

Systems and Individual Advocacy for vulnerable People with Disability

Independent Assessments

Submission by Queensland Advocacy Incorporated

Joint Standing Committee on the National Disability Insurance Scheme

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About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (QAI) 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 promote, protect and defend the fundamental needs and rights of the most vulnerable people with disability in Queensland. QAI's board is comprised of a majority of persons with disability, whose wisdom and lived experience of disability 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; the Human Rights Legal Service, the Mental Health Legal Service and Justice Support Program and more recently, the National Disability Insurance Scheme Appeals Support Program, Decision Support Pilot Program, Disability Royal Commission Advocacy Program, Education Advocacy Program and Social Work Service. Our individual advocacy experience informs our understanding and prioritisation of systemic advocacy issues.

QAI's recommendations

QAI recommends:

- 1. Independent assessments should be introduced as an option for prospective participants who do not have the financial resources to obtain a functional capacity assessment. Prospective participants should be supported to obtain an assessment from a provider of their choice. The need for the assessment process to remain flexible and tailored to the individual's needs is critical to the entire premise of the NDIS. To impose a standardised process onto something which cannot be standardised is at odds with the nature of disability and the overall scheme.
- 2. Inconsistency in decision-making by NDIA delegates could be improved through greater training and awareness and by increased clarity and consistency with regards to the information required for access decisions or plan budget considerations.
- 3. Participants who complete an independent assessment must be provided a full copy of the assessment report upon completion, not a summary.
- 4. Participants must be able to review/appeal the outcome of an independent assessment outside of the narrow scope proposed.
- 5. Participants must be able to review/appeal the decision of an NDIA delegate to grant an exemption from undergoing an independent assessment.
- 6. Participants must continue to be able to provide clinical evidence of their choosing that will be considered in relation to their access request and/or plan budget considerations.
- 7. Planning meetings must allow participants to raise the need for reasonable and necessary supports which may not have been identified by an independent assessment, evidenced by relevant clinical information.

Introduction

The historic remodelling of disability service provision created by the National Disability Insurance Scheme (NDIS) has changed the lives of many Australians with disability. Despite assertions that the introduction of independent assessments will address many of the inequities experienced by people with disability seeking access to, or utilising the scheme, QAI is concerned that the use of independent assessments will erode the personcentred ethos upon which the NDIS is founded. The introduction of an individualised model of disability service provision resulted from lengthy and arduous systemic advocacy regarding the inadequacies of the previous model, many of which were highlighted in the 'Shut Out: The Experience of People with Disabilities and their Families in Australia' report. QAI is concerned that proposed changes will reduce a person with disability's choice and control, limit a person with disability's capacity to pursue any grievances and deny their right to reasonable and necessary supports, all of which are legislative objects of the National Disability Insurance Scheme Act 2013 (Cth) (NDIS Act) and which resonate with the previous model of disability services.

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. This submission draws upon QAI's experience in delivering non-legal advocacy for people engaging with the NDIS through its NDIS Appeals Support Program and Decision Support Pilot Program.

The reasons and justifications for the introduction of Independent Assessments

QAI agrees that the financial costs associated with obtaining evidence of a person's functional capacity can be a significant barrier for some people seeking access to the NDIS. QAI further agrees that there has been an unacceptable level of inconsistency in decision-making by the National Disability Insurance Agency (NDIA) in relation to access requests. However, introducing mandatory independent assessments for all prospective participants is not the only solution to overcoming these barriers and it is QAI's position that such a reform will introduce further inequities rather than reduce them. Despite the NDIA's assertion that the introduction of independent assessments is in line with the recommendations of the Tune review, the use of mandatory independent assessments was not recommended. Indeed, the Tune review explicitly referred to independent assessments as being a discretionary measure available to participants who incidentally, must retain the ability to choose their assessor and, perhaps most importantly, retain the ability to seek a review of or appeal the outcome of the assessment. To reference the proposed introduction of mandatory independent assessments as an outcome of the Tune review is to misrepresent the recommendations of a lengthy and well-considered inquiry.

