-ordinate her eyes and limbs.

Penny and her partner sold their home around the end of 2019 and decided to travel around Australia by caravan. After they began their trip, her condition suddenly worsened and she became unable to mobilise without a wheelchair, as well as requiring substantially higher levels of care.

Unfortunately, the caravan Penny and her partner were travelling in is completely unsuitable for her current needs, and she is unable to safely access the toilet or shower in the caravan or at public campsites. As Penny has no stable home, she has been effectively homeless for the past two years. She and her partner have to move the caravan regularly, to find another campsite where there is an available caravan space. She has lost a lot of weight, and has been admitted to hospital multiple times due to the damage to her health from her living situation.

Penny's deteriorated condition means that she now requires SDA. Penny requested SDA in August 2021, flagging the above issues, but waited for months with no response from the NDIA. In December 2021, she tried to escalate the matter – the NDIA told her that they wouldn't be able to meet with her and make a decision until February 2022. In March 2022, Penny was told verbally by an NDIA staff member that the NDIA would fund her for shared SDA (despite the fact that she had requested to live alone), but still has not received a formal written decision.

Penny remains transient, living out of her caravan, with no funding to access SDA. \*Name has been changed.

In each of these situations, the NDIA's very long wait times have especially significant consequences. While the NDIA must fix and reduce wait times for all participants, it must give the highest priority to SDA applications for people in hospital, YPIRAC, and people at risk of or experiencing homelessness.

#### **Recommendation 4**

That the NDIA urgently prioritise decisions relating to people seeking SDA who are in hospital awaiting discharge, living in RAC as a younger person, and/or facing homelessness. In these cases participant choice, needs, and the potential for SDA to maximise independence and create a pathway back to community living should be given even higher weight in decision-making.

#### 4.2.3 Disregarding evidence and documents provided by participants

Decisions made about SDA need to consider a person's personal goals and desires for the future, the impacts of their disability on their life, support and treatment needs, and current circumstances. Preparing a request for SDA can often be a time-consuming and stressful process. Most NDIS participants are anxious to make sure the Agency understands their situation and the reasons they need a specific type of SDA. This can include filling in lengthy forms, writing personal statements of their life experience, being examined by doctors and specialists and paying for medical and expert reports, and getting letters from family, friends and employers. Many SDA applications are well over 100 pages long, which is necessary to make sure the NDIA has all the information it needs to make a decision in line with eligibility criteria.

In spite of this, in many cases it is apparent that the NDIA has not fully considered all the documents provided, or even read them. Many participants complain that they are asked to provide a document that has already been provided, suggesting the NDIA has not looked at the information provided. One NDIS participant wrote to the Parliamentary Joint Standing Committee on the NDIS to express their frustration:

NDIA demand 'more evidence' endlessly – as soon as one report is provided by us, we are told we need to provide more evidence. This has happened countless times, and for one of our plans we have provided over 20 reports. When we ask what evidence is needed, or what was missing from the previous reports, or what questions have been left unanswered in the material we have provided, these have not been clarified or specified. Providing endless reports, particularly with inadequate information about what NDIA is seeking, has been time-intensive, highly anxiety-inducing, and at times financially costly.

NDIA ignore evidence that has been provided, even though this evidence has been requested by them, and is expert and comprehensive. I have even been told by a delegate that specialist reports are not evidence, and that they are not obliged to pay attention to the contents. If that is true, why are we sent to get more and more evidence? It is unfathomable how delegates with limited expertise in specialised areas get to override the expertise of multiple specialists with high levels of expertise.<sup>74</sup>

In NDIA decisions where the decision-maker lists all of the documents that were considered, participants are frequently dismayed to see that many documents they provided are not listed. In some cases, the NDIA has openly expressed that it did not look at the documents that were sent – see Case Study 6.

This experience aligns with what PIAC has seen in many cases. It is not only unacceptable, but also unlawful. When making a decision, the NDIA has a legal obligation to consider all relevant matters, including evidence and documents that are provided to it by the participant.<sup>75</sup> The NDIA must improve the quality of its decision-making, and should have clear processes for monitoring and addressing poor-quality decision-making.

<sup>&</sup>lt;sup>74</sup> Submission to the Joint Standing Committee on the National Disability Insurance Scheme, General Issues around the implementation and performance of the NDIS, *Submission 80 – Name Withheld* (27 February 2019)

<sup>&</sup>lt;sup>75</sup> See, for instance, Minister for Aboriginal Affairs v Peko-Wallsend Ltd (1986) 162 CLR 24

#### Case Study 6: Example of NDIA maladministration - Philip\*

Philip is in his early 30s, and has an acquired brain injury. He lives with his parents, but wants to move into his own home.

Philip applied for SDA, and provided a large number of documents including reports from doctors, occupational therapists and support coordinators, letters from his family, and details of his proposed SDA home and support arrangements. The NDIA decided he was not eligible for SDA, and confirmed that decision after an internal review.

Philip applied to the AAT. One day before the first AAT case conference, the NDIA's lawyers wrote to Philip and admitted that the NDIA had not considered the documents he had given them over six months ago.

Philip and his family were very frustrated that the NDIA had ignored the documents they had spent a lot of time and effort to provide. This failure meant that Philip's internal review decision was not made fairly, and that his AAT application was delayed while the NDIA took time to belatedly review those documents.

\*Name has been changed.

