Title: COVID-19 and blind spaces: Responding to digital (in)accessibility and social isolation during lockdown for blind, deafblind, low vision, and vision impaired persons in Aotearoa New Zealand

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Chrissie Cowan (Ngāti Kahungunu, Ngāti Porou) is the Chief Executive for Kāpō Māori Aotearoa New Zealand Inc., a national Indigenous organisation founded by blind, low vision, vision impaired and deaf blind Māori and their whānau. We are guided by Māori values, principles and practices, and support tāngata whakaha (disabled people) and their whānau to attain whānau ora (wellbeing), be strong self-advocates and leaders in their whānau and communities and contributes to educating Aotearoa society about Indigenous disability.

Amanda Stevens is the Executive Officer for Deafblind Association NZ Charitable Trust. She found the social impact from dual sensory loss initially very challenging, and now works tirelessly with those like herself who have lived experience of deafblindness to meet the needs of their whānau and community.

Rose Wilkinson is Chief Executive for the Association of Blind Citizens of New Zealand Inc. Established in 1945 by blind people themselves, Blind Citizens NZ is a disabled people led organisation that exists to give voice to the lived experiences of blind, deafblind, low vision and vision impaired people living in NZ – it aims to achieve this through advocacy that heightens awareness of people's rights to live in an accessible, equitable and inclusive society, with confidence and dignity.

In response to increasing confirmed cases of COVID-19, the resident population of Aotearoa New Zealand (NZ) entered a seven-week lockdown at midnight on the 25 March 2020. The first five weeks were at Level 4, with the population instructed to remain in their homes and associate only with those in their immediate household. All public gatherings were banned, non-essential businesses required to close public-facing services, domestic travel severely curtailed, and the border closed to all non-citizens. Official sources of information were daily 1pm briefings by the Prime Minister and the Director General of Health. These were broadcast live via radio, television, news websites, and social media. There was also a dedicated COVID-19 information website[1]. The requirement to stay at home saw increased numbers of people working at home and increased use of video conferencing software (e.g. Zoom) as a mechanism for 'meeting with' colleagues, family, and friends. In this manner, digital and associated technologies extended the interpersonal space of the home beyond the physical confines of the domestic dwelling, drawing people together in digital spaces. Digital technologies integrated the previously separated workspace into the home environment allowing work colleagues to 'see into' personal spaces. This blurring of work and home shifted thinking about work contexts. Overall, the combination of lockdown, daily briefings, and increased digital connectivity contributed to a sense of shared experience across the country. However, these shared experiences were not equally available across the citizenry, with the COVID-19 pandemic exacerbating existing inequities.

Contemporary digital spaces inhabited during lockdown prioritized the needs of the fully able citizenry. Consequently, inherited power structures and hierarchies were digitally (re)produced (Lefebvre, 1991). Everyday space is typically designed by and for non-disabled people (Chouinard et al, 2010). Additionally, disabled people are marginalised from everyday

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[1] www.covid19.govt.nz

social, economic, and political processes and spaces (Milner & Kelly, 2009). As a result, disabled persons are prevented from full participation as active and engaged citizens by abled persons in positions of decision-making power. In understanding the ways in which digital space(s) were (re)produced for blind, deafblind, low vision and vision impaired (BLV) persons during COVID-19 lockdown we make visible how contemporary urban society perpetuates historical processes of exclusion.

NZ's founding document, Te Tiriti o Waitangi[2], is an agreement between Māori (Indigenous people of Aotearoa) and the Crown to reside together as equal partners. To that end, our chapter brings together Māori (BMA, CC) and non-Māori authors (RG, AS, RW) in critically examining the experiences of BLV persons during the COVID-19 lockdown. In considering these experiences we also acknowledge the value of working together as academics (RG, BMA) and disability advocates (CC, AS, RW). NZ is also a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Despite a stated commitment to disabled persons and to Māori, economic and accessibility inequities for both groups remain entrenched. Historical experiences by persons with disabilities are of being marginalized from economic opportunities and excluded from societal participation (Johnson, 2020). Disabled persons and Māori are disproportionately represented in NZ's disparity statistics (Hickey, 2020; Johnson, 2020), and digital access is no exception. Twenty nine percent of New Zealanders with disabilities do not have internet access (Grime & White, 2019). Māori are also over-represented in digital exclusion statistics, with factors such as poverty, health, education, and social needs that disadvantage Māori generally having a direct

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[2] There are two versions: one in English (the Treaty of Waitangi) and one in te reo Māori (Te Tiriti of Waitangi). Throughout this chapter we refer to Te Tiriti, the version written in te reo Māori.

correlation to the accessibility of digital spaces (CAB, 2020). Despite government awareness of these inequities, progress towards ensuring inclusivity in digital spaces has been slow-moving.

