AUTISM QUEENSLAND SUBMISSION TO THE JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME – INDEPENDENT ASSESSMENTS INQUIRY

INTRODUCTION

Autism Queensland is a not-for-profit organisation with a vision for a life of participation, opportunity and choice for people with a diagnosis of Autism Spectrum Disorder.

We provide specialised education, therapy and support services for people of all ages on the autism spectrum and their families, and are Queensland's longest serving and most experienced agency in the delivery of early childhood supports, education and training, therapy, and accommodation services.

Autism Queensland is also involved in a variety of research programs in collaboration with universities and the Cooperative Research Centre for Living with Autism (Autism CRC) to better understand autism and develop improved supports and services for people on the spectrum in the future.

We employ over 400 staff and our policies and services are overseen by a Board of Directors.

Just over 30% of all NDIS participants have autism as their primary diagnosis. The percentage in younger NDIS participants is much higher – well over 50% of those aged 7–18 years have a primary autism diagnosis. It would seem obvious that the NDIS needs to work well for, and reflect a deep understanding of, people on the autism spectrum. This introduction of independent assessments - the implementation process, consultation, and information-sharing (or lack thereof), as well as the actual assessments themselves - does not seem to take this into consideration.

JOINT STANDING COMMITTEE TERMS OF REFERENCE

a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS

The process has been developed without consultation

Autism Queensland notes that, despite the use of terms such as 'pilot', 'trial' and 'consultation', independent assessments are confirmed. This is concerning, particularly in light of many very serious and real issues that have been raised by participants, their families, peak bodies, and providers representing their clients. A parent made the following comment:

> I do find it disappointing that this appears to be so much change at a time when people are doing it tough enough especially given Covid has caused huge stress and upheaval for many too. I understand and appreciate you always need to improve and that means change, I just wish more consultation was done with community as it really appears this is a done deal. I feel for so many people who this will just be yet another thing we need to advocate for and often we are already at breaking point and need support and by that means listening to the needs of the participants and carers.

This apparent lack of interest in the opinions and experiences of participants and providers has been further clarified by the release of the names of those organisations that have been granted the tender to be independent assessors, just three days after the closing date for submissions on this topic. This would indicate that any of the feedback provided in these submissions about the assessors and their selection is unable to be accommodated which begs the question on why submissions were asked for – there were specific consultation questions asking for feedback on what qualities were wanted in assessors, and more. It is unclear what respondents are supposed to make of the total ignoring of their information on this topic.

Furthermore, the joint submission by DSS and the NDIA to this Joint Standing Committee on NDIS concludes with a section entitled 'Timetable for legislative changes' which again clearly illustrates that the NDIA will implement these assessments regardless of feedback provided in response to its 'consultations'.

Critical questions are not answered

Pre-submission information sessions for providers and participants conducted by NDIA staff, were presented as being for the purpose of providing clarification and explanation.

In the joint submission by DSS and the NDIA, it is stated:

"…the NDIA held over 170 virtual and face-to-face public and stakeholder events and sessions to be delivered between November 2020 and February 2021 to inform participants, family members, carers and the broader public of the intent of these reforms and seek feedback on their implementation".

Having participated in a number of these events/sessions, Autism Queensland observed that time and again, key questions from participants, their carers and providers were not able to be answered by those presenting the information.

This disempowers participants as they are unable to gain the information they need to be able to complete a submission, or even just to feel comfortable about the upcoming change. This lack of respect for participants' perspective is deeply concerning.

How will independent assessment results be used to determine a participant's funding?

Overwhelmingly, the most important question that has been asked is for information on how the results of an independent assessment are then used to determine the participant's plan budget. We are no closer to having any such information now than we were at the start of the consultation process.

Initial information sessions had NDIS staff indicating that they would find this out and pass the information on to all who participated, but absolutely no follow up information of any kind was provided. Information sessions held closer to the closing date for the submissions, saw NDIS staff acknowledge that this was a critical issue but that they had no more information than anybody attending the sessions, on how this would occur.

The independent assessment pilots have not included this aspect in their processes, so a key component of this change is unexamined.

Information from the NDIA, including in the joint DSS and NDIA submission to this Joint Standing Committee, places heavy emphasis on the improvement that will be the outcome of participants not having to go to their planning meeting and discuss each support they would like to access and its cost, along with the evidence of why these supports would be valuable. Certainly, this is a cumbersome and stressful process. However, it does allow all involved to see how the final amount was decided upon.

The steadfast refusal of the NDIA to respond to questions about this or provide any acknowledgement of this critical step in their new process, is doing great harm to the working relationship between the NDIA and participants.

