

National Disability Advocacy Framework 2022-2025

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The Department of Social Services (DSS)



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

First Peoples with disability and their families are amongst the most seriously disadvantaged and disempowered members of the Australian community. FPDN gives voice to their 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. To do this, 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 (CRPD), to which Australia is a signatory, and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).

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.

Introduction

First Peoples Disability Network is pleased to see Commonwealth, state and territory governments commit to updating Australia's National Disability Advocacy Framework (NDAF), supporting the implementation of *Australia's Disability Strategy 2021-2031* and the *Closing the Gap National Agreement*. We believe that there are five pillars required to enhance access to advocacy for First Peoples with disability. These five pillars are:

1. Individual Advocacy
2. Education & Community Development
3. Legal Advocacy
4. Systemic Advocacy
5. Self-Advocacy

In accordance with these five pillars of advocacy, FPDN makes the following recommendations:

- Invest in independent Indigenous owned and operated individual advocacy services, recognising the limitations of the community-controlled sector to deliver the breadth of advocacy required by First Peoples with disability.
- Introduce a community education and development specialisation under the NDAF, focused on giving Aboriginal and Torres Strait Islander communities the opportunity to discuss 'disability'.
- Introduce a legal advocacy specialisation under the NDAF, focused exclusively on the cohort of Aboriginal and Torres Strait Islander people with disabilities in Australian prisons.
- Provide sustainable and ongoing funding to peaks, such as FPDN, to deliver culturally relevant human rights training, supporting the leadership of self-advocates.
- Support Aboriginal and Torres Strait Islander communities to not only have access and use of, but to collect, maintain and have control over culturally relevant data on disability amongst First Peoples.
- Address the broader issues surrounding access to disability services and supports such as the NDIS and DSP for First Peoples with disability through a genuine co-design process with First Peoples with disability.

We thank the Department of Social Services (DSS) for the opportunity to provide feedback on Australia's draft *National Disability Advocacy Framework 2022-2025* and would be happy to discuss the matter further with you.



Damian Griffis
CEO, First Peoples Disability Network

Advocacy for Australia's First Peoples with Disability: An Area of Critical Unmet Need

By any measure Aboriginal and Torres Strait Islander people with disabilities are amongst the most disadvantaged people in Australia. They face discrimination based on their disability and discrimination based on their race, often referred to as a double disadvantage.¹ This double disadvantage often interacts with the consequences of ongoing colonial violence, including poverty² and trauma, alongside broader 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. All of these barriers stand in the way of Aboriginal and Torres Strait Islander people with disabilities' meaningful participation within their own communities, as well as participation within the wider Australian community.

Concerningly, the vast majority of Aboriginal and Torres Strait Islander people with disabilities are at the periphery of not only the health, education, housing and welfare systems, but all aspects of the disability services sector; experiencing unequal access to disability services, including those offered under the National Disability Insurance Scheme (NDIS), as well as income support, such as the Disability Support Pension (DSP).

When it comes to accessing individual disability advocacy services, this inequality is particularly acute, even though, for many of the reasons explored above, Aboriginal and Torres Strait Islander people with disabilities are the group within the Australian community who are most in need of individual advocacy support. The First Peoples Disability Network (FPDN) continues to state that meeting the needs of Aboriginal and Torres Strait Islander people with disabilities is one of the most critical social justice issues in Australia today.