Additionally, the NDIA provides little guidance as to the kind of evidence it thinks is most relevant, and the sorts of details and information it would like participants and their professional supports to provide when requesting SDA. If the NDIA was more transparent about how it makes decisions and the information it needs to do so, it would allow participants to provide more specific and succinct reports and evidence, and increase the efficiency of the decision-making process.

#### **Recommendation 5**

That the NDIA ensures decision-makers review and consider all evidence provided by the applicant, in line with legal principles regarding administrative decisions. This should include preparation of appropriate policies, introducing review and quality-control mechanisms for decision-makers, and providing training and accountability processes for decision-makers who fail to meet minimum standards.

#### Recommendation 6

That the NDIA prepare and publish written guidelines regarding the specific evidence needed for a timely SDA decision, to enable stakeholders to assist the NDIA by providing concise and relevant information that is aligned with the NDIS legislation. Guidelines and FAQs could be developed for different stakeholders including NDIS participants, Support Coordinators, Occupational Therapists and other allied health and health professionals.

#### 4.2.4 Opaque process for SDA decisions

As explained above (see 2.3), when a participant requests SDA their application is escalated to a specialist panel within the NDIA, made up of senior staff who specialise in making these kinds of funding decisions. This panel has variously been named the 'Home and Living Panel' and the 'SDA Panel', but its function remains the same.

The decision-making processes of the Panel are opaque. Its operational guidelines and minutes are not published, and there is little public information about it available on the NDIS website. Furthermore, NDIA planners do not explain the role of the Panel to participants. Everything known publicly about the Panel has been gathered through freedom of information requests to the Agency, and reviewing information provided under questioning at places like Senate Estimates hearings. This means that most NDIS participants who ask for SDA funding have no real way of understanding how the NDIA will consider their request.

From the information PIAC has gathered, it is understood that the Panel meets each week for 1-1.5 hours and in that time decides between 5-15 participants' requests for SDA. To look not be Panel works off a summary document prepared by the planner using an internal NDIA template — which the participant is not shown, and has no opportunity to contribute to or comment on. The Panel issues binding decisions on each request for SDA, which are then communicated to the participant by their planner.

A number of participants have expressed serious concerns to PIAC about this process. Based on the duration of meetings and number of decisions made at each meeting, the Panel seems to spend somewhere between 5 and 20 minutes to consider a funding request and make a decision. As SDA requests often contain hundreds of pages of expert reports, statements from participants, letters from friends and family, and extremely complex law, many participants believe that the Panel does not allow enough time to properly consider their request and is overlooking important information in their request.

Other participants are frustrated that they have no opportunity to speak directly to the people who decide their SDA request, or to respond to any questions or concerns the Panel might have about their request. Many feel that as the Panel is made up of senior NDIA staff it may not be appropriately considering their personal circumstances and, instead, making decisions based on wider factors such as budgetary savings.

PIAC does not necessarily oppose the use of Panels like these by the NDIA; and, indeed, welcomes the use of specialised knowledge to assess complex matters. However, the opaque processes of the Panel have the unfortunate effects of fostering suspicion among many participants and eroding faith in the decision-making process. The opportunity is also lost for participants and stakeholders to give input on how to make the Panel and the NDIS as a whole work better.

<sup>&</sup>lt;sup>76</sup> As at the date of this report, there were two passing references made to a Panel, neither of which provided any substantive information about its operations. One was from a speech given by the NDIA CEO in 2019; the other was in minutes of a Working Group. NDIA (2019). 'Housing Options for People with Disability are Increasing Under the NDIS.'

https://www.ndis.gov.au/news/3475-housing-options-people-disability-are-increasing-under-ndis; NDIA (2019). 'SDA Reference Group.' https://www.ndis.gov.au/about-us/reference-group-updates/sda-reference-group/december-2019-sda-reference-group

<sup>&</sup>lt;sup>77</sup> NDIA Executive Brief ref EC21-000663 (13 September 2021), p1 - released pursuant to FOI request NDIA 21.22-0422

<sup>&</sup>lt;sup>78</sup> FOI request NDIA 21/22-0754

#### Recommendation 7

That the NDIA provide greater transparency around the operation of the Home and Living Panel by:

- Publicising information on the NDIA's website about the Panel's existence and role, including its terms of reference/procedures and guidelines
- Publishing information about the internal processes for SDA applications and the process for reviews to allow greater transparency
- Directing representatives that Panel documents must be included in all document disclosures prepared by the NDIA for relevant AAT proceedings (known as 'T-documents')
- Proactively engaging with applicants whose matters are set to be sent to the Panel, by informing them of this process and providing an opportunity to write to the Panel directly

#### 4.3 The NDIA makes regular and significant errors in administering processes

There is a detailed and complex legal framework for the NDIA to make decisions about SDA. This includes the matters that the NDIA needs to take into account, the process for considering them, and the way that a person can ask for a review of a decision they do not agree with. The result is that the law in this area can be difficult to understand. In our experience, participants are further disadvantaged by the NDIA failing to follow laws and processes correctly, and providing incorrect information and advice to participants.

#### 4.3.1 NDIA errors and maladministration of SDA applications

In PIAC's work with NDIS participants, we have been surprised at how often the NDIA makes fundamental mistakes in processing applications for SDA. These errors include:

- Incorrectly processing requests for an internal review of an SDA decision as requests to consider making a new plan
- Failing to save supporting documentation received from participants, meaning that those documents are lost and not considered properly
- Not informing participants that they have initiated a review of the participant's NDIS plan
- Only considering some requests for support funding that a person has asked for, and ignoring requests for other supports
- Sending correspondence to participants that is described as a 'decision', but does not meet the legal requirements to be a lawful decision
- Failing to notify participants who have requested SDA that a decision has been made on their request. This has particular implications for participants requesting reviews of decisions, given the time limits that apply to internal reviews and AAT applications

Of the matters reviewed by PIAC for this project, over half of them involve at least one of these errors.

