

**FIRST PEOPLES DISABILITY NETWORK (Australia)**

**Response to the Productivity Commission Position Paper on National Disability Insurance Scheme (NDIS) Costs**

**July 2017**

# About First Peoples Disability Network

The First Peoples Disability Network (FPDN) is a national organisation established by, for and on behalf of Aboriginal and Torres Strait Islander people, families and communities with lived experience of disability. All of the Directors on the Board are First Peoples with disability. We are guided by the lived experience of disability in determining our priorities and our way of doing business. FPDN can trace its origins to a gathering of Aboriginal and Torres Strait Islander people with disability held in Alice Springs in 1999.

FPDN is committed to research and policy development that captures the knowledge, expertise and experience of disability in our communities. FPDN aims to be the interface between the First Peoples disability community, policy makers and researchers in generating practical measures that secure the human rights of First Peoples within a social model of disability. We have a long-standing and ongoing role advocating for the rights of First Peoples with disability through high-level policy advice to Australian Governments and in international human rights forums.

FDPN is undertaking a community-directed research program, called ‘Living our ways’ which is supported through the National Disability Research and Development Scheme, which is contributing to the research and evidence base on the unique circumstances and needs of Aboriginal and Torres Strait Islander people with disability.

# Scope

This submission specifically addresses the request for information 6.1 (sub-point 4) regarding the implementation of the NDIS in Aboriginal and Torres Strait Islander communities as requested by the Productivity Commission in its position paper on NDIS costs (June 2017).

# FPDN’s observations on NDIS Cost Drivers with reference to issues relating to the Aboriginal and Torres Strait Islander disability market

1. **The unique circumstances of Aboriginal and Torres Strait Islander people, its communities, and hence the attributes of the Aboriginal and Torres Strait Islander disability market, are not sufficiently understood within the NDIA and other government agencies.**

In March 2017, the Australian Bureau of Statistics produced an occasional paper ‘Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People with Disability’ (ABS, March 2017, Rel. 4174.0). Using data from the National Aboriginal Torres Strait Islander Social Survey, which surveys Aboriginal and Torres Strait Islander people aged 15 and over living in private households, the occasional paper was produced as a consequence of an historic partnership with FPDN. The purpose of the partnership is to produce consistent data on prevalence and comparative health and wellbeing outcomes for Aboriginal and Torres Strait people with disability compared to the Aboriginal and Torres Strait Islander population as a whole. The complete ABS paper and FPDN’s data synopsis are attached as Appendices to this position paper, with key statistics highlighted below:

*Prevalence of disability:*

|  |  |
| --- | --- |
| Percent of Aboriginal and Torres Strait Islander population reporting some disability (rate) | 45% |
| No. of Aboriginal and Torres Strait Islander people aged 15 and over with severe and profound disability | 34,300 |
| Percent of Aboriginal and Torres Strait Islander with severe and profound disability (rate) | 7.7% |
| Comparator: Other Australians - No people with severe and profound disability | 4.6% |
| Age adjusted ratio | 2.1 times higher amongst Aboriginal and Torres Strait Islander people |

In addition to data on prevalence, across every social and economic indicator, Aboriginal and Torres Strait Islander people with disability experienced poorer health and wellbeing across all indicators (such as health status, educational attainment, personal safety, employment) compared to the Aboriginal and Torres Strait Islander population as a whole. The rate of participation in community and cultural activities is the one notable exception as outcomes are on par.

This data quantitatively demonstrates the intersectional impact on health, wellbeing and social outcomes on a person who is Aboriginal or Torres Strait Islander *and* has disability. It demonstrates how the systemic barriers that affect Aboriginal and Torres Strait Islander people have interacted with the systemic barriers that affect people with disability to create a unique exposure of disadvantage. There has been no sophisticated discussion to date on how the interaction of these systemic barriers create a unique inaccessibility to the NDIS for people who are most in need of support.

It further demonstrates the inadequacies of past policy approaches which are sectional (ie. addressed through disability policy *or* Indigenous policy) rather than intersectional (ie. considers the unique experiences of Aboriginal and Torres Strait Islander people as a discrete vulnerable population). The sectional approach to policies sees Aboriginal and Torres Strait Islander people as incidental within disability policy; and reciprocally people with disability are seen as incidental within Indigenous policy.

The data shows that sectional policy approaches have failed Aboriginal and Torres Strait Islander people with disability and therefore, to close the emerging gap in equitable access to the NDIS, Aboriginal and Torres Strait Islander people are a discrete market segment within the NDIS. If this is not acknowledged and supported with specific mechanisms in the NDIS, it can be reasonably expected that, through free market operation of the scheme, the present inequities experienced by Aboriginal and Torres Strait Islander people will be compounded.

