



Capability and Culture of the NDIA

**Submission by
Queensland Advocacy for Inclusion**

**To the Joint Standing Committee on the
National Disability Insurance Scheme**

October 2022

About Queensland Advocacy for Inclusion

Queensland Advocacy for Inclusion (**QAI**) (formerly Queensland Advocacy Incorporated) is an independent, community-based advocacy organisation and community legal service that provides individual and systems advocacy for people with disability. Our purpose is to advocate for the protection and advancement of the fundamental needs, rights and lives of people with disability in Queensland. QAI's Management Committee is comprised of a majority of persons with disability, whose wisdom and lived experience is our foundation and guide.

QAI has been engaged in systems advocacy for over thirty years, advocating for change through campaigns directed at attitudinal, law and policy reform. QAI has also supported the development of a range of advocacy initiatives in this state. For over a decade, QAI has provided highly in-demand individual advocacy services. These services are currently provided through our four advocacy practices: the Human Rights Advocacy Practice (which provides legal advocacy in the areas of guardianship and administration, disability discrimination and human rights law and non-legal advocacy support with the Disability Royal Commission and the justice interface); the Mental Health Advocacy Practice (which supports people receiving involuntary treatment for mental illness); the NDIS Advocacy Practice (which provides support for people challenging decisions of the National Disability Insurance Agency and decision support to access the NDIS); and the Disability Advocacy Practice (which operates the Pathways information and referral line, and provides non-legal advocacy support with Education and other systems that impact young people with disability).

From 1 January 2022, we have been funded by the Queensland Government to establish and co-ordinate the Queensland Independent Disability Advocacy Network (QIDAN), which includes operating the Disability Advocacy Pathways Hotline, a centralised phone support providing information and referral for all people with disability in Queensland. We have also been funded to provide advocacy for young people with disability as part of the QIDAN network, which we provide in addition to our non-legal education advocacy for Queensland students with disability. Our individual advocacy experience informs our understanding and prioritisation of systemic advocacy issues.

The objects of QAI's constitution are:

- To advocate for the protection and advancement of the needs, rights and lives of people with disability in Queensland;
- To protect and advance human rights including the Convention on the Rights of Persons with Disabilities (CRPD);
- To be accountable to the most disadvantaged people with disability in Queensland; and
- To advance the health, social and public wellbeing of disadvantaged people with disability.

QAI's recommendations

- Clarify the role of, ensure consistency in, and improve the quality of Local Area Coordination.
- Ensure language and processes are accessible to all people with disability, including people from Culturally and Linguistically Diverse backgrounds and First Nations Australians.
- Improve evidence gathering processes with regards to access and ensure staff take into consideration all material provided. For example, develop templates for reports or assessments and make these available for prospective participants to use.
- Ensure participants are appropriately supported during planning processes, for example in relation to self-management and ensure participants are fully informed of the risks and responsibilities involved. Further, ensure that planning meetings only occur at pre-planned times and when participants have received sufficient time and support to adequately prepare.
- Ensure participants can access reasonable and necessary disability related supports, pursuant to section 34 of the *National Disability Insurance Scheme Act 2013* (Cth) and the NDIS Supports for Participants Rules, irrespective of which impairment the supports relate to. In other words, cease the practice of denying funding for supports that relate to an impairment other than the person's primary disability, or disability for which they gained access to the scheme.
- Ensure planning processes cater for the unique and often complex needs of families who have multiple NDIS participants.
- Ensure Agency staff provide detailed and quality reasons for their decisions in a manner that is compatible with the *Acts Interpretation Act 1901* (Cth).
- Prevent the Agency issuing new plans to participants who currently have a matter before the Administrative Appeals Tribunal (AAT) in circumstances where the creation of the new plan may jeopardise the jurisdiction of the AAT.
- Remove the use of legalistic language and ensure information is provided to participants in Plain English, including with regards to review and appeals processes.
- Introduce operational safeguards around the role of plan nominees to ensure participants are protected from undue influence and exploitation.
- Ensure that every member of staff at the Agency has a sound understanding of disability related issues, including displaying competence in supported decision-making practices.
- Improve the communication practices of all Agency staff, including ensuring participants who submit a request for internal review are always contacted by the Agency and that their communication preferences are always followed.
- Implement measures to ensure Agency lawyers adhere to the model litigant rules.

