Disability Advocacy NSW

Submission to the NDIS Joint Standing Committee

NDIS Performance and Implementation: Burden of Evidence

Disability Advocacy NSW

About Disability Advocacy NSW (DA)

DA has over 35 years of experience providing individual advocacy to people with disability (PWD) of any age. The organisation services over two thirds of NSW, making it the largest individual disability advocacy organisation within NSW.

While DA has a presence in Sydney, it has a strong commitment to regional, rural and remote (RRR) areas in NSW. With local disability advocates – on the ground - in Western Sydney, Armidale, Bathurst, Broken Hill, the Blue Mountains, Coffs Harbour, Dubbo, Newcastle, Central Coast, Port Macquarie, Tamworth and Taree – DA has firsthand insights and observations of the lived experiences of PWD and their families living in these areas.

DA's systemic advocacy draws on coalface information from clients, disability advocates, and the disability sector more broadly to identify and address emerging policy issues. In this submission, we focus on issues relating to the implementation and performance of the NDIS with a focus on RRR areas in NSW. In addition to this submission, we invite members of the NDIS Joint Standing Committee to conduct site visits to our RRR offices alongside our policy officer (contact details below) to hear more about the experiences of PWD living in RRR areas.

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Introduction

DA welcomes the opportunity to make this submission regarding the ongoing enquiry into general issues pertaining to the NDIS. In previous submissions[1][2], DA has discussed issues PWD experience living in RRR areas face. In this submission, we build on this to focus on the burden of evidence PWD must navigate when attempting to access the NDIS, and during internal and external reviews. In our view, the NDIA's requirements for evidence is vague and unclear for both participants and practitioners and clinicians, which makes providing evidence unnecessarily onerous. In turn, it creates implications that restricts access to the NDIS and/or limit funding in people's plans.

For PWD in RRR, there is the additional burden of thin markets that obstructs efforts to gather evidence. With few affordable services, waitlists are common, and there is often a need to travel lengthy distances to access services. This can place significant strain on PWD who have limited resources (e.g., funds to travel and see specialists, support to travel, transport), which can dissuade people from attending appointments to obtain evidence. This then hampers their efforts to access the NDIS and receive necessary supports and services.

Alongside this, practitioners and health professionals are often overwhelmed with evidentiary requirements. They are time-poor and ill-equipped to write reports for the NDIA. This leads to documentation that the agency routinely questions and/or disregards, prompting their requests for practitioners and clinicians to provide further information. Yet, in doing so, the agency does not provide clear instructions about what specifically is required. This process is time-consuming and resource intensive for both practitioners and participants.

Additionally, there is inconsistent decision making within the NDIA. With a high variance of skills and knowledge of planners/decision among NDIA makers, there are inconsistencies with how evidence is interpreted. This results in inconsistent decision making around what is accepted to inform the particulars of an individual's plans.

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[1] NDIS Joint Standing Committee's Inquiry into NDIS' Implementation and Performance (submission number 79).

[2] NDIS Joint Standing Committee's Inquiry into the NDIS' implementation and forecasting (submission number, 81).

In many instances, the burden of evidence is an issue that protracts NDIS matters, leading to time-consuming and costly internal and external reviews. After extended periods of time, most matters are ultimately resolved in the participants' favour. While this may seem positive, it is important to emphasize there are significant costs with matters that progress to the ATT. These involve the NDIA's exorbitant use of external lawyers, the costs of funding advocates, registrars, case managers and so on. Additionally, many participants exhaust their already limited funds in their plans to obtain the evidence that the NDIA requests of them. This is an unnecessary use of taxpayer's moneys.

Perhaps most concerning, is the significant cost to PWD's psychological well-being. Taking NDIS matters to the AAT can result in significant mental distress. The prolonged stress of going through an appeals process, combined with complex and litigious administrative systems deters many people from pursuing their NDIS matters. Put simply, it is a process that privileges those with the most cognitive and material resources given what is needed to engage in the appeals process. It disadvantages the most vulnerable in the disability community that are not equipped with knowledge, skills, finances, time, and energy to navigate what is increasingly becoming an overly legalistic process at the AAT.

Based on the issues outlined in this introduction, the submission makes the following recommendations listed below.

1. The NDIA provides clearer guidelines to both participants and practitioners/clinicians. Greater transparency is need from the NDIA regarding how and why some evidence is deemed unsatisfactory, and other evidence is acceptable. A potential model to draw on is the Disability Support Pension requirements that provides clear instructions for clinicians and practitioners about what is considered satisfactory. Having clear guidelines will minimise requests for additional information that is time-consuming for both participants and clinicians.
2. If the NDIA requires more information from treating clinicians/practitioners, they must provide funds to participants to obtain additional reports rather than have participants use funds in their plans, and they must provide targeted questions for practitioners and/or clinicians. While there are currently measures in place for this, the implementation of this is

inconsistent, pointing to a need for clearer directives. Providing financial assistance for evidence will ease financial strain for many NDIS participants/applicants, and targeted questions will ensure that clinicians/practitioners have clarity around what information is needed.

