

An analysis of the NDIA's proposed approach to Independent Assessments

A response to the National Disability
Insurance Agency (NDIA) Consultation

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February 2021



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Independent Assessment – An Analysis of the NDIA’s Proposed Approach

Introduction

This submission is being provided in my capacity as Executive Chair and Director of the Melbourne Disability Institute and as one of the key architects of the National Disability Insurance Scheme (NDIS or Scheme). MDI is a major interdisciplinary research Institute focused on transforming the social and economic wellbeing and health of people with a disability through high-quality research, teaching and translation of knowledge. The five themes of our work include: Opportunity and Equity; Inclusive Communities; Health and Wellbeing; Markets and Sustainability; and Policy and Practice. All of these themes are relevant to independent assessments.

I was the co-author of a submission to the 2020 Summit in 2008 in which I coined the term National Disability Insurance Scheme. I was also a member of the Disability Investment Group in 2008 and 2009, Chair of the Advisory Panel to the Productivity Commission during its Inquiry into Disability Care and Support in 2010 and 2011, Deputy Chair of the COAG NDIS Advisory Group from 2011 to 2013 and inaugural Chair of the National Disability Insurance Agency from 2013 to 2016.

Given my many roles in establishing this landmark reform, I have a unique perspective on the proposed introduction of independent assessments (IA) to the NDIS. I am motivated to make this submission because I believe the introduction of mandatory IA represents the largest and most fundamental changes to the Scheme since its conceptualisation and introduction.

The approach to any major change to the NDIS must start with the people it supports. It must also start with the UN Convention on the Rights of Persons with Disability (UNCPRD) and its requirement to “promote, **protect** [emphasis added] and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”. The UNCPRD is of course referenced in the Objects of the NDIS Act (2013).

Unfortunately, it is clear that the announcement of the introduction of IA has created enormous fear, stress and concern amongst NDIS participants, their families and carers. They all also now potentially face ongoing uncertainty as the plan is to undertake IA every five years. Many of these people are vulnerable. It is essential to maintain their confidence and the confidence of the Australian community that the Scheme is well-managed. This points to the need for a nuanced and careful approach to any proposed reform, based on evidence and genuine co-design with people with disability, their families and carers. Unfortunately, this does not appear to be the case with the introduction of IA as currently planned.

This submission focuses on the most important aspects of the proposed introduction of IA, which must be addressed most urgently. These are:

- the absence of strong evidence that the IA tools are valid;
- individual goals should continue to influence reasonable and necessary supports; and
- AAT appeal rights must be maintained and if IA is introduced it must be reviewable, so the rights of NDIS participants are safeguarded.

This submission also puts forward an alternative fair way forward. This alternative approach is designed to ensure that assessments are valid, equitable and consistent and that the NDIS is sustainable, both now and into the future.

Table of Contents

Introduction	2
Background	4
Independent Functional Assessment (IA) tool validity	6
Goals should influence reasonable and necessary supports	11
Appeal rights and complaints.....	12
An alternative fair way forward	15

Background

The idea of IA has been around since the initial Productivity Commission report in 2011 and was one of its recommendations. The origins of this idea lie in no-fault accident compensation schemes, which have routinely relied on functional assessments, but now increasingly rely on assessment teams because of the challenges with functional assessments. Moreover, there are marked differences between the NDIS and accident compensation schemes, which make functional assessments much more complex in the NDIS.

In accident compensation schemes there are only three types of severe disabilities: spinal cord injuries, acquired brain injuries and severe burns. This stands in stark contrast to the NDIS which includes disabilities of all types and every functional impairment. Participants in the NDIS range from people whose disabilities were present from birth, as well as those acquired later in life.

It has therefore never been clear whether functional assessments could be successfully extended effectively to include all disabilities/functional impairments, as part of the NDIS.

Further, because accident compensation schemes seek to restore a person back to the position they were in prior to their accident (reflecting tort law), the level of functional impairment is the only consideration which determines funding. Unlike the NDIS, there is no allowance in accident compensation schemes for individual life goals, capacity building or the role of informal supports when determining funding levels. Therefore, implementing IA under the NDIS to determine reasonable and necessary supports is both much more complicated and fundamentally different to accident compensation schemes. As a result, accident compensation schemes provide a very limited guide for NDIS purposes.

