



Access and Eligibility Policy with independent assessments - Submission

About Advocacy for Inclusion

Advocacy for Inclusion is a leading independent organisation providing dedicated individual and self-advocacy services and training, information and resources in the ACT. We deliver reputable national systemic advocacy informed by our extensive experience in individual advocacy and community and government consultation.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience and is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations *Convention on the Rights of Persons with Disabilities* and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the *Human Rights Act 2004*.

Contact details:

2.02 Griffin Centre
20 Genge Street
Canberra City ACT 2601
Phone: 6257 4005
Email: info@advocacyforinclusion.org
ABN: 90 670 934 099

February 2021

Prepared and written by Stacy Rheese, Team Leader Policy
Authorised by Nicolas Lawler, Chief Executive Officer
© Copyright Advocacy for Inclusion Inc.



Advocacy for Inclusion acknowledges the Aboriginal and Torres Strait Islander peoples as Traditional Custodians of the lands where we live, learn and work.



We respect and celebrate diversity of individuals, including those amongst the lesbian, gay, bisexual, trans, and intersex communities and we value and promote inclusion and diversity in our communities.

Introduction

Advocacy for Inclusion (AFI) welcomes the opportunity to provide feedback concerning the new Access and Eligibility process for the National Disability Insurance Scheme (NDIS). By providing this feedback, AFI is not endorsing or supporting the proposed changes to the access and eligibility process.

The development and proposal of mandatory independent assessments highlights the need for the National Disability Insurance Agency (NDIA) to work in partnership with people with disability to co-design reforms that adequately address needs and do not negatively impact participants or undermine trust and confidence in the NDIS.

We hold significant concerns that there has not been sufficient consultation with people with disabilities and their representatives in making the decision to move to mandatory independent assessments, in the development of the model to be used, or in addressing the concerns raised since the announcement of independent assessments.

Lack of Consultation

The Senate Community Affairs Legislation Committee in October 2020 revealed that only 28% of people involved in the first pilot of independent assessments completed the NDIA feedback survey. Of the 28% who provided feedback, only 35 were NDIS participants, while the remaining responses were from carers.¹ This is not an adequate level of testing or consultation from which to rollout a policy that will affect 400,000 people.

It should be noted that in this first pilot 86% of participants fell into what are commonly regarded as child and youth age ranges (7 - 24 years).² Only 14% of participants were aged between 25 - 64 years.³ The age of the participants is an important consideration concerning the participants' level of independence and the development of self-advocacy skills. If the intention of the first pilot was to gain significant insight into the views and experiences of people with disabilities participating in the assessments, it seems unusual for 62% of the participants to be aged only 7 - 14 years old.⁴ This also raises questions regarding the feedback process, and whether it was age appropriate. The details of the feedback process, including the questions asked, do not appear to have been released.

The 2019 Review of the NDIS Act (Tune Review), emphasised that an introduction of an independent assessment model 'will require extensive consultation with participants, the disability sector, service providers and the NDIA workforce.'⁵ It is AFI's view that this has not happened, and that the apparent lack of meaningful engagement and consultation has resulted in a substantial reduction in choice and control and significant apprehension and distrust of the independent assessment model amongst prospective and current NDIS participants.

¹ Commonwealth of Australia, Official Committee Hansard Senate Community Affairs Legislation Committee Estimates 29 October 2020, Canberra;
See also Clun, R. 'Just Not OK': Only 6 per cent of NDIS trial participants completed survey December 23, 2020 <<https://www.smh.com.au/politics/federal/just-not-ok-only-6-per-cent-of-ndis-trial-participants-completed-survey-20201221-p56pbc.html>>.

² National Disability Insurance Agency, *Independent Assessments, Pilot learnings and ongoing evaluation plan*, September 2020 p 23.

³ Ibid.

⁴ Ibid.

⁵ Tune, D. *Review of the National Disability Insurance Scheme Act 2013 Removing Red Tape and Implementing the NDIS Participant Service Guarantee*, December 2019.

