

People With Disabilities (WA) Inc.
WA's Individualised Services (WaiS)



Submission

Joint Standing Committee on the National Disability Insurance Scheme – Inquiry into Independent Assessments under the NDIS

People with Disabilities (WA) Inc. (PWdWA) and WA's Individualised Services (WaiS) would like to thank the Joint Standing Committee on the NDIS for the opportunity to provide comment on the NDIA's Independent Assessment Framework and proposed Access and Eligibility and Planning policies.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy. PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

WaiS is a niche, member-based, organisation. WaiS support people, families, and services providers to understand, design and develop supports and services that are individualised and self-directed. Through individual and service provider memberships, WaiS seek to provide strategic advice to government.

People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

PWdWA receives both state and federal funding to provide advocacy around issues experienced by the community concerning the National Disability Insurance Scheme (NDIS). In particular we are funded by the Department of Social Services to provide support with NDIS Appeals.

WA's Individualised Services (WAIIS)

WAIIS is a member-based community organisation working in partnership with people, families, service providers and government agencies to promote and

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advance individualised, self-directed supports and services for people living with disability, including psychosocial disability.

Since our inception in 2010, we have evolved to become thought leaders in this space, providing comprehensive, intentional support with integrity, passion and authenticity at our core. By leveraging our extensive local, state, and international network, we seek to lead, influence, innovate and inform to create meaningful and lasting change, supporting people to build capacity and live their lives on their own terms.

Unlike any other organisation, we partner and work with all sector stakeholders, as well as providing vital links, ensuring that disability services respond to the unique needs of people. We work to ensure that people can access and navigate the services and the sector to achieve their goals.

WAIIS is the only organisation that has a specific focus and purview of supporting and developing the capacity of people, families, service providers, Local Coordinators and government, specifically in the area of individualised, self-directed supports and services.

Introduction

Fundamental to the NDIS are its legislated Objects and the Principles that underpin it that are strongly embedded with Human Rights. The very first object is to “give effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities”. In doing so, the Scheme is to “support the independence and social and economic participation of people with disability” and “enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports”.

Consequently, people’s access to adequate, appropriate, responsive and individualised supports funded under the NDIS to support them to live a good life is an extremely important aspect of both PWdWA’s and WAIIS’s work at both a systemic and individual level. Our joint submission is compiled based on the

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experiences of people with disability, their families and carers as well as advocates and advisors who provide information and support to people. We have provided scenarios where appropriate to furnish our statements.

We highly welcome the intention of the NDIA's proposed processes, which is to create a way for people with disability to have access to a system which provides a total funded support budget, that can be utilised flexibly and responsively in line with the persons vision and goals. We also highly welcome exploring ways to make the scheme equitable and sustainable.

We are extremely concerned with the proposed changes from NDIA and the lack of meaningful co-design or consultation that is occurring. It is telling that the recent NDIA consultation papers failed to ask people central questions such as: Should Independent Assessments be mandatory? PWdWA continues to see rising numbers of people seeking significant advocacy support in relation to NDIS. We believe that the proposed changes will further exacerbate the entrenched disadvantage experienced by many of the people we support, expose them to an increased risk of harm, not achieve the NDIA's espoused intent, and will further increase the burden on the advocacy sector. The points raised in this submission are reflective of the hundreds of people we have assisted with information, support, and advocacy in relation to the NDIS over the past year.

Section 1: Recommendations

Recommendation 1:

Immediately cease the rollout of mandatory assessments as currently planned.

Recommendation 2:

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

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experts and co-designed with people with disability, their families and the organisations that support them.

Recommendation 3:

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.

Recommendation 4:

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

Section 2: Response to Terms of Reference

a. The development, modelling, reasons and justifications for the introduction of independent assessments

Design and Development

The General Principles of the NDIS Act are clear that people with a disability have the right to be “*equal partners in decisions that will affect their lives*”.¹ The Tune Review was also very explicit in its recommendations around the introduction of Independent Assessments (bold emphasis added):

*4.33. This change in approach will require **extensive consultation** with participants, the disability sector, service providers and the NDIA workforce.*

We disagree with the approach the NDIA has taken in the design and development of both the Independent Assessment Framework as well as the Access and Eligibility Policy and Planning Policy. Instead of adopting a co-design approach which would

¹ NDIS Act 2013 Part 2: 4(9)

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engage people with a disability to develop a policy to address issues of inequity seen within the scheme, the NDIA have come up with an approach and are asking for feedback on how to implement it. They are not asking people whether they believe the approach is suitable, or if it will address instances of inequity seen within the scheme. We also note that the tender for the Independent Assessor role had already been finalised with the organisations chosen for the panel being announced days after the consultation process ended. Based on this timeline any information gathered during the consultation process could not have been genuinely fed into the tendering process, making consultation about this aspect of the changes disingenuous. This approach is reflective of a system that seems to be going back to a 'we know what's best for you', medicalised professional approach, which is in direct conflict with the principles of the NDIS.

Additionally, there is very little details about how key parts of the new framework and policies will work. This includes how Independent Assessments will be translated to budgets and the amendments that will be introduced into the NDIS Act 2013 in order to give effect to the proposed changes. It is difficult to provide feedback on a process where aspects of it are not transparent. It reinforces the sentiment that the consultation process that took place was perfunctory, rather than genuine. These concerns were present in community consultations we undertook about the proposed changes from the NDIA:

[regarding the introduction of independent assessments]...Not until a LOT more trial and consultation has been done and there is transparency in WHY we have to be subjected to them

I wonder just how much actual LISTENING and COMPREHENSION of the concerns people with disability express is actually going on in the NDIA and the Minister's office. The whole thing is being presented as a fait accompli

Not enough consultation Not enough trials Not evidence based Basically this will turn into the participant having to do an IA, so they can stay in the system and the Assessor writing a report that the Agency will use to exit the participant anyway.

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Pilot Evaluation

The NDIA has stated that the proposed changes to access, planning and the introduction of Independent Assessments are based on recommendations by the Tune Review² and supported by the results of two NDIS pilots of the Independent Assessment Framework.