Moreover, there are no functional impairment tools which have been designed to provide accurate and reliable estimates of reasonable and necessary funding for all impairments/disability types.

Given the recommendation from the Productivity Commission, independent functional assessments were first trialled by the NDIA in late 2013 to see whether they could be successfully used to calculate resource allocation/reasonable and necessary supports. This was known as the Support Needs Assessment Tool (SNAT). The trial found it was not fit for purpose and it was therefore discontinued after one year¹. Following this work further assessment tools were trialled by the NDIA in 2015 and 2016².

The two preferred tools in the trials were PediCAT (for children) and WHODAS (for adults). It is notable that these two tools lie at the heart of the proposed new version of IA. The question, then, is: Will the tools which have been added to PediCAT and WHODAS make the process of assessment valid, reliable and equitable? It is possible that they may achieve reliability and result in consistent decisions, but this does not mean they are valid for the purpose of the NDIS. This is a critical distinction.

Further, the current proposal to introduce IA seeks to apply a limited range of functional assessment tools to all disability types. As currently planned, the toolkit ignores agreed best functional assessment tools for segments of the NDIS population, such as the Gross Motor Function Test for people with cerebral palsy. This raises serious doubt about the likely accuracy of the current approach.

¹ NDIA, Assessment of Functional Capacity for NDIS – Development and Framework, August 2020, page 3

² Productivity Commission, NDIS Costs Study Report, October 2017, pages 191-193

More broadly, the proposed approach to the implementation of IA seeks to rely on a single assessment in a pre-set time period. This is despite that fact that it is well-known that the most accurate assessments of disability are provided through multi-disciplinary teams observing the person with disability in multiple settings. It is difficult to understand why administrative 'efficiency' is being prioritised over accuracy, especially given that the accurate determination of both eligibility and reasonable and necessary supports are foundational to the success of the NDIS. Fairness and consistency can only be achieved through accurate, valid assessments and governments need both accurate and consistent assessments for funding to be predictable and sustainable.

Against this background, the key issue which needs to be addressed is whether the proposed approach to IA will produce valid estimates of reasonable and necessary funding consistent with the NDIS Act. This evidence must be sufficiently robust and then be disseminated widely to establish the confidence of all stakeholders. The disability community must have trust and confidence that these major changes to the assessment and planning processes will deliver the twin aims of fairness and consistency. The evidence must also be sufficiently robust to demonstrate to the Australian community that the proposed changes are necessary and essential to the good management and operation of the Scheme, because the NDIS provides a safety net for all Australians. They will rightly want to know that the Scheme stands ready to support them or their child or grandchild if they need it. Finally, the evidence must be compelling from the perspective of all governments. The Commonwealth and States and territories are approximately equal shareholders in the NDIS and have shared responsibilities to people with disability, their families and carers and so all must have confidence in the effectiveness and reliability of NDIS processes.

Independent Functional Assessment (IA) tool validity

In the paper *Assessment of Functional Capacity for NDIS* it is stated that:

At present no assessment tools have been identified that are suitable for the scope of the NDIS which map to the whole ICF. There are ICF 'core sets' that have been created with reference to specific conditions, which provide "a list of essential categories that are relevant to specific health conditions and healthcare context", however, there are difficulties with the core sets methodology.

In the absence of a single diagnosis-neutral assessment tool that maps directly and precisely to the whole ICF, an alternative for the NDIS context is to use a suite of assessment tools. This means that multiple assessment tools are used side-by-side, complementing each other in gathering information on a person's functional capacity across the ICF domains. These tools are mapped collectively rather than separately to the whole ICF with the caveat that, for practical reasons, this is not a 'perfect fit' but is the 'closest fit'.

In the paper *Assessment of Functional Capacity for NDIS* it is stated that:

This ideal solution is, however, unattainable at present as the ideal assessment tool does not exist [emphasis added]. In 2011, the Productivity Commission Inquiry Report recognised the relatively limited research into generic assessment tools and recommended that the Government should not delay the implementation of the NDIS in the absence of 'perfect' tools. ***Currently, the perfect tool remains elusive, compelling the NDIS to undertake the process of determining the 'best fit' suite of assessment tools instead*** [emphasis added].

In the paper *Access and Eligibility Policy with independent assessments* it is stated that:

The suite of assessment tools used in independent assessments will enable us to make fair access decisions for the majority of people. There may be times when it will be necessary for delegates to request other specialised reports and assessments, ask more questions, or source extra information. Further information about the use of additional information in the planning process is provided in the proposed planning policy for personalised budgets and plan flexibility consultation paper.

