

Independent Assessments Inquiry

Submission

Joint Standing Committee on the National Disability Insurance Scheme



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Introduction

First Peoples Disability Network opposes the introduction of independent assessments as outlined by the National Disability Insurance Agency (NDIA). These proposals are causing a great deal of distress in our communities.

We believe the current reforms need to stop immediately, and that the NDIA needs to urgently work to repair trust with Aboriginal and Torres Strait Islander people with disability.

We make the following recommendations that the NDIA:

- immediately cease the implementation plan for independent functional assessments and outline a consultation process with people with disability and their representative organisation around the implications of the proposed changes.
- consult specifically with First People with disability and their representative organisations about the risk for our community in relation to independent assessments, the specific considerations needed and the parameters for tailored pilots with First Peoples with disability prior to any broader implementation.
- address the broader issues about access to the NDIS for First Peoples with disability through a genuine co-design process with First Peoples with disability.

We thank the Joint Standing Committee on the National Disability Insurance Scheme for examining this issue, and would be happy to discuss the matter further with you.

About Us

The First Peoples Disability Network Australia (FPDN) is a national organisation of and for Australia's First Peoples with disability, their families and communities. Our organisation is governed by First Peoples with lived experience of disability.

We proactively engage with communities around Australia and advocate for the interests of First Peoples with disability in Australia and Internationally. We follow the human rights framework established by the United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory, and the United Nations Declaration on the Rights of Indigenous Peoples.

First Peoples with disability and their families are amongst the most seriously disadvantaged and disempowered members of the Australian community. We give voice to their needs and concerns and share their narratives of lived experience.

We work for the recognition, respect, protection and fulfilment of the human rights of First Peoples with disability and their families.

We work within a social model of disability, in which we understand 'disability' to be the result of barriers to our equal participation in the social and physical environment. These barriers can and must be dismantled. The social model stands in contrast to a medical model of disability, which focuses on diagnosis.

First Peoples with disability and the NDIS

FPDN launched a 10-point-plan¹ for the implementation of the NDIS in Aboriginal and Torres Strait Islander Communities, with bipartisan support, in 2013 and updated it in 2018, with a broader, more comprehensive plan to fix the NDIS. However, the expertise and community connection of FPDN has not been adopted. A key recommendation that FPDN has long argued for is the establishment of a formal advisory structure made of First Peoples with disability and other First Peoples stakeholders to advise the NDIA. Such an approach has never been undertaken by the NDIA. This is in contravention of NDIA's own guiding document on engaging with First Peoples. Furthermore, we have long argued for a First Peoples representative to be on the board of the NDIA also to no avail.

FPDN has made a number of submissions, and contributed to many consultation processes about the functioning of the NDIS. It is estimated that 45% of First People have disability, yet our community does not receive equal support.

These priorities are:

1. Invest to create an Aboriginal Community Controlled Disability Service Sector for the provision of disability supports by Aboriginal and Torres Strait Islander people with disability for their communities
2. Address the barriers facing Aboriginal and Torres Strait Islander people in accessing the National Disability Insurance Scheme (NDIS)
3. Prioritise timely intervention to ensure supports and services are provided, and available over the long-term, and at the right time in people's lives
4. Recognise and value the existing knowledge, skills and expertise within Aboriginal and Torres Strait Islander communities. We are leaders in the inclusion of people with disability
5. Resource a community-directed research strategy which specifically focuses on Aboriginal and Torres Strait Islander disability
6. Endorse and support peer-to-peer leadership to ensure that Aboriginal and Torres Strait Islander people with disability lead the engagement with community themselves
7. Develop and implement an access to justice strategy for First People with disability, particularly those with cognitive impairment, sensory and intellectual disability
8. Develop and implement programs for inclusive education and employment for First People with disability in line with national strategies for their full social participation
9. Create links between the National Disability Strategy and Closing the Gap Framework for coordinated policy and programs at the Commonwealth, State and local levels in partnership with Aboriginal and Torres Strait Islander people with disability and their organisations
10. Develop an Aboriginal and Torres Strait Islander Disability Performance Framework for the independent monitoring of the social and economic outcomes of Aboriginal and Torres Strait Islander people with disability

