



*Submission on Independent
Assessments to the
Joint Standing Committee on
the National Disability
Insurance Scheme
(NDIS)*

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1. Introduction

1.1 Overview

The Autism Association of Western Australia fully supports an equitable and fair NDIS. However, we have significant concerns that the planned approach to “Independent Assessment” will not achieve these ends. This is due to the fact that:

- i) The Assessment Tools are not valid for the purpose they are being used.
- ii) The methodology has not been subject to independent review.
- iii) The process lacks procedural fairness and natural justice.
- iv) The experience and expertise required by the NDIA Tender for Independent Assessors is inadequate.

Under the planned changes, Panels of “independent assessors” will be established. This will fundamentally alter the person-centered nature of NDIS and will do little to establish the NDIA's goals of fairness and equity.

1.2 The Premise

There is an absence of evidence to support the use of these tools for the purpose NDIA is using them. There is no evidence that links these tools to producing funding-budgets or equitable funding decisions. These tools are tools designed solely for use by skilled clinicians to guide clinical decision making. Moreover, there are no functional impairment tools that have been designed to provide accurate and reliable estimates of reasonable and necessary funding purposes.

1.3 The “Assessments” are Not Independent

The Assessors are contractors of the Agency and it is clear from the Tender documents that they are subject at all time to current and any future guidelines NDIA may wish to implement. Consequently, these contractors are not independent. This point is critically important as it is the claim to independence that is supporting the denial of natural justice to a participant in being able to appeal the assessment's determination.

***The only way these assessments can be independent is by allowing the person to see a clinician of their choice and have the assessment conducted on NDIA approved tools.
Even then, this assessment will not yield a budget or a profile of person-centred support-needs.***

2. Executive Summary

There are broad concerns in the disability community that can be summarized as follows:

i) The Proposed Assessments

- The tools do not provide an accurate representation of the person's needs.
- The clinical tools are not valid for a purpose they were not designed.
- Fairness and consistency can only be achieved through accurate, valid assessment that engenders the support of people with disability and the Australian community at large. Without this there will be no confidence in the outcome.
- The process lacks a transparent evidence-based methodology to link assessment scores to a funding budget.
- The assessments are not independent. They are undertaken by NDIA contractors who are subject at all times (according to the Tender document) to the guidance and Guidelines provided by NDIA.
- The assessments can be conducted by contractors without the necessary expertise or experience in the use of these tools. The Call for Tender gives no weight to past experience of assessors.
- There is no requirement for the assessor to be knowledgeable of the disability impacting on the person. An experienced clinician, however, will be able to assess when the assessment question being asked is only eliciting a part-answer from a participant; or if the person does not fully understand the nuance of the question. The experienced clinician will then be able to compensate (from their disability-specific knowledge), to address the tool's shortcomings, or the person's comprehension, with an additional qualifying question. Unfortunately, this is not provided for in the methodology being used.
- No evidence has been put forward on how Independent Assessments will lead to more valid and equitable decision making. There is no transparency on how the assessment links to a funding budget.

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- Assessors with potentially limited understanding of the assessment tools (one day training) will be required to make judgements on which of the suite of tools to combine to give an accurate picture of the person's needs. This is a very skilled undertaking and, on the basis of the skill requirements of the tender, there is little evidence that the assessors will have these skills.
- It is not clear how these assessments will be used to render a person with a disability ineligible. This needs to be stated clearly and transparently. This is not only important vis a vis individual need, it is also critically important in order to assess the potential mission-drift from the original intent of NDIS supported by the Australian community.

ii) **Procedural Fairness**

The process lacks procedural fairness in that:

- The participant cannot appeal the outcome of the assessment.
- It denies the participant the right to view the assessment at source. This includes being denied the right to view the private information they have provided verbally to the assessor; or to consider the accuracy of the observation undertaken by the assessor.

iii) **Transparency and Good Faith**

- The design and methodology of the small Pilot undertaken by NDIA to inform the Independent Assessment process has not been released for review or independently assessed.
- There is no knowledge as to whether any research institution was involved in the development of the Pilot or its methodology.
- There is no published evaluation of this Pilot by an independent research body.
- The Tender for contractors to conduct "independent" assessments was released before the Pilot is completed.
- The recommendations to NDIA on the use of these tools for the purpose they are being used has not been made publicly available, or subject to tertiary peer review.