3. The NDIA works with practitioners' and clinicians' professional bodies (e.g., Allied Health Professionals Australia) to codesign and agree on guidelines that specify clear evidentiary requirements. This will ensure that there is greater clarity and accountability for NDIA staff around standards of evidence.
4. The NDIA develops policy and guidelines that has an improved and revised skillset and knowledge of planners/decision makers to ensure that evidence is correctly and adequately interpreted. This may also minimise requests for additional evidence, and in turn, minimise the unnecessary consumption of resources (e.g., time, energy, finances) of participants, and clinicians/practitioners that are used to provide additional evidence.
5. The NDIA instate an independent panel of in-house clinicians/practitioners who have relevant experience and can provide oversight and independent advice to planners for complex matters. This will ensure that evidence and plans are adequately assessed, and accurate and fair decisions are made. In turn, this should reduce requests for internal reviews and subsequent external reviews.
6. Department of Social Services develop Information and Linkages and Capacity Building (ILC) programs to enhance capacity of communities to navigate the NDIS. This could involve local advocacy organisation providing workshops to participants and health professionals. This training would be best developed through and with other independent agencies outside of the NDIA to ensure there are diversity of approaches.

To support these recommendations, the remainder of this submission presents evidence based on research conducted by DA. It draws in scoping researching involving survey and interviews with PWD and/or their families[3], consultations with DA advocates, and advocacy trends with DA.

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[3] Surveys sample *N* = 317. Interview sample *N* = 28.

Obtaining evidence in thin markets

As we have noted elsewhere[4], PWD living in RRR area 'double disadvantaged'. They must live with the challenges associated of living with a disability in communities that are geographically and socially marginalised. These conditions contribute to thin and absent markets, where affordable good quality disability services are inaccessible with closed books and/or lengthy waitlists. The limited amount or absence of services undermines the NDIS's principle of 'choice and control'. It does not foster competition and is often associated with difficulties finding practitioners with the appropriate level of skills and knowledge that participants are comfortable with.

As a result, people are left with little choice but to go without services, accept subpar services or they must travel vast distances to attend appointments. But travelling can be with unreliable and unaffordable transport options in RRR areas. Additionally, some PWD may require support to travel to appointments. Without funds for travel, or support, traveling to appointments may not be possible. Lastly, while service providers may travel to RRR areas, the financial incentive is often too low to regularly attend RRR areas unless they can group several appointments in areas. These thin market issues create barriers for PWD to obtain evidence.

Accordingly, DA's advocacy trends reflect these issues with obtaining evidence in RRR areas. For internal reviews, NDIS matters on average take longer to resolve[5] with a lower success rate in RRR areas (48%) compared to metropolitan areas (53%). Reasons for this were limited availability of allied health practitioners and clinicians with long waitlists. Participants reported that they were restricted with availability of providers (27%), and some reported that were unwilling or unable to travel (30%). These challenges with evidence appeared to contribute to higher rate of PWD in RRR (16%) withdrawing their request for a review compared to those who lived in metropolitan areas (7%).

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[4] NDIS Joint Standing Committee's Inquiry into NDIS' Implementation and Performance (submission number 79).

[5] Extra hours spent on cases in RRR is not strictly travel-related as majority of support in still remotely provided.

The burden on practitioners

Case study 1: A full time job organising evidence

Jock described accessing the NDIS, as ‘like having a full-time job’ with having to organise evidence and go through the reviews and appeals process. He explained that his GP did ‘not have the knowledge on how to fill in the forms correctly as how the NDIA people wanted them’ despite his doctor providing ‘lots of evidence… 30 pages long’. Jock said his initial access request was knocked back. He explained that ‘it was like they continually wanted more evidence’. Even though he had a support coordinator assist him through the process where he was eventually granted access, he described it as feeling like he was ‘continually chasing [his] tail’.

Little guidance is available for practitioners/clinicians to equip them with the skills needed to write reports for the NDIA. While they have formal training as part of their education to write reports, the NDIA’s requirements are often technically specific. A core issue here is that the agency does not provide clear guidelines and information about their evidentiary requirements. With no detailed information and lack of guidance, many practitioners find that the NDIA will deem their reports and assessments as unsatisfactory, and they will need to provide additional information as reflected in Jock’s experience (case study 1, above).

