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COVID-19, Intersectionality, and Health Equity for Indigenous Peoples with Lived Experience of Disability

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ndigenous scholars and others have highlighted the increased risks to Indigenous Peoples of the adverse impacts of the COVID-19 pandemic, and related calls to action have been made.¹ Additionally, people with lived experience of disability are at increased risks due to underlying health conditions and increased exposure to COVID-19 in community care settings and they encounter issues of equity in access to and quality of health care.² However, little attention has been given so far to the impacts of the COVID-19 pandemic on Indigenous Peoples with lived experience of disability and their communities. This pandemic, and the subsequent health systems responses, have brought into sharp focus the longstanding inequities for Indigenous populations. Also evident is the importance of Indigenous voices in health and disability system design and decision making, as the pandemic has seen the emergence of new mechanisms that have the potential to contribute to inequities such as frameworks for resource rationalization that are entrenched with negative views of ethnicity and disability.

Some may find the idea of leaving decisions about access to care in potentially life or death situations to chance a somewhat arresting proposition. However, what should be alarming . . . and prompt an immediate call to action, is that our society is structured in such a way that for some people, a toss of a coin offers the best odds of a fair, equitable outcome.

> —Donna Cormack, Decision-making in Healthcare: Values, Ethics and Colonial Myths

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Research highlights that the lived experience of disability for Indigenous Peoples is considerably different to that of non-Indigenous Peoples.⁷ Indigenous Peoples experience "additional and diverse historical and contemporary impacts of disablement arising from colonization, societal discourses about racism, subjugation and dysfunction that are in themselves disabling."⁸ As scholars point out, "cultural diversity and social inequality are often ignored or downplayed in disability services. Where they are recognized, racial and cultural differences are often essentialized, ignoring diversity within minority groups and intersectionality with other forms of oppression."⁹ For tāngata whaikaha in New Zealand, disablement occurs secondary to being excluded by a society that "takes no account of their culture, identity or the meanings that Māori themselves give to disability ... Māori have been disabled through deficit theorizing and assimilatory ... practices that have marginalised and excluded Māori from their own knowledge base, language, cultural values, and practices."¹⁰

In this commentary, we draw upon intersectionality as an analytical tool for understanding how the adverse impacts of the COVID-19 pandemic are likely to be compounded for tāngata whaikaha. In doing so, we choose to use the term "tāngata whaikaha" when referring to Māori with lived experience of disability and their "whanau" (extended family), while acknowledging that Māori use a range of other terms to describe their own lived experience of disability. Lastly, we highlight the urgent requirement to reject current universal approaches with focus instead on health equity for tāngata whaikaha in the New Zealand government's response to the pandemic, proposing a "call to action" framework.

Compounded Impacts of Covid-19 for Tängata Whaikaha

Intersectionality analyzes the means by which "intersecting power relations influence social relations across diverse societies as well as individual experiences in everyday life."¹¹ Scholars note that "power relations of race, class, and gender, for example, are not discrete and mutually exclusive entities, but rather build on each other and work

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together."¹² Within the context of the COVID-19, intersectionality has been declared an essential requisite for an equitable public health approach to the COVID-19 pandemic.¹³ In their call for intersectionality-informed approaches,¹⁴ scholars emphasize how the pandemic "will differentially impact individuals by interacting and overlapping with context-specific drivers of vulnerability and marginalization".¹⁵

For Māori and for people with lived experience of disability in New Zealand, all of the issues described in the following sections are summative in their contribution to worse impacts for tāngata whaikaha, secondary to an interconnection of the risk factors described occurring within current systems, structures, and axes of power, privilege, and oppression. As scholars reiterate, such "processes are historically rooted in structures of privilege and oppression shaped by patriarchy, structural racism, xenophobia, colonialism, imperialism, homophobia and ableism."¹⁶ Māori compared with non-Māori have a higher prevalence of disability (24% compared with 16% in 2013), have a higher proportion of disability across all age groups, and experience less privilege across almost all socioeconomic indicators.¹⁷