1. **The Aboriginal and Torres Strait Islander disability market is *fragmented* (not ‘thin’)**

The position paper has bundled the Aboriginal and Torres Strait Islander disability market with other market segment in the category of a ‘thin market’, which is understood to mean there are few purchasers and providers and few transactions within the marketplace. The data does not support this assessment, and is instead a reflection of how much of the Aboriginal and Torres Strait Islander disability market is hidden from an orthodox outsider analysis.

A reasonable assessment of the demand can be made by extrapolating the ABS generated prevalence data for Aboriginal people aged 15 and over and equating it to the entire Aboriginal population. The ABS data indicates there are a minimum 60,000 Aboriginal and Torres Strait Islander people with severe and profound disability who are potentially eligible for the NDIS.

Based on the budget commitments to the NDIS, this cohort represents a $1.6 billion share of the market at full implementation if the NDIS is equitably distributed based on population and the ‘burden’ of disability. This is therefore not a ‘thin market’.

It is more apt to describe the Aboriginal and Torres Strait Islander disability market as a *fragmented* market, in which there is high demand for a customisable product; a large number of small, niche providers, many of whom provide informal care without support and therefore not reflected in the data; and small number of medium-scale service providers providing a generic product which may or may not meet the demand.

This is a vital distinction to make because the policy response will be informed by the market assessment and data. The emerging research and data highlights the fact that the Aboriginal and Torres Strait Islander disability market is larger than is generally accepted, and warrants significant investment in building a comprehensive larger scale market infrastructure. While understanding that the Aboriginal and Torres Strait Islander disability market is fragmented it must also be acknowledged that there is unmet demand for support to Aboriginal and Torres Strait Islander people with disability and an undersupply of adequately qualified providers.

1. **There is an increasing concern that the NDIA is not adhering to best practice protocols in the cultural engagement of Aboriginal and Torres Strait Islander people and their communities, which will undermine the long-term viability of the NDIS in these communities.**

In addition to having sound economic principles, successful implementation of the NDIS in Aboriginal communities will require a competent understanding of and respect for the cultural practices and ways of doing business.

In mid-2015, FPDN and other non-government organisations worked with the NDIA to develop its ‘Aboriginal and Torres Strait Islander Engagement Strategy’. It outlined the core principles of respect and two-way learning as the basis for which the NDIA and Aboriginal people and organisations would work in the implementation of the Scheme. At the time, this was considered a platform for future co-design of the implementation strategy, which would include workforce development, building a research and evidence base to support decision-making, and quality assurance.

The Aboriginal and Torres Strait Islander Engagement Plan was not launched by the NDIA until March 2017. There is increasing concern that the involvement in decision-making by Aboriginal people and their communities has not continued in a way that reflects the original intent.

Whilst there has been considerable energy in the communications and marketing promotions of the NDIS, we are concerned that this has come at the expense of longer-term strategies for sustainability, particularly in the ‘hard to reach’ areas of access and policy.

1. **The linkages between the NDIS, the National Disability Strategy and strategies to address Aboriginal and Torres Strait Islander disadvantage (eg. Closing the Gap Framework, Indigenous Advancement Strategy) are not evident.**

The current fragmented market structure is a legacy of the pre-NDIS era of government supported disability programs. At its core, Aboriginal and Torres Strait Islander disability straddles government agencies with responsibility for disability policy and programs and those government agencies with responsibility for Indigenous policy and programs. However, agencies responsible for education, justice, transport, housing, employment, and various dimensions of health have an interest or obligation in providing programs which support Aboriginal and Torres Strait Islander people with disability.

There are nine governments at the Federal, State and Territory level, so more than fifty government agencies have a stake in disability programs to Aboriginal and Torres Strait Islander people. There are infinitely more teams and units within departments, as well as those that operate at the local government level.

The links between the various policy approaches are tenuous at best. A coherent strategy is required which connects all related policy in a coordinated and complementary way. Bringing Aboriginal and Torres Strait Islander disability under the Closing the Gap Framework would be the most logical locations. Without some overarching strategy however, future cost management of the NDIS will suffer.

1. **Greater attention needs to be given to the impact of the avoidable burden of disability, which if unmanaged will adversely affect future costs.**

Through the ‘Living our ways’ research programs and other community consultations, FPDN is gathering evidence of practices and policies which risk increasing the burden of disability.

Examples include:

* An absence of timely diagnosis and intervention: There are opportunities to diagnose and provide support to manage disability, which are routinely foregone. Much of this oversight can be attributable to stigma and stereotyping. If disability is not accurately diagnosed and supported at the earliest opportunity, it places a person on a trajectory of disadvantage that accumulates over the rest of their life.
* There are inadequate supports in the early years of a child’s life. Children who are removed from their families and communities are particularly at risk of slipping through the cracks in the system.
* Institutional racism and unconscious bias can lead to sub-standard healthcare afforded to Aboriginal people, and can turn acute conditions or diseases into disabilities requiring long-term support. In effect, short cuts in health care is a cost shift into the NDIS down the track.
* The unnecessary incarceration of Aboriginal and Torres Strait Islander people, particularly those with cognitive and/or hearing impairment, adds trauma to any pre-existing disability. Every Aboriginal and Torres Strait Islander person leaving the justice system is a person requiring complex case management.

