



Australian National Audit Office
Access to the NDIS Inquiry
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ANAO Inquiry into NDIS Access processes.

Thank you for the opportunity to participate in this inquiry. The ACT Disability Aged Carer and Advocacy Service (ADACAS) has been providing individual advocacy to people with disability, older people, people with mental health issues and their carers for over 25 years. We are an independent, not for profit organization. ADACAS provides support for people appealing National Disability Insurance Agency (NDIA) decisions (both internally, and also at the Administrative Appeals Tribunal (AAT)). ADACAS also delivers support coordination (with an advocacy style approach) to NDIS participants. Additionally, we deliver a range of supported decision making and other community capacity building activities. ADACAS is a member of the Disability Advocacy Network of Australia (DANA), as well as ACT and NSW disability advocacy networks.

As the ACT is the first jurisdiction to have fully transitioned to the NDIS, ADACAS has considerable experience, over several years, with all aspects of the NDIS process. We have supported many clients who have been dissatisfied with NDIS processes or have needed advocacy assistance to engage with the NDIA. In addition ADACAS continues to participate in systemic reviews and inquiries regarding the NDIS so that the experience of our clients informs these processes. ADACAS also meets regularly with senior officials from the ACT NDIS Office to raise thematic concerns. On the whole however, we have found that as the rollout progressed the local office has had reducing capacity to respond to thematic issues and the NDIA head office has not been accessible to us to enable these issues to be raised with relevant decision makers.

The points below provide a distillation of a range of issues with the access process which have been experienced through our case work (these are not presented in a ranked order). They identify both broad and specific concerns with the manner in which access decisions are made and in total, present a fairly bleak picture of the quality, timeliness and consistency of access decision making within the NDIA.

- Lack of adequate support for participants to prepare access request forms.
- Inadequate medical input is leading to access being denied because information is not complete or not in the form preferred by the NDIA. It's essential that both GPs and medical specialists get better training in how to both complete the forms and provide useful supporting documentation.

- NDIA staff mis-informing people about access. For instance clients being told that NDIA are prioritising particular disability types which deters others from putting in their applications.
- Access decisions are to be made within 21 days according to the legislation – current wait is at least 4 months
- When poor paperwork leads to denial by NDIA many people are giving up and not seeking a review. Which means there are potentially eligible people who cannot access services they need.
- Some access decision letters are not providing the specific reasons for decision which impedes the participant seeking a review or appeal. They instead cite all of both paragraphs S24 and S25 of the legislation (even when it is clear from the access paperwork that it is unlikely that all conditions across both these sections were unmet) instead of being specific as to the exact grounds for ineligibility.
- Access denial letters not being received by Participants. Case study:
 - person applied for access in 2016, and contacted advocate in February 2017 because they had not heard any outcome. Advocate found out that NDIA had denied entry in July 2016 but no letter had been sent. NDIA agreed to undertake a review of decision but will not provide a timeframe for how much longer the person needs to wait for an outcome.
- Internal review processes are not being followed properly. The process requires NDIA to have a different person review the decision. However NDIA staff have told us that internal review requests are firstly sent back to the original decision maker, who has the chance to re-look at their decision in light of any new information provided. If the original decision maker changes the decision, the participant is advised accordingly. If the original decision-maker upholds their original decision, then and only then is it sent to a new decision-maker. By involving the original decision maker as part of the review process – giving them a chance to review or confirm their first decision- it means that all requests for internal review reaching the new decision makers are ones that the original decision maker has denied. This has the potential to influence the new decision maker and introduce bias. It is not a transparent/fair review process
- NDIA staff do not have sufficient expertise to make decisions. For example:
 - a person that requires palliative care is not necessarily at end of life and imposing what seems to be a blanket rule that people who need palliative care should be able to have their needs met by the health system means people in this group who are also in need of disability supports are missing out on them.
 - Another case study where the in-expert opinion of the assessor led to the person being denied access: Female aged 40
 - Impairment is Trigeminal Neuralgia (TN), a chronic pain condition affecting the trigeminal nerve in the face. There are treatments for this

impairment include medication and also surgery, these are not a permanent fix.

- NDIS denied access after 7 months from submission (September 2016 submission, April 2017 denial), giving an explanation of the delay that it had to go through to a specialist team for review. Denial on the grounds that TN is not permanent.
 - NDIS National Access Team made a phone call to the person stating that there were surgeries and medications available to treat TN, prior to the denied access letter being sent to out. During this phone call the NDIS team member had made mention of two surgery options. However the client informed the NDIA officer that one of the surgeries is not available in Australia and the other surgery (microvascular decompression) was a temporary solution, giving up to 3 years relief (each surgery would have diminishing returns) but there is a 5 year wait period to obtain this surgery on the Australia Public Health Scheme. Client has stated that all medications had been attempted but were not effective. Despite providing this information, access was denied.
 - Is now gathering information from specialists and other allied health professionals addressing the permanency of the condition for internal review.
- Access process does not adequately account for the cumulative impact of having multiple disabilities (especially where mental health issues are present). Assessing the significance of each disability in isolation does not recognise the cumulative impact of multiple 'moderate' disabilities leads to highly significant impairment overall.
 - Access is supposed to be based on functional impairment however NDIA are requiring medical diagnosis. This requirement is inconsistent with the intent of the Act.
 - People are being told that they must have specialist confirmation of diagnosis dated within the last two years. This is unreasonable – cost of specialists/diagnosis is prohibitive, in addition there are long delays to get to see a specialist. It places unnecessary extra pressure on the health system. It also negates the reality that many disabilities are lifelong.
 - For example, we heard recently that a person was asked to provide a new diagnosis of Downs Syndrome. As a genetic condition this is not something that will change across the person's lifespan.
 - Access team making inappropriate assumptions and referrals. We had a client whose access request included a support letter from the pain management clinic emphasising the need for disability supports in addition to what they could provide. The NDIS response stated that the health system would meet needs (and referred client back to the pain management clinic for that help), despite the original support letter from the pain management clinic being clear that the client was already accessing their service,

and that extra disability specific support was needed (in addition to what pain management clinic could offer) from the NDIS. In other situations, clients have had their request for assistance refused with the generic statement that their needs can be met by the health system, but without any guidance at all as to how or where to access extra support from the health system. This can be an especially distressing response for potential participants to receive.

- Participants moving from the Early Intervention model to the main scheme are being pressured inappropriately, including:
 - NDIA deciding to review only a few months into the plan,
 - NDIA requiring new specialist reports within an impossible timeframe,
 - automatic cut off based on age instead of individualised assessment of whether the person needs further support.
- Many applications are being lost or delayed due to system failure. We are aware of applications made by hand, by post and by email which have been lost by the NDIA.
 - In one example 2 applications from the one family lodged, one of these was lost while one was processed. Leads to great stress for participants.

In addition to access issues, ADACAS is aware of a range of issues related to planning, plan implementation, plan review and appeal. If the ANAO is also interested in these further aspects of NDIA processes we would be pleased to provide examples of our experiences with clients on these as well. Thank you for the opportunity to take part in this inquiry. If we can provide any further information please contact me at

Yours sincerely

Fiona May
CEO

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