



Information gathering for access and planning

**Submission by
Queensland Advocacy for Inclusion**

to

National Disability Insurance Agency

July 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 mission 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.

Introduction

QAI welcomes the opportunity to provide feedback on the *Information Gathering for Access and Planning Survey*.¹ This submission is informed by QAI's experience delivering non-legal advocacy for people engaging with the National Disability Insurance Scheme (NDIS) through its NDIS Appeals Support Program and Decision Support Pilot Program. Whilst we have answered the online survey to our best of our ability, we provide this submission for clarity and are happy to provide further information or clarification of any of the matters raised upon request. The submission responds to key questions in the survey that directly pertain to the experiences of participants collecting information about disability when applying for the NDIS; experiences of participants collecting information for planning meetings; and suggestions for improvement to the access and planning processes.

Q.11 After you submitted your application, did the NDIS ask for more information about your application? Q.12 What additional information did the NDIA ask for?

In QAI's experience, the NDIA often requests additional evidence to support a person's application, such as confirmation of different treatments tried to establish permanency, yet 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. Sometimes the Agency will ask for more information, for example with regards to the permanence criterion, without providing any guidance as to what information is 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.

Conversely, when matters proceed to the Administrative Appeals Tribunal (AAT), QAI has experienced a number of matters being delayed due to the NDIA's refusal to accept evidence provided, for example by a GP, as opposed to a specialist, in relation to particular supports in dispute, yet there is nothing in the *National Disability Insurance Scheme Act (2013) (Cth) (NDIS Act)* or Rules which stipulates that evidence from medical specialists rather than GPs will only be accepted.

This level of inconsistency and perceived inability of the Agency to obtain key information from medical reports or documentation suggests both a lack of understanding on behalf of Agency staff, as well as ad hoc processes that make it extremely challenging for people with disability and those supporting their applications, to know what to expect from the process and plan accordingly. Sometimes it appears that the evidence obtained has not even been properly looked at or considered by the Agency, who go on to request additional information anyway. This can be very frustrating and distressing for people who see their efforts to obtain evidence as a waste of time, money, and resources.

¹ <https://myform.apps.ndia.gov.au/?src=https://forms.apps.ndia.gov.au/jpgbthlbzknpuvv/igaprojectcs?&org=ndis&theme=ndis>

Q.13 Overall, how would you rate your experience applying for the NDIS? What made you choose that rating?

Many of QAI's clients report negative, convoluted, and challenging experiences applying for the NDIS. It can take a long time to gather the necessary documentation and liaise back and forth with the Agency. In the meantime, the person could be going without important disability related support services. Often the information is provided across numerous documents but, in the absence of a cover letter spelling it out explicitly (or in the absence of the skills and time to produce this cover letter or access to a support person with the skills and time to produce this letter), the Agency rejects the application. This could be due to many reasons, such as the Agency workers' inexperience in working in the disability sector and their lack of understanding. Further, the alarming frequency with which Agency staff routinely ignore a person's communication preferences as stated in their Access Request Form adds further accessibility barriers and directly impacts outcomes in relation to the application process.

Q15 What were the biggest challenges when you were applying for the NDIS?

One of the most significant challenges when applying for the NDIS is undoubtedly the financial burden and prohibitive costs associated with obtaining evidence and paying for allied health appointments, assessments, and reports. Bulk billing is usually not an option, leaving a very large and unaffordable gap fee following a small Medicare rebate. For example, accessing an appointment with a psychologist through a Mental Health Care Plan typically requires the person to pay \$215 on the day of the appointment before waiting a few days to receive a Medicare rebate of \$131.65. The out-of-pocket amount is \$83.35 per appointment, which, given the fact that many people applying to the NDIS are in receipt of a social security payment, such as the Disability Support Pension or JobSeeker payment, makes this completely unaffordable and an inaccessible way to obtain evidence for access. Even if a person with disability *is* able to overcome these cost prohibitors, there is no way of ensuring that assessments completed through the health system will align to the access requirements as per section 24 of the NDIS Act. It is also our experience that hospital staff and specialists will usually not provide a report or even support letter to support an NDIS access request.

