



## **Submission**

### **Consultation Paper – Access and Eligibility Policy with independent assessments (NDIS)**

People with Disabilities (WA) Inc. (PWDWA) and WA's Individualised Services (WAiS) would like to thank the NDIA for the opportunity to provide comment and recommendation on their proposed Access and Eligibility Policy, along with the proposed implementation of independent assessments.

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.

This submission should be read in conjunction with our submission 'Submission in response to Consultation Paper – Planning Policy for Personalised Budgets and Plan Flexibility (NDIS)'

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

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**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

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(NDIS). In particular we are funded by the Department of Social Services to provide support with NDIS Appeals.

**WA's Individualised Services (WAiS)**

Western Australia's Individualised Services (WAiS) is a member-based community organisation working in partnership with people, families, service providers and government agencies to promote and 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.

WAiS is the only organisation that has a specific focus and purview of supporting and developing the capacity of people, families, service providers, Local Co-ordinators 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

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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 WAiS's work at both a systemic and individual level. Our joint submission is compiled based on the 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 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 consultation paper fails to ask people central questions such as: Should Independent Assessments be mandatory? PWdWA, in particular, 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 disadvantaged experiences by many of the people we support, expose them to an increased risk of harm 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: Summary of Recommendations**

This submission provides a number of recommendations that PWdWA and WAiS strongly urges the NDIA to consider. These recommendations have been developed as a result of issues brought to our attention through our individual advocacy work and systemic NDIS work, including the PWdWA NDIS Experience Survey. Our responses are also informed through PWdWA and WAiS collaboration with the disability and advocacy sectors.

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**Recommendation 1:**

Halt the implementation of the Independent Assessment Framework and the Access and Eligibility Policy

**Recommendation 2:**

Develop policy to address the inequity of the scheme through Co-Design with people with a disability. Ensure that any approach maintains choice and control.

**Recommendation 3:**

Deliver a pilot that will adequately measure the impact of any proposed policy changes before they are rolled-out nationally. Evaluation of the pilot should be by an Independent Evaluator. We recommend this occur anytime a significant policy or practice change is being considered.

**Recommendation 4:**

NDIA do not introduce **mandatory** Independent Assessments

**Recommendation 5:**

NDIA co-design a discretionary approach to assessments for supporting evidence which:

- Provides clear rationales for when a person would need to undertake an Independent Assessment
- Allows a person real choice and control about who completes their assessment
- If NDIA decides an assessment is required - Makes the decision not to grant an exemption be considered a reviewable decision under Section 100 of the Act
- Requires the NDIA (or a third-party provider) to have made all effort possible to support a person to complete an Independent Assessment by the 90-day timeframe before withdrawing an access request
- Provides discretion to extend the 90-day timeframe

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**Recommendation 6:**

Anyone who undergoes an Independent Assessment will have the opportunity to provide feedback on a draft report and sign off or note if they agree or disagree with the assessment prior to it being submitted.

**Recommendation 7:**

Ensure that anyone who undergoes an Independent Assessment has the right to request a second assessment for whatever reason.

**Recommendation 8:**

NDIA work with people with a disability and medical practitioners to identify clear guidelines around disabilities that should be considered to meet the impairment and permanency criteria in Section 24(1) a-b of the *NDIS Act 2013*. Where a person fits this category there should only be a requirement to provide evidence of the diagnosis to demonstrate Section 24(1) a-b are met.

**Recommendation 9:**

Ensure that people who are assessing NDIS eligibility have the appropriate knowledge and experience to make an informed decision about the evidence provided

**Recommendation 10:**

Work with people with disability and health professionals, and the Health system to create a clear, streamlined pathway to request additional evidence for the purpose of demonstrating a person's eligibility for the Scheme

**Recommendation 11:**

Work with people with a disability and health professionals to co-design a report template which can be used to support a person's NDIS application

**Recommendation 12:**

Decision about whether a person has accessed all reasonable treatment options should only be made by a person with the appropriate clinical background. Decisions should consider whether treatment recommendations are affordable or accessible.