QAI raises the following concerns in relation to the proposed use of mandatory independent assessments for all prospective NDIS participants:

The **financial costs** incurred by prospective participants will not be removed by the introduction of independent assessments. Prospective participants will still need to provide evidence that they have a disability that is attributable to one or more of the listed functional impairments, and that the impairment is, or is likely to be, permanent. This includes providing information in relation to treatment options that have been considered and exhausted. The costs involved in accessing specialists, along with lengthy waiting times for appointments that have been cited as reasons to introduce independent assessments, will therefore still be incurred by people with disability. Further, the incentive to save money is at odds with the NDIA's proposed refusal to accept functional capacity assessments which the prospective participant already has access to. For example, a recent allied health assessment. To force a person to undergo an unnecessary assessment in this scenario is arguably a waste of tax-payers' money.

The NDIA's assertion that independent assessments will provide a consistent, transparent and equitable way to capture information about a person's functional capacity is inaccurate. There is no transparency in a process that proposes to withhold the completed assessment report from the participant. Providing only a summary and forcing people with disability to go through bureaucratic information request processes is inappropriate and unnecessary. The information concerned relates directly to the prospective participant and should therefore be their information to share rather than fight to obtain. The lack of transparency inherent in the participant's proposed inability to seek a review of their assessment is also deeply problematic. By narrowly confining the circumstances in which a person can request an alternative assessment and by providing only a complaints mechanism as a form of redress for inadequate assessments, the assessors are placed into a position of considerable power and yet have very little oversight. The inability of a participant to seek a review of a delegate's decision to grant an exemption is similarly alarming. In some situations, this may perversely prevent a person from obtaining required functional capacity assessments in order to meet access and yet they will be denied an avenue to appeal this decision. This may be particularly relevant for prospective participants in prison, a cohort notoriously overlooked and for whom very little information exists with regards to their potential access to independent assessments. Indeed, in the event of an exemption being granted, will the NDIA fund the participant to obtain evidence of their substantially reduced functional capacity through an alternative means?

The concealment of information and shrouding of decision-making outlined in changes being proposed by the NDIA raises fundamental questions of procedural fairness. To deny the appeal rights of people with disability is to silence them from decision-making regarding their every-day lives. It removes essential checks and balances and does little to quell rising concern within the disability sector that the introduction of independent assessments has ulterior motives. That is, that they provide a mechanism for the agency to reduce costs as opposed to the outwardly benevolent intentions of removing financial barriers for participants and improving consistency in decision-making.

The notion that independent assessments will allow the NDIA to focus more upon the person's functional capacity rather than diagnosis is at odds with other statements

made by the agency, for example in relation to their stated intention to 'make clearer the distinction between disability and chronic, acute or palliative health conditions'. If the NDIA want to focus on building an overall picture of an individual's strengths and support needs, including their environmental factors and focus on capability rather than disability, why is there a need to make superfluous distinctions between 'disabilities' and 'health conditions' when a person's resulting need for disability related supports is clearly evident? The nature of a diagnosis, whether it is a 'disability' or 'health condition', is purposefully omitted from the NDIS Act, with the focus being upon the level of impairment or rather, substantially reduced functional capacity. To make arbitrary distinctions based upon semantics is contradictory to the intentions of the scheme and leaves people with significant support needs without access to essential disability services.

The 'one-size-fits-all' approach implied in the use of a single, standardised assessment process is highly 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 simply not suffice. Assessing the functional capacity of people with disability in this way ignores 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. The ability of an assessor to accurately capture the complex support needs of a person with disability whom they have never met and within such tight time constraints is doubtful. The need for the assessment process to remain flexible and tailored to the individual's needs is critical to the entire premise of the NDIS. To impose a standardised process onto something which cannot be standardised is at odds with the nature of disability and the overall purpose of the scheme.

The hope that independent assessments will create an NDIS that empowers participants to exercise **greater choice and control** is undermined by the introduction of a process whereby participants can only choose their assessor 'where possible', the participant has no appeal rights in relation to the process they are forced to undergo, and the participant is prevented from utilizing the experience or attributes of health professionals with whom they have developed trusting relationships. This not only contradicts the notion of choice and control but is in direct contravention with section 3(1)(e) of the NDIS Act.

