

# Response to Joint Standing Committee on the NDIS: Independent Assessments

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## Executive Summary and Recommendations

We call on the National Disability Insurance Agency to:

- Immediately cease the rollout of the compulsory assessments as currently planned
- Undertake a robust and transparent outcome evaluation of the current pilot of the new assessment process. This evaluation must be independent of the NDIA, led by experts and co-designed with people with disability, their families and the organisations that support them.
- Undertake robust, independent and transparent trials of alternative approaches to improving consistency in access and planning – such as allowing a person’s existing health professionals to complete assessments using the same tools.
- Once the trials and evaluations are complete, engage in a meaningful co-design process with people with disability, their families and the organisations that support them to ensure a fair and consistent approach to both access to the scheme and planning and to ensure people with disability receive the support they need
- Demonstrate a commitment to equity of access by providing funded assessments by the health professional of the Prospective Participant’s choice to applicants who request them, effective immediately
- Make clear the mechanism by which an assessment by an allied health professional would generate a funding figure, including how environmental factors would be considered, the human intervention to this process, and safeguards to prevent dangerous outcomes

The signatory organisations to this document provide advocacy support to a broad spectrum of individuals with disability who are overwhelmingly expressing acute fears regarding the risks to their health, wellbeing and access to reasonable and necessary supports raised by the currently proposed NDIS reforms.

The signatory organisations urge the National Disability Insurance Agency to commit to halting the currently proposed reforms and rebuilding them with an end-to-end codesign process directly involving people with disability, in line with Australia’s obligations under the UN Convention on the Rights of People with Disability and the objects and principles of the NDIS Act itself.

## Introduction

The NDIS Appeals National Advocacy Network (“the Appeals Network”) serves as a means for Advocacy organisations funded under the Department of Social Services NDIS Appeals program to connect and share information regarding developments in the sector.

This submission was produced as a collaboration between several member organisations of the Appeals Network in response to the proposed reforms of the NDIS announced in November 2020 (“the proposed reforms”) but does not constitute an official position of the entire Appeals Network.

Signatory organisations to this document (“the signatories”) have contributed based on the experiences of, and feedback from their clients, representing a very diverse range of individuals and perspectives. As such, individual issues discussed in this document may vary significantly between regions and may not represent all the signatories’ views.

All the signatories have endorsed the recommendations made herein.

The signatories note that many of the proposed reforms cover matters which are most appropriately responded to by specialist or professional organisations, including but not limited to professional associations for Occupational Therapists and other allied health professionals, Early Childhood specialist organisations, and bodies representing demographics with particular needs such as First Nations or Culturally and Linguistically Diverse (CALD) people with disability. The signatories strongly recommend the NDIA proactively engage in direct and detailed consultation with these organisations and bodies on the proposed reforms. The NDIA should be prepared to be flexible on their policy based on the consultations.

This consultation paper was developed in a relatively short timeframe, particularly given the brief consultation window which included the Christmas-New Year period. This document therefore only covers critical concerns. It will be supplemented by more comprehensive submissions from individual organisations via other processes and as further information is released, eg. draft legislative amendments to the NDIS Act.

All case studies have been de-identified, and names have been changed.

## A Human-Rights-Based Approach

The first object of the *NDIS Act 2013* (“the Act”) is stated as being to give effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities (CRPD). The objects of the Act also include giving effect to Australia’s obligations under:

- The International Covenant on Civil and Political Rights,

- The International Covenant on Economic, Social and Cultural Rights,
- The Convention on the Rights of the Child,
- The Convention on the Elimination of All Forms of Discrimination Against Women, and
- The International Convention on the Elimination of All Forms of Racial Discrimination.

All reforms to the National Disability Insurance Scheme must be principally and primarily centred around a human-rights-based approach and in line with the Act's objects and principles.

In particular, in section 4 "General principles guiding actions under this Act", Principle 8 indicates that people with disabilities have the right to engage as equal partners in decisions that will affect their lives. This can, and should, extend to include decisions regarding any significant reforms to the functioning of the NDIS itself. Given the enormous scope of the proposed reforms, it is concerning that the principles of codesign were not effectively employed in their development as required by the CRPD Article 4(3).

The signatories are concerned that the proposed reforms are not consistent with a human-rights-based approach and may significantly undermine the rights of people with disability in Australia.

## Why is the NDIA taking this approach?

The NDIA states that the proposed reforms being introduced will “*level the playing field*” so that financial, cultural, social, education and literacy factors do not contribute to barriers to accessing the scheme or issues with plan budgets. They propose the reforms will address several key issues with the scheme including:

- Inequities in access due to the cost of gathering evidence
- Inconsistency in the type and quality of evidence provided
- Inconsistent and inequitable access and planning decisions
- Insufficient information about environmental factors

We address each of these issues below, and comment on whether the proposed process will contribute to resolution or improvement of these issues.

### Inequity of Access

We acknowledge that the use of Independent Assessments would have the potential to reduce inequity in access to the NDIS for some individuals who:

- Do not have the necessary medical evidence for a successful application for access; and
- Are unable to access such evidence due to factors including cost, location, and availability of medical professionals to write appropriate reports

### The Access Requirements

The requirements for access to the Scheme can be summarised as age, residence, disability and permanence.

An individual seeking access will not be referred for an Independent Assessment if they have not been able to provide evidence of their age, residence, disability and permanence, and will be deemed to have not met access requirements.

There are several assumptions that are apparent here including:

1. Demonstrating the impact on functional capacity is the sticking point in the access and eligibility process
2. A person will not have sufficient evidence of their functional capacity already available through gathering information for the other Access criteria

3. Information about functional capacity will not be needed to help determine permanency

In our view, these assumptions are highly problematic, and we do not consider that the proposed changes adequately acknowledge or address concerns. We believe that the introduction of Independent Assessments will not improve access for many of those who are already experiencing barriers to making an Access Request. Based on our experience, these barriers will continue to disproportionately impact on those who are already the most vulnerable including:

- People who are, or have been, homeless, or have had to leave their home urgently for reasons such as domestic violence
- People with psychosocial disability
- People in rural, regional, or remote areas
- People who are in custodial settings such as prison
- People with limited informal supports

## Age and residence

Whilst obtaining evidence of age and/or residence can be barriers for a range of demographics (those currently or previously homeless, individuals leaving domestic violence situations, indigenous people in remote communities and etc), Independent Assessments will not change this. Access to advocacy and community support is critical for many individuals overcoming such documentary barriers.

## Disability

Under the proposed process, individuals will need only to provide evidence of a disability, rather than the current requirement that they provide evidence of the significant impairment of function under the relevant domains.

This would then imply that the NDIA is going to provide a definition of “disability” for this purpose. What is this definition? How is a medical practitioner going to know whether the condition experienced by their patient is a “disability” for the purposes of this evidence?

Definition notwithstanding, it is unclear how this improves equity of access if the applicant is still unable to access evidence of their disability due to cost, location and availability of appropriate medical practitioners to write such a report.