We have several concerns about the validity and usefulness of the pilot data in determining the appropriateness of the Independent Assessment Framework and associated access and planning policies:

- The initial pilot focused on participants with Autism Spectrum Disorder, Intellectual Disability and Psychosocial Disability. While this may represent 63% of participants it did not necessarily represent all people in the scheme requiring high or complex levels of support.
- Both pilots are an opt-in model where participants have choice and control as to whether they received an Independent Assessment meaning there is potential selection bias. For example, those who are more comfortable talking about their disability and able to articulate themselves may be more inclined to participate and therefore have a better experience of the assessment.
- The pilots do not allow individuals without a support person to elect to be part of the trial. The suitability of the Independent Assessments has therefore not been assessed for this cohort of individuals.
- The majority of pilot participants have already been granted access to the NDIS and the Independent Assessment did not have any bearing on their Access Request. It is noted that 8% of participants had functioning within a 'typical range' meaning they would not likely be considered eligible for the scheme based on the assessment.
- Participant satisfaction was measured in relation to the undertaking of the Independent Assessment and the person conducting it. Participants and their supports did not have the opportunity to provide feedback on the accuracy and comprehensiveness of the assessment report.

² <https://www.ndis.gov.au/news/ceo/stay-informed-ceo>

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- Participant Satisfaction surveys were mostly completed by carers rather than the person with a disability.
- The assessment had no bearing on a participant access request or plan budget. We are unsure how meaningful data on a participant experience and the accuracy of decisions made based on Independent Assessments can be gathered if there is no measurement of the impact the assessment will have on decision making processes.
- There was no comparison between the outcome of decisions made using the current frameworks/policies and decisions made using Independent Assessments and the proposed policies. There is no data which looks at the accuracy of any proposed model to translate this information through to decisions.

We do not believe the pilots provide sufficient evidence to make a fully considered decision about the efficacy of the Independent Assessment Framework and the proposed access and planning policies. Aside from the issues with how the pilots are being rolled out and evaluated, we also note that the second pilot is still underway, meaning that decisions have been made without a final evaluation of the larger pilot.

Addressing Equity Issues

The NDIA state³ that some of the challenges that the Independent Assessments are trying to address include:

- Long wait times to seek information about the impact of a person's disability from health professionals
- The cost of seeking information about the impact of a person's disability from health professionals
- There is no standard way to provide evidence on the impact of a person's disability resulting in variability of information provided and decisions made by NDIA
- Inconsistent and inequitable decisions including plan budgets

³ NDIA Independent Assessment Framework August 2020

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Additionally, the Independent Assessment Framework States:

For others, the ability to ask the right questions, to locate the appropriate centre, to navigate the health system, to know which services are available and/or how to access them, is an additional barrier. Social, cultural and language barriers, as well as the individual's functional ability, can magnify these concerns even further.

NDIA propose that the changes being made through the introduction of Independent Assessments will “level the playing field” so that financial, cultural, social, education and literacy factors do not contribute to delays or barriers to accessing the scheme or the amount of funding in a person's plan.

The NDIA also state that Independent Assessments will address the variability in information provided to the NDIA. They highlight several issues relating to the evidence they receive for decision making in the Independent Assessment Framework:

- Qualifications, skill level, experience and understanding of function capacity differ between assessors
- Different professionals use different tools, or may prefer a specific tool
- Assessments vary in the level of detail provided
- Not all assessments are standardised
- Some assessments are old and do not have current information
- Assessments are conducted differently and interpreted differently

We do not believe the above reasons provide enough of a rationale for the sweeping changes being proposed by NDIA. It is also highly probable for some of the above issues to continue to exist under the proposed system and not be alleviated as intended. For example, if the person from NDIA picks an inappropriate assessment tool or if the person undergoing the assessment chooses a different assessment method (e.g. home vs phone vs work).

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We believe many of these issues could be addressed by:

- Developing clear guidelines around the type of functional evidence needed to inform decision making
- Creating a capability framework for functional assessments
- Providing training for people who wish to conduct functional assessments for the purposes of the NDIS
- Developing better training and guidelines for decision makers to ensure fairer, consistent decisions

Access Inequity

With the introduction of Independent Assessments, the NDIS Access process would essentially become a two-step process. As we understand it the new process will require a person to provide evidence that:

- They meet the age requirements
- They meet the residence requirements
- They have a disability attributable to one or more functional impairments
- Their impairment is, or is likely to be, permanent

Only once a person meets these criteria will the final criteria, the impact of an impairment on their functional capacity, be assessed. There are several presumptions 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 the impact of their impairment already available in gathering information for the four criteria
3. Information about functional capacity will not be needed to help determine permanency

These presumptions are difficult to substantiate, and we consider that the proposed changes do not adequately acknowledge or address them. Additionally, it is not clear in which part of this two-stage process that evidence a person meets the disability requirements under the NDIS Act 2013 Section 24 (1) d-e will need to be provided:

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(d) the impairment or impairments affect the person's capacity for social and economic participation; and

(e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime

Disability attributable to an impairment and permanence

As stated above the proposed changes presume evidence of functional capacity has not been the only sticking point in the Access process for people. Gaining a diagnosis, and proving permanence are a considerable barrier for many of the people supported by PWdWA. This is also acknowledged by the Tune Review with respect to 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

The introduction of Independent Assessments will not improve access for many people who are already experiencing barriers to making an Access Request. More information about those barriers is provided below. 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
- 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
- People who are disengaged with formal services

People without a regular treating health professional

There are many people with a disability in the community who do not have a regular treating health professional. In some cases, this may be because they have a longstanding disability that is being managed by a GP, or no longer requires ongoing specialist intervention. In other cases, it may be because they do not have ongoing

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access to a single regular treating health professional, such as people who are homeless and rely on mobile medical services. PWdWA have also supported many individuals who are suspected to have a longstanding disability that have not been diagnosed. This includes adults with intellectual disabilities, autism spectrum disorder and acquired brain injuries. In other cases, people's disabilities may be rare or the cause of their disability unknown despite rigorous investigation. In these instances, people have been denied access to the NDIS on the basis that without a diagnosis they cannot determine if the disability is permanent or will require lifelong supports.

In these circumstances it is hard to meet the evidentiary requirements set out by the NDIA stating the treating health professional who provides evidence of the disability should have treated the person for a significant period of time (e.g., at least 6 months).⁴

PWdWA have also supported many individuals whose medical records are spread out over multiple locations, and with multiple health professionals. 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. Often, because reports are older, or not specifically produced to satisfy the requirements of the NDIA for establishing a person meets Section 24(1)a-b, further reports are then required to be sought. This will lead to further barriers outlined below such as waitlists and report costs.

Feedback from our consultation process further highlighted the difficulty caused by these issues:

I have a life long disability so I hadn't seen a specialist for over 30 years, the Specialist didn't know me and had no benchmark to base his comments on. The Specialist didn't know what information the NDIS required...

⁴ <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/providing-evidence-your-disability>

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My daughter's Diagnosis was 25 years ago, so to access all records again from DSC, and then go through all that again and again is extremely frustrating.