Autism Queensland notes that in the recently released **NDIS Post-consultation Reports**, this issue is still not addressed – there is acknowledgement that the question has been asked (in the post-consultation report for plan flexibility), but the only response under Further Information on Personalised Budgets is, *"The assessment will provide the information we will use to inform the amount of funding provided in your draft plan."*

Additionally, it must be recognised that nowhere else in the world, ever, have the assessment tools in question been used for such a purpose, nor were they intended for this purpose.

Diagnosis or a specialist's statement that the person's disability is permanent is still required before the person can then progress to an independent assessment

Another strongly emphasised rationale for the introduction of independent assessments is it will reduce the burden on participants to seek and undergo expensive, time-consuming, and difficult-to-access appointments with specialists and allied health professionals. For example, the Consultation Paper stated: "The current access process requires people with disability to seek information about the impact of their disability from a variety of health professionals, including doctors and specialists. This can often involve long wait times. Appointments to see doctors and specialists can also cost a lot of money."

At no point is there any acknowledgement or discussion around the fact that for a participant to progress to accessing an independent assessment, they must first provide evidence that they have a disability. From the perspective of the people on the autism spectrum, the long waiting times are for **diagnostic** assessments. As participants will still require a statement from an appropriate specialist that their disability is likely to be permanent before being able to progress to an independent assessment; free independent assessments do not represent any improvement in their situation – **a diagnosis, or comprehensive information from professional staff, is still required**. Diagnosis, as a requirement for NDIS access, has been the cause of incredible stress and distress for many people on the spectrum and their families. This was particularly stressful for those who already had a diagnosis that was deemed not acceptable due to the period since the diagnosis was made. Most participants and their families do not understand why the diagnosis needs to be reassessed or confirmed, since autism is widely understood to be a lifelong condition.

The introduction of independent assessments does not improve the enormously problematic issue of waiting times and costs for participants to see specialists.

At the very least, it should be considered that any person who has an official diagnosis of autism, no matter how long ago it was given, should be able to progress to being offered an independent assessment. Not only does this indicate the proper acknowledgement that this is a life-long diagnosis, but it would also reduce the number of people on waiting lists to have their diagnosis reviewed and confirmed, thereby making such appointments more available for those who do not yet have a diagnosis.

b. the impact of similar policies in other jurisdictions and in the provision of other government services

Proposed changes to the assessment process through NDIS appear to be similar to the reform introduced around the Disability Support Pension which reviewed eligibility requirements according to the extent of impairment demonstrated against set criteria and with a welfare mindset, rather than examining individual circumstances and participation in meaningful roles. The NDIS has committed to moving away from a welfare model and towards control and choice, yet looks to embrace a one-size-fits-all approach to determining need for supports.

c. the human and financial resources needed to effectively implement independent assessments

There is already a known shortage of allied health professionals (AHPs). Participants are having to wait for periods of over a year to gain access to AHPs, with this being especially challenging in regional and remote areas.

For independent assessments to be offered in a prompt and timely fashion, the number of AHPs required by the organisations granted the NDIS independent assessment tender will be very large. The Consultation Paper and information sessions on independent assessments by NDIS staff have emphasised that independent assessors will be qualified and experienced. The most significant pool of such AHPs is with service providers, so it is expected that providers' workforce challenges and participants' lack of access to required supports will become a great deal more problematic.

This issue has been raised by all service providers during information sessions and by participants and parents attending participant-focused information sessions – for example:

> … taking these therapists from therapy work into purely assessment work is surely a step backwards. By diminishing an already difficult resource to engage I would think an NDIS goal would be to ensure there are the supports available that are so vital to help our children and adults to live their best life.

In each case, it has been acknowledged by the NDIA staff as a genuine concern but absolutely no information has been provided on how this is going to be managed or how the impact on participants is going to be ameliorated. It is interesting to note in the DSS and NDIA joint submission to this Standing Committee the statement is made, "The recent focus has been…while also assisting providers to develop and expand their workforce…".

Autism Queensland would like further information on what this assistance has consisted of.

d. the independence, qualifications, training, expertise and quality assurance of assessors

Parents of children on the autism spectrum have had this to say about this aspect:

> I'm concerned about the assessors. If they are just part of an organisation that does assessments and they have certain skils (sic) tags, they aren't going to be professionals practicing in autism say on an everyday basis. Therefore, they aren't going to be up with the latest research or know the nature of the disability as well as a professional that practices in it in the real world everyday.

> My child currently see's 4 therapists, how will one assessor cover all those different types of skilled therapists? I.e. A physio does not have the skills that a OT has and can't accurately assess what an OT can assess etc.