The same individuals who have not been able source evidence for an access request under current arrangements will experience the same issue under the proposed process including:

- Individuals with no treating doctor, and minimal or outdated medical history
- Individuals who have relied solely on the closest bulk billing clinic for urgent issues, and their records are spread across multiple clinics, none of which relate to the underlying disability
- Individuals who are, or have been homeless, escaping from domestic violence, in prison or other custodial detention
- Individuals who experience other forms of intersectional disadvantage, such as lower socioeconomic status

In these circumstances it is hard to meet the evidentiary requirements set out by the NDIA, including requiring the treating health professional who provides evidence of the disability to have treated the person for a significant period of time (e.g., at least 6 months). For example, people in rural and remote areas may only have access to visiting treating health professionals who travel to their region every few months and already have long waitlists.

The signatory organisations have supported many individuals whose medical records are spread out over multiple locations, and with multiple health professionals. This includes, for example, people who are homeless who may only access mobile health clinics when they are in crisis. Considerable time and effort are needed in these cases to locate the relevant information, and ensure it provides adequate evidence to both demonstrate the impairment and its permanency. This includes going through various FOI processes, which can cause substantial delays. Often, because reports are older, or not specifically produced to satisfy the NDIA's requirements for establishing a person meets criteria in Section 24(1), further reports are then required to be sought. This leads to further barriers such as waitlists and report costs.

We have supported many people with disability who have had to pay to access information which provides evidence of their diagnosis and treatment. This includes obtaining reports from specialists, having reports supplemented to provide additional evidence, and payment for accessing private records under the Privacy Act. Additionally, people located in rural and regional areas have had to travel to metro areas to attend both public and private appointments. This comes with the added cost of transport and accommodation. These are upfront costs that will not be alleviated by the introduction of mandatory Independent Assessments. Cost will continue to be a barrier for many people who are yet to test their eligibility, and a reason why many people have not even considered attempting access to the scheme.



## Permanence

Whilst we acknowledge the benefit of access to a free functional assessment for individuals seeking access to the NDIS and who do not have evidence of significant functional impairment for reasons as stated above, they will still be required to provide evidence of permanence.

This suggests the NDIA assumes that the evidentiary issue is related solely to functional impairment and not to permanence. In the experience of the signatory organisations, this is incorrect, and there is in fact a significant crossover of the two populations.

## Psychosocial disability

In our experience, individuals with psychosocial disability are equally or more likely to have their access request rejected due to the question of permanence as they are functional capacity. Such applicants, even with evidence that the disability has been present for decades, will receive notice that they have not met the permanence requirement. For such individuals the proposed process will not improve equity of access and will continue to leave them at risk of further loss of functional capacity and increased isolation due to unmet support needs.

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## CASE STUDY

*Phillip lives alone in public housing, and has been accessing the DSP for 18 years on the basis of depression and anxiety. While Phillip trialled a wide variety of treatment options early on after his diagnosis, medical records of these treatments were lost, and Phillip is unable to access evidence from the practitioners who originally diagnosed and treated him.*

*On attempting to access the NDIS, Phillip was told he had insufficient evidence of the permanence of his disabilities, as he had not demonstrated that all treatment pathways had been explored. Phillip was unwilling to re-trial medications which he already knew would not work for him purely for the purposes of gathering NDIS evidence. Phillip attempted to get further information for the NDIA, asking his general practitioner to write another letter, but this was considered insufficient and his Access request was deemed to be withdrawn.*

*Phillip was supported by an advocate to understand that he could make a new Access request, but he stated that the process of his previous application had had an extremely detrimental effect on his mental health, and he did not feel able to safely undertake another attempt.*

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## Complex and multiple disabilities

In our experience, individuals with complex and multiple disabilities, especially conditions such as ME/CFS or autoimmune conditions, are equally or more likely to have their access request rejected due to the question of permanence as they are functional capacity. Such applicants, even with evidence that the disability has been present for decades and a diagnosis was only made after all other possibilities were excluded, and whose medical practitioner has stated there are no treatments available, will receive notice that they have not met the permanence requirement. Further, the NDIA regularly attempts to separate out each of the causes of the impairment, and refute them one by one. This process is deeply problematic in that it is arbitrary- it is often impossible to determine which impact arises from which disability- and does not adequately recognise the compounding impacts that inevitably occur when there are multiple disabilities. For such individuals the proposed process will not improve equity of access.

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## CASE STUDY

*James has fibromyalgia, ME/CFS and ADHD, which were first identified in the early 2000s.*

*James is unable to stand for more than a few minutes without extreme physical consequences; his functional capacity has been stable since 2010. James' doctors have expressly forbidden him from undertaking Graded Exercise Therapy (GET); he has previously undertaken courses of Cognitive Behavioural Therapy (CBT) that produced no improvement in his condition. Over the years, James has trialled a wide range of medications for his conditions, but it has been established that treatments intended to treat ADHD worsen his ME/CFS, and vice versa. The interaction of James' conditions means that medications ordinarily used to treat either his physical or neurological conditions are contraindicated- his conditions cannot be considered separately.*

*James has sought NDIS Access multiple times to date, with the assistance of an advocate and extensive evidence of his medical history and past treatments. The NDIA have maintained to date that James has not demonstrated permanence of disability, as he has not undertaken GET or "sufficient" CBT and does not currently take the medications which he has previously trialled unsuccessfully.*

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## Newly acquired disabilities

Individuals with newly acquired disabilities, including brain injury from stroke, partial paraplegia following a medical event or surgery, and other similar conditions, are more likely to have their access request rejected due to the question of permanence than due to functional capacity. Such applicants, even with evidence that it is highly unlikely that any further improvement is achievable, will receive notice that they have not met the permanence requirement.

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### CASE STUDY

*Alice is aged in her 40s and lives with her partner. She has an acquired brain injury (ABI) from a car accident, and hearing impairment. Alice's car accident occurred approximately 3 years ago, and the functional impairments from her ABI are considered stable.*

*On seeking NDIS Access, Alice was unable to demonstrate permanence for her ABI, despite reports from her neurologist indicating that her functional capacity was not expected to improve further regardless of treatment. Although Alice's hearing impairment is not the cause of the majority of her support needs, her Local Area Coordinator recommended that Alice list her hearing impairment as her primary disability, as it would be "much easier" to demonstrate permanence. Alice was granted access on the basis of her hearing impairment; her ABI is still unrecognised by the NDIS.*

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## Long term barriers

Individuals who have always been assumed to have a disability, but have not been diagnosed by a suitably qualified medical practitioner and did not transition from a defined program, often lack the relevant evidence of the nature of their disability, which means they may also not be in a position to demonstrate permanence to the NDIA's satisfaction.

Such individuals have often existed on the periphery of the community, and may have had extended periods of homelessness and un- or under-employment, ongoing interaction with the justice system, co-occurring substance abuse issues, and minimal informal supports.

