



12 March 2024

Committee Secretary  
Joint Standing Committee on the National Disability Insurance Scheme

**FPDN Submission: Inquiry into NDIS participant experience in rural, regional and remote Australia**

The First Peoples Disability Network (FPDN) welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into the NDIS participant experience in rural, regional and remote Australia.

In summary, FPDN highlights the following as both opportunities and limitations to respond to the many adverse experiences First Nations people with disability in rural, regional and remote Australia experience, and a need to :

- Apply the Cultural Model of Inclusion Framework to determine the extent the NDIA/NDIS is culturally safe, inclusive and disability rights informed;
- Centre Country and First Nations cultures in the design and implementation of the NDIS;
- Provide access and awareness to information about the NDIS by services and the community;
- Increase availability and access to culturally safe, inclusive and disability rights informed diagnostic testing, early intervention support and intervention to support children and families with developmental delays;
- Increase culturally safe, inclusive and disability rights informed services, organisations and workforce; and
- Increase culturally safe, inclusive and disability rights informed available services, or 'thin markets' in regional, rural and remote locations.

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. Our submissions also draw from previous consultations and data collected with and for community, particularly undertaken as part of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and NDIS Review, in ensuring the NDIS meets the rights and diverse needs of our community.

### **About FPDN**

The First Peoples Disability Network (FPDN) is the national peak organisation of and for Australia's First Peoples with disability, their families and communities. We actively engage with communities around Australia and represent Aboriginal and Torres Strait Islander people with disability in Australia and internationally. Our goal is to influence public policy within a human rights framework established by the United Nations Convention on the Rights of Persons with Disability and the United Nations Declaration on the Rights of Indigenous Peoples. Consistent with our principle of community control, our organisation is governed by First Peoples with lived experience of disability.

FPDN is the First Nations' Disabled Peoples Organisation and Disability Representative Organisation, as well as the Aboriginal community-controlled disability peak, and member of the Coalition of Peaks, a partner to all Australian governments through the National Agreement on Closing the Gap (the National Agreement). FPDN led the development of the Closing the Gap (CtG) Disability Sector Strengthening Plan and in line with disability as a cross-cutting outcome area, we are actively involved in policies across the life-course and across all sectors; for example FPDN is a member of the CtG Housing Sector strengthen agenda, the CtG Justice Policy Partnership and the CtG Early Childhood and Development Policy Partnership and Steering Committee National Plan Aboriginal and Torres Strait Islander Family Safety. FPDN is also a key Commonwealth partner dedicated to progressing implementation of Australia's Disability Strategy 2021-2031 and all associated advisory groups.

We follow the human rights framework established by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 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<sup>1</sup>. 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 from merely negating the adverse impact of difference. 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.

### **National Disability Insurance Scheme**

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.<sup>2</sup> Under the NDIS Act, a key principle of the NDIS is that people with disabilities 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) in practice<sup>3</sup>.

Under the NDIS Act and in line with Australia’s obligations under the United Convention on the Rights of Persons with Disabilities (UNCRPD), it is stated, among a number of other objectives, the NDIS aims to ensure that people with disability have access to high quality and innovative supports that support their full societal participation and to ensure that people with disability are able to exercise choice and control in the planning and delivery of their supports<sup>4</sup>. However, as will be outlined in this submission, these objectives, and in turn, Australia’s UNCRPD obligations, are not currently being fulfilled for First Nations peoples.

While there is currently no international convention on the rights of Indigenous peoples, FPDN draws the attention of the NDIS Review to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP),<sup>5</sup> to which Australia is also a signatory as well as to the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee) 2019 Concluding Observations on the combined second and third periodic reports of

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<sup>1</sup> S Avery, ‘[Culture is Inclusion](#),’ 2018, First Peoples Disability Network.

<sup>2</sup> National Disability Insurance Scheme (NDIS) (2022) The NDIS Act, National Disability Insurance Agency, accessed 18 August 2023.

