



August 2023

The NDIS and Medical Model Gatekeeping

Moving away from a need for diagnostic evidence to ensure equal access to disability supports for First Nations people

For the National Disability Insurance Scheme (NDIS) Review

Acknowledgements

FPDN greatly acknowledges the voices and expertise of First Nations people with disability who have had experience with the NDIS and thanks them for sharing their stories.

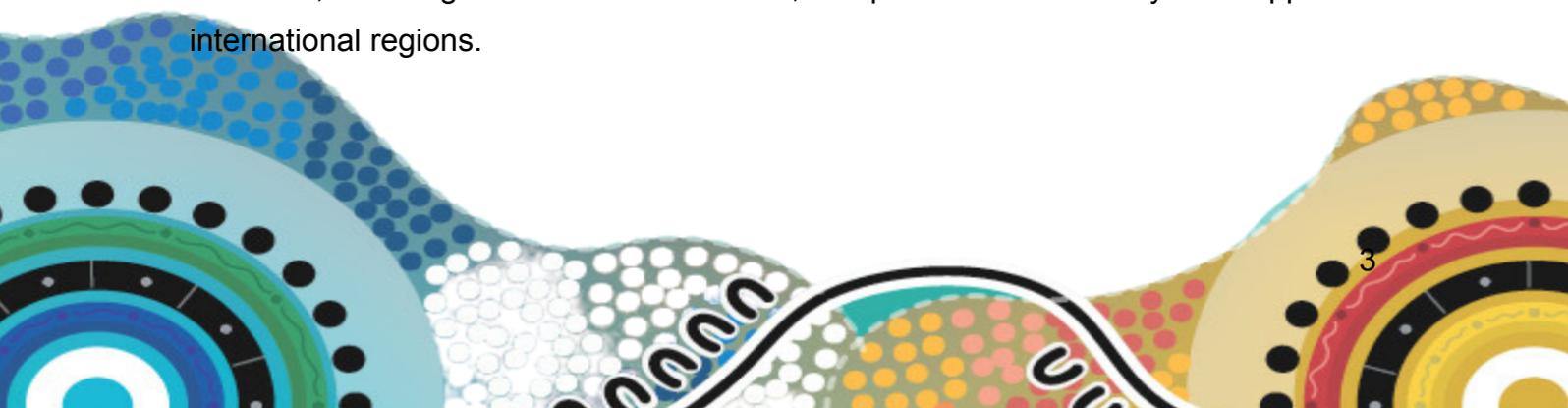
FPDN acknowledges the funding and support from the Department of Social Services and the NDIS Review Secretariat to undertake consultation with community to inform our submissions to the NDIS Review. Our submissions also draw from previous consultations and data collected with and for community in ensuring the NDIS meets the diverse needs of our community.

About FPDN

The First Peoples Disability Network (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 are the custodians of the narratives of First Peoples with disability, their families, and communities, and we recognise this important responsibility.

FPDN was established informally in 2010 and registered as a public company limited by guarantee in 2014 and has a network across Australia in remote, regional and urban locations. FPDN is the community-controlled disability peak and a member of the Coalition of Peaks, a partner to all Australian governments to the Closing the Gap National Agreement. We are also the First Nations Disability Representative Organisation actively representing the voices of First Nations peoples within Australia's Disability Strategy governance structures. For millennia, First Nations peoples, communities, and cultures have practiced models of inclusion. However, despite this, since colonisation, First Peoples with disability and their families have been and continue to be amongst the most seriously disadvantaged and disempowered members of the Australian community. FPDN gives voice to their aspirations, needs and concerns and shares their narratives of lived experience.

Our purpose is to promote recognition, respect, protection, and fulfilment of human rights, secure social justice, and empower First Peoples with disability to participate in Australian society on an equal basis with others. Our extensive national work includes community engagement, capacity building and rights education; systemic advocacy, policy, research, evaluation and data; the development and delivery of evidence-informed training and resources with community for community and to a range of sectors including the Community Controlled sector and mainstream disability sector, Commonwealth and state/territory government policy and service delivery agencies and departments. FPDN also has an international presence and networks, including with the United Nations, and provides consultancy and support to international regions.