In the Paper *Planning Policy for Personalised Budgets and Plan Flexibility*, in section 3.2 *Personalised budgets*, it is stated that:

A person with disability who is found eligible under the NDIS Act (known as a participant) will receive a personalised budget after they complete an independent assessment.

A personalised budget is a participant's final, approved budget which represents the reasonable and necessary level of funding they will receive in their NDIS plan. It is the total amount of funding included in a participant's NDIS plan, with funds allocated to flexible and fixed budget categories. The personalised budget is determined by an NDIS delegate after meeting with the participant and discussing a draft budget.

Then in section 3.3 *Determining reasonable and necessary funding* it is stated that:

The draft budget will be considered by the delegate before it is provided to a participant. The delegate will make sure no errors have been made and assess whether any specific additional supports were identified during the independent assessment, and whether additional assessments, evidence or information is required to include them in a plan.

A change to the draft budget will ***only be made in specific circumstances*** [emphasis added], including where:

- a participant has extensive and/or complex support needs (for example where a participant has substantial behavioural support needs, a plan is expected to be of extreme high-value, or a participant requires increased temporary support in response to an emergency)
- there are additional high-cost supports required that are not accounted for in the independent assessment. These supports include Specialist Disability Accommodation, high-cost or complex assistive technology and home modifications.

Following consideration by the delegate, and combined with any additional supports as outlined above, the personalised budget will be considered the total reasonable and necessary level of funding for a participant.

However, the evidence to support the conclusion that IA is fit for purpose and that it will lead to more valid, equitable and consistent planning decisions is missing. Many important questions remain unanswered.

For example, there is no information provided on how the multiple tools will be combined in a systematic way in order to provide an accurate picture across all disability types/functional limitations. There is also no information provided about how the NDIA has judged that the different sets of tools, as a combined group, will provide accurate measures of functional impairments.

In the NDIA paper *Independent Assessment Selection of Assessment Tools*, page 19 states that "details from the assessment suite are considered collectively and with reference to the person's particular circumstances." It is therefore unclear how the assessment tools will be combined or how they will be weighted and combined. If there is judgement involved in combining the tools, what guidance will be provided to the assessors and how will their judgements be reviewed for accuracy and consistency?

In the paper *Independent Assessments Pilot learnings and ongoing evaluation plan*, page 14 states that "in the first pilot, for the purposes of evaluation, an assumed "typical population range" was also set for each assessment tool in order to determine a participant's likely functional capacity". It would appear that if a participant lies within the typical population range, they will not be eligible for the NDIS. Therefore, how has the typical population range been set and aligned with the target population for the NDIS?

Further, given that multiple tools are being used, each with their own typical population range, how will eligibility and supports be determined? For example, if a person's functions lie within the typical population range using one tool, but outside the range on another, how will these results be combined? Combining tools needs to be undertaken with great care, particularly given that the tools have not been designed to be combined. Their combination could lead to inaccurate and misleading results. For example, an individual might have excellent receptive communication but cannot talk (expressive communication) and so still need speech therapy.

Further, in the NDIA paper *IA Selection of Assessment Tools* page 21 shows that tools were rated highly based on "one study of excellent quality AND a total sample size of greater than equal to 100 patients". This is a very small sample size given that IA will be applied to more than 500,000 participants.

Therefore, in order to be confident that the tools that have been selected to underpin IA are **valid for NDIS purposes** there needs to be much great testing of their combined suitability, including the application of typical population ranges across multiple tools. The testing also must include validation across multiple functional assessments/disability types, which are representative of the NDIS population. There must also be control groups, in order to have full confidence in the results.

In the paper *Independent Assessments Pilot learnings and ongoing evaluation plan*, page 12 states "estimates on the impact of IA's on plan budgets were also calculated where a participant had a completed plan by the end of the pilot". However, there was no further information provided about the plans or the levels of funding in them. There was for example no information about whether the plans were accurate and or how accuracy should be/was measured.