Going Beyond the Recommendations

Despite referencing recommendations from the Productivity Commission's 2011 Inquiry and the Tune Review, the proposed scope of independent assessments goes beyond those recommendations, and the NDIA has not implemented the key protections emphasised in the recommendations during the development and rollout of the trials. Some of the key protections, which the Tune Review stated 'need to be embedded as this approach rolls out', and which do not appear to be incorporated into the proposed model include:

- a. participants having the right to choose which NDIA-approved provider in their area undertakes the functional capacity assessment*
- b. participants having the right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment or seek some form of arbitration if, for whatever reason, they are unsatisfied with the assessment*
- c. the NDIA-approved providers being subject to uniform accreditation requirements that are designed and implemented jointly by the NDIA and appropriate disability representative organisations⁶*

Other organisations have commented that the proposed model of independent assessments has also gone beyond early proposals which they may have initially supported.⁷

Mandatory Independent Assessments

The decision to make independent assessments mandatory is a considerably troubling move. The Tune Review recommendation never proposed repeated mandatory assessments for every current and prospective NDIS participant. The Tune Review explicitly states that 'functional capacity assessments would not always be required.'⁸ The power to require a participant to undergo an assessment was recommended to be 'discretionary' with 'clear operational guidelines for decision makers in exercising this discretion.'⁹

The Tune Review suggested independent assessments (with key protections in place) could be made available to people 'who would like to test their access for the NDIS or who require further evidence to support decision-making about the supports in their plan'¹⁰ – not that independent assessments be made mandatory for every participant regardless of whether they have already provided sufficient evidence regarding their support needs.

This is substantially different to the proposed model:

The use of independent assessments in access and planning processes will apply to all participants and prospective participants (excluding those under

⁶ Tune, *Review of the National Disability Insurance Scheme Act 2013* above n 5, p 66.

⁷ People With Disability Australia, *We Are Concerned About "Independent Assessments" For The NDIS* <https://pwd.org.au/we-are-concerned-about-independent-assessments-for-the-ndis/> [07.02.2021].

⁸ Tune, *Review of the National Disability Insurance Scheme Act 2013* above n 5, p 67.

⁹ *Ibid.*

¹⁰ *Ibid.*

the age of 7 until the NDIA has finalised how independent assessments will apply to this cohort) with limited exceptions.¹¹

Imposing mandatory independent assessments on prospective and current participants, including those who have repeatedly proved their eligibility, is likely to cause significant distress. People with disability will be subjected repeatedly to intrusive scrutiny and are being repeatedly forced to crawl through hoops to 'prove' their need.

The Tune Review stated that '[f]undamentally, however, the success of the program will largely be dependent on... the willingness of prospective participants and participants to work with NDIA-approved functional assessors¹². Making independent assessments mandatory markedly impedes any possibility of a notion of 'willingness'.

Limited Time for Assessments

It has been reported that the NDIA tender relating to independent assessments stated that assessors are required to undertake a minimum 20-minute observation session, and that the average time taken for observation, assessment and report writing is expected to take 2.5-3 hours.¹³ The NDIA states '[i]t is estimated that the assessments will take around 3 hours on average.¹⁴ It is well-documented that 'time constraints' are both 'a barrier to good communication about complex medical problems' and impede 'the possibility of developing a trusting, respectful relationship.'¹⁵

Many people with disability have spent years working with health professionals to determine and understand the impact of their disabilities. A lone independent assessor may not have any knowledge or experience of the disabilities being assessed, or an understanding of the related barriers and stigmas an individual faces.

During an assessment there may also be many additional complexities present which impact on the efficiency and effectiveness of the communication of needs and utilisation of assessment tools, such as the individual experiencing distress, communication difficulties, or the presence of multiple or complex disabilities. The notion that an independent assessor will have the ability to effectively comprehend and exhaustively capture the diverse experiences and full impact of various disabilities in under 4 hours is deeply problematic.