We follow the human rights framework established by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), to which Australia is a signatory, and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).

We are also guided by both the social and cultural models of disability. The social model views 'disability' to be the result of barriers to equal participation in the social and physical environment. These barriers can and must be dismantled. However, FPDN recognises the critical need to move beyond a social model to ensure the cultural determinants of what keeps First Nations people with disability strong is centred when working with and in designing policies and programs to improve outcomes for First Nations people. We call this a cultural model of inclusion.

A cultural model of inclusion recognises the diversity of cultures, languages, knowledge systems and beliefs of First Nations people and the importance of valuing and enabling participation in society in ways that are meaningful to First Peoples (Avery 2018). A First Nations cultural model of inclusion includes the human rights framework and the social model of disability to ensure that enablers, approaches, services and supports are culturally safe and inclusive, and disability rights informed. It is the only disability model that seeks to improve the human condition through focussing on what keeps people strong, as distinct to merely negating the adverse impact of difference.

Our community has to operate in multiple worlds – First Nations, disability, and mainstream society. The disability sector reflects this and is a complex and interconnected web of approaches to enable First Nations people with disabilities to realise their rights to participate in all aspects of their life, including the NDIS. These enablers, approaches, services and supports need to exist across the entire life-course, including the Aboriginal and Torres Strait Islander Community Controlled Sector and mainstream disability sector, as well as mainstream organisations and services. They also need to exist across the early childhood development and care, education, health, social and emotional wellbeing, employment, housing and justice sectors.

We recognise the unique opportunity the NDIS Review offers in improving its design and implementation to ensure First Nations people with disability engagement and

benefit of the scheme is culturally safe and inclusive, equitable and disability rights informed. By centering a cultural model of inclusion, through elevating the experiences, aspirations, needs and rights of First Nations people with disability the NDIS can be strengthened not only for First Nations people with disability but for all.

Executive summary

For millennia, First Nations peoples, communities, and cultures have practiced models of inclusion. This embracing of diversity and inclusion “is derived from a belief system and worldview of humanity in which biological, physical and intellectual differences are accepted as part of the fabric of society (Avery, 2018).” Drawing on nation-wide available data, First Nations people with disability are included in their own communities across social, cultural and community events on average more than other Australians with disability.

However, despite this strength, since colonisation First Nations people with disability experience significant levels of inequality across all other life areas compared to other Australians, including in areas of health, education and social inequality (Avery 2018; ABS 2016). Whilst population prevalence data is limited⁴, First Nations people are twice as likely to experience disability than the rest of the Australian population (ABS, 2016). Using the statistical definitions of ‘severe and profound disability’ in the Australian Bureau of Statistics (ABS) datasets, including the ABS Survey of Disability, Ageing and Carers (SDAC), 2018, it is estimated that over 60,000 Aboriginal and Torres Strait Islander people live with severe or profound disability in Australia today (Avery 2018)⁵.

First Nations people with disability experience many intersectional forms of discrimination, including discrimination based on age, gender, sexuality and geographic location. These intersecting forms of discrimination are institutionalised and embedded in how policies and programs have been designed, including the NDIS. The use of medical model-based diagnostic testing as the basis to access to the NDIS is an example of institutional discrimination as it actively excludes First Nations people from participating in the NDIS.

Drawing on the experiences of First Nations people through a range of data collection methods, including recent and past consultations, a national survey and previous research undertaken by FPDN, this submission highlights how the NDIS' reliance on the Medical Model of Disability ultimately fails First Nations people, who face unique and significant barriers to accessing formal diagnoses for their conditions. In addition to the fundamental flaw in the diagnostic tests as being culturally inappropriate especially the WHODAS and Pedi-CAT, key barriers include locational barriers to undertaking the diagnostic testing, financial barriers associated with obtaining the diagnostic tests, medical diagnoses were described as being inaccessible to First Nations communities

