

Statement by the Autism Family Support Association



NDIS Funded Assessments (Independent Assessments) are a bad idea, especially for people with autism and the families who support them. Why do we say this?

- Independent Assessments (IA's) do not represent "choice and control".
- IA's should **not** be introduced and should definitely not be used for people with autism.
- These proposed assessments have the potential to impact disastrously on many people with autism and the families who support them.
- People with autism seeking entry to, or continued funding by the NDIS, need proper assessments conducted by qualified professionals and therapists. Assessors need to **understand autism, and know the person.**

AFSA represents parents, carers and families of people with autism and we have a particular focus and concern for people with autism who have complex and/or high support needs and the families who support them.

Families and carers of those with complex and/or high support needs are already under significant stress. They are already managing a multidisciplinary team of professionals involved in providing assessments and ongoing therapeutic support and management strategies for their loved one/s. The proposed IA is redundant at best, or malignant at worst.

It is AFSA's view that the Government and the NDIA are using the "cover" of a response to the Tune Review to introduce the use of "Independent Assessments".

The use of so called "reviews" in the granting of Disability Support Pensions a few years ago demonstrated that such reviews are a "blunt instrument". These types of reviews hide "cost cutting" agendas and can be shown to cause trauma and dismay to participants and those that care for them.

About Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a complex, lifelong condition presenting as severe social and communication impairment, restricted interests and repetitive behaviours that substantially interfere with every-day functioning. The presentation of ASD varies considerably depending on factors such as cognitive ability (IQ), personality and age. In short, **no two individuals with ASD are the same.**

It is critically important to note that:

- some people with ASD have significant learning difficulties whilst others have an average or above average IQ;
- almost all individuals with ASD find understanding and relating to other people challenging and anxiety provoking; and
- almost all individuals with ASD experience sensory processing challenges and the majority express these challenges through their behaviour.

Behaviour is Communication and individuals with ASD vary enormously in their communication skills:

- some may not develop speech but will be able to effectively communicate through alternative assisted communication methods such as signing, picture exchange systems, printed word or communication devices;
- some people require intensive assistance to communicate even the most basic needs;
- some may acquire simple language, whilst others will develop fluent and effective language;
- some have sophisticated vocabulary and/or the ability to speak with great technical complexity on certain topics, but may still have difficulty understanding or expressing complex or abstract concepts;
- for some, conversations may be very one-sided because they struggle with the back-and-forth nature of conversations;
- some have comprehension problems, often more so than is suggested by their expressive language;
- even the most able individuals with ASD report auditory comprehension difficulties at some level; and
- many rely heavily on their visual skills to compensate for auditory comprehension problems.

The Australian Advisory Board on Autism Spectrum Disorders (AABASD) pointed out during the NDIS design phase that the **functional assessment** of people with ASD must reflect the unique nature of the disability and that those who interact or deliver services to people with autism must be **skilled, competent and trained** in the unique supports and interventions required.

If Independent Assessments are introduced, we believe a number of protections and safeguards must be put in place to ensure they truly meet their stated purpose. Independent Assessments will need to be carried out in a way that recognises the challenges that people with ASD face, using the right mix of professionals to assess and report on their functional abilities and appropriate support needs.

The proposed model of Independent Assessments does not suit people with Autism Spectrum Disorder.

Current NDIS participants with ASD and those with ASD who may seek entry to the NDIS and who have complex and/or high support needs, and/or are currently on the DSP, should not be subject to IA's. The experience of a stranger coming into their home or of having to go to an unfamiliar setting can trigger significant stress and anxiety in many individuals with ASD.

There will be situations where autistics with intellectual disabilities do not want to admit they need assistance or cannot do something. They may have spent their whole lives being bullied or looked down upon as “lesser”. The person may not understand the significance of an assessment or of the NDIS. So when questioned they will say what they think is the ‘right’ answer - especially to someone they don’t know.

These real life experiences highlight the unreasonableness of deliberately putting people in situations that they should not be put in.

- *A 19 year old autistic young woman with an intellectual disability, limited communication and other co-morbidities, becoming highly distressed after having to attend a crowded Centrelink Office to be identified for a DSP application. This led to significant anxiety and behaviours exhibiting her distress. This caused anxiety and challenges for the carer in supporting the person to manage and then safely exit from the office. Like many people with autism, changes of routine can create fear.*

- *An 18 year old man with autism, intellectual disability and a language deficit, when questioned by an NDIS Planner at his very first plan meeting said he could do ‘everything’. This was despite him receiving significant supports at home and in the community from his parents, and having a 1:1 support worker funded under a previous state funded package and attending a special school his entire life. This experience heavily impacted on his first Plan in a negative way until there was the opportunity to provide evidence supplied by the therapists who knew him and had worked with him.*

IA’s conducted by assessors with no knowledge of the person or of autism will result in major mistakes, miscarriages of justice and massive reverse workflows for families and the NDIA.

The families that AFSA represents have raised many questions and concerns about what an Independent Assessment will mean for them.