Digital exclusion (those who have limited or no access to or won't or can't use digital technology) occurs along existing lines of inequitable access to resources and insufficient funding (Grimes & White, 2019); the biggest barrier to digital access is poverty (CAB, 2020). Prior to the pandemic, people with a range of disabilities engaged with publicly funded services such as Citizens Advice Bureaux and local libraries to access information via the internet and navigate online spaces. It was not uncommon for low-income and older BLV persons to utilize internet services via their local library, which typically offer free internet access alongside familiar text-to-speech software for use with digital technologies. With such services closed due to the nationwide lockdown, BLV persons found themselves disconnected and locked out of digital spaces.

Digital exclusion also occurs when websites are inaccessible. During the first[3] COVID-19 lockdown digital sites such as social media and websites were key spaces for the dissemination of health information. While NZ has made legislative efforts with accessibility (e.g. Office of the Minister of State Services, 2003; Office of the Minister for Disability Issues, 2020), the initial response to COVID-19 did not reflect this progress. The initial dedicated COVID-19 website did not meet the government's web guidelines for minimum requirements for government websites (as outlined in the aforementioned 2003 cabinet paper) with regards to accessible design and content. This oversight resulted in BLV persons who

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[3] At the time of writing, the urban centre of Auckland, NZ was undergoing a second, three-week lockdown at Level 3.

did have digital technologies and internet access within the domestic space of their home being unable to access timely and up-to-date information regarding COVID-19. This was particularly problematic in the context of a deadly global pandemic where health information was fast-paced and constantly changing. Despite legal protections and recognised rights as per Article 9 of the CRPD, the (re)production of inequities in digital spaces during a rapidly shifting environment re-marginalised and excluded BLV persons.

During the COVID-19 lockdown, digital spaces became key sites for engaging in societal interactions, retaining social support systems, and extending the life-space (Lewin, 2013). Life-spaces stretch through time and space and are ordered by the strength of the relationship, not the physical distance (Lewin, 2013). Life-space connections became even more important during a nationwide lockdown constraining people to the domestic space of the home and severely curtailing in-person interactions. The life-space of BLV persons and a corresponding sense of agency, independence and dignity was impacted by the shift to digital spaces for social interactions. For example, a BLV person may have digital technology and internet access but requires a sighted family member or support worker to guide them through first-time use of new websites and applications. Without in-person support, navigating first-time use of a video conferencing tool becomes next to impossible. In this way, for BLV persons left without necessary supports, the relational space(s) they inhabited were spatially and temporally reduced. This in turn impacted on their sense of agency, independence, and dignity.

In response to increased digital exclusion at a time of increased digital reliance, BLV organisations (such as those represented in the authorship) advocated with government ministries and provided financial and practical assistance to BLV persons. Challenging reproductions of power and exclusion required sustained effort and creative thinking at a time of great stress. For example, BLV organisations arranged to print and post hard copies of COVID-19 related information in Braille and Large Print formats, as well as audio CD's. Doing so necessitated creative interpretations of lockdown regulations and subverting the newly imposed social norms. BLV organisations also strengthened existing relational networks via familiar technologies (e.g. telephone) in order to mitigate experiences of exclusion. Being able to maintain and sustain a sense of connection with others is vital to fostering a sense of belonging. BLV persons who were embedded within existing communities and whose communities were able to sustain social interactions via telephone and postal services found the lockdown was less corrosive to their sense of belonging. However, for BLV persons without access to their usual supports, the experiences of lockdown brought new and increasing levels of social isolation. This contributed to a reduced a sense of belonging and left people feeling 'forgotten' by wider society.

In this next section we aim to make visible the narratives and experiences of BLV Māori (Kāpō Māori). Māori move in and through a range of subjectivities at different times and in different places (Simmonds, 2011). Being Māori and being disabled positions Kāpō Māori in complex and tricky spaces that require careful negotiation. This includes embodied geographies of place and space that are localised and place specific (Simmonds, 2011), as well as constructions of disability that are not a separate identity but rather a natural consequence of life itself (Hickey, 2020). As such, the life-spaces of Kāpō Māori are textured with past and future relational connections as well as cultural understandings of what it means to be Māori here and now.

