

31 October 2021

Committee Secretariat
Joint Standing Committee on the National Disability Scheme
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Parliament House
Canberra ACT 2600

By email: ndis.sen@aph.gov.au

Dear Committee Secretariat

General issues around implementation and performance of the National Disability Insurance Scheme | Current Scheme Implementation and Forecasting for the NDIS

Thank you for the opportunity to provide feedback on issues related to implementation, forecasting and performance of the National Disability Insurance Scheme (the **NDIS**). Aged and Disability Advocacy Australia (**ADA**) has considered the terms of the Committee's inquiries into the general implementation and performance of the NDIS, as well as the terms of reference provided in relation to forecasting needs (the **Inquiries**). As the issues related to each of these inquiries intersect, we seek to provide feedback to the Inquiries in this correspondence. ADA appreciates being consulted on the important issues considered by the Inquiries.

About ADA Australia

ADA is a not for profit, independent, community-based advocacy and education service with nearly 30 years' experience in informing, supporting, representing and advocating in the interests of older people, and persons with disability in Queensland.

ADA also provides legal advocacy through ADA Law, a community legal centre and a division of ADA. ADA Law provides specialized legal advice to older people and people with disability, including those living with cognitive impairments or questioned capacity, on issues associated with human rights, elder abuse, and health and disability legal issues related to decision-making.

Advocacy for persons with disability

ADA provides information, assistance and individual advocacy to people with disability who are experiencing issues with abuse, neglect and discrimination as well as to those requiring support to access or interact with systems and support services. In relation to the NDIS, we support clients who are experiencing difficulty with gaining access to the scheme, accessing supports, planning, service delivery and reviews.

The NDIS is a critical social program and a key tool in the funding and delivery of disability services. However, there are ongoing concerns in relation to its operation, procedural fairness, transparency and consistency in decision-making, and the impacts of these upon the scheme's ability to provide Australians with disability with equal opportunity for community participation, choice and control, in accordance with the requirements of the *National Disability Insurance Scheme Act 2013* (the **Act**).

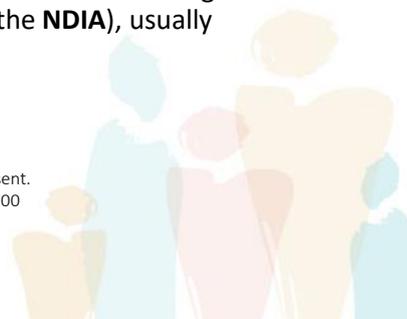
Our advocates report that clients with disability regularly encounter significant barriers when seeking access to the scheme and in dealing with the National Disability Insurance Agency (the **NDIA**), usually

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associated with undertaking a review of approved support services or negotiating a change in circumstances. The issues raised demonstrate a need for cultural reform, to ensure that the NDIA and delegated arms reflect the principles and objectives of the Act.

General issues around implementation and performance of the NDIS

Access, communication and eligibility criteria

ADA advocates regularly assist persons with disability who seek to access the NDIS. Clients consistently describe experiencing confusion, distress and prolonged delays when engaging with the NDIA. Whilst the NDIS website includes useful accessibility options to assist a wide range of stakeholders and possible applicants in obtaining general information about the NDIS, our clients regularly face communication obstacles and process inflexibility when engaging the NDIA in relation to scheme application or plan review. Examples of this include NDIA officers only communicating with a client using means which are inaccessible to the individual, such as attempting to use the telephone for a person who is hearing impaired despite requests to communicate via email. This inflexibility leads to the exclusion of persons from the scheme who meet the eligibility criteria set out in the Act.

Limiting means of communication is a breach of Article 21 of the Convention on the Rights of Persons with Disabilities (the **CRPD**), which confers a positive obligation on the Australian government and its agencies to ensure that persons with disabilities enjoy the freedom to seek, receive and impart information on an equal basis with others, through *all forms of communication of their choice*.