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**Recommendation 13:**

Co-design and fund an NDIS Navigator program to ensure people who need support to navigate the NDIS have access to it.

**Recommendation 14:**

Any changes that are made by the NDIA must have choice and control at their centre if they are to be in line with our obligations under the United Nations Convention on the Rights of Persons with Disability

**Recommendation 15:**

The NDIA embeds co-design in all Scheme development and encourages feedback on all part of the process.

**Section 2: Highlighted Issues**

**2.1 Independent Assessments and Eligibility**

We highly welcome the intention of the NDIA's proposed processes, which is to create a way for people with disability to have 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.

However, PWdWA and WAI S disagree with the NDIA's decision to use mandatory Independent Assessments as the method to achieve the outcomes they seek. We have a number of concerns in relation to the Independent Assessment Framework and the proposed Access and Eligibility Policy.

**2.1.1 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*".<sup>1</sup> The Tunc

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<sup>1</sup> NDIS Act 2013 Part 2: 4(9)

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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 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. People are not being asked whether they believe the fundamental approach is suitable, or if it will address instances of inequity seen within the scheme.

Additionally, there is very little details about how key parts of the new policies will work. This includes how Independent Assessments will be translated to budgets. We will address this further in a separate Submission on the proposed Planning policy.

*[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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**Recommendation 1:**

Halt the implementation of the Independent Assessment Framework and the Access and Eligibility Policy

**Recommendation 2:**

Develop policy to address the inequity of the scheme through Co-Design with people with a disability. Ensure that any approach maintains peoples' choice and control.

**2.1.2 Evidentiary support for changes**

The NDIA has stated that the proposed changes to access, planning and the introduction of Independent Assessments are based on recommendations by the Tune Review<sup>2</sup> 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 for assisting with Access Requests:

- The initial pilot focused on people with Autism Spectrum Disorder, Intellectual Disability and Psychosocial Disability. While this may represent 63% of Scheme participants it did not necessarily represent people in the scheme requiring high or complex levels of support.
- Both pilots are an opt-in model where people 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 did not allow individuals without a support person to elect to be part of the trial. The suitability of the Independent Assessments with therefore not be assessed for this cohort of individuals.

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

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- 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 what was stated as 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.
- Participant Satisfaction surveys were mostly completed by family and/or carers rather than the person with a disability.
- The assessment had no bearing on a person’s 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.

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 new Access and Eligibility Policy. Aside from the issues with how the pilots are being rolled out and evaluated, we also note that the second pilot is still underway.

We also have concerns about how the NDIA has interpreted the recommendations made by the Tune Review. These will be addressed under specific areas of feedback about the Independent Assessment Framework and the Access and Eligibility Policy.

**Recommendation 3:**

Deliver a pilot that will adequately measure the impact of any proposed policy changes before they are rolled-out nationally. Evaluation of the pilot should be by an Independent Evaluator. We recommend this occur anytime a significant policy or practice change is being considered.

### **2.1.3 Mandatory Nature of Assessments**

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 requires all Prospective and Current Participants to undergo a mandatory functional capacity assessment. This is in no way discretionary and cannot be seen to align 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*

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*control is maximised in a way that is appropriate to their circumstances and cultural needs.<sup>3</sup>*

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 have not seen sufficient evidence to support a mandatory assessment as 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 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. We discuss our concerns about this issue further in Section 2.3.

Respondents to our consultation process indicated that they 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.

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<sup>3</sup> NDIS Act 2013 Part 2: 4(8-9)

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*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 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 PTSD 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

These themes are explored in more detail below.