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### CASE STUDY

*Andrew grew up in the out-of-home-care (OOHC) system and was subject to institutional child abuse, going on to develop severe PTSD and substance abuse issues. On "aging out" of the OOHC system, he was unable to maintain stable accommodation and began living on the*

*streets, where he has lived for at least 15 years. Andrew is short statured, but has never received any formal diagnoses of any kind. Andrew is interested in the supports that might be offered by the NDIS, including supported independent living, but has no way to access evidence to formally demonstrate disability or permanence.*

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Finally, Independent Assessments will make no difference to the situations where the NDIA ignore their own policies and guidelines. Despite their own assertions to the Tune Review regarding how they deal with multiple impairments:

*4.48. In circumstances where a prospective participant or participant has multiple disabilities, the NDIA has advised the disability causing the greatest impact on functioning will be listed as the primary disability. Where it is unclear which disability results in greater functional impact, further advice is sought from the treating health professional (where consent is provided) or from the participant to determine which should be listed first. The NDIA has also confirmed that holistic assessments of the impact of the person's functional impairment drives all planning decisions, and the setting of a plan budget occurs independently of how disability type is recorded.*

*4.49. The legislation does not distinguish between a primary or secondary disability. Rather, the planning process, as set out in Part 2 of Chapter 3 of the NDIS Act, provides that a holistic approach should be taken to planning. It does not matter how many disabilities a person may have, or which satisfied the access criteria.*

*4.50. While recording primary disability may be relevant for data and research purposes, the NDIA should take every effort to inform participants that the recording of primary disability does not in any way affect the supports they are to receive under the NDIS.*

the NDIA continue to assert otherwise in relation to individual circumstances.<sup>1</sup>

## Inequity in planning outcomes

The NDIA propose that the introduction of Independent Assessments and the new planning processes will address inconsistent and inequitable plan budget decisions and result in fairer

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<sup>1</sup> Experienced in relation to numerous matters at internal review, external appeal, and represented also in the above case studies. See also VGCP and National Disability Insurance Agency [2020] AATA 5107 <http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2020/5107.html>

funding for all participants. We agree that there are longstanding issues with the quality of people's plans and funding decisions that must be addressed.

We disagree with the NDIA's proposition that: "Unlike the TSP, the personalised budget will ensure a stronger link between a participant's level of functional capacity, including their environmental and personal context, and their level of plan funding." We have concerns that, if anything, the proposed changes will further disadvantage those who are already struggling to navigate NDIS processes.

It is difficult to provide a fully informed position about whether the proposed changes will result in outcomes that are consistent with reasons and justifications provided by the NDIA. The lack of transparency around how an Independent Assessment will be translated to a budget, along with the issues surrounding the pilots (as outlined elsewhere in this document) means that we have limited understanding of what the new process entails and the results it will achieve. We do, however, have clear concerns based on the information provided by the NDIA that the processes proposed will create further inequities and add more layers of bureaucracy, while also limiting choice and control.

People have strong concerns about the ability of an independent assessment, undertaken by someone with no previous relationship nor depth of understanding of the person, their situation, history and context and within a proposed 3-4 hour time period, to appropriately be translated into a budget appropriately aligned with peoples' individual needs and goals. It is a near practical impossibility to be able to effectively assess not only a person's functional capacity, but also their support needs and environmental context in such a short period of time, by people who don't know the person, particularly for people who have complex communication access needs, and/or who are living in challenging or complex situations.

## Insufficient information about environmental factors and associated support need decisions

The assessments identified in the proposed reforms do not, in themselves, result in a recommendation for funding or supports; they provide an indicator of functional impairment. The mechanism by which the Independent Assessment is used to inform or calculate a proposed level of support need and funding has not been disclosed to date, and has not been subject to any clear consultative process.

It is not clear how environmental factors captured during the Independent Assessment will impact access or funding decisions, to what extent this data will be captured, or how sensitive this capture will be to the multiple and complex environmental factors which some cohorts can experience.

If the assessment identifies informal supports as being available, it is not clear how differing levels (and appropriateness) of existing support will translate into the assessment's findings and subsequent funding levels. For example, two people may both have live-in carers, but in one case there may be a reciprocal care arrangement as the carer themselves also has a disability, or one carer may be a sibling or extended family member who is not the most appropriate person to provide the intimate care support the person needs. Given the potential for significant decision making on the basis of such data, the process by which assessment data will be translated into Access decisions or plan funding must be made transparent. Further, the accuracy of such a process must be monitored carefully to ensure that inaccurate modelling does not cause significant cohorts of NDIS participants to suddenly lose access to supports and be forced into complaints and appeals processes.

Concerns have also been raised regarding safety mechanisms to address human error such as data input errors, or the failure to attach or consider supporting evidence, which are regularly seen by clients under the current process. Given the likelihood that an adverse finding from an Independent Assessment may lead to reduced funding or a participant being exited from the NDIS, many clients fear they may suddenly lose access to necessary supports unless further safeguards and quality checks are implemented.

The signatories do not see that environmental factors will be captured more accurately or more effectively using this process, and do not see that this will lead to more equitable outcomes in any way.

## The Tune Review and Mandatory assessments

The NDIA states that the introduction of mandatory independent assessments is supported by the Tune Review. We refer to the relevant sections of the Tune Review which state:

*"4.38. Notwithstanding this, it may not always be possible to source an appropriate provider, or there may be particular individual circumstances where it is more appropriate for non-NDIA approved providers to undertake the assessments. In addition, functional capacity assessments would not always be required, for instance if a participant's functional capacity is stable."*

*4.39. Therefore, it is reasonable that the NDIS Act is amended to enable the NDIA to require the provision of a functional capacity assessment by a NDIA-approved provider, but that this power be discretionary. To support this, the NDIA will need to develop clear operational guidelines for decision makers in exercising this discretion.*

**Recommendation 7.** The NDIS Act is amended to:

- a. *allow evidence provided to the NDIA about a prospective participant or participant to be used for multiple purposes under the NDIS Act, including access, planning and plan review processes*
- b. *provide discretionary powers for the NDIA to require a prospective participant or participant undergo an assessment for the purposes of decision-making under the NDIS Act, using NDIA-approved providers and in a form set by the NDIA.”*  
(underlining added)

The power for the NDIA to require prospective participants to undergo an independent assessment was intended to be discretionary, and therefore limited to relevant purposes under the Act. A mandatory assessment is not discretionary and cannot be seen to comply with the purposes of the Act.

The NDIA states, at 2.1 of the *Access and Eligibility Policy with Independent Assessments*, that the issues to be addressed by independent assessments are the private costs incurred in providing evidence for access decisions and resultant inequity of access decisions.

These factors may be relevant to exercise a discretionary power where, for example, a prospective participant does not have evidence of functional capacity for an Access decision, and is disadvantaged by their financial capacity to request such evidence. However, funding such an individual to receive an assessment from any suitably qualified professional of their choice would resolve this issue and would more clearly comply with the principles of choice and control upon which the Scheme is founded.

These factors are not relevant where an individual does already have access to relevant evidence of their functional capacity. In such a circumstance there is no reasonable use of a discretionary power to compel the individual to undergo an independent assessment. Further, the Tune Review makes specific reference to additional assessments not being required where the participant’s functional capacity is stable.