<sup>3</sup> See e.g. Tune, D (2019) Review of the National Disability Insurance Scheme 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee, accessed 11 August 2023, p. 25.

<sup>4</sup> NDIS objectives

<sup>5</sup> 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.

Australia, which highlighted the difficulties faced by First Nations people with disability in accessing accessible and appropriate services through the NDIS<sup>6</sup>.

The National Disability Insurance Scheme (NDIS) presents many opportunities to enable the participation of First Nations people with disability in community, cultural, social, educational, economic participation. However, there are too many barriers for First Nations people with disability, at every stage of their NDIS journey. This includes applying and gaining access to the NDIS to the design of a plan that meets participants needs in all aspects of their lives. Putting a plan into action and ensuring that participants have appropriate access to services and ensuring that these supports are appropriately funded but also making sure that participants' needs are continually met throughout their lifetime on the scheme particularly as they grow and change. For First Nations NDIS participants living in rural, regional or remote areas accessing services can be significantly limited due to a multitude of barriers, some of which will be discussed throughout this submission.

### **Disability Royal Commission into abuse, neglect and exploitation and NDIS Review**

The final reports of both the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('DRC') on 29 September 2023, and the Australia Government's Independent Review into the National Disability Insurance Scheme ('NDIS Review') on 7 December 2023 has the opportunity for real reform. Throughout both the DRC and the NDIS Review, FPDN actively enabled and represented the voices of First Nations peoples with disability to be elevated. The findings and recommendations of both the DRC and NDIS Review highlighted the strengths and opportunity of a First Nations cultural model of inclusion to guide the reforms for a more inclusive society for all. The findings also saw the need for dedicated responses to address the disproportionate adverse experiences that First Nations people and families with disability experience due to ongoing legacies of colonisation - institutionalisation, incarceration, removal of children and of institutionalised racism and ableism in policies, programs and services.

Both the DRC and NDIS Review documented recommendations specific to First Nations people with disability, the community controlled sector, and specific to regional, rural and remote communities. FPDN is currently reviewing the recommendations, as is all Australian governments, however, we note a number of recommendations throughout this submission. However, in line with the National Agreement on Closing the Gap, the four Priority Reforms of the National Agreement should guide the review and implementation of the recommendations. This will offer a structure to government to ensure First Nations peoples with disability have:

- a greater say in how policies and programs are designed and delivered;

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<sup>6</sup> 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.

- 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.

### **First Nations Inclusion, Disability and Prevalence**

For millennia, First Nations peoples, communities, and cultures have practised 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.”<sup>7</sup> 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<sup>8</sup>.

As noted in the Disability Sector Strengthening Plan, First Nations people with disability sit on the periphery of both national disability policies, frameworks, data infrastructure or research agendas. In effect, this means data about and evidence by First Nations people with disability are often not captured in its own right. This has key implications for how data and evidence obtained in relation to First Nations people with disability and their unique experiences of interaction with the service systems and all other aspects of life, including what living well looks like for a First Nation person with disability. Existing data and research are often limited in scope, and often do not provide sufficient focus to all experiences of disability in regional, remote or urban contexts.

Whilst population prevalence data is limited due to different definitions used by either population data sets, Indigenous data sets or Disability data sets, First Nations people are twice as likely to experience disability than the rest of the Australian population<sup>9</sup>. 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*,<sup>10</sup> it is estimated that over 60,000 Aboriginal and Torres Strait Islander people live with severe or profound disability in Australia today<sup>11</sup>. However, research that has been conducted has found that First Nations people with disability are under-represented in the NDIS and as a

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<sup>7</sup> S Avery, ‘[Culture is Inclusion](#),’ 2018, First Peoples Disability Network.

<sup>8</sup> S Avery, ‘[Culture is Inclusion](#),’ 2018, First Peoples Disability Network.

<sup>9</sup> Australian Bureau of Statistics (ABS) (2016) National Aboriginal and Torres Strait Islander Social Survey, (NATSISS) 2014-15 (Release 4714.0).