The paper *Independent Assessments Pilot learnings and ongoing evaluation plan* on page 15 refers to participant satisfaction with assessments. Unfortunately, the questions asked in the survey appear to have focused on the assessment process itself, rather than the resource allocation (presumably because volunteers were not provided with the results). The paper suggests that, on the whole, participants who had IAs were broadly satisfied with the process. The same paper goes on to provide an indication of early results from the second pilot. The second pilot is described as "delving more deeply into pilot participant's ratings of having an IA" and then lists the following responses areas:

- Satisfied with the length of the appointment
- Comfortable talking to the assessor about their disability
- Agreed that the assessor understood their challenges
- Agreed that the assessor was familiar with their disability
- Agreed the assessor understood their strengths, and
- Were satisfied with the NDIA's decision to select the assessor for them.

However, **none** of these criteria assess the validity of the independent assessment or the resource allocation. This is the most fundamental criteria on which the success or otherwise of the IAs must be judged. And it is this issue which must be addressed before all stakeholders (participants, families, governments and the Australian community) can be confident that IA will achieve its aims.

The second pilot, amongst 4000 participants is also small and can be contrasted with the initial 30,000 people who participated in the NDIS trial phase from 2013 to 2016.

If reliable tools become available, it is also essential that the tools are used with high fidelity to ensure their reliability. This is particularly important as the Agency is proposing that the tools will be used every day by many different assessors with different professional qualifications. It is well known that often tools perform better in research settings, with fewer individuals doing assessments, than in real world conditions.

It is also important to note that "independent" in the context of IA really means that it is being undertaken by someone who was not known to the participant prior to the process. However, this is

distinct from the core questions, above, which address whether the tools, when used appropriately by the independent assessors, lead to accurate and equitable funding for each participant.

It is only after all of these questions and concerns are addressed that the NDIA should consider implementation of any major changes.

It will take the assessor considerable time to get to know the participant's needs, goals and informal support arrangements and to have the opportunity to independently assess their capabilities in multiple settings. From the NDIA consultation documents and tenders for the IA pilots, it seems unlikely that assessors will be given the necessary time to carefully and accurately use the tools and so complete an accurate assessment. Without sufficient time, the capacity to develop valid individualised plans will be undermined.

In addition, there are a number of comments/observations in the paper *Independent Assessments Pilot learnings and ongoing evaluation plan*, which require further analysis and evidence:

- **Page 9** notes that language and cultural adjustments are easier to achieve with a small number of assessment tools. This is understandable, but there is a lack of detail about how cultural appropriateness and language translation will be managed. Further, it is not clear whether the tools have been tested in multiple languages and settings, as well as in English. This is particularly important given that the assessment tools ask a lot of nuanced questions. Accurate translation and culturally appropriate processes will be essential to an accurate assessment for all NDIS participants. It is also notable that many of the tools are from other countries and may not translate to Australia, particularly in relation to the importance of environmental factors.
- **Page 11** again highlights that ease-of-use/low training needs were a key selection criteria in the choice of the tools. However, the consultation documents do not provide an indication of whether a single independent assessor can use the tools accurately given minimal training. Page 12, for example, refers to use of "comprehensive training guides", rather than comprehensive training. It is important to note that the NDIS supports many people with disability with complex needs. They would ordinarily be assessed by a multi-disciplinary team working together and observing the participant in multiple settings. Multidisciplinary assessment is now considered best practice in health, accident compensation schemes and other settings, but the paper is silent as to why this best practice approach has not been selected for assessment in the NDIS.
- **Page 12** also notes that assessors in the trials of the tools were asked whether they were confident to apply their learnings during the pilot - not whether they were confident that the tools were reliable and that they were confident in their use. This is a major flaw. It suggests a need for greater reliance on implementation science, which is its own area of specialisation and should be used to support the introduction of IA.
- **Page 12** states "estimates on the impact of IA's on plan budgets were also calculated where a participant had a completed plan by the end of the pilot". There is no reference to whether the plans were accurate. Nor is there any indication of how accuracy was or should be measured. Given that translating IAs into a resource allocation is the ultimate objective of the introduction of independent assessments, the absence of any evidence on this point represents a glaring omission.

It is also notable that reports on the second pilot of IA indicate that a number of questions require participants and their families to rate their disability and functional impairments on a scale of 1 to 5. If this is correct, it is entirely subjective and risks participants answering in ways which are designed

to maximise funding. Other questions which are being piloted, such as “Can you dress yourself independently?”, frequently cannot be answered with a simple “yes” or “no”. Without further information and context, simplistic responses risk misleading or inaccurate scores. This jeopardises the validity of the entire assessment – and the resource allocation which will follow it. Consequently, the current piloting of IA leads to major questions about whether it will in fact result in improved equity and fairness.