It has taken 25 years to get my diagnosis of Ehlers Danlos Syndrome and Dysautonomia. These conditions have only recently become more widely known...I've had trouble with my specialists using different definitions and terminology.

Needed to get a formal diagnosis of autism. As an adult in my 40s, this was also expensive.

People requiring diagnosis/evidence where there are lengthy waitlists

For someone with a newly acquired disability, or someone who has not been actively receiving treatment from the health system it can be a long wait to see an appropriate treating health professional who is able to provide a report that details their disability and permanency. Additionally, 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.

If further evidence is required from a health professional to demonstrate the NDIS access criteria then often people are placed back on waitlists for an appointment before the health professional will review the report, if they even agree to providing further evidence.

The following points were raised by people who participated in our community consultation:

It took months of asking medical specialists. They advised the hospital didn't know how to handle such requests.

It is too expensive and wait times are impossible and travel to get assessments is difficult, as well as finding drs and professionals who listen to get referrals

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Cost of obtaining evidence

One of the rationales NDIA gives for introducing Independent Assessments is to address the inequity caused by the cost of gathering evidence for an access request. We fundamentally disagree with mandatory assessments being the best way to address this inequity in line with the guiding principles of the Act, or indeed the UNCRPD. A discretionary decision to fund an assessment through an appropriately qualified provider of the person's choice would address any financial barriers to providing evidence about functional capacity whilst also maintaining choice and control. Additionally, forcing a person to undergo an assessment would be a waste of financial resources where a person already has sufficient evidence to show their functional capacity.

PWdWA have supported many people who have had to pay to access information which provides evidence of their diagnosis and treatment. This includes obtaining reports from specialists, having reports amended to provided 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. This was highlighted in our consultation process:

I had to pay upfront for the Specialist appointment before I had become a NDIS participant. It was very very expensive to get a brief report.

No psychiatrists in the public health system are able to diagnose adults with neurological conditions like ADHD, Autism...

Remove the cost barrier or imposition to go to GP or Specialist whether that's a Medicare item or however that stuff works. People shouldn't have to bear a cost to get reports or get evidence

Cover the cost of appointments required to get evidence and the time required for medical professionals to write reports/complete paperwork.

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Ideally, NDIA and the federal government should collaborate with state governments to make free diagnostic assessments available for everyone.

Scenario

A man with an undiagnosed Intellectual Disability sought advocacy support with an Access Request. It was clear from the man's circumstances that he needed daily support, but he had not previously accessed disability services. He had a report which he paid for as part of his Disability Support Pension Application which identified he was 'extremely low functioning' under all the WAIS-IV scales. However, the report could not give a formal diagnosis of an Intellectual Disability because he had no third party available to verify the information he provided. He was told verbally by NDIA that the report required the practitioner formally state he had an intellectual disability, and he did not meet the access requirements. The advocate tried to refer the man for state and health funded assessments and was declined. The advocate then approached the organisation who had completed the original assessment and requested that they amend the report, so it satisfied NDIA's requirements. They declined and advised they would need to try further assessments to see if the diagnosis could be confirmed. While the advocate was able to negotiate a reduction in the cost of the assessment the man still could not afford the assessment and decided that he was too tired to fight NDIA further. In this situation the man would not have met Section 24(1)a-b and would not be referred for an Independent Assessment under the proposed policy.

Evidence of treatment and permanence

The Access and Eligibility Consultation Paper states that:

Health professionals will be required to provide information about what interventions or supports have been considered and, where applicable, all reasonable supports and treatments have been identified and/or administered.

While this is nothing new in terms of the level of evidence required to access the NDIS it is a significant barrier for many people. In fact, proving that a person's

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disability is permanent has been as much of an issue for many people as demonstrating their impairment has a substantial impact on their functional capacity. This is particularly true for people who have a newly acquired disability or where further treatment is recommended, even if this treatment is not expected to improve their function. In some cases, people have been declined access because they have chosen not to undergo treatment which is high risk, may not alleviate the impairment, has a lengthy waitlist in the public system, or would be significantly expensive to access through private systems without private health insurance.

Scenario

Lana has a chronic pain condition caused by neuropathic pain syndrome. She was unable to drive herself, and had difficulty managing daily tasks due to the impact of her pain. She sought treatment for her impairment through a private pain specialist after finding little relief through the public pain management system other than drugs. Her private pain specialist recommended an implanted neuromodulation treatment. This involves the surgical implantation of a neural stimulation device. There is no guarantee that undergoing the treatment would provide enough relief to substantially improve Lana's function. It is very difficult to access this intervention through the public health system. Without private health insurance the cost of the procedure is very high. Lana could not afford to take out private health insurance and even if she did would be required to undergo a waiting period to be covered. Because her private pain specialist recommended the treatment NDIA determined that Lana's impairment could not be considered permanent. They did not consider whether it was reasonable to require Lana to undergo a costly private procedure.

In PWdWA's experience medical professionals can also be reluctant to say that a person's impairment is permanent, or their function will not improve. Alternatively, they may recommend further treatment but fail to comment on the impact of this treatment on the person's function. For many people we support, further treatment is about managing the impact of the impairment or preventing further deterioration. However, the NDIA take the approach under section 8.2 of the Operation Guidelines that an impairment is not permanent if:

- There are known, available and appropriate evidence-based treatments that would be likely to remedy the impairment

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- The impairment does not require further medical treatment or review for its likely permanency to be demonstrated

The Operational Guidelines allow that an impairment may continue to be treated and reviewed after permanency is demonstrated. Our experience has been however that often NDIA do not take a nuanced approach to this criterion. In many cases where a person's treating health professional has suggested further treatment, and there is no evidence as to the impact of this treatment, the NDIA will make the decision that the impairment cannot be considered permanent. A more proactive approach would be to request further evidence from the treating health professional as to whether treatment will remedy the impairment or improve function. If the NDIA was to request and pay for this evidence, it would also alleviate some of the cost barriers people face seeking this kind of additional evidence.

