"At Risk" and "Vulnerable"! Reflections on Inequities and the Impact of COVID-19 on Disabled People

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ABSTRACT

This professional perspective provides background knowledge and evidence to support reflection on disability outcomes internationally and in Aotearoa New Zealand. Over one billion people live with disability worldwide. Approximately 4.5% of the world's population live with significant difficulties in function, activity, and participation. In Aotearoa New Zealand, approximately 1.1 million (24%) people have a disability, making disability the largest minority group. Yet disabled people face extreme health inequities. These are exacerbated when response planning and service delivery during times of humanitarian emergency, such as COVID-19, fail to include and consider the impact decisions will have for disabled people. Disabled people are more "at risk" of contracting COVID-19, and some disabled people are "at risk" of poorer health outcomes from COVID-19. However, "vulnerability" arises from the continuation and exacerbation of discriminatory policies, including health professionals' conscious and unconscious biases, in times of crisis but also within conventional health service delivery. As part of the health system, it is perhaps timely for physiotherapists to reflect upon their knowledge of the health inequities disabled people experience, and to consider personal and collective bias. There are strategies physiotherapists might adopt to challenge interpersonal, internalised, and institutional bias. These steps will help affirm disability inclusiveness at all levels of the health system and support a human rights expectation that all New Zealanders should have equitable health outcomes.

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CONTEXTUAL DISCLAIMER

Meredith Perry is an academic and physiotherapist who has built a platform of research on the ora (health) of people with life-long conditions. She is also the mother of two children with disability, one receiving very high Ongoing Resourcing Scheme (ORS) funding.

Tristram Ingham (Ngāti Kahungunu, Ngāti Porou) has a lifetime of lived experience of disability. He is an academic clinical epidemiologist. He chairs the Ministry of Health's Māori disability advisory group, Te Ao Mārama, and the Muscular Dystrophy Association of New Zealand (one of seven nationally recognised disabled persons organisations [DPOs]). He has governance roles across three central district health boards as a board member of the Health Quality and Safety Commission, and Capital Coast District Health Board. Bernadette Jones (Ngā Wairiki Ngāti Apa) is a nurse with lived experience of disability. She is a senior Māori researcher specialising in Māori health inequities and disability.

Brigit Mirfin-Veitch has been involved in disability research and the disability sector for over 2 decades. She is the Director of the Donald Beasley Institute and a Senior Research Fellow with the Centre for Postgraduate Nursing Studies, University of Otago.

The work presented below reflects the professional perspective of the authors, based on their personal and professional knowledge and lived experience of disability. All authors were part of the Ministry of Health's Disability Directorate COVID-19 Communications Response Team. However, the views presented here demonstrate their own critical thinking of the evidence of COVID-19 and the implications of COVID-19 for disabled people, and are therefore not representative of all disabled people nor the Ministry of Health.

INTRODUCTION

The intent of this professional perspective is to provide background knowledge and evidence to support reflection on disability outcomes internationally and in Aotearoa New Zealand. As health inequities are magnified during humanitarian crises, COVID-19 has provided an opportunity to consciously consider how physiotherapists as health professionals, and the systems we operate within should respond to health inequities, including and especially those affecting disabled people. As physiotherapists, we are professionally obliged to explore health inequities and take proactive steps to mitigate them (Physiotherapy Board of New Zealand, 2020). International and local research shows that health professionals fail to recognise disabled people as a distinct population in the same manner as they view older persons, children, racial minorities, and other groups (DeJong et al., 2002). Furthermore, while individual health professionals might arguably have limited capacity to advocate for structural change at higher levels in the system, lack of specific knowledge of disability (including health inequities in this population), and conscious and unconscious bias towards disabled people enables the perpetuation of unmet health needs (Pelleboer-Gunnink et al., 2017; Ravichandran et al., 2020; Sahin & Akyol, 2010). This commentary describes the systemic discrimination experienced by disabled people, including within the health system, and how these multi-factorial and cumulative events result in health inequities. It also provides examples of how decisions during times of humanitarian crisis can unfairly impact disabled people, exacerbate already existing health inequities, and infringe disabled peoples' human rights. Finally, the commentary encourages physiotherapists to reflect upon, recognise, and challenge systemic bias, and proposes strategies physiotherapists might take to help mitigate and address health inequities in Aotearoa New Zealand.