¹ FPDN Ten Priorities to Address Inequity In Aboriginal and Torres Strait Islander Communities for the National Disability Strategy and National Disability Insurance Scheme
<https://fpdn.org.au/wp-content/uploads/2018/10/FPDN-ten-priorities-2018.pdf>

In a previous submission about proposed changes to the NDIS, we made the following key points about how the NDIS is functioning for Aboriginal and Torres Strait Islander people with disability that are relevant to the discussion about independent assessments.

Aboriginal and Torres Strait Islander people with disability:

- experience severe aggravated disadvantage because of the intersection of their Aboriginality with disability,
- face significant barriers to access the NDIS, asserting their rights and being aware of what supports are available,
- need culturally sensitive resources to manage supports and the associated administrative obligations,
- can be reluctant to engage with Government agencies for fear of unwanted surveillance and intervention in their lives,
- face barriers with mainstream disability service sector,
- need culturally safe, and available, diagnosis capacity, particularly of highly prevalent, stigmatised disability types such as Foetal Alcohol Spectrum Disorder (FASD).

We have continually raised concerns that, as with other Government service delivery mechanisms, the NDIA sits within a western bureaucratic structure that has been designed and functions without, and often conflicts with, Aboriginal and Torres Strait Islander culture (including our approach to disability) and structures.

Whilst investment is needed in shifting the service design and delivery, and building a workforce to be appropriate and responsive for Aboriginal and Torres Strait Islander people with disability, so too must there be dedicated, long term investment in building individual and community capacity and confidence to understand, negotiate, and assert their rights in a way that recognises and acknowledges cultural norms around care and community.

This includes navigating access and planning processes, avenues for recourse, safety and support where there is poor quality service, discrimination, or abuse, neglect or violence (including as relates to the Disability Discrimination Act and the NDIS Quality and Safeguards Commission).

We stress here that this is not just about providing accessible information in multiple formats, or educating people to better understand and navigate the actual processes and functions within the NDIA (although this is crucial). This is about investing in First Peoples with disability themselves (and their families and carers) to counteract the legacy of structures that have undermined individual and community autonomy and trust.

This is investment in building understanding more broadly around rights and entitlements, and building confidence to assert these rights, in order for First Peoples with disability to develop as self-advocates, and informed, confident consumers within the disability service structure.

The Tune Report notes:

‘Aboriginal and Torres Strait Islander people may also have a rational fear or mistrust of government agencies and service providers, resulting from racially-based

intergenerational and historical mistreatment, social exclusion and discrimination. In delivering outreach activities, it must be recognised that discussions about disability may not be easy for Aboriginal and Torres Strait Islander people and historical perceptions, past experiences and beliefs may hinder engagement. The task ahead for the NDIA in overcoming these issues is significant’.

and:

‘Aboriginal and Torres Strait Islander people are more likely to find out about the NDIS from speaking to someone. This suggests the best prospects of an Aboriginal and Torres Strait Islander person engaging with the NDIS will be if the information is provided by a trusted member of their own community, in the language spoken within that community’².

FPDN acknowledges some of successes in terms of successful engagement with First Peoples and their communities. But such success is very limited to only a small number of locations. This is far from a universal experience for First Peoples with disability. FPDN is regularly contacted by community members from around Australia that express often very serious allegations that range from feeling seriously marginalised because of race, to feeling patronised and talked down to. A further regular comment from community members is that the expectation is that First Peoples with disability and their families have to fit into the NDIA system and that the system simply does not properly or adequately understand the real lived experiences of many First Peoples with disability which often relates to people living in extreme poverty.

We urge the Committee to consider these wider issues as they consider any changes to accessing and using NDIS supports.