The prevalence of disability amongst Aboriginal and Torres Islanders is twice that of the general population³. Until recently, these rates of disability within First Nations communities had been only anecdotally reported. However, the *2018-19 National Aboriginal and Torres Strait Islander Health Survey* concluded that at least 46% of all Aboriginal and Torres Strait Islander people over the age of 15 have some form of disability or long-term health condition⁴. This equates to approximately 248,100 Aboriginal and/or Torres Strait Islander people with disability over the age of 15 in Australia today. Aboriginal and Torres Strait Islander children are shown to experience disability compared to their non-Indigenous peers at an even more

¹ Uncle Lester Bostock, 1991 Meares Oration

² 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>

³ *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*,
<https://disability.royalcommission.gov.au/system/files/2020-11/First%20Nations%20people%20with%20disability%20-%20Infographic.pdf>

⁴ *2018-19 National Aboriginal and Torres Strait Islander Health Survey* <https://www.indigenoushpf.gov.au/measures/1-14-disability>

disproportionate rate, with 22% of First Nations children under 18 years living with disability, in contrast to 8% of non-Indigenous children under 18⁵.

Regrettably the fact remains that governments have been slow to realise the high prevalence of disability in Aboriginal and Torres Strait Islander communities and still today this prevalence data is not widely known. Indeed, at the time when the National Disability Advocacy Program (NDAP) was first developed in the 1980's, it would appear that Aboriginal and Torres Strait Islander people with disabilities were not mentioned.

The high prevalence of disability, approximately twice that of the non-Indigenous population, occurs in Aboriginal and Torres Strait Islander communities for a range of social reasons, including poor health care, poor nutrition, exposure to violence and psychological trauma (e.g., arising from removal from family and community) and substance abuse, as well as the breakdown of traditional community structures in some areas. First Peoples with disability are significantly over-represented on a population group basis among homeless people, in the criminal and juvenile justice systems², and in the care and protection system (both as parents and children).³

Historically much of the focus on Aboriginal and Torres Strait Islander people with disabilities has been from a health perspective. Whilst this is essential, particularly regarding primary health interventions, it has come at the cost of failing to recognise the social aspects of Aboriginal disability. This has meant that the barriers that produce discrimination against Aboriginal people with disability remain firmly entrenched and the general well-being of Aboriginal people with disability has not improved in any meaningful way.

Furthermore, the impact of colonisation and the resultant dispossession of land and displacement from places of cultural significance have ongoing impacts on the lives of many Aboriginal people with disability which is difficult to measure. All of these factors contribute to the fact that disability rights from an Aboriginal and Torres Strait Islander perspective is an emerging social movement. In many ways, this social movement is starting from a baseline position.

⁵ *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, <https://disability.royalcommission.gov.au/system/files/2020-11/First%20Nations%20people%20with%20disability%20-%20Infographic.pdf>

² Aboriginal people are 11 times more likely to be imprisoned than other Australians. Source: *Overcoming Indigenous Disadvantage Key Indicators 2005; Steering Committee for the Review of Government Service Provision*. There is no empirical evidence to quantify the number of Aboriginal people with disability in particular with intellectual disability and mental illness in the criminal justice system. The prevalence of intellectual disability for instance in the prison population is often contested with wide variation in percentages. However a report by the Law Reform Commission published in 1996 entitled *People with an Intellectual Disability and the Criminal Justice System* noted that 12-13% of the prison population were people with an intellectual disability.

³ *Overcoming Indigenous Disadvantage Key Indicators 2005; Steering Committee for the Review of Government Service Provision* states 'The rate of children on care and protection orders (for a combination of all states and territories except NSW) was five times higher for indigenous children (20 per 1000 children in the population aged 0 – 17 years) than for non-indigenous children (4 per 1000 children). Pg 9.5

A Model of Advocacy for First peoples with Disability: The Five Pillars

The nature of advocacy for Aboriginal and Torres Strait Islander people with disabilities differs in many ways to that which is required by the general population and undertaken by mainstream providers and organisations. This is because, in many ways, 'disability' is a new conversation in many Aboriginal and Torres Strait Islander communities.