Scenario

Mary had several co-occurring disabilities including Osteoarthritis and a psychosocial disability. Mary lived alone, had limited supports and the pain from her Osteoarthritis, along with the impact of her mental health, meant she was unable to manage daily tasks by herself and was becoming increasingly isolated which was further exacerbating her psychosocial disability. In their decision not to grant Mary access to the NDIS, the NDIA specifically focused on the possibility of further treatment being available to Mary. Mary only had access to older specialist reports and had relied on her GP for the ongoing management of her disabilities. She had continued to access psychiatric support through a mental health care plan, but reports providing the exact information required by the NDIA were not readily available. It was her GP's opinion, based on their clinical judgement and knowledge of Mary's treatment history, that Mary's conditions were permanent and that the treatment options available to her would not improve her function. Instead of working with Mary to clarify what information they would need to demonstrate permanency, and requesting evidence of this information from Mary's GP, the NDIA declined access and upheld the decision on Internal Review. This was two opportunities that the NDIA had to exercise their discretionary powers to request additional evidence where they failed to do so. When the appeal reached the AAT, Mary sought further evidence from a psychiatrist. At this stage she had no further sessions left under the Mental Health

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Care Plan and was paying for her own supports and it left her without the financial means to pay her utilities. It was only after she was able to provide this report, at her own expense, that she was found eligible for the NDIS. We note that in these circumstances an Independent Assessment would not have made it easier to access the NDIS for Mary as she would not have passed the initial access requirements to be referred for one.

Scenario

Andy was a 62-year-old man with a number of health conditions and disabilities which meant he needed equipment/aids and supports with tasks to manage the daily activities of life and access the community. Andy had a condition which caused him to be a falls risk, for which there was no definitive diagnosis. NDIA did not view the condition as permanent and would not accept any assessment of function which considered the impact of this impairment, despite it being a significant risk to Andy's safety. He also had Osteoarthritis and a degenerative back condition. In their decision to deny Andy access to the NDIA they considered that he already had the equipment and aids he needed to mobilise and was able to access support through the My Aged Care System and therefore would not need support from NDIA for his lifetime. That Andy was borrowing the equipment/aids, and that My Aged Care was only accepting Andy before the age of 65 only because NDIA had rejected him and there was a significant risk to his safety, was not considered. From this case we can see that Andy's issue with access did not only stem from evidence about substantially reduced functional capacity. The issues he faced would likely not be addressed by the introduction of mandatory Independent Assessments.

Planning Inequity

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 funding for all participants. We agree that there are longstanding issues with the quality of peoples plans and funding decisions that must be addressed. However, PWdWA and WAIIS 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

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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.

Current Issues with Planning

The NDIA state that some of the planning challenges that Independent Assessment will address include:

- Lack of transparency around how NDIA make decisions
- Not being recognised as experts in their disability
- NDIA staff not understanding the nature of a person's disability or the challenges they encounter
- Inconsistent decision making about supports
- High volumes of reviews

We have reservations about the ability of the proposed reforms to alleviate these challenges.

The NDIA identify confusion around support budget categories and plan implementation as one of the key issues the new planning process will address. PWdWA and WAIIS fully endorse the ability for people to have flexibility with their budget. This would be the ultimate endorsement of people having choice and control. However, flexibility is great if budgets are actually fundamentally flexible in implementation. If the NDIA decides to dictate that certain types of supports need to be fixed leaving very little able to be flexible, this would then negate this promoted intent for budget flexibility.

With a move to more flexible budgets there must also be greater support for people to understand and implement their plans. The experience of both PWdWA and WAIIS has been that people have difficulty understanding how they can use their NDIS funding, even when it has been allocated to specific types of supports.

A clear example of this can be seen where people are given amount of funding to use flexibly for therapy supports. Many people need to spread this funding out amongst multiple therapists such as a Speech Pathologist, OT and Physio. The experience of PWdWA and WAIIS has been that people have had difficulty breaking

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down how a bulk dollar amount translates into the support they need. This includes things like:

- How they might split the budget between multiple supports
- How much a service provide can charge for a specific support
- How many hours of support they can access based on a dollar amount
- How to budget for the time providers need to write reports and communicate with participants
- If the budgeted amount does not provide enough money for the required therapy – understanding how NDIA came to a decision about how much funding they received

We are concerned that the proposed process will exacerbate these difficulties without significant ongoing investment to build the capacity of individuals to understand and implement their budget. The NDIA has proposed that there will be an in-depth discussion with the planner about how a person could use their budget to meet their goals. Based on our experiences, however, we believe that further support will be required outside of this initial planning meeting. While the proposed 'check-in' could be a proactive way for the NDIA to support people with the implementation of their plan, the person doing the check-in must have adequate knowledge of the person and their plan and cannot be the only ongoing support available.

Additional issues relating to determining if a budget is adequate and appealing a budget are explored in more detail below.

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 above) 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.

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b. The impact of similar policies in other jurisdictions and in the provision of other government services

Disability Support Pension

PWdWA has extensive experience with the impact of processes like the ones proposed by the NDIA, through advocacy around Centrelink's Disability Support Pension (DSP) eligibility process. 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 poverty. It continues to be one of the most frequent issues that people seek advocacy support for, behind issues with the NDIS. As such we are highly concerned that changes being proposed by the NDIA will follow a similar path. The two steps 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.

When I think of and hear the term independent assessments, I fear that they could become like a Centrelink process which can be incredibly stressful, dehumanising and confronting. The last thing I want to see happen is to go down the path⁵

⁵ PWdWA Feb 2021 Community Consultation Participant

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Evidence of Permanence

One of the requirements to demonstrate permanency of an impairment under the DSP is that the condition is fully diagnosed and treated. Similar standards of medical evidence are required to those under the NDIA Operational Guidelines⁶ including:

- Diagnosis must be from an appropriately qualified medical practitioner
- In determining if a condition is fully treated the following must be considered:
 - The nature and effectiveness of past treatments
 - The expected outcome of current treatments
 - Plans for further treatment
 - Whether past, current or future treatment can be considered reasonable
- No significant functional improvement is expected even with reasonable treatment
- A person has a significant functional impairment as defined under the DSP Tables of Impairment – 20 points in one table to be manifestly eligible

In July 2015 Centrelink transitioned from using a Treating Doctors Report to provide evidence of a person's impairment, to requiring people to provide medical reports and records. The Treating Doctors 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 PWdWA support, basic medical records which they have access to do not contain the required information to demonstrate eligibility. This is consistent with the experience of other support services.⁷ Even when providing a treating health professional with information on

⁶ NDIA Operation Guidelines 8.2. Retrieved from <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-disability-requirements#8.2>

⁷ National Social Security Rights Service. (January 2018). Disability Support Pension (DSP) Project: A snapshot of DSP client experiences of claims and assessments since the 2015 changes. p. 5 Retrieved from: https://ejaustralia.org.au/wp/wp-content/uploads/2018/02/NSSRN-DSP-Report-2017-BRQ-case-snapshot-2018_01_31.pdf

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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.