Background

This submission is informed by QAI's experience delivering advocacy for people engaging with the National Disability Insurance Scheme (NDIS) through our Appeals Support Program and Decision Support Pilot Program. We are funded by the Department of Social Services and are currently experiencing a huge demand on both of our services.

Our NDIS Appeals team provides:

- Representation at the Administrative Appeals Tribunal (AAT) for clients unable to navigate the appeals process without assistance;
- Discrete advice services designed to assist clients to self-advocate at the AAT, for example assisting clients to understand legal documentation and to articulate their needs to the Agency;
- Community education, for example by speaking at events and creating fact sheets.

Our NDIS Decision Support Pilot team provides advocacy and decision-making support for people with disability who have limited decision-making capacity and require assistance to engage with the NDIS at any stage of the process. Operating within a supported decision-making framework, our advocates assist with gathering evidence for access requests, preparing for and attending planning meetings, supporting a client to choose a support coordinator or problem-solve issues during implementation of the participant's plan.

Introduction

QAI welcomes the opportunity to provide a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) in response to its inquiry into the *Capability and Culture* of the National Disability Insurance Agency (NDIA). The historic remodelling of disability service provision instigated by the rollout of the NDIS has changed the lives of many Australians living with disability. It has also impacted service delivery in almost every sector. Despite several inquiries into the operation of the scheme and associated opportunities for reform, many people with disability continue to have negative experiences of the NDIS. In our view, these negative and often harmful experiences typically occur due to the way in which Agency staff perform their duties, interpret and apply legislation, rules and operational guidelines, and generally fail to understand the unique and complex needs of some people living with a disability.

This submission will outline QAI's observations of the *Capability and Culture* of the NDIA in relation to operational processes and procedures, and the nature of staff employment, before describing the impact on participants trying to access and utilise the scheme. We have interpreted the term 'capability' to mean the ability of the Agency to perform its core functions, in other words, how well it achieves its stated aims, and the term 'culture' to mean the observed behaviour, attitudes and norms of the Agency when performing its core functions. Our observations reflect an Agency thwarted by a lack of knowledge and understanding of people with a disability, poor communication practices, inconsistent decision-making and a focus on cost-cutting, the latter being more synonymous with a welfare program rather than a rights-based scheme. At its core, the NDIS is about improving the lives of Australians with disability and this must remain at the forefront of policy reform in this area.

Operational processes and procedures

QAI has encountered several alarming trends regarding NDIA operational processes and procedures, impacting its ability to successfully achieve its core functions and the objects of the *National Disability Insurance Scheme Act 2013 (Cth)* (the **NDIS Act**).

In relation to access:

- The role of Local Area Coordinators (LACs) is often unclear and inconsistent, with some LACs assisting with Access Requests, for example, and others providing information and referral services only. QAI is also aware of significant delays in participants receiving call backs from LACs, if call backs are received at all.
- The use of certain language and processes can be inaccessible for participants from Culturally and Linguistically Diverse (CALD) backgrounds and First Nations Australians. For example, First Nations Australians do not have a culturally equivalent word for 'disability' and may therefore find the task of gathering evidence to describe their disability additionally challenging.
- When processing Access Requests, the NDIA often requests additional evidence to support a person's application, such as confirmation of different treatments tried to demonstrate permanency, when this information is already provided through multiple documents supporting the original application. Additionally, the NDIA might ask for information relating to functional capacity and advise that this information can be provided by the person's General Practitioner (GP), however GP's rarely have the time or skillset to provide or complete functional assessments. On the other hand, the Agency might stipulate that evidence from a specialist is required, despite there being no rule or operational guideline stating when evidence from a specialist as opposed to a GP is needed. Further, sometimes the Agency asks for more information, for example with regards to the permanence criterion, without providing any guidance as to what kind of information is specifically needed. This can lead to doctors writing generic statements and letters or using language that better relates to eligibility for other systems, such as the Disability Support Pension, as opposed to the NDIS.