The adverse impacts of the COVID-19 pandemic and the inequities occurring for Indigenous Peoples have been reported globally.¹⁸ In New Zealand, Māori are likely to experience disproportionate adverse impacts from the COVID-19 pandemic, with regard to severe illness and death in the event of community transmission and from the broader impacts of the pandemic.¹⁹ These increased risks are related to social determinants of health equity that drive inequitable outcomes—those associated with increased transmissibility of communicable diseases, for instance, such as household crowding.²⁰ Additionally, Māori are more likely than European ethnic groups to have underlying health conditions related to serious illness and death from COVID-19,²¹ are more likely to develop these comorbidities at a younger age, and are more likely to have multiple comorbidities,²² where a higher number of comorbidities has been found to be associated with higher risk of intensive care unit (ICU) admission and/or mortality.²³ In addition, Māori experience differential access to high-quality healthcare.²⁴

These significant inequities are driven by racism existing across the New Zealand health and disability system, including implicit and explicit racial/ethnic bias against Māori at the level of the health practitioner. As a result, scholars highlight that Māori are likely to experience a number of adverse health impacts of COVID-19, including increased risks of undetected COVID-19 cases, in addition to intensification of current inequities as a result of overstretched health and disability services.²⁵ Other concerns relate to the disproportionate impacts of social/physical distancing provisions and "shut down" requirements, causing disruption to collectivist cultural/social norms and practices and suspension of key cultural practices—for instance, *tangihanga* (Māori cultural practices around death)²⁶—and importantly, the restrictions on Indigenous leadership. This was demonstrated by the lack of any Māori taking part in the New Zealand government's public daily briefings on COVID-19 as part of its national public relations campaign.²⁷

As has been noted with regard to Indigenous Peoples, evidence indicates that people with lived experience of disability are also at increased risk of severe illness and death from COVID-19 due to evidence of higher prevalence of underlying chronic health conditions associated with adverse morbidity and mortality outcomes from COVID-19.²⁸ Tāngata whaikaha over twenty-five years of age are more likely to have diabetes, stroke, and cancer, and are more likely than non-Māori with lived experience of disability to be admitted to hospital for cardiovascular diseases such as high blood pressure and ischemic heart disease,²⁹ comorbidities which are associated with severe illness and death from COVID-19. Tāngata whaikaha experience higher proportions of unmet need compared with non-Māori with lived experience of disability, including access to health professionals and special equipment, and are likely to have lesser access to disability support services.³⁰ Research also indicates that tāngata whaikaha experience substantial barriers to healthcare such as time to appointment, cost, and location, with particular impacts for tāngata whaikaha who live in rural areas.

In New Zealand, inequitable access to personal protective equipment (PPE) for home and community disability care and support workers, and lack of communityspecific guidelines regarding use of PPE have been reported for people with lived experience of disability.³¹ Other significant concerns include inequitable access to PPE, barriers to carrying out daily living in the community for people who may be reliant on family, friends and/or caregivers, and risks of neglect and/or seclusion and/or restraint against people living in institutions. People with lived experience of disability interacting with the health and disability system have reported higher levels of unmet need and decreased access to health care. Lack of access to real-time information accessible in all modes and formats (for instance, online as well as non-digital, inclusive language and Easy Read, Braille, and Sign Language), has also been reported.³²

Further concerns relate to the overrepresentation of people with lived experience of disability in population groups reported to have increased risk of severe illness from COVID-19—for instance, lower socioeconomic status, living in institutions or residences and prisons, and houselessness.³³ People with lived experience of disability who are incarcerated are at increased risk of COVID-19 infection. People with lived experience of disability are reported to be overrepresented in the prison population, particularly those with lived experience of learning/intellectual disability.³⁴ Similar to the situation for many Indigenous Peoples internationally, Māori are overrepresented in prison populations and are at increased risk of contracting the illness due to unhygienic overcrowded living conditions and less access to high-quality healthcare.³⁵

In addition to the inequities between tāngata whaikaha and non-Māori with lived experience of disability, there are inequities within tāngata whaikaha groups because of differential government responses to impairments depending upon their cause, such as accidental injury versus non-injury-related impairments, for example.³⁶ Within the Māori population, inequities also exist for tāngata whaikaha compared to Māori without lived experience of disability. Among disproportionate impacts, people with lived experience of disability are more likely to have lower household income and less likely to have secure employment. For instance, tāngata whaikaha are less likely to be in the labor force than Māori without lived experience of disability. The NZ Disability Rights Commissioner has raised concerns that people with lived experience of disability.

hit hard by the adverse impacts of the pandemic on employment.³⁷ In addition, tāngata whaikaha are more likely to have lower incomes than Māori without lived experience of disability.³⁸

It has been reported in New Zealand that Māori are almost twice as likely as non-Māori to have experienced any type of racial discrimination.³⁹ However, experience of discrimination is more common among tāngata whaikaha Māori than it is for Māori without lived experience of disability. For example, 23 percent of tāngata whaikaha have reported having experienced discrimination in the past 12 months, compared with 13 percent of Māori without lived experience of disability.⁴⁰ There are also the potential increased risks of gender, sexual, intimate partner, and domestic violence against people with lived experience of disability. Additionally, lack of access to resources supporting education online in the event of disrupted schooling (for instance, Internet access and accessible materials and equipment) is more likely to occur for children and young people with lived experience of disability, who are already more likely to be excluded from education.⁴¹

Inequitable impacts from the COVID-19 pandemic for tāngata whaikaha are likely to be exacerbated by universal approaches to service provision that encompass the New Zealand government's public health response. Within the context of New Zealand health and disability services, scholars (including tāngata whaikaha) have highlighted the "tendency for dominant cultures in any country to assume that their mainstream health care services are somehow acultural—a kind of *tabula rasa* (i.e., a neutral platform) for the fair and equitable provision of treatments and interventions for all people that they serve."⁴² However, tāngata whaikaha experience significant barriers to accessible versions of COVID-19 information developed by the New Zealand government, such as information in te reo Māori (the Māori language), in Easy Read, Braille, and Sign Language. Any communication-related barriers are likely to be amplified in situations of isolation during periods of "shut down" and in cases of disrupted and/or new connections as a result of new caregivers and/or provider agencies.

Historically, the aspirations and needs of tāngata whaikaha have not been prioritized,⁴³ resulting in limited preexisting relationships between the government and tāngata whaikaha communities to draw upon, and a paucity of existing Māori-led disability service providers to address COVID-19 impacts for tāngata whaikaha in culturally safe ways.⁴⁴ For instance, of a total of about 980 disability service providers across the entire country, only thirty-three are Māori-led.⁴⁵ Moreover, the New Zealand Ministry of Health's "Initial COVID-19 Māori Response Action Plan," published in April 2020, makes no mention of tāngata whaikaha and their communities.⁴⁶ When updated in July 2020, tāngata whaikaha were mentioned only four times.⁴⁷

The Urgent Requirement for *Both* High Quality Real-Time Ethnicity and Disability Data

The World Health Organization has reported there are over a billion people with lived experience of disability worldwide,⁴⁸ although the number of Indigenous Peoples with lived experience of disability is still unclear due to a lack of high-quality data.

Considerable concerns have been raised about the paucity of disability data to enable accurate monitoring of the impacts of COVID-19. Scholars point out that without disability data, the impacts of the pandemic on people with lived experience of disability continue to be largely unknown,⁴⁹ stating that, "lack of data perpetuates the exclusion of disabled people from discussions of health equity and policies that are data driven."⁵⁰ In alignment with other Indigenous scholars,⁵¹ Māori scholars within New Zealand have also promoted the urgent need for high quality ethnicity data and rapid analysis, real-time modeling, and dissemination of COVID-19 data in order to monitor impacts of the pandemic, to inform public health policies, and to intervene on behalf of Māori.⁵²

Similar to issues with data collection internationally, the New Zealand government relies on smaller sample surveys of disability data (such as the Statistics New Zealand Disability Survey) to measure the prevalence of disability, rather than utilizing population-level data to do so. The Washington Group Short Set questions have been introduced to the most recent 2018 New Zealand Census.⁵³ However, rather than measuring prevalence, they are used as a variable for comparative outcomes by population subgroups, and, significantly, have not been designed by, with, and for Indigenous Peoples with lived experience of disability.⁵⁴ In New Zealand, the government conducted a Disability COVID-19 survey during April and May 2020 in order to understand the impacts of the pandemic on people with lived experience of disability.⁵⁵ However, this survey had a limited focus on tāngata whaikaha, with survey reports not including disaggregation by ethnicity. Raw survey data (that did include ethnicity data) was not disseminated in accessible formats for tangata whaikaha and their communities. Again the aspirations and needs of tāngata whaikaha for high quality data in order to utilize to address existing and exacerbated inequities were marginalized.

Information on COVID-19 cases is now disaggregated by ethnicity, but not by disability.⁵⁶ The authors approached New Zealand health agencies in May 2020 requesting information about the numbers of COVID-19 hospitalizations and deaths disaggregated by ethnic groups, and by disability. While most (but not all) health agencies could provide some of the data by ethnicity, no agency was able to supply information about hospitalizations or deaths by ethnicity as well as disability. The government's universal approach to COVID-19 monitoring, and the resultant paucity of data responsive to the aspirations and needs of tāngata whaikaha and their communities during the pandemic, is of significant concern.

Harms Amplified for Tāngata Whaikaha: Prioritization Tools in the Allocation of "Scarce" Resources during the COVID-19 Pandemic

The United Nations have raised concerns around the development of discriminatory tools in the allocation of resources during the pandemic, emphasizing that such tools "reveal medical bias against persons with disabilities concerning their quality of life and social value. For example, triage guidelines for allocation of scarce resources with

exclusion criteria based on certain types of impairment, having high support needs for daily living, 'frailty,' chances of 'therapeutic success,' as well assumptions on 'lifeyears' left should they survive."⁵⁷ Prioritization tools for ICU triage have been heavily critiqued for their potential to discriminate against population groups who already experience multiple forms of oppression.⁵⁸ In response to the proliferation of such tools, disability rights organizations and individuals with lived experience of disability in the United States have filed complaints with the Office for Civil Rights (OCR) at the Department of Health and Human Services. In April 2020, the OCR intervened in Alabama, resulting in the withdrawal of its crisis standards of care policy, which had specified the denial of ventilators to people with lived experience of learning/ intellectual disability.⁵⁹

Others have critiqued the general lack of transparency and public engagement around the development of prioritization tools, such as those used in intensive care unit (ICU) triage within the context of pandemics.⁶⁰ They observe how communities potentially impacted by the prioritization tools had little awareness of their existence, nor had they the opportunity to be involved in their development. Instead, the tools "had been hashed out by professionals who, by dint of being professionals, could be expected to share many relevant values and implicit biases. The protocols themselves often gave lip service to the ethical duty to solicit public input."⁶¹ Additionally, scholars point out such tools are neither objective nor neutral with regard to the values that underpin them. Use of algorithms, for instance, "provide no inoculation against bias; on the contrary, they may not only embed the prejudices of their architects, but also amplify and transform them into systemic biases."⁶² Instead of being value-free, they are value-laden.⁶³

Other scholars point out that situations of scarcity are a consequence of the overwhelming lack of pandemic preparedness and responsiveness and poor leadership, with the resultant burden falling upon population groups who already experience discrimination within societies.⁶⁴ In the context of withholding of ICU support for people with lived experience of disability who have COVID-19, they observe that situations of scarcity do not derive from "natural fact" but are instead a direct result of decisions made by society. For instance, the "decision to fail to maintain an adequate stock of ventilators to serve all patients who would need them if a pandemic breaks out. ...[and] once a pandemic breaks out, to use patients' pre-existing disabilities as a basis for denying them the use of those devices."⁶⁵

Similar algorithm-based tools for the prioritization of resources are being developed in New Zealand (specifically within the context of ICU triage),⁶⁶ but have also been suggested for use within other situations such as COVID-19 vaccination.⁶⁷ Te Mana Raraunga (the Māori Data Sovereignty Network) emphasize how in colonial, racist societies it is "highly likely that algorithms will produce racialised inequities."⁶⁸ Māori scholars further point out that as "colonial, racist, capitalist conditions of our society are reflected in the racialised distribution of the determinants of health and in health inequities.... to then use these same criteria to make decisions about access to potentially life-saving healthcare, is a doubling-down on racism and ableism."⁶⁹ Thus, prioritization tools not underpinned by equity that are then used to make decisions about access to ICU ventilators or vaccinations will increase the likelihood of inequitable outcomes for population groups who already experience multiple forms of systematic and structural oppression. Māori scholars note such tools will "reproduce, not disrupt, colonial, racial logics... To do otherwise would require radical and fundamental rethinking and restructuring of systems and resources—a commitment to which has not been demonstrated by the [New Zealand] government."⁷⁰

For tāngata whaikaha and other Indigenous Peoples with lived experience of disability, colonization, colonialism, racism and ableism have resulted in a higher burden of comorbidities⁷¹ that are likely to be associated with severe illness and death from COVID-19.⁷² Therefore, prioritization tools designed to measure the severity of the disease when it first presents and include comorbidities as predictors of mortality will likely result in reduced access to ICU ventilators, vaccines, and necessary resources for tāngata whaikaha and other Indigenous Peoples with lived experience of disability.

A CALL TO ACTION

In this commentary, we have used intersectionality as an analytical tool to provide an understanding of how tāngata whaikaha are at markedly increased risk from the wider adverse impacts of the pandemic. Indigenous scholars point out however, that "despite the marginalization of Indigenous Peoples in countries' COVID-19 responses, Indigenous communities are instituting their own measures in the presence of universal approaches to managing not only the spread of COVID-19 but in addressing the needs borne out of poverty, housing and food insecurity."⁷³ Tāngata whaikaha continue to develop and enact strategies of resistance to COVID-19, and to the impacts of the global pandemic on their loved ones and communities.

We declare a call to action for the New Zealand government to honor its obligations to te Tiriti o Waitangi (Māori version of the Treaty of Waitangi). Government, in genuine partnership with tāngata whaikaha and their communities, must work to protect and promote the health and well-being of tāngata whaikaha, and ensure equitable outcomes for tāngata whaikaha during, and beyond, the COVID-19 pandemic. As others have done before us, we stress that equity is neither an add-on nor a retrofit.⁷⁴ Equity must be embedded from the outset in the New Zealand government's policy, program and intervention responses to the COVID-19 pandemic, and mechanisms must be adequately resourced that will allow tāngata whaikaha to participate in genuine partnerships with the Crown and agencies in designing, implementing, and evaluating these responses. We call for action to embed long-term change, which, beyond the COVID-19 pandemic, gives full expression to the Indigenous and disability rights of tāngata whaikaha contained within the United Nations Declaration on the Rights of Indigenous Peoples and the Convention on the Rights of Persons with Disabilities.⁷⁵

We propose a framework for action that realizes tāngata whaikaha rights articulated under te Tiriti o Waitangi and international human rights instruments, and is also informed by a "moral and practical compass" to navigate the impacts of the COVID-19

pandemic outlined by Camara Jones.⁷⁶ The framework comprises four elements. These are: (1) guaranteeing self-determination for tangata whaikaha; (2) addressing all forms of racism, ableism and other structural forms of oppression; (3) rectifying historical injustices including those associated with colonization and colonialism; and (4) allocating resources for the COVID-19 pandemic and beyond in alignment with need. Self-determination necessitates that states observe Indigenous rights, the rights of people with disabilities, and state-specific obligations to Indigenous nations. In New Zealand, this means honoring the commitments outlined in te Tiriti o Waitangi, ensuring that tangata whaikaha exercise self-determination in the design, delivery, monitoring, and evaluation of the COVID-19 response. At its heart, this requires that the COVID-19 (and any future pandemic) response reject universal approaches that pay no heed to achieving equity. Decision making regarding the COVID-19 response must occur in genuine partnership with tangata whaikaha and their communities and be centered on achieving equity for all population groups. Self-determination also extends to the rights for Indigenous Peoples to be, or to remain in voluntary isolation⁷⁷ and to make their own decisions about how to safely observe Indigenous cultural practices—for instance, practices around death such as tangihanga—even at times of state restriction on movement and gathering. To adhere to the principle of selfdetermination means that government decision-makers must ensure tangata whaikaha are in roles that oversee responses to the impacts of the COVID-19 pandemic.