This submission provides seven key recommendations to improve the NDIS. FPDN expects the recommendations to be implemented in line with the Closing the Gap National Agreement Priority Reforms and the Disability Sector Strengthening Plan Guiding Principles. The Priority Reforms focus on changing the way governments work with Aboriginal and Torres Strait Islander peoples and the Disability Sector Strengthening Plan outlines high-level priorities and actions at a national level to strengthen and build a Community Controlled Disability Sector. The Commonwealth government, including the NDIA and other agencies connected to the NDIS, is a signatory and partner to the National Agreement and also the Disability Sector Strengthening Plan. The Priority Reforms are:

1. Formal partnerships and shared decision-making
2. Building the community-controlled sector
3. Transforming government organisations
4. Shared access to data and information at a regional level

Applying the Closing the Gap approach to disability as a cross-cutting outcome through the Priority Reforms, they offer the NDIS Review, the panel, and the NDIA a structure to ensure First Nations peoples with disability to have:

- a greater say in how policies and programs are designed and delivered;
- have access to community controlled services and sectors that delivers culturally safe, accessible and inclusive, and disability right informed services;
- have access to mainstream organisations and services, such as NDIS services, hospitals, schools and government agencies, that are culturally safe, accessible and inclusive, and disability right informed;

- and have access to, and the capability to use, locally-relevant, First Nations disability informed, data and information.

The National Agreement, supported by extensive community consultation and data acknowledges that Aboriginal and Torres Strait Islander community-controlled services are better for Aboriginal and Torres Strait Islander people, achieve better results, employ more Aboriginal and Torres Strait Islander people and are often preferred over mainstream services. FPDN, as the First Nations disability peak, is well placed to partner with government on designing and implementing these recommendations.

This submission urges the NDIS Review to consider the following recommendations:

Recommendation 1 – Redefine the NDIS access criteria to align with a Cultural Model of Inclusion Framework of disability, centring Human Rights to

recognise First Nations people with disability as having a fundamental right to full societal participation on an equal basis with non-disabled people. This should ensure that the NDIS determines access and funding decisions based on individual support needs and what keeps First Nations people strong and participating in community, rather than formal diagnoses and Functional Capacity assessments that are not culturally appropriate.

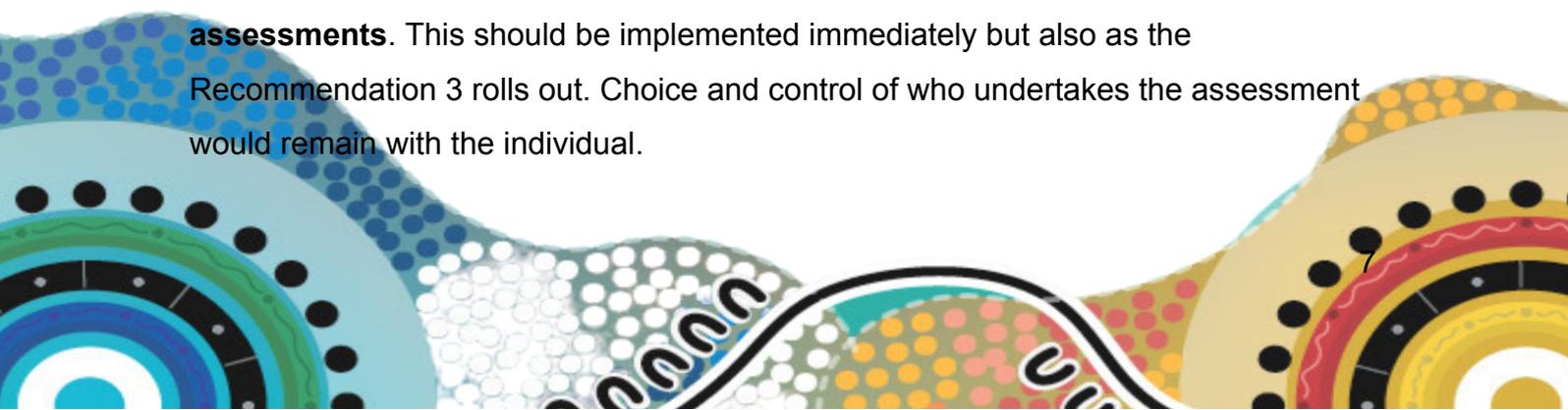
Recommendation 2 – Support a program of work to develop and implement culturally responsive diagnostic testing tools. This would include undertaking

mapping into existing culturally responsive diagnostic tools nationally and Internationally; developing new culturally responsive diagnostic tools; and building a First Nations workforce to undertake the culturally responsive diagnostic testing.