> My children already have assessments with their four therapists so that they can better plan their therapy for the year and know what to focus on for the year and try to improve/assist. They also attend school. They go through enough as it is, let alone another assessment where we are having to discuss all their negative qualities. This will destroy their self-esteem which we are working on daily to improve. Life is hard enough without having to jump through these hurdles.

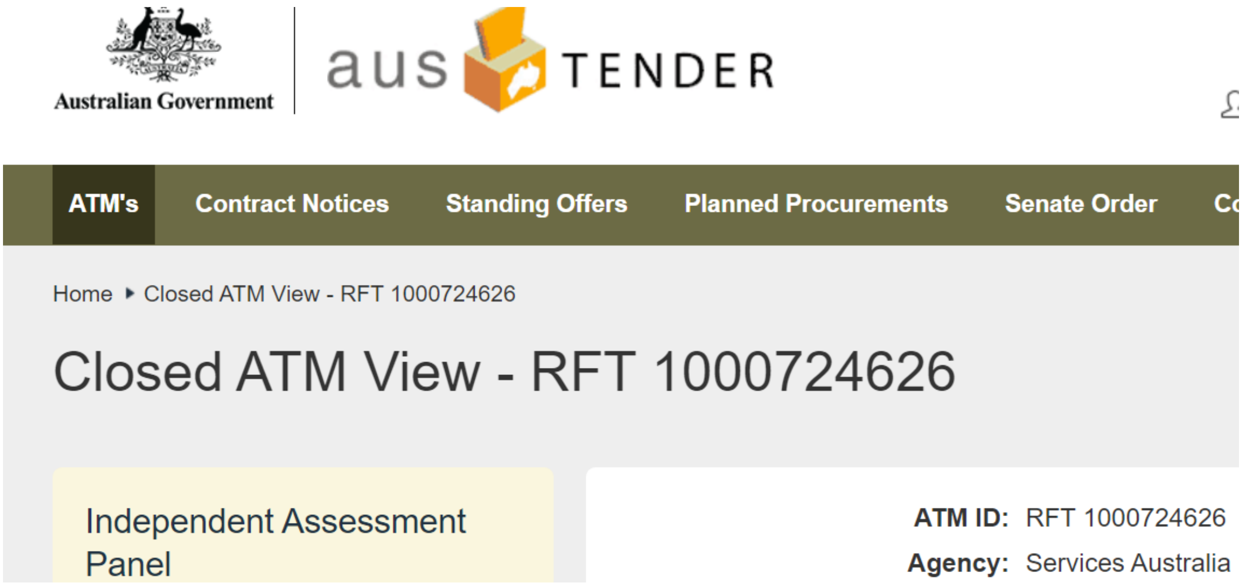
This also applies to adults with ASD as well not coping well with new people asking them questions

My ASD children like routine and consistency, so a independent /stranger assessing them isn't appropriate.

Why does the NDIA believe that one person with a set questionnaire can replace the years of specialist training that OTs, speechies, psychologists, developmental pediatricians etc undergo? I note that an allied health professional will conduct the assessments - however never in the past has my child's psychologist thought she had capacity to assess my child's OT or physiotherapy needs? And vice versa. Professionals undergo training for a reason, To think a checklist can replace that seems extraordinarily strange logic.

Autism Queensland has been concerned to read that a number of the organisations successful in winning a tender to deliver independent assessments may not be as independent as the Consultation Papers and tender application documents seem to indicate is a requirement.

We are also confused by the information provided by NDIA staff in pre-submission sessions that the tender application process was ongoing, with an NDIA expectation that organisations delivering independent assessments would continue to be added to the list and yet the tender application on the Australian Government tender website is closed.



Closed ATM View - RFT 1000724626

Independent Assessment Panel

ATM ID: RFT 1000724626

Agency: Services Australia

It would seem beneficial to have as large a number of organisations as possible delivering this service rather than locking it down, especially as there may be many relevant organisations who would have applied but were unaware of the tender prior to its closing date.

e. the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding

Autism Queensland has concerns that the list of "disability-neutral" standardised assessment tools that the NDIS plans to use (as per the NDIS document released in September 2020 on "*Independent Assessment: Selection of Assessment Tools"*) may not adequately address the functional capacity of some adults on the autism spectrum. For example, these assessments are unlikely to be sensitive to the needs of people on the autism spectrum with university degrees, who struggle to find meaningful employment commensurate with their skills, and who are socially isolated, dependent on their aging parents and who frequently have both diagnosed and undiagnosed mental health issues. These adults need and deserve support to live an ordinary life and can make significant gains from targeted support. Furthermore, this support may ultimately reduce their dependence of social welfare and mental health services.