#### **2.1.3.1 Access to Exemptions**

NDIS does state 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

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

### *2.1.3.2 Timeframe for completion*

Another point of concern is 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

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

### **Recommendation 4:**

NDIA do not introduce **mandatory** Independent Assessments

### **Recommendation 5:**

NDIA co-design a discretionary approach to assessments for supporting evidence which:

- Provides clear rationales for when a person would need to undertake an Independent Assessment
- Allows a person real choice and control about who completes their assessment
- If NDIA decides an assessment is required - Makes the decision not to grant an exemption a reviewable decision under Section 100 of the Act
- Requires the NDIA (or a third-party provider) to have made all effort possible to support a person to complete an Independent Assessment by the 90-day timeframe before withdrawing an access request
- Provides discretion to extend the 90-day timeframe

#### **2.1.4 Quality Control of Functional Capacity Evidence**

NDIA have repeatedly stated that Independent Assessments will act as a quality control mechanism in providing evidence about functional capacity. NDIA propose Independent Assessments will address the issues around consistency, and the

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"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 nor does the NDIA's position account for allied health professionals requiring registration with and accountability to regulator such as Ahpra.

This is reflective of the cultural attitude within NDIS 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 time and time again where the NDIA has requested further evidence as part of AAT reviews only for the persons 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.*

*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*

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*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 have advised in the tender that training on the use of the Independent Assessment framework will be a “train-the-trainer” model and oversight of skills and qualification will be the supplier’s requirement. 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. 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.

People we 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

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

### *2.1.4.1 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 nominate Functional Capacity Assessment Tools.<sup>4</sup>

It does not appear the assessor will have access to any information from health professionals already supporting the person. 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.<sup>5</sup> 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, which will result in corners being cut and the bare minimum time being spent 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*

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<sup>4</sup> Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 3.3 The Assessments.

<sup>5</sup> Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 3.7 Assessment Duration

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*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 those who have experienced abuse and trauma, and those 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?*

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

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

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a person's supporting 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

### *2.1.4.2 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 in any way.<sup>6</sup> Even with rigorous training for Independent Assessors no process involving a human is free from errors. We would argue that given the Independent Assessor must not know the person and will have a limited time available to complete the assessment, there will always be the chance that an assessment will be inaccurate. In the AAT matter of Ray v National Disability Insurance Agency<sup>7</sup> 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.

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***

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<sup>6</sup> Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 4.2 Report Types and Delivery Timeframes

<sup>7</sup> <https://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2020/3452.html>

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***participate, and in particular to challenge or affirm the appropriateness of the categories being used and the assessment assigned<sup>8</sup>***

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.<sup>9</sup> We are at a loss as to how they will 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.

**Recommendation 6:**

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<sup>8</sup> World Health Organisation. (2001). International Classification of Functioning, Disability and Health. World Health Organisation: Geneva. Annex 6, p 252

<sup>9</sup> Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 4.3 Errors and Amendments

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Anyone who undergoes an Independent Assessment will have the opportunity to provide feedback on a draft report and sign off or note if they agree or disagree with the assessment prior to it being submitted.

### **2.1.5 Right to Appeal**

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.<sup>10</sup> No information is provided about how a person can exercise this right and it is contradictory to the information provided in the Access and Eligibility policy. There is no clear pathway to challenge the results on an Independent Assessment, including the right to undertake a second assessment or seek arbitration for whatever reason (as specified in the Tune Review).

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<sup>10</sup> Attachment 1 – Statement of Work: Request for tender – Independent Assessment Panel. Reference Number 1000724626. Section 3.8 Appeals Processes.

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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 unless the person has the capacity to understand and articulate how the assessment was inconsistent with the Independent Assessment Framework.

*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

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- 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.

### **Recommendation 7:**

Ensure that anyone who undergoes an Independent Assessment has the right to request a second assessment for whatever reason.

### **2.2 Addressing Equity Issues**

The NDIA state in their consultation paper on the new Access and Eligibility Policy that some of the access 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

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.*

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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. 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 four 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 evidence of the impact of their impairment already available in gathering information for the first four criteria
3. Information about functional capacity will not be needed to help determine permanency

These presumptions are highly problematic, and we consider that the proposed Access and Eligibility Policy does not adequately acknowledge or address them in its approach. 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:

- (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*

## **2.2.1 Removing the eligibility lists**

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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. 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*

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

**Recommendation 8:**

NDIA work with people with a disability and medical practitioners to identify clear guidelines around disabilities that should be considered to meet the impairment and permanency criteria in Section 24(1) a-b of the *NDIS Act 2013*. Where a person fits this category there should only be a requirement to provide evidence of the diagnosis to demonstrate Section 24(1) a-b are met.