<sup>10</sup> ABS, ‘Disability, Ageing and Carers, Australia: Summary of Findings,’ 2018, accessed 29 August 2023.

<sup>11</sup> S Avery, ‘[Culture is Inclusion](#),’ 2018, First Peoples Disability Network.



result 28% less likely to access and receive services through the NDIS<sup>12</sup>. This is when comparing the rate at which First Nations people access and receive services from the NDIS in comparison to non-Indigenous people with disabilities.

In the second quarter of 2023-24, there were 50,630 First Nations people who have been determined eligible and have an approved plan. We note that not all these individuals live in regional, rural or remote locations, however, this is increasing with an upward trend. The participant data however doesn't reflect the number of participants who have actively been able to utilise their plans. The recent NDIS Review found that for participants who have been on the scheme for at least a year 40% are not receiving access to daily support and 33% are not getting access to vital therapy support. This data highlights there are not only significant barriers in gaining access to the scheme but once participants are on the scheme it is not easy to implement the services that they have been funded.

For the purpose of this submission, it is important to note that there are a greater number of First Nations people than non-Indigenous people who live in rural and remote communities; 55 percent, compared to 30 percent respectively<sup>13</sup>. If the NDIS is responsive to First Nations people with disability, non-Indigenous participants will also benefit.

### **Applying the Cultural Model of Inclusion Framework to the NDIS in regional and remote Australia**

FPDNs Cultural Model of Inclusion Framework (the Framework), designed by and with First Nations people with disability and other evidence, has eight key concepts to determine whether a policy or program is culturally safe, inclusive and disability rights informed. By applying the Framework to the NDIA, NDIS processes, and associated services and systems, it provides the Joint Standing Committee on the NDIS a framework to understand the experiences and limitations of the NDIS for First Nations people with disability in rural, regional and remote locations through the perspective of what matters to First Nations people with disability.

The following table sets out the Framework and key questions:

<b>Framework Concept</b>	Determining the extent to which the concept applies to the NDIS for First Nations people with disability in rural, regional and remote locations.
<b>Country and Culture</b>	To what extent does the NDIA and NDIS processes, and associated services and systems honour the diversity of First Peoples worldviews, including cultures of inclusion, responsibility, reciprocity and connection to Country, and be

<sup>12</sup> DRC Research Report: Options to Improve Service and Accessibility for First Nations People with Disability June 2023

<sup>13</sup> DRC Research Report: Options to improve a service and accessibility for First Nations People with Disability June 2023

	led by cultural determinants of living well?
<b>Power up First Nations people with disability</b>	To what extent does the NDIA and NDIS process, and associated services and systems foster the strengths of First Nations people with disability in how it interacts with First Nations people with disability in regional, rural and remote locations? This includes ensuring that the NDIA and NDIS processes, and associated services and systems address intersectional experiences of discrimination, and are trauma-informed.
<b>Welcoming and Safe</b>	To what extent does the NDIA and the NDIS process, and associated services and systems create an inclusive and safe environment in which people can be proud of their multiple identities?
<b>Community</b>	To what extent does the NDIA and NDIS process, and associated services and systems reflect knowledge of the communities they need to work with and how to have respectful discussions with them?
<b>Voice</b>	To what extent does the NDIA and NDIS process, and associated services and systems uplift the voice and presence of First Nations people with disability
<b>Doing the rights work</b>	To what extent are obligations to Human Rights Frameworks, including the Convention on the Rights of Persons with Disability and UN Declaration on the Rights of Indigenous Peoples upheld by the NDIA, NDIS processes, and associated services and systems
<b>Walking gently</b>	To what extent does the NDIA and NDIS processes, and associated services and systems accept with grace the gift of First Nations knowledges and cultures, seeking to support what matters to them beyond all other interest
<b>Accessibility</b>	To what extent is the NDIA/NDIS processes, and associated services, systems, and infrastructure accessible to First Nations people with disability living in regional, rural and remote locations?