This responds to the lack of cultural appropriateness of the WHODAS and Pedi-CAT.

Recommendation 3 – Identify options to offer financial support or subsidy program based on ‘priority of access’ process to undertake initial assessments. This should be implemented immediately but also as the

Recommendation 3 rolls out. Choice and control of who undertakes the assessment would remain with the individual.



Recommendation 4 – Improve and maintain quality of culturally safe and inclusive, and disability rights informed National Disability Insurance Agency (NDIA) and NDIS Quality and Safeguards Commission through the design and implementation of an NDIS specific version of FPDN’s Cultural Model of Inclusion capability framework. The framework will incorporate an intersectionality approach including gender specific elements. This includes whole of organisation (culture and leadership, governance, workforce and services/programs) capability uplift including training.

Recommendation 5 – Conduct targeted and measurable workforce planning and implementation to grow a First Nations NDIS workforce and within the disability service sector. This should include, and prioritise, long term targeted approaches that build on an evidence-base of the community, cultural, system and legislative opportunities and barriers to increasing the workforce. There should be a specific focus on building a rural and regional First Nations workforce to respond to the significant workforce shortages. This work should align with other workforce strategies, plans and frameworks, including the Disability Sector Strengthening Plan. Refer to FPDN NDIS Review Paper Workforce for specific recommendations.

Recommendation 6 - Establish a program of work, including pilots, focussing on early intervention in children and young people and the justice system or in communities of high incarceration rates. Fair and equitable access to early intervention supports.

Recommendation 7– Investment in strengthening data and evaluation and dissemination of data and evaluation back to communities, in line with Priority Reform 4, and aligning with principles of Indigenous disability data sovereignty.



1. Introduction

The National Disability Insurance Scheme (NDIS) is currently undergoing a major review to examine the design, operations and sustainability of the NDIS. The Review is looking at ways to make the market and workforce more responsive, supportive and sustainable.

In June and July of 2023, FPDN conducted consultations with First Peoples with disability, their families, communities and support organisations, to inform our NDIS Review submissions. These consultations involved individual and community meetings in the Kimberly region, including in Mowunjam, Broome, Fitzroy Crossing, Bidyadanga and the Peninsular communities of Lombadina and Beagle Bay; as well as a national online survey of FPDN members.

As of mid-August 2023, the community consultations had engaged 49 First Nations people and 34 organisations; while the survey has been completed by 22 First Nations people and five others. More consultations were underway in late August.

Drawing on the feedback and stories gained in these consultations, this submission highlights the ways in which the NDIS is inaccessible to First Nations communities. In particular, the submission highlights a need for the NDIS to consider access pathways for those without formal diagnoses for their conditions.

Throughout the submission, de-identified summaries are provided of First Nations people's experiences with the NDIS. Direct quotes from the FPDN NDIS Review survey are also incorporated.



2. The dominance of the Medical Model of Disability

The NDIS was first implemented through the *National Disability Insurance Scheme Act 2013* (the “*NDIS Act*”) in 2013 as the first nationally coordinated attempt to address the rights and support needs of people with disability.¹

Under the *NDIS Act*, a key principle of the NDIS is that people with disability have a right to the supports they need to participate on an equal basis in all areas of social, economic and cultural life. To this end, the NDIS, when viewed in conjunction with other legislative and policy frameworks such as the *Disability Discrimination Act 1992* and the *Australian Disability Strategy (ADS)*, has been praised both within Australia and internationally as a means to implement the United Convention on the Rights of Persons with Disabilities (UNCRPD), as well as other human rights treaties, in practice.²

However, while the UNCRPD is premised on a Human Rights Model of Disability,³ which recognises that the disadvantages experienced by people with disability are a product of societal structures, not individual impairments;⁴ the processes for determining access to the NDIS require individuals to have a documented medical impairment or diagnosis – in line with Medical Model theory.⁵

Drawing on the experiences of First Nations people that were described in the FPDN consultations, this submission highlights how the NDIS reliance on the Medical Model of Disability fails First Nations people, who face unique and significant barriers to accessing formal diagnoses for their conditions.

