



Summer Foundation Submission to the Independent Assessments Consultation

February 2021

Introduction

The Summer Foundation wants to see the NDIA take action to enable fast, fair and equitable decisions, made with a strong evidence base. This requires NDIA funded and well-trained assessors who have experience working with people with disability.

However, we believe the decision by the NDIA to introduce independent assessors across the board and to make this compulsory was made without sufficient consultation with people with disability. We welcome this opportunity to provide input, yet the Summer Foundation is concerned that based on the consultation questions, the concerns of people with disability about the introduction of Independent Assessments (IA) are not within scope of this consultation.

The Summer Foundation believes it is important for the government to respond to concerns about the quality of the assessments that can be provided by assessors who are not familiar with the individual. We know it can take time and experience working with a person to have a full picture of their functional capacity and of what support they need. Without this experience and knowledge, assessments may not be an accurate representation of the functional capacity of the person being assessed.

The following quote is from a participant who contributed their concerns about IA for our submission:

"...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."

Our concerns related to the introduction of IA include:

- Being assessed by a stranger can be physically and emotionally difficult and traumatic
- Individual needs and preferences may not be part of the assessment process. The NDIA must ensure that funding allocations are informed both by their needs and a person's goals and how they want to live their life
- A once-off IA from a stranger may not give an accurate picture of the person's needs. We know people can present very differently day-by-day, depending on whether they are having a 'good day' or a 'bad day'
- Ombudsman [reports](#) have shown that some workers' compensation insurers have chosen independent assessors who are more likely to recommend terminating or minimising supports. There is a risk that such bias may occur with NDIA-appointed independent assessors without appropriate measures to address conflicts of interest
- Without independent governance and oversight, there is a risk the training may be biased towards producing reports that will reduce the costs to the scheme
- There may be additional delays as a result of requiring IA
- Cognitive and psychosocial issues are poorly addressed in the battery of tools being proposed, according to [OT Australia](#).

To address the concerns, the Summer Foundation recommends the following:

- IA should be delayed until proper consultation has been undertaken, which contributes to the development of an IA framework
- The evaluation of the first IA pilot should be made publicly available
- The second pilot of IA should be used to trial approaches that demonstrate fairness, accessibility and appropriate assessments. Evaluation of this trial should be completed and made publicly available prior to any decisions being made
- The NDIA should introduce optional IA to reduce the cost and burden to the individual who without this would have to continue arranging and paying for their own assessments. This is vital for people who have newly acquired disabilities and may be stuck in hospital or residential aged care (RAC)
- In line with the recommendations of the *Tune Review*, the NDIA should consult with people with disability and other disability experts on the Independent

Assessments Framework. The NDIA should convene an expert panel that includes people with disabilities and their representative organisations as well as other experts to consider the outcomes of the IA pilot project. This expert panel should consult with the disability sector and make recommendations regarding the framework for the implementation of assessments and the future of IA

- The NDIA should guarantee that participants will have the option to provide reports and assessments conducted by their preferred allied health professionals and these will be funded by the NDIA
- The NDIA should invest in building the capacity of allied health professionals and standardise the training modules it is developing for IA to all allied health professionals working with NDIS participants. This will assist with transparency and increase the consistency and reliability of allied health assessments that are conducted in the community
- The NDIA should ensure the governance of IA includes people with disability and others with disability knowledge and expertise including disabled persons organisations
- 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
- Assessors must have the ability to meet high standards and include a broad spectrum of experts to accommodate a wide range of impairments that are represented among NDIS participants
- 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
- The NDIA should accept further evidence of disability from allied health professionals during the time after IA and before the access decisions and planning meeting. This evidence must be able to increase the funding in a participant's plan above and beyond the initial indicative budget
- NDIS participants should be provided the full report from an IA, not just a summary. It is understood that the NDIA is providing the 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 representing their needs in a planning meeting.

Responses to Independent Assessments Discussion Paper

Learning about the NDIS

1. What will people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?

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.

People will need to know what these assessments are, how they will work, and how they are different to an assessment by their current health professionals. This is in addition to an explanation of the application process and what it entails. It is critical to ensure people fully understand and are able to fully and effectively participate during the transition to IA. Participants must understand:

- How they can use evidence from their current health professionals to supplement the IA and what the cost of obtaining this evidence might be
- What the eligibility requirements are and how to work with the assessors in order to provide the necessary evidence
- Who they can bring to their assessment, including supporters and health professionals.

The timeframe for application, determinations, and assessments Participants should know the expertise and experience of the assessor in order to have confidence in the assessor's ability to make a fair and informed assessment of their disability and support needs. There should be a minimum standard of qualifications for assessors with a match of experience and expertise to expedite the process of allocation of an assessor.

Information provided to participants should be given in a range of formats including:

- Plain English
- Easy English
- Audio visual (with captions and audio-described).