## “Sympathy bias”

The NDIA’s rationale for needing an independent person to assess functional capacity comes from an assertion made by the Productivity Commission around “sympathy bias”. The NDIA have said they are concerned about the potential of health professionals to overstate the needs of a person with a disability in reports.

We do acknowledge the theoretical possibility that allied health professionals could overstate the level of support needed to access increased funding in a person’s NDIS Plan, we note the NDIA has provided no evidence of professional misconduct among evidence providers.

In our view this is an unsubstantiated and exaggerated claim; the NDIA has provided no evidence of professional misconduct to support the notion that sympathy bias is a significant factor in the current issues faced by the Scheme. In essence the NDIA are suggesting that treating health professionals cannot maintain professional boundaries, have biased clinical judgement, and do not conduct their assessments in an ethical manner. This is reflective of the cultural attitude within NDIS that devalues both the knowledge and experience of a person's professional supports *and* of people with disability and their families in knowing their own capacities and support needs.

## How the NDIA is approaching this

### Reliance on the Tune Review

In communications to date, the NDIA has implied or directly stated that the proposed reforms around Eligibility and Independent Assessments are consistent with and supported by the Tune Review recommendations.

However, there are significant differences between the Tune Review's recommendations and the proposed reforms, including but not limited to:

- The lack of codesign principles and proper consultative processes during the development of the proposed reforms
- The discretionary nature of Independent Assessment application. This includes the need for this discretion to be exercised in a manner consistent with the objects and principles of the Act, a human-rights-based approach, and ensuring equity of access
- The failure to implement key protections recommended by the Tune Review, including the participant's right to challenge capacity assessment results, and to a second opinion

### Co-design and Consultation

We refer to the relevant section of the Tune Review which states:

*"4.33. This change in approach will require extensive consultation with participants, the disability sector, service providers and the NDIA workforce. Fundamentally, however, the success of the program will largely be dependent on:*



- a. *the willingness of prospective participants and participants to work with NDIA-approved functional assessors*
- b. *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.” (underlining added)*

The Tune Review clearly recommended extensive consultation prior to rolling out any independent assessment program. Importantly, the use of the word “willingness” suggests it was anticipated that participants had a choice in the matter. The proposed process does not give participants any choice in the matter and threatens them with loss of reasonable and necessary supports, or denial of access to the Scheme, if they do not comply.

It is concerning that the introduction of the mandatory Independent Assessments policy has not been open to any such consultation.

Article 4(3) of the CRPD requires close consultation and active involvement from persons with disabilities in the ‘development and implementation of legislation and policies’ concerning them. Similarly, the Tune Review discusses consultative processes for reform of the NDIS at [4.34] pg 66:

*“...there are several key protections that need to be embedded as this approach rolls out, including:...*

*(c) the NDIA-approved providers being subject to uniform accreditation requirements that are designed and implemented jointly by the NDIA and appropriate disability representative organisations”*

The consultation offered by the NDIA on the proposed reforms has been *how* to implement the policy, and not the development of the policy itself. The NDIA consultation and pilot programs have not asked people with disability whether they believe the approach is suitable, or if it will address instances of inequity seen within the Scheme. Many key details about how the proposed reforms would work have not been made available, including how Independent Assessments will be translated to Plan budgets.

It is difficult to provide meaningful feedback on a process that has little transparency. This approach is reflective of a system that seems to be returning to paternalistic ‘we know what’s best for you’ attitudes, which is in direct conflict with the principles of the NDIS. The signatories also note that the tender process for Independent Assessors was well underway before the consultation process was finalised. The organisations chosen for the panel were announced just days after the consultation process ended. It is difficult to see how information gathered during the consultation process could have genuinely been fed into the process of engaging Independent Assessors as the NDIA has suggested it would.

Lastly, we note that the pilot program relied upon to support the Independent Assessments was limited, and the second pilot is still underway. We have several concerns about the pilot programs, including:

- The pilots are an opt-in model, which may lead to selection bias and limit the number of people engaging in the pilots who would have difficulty undertaking them.
- Participant satisfaction results have been based on the experience of undertaking the assessment process and the interactions with the pilot assessors. There has been no data released about whether they thought the resulting report was accurate and comprehensive.
- Participant satisfaction surveys were mostly completed by carers rather than the person with a disability in the first pilot.
- Pilot assessments have no bearing on the outcome of a person's eligibility or plan budget meaning participants satisfaction with outcomes resulting from their assessment has not been assessed.
- There has been no data released comparing decisions made under the current process vs the proposed reforms e.g. plan budgets. It is unclear whether this data has been collected as part of the pilot. Without this data there is no evidence that the proposed reforms will improve decision making.
- Relative to the significant changes the proposed reforms will create, extensive trialling (not piloting) needs to occur. For feedback from the pilot programs to be meaningful testing needs to include a greater size and a full range of environmental factors. To date this has not occurred.<sup>2</sup>
- Despite the assertions that Independent Assessments are expected to make the process fairer, those individuals who could benefit from an Independent Assessment now are not able to access them under the pilot. Those members of the community who are seeking access to the scheme but do not have evidence of functional impairment and cannot afford to engage an appropriately qualified allied health professional to provide such evidence, remain at a disadvantage. Overwhelmingly these are people who have fallen through the cracks of previous systems. If the intent were legitimately to demonstrate the value of these assessments, we believe that the NDIA had an opportunity to provide them to these individuals immediately. Their failure to do so is entirely inconsistent with assertions that this is about fairness.

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<sup>2</sup> See *An analysis of the NDIA's proposed approach to Independent Assessments*, Professor Bruce Bonyhady AM Executive Chair and Director Melbourne Disability Institute (February 2021) page 8, 15

## Appeal and Review Rights

We refer to the relevant sections of the Tune Review which state:

- “4.34. The NDIS Act should be amended to support the use of functional capacity assessments as proposed above. However, there are a number of key protections that need to be embedded as this approach rolls out, including:*
- 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 organisations*
  - d. the NDIA providing clear and accessible publicly available information, including on the NDIS website, on the functional capacity assessments being used by the NDIA and the available panel of providers.”*

The right to seek a second opinion is enshrined in the Australian Charter of Healthcare Rights. We also note that the World Health Organisation’s Ethical Guidelines on the use of ICF specifically state that:

- (4) The information coded using the ICF should be viewed as personal information and subject to recognized rules of confidentiality appropriate for the manner in which the data will be used...*
- (6) Wherever possible, the person whose level of functioning is being classified (or the person’s advocate) should have the opportunity to participate, and in particular to challenge or affirm the appropriateness of the categories being used and the assessment assigned*<sup>3</sup>

The tender document for the Independent Assessor Panel states that people will have the right to challenge the results of their assessment if they are unsatisfied.<sup>4</sup> No information is provided about how a person can exercise this right, and it is contradictory to the

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<sup>3</sup> World Health Organisation. (2001). International Classification of Functioning, Disability and Health. World Health Organisation: Geneva. Annex 6, p 252

<sup>4</sup> Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 3.8 Appeals Processes.

information provided in the NDIA's proposed Access and Eligibility policy. The process will not include the necessary safeguards recommended by the Tune Review and will not:

- Provide participants with a complete copy of the assessment outcome, only a summary<sup>5</sup>
- Provide a right to challenge the results of an assessment<sup>6</sup>
- Regulate the conduct of the assessors beyond the relevant professional and regulatory frameworks which already exist<sup>7</sup>

While the NDIA states that a person can still make a complaint if they are unhappy with their Independent Assessment, the policy is clear that a second assessment can only be obtained if the assessment was not consistent with the Independent Assessment Framework or there has been a significant change to the functional capacity or circumstances.