The following section provides in more detail some of the experiences, limitations and key barriers of the NDIS for First Nations people with disability in regional, rural and remote Australia.

### **Barriers that are present for First Nations People with Disability throughout all stages of their NDIS journey**

Many First Nations people with disability who are eligible to access the NDIS face a range of difficulties in accessing the scheme. This includes the availability, responsiveness, consistency and effectiveness of the NDIS in being responsive to rural, regional and remote communities<sup>14</sup>. For example:

- Lack of centring Country and First Nations cultures of inclusion in the design and implementation of the NDIS
- Lack of access and awareness to information about the NDIS by services and the community
- Lack of availability and access to culturally safe, inclusive and disability rights informed diagnostic testing, early intervention support and intervention to support children and families with developmental delays. This can then lead to later diagnosis as well as an increase in the need for enablers and supports such as the NDIS
- Lack of culturally safe, inclusive and disability rights informed services, organisations and workforce
- Lack of culturally safe, inclusive and disability rights informed available services, or 'thin markets' in regional, rural and remote locations.

The following provides further support to these claims.

#### **The need to centre Country and cultural values of inclusion**

For First Nations people with disability, connection to Country and culture is deeply important to both individual and collective identity, to wellbeing, to self-determination and to resilience<sup>15</sup>. However, many First Nations people with disability are not able to access the NDIS packages and services on Country, or where they live, either leading to lack of plan utilisation, or that individuals need to leave Country to access the services they need. This impacts on wellbeing, responsibilities, obligations, connection and participation on and with Country, family and community.

One NDIS participant said "if we're not connected to our culture, how do we then get the right support". (DRC Research Report : Options to improve service and accessibility for First Nations People with Disability June 2023). Or, as **described by a Torres Strait Islander man, who is not able to live and access NDIS supports on the Torres Strait Islands and asked about living in Cairns -**

**"Miss fishing...miss mum....goal next year is to go back home."**

In ensuring access to the NDIS, This further highlights that the disability sector and its processes and structures were never designed to consider the needs for First Nations People

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<sup>14</sup> Disability Royal Commission Report 2023

<sup>15</sup> Disability Sector Strengthening Plan



to provide culturally safe and **effective** outcomes that respond to the needs of First Nations People with disability.

Another challenge, which is detailed further below is the limited number of Aboriginal Community Controlled Organisations (ACCOs) and Aboriginal Community Controlled Health Organisations (ACCHOs) that deliver NDIS services. If there was investment in the ACCOs and ACCHOs to deliver NDIS services, First Nations NDIS participants are more likely to be able to remain on Country which is vital when considering the cultural needs of participants and their communities<sup>16</sup>.

Whilst any recommendation in the DRC Final Report needs to be examined in line with the NDIS Review recommendations to ensure the intent and is not limited, another recommendation that has come from the Disability Royal Commission is that ‘in consultation with the First Nations Advisory Council, the NDIA (should:

- “Create a new line item in the Pricing Arrangements recognising cultural supports and return to Country trips
- Develop guidelines for NDIS staff on including cultural supports and return to Country trips as reasonable and necessary supports in plans
- Educate First Nations participants about the availability of cultural supports and return to Country trips included in their plan”

FPDN welcomes consultation on this recommendation with the First Nations advisory Council and suggests further consultation on the limitations of “return to country trips” rather than support to move back on to Country being a focus area.

### **Access to Information and communication about the NDIS**

One major issue that has previously been reported by FPDN is a lack of understanding and knowledge about the NDIS among First Nations communities. In the FPDN NDIS Review consultations, it was evident that many individual participants, their families and support people did not know how to access the NDIS, what supports NDIS access could facilitate or how NDIS funding could be utilised. Concerningly, this knowledge gap was also reflected in consultations with organisations and practitioners across a range of remote communities. In recent community engagement by FPDN across remote communities, it was noted that local General Practitioners, medical staff and services had limited or no knowledge about the NDIS system. In a recent survey conducted by FPDN, participants also cited experiencing a number of issues communicating with the NDIS related to language barriers, geographical and cultural differences.