Addressing all forms of racism, ableism and other structural forms of oppression requires governments, their agencies, and health and disability providers to design, develop, and implement anti-racist and pro-equity policies, programs, and interventions that protect tāngata whaikaha and other Indigenous Peoples with lived experience of disability from the impacts of COVID-19. In addition, health practitioners are ethically required to demonstrate critical thinking when it comes to the rationing and prioritization tools for ICU ventilators potentially might cause real harms for tāngata whaikaha and other Indigenous Peoples with lived experience of disability. This requires cultural safety at practitioner, organizational, and system levels and—as a fundamental element of eliminating inequities for tāngata whaikaha and other Indigenous Peoples with health practitioners are "prepared to critique the taken for granted' power structures."⁷⁸

Rectifying historical injustices, including those associated with colonization and colonialism, requires decision makers to understand the root causes of inequities for Māori, and for tāngata whaikaha specifically. Historical injustices that result in the marked inequities experienced by tāngata whaikaha are evidence of breaches of te Tiriti o Waitangi.⁷⁹ Māori scholars have proposed twelve projects that are necessary to improve Indigenous health that align with individual and collective Indigenous rights.⁸⁰ Rectifying injustices thus align with "the right to truth-telling about colonial history and its effects, the right to reconciliation and a process for setting right of past grievances [and] the right to recognition of historical trauma and the resources to heal."⁸¹ This requires effective mechanisms for accountability and redress to ensure government agencies deliver on their obligations to tāngata whaikaha.

Examples of actions aligned with this principle include a ceasing of the detention and the immediate decarceration of tāngata whaikaha from state-run institutions, including youth justice residences and prisons,⁸² noting that many of these institutions have perpetrated or enabled systematized violation of human rights as well as criminal abuse of tāngata whaikaha,⁸³ and providing equitable resource and support in the community through family and/or informal networks or Māori-led health and disability service providers. This includes ensuring the option for tāngata whaikaha to access Māori-led health and disability service providers.

Lastly, we call for allocating resources for the COVID-19 pandemic and beyond in alignment with need. This includes ensuring that high-quality information for tāngata whaikaha in a range of accessible formats is produced; taking immediate steps to redress the inequities in access to affordable digital technologies (especially assistive technologies) as a means of communication and connection; and essential equipment such as PPE is more efficiently and equitably made available to Indigenous People with lived experience of disability and those providing care and disability supports. In allocating resources according to need, we explicitly note that by "need" we do not merely refer to the proportion of current individual (health or disability or welfare) needs, but also to the structural needs of communities. These structural needs relate to supporting the development and maintenance of leadership capability and capacity, collective voice, and mechanisms for effective engagement with, and action by, the New Zealand government.

There are two critical prerequisites for this framework. First, each agency who has responsibility for public services must ensure that their policies, practices, and any services they commission are designed, implemented, and evaluated in genuine partnership with tāngata whaikaha and their communities so that they will meet diverse aspirations and needs. Second, high quality ethnicity data and disability data responsive to the epistemological aspirations and needs of tāngata whaikaha—for instance, *mātauranga* (Māori knowledges)⁸⁴—is required. Underpinned by principles of Indigenous Data Sovereignty⁸⁵ that include tāngata whaikaha governance and decision-making around government usage of data, rapid analysis, real-time modeling, and dissemination of data via accessible modes and formats is required in order to inform, monitor, and evaluate policies, programs, and interventions that address the impacts of the pandemic for tāngata whaikaha.

CONCLUSION

The impacts of COVID-19 have been felt around the world, but the disproportionate adverse impacts on Indigenous Peoples with lived experience of disability must be understood. We highlight intersectionality as an essential analytical tool and critical vantage point by which to achieve this in the era of COVID-19. To deliberately remedy these adverse impacts, governments must guarantee self-determination for Indigenous Peoples with lived experience of disability; address all forms of racism, ableism, and other systems of structural oppression; rectify historical injustices; and allocate resources according to need. These elements combined necessitate immediate

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action to ensure access to essential resources including PPE and culturally safe, high-quality health and disability care, as well as the rejection of racist, ableist, and discriminatory prioritization tools. The impacts of COVID-19 on Indigenous Peoples with lived experience of disability must be monitored and addressed using real-time, high-quality ethnicity and disability data.

Governments around the world must now act with renewed urgency to develop equitable power-sharing structures with Indigenous Peoples with lived experience of disability. This is not only to mitigate the significant and inequitable burdens of COVID-19 on their communities, but also to fulfil both the legal (including domestic legislation, treaties, and international conventions) and moral imperatives they have to uphold the individual and collective human rights of all Indigenous communities across the globe.

Notes

+ For the epigraph on page 71 by Donna Cormack, see endnote 69.

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