



## Autism Advisory and Support Service

ABN 63 073 684 085

"Empowering children and adults with autism and their families through knowledge and support"

### Independent Assessment Submission 23/02/2021

**Please find enclosed Independent Assessment from the Autism Advisory and Support Service.**

#### **Terms of Reference:**

- a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;
  - If the assessors are hired through an NDIA tender, are they really independent or is it in line with who provides the lower cost for delivering the service in terms of value for money. This will have an impact on the outcomes and quality of assessments.
  - Length of assessment ie 20 minutes to three hours of interactions and observation (what information can you get to ensure that it is holistic and captures the needs of participants? One of the questions in the assessment asks for an observation of 15-20 minutes of the participant in an activity of their choosing. Most people will choose an activity they are comfortable with. Participants with Autism will always choose restricted and repetitive activities. Participants with a profound disability may not be able to choose. The outcome will generally be favourable as the participant has chosen an activity within their comfort zone and will not reflect their capacity in the community.
  - Needs change, is the assessment going to be used for supporting / plan reviews and if there's major change in circumstances, what opportunity is there to review the way NDIS plan is funded?
  - Transparency with the whole IA development model.
- b. the impact of similar policies in other jurisdictions and in the provision of other government services;
- c. the human and financial resources needed to effectively implement independent assessments;
- d. the independence, qualifications, training, expertise and quality assurance of assessors;

According to the NDIS website, the qualifications of an independent assessor are: Independent assessors will be health care professionals from a range of areas including:

- occupational therapists
- physiotherapists
- speech pathologists

Autism Advisory and Support Service \* 88 Memorial Ave, Liverpool NSW 2170

\*TEL: (02) 9601-2844 \*FAX: (02) 9601-1339 \* Email: [info@aass.org.au](mailto:info@aass.org.au) \* Web: [www.aass.org.au](http://www.aass.org.au)



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- clinical and registered psychologists
- rehabilitation counsellors
- social workers.

It is common knowledge that allied health professionals are so limited in supply to deliver therapy under the NDIS that there are waiting lists across the board in excess of 12 months. We can assume that the range of care professionals will be more likely social workers and rehab councillors. This set of professionals will only have very limited knowledge around Autism and other neuro diverse disabilities.

It is important to set specific standards on experience and/or extensive education around these disabilities. Given this fact participants will benefit more from having their assessment from an allied health professional who is currently working with them or has done in the recent past.

Originally, NDIS planners and LAC's were supposed to have an array of experience including professional disability and lived experience. This has not eventuated given the lack of applicants with these qualifications. There are many whose only qualification to the job is having English as a second language. This is evident in the frustration and lack of understanding during the planning process and the plan outcome. There is a risk this will occur in this instance.

If we look at the TUNE REVIEW, it states that **discretionary powers for prospective participants to undergo assessments are recommended. It goes on to say that the NDIS should NOT implement closed or deliberately limited panel of providers to undertake IA's.** The current model clearly goes against this recommendation. The current model has IA's for all participants, irrespective of whether they are in the NIDS or not. The uptake of pilot IA's is not popular. We have had a number of our vulnerable participants being contacted and congratulated as being chosen by the NIDA to undertake an IA. **They were offered a payment of \$150 to participate.** This jeopardises the validity of the pilot process.

<https://www.ndis.gov.au/participants/independent-assessments/second-independent-assessment-pilot/participants-second-independent-assessment-pilot/assessment>

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

Once again, the NDIS has a focus on participants with a physical disability. Participants with neuro diverse disabilities require forensic questioning prior to assessment to determine which assessment tool is appropriate for their needs and goals. the implications of independent assessments for access to and eligibility for the NDIS;

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



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For participants with Autism, the areas most impacted are social, communication and psycho social difficulties (eg anxiety) and other comorbid conditions associated with Autism. Perception with participants with Autism varies and can often depend on their cognitive ability. EG if you ask a person with Autism if they need help they will likely say no, even though they require substantial support. Participants with Autism can often be guarded about the information they provide to anyone. They can often be reluctant to engage with new people and can mask a lot of their difficulties. An accurate assessment will not be possible with an independent assessor in these cases, in particular given the limited time frame offered for the assessment.

The implications are that more individuals with Autism will not be able to access the NDIS. They will then be lost in the mainstream system where there are no services or supports catering to their needs. They will not be able to live independent and meaningful lives that they could under the NDIS. The cost to the Government will be astronomical.

For most participants, home is their safe haven. If an IA is completed in the home environment, they will quite likely not be eligible for NDIS supports. IA's MUST be assessed in all environments, including community and social situations where the majority of difficulties occur. This will require more than 3 hours by a person who has never met the participant before (community settings such as shopping centres, transport, school, early childhood settings, work)

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

Each time a participant engages in an assessment, the family are forced to relive details of their loved one that results in additional stress and depression. The process is demoralizing as they have to prove there is a disability when in many cases it is quite obvious. For many families, regardless of cultural background, having a loved one with additional needs has a stigma and they are reminded daily of how difficult it is to get supports for their loved one.

If a person has a profound or lifelong disability, they should not have to be subjected to an IA. The spirit of the NDIS is all about a person centred approach. This can only be achieved through collaboration with specialized professional who have known and worked with the participant and the family.

If a person has behaviours of concern eg violent and aggressive, sexualized etc they should not require an IA. An IA will not capture the needs and capacity of the participant including risks to self, family and community in a few hours. This should only be undertaken by specialized behaviour support clinicians per NDIS guidelines. Children and young adults for whom their parents are their voice should not require an IA. Under the ECEI best outcomes guidelines as followed by all NDIS providers, the IA should be taking into consideration a collaborative approach in obtaining information that is holistic, individualized as well as delivering family centred approach to obtaining information.



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- h. opportunities to review or challenge the outcomes of independent assessments.

The NDIA MUST be transparent throughout this whole process. Provision should be made so participants can access their own IA results without having to jump through hoops. This will allow participants to ensure the information collected is a reflection of their needs as well as factual.

- i. 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;

It will disadvantage cohorts of people with a disability and cultural / linguistic needs. South west Sydney has one of the highest culturally and linguistically diverse populations in Australia and is over represented in the NDIS. Families from these vulnerable backgrounds are used to hiding their loved ones disability from their cultural peers for a variety of reasons. This often carries over when they are questioned by professionals on the capacity and needs of their loved one. It often takes someone with a lived experience to break down this barrier and establish trust for an accurate portrayal of the persons functioning.

For children in out of home care, this is detrimental as the carers do not want to be seen as not having the capacity to care for the child, therefore information provided may not be accurate with an IA.

- j. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability; and

Information may not be forthcoming from participants with psycho social disabilities, Autism and intellectual disabilities. For many participants with Autism, they will have these as co morbid conditions. In order to achieve a holistic view of participants functional capacity, it requires a collaboration of a range of allied health therapists, formal and informal supports to capture accurate and meaningful information.

- k. any other related matters

Yours Sincerely,

**Grace Fava OAM**

**Founder/CEO**

Autism Advisory and Support Service  
88 Memorial Ave Liverpool 2170  
Phone 9601 2844 (between 9am and 4pm)  
Fax 9601 1339  
[www.aass.org.au](http://www.aass.org.au)