*“If I was able to call a 1800 number that I could speak with a First Nations person I would like a First Nations planner - female I would like staff that I deal with have cultural capability and trauma informed practice I should be offered meetings in the locations and formats that suit my needs NDIS resources should be available in First*

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<sup>16</sup> Options to improve service and accessibility for First Nations People with Disability June 2023

*Nations languages (in voice format)."*

*"There was no one who would help me without making me feel stupid."*

*"My culture wasn't considered in either applications (I've made 2)."*

*"I wish it was made more clear about who can and can't receive NDIS. I was made to believe I would easily access NDIS, but was denied twice. First time I was told I didn't give enough information, and on the second try I was told I didn't qualify, despite being physically and psychosocially disabled. I was told I had to be on treatment for 3 years before I could receive NDIS."*

In addition, the lack of a range of available resources that are responsive to the different English literacy and numeracy levels across communities is also a barrier.

### **Culturally Responsive Diagnostic Tools**

Another key challenge for regional, rural and remote First Nations participants is the lack of culturally responsive diagnostic tools that centre value systems or cultural ways of seeing the world, designed by western non-Indigenous frameworks, often numeracy and English literacy heavy<sup>17</sup>. As noted in FPDNs NDIS Review submissions, 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 but first nations have a hard time accessing these support at the best of time. Nevertheless having disability."*

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

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<sup>17</sup> DRC Research Report : options to improve service and accessibility for First Nations People with Disability June 2023

with disability in particular, expressed fear of having their children removed if they are identified as having a 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.”*

In some remote 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 so 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 particularly psycho-social disabilities, 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 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.

### **Cultural differences in understandings of disability and diagnostic testing**

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, 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<sup>18</sup>; so the NDIS requirement for a diagnostic label, sits at odds with their cultural values.

In FPDN's 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.

*"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."*

### **Functional Capacity Assessments (FCA's)**

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 recent remote 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."*

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<sup>18</sup> Velarde, M (2018) 'Indigenous Perspectives of Disability,' *Disability Studies Quarterly*, Vol. 38, no. 4, accessed 19 August 2023.



*“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.”*

### **Lack of culturally safe, inclusive and disability rights informed First Nations and non-Indigenous workforce**

Once participants have access to the NDIS, First Nations participants across regional, rural and remote communities, often are faced with a lack of culturally safe, inclusive and / or disability rights informed services that do not have the competencies to provide services in line with the cultural model of inclusion framework. Across recent FPDN remote community consultations, this issue was significant, with participants explaining that services and support workers lacked cultural awareness and that they would do things or ask questions that were offensive or irrelevant.

As noted in recent FPDN submissions to the NDIS Review, FPDN survey responses similarly indicated that a lack of cultural competence among the NDIS workforce greatly impacted the experiences of First Nations participants. In a question about whether participants felt culturally safe in NDIS interactions, an overwhelming 66.7% said ‘no’ and when asked about what the NDIS should know, a number of participants described a need for a culturally competent workforce.

*“I have had issues with racism and discrimination from service providers. It has been almost impossible to find culturally safe supports in my region.”*

*“Including cultural awareness competency a requirement for services to deliver services.”*

*“Need to develop a workforce that is culturally aware.”*

*“NDIS should consider directly funding organisations to provide cultural pairing - First Nations workers who work with non-Indigenous workers to provide supports NDIS should make sure that all non-Indigenous service providers have a cultural framework and trauma informed practice underpinning their service provision or they cannot register to provide services under NDIS.”*

*“In the 8 years, I've been working within access and planning meetings. I have not come across many planners that have an understanding of ATSI people and the culture. Improving this or specifically having ATSI planners would be more appropriate. Not swapping planners for people to explain their story every year, and having one planner per household.”*

In another question about what could be done to make the NDIS culturally safer, one participant also spoke about a need for gender-sensitive and trauma-informed services.