In summary, there is insufficient evidence to conclude that the set of tools selected for IA will lead to valid, equitable and consistent decisions. It is therefore disturbing that the NDIA intends to replace the current planning process with an almost total reliance on IA. IA should not be introduced until it can be clearly demonstrated that it is valid. This information must be made available to participants and families in accessible formats in order to establish trust and confidence in the new process. In the absence of sufficient evidence, their fears and anxieties will understandably continue, undermining confidence in the scheme and its management. Moreover, unless the NDIA changes course, there is a very real danger that IA will have all the hallmarks of automated “robo planning”, rather than the individualised planning and funding process that people with disabilities and their families fought so hard for when campaigning for the NDIS.

My personal involvement in the NDIS began 15 years ago, when I met a mother who was disadvantaged and unconnected, who asked me why her disabled son could not get the services he then needed. I was also shocked by many other heart-wrenching stories of unmet needs and from ageing parents who needed certainty of support for their disabled sons and daughters, in order to enable themselves to die in peace. So, for a decade and a half, meeting individualised needs, ensuring fairness and justice for people with disability, especially those facing multiple disadvantages have been the driving forces behind my commitment to what is now the NDIS. Regrettably, IA is totally inconsistent with this vision.

Goals should influence reasonable and necessary supports

The current NDIA planning process begins with goals. It then takes account of sustainable informal supports. The final step is the assessment of functional impairments. All three combine to determine reasonable and necessary supports. This process of starting with participants' goals is absolutely critical to the culture of the NDIS. The focus is, and must continue to be, on what people with disability can do and the support required to exercise their full citizenship - rather than what they cannot do.

The central importance of goals is reflected in section 34 of the NDIS Act (2013) which describes reasonable and necessary supports and begins its list by noting that:

For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

- (a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;

This stands in stark contrast to what is being proposed with the introduction of IA. IA will reverse the current process by starting instead with functional impairments. It is therefore contrary to section 34. It is also absolutely contrary to what people with disability, their families and carers fought for – and thought they had won – with the introduction of the NDIS.

Under IA, the assessment processes will, inevitably, focus on what people with disability cannot do. It is a deficit-based approach. It will inevitably lead to participants and their advocates identifying every impairment in order to increase the likelihood of a sufficient resource allocation. As a result, it could have the unintended consequence of potentially undermining the sustainability of the scheme. It is also likely to generate inequity, as those who are better educated or more knowledgeable about the underlying assumptions of the questions will be more successful in detailing their impairments in a particular way.

The proposed introduction of IA represents a totally top-down approach to planning. It begins with a participant's impairments, rather than their goals and aspirations. It puts people in boxes before they have had a chance to outline what they would like to achieve or the ways in which they hope their lives change. It could mean that aspirations like leaving home or increased independence will need to be traded off against essential supports or that funding to support these activities will be lost if not used. It is also unclear how environmental factors, such as **sustainable informal supports** (not informal supports) will be included in IA. This is counter to everything that people with disability and their families and carers hoped for in the creation of the NDIS and fundamentally undermines the principles on which it was founded.

Current planning structures and processes start with goals, then assess environmental factors, including sustainable informal supports, and finally examine functional impairments leading to a determination of reasonable and necessary supports. This structure and order to the planning process must be maintained.

Appeal rights and complaints

In the paper *Planning Policy for Personalised Budgets and Plan Flexibility* it is stated that:

Independent assessment results will not be directly reviewable by the AAT.

Disagreeing with the results of an otherwise sound and robust independent assessment will not be sufficient for the NDIA to fund another assessment. Participants will be able to request a second assessment where the assessment was not consistent with the independent assessment framework, or if there has been a significant change to their functional capacity of circumstances.

In the paper *Access and Eligibility Policy with independent assessments* it is stated that:

The suite of assessment tools used in independent assessments will enable us to make fair access decisions for the majority of people. There may be times when it will be necessary for delegates to request other specialised reports and assessments, ask more questions, or source extra information.

The delegate's decision not to grant an exception for an independent assessment will not be a reviewable decision.

While not stated, it would also appear that a delegate's decision on whether or not to request other specialised reports and assessments will also not be reviewable.

There are a number of significant problems with this approach.