In outlining these failures, FPDN draws the attention of the NDIS Review to Australia’s obligations under CRPD, in combination with the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP);⁶ and emphasises the United Nations Committee on the Rights of Persons with Disabilities (the UN

¹ National Disability Insurance Scheme (NDIS) (2022) [The NDIS Act](#), National Disability Insurance Agency, accessed 18 August 2023.

² Tune, D (2019) [Review of the National Disability Insurance Scheme 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee](#), prepared for the Australian Government, Canberra, accessed 18 August 2023, p. 27.

³ Korolkova, J. and Anthony, A. (2016) [The United Nations Convention on the Rights of Persons with Disabilities and the right to support](#), Prepared for the Disability Human Rights Clinic, University of Melbourne, accessed 19 August 2023.

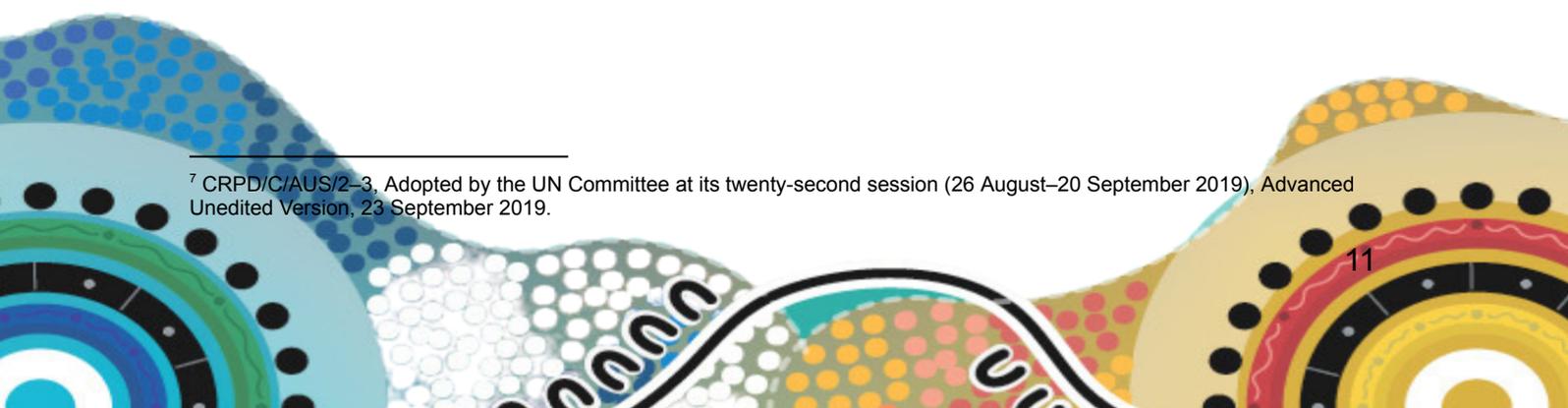
⁴ Degener, T (2014) ‘A Human Rights Model of Disability’, from: [Routledge Handbook of Disability Law and Human Rights](#), accessed 19 August 2023.

⁵ Medical Model

⁶ United Nations Declaration on the Rights of Indigenous Peoples, GA Res 61/295, UN GAOR, 61st Sess, 107th plenary mtg, Agenda Item 68, Supp No 49, UN Doc A/Res/61/295, Annex (2 October 2007) 295.

Committee) 2019 Concluding Observations on the combined second and third periodic reports of Australia, which highlighted the NDIS access barriers experienced by First Nations people.⁷

⁷ CRPD/C/AUS/2–3. Adopted by the UN Committee at its twenty-second session (26 August–20 September 2019), Advanced Unedited Version, 23 September 2019.