There is an unacceptable level of inconsistency in decision-making by the NDIA in relation to access requests, as well as a poor understanding of the functional impacts of some health conditions, such as fibromyalgia, which frequently get rejected due to arbitrary conclusions drawn about the intersect between health conditions and disability. Inconsistent decision-making by NDIA delegates could be addressed through greater training, awareness and consistency in information both provided by and supplied to, NDIA delegates. Rather than controlling *who* assesses participants and *how* the required information is obtained, the NDIA would do better trying to achieve greater consistency by focusing on *what* information they require.

The small size of the boxes on the Access Request Form also implies that the level of evidence required is much less than is actually required and typically demanded by the Agency for access requests. The way in which the Agency describes 'the evidence you need' makes the process sound simpler than it is in practice. Moreover, the level of information and evidence required by the Agency at the AAT is even greater and more complex compared to the initial access request. Some of our clients have expressed frustration at learning they have to be able to demonstrate Rule 5.4-5.8 of the 'Becoming a Participant' rules for example, as this has previously not been explained or communicated to them.

Other challenges to the application process include:

- Unreliable support from Local Area Coordinators, such as failing to return peoples phone calls;
- The lack of training among GPs to complete the new Access Request Form. QAI has also heard that the new form is not compatible with the GP network's computer system which would allow for easy extraction of relevant clinical information into forms and would assist with evidence gathering;
- The use of language and processes that are inaccessible for participants from Culturally and Linguistically Diverse (CALD) backgrounds or First Nations Australians. For example, First Nations Australians do not have a culturally equivalent word for 'disability', therefore finding evidence to describe a person's disability is additionally challenging.

Q.26 Is there anything else that would be important to you when applying for the NDIS?

There is a need to leverage existing government institutions to help potentially eligible participants apply and meet access to the scheme. This is particularly vital for certain cohorts of the community, such as people in prison or other closed institutions, who are falling through the ever-widening gaps created by funding disagreements of the state and federal government. Utilizing existing touchpoints with potential NDIS participants is essential to avoid duplication of assessments and the unnecessary drainage of resources. Despite the initial investment required, it is arguably more economically viable in the long-term, as people with inadequate access to disability supports are more likely to interact with and utilize other government services, such as the health and criminal justice systems.

There needs to be transparency in all processes as well as full review and appeal rights. This is particularly important for clients who feel frustrated when, their doctor or specialist confirms the permanency of their impairment or the severity of their disability, but this is then rejected by an Agency staff member who is unlikely to have a background in health or disability.

Further, obtaining information for the purposes of applying for the NDIS should not occur through the use of single, standardised assessment processes that can be inappropriate for determining the diverse needs of people with disability who are known for their heterogeneity. For some people with disability, the need to build trust and rapport with an assessor is essential to their ability to successfully understand and complete an assessment, something which a fixed process will not permit. For others, the episodic nature of their impairment means that their 'functional capacity' is not a clearly observable fact. A uniform approach that fails to cater for the individual needs of the participant will not suffice. Assessing the functional capacity of people with disability in this way would ignore the very functional limitations that a person may experience as a result of their impairment. For example, people who may lack insight into their condition or who may not have the ability to articulate its impact or who may experience difficulties communicating with other people.

In accordance with the scheme's focus on maximizing choice and control of people with disability, participants should be free to obtain reports and information from health professionals with whom they have developed trusting relationships. The preference for clinical information from a clinician who is known to the participant and who likely has a better understanding of the person's support needs is well established in the Administrative Appeals Tribunal (AAT) jurisprudence. Participants must be afforded the opportunity to provide additional clinical information that pertains to their functional capacity that will be considered by the NDIA for the purposes of determining their access request.

The NDIA could utilize its legislative power to remove the financial barriers for prospective participants seeking clinical evidence to support their access requests, as per section 6 of the NDIS Act, and pay for the required assessments. This could be utilized as a discretionary measure for NDIA delegates and would allow the NDIA to fund a functional capacity assessment at a provider of the participant's choice. QAI sees this occur in some matters before the AAT, however it would be far more beneficial for the participant and cost effective for the Agency if this power was utilised at the access stage.