f. the implications of independent assessments for access to and eligibility for the NDIS

There has not been a robust, transparent trial of independent assessments, or any alternative options, that would look to improve consistency in access and eligibility to the scheme.

g. the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports

The information provided about the process has stated that the participant's goals will be discussed at the planning meeting, that is, *after* the independent assessment has occurred and *after* the funding amount has been determined. Assessment before goal-setting diminishes the participant's choice and control and does not promote a person-centred approach.

h. the circumstances in which a person may not be required to complete an independent assessment

A large proportion of individuals on the autism spectrum and those with other disabilities experience communication challenges – barriers to understanding expectations of others, as well as barriers to expressing needs, ideas, and opinions. These individuals deserve to have access to familiar and trusted supports for their communication needs. An independent assessment process, as outlined by NDIS to date, does not allow for consideration of communication impairment.

A large proportion of individuals on the autism spectrum and those with other disabilities experience co-occurring mental health challenges. An independent assessment process, as outlined by NDIS to date, does not allow for consideration of mental health challenges.

i. opportunities to review or challenge the outcomes of independent assessments

Information provided by the NDIS in its Consultation Papers and pre-submission information sessions has indicated that the actual results of a participant's independent assessment cannot be challenged, although the plan itself can. The question is, therefore, if the plan and funding amount are challenged but those decisions were dependent on the independent assessment which is not able to be challenged or changed, what can a participant use to support their stance that the plan is not appropriate?

j. the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds

Concerns regarding participant/potential participants in regional and remote locations

Whilst the rationale for the introduction of independent assessments is for there to be equity and consistency for all, there are some troubling comments and gaps on exactly how this will be achieved for those in regional and remote areas. Suggested solutions to address the provision of independent assessments to those living in these areas all seem to consist of providing them with a service that is lower quality than those living in metropolitan areas would receive.

The tender document for organisations to apply to become a provider of independent assessments says:

"The NDIA expects that most Assessors will hold qualifications in one of the Assessor Categories described above, but may consider additional Assessor Categories in certain circumstances, for example in rural and remote regions. Tenderers wishing to tender for additional Assessor Categories must clearly indicate their proposed professions in the Tender Response Forms."

AND

"The Supplier may only use a Telehealth service or other remote method to conduct an Assessment in limited circumstances where distance to a rural town or remote community would make face-to-face Assessment Services impractical."

The parents of Autism Queensland clients participating in a pre-submission information session provided by the Queensland NDIS Community Engagement Team made the following comments:

Has the NDIA made comment on how they will ensure adequate assessors to implement timely IAs? Living regionally we struggle to find adequate support services and therapists - its not likely local assessors will be available.

In the case of regional towns, are assessors local or will they be flown in?

Living rural I have been on wait list for therapy assistance for 18 months.

How will they assess someone over the phone? Especially if the person is a child?

Can you explain how assessments are to occur over the phone, how does that work, in regards to lack of observations,

In regards to independent assessors, will they be available in regional areas? ie available to come to our home?

Autism Queensland acknowledges the challenges in providing services to those living in areas outside the metropolitan areas, especially to those in remote locations. However, people with disability in those areas are entitled to the same quality of service as those living anywhere else. Watering down and accepting less than best practice service provision is not acceptable. Other solutions need to be found.

Any requirement for further information may be a further barrier for participants in regional and remote areas.

The Consultation Paper states:

"In some circumstances other information may be needed to determine if a person is eligible for the NDIS. If required, we will request this information. We will consider all evidence provided in relation to impairment and the permanence, or likely permanence, of that impairment. Where appropriate, this information can be provided by the applicant's treating health professional.

"Clinical information and reports from the applicant's usual treating health professional can provide an understanding of the supports or interventions that have and have not worked in the past, as well as any barriers and proposed supports for the future. Independent assessments provide a holistic view of functional capacity at a point in time, and do not replace the clinical relationship and expertise that are important for achieving outcomes and supporting a participant throughout their life. "

Accessing this kind of additional information is going to be challenging and, in some cases, impossible to achieve for those in regional and remote areas due to lack of availability of allied health professionals and specialists. How is this additional disadvantage going to be addressed?