*"I believe the NDIS should have a section for cultural funding so that I can participate in cultural events, or host events like this themselves (unaware if they do, and if so it's not accessible). I believe there should be more education around cultural awareness and especially the topic of mens and womens business. I live in disability accommodation through NDIS with staff on site 24/7 and multiple times I have had male staff come into my house without properly announcing themselves or being welcomed in, even coming right to my bedroom door before making themselves announced. As a woman this makes me very uncomfortable and as if they have no cultural awareness of womens business. Also this past NAIDOC week they put a lot of pressure on me as the only Indigenous client to come up with NAIDOC week events for the rest of the clients/ neighbours in the program. I felt I was pressured to do this, and it's the only time they've embraced my culture or asked questions or been interested when I do speak of my culture. I do not believe there is informative enough content on caring for Indigenous clients or building cultural awareness in their one unit, if that, when they study to become a support worker. I have also struggled to find Indigenous support workers. I wish they would embrace my culture more than one week a year, like mentioned before there should be extra support including funding to actually participate in cultural events and activities, because I believe culture is very closely related to mental health, and in our culture our traditions are focused on healing. There should be more NDIS funded events celebrating our culture and allowing us to build connection to ourselves and our identities and to land and culture, which is one of the biggest strengths we have. This would help to heal intergenerational trauma as well. Also being able to recognise the NDIS as an ally because of their continuous effort in supporting the indigenous community and helping to host or fund these events would bring a lot more cultural safety and trust."*

In this context, it is important to recognise that First Nations people with disability, in particular, those who are women and girls, face disproportionately high rates of violence, abuse, neglect and exploitation, including from within government and private sector service systems, and therefore, need services they access to be trauma-informed and sensitive to their experiences.

Overall, the DRC and NDIS Review highlighted the need to increase the cultural capabilities of the non-Indigenous disability sector workforce. FPDN recommends that its Cultural Model of Inclusion Framework and Organisational Tool (self-assessment organisational monitoring tool), training and capability development activities be adapted specific for the NDIA. That organisational competencies be incorporated into accountability frameworks (such as registration processes) and quality standards, and an intermediary or independent mechanism be established to monitor implementation.

### **Lack of Aboriginal and Torres Strait Islander staff and services**

Related to there being a lack of culturally safe and inclusive staff and services available to support First Nations individuals and communities, many consultation participants identified a need for more First Nations support staff and services that are led by First Nations people. In response to the survey question about what would improve the cultural safety of the NDIS for instance, participants said:

*“Aboriginal workers, an understanding of what disability means in Aboriginal context.”*

*“Having a local Aboriginal staff member either with the partners or NDIS for Client’s to feel connected to.”*

Notably, the survey and community consultations highlighted how a lack of culturally competent and First Nations disability services and support staff available through, or even outside the NDIS, meant that First Nations people with disability had to heavily rely on family networks, but were concerned that this was not being appropriately recognised by the NDIS.

*“NDIS plan need to be more flexible to consider kinship caring models NDIS need to think about more respite particularly for people when transitioning from custodial settings”.*

Drawing on the Disability Sector Strengthening Plan, whilst there is a lack of current and comprehensive workforce data across the sector, the available data suggests that overall the First Nation disability workforce is either emerging or limited. Despite national and jurisdictional employment and workforce strategies, they do not pay specific attention to the community-controlled disability workforce. An Aboriginal and Torres Strait Islander Human Services Workforce Plan will go some way to address this gap. However, a broader focus on workforce data will be required to achieve a more comprehensive understanding of existing gaps.