In relation to planning:

- Participants typically receive little information, support, or preparation to self-manage their plans. For example, the need for self-managed and plan-managed participants to ensure unregistered service providers are adequately insured is seldom discussed yet puts the participant at significant risk if an unregistered service provider incurs a workplace related injury during the course of their service delivery. Further, there is seldom any discussion regarding the advantages and disadvantages of engaging registered versus unregistered providers, or the risks of engaging wrap-around supports from a single service provider. Whilst the principle of choice and control is central to the operation of the scheme, this can only truly occur when participants are fully informed of the risks of their potential choices.
- In relation to participants whose circumstances have not changed, or are unlikely to change, QAI is supportive of the NDIA issuing longer-term plans (of 24 – 36-month duration), rather than 12 monthly plans. Requiring participants to undergo a plan review on a scheduled annual basis is a needless use

of resources and imposes unnecessary emotional stress on participants. Furthermore, collecting information for planning meetings can sometimes unnecessarily use up capacity building support funding when there has not been a change in the person's function or therapy needs. The need for reports in these circumstances can sometimes feel tokenistic and is a waste of the scheme's limited funds.

- When considering requests for supports, the NDIA often exclude funding for requested supports on the basis that they are 'not related' to a person's primary disability. In other words, the requested supports do not relate to the impairment for which the participant gained access to the scheme. For example, see *'Fair supports for your disability needs'*¹. However, this is not a criterion within section 34 of the NDIS Act, nor within any of the Rules. Once a person becomes a participant, their function and needs are, and should be, viewed as a whole and their status as a participant is not qualified. That is, they are not a participant only in relation to conditions A or B. They either are a participant or they are not. While the issue was considered in the case of *McLaughlin*, in which the AAT found that "supports that may be funded in a participant's plan are not limited to supports which relate to the impairment/s which qualified them for access to the NDIS",² the NDIA are yet to change their approach which appears to be based on a misinterpretation of rule 5.1(b) of the NDIS (Supports for Participants) Rules.
- When considering requests for supports, QAI has also borne witness to inconsistent decision-making, including instances where supports are approved following an appeal to the AAT yet refused at the subsequent planning meeting despite there being no changes to the participant's circumstances. Such inconsistency is also apparent with regards to planning decisions such as whether or not a participant receives a referral to the Complex Support Needs Pathway.
- Participants also report difficulties understanding their plans and knowing which funds are intended for what purpose. This is particularly true for first-time participants of the scheme. For example, QAI supported a client who had a plan where the NDIA approved \$98,000 of a 'floating amount' in their core funding. The client has been unable to ascertain an explanation as to how this amount was calculated. Accordingly, QAI considers that the Agency should provide all participants with a draft plan, as recommended by the Tune Review, which stated *'the provision of a whole draft plan is an important mechanism to ensure decision-making processes are transparent and for keeping the participant at the centre of the planning process'*.³ This would provide opportunity for participants to ask questions, provide feedback and additional documentation if required, and receive further education about how to utilise their plan before the final plan is issued. This would also likely reduce the number of internal and external reviews.
- Current processes relating to the approval of funded supports also fail to cater for the unique and often complex needs of families who have multiple NDIS participants. Rather than each participant in the family receiving and undergoing separate planning processes, families with multiple NDIS participants would benefit from a support coordinator to oversee the coordination of all of the family's

¹ <https://ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/what-principles-do-we-follow-create-your-plan/what-principles-do-we-use-create-your-plan/fair-supports-your-disability-needs>

² *McLaughlin and National Disability Insurance Agency* [2021] AATA 496, see 57, 59 and 661

³ David Tune AO PSM, Review of the National Disability Insurance Scheme Act 2013, December 2019, page 11

supports in order to ensure their lives and daily supports are considered holistically rather than in silo from each other. Funding for therapy and capacity building could and should remain with each individual, however core funding for support workers could be better utilised if it was able to be used to meet the needs of the family as a whole.