Lack of information on how independent assessments will improve outcomes for currently disadvantaged cohorts

A focus of the rationale for the introduction of independent assessments is to overcome the current inequalities as evidenced by the variability in funding amounts received by participants from the lowest socio-economic category compared with those in the highest socio-economic bracket, and other inequities for those from CALD or indigenous backgrounds. Autism Queensland completely endorses the importance of addressing these issues. However, there is no information provided on how this process is going to be more accessible for those people. Independent assessments are still a process that the person must know about, engage with, understand, and navigate. What is being proposed to achieve the stated desired outcome?

k. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability

Undergoing an independent assessment has the potential to be of great detriment to the emotional and mental health of the participant and the participant's carers:

a. The requirement to engage with an unknown person will cause enormous stress and anxiety in many people on the autism spectrum.
b. The requirement for the participant or their chosen representative to provide detailed information on the challenges they face will be extremely damaging to their self-esteem and will cause further anxiety and stress.

Families who engaged in recent consultation and information sessions were passionate and articulate in expressing their concern, in writing, on this issue:

How on earth can it be seen as ethical to make children aged 7, to 17 sit and tell a complete stranger about their limitations - and many children aren't even AWARE of the issues they face? I certainly don't want to sit and speak about all of my child's challenges in front of her = and she doesn't have enough awareness of some of her challenges to represent herself. the damage to her self esteem if I sit and tell someone in front of her face about all her social and other deficits etc would be hartbreaking (sic) for her. Self esteem destroying. And increase her anxiety. To me this can almost certainly will) cause HARM. So I do not understand how this is seen as a good process. Many families believe it is a way for NDIS to save money as families won't be prepared to put their kids through that due to the capacity for the process to cause harm to the child.

My children already have assessments with their four therapists so that they can better plan their therapy for the year and know what to focus on for the year and try to improve/assist. They also attend school. They go through enough as it is, let alone another assessment where we are having to discuss all their negative qualities. This will destroy their self-esteem which we are working on daily to improve. Life is hard enough without having to jump through these hurdles.

There is great risk and likelihood that an independent assessment will not accurately identify the true needs of a person on the autism spectrum:

- Assessments, particularly functional assessments, have been known for decades to be notoriously poor at picking up and appropriately identifying the needs of people on the spectrum.
- This situation is exacerbated if the person administering the assessment does not have a deep understanding of autism.

Again, families connected with Autism Queensland have expressed their fears and experiences on this:

The issue of children being able to adequately represent themself is a very important one. Please don't ignore it if it seems too hard. There is no way my child can give valid info but how will the assessor know that? Assessment tools are notorious for not being specific enough around these kinds of issues. Ask my daughter - can you make friendships - she will say yes. Ask her teachers, school, parents if she has capacity to independently make and maintain friendships -answer is no. Her self perception is different to reality.

How can a 3hr assessment with a stranger be beneficial for a person with ASD. Assessment needs to take into consideration the history of the child. A lot of ASD children camouflage, and cover up their anxiety. So they may look perfectly fine at the time of assessment, however they are not! You won't see their anxiety or their meltdowns or incapacity to function.

How can an Independent assessor make a report based on a few meetings , given this is key evidence, having time to know child, history, and functional impacts?

My teenager won't interact with anyone new and will need rapport built before any assessment could take place. I'm concerned a "cold" assessment will not get any information from my child directly and will cause problems.

People on the autism spectrum represent a very significant proportion of the total number of people accessing the NDIS. The introduction of any system needs to be designed for such individuals, rather than continue with the previous models that have served people on the spectrum so poorly.

Family members representing the functional capacity of a person on the spectrum may also be challenged to accurately respond to standardised "tick-the- box" questionnaire items which offer little opportunity to provide more nuanced or detailed information about the participant's unique characteristics or contextual information related to their physical or social environment. For example, when asked if the person "*bathes or showers and dries self*", the response may not convey the person's reliance on frequent reminders and environmental cues or a tendency to completely neglect this task for prolonged periods if intensely engaged in a narrow interest area (an autistic trait). In terms of context, the capacity to perform this task in an unfamiliar environment when away from home or with unfamiliar carers can also not be conveyed in a single "tick-the- box" questionnaire item.

Autism Queensland believes participants should have the right to engage their own allied health professionals to undertake the assessments. This will go some way to alleviating concerns about the stress associated with an assessment being performed by an unknown therapist. Experienced allied health professionals who are familiar with the participant will have gathered information from multiple sources including conducting a task-analysis of the person performing functional tasks in different contexts, gathering information from other settings (e.g., childcare, school or supported accommodation) and exploring the person's typical participation in activities across their week. They are therefore better positioned to provide more accurate and meaningful information.

l. any other related matters

Autism Queensland welcomes the opportunity to provide its feedback to the Joint Standing Committee on the NDIS Inquiry into Independent Assessments.

Submitted 31 March 2021
by Autism Queensland Ltd
admin@autismqld.com.au