

# **AUTISM QUEENSLAND RESPONSE TO THE NDIS CONSULTATION PAPER: ACCESS AND ELIGIBILITY POLICY WITH INDEPENDENT ASSESSMENTS**



Autism Queensland welcomes the opportunity to provide its feedback on the above Consultation Paper.

Autism Queensland has a number of significant concerns about the proposed introduction of Independent Assessments (IAs), as laid out in the Consultation Paper. We will provide feedback on these concerns in this submission, along with our responses, where relevant, to the questions posed at the end of the Consultation Paper.

However, most of our concerns boil down to three critical issues that this process will cause for people on the autism spectrum, along with their families and loved ones:

1. Undergoing an IA will 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 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 no earth can it be see (sic) 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 an 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.*

2. There is great risk and likelihood that an IA will not accurately identify the true needs of a person on the autism spectrum.
  - a. Assessments, particularly functional assessments, have been know for decades to be notoriously poor at picking up and appropriately identifying the needs of people on the spectrum.
  - b. 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 themselves 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? Ask her - can you tie your shoelaces. Answer is - yes. Ask her - can you get your shoes onto your feet and tie your shoelaces so that they are tight and secure and you are able to walk around safely in them - answer is no - she can tie a bow now. But she can't put on shoes and tie laces so the shoes can be worn. 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 to 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 AHPs 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 AHPs 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 accurate information.

Autism Queensland also 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 on 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 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.

3. The lack of consultation with participants and providers around the most significant components of these changes, coupled with the lack of evidence for using assessment tools to determine financial outcomes for participants. The input that is being requested is relating to how to manage outcomes of a process that was not prepared in a consultative manner. Autism Queensland strongly requests that the implementation of IAs does not go ahead in the planned time-frame, but is re-considered, through a process of genuine consultation.

### ***Other Autism Queensland comments on issues not covered by the Consultation Questions***

#### THE IMPACT ON WORKFORCE

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 IAs to be offered in a prompt and timely fashion, the number of AHPs required by the organisations granted the NDIS IA tender will be very large. The Consultation Paper and information sessions on IAs 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 also by 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.

Additionally, it is also anticipated that the shortage of Allied Health Professional workforce will also impact Assessor availability, and significant waiting times for assessment are a distinct possibility. Has there been any consideration of how to manage this situation, should it eventuate?

A strategy that will create additional demand for an already limited resource seems ill conceived. Surely the focus now must be on building a competent AHP workforce to meet the support needs of participants.

#### HOW WILL IA RESULTS BE TRANSLATED INTO DOLLAR AMOUNTS?

A central feature of this process is that the data from an IA is used to identify the funding available in the individual's NDIS plan. Despite frequent requests to a range of NDIS staff and through various channels, no information whatsoever has been provided on the mechanism by which this will occur. Furthermore, we are not aware of any research that supports the use of these assessments as a tool for establishing funding. This is critical information that participants, providers and the community need to know and provide feedback on.

If that mechanism has not yet been determined, then that is of concern given the importance of this step and the close starting date for this new process.

If the mechanism has been determined but is not being disclosed, then the lack of transparency is adding to the general sense that the primary focus of this new process is to cut funds to participants.

#### 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

The Consultation Paper states: *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.*

From the perspective of the people on the autism spectrum, the long waiting times are for **diagnostic** assessments, not functional impairment 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 (IA), this change does not actually represent a great improvement in their situation – **a diagnosis 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, particularly those who already had a diagnosis but which was deemed not acceptable due to the period of time since the diagnosis was made. Most participants or their carers do not understand how the diagnosis of what is known to be a life-long condition is required to be made again.

In terms of the functional capacity information that was then needed for the planning process, a number – not all, certainly, but a considerable number – of participants who are on the autism spectrum would already have been accessing one or more allied health therapist and other appropriate professionals as a direct outcome of their diagnosis, meaning that relevant information about the person's functional capacity was already going to be available.

For those who did not have this information, a viable option at the planning meeting was to create a short-term plan with funding specifically for the purpose of gaining the necessary assessments and reports to then inform a longer plan. Whilst this option was not often spontaneously offered by Partners, when participants requested and received this in their planning meetings, it led to good outcomes for participants. Not only were they getting appropriate and comprehensive assessments but they were also able to commence ongoing therapy sessions with the professionals who conducted the assessments, which avoided the need for a new treating professional to also build a relationship with the participant and conduct some of their own assessments.

