

# NDIS Consultation on Independent Assessments

*Autism Aspergers Advocacy Australia*, known as A4, offers the following response to the NDIA's [Consultation Paper on Independent Assessments](#) (webpage [here](#)).

A4 does not regard the so-called "Independent Assessments" as independent. We regard the NDIA's use of this term as deliberate intent to mislead.

While the paper says, "Community and sector consultation is important to us" and "we want to hear from participants, their families and carers, and the disability sector ...", A4's experience is that the NDIA consistently ignores and rejects its input, suggestions and advice. A4 knows that the NDIA's [Participant Service Charter](#) is a sham. However, we will provide a brief response in the hope that our view might make a difference for once.

A4 supports contracted assessments for people, especially children, who do not already have a diagnosis and are likely to be better informed through immediate access to NDIS contracted diagnoses and assessments. We are not keen on contracted assessments designed to contradict the results of properly conducted previous diagnoses. We are also keen to see diagnostic assessments that resolve previous Developmental Delay and Global Developmental Delay diagnoses. But this implies the use of non-standard tools – it is not what the NDIA's so-called "Independent Assessments" will do.

A functional assessment scheme to replace diagnoses is inappropriate. We would support assessments that extend diagnoses with functional capacity information that goes beyond what an individual's diagnoses tell us. Assessments that compliment diagnoses, or where support is needed and for some reason diagnosis doesn't happen, would be welcome.

Previously, [A4 wrote to the NDIA's CEO](#) in response to his letter to participants about the so-called independent assessments. Neither the NDIA nor its CEO responded.

While we have all "heard many examples of inconsistent and inequitable access and planning decisions", we question that the NDIA's so-called "Independent Assessments" will improve outcomes; we expect it will make NDIS Plan inconsistency and inequity worse.

The Government and the NDIA are going to implement their so-called Independent Assessments no matter what we say.

Our response below relates to children and people 7 years and older. Issues relating to younger children, aged 0 to 6 years, are discussed in our separate response to the ECEI Reset issue.

The consultation paper says, "How a person's disability or disabilities impacts their ability to carry out everyday tasks is one of the key factors in determining eligibility for the NDIS under the NDIS Act". People with disability are unable to do so-called "everyday tasks". People with disability find that some everyday tasks are unnecessary, or that their lives are better if the use alternatives to everyday tasks. It is a mistake to determine eligibility (and support levels) primarily on one's "ability to carry out everyday tasks".

A child's "ability to carry out everyday tasks" is a poor indicator of the support that the child needs. A child's current functioning does not indicate their needs: early intervention aims to improve their future based on what their diagnosis tells us about their future, not their current, functioning. For

example, a young child cannot cook and may not manage their hygiene well. The issue is that without best practice early intervention, an autistic child is substantially less likely to learn these skills and function more independently as an adult. This means that they are very likely to have higher support needs as an adult. Children need early intervention that only indirectly relates to their current functioning.

Extensive evidence shows that if autistic children's development is not addressed as early as possible, they experience substantially more limited functional capacity in the future. Functional capacity measures for autistic children are a) difficult to assess, b) an unreliable predictor of their adult functioning, and c) inappropriate basis for resource allocation.

This is equivalent to saying when a child has preventable hearing or vision loss, or decaying teeth, that they should not be treated until they lose their functional capacity, that is their hearing, vision or teeth, ... that preventing the likely loss of *functional capacity* is not an acceptable option.

The NDIS is meant to be based on *Insurance Principles* but clearly the NDIA has a "creative interpretation" of the term in relation to autistic children.

"To be eligible for the NDIS a person's disability must be permanent and have a substantial impact on their functional capacity in one or more of these activity domains:

- communication
- social interaction
- ...

These two items are Part A of every ASD diagnosis. An ASD diagnosis documents that a clinician has determined that the person needs support in the areas of communication and social interaction, ... and in relation to behavioural dysfunction.

The Consultation Paper says, "Population surveys on disability undertaken by the Australian Bureau of Statistics do not support these levels of difference". The only population survey that the ABS does on people with disability is the National Census, and it does *not* ask questions that could support this claim. On the other hand, the ABS SDAC highlights many issues for autistic Australians that the NDIA refuses to address; issues that the NDIA refuses to even consider or discuss with autism representatives.

The Consultation Paper says, "As required under the NDIS Act, we need high quality and consistent information on a person's functional capacity so that we can make accurate and timely decisions". This is not what the NDIS Act 2013 say at all. The Act has 8 mentions of "functional capacity". Most mentions relate to early intervention. Most mentions relate to changes in functional capacity; none of the mentions relates to measurement or "information on a person's functional capacity".

The Consultation Paper says, "We are working towards a future NDIS that is simpler and fairer". From the outset, the NDIS was not going to be simple for government. Disability is complex; the plan was always to address individual need, not to create simple and easy to administer bureaucracies. We had a range of simpler systems before the NDIS. None of them worked satisfactorily. This is reason to suspect that a simpler NDIS is unlikely to work.