3. Access Issues

Across the sector, it is well known that First Nations people with disability face significant barriers to accessing the NDIS. Despite making up more than one-quarter (24.0% or 139,700 people) of the First Nations population,⁸ First Nations people with disability account for just over 40 000 NDIS participants,⁹ and experience significant barriers to accessing accessible and culturally appropriate services, even within the NDIS system.

In previous reports and submissions, FPDN has highlighted how the NDIS access requirements disadvantage First Nations people;¹⁰ many of which were reflected in FPDN's recent NDIS Review consultations.

a. Medical diagnoses are often inaccessible

Across all of the NDIS Review community consultations and the survey, participants expressed frustration about the reliance of the NDIS on medical diagnoses when determining access eligibility. Due to barriers associated with location, finances and cultural differences, medical diagnoses were described as being inaccessible to First Nations communities. In response to a question about what could improve the NDIS for example, participants said:

“Need to help First Nations people get access to earlier assessments and diagnosis so that they can have supports earlier. These should be funded in NDIS plans as most people cannot get these done and without them, they cannot get access to NDIS.”

“More wrap around support with health and education I know NDIS doesn't support this but for first nation have a hard time accessing these support at the best of time. Nevertheless having disability.”

⁸ Australian Bureau of Statistics (2021) 'Aboriginal and Torres Strait Islander people with disability,' Data from the [Disability, Ageing and Carers, Australia: Summary of Findings Report](#), accessed 18 August 2023.

⁹ National Disability Insurance Agency (2023) '[More First Nations Australians Receiving NDIS support](#),' accessed 18 August 2023.

¹⁰ See e.g. FPDN (2021) 'Submission Joint Standing Committee on the National Disability Insurance Scheme,' *First People's Disability Network*, Sydney; FPDN (2013) 'Ten Priorities to Address Inequity In Aboriginal and Torres Strait Islander Communities for the National Disability Strategy and National Disability Insurance Scheme,' *First People's Disability Network*, Sydney.

In the Kimberly region consultations, individual participants and organisations similarly spoke about how accessing a diagnosis was virtually impossible for a range of reasons.

Due to a severe lack of specialists and services in the regions for example, participants spoke about having to travel extremely long distances to access diagnostic assessments. While most of the communities were visited by General Practitioners (GPs) on a fly in, fly out (FIFO) basis, the GPs were often different each time, and therefore lacked the medical 'history' knowledge required to make accurate diagnostic assessments.

Additionally, a number of First Nations people in both the community consultations and the survey expressed hesitancy about accessing medical and government services, due to having experienced historical mistreatment and abuse from these providers. Parents of children with disability in particular, expressed fear of having their children removed if they are identified as having disability.

“Give opportunity to First Nation people to funding but allow them time to process the influx of support gradually as there is a trust issue with Government agencies for First Nations people.”

When First Nations individuals and families had accessed diagnostic services, they also described experiencing medical dismissiveness or mis-diagnoses, which prevented them from accessing appropriate supports and services. In a number of cases for instance, families spoke about their children being mis-diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) - instead of Autism or Foetal Alcohol Spectrum Disorder (FASD) - which is not eligible for funding under the NDIS.

“I am so disabled that I cannot even manage to get help accessing the NDIS. My family is so overwhelmed just surviving day to day that there is no-one to help me. Doctors routinely ignore what I say and just tell me to eat better. They don't know what I eat. I cannot even get doctors to take all my health problems seriously enough to even get scans or tests or advice or a diagnosis. My regular doctor retired. She never even thought to suggest I am neurodiverse even though it's clear that I am extremely so.”

b. The NDIS and Psychosocial Disability

Across all of the Kimberly consultations, participants spoke about mental health conditions being common due to issues such as social isolation, substance abuse and a lack of effective prevention initiatives. In a number of instances, individuals were aware that they had a psychosocial disability, and in some cases, had done for years, but did not have a name or diagnosis for their condition.

In other cases, it was highlighted that First Nations people received an accurate diagnosis and access to the NDIS, only once they had had interactions with the criminal justice system or experienced incarceration.