² Review of the National Disability Insurance Act, Removing Red Tape and Implementing the Participant Service Guarantee’ David Tune AOP PSM (2019), p.84 5.58
<https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disabilityinsurance-scheme/review-of-the-ndis-act-report>

Independent Assessments

Independent Assessments (IAs), with their one-kind-fits-all approach are totally inappropriate to assess the needs to Aboriginal and Torres Strait Islander people with disability, and will lead to our community having plans cut, or losing access altogether.

There are several serious issues that we believe will be made worse by the introduction of IAs. These include:

- Greater surveillance of Aboriginal and Torres Strait Islander people,
- More children and young people being removed from families who can't access NDIS supports,
- Lack of cultural safety in process, delivery or staff,
- Risk of racial stereotyping by assessors, and lack of respect for cultural practice, including women's and men's business.

We acknowledge that for many First Peoples with disability, access to the scheme is hindered by the expectation to produce multiple forms evidence to support their application and demonstrate impairment and the impact that this has on their lives. There are many factors to take into account here, including access to specialist services that are culturally appropriate and responsive, understanding of health and other professionals of what is required, costs of reports and tests, as well as the costs to travel to access services etc.

In proposing the introduction of independent assessments, the Tune Review notes with concern that:

‘One of the biggest risks in implementing the new functional capacity assessment process will be disengagement – that is, people with disability refusing to interact with any of the NDIA-approved providers. As with the NDIS as a system more generally, this is a particular risk for Aboriginal and Torres Strait Islanders, those from CALD backgrounds and those with psychosocial disability’. And that; ‘Given this, the depth of the NDIA-approved panel of assessors must be sufficient to mitigate any engagement risks for these cohorts as well as any other issues relevant in specific locations, communities, or for particular disability types.’³

The Committee would be aware of the extreme distress that the announcement of the independent assessments has caused amongst people with disability, and of concerns raised directly with the Minister and the NDIA.

Whilst the NDIA has undertaken a consultation process with disability representative organisations in relation to the assessments, this process has been rushed, and leaves little opportunity to consult broadly across the community as to the implications for people with disability, their families and carers. The consultation has also focused on how to implement the independent assessments, rather than on whether to implement them at all.

³ Review of the National Disability Insurance Act, Removing Red Tape and Implementing the Participant Service Guarantee' David Tune AOP PSM (2019) <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurancescheme/view-of-the-ndis-act-report>, P.67, 4.35

We hold significant concerns in relation to this process for First Peoples with disability, including:

- The functional assessments have been moved forward based on very small pilot projects, which had no specific focus on Aboriginal and Torres Strait Islander communities. In addition, the data released in relation to the pilots is incomplete and in no way represents proof of effectiveness, or demonstrates positive outcomes for participants.
- Lack of sufficient skills and knowledge from contracted assessors and question how the NDIA are going to build the trust within communities or gain requisite knowledge or understand of individual circumstances during a proposed 1-4 hour meeting. Findings of the research report *Culture Is Inclusion*⁴ acknowledged the process of relationship building is foremost in dealing with our people.
- The assessments, it is suggested by the NDIA, will provide more equitable access for all potential participants to eligibility assessment without the need for additional reports, or travel to see specialists. For many First Peoples with disability, particularly those in remote areas, they do not have access to technology and phone required to be able to communicate with the Agency and as raised by the Tune Review, are much more likely to either disengage from a process, or not pursue access at the outset where there is no trust or relationship with an independent assessor.
- It is proposed that assessors will use the same set of assessment tools to ensure 'everyone is treated in a fair and consistent way'⁵. We argue that due to the multiple factors affected our community, including; poverty, lack of access to appropriate services, discrimination, and wellfounded fear of bureaucratic structures and authority. A one size fit all approach is not appropriate for First Peoples with disability.