There are a range of First Nations workforce challenges<sup>19</sup> including:

- Workforce attraction and retention to meet growth and demand, including non competitive remuneration
- Limited recognition, opportunities and / or support for the development of local First Nations workforce and their cultural knowledge, community connection and skills and the long-term commitment to supporting their communities.
- In regional and remote communities, services are often reliant on an external workforce; the need for transportation into and between remote communities, difficulty recruiting, training and retaining staff, lack of accommodation options for staff and limited support for staff.
- First Nations peoples experience barriers in obtaining requisite qualifications due to barriers such as birth certificates, drivers licences
- There is a gender imbalance to caring roles

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<sup>19</sup> 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

- Existing carer responsibilities are not remunerated
- Limitations within the Disability Support Pension policies regarding work

### **Lack of appropriate funding and resourcing to the community controlled sector**

The disability sector is becoming one of the fastest growing sectors of the Australian economy over the coming decade, as noted by the Care and Support Workforce Taskforce. Given the critical role local, place based ACCOs and ACCHOs play in improved outcomes for First Nations peoples, communities, and self-determination, there needs to be greater investment in building the capacity of First Nations community controlled organisations to develop services with and for First Nations participants. Some of the current challenges include the registration process and when ACCO's and ACCHO's are being asked to deliver disability services with insufficient funding and resourcing<sup>20</sup>. As noted in the Disability Sector Strengthening Plan, the requirements in becoming a registered NDIS provider and maintaining registration presents significant challenges, particularly for smaller service providers. There is a need to build capability and systematise promising practice across the sector. FPDN notes that the NDIS Review has identified a range of recommendations in relation to provider registration and regulation and notes the newly set up NDIS Provider and Worker Registration Taskforce. Further understanding of the implications of the market mix of registered and unregistered providers in remote markets and whether policy settings around the use of registered and unregistered providers are best enabling participants to purchase the services they need. This would include considering registration requirements and other settings that shape the market.

A separate recommendation from DRC Final Reports<sup>21</sup> speaks to ways in which the above concerns can be addressed. Recommendation 9.5: The NDIA should provide block funding for First Nations community controlled organisations to flexibly deliver supports to First Nations people with disability that this could include:

- Respite or accommodation in connection with their plan or disability services
- Cultural supports to maintain or improve health and wellbeing
- Essential supports such as food, bedding and clothing
- Supports that enable access to therapy, such as transport and fuel
- Translation or other services to build understanding around disability and the NDIS
- Other matters as agreed by the NDIA and First Nations Community Controlled Organisations.

### **Thin markets of service providers and barriers to choice and control**

It is well known that with the introduction of the NDIS, disability service provision moved towards a market-based system, with disability supports being provided through businesses which are pivoted toward profit from the funding made available through individual NDIS participants. While this system, it has been argued, provides more choice and control to

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<sup>20</sup> Disability Sector Strengthening Plan

<sup>21</sup> Disability Royal Commission Final report into Abuse, Neglect, Violence and Exploitation of People with Disabilities 2023

individuals about the services they access,<sup>22</sup> the opposite is true in rural, regional and remote locations, where populations are more sparse and in turn, services are limited.

Further to this, in First Nations communities people with disability often have greater complexities when it comes to the nature of their disability, due to the severity which is often higher<sup>23</sup>. Living in rural, regional and remote communities presents an increasing amount of barriers when it comes to accessing much needed services and the availability of these services is often limited which leads to less choice and control for First Nations participants living in these communities. Reasons for this include:

- Distance from specialist providers
- Difficulty in finding service providers that are culturally safe, inclusive and disability rights informed.
- Lack of understanding of where people and communities can go and gather information about the NDIS. First Nations communities experience great difficulty understanding and navigating the system and there is little assistance in these rural and regional communities<sup>24</sup>.
- Not having access to culturally appropriate services is also a major barrier in thin markets.

The barriers listed above have led to underutilised NDIS packages. This suggests that First Nations participants are missing out on vital support that they would otherwise access if they had the availability of providers which are culturally safe, inclusive and disability rights informed. In FPDN remote consultations for instance, participants explained that services were so limited that they would often go days or weeks without access to basic assistance, such as assistance with showering or buying perishable items. In order to fill these support gaps, participants described having to rely on family members (who are ineligible for financial compensation under NDIS legislation) which they said put pressure on their relationships. In many cases, these communities also relied on 'fly in – fly out' (FIFO) services, which lacked adequate understanding of individuals and communities, and were present at inconsistent interims.