For those that did have diagnoses, there were also additional issues associated with a lack of availability of psychologists and counsellors, and with service sectors providing confusing and conflicting information about who is responsible for ongoing case management and service provision. In a number of cases, participants and service providers said that individuals were often handballed between the NDIS and mental health sector services, with the NDIS saying 'we don't fund X' and vice versa.

c. Cultural differences in understandings of disability

Another issue with the NDIS relying on diagnoses for scheme entry is that there are differences in cultural understandings of disability among First Nations communities.

Unlike non-indigenous communities, First Nations people often do not see disabilities as deficiencies or problems within individuals,¹¹ but rather as being difference that is equal to all other differences among individuals. For many First Nations communities, disability is seen as a western label that does not apply to their people;¹¹ so the NDIS requirement for a diagnostic label, sits at odds with their cultural values.

In the NDIS review survey, a number of participants raised this issue in response to questions about how the NDIS could improve the experiences of First Nations people.

¹¹ See e.g., Velarde, M (2018) '[Indigenous Perspectives of Disability](#),' *Disability Studies Quarterly*, Vol. 38, no. 4, accessed 19 August 2023.

“Aboriginal people don’t recognise disability.”

“An understanding of what disability means in Aboriginal context.”

“Recognition on how families see and manage disabilities as the person is not treated any different than someone without a disability.”

“We are NOT A BURDEN. People who wear glasses or contact lenses ARE DISABLED...but they have access from birth to ACCESS ASSISTANCE for their disability. So much that we don't even SEE IT AS A DISABILITY!!!! Why is that the only disability that we have achieved this for? Dream a world where every disability has the same amount of annual access assistance from birth.”

d. Functional Capacity Assessments (FCA’s) are culturally inappropriate and insensitive

Another major access issue previously raised by FPDN, which emerged strongly in the NDIS Review consultations is the requirement to prove the impact of disability with medical reports and Functional Capacity Assessments (FCA’s).

In previous reports and submissions, FPDN has raised significant concerns about the cultural appropriateness of FCA’s for First Nations people and has highlighted how the NDIS requirement to provide substantial evidence of impairment prevents access due to factors such as: a lack of access to specialist services that are culturally appropriate and responsive, prohibitive costs of reports and tests and a need to travel from remote areas to access assessments; all of which were issues reflected in the NDIS review consultations.

In the Kimberly region consultations for instance, a number of individuals and families spoke about FCA’s being culturally inappropriate for First Nations people and therefore, said that there was community hesitance to pursue assessments. In the survey, a number of participants also suggested a need to remove the need for FCA’s and other substantial ‘evidence’ to access the NDIS.

“Better Communication from NDIS access team when impairment evidence is not sufficient and more evidence is requested, also intergenerational trauma, and household challenges excepted as evidence.”

“It needs to be a simple process without the overwhelming need to obtain substantial evidence to prove disability.”



4. Conclusion and Recommendations

Drawing on the findings from FPDN's NDIS Review consultations, this submission has outlined how the requirement to have a formal medical diagnosis to access the NDIS denies disability supports to First Nations people, who face a range of barriers to accessing professional clinicians and diagnostic assessments.

While the NDIS has been described as being a key means to implement the rights of people with disability under the UNCRPD, the NDIS reliance on diagnoses and evidence of impairment, in the form of FCA's and reports from professionals, reflects the logic of the Medical Model of Disability, which sits at odds with the UNCRPD's human rights framework and omits First Nations cultural differences in how disability is valued and considered.

In order to ensure that First Nations people with disability are able to access supports and services that are adequate, accessible and culturally relevant, FPDN urges the NDIS Review to consider the following recommendations for implementation:

Recommendation 1 – Redefine the NDIS access criteria to align with a Cultural Model of Inclusion Framework of disability, centring Human Rights to recognise First Nations people with disability as having a fundamental right to full societal participation on an equal basis with non-disabled people. This should ensure that the NDIS determines access and funding decisions based on individual support needs and what keeps First Nations people strong and participating in community, rather than formal diagnoses and Functional Capacity assessments that are not culturally appropriate.

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