The need for operational changes to improve communications by the NDIA and the consequential impact upon participant experience is well-known, recently described in the 2019 review by Mr David Tune AO PSM (the **Tune Review**)¹ and acknowledged in the Australia government's response to the review.²

We note that some recommendations relating to improving communication by the NDIA were agreed by the government, and others supported in principle. Whilst the implementation of some recommended strategies is welcomed, such as additional funding to support people with disability navigate the NDIS, uncertainty persists regarding the continuation of these services. Funding provided for these measures is based upon short term delivery periods, despite an ongoing need for assistance.

For example, ADA supports the introduction of the targeted outreach program to spread awareness of the NDIS in Aboriginal and Torres Strait Islander communities. However this program is limited in its efficacy because it does not extend to assisting an individual navigate the application process – as recommended by the Tune Review. Rather, the expectation of the program is that an individual who is made aware of the scheme via the outreach program will then seek access having independently

¹ Tune, David, *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*, December 2019 < https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf>.

² Australian Government response to the 2019 Review of the *National Disability Insurance Scheme Act 2013* report, August 2020, < https://www.dss.gov.au/sites/default/files/documents/08_2020/australian-government-response-tune-review-28-august-2020-release.pdf>.

prepared their application. Our advocates report that this is rarely the outcome for persons in community. We also note that the targeted outreach program is only funded to operate for relatively short periods in each identified area. For example, phase 2 relating to the Townsville LGA, Rockhampton, Bundaberg, Toowoomba and west to the borders was funded to operate between September 2020 and August 2021 only. Phase 3 covers a significant number of geographically diverse communities located across a very large land area, including Mackay, Burdekin, Mount Isa, the Gulf, Cairns, Cape York and Torres Strait, and is funded for the period of March 2021 to February 2022.

The permitted timeframes allocated to each region are insufficient, and do not make adequate provision for the time it takes to ingratiate and build trust in community. Doing so is particularly important for government agencies, for whom there remains significant wariness and distrust amongst Aboriginal and Torres Strait Islander communities. This is a key reason why referrals through this program have not reached expected levels.

These efforts alone do not deliver sufficient assistance to aid eligible persons in these areas gaining access to the scheme, and Aboriginal and Torres Strait Islander persons (particularly those in remote areas) continue to be at a greater disadvantage in respect of opportunity to access the NDIS. The numbers of Aboriginal and Torres Strait Islander NDIS participants will continue to be under-representative of disability rates in these communities if initiatives such as the targeted outreach program are not continued and expanded.

Generally, information resources established by the NDIA for Aboriginal and Torres Strait Islander persons with disability are useful. However, there are concerns about the degree of cultural understanding and competency held by the agency and demonstrated by its officers, delegates, and within its processes.

There is an urgent need for Aboriginal and Torres Strait Islander NDIA planners and delegates in community, to improve cultural competency and assist eligible Aboriginal and Torres Strait Islander persons with disability in accessing the scheme and necessary support services. For many NDIS participants, undergoing a yearly review is a difficult and draining process. The negative impacts of this are amplified for Aboriginal and Torres Strait Islander persons with disability who are exposed to the NDIA's lack of cultural competency. We suggest the establishment of a dedicated team within the NDIA, including identified positions for Aboriginal and Torres Strait Islander staff who can identify how internal processes can be adapted to provide cultural safety. This would improve Aboriginal and Torres Strait Islander persons' engagement with the scheme.

File management by the NDIA

ADA acknowledges that the NDIA has sought to introduce measures aimed at service enhancements and participant experience, for example, through the National Information Program, the Individual Capacity Building (ICB) Program, and the Information, Linkages and Capacity Building Program. ADA supports the intention of these programs, which aim to deliver longer term capacity building and scheme understanding for individuals, community and support services.

In the meantime, significant issues regarding NDIA communication and management of files continues to impact individuals across all aspects of the scheme. This includes applicants who are

seeking a review of a decision about NDIS access, participants seeking a plan review, and general communication with participants who have requested information or clarity about their plan.