People have had their claims rejected in regard to permanency on the grounds of:

- Evidence being too old
- Treating Health Professional relationship being too short (disregarding historical evidence, no consistent treating health professional)
- Inconsistent treatment recommendations between treating health professionals
- Person is undergoing treatment – treating professional will not definitively say function will not improve
- A person has a medical condition unrelated to their application and has not provided evidence of diagnosis and treatment
- Decision maker misinterpreting or failing to understand evidence provided
- Possible treatments have not been exhausted

The experience of PWdWA advocates has been that decision makers rarely seek clarifying evidence, and many people are determined to be ineligible based on this criterion. Many of the people PWdWA support feel as though Centrelink are looking for any small error, inconsistency, or ambiguity in their application so they can deny a claim even when it is clear a person should meet the eligibility criteria. Additionally, the process of collecting evidence is burdensome and leads to adverse mental health impacts for many of the people supported by PWdWA.

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.⁸ People with cognitive, intellectual, or psychological conditions may find it more difficult to manage the increased administrative burden introduced by such policies, including gathering

⁸ 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

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complex medical information.⁹ We strongly believe that the removal of the eligibility lists will create a situation similar to that experienced by people applying for the DSP.

Job Capacity Assessment

Many people who apply for the DSP are required to 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. PWdWA 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 of PWdWA and other organisations¹⁰ that Job Capacity Assessors will 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.

Automated Decision Making – Robodebt

PWdWA and WAIIS would also like to highlight the problematic nature of automated decision making. While the NDIA acknowledges that decision making cannot be automated some of the points raised in the Independent Assessment Framework infer that some level of automation may occur. The Independent Assessment Framework talks about 'quantifying' the magnitude of an individual's functional capacity. No information has been provided by the NDIA on how this 'measure' is translated to a plan budget. We can only presume that an algorithm/logic has been developed to determine how the results of an Independent Assessment translate into a particular budget amount. Without clear, transparent information on how the

⁹ Ibid.

¹⁰ National Social Security Rights Service. (January 2018) *DSP Project*. p. 5. Retrieved from https://ejaustralia.org.au/wp/wp-content/uploads/2018/02/NSSRN-DSP-Report-2017-BRQ-case-snapshot-2018_01_31.pdf

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Independent Assessment is being translated to a plan budget there is no assurance that this process is not based, at least in part, on automated decision making.

Essentially both the information a decision is based on and the process for making that decision are unable to be scrutinised. The lack of effective remedy in these circumstances makes it all the more concerning.

c. The human and financial resources needed to effectively implement independent assessments

The NDIA have estimated the cost of assessments associated with accessing the NDIA to be \$130-170 million per annum. It is unclear how the NDIA reached this figure and what type of assessments it refers to e.g. functional capacity assessment or diagnostic/medical assessments.

The NDIA have offered no financial modelling to compare the estimated cost of implementing Independent Assessments vs paying for a persons' own treating health professional to provide information. There is nothing available in the public domain to clearly demonstrate this is the best model financially to produce the outcomes they are setting out to achieve.

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
- to meet KPIs and manage costs the quality of reports produced leads to poor decisions and results in continued or increased numbers of reviews being requested

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d. The independence, qualifications, training, expertise and quality assurance of assessors

Independence

NDIS have repeatedly stated that Independent Assessments will act as a quality control mechanism in providing evidence about functional capacity. NDIA propose Independent Assessments will also address the issues around consistency, and the “right” information being provided in reports to the NDIS, to ensure they have enough evidence to make a sound decision. They have raised concerns about ‘sympathy bias’ of professionals and the potential to overstate the needs of the person with a disability in reports. In essence the NDIA are suggesting that treating health professionals cannot maintain professional boundaries, use unbiased clinical judgement, or conduct their assessments in an ethical manner. To our knowledge there has been no widespread report of professional misconduct to support these suppositions.

This is reflective of a cultural attitude that devalues both the knowledge and experience of a person’s professional supports AND also the people and families themselves, knowing their own capacities and support needs. We have seen on many occasions where the NDIA has requested further evidence as part of AAT reviews only for the person’s own treating professionals’ evidence to be found suitable. We have supported many people through Internal Reviews where planners have dismissed the opinion of a professional supporter only for their assessment of function and needs to be upheld later. This sentiment was echoed by people who participated in our consultation:

I have three rare conditions that interact to cause more disability combined than any one would alone. It has taken 25 years to find specialists who understand these conditions and how they are related. There is no way that a generalist healthcare professional would be able to understand and assess my disability in 3 hours. I have evidence from a rheumatologist, a cardiologist and a neurologist as well as a physio and OT with many years of experience in connective tissue disorders.

There is no point for people that are already on the ndis as their providers already know how to support them

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I was 'assessed' when I first became a client. MY health professionals are in a FAR better position to assess how I'm going. Having an NDIA-appointed (and paid by) some random 'independent' nonentity who I don't know and who doesn't know me and my story cannot possibly work in ALL cases. Disability is NOT an area where some 'cookie-cutter' approach can be applied - especially with individuals with COMPLEX diagnoses like myself

A random independent assessor without specialist experience will NEVER be able to know more than experts in the relevant areas of impact relating to a person's disability.

BY DOING THIS ARE YOU TRYING TO SAY YOU DON'T TRUST the AHPRA registered therapists, Drs who have already done these assessments

NDIS will also 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 decision maker will have in order to determine what tools are most appropriate depending on a person's age, disability and circumstances. There is also no information on how an NDIA decision maker would determine if a person was eligible for an exemption.

PWdWA and WAIIS have concerns about an inherent conflict of interest with assessors being contracted to undertake a service by the NDIS. The services engaged through the tender process have KPIs to meet (such as timeframes for submitting completed reports) and will ultimately be accountable to the NDIA. The NDIA can request information and assistance from assessors in relation to appeals processes. The NDIA is also able to return an assessment to have errors and omissions remediated. 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. Assessors are not allowed to provide any information about the assessment, or its outcome to the person with a disability. Therefore, assessors, if not actual, will be perceived to be working in the interest of the NDIA, and not the participant, and not be seen as independent.

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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

Training

NDIS have advised in the Independent Assessor tender that training on the use of the Independent Assessment framework will be online and a "train-the-trainer" model. The oversight of skills and qualification will be the supplier's requirement. The NDIA anticipate that an Assessor will only require 1 day of training prior to commencing assessment services.¹¹

They refer to a yet undefined Quality Assurance Framework which they state will ensure the validity of assessment results and inter-rater reliability between Assessors. However, this Framework does not currently exist and there is limited information about how it will ensure consistency and quality.