As the peak body promoting the human rights of Aboriginal and Torres Strait Islander people with disabilities, FPDN sees five key pillars as crucial foundations for a National Disability Advocacy Framework capable of meeting the needs of First Peoples with disability, their families and communities. These pillars are:

1. Individual Advocacy
2. Education & Community Development
3. Legal Advocacy
4. Systemic Advocacy
5. Self-Advocacy

Individual Advocacy

Historically access to individual advocacy services for Aboriginal and Torres Strait Islander people with disabilities has been very poor, despite the high prevalence of disability amongst Aboriginal and Torres Strait Islander communities and the urgent need for advocacy support in response to the many ongoing human rights violations First Peoples with disability experiences. Indeed, when the NDAP was first established, it would appear that Aboriginal and Torres Strait Islander people with disabilities were not referred to.

FPDN (alongside the former Aboriginal Disability Network NSW with which FPDN merged) has undertaken individual advocacy for Aboriginal and Torres Strait Islander people with disabilities for more than a decade, in an entirely unfunded capacity. This lack of resourcing for culturally safe and relevant individual advocacy services has meant the disadvantage experienced by First Peoples with disability has become only further entrenched.

Currently the number of Aboriginal and Torres Strait Islander people with disabilities accessing individual advocacy services remains very small. As stated above, the small numbers of First Peoples with disability who have accessed the NDAP have done so largely due to referral to People With Disability Australia (PWDA) from either FPDN or the former Aboriginal Disability Network NSW.

One of the most basic reasons for why this continues to occur is because many Aboriginal and Torres Strait Islander people with disabilities do not identify as people with disabilities. This occurs for a range of reasons including:

- Why would you identify as a person with disability when you already experience discrimination based on your Aboriginality, i.e., why take on another perceived negative label.
- In traditional language there was no comparable word to disability, which suggests that disability may have been accepted as part of the human experience.
- In some communities, particularly communities that continue to practice a more traditional lifestyle, disability may be viewed as a consequence of 'married wrong way.' That is many Aboriginal people with disabilities, their parents and family members experience stigma related to a kind of 'bad karma' type view of disability.
- The predominance of the medical model of disability, which has had a profoundly negative impact on the lives of many Aboriginal and Torres Strait Islander people with disabilities.

Another major barrier to accessing individual advocacy for many Aboriginal and Torres Strait Islander people with disabilities, their families, and carers, and indeed the wider Indigenous community in which a person with disability may be living is access to information. Throughout Australia the disability system is overly complex. In NSW for example it is possible that a carer or parent of an Aboriginal child with disability may have to deal with as many as six or seven different government departments during the early years of the life of the child. The same sort of scenario is often replicated in other jurisdictions. Many Aboriginal parents and carers, or the person with disability themselves, may already be reluctant to engage with the service sector, particularly if it is government operated, for reasons that are now well established such as a general distrust of government. This distrust is only exacerbated by an overly complex and often cumbersome system.

It is also the experience of FPDN that the type of individual advocacy required by First Peoples with disability is far beyond the scope or understanding of mainstream advocacy services. Often Aboriginal and Torres Strait Islander people with disabilities require advocacy support for complex matters. What may present initially as a simple matter of supporting an individual to access the Disability Support Pension (DSP), for instance, invariably turns into a matter related to housing, education, employment, access to health services or any number of other more substantive issues.

Similarly, individual advocacy for First Peoples with disability often includes engagement not only with the individual, but the wider family and community. For example, it may often be the case that multiple members within a family have disability, requiring coordinated support. This advocacy is invariably complex in nature and is very rarely issues based. Once a relationship is established with an advocate, then that advocate will likely be required to provide support in a range of additional ways that are not easily defined in a classic issue-based way.

For example, in regional and remote Australia, it is commonplace for FPDN staff to be required to drive community members between communities as the staff member may be the only person with a car in the community at the time they are visiting. Similarly, it is FPDN policy before visiting regional and remote communities that staff bring groceries, clothes, and supplies, as many First Peoples with disability based in

the communities with which FPDN works are living in abject poverty. Such responsibilities are not well understood when it comes to recognition of the diverse nature of individual advocacy that is necessary for First Peoples with Disability. All of these factors explain why access to Indigenous owned and operated individual advocacy services are fundamental in beginning to address unmet need.

