



Joint Standing Committee on the NDIS Inquiry into Independent Assessments

Submission by the Summer Foundation

March 2021

The Summer Foundation welcomes the opportunity to contribute to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) inquiry into Independent Assessments.

Key points

a. Changes to the NDIS go beyond what has been recommended and must involve the people affected

The NDIS Tune Review recommended the National Disability Insurance Agency (NDIA) introduce assessments for prospective participants for the purposes of decision-making, using NDIA-approved providers. This change has the potential to deliver positive outcomes for participants stuck in hospital and in residential aged care (RAC) through rapid and free assessments.

However, the Independent Assessment Framework (the Framework) put forward by the NDIA diverts from what was recommended by Tune. The Framework requires independent assessments for all NDIS participants, fundamentally changing the access and planning processes in a way that will severely limit the goals and preferences of the individual. It is also progressing without the recommended consultation with the disability sector, and most importantly, people with disability.

Changes to the NDIS of this magnitude must involve the people that they are most likely to impact and their representative organisations. Extensive and in-depth consultation is required alongside application of [codesign principles](#). However, consultation has been minimal and important principles of codesign have been ignored.

The proposed mid-year rollout of independent assessments is concerning. In-depth independent evaluations of both the pilots remain unpublished, and the second pilot is still underway. Learnings from the 2 pilots must be applied to the Framework in a manner that increases positive outcomes for people with disability.

“Bringing in such a huge change to the whole NDIS planning process, without consulting NDIS participants is the big brother approach that the NDIS was supposed to get rid of.

It seems we're reverting to the bad old days where having a disability means losing control of your life and having it controlled by others.

It is totally disrespectful to put such fear into the minds of people who have had enough to deal with over the years.

The NDIS was just starting to seem as if it was allowing participants to drive their own lives and now it seems they'll be subjected to a series of tick box tests. Who else in society would put up with this?”

– Carol – mother of participant

b. Independent assessments should not be used to take away reasonable and necessary support

The 1st quarter 2020-2021 NDIS [Quarterly Report](#) states “[t]he change in the way assessments are undertaken is needed to implement a Scheme that, from a participant’s perspective, is more consistent, fairer, and lower cost...” (p.9). While we support consistency and fairness, we are concerned that these changes will lead to cost cutting. We are concerned that participants with high and complex needs, younger people in residential aged care (YPIRAC) and those at risk of admission to RAC may be worse off if independent assessments are used as a tool to reduce the allocation of funding.

“I also can’t help but be concerned about [independent] assessments being brought in every 5 years for people already part of the NDIS. My first concern is that if this is done within the context of cost-cutting, it could become a disincentive for people to improve their skills and general functioning. Secondly, when we are talking about people who have their housing and supports they need to live there dependent on funding from the NDIS, the potential for major disruption (or fear of disruption) could be a major issue.”

– Helen, participant

c. Individual goals and preferences must remain central to the NDIS

Independent assessments bring a shift away from considering the participant's personal goals, needs and preferences in the planning process. The proposed Framework which determines a funding allocation without consideration of these important elements is a serious threat to the fundamental principles of the NDIS, specifically, choice and control, self-determination and an ordinary life in the community.

d. A summary of what we recommend

The Summer Foundation recommends postponing the proposed midyear rollout of independent assessments and implementing an evidence-based pilot with consultation and input from people with disability. There must be significant changes to processes and implementation of independent assessments, codesigned with people with disability.

Assessment toolkits and instruments must ensure a 'no disadvantage' approach by including objective instruments that are fit for purpose and apply clinical reasoning to assess participants' functional capability as well as determining needs. These should be independently evaluated by experts to ensure they are both effective and appropriate.

Individual needs and preferences must remain central to the planning process and individual goals must be taken into account when determining funding. Participants with high and complex needs should have the option to choose an assessor who is familiar to them. Additionally, we recommend that free and timely assessments be made available to people stuck in hospital.

Potential benefits of independent assessments

The NDIA [cites](#) independent assessments as addressing inconsistency, subjectivity and cost. The Summer Foundation is aware of problems with the current system that may be addressed by independent assessments.

For people with high and complex needs stuck in RAC or in hospital, the onus is on the individual to gather and often pay for assessments to gain access to the NDIS. Many health professionals are unsure of the assessment requirements for the NDIS and therefore may not be well suited to providing an assessment. The implementation of independent assessments may significantly benefit this cohort, providing a free and rapid response, if a comprehensive and effective framework is in place.

"The cost of reports is prohibitive in some circumstances. A well conducted assessment could save money, time and stress on reports, but it would have to be very thorough. Independent assessments done properly may pick up what a therapist had missed. It would put those who don't have access to the best therapists, or couldn't afford reports, on even ground with those who do. It will also weed out the minority of therapists who misquote needs to suit their business."