This places a burden on time-poor and under resourced practitioners/clinicians operating in RRR areas. Bulkbilling practitioners/clinicians, in particular, are often time-poor and are in high-demand in RRR areas where there are lower socioeconomic groups. This impacts on their ability to write reports to the standard the NDIA requires because they are often neither informed and/or lack the time and resources. It is unsurprising then, that in DA’s advocacy trends, the NDIA’s requests for additional evidence in RRR are twice as high in comparison to metropolitan areas for internal and external review matters.

For matters at the AAT, evidentiary requirements become more onerous for practitioners as the standards increases to the level needed for a court of law. At this stage, it is common for NDIA to employ medico-legal experts to interrogate and erode the credibility of evidence. This legalistic conduct deters practitioners/clinicians from providing reports for their clients. The increasing use of summons in AAT proceedings has led to some regional practitioners/clinicians declining to assist clients with NDIS Appeals. The NDIA’s legalistic approach taken to litigation in the AAT is akin to

Workers Compensation and Personal Injury proceedings and practitioners/clinicians are treating it as such, by declining to be a part of the litigious process. The subsequent difficulty of securing evidence often leads to participants choosing to withdraw their case, or they need to request an extension of time to provide the evidence. Arguably, this may explain the longer amount of time needed to resolve external reviews for RRR participants in comparison to metropolitan participants. The implication of prolonging resolution is that the participants must endure precarious conditions where they must ration and go without much needed support and services.

Inconsistent decision-making

There is often inconsistent decision-making around how evidence is interpreted and used to determine the level of funding in plans. A part of the problem is the demarcation of responsibilities between local area coordinators, co-ordinators of support and planners in RRR areas. These roles often overlap in the planning process, with variability in skills and knowledge. This largely affects how well these workers can inform a participant of evidentiary requirements and how much a participant's interests are represented within decision-making.

Both advocates and participants commonly report variability in decision-making, attributing it to the skill, experience, and knowledge of the workers. As one participant remarked:

> It's the *planner* that you've got to have the right plan. You do need the right planner and having those knowledgeable planners, is a needle in a haystack… I had nice lady last year, and she kept saying, 'Oh, I've got a niece with CP', and in my head, 'I can think, yeah, everyone knows someone. I'm the one living in it', but she actually did care and understand.

As the quote above suggests, knowledge, experience and understanding are pivotal in receiving an appropriately funded plan. But as suggested by the participant, finding an appropriately skilled planner[6] is often a rarity. Participants and advocates commonly report that funding in individual plans can differ significant from year-to-year depending on *who* conducts the plan review. Again, this points to a planner's ability to firstly, review evidence and then comprehend the significance and

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[6] Or other workers responsible for conducting plan reviews.

permanence of an individual’s impairments. Secondly, it highlights a level of knowledge to understand a PWD’s entitlements under the scheme’s policies.

Invisible disabilities

The issues relating to worker’s skills and knowledge of disability and interpreting evidence are particularly problematic for people with invisible disabilities. Participants and advocates frequently report that a lack of knowledge about invisible disabilities among decision-makers often results in inadequately funded plans. This occurs despite participants providing ample evidence from their treating practitioners and clinicians that specify the level and types of supports and services needed.

Case study 2: Invisible disability

Jean* has multiple sclerosis, a condition that affects the central nervous system – an invisible disability. They reported that during a review meeting, a planner looked them up and down, and stated, ‘you don’t look *that* bad’ (participant’s emphasis).

Despite providing reports from their practitioners and clinicians, Jean subsequently, received significantly lower funding in their plan. As Jean, described:

> [T]here's a general lack of understanding among the community in how they deal with people in disability, at first, they *look* at it. In my case, the disability is one that is not so visible.

Jean believes that the ‘general perception of disability are not ordered and given the equal status,’ because of their level of visibility.

Jean appealed the decision, which ultimately proceeded to the AAT where it was resolved in their favour.

In the case study above (p. 9), Jean discusses concerns about invisible disability having unequal status as visible physical disabilities. They suggest a reason for this this may be due to planners relying on rudimentary assessments based on what they *see*. In doing so, they disregard evidence presented to them, and use their own discretionary assessment, which can significantly influence people's plans. Decision-making, in this sense, is often subjective, prone to bias and can lead to inconsistencies depending on who is involved in the planning process.

Likewise, participants with psychosocial disability often have difficulties with inconsistent decision-making. Again, key issues here are a lack of understanding of diagnoses and entitlements, and abilities to interpret evidence in relation to eligibility criteria. Case study 3 (p. 11) represents common concerns reported by numerous participants with psychosocial disability.