People will have to apply for a copy of the full assessment through the Participant Information Access Scheme, which can take up to 28 days. If they are unhappy with their assessment, they will then need to make a complaint, to which the NDIA has 21 days to respond. This means a person may potentially be waiting 49 days for NDIA to even acknowledge their concerns, and there is no guarantee of a second assessment unless the person has the capacity to understand and articulate how the assessment was inconsistent with the Independent Assessment Framework. This would require a thorough knowledge of the framework and what could be considered inconsistent, then using the right language when making a complaint to ensure it meets the criteria. This will create further inequity in the scheme because those who are most vulnerable, with the least capacity and no support, will have the most difficulty navigating this process successfully.

The lack of appeals rights coupled with the fact that a person only receives a summary of their Independent Assessment is, in our opinion, a significant quality and safeguarding risk. It is an approach that presumes:

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<sup>5</sup> Paragraph 3.8 of the *Consultation paper: Access and Eligibility Policy with independent assessments* states that "all applicants will be provided with both a summary of their independent assessment results and an explanation of the access decision. Guidance to help applicants understand their independent assessment results will also be provided."

<sup>6</sup> 3.11 of the *Consultation paper: Access and Eligibility Policy with independent assessments* states "Disagreeing with the results of an otherwise sound and robust independent assessment is not sufficient for the NDIA to fund another assessment. Applicants can only seek a second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances."

<sup>7</sup> 3.11 of the *Consultation paper: Access and Eligibility Policy with independent assessments* states "We are developing a quality assurance framework for the delivery of independent assessments. This will ensure they meet the standards under relevant professional and regulatory frameworks."

- Independent assessments are infallible and consistent and/or
- Participants will have the capacity to identify and articulate when an assessment is inconsistent with the Independent Assessment Framework and/or
- A complaints process is the best avenue to manage quality issues arising from Independent Assessments

Given the significant impact an assessment can have on a person's life, their access to the NDIS, and their access to supports, it is insufficient that a second assessment can only be requested in the circumstances stated, and that otherwise a participant must rely on a complaints process.

The NDIA have based their assertions that this process is necessary on arguments about fallibility and inconsistency of clinical assessments; should an assessor organisation be producing inaccurate and/or inconsistent outcomes, this must be possible to identify through reasonable access to second opinion assessments.

In the event of a second assessment "the initial assessment and outcomes are to be considered invalid for all further decision making purposes." This is useful to the specific participant who has had the capacity to demonstrate that there was an issue with the way the assessment was conducted, but what then of the assessments such an organisation has completed for other participants? If similar issues were found to exist, it may be appropriate to make changes to those other assessments by the consent of the individual people with disability involved.

Where a participant receives an outcome of an Independent Assessment which is significantly different to the reports and materials provided by their medical practitioners and/or other clinicians, over an extended period, they will have no legal right to challenge this.

Despite the Administrative Appeals Tribunal finding that an assessment by a stranger for a few hours provides less useful and reliable outcomes than the evidence of clinicians with whom the individual has a long standing relationship,<sup>8</sup> the absence of a review mechanism forces the individual to seek an internal review and then apply to the Administrative Appeals Tribunal for external review.

There is little transparency about whether issues with an Independent Assessment can be addressed as part of a review process. For example:

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<sup>8</sup> For example Ray and National Disability Insurance Agency [2020] AATA 3452 (<https://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA//2020/3452.html>)

- Can a review delegate request a new or amended Independent Assessment?
- Can a review delegate make a review decision that is inconsistent with the results of an Independent Assessment if they believe there was an issue with the assessment?
- Will a participant be required to go through both a complaints and review process if the issue stems from the Independent Assessment?

Given the length and difficulty of that process, there must be a way for significant inconsistency of opinion to be addressed at an earlier stage.

Finally, with regards to planning, it remains unclear how the outcome of the assessment and subsequent budget allocation will be able to be reviewed given there is little transparency as to how independent assessments will be converted into a budget and given the independent assessments themselves are not reviewable.

Without knowing how individual assessments will be translated to plan budgets, there will be insufficient information available for people to determine whether their plan budget meets their needs. As a consequence, people may be forced to provide evidence of a comprehensive list of their specific needs for a review, rather than just being able to focus on the area of funding that the NDIA did not fund, as is currently the case.<sup>9</sup>

Further, the concept of an internal review becomes problematic when a decision maker bases their “decision” solely on an external assessment, and the link between assessment outcome and decision is unclear.

## Quality and Safeguards

The NDIA refers to a yet undefined Quality Assurance Framework which they state will ensure the validity of assessment results and inter-rater reliability between Assessors. There have been no uniform accreditation requirements established and there is no suggestion they will be designed and implemented by people with disability, disabled person’s organisations or disability representative organisations. It is also unclear how assessor organisations will be subject to the NDIS Code of Conduct or other mandatory requirements, when the participant is not provided with a copy of the assessment.

At this stage, there is no evidence that appropriate reasonable adjustments- as required under the Disability Discrimination Act 1992- will be made available to people with disability who undergo independent assessments. Other submissions and statements made by allied health professional organisations (such as that made to the Joint Standing Committee by

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<sup>9</sup> The current system enables a person to specifically identify what supports the NDIA has and has determined are not reasonable and necessary, with the internal review process articulating what support was requested, and the reasons why it was rejected.

Occupational Health Australia in October 2020) have raised concerns that the standardised assessment tools indicated for use in Independent Assessments are not reliable indicators of the functional capacity of people with disability.

If Independent Assessments are to be implemented, we expect guarantees that the allied health professionals administering the assessments will be fully qualified with a minimum 3 years experience in practice with the disabilities they are assessing, trained in the assessment tools, and trained in understanding the CRPD. We expect regular accreditation processes that test the accuracy of outcomes. We expect that unprofessional assessors will be removed from their role to protect the rights, safety and welfare of Participants. We recommend the quality assurance framework is also co-designed with persons with disabilities and their representative organisations.

We note the ICF Practice Manual states in regards to observational assessments:

*“Information may also be gained through observation by an experienced professional. Observations are subsequently organised into the framework of the ICF. Clinical judgement or professional reasoning is used to identify the target category and define the severity level.”*

We also note that some of the Independent Assessor organisations have advertised for recent graduates and people with as little as 12 months’ work experience post general registration.<sup>10</sup> We have serious concerns about the level of clinical judgement a person with such limited experience will have.