Accessing the NDIS

2. What should we consider in removing the access lists?

Regarding removing access lists, the NDIA must consider a variety of issues. Firstly, the Summer Foundation is concerned about a potential delay in timely access to the NDIS for people in RAC and hospital. It is important that the removal of access lists does not cause delays and wait times for people in RAC and hospital. This must be monitored closely with a risk mitigation strategy activated as needed.

Switching from the lists to IA leaves uncertainty around eligibility for various conditions. For example, many conditions are difficult to adequately capture with snapshot assessments, such as psychosocial issues and episodic disabilities where the person's functional capability can fluctuate. Participants must know whether the change to IA may lead to reassessments and differing determinations, and what proportion of applicants deemed eligible on access lists are expected to become ineligible with IA.

The mass implementation of IA will mean that contracts are given to large organisations with numerous assessors. Assessors must have the ability to meet high standards and include a broad spectrum of experts to accommodate the wide range of impairments represented among participants.

The training of assessors must be of significantly high quality with thorough capability development around required tools and assessment instruments. The quality of each assessor, the assessment and outcomes must be closely monitored and regularly peer reviewed to ensure consistency in assessment practice, application and determinations.

3. How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long?

For health professionals to meet the evidence requirements with clear and holistic assessments, the NDIA must ensure that health professionals are aware of their responsibilities and the scope of their work.

The NDIA must ensure that:

- a. Health professionals provide evidence of professional qualifications and registration, as well as a description of their role and relevant experience and expertise
- b. A clear and simple outline of what is being required of various health professionals is provided
- c. If required, evidence may be obtained from more than one person in order to provide a more holistic understanding of a person's disability.

These 3 aspects are critical for providing clear and simple processes. The NDIA should provide a clear and simple outline to health professionals around what information is required and who is required to obtain it. For example, a person's treating health professional must provide evidence of disability for parts (a) and (b) of *NDIS Act 2013 Section 24 (1)*, comprising information and clinical judgement that a disability or disabilities are:

- Attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments, or
- Attributable to one or more psychiatric conditions (or as proposed through legislative amendments, to a psychosocial condition), and
- Evidence as to whether the impairment is permanent or likely to be permanent (including for the early intervention requirements).

Health professionals must understand that the remaining sections 1c) - 1e) will be provided separately by the NDIA-funded IA.

It is critical that health professionals understand how impairments are defined in relation to intellectual, cognitive, neurological, sensory or physical impairments and psychiatric conditions. This ensures health professionals are aware of the scope of their work and their responsibilities towards provision of evidence.

The NDIA should provide a list of questions for the health professional to answer. Such questions must be enquiring and seek to understand the scope, individual aspects and variability of a person's needs. Questions may be phrased as:

- Describe the person's relevant diagnosis, related impairments and disability
- Within the scope of your qualifications, experience and role, state whether you believe the impairments and disability are likely to be permanent and lifelong. Explain why you have determined this timeline. Provide evidence and examples related to this person, that support your determination
- If the impairments and disability is acquired or new, why will the person not recover? Provide evidence and examples related to this person to support your determination
- Does the person take medication related to the impairments and disability?
 - Explain the purpose of the medication, how it functionally impacts on the person and the impairments and the disability, and for how long
 - Does taking medication mean the person's level of impairment and disability changes? Explain how and to what level or explain why not.

4. How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

While there must be clear definitions of each, it must be understood that most disabilities are a by-product of a health condition, whether the health condition is temporary, episodic or permanent. Permanence and practical functional limitations on a person's capacity are the factors to be considered for eligibility purposes.

Because of this, disability cannot be fully based on severity at the time of assessment as many disabilities are episodic and others are progressive with varying effects on functional capacity. Snapshot assessments that try to capture the whole of a person's disability, whether on a good day or a bad, must consider:

- Permanency of the condition
- Timeframe
- Whether rehabilitation will have any impacts on function.

Acute health concerns should not be directly addressed by the NDIS. However, any condition that impacts, contributes, or causes a participant to experience functional limitations that are permanent must be covered by NDIS supports.

Chronic health conditions are best handled by health services if they are unrelated to disability. In cases where they cause or exacerbate disabilities, the NDIA must provide appropriate supports.

There are many people living with health conditions that are palliative. When these health conditions lead to disability, they have the same rights as others to access the NDIS. The exclusion of people with palliative health conditions from the NDIS is something we have observed in a range of settings but particularly in RAC. Too often, people with palliative conditions are forced into RAC and are not provided with the disability-related supports that they are entitled to under the NDIS Act.

The NDIS must adhere to its operational guidelines stated below:

Where a NDIS participant has a palliative care plan in place and is not hospitalised, the NDIS will fund supports required as a direct result of the disability where the support assists the participant to undertake activities of daily living. These supports may be provided at the same time as palliative care supports. The NDIS is, however, not responsible for palliative care. Palliative care is provided by the health system.