So, overall, along with the concerns about the IAs and their impact on participants' eligibility and plans, this proposal does not improve the enormously problematic issue of waiting times and costs for participants to see specialists.

#### LACK OF CONSULTATION ON THE IMPLEMENTATION OF IAS

Autism Queensland notes that, despite the use of terms such as 'pilot', 'trial' and 'consultation', IAs are confirmed. This is concerning, particularly in light of many very serious and real issues that have been raised by participants, their families and providers representing their clients, not to mention the questionable data gained from the IA pilots (see next point). A parent participating in a recent information session said it very clearly:

*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.*

#### CONCERNS REGARDING THE IA PILOT PROJECTS

1. Running a pilot during the COVID lockdown period seems likely to have led to skewed results
2. The data from the first IA pilot project is extremely small and not statistically valid.
3. Crucially, the first pilot did not use the IA results to determine the participants' budgets, so participants' rating of satisfaction was based purely on the actual process of having an IA. The most significant concern being raised by Autism Queensland staff and clients is how IA results will be interpreted into funding amounts and how it will change the planning process for participants. The pilot/trial projects have not tested this and yet the decision has been made to implement the process anyway. It is not known whether this step will be included in the second pilot.
4. Many parents of children and adults on the autism spectrum have chosen *not* to participate in the second pilot due to their grave concerns about the negative impact of this process – as highlighted in our introductory comments – on their sons and daughters. This means that the data from this pilot is missing input regarding a critical area of concern.

#### CONCERNS REGARDING PARTICIPANT/POTENTIAL PARTICIPANTS IN REGIONAL AND REMOTE LOCATIONS

Whilst the rationale for the introduction of IAs 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 IAs 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 IAs 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 recent 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 – it's not likely local assessors will be available. And what qualifications do the assessors hold? - I have 4 to 5 separate qualified professionals informing the current plan.*

*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 18months.*

*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.

Those in regional and remote areas are also going to be negatively impacted in the situations where an Independent Assessor requires additional information. 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 AHPs and specialists. How is this additional disadvantage going to be addressed?

#### **LACK OF INFORMATION ON HOW IAs WILL IMPROVE OUTCOMES FOR CURRENTLY DISADVANTAGED COHORTS**

A focus of the rationale for the introduction of IAs 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 IA process is going to

be more accessible for those people. IAs are still a process that the person has to know about, engage with, understand and navigate. What is being proposed in order to achieve the stated desired outcome?

## Autism Queensland responses to the Consultation Questions

1. What will people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?

- They need to know that preliminary eligibility is required before an IA can take place.
- They need to know specifically, that preliminary eligibility requires an appropriate professional to determine that the person's disability is likely to be permanent – and that this means that a diagnosis is required before an IA can take place.
- They need to know how recent such information needs to be – current requirements state a diagnosis must be less than 2 years old. Given that the majority of diagnoses prior to the commencement of the NDIS in any area would not have included the specific wording that the disability is life-long as that was considered to be implicit in the diagnostic label itself, will all those who are attempting to enter the NDIS who only have a diagnosis from more than 2 years ago all need to go back to a specialist to get an updated diagnosis / inclusion of the statement that the disability is life-long? As raised at the start of this submission, this has been a huge issue for many Autism Queensland clients in terms of access to a specialist, waiting times and costs.
- Information is best provided in a simple step-by-step format – more straightforward but also more detailed than the example in the Consultation Paper. For example, Step 1: go to <https://www.ndis.gov.au/how-apply-ndis/what-access-request-form#access-request-form> to download Access Request Form (ARF) or to organise how to get it sent to you; Step 2: complete ARF and attach proof of address (bill for electricity, rates, library card), proof of age (birth certificate, passport, driver's licence), proof of diagnosis (letter from medical specialist); etc.

What should we consider in removing the access lists?

- One of the reasons for the Access Lists was that there are many disabilities that are known to be life-long and where the person is clearly going to need support throughout their life. Requiring this to be individually stated by a health professional for each person is inefficient.
2. How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is or is likely to be permanent and life long?
- There should be recognition of health professionals' expertise in making this determination.
  - There should be recognition that there are many disabilities that are known to be life long and that the diagnosis alone is sufficient to communicate this. Requiring a person to provide evidence that their amputation, Down syndrome, autism, cerebral palsy, etc., is going to be permanent is offensive and unnecessary.
  - Training for the NDIS staff who are reviewing this documentation in their knowledge of disabilities.