The NDIA's obligation to provide relevant and accessible information, and to ensure that persons with disabilities can exercise the right to freedom to seek, receive and impart information and ideas on an equal basis as per Australia's obligations under Article 21 of the CRPD, extends not only to the availability of accessible general information (such as the information published on the NDIS website) but also to reports, information, file notes and management of individuals. The obligation includes implementing a communication strategy with each individual that uses contact methods that are effective and accessible to the person with disability.

In our experience, this is seldom the reality. File transfer of an individual's active matter to a new NDIA officer is a regular occurrence, and upon this transfer it is commonplace for the individual to be advised that the new NDIA contact does not have access to the information, reports or evidence that has already been provided, or has not yet had the opportunity to read this evidence. The same frequently occurs when carriage of a matter is transferred by the NDIA to an external solicitor to represent the agency before the Administrative Appeals Tribunal (the **AAT**).

The result is further delay to resolution of the issue and increased confusion, distress and anxiety for an individual. Being compelled to repeatedly tell your story of disability and hardship can be very traumatising – particularly when an individual has already gone to significant effort to obtain and provide information for the NDIA, often a complex and costly process in itself. For persons with psychosocial disabilities who are subjected to delays, miscommunication and NDIA requests for information which has already been provided, can have the effect of exacerbating the symptoms of their disability.

Lack of understanding by the agency to appreciate and accommodate individual circumstances continues to be a concern. For example, a recent client and NDIS participant who has experienced domestic violence was sent an email by the NDIS advising that her request had been rejected. Participants who are affected by domestic violence are managed by the NDIA's Restricted Access team, comprised of specialist staff who operate in accordance with higher level privacy protections. The email received by our client was sent from a generic email address and appeared to be a template response. The client attempted to call the NDIA to seek clarification, expecting to be transferred to the NDIA Restricted Access team. However, in order to be transferred the client was advised that she needed to provide the NDIA officer on the general enquiry line with detailed information – including her full name, address, NDIS participant number and a reason why she should be put through.

The presumed motive for this process is well-founded: to ensure that only approved persons are transferred to the Restricted Access team. However in practice it fails to recognize that persons who have experienced domestic violence are likely to be deeply concerned about sharing identifying details – particularly their address – with NDIA officers who are not part of the Restricted Access team. This interaction, and the fear associated with providing her residential address, caused the client considerable distress. Further education for general NDIA staff about the importance of confidentiality, and how to appropriately have these discussions with a concerned individual would be beneficial. Alternative processes may also be considered, such as requiring only the NDIS participant number by the general enquiry line before transferring the participant to the Restricted Access team, who can then undertake further identity screening before providing information to the caller.

Subordinate legislation, guidelines and NDIA policy

Part 2 of the Act sets out the objects and principles underpinning the operation of the scheme. We note the independent review undertaken by Ernst & Young in 2015 in accordance with section 208 of the Act. In a report tendered to the government, the review recommended legislative amendments to sections 4, 5 and 17A of the Act. ADA supports the review's recommendation to amend these sections, which are necessary to ensure that these sections reflect the inclusive intention of the scheme.

The objects, general and guiding principles of the Act set out in this Part are the basis upon which all subordinate legislation relating to the scheme must be grounded.

It is difficult to assess if this is the case, as guidance materials which appear to be relied on by the NDIA to assist decision-making are often not publicly available. It is our strong recommendation that comprehensive public consultation involving key stakeholders should inform development of all guidelines and policies associated with the scheme. This would assist in ensuring that these documents align with the primary Act and are fit for purpose. It would also invite public engagement with the NDIA about the scheme, building the relationship with the community and improving understanding and transparency.

Examples of inadequate understanding of the legislation or misinterpretation of the subordinate legislation by the NDIA or its delegates are common. For example, NDIA officers attempting to draw inferences from the Operational Guideline to support decisions, though no corresponding authority can be found in the primary Act.