3. Assessment and Methodology

3.1 The Use of the Assessment Tools

These clinical tools are most frequently used as a broad guide by experienced professionals in clinical support of people with disability. They are not designed as a funding measuring mechanism; and there is no evidence or validity to support their use in this way. In addition, these tools do not give the full picture of the person's needs and were never intended to do so.

3.2 Lack of Funding Transparency

There is no evidence to link clinical assessment to disability support budgets. Consequently, it is far from clear how budgets will be calculated. For example, how is a dollar value arrived at for the functional impact of reduced mobility compared with impaired communication?

3.3 Assessor Competency and Lack of Expertise

Even leaving aside the lack of evidence-base in how these tools are being used, there are also other concerns. One significant concern is in relation to the lack of required expertise of the contractors engaged to undertake these "assessments".

The Tender specifications place no weight on disability-specific expertise in relation to different disability populations; nor does it require prior experience in the use of these clinical tools. One day training on the tools will be provided to contractors who have Allied Health and other backgrounds. However, few people would be prepared to employ a tradesperson with no expertise in the tools they are using (or past experience in the work they are undertaking), and yet this is the case when it comes to assessing the needs of people with Autism. This is made even more extraordinary by the fact that the "assessment" is not appealable.

It is critical that the professional using these tools has working experience of Autism in order to fill in the gaps that the tools do not take into account. For example, a person with Autism may answer a question that s/he is able to microwave a meal and to shop. So, in a functional assessment, this sounds pretty good i.e. the person can shop and cook for themselves. However, what the questions do not pick up is that this person does not make the connection between the food in their cupboard being depleted and the need to shop. In other words, the literal answers to the question do not give an accurate picture of the person's ability to care for themselves and, consequently, the support they need.

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However, an experienced clinician will be aware of the assumptions built into these questions and draw from their Autism experience to ensure they qualify the question with the person and make the correct assessment.

Accurate assessment can only be undertaken by clinicians with expertise in the nature of a particular disability; that preferably know the person and their capacity in everyday life; have the time to undertake the assessment properly; and use the tools for the purpose for which they were intended.

4. Ethical Concerns

4.1 The Ethics of the Assessment Process

In the Tender document for Assessors it states that “Assessors ***must not*** provide Participants, or Prospective Participants, with copies of the Assessment Reports or discuss results or outcomes with Participants or Prospective Participants ***in any way.***”

Natural justice dictates that the person (or their family/advocate) should have an opportunity to see how the Assessor has transcribed accurately the answers to the questions that have been put to them. Also, they should be able to check the accuracy of the observations made; or bridge the gap in the Assessors’ understanding of what they believe they have observed.

NDIA says the person may request to see the report (or a version of the report after-the-fact) when it has been received and processed by NDIA. However, once it has been received by NDIA, the findings under their rules make the assessment too late to contest. This is grossly unfair. As a bare minimum, the person (their family member/advocate) should always have the time to read, understand and potentially dispute what has been transcribed or observed.

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4.2 This Process Raises Significant Professional Concern

The manner in which this “assessment” is being undertaken is highly problematic i.e.