That the results of such an assessment will then be used to determine an individual's access to the daily supports needed to survive is alarming.

Observation and Dignity of the Individual

Requiring a person with disability to be 'observed' in the manner proposed by the NDIA, by an unknown person, who is not of the individual's choosing, to justify support needs is not

¹¹ National Disability Insurance Agency, *Information Paper Improving the National Disability Insurance Scheme Better Participant Experience and Improved Access and Planning* 24 November 2020 (Updated 1 December 2020 to refer to NDIA papers now released) p 17.

¹² Tune, *Review of the National Disability Insurance Scheme Act 2013* above n 5, p 66.

¹³ Naufal, E. *Not So Independent Assessments*, September 2020
<<https://teamdsc.com.au/resources/independent-assessments>>.

¹⁴ National Disability Insurance Agency, *Consultation Paper: Access and Eligibility Policy with independent assessments*, November 2020, p 18.

¹⁵ Sharby, N, Martire, K, Iversen, M. *Decreasing Health Disparities for People with Disabilities through Improved Communication Strategies and Awareness*, *Int J Environ Res Public Health*. 2015 Mar; 12(3): 3301-3316. Published online 2015 Mar 19.

in alignment with the principle of dignity of the individual. Further, to have their disability supports hanging in the balance dependent on the outcome of this limited interaction can be extremely stressful. An inherent imbalance of power occurs in such an interaction, which can leave a person with disability feeling depersonalised and disembodied.¹⁶ The potential for distress is likely to be heightened by the enforced nature of mandatory assessments, and the lack of choice and control an individual will have in choosing the assessor.

The intrusion of having an unknown assessor come to an individual's home and observe them in their environment raises concerns regarding the privacy and security of home for people with disabilities, especially for those who may not have control over the decision of the assessor attending (such as those in group homes, or whose carer makes this decision). While the NDIA has stated that an assessment can take place 'wherever an applicant chooses',¹⁷ it has not been made clear how an individual will be enabled to exercise choice in this regard, or whether they will be required to justify a request for a different location, as the NDIA has also stated that:

In most cases, interaction sessions will take place in the person's everyday environment. This will allow assessors to observe the participant or prospective participant's interactions with family members or participation in routine daily activities. This will help assessors understand how the person's disability affects their daily functional capacity against the six activities specified in Section 24 1(c) of the NDIS Act.¹⁸

No Trauma-Informed Approach

The impact of the potential trauma and distress caused by stringent functional assessments must not be minimised. Adverse mental health outcomes associated with such functional assessments, including increased suicide risk, have been recorded in other jurisdictions.¹⁹

The NDIS process can already be severely stressful and detrimental to the mental health of participants. AFI clients have experienced severe anxiety and distress through NDIS planning and review processes, including suffering panic attacks prior to, and during planning meetings. One AFI client with cognitive disability told their advocate that they were already worried and would have to start preparing for their next annual plan review, as they were exiting an annual planning meeting. The NDIA should be prioritising reducing the distress being caused to participants. People with disabilities are at greater risk of experiencing violence or trauma than the wider population, yet the proposed model of

¹⁶ Clifton, S. *Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability*, Research Report, October 2020, p 9.

¹⁷ NDIA, *Consultation Paper*, above n 14, p 19.

¹⁸ NDIA, *Independent Assessments*, above n 2, p 9.

¹⁹ Barr B, Taylor-Robinson D, Stuckler D, et al. (2016) 'First do no harm': are disability assessments associated with adverse trends in mental health? A longitudinal ecological study. *Journal of Epidemiology and Community Health* Vol 70 (4) 339–345.

See also Mills, C. orcid.org/0000-0003-0615-234X (2017) 'Dead people don't claim': a psychopolitical autopsy of UK austerity suicides. *Critical Social Policy*. ISSN 0261-0183.