In relation to AAT appeals and Agency decision-making:

- When providing reasons for their decisions, the Agency provides ‘outcome letters’ which often fail to satisfy section 25D of the *Acts Interpretation Act 1901* (Cth) which states that the instrument giving the reasons shall, among other things, set out the findings on material questions of fact and refer to the evidence or other material on which those findings were based. Quoting sections of the legislation verbatim and in isolation of personalised information is not helpful nor adequate, yet, for example, a prospective participant deemed not to have met access receives a template letter which has no personalised information as to why they did not meet access and often includes mistakes. Further, the reasons provided are not written in Plain English, typically leaving participants unsure as to the meaning behind certain decisions.
- QAI and other advocacy groups have observed the difficulties caused by the Agency issuing ‘new’ plans whilst a participant’s matter is still before the Tribunal. The ‘new plan’ replaces the ‘original decision’ under review at the AAT so that the Tribunal is no longer reviewing the most recent decision impacting the participant and their access to disability related supports. Sometimes this occurs because Agency staff are unaware that a matter is before the AAT, despite the reported existence of an internal flag on their system which is supposedly meant to alert staff to when this is occurring. The result is that any decision made by the Tribunal relating to the original decision under review applies only from the date of the original decision to the date at which the Agency replaced that decision through issuing a new plan.

It appears that recent amendments to the NDIS Act (inclusion of s103(2)) may have inadvertently worsened this practice. While the inclusion of s103(2) addresses this issue for any application lodged in the AAT after 1 July 2022, there remain thousands of matters before the AAT that were lodged prior to this date, and therefore, are susceptible to an unwitting NDIA staff-member issuing a ‘new plan’, which then necessitates a time-consuming and resource intensive sequence of steps to re-establish the Tribunal’s jurisdiction.

- The use of overly legalistic language by lawyers at the AAT makes the process unnecessarily complicated and inaccessible to applicants, the majority of whom are self-represented or supported by a non-legal person or advocate. For example, the use of the term “Respondent” is not ordinarily understood by the lay person and using the “NDIA” in correspondence to participants would be more understandable. It is not uncommon for clients of our service to either seek our advice in relation to whether they should withdraw their application to the AAT following receipt of what they perceive to be an intimidating letter from the NDIA’s representatives, or incorrectly think that they have been assigned a lawyer by the NDIA to assist them.

In relation to plan nominees:

- Many participants have arrangements whereby a person is appointed in writing, at the request of a participant, or on the initiative of the NDIA, to act on behalf of, or make decisions on behalf of, a participant for the purposes of the NDIS Act. Nominees have a 'duty to ascertain the wishes of the participant and act in a manner that promotes the personal and social wellbeing of the participant'.⁴ Whilst many nominees successfully fulfil this requirement, not all nominees perform their duties in accordance with the Operational Guidelines and QAI has encountered situations where nominees have failed to act in a manner that promotes the personal and social wellbeing of the participant, and have exerted control over the participant to make decisions in accordance with their own interests.

Despite nominees having comparable powers to a guardian, there are no formalised safeguards within the NDIS regulatory framework that minimise the risk of undue influence or exploitation of participants by nominees. For example, nominees are often appointed following casual conversations during planning meetings and can occur in the presence of the person who is being appointed as nominee. This can be challenging for participants who may feel pressured to agree with the suggested appointment to avoid an embarrassing or potentially threatening situation. Similarly, there is no current process by which nominee arrangements are regularly reviewed. A recent consultation paper by the NDIA suggested the possibility of introducing 'desktop reviews' of nominee arrangements. However, this is unlikely to be sufficient and fails to address situations where participants are subjected to the undue influence of their nominees or have their correspondence intercepted by their nominees.

Furthermore, the Agency has power to appoint nominees for participants at their own initiative yet does so without the transparency or accountability of a state/territory tribunal. For example, the Agency can appoint nominees in the absence of a participant having undergone an independent capacity assessment. The Agency is also arguably an interested party to the matter, standing to financially benefit from the appointment or removal of certain nominees and thus do not have the independence of a tribunal either. There are also no compensatory remedies for participants who have suffered harm as a result of a nominee's actions. The lack of safeguards around guardianship type arrangements in the NDIS is therefore a human rights issue that requires urgent attention.