**2.2.2 Disability attributable to an impairment and permanence**

As stated above the proposed Access and Eligibility Policy presumes evidence of functional capacity is the only sticking point in the Access process. Gaining a diagnosis, and proving permanence are a considerable barrier for many of the

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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*

We believe that the introduction of Independent Assessments will not improve access for many of those who are already experiencing barriers to making an Access Request. 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 without supporting health professionals

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 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.

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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).<sup>11</sup>

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...*

*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.*

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<sup>11</sup> <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/providing-evidence-your-disability>

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### *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 waitlist.

If further evidence is required from a health professional to demonstrate the NDIS access criteria then often people are placed back on waitlist 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*

### *Cost of obtaining evidence*

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

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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.*

*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 found he had 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

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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 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 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

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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
- 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 persons' 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.

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### **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 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 at risk of falling, for which there was no definitive diagnosis. NDIA did not view

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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 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, we can see that Andy's issue with access did not only stem from evidence about substantially reduced functional capacity. The issues he faces would likely not be addressed by the introduction of mandatory Independent Assessments.

### **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 found he had 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.

### **2.2.3 Impairments arising from health conditions**

There is considerable concern in the community that as part of the changes being made the NDIA are seeking to limit access to the scheme for people whose chronic health conditions are disabling. The Consultation Paper asks for feedback on the making the distinction between disability and chronic health conditions clearer. The current legislative and operational approach does not specifically separate out 'disability' and 'health conditions'. Instead, the definitions allow disabling chronic health conditions to be included under the scope of the disability access requirements.

We do not support an approach which would restrict access to the scheme for people who have a chronic health conditions that has a substantial impact on their functional capacity. Rather than making a distinction, we propose the NDIA provide further guidance on when a chronic health condition should receive access to the NDIS.

### **2.2.4 A process that emulates the Disability Support Pension**

We would like to take this opportunity to highlight the concern that the proposed changes are moving the NDIS towards the Centrelink model of funding disability. The DSP has become incredibly hard to access as a result to changes in eligibility process that were introduced as a cost cutting measure. Applying for the Disability Support Pension (DSP) is now a highly traumatic, overly bureaucratic process. In the experience of PWdWA, Job Capacity assessors and people assessing DSP applications do not have the knowledge or expertise to appropriately consider a person's application. People feel that Centrelink staff are looking for any excuse, or the smallest inconsistency, to justify denying access. This is often related to exhausting treatment options or demonstrating permanency.

There is real fear in the community that the changes being made by NDIS are part of cost-cutting measures and the lack of transparency in the process does little to alleviate these fears. There are also concerns about people without relevant clinical

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backgrounds making decisions about medical information, such as treatment options, in determining access which is common under the Centrelink system.

*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 path*

*They could always accept copies of reports from radiology, haematology, specialists and they need to understand the full meaning/diagnosis of reports and medical and psychological conditions. Admin people should not be making decisions of behalf of medical issues that they are unable to understand.*

*Better trained and qualified Delegates.*

*I think they [Independent Assessments] are a way for the NDIS to slash participants funding and justify it.*

**Recommendation 9:**

Ensure that people who are assessing NDIS eligibility have the appropriate knowledge and experience to make an informed decision about the evidence provided

**Recommendation 10:**

Work with people with disability and health professionals, and the Health system to create a clear, streamlined pathway to request additional evidence for the purpose of demonstrating a person's eligibility for the Scheme

**2.3 What does an Access and Eligibility Policy that addresses inequity look like?**

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We believe it is a positive step forward that the NDIA has asked for feedback on how to make it easier to provide evidence of a person's disability. As outlined above there are a number of reasons why evidence of a person's disability act as a barrier to gaining access to the Scheme. To mitigate some of these barriers PWdWA has taken a number of approaches including creating a fillable report template with guidance on how to complete it. This template has proven more helpful in gaining the required information to demonstrate the permanency and impact of an impairment than the NDIS Access Form. However, unless it becomes easier for people to provide evidence of their disability there will continue to be a need for advocacy to assist with access requests and reviews.

