

Committee Secretary
Joint Standing Committee on the National Disability insurance Scheme
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ADACAS Submission to the Joint Standing Committee on the NDIS: Independent Assessments Inquiry.

We join with other Advocacy agencies and groups across Australia to voice strong concerns and opposition to the Federal Government's planned reforms to the National Disability Insurance Scheme and in particular the requirement of a mandatory Independent Assessment to access the scheme after proving eligibility.ⁱ

Rather than achieving the intended aims, ADACAS believes the proposed changes will increase the barriers and inequities in access to the NDIS and unduly disadvantage many people with disability, including some of the most vulnerable individuals in our society. We endorse the joint statement from the disability sector on the reforms to the NDIS. In line with this we call on the Federal Government to halt the rollout of the changes to the NDIS to allow for proper consultation with people with disability, families/carers and the relevant representative organisations and to require co-design of any future reforms.

ADACAS is a disability advocacy service providing individual advocacy to and working with people with disability of all ages (and people who experience mental ill health.) We have been operating in the ACT for 30 years and more recently commenced working with people living with disability in specific parts of NSW. ADACAS is a member of both the Disability Advocacy Network of Australia and the Older Persons Advocacy Network, both of which represent organisations working with people with disability across all areas of Australia. ADACAS acknowledges the Ngunnawal people, the Dharawal and Yuin people as the traditional custodians of the lands on which we work, and pay our respects to their Elders, and to all Aboriginal and Torres Strait Islanders in our communities.

As an advocacy service, ADACAS is frequently working with people who are "falling through the cracks" in the current service systems and facing barriers to their rights being upheld. We advocate to support people to access services and supports in a range of areas including: housing; quality of services; access to justice; aged care services; child protection; domestic violence; NDIS access and appeals; and Redress Scheme support. We have supported many people through the NDIS Appeals process and have worked successfully with the NDIA to address some of the issues that have arisen for various individuals.

First of all we note that the proposed reforms were drawn up without sufficient nor adequate consultation and engagement with people with disability or their representative groups whose lives will be directly affected by the changes. As set out in the General Principles of the NDIS Act (2013)ⁱⁱⁱ and Article 4 of the UN Convention on the Rights of People with Disability (UNCRPD)^{iv} to which Australia is a signatory, people with disability are entitled to be involved in decision-making which affects their lives. Refusing people with disability and their families/carers the right to be

adequately consulted as such significant reforns were being developed, shows disregard and disrespect towards people with disability, and a reduction of the choice and control over their lives the NDIS was designed to establish. Additionally, we have not seen the proposed legislative reform drafts as yet, and that the reforms and approaches to date could put at risk the entire foundations of the NDIS. Recent leaks of a draft of proposed changes to the legislation caused distress and confusion among people with disability and their families and carers.

We also note also the likely increased disadvantage resulting from the proposed **abolition of the list of conditions which make an applicant automatically eligible for inclusion in the Scheme (List A)** and the other lists, which provide guidance on entry. Many of our most vulnerable clients will continue to lack the funds or supports to get the evidence required to admit them to the scheme.

With regards to Independent Assessments, primarily we believe that a limited assessment interview with a single assessor is totally inadequate for the assessment of the complexity of individual situations and disabilities. As always, it is the **most vulnerable and unsupported** who are likely to be most disadvantaged by the changes. Instead of streamlining the assessment and access process to the supports they need, the proposed changes are likely to result in them being further disadvantaged by the Scheme that was set up to protect and promote their rights.

Our specific concerns include:

a. The Proposed revisions to the assessment process

- Many of our clients have relied on reports from their own medical and allied health professionals to provide evidence of the impact of their disability or disabilities. The lack of chosen professional support through the assessment of impact process will increase the difficulty in ensuring that this information is fully conveyed by increasing reliance on what the person is able to say themselves during a potentially stressful situation and/or increasing reliance on informal or family supports who may not always accurately convey the experience and preferences of the client.
- There is no recognition of potential trauma for some participants in the process of
 assessment. Many of our clients have previously been traumatised as a consequence of
 their dealings with the NDIA and/or from other occurrences in the past such as abuse,
 violence or a traumatic event. They may be re-traumatised by the experience of a single
 assessment interview with someone who does not know them and on whose assessment
 their access to support and funding depends.
- There is limited information and no transparency about the proposed automatic process for making a decision about a person's entitlement for funding and a support plan, after the assessment has taken place, nor guarantees that the medical information provided in the initial eligibility process will be taken into account along with the results of the independent assessment. Yet the medical information may be essential for an assessment about the level of supports required by the individual to be able to participate in society.
- The NDIA has said that participants will receive only a written summary of their assessment automatically instead of, as should be their right, a full copy of the assessment. Additionally, no details have been released about the Quality Assurance Framework to be put in place. How can participants be confident that the assessment process will be fair and include all the information provided?
- There are no details about how the **actual time given to an assessment** will be decided or if the client will have an opportunity to extend the time of the assessment; or what recourse