#### 4.3.2 Incorrect and misleading advice to participants

Given the opacity and complexity of Agency processes, many participants rely upon guidance from NDIA staff to make their requests for SDA. PIAC has regularly seen legally incorrect advice provided by the NDIA to participants. Examples include:

- A support could not legally be funded and so should not be requested for inclusion in an NDIS plan (when no such legal bar to funding exists)
- A particular decision could be reviewed by the AAT (when it could not)
- The participant needed to get a new plan drawn up in order to have a support considered, while neglecting to inform the participant of their right to have their existing plan reviewed
- The participant had to withdraw their request for an internal review (when no such requirement existed)

#### 4.3.3 Interactions and consequences of process issues

The two categories of issues discussed above compound one another – for instance, administrative errors can be made much harder to unravel by subsequent incorrect advice, as has happened in a number of matters that PIAC have reviewed.

#### Case Study 7: Example of NDIA maladministration – Jeremy\*

Jeremy asked for SDA that would allow him to live in his own home with shared onsite support. After a lengthy wait, the NDIA decided to only fund him for shared SDA.

Jeremy submitted a form requesting an internal review of this decision. However, the NDIA staff member who received his form entered it into the NDIA systems incorrectly, as a request for a new plan. Jeremy was not told of this mistake.

The Agency then sent a number of inaccurate and confusing letters to Jeremy. One letter said that his plan was being reviewed. Another letter said that the NDIA had decided not to review his plan. When Jeremy complained about the contradictory letters, and the long time the NDIA was taking on his internal review, he was assured that the internal review was ongoing and would be finished soon.

The NDIA then made a decision about Jeremy's SDA, but instead of making an internal review decision, they gave Jeremy a new plan (which still did not have the SDA funding he requested). When Jeremy asked the NDIA why this had happened, he was (incorrectly) told that the form he had submitted was the form for a new plan, and so they had not done an internal review of his plan.

Finally, the NDIA sent him an email saying that they would not approve his funding, but that he could appeal this to the AAT. This advice was also legally incorrect. Since the NDIA had not provided Jeremy with an internal review decision, he was ineligible to request an external review.

By this time, Jeremy had been waiting on the internal review process for over seven months. He was frustrated and confused. Fortunately, Jeremy was able to speak to a lawyer and get detailed legal advice. It took the lawyers working with Jeremy several hours of reviewing his documents and email trail to discover the many mistakes that the NDIA had made, and explain to Jeremy what his options were.

\*Name has been changed.

As the TMS data above illustrates, participants often find that the NDIA is firm in its refusal to fund them for the SDA that they want. In these cases, the only way to get a fair amount of funding for SDA is to take their case to an external body, by challenging these decisions before the AAT. However, before a case can be appealed to the AAT, there are a number of procedural steps that must be followed within the NDIA internal review. These steps must all happen in sequence, within strict time limits, and in the correct format. Any interruption or procedural error will prevent the participant from taking their case to the AAT for an external review of their case.

This happens frequently, as a result of the problems outlined above. The end result is that a participant who has spent months navigating the NDIA's lengthy and delayed processes may have their case interrupted as a result of faulty advice or NDIA mistakes. This means they may lose their right to review by the AAT, and be forced to go back to the start of the process of requesting funding for SDA.

#### Recommendation 8

That the NDIA urgently overhaul its internal processes and policies to eliminate critical administrative errors and the delivery of incorrect advice to participants. In doing so, it should consider conducting a top-down audit of processes, policies, and service delivery by staff at all levels.

# 4.4 The NDIA regularly fails to meet obligations to participants when reviewing funding decisions

The problems discussed above arise from the NDIA's internal processes to decide whether to fund a person for SDA. If, at the end of this, the person decides to appeal that decision to the AAT, they face further systemic issues.

#### 4.4.1 Failing to give adequate reasons for decisions

Good governance requires that government agencies should give reasons for the decisions that they make that affect people's rights and lives. In many situations, the NDIA has a legal obligation to provide detailed reasons when they make an internal review decision not to fund somebody for their preferred SDA.<sup>79</sup> These reasons need to include all of the Agency's findings about relevant facts, the evidence they used to make those findings, and the way that those findings have led them to their final decision.<sup>80</sup>

Unfortunately, the NDIA often does not comply with this obligation. When the NDIA makes an internal review decision, it provides a letter titled 'Outcome of your internal review request', with subheadings titled 'Basis of Decision...'. However, in most cases that PIAC have seen, the letters are made up almost entirely of boilerplate text, and provide only one or two sentences of actual explanation about the reasons for refusing the participant's specific request. This is legally inadequate, and leaves participants with little understanding of why the decision has been made or whether it should be reviewed.

<sup>&</sup>lt;sup>79</sup> Administrative Appeals Tribunal Act 1975 (Cth) ss 28, 37.

<sup>80</sup> Ibid

In PIAC's experience, after a person has applied to the AAT the NDIA's lawyers often raise a number of reasons why the AAT should uphold the original decision, in *addition* to those originally provided by the NDIA as reasons to refuse the request. For instance, in several cases PIAC has seen, the NDIA's internal review decision letter provided a single reason why the participant's request had been refused. Then, soon after the participant applied to the AAT, the NDIA's lawyers have filed a 'statement of issues' with the AAT, stating that they wanted to uphold that decision for several further reasons. No new evidence or information has been provided to the NDIA, meaning that these additional reasons could and should have been included in the internal review decision letter. This suggests that the decision-maker has failed to take into account all relevant matters or has failed to fully explain their reasoning in the internal review decision.

#### **Recommendation 9**

That the NDIA adopt a policy of providing full and detailed reasons for reviewable decisions that comply with the requirements of s 28 of the *Administrative Appeals Tribunal Act 1975* (Cth), to allow a participant to properly assess whether the information they provided with the NDIA has been considered and the strength of their argument that the funding provided is reasonable or otherwise.

#### 4.4.2 Poor conduct of NDIA lawyers in AAT litigation

The NDIA spends millions of dollars each year on lawyers to defend its decisions at the AAT. For the 2020-2021 financial year, the NDIA spent \$21.6 million on external lawyers (a figure which does not include the cost of the NDIA's own in-house legal team, which comprised 32 staff). Often, due to the lack of legal services for NDIS appeals as discussed above, these lawyers are running the NDIA's case against a participant who is representing themselves, or being helped by a family member or friend.

The power imbalance between the lawyers representing the government and the NDIS participants is considerable. An important first step to addressing this imbalance would be increasing funding and resources to Legal Aid commissions in each state, to give more participants access to legal representation. The NDIA is required by law to act as a 'model litigant' and held to a higher standard of honesty and fairness as the representative of the government in a case against an individual.<sup>82</sup> Unfortunately, the NDIA's actions at the AAT have, in our experience, often failed to meet these standards.

In a number of the cases PIAC and the TMS have seen, the NDIA's lawyers have variously:

- Made additional and unnecessary requests for extra evidence from the participant
- Made last-minute settlement offers just before the hearing (for example, see above at 4.4.1)
- Failed to give the participant all of the documents and evidence they are legally required to provide
- Failed to meet deadlines set by the AAT, delaying the case

<sup>&</sup>lt;sup>81</sup> Clun, R. (2022). 'National Disability Insurance Agency Spends Millions on External Legal Costs.' Sydney Morning Herald, 17 February. https://www.smh.com.au/politics/federal/national-disability-insurance-agency-spends-millions-on-external-legal-costs-20220216-p59wxs.html; Commonwealth (2022). 'Community Affairs Legislation Committee Hansard.' 17 February, p. 79. https://parlinfo.aph.gov.au/parlInfo/download/committees/estimate/25620/toc\_pdf/Community%20Affairs%20Legislation%20Committee\_2022\_02\_17.pdf;fileType=application%2Fpdf#search=%22committees/estimate/25620/0000%22
<sup>82</sup> Legal Services Directions 2017 (Cth), Appendix B.

One particularly stark example of poor conduct involves cases where the NDIA's lawyers attend Tribunal conferences with insufficient instructions from the NDIA to progress the case. When this happens, the conference is often a waste of time for the participant, their representative(s), and the Tribunal. The NDIA has disclosed that between 1 March 2021 and 28 February 2022, there were eleven case conferences where the NDIA's lawyers had no instructions whatsoever. In many other cases that PIAC and the TMS are aware of, the NDIA's representatives have attended case conferences with instructions that are insufficient.

Each of these issues is frustrating and disempowering for participants, who are often already stressed and anxious in dealing with the AAT process. The NDIA must ensure that people who appeal its decisions are treated fairly. Additionally, the harm caused by such practices is compounded when applicants do not have their own legal representation.

As set out above (see 2.4), for many participants who would like legal help to challenge an NDIA decision at the AAT their only option is a lawyer from Legal Aid; and even this help is often limited by resource constraints. Greater funding and resourcing to Legal Aid Commissions would help to level the playing field, and reduce the stress and harm caused by litigation.

#### **Recommendation 10**

That the NDIA adopt policies regarding lawyers acting for the Agency in AAT matters, such that:

- All external lawyers receive training regarding disability rights and awareness
- Settlement offers are made as early as possible
- Additional reports and evidence are only requested where they are clearly necessary and will not cause undue delay or stress to the applicant
- T-documents are provided in a complete form and do not omit significant documents such as correspondence with the Panel or internal NDIA materials that are pertinent to the decision made
- Compliance with model litigant obligations is proactively monitored by the Agency

#### **Recommendation 11**

That state and federal governments significantly increase funding to Legal Aid Commissions, in order to meet current and future growing demand for legal assistance and representation with NDIS participant appeals to the AAT.

<sup>&</sup>lt;sup>83</sup> Commonwealth (2022). 'Senate Community Affairs Legislation Committee: Answers to Questions on Notice.' Social Services Portfolio, Estimates. Question No: NDIA SQ22-000009

#### 4.4.3 Refusal to publish settlement outcomes at the AAT

The NDIA has historically settled a very large number of AAT cases before the AAT has reached a decision. The most recent Quarterly Report states that approximately 64% of all finalised cases before the AAT were settled by agreement.<sup>84</sup> These settlement outcomes are not published or made public.

The failure to publish information about these outcomes means there is little transparency about how the NDIA responds to these appeals. In turn, there is no way for participants to hold the Agency accountable and ensure that it makes consistent decisions. Publishing de-identified results would allow greater public scrutiny of the NDIA's decision-making. It would also allow participants to better understand their chances of winning if they appeal a case to the AAT, reducing the number of hopeless appeals that are filed, and would help NDIA planners and the Panel to make better decisions.

Publishing these settlement outcomes would be a simple and effective reform that the NDIA could make. It has been recommended twice, in 2019 and 2020, by the Parliamentary Joint Standing Committee on the NDIS, as well as by the Australian National Audit Office.<sup>85</sup>

#### **Recommendation 12**

That the NDIA publish information around AAT settlement outcomes in a manner which balances confidentiality and privacy obligations with the need for transparency and accountability. In determining the information to be published, the NDIA should consult with participants and advocates, and should have regard to the information published in the Australian Human Rights Commissioner's Conciliation Register.



<sup>&</sup>lt;sup>84</sup> NDIA (2022). 'NDIS Quarterly Report to Disability Ministers: Q2 2021-2022,' p. 62.

<sup>&</sup>lt;sup>85</sup> Joint Standing Committee on NDIS, *NDIS Planning Interim Report* (December 2019), [3.96], Recommendation 6; Joint Standing Committee on the NDIS, *NDIS Planning Final Report* (December 2020), [2.81]-[2.84], [10.85]-[10.87], Recommendation 34; Australian National Audit Office, *Decision-making Controls for NDIS Participant Plans* (Report, 29 October 2020), [3.84], Recommendation 2.

### 5. Detailed case studies

This chapter provides two in-depth case studies from real cases that have progressed through the internal review process to the AAT. The first case, 'Harry', is of a de-identified participant whose request for SDA funding was not met by the NDIA at the initial or internal review stage, and has now requested a review by the AAT. The second case study draws on publicly available information about NDIS participant Anna, in whose case the Tribunal decided in February 2022 to set aside the Home and Living Panel's SDA funding decision.<sup>86</sup>

#### 5.1 Detailed Case Study 1: Harry

Harry is an NDIS participant in his early 30s. He has a rare neurological disease – a form of congenital muscular dystrophy – which results in progressive muscle wasting and a reduction in his physical capabilities. Harry began using a wheelchair in 2019, and a powered wheelchair in 2021. While Harry had previously lived in a rented apartment and shared accommodation, the increase in his needs and progress of his disease meant that these homes were no longer safe for him, and he had to move back into his parents' home. He requires regular support.

#### Harry's difficult current living situation

Harry's parents live in a rural town on the far outskirts of the Greater Sydney area. The house has been modified somewhat to allow Harry to live there. These modifications include the installation of home-made timber ramps so that Harry can take his wheelchair up stairs, but the house remains difficult for Harry to access. Problems for Harry include:

- The long gravel driveway is difficult for him to cross in his wheelchair, and parts of the home like the kitchen aren't modified for Harry to use
- There is no accessible public transport for Harry in the area, meaning that he is very cut off from everybody in his social circle apart from the family members that he lives with.
- Harry has a number of friends in Sydney who he would like to see more often, but struggles
  to do so because he lives so far away and has no convenient way to travel to see them. As
  a result, he has found himself becoming very socially isolated and cut off since moving back
  to his parents' home
- Harry does not need constant support throughout the day, but he does need a support
  person to be available 'on-call' in the case of accidents. He also needs two people to help
  him transfer safely into his wheelchair from bed, and help with other day-to-day tasks like
  cutting up food to eat, brushing his teeth, or dressing. His parents provide this support to
  him at present, but have struggled and felt burnt out at times, including from the need to
  always be around in case to provide support
- While the NDIS provides some funding to use for Harry to pay support workers, it has been very difficult for him and his family to hire appropriate people due to their remote location

#### Harry's goals and plans

Harry wrote down a number of goals in his NDIS plan, which included wanting to see his friends more, go to social events like sporting events and pubs, live independently, and explore study and work options, including one of his passions: video editing. Harry had previously worked in multiple different jobs and volunteered regularly, including providing phone and logistical support to people with similar disabilities to him.

<sup>&</sup>lt;sup>86</sup> Boicovitis and National Disability Insurance Agency [2022] AATA 204. A copy of the full decision can be viewed at http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2022/204.html

After considering his goals, he decided that he would need to move out of home to pursue them. He and his parents looked into the different options that were available, including public housing, community/social housing, purpose-built homes, and group homes and home-sharing arrangements. They decided that the only solution that would meet all of Harry's needs for support, independence and freedom would be a single occupant SDA apartment located in Sydney.

Harry started looking at apartments that would suit him best, and in early 2021 he found a one-bedroom apartment in urban Sydney that fitted his goals perfectly. It was part of a group of apartments, within a '10+1' model which would allow 10 SDA apartments to share one onsite support worker between them (so there would always be an on-call support) and split this support cost across 10 NDIS participants. This would give him the freedom to live alone, but also to call for immediate help when he needed it. The apartment would let him have his own space, with the privacy for work and study. Harry would also be able to see his friends regularly, and move around the city on his own using accessible transport.

Harry was excited at what this new home could mean for his life.

#### Harry's application for SDA

Harry applied to rent the apartment from the SDA provider, which provisionally accepted his application, conditional upon receiving the required SDA funding from the NDIA.

In early 2021 Harry submitted an SDA funding request to the NDIA. In his request he explained what he wanted in a home, why this apartment would be perfect for him, and why other options would not suit him well. He provided a detailed statement, an occupational therapist's report, and a letter from a psychologist, all explaining how this single occupant SDA apartment would best meet his goals, needs and preferences.