The assertion that the use of mandatory independent assessments will provide a **more** accurate picture of an individuals' capacity and support needs can also be disputed. The extent to which assessors will truly provide 'independent' accounts of a person's functional capacity is questionable, given their contractual reliance upon the NDIA and the conflict of interest that will tarnish their assessments. Key performance indicators placed upon providers to complete independent assessments within ten days of a referral creates unnecessary workload pressures that are likely to influence the quality of assessments.

Providers will likely become anxious to meet targets as opposed to focusing on accurately capturing the participant's support needs, which may require the assessor getting to know the participant over a longer period of time than is permitted by the proposed assessment process. Further, the refusal of the agency to consider other information that is directly relevant to the prospective participant's functional capacity completely undermines the assertion that they will be making decisions based upon a more accurate understanding of the participant. 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 now 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 or plan budget allocation. To deny the use of relevant information in this way is to overtly limit the NDIA's knowledge of a person and to openly restrict rather than enhance their understanding of the person and their functional capacity. The implied distrust of allied health assessments completed outside of the independent assessment process suggests broader issues with the allied health sector; a position that has not been stated or evidenced.

It is therefore QAI's position that, in line with the recommendations of the Tune Review, independent assessments should be introduced as an *option* for prospective participants who do not have the financial resources to pay for a functional capacity assessment. This option, available as a discretionary measure for NDIA delegates, would allow the NDIA to fund a functional capacity assessment at a provider of the participant's choice. QAI notes that the NDIA already has legislative power to remove financial barriers for prospective participants seeking clinical evidence to support their access requests or plan budget requirements, as per section 6 of the NDIS Act. This extends to prospective participants who require specialist reports to evidence the permanency of their impairment. This access criterion is equally challenging for many people seeking access the NDIS and yet is not included in the proposals to use independent assessments. In QAI's experience, this option is rarely used by the agency and yet provides the required legislative remit for the NDIA to remove the financial barriers experienced by people with disability without introducing mandatory independent assessments.

Consideration would of course extend to the suitability of the provider to undertake the assessment (e.g. in relation to required professional qualifications), the assessment tools to be used (the agency could provide further guidance around which assessment tools are preferred in different circumstances), required reporting formats and the proposed fees to be charged. This would assist the participant to overcome the financial barrier associated with this particular access criterion, whilst supporting them to retain choice and control as per the NDIS Act. It would also prevent the NDIA spending scarce resources on unnecessary assessments when the participant already has the required information. Moreover, it would ensure the participant's dignity and right not to be subjected to needless assessments is upheld.

¹ For example, Arnel and National Disability Insurance Agency AATA 4778

QAI further considers that inconsistent decision-making by NDIA delegates should 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. Providing clarity on the information required to inform access decisions can be achieved without subjecting prospective participants to a dehumanizing assessment process that may be unwarranted and is likely to produce inaccurate information pertaining to their functional capacity. Indeed, without addressing the decision-making skills of NDIS delegates, inconsistencies in decision-making are likely to continue to plague the experiences of people with disability seeking access to the scheme, notwithstanding the introduction of independent assessments.

Implications of Independent Assessments for NDIS planning, including decisions related to funding reasonable and necessary supports

The proposed idea of determining a participant's plan budget based upon the outcome of a mandatory independent assessment relies upon the premise that independent assessments will accurately capture the true extent of a participant's reasonable and necessary support needs, a notion strongly contested above. Greater consistency in planning decisions can be achieved without removing a participant's choice and control over the evidence-collating process and without silencing people with disability from planning discussions in relation to individual reasonable and necessary supports. In seeking to make the NDIS more 'consistent and fair', the proposal to base plan budgets upon the outcomes of mandatory independent assessments will perversely create further inequities. People whose disabilities impact more severely on their ability to communicate or socially interact for example, will likely struggle to articulate and convey the true extent of their support needs within the rigid assessment process proposed. People with disability who have informal supports to help navigate assessment processes will likely experience different outcomes to those who lack such support. These barriers will apply not only to access requests but will then hinder the extent to which people with disability can secure essential disability supports from their plans.