Additionally, the process of assessment itself raises a number of quality and safeguarding concerns. The tender document for Independent Assessors states that an assessor must spend a minimum of 20 minutes observing a person, complete a set of Functional Capacity Tools nominated by the NDIA and then submit a report to the NDIA. The report must be submitted within 10 business days of receiving the referral. There is a maximum timeframe of 20 business days to submit the report before the referral is returned to the NDIA.

The NDIA will determine which of the Assessment Tools need to be used as part of the Independent Assessment. There is no information on what skills, training, and qualifications the NDIA delegate will have in order to determine which tools are most appropriate depending on a person’s age, disability and circumstances.

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<sup>10</sup> Plena Healthcare Seek Advertisement (<https://www.seek.com.au/job/51839518?type=standout>); Zenitas Healthcare Jora Advertisement ([https://au.jora.com/job/NDIA-Independent-Assessor-37cd12c0092f8f55c5e50b90a6598659?from\\_url=https%3A%2F%2Fau.jora.com%2FIndependent-Assessors-jobs-in-Australia&sl=Australia&sol\\_srt=aaa93e9e-2475-4f7a-91a5-8018a0adcb6b&sp=serp&sponsored=false&sq=Independent+Assessors&sr=1&tk=znq9kHBGf0bCh5x8wLEM-4O7Pi9I9uaqYv9c92LpE](https://au.jora.com/job/NDIA-Independent-Assessor-37cd12c0092f8f55c5e50b90a6598659?from_url=https%3A%2F%2Fau.jora.com%2FIndependent-Assessors-jobs-in-Australia&sl=Australia&sol_srt=aaa93e9e-2475-4f7a-91a5-8018a0adcb6b&sp=serp&sponsored=false&sq=Independent+Assessors&sr=1&tk=znq9kHBGf0bCh5x8wLEM-4O7Pi9I9uaqYv9c92LpE))

The NDIA have estimated that the entire assessment process will take 2.5-3 hours. This includes both meeting with the person, completing all assessment tools AND writing the report. We question how the NDIA came up with this estimate, as it seems woefully inadequate based on our experience supporting people in the scheme who have undergone full Functional Capacity Assessments through qualified Occupational Therapists. We contend that this is not sufficient time to develop a full picture of the impact of a person's disability and the circumstances that may impact on their support needs. We are concerned that there will be pressure to meet KPI's, as seen with LAC partners, and Job Capacity Assessors for Centrelink, which will result in corners being cut and the bare minimum time being spent with a person. We also contend that the limited timeframe and being forced to interact with an unknown person may lead to harm for many of the individuals we support, especially those who have experienced abuse and trauma, and those with a psychosocial disability.

We also question the quality of the reports that will be produced. Even with rigorous training for Independent Assessors no process involving a human is free from errors. We would argue that given the Independent Assessor must not know the person and will have a limited time available to complete the assessment, there will always be the chance that an assessment will be inaccurate. As outlined above, the inability to review and seek a second opinion also have implications for quality and safeguarding.

Additionally, costs have been estimated based on a model assuming 2.5-3 hours of work from meeting a person through to producing a finalised report. If there is a focus on quality rather than quantity, we do not believe that this timeframe is realistic. The risk here is that either:

- there is a cost blowout for the Independent Assessment Framework as assessments take longer than anticipated to complete, or
- given that the cost is fixed, to meet KPIs and manage costs, the quality of reports produced will be low, leading to poor decisions and resulting in continued or increased numbers of reviews being requested

## Independence

We also question how 'independent' the assessors will truly be. The services engaged through the tender process have KPIs to meet (such as timeframes for submitting completed reports) and will be accountable to the NDIA. The NDIA specifically states that assessors must not provide a copy of the report or discuss the results with the person with a disability in any way.<sup>11</sup> The NDIA however, can request information and assistance from

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<sup>11</sup> Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 4.2 Report Types and Delivery Timeframes



assessors in relation to appeals processes. The NDIA is also able to return an assessment to have errors and omissions remediated. We are at a loss to understand how the NDIA will identify these errors or omissions without input from the person with a disability. The assessors submit their reports to the NDIA who have full access, whereas the person with a disability must apply for a copy of the full report. Therefore, assessors are clearly working in the interest of the NDIA and cannot be considered independent.

Many of the health professionals currently providing evidence are from the same health professional background highlighted in the tender document and have training on the same assessment tools the NDIA is proposing to use. There is no reason that a person's treating health professional could not undertake the proposed process in the independent assessment framework should they:

- have the appropriate qualification to complete the required assessments
- have completed the online training that is being proposed in the tender document
- provide assessments/reports consistent with a quality assurance framework co-designed by people with a disability

## Demonstrating Permanence

Specialist allied health groups and organisations, such as Occupational Therapists Australia and various mental health occupational therapists' groups, have already provided comment elsewhere on their concerns regarding predicted negative impacts of the currently proposed format for independent assessments, including an overall reduction in equity of access. In fact, the Tune Review clearly acknowledges the interrelation between permanency and functional capacity for people with a psychosocial disability:

*5.12 Accordingly, this review considers greater weight should be given to functional capacity assessments than diagnosis in determining permanency for people with psychosocial disability*

While the NDIA has communicated that Independent Assessments are intended to reduce the costs of obtaining evidence for NDIS Access and inconsistencies in decision-making and therefore increase equity, the signatories note that demonstrating permanency of impairment frequently presents a more significant barrier for people with disability seeking to access the NDIS.

To date, the existence of Lists A and B has served as an attempt to reduce this impact; while there should continue to be review of which conditions and diagnoses are present on these lists, the signatories oppose their outright removal at this time, as their presence significantly reduces administrative burden on individuals with those conditions. The

signatories note that the NDIA have indicated they intend to release an Operational Guideline containing further clarification around details of what evidence will be required to demonstrate permanence, the most appropriate treatment system for “health conditions”, and dealing with issues related to the functional impact of “chronic, acute and terminal health conditions” and welcome such clarification. However, we remain concerned that significant inequity will continue in regards to demonstrating permanency for individuals with chronic health conditions versus those with disabilities arising from other factors.

Increasingly, people with disability in Australia are expressing concern that disability associated with diagnoses deemed to be health conditions is being increasingly excluded from support under the NDIS. While the signatories acknowledge and respect that the NDIS should not duplicate the scope of federal and state Health systems, the Act itself does not differentiate between health conditions and disabilities. Many advocacy clients present with chronic health conditions that create very significant disability and which require disability-specific supports that would not be appropriate to be provided under health or any other mainstream systems.

Multiple AAT decisions have been published to date confirming that health conditions may also be disabilities. It is the experience of the signatories that inconsistencies in decision making regarding permanence for individuals with chronic health conditions most frequently originate from the delegates, rather than from the evidence provided by prospective Participants; as such, Independent Assessments will not address inconsistencies in decision-making in this way.

## Exemptions from Independent Assessments

As noted above, the Tune Review recommended discretionary assessments, however the proposed process would make such assessments mandatory. The NDIA then proposes a person may be exempt from needing an Independent Assessment under ‘exceptional circumstances’. There is no clarity around the process of granting an exemption and under what circumstances a person may need to apply for an exemption.