Outputs to date of the NDAP under previous frameworks have failed First Peoples with disability miserably. There currently does not exist any substantive Indigenous owned or operated disability advocacy organisation funded under NDAP aside from a small organisation located in Western Sydney. Furthermore, FPDN research shows that in NSW and Queensland for example, as much as 75% of the Aboriginal population is not being adequately serviced. This is due not only to a lack of access to Indigenous owned advocacy, but to the failures of mainstream organisations that are funded to provide state-wide advocacy (or to cover several regions) to make any meaningful difference, often because of a lack of shopfront presence.

Regions that are predominantly Aboriginal and/or Torres Strait Islander, such as Western NSW, Cape York, and Torres Strait Island communities, as well as virtually the whole of the Northern Territory, are the most glaring examples of how mainstream advocacy providers are failing First Peoples with disability. For example, in the Orana region of NSW i.e., Dubbo out to Broken Hill and down to Condobolin, and even to Bathurst and Orange, there are large Aboriginal populations. The mainstream advocacy provider funded for some of these regions would only have resources to visit some of these towns and communities once a year. Such a piecemeal approach will not enable community development, nor enable any kind of rapport to be built with the Indigenous communities in these areas. FPDN is strongly of the view that this will result in continuing low numbers of Indigenous people accessing advocacy.

Whilst FPDN supports the *National Disability Advocacy Framework 2022-2025* commitments to strengthening the community-controlled sector to deliver advocacy and enhancing the cultural safety and capabilities of non-Indigenous disability advocacy services, we are firmly of the belief that the NDAF needs to explicitly commit to greater investment in independent Indigenous owned and operated individual advocacy providers, beyond those advocacy services that can be delivered by the community-controlled sector.

It is a well-established fact that Aboriginal people with disability and their families will want to engage directly with Aboriginal advocates for a range of reasons, including the fact that Aboriginal people feel culturally safe talking with other Aboriginal people. Due to the often-sensitive nature of the conversation and the risks associated with asking for help (e.g., families reaching out for individual advocacy support may risk the unwanted attention of government authorities), the most effective and meaningful way to provide advocacy to Aboriginal people with disabilities and their families is for it to be provided by Aboriginal people and organisations. Ensuring that First Peoples with disability have access to Indigenous owned and operated advocacy providers who are independent from the health and disability services they may access, often through the community-controlled sector, is critical in ensuring the human rights of First Peoples with disability are upheld.

Education & Community Development

In many ways 'disability' is a new conversation in Aboriginal and Torres Strait Islander communities. It is critical that communities across the country be given the opportunity to discuss 'disability', and that community education and development be considered by the new NDAF as an equally important part of addressing the advocacy needs of First Peoples with disability. FPDN strongly argues that equally investing in community development in addition to individual advocacy is the only practical way in which change will begin to occur. Getting outcomes for individuals, whilst critical, will not change whole community perception necessarily. It is also inconsistent with a more Indigenous approach to life in general; one of solidarity and whole of community well-being.

The important relationship between individual advocacy and broader education and community development can be seen in the way FPDN supports many Aboriginal and Torres Strait Islander communities. A standard process that FPDN uses is to call a community gathering of all interested people to discuss 'disability'. At the end of the community forum, private interviews are held with individuals, which act as formal intakes for individual advocacy matters. The reason why this approach is done and why it continues to prove so successful is that firstly, by holding a community gathering, people can learn their rights and entitlements as carers of or as people with disabilities in a safe environment. This has the potential to influence the wider community because a broad cross-section of people from that community are likely to attend. It must be noted that FPDN has never been funded under frameworks to provide this whole-of-community scale advocacy.