People consulted with made some recommendations to ensure the quality of a **non-mandatory** independent assessment model including:

- Not establishing KPI's
- Ensure people have access to advocacy if required
- Being able to review reports before they are submitted and appeal if necessary
- Be responsive to complaints about the quality of assessors
- Assessors have adequate knowledge of a person's disability

¹¹ Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 2.2 Training Requirements

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- Assessors focusing on the person and their needs and not the system outcomes
- Allowing the person to use their own health professional to complete an assessment

Assessment Process

We note that the NDIA tender document for the Independent Assessment Panel specifies the assessor must:

- Undertake a minimum of 20 minutes interaction or observation, in which they will take summary notes to include in the Report
- Complete the nominated Functional Capacity Assessment Tools.¹²

It does not appear the assessor will have access to any information from treating health professionals. The NDIA expects the process of meeting with a person, conducting the assessment and writing the report will take approximately 2.5-3 hours on average.¹³ PWdWA and WAIIS experience is that an independent assessor who doesn't know nor have any previous relationship with the person, will not be able to adequately complete a holistic, individualised functional assessment in this timeframe. Notably, the NDIS has provided no evidence to the disability sector that this prescribed assessment time is appropriate.

NDIA also require the completed Assessment Report to be submitted within 10 business days of receiving the referral. The maximum timeframe to complete a referral is 20 business days before NDIA require the referral to be returned. We contend that this is not sufficient time to develop a fully 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

¹² Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 3.3 The Assessments.

¹³ Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 3.7 Assessment Duration

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being cut and the bare minimum time being spend with a person. Similar concerns were raised in our consultation with community:

Lack of skills and insight into the impact of the conditions they are being asked to assess.

These Assessments will NOT give any true picture of the needs of PWD, Assessments have to be done over a great length of time and input of all regular therapists, Drs, Family ,Support workers is needed, 3 hour assessments are a joke, and there is absolutely NO need for these for PWD who is an adult with life long intellectual disability, subjecting them to this is violation of their privacy and rights

Like all other NDIS employees and contractors, the Independent Assessors will be given Key Performance Indicators (KPIs) to meet, resulting in rushed and poor quality assessments, as we are seeing with the huge number of rushed and poor quality NDIS Plans due to NDIA, APM Communities and Mission Australia having competitions for who can crank out the highest number of NDIS Plans in the shortest timeframe. Independent Assessments are NOT in the best interests of people with disability.

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 people who have experienced abuse and trauma, and people with a psychosocial disability.

I doubt that they will have an understanding about how to communicate with all types of people with all types of disabilities in the most accessible manner. I doubt they will know how to communicate with people with complex communication difficulties. For example- a person who is Deafblind from a CALD background and how has trust issues from past traumas.

The plan review process seems to be already stressful. This seems to add another layer of stress. Retell your story to Another person. Do the NDIS understand how much we already do this?

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My children and I cannot handle being around strangers and it will cause long lasting psychological difficulties that take weeks to recover from

Quality of Reports

The NDIA specifically states that assessors must not provide a copy of the report or discuss the results with the person with a disability.¹⁴ 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 risks of inaccuracies. At the AAT, in the matter of *Ray v National Disability Insurance Agency*¹⁵ it was found that the NDIA's Independent Assessor was mistaken in her understanding of Mrs Ray's disability and rejected her evidence. The independent assessor was a Qualified Occupational Therapist who spent 3 hours with Mrs Ray as well as reading through medical evidence pertaining to Mrs Ray's disability.

We also question the rigorousness of quality assurance processes if there is no option to get a second opinion. Getting a second opinion is enshrined in the Australian Charter of Healthcare Rights. We also observe that the World Health Organisations Ethical Guidelines on the use of ICF specifically state that (bold emphasis added):

(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***¹⁶

¹⁴ Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 4.2 Report Types and Delivery Timeframes

¹⁵ <https://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2020/3452.html>

¹⁶ World Health Organisation. (2001). International Classification of Functioning, Disability and Health. World Health Organisation: Geneva. Annex 6, p 252

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Given the Independent Assessment will have a significant impact on access and planning decisions it is wholly inadequate that a person will not have the opportunity to review the accuracy of the report or challenge the findings, including by seeking a second opinion. NDIS have provided the means for themselves to seek immediate remediation if they find an error or omission in a report.¹⁷ However, they will be unlikely to identify these errors or omissions without input from the person with a disability.

Will the IA Assessor understand how to communicate with me. Will they understand about the different types of accessible information. Will they listen to me. Will they understand where I fit in the family structure. Will they have unconscious bias like an in depth knowledge of physical disabilities and no knowledge of sensory disabilities. Will they write a report that means I am forced out of the NDIS or my Plan is reduced to a dramatically smaller amount of funds that can't meet my needs based on my disability.

We do not believe that the proposed Independent Assessment Framework and policies provide adequate safeguards around service quality or continuous improvement mechanisms. We assert that there is no valid argument for quality control that prevents a person's own provider from completing an Independent Assessment. In fact, based on our experiences being able to use the provider of your own choice will result in a report with more depth and nuance.

e. The appropriateness of independent assessment tools selected for use in independent assessment to determine plan funding

Under the proposed framework, the NDIA is determining what tools the assessors will be required to use. As mentioned above there is no information on what skills, training, and qualifications the NDIA decision maker will have to determine what tools are most appropriate depending on a person's age, disability and circumstances.

¹⁷ Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 4.3 Errors and Amendments

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f. The implications of independent assessments for access to and eligibility for the NDIS

We explored the NDIA's reasons and justifications for the introduction of Independent Assessments above (section a). This section highlighted why the introduction of Independent Assessments will not improve access to and eligibility for the scheme. In addition to not achieving their proposed purpose we also have concerns that the changes will create further access/eligibility barriers.

Removing the eligibility lists

The NDIA has always required information from a person's medical practitioner to demonstrate they have an impairment as defined under the *NDIS Act 2013* and that their impairment is permanent, or likely to be permanent. However, the existence of the List A/List B/List C categories was a streamlined way to identify diagnoses that meet the definition of impairment under the Act and are considered permanent. In these cases, a person could usually produce an existing report confirming their diagnosis and then, depending on whether they were List A, B, or C, would only be required to provide information about their functional capacity. It meant that specific information about what interventions and supports have been considered was not required, reducing the need to gather further evidence from medical practitioners.

We acknowledge that the Lists are not perfect, and we do not necessarily oppose their removal *if* an appropriate alternative is introduced. If the lists are removed, without any alternative being introduced, it will likely be more complex, and difficult for people to provide evidence that they meet Section 24(1) a-b of the NDIS Act 2013. We believe it will result in more people experiencing the access barriers we highlighted above (section a). We also refer to the impact of similar policy changes as discussed above (section b). Consultation participants provided the following thoughts on the Lists:

I have been thinking the NDIA should keep the automatic eligibility tables as the main entry point into the NDIS and then, if people don't quite meet that, then maybe they have an independent assessment

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It [Independent Assessments] absolutely should NOT be compulsory, and the current eligibility lists need to remain.