- i) In the tender document released by NDIA, the assessor has a total of 2.5 to 3 hours to gather all relevant information, undertake formal participant observations, undertake questionnaires, interview the person and related stakeholders, formalize scoring, write report and enter data on to NDIA Portal. Also, in the tender it is made clear that the Assessor only needs to spend 20 minutes “observation or interaction” with the person prior to writing the report.
- ii) The person undertaking the assessment will have no knowledge of the person or have met them previously. Consequently, they will be unable to assess the extent to which the person fully understands the question being put to them. In the case of Autism and the Autistic person’s very literal understanding of language, this can produce a significant overestimate of their abilities in an everyday context.
- iii) Under the terms of the NDIA contract, the Assessor will have no need of previous experience in the use of the tools they will use. The supplier of the tools will provide an introductory training course. Thereafter, training can be conducted via a train-the-trainer model i.e. those given introductory training can now train others.
- iv) After this short, sharp speed-process, undertaken with no contextual knowledge of the person, carried out by an Assessor with potentially no experience in the use of the tools and only a rudimentary knowledge of how to use them, this life-impacting “assessment” will be completed.
- v) The person will have no right to view or review anything that is transcribed by the Assessor for accuracy. This is quite extraordinary not only from the perspective of natural justice but also from the need to check the accuracy of the private and confidential information given to the assessor that will determine their support.

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- vi) There is no information as to how this assessment will be scored i.e. by skill-domain or composite scores. This is critically important in Autism because of the scatter of the person's skills e.g. above average scores in mobility while potentially significantly below in others. A composite score can present the picture of someone functioning much better overall than they are.
- vii) As far as one can see, no account is taken in the assessment of the impact of maladaptive behavior on the individual's function. This is a critically important flaw. Without taking account of maladaptive behavior (behaviors of concern) on functioning in everyday life, a very misleading picture of the person's needs will be produced.

5. Process Not Aligned with The Tune Review

5.1 The Tune Review

Recommendation 7 of The Tune Review: The Tune Review recommended that the Act be amended to allow prospective participants to undergo assessments using approved providers. However, the Tune Review specifically recommended on page 67 that NDIA should ***not*** implement a closed or deliberately limited panel of providers to undertake functional capacity assessments.

To be consistent with the Tune Review, any Allied Health Practitioner (subject to the professional and ethical standards of their accrediting body), should be able to undertake these assessments.

Participant Service Guarantee: The Tune Review stipulates that the *"Participant Service Guarantee should empower participants to be able to review and consider a full version of their draft plan before it is approved, inclusive of the estimated plan budget"*. The spirit of this recommendation applies equally to seeing the documentation collated by the contractor prior to it being submitted for a decision on which a budget determination will be made.

The Principles of the Participant Service Guarantee Are:

- **Transparent, Responsive,**
- **Respectful, Empowering, Connected.**

These principles are not evident in the prescribed assessment process.

6. Conclusions and Recommendations

6.1 The Way Forward

While the NDIA needs good and relevant information, the way forward is not through the introduction of a system that is based on:

- An unfinished Pilot.
- That has not been open to scrutiny by independent research.
- The methodology of which is questionable.
- That will be undertaken by contractors who do not necessarily have relevant experience.
- That lacks funding transparency.
- That lacks Natural Justice and Procedural Fairness.
- That is not in the spirit of the Tune Review.
- That does not take account of the damage done to people with disability by being required to have repeated assessment throughout their life – especially when their functional capacity is materially stable.
- That is rejected by individuals, by families, by advocates, by Peak bodies and by service providers.
- That has called for Tender prior to the pilot being completed or evaluated.

6.2 Recommendations

- i) Outsource a robust and transparent evaluation of the methodology applied to the current Pilot.
- ii) Align any and all NDIA initiatives with the spirit of the Commonwealth's Tune Review.
- iii) Outsource a review of the role and limitations of functional assessment in determining disability support budgets.
- iv) Immediately cease the rollout of compulsory assessments as currently planned until further work and evaluation is complete.

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- v) Where independent assessment is required, allow the participant to choose their clinician using a suite of tools agreed with NDIA.
- vi) All processes undertaken by NDIA should be subject to review and appeal.

7. In Summary

There is insufficient evidence to support the approach being taken by NDIA will lead to valid, equitable and consistent decision-making.

Independent Assessments should not be introduced until it can be clearly demonstrated that it is valid and consistent method for assessing functional needs in context.