First, on 8 September 2020 the AAT, in the case *Ray versus National Disability Insurance Scheme*, handed down a decision which rejected the NDIA's use of an independent assessment. This calls into question not just the legal basis of the introduction of IA, but even more fundamentally, whether it will actually lead to more valid and equitable outcomes.

In this case, Mrs Ray had provided evidence from multiple health professionals over a period of a decade to the NDIA. Against this the NDIA provided evidence from an independent assessor who had seen Mrs Ray once. This evidence had all the hallmarks of the current proposal for IA.

The Tribunal compared the evidence of the independent assessor to Mrs Ray's treating psychologist Teana Barry, stating:

The Tribunal considers the observations made by Ms Barry are more reliable than those made by (the independent assessor), as Ms Barry has seen Mrs Ray on approximately 50 to 60 occasions, including out of the comfort and familiarity of her home environment, whereas (the Independent Assessor) had only seen Mrs Ray once for a period of three hours in her home environment.

The Tribunal noted that the opinions of the Independent Assessor were at odds with those allied health professionals who knew Mrs Ray and had carried out multiple assessments over an extended period, concluding that the Tribunal had:

"(lost) confidence that (the Independent Assessor's) opinions were based on an accurate understanding of Mrs Ray's background past achievements and her current state".

This issue of accuracy goes to the heart of the issues with the implementation of IA.

Further, if IA results are not reviewable, there will not be any mechanism for the courts to drive refinement and improvement. This is because the AAT will not be able to examine how IA has been applied to individuals who appeal their planning decisions.

However, there is an even more significant issue and that is what will and will not be reviewable by the AAT.

In the paper *Access and Eligibility Policy with independent assessments*, in section 3.11 Appeal rights and complaints it is stated that:

We will not be changing the review process. The access decision remains a reviewable decision and the applicant can request an internal review and then appeal the decision at the Administrative Appeals Tribunal (AAT).

In the paper *Planning Policy for Personalised Budgets and Plan Flexibility* it is stated, in section 3.10 Appeal rights and complaints, that:

Planning decisions, including decisions about what is a reasonable and necessary level of funding, will continue to be reviewable decisions. We will not be changing the review process. Participants can request an internal review, and if dissatisfied with the outcome of that, appeal the internal review decision at the Administrative Appeals Tribunal (AAT). A delegate's decision to approve a plan is reviewable under section 100 of the NDIS Act and, in turn, by the AAT.

However, if a delegate has strictly followed the processes of IA, potentially under a new Direction from the CEO of the NDIA, and IA is not reviewable, what appeal rights will actually be available to participants? This is especially concerning given the lack of evidence that the IA tools will generate valid results, as outlined earlier in this submission. Moreover, if the Agency goes ahead with the implementation of IA as currently proposed, appeal rights to the AAT will be even more important than they have been to date.

The latest Quarterly Report from the NDIA, for the December Quarter 2020, shows that 3,721 AAT cases have been closed since the NDIS commenced. Of these, 3,641 were "resolved before hearing", many literally "on the steps of the AAT", with only 80 being heard by the AAT. Taking an issue to the AAT requires enormous time and financial resources to obtain the necessary reports. Under IA this path will still be open, but it will be a source of great inequity as it is a course of action that is largely only available to those who already have other advantages. It also seems likely that if the results from IA are not reviewable that the NDIA will also continue its practice of resolving issues before hearing, as it will not want any deficiencies in the IA results to become publicly available.

In the paper *Access and Eligibility Policy with independent assessments*, in the section *Exemptions from independent assessments*, it is stated that:

Outside of these exceptions, if an applicant chooses not to complete an independent assessment, we will consider that the applicant has withdrawn their access request.

Then, in the paper *Planning Policy for Personalised Budgets and Plan Flexibility*, also in the section *Exemptions from independent assessments*, it is stated:

Consistent with the NDIS Act, where a participant refuses to attend an independent assessment and none of the exemptions apply, the delegate may... Not make a decision to determine a new plan until such time that an independent assessment is undertaken.

Taken together, it is clear that there will be no exemptions from independent assessments, other than those determined by the NDIA. If a participant refuses an independent assessment, they will have no legal rights of appeal, because the AAT does not have jurisdiction where an access request has been withdrawn or the NDIA has not made a decision. This will place the participant in a legal 'no-man's land'.