– Carol – mother of participant

Independent assessments could address many barriers existing in the current process, with the right framework:

- Independent assessment may fast-track access decisions and get applicants into appropriate housing more quickly. Current assessment processes can be difficult, slow and costly, especially for people who are yet to gain access to the NDIS
- A new toolkit for assessment may improve access and planning decisions for participants affected by a lack of standardisation resulting in inconsistent and inequitable outcomes. This is particularly true for appropriately assessing psychosocial disabilities
- Independent assessments may reduce potential conflict of interest and bias from existing assessors if implemented in a fair and transparent way. Providers currently stand to benefit from additional funding being made available in their client's plan
- Training within independent assessment organisations should ensure that assessors have the necessary understanding of NDIS legislation and how it impacts a person's access to the NDIS and plan outcome. This improves the wide variability in allied health professionals' understanding.

Problems with independent assessments

The Summer Foundation has identified the following key problems with independent assessments:

1. Funding allocations failing to account for participants' goals as outlined in the *NDIS Act 2013*

An independent assessment will be the primary tool to determine a person's NDIS budget with limited consideration of the individual's goals and preferences. While the NDIS has indicated that goals are still important, there will be very few circumstances where the plan and budget can be changed after the assessment is complete. It is incredibly difficult to negotiate changes and provide supplementary evidence at planning meetings, even with assistance. We are concerned this will result in a planning process that undervalues individual choice and autonomy.

This is a very concerning move away from the principles of the *NDIS Act 2013*.

Section 4 (4) of the Act states: People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.

Section 4 (11) of the Act states reasonable and necessary supports for people with disability should: Support people with disability to pursue their goals and maximise their independence.

“Planners, assessors and everyone involved needs to approach their work seeing possibility, not just problems. If the aspirations and goals of people with disability are taken out at the early stages – i.e. in the development of the personal budget – it seems that the foundation of the process/eventual plan could be in danger.”

– Helen, participant

The independent assessment toolkit has not been validated to determine functional capability or funding allocations.

As Occupational Therapy Australia has [reported](#), “[t]he proposed toolkit is predominantly based on self-report measures that are neither designed as assessment tools or as tools to determine functional capacity” (p.5). At the same time, the results from the 2 pilots remain unpublished and therefore little is known about how the tools perform as a reliable predictor of funding need. This will inevitably lead to participants being disadvantaged and inadequately funded by the proposed assessment toolkit and process.

“How would [my daughter] be able to answer a self-assessment tool when she doesn’t have memory or insight into how her disability affects her due to her cognitive injury. The support that is there allows her to function well with her everyday routines.

This is very scary because if you talk to her on her own, she has this wonderful, beautiful attitude. She is very positive and knows she has come a long way.

‘I do it all’ she would say, and she does but it’s with a lot of one-on-one support and planning that enables her to do this.

[Independent assessors] would not get the accurate knowledge of the severity of her injury and the way it impacts her everyday with an independent assessment without allied health input, where a relationship has been built with her and they understand her disability and work with her to improve. We try and contain consistency in allied professionals to allow [my daughter] to build trust and memory.

I think it would be very detrimental to her.”

– Ann – mother of participant

2. Uncertainty around submission of additional evidence and documentation from allied health professionals

It is unclear whether participants with additional evidence and reports from allied health assessments will have this evidence taken into consideration once the independent assessment has been completed and before the planning meeting has taken place. If participants are able to provide this additional evidence, it will come at the same cost and with the same challenges that arise now. This means that the NDIA is simply duplicating the effort and cost for assessment.

3. Being assessed by a stranger can be traumatic, yet there is no alternative being offered and refusing to take part is not allowed

As for all of us, it can take time to build trust and to feel safe with allied health professionals. Being forced to answer personal and intrusive questions by a stranger can be intimidating for some people. Having to see independent assessors and talk about your difficulties multiple times is anxiety provoking. Applicants who feel uncomfortable with independent assessments will have little choice in the matter. The NDIA will consider the refusal to complete an independent assessment as a withdrawal of an access request.

4. A once-off snapshot assessment by a stranger is unlikely to give an accurate picture of a person's needs

We know that people can present very differently day-by-day depending on whether they are having a 'good day' or a 'bad day'. When health professionals who are familiar with the person are replaced by strangers without the same level of insight into the person's disability and support needs, the assessment process can become less effective. This point has been made clear by NDIS participants:

"Anything they do that takes away your ability to work with people that already know you, gives you a ton more work as you have to tell them all the backstory, particularly for me as my disability is so unusual. A half hour assessment for me can take a couple of weeks for recover."

