Response to Consultation on Proposed NDIS Reforms: Access and Independent Assessments

Executive Summary and Recommendations

We call on the National Disability Insurance Agency to:

- Cease progress towards rollout of mandatory Independent Assessments until the Tune Review recommendations are relied upon in context, including extensive consultation with participants and the community
- 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
- Review the many significant risks to the safety of participants under the proposed exemption arrangements, and ensure that those with least capacity to engage are not further disadvantaged
- Make clear the mechanism by which an assessment by an allied health professional generates a funding figure, including the human intervention to this process to prevent dangerous outcomes
- Make clear the mechanism by which environmental factors will be understood, recorded, and affect funding, and how a change in these factors will impact funding
- Assure participants and prospective participants that their individual circumstances will be fully considered in the independent assessment process to ensure relevant information is not omitted.

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 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 pro-actively 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.

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.

Eligibility and Independent Assessments

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 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 <u>will require extensive consultation with participants</u>, the disability sector, service providers and the NDIA workforce. Fundamentally, however, the success of the program will largely be dependent on:*
>
> *a. <u>the willingness of prospective participants and participants</u> 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 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 <u>designed and implemented jointly</u> 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.

Lastly, we note that the pilot program relied upon to support the Independent Assessments was limited. Feedback was very low and provided mostly by carers and not people with disability. Consultation MUST occur with the individuals who would be subject to this. Another key limitation was that the assessments have not been used to inform access or funding in the pilot, therefore there was no ability to review whether people were happy with how it is being proposed to be used.

Discretionary assessments

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, <u>functional capacity assessments would not always be required, for instance if a participant's functional capacity is stable</u>.

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, <u>but that this</u>

> *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 inequitably of access decisions.

These factors may be relevant to exercise a discretionary power where, for example, a prospective participant does not have evidence 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 disability. 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.

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 proposed process does not provide participants with a right to challenge the results of an assessment, ability to undertake a second assessment or seek some form of arbitration.

There have not been 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.

The process will not include the necessary protections recommended by the Tune Review and will not:

- Provide participants with a copy of the assessment outcome, only a summary[1]
- Provide a right to challenge the results of an assessment[2]
- Regulate the conduct of the assessors beyond the relevant professional and regulatory frameworks which already exist[3]

It is 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.

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

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[1] 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."

[2] 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. "

[3] 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."

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,[4] the absence of a review mechanism forces the individual to seek an internal review (which is presumed to fail, as the internal reviewer is also required to rely on the assessment) and then apply to the Administrative Appeals Tribunal for external review.

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.

The NDIA has noted it is preparing a quality assurance framework to deliver independent assessments. We expect guarantees that these workers 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 the IA's outcomes. We expect that unprofessional IAs 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.

Underlying principles

The *Consultation paper: Access and Eligibility Policy with independent assessments* states that the issues to be addressed by this process are:

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

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[4] 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)

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

Equity of Access

Sources of inequity

Independent Assessments have the potential to remove inequitable access to the NDIS for 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 are 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.

Age and residence

Whilst obtaining evidence of age and/or residence can be barriers for a range of demographics (those currency or previously homeless, individuals leaving domestic violence situations, indigenous people in remote communities and etc), these matters will not change under the proposed process.

Disability

Under the proposed process, individuals need only 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 to afford the 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

- Individuals who are, or have been, escaping from domestic violence
- Individuals who are, or have been in prison or other custodial detention
- Individuals who experience other forms of intersectional disadvantage

Permanence

Whilst we acknowledge the benefit of access to a free functional assessment for individuals seeking access without being able to provide 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 the two populations:

- 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 need.
- 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. For such individuals the proposed process will not improve equity of access.
- 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. For such individuals, the proposed process will not improve equity of access.
- 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,

comorbid substance abuse issues, and minimal informal supports. For such individuals, the proposed process will not improve equity of access.

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.

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 process by which certain individuals can seek 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, under which those who are at risk from the process or for whom there are no informal supports to assist them can **request** an exemption, 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 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 in access and planning decisions

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

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 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 work 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.

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.

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.

Signatory Organisations

DANA
Disability Advocacy
Network Australia

ACTION
FOR PEOPLE WITH DISABILITY

ADACAS
ADVOCACY

Advocacy for
Disability
Access and
Inclusion Inc.

Advocacy
Tasmania

advocacy
WA

aed
LEGAL CENTRE
JUSTICE FOR PEOPLE WITH DISABILITY

AMIDA

Brain Injury
SA.
Embrace life after brain injury

CORAS
COLAC OTWAY REGION
ADVOCACY SERVICE INC

Disability
DA
NSW
Advocacy

DACSSA
DISABILITY ADVOCACY

DAS
Disability Advocacy Service Inc.
"Making Connections"

EDAC

GDA
Gippsland
Disability Advocacy

IAT inc.
Independent
Advocacy in
the Tropics Inc.

ideas.

PWdWA
people with
disabilities
western
australia

Leadership+
Plus

Queensland Advocacy Incorporated

riac
your rights, your voice

SPEAKOUT
ADVOCACY

SUFY
SPEAKING UP FOR YOU

Villamanta Disability Rights
Legal Service Inc.

VMIAC
by and for consumers