"The inscription of worry onto bodies is evident in the death of Elaine Christian, who was 'found dead in a drain [and] had been worried about attending a medical appointment to assess disability benefits'... The inquest heard that Elaine, who died from drowning and whose wrists were covered in self-inflicted cuts, 'had been worrying about a meeting she was due to have to discuss her entitlement to disability benefits'" in Mills, C (2017) p 9.

independent assessments does not seem to be designed in line with a trauma-informed approach.

AFI is also concerned by the NDIA intention to require participants to repeatedly undergo independent assessments. This will increase stress and likely cause people with disabilities to fear they may lose supports at crucial life stages, or when requesting a plan review. Again, AFI notes that this appears to go beyond the recommendations of the Tune Review, which stated that 'functional capacity assessments would not always be required, for instance if a participant's functional capacity is stable.'²⁰ Repeated mandatory assessments, especially where functional capacity is stable, seem to lack efficiency and appear intrusive and punitive.

Reasons & Justifications for Changes

Socio-economic Barriers

The NDIA has suggested that independent assessments will "level the playing field", such that financial, cultural, social, education and literacy factors do not contribute to delays or barriers to accessing the NDIS.²¹ AFI is concerned that independent assessments may do little to reduce current barriers, and will likely perpetuate disadvantage amongst vulnerable cohorts.

While independent assessment will substantially reduce choice and control for many people with disabilities, it is questionable how much impact independent assessments will have in reducing socioeconomic barriers. Given that prospective participants will still be required to provide evidence of their disability and its permanence,²² participants are still likely to face financial burden related to sourcing further assessments. Particularly for certain disabilities, such as psychosocial, which often involve lengthier periods to diagnose and explore treatment options before they may be considered 'likely to be permanent', the introduction of independent assessments may do very little to relieve any financial burdens associated with accessing evidence of functional capacity.

Further as the independent assessments will not provide recommendations for supports, the only option for any individuals who want guidance as to appropriate therapies and supports seems to be to participate in the independent assessment and then additionally seek functional assessments which provide support recommendations at their own expense. The NDIA seems to suggest planners will discuss ways in which funds can be used, but this does not replace the expertise of professionals such as Occupational Therapists who assess support needs and make recommendations of appropriate therapy plans. If funding is provided but participants have not received any support recommendations, this will likely cause participants to experience increased confusion and difficulty in effectively using their funds, which may result in the underutilisation of plans. Again, those who are able to access and afford additional assessments and services will likely still have easier access to appropriate supports. Independent assessments do not appear to be an effective solution to access issues, but instead are predicted to shift

²⁰ Tune, *Review of the National Disability Insurance Scheme Act 2013* above n 5, p 67.

²¹ Commonwealth of Australia, *Joint Standing Committee on the National Disability Insurance Scheme General issues*, December 2020, p 18.

²² NDIA, *Consultation Paper*, above n 14, p 8.

the current difficulties experienced in accessing the NDIS to another stage in the planning process.

Sympathy Bias

It has also been suggested that 'using an independent assessor rather than a person's usual health professional is also intended to address real or perceived bias.'²³ While the NDIA has cited sympathy bias as a 'potential' risk,²⁴ the NDIA has not produced any evidence that supports the existence or impact of such bias in NDIS supports. It can also be inferred that any suggested 'potential' risk of sympathy bias is not significant, as the NDIA provides examples of circumstances in which this potential risk is 'outweighed' by the need to complete assessment processes.²⁵

Suggestions of 'sympathy bias' impugns the ethics of health professionals. It is disappointing to need to argue this, but compassionate and experienced support by health professionals of people with disability should be encouraged, not disparaged. Biases certainly can exist, however health professionals undergo significant training and education in objectivity. Paradoxically, the NDIA has not stated how it will address the potential risk of biases in independent assessors, who will not necessarily have experience or knowledge of working with people with disability.