DISABILITY

What is disability?

Disability is inherent in humanity (World Health Organisation [WHO], 2011); almost everyone will experience temporary and/ or permanent disability, particularly as we age (WHO, 2011). The New Zealand Disability Strategy suggests that:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments... Disability is something that happens when people with impairments face barriers in society...this is the thing all disabled people have in common. (Office for Disability Issues, 2017)

Disability identity

Many academic journals and publication styles recommend bias-free and person-first terminology, such as "person with disability" or "people with stroke", but with the caveat that identity-first language (for example, autistic people or the Deaf community) may also be appropriate (American Psychological Association, 2020; Mousavi et al., 2020; New Zealand Journal of Physiotherapy, 2020). Contextually, placing disability before the individual was considered de-humanising, thus a shift from placing disability first has occurred. Yet, as person-first language has increased editorially, increased discrimination from its application has also been observed, as there is not an equivalent term for "people with ability" (Gernsbacher, 2018). Identity-first language derives from the social model of disability. This is a model which acknowledges the barriers created by society (for example, attitudinal, environment, systems) which limit participation (Andrews, 2017; Retief & Letšosa, 2018). In contrast, the biomedical model creates a divide between an idealised "health normalcy" and the alternative presence of deficit or impairment (Watermeyer, 2013). For many disabled people, their uniqueness is a part of their identity and a source of pride. Therefore, affirming disability as an identity enables an individual to positively identify aspects of their individuality at their own discretion, rather than being told how to identify by an external (usually non-disabled) "authority". Currently, the term "disabled people" and "disabled person" is the preferred term by many disability organisations in Aotearoa New Zealand (Disabled Persons Assembly, 2020; Office for Disability Issues, 2020).

Not all members of the disability community identify with identity-first language. Importantly, Māori typically prefer to identify as Māori first, with collectivism, relational, and holistic cultural values (for example, whānau, language, whakapapa to terrestrial and spiritual worlds) paramount to te ao Māori (Hickey & Wilson, 2017; Ministry of Health [MoH], 2018). In te ao Māori, disability is just an aspect of the collective cyclical experiences of life (Hickey & Wilson, 2017). Specific terms for Māori with disability exist, including "whānau hauā", and more recently, "tāngata whaikaha" (literally, "people with strength") (MoH, 2018). The positive imperative ascribed to tangata whaikaha is worth acknowledging: "people with disabilities who are determined in some way to do well and create opportunities for themselves as opposed to being labelled, as in the past" (MoH, 2018, p. 8). With deference to current preferred terminology by representative groups, a conscious decision was taken to use the term "disabled people" and "tangata whaikaha" throughout this commentary.

Why disability rights are relevant to all physiotherapists

Over one billion people (15% of the population) live with disability worldwide (WHO, 2011). Approximately 4.5% of the world's population live with significant difficulties in function, activity, and participation (WHO, 2011). In Aotearoa New Zealand, approximately 1.1 million (24%) people have a disability (MoH, 2014), making disability the largest minority group. Consequently, a large proportion of physiotherapists' patients will have a disability.