In basing a participant's plan budget solely upon the outcome of an independent assessment, the NDIA is proposing to cease considering individual reasonable and necessary supports as is required by the NDIS Act and which has been determined to be a separate decision-making process to access decisions by the Federal Court of Australia.² Instead, the agency is proposing to determine the person's budget in accordance with their perceived level of functional capacity. A budget that reflects only perceived functional capacity to the exclusion of individual reasonable and necessary supports is not personalised. Arriving at a monetary figure from an assessment that was not designed to produce a financial measurement of a person's functional impairment is an inappropriate

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² Mulligan v National Disability Insurance Agency [2015] FCA 544 - 03 June 2015, paragraphs 32-34.

use of such assessment tools. The lack of information regarding how the agency will turn assessment scores into monetary amounts is concerning. This approach will prevent the participant from accessing an individualized budget that reflects their unique set of circumstances. Despite claims that this will make the NDIS more 'consistent and fair', the introduction of standardised processes will fail to capture the individual needs of people with disability and will fundamentally alter the nature of the NDIS by moving toward generic support packages that are more akin to the aged care system, thus eroding the individualised model originally envisaged for the NDIS.

The likelihood of independent assessments accurately capturing all of a participant's reasonable and necessary support needs is low, as discussed above. The NDIA's proposed refusal to consider pre-existing evidence pertaining to a participant's support needs and incorporating this into their budget deliberations is similarly of concern. The potential for additional evidence to mitigate the risks of inaccuracies from one-off, standardised assessments is clear, and yet the proposed use of independent assessments by the agency explicitly prohibits this. The exclusion of participants from the evidence-collating process also denies their right to choice and control in relation to their disability services.

Of equal concern is a proposal for planning meetings to no longer include conversations between planners and participants regarding the reasonable and necessary supports which the person with disability requires. The budget will be pre-determined by the outcome of the inherently problematic independent assessment, with changes only possible in specific circumstances, including where the person has extensive or complex needs or if there are additional high cost supports required. This removes the rights of people with disability to be involved in decision-making that affects them, as is legally required by the NDIS Act and Convention on the Rights of Persons with Disabilities (CRPD). The possibility that some required supports will not be captured by an independent assessment is high, and yet people with disability will be denied the opportunity to appeal the outcome of the assessment or articulate this during the planning meeting. The only option for participants to raise concern about inadequate plan budgets will be to seek an internal review of the delegate's plan decision. This will likely lead to an increase in requests for internal reviews and subsequent appeals to the AAT, something which the advocacy sector is insufficiently funded to cope with.

The NDIA's suggestion that these changes will benefit participants by facilitating conversations on 'how funds can best be used rather than on justifying each and every support' and by allowing participants and planners to attend the planning meeting with a 'shared understanding of the person's functional capacity' ignores the purpose and widely accepted benefits of separate plan implementation meetings. It is also patronising to people with disability by assuming they will agree with the outcome of their independent assessment and that they will not want to discuss the benefits of specific individual supports.

QAI considers that participants must retain the ability to raise and discuss the need for reasonable and necessary supports which may not have been identified in an independent

assessment. Participants should be able to provide additional clinical evidence to support their requests for specific reasonable and necessary supports which must be considered by delegates when determining the participant's plan budget. Participants should continue to benefit from separate plan implementation meetings that are not at the expense of important planning discussions between participants and planners. Only then will participants truly have access to individualised plan budgets that respect their legal right to be involved in decision-making that affects them. A participant's right to appeal the outcome of an independent assessment must also be enshrined into any policy reform. To deny this most basic legal prerogative is alarming and indicative of an agenda that seeks to infringe rather than protect the fundamental human rights of people with disability in Australia.

Conclusion

QAI welcomes the opportunity to provide feedback on the proposed introduction of independent assessments in the NDIS and is happy to provide further information or clarification upon request.