AFSA believes that these assessments will place significant additional burden on the carers/family of individuals with ASD. They will need to be actively involved with the whole process and understand the implications of an IA, especially for those loved ones with complex and/or high support needs. How practical will the IA process be? AFSA members have expressed many questions central to our concerns:

- Where will assessments be conducted?
- Will participants, their families, carers or advocates have a say in who will conduct the assessment?
- Who assesses the Assessor for their professional expertise with ASD and monitors their performance?
- What protections will the NDIS put in place to ensure integrity in assessments?
- What format will the proposed assessments take – interview? observation? medical examination? testing instruments?
- Will the tests applied be able to reflect the true capacity or difficulties the person lives with on a day to day basis?
- Will it be tailored to the circumstances of individual participants and their families?
- What role or support will be expected from parents, carers and families before, during and after an assessment?
- What weight will be given to IA's? What part will they play in funding level reviews - as in - what weighting does it have with the planners and delegates in approving funds and services in the individual's plan?
- What will be the qualifications of those conducting the assessments? Will there be more than "occupational therapists" in the pool of assessors?
- A parent or carer may have multiple family members with support needs. Will the NDIS pay for the care of other family members needing support while the carer is assisting with the participant's assessment? Will the NDIS pay for transport expenses or even childcare?
- When will participants or their families get access to the IA report? AFSA understands that the proposed assessment is not actually shown to the participant (or their family/carer) before being lodged. This leaves it wide open to error.
- What privacy protections will there be for personal information that a participant is forced to share?
- How transparent will the internal NDIA processes be so that participants and their families can be assured that NDIS planners and delegates give proper weight to all the evidence available especially if a participant's funding decreases?
- What will be the complaint process – what will the chain of review look like?

- What review and appeals processes will exist? And will they be timely and cost effective for all especially if matters go to the AAT.
- How can things like abilities around social interaction and communication be assessed in just one setting? The NDIS is not just meant to provide supports to an individual at home but in the community as well. These are major issues for people with autism.
- How can things like the ability to travel safely in the community be assessed? There is a difference in being able to perform a task and being able to perform it consistently and safely in every setting. This can place participants at great risk. Nor can just one day present a clear picture. Behavioural challenges may not occur every day and every hour or when a therapist is present for a brief time in that setting.
- Where, if at all, do providers and their representative body National Disability Services (NDS) fit into the picture where funding for a participant may be reduced or even lost because of an IA?
- It is proposed initially that IA's will be used to qualify for NDIS and then moving forward for every plan review. How can a screening tool be used to decide what actual supports are required in a review?

The following was provided by a member of AFSA and illustrates why we are asking these questions.

How can a therapist unknown to a participant, in a brief amount of time, produce a more accurate and valid functional assessment than that of one or multiple therapists who engage regularly with a participant in multiple settings and who has the participant's trust? The AAT made such a ruling recently.

Currently, a functional capacity report completed by an OT known to the participant takes approximately 10 hours. The NDIS can and does fund preparation of this report. How realistic is it to expect an assessor who is a complete stranger to be able to produce something similar in a maximum of 4 hours including report writing for a participant who may have multiple disabilities, impaired communication and challenging behaviours. Currently those participants with autism, complex needs and high supports often have multiple therapists and so already have access to reports and assessments. Why replace this with something less i.e. a brief assessment carried out by a therapist who is completely unfamiliar to them and of them in just one setting? How can one therapist possibly assess all areas like functional capacity, language, behaviour, and physical challenges?

It takes years to develop trust with therapists and those doing assessments. It takes a multidisciplinary team to assess complex needs and it is surely a waste of time and money (therefore not complying with the 'reasonable and necessary' component of NDIS) to have to undertake a review each year. Will all participants really need an IA each year?

Another AFSA member asks:

Who will decide which Assessor will be used in any particular case? Which professional could possibly know the appropriate assessment tools to use and on whom? Are the assessment tools themselves all inclusive? It would be like asking a musician who plays the French Horn to be able to play every other instrument in an orchestra perfectly without missing a beat. The chances of that are, of course, highly improbable and prone to disharmony, confusion and distress to all involved.

There is a serious risk to the well-being of a participant who already suffers the anxiety and fear of not knowing whether they will be listened to or understood if they are subjected to further scrutiny and mistrust. "Choice and control" will be eliminated with IA's if you cannot choose who does the review and if you cannot see the final report. There will be unjustifiable stress these participants will be put through in having the assessment done. There will be a fear that desperately needed supports are to be removed if the assessment goes badly.

The NDIS needs to articulate clearly what it will be doing with the information already provided by multidisciplinary teams representing the needs of the participant. The NDIS was set up for disabled persons not to be "judged", yet AFSA believes that an IA will be a judgement tool in the guise of an 'assessment tool' and of dubious weight and of dubious value.

In conclusion - **Much Greater Clarity and Transparency is required by the NDIA**

Greater clarity about and scrutiny of the purpose of IA's needs to occur.

Why exactly does the community need them? Where is the benefit for participants and their families and carers? Why is there such haste in the introduction? What are the results of the trial?

The introduction of IA's implies that assessments and reports prepared by a range of professionals for participants need to be "checked".

What consultation has occurred with relevant professional bodies about this implication that assessments and reports by their registered professionals are not able to be relied upon?

AFSA cannot see where in the Tune review it is suggested there be such a review process.

Instead of the time and expense of the proposed IA process, why wouldn't scarce NDIS resources be better directed to a process that would supplement gaps that might exist in a participant's existing multidisciplinary team?

For example, if a participant has an OT, speech therapist and behavioural therapist already, but doesn't have a psychologist, or social worker, or mental health nurse, why can't those professionals be funded to enhance the information provided by an existing group of professionals?

If the proposed assessments have to occur to ensure a participant qualifies for entry or continuation in the NDIS, AFSA prefers the word **Accessible** to Independent.

Accessible Assessments should be facilitated by the NDIS to create a level playing field so that all participants and families are able to access the assessments they need from the right mix of professionals and therapists. Any assessments must remain the choice of the participant as to who is engaged, and the type of assessment tools that are used.

The NDIS should pay for **Accessible Assessments** as an adjunct to a person's existing reports in order to facilitate acceptance onto the NDIS scheme and in addition to the formal/informal support network already in place, not as replacement.

AFSA believes strongly that Independent Assessments should not be introduced.

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