A discretionary assessment serves as a potential mechanism for individuals who cannot afford evidence of functional impairment to be assisted to access the scheme, it assists the disadvantaged and seeks to address issues of inequity.

In contrast, a mandatory process creates further inequity. The exemption process itself is inequitable as it requires those individuals who are at most risk, with the fewest supports and least capacity to do so, to undergo the highest level of interaction to justify an exemption.

Even where individuals are able to request an exemption, under the proposed process it can be refused. The refusal is not a reviewable decision, leaving no appeal rights for those unwilling to subject themselves to a process they believe will be harmful. Again, an exemption process imposes the greatest burden on those individuals least likely to be able to cope with it, and in itself has potential to do harm and cause undue stress. It is evident from the Tune Review and the Joint Standing Committee reports into the NDIS that many participants already experience very high levels of stress, uncertainty and inconsistent decision making when interacting with the NDIA. There are a variety of potential alternative discretionary processes for Independent Assessments that should be explored first as part of a codesign process with people with disability and disability representative organisations instead of resorting to a mandatory/exemption model.

## Inconsistency and barriers

As noted above, the signatories have significant concerns regarding the assertions of improved access for cohorts with the highest levels of disadvantage, isolation and unmet support need.

At every step of the proposed process, these cohorts are excluded by the proposed process, rather than assisted:

- At initial application stage they are less likely to have the relevant evidence to progress to the stage of referral to an Independent Assessment
- At Independent Assessment stage, they are less likely to have capacity to cope and/or comply with this process, and more likely to be required to apply for an exemption
- They are less likely to be able to engage with the process to apply for an exemption, and as a result their access may be entirely prevented
- They are less likely to be able to engage with complaints processes to challenge adverse decisions made at any stage, especially without the formal right to appeal these decisions

Further, there are specific barriers to these cohorts within the proposed process itself:

- If a participant does not respond to a request for an Independent Assessment, or cancels it
- If a participant refuses to attend an Independent Assessment and a decision is made that none of the exemptions apply

- Reliance on others to speak for the participant where support relationships may not be strong enough to provide reliable or consistent evidence
- Increased likelihood that the Independent Assessor will not have appropriate experience or qualifications to assess an individual's highly complex disability or circumstances

### Where the Participant does not respond to request

We refer to section 3.5.12 of the *Consultation paper: Access and Eligibility Policy with independent assessments* which states:

*“Assessor organisations will be required to contact the applicant within two days of accepting the referral and schedule the assessment within 10 days. The applicant can reschedule their appointment and pause their NDIS access request if a later assessment date suits them better. However, the independent assessment needs to be done within 90 days, in line with the timeframes included in the Participant Service Guarantee. ”*

This statement assumes the capability of the applicant to ensure this process is complied with and completed within the 90 day timeframe. If the applicant does not, the only information available is 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” (at 3.7).

The signatories have seen the current NDIS Access process fail many of our clients. The addition of a third party provider will simply exacerbate the existing barriers, which fall disproportionately on those who do not have informal supports, are not capable of independently engaging with the process, and who experience a range of barriers to exclusion to the community at large. Examples include:

- An Access Request Form was submitted on behalf of an individual by a representative, acting under the instruction of the applicant's financial administrator. The representative provided their contact details, but did not indicate that they would be the applicant's nominee as this was beyond the scope of their role. The NDIA requested further information, but sent this request to the applicant, and not the representative. The nature of the applicant's disability meant that they were unable to understand the nature of the request, and did not action it. The application lapsed.
- An Access Request Form was submitted on behalf of an individual, and the only contact details available were those of the aged care in which they resided. The NDIA sought to contact the individual, and an unnamed person answered the phone.

In the discussion that followed, they apparently stated that “(applicant) doesn’t have any interest in that” and the NDIA marked the application as withdrawn.

- An individual called to request access to the NDIA. An Access Request Form was sent to them by mail. The individual could not read, so they did not know what to do with them. The application lapsed.
- An individual was contacted by the NDIA to request additional information to demonstrate permanency. However, the individual was unable to coordinate appointments with their practitioners or communicate what information was required within the given timeframe, and the application was withdrawn.

There could be many reasons why individual people with disability might not comply with the proposed process:

- They do not understand what is being asked of them
- They do not have the capacity to follow up on the request, or to explain why they cannot
- They are in prison or otherwise detained
- They are unwell or are in hospital (whether by choice or under an order)
- They are homeless

NDIA have also advised that an Independent Assessment supplier would be required to return a referral back to the NDIA if they have been unable to complete an Assessment Report within 20 business days of receiving the referral. It is unclear what process follows to ensure a person is supported to complete an Independent Assessment or review them for an exemption.

A process that relies on the applicant to the NDIS having the capacity to ensure the process is completed, and within relevant timeframes, without support, will not lead to better access decisions. It will lead to more entrenched exclusion of certain cohorts and risks severe adverse outcomes for some individuals, such as permanently decreased functional capacity or even death, due to lack of support.

## Refusal to attend

### Access requests

Many of the signatories’ clients report having had negative experiences or trauma and require trauma-informed processes, including interacting with people with whom a trusted working relationship is already in place. The nature of their disability makes it extremely challenging for them to explain their situation and their difficulties, and they require a significant period of time to trust new people and speak freely.

A significant proportion of these clients also have no informal supports with the capacity to assist them to explain this to others, and/or reduced or no capacity to understand the necessity of responding to a request to attend an Independent Assessment or to request an exemption. Whilst some may have a health professional who could explain this if asked, they are unlikely to be aware that a request was even made.

Many clients will delay or avoid acting on these requirements out of fear of harm or lack of understanding, and have access refused as a result. This will lead to greater inconsistency in decision making for such Access requests.

#### Current participants

Many people with disability report feeling deeply traumatised by their dealings with the NDIA. The signatories have supported a significant number of people with disability who refuse any further involvement with the NDIA, even where this has been to their detriment, due to unwillingness to expose themselves to further risk of harm. Many people with disability have had their funded supports significantly reduced, resulting in significant adverse outcomes for them, and have had to fight for months- or years, if they have to go to external appeal- to have necessary supports restored.

People with disability report that the NDIA have not always communicated in the way they have stated that they will. Despite written assurances from the CEO Martin Hoffman that no participant would have their access threatened without a conversation, a number of the signatories continue to receive contact from NDIS Participants who report that they had received a letter dated two weeks prior stating that they would be exited from the scheme if they did not provide additional evidence of their eligibility, and that their supports would be immediately revoked if the evidence was not provided within 28 days. The specific evidence required was not stipulated, and many people with disability received these letters while under COVID-19 lockdown or restrictions. People with disability supported by the signatory organisations reported calling the National Contact Centre, who stated that a member of the National Access Team would call the participant back; a significant majority of the people with disability concerned reported that they did not receive callbacks.

These types of experiences have led many people with disability to feel extremely distressed and anxious about requests made by the NDIA. For many people with disability, any request for them to undertake an Independent Assessment is likely to cause a harmful degree of anxiety and distress. It is the signatories' view that the NDIS has a duty of care to avoid further trauma or harm to these individuals.