As a group, Māori have a long history of decision-making that prioritises the health and well-being of their people (Graham & Masters-Awatere, 2020). Prior to the COVID-19 lockdown, digital spaces were drawn on to support wellbeing of whānau (family), with whānau members interacting online to maintain relational links and uphold shared values (Keegan & Sciascia, 2018). During lockdown, the value of whānau wellbeing came to the fore, with Kāpō Māori remaining connected to one another through acts of caring and support. This included mundane activities such as supermarket shopping and telephone calls, through to the organising of care packages and health checks. These acts reduced a sense of isolation, increased a sense of care and connection, and reinforced the shared values and identities associated with being Māori (Simmonds, 2011).

Throughout the pandemic iwi (Māori tribal) leaders continually made decisions that had the health and well-being of their people at the centre, such as the decision to close roads into Māori communities. Despite this and stated commitments to Te Tiriti and UNDRIP, the NZ government struggled to trust iwi leaders to determine culturally appropriate practice during lockdown. This was evident in government officials specifically naming marae (Māori meeting ground) as a space where the Police could enact “no-knock order beaches” during the lockdown period. That is, marae were singled out as spaces that agents of the Crown could enter without asking and without following the usual cultural protocols. The absence of shared decision-making processes was also exemplified in decisions regarding tangihanga (Māori funeral rituals) which saw a primarily non-Māori decision-making team imposing new rules onto tangihanga during lockdown.

Tangihanga as a cultural practice reflects ongoing change as values and practical realities change across generations (Nikora et al., 2012). Recent adaptions have seen increased use of digital technologies to meet cultural needs of the Māori diaspora (O'Carroll, 2015). Instead of lockdown changes to tangihanga practices being determined in conjunction with iwi leaders and kaumātua, the dominant colonial values and ideological parameters of the Crown were imposed into Māori. This directly impacted on Kāpō Māori kaumātua (elders). One Kāpō Māori kaumātua, who would usually speak on the marae paepae (orators' bench) to farewell and honour a loved one during tangihanga, was deeply distressed at being locked out of determining how to best adjust his cultural practice to meet the needs of his bereaved whānau. The role of guiding the bereavement for whānau is a core part of identity as a kaumātua and reflects a shared responsibility to represent and connect the past with the present. Being unable to fulfil this core role resulted in feelings of grief and a sense of being "cut off" from vital cultural spaces. Compounding these feelings was the imposition of government rule over-riding Māori self-determination, resulting in non-Māori dictating to Māori how they enacted their own cultural practices. Doing so reproduced historical power relationships and cultural memories of distrust, causing harm and negatively impacting on a sense of agency over one's own cultural spaces and practices.

In reflecting on our combined experiences and observations, we note improvements by government departments in providing information in an accessible format in a timelier manner (current wait time is 3 working days). We also note increased commitment to partnership with Māori, such as the implementation of an Iwi Chairs Forum for COVID-related matters. Such examples give us hope that NZ, as a government and as a society is committed to improving inclusivity and accessibility. However, poverty-related exclusion remains. Low-income households continue to have reduced access to digital technologies and appropriate protective equipment, such as face masks (which bring their own challenges for disabled persons). The general public, while well-meaning, still struggle to consider the needs of disabled persons. For example, despite clear requests to place NZ COVID Tracer QR code posters[4] "on the left-hand side of your front window or entrance, with the top approximately 130cm from the ground", posters were located at inaccessible heights for wheelchair users, and inconsistently placed with regards to height and location, making them difficult for BLV persons to locate and use.

As we have documented in our chapter, decision-making processes remain textured with implicit bias, racism, and ableism. The complexities and nuances of issues such as website access and imposed tangihanga rules were brushed aside and/or rendered invisible. There is potential societal risk if we continue to exclude disabled persons and Māori from decision-making spaces. We need a systems shift. We must primarily design around the needs of disabled and marginalised persons, rather than being designed for and by people who are fully able, healthy and with access to economic resources.

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[4] See https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-resources-and-tools/nz-covid-tracer-app/nz-covid-tracer-qr-codes

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