It should be noted that there seem to be circumstances in which the NDIA appears to approve of receiving direct evidence from a person's usual health professional regarding their support needs, such as if that evidence may go towards proving a reduction in support needs: 'The applicant's treating health professional may also be asked to provide evidence that early intervention supports would be beneficial and likely to reduce their future support needs.'²⁶

Inconsistencies in Evidence of Functional Capacity

The prominence to be given to single independent assessments to determine functional impact devalues the expertise of health professionals. Many people with disability have spent years working with health professionals to determine and understand the impact of their disabilities, which results in a wealth of knowledge and expert opinion held by trusted professionals.

Given the lack of evidence of sympathy bias, it is not clear that contracting a new workforce of independent assessors, which will require training, significant oversight and monitoring, is in any way an efficient approach to accessing information which in many cases already exists through health professionals. It is not clear why this approach was chosen when health professionals, who already possess comprehensive knowledge and the ability to provide reliable and accurate evidence, could have been provided resources and training to assist them to provide information to the NDIS in a consistent way.

AFI has worked with many consumers preparing Access Requests, and often found that health professionals did not know what was needed for NDIS supporting evidence, or the

²³ Commonwealth of Australia, *General Issues*, above n, p 18

See also National Disability Insurance Agency, *Independent Assessment Framework*, August 2020, p 27

²⁴ NDIA, *Independent Assessment Framework*, above n 23, August 2020.

²⁵ *Ibid*, p 26

²⁶ NDIA, *Consultation Paper*, above n 14, p 13

best form to provide this in. In many ways, the language and formats used by the NDIS are not congruent with medical practice, such as in the case of psychosocial disability (where the 'recovery model' language and practice of medical professionals does not align easily with NDIS criteria. Inconsistencies in the evidence being provided is unsurprising, given the lack of clear guidance given to health professionals.

However the NDIA is now focusing on providing clearer guidance, including outlining 'what [the NDIA] need from medical professionals to understand the permanence of a person's disability.'²⁷ Additional resources have also been co-designed with GPs.²⁸ Such steps also could have been taken in regards to functional capacity.²⁹

Independent Assessment Model

The Use of Independent Assessors

The NDIA emphasises the importance of the independence of its assessors, however the extent to which assessors can be considered independent is problematic, as they are contracted by the NDIA. Other initiatives involving similarly 'independent' assessors contracted to provide assessments, such as Work Cover, provide a multitude of examples of questionable outcomes, complaints of bullying, unfair treatment and distress caused to those being assessed. The Tune Review stated that the success of independent assessments would be 'largely dependent on ...those assessors providing truly independent functional capacity assessments, so they are not perceived as agents of the NDIA or a tool designed to cut supports from participants.'³⁰

The qualifications and experience of those contracted to provide the assessments is also a concern as they will not be required to have specific disability knowledge or experience. The NDIA itself has listed the most appropriate health professionals 'to provide the standardised assessments that are considered "best practice" in evidence' for a variety of primary disabilities.³¹ This included professionals such as audiologists, neurologists, psychiatrists, ophthalmologists and Acquired Brain Injury health professionals, none of which have been included in the list of professionals who will conduct independent assessments.

Concerningly, in the admittedly few feedback responses in the first pilot of independent assessments, only 72% of those responding felt that the assessor was familiar with their disability.³² This must be considered in the context that this trial only included volunteers with a primary disability of Autism Spectrum Disorder (ASD), intellectual disability or psychosocial disability,³³ and did not include participants with a diverse range of much less

²⁷ NDIA, *Consultation Paper*, above n 14, p 8.

²⁸ Tsirtsakis, A. *New resources to help GPs and patients navigate the NDIS*, October 2020 <<https://www1.racgp.org.au/newsgp/clinical/new-resources-to-help-gps-and-patients-navigate-th>> .

²⁹ "If the issue the NDIA is trying to address is inconsistencies in reports they receive, we think better training, consultation and support for GPs and allied health professionals in preparing reports would be a better option." In Hales, L. *Patients Lose Choice of Assessor in NDIS Reforms*, November 2020, <<https://medicalrepublic.com.au/patient-choice-lost-in-new-ndis-assessments/37403>>.