– Ricky Buchanan, participant

"...my therapists know my needs and they know my family and my home setting. My therapists have a well-rounded knowledge of my history because they have worked with me for a long time. My therapists see me regularly so they can talk about the capacity I have built since the last plan.

I don't feel like the assessor will know me well enough to know what I need or possibly understand my speech as I am often difficult to understand if you don't know me and that makes me feel uncomfortable, embarrassed, frustrated and vulnerable. They may then assume that I don't have the required cognition to answer them or know what I need.

I am uncomfortable having someone unknown to me, assessing me and my needs and they might not get the whole picture of what I need including transport, home mods etc.

They won't know how I am in other settings and won't offer what I require to be independent. I would feel worried that I might not have what I need in the future.

I would feel intimidated by having a person who doesn't know me making decisions about my life."

– Participant

5. The NDIA has provided no assurance that independent assessors will have proper training, governance and oversight in consultation with people with disability

Currently, the NDIA's work with independent assessment organisations requires assessors who:

- Have a minimum of 12 months full time clinical experience (post General Registration) working in their field with an appropriate level of clinical supervision
- Have direct face-to-face experience working with a variety of clients, covering a wide range of disabilities, support needs, skills and backgrounds.

We do not know if NDIS training for assessors will include feedback and learnings from a peer-reviewed evaluation of the pilots or any consultation with people with disability and disability organisations. High quality assessments in line with participant expectations require adequate consultation and should incorporate principles of codesign.

While the NDIA has explained its process in choosing organisations that will provide independent assessment, they have not commented on why the recruitment process proceeded prior to consultation with people with disability. This potentially means that the independent assessor pool may not adequately meet the needs of participants.

Furthermore, Ombudsman [reports](#) have shown that some workers' compensation insurers have chosen independent assessors who are more likely to recommend terminating or minimising supports than addressing participants' needs. There is a risk that such bias may occur with NDIA-appointed independent assessors without a well-defined independent assessment framework and appropriate measures to address conflicts of interest.

Without independent governance and oversight, there is a risk that training may be biased towards producing reports that will reduce the costs to the Scheme.

“There shouldn't be anything standard about this as there isn't anything standard about a brain injury, it's very unique.

The introduction of the NDIS and the funding that has been granted has enabled [my daughter] to live her best life so far, but I feel this is now going backwards. What is the whole point of having this scheme if it goes back to generalised testing?”

– Ann – mother of participant

6. Participants who feel their needs are not appropriately captured have little recourse to challenge the outcomes of independent assessment

According to the NDIA's [consultation paper](#) on independent assessment, participants will not be able to appeal their independent assessment or request a new assessment if they disagree with the results unless the assessor did not adhere to the Framework or if the applicant has had a significant change to their functional capacity or circumstances. This is because independent assessment results are not reviewable as they are classified as 'informing an access decision' rather than being a decision. While a decision based on the independent assessment can be appealed, the decisions not to grant exceptions for an independent assessment will not be reviewable. This gives independent assessors a great deal of power with little accountability.

"Participants should be able to disagree at any time whenever they believe their needs are not being met by their NDIS plan. The NDIS is not a welfare scheme and disallowing reviews tends to suggest that it is becoming more like welfare than a plan to improve quality of life for people with disabilities.

The NDIA needs to go right back and look at why the NDIS was established in the first place, rather than reverting back to pre NDIS days when there was no choice and control for people with disabilities. "

– Carol – mother of participant

"Something like this always goes back to the family, all the stress, what is going to happen. When will we be able to say this is working well? You are never at peace – there is always fear that things will be taken away. Feels like you're always battling, already battling injury and battling life. That should be enough, [she] shouldn't be fighting for service provision when she has been diagnosed with a BI for the rest of her life. Why are we always nervous things will be taken away, when she is living her best life possible? How many times do we have to relive this injury? How many times do we have to prove she needs this support? We understand a review, but this is something different."

– Ann – mother of participant

Recommendations

Recommendation 1: Halt any rollout of independent assessments and undertake the necessary consultation to develop the Independent Assessment Framework

- a. Independent assessments should not proceed without a proper evidence-based pilot, consultation and input from people with disability, representative disability organisations and other experts
- b. The current lack of information around the pilots, as implementation approaches, is concerning. The NDIA must complete the second pilot and ensure an in-depth independent evaluation takes place before proceeding with implementation.

Recommendation 2: In line with the recommendations of the Tune Review, the NDIA should consult with people with disability and other disability experts on the design of the Independent Assessments Framework. A process in line with codesign principles is strongly recommended

- a. The NDIA should convene an expert panel that includes people with disability and their representative organisations as well as other experts to consider the outcomes of the independent assessments pilot project. This expert panel should consult with the disability sector and inform the design of the Framework for independent assessments
- b. The NDIA should ensure the governance of independent assessments includes people with disability and others with disability knowledge and expertise including disabled persons organisations.