Undertaking an independent assessment

5. What are the traits and skills that you most want in an assessor?

Discussions with participants have yielded a variety of desired traits and skills. Participants need to know that assessors have a wide range of critical skills to accurately and meaningfully capture the scope of a person's disability in a respectful and empathetic way. To do so, assessors need skill sets that understand and gather evidence to ensure they are covering everything needed for a rigorous IA. This requires both clinical reasoning and experience.

Hard skills

Assessors require:

- The ability to combine formal and standardised assessment results with informal, qualitative data collected from skilled observation and discussion with the participant
- The ability to provide evidence-based information and individualise benefits to inform decision-making and autonomy
- Understanding of other supports involved
- Resources that incorporate the experience of other participants and how they have used their plans
- Clear and thorough report writing skills

- The ability to review, collate and translate previous history to avoid repetition and effort
- Understanding of specific disability, for example, in relation to fluctuation of functional capability in episodic disability Awareness of collateral history to inform the assessment to make sure context is available about a person's function
- Understanding of complex developmental disabilities
 - For example, a participant with an acquired brain injury who has mild to severe cognitive and executive impairments that severely impact functional capacity may perform very well on structured assessments while having very limited insight into changes to their skills due to the brain injury. Such assessments need to be conducted by experienced ABI clinicians
- Understanding of and experience in supporting people with progressive conditions. Assessors must have knowledge of the progression of particular conditions and be able to comment, particularly in relation to housing and SDA, about:
 - The current presentation of the person
 - The likely presentation of the person in the next 6 months
 - The likely presentation of the person in the next 12 months.

Soft skills

Assessors require:

- Great rapport-building skills and empathy to enable the participant to feel at ease and to elicit information that reflects the participant's needs and preferences
- Awareness of the importance of adopting person-centred and holistic approaches
- Collaborative skills and the ability to work with the whole team and with the participant
- A commitment to holding both formal and informal assessment as equally valuable and holding equal weight
- Open communication among the team and with the participant
- A commitment to individualise approaches to the participant
- Good problem-solving skills to adapt to participant needs.

6. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

Access must be done in light of individual circumstances. Assessors must consider how to tailor and individualise information as well as what supports are present during the IA process.

Participants must feel there is clear communication and that they are being provided with options in their preferred and accessible communication style. This facilitates better outcomes to carry out recommendations, and to support or guide participants around organising support structures.

For settings, assessors must ensure that the individual:

- Has choice and control over where and how the assessment is completed. Assessment should take place in an environment of the person's choice and best reflects their everyday setup in order to participate optimally
- Consents to any other parties or networks present, and that these parties have appropriate access to the assessment to ensure collaboration and transparency
- Feels that the plan can be adapted overtime if circumstances change.

7. How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

The Summer Foundation acknowledges the importance of delivering IA in a culturally safe and inclusive manner. Both the IA and assessor must be sensitive to each individual's circumstance and the IA must be conducted in the individual's preferred environment with the appropriate supports to ensure cultural safety and inclusion. We defer to organisations with expertise in this area.

Exemptions

8. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

As stated within the *NDIS Consultation Paper* for IA, issues around risk and safety as well as inaccessible or invalid assessments are clear grounds for consideration of exemptions. In addition to this, we have found that many complex, progressive and behavioural disabilities are more appropriately measured by familiar health professionals over an extended period of time, rather than a snapshot approach by an unfamiliar assessor.

Considerations for an exception should also be given for:

- End stages of progressive disability. Participants should not have to wait for assessment and processing times
- A person who is in hospital or RAC and independent assessors are unable to enter to complete the assessment.

Quality assurance

9. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

High quality assessment in line with participant expectation requires the IA to be a co-designed process that is inclusive of participants.

The NDIA must ensure the process remains standardised and includes sufficient training to reduce variability across assessors. The NDIA should conduct a more robust pilot program prior to rollout and seek feedback for ongoing evaluation during this period. This would include peer review and quality checks to ensure consistency across assessors.

Assessors must have thorough, standardised training to ensure accountability and quality provision of IA to all participants. In addition, all participants must have clear and simple ways to make complaints about the experience and results of IA. There must be robust and transparent mechanisms to review both assessors and the experience and results of IA.

After IA is completed, participants must be able to submit further evidence as part of the process to ensure access and planning decisions account for the full range of participant needs.

Communications and accessibility of information

10. How should we provide the assessment results to the person applying for the NDIS?

Participants should be provided with full and summary results written in plain or easy English as part of the process once IA is completed. These should be relayed to the participant, their family, and their team in their preferred format.

This report provided to the participant should be clear and easy to understand and not include information that may impact on the integrity of the assessment tools.