Nature of staff employment

QAI has also encountered concerning trends regarding the way in which Agency staff perform their duties, including how they behave and interact with current or prospective participants of the scheme. For example:

- Many Agency staff members appear to have a poor understanding of disability and its various functional impacts, and lack an understanding of the way in which people with disability are marginalised and devalued by wider society and how this influences how people interact with and perceive a person with a disability. Some staff have reportedly never worked within the health or disability related fields prior to their employment at the NDIA. This lack of knowledge and

⁴ National Disability Insurance Agency, *Nominees Operational Guideline – Duties of nominees*; <https://www.ndis.gov.au/about-us/operational-guidelines/nominees-operational-guideline/nominees-operational-guideline-duties-nominees>

understanding can make it very challenging and tiresome for prospective participants and participants who then have the burden of educating Agency staff about their disability. It can also directly influence decision-making regarding access to supports and shape the way that staff members (inappropriately) engage with participants.

There is a distinct lack of understanding with regards to the decision-support needs of many participants. For example, staff frequently fail to follow or respect the communication preferences of some participants, ignoring requests to make contact via a support person or nominee and calling the participant directly, or failing to register that a person with a visual impairment may require communication in a format other than written correspondence. Sometimes, communicating with the participant directly is perceived to be 'too difficult' so staff revert to a substituted decision-making framework and thus bypass meaningful attempts to implement supported decision-making practices. QAI has also known Agency staff to rely upon third parties, such as support coordinators, to relay information and communicate to the participant on behalf of the Agency.

These practices ignore the extremely high and complex decision-support needs of some participants in the scheme. For example, some participants may experience cognitive challenges, have difficulty processing abstract concepts or experience poor memory recall, or may experience expressive communication challenges. These participants are also extremely vulnerable to undue influence when their only form of decision-making support comes from paid support workers or service providers whose own interests will inevitably conflict with those of the participant. Such participants likely require support from independent, specialist advocates to elicit their will and preferences and to make sure their right to exercise choice and control is upheld, yet this is not routinely offered to participants nor always readily available in their local area.

- NDIA and LAC staff can have a tendency to downplay the seriousness of planning meetings, making them seem informal so as to reduce any anxiety on behalf of the participant, however the reality is that these conversations do inform the amount of money the participant receives in their plan and it is therefore important that participants are afforded every opportunity to adequately prepare for them. Similarly, planning meetings sometimes occur during unscheduled phone calls and again, in situations where Agency staff have failed to adhere to the communication preferences of the participant as noted in their plan.
- Concerningly, it is not standard practice for Agency staff to contact participants in relation to their request for an internal review of a decision, pursuant to s100 of the NDIS Act. QAI understands that this practice only occurs in certain situations, such as when the plan funding has been cut by at least 20%. Furthermore, QAI has observed a significant increase in the number of decisions being upheld at the internal review stage following the introduction of the Participant Service Guarantee timeframes. This suggests that targets or other motivating factors are driving decision-making at this stage as opposed to the individual merits of the review.⁵
- QAI has observed a highly litigious and contentious approach taken by some Agency lawyers when pursuing matters at the AAT. It is also not uncommon for Agency lawyers to attend case conferences without having read the material before them and without having received instructions from the

⁵ QAI, *Analysis of NDIS Appeals Report*, 2022; <https://qai.org.au/2022/08/11/analysis-of-ndis-appeals-report/>

Agency. There is significant concern within the advocacy sector regarding the failure of Agency lawyers to adhere to the model litigant rules. QAI endorses fully, and urges the Committee to read the submission '*National Disability Insurance Scheme appeals at the Administrative Appeals Tribunal*'⁶ by Disability Advocacy NSW, Your Say Advocacy Tasmania and Villamanta Disability Rights Legal Service which outlines these issues in greater detail.

- Further, QAI's Appeals advocates have noticed a recent trend in Agency representatives providing 'T Documents' to participants across multiple emails and files and without indexing each of them properly to assist the participant and their representative to navigate through the material. This is in breach of an AAT Practice Direction which requires each of the document files to be individually indexed. It is not uncommon for QAI's clients who are appealing an NDIS decision to express 'they are lost' within the multiple files sent by the Agency, making it difficult for QAI's advocates to draw the client's attention to relevant documents within the context of an advice appointment.