Research from Professor Chris Cuneen has found that, for Aboriginal and Torres Strait Islander people, "new obligations imposed through welfare conditionality have involved increased systems of regulatory surveillance as a condition of receiving social services. Importantly, social welfare has come to be informed by the same values and philosophies as criminal justice: deterrence, surveillance, stigma and graduated sanctions."⁶

This new way of assessing disability, proposed by the NDIA, will impose a new layer of surveillance on a community already significantly under scrutiny, in order to gain access to essential services. That increase in surveillance will add to an already disproportionate level of scrutiny on Aboriginal and Torres Strait Islander people with disability that often leads to child removal or the justice system, rather than to appropriate disability supports.

There has been no specific testing of the independent assessments with First People with disability, including to test the cultural safety of the process. There is also likely to be a very small pool of available Aboriginal and Torres Strait Islander people who could perform the assessments, which will contribute directly to the lack of cultural safety. There is currently no indication that independent assessors will understand or know about cultural practice, such as women's and men's business.

⁴ Avery, S. (2018) 'Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability'

⁵ Joint Standing Committee on the National Disability Insurance Scheme, public hearing October 12, 2020. Evidence from NDIA CEO, Mr Martin Hoffman, accessed in Hansard p.2

⁶ Surveillance, Stigma, Removal: Indigenous Child Welfare and Juvenile Justice in the Age of Neoliberalism, CHRIS CUNNEEN (2016) 19(1) Australian Indigenous Law Review 32

Child removal and disability

For many First Nations families, disability is first recognised in their lives when children come into contact with the child protection system. Up to that point, that family has likely had a pathway of unrecognised and unsupported disability. This may be disability from birth, or acquired disability through the course of their life. Disability, coupled with intersectional discrimination, poverty⁷ and trauma interacts with system failures, including a lack of appropriate health care, a lack of inclusive and culturally appropriate education, insecure and inaccessible housing in community, and punitive welfare policies.

The many and various interactions with service systems that these families have, provides numerous entry points for disability to be recognised and referrals for support. In our experience with community, this rarely occurs due to disjointed and siloed services, and many of these families do not have the knowledge of their rights, or the capacity or confidence to proactively reach out for such support. The system failures create a trajectory of institutionalisation through child protection and criminal justice systems that in many cases could have been avoided.

From FPDN's experience in community, we know that these paternalistic assumptions can lead to parents with disability, and/or parents of children with disability doubting their right and ability to parent and being encouraged to surrender their children, rather than support being put in place to ensure families can stay together, in their communities, where possible. The NDIS has expectations about parental responsibility and the balance with funded support⁸. Some families, struggling with poverty, insecure and inaccessible housing and the care of other siblings, are left feeling they have no choice but to relinquish care.

For families who may require communication, or decision making support, or who face barriers of literacy and language, understanding and navigating the system is impossible. Disability advocates can assist families by working with them to understand the processes involved, seeking disability support and assistance, and linking them with other social services and legal assistance. This legal assistance can be essential to negotiate court proceedings. The absence of this support may result in negative guardianship judgements that sever families forever and leave parents with no ongoing say in their children's lives. A critical shortage of First Nations disability advocates in local communities means that families are often left with no help.

From our perspective, there is no evidence that the NDIS is positively working with other social services to support families to avoid child protection issues arising, or putting in place supports which prioritise children remaining in their family where child protection concerns occur. The proposed Independent Assessments⁹ present a significant risk of increasing family separation and child removals.

⁷ Research has also shown the increased financial stress on carers within First Nations families <https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0668-3>

⁸ Children and Young People with Disability Australia October 2019 *Improving the NDIS for children and young people with disability* Submission to the consultation on Establishing a Participant Service Guarantee and removing legislative red tape review <https://engage.dss.gov.au/wp-content/uploads/2019/11/Children-and-Young-People-with-Disability-Australia.pdf>

⁹ See First Peoples Disability Network submission to the Joint Standing Committee on the National Disability Insurance Scheme – General Issues around the implementation and performance of the NDIS, awaiting publication https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS