

15 December 2023

Department of the Prime Minister and Cabinet - Australian Government

Re: Inquiry into the Commonwealth Government's response to the COVID-19 pandemic

FPDN welcomes this opportunity to make a submission to the inquiry into the Commonwealth Government's response to the COVID-19 pandemic ('The Inquiry'). This submission provides key points for the Australian Government to consider when reflecting upon the effectiveness and failures of the pandemic response towards First Nations people with disability. FPDN also wishes to highlight that much of what is contained in this response can and should be considered in relation to the Government's preparedness to respond to *any* natural disaster or emergency situation in a way that is both effective and culturally inclusive of First Nations people with disability.

Response to The Inquiry:

FPDN has elected to focus on '*Mechanisms to better target future responses to the needs of particular populations (including across genders, age groups, socio-economic status, geographic location, people with disability, First Nations peoples and communities and people from culturally and linguistically diverse communities)*'. In short, it is FPDN's view that, if the Government is to better target the needs of First Nations persons with disability in the future, a 'top to bottom' change in approach and planning is required. In targeting one of Australia's most excluded communities, it will improve responses for all.

Collecting disaggregated data:

The existence of accurate data is absolutely fundamental to the creation of an effective response. FPDN is disappointed that, when recording COVID statistics, the number of individuals with a disability who died as a result of COVID-19 was not recorded. ABS statistics instead record the number of deaths for individuals with a 'pre-existing condition', which is a far broader category that is not widely useful for assessing the impact of COVID-19 on disabled persons specifically, yet alone First Nations persons with a disability. FPDN calls on the Government/ ABS to ensure comprehensive approaches to data collection. For example, the United Kingdom was able to record COVID-19 deaths by disability status.¹

Organisations such as FPDN (and the Government itself) need to be able to access disaggregated data that pertains specifically to First Nations persons with disability (this is also in line with Closing the Gap National Agreement Priority Reform 4). This is as true in relation to COVID-19 as it is for any other social, health or justice issue. The Government should understand it cannot seriously and meaningfully create '*[m]echanisms to better target future responses to the needs of particular populations*' if the data that is required in order to identify those needs simply does not exist in the first place.

Recognising Intersectional Disadvantage:

Any response by the Government which fails to consider the concept of intersectional disadvantage is limited in its effectiveness. Government should not develop separate plans for First Nations people on one hand and

¹ United Kingdom Office for National Statistics, '[Updated estimates of coronavirus \(COVID-19\) related deaths by disability status, England Articles](#)', accessed 22 November 2023.

people with disability on the other. For First Nations persons with disability, sources of discrimination and disadvantage are fundamentally intertwined. Many First Nations persons with a disability are often further disadvantaged, such as those who live in rural/remote communities with limited access to information, resources and facilities.

It is also important to bear in mind that a failure to account for the needs of persons with disability will innately constitute a failure to consider the needs of First Nations people, who are twice as likely to experience disability than the rest of the Australian population.² 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)*, 2018,³ it is estimated that over 60,000 Aboriginal and Torres Strait Islander people live with severe or profound disability in Australia today.⁴

To give an example of a specific issue with the Government's COVID-19 response, FPDN was made aware that COVID-19 immediately placed strain on regional hospitals, which were forced to contend with the possibility of needing to ration extremely limited amount of beds and ventilators within Intensive Care Units (ICU). During these early stages of the Government's response, Australia was one of a number of countries with a reasonably well-developed health care system that considered focusing on practical decision trees or algorithms for frontline clinicians, as part of developing COVID-19 critical care protocols.⁵ FPDN does not intend to recount the whole process, but serious consideration was given towards implementing a process of critical care triage that, in focusing on algorithms and assumptions about survival rates, would unjustly discriminate against and de-prioritise the medical treatment of a broad population of people with disability. It is alarming that such an ableist view of determining who is 'worthy' of treatment was seriously considered at all, despite the disproportionate effects that would follow, especially for First Nations peoples. In order to move forward, the Government must recognise that intersecting forms of discrimination can be (unintentionally) institutionalised and embedded in how policies and programs are designed.