they will have if they are unable to complete the assessment due to illness, trauma, or anxiety, for example. (The current proposal that a person with disability will have their NDIS application considered to be withdrawn if they are unable to complete the independent assessment process, is unacceptable.) Our experience also of Independent Assessments through the Appeals process is that in some circumstances the assessors follow the procedures about how the independent assessments operate too strictly. Working with people with disability requires the assessors to make reasonable adjustments when required otherwise the rules become discriminatory or, in some circumstances, can risk the person's health or mental health.

Scenario:

An ADACAS client* with multiple and severe physical disabilities and health conditions who recently underwent an Independent Assessment by a health professional unknown to her as part of an NDIS Appeals process, was put at critical risk of falling when the assessor, after requiring her to complete written assessments for over 2 hours, asked her to demonstrate her movement using her assistive technology, at a point in time when she was exhausted and unable to complete that task. Whilst in that instance, others were able to intervene, if there had not been a trusted additional person who was present, the person with disability may have felt compelled to seek to comply, despite the situation putting her at great risk.

*Client has provided consent for this scenario to be de-identified and used.

- The proposed changes to Independent Assessments put too much responsibility and authority on individual assessors to understand and accurately administer the assessment tools which were not designed for the purpose of allocating funding and developing plans. They also put participants at risk of skewed assessments due to the assessors' level of knowledge, lack of expertise in a specific allied health field, communication skills, and individual prejudices and biases. And there is limited opportunity to challenge the results.
- The process of reviewing an Independent Assessment decision or eligibility for a second independent assessment has been restricted. This presents more barriers to those for whom the first independent assessment session does not provide an accurate assessment of their functional capacities due to a myriad of reasons such as trauma; communication difficulties; bias or ignorance of the assessor; anxiety etc.
- b. Requiring an Independent Assessment by someone not known to the person with disability, is likely to increase the chance that discrimination will be experienced by people in priority populations, including:
 - People with disability who are from Aboriginal and Torres Strait Islander communities experience significantly higher rates of discrimination and abuse^{vi} when compared with others from the general Australian population. Aboriginal and Torres Strait Islander communities have also experienced decades of intergenerational abuses and traumas. The proposed model undervalues the importance of trusted relationships, of culturally informed and sensitive approaches, of trauma-informed approaches and the specific needs of Aboriginal and Torres Strait Islander people with disability. It also demonstrates a lack of understanding of the importance of Aboriginal and Torres Strait Islander community-led solutions.
 - People with disability who are from the **Culturally and Linguistically Diverse** (CALD) backgrounds additionally are at risk of experiencing discrimination in this proposed model.

A structure whereby there is a short assessment by an assessor not known to the person with disability from a CALD background, is considerably more likely to result in cultural misunderstandings and necessary information not being able to be conveyed. Additionally, if interpreters and translated materials are required, there is an immediate need for there to be reasonable adjustments to the duration of assessments/materials provided. If people experienced trauma in their home countries (e.g., the experience of many refugees), trauma informed approaches are also additionally important.