Here, there is often a higher evidentiary burden for people psychosocial disability attempting to access to the scheme. DA advocacy trends reveal that NDIS internal and external reviews where psychosocial disability is listed as the primary disability take 18% and 34% respectively longer to resolve compared to matters with physical disability listed at the primary diagnosis. As Michael in case study 3 describes, it seems the NDIS was not adequately set up for people with psychosocial disability. His experience exemplifies issues related to inconsistent decision-making that depends largely on *who* is involved in the planning process, and *how* their expertise influences the interpretation of evidence against the eligibility criteria.

Case study 3: Psychosocial disabilities

Michael is participant on the NDIS. He has a psychosocial disability and believes that the NDIS is mainly set up for people with physical disability. Reflecting on his experience with trying to gain access the scheme, he described, ‘it’s really easy to prove you got a physical disability, but when it comes to psychosocial – mental health, it’s a whole lot harder.’ Michael attributed this to the NDIS Act eligibility criteria, which requires people with psychosocial disability to prove their disability through a framework more suited to physical disability.

At the time of writing, Michael was on his second NDIS plan. He reported that his first plan was not as good as his current one because it missed several supports and services he requested. He explained in the first plan, he spoke with a LAC, provided them with information and evidence that was then sent to a planner. However, ‘a lot of things were missed’.

However, with his second plan, he requested to meet with a planner face-to-face. During this meeting, the planner provided him with useful information about was what available to him (e.g., funding for transport and the right the review a plan).

This did not occur in during his first plan. Therefore, he was unaware of his right to request a review. This meant that he had inadequate supports for the duration of his first plan. Another important factor with his second plan, is that he had support from Flourish – a mental health specific organization that could advocate on his behalf. They assisted Michael by contact his community health workers and doctors to guide them through the evidentiary requirements.

Michael’s experience reveals how having the support of an agency that specialise in psychosocial disability was a significant factor in receiving an appropriately funded plan. His support coordinator guided Michael through the planning process and worked with his treating specialists to guide them through providing appropriate evidence. Not only does this demonstrate the importance of providing guidance to practitioners and clinicians, but it also highlights the importance of the combination of the skills and knowledge of the both the support coordinator and the planner. In this instance it contributed to a favourable outcome for Michael. This stands in contrast to his first plan where he did not have support to obtain evidence and inform him of his entitlements and rights during and after the planning process. Concerningly, he was not informed of his right for an internal review and had to make do without adequate funding for the duration of his plan.

Disproportionate representation at internal and external reviews

The burden of evidence is a contributing factor to the increase of NDIS appeals. From December 2020 to December 2021, there was steady growth in NDIS matters pertaining to internal reviews, AAT appeals, and access and planning[7]. In this, there was a significant trend concerning PWD in RRR areas, where approximately 61% of cases in RRR areas were identified as having difficulty obtaining adequate evidence to support NDIS evidence requirements due to limited accessibility of service providers (i.e., requiring travel to city/ towns for specialists, etc). Here, DA successfully resolved 72% of matters during this period. However, 11% withdrew their matters (opposed to 4% that were unresolved), often reporting difficulty navigating the system and meeting the evidence requirements due to poor accessibility. This means that PWD who live in RRR areas are often disadvantaged with fulfilling the requirements needed to access the NDIS due to their locality, which is often characterised by thin markets.

While internal and external reviews allow PWD to challenge decisions made about them, these avenues inherently disadvantage some of the most vulnerable members of the disability community. There have been drastic increases in the volume of PWD requesting reviews of decisions that they believe are unfair[8]. In doing so, many experience victories with overturned decisions. However, this is not without financial and emotional costs. Many report that even though they had matters resolved in their favour, problems relating to unfair decisions persisted down the track, with many needing to appeal decisions for a second or sometimes, even third time. As one participant remarked, ‘I’m just waiting for something to go wrong from week to week.’ Understandably, the stress associated with enduring constant battles can negatively impact on people’s well-being, deterring them from pursuing matters any further.

An important consideration within this, is that people who challenge decisions are likely to be the most resourced to be able participate and persist in the review processes. Speaking up for fairness requires resources that are not equally distributed. Specifically, it requires more cognitive resources to navigate complex systems, as well as funds, time and energy to obtain evidence, which again

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[7] Refer to previous submissions
[8] See Model Litigant Obligations and the NDIA report

favours those who have material resources needed to fund and attend appointments with specialists to obtain documentation. Therefore, those who can go through one review and appeal process, yet alone several, are most likely those who have the most resources. As we saw in Michael's experience (case study 3, page 11), being equipped with resources (e.g., knowledge of rights, support to organise evidence) was pivotal in receiving an appropriately funded plan. Without this, he was not aware of his right to appeal a decision and lived for a year with inadequate support. In this sense, it is worrying to consider if the most vulnerable members of the disability community are equipped with support and resources to challenge decisions made about them that are unfair.