Automatic Withdrawal of Access Requests

It is of concern that if a person fails to complete an Independent Assessment within 90 days of being requested, and they don't have an exemption, the NDIA will consider that the person has withdrawn their access request. There are many reasons why a person may not be able to meet the 90-day deadline including but not limited to:

- The availability, capacity, flexibility and cultural awareness of an Independent Assessor
- Failure of the NDIA or third parties to communicate effectively with a person in a way they can understand
- The person requires support to action the request
- The person is in a setting which restricts access and/or ability to undertake an assessment e.g. hospital, prison, homeless
- The system and/or the Independent Assessor is not flexible to engage or find ways to engage with people who have been historically let down and or discriminated against, by the system.
- The person has other more serious competing priorities affecting them where support is required, prior to accessing and/or planning in the NDIS.

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. We argue that this would create further barriers to those who are already the most vulnerable and having the most difficulty accessing the scheme.

It is also unclear the level of responsibility taken by the Independent Assessor for the outcome or lack of. There is a real risk that people will be blamed and labelled as not

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'complying' with requests when it could be the result of the Independent Assessors approach.

g. The implications of independent assessment for NDIS planning, including decisions related to funding reasonable and necessary supports

As highlighted above there is very little detail nor transparency about how Independent Assessments will be translated to budgets. This will undermine people's ability to both (a) trust the process; and (b) understand the justification for the draft budget.

People have significant 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.

It is also inherently illogical and completely counter to individualised, person centred planning and principles outlined in the NDIS Act itself to have a draft budget BEFORE any planning has taken place. This proposed planning process is in direct conflict with the very principles the NDIA's planning policy espouses:

- a) provide **personalised budgets** which balance individual circumstances and the sustainability of the NDIS
- b) **recognise participants as experts in their own lives** and maximises flexibility and participant control over their personalised plan budget
- c) maximise the opportunities for community participation with support from mainstream and community services, and/or funded supports
- d) **recognise the participant's autonomy and independence in decision making processes that affect them**, and support them to make decisions for themselves

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- e) maximise the participant's opportunities for informed decision-making based on the best available evidence about supports and recognises the dignity of risk
- f) be as accessible as possible, **holistic and strength-based**, where participants can adapt their supports to their life circumstances and environment

In particular, we draw attention to the principles relating to participation of people with disability legislated for in the NDIS Act, section 17A:

- (1) People with disability are assumed, so far as is reasonable in the circumstances, to have **capacity to determine their own best interests and make decisions that affect their own lives**.
- (2) People with disability will be **supported in their dealings and communications with the Agency** so that their **capacity to exercise choice and control is maximised**.
- (3) The National Disability Insurance Scheme is to:
 - (a) **respect the interests of people with disability** in exercising choice and control about matters that affect them; and
 - (b) **enable people with disability to make decisions that will affect their lives, to the extent of their capacity**; and
 - (c) support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.

And, we also draw your attention to principles relating to plans legislated for in the NDIS Act, section 31. In particular, these sub-clauses:

The **preparation, review and replacement** of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

- (a) be **individualised**;
- (b) be directed by the **participant**;...
- (j) facilitate **tailored and flexible responses to the individual goals and needs** of the participant

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Through our consultation people stated that:

The barriers are that an assessment team – some of whom have no experience in the disability sector are making decisions that affect the lives of [people] – without even meeting the individuals...Some NDIS people – in fact most do not understand my particular disability.

My belief is that the IA will be a BLUNT tool.

Deciding how much to allocate to an NDIS recipient should be based on need. Allocating fixed amounts will mean some people get far less than will meet their needs, while others receive more than needed.

Needs can't be identified in 3 hours stacked in with an independent assessment for access performed by someone who can't possibly be qualified enough to understand the complexities of living with rare or complex conditions, or even common conditions within a complex social context.

Independent Assessments will NOT make good Plans and Budget, No assessment done in 3 hours by a stranger can give a NDIS plan, this is a step completely against what NDIS stands for ie Human Rights and Choice and control of PWD, To make independent assessments the basis for funding amounts is total disregard to the person with disability, it's extremely harmful and nothing good can come of this type of assessment.

Amending draft budgets

We note that section 3.3 of the Consultation Paper states that changes to draft budgets will only be made in specific circumstances including:

- where a participant has extensive and/or complex support needs
- there are additional high cost supports that are not accounted for in the independent assessment e.g. Specialist Disability Accommodation, AT or home modifications

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There is no clear guidance on what would constitute extensive and/or complex support needs. If a plan budget is inadequate, we are concerned that people who are already particularly vulnerable are going to have to argue that their support needs are extensive and/or complex in order to access changes.

There is also no explanation as to what changes can be made when a person meets this criterion. Additionally, if a person does not meet the above criteria, they will be forced to go through a review process, rather than being able to address issues at the planning stage itself. We have supported many people who have been left vulnerable and at risk by inadequate access to supports and have concerns that this proposed process does not alleviate this issue.

It was identified through a consultation process that people have strong concerns about how much flexibility there will be for draft budgets to be adjusted as a result of a planning meeting to take into consideration individual circumstances, in particular, people with complex support needs.

People need to have the right to access support to live a good life.

This process shows a distrust of people and people's capacity to know what's best for themselves. It's a real departure from the NDIS premise of choice and control.

I don't think independent assessors will make good plans and budgets, because its changing the process and reversing the order.

People are going to get a budget and plans will be built around that.

As it stands now, people's needs are assessed and then get a budget according to their needs and their goals. There's no mention of goals in this independent assessors stuff and that really concerns me. It's changing the focus.

Relevance of Goals

The NDIS Act states that the NDIA must have regard to a participant's statement of goals and aspirations when deciding to include supports in a participant's plan (section 33(5)(a)). Secondly, before including any support in a participant's plan, the NDIA must also be satisfied that the support will assist the participant to pursue the

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goals, objectives and aspirations included in the participant's statement of goals and aspirations (section 34(1)(a)). Therefore, the link between participant's statement of goals and aspirations and the statement of participant supports is explicit and ensures that the participant's statement provides the important foundation for the subsequent selection of supports.

We note that in the NDIS consultation paper, it is stated that "The NDIS Act does not provide that a participant's goal or aspirations determine their reasonable and necessary supports, or that a particular support must be linked to particular goals in the plan, or vice versa".