Yet disabled people face extreme health inequities (Marmot et al., 2008; WHO, 2018). Physiotherapists are obliged to uphold legislation, standards, and conventions as described in the Physiotherapy Standards framework (Physiotherapy Board of New Zealand, 2020). This includes legislation, such as the Health Practitioner Competence Assurance Act 2003, the Code of Health and Disability Services Consumers' Rights 1996, and the United Nations Convention on the Rights of Persons with Disabilities. These highlight factors that perpetuate health inequities and underscore the ideal: bias-free and just service delivery. Moreover, physiotherapists are ethically obliged to consider their personal and collective role in addressing such inequities (Physiotherapy Board of New Zealand, 2020). This is particularly relevant now as physiotherapists have and will continue to have an integral role in the acute hospital management of people with COVID-19, the rehabilitation and recovery of people following COVID-19 infection, and the primary management (including telehealth) and acute care management of people with other health and disability issues (Silva et al., 2020; Haines & Berney, 2020; Quigley et al., 2020; Sheehy, 2020; Thomas et al., 2020; Turolla et al., 2020).

SOCIAL DETERMINANTS OF HEALTH

The social determinants of health are the material circumstances, biological, behavioural, and psychosocial factors individuals/whānau are born with, are exposed to, or exhibit (these are sometimes called the individual or intermediary determinants) (Whitehead & Dahlgren, 1991; Whitehead & Dahlgren, 2006). However, health is also determined by social cohesion and capital, and more structural determinants, such as education, occupation, cultural and societal values, and policies (macroeconomic, social, and public) (Whitehead & Dahlgren, 1991; Whitehead & Dahlgren, 2006). For instance, inequities in education and employment affect relative income within a country, housing, and health (Heaphy et al., 2011). The stepwise or linear decrease in health is known as the "social gradient", and results in a higher risk of illness and death, and a shorter life expectancy (Marmot, 2004). Thus, avoidable, unfair, and unjust structural inequalities in multiple domains or systems of the social determinants of health create and maintain health inequities for disabled people (Marmot, 2004; Whitehead & Dahlgren, 1991; Whitehead & Dahlgren, 2006).

Examples of social outcomes creating and maintaining health inequities for disabled people in Aotearoa New Zealand

This section demonstrates how inequities in one domain or system can negatively influence another system, resulting in a perpetuating downward gradient of health inequity. There are large discrepancies in social outcomes for disabled people compared to the general population in Aotearoa New Zealand. Almost 27% of disabled people aged 16 to 39 years of age have no school qualification compared to 12% in the general population (MoH, 2014; Statistics New Zealand, 2015). Only 39% of disabled people aged 18 to 64 are employed compared to 81% in the general population (Stats New Zealand, 2020b). Recent statistics (June quarter, 2020) show that 23% of disabled adults do not have enough money to meet their everyday needs and live off a median weekly income of \$402. In comparison, 6.5% of adults the same age in the general population do not have enough money to meet their everyday needs and report a median weekly income of \$713 (Stats New Zealand, 2020b, 2020c).

Compared to adults aged between 18 and 64 years in the general population in Aotearoa New Zealand, disabled people report higher levels of loneliness (12% versus 3.8%), poor life satisfaction (44% versus 15%), and poor mental well-being (46% versus 19%) (Stats New Zealand, 2020b, 2020d). While disabled people access health services twice as often as that of the general population, they report multiple barriers with accessing these services, including discrimination by health providers (Health and Disability System Review, 2020).

Importantly, increased use of health services results in financial distress (Mitra et al., 2009). The burden of additional health- and disability-related services expenditure on family income is 4.4% for disabled people compared to 1% for the general population (Mitra et al., 2009). Increased poverty due to increased health needs further reduces educational and employment opportunities, and financial stability, thus negatively impacting health outcomes even further (Mitra et al., 2009), exemplifying the downward social gradient. The recent Health and Disability System Review (2020) noted that all determinants combined result in high unmet health needs and inequitable health outcomes for disabled people. In short, disabled people are not subject to the same privileges as the general population.

The multiplicative effect of intersectionality

Intersectionality is the multiplicative effect from discrimination occurring due to the presence of two or more identities which are marginalised. For instance, international statistics show that disability is more prevalent in women, children, and indigenous populations (WHO, 2011). These groups face discrimination due to gender, age, and ethnicity, and are more vulnerable to socio-economic inequities, irrespective of disability identity. But due to the social gradient, the health inequities these groups face consequently increase the risk of disability (Marmot, 2004). When two or more marginalised identities occur, health inequities increase even further.