Effective communication, including publication of factors considered by the NDIA when determining whether an applicant is likely to meet the eligibility criteria as set out under the Act, is urgently required. Doing so will not only clarify the assessment process for NDIA staff, but it will also allow persons with disability, carers and advocates to better self-assess the prospects of success for a person who is weighing up making an application or considering plan review. Application and review processes are complex, involved and exhausting, and receiving notice of rejection is distressing. This may be avoided in some cases. Publication of guidance material relating to eligibility and review assessments and criteria will also drive greater consistency in decision-making by NDIA officers.

ADA strongly supports recommendations 1 – 4 made by the Public Interest Advocacy Centre in its submission to this Committee dated 13 July 2020, which relate to the publication of NDIA guidelines and settlement outcomes for matters before the AAT.³ Publication is in the interests of transparency and will increase community understanding and confidence in the scheme.

³ Joint Standing Committee on the National Disability Insurance Scheme, Inquiry: General Issues around the Implementation and Performance of the NDIS, Public Interest Advocacy Center, Submission 33, 13 July 2020, <https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/GeneralIssues/Submissions>.

Failure to appropriately manage the application/review process and act in accordance with the general principles

ADA's advocates report numerous examples in which an application was rejected based on what amounts to administrative error, rather than the application lacking substance. This is evidenced by examples where an individual has received a rejection decision which appears to accept the reports tendered by medical specialists, but suggest that the evidence does not use the correct language or terminology preferred by the NDIA and therefore, cannot be approved.

Significant administrative work, organisation and cost is often associated with making an application. This is usually undertaken by the person with disability, their families and carers. For persons with complex or psychosocial disabilities, the reports and information provided in the course of review (often additional to that provided in the original application, at the NDIA's request) are costly and extensive.

The considerable power and resources imbalance between applicants and the NDIA is well-known. A reasonable degree of mistake and administrative oversight in an individual's application is to be expected, and processes should be implemented by the NDIA to determine:

- if the error/oversight is substantial enough to necessitate correction; or
- the application can otherwise be approved having regard to the balance of the evidence provided, in accordance with the principles of the Act.

This approach would reduce the significant number of NDIA decisions which are overturned or amended by the AAT in favour of the applicant, as well as reducing distress and delay caused to individuals, and NDIA expenditure on legal fees. We note the NDIA's testimony to the Senate Community Affairs Legislation Committee on 29 October 2020 that the agency spent over \$29 million on external legal fees in the 2019-2020 financial year. \$13.4 million of that amount was spent on matters involving the AAT.⁴ The NDIA has acknowledged that 65% of applications made to the AAT lead to a new decision or a new settlement of some form. The remaining 35% of applications are withdrawn, or the AAT finds that the decision stands.⁵

Evidence and time frames

Many clients with psychosocial disabilities struggle to provide enough evidence to support an application.

We note the introduction of the National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021 (the **Bill**). ADA will provide detailed feedback about the Bill in a separate submission. For the purpose of this inquiry, ADA supports making amendments to the Act which are intended to improve flexibility and certainty for applicants. This includes clarification of the eligibility criteria for persons with psychosocial disability, and recognition that

⁴ Commonwealth of Australia, Senate Community Affairs Legislation Committee, Estimates, 29 October 2020, <https://parlinfo.aph.gov.au/parlInfo/download/committees/estimate/1bad3d3e-80f8-498e-a93b-585809f8dd26/toc_pdf/Community%20Affairs%20Legislation%20Committee_2020_10_29_8267_Official.pdf;fileType=application%2Fpdf#search=%22committees/estimate/1bad3d3e-80f8-498e-a93b-585809f8dd26/0000%22>

⁵ Ibid, 40.

disability of this kind can be fluctuating in nature. We hope that this will reduce the evidentiary burden for many clients with psychosocial disability.

ADA also supports the Bill's proposal to introduce timeframes by which the NDIA must advise an applicant of a decision. However, these changes will only result in improved outcomes for persons with disability *if* implemented in conjunction with other operational, communication and file management advancements which are urgently required. For example, persons with psychosocial or complex conditions often encounter significant delays in receiving a decision. Lengthy delays almost always occur when a file is transferred between NDIA officers, or to external legal advisors. Evidence previously submitted is unread, sometimes as a result of file transfer. Clients are then often advised that their evidence is now too old, and they need to submit a more recent report. This is very distressing and frustrating. For many people, obtaining a new report is impossible due to cost. The application stalls or is rejected, and an individual is forced to make an application to the AAT if they wish to proceed. Most people with disability and families are worn down by the application process and feel intimidated and anxious about making an application to the Tribunal.

Quality and Safeguards Commission – registration process

Our advocates have observed that new providers with poor practices and understanding of disability are enabled by the lack of adequate safeguards for plan and self-managed participants, who may utilise providers that are not registered.

Registration is complex, lengthy and expensive, and often discouraging for new providers. However it ensures that persons with disability are better supported, conflicts of interest are appropriately managed, and critically, that the client's safety is at the forefront.

Uncertainty of SDA and rental rights

A lack of clarity regarding rental rights exists in relation to specialist disability accommodation (**SDA**). Legal rights and avenues for persons with disability differ depending on their location: for example in Victoria, SDA residential agreements became part of the *Residential Tenancies Act 1997* (Vic) in 2019, providing a legislative framework for this specialist accommodation. Queensland has developed four principles for inclusive communities in the Queensland Housing Strategy 2017-2027 - rights, control, choice and inclusion. Whilst development of the principles is an important and welcome step, the Queensland legislation governing residential tenancy agreements does not include specific provisions about persons in SDAs.

This is a complex area that can be very difficult to navigate. Persons who require SDA housing already face limited choices about where they can live, and a substantial power imbalance often exists between landlord and tenant. For example an ADA client residing in an SDA experienced a sudden increase in rental payments without reasonable explanation, placing them in a vulnerable position. The NDIS Quality and Safety Commission (the **NDIS Commission**) considers this a rental payment dispute and will not assist.

Whilst we appreciate the complexity and limitations of a dispute involving issues governed by both federal and state laws, the current gap in assistance and necessary safeguards can leave persons in an SDA in an exposed and vulnerable position.

The federal government should engage with state and territory governments to consider if there should be an intersection between the role of the NDIS Commission and state/territory rental laws, and particularly, whether the NDIS Commission's safeguarding procedures might be appropriately utilised in this space.

Resistance of NDIA to support applicants' accommodation choices

Our advocates report multiple examples of clients requiring assistance in dealing with the NDIA regarding housing needs. Often, this occurs because the person with disability encounters resistance from the agency in approving housing that meets their needs.

For example, an ADA client with severe psychosocial disability and in need of robust housing was living in a supported independent living (**SIL**) arrangement that did not meet her needs. A section 100 review process was commenced, supported by a large team of allied health and housing support professionals who all provided reports to evidence the application for an SDA. In spite of the extensive evidence submitted, the NDIA planner decided that the client did not meet the criteria, though no reasonable explanation was provided to support that finding. The client was extremely distressed by the experience, worsening the symptoms of her disability and resulting in hospitalisation for self-harm. The matter has since been referred to the AAT, which we hope will correct the decision. Even if it is corrected, it will have been at significant mental, emotional, and physical cost to the client and her family.

Oftentimes, the NDIA will refer to section 34(c) of the Act to suggest that there may be equivalent alternative accommodations available at a lower cost, such as living in a SIL arrangement rather than an SDA. This thinking often negates to consider other key principles of the Act: choice and control of the individual, as well as the other requirements of section 34. It also identifies a misconception that SDA costs equates to less value for money than the SIL model. For example, a SIL model with support worker arrangements for 24/7 assistance of 3 residents may be significantly higher overall than an SDA in a specialised building or complex with concierge support workers onsite, as required.

Current Scheme Implementation and Forecasting – response to terms of reference

The limited consultation period to provide the Committee feedback on the terms of reference does not permit ADA to deliver a comprehensive response. We provide the following comments for your consideration.

- a. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:
 - i. the availability of support outside the NDIS for people with disability (e.g. community-based or 'Tier 2' supports), and
 - ii. the future of the Information, Linkages and Capacity Building grants program;

With respect to a(i) – the availability of supports outside the NDIS, and within it, is heavily determined by an individual's location and personal circumstances (including, for example, educational and financial capacity of the person and/or their family).

The Information, Linkages and Capacity Building grants program has been a helpful initiative for support services to develop resources intended to build capacity and connection with individuals. We are pleased to see funding for the Individual Capacity Building and Economic and Community Participation streams will continue until 2023.

- b. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;

ADA considers that better integration between the NDIS and aged care, hospital and healthcare systems, and education institutions is required. Our advocates regularly assist clients and carers seeking to ensure NDIS support services can continue when a person with disability attends one of these settings. Issues affecting support continuation are frequently encountered in schools and hospitals.

For example, a recent ADA client was supporting a child with Autism Spectrum Disorder (**ASD**). As a result of the child's distressing behaviours, a home school program was implemented until learning support from Autism Qld became available (approximately a 5 month wait list). The client's request for increased support worker input at home to assist with home school was rejected, with the agency advising that home-schooling was both a 'parental responsibility' and a 'Qld Education issue', and unrelated to the NDIS. As with housing, improved integration between the NDIS and state-based education systems is required.

Similar gaps are experienced by NDIS participants who are hospitalised. An ADA client with Down Syndrome and NDIS participant who requires assistance with eating and drinking was admitted to hospital. Staff brought the man three meals a day, but the hospital would not provide any staff to physically assist him with eating even though he was unable to do it himself. Upon advising the NDIA about the issue, the client was advised that no funding will be used to support a person in hospital. As a result, persons without family or friends who are able fill this gap are left in an impossible situation, and hospital staff or NDIA support coordinators are forced to 'break the rules' to ensure that basic needs are met.

- c. The reasons for variations in plan funding between NDIS participants with similar needs, including:
 - i. the drivers of inequity between NDIS participants living in different parts of Australia,
 - ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and
 - iii. measures that could address any inequitable variation in plan funding;

We refer to issues raised above (see particularly pages 3 – 7). Intersecting challenges, including access to specialists and ability to procure multiple reports or additional evidence when requested by the agency interplay with the NDIA's file management, communication and interpretation of guidance material and subordinate legislation when making a decision.

Invalid interpretation of the Act and/or supporting legislative framework, an applicant's location, and inconsistent decision-making by the NDIA will all influence an applicant's opportunity to receive equitable funding.

- f. The measures intended to ensure the financial sustainability of the NDIS (e.g. governance, oversight and administrative measures), including:
 - i. the role of state and territory governments, and the Disability Reform Ministers Meetings,
 - ii. the arrangements for providing actuarial and prudential advice about the scheme, and
 - iii. the way data, modelling, and forecasting is presented in public documents about the NDIS, (e.g. NDIS Quarterly Reports and Reports by the Scheme Actuary), and
 - iv. measures to ensure transparency of data and information about the NDIS;

ADA supports a comprehensive and public consultation into the scheme's financial sustainability, including a review of the NDIA's spending model, the NDIA price guide, and reconciling the full costs associated with correction of incorrect decision-making (including NDIA labour costs associated with undertaking an internal review, as well any external legal fees).

Increased transparency is urgently needed to improve community confidence in the scheme. This should include publication of all data and information relied upon to support policy and process development.

Thank you again for the opportunity to comment. ADA would be pleased to further assist the Committee with its inquiry. Should you wish to discuss this submission, please do not hesitate to contact Vanessa Krulin, Solicitor and Senior Policy and Research Officer on 07 3637 6036 or via vanessa.krulin@adaaustralia.com.au.

Yours faithfully



Geoff Rowe
Chief Executive Officer