# Recommendations

1. **There needs to be a deliberate strategic approach to support the unmet need of Aboriginal and Torres Strait Islander people within the NDIS and other priorities within the National Disability Strategy, with Aboriginal and Torres Strait Islander people with disability taking a lead role.**

In May 2017 FPDN developed a new *10 Point Plan for meeting the needs of Aboriginal and Torres Strait Islander people with disability.* The plan was developed in consultation with other national Aboriginal peak organisations and based upon more than a decade’s direct consultation with Aboriginal and Torres Strait Islander people with disability and their families. The plan has been developed to create a clear and prescriptive way of bringing life to both the National Disability Strategy and the National Disability Insurance Scheme and to facilitate a meaningful way of addressing the unmet needs of Aboriginal and Torres Strait Islander people with disability and their families. The new *10 Point Plan* will be formally launched in August 2017. The first plan was launched at Australian Parliament House in May 2013.

1. **The NDIS and other policy approaches affecting Aboriginal and Torres Strait Islander people with disability needs to be responsive to the unique cultural attributes of Aboriginal and Torres Strait Islander communities and their market characteristics.**

FPDN has long advocated for what it refers to as the *Whole of Community Response* to disability. This program, which has not yet been funded, is based on a long established program of supporting people with disability in income poor settings know as *Community Based Rehabilitation* provides the opportunity to address the infrastructure problems that face many Aboriginal and Torres Strait Islander communities which the NDIS will not be able to address because it takes an individualised approach to meeting needs. For example, the NDIS will not build accessible footpaths in remote Australia because it is a person-centred scheme. Yet such infrastructure is critical to being able to participate in community life. As one Elder in a remote community put it recently ‘you can have the best wheelchair in the world but it doesn’t mean anything if I can’t get out of my house and down the road’. In some of our communities meeting the needs of our people with disability is a community development endeavour and not an individualised endeavour that assumes that there is already infrastructure in place.

The NDIS does not have responsibility to fund outside its mandate of funding of disability support. The responsibility for community infrastructure, such as accessible housing, footpaths and the built environment are the joint responsibilities of Commonwealth, State and Territory and local governments. There needs to be mechanisms through which the NDIA and COAG cooperate with the relevant agencies and Aboriginal and Torres Strait Islander community organisations to fulfil their responsibilities. These coordination activities include formalised partnership agreements and through Disability Inclusion Plans which are designed, resourced and implemented with community input to complement and support the roll out of NDIS in specific areas.

A specific focus upon the housing needs of Aboriginal and Torres Strait Islander people under the Specialist Disability Accommodation component of the NDIS is critical to addressing the fundamental human rights violation that many Aboriginal and Torres Strait Islander people with disability experience around the country because they do not have access to shelter. FPDN has well developed partnerships with Indigenous architects and builders that if resourced will mean that the creation of universally accessible and cost effective housing can become a reality for Aboriginal and Torres Strait Islander people with disability, in many cases for the very first time. This program could also generate employment in many communities.

1. **There needs to be a performance framework for Aboriginal and Torres Strait Islander disability**

The Aboriginal and Torres Strait Islander disability market is of sufficient size and complexity to warrant an equivalent level of decision support and analysis. It represents a market equivalent to over $1.6 bn of the NDIS but is underserviced in relation to data, research and evidence which must be available to inform decisions, both at the local provider level and at the national policy level particularly in comparison to other sectors such as health, where the *Aboriginal and Torres Health Performance Framework* has been monitoring progress and health outcomes since 2006 and is now in its sixth iteration.

1. **There is a greater role for the independent monitoring in the protection of the economic and human rights of Aboriginal and Torres Strait Islander people with disability**

Aboriginal and Torres Strait Islander people with disability remain some of Australia’s most marginalised citizens. They have an economic right to participate in markets both as consumers and providers. This right is currently being denied to them by the interaction of systemic barriers which impede access to the market.

Independent mechanisms act as a moderator to the excesses of a completely free market economy, which will not work in Aboriginal and Torres Strait Islander communities. This includes a specific voice for Aboriginal and Torres Strait Islander people into independent Quality Assurance structures which monitor the operation of the NDIS.

FPDN also recommends that the Aboriginal and Torres Strait Islander people with disability’s access to and participation in the NDIS must be a top priority issues for the new Indigenous Productivity Commissioner when that position starts.

# Attachments

First Peoples Disability Network (May, 2017) Snapshot of Aboriginal and Torres Strait Islander disability data and research.

Australian Bureau of Statistics (2017) National Aboriginal and Torres Strait Islander Social Survey (Re. 4714.0) *Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People with Disability.*

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