A discretionary power to seek Independent Assessments, where they will benefit the prospective Participant and support consistent decision making, would be sufficient to improve outcomes. Based on the observed experiences of the signatories in supporting

clients, a mandatory process will cause significant harm to many clients and will not significantly improve decision making consistency.

## Reliance on others

We refer to section 3.5.12 of the *Consultation paper: Access and Eligibility Policy with independent assessments* which states:

*“Several of the assessment tools can be completed by either the applicant and/or a person who knows them well. One assessment tool (the Vineland) is not self-reported and requires another person to attend to talk with the assessor and provide information. Choosing who else attends the independent assessment is up to the applicant. Where no support person is nominated, we will initiate a process to help identify an appropriate person or persons if requested by the applicant.”*

We understand that the current Independent Assessment trial, which is opt-in, does not allow individuals without a support person to elect to be part of the trial.

This presents problems in the following ways:

- Section 4(8) of the *National Disability Insurance Scheme Act 2013* (Cth) states that *“People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.”* Requiring others to speak for the participant will present a breach of this principle in many cases.
- Section 4(10) of the *National Disability Insurance Scheme Act 2013* (Cth) states that *“People with disability should have their privacy and dignity respected.”* A requirement that others attend this assessment and speak on behalf of the participant will present a breach of this principle in many cases.
- The responses to the Independent Assessment pilot were overwhelmingly from carers rather than from participants, meaning the most critical voices in any consultation were not captured

In working with clients accessing or attempting to access the NDIS to date, the signatories have already observed the risks associated with reliance on third parties to speak on behalf of participants, including:

- Carers or family members with vested or conflicting interests giving inaccurate information to the NDIS planning meeting. For example, in one instance, the step-sibling of the participant who had no legal authority to speak on their behalf, was

present and the participant was absent. The step-sibling stated that the participant wished to move from the family home, which the planner accepted as their goal. When the participant later engaged with advocacy, they reported they had no such goal, but rather the step-sibling had wanted to remove the participant from the home in order to sell the property. This example represented multiple breaches of the client's rights under the CRPD.

- Family members who do not support increasing the independence of the participant understating their support need, so as to reduce their access to external supports.
- Family members who do not have capacity to provide the necessary information, for example due to advanced age or disability, giving inaccurate representations as to the participant and their life.
- Service providers with vested or conflicting interests misrepresenting capacity so as to avoid the involvement of other independent parties, such as support co-ordination who might easily identify significant issues with the arrangements in place, or to financially exploit the client's NDIS Plan.

## Lack of independent professional support during the Access process

The signatories note there is already a significant gap in the sector for accessing professional outreach assistance to support through the NDIS access process. Local Area Coordinators (LACs) are not equipped or resourced to provide individualised support, and the support currently provided is generally limited to simply giving information and paperwork and directing prospective participants to their informal supports and treating professionals.

The signatories have seen the strain on advocacy organisations, community health services, schools, service providers and informal supports providing unfunded or out-of-scope support to assist through the complex NDIS Access process. This is not sustainable and results in prospective participants disengaging with NDIS access and potentially causing further risk to their wellbeing and impacting their human rights. We note there have been only limited programs funded to provide NDIS Access support in specific regions to date which, while reasonably effective for those few who were able to utilise them, have provided no meaningful relief for the overwhelming majority of clients.

In its current format, the proposed reforms are expected to significantly increase demand for support from advocacy, informal supports and under- or unresourced mainstream supports, both through the requirements of supporting clients to prepare for and participate in the Independent Assessments process itself, and to navigate and cope with the anticipated surge of appeals cases and complaints discussed elsewhere across this document.



We urge the federal government and the NDIS to implement reforms in line with the Tune Review's recommendations in their full context rather than in the currently proposed form, and ensure there are appropriate services available to support prospective participants to have equitable access to support during the NDIS access process regardless of their background.

## Similarities to the Disability Support Pension

Signatory organisations have much experience with the impact of processes like the ones proposed by the NDIA, through advocacy around Centrelink's Disability Support Pension (DSP). The changes proposed by NDIA are reminiscent of the changes made to the DSP eligibility process in 2011 and 2015. Significantly, since the introduction of similar changes to the DSP process there has been a decrease in the number of people granted access to the DSP, many of whom have been long term unable to work. We have seen many people who are unable to work falling through the gaps as they try to navigate a system that is seemingly designed to keep them out. It leads to high rates of mental health issues, distress and has left people in dire poverty.

The two step process proposed by the NDIA is very similar to the process used to assess DSP claims, in that before a person's functional capacity is assessed they must prove that they have a permanent (or likely to be permanent) impairment. Similarly, the removal of the eligibility lists and the focus on medical evidence brings the NDIS process further in line with that of the DSP.

In July 2015 Centrelink transitioned from using a Treating Doctor's Report to provide evidence of a person's impairment, to requiring people to provide medical reports and records. The Treating Doctor's report was a guided report that a treating doctor could complete which collected information needed to address all the eligibility requirements for the DSP. Time spent completing this report was claimable by a doctor under Medicare.

Since this change in policy there has been an exponential growth in people needing support to provide medical evidence to claim the DSP, and an increase in the rejection rate for claims. For most of the people we support, basic medical records which they have access to do not contain the required information to demonstrate eligibility. Even when providing a treating health professional with information on what evidence they need to include in a report, the time taken to write a comprehensive report, and ensuring a report has all the required information means people are often still rejected because they do not have sufficient evidence.

The removal of the eligibility lists for the NDIA means that more people will be required to produce evidence similar to that required for the DSP in order to pass the first eligibility hoop, before they even get to the stage of an Independent Assessment. Evidence from

existing literature on similar policy changes shows that they have been linked to adverse health outcomes.<sup>12</sup> People with cognitive, intellectual, or psychosocial impairments may find it more difficult to manage the increased administrative burden introduced by such policies, including gathering complex medical information.<sup>13</sup> We strongly believe that the removal of the eligibility lists will create a situation similar to that experienced by people applying for the DSP.

Many people who apply for the DSP also undergo a Job Capacity Assessment (JCA). The purpose of a JCA includes identifying a person's level of functional impairment resulting from any permanent medical conditions. As part of this process assessors have access to a person's medical information and reports and can liaise with treating doctors and other health professionals. Advocates have had assessors admit to having limited time to read through information, conduct their assessment, and write their report. In our experience this results in an assessment which may contain errors of fact, is not thorough, and does not have the nuance required to understand the impact of a person's disability. Additionally, it is the experience advocates that Job Capacity Assessors will frequently make findings inconsistent with the medical evidence provided. In most cases the Assessor does not contact the treating health professional to seek clarification and does not ask for advice from the DHS's Health Professional Advisory Unit. We are concerned that the NDIA is introducing a process that will result in similar adverse impacts.

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<sup>12</sup> Collie, A., Sheenan, L., & Lane, T. (2021). Changes in Access to Australian Disability Support Benefits During a Period of Social Welfare Reform. *Journal of Social Policy*, 1-23. doi:10.1017/S0047279420000732

<sup>13</sup> Ibid.

## Signatory Organisations