If on the other hand, the NDIA wants to make the NDIS simpler for individual participants, then it should listen to people with disability and their representatives. But it refuses to do that.

There is no prospect that the NDIA's so-call "Independent Assessment" sausage machine approach will be fairer. It will depend on people's ability to demean themselves to contracted assessors, who

are strangers often with insufficient training, using often inappropriate tools and working to unreasonable or impossible performance expectations.

Figure 1 in the Paper shows Step 4 as mandatory. For a person, especially an autistic child who already has a diagnosis, this step will either duplicate or contradict what is already known. Duplicating the outcome is associated with delay. None of these outcomes is positive.

The NDIA's so-called "Independent Assessments" process as described lacks natural justice: there is no option for review or a second opinion. It is probably illegal. It is certainly immoral.

The Paper relies on "initial eligibility requirements (Step 2)" but does not define/describe them.

For 3.2 in the Paper, there is no current NDS. Autistic people are not "supported by mainstream service systems including health, mental health, early childhood, education, transport, justice, housing and employment".

In [his letter to everyone](#), the NDIA's CEO wrote "The [assessment] tools have been ... used all over the world for many years." There is no assessment tool for autistic teenagers or adults, nor is there an accepted and reliable tool for assessing the functional capacity or the needs of autistic children. Further, Section 3.4 of the Discussion Paper says, "The Autism Collaborative Research Centre's study of the reliability, validity and usability of assessment and functioning tools for ASD in the Australian context provided evidence of good reliability for the PEDI-CAT (ASD)." – clearly, this assessment tool has *not* "been ... used all over the world for many years", as the CEO wrongly claims.

The NDIA says it is "transparent". So far, we are not aware that the NDIA has released the Autism CRC's review of the PEDI-CAT (ASD). Keeping it secret is not transparent.

The NDIA's consultation paper on Budget Flexibility says:

The current process for building plan budgets, based on a need to assess whether every individual support is reasonable and necessary, has resulted in inconsistent decision-making and a high volume of reviews. Currently, participants with similar levels of functional capacity and environments may have very different levels of NDIS funding. Significantly, evidence exists that the current approach to assessing a person's functional capacity is leading to inconsistent and inequitable plan budgeting decisions.

Participants in the highest socio-economic cohorts are receiving more funds in their plans than those who are most disadvantaged. Payments differ by socio-economic areas for both children and adults, with participants living in higher socio-economic areas receiving higher payments on average. As show in the latest NDIS Quarterly Report, payments are 23% higher in the highest socio-economic decile for children, compared with the lowest and 13% higher for adults.

Apparently, the NDIA wants to base supports it provides in an individual's NDIS Plan on the limited items that are reported via "functional capacity" assessed through standardised assessments tools. The NDIA aims to avoid the Objects of the NDIS Act 2013 including:

- Giving effect to the CRPD (Section 3(1)(a))
- "support the independence and social and economic participation of people with disability" (Section (3)(1)(c))
- provide any "reasonable and necessary supports" (Section 3(1)(d))
- "enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports" (Section 3(1)(e))

- “promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the mainstream community” (Section 3(1)(g))
- “raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability” (Section 3(1)(h))
- “give effect to certain obligations that Australia has ...” (Section 3(1)(i))

The NDIA’s goal is for people with the same or similar assessment outcomes using very limited tools, to have consistent supports. It does not matter that different people have different goals that usually involve different levels of support.

We agree that it is unfair that people from lower socio-economic areas fare worse in the NDIS process. This can only be due to the unfairness of the NDIS administration.

The NDIA does not recognise that the inequity it sees in its current system is due to:

- Their NDIS being hard to understand and navigate, so educated and people with better informal supports do better from their system.
- NDIA staff with inadequate understanding of disability and working to unclear rules delivering highly inconsistent planning outcomes.
- Support quality is unmonitored and extremely variable – poor support often ends up being substantially more expensive, and the NDIS is reluctant to recognize and pay properly for good quality support.

The so-called Independent Assessments will be even harder to “navigate” and the result will be more inequity.

The reduced variability for adults simply suggests that people with more experience of unfair systems fight harder for fairer planning outcomes. The NDIA’s so-called Independent Assessments will just make that worse.

The NDIA now has an established history of lying to the ASD community. Nothing it says can be believed. Its intentions towards the ASD community are often malevolent.

## Consultation Questions

### Learning about the NDIS

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

People need to know that

- these contracted assessments are not independent and they are inconsistent with Subsections 3(1)(e, g & i) of the NDIS Act 2013.
- these assessments are intended to limit their support.
- what the NDIA tells them about these assessments is unlikely to be accurate or sufficient information; it is likely to be incorrect, inconsistent and confusing.
- functional assessment does not relate to individual goals (which is the purpose of the NDIS).
- there is no evidence-based for standardized functional assessment of autistic people.