³⁰ Tune, *Review of the National Disability Insurance Scheme Act 2013* above n 5, p 66.

³¹ National Disability Insurance Agency, *Types of Disability Evidence*, viewed 7 February 2021, <<https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/types-disability-evidence>>.

³² NDIA, *Independent Assessments*, above n 2, p 15.

³³ NDIA, *Independent Assessments*, above n 2, p 10.

well-known disabilities. Presumably the assessors taking part in the trial may also have been aware that the only volunteers involved would have the listed disabilities. While the assessments are designed to not be disability specific, a lack of awareness and experience amongst the assessors raises significant concerns regarding their ability to effectively and appropriately engage with participants. AFI is especially concerned about the discomfort and stress which could be caused to an individual if they feel the need to educate and inform the assessors about their disability to feel they have been accurately understood.

Standardised Assessment Tools

In the pilot evaluation the NDIA states that '[g]enerally, independent assessors found the instruments to be comprehensive and reflected a participant's functional capacity.'³⁴ It is concerning and illogical that the NDIA focused on the opinion of independent assessors (who presumably, as independent assessors, have no other knowledge of the participant's functional capacity) as to whether the assessment tools were comprehensive. AFI would be much more interested in the opinions of the participants, their supports and their trusted health professionals' opinions of whether the assessment tools provided an accurate reflection of functional capacity.

The 2020 Administrative Appeals Tribunal decision in *Ray v National Disability Insurance Agency* has already highlighted the worrying disparities which can occur between the opinions of an independent assessor and an individual's regular supports, and highlights the risk involved with overly simplistic approaches to assessing disability.

There is significant concern that a few standardised assessment tools will not be able to accurately and comprehensively assess the wide diversity of experiences of people with disability, particularly those with complex needs and multiple disabilities. It is not uncommon for people with disabilities to be treated by multiple specialists, receive varying diagnosis, and for disabilities to present with unique and atypical features.

Noting that '[d]epending on a person's age and disability, three or four different assessment tools may be used'³⁵ this is likely to be more disadvantageous to people with particular disabilities such as psychosocial and cognitive disabilities who may experience higher stress and anxiety, and have more difficulty understanding the utilisation of 'tools' and how the assessment is being conducted. It is likely to be difficult for independent assessors who lack specific disability experience to ensure these participants are fully informed and comfortable with assessment process.

The fact that the assessment tools 'use a combination of interactions, discussions and questionnaires that take into account different settings and different times'³⁶ raises significant concerns regarding individuals who have difficulty with processing and comprehending abstract reasoning. Such tools could be inaccessible to individuals who experience impaired functioning associated with cognitive impairment, psychosocial and intellectual disability, and other disabilities that affect the ability to comprehend and effectively communicate abstract concepts such as 'time'.

³⁴ NDIA, *Independent Assessments*, above n 2, p i.

³⁵ NDIA, *Information Paper*, above n 11, p 14.

³⁶ NDIA, *Consultation Paper*, above n 14, p 18.

An AFI client and NDIS participant with cognitive impairment, Echolalia, complex trauma and severe social anxiety communicated in a way which included regularly answering questions in the affirmative (whether this was accurate or not), repeating words such as the names of medical conditions and disabilities, and providing 'rehearsed' or rote answers instead of spontaneous responses. This regularly caused significant miscommunications.

During an NDIS review the planner incorrectly listed the participant as currently undertaking higher education, when in response to the planner's assessment questions the participant communicated that they were studying art. The planner clarified that this was higher education in follow up questions, and the participant affirmed that this was indeed correct. The planner accepted this, and the participant's advocate had to clarify that the participant was actually referring to their attendance at a community art group and was not undertaking any further education.