An alternative to NDIA-funded assessments would be for prospective participants to be able to access clinical assessments and reports for the purposes of an NDIA access request through the health system, funded through a newly created line item in Medicare.

The barriers to eligibility for New Zealand citizens is also particularly unjust, given that many New Zealand citizens work and pay taxes to live in Australia, and therefore contribute towards the costs of a scheme which they are prevented from accessing if they incur a disability in their lifetime. New Zealand citizens should therefore be eligible to apply for the NDIS if they meet all other required eligibility criteria.

More guidance is needed for treating practitioners with respect to which assessment tools are most appropriate for different people. Assessments can be an arbitrary appraisal of a person's abilities and the use of certain assessment tools over others can sometimes reflect the treating practitioner's preference as opposed to the individuals' clinical presentation. Sector development is therefore needed in this regard.

Q.18 Overall, how was your experience with your latest NDIS planning meeting? What made you choose that rating?

In our experience, NDIA and LAC staff 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 that person receives in their plan and it is important that participants are afforded every opportunity to adequately prepare for them. Increased information about planning meetings and how to prepare would therefore be beneficial.

Sometimes planning meetings occur during unplanned phone calls and in situations where agency staff have failed to adhere to the communication preferences of the participant as noted in their plan, e.g. contact to be made via their nominee. The inability of agency staff to follow communication preferences of participants reflects a broader issue with a lack of adherence to and understanding of supported decision-making by agency staff. Agency staff don't appear to acknowledge that, if inappropriately or unsupported with regards to decision-making, some people with disabilities may agree to things that they do not fully understand, and this may negatively impact their NDIS plan.

Q.21 What were the biggest challenges collecting information and reports for your latest planning meeting?

It can be unclear what level of evidence is required for the planning meeting and the sort of information the planners require. Our advocates have observed that concepts such as 'reasonable and necessary' are only

explained during the planning meeting, rather than before. It would be helpful if these concepts were explained beforehand, so that participants were supported to obtain the necessary evidence.

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.

Q.23 Have you had out of pocket expenses for appointments with health professionals to get reports for your NDIS application or planning meetings? Q.24 Which appointments or reports have you paid for yourself?

QAI supported one client who disputed an access request decision and who paid for a physiotherapy report themselves with a clinician with whom they had good rapport. At the AAT, the Agency paid for an occupational therapy assessment, however the report was very poor, forcing the participant to then self-fund a second, supplementary occupational therapy report. Both the physiotherapy report and the self-funded occupational therapy reports were then used during the participant's planning meeting once they had met access.

QAI has also had clients who have self-funded a therapy report where that report has not been funded and a participant needs a report to support the funding of that therapy.

Q.28 Is there anything else that would be important to you in a new planning process?

Further investment targeted towards increasing the understanding of 'reasonable and necessary' by Agency staff and other stakeholders, through the development of more case examples that illustrate how the legislative definitions can apply. Much misinformation exists around what constitutes a 'reasonable and necessary' support, and is spread by the NDIA's failure to make timely updates to their operational guidelines. For example, the operational guidelines still state that a gym membership will not be considered a 'reasonable and necessary' support. This is despite the cases of *King and National Disability Insurance Agency 2017 AATA 643* and *Milburn and National Disability Insurance Agency 2018 AATA 4928* heard in the Administrative Appeals Tribunal (AAT) which found that funding for gym memberships can indeed be 'reasonable and necessary', and has since been included in numerous participant plans. Likewise, misinformation about transport funding persists due to the NDIA's continued attachment to its 'three level' system despite the Federal Court finding in *McGarrigle v National Disability Insurance Agency [2017] FCA 308*.

Training should also support planners to better understand and interpret clinical evidence, the recommendations of which are often ignored during planning meetings. Training should also focus upon the bilateral agreements. QAI acknowledges the complexity inherent in these agreements and the ever-evolving understanding of their application. A highly skilled and knowledgeable agency staff is critical to the overall success of the scheme.

