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

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 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. 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. 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.

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Australian Bureau of Statistics, Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People with a Disability
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.