First Nations persons are already at heightened risk of discrimination when attempting to access hospital services such as via 'diagnostic overshadowing', which is the concept of discriminatory assumptions (e.g. regarding race) 'overshadowing' the diagnosis and treatment of an underlying disease/condition.⁶ During a triage for COVID-19 treatment, First Nations persons with disability are at a heightened risk of 'diagnostic overshadowing' on account of *both* their race and disability status. In reality, many other relevant disadvantages also exist, such as the historically grounded distrust that many First Nations individuals feel towards accessing and making frank disclosures to medical services. Given the Government's lack of cohesive planning, it is difficult for FPDN to imagine how a First Nations person with symptoms of COVID-19 and a significant disability would not have been at high risk of 'falling through the cracks' of the system. To date, no

² Australian Bureau of Statistics (ABS) (2016) *National Aboriginal and Torres Strait Islander Social Survey*, (NATSISS) 2014-15 (Release 4714.0).

³ ABS, '[Disability, Ageing and Carers, Australia: Summary of Findings](#),' 2018, accessed 29 August 2023.

⁴ S Avery, '[Culture is Inclusion](#),' 2018, First Peoples Disability Network.

⁵ J L Scully, '[Disability, Disablism, and COVID-19 Pandemic Triage](#)' 2020.

⁶ S Avery, '[Culture is Inclusion](#),' 2018, First Peoples Disability Network.

commitment has been made by the Government to ensure that such individuals will have access to appropriate interpreters and advocates at the point of triage, especially in remote areas.

Even though Australia did ultimately adopt more of an 'ethics-based' approach to triage guidance, FPDN would submit that the haphazard response which occurred should have been entirely avoided via the prior existence of a robust national disaster response plan.

Effective communication and collaboration

FPDN does not believe that the COVID-19 response was satisfactory and no mechanism proposed by the Government will meaningfully improve the effectiveness of any pandemic response if it is not designed to be accessible by the target audience. FPDN also suspects that the true extent of poverty affecting First Nations communities is still not well understood by the Government.

FPDN considers that specialised, local community-managed organisations are best placed to understand and respond to the specific needs of their communities and encourages a Government response founded upon such, which would be consistent with the Government's core obligations under the Convention on the Rights of Persons with Disabilities (CRPD), Closing the Gap Agreement and the Disability Sector Strengthening Plan. To the extent that the Government was capable of rapidly producing and distributing public guidance material about COVID-19, that material was not necessarily accessible to disabled persons and certainly was not part of any comprehensive campaign to target First Nations persons. In response, FPDN, without funding, designed relevant material, which was well received and adopted/distributed by other agencies.

Overall, FPDN's experience is that the Government's responses to communities and individuals needing the most preventative and ongoing supports, were bureaucratic and slow. At times, FPDN staff purchased food and disability supplies, and delivered it to community members who could not access or were not familiar with food banks. Meaningful conversations about the provision of Government support were occurring, but at a rate which left those communities with a high degree of anxiety, uncertainty, and perceived risk of 'death by committee'.

Following the outbreak of COVID-19, ACCOs, advocacy groups and other community-run organisations were effectively forced, in an ad-hoc capacity, into becoming 'accidental emergency workers' for the provision of food, medication, disability supports and other essentials. Whilst they did provide supplies, information and support at a rapid pace, this was without the support of governments. FPDN was particularly appalled by incidents where Aboriginal communities were locked down and prevented from obtaining essential medications, while others were left without the means to secure clean, uncontaminated drinking water.

Ongoing role of FPDN during The Inquiry:

FPDN wishes to play an ongoing role in providing evidence as a part of The Inquiry. FPDN has been highlighting numerous areas of concern regarding the COVID-19 response for some time, such as within the '*COVID-19: Ethical decision-making for First Peoples living with disability*' ethics paper that has been attached as 'Annexure B' and notes the contents of this response only reflect a small portion of the total number of issues and observations made by FPDN and the communities we represent.

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Appendix A

About FPDN

FPDN is the community-controlled disability peak and a member of the Coalition of Peaks, a partner to all Australian governments to the Closing the Gap National Agreement. We are also the First Nations Disability Representative Organisation actively representing the voices of First Nations peoples within Australia's Disability Strategy governance structures. For millennia, First Nations peoples, communities, and cultures have practiced models of inclusion. However, despite this, since colonisation, First Peoples with disability and their families have been and continue to be amongst the most seriously disadvantaged and disempowered members of the Australian community. FPDN gives voice to their aspirations, needs and concerns and shares their narratives of lived experience. Our purpose is to promote recognition, respect, protection, and fulfilment of human rights, secure social justice, and empower First Peoples with disability to participate in Australian society on an equal basis with others. To do this, we proactively engage with communities around the country, influence public policy and advocate for the interests of First Peoples with disability in Australia and internationally.

Our extensive national work includes community engagement, capacity building and rights education; systemic advocacy, policy, research, evaluation and data; the development and delivery of evidence-informed training and resources with community for community and to a range of sectors including the Community Controlled sector and mainstream disability sector, Commonwealth and state/territory government policy and service delivery agencies and departments. FPDN also has an international presence and networks, including with the United Nations, and provides consultancy and support to international regions.

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

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

A cultural model of inclusion recognises the diversity of cultures, languages, knowledge systems and beliefs of First Nations people and the importance of valuing and enabling participation in society in ways that are meaningful to First Peoples.⁷ A First Nations cultural model of inclusion includes the human rights framework and the social model of disability to ensure that enablers, approaches, services and supports are culturally safe and inclusive, and disability rights informed. It is the only disability model that seeks to improve the human condition through focussing on what keeps people strong, as distinct to merely negating the adverse impact of difference.

Our community has to operate in multiple worlds – First Nations, disability, and mainstream society. The disability sector reflects this and is a complex and interconnected web of approaches to enable First Nations people with disabilities to realise their rights to participate in all aspects of their life, including safe, affordable, accessible and inclusive housing. These enablers, approaches, services and supports need to exist across the entire life-course, including the Aboriginal and Torres Strait Islander Community Controlled Sector and mainstream disability sector, as well as mainstream organisations and services.

The policy context

FPDN recognises the unique opportunity both Closing the Gap and Australia's Disability Strategy to ensure the legislation, policies, programs and service delivery are accessible, inclusive and equitable for First Nations people with disability, including during emergency responses such as during Covid 19.

FPDN discussion points are in line with the Closing the Gap National Agreement Priority Reforms and the Disability Sector Strengthening Plan and its Guiding Principles. The Priority Reforms focus on changing the way governments work with Aboriginal and Torres Strait Islander peoples and the Disability Sector Strengthening Plan outlines high-level priorities and actions at a national level to strengthen and build a Community Controlled Disability Sector. The Commonwealth government, all State and Territory Governments and the Local Government Authority are signatories and partners to the National Agreement and also the Disability Sector Strengthening Plan. The Priority Reforms are:

1. Formal partnerships and shared decision-making

⁷ S Avery, '[Culture is Inclusion](#),' 2018, First Peoples Disability Network.

2. Building the community-controlled sector
3. Transforming government organisations
4. Shared access to data and information at a regional level

Applying the Closing the Gap approach to disability as a cross-cutting outcome through the Priority Reforms offer structure to government to ensure First Nations peoples with disability have:

- A greater say in how policies and programs are designed and delivered;
- Have access to community-controlled services and sectors that delivers culturally safe, accessible and inclusive, and disability right informed services;
- Have access to mainstream organisations and services, such as NDIS services, hospitals, schools and government agencies, that are culturally safe, accessible and inclusive, and disability right informed;
- And have access to, and the capability to use, locally-relevant, First Nations disability informed, data and information.

Such an approach would enhance any disaster response.

First Nations people with disability

For millennia, First Nations peoples, communities, and cultures have practiced models of inclusion. This embracing of diversity and inclusion “is derived from a belief system and worldview of humanity in which biological, physical and intellectual differences are accepted as part of the fabric of society.”⁸ 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.⁹ Whilst population prevalence data is limited, First Nations people are twice as likely to experience disability than the rest of the Australian population.¹⁰ 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)*,

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

⁹ S Avery, ‘[Culture is Inclusion](#),’ 2018, First Peoples Disability Network: Australian Bureau of Statistics (ABS) (2016) *National Aboriginal and Torres Strait Islander Social Survey*, (NATSISS) 2014-15 (Release 4714.0).

¹⁰ Australian Bureau of Statistics (ABS) (2016) *National Aboriginal and Torres Strait Islander Social Survey*, (NATSISS) 2014-15 (Release 4714.0).

2018,¹¹ it is estimated that over 60,000 Aboriginal and Torres Strait Islander people live with severe or profound disability in Australia today.¹²

First Nations people with disability experience many intersectional forms of discrimination, including discrimination based on age, gender, sexuality and geographic location. These intersecting forms of discrimination are institutionalised and embedded in how policies and programs have been designed, including disaster responses, such as during Covid 19.

Consistent with the social and cultural models of disability within which FPDN works, we recognise that Aboriginal and Torres Strait Islander people are disproportionately affected by poor outcomes. This impact is widespread and has social, emotional, physical, economic and cultural impacts.

First Nations Disability Data Gap

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 is captured 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 is often limited in scope, and often does not provide sufficient focus to all experiences of disability in regional, remote or urban contexts. FPDN is in the process of developing a broad First Nations disability data strategy, however, there is a need for dedicated First Nations Disability data project with specific intersectional data that would continue to support targeted action and monitoring of the impact of disaster responses to our community.

¹¹ ABS, '[Disability, Ageing and Carers, Australia: Summary of Findings](#),' 2018, accessed 29 August 2023.

¹² S Avery, '[Culture is Inclusion](#),' 2018, First Peoples Disability Network.

Appendix B

First Peoples Disability Network Australia, 'COVID-19: Ethical decision-making for First Peoples living with disability'.



First Peoples
Disability Network
Australia

COVID-19: Ethical decision-making for First Peoples Living with Disability

fpdn.org.au

COVID-19: ETHICAL DECISION-MAKING FOR FIRST PEOPLES LIVING WITH DISABILITY

The COVID-19 pandemic raises significant issues of disability and racial inequality in health-care delivery. The primary risk of the pandemic to people with a disability is that healthcare resources (such as intensive care) may not be provided to them in times of scarcity¹. The pandemic is also highlighting some of the serious structural problems that health systems experience when providing care to people from different racial backgrounds. For example, we have noted with concern the disproportionate impact that COVID-19 is having on people of colour in the United States.²

The combination of these discriminatory forces poses an enormous threat to the First Peoples of Australia living with disability. First Peoples with a disability experience intersectional discrimination through health and social welfare systems that struggle to provide reasonable accommodation for disability, and from the history of political and institutional racism that has harmed Aboriginal and Torres Strait Islander peoples since 1788. During this pandemic it is essential that decision-makers listen to and understand the unique voices of First Peoples with disability so that their experiences can be incorporated into planned responses.

Recently the Federal government released its *Australian Health Sector Emergency Response Plan for the Novel Coronavirus (COVID-19)* ("The Plan"). The Plan lays out a framework for management of resources during the pandemic with the express recognition that care should be provided in an 'equitable' manner. The Plan emphasises the special needs, cultural values and the religious beliefs of different members of the community, with a special recognition of the cultural and linguistic diversity of Aboriginal and Torres Strait Islander peoples. The Plan also highlights the need for effective communication with Aboriginal and Torres Strait Islander peoples. We also note the Federal government's *Management Plan for Aboriginal and Torres Strait Islander Populations*³ which repeats the principles of shared decision-making between Government and Aboriginal and Torres Strait Islander people, and the need for appropriately informed and culturally safe care (but which fails to discuss disability in Aboriginal and Torres Strait Islander populations at all).

The principles of equity, recognition and cultural competence accord with the government's human rights obligations under the *Convention on the Rights of Persons with Disabilities* and the *Declaration on the Rights of Indigenous Peoples*. The challenge is how to give effect to these ideals in decision-making during the pandemic. The First Peoples Disability Network believes that the following are necessary steps towards achieving the kind of equity, shared decision-making and culturally safe care:

¹ Robin Banks, Andrew Byrnes, Kevin Cocks, Megan Davis, Graeme Innes, Rosemary Kayess, Ron McCallum, Jackie Leach Scully, Statement of Concern – *COVID-19: Human rights, disability and ethical decision-making* 16 April 2020.

² Jamelle Bouie, 'Why Coronavirus Is Killing African-Americans More Than Others' *New York Times* 14 April 2020.

³ *Management Plan for Aboriginal and Torres Strait Islander Populations* <https://www.health.gov.au/resources/publications/management-plan-for-aboriginal-and-torres-strait-islander-populations>.