Consultation with the community highlighted the following recommendations to make it easier to provide evidence of disability:

- Take the time to talk directly to health professionals/doctors
- Provide a report template that outlines exactly what NDIS wants to know
- Ensure that evidence is properly recorded on the system
- Recognise and value the knowledge and expertise of the persons treating healthcare professional

Some of the comments from consultation participants included:

*B[y] looking at her medical and professional doctors assessments, plus talking to current professionals about her abilities.*

*A formatted letter with fillable fields, that outlines exactly what NDIS want to know. The access form has very limited space, and the questions are very narrowly phrased, making it hard to apply them to the wide variety of disabilities that people live with. The same for letters from specialists. Fillable fields should not be too limited, allowing a reasonable word count. Without this guidance it is left up to applicants to explain to specialists what information that ndis need, which is difficult in many cases.*

*Forms online.*

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*To stop losing submitting documentation would be a good start, then having staff that actually read it and are able to understand.*

*The difficulty is that assessors are not medically trained, so the onus is placed on applicants to demonstrate the conceptual chain from diagnosis to symptoms to functional impairments to barriers to participation. Because assessors are not medical qualified to make that conceptual link, applicants are not able to use medical language or write about symptoms. Instead, we are required to provide evidence of diagnosis but can't describe our experiences using medical terms or symptoms.*

**Recommendation 11:**

Work with people with a disability and health professionals to co-design a report template which can be used to support a person's NDIS application

**Recommendation 12:**

Decision about whether a person has accessed all reasonable treatment options should only be made by a person with the appropriate clinical background. Decisions should consider whether treatment recommendations are affordable or accessible.

**2.3.1 Adequate Support to Navigate the Process**

There will always be people who require support to navigate the NDIS. Whether this is someone with a newly acquired disability, or people who are only just testing their eligibility. There needs to be dedicated resources to help people who need it to navigate the system.

This need has been recognised in the Aged Care system with pilots of Aged Care Navigator supports currently underway. Until dedicated supports are available, either through the LAC model, or other avenues there will continue to be a burden placed on advocates, support coordinators and service providers to fill this gap.

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**Recommendation 13:**

Co-design and fund an NDIS navigator program to ensure people who need support to navigate the NDIS have access to it.

**2.3.2 Working with Health to break down barriers**

We believe more can be done to improve the interface between Health and the NDIA. The Tune Review specifically recommends:

*4.44. Section 6 of the NDIS Act already provides broad powers for the NDIA to provide support and assistance (including financial assistance) to prospective participants and participants in relation to doing things or meeting obligations under, or for the purposes of, the NDIS Act. Taking into account that other supporting material may be required by the NDIA to support decision-making, the NDIA should consider whether there are other areas where increased use of this power would remove cost as a barrier to the NDIS, noting there could be interactions with other service systems, including Medicare rebates.*

As noted in a number of our recommendations we support the recommendations by the Tune Review for the NDIA to increase the use of their discretionary power to see further evidence both for making access decisions as well as planning and review decisions.

**2.3.3 Maintaining Choice and Control**

One of our primary issues, as highlighted throughout this submission and our submission on the proposed Planning Policy is that it does not promote choice and control.

*I feel that the very basis of NDIS which was choice and control for PWD is being discarded by bringing these assessments (Consultation Participant)*

**Recommendation 14:**

Any changes that are made by the NDIA must have choice and control at their centre

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if they are to be in line with our obligations under the United Nations Convention on the Rights of Persons with Disability

**2.3.4 Co-design not Confirmation bias**

We have outlined our concerns about the approach taken by the NDIA to these consultations, including a lack of transparency, lack of co-design and the 'we know best' attitude. For the Scheme to be what it was envisioned any changes made must be co-designed. People must have access to all the information required to form an informed opinion and make informed recommendations. Consultation should be conducted in a way that seeks and acts on critical feedback rather than limiting it to implementation and not the process itself.

**Recommendation 15:**

The NDIA embeds co-design in all Scheme development and encourages feedback on all part of the process.