This is in direct conflict with the Act.

In order for there to be a meaningful link between goals and a personalised budget, it requires an approach that flows from goals to support needs to budget. It is, meaningless to identify goals and support needs after a budget has been set.

NDIA acknowledge that legislative changes will be required and based on the consultation, and new Planning Operational Guidelines will be produced. However, we contend that consultation process has little opportunity to provide meaningful input into the changes given:

1. There has been no information about the legislative changes that are intended
2. There is no information about how Independent Assessments will be translated to personalised budgets
3. The consultation requests feedback on implementation, rather than the process itself

We are concerned by the suggested legislative changes that would be required to make the proposed changes possible including changes to section 34's "reasonable and necessary" criteria. Recent draft versions of the changes to the NDIS Act 2013 have further highlighted that this fundamental principles is not safe. The reasonable and necessary criteria are the fundamental basis of being able to access personalised supports. There was no recommendation from the Tune Review to make any changes to the criteria. The AAT have also stated that the criteria are

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“straightforward and pragmatic”.¹⁸ There is no evidence that the criteria itself lead to inconsistent outcomes, more so, concerns centre around the inconsistent implementation of section 34 of the Act by NDIA. This is consistent with the experiences of PWdWA advocates supporting people to review the reasonable and necessary supports in their plans.

h. The circumstances in which a person may not be required to complete an independent assessment

The Tune Review makes a number of statements which clearly recommend a discretionary approach to Independent Assessments including (bold emphasis added):

*4.11 The legislation should be amended to recognise the importance of appropriate assessments and what they can be used for, noting it is a reasonable expectation that participants might need to undertake further assessments **from time to time** to ensure their plans remain fit for purpose.*

*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.*

The proposed Independent Assessment Framework, Access and Eligibility Policy and Planning Policy and requires all prospective and current participants to undergo a mandatory functional capacity assessment. This is in no way discretionary and

¹⁸ *National Disability Insurance Agency v WRMF* - [2020] FCAFC 79

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cannot be seen to comply with the recommendations of the Tune Review, or in fact the General principles guiding actions under the NDIS Act (the Act):

(8) 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

*(9) People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.*¹⁹

Respondents to our consultation could see some benefits from a non-mandatory independent assessment process including:

It might be helpful for a very narrow cohort, and only if the assessors were allocated according to their medical speciality. Examples might be for those unable to gather evidence due to cognitive, intellectual or psychosocial reasons.

*For people trying to access the scheme who cannot afford reports, etc
Some people need to look further than the assistance they are currently getting and it might be helpful to get a different view. As long as the independent assessor is fair and openminded and working for the needs of the individual with a disability. Some doctors and associated professionals are not familiar with the NDIA and its red tape*

However, most respondents did not support the introduction of mandatory independent assessments.

I think Independent Assessments should be an OPTION for people who are having trouble sourcing evidence of disability to gain access to NDIS...It absolutely should NOT be compulsory...Having a Functional Capacity Assessment performed by the allied health

¹⁹ NDIS Act 2013 Part 2: 4(8-9)

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professional(s) of your choice at key points in your life works far better than Independent Assessments ever will.

People have the right to choice and control. This breaches choice and control...Compulsory Independent Assessments in the current format are an extremely bad thing.

It further disempowers disabled people, removes our right to choose which medical professionals participate in our assessment/treatment, which is damaging, especially for anyone with PTSD or cPTSD caused either by medical mistreatment or other forms of disempowerment.

The only area this might be useful would be for people who struggle to gather their own evidence. That should only ever be voluntary

Some of the concerns they raised included:

- The knowledge, experience and training of the assessors
- The impact of the process on wellbeing
- There is no evidence the process will improve equity
- The need for an assessment to respond to significant changes in environmental factors rather than personal factors
- The ability to do a thorough assessment in the proposed timeframe

Access to Exemptions

NDIS states that under 'exceptional circumstances' a person may be exempt from needing an Independent Assessment where there is a risk to safety, or an assessment is deemed inaccessible or invalid. This wording is vague and would arguably include most of the people who access PWdWA for advocacy support. We also argue that the exemption process itself is inequitable. It relies on those who are most vulnerable, with the least capacity, to be able to articulate their need for an exemption. As seen in other areas of the NDIS those who have more access to information and can better articulate themselves will be in a better position to argue for an exemption. An example of this inequity can be seen in the decision to grant an urgent review. Where a person uses the right 'language' and knows the system they often have a better chance of having matters acted upon urgently. Additionally, the

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decision not to grant an exemption isn't reviewable, meaning there is no inbuilt safeguarding and quality control of decisions being made.

i. Opportunities to review or challenge the outcomes of independent assessments

The NDIA have stated that the contents of an Independent Assessment will not be open for review as defined under Section 100 of the *NDIS Act 2013*. They state that it is not a decision, and therefore not reviewable. However, the Tune Review was explicit in its recommendation about safeguards that should be included if Independent Assessments were rolled out (bold emphasis added):

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*

Additionally, the tender document for the Independent Assessment Panel states that people will have the right to challenge the results of their assessment if they are unsatisfied.²⁰ No information is provided about how a person can exercise this right and it is contradictory to the information provided in the proposed Access and Eligibility policy. There is no clear pathway to challenge the results on an

²⁰ Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 3.8 Appeals Processes.

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Independent Assessment, including the right to undertake a second assessment or seek arbitration *for whatever reason* (as specified in the Tune Review).

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. The current system enables a person to specifically identify what supports the NDIA has and has not determined are reasonable and necessary.

Other concerns arise. For example, what happens if the issue lies with the Independent Assessment itself? Will a delegate be able to make a review decision that is inconsistent with the Independent Assessment? Will the delegate have authority to request a new or amended Independent Assessment? Will the participant be required to go through both a complaints process about the Independent Assessment as well as seek a review of their budget?

While the NDIA state 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. There appears to be no mechanism to request a correction or second opinion if the person disagrees with what is written in the Independent Assessment.

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 and 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

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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.

My concern is that this change further disempowers people living with disability, removing our right to choose and taking diagnostic assessment out of the hands of qualified medical specialists. Given how many people with genuine need are rejected arbitrarily, because someone hasn't read one of their reports or the "wrong" language was used, removing the right to appeal strikes me as a cruel attempt to reduce the number of participants in the NDIS.

They have to have a robust and workable feedback mechanism. This is paramount to the success of the IA

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:

- 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

Where errors in fact or 'judgement' cannot be quickly and easily appealed NDIA risk erroneously preventing access to the scheme or not providing enough supports to meet a person's needs. This could result in actual risk to a person's safety and wellbeing.