- People with disability who also identify as LGBTQI+ often face additional systemic barriers, an increased risk of discrimination, abuse, impacts on health and wellbeing, reduced social connectedness, and a reduced sense of safety in accessing supports and servicesvii. Allied health workers also often receive limited if any training on the rights, experiences and impacts of intersectional disadvantages that can occur for LGBTQI+ people with disabilityviii, and/or on how to work in a trauma-informed way in the instances when this is needed. The uncertainty as to whether the assessor will have the knowledge and skills to assess in a way that is supportive, and without discriminating or demonstrating bias, could cause considerable extra stress for an LGBTQI+ person with disability during what is potentially already a very stressful assessment process.
- Many of our clients have complex or co-occurring disabilities and conditions and it is the interactions of these disabilities and conditions which can cause the greatest functional incapacities whether this is consistent or episodic. When people have multiple disabilities and/or health conditions, the impacts are often compounding. We also have clients who have periodically recurring disabilities. For individuals in both these groups functional capacity may vary dramatically depending on when it is assessed, and a single assessment of limited duration is unlikely to adequately measure impact.
- People who are sensitive to environmental factors such as lighting, noise, screens, and
 whose sensitivities inhibit their capacity to think, respond, or take part in a series of
 assessments on one occasion. Similar problems exist for frail or ill individuals who may find
 the single independent assessment session too difficult to participate in or complete.
- People in circumstances where additional expertise, experience, time or a pre-existing level of trust or relationship is likely to be required to ensure that an assessment is completed, for example, many people with psycho-social disabilities. Other people who are homeless; people who use substances; or people with rare and unusual conditions the functional impact of which can only adequately assessed by experts. Individuals in all these groups will find a single independent assessment by an assessor who does not know them is likely to result in an undue and unfair outcome, and thus be an experience of discrimination.
- People who do not have access to informal supports to enable them to successfully
 complete all the requirements of the initial application and the independent assessments at
 all, or in the time frames required.
- People from remote or regional communities who do not have access to specialist medical
 or allied health practitioners will still be disadvantaged because these specialists are
 required for assessments for initial eligibility at the applicant's cost.
- The NDIA proposal to **require people to seek exemptions** in situations where independent assessments are especially unsuitable in effect **creates added barriers for people who have**

multiple/complex needs or who are in complex situations. Whilst we welcome the NDIA recognising that independent assessments are not a suitable approach, the model of requiring exemptions is also inherently problematic, in that in effect it is adding barriers/steps for people who often are already facing added systemic barriers to the support they need.

For all the reasons outlined above, we endorse the joint statement by the disability sector, the Response to Consultation on Proposed NDIS Reforms: Access and Independent Assessments^{ix} and call again on the NDIA and the Federal government to **halt the rollout of the proposed changes to the NDIS** and **instead conduct proper consultation and co-design** with people with disability, families/carers and the relevant disability representative organisations such that **better solutions and reforms can be developed.** It is our deep concern, that if these changes go ahead as planned, we will see many more people without the reasonable and necessary supports to live a life of dignity which includes choice and control.

Sincerely

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- vii Leonard, W. and Mann, R. (2018) The everyday experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability, No.111 GLHV@ARCSHS, La Trobe University: Melbourne, accessed via <a href="https://www.rainbowhealthvic.org.au/media/pages/research-resources/the-everyday-experiences-of-lesbian-gay-bisexual-transgender-and-intersex-lgbti-people-living-with-disability/1242611313-1605661766/the-everyday-experiences-of-lesbian-gay-bisexual-transgender-and-intersex-lgbti-people-living-with-disability.pdf in March 2021.
- viii Leonard, W. and Mann, R. (2018) The everyday experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability, No.111 GLHV@ARCSHS, La Trobe University: Melbourne, accessed via <a href="https://www.rainbowhealthvic.org.au/media/pages/research-resources/the-everyday-experiences-of-lesbian-gay-bisexual-transgender-and-intersex-lgbti-people-living-with-disability/1242611313-1605661766/the-everyday-experiences-of-lesbian-gay-bisexual-transgender-and-intersex-lgbti-people-living-with-disability.pdf in March 2021.
- ix Disability Advocacy Network of Australia and others (2021), "Joint statement on the Australian Government's planned reforms to the NDIS", accessed via https://www.dana.org.au/ndis-concerns/ in March 2021.

ⁱNDIS (2021), "Access and eligibility policy with independent assessments", papers available via "https://www.ndis.gov.au/community/we-listened/you-said-we-heard-post-consultation-reports/access-and-eligibility-policy-independent-assessments, accessed in March 2021.

ii Disability Advocacy Network of Australia and others (2021), "Joint statement on the Australian Government's planned reforms to the NDIS", accessed via https://www.dana.org.au/ndis-concerns/ in March 2021.

iii Australian Government (2013), National Disability Insurance Scheme Act 2013, accessed via https://www.legislation.gov.au/Details/C2020C00392 in 2021.

iv UN General Assembly (2006), Article 4 of the Convention on the Rights of Persons with Disabilities, available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html, accessed in March 2021.

^v Harris, R (2021), "Leaked Laws reveal plan to kick Australians off the 22 billion dollar NDIS", published in the Sydney Morning Herald, on 26 March 2021, accessed via: https://www.smh.com.au/politics/federal/leaked-laws-reveal-plan-to-kick-australians-off-the-22-billion-ndis-20210325-p57dym.html in March 2021.

vi Avery, S (2021), Executive Summary: Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability, accessed via: https://fpdn.org.au/wp-content/uploads/2018/07/Culture-is-Inclusion-exec-summary-2.pdf in March 2021.