Targeted resources that inform participants of the benefits of self-management, provide a user-friendly checklist on the steps required to successfully self-manage, as well as training sessions to upskill participants interested in self-managing would assist to remove some of the fear and uncertainty around taking up the option of self-management. This would reduce the scheme's expenditure on agency-managed and plan-

managed plans. Building the capacity of participants to self-manage is also in keeping with the scheme's underlying philosophy, so long as the decision whether to self-manage is a fully informed choice that remains within the control of the participant.

The idea of using plan check-ins to replace arbitrary and unwarranted plan reviews for participants whose functional capacity and support needs have stabilized, is a welcome change. However, there must be clarity around these new processes and any changes should be accompanied by an increase in support for people with disability to fully understand and implement their plans and a guarantee that the check-ins are conducted in a manner that meets the diverse communication and support needs of people with disability.

Information gathering processes need to suit people whose disabilities impact on their ability to communicate or socially interact. For example, people who may struggle to articulate and convey the true extent of their support needs or people without informal supports to help navigate assessment processes.

Budgets should continue to consider requests for individual reasonable and necessary supports, enabling participants to access an individualized budget that reflects their unique set of circumstances. Furthermore, participants would benefit from greater knowledge about the kind of supports they can access with NDIS funds – if you don't know you can access something or if a support exists, then people don't know to request it.

Moreover, participants would benefit from a plain English breakdown included in their plans. QAI supported a client who had a plan where the NDIA approved \$98k of 'floating amount' in their core funding. The client has been unable to ascertain an explanation as to how this amount was calculated.

A breakdown of funding would also help to avoid some requests for internal reviews of planning decisions, as sometimes these requests are initiated when participants do not fully understand the funding they have been given. This breakdown therefore should be accompanied by a list of reasons for the planning and funding decisions that have been made, based upon which pieces of evidence etc. Further investment in this stage of the process would substantially improve outcomes for participants and would reduce the number of internal reviews and appeals.

Participants should also continue to be able to provide additional clinical evidence to support their requests for specific reasonable and necessary supports to be considered by delegates when determining the participant's plan budget. Participants should also continue to benefit from separate plan implementation meetings that are not at the expense of important planning discussions between participants and planners.

In the event that a nominee appointment is needed or requested, such an appointment should be made separately to a plan review meeting. Discussions regarding the appointment of plan nominees, particularly in the presence of family members or support coordinators, can be challenging for participants who may feel obliged to agree with the suggested appointment, to avoid an embarrassing or awkward situation. Nominee appointments should not occur following casual conversations in plan review meetings, but should follow a formal and separate process whereby the genuine wishes of the participant are obtained independently from discussions regarding their funding, and concerted efforts have been made to ensure the participant is well-informed as to the scope of a nominee's role.

Agency staff require additional training on how to implement supported decision-making practices, utilising the skills and experience of external experts on supported decision-making. Further, improved *understanding* of supported decision-making should not be the sole indicator of success, rather, improved *competency* in supported decision-making practices by Agency staff should also be an indicator of success, subject to appropriate evaluation processes.

It would also be greatly beneficial if draft plans were provided to all participants. The provision of a draft plan would help to reduce confusion, improve communication, and increase transparency of decision-making, particularly given that many participants complete a planning meeting with a Local Area Coordinator as opposed to a delegate of the Agency, increasing the number of people involved and therefore opportunities for miscommunication. It may also result in a reduction to the number of internal reviews initiated by participants who receive plans that are markedly different to what was discussed at the planning meeting. It would provide an important opportunity for the participant to provide additional, outstanding information so that they can receive the supports that they need. It would also help to reserve scarce advocacy resources for more complex situations as opposed to scenarios that have manifested because of poor communication.

There are also myths that exist in relation to participant funding. For example, the myth that if a person's funding is used up ahead of the expiration of their plan, that they will automatically receive more funding due to their ability to demonstrate increased need for support. Targeted education and awareness raising in relation to these issues would be beneficial.

Finally, QAI considers that planning processes should 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 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.