Such miscommunications, which if left uncorrected would have heavily impacted planning decisions, happened repeatedly as the planner questioned the participant. The participant also had difficulty communicating concepts such as time, and frequently moved from discussing the supports they currently did have, to describing hypothetical supports they wished they had, which was interpreted by the planner as being further current supports. The advocate was only able to identify this and clarify what was being communicated because they had spent months getting to know the participant's communication style, exploring their support needs and clarifying these repeatedly on different occasions.

This participant experienced many other significant miscommunications. On one occasion the participant presented for a psychological assessment to support their NDIS review. The assessor was not aware of the client's disabilities. The client underwent multiple assessments for autism conducted by a psychologist, despite having never had a suggested diagnosis of autism. While the psychologist who had conducted the assessments believed that the participant had communicated to them that they had an autism diagnosis and had requested these assessments, the participant was not aware of this and had not understood the purpose or results of the assessments. When this mistake was addressed with the psychologist, they expressed shock at the misunderstanding, stating that the participant 'presented so well.'

It is feared that independent assessments would be vulnerable to similar miscommunications, given their lack of specificity, as well as the lack of assessor knowledge of a participant's particular disability.

This already appears to have been the experience of a participant during the pilot:

'For example, when asked if he independently takes care of his financial planning, his response was, "Yep!". But financial planning means different things to different people. Jack told the assessor about how he has the St George app. He knows how to tap and pay and how to check his balance. But he doesn't make transfers and he doesn't yet understand the value of money. If somebody in a shop told him it was \$5000 for a bottle of water, he wouldn't question it.'

He was also asked if he can use public transport. He said that he can get anywhere. But the story is a bit more complicated. He knows how to get to the 12 places that he goes to regularly, which is bloody excellent, but if you are really assessing his independence, you need to take a more nuanced approach. Because if he has to go somewhere new, he can't work out how to get there.³⁷

In Jack's case his mother was able to clarify his responses and ultimately end the assessment when she deemed it inappropriate. In the case of the AFI client discussed above, they are extremely isolated and have no familiar supports, yet would likely agree to the assessment and participate without support.

AFI holds significant concerns for such participants, who could be severely disadvantaged through the assessments (or be deemed ineligible), because they 'present well' yet may have communication difficulties and may not fully comprehend the assessment process. There does not appear to be any oversight mechanism in the independent assessment process that would identify this if it occurred.

Lack of Control/Participation

AFI is also concerned about the assessments which will be conducted without the participant in attendance, such as the Vineland-3 and LSP-39, or that a participant may be required to 'leave the room' so another person can answer questions.³⁸ Carers, family members and friends can give differing accounts of an individual's needs. They may be motivated by a desire to focus on a participant's strengths, to not cause hurt feelings, or a lack of knowledge (as an individual knows their needs best). For those who are isolated and have no close supports, they may be significantly disadvantaged by the input of someone who does not know their needs intimately.

The NDIA states that '[w]here no support person is nominated, we will initiate a process to help identify an appropriate person or persons if requested by the applicant.'³⁹ Though it is not clear, it does appear that it will be a requirement for another person to complete a part of the assessment on a participant's behalf.⁴⁰ If a person is living alone or has no close supports, it is not likely any other person will be able to provide accurate knowledge of their functioning in such areas as dressing, washing, hygiene, and household chores. Many of AFI's clients are isolated or have no supports, and would likely be disadvantaged by an inability to source a person for this assessment, or by being required to have a person involved who cannot give accurate information.

Such assessments may also be very inappropriate for many participants. For an individual who has insight into the impact of their disability, and is able to communicate their needs effectively, it is undermining and disrespectful to require another person, who may have no better knowledge of their functional capacity, to have input on their needs on their behalf, and without their participation. This goes against the principle of choice and control.

³⁷ DSC, *Test Drive or Crash Test? Independent Assessments*, February 2021, <<https://teamdsc.com.au/resources/test-drive-or-crash-test-independent-assessments>>.

³⁸ NDIA, *Independent Assessments*, above n 2.