Harry then waited for over three and a half months for the NDIA to make an initial decision about his SDA funding. After this time, the NDIA told him that they would fund him for SDA, but only to live in a house with two other people, and only in the same rural area where he was already living. The decision did not include any reasoning behind the determination, but Harry understood that this was because the NDIA thought both his current location, and sharing a home, would be cheaper than Harry's preferred single occupant SDA apartment in Sydney.

Dissatisfied with the outcome, Harry requested an internal review of its decision. With his request, Harry explained that there were many reasons why he couldn't live in the shared home that the NDIA had suggested:

- He had started a new full-time job, which included having highly-sensitive phone calls.
   Therefore, he needed privacy and would not be able to do his job in a shared home
- He also provided medical evidence explaining that his condition has weakened his lungs, and places him in serious danger if he catches a respiratory disease. As a result, living with others would place him in serious danger, and having a housemate's family, friends, support staff and visitors regularly around the home would place him at risk of severe illness and death
- Harry's psychologist explained that Harry would experience anxiety and poor mental health
  if he was not able to control who came and went from his house, due to the risk of infection
  and the feeling of being unsafe
- Harry also engaged professionals with experience in finance to compare the costs of him
  living alone in his chosen apartment to the costs of him living in the three-bedroom house.
  These professionals prepared a report, finding that there would be a number of long-term
  benefits to Harry from living in his own home, which could save the NDIA a lot of money as
  Harry might need less support services as a result. The report also said that, because of

the 10+1 model which would allow him to share a single support worker with nine others, Harry would need less support hours if he was funded for his requested SDA than if he was forced to live in the three-bedroom house. Harry's preferred single occupant SDA would be a lot cheaper overall than the three-bedroom house the NDIA had agreed to fund

Harry wanted to live in urban Sydney, in order to meet his work and life goals. The area the
Agency had funded him to live in would mean that Harry would continue to be isolated from
his friends and supports, and would still struggle to find appropriate support workers

The internal review documents that Harry provided were very comprehensive, and were approximately 50 pages in total. Harry waited another two and a half months before receiving a response from the NDIA. The NDIA refused to change Harry's SDA, on the sole basis that they thought his preferred apartment was not good 'value for money'. The decision said:

You were provided a housing response for Supported disability accommodation (High Phsyical Support Design, 3 bedroom and 3 residemt) and living supports (Supported Independent living) based on your disability related needs. This support is also inclusive of active overnight support to ensure appropriate staffing is available to you immediately should you require it. It is important to source out appropriate accommodation based on the current approved level of support available to you. (errors in original)

Harry was very disappointed that this decision did not seem to have considered all of the points he had raised, including about the total cost of his planned apartment and the reasons he needed a single occupant apartment in Sydney. He appealed this decision to the AAT, and is waiting for the AAT to consider his case. However, he understands that this could take months or even a year to reach a decision. In the meantime, he has had to continue living in unsuitable circumstances in his parents' home.

#### 5.2 Detailed Case Study 2: Anna

Anna applied for SDA towards the end of 2020. She was in her mid-50s, and was living with her mother. Anna and the NDIA agreed that by November 2020 this situation had become extremely dangerous for her. Her mother had begun to verbally abuse Anna, controlling her behaviour, refusing to let Anna use her wheelchair in the home, and treating her in a way that Anna said was traumatic. When the AAT decided Anna's case, it agreed that there was 'a pressing and immediate need for [Anna] to leave the home', and that 'there was a serious and pressing risk' to Anna.<sup>87</sup>

Anna submitted a funding request to the NDIA to live alone in SDA. She noted that her disability required a lot of equipment including her wheelchairs, walking frame, medical supplies, ventilator and gastronomy equipment. Any person that she lived with would probably need the same kinds of equipment, and the house would be very cluttered and hard to move around in. She was worried that this could also cause risks to her, such as if it led to her ventilator being bumped or switched off.

More importantly, Anna also said that she thought most people at her stage of life would not want to live with a housemate; neither did she. She wanted her own space and privacy. One of her hobbies was aromatherapy, and she was worried this could be disruptive to a housemate. Anna's condition makes it very difficult for her to communicate with people who do not know her well, as she is unable to speak louder than a whisper. This made her, and her support workers, worried that she would struggle to manage aspects of a housemate relationship, such as use of common spaces and/or schedules for visitors.

<sup>&</sup>lt;sup>87</sup> Boicovitis and National Disability Insurance Agency [2022] AATA 204.

Anna also requested funding to live in the inner city of Melbourne, so that she would have access to public transport, shops and facilities, and so that she would be near her family, friends, doctor and physiotherapist. However, while there were a lot of single occupant SDA apartments in inner Melbourne, there were no suitable two-resident SDA properties in the area. This meant that if Anna was only funded to live with another person, she would probably need to live a long way away from her preferred area.

Anna and her support team explained to the Agency why she didn't want to live with another person. However, the NDIA thought that she could live in a shared home, and only agreed to fund her to live in a two-resident apartment. Anna requested an internal review, and on 22 June 2021, the NDIA refused to change its initial decision. Anna then applied to the AAT for an external review.

#### The AAT's decision in Anna's case

The AAT proceedings took over six months. In the course of the case, because the NDIA did not accept the evidence of Anna's occupational therapist, the NDIA arranged for a report from their own occupational therapist. After this long process, the Tribunal considered the overall situation, and agreed with Anna that she should be funded to live on her own in SDA.

The Tribunal agreed that anybody Anna lived with would almost certainly have a lot of their own equipment. They would probably also need a wheelchair, and require help from a support worker. The AAT said that this would create a very crowded house that would be unpleasant to live in, and perhaps risky. It found, as Anna's occupational therapist had said, that there was a major risk that difficulties in managing a relationship with a housemate could lead to Anna becoming very isolated from other social contacts, and spending most of her time in her bedroom. The Tribunal said that it was important to support Anna to feel safe in her own home, and to have privacy and independence. It agreed that the best way to support Anna in these ways would be for her to live alone. The alternative, funding her for a shared SDA home, would be worse at achieving these outcomes, while also forcing her to live far away from her preferred location.

Anna said afterwards that she was pleased about the outcome that she got, but had been frustrated at the NDIA's initial responses, and how long and difficult the process had been. She said:

I knew it was possible for me to achieve my goal of living independently with the right supports, so many people I know are, I wanted to provide a future for myself. I wasn't aware of how difficult, unfair, and how long a process the NDIS were going to make it for me. I have Muscular Dystrophy. I was told I needed to put in place in my NDIS plan that I wanted to live alone with the right supports, which I did but after months the NDIS came back with a shared living proposition.

I needed a high physical support 1 bedroom apartment arrangement, now NDIS have asked me to find a 2 bedroom shared apartment, so after some looking into I found that what the NDIS wanted me to find, actually doesn't exist in the current market. I've fought this decision for a year, after the tribunal then a hearing, 9 weeks after the hearing I got the result I wanted at last.

YAY!

I'm not surprised, people tend to give up easily, fortunately for me I'm a fighter, I was going to see this through, I just wasn't prepared it would take 18 months an extremely slow and long process. Delay after constant delay. That's why I encourage people to fight, if they truly believe the decision/decisions that have been given to them is unfair and unjust.<sup>88</sup>

<sup>&</sup>lt;sup>88</sup> Villamanta Disability Rights Legal Service (2022). 'Single Occupant SDA Decision by AAT', *Villamanta Disability Rights Legal Service Inc.* 13 February. https://villamanta.org.au/news/single-occupant-sda-decision-by-aat/

## 6. Conclusion

Despite the life-changing potential of the NDIS, many participants who request funding for SDA experience opaque decision-making and long delays from the NDIA. This report summarised the initial findings from a collaborative project between the Housing Hub and PIAC and provides evidence-based solutions for improving the NDIS participant experience.

Nearly six years after SDA funding became possible, just over half of the anticipated 6% of all NDIS participants eligible for SDA are receiving payments. <sup>89</sup> In recent months, participants and providers have seen an increasing number of participants who request funding for SDA receive decisions from the NDIA's Home and Living Panel that do not align with the evidence they have provided and the kind of housing they have requested. Many of these Agency decisions have been inconsistent with the *SDA Rules*, previous funding decisions for participants with similar functional capacity and support needs, and the funding outcomes for participants who request an AAT review. The choices and preferences of participants have been disregarded, leaving them and their families confused, stressed, and uncertain about the eligibility criteria for SDA.

Collating and analysing administrative data on outcomes and timeframes for NDIA decisions from the Housing Hub's TMS – drawn from work supporting hundreds of participants to request SDA funding – has confirmed that these observed problems are widespread and systemic. TMS data reveals that many participants it supports receive decisions that ignore the evidence they provide, and overrides their expressed needs and choices, at the initial request or internal review stage. Furthermore, significant delays are associated with both of these stages, with median wait times of 97 and 99 days respectively. Of the participants supported to request an external review, the median wait time for an outcome to be reached was 205 days. So for a participant who requests both an internal and external review of an initial funding decision, the entire process could take over 13 months.

Of the 48 participants seeking an external review, 12 had concluded the AAT process and reached an outcome. In total, 11 of these participants ended up receiving the SDA funding decision which they had initially requested from the NDIA, after months (or years) of delay. This indicates that decision-makers – whether the NDIA's lawyers offering settlements, or the independent Tribunal members – are ultimately finding that participants' requests are reasonable and supported by evidence. It also raises questions as to why NDIA internal processes do not lead to similar conclusions.

PIAC's work has highlighted the costs to participants of these delays and practices. As set out throughout Chapter 4 above, these kinds of delayed and incorrect decisions by the NDIA are the result of flawed and opaque processes, poor administration by the Agency, and a widespread failure to consider the individual needs and circumstances of participants requesting this funding. The case studies presented in this report show the real human impacts that these issues can have for participants.

One of the major goals of the NDIS is to ensure that people with disability have the same rights as other members of Australian society, and the same opportunities to live their lives the way they want to. 90 Most Australians would not accept being told that they needed to live with housemates that they do not know or want, or that they needed to live in an area or home that does not suit their needs. People who request SDA funding should not be forced to accept this either. The delays and issues with NDIA decision-making on SDA funding reflect a lack of adequate oversight and accountability, and require action from the federal government.

<sup>&</sup>lt;sup>89</sup> NDIA (2022). 'NDIS Quarterly Report to Disability Ministers: Q2 2021-2022.'

<sup>90</sup> NDIA (2021). 'Consultation Paper: An Ordinary Life at Home.' https://www.ndis.gov.au/media/3227/download?attachment

Further work is required to design and implement systems that reflect the needs and experiences of NDIS participants requesting SDA. More transparency and consistency is needed from the NDIA when making funding decisions. A commitment by the government for further engagement and collaboration with all stakeholders – including people with disability, providers and health professionals – would be warmly welcomed. The findings and recommendations in this report provide constructive advice for the NDIA, so that it can improve its delivery of NDIS and, in particular, life-changing SDA funding for those who need it.

#### 6.1 Next steps

The PIAC and Housing Hub collaborative project is continuing to assist participants with AAT appeals. Tribunal decisions on these cases will help to clarify and shape the law and policies for SDA decision-making and provide guidance to the Agency and future participants. The project team will continue to speak to the public and to stakeholders about the results and lessons learned, which will be included in future reports as the project progresses.

The project may also develop training materials and templates to assist other lawyers, advocates and participants to achieve fair outcomes and hold the NDIA accountable. Both PIAC and the Housing Hub would be happy to work in collaboration with other participants and organisations who are interested in constructively addressing the issues raised in this report.

Most of the issues raised and recommendations in this report will need government engagement and action. In early April 2022, the NDIA announced 'new and significant changes to the NDIS home and living supports,' developed in consultation with participants and providers. <sup>91</sup> Minister Reynolds stated that the changes would 'remove a number of practical and administrative concerns participants and providers have raised, to ensure it's easier for participants to access home and living supports.' The changes would help to improve the 'consistency and timeliness of home and living decisions.' The NDIA also committed to publishing metrics specific to decisions made by the Home and Living Panel and providing a point of contact to explain these decisions to participants.

This commitment by the government to improve administrative processes related to home and living supports is welcome and appears to be an important step in the right direction. However, it remains unclear what the specific changes are likely to be at a process and policy level within the NDIA, and how they will be implemented. The Housing Hub will continue to collect data and monitor the impact of these initiatives on wait times, experiences and outcomes for NDIS participants requesting funding for SDA and support.

PIAC and the Housing Hub hope to continue collaborating with the NDIA and responsible figures within the federal and state governments about how to ensure that the NDIS produces fair outcomes for all Australians with disability.

<sup>&</sup>lt;sup>91</sup> NDIA (2022). 'Government Improving Home and Living Supports for NDIS Participants, Including SIL.' 6 April. https://www.ndis.gov.au/news/7645-government-improving-home-and-living-supports-ndis-participants-including-sil

## **Appendix A: Participant data**

**Table 3 –** Participant demographics for full dataset (n = 357)

Age		
Mean		47
Range	1	8-70
Gender	n	%
Male	193	54.1%
Female	157	44.0%
Unspecified	7	2.0%
Primary disability	n	%
Acquired brain injury	46	12.9%
Cerebral palsy	49	13.7%
Multiple sclerosis	36	10.1%
Other neurological condition	38	10.6%
Other intellectual	12	3.4%
Other physical	49	13.7%
Other	31	8.7%
Progressive neurological	19	5.3%
Stroke	21	5.9%
Spinal cord injury	56	15.7%
Living arrangement	n	%
Private home	207	58.0%
Residential aged care	34	9.5%
Hospital	30	8.4%
Supported accommodation	38	10.6%
Crisis housing and transitional housing	17	4.8%
Other	31	8.7%
State/Territory	n	%
New South Wales	118	33.1%
Victoria	104	29.1%
South Australia	50	14.0%
Western Australia	24	6.7%
Queensland	41	11.5%
Australian Capital Territory	8	2.2%
Not recorded	12	3.4%

**Table 4 –** Outcomes and wait times for initial funding decision (n = 172)

Decision	n	%	Days waiting (median)	Range
Aligns with request	37	21.5%	96	17-378
Does not align with request	94	54.7%	92	6-334
Ineligible for funding	11	6.4%	99	44-224
Pending	30	17.4%	99.5	9-624
Total	172	100%	97	6-624

**Table 5 –** Wait times for initial funding decision, by living arrangement (n = 172)

Living arrangement	n	%	Days waiting (median)	Range
Hospital	16	9.3%	49.5	6-626
Private home	109	63.4%	106	7-396
Residential aged care	13	7.6%	54	9-201
Crisis and transitional housing	5	2.9%	95	26-346
Supported accommodation	15	8.7%	119	55-343
Other	14	8.1%	88.5	22-178
Total	172	100%	97	6-624

**Table 6 –** Outcomes and wait times for internal review of initial funding decision (n = 92)

Decision	n	%	Days waiting (median)	Range
Aligns with request	19	20.7%	76	15-380
Does not align with request	54	58.7%	76	6-341
Ineligible for funding	3	3.3%	120	115-168
Pending	16	17.4%	231	14-396
Total	92	100%	99	6-396

**Table 7** – Wait times for internal review of initial funding decision, by living arrangement (n = 92)

Living arrangement	n	%	Days waiting (median)	Range
Private home	54	58.7%	110.5	6-396
Hospital	6	6.5%	61	19-239
Residential Aged Care	5	5.4%	63	17-126
Supported accommodation	14	15.2%	110	23-296
Crisis and transitional housing	4	4.3%	117	49-279
Other	9	9.8%	43	25-393
Total	92	100%	99	6-396

**Table 8 –** Stages and wait times for external review of initial funding decision (n = 48)

Stage	n	%	Days waiting (median)	Range
Filed and awaiting first case conference	17	35.4%	70	18-397
Awaiting hearing	3	6.3%	274	140-274
Case conference(s) in progress	13	27.1%	241	101-513
Decision varied or set aside by consent	11	22.9%	202	103-413
Conciliation in progress	1	2.1%	210	-
Matter determined by AAT	1	2.1%	282	-
Application withdrawn by participant	2	4.2%	-	-
Total	48	100%	-	18-513