Impacts on people with disability

The consequences of the aforementioned processes and behaviour can be devastating for participants. Some participants have reported experiencing the following:

- An unnecessary and disproportionately large evidentiary burden, with an associated financial cost, when people are repeatedly asked to provide further or alternative evidence when this is not required. The cost might be individually incurred if the person is a prospective participant of the scheme, or it will be experienced as an accelerated use of capacity building funds if the person is already a full participant of the scheme.
- Delays in accessing vital disability related supports, such as pieces of assistive technology or access to personal care support as a direct result of inefficient and cumbersome bureaucratic processes. Participants can find themselves 'stuck' in between government departments attempting to absolve themselves of the responsibility to provide the requested support.
- Insufficient funding due to impromptu planning meetings and no opportunity to adequately prepare or articulate the need for certain required supports, and furthermore no opportunity to provide feedback on a draft plan before a final plan is approved.
- Significant anxiety, frustration, and distress due to poor and sometimes contradictory communication from the Agency. Participants report having to repeatedly state their needs and tell their stories to Agency staff, none of whom typically work with a participant for an extended period of time. This can be emotionally draining and, in some situations, retraumatising for participants.
- Confusion as to what is being asked of them and what their options are, due to poorly worded correspondence, inaccessible documentation, and the use of legalistic language. Significant time and energy are then spent trying to clarify matters, or where clarification isn't sought or forthcoming,

⁶ <https://advocacytasmania.org.au/wp-content/uploads/2022/06/Model-litigant-obligations-and-NDIS-Appeals-Final-version-7.6.22.pdf>

significant time and resources are spent pursuing unnecessary internal and external review applications.

- The AAT process is experienced as particularly stressful for participants, many of whom have experienced trauma in their lives. For example, participants at the AAT are often devastated following a case conference, which they have waited months for, only to find that the Agency has not considered all the material they have provided or does not seem to understand the issues in dispute. We understand NDIA representatives have high caseloads and therefore limited time but a person with disability's needs in this regard must be given primacy. Simple steps, like apologising for a delay by the Agency can make a real difference to a person's experience.
- An unfair advantage is effectively given to participants who do not require decision-making support or who have access to formal and informal supports to help them navigate the system. The system must be accessible to everyone and should not favour those in situations of privilege, for example, participants who have a formal education.
- A risk of being exploited or experiencing undue influence because of insufficient safeguards and procedures surrounding the role of plan nominees.
- Continued devaluation by the wider community, including by Agency staff, due to media reporting of Agency concerns about scheme sustainability and the subsequent casting of participants and people with disability into the roles of 'burden' or 'drain on public resources.' Similarly, participants of the scheme are often incorrectly presumed to have all their disability related needs met by virtue of their status as a participant, when in reality, many participants have to advocate fiercely and tirelessly to ensure their basic needs are met by the scheme on an ongoing basis.
- There are also implications for the disability advocacy sector, with the abovementioned issues causing an increase in demand for advocacy support at a time when advocacy funding, certainly at the state level, has seen an effective reduction in the availability of disability advocates. In Queensland, QAI operates the Pathways hotline, a centralized phone support providing information and referral for all people with disability in Queensland. From 01 January 2022 to 30 June 2022, Pathways received 395 enquiries, of which 35% were for NDIS related issues. Similarly, among the Queensland Disability Advocacy Program funded organisations, 36% of advocacy services delivered within the same timeframe were for NDIS related issues. Of the NDIS related inquiries, almost half were for access related problems. This is a significant portion of increasingly scarce advocacy resources and highlights the ongoing plight of many Queenslanders seeking access to and supports from the scheme.

Conclusion

QAI thanks the Joint Standing Committee for the National Disability Insurance Scheme for the opportunity to contribute to this inquiry. We are happy to provide further information or clarification of any of the matters raised in this submission upon request, and we consent to the publication of our submission.