³⁹ NDIA, *Consultation Paper*, above n 14, p 19.

⁴⁰ 'She knows someone who knows her well will need to speak with the assessor' Ibid, p 15.

Results of Independent Assessments

While the NDIA states that '[r]egardless of the access request outcome, all applicants will be provided with both a summary of their independent assessment results and an explanation of the access decision'⁴¹ it is not clear *when* participants will receive this summary, or if they will ever be given the full results. Further it must be clarified if the full results of an independent assessment will be made available through disclosure of documents if a participant chooses to go to AAT.

The full results of an independent assessment must be shared with the participant, prior to planning meetings to allow them the opportunity to understand and challenge the results if necessary. This was a key protection highlighted in the Tune Review:

*participants having the right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment or seek some form of arbitration if, for whatever reason, they are unsatisfied with the assessment*⁴²

The NDIA must also take a trauma-informed approach in providing results to participants. The results may potentially be distressing and confusing to participants, who may not have supports in place to assist them. Results of such assessments may usually be presented and discussed by a health professional an individual has an established relationship with. The NDIA will have a responsibility to support participants and not cause them harm in delivering the results of the assessments.

Disparity in Assessments

In the Pilot Learnings and Ongoing Evaluation Plan it is stated that:

*To the extent that the PEDICAT and Vineland 3 instruments provide valid assessments of functioning in line with the NDIS Act (Section 24 1(c)), 8% of participants results in the first pilot suggested functioning within the assumed typical range across all domains of both instruments.*⁴³

As 95% of the participants involved in the pilot program had already been granted access, this indicates that at least a portion of people who had been considered to have reduced functioning through the previous access process were not found to have reduced functioning through the independent assessments. During a pilot program testing the use of standardised assessment tools, this should indicate a disparity in assessments. It is concerning that this is not more thoroughly explored, given that the pilot could have been an evaluation of independent assessments. Instead, the assumption seems to have been made that the assessment results are correct, with the conclusion that '[t]he results indicated that providing these participants with early intervention rather than permanent disability supports would likely have been more appropriate.'⁴⁴ From this it can be assumed that a proportion of current NDIS participants may similarly be found to not have reduced functioning if independent assessments are rolled out, despite already being found eligible.

⁴¹ NDIA, *Consultation Paper*, above n 14, p 21.

⁴² Tune, *Review of the National Disability Insurance Scheme Act 2013* above n 5, p 66.

⁴³ NDIA, *Independent Assessments*, above n 2, p 14.

⁴⁴ *Ibid*, p 15.

Exemptions

While the NDIA has stated that '[t]he delegates decision not to grant an exception for an independent assessment will not be a reviewable decision,⁴⁵ NDIA representatives have stated that will not be the case in a recent community consultation session. This decision should be a reviewable decision. An individual also should not be required to justify an exemption (such as providing evidence that they have experienced trauma).

Using the NDIA suggestion of considering exemptions on the basis of risk and safety, AFI has identified a number of ways in which the process of independent assessments may be likely to 'do more harm than benefit to the individual'.⁴⁶

Further, AFI is concerned that standardised assessments performed by independent assessors without specific disability knowledge risk disadvantaging the most vulnerable: those who are isolated or have experienced trauma, people with multiple, complex and fluctuating disabilities, people with intellectual and psychosocial disabilities, CALD and Aboriginal and Torres Strait Islander peoples.

Conclusion

AFI holds significant concerns about the proposed introduction of mandatory independent assessments, and the risk they pose to people with disabilities. The proposed changes indicate an urgent need for the NDIA to reconsider both the rollout of independent assessments and the further proposed changes to the access and eligibility process, and instead engage with people with disabilities with the intention of co-designing solutions to adequately address areas of need within the NDIS.

⁴⁵ NDIA, *Consultation Paper*, above n 14, p 21.

⁴⁶ NDIA, *Information Paper*, above n 11, p 17.