A tailored program under the NDAF as it relates to First Peoples with disability would recognise and value the importance of community development as a key function, resourcing a concerted outreach approach that would have much of the advocacy work being undertaken in a 'field work' capacity appropriately. A phone-based or occasional visit to community approach will simply not work, for the simple reason that many Aboriginal and Torres Strait Islander people with disabilities don't own telephones or they are distrustful of 'fly in fly out' type service delivery. In addition, the current approach tends to imply that Aboriginal and Torres Strait Islander people with disabilities have to come to services as opposed to the service going out to people. If this approach continues and is not meaningfully changed under the new NDAF, then FPDN argues strongly that the NDAP will continue to see low numbers of Aboriginal and Torres Strait Islander people with disabilities accessing advocacy services.

Legal Advocacy

Based upon more than a decade of community engagement with First Peoples with disability, FPDN has regularly encountered stories of First Peoples with disability's discriminatory interactions with the criminal justice system; a system which remains underpinned by institutionalised forms of discrimination. It is a well-established fact that both Aboriginal and Torres Strait Islander people and people with disability often

experience discrimination in their interactions with the justice system, including interactions with police, the courts and judicial system more generally. This discrimination is particularly acute for First Peoples with disability, who experience the compounding effects of systemic racism and ableism, and distressingly continue to die in custody.

In spite of the findings and recommendations delivered by the Royal Commission into Aboriginal Deaths in Custody (RCADIC) in 1991, the overrepresentation and indefinite detention of First Peoples, particularly First Peoples with disability, has not changed over the last several decades. In 2015, a report by the University of NSW entitled *A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system* estimated that there are at least 676 Aboriginal people with cognitive or psychosocial disability in the prison population in NSW, and that with appropriate advocacy support before their interactions with police, a significant number of these Aboriginal people with disability could have avoided prison altogether.⁶

More recent data reveals that Aboriginal and Torres Strait Islander people with disability are 14 times more likely to be imprisoned, with one third reporting a disability, 50% reporting a history of psychosocial disability, and 25-30% of prisoners having an intellectual disability.⁷ Of particular concern is the even higher overrepresentation of Aboriginal and Torres Strait Islander children with disability imprisoned within the youth justice system, with localised data indicating that on any given night, half of all Australian children imprisoned are Indigenous, with nearly all these Indigenous children having some form of cognitive impairment.⁸

By the time an Aboriginal or Torres Strait Islander person with disabilities has come into contact with the justice system, they are likely to have had a lifetime of their disability related needs having been unsupported. For example, in 2016, FPDN met with staff from the Youth Koori Court in Western Sydney. Staff, including the magistrate, advised FPDN that at the time they had 50 young Aboriginal people appearing before the Youth Koori Court, with at least 20 of the 50 young Aboriginal people having significant disability. None of those 20 young people were receiving any meaningful support for their disability.

Furthermore, all of these young people were at greater risk of going without suitable supports, with the NSW government divulging its responsibilities to provide disability services to the National Disability Insurance Scheme (NDIS). Given the multiple barriers First Peoples with disability face in accessing the scheme, there remains the very real risk that both these young people, and undoubtedly most young Indigenous people currently in contact with the criminal justice system, will fall through the gaps completely, especially those young people who are not considered to be severely or profoundly disabled.

⁶ <https://www.mhdcd.unsw.edu.au/a-predictable-and-preventable-path-iamhdcd-report.html>

⁷ <https://fpdn.org.au/media-release-the-overrepresentation-of-first-nations-people-with-cognitive-disability-in-the-criminal-justice-system-warrants-own-disability-royal-commission-hearing/#:~:text=Aboriginal%20and%20Torres%20Strait%20Islander,prisoners%20having%20an%20intellectual%20disability.>

⁸ Ibid

Since speaking to the Youth Koori Court, FPDN has continued to witness the many barriers to accessing disability related supports that remain entrenched within all contact points of the criminal justice system. For instance, FPDN advocates are still reporting significant challenges for First Peoples with disability accessing the DSP when exiting prison. Aboriginal and Torres Strait Islander people with disability who enter prison lose eligibility to the DSP, then have to meet new eligibility criteria when exiting.