Therefore, there is a need for much more complete and transparent appeal processes. There must not be any diminution in the right of participants and those advocating for them to appeal to the AAT and IA itself should be reviewable.

An alternative fair way forward

Against this background, it will be necessary for the NDIA to totally rethink IA; to start again, based on strong, transparent and accessible evidence and co-design. The key elements of an alternative approach which would ensure that assessments are valid, equitable and consistent, make the NDIS sustainable and align with the UNCPRD and the original vision of the NDIS are:

- An assessment process which is genuinely co-designed with people with disability, their families, carers and representative organisations and which has strong evidence for its validity. This must include transparent testing and feedback on any questionnaires to understand strengths and weaknesses. There must also be opportunities to include expert reports as part of assessments, especially when these reports have been gathered from experts who have known the participant for many years (as highlighted in the Ray v NDIS case).
- The assessment process must start with the goals of the participant and so be individual while also allowing for environmental factors, including sustainable informal supports. It should include an expected range (not a single point estimate) of funding for reasonable and necessary supports, based on individual functional impairments. This implies a balancing of 'top-down' and 'bottom-up' planning. This will also ensure that goals are considered first rather than squeezed into a pre-determined funding level based on functional impairments alone.
- Then any planned new approach will require extensive trialling, not piloting. It will need to be based on a whole of population study and include control groups. It is notable that when the NDIS was initially trialled in 2013, the minimum size for the trial was considered to be at least 10,000 participants. In the end 30,000 was chosen as the final figure. Any testing would need to include the full range of environmental factors, including ensuring the full range of geographic locations from metropolitan to very remote.
- Once a valid, equitable and consistent assessment process has been evaluated, the evidence for its effectiveness must be made available in accessible formats to people with disability their families and carers, so there is an evidence base on which confidence and trust can be rebuilt.
- Assessments should then be undertaken by multi-disciplinary teams and, if needed, in multiple settings. Setting short, arbitrary limits on assessment times is a false economy. It will only lead to needless reviews and appeals, cause avoidable stress and fear amongst participants and their families and contribute to increasing inequity. Specifically, administrative efficiency should be designed to underpin the accurate determination of both eligibility and reasonable and necessary supports - not compromise these foundational aims. Then, when assessments are scaled up, implementation science should be used to ensure that the assessment tools and processes are used with high fidelity and so are reliable and lead to consistent results.
- Funding should then be allowed to be used very flexibly by participants, with a minimum number of fixed categories, as envisaged as part of IA.
- Even with all of these careful steps it is inevitable that further lessons will need to be learned. Continuous evaluation must therefore be a feature of the implementation of any new assessment processes. This should be independent of the Agency and any NDIA partner implementing the new assessment processes. It must include lived experience of disability, implying co-designed evaluation, as well as co-design in the development of new assessment processes.

- Internal reviews and successful AAT claims should be seen as opportunities to learn and improve and all aspects of the implementation of the NDIS should be reviewable. The current practice of settling meritorious AAT appeals “on the steps of the AAT” must cease.
- There must also be sufficient investment in what the Productivity Commission in its Inquiry into Disability Care and Support described as Tier 2 (people with disability not eligible for the NDIS), so there is no longer a “cliff” at the edge of the NDIS. This is a key foundation for the NDIS and would lead to greater equity between NDIS participants and those not eligible for support. In the absence of this investment in Tier 2, all assessment processes (not just IA) will fail to meet their essential objectives, even if they are well designed and implemented. Failure to invest in Tier 2 will also continue to place on going pressure on scheme sustainability.
- The duties and responsibilities of Local Area Coordinators should be aligned with the original intent, with a primary focus on building trusted relationships, assistance with service navigation and service development.

My strong recommendation is therefore that the NDIA must go back to the drawing board. There is an opportunity to use the data that has been and could be collected through the NDIS to realise its vision of becoming the best disability system in the world, based on individual needs, control and choice and which is equitable and sustainable. This is how the data should be used, not to establish automated “robo-planning”. There is therefore a pressing need to establish much more inclusive and evidence-based processes to design a valid, equitable, consistent and sustainable way forward for the NDIS which aligns with its original vision. MDI would be pleased to assist in these processes. We would bring all our convening power across the University of Melbourne and throughout the disability community to work together to ensure the scheme delivers on its original vision and meets the needs and expectations of those who are dependent on it.



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22 February 2021