Enabling choice and control for First Nations participants ensures service **durability and effectiveness**. One recommendation in the Disability Royal Commission Final Report that would help to expand services and decrease the number of underutilised NDIS packages is establishing a criteria for funding family supports.

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<sup>22</sup> 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 11 August 2023, p. 27.

<sup>23</sup> DRC Research Report : options to improve service and accessibility for First Nations People with Disability June 2023

<sup>24</sup> DRC Research Report : Options to improve service and accessibility for First Nations People with Disability June 2023



### Recommendation 9.9 Criteria for funding family supports

The National Disability Insurance Agency (NDIA), the First Nations Advisory Council and First Nations Community Controlled Organisations should co-design policy guidelines on funding for First Nations family members to provide support to participants in remote communities. Any policy guidelines should consider; the risk of financial exploitation, the need for a regulatory framework and oversight, and whether a similar approach would apply to non-First Nations carers in remote communities in similar situations.

- the availability of suitable services, including culturally safe services
- training for NDIA staff on how to apply the policy guidelines, including how staff can support family to apply to be paid for the care provided
- building awareness of the circumstances in which participants and their families can apply to be paid
- how to build the capacity of family and community members to become part of the local workforce, such as trained support or community workers, which may include connecting family members with a First Nations Community Controlled Organisation.

Whilst FPDN considers some aspects of this recommendation as being culturally safe, inclusive and disability rights informed, FPDN also recognises that this should be considered for all First Nations people with disability, not just remote, and the need to ensure critical safeguards are put in place for both the safety of participants and their families.

### **Alternative Commissioning**

FPDN is very supportive of the opportunity alternative commissioning can offer in identifying new approaches to the NDIS in regional, rural and remote settings, where “Alternative commissioning approaches could be designed to coordinate demand for a number of NDIS supports within the community” to deliver more sustainable, efficient and appropriate support for First Nations communities”<sup>25</sup>). However, the design, implementation, and evaluation of such alternative commissioning models needs to be undertaken in line with the National Agreement of Closing the Gap. This includes place-based partnerships with communities and the community controlled sector, including FPDN as the peak. It may also require sector strengthening of the community controlled and non-Indigenous disability sector to build a localised culturally safe, inclusive and disability rights informed sector. Ensuring that such approaches are then evaluated with First Nations disability evaluation principles, and in line with the Cultural Model of Inclusion Framework will ensure that the measures of success for First Nations people with disability living in regional, rural and remote locations guide the alternative commissioning approaches, as well as identify opportunities for upscaling.

### **Conclusion**

This submission highlights a range of limitations and barriers First Nations people with disability living in regional, rural and remote settings face in accessing and utilising the NDIS. They include a lack of centring Country and culture; lack of information on the NDIS for

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<sup>25</sup> NDIS Review Alternative Commissioning for remote and First Nations communities



community and local services; culturally responsive diagnostic testing and associated processes; culturally safe, inclusive and disability rights led workforce challenges; and market drive - thin markets.

FPDN has documented a range of recommendations as part of the NDIS Review process and encourages the Standing Committee to consider these recommendations, together with the NDIS Review and DRC Recommendations in relation to regional, rural and remote, as well as First Nations people with disability. The Closing the Gap National Agreement requires that this be done in relation to four priority reforms.

Finally, by applying FPDN's Cultural Model of Inclusion Framework, the NDIA/NDIS processes, and associated services and systems will increase the design, implementation, monitoring, evaluation and access to a culturally safe, inclusive and disability rights informed NDIS. This in turn will improve the rights of First Nations people with disability in regional, rural and remote Australia to participate in community, cultural, social, education and the economy equal to First Nations people in urban communities, as well as non-Indigenous people in any location of Australia.

FPDN thanks the Joint Standing Committee on the National Disability Insurance Scheme for the opportunity to make a submission.

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