3. How should we make the distinction between disability and chronic, acute or palliative conditions clearer?

- Clearer for whom?
- Consult with medical specialists with this expertise. These terms exist because they have meaning within their relevant sector and definitions / explanations would already exist.
- The question itself indicates that the NDIA considers there to be a distinction so does the criteria for this not already exist? If the NDIA itself cannot make this distinction, then it should not be in the process.
- Training for the NDIS staff who are reviewing this documentation, in their knowledge of disabilities.

4. What are the traits and skills that you most want in an assessor?

- The inclusion criteria state that the assessment tools should be able to be used by AHPs of any discipline without the need for extensive or specialised training. The assessment process would be more rigorous if completed by a multidisciplinary team integrating knowledge from different disciplines. From the perspective of autism, assessment is complex and it is important that the AHPs have training and experience in working in the autism field; undoubtedly this is true for other disabilities.
- Assessors and the process need to be mindful of the need to build rapport, and of the additional barriers for many people on the autism spectrum. The assessment process is likely to be highly stressful (unknown therapist, change in routine, high importance to funding outcome).
- An assessor needs to be skilled enough to probe further rather than accept answers at face value.
- Feedback from NDIS staff during information sessions has mentioned the likelihood of assessors who are 'skills-tagged', that is, have expertise specific to a particular disability and therefore appropriate to do the assessments of people with that disability. Autism Queensland supports this suggestion.
- However, it needs to be recognised that if a professional moves into a position that focuses solely on carrying out assessments rather than working therapeutically with people over time, their skills and understanding of the complex nuances of that disability will erode.
- Parents of children on the autism spectrum have had this to say about this aspect:

*My child currently see's (sic) 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 daughter'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.*

*I'm concerned about the assessors. If they are just part of an organisation that does assessments and they have certain skills (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 (sic) as well as a professional that practices in it in the real world everyday.*

5. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?
- Ensuring that the time is taken to develop rapport and make the person as comfortable as possible during the process.
  - Enabling the person's treating professional to attend and be able to charge for this time. If the treating professional's time is not funded by the NDIS, there is a significant risk of inequity, as families who have the capacity to pay for a private therapist will likely have better access to NDIS funding than those who are unable to pay for this assistance.
  - The estimation of an average 3-hour time frame may be unrealistic – there is likely to be a requirement to observe the person in more than one environment, as well as the time needed to settle the person in and build rapport.
  - Will participants in remote areas have access to the same array of accessibility options as those elsewhere – e.g. holding the assessment at their home?
  - Accessibility should not be at the expense of validity – a person on the autism spectrum may consider an assessment over the phone to be accessible in that it reduces stress around travel and organisation but may not be indicative of that person's capacity to function under different circumstances.
  - There should be a pre-assessment risk assessment to identify any factors that need to be taken into consideration to protect the participant, carers and/or staff member.
6. How can we ensure that independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?
- Consultation with relevant cultural groups to define training and arrangements needed.
  - This would be easier to achieve if the assessments were administered by AHPs known to the participant.

7. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

- Information already available demonstrates the supports required.
- Recently conducted functional assessment through another channel.
- High levels of anxiety.
- Risks to participant, family and/or assessor due to behaviours of concern – this also needs to take into consideration the risks to the family and participant *after* the assessment as some people on the autism spectrum will mask their stress and anxiety during the appointment and then experience an extreme melt-down, including aggression to others and self-harm, once the session has concluded.
- What if the person refuses to participate in an independent assessment? There are a number of people on the autism spectrum who will not undertake such an activity because they are experiencing high levels of anxiety and depression and their response is to refuse to engage; or who are in denial of their diagnosis and difficulties and will not engage in any activity that references this; or the diagnosis itself compromises their self-awareness of their own challenges. These responses are in no way indicative that the person does not have substantial support needs. Comments from parents include:

*Good luck if you can even get an ASD child out of their bedroom to see an independent assessor!*

*Or to get them to actually answer any questions from a person they aren't comfortable with!*

8. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

- The interplay between the compulsory participation in an IA, the funding outcome that is determined by the IA and the fact that IA results cannot be challenged is causing many participants and their families to be cautious and deeply suspicious of the overall process:
  - More receptiveness to information that participants already have from their own AHPs and specialists is needed.
  - Transparent communication on exactly how IA results are converted to the participant's funding is critical.
- IA providers need to be subject to a rigorous audit process through the NDIS Quality & Safeguard Commission similar to that for registered providers.

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