1. Recognise the reality of disability for First Peoples

The first step must be to recognise the reality of disability for First Peoples in Australia. They experience a disproportionately high percentage of disability within their populations.⁴ Any resource allocation decision that emphasises disability as a criterion for exclusion from care will automatically discriminate disproportionately against Aboriginal and Torres Strait Islander Peoples. ***All Federal, State and Territory government agencies must remove disability from consideration of resource allocation when it is used as a broad criterion for exclusion from critical care.***

2. Listen and understand the problems of delivery of healthcare to First Peoples with disability

If healthcare is going to be effectively provided to First Peoples during the pandemic, the healthcare sector needs to listen and understand the specific problems of delivery that are experienced by First Peoples with a disability. Many First Peoples live in remote communities here, healthcare delivery is incredibly challenging, especially to those with a disability. Care is often provided by family members rather than healthcare professionals and the bulk of family care is disproportionately provided by women, who may themselves be facing significant health challenges. Any decisions made about healthcare for First Peoples during the pandemic must include First Peoples themselves for the healthcare to be effective. State and Federal health authorities must commit to including ***First Peoples with a disability in planning for decision-making regarding healthcare during the pandemic.***

3. Acknowledge the history of the relationships between the health sector and First Peoples with disability

The pandemic is creating new problems for the healthcare system – but it is also exposing the old problems of discrimination that lie at the roots of Australian healthcare. The relationships between communities of First Peoples and the healthcare sector have not always been happy ones. In places where the relationship is strained, it is important for the healthcare sector to reach out and try to build confidence and trust. During this pandemic all Australians are being called upon for compliance, but that compliance draws on wells of trust. In some places, this trust remains to be built with First Peoples. ***State and Federal health authorities must commit to identifying areas of strain and work to re-establish strong relationships of trust and confidence with the First Peoples affected. In cases where that cannot be implemented, arrangements should be made to give access to alternative healthcare resources.***

⁴ Australian Bureau of Statistics, *Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People with a Disability* [https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Feature%20Article~Social%20and%20economic%20wellbeing%20of%20Aboriginal%20and%20Torres%20Strait%20Islander%20people%20with%20disability%20\(Feature%20Article\)~10001](https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Feature%20Article~Social%20and%20economic%20wellbeing%20of%20Aboriginal%20and%20Torres%20Strait%20Islander%20people%20with%20disability%20(Feature%20Article)~10001)

4. Accommodate the Laws

Healthcare for First Peoples may be complicated by their Laws, which have created a rich tapestry of rules around information provision, touching and care. Effective healthcare must be based on an effective understanding of the cultural diversity of the Laws and accommodate them within delivery. ***State and Territory policies on pandemic healthcare must expressly refer to the need to be culturally competent when providing services to First Peoples with a disability.***

5. Grow the cultural capacity of the healthcare sector

Even in the absence of a pandemic, healthcare providers in all States and Territories should be employing appropriately trained and registered Aboriginal and Torres Strait Islander Healthcare Workers. This nationally registered health profession specialises in providing a culturally safe workplace, free from racism so that First Peoples can enjoy a healthy life is enriched by a strong living culture, dignity and justice. At present there are only 750 registered professionals, and more are desperately needed. ***The State and Territory governments must look at how more students can be transitioned into the Aboriginal and Torres Strait Islander Healthcare workforce.***

6. Value cultural worth held by Elders of the First Peoples of Australia

The Elders of First Peoples' communities hold a revered place as the custodians of language, Law and culture. Their knowledge must survive for it to be passed on to future generations. It is widely understood that COVID-19 is particularly aggressive in older people, who face a much higher risk of death as a result. Widespread infection of Elders with COVID-19 may threaten the very cultural existence of First Peoples. ***State and Territory governments must understand this existential threat and take whatever action is necessary to protect Elders as the guardians of First Peoples' cultures.***

The pandemic is a test for all Australians. Part of that test will be how, in the toughest of times, the healthcare system treated First Peoples with a disability. The four points of action we have outlined put First Peoples with a disability in a position where they can speak to decision-makers and help them provide appropriate responses to the pandemic. First Peoples with disability speak with unique voices that convey powerful messages. Now is the time for those voices to be heard and for the messages to be acted upon.