Recommendation 3: Create a fit for purpose assessment toolkit

- a. The proposed toolkit must be independently evaluated to determine if it is fit for purpose
- b. The assessment must be tailored to the individual. Standardised toolkits must include flexible measurement tools for particular disabilities and diagnoses, functional capability and environmental concerns while addressing participant's goals. The assessment should ensure a 'no disadvantage' approach whereby the tools used should not disadvantage the participant in any way
- c. The NDIA must ensure that assessments can include well informed insights from health professionals and family members who know the person well.

Recommendation 4: Introduce optional independent assessments for people who need them

- a. Independent assessments must be optional for all participants. This is particularly true for participants with progressive neurological conditions, acquired brain injuries or complex disabilities who are better served by dealing with familiar health professionals who understand their needs. Such assessments capture their disability over time and their functional capacity in a variety of environments and situations. This results in appropriate supports that snapshot independent assessments cannot produce
- b. There are currently people stuck in hospital and in RAC who urgently require assessments to gain access to the NDIS and who are unable to arrange these themselves. The provision of independent assessment to this cohort would enable effective access and support hospital discharge and relocation from RAC into stable housing.

Recommendation 5: Ensure that personalised budgets are informed by a participant's individual needs and goals, as prescribed in the Act

- a. Individual needs and preferences must be considered in addition to functional capacity. The NDIA must ensure that the personalised budget reflects how the individual chooses to live their life. This can only occur when the participant is actively engaged in the planning process, and where personal goals are central to the plan
- b. Independent assessments should take into consideration a person's goals and help to define these in the context of the NDIS.

Recommendation 6: Ensure training, qualifications and suitability of independent assessors

- a. Assessors must have thorough, standardised training to ensure accountability and quality provision of independent assessments to all participants
- b. The NDIA must ensure processes are updated with learnings and feedback from participants. Updated processes must remain standardised and include sufficient training to reduce variability across assessors
- c. Training should include feedback from peer-reviewed evaluation of the pilots as well as consultation from people with disability and disability organisations
- d. Assessors must have the ability to meet high standards and include a broad spectrum of experts so they can be appropriately matched with NDIS participants based on their expertise
- e. Assessors must have expertise and a background that reflects knowledge and understanding of an applicant's disability.

Recommendation 7: Provide allied health professionals with access to training and the framework used by independent assessors to ensure quality and consistency

- a. Participants who are being assessed by known allied health professionals, rather than independent assessors should be able to have assessments done in line with the prescribed requirements of the NDIA and in the format that they require
- b. The NDIA should invest in building the capacity of allied health professionals and make available the training modules that it is developing to all allied health professionals working with NDIS participants. This will assist with transparency and increase the consistency and reliability of allied health assessments across the board
- c. The NDIA should accept further evidence of disability from allied health professionals during the period of time after the independent assessment and before the access decision or planning meeting. This evidence must inform the funding allocation in a plan.

Recommendation 8: Increase choice and control over assessment and assessment options for participants

- a. Participants should be informed of the expertise and experience of their assessor in order to have confidence in the assessor's ability to make a fair and informed assessment of their disability and support needs where an independent assessment is required
- b. The NDIA should guarantee that participants will have the option to provide reports and assessments conducted by their preferred allied health professionals and that these will be funded by the NDIA
- c. Participants with advanced progressive disability should not have to wait for new, or be subject to many, assessments in order to receive increased supports
- d. Considerable work must be undertaken to ensure that participants and those applying for the NDIS have access to relevant information in accessible formats that will assist them to fully and effectively participate in the assessment process
- e. Participants should be given the option to seek a second independent assessment with allied health professionals who are familiar with the participant. A second assessment acts to verify findings and filter human error.

Recommendation 9: Develop an appeal process for independent assessments

- a. Participants must have clear and simple ways to make complaints or challenge the experience and results of independent assessments
- b. There must be robust and transparent mechanisms to review assessors and ensure both quality and accountability. As it stands, independent assessors hold a great deal of power with little accountability and ineffective independent assessments will significantly impact participants.

Recommendation 10: NDIS participants should be provided the full report from an independent assessment

- a. It is understood the NDIA is providing the assessment summary to ensure NDIS participants have access to the outcomes of their assessment in an accessible and easy to read format. However, holding back the full assessment precludes the NDIS participant and their supporters from fully representing their needs
- b. Participants have the right to know what has been written about them in the independent assessment without any missing information, except for tool metrics that may compromise the integrity of future assessments. Participants should be supported to understand the results of their assessment
- c. The full report must be sharable with the participant's team and clinicians. This allows assessment results to inform therapy, support and training of support workers.