FPDN argues that a legal advocacy specialisation is required under the new draft NDAF, focused exclusively on the cohort of Aboriginal and Torres Strait Islander people with disabilities in Australian prisons. Recognises that the current funding available under NDAP will not adequately address this cohort of people, FPDN proposes a collocated model of legal advocacy that places 7 legal advocates collocated within Aboriginal Legal Services in each state and territory. Whilst it is anticipated that these specialised legal advocates for incarcerated First peoples with disability will be overwhelmed in terms of caseload, embedding legal advocacy within the NDAF will at least begin to address this urgent and often overlooked area of need.

Systemic Advocacy

Systemic Advocacy is fundamental to creating meaningful change for all people with disability, however it is particularly acute for First Peoples with disability. This is because the intersectional discrimination experienced by First People with disability is not addressed in any single, comprehensive strategy, policy or program. Australia's Disability Strategy and the Closing the Gap National Agreement operate independently and neither address the issue of first people with disability satisfactorily.

At a minimum, a specific action plan that bridges the gap between these two strategies, and coordinates policy and programme development and implementation needs to be developed in true partnership with first peoples with disability as a matter of urgency. Such an action plan would provide a concerted direction for the adequate resourcing of both individual and systemic advocacy for First Peoples with disability. There has never been any meaningful targeted funding provided for such critical work under the National Disability Advocacy Program.

First Peoples Disability Network has recently been funded by the Commonwealth Government for systemic policy and advocacy for a period of two years. However a commitment for ongoing funding to FPDN is critical to ensure first peoples with disability have a collective voice advocating for their rights, interests and needs.

Self-Advocacy

As the draft *National Disability Advocacy Framework 2022-25* identifies, advocacy is not only about supporting people with disability to access services and uphold their human rights, but about building the capacity of people with disability to make and

participate in decisions that impact their lives. Keeping in-line with the principle of *'Nothing about us, without us'*, a phrase emphasising the importance of self-determination not only within Disability Rights movements, but also within Indigenous Rights movements, the draft NDAF must include a commitment to culturally safe self-advocacy training for First Peoples with disability.

One of the major barriers for the realisation of the human rights of First Peoples with disabilities is an individual acting of their own volition. Much of Aboriginal Australia, as is well known particularly in regional and remote Australia, is so seriously disenfranchised that the ability and willingness to speak up for oneself is now very seriously diminished. In some communities, Aboriginal people have become highly skilled at saying what they believe people from outside, particularly government, wants to hear. Too often Aboriginal and Torres Strait Islander people with disabilities have decisions made for them, whether that be on a whole-of-community scale when it comes to program design and implementation, or on an individual scale, with legal arrangements such a guardianship depriving First Peoples of choice and control.

Empowering First Peoples with disability to feel confident in advocating for their human rights requires the ongoing resourcing of training and opportunities focused on building the leadership of First Peoples with disability self-advocates. FPDN has been building the self-advocacy leadership and capacity of First Peoples with disability for years, having developed our Lester Bostock Human Rights training; a culturally safe *'Know your Human Rights'* workshop to empower community to understand how to use this knowledge and be confident to speak up for their rights. FPDN's workshops are a safe space where First Peoples with disability can learn, yarn, and share stories about:

- The United Nations Convention on the Rights of Persons with Disability (UNCRPD)
- The United Nations Declaration on the Rights of Indigenous peoples (UNDRIP)
- The Disability Discrimination Act (DDA)
- The Racial Discrimination Act (RDA).

To ensure opportunities like the Lester Bostock Human Rights training continue to be accessible to First Peoples with disability across the country, and to continue building upon the number of disability self-advocates prepared to engage with processes like providing evidence to the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, FPDN strongly believes that funding for self-advocacy opportunities and training for First Peoples with disability must be included under the draft NDAF.

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