Clearly, the NDIS will not tell them this. It is best provided independent of the NDIA and by people who give higher priority to the best interests of participants rather than the NDIA’s immediate bottom line.

## Accessing the NDIS

### 2. What should we consider in removing the access lists?

There is nothing to consider since the decision is already made. You should recognise that:

- most applicants, all those who already have a diagnosis of serious and permanent disability such as autism with either severity rating above 1, will have their access delayed while they await their contracted functional assessment.
  - additional assessment is an unnecessary cost for those who already have a diagnosis.
  - the process will either duplicate the previous diagnosis or result in a different conflicting assessment result. Getting a different result adds confusion and may result in delays.
- ### 3. 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?

In relation to ASD, the NDIS's deep reluctance to provide evidence-based early intervention ensures autistic children are likely to have permanent and life-long disability.

The items in List A and List B were always [gobbledygook](#) in relation to autism/ASD. The NDIA promised to revise them, but persistently broke its promise.

Removing eligibility for people with some specific diagnoses is just silly; for example, young children with autism need automatic access to early intervention which the NDIS is now the only source of funding. The existing gobbledygook should be replaced with better access lists or processes.

The DSM-5 says

... Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naive and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression. Many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from the stress and effort of maintaining a socially acceptable facade. Scarcely anything is known about old age in autism spectrum disorder.

Autistic people have life-long neurological differences. Some autistic people learn to function effectively with their neurological differences; most of them have some aspects of their lives where they function exceptionally well, but most of them also need services and support in areas where they are functionally disabled.

Allied health professionals, as they work with and come to understand each autistic individual, should recognise the services and supports that each autistic individual needs. This is a complex process. No standardised testing is known to achieve satisfactory results.

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

In relation to ASD, the health sector needs thorough re-education. Their practice is to regard autistic patients as not deserving treatment for their health conditions. The health system leaves disability services to address most or all the health needs of autistic people.

It is reasonable for the NDIS to object to this practice, but they seem unable to get the health system to properly support the health needs of autistic people.

A fair system would impose real penalties on senior officials in both the health and disability sectors whenever a person with disability does not get, or cannot access, a reasonable and necessary support. Currently, government practice is to reward senior staff in both the health and the disability sector for denying people with disability services and supports if they can get away with it.

#### Undertaking an independent assessment

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

People assessing young children diagnosed with Developmental Delay or Global Developmental Delay should have the skills needed to diagnose properly; especially for children who have autism spectrum disorder (ASD).

People assessing older participants need:

- comprehensive skills in supporting autistic people; demonstrated and reliable skills in recognising and describing the service and support needs of autistic clients with experience in delivering outcomes effectively.
- To recognise and respect the knowledge and skills of autistic people, their family and associates.
- Respectful appreciation of difference and the benefits that it brings.

6. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

First, the NDIA's so-called "Independent Assessment" process should be avoided when it will either duplicate or contradict an existing diagnosis and assessment.

For those who need it, there should be options available. And the NDIA should be open to other creative or innovative approaches should they be suggested.

7. How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

Work with the various cultural groups.

They won't do this with autistic representatives, so it is unlikely they will do it with numerically smaller groups.

#### Exemptions

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

People with an existing assessment, from a clinician who already knows them and has a full understanding of the person, typically do not need further assessment that either duplicates or contradicts their existing assessments.

#### Quality assurance

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

It will be necessary to repeat assessments for a carefully constructed sample of people with their own specialist assessments, and check that both assessments get very similar results.

Also, participants who have multiple assessments over time should have their assessments checked for longitudinal consistency in the context of the supports provided in their plans.

#### Communications and accessibility of information

10. How should we provide the assessment results to the person applying for the NDIS?

The results for a participant should be provided in a form that is accessible for the individual participant.

The results should explain how they will be (or were) used in NDIS planning.

Where there are a series of assessments, results should be presented showing how the assessed items vary over time.

### Question that should be asked

The questions above are really directed to avoiding key issues. Were the NDIA interested in improving NDIS planning outcomes it would be asking questions like the following.

11. How can the NDIS be improved?
12. How can NDIS Planning be improved? Currently NDIS Planning is inconsistent and inequitable results: how can the NDIA get far more consistent and equitable planning outcomes consistent with the Objects of the NDIS Act 2013?
13. Should the NDIA use its experience of the NDIS so far to update its expected number of participants and their support needs? How would it do that?
14. The NDIA culture is to distrust people with disability, informal carers, and clinicians. Is this an appropriate and constructive culture? Does the data justify this prejudice, or should the majority of the NDIA's distrust be directed instead at service providers?
15. How will the NDIA monitor its processes to ensure they are fair and effective?
16. How can *Developmental Delay* (NDIS Act 2013, Section 9) and *Global Developmental Delay* (DSM-5) meet NDIS eligibility requirements in Sections 24(1)(b) and 25(1)(a)(i) of the *NDIS Act 2013* when both these diagnoses cease by age 7 years (these are not permanent disorders)?

Feel free to contact us if you are interested in answers to these more critical issues.