This is seen in Aotearoa New Zealand too. Te Tiriti o Waitangi principles of partnership, tino rangatiratanga (self-determination and participation), options, active protection (MoH, 2019), and equity have been largely reneged by two centuries of colonisation, including subjugation of rights, confiscation of lands, and racism towards Māori (Waitangi Tribunal, 2019). As a marginalised group, Māori are 10 times more likely to experience multiple types of discrimination compared to non-Māori (Harris et al., 2006). Discrimination is observed in acts of interpersonal¹, internalised², and institutional racism³, which leads to systemic biase (Harris et al., 2006; Reid & Robson, 2007). Systemic biases explicitly and implicitly affect the social determinants of health, and have a multiplicative effect, resulting in unequivocal inequity (Moewaka Barnes & McCreanor, 2019; Pitama et al., 2007).

It is unsurprising, therefore, that Māori people have a higher prevalence of disability (age adjusted at 32% and 26% respectively) compared to European (24%) and Asians (17%) (MoH, 2014). The multiplicative effect of intersectionality is observed with tāngata whaikaha experiencing extremely poor health outcomes (Waitangi Tribunal, 2019). For example, more tāngata whaikaha (25%) than disabled people of other ethnicities (23%) have insufficient household income to meet their daily needs, 66% have a personal annual income of less than \$30,000 NZD, and over 40% have no school qualification (Statistics New Zealand, 2015). Cold and damp housing is more

¹ Interpersonal racism is the differential expectations of ability by ethnicity (Jones, 2020)

² Internalised racism is the acceptance of negative stereotypes about ability and intrinsic worth by stigmatised groups (Jones, 2020)

³ Institutional racism is the differential provision of and access to good, services, and opportunities by ethnicity (Came et al., 2018)

common, rates of unemployment higher, and participation in culturally popular recreational activities lower for tāngata whaikaha compared to Māori without disability (Statistics New Zealand, 2015). In addition, tāngata whaikaha specifically report issues with insufficient assessments, treatment, and access to culturally acceptable support, equipment, and care funding (Hale et al., 2018; Ratima & Ratima, 2007; Statistics New Zealand, 2015).

COVID-19 AND DISABILITY

On 20 January 2020, WHO declared the outbreak of a novel coronavirus disease, COVID-19, to be a public health emergency of international concern due to the speed and scale of transmission (WHO, 2020). This was upgraded to pandemic status on 12 March 2020 due to the rapid increase in confirmed COVID-19 cases in multiple countries across the world. The potential heightened risk of COVID-19 for specific groups of people was already recognised, as those with the poorest health outcomes are typically more severely affected by crisis situations, including pandemics (WHO, 2020).

Some disabled people may be at greater risk of contracting COVID-19 or other droplet-borne viruses for numerous reasons. These include difficulty implementing hygiene measures due to environmental and physical barriers, difficulty implementing physical distancing recommendations due to additional health and support needs which require close physical contact, and risk of exposure due to multiple external support service providers/ caregivers (United Nations, 2020; WHO, 2020).

In addition, some disabled people are "at risk" of poorer health outcomes from COVID-19 specifically. While impairment is frequently conflated with poor health status disability per se, it often has limited, or no overall health impact (Scully, 2020). Nevertheless, secondary health conditions, comorbidities (such as diabetes), chronic medical conditions (such as heart disease), a compromised skin barrier due to open wounds or medical devices (for example, ileostomy, tracheostomy, and feeding tubes), impairments, and medications are prevalent in disabled people (Battalio et al., 2019; Hole & Stainton, 2020; McGuire et al., 2020; United Nations, 2020). The presence of these factors leads to greater risk of morbidity and mortality from COVID-19 (United Nations, 2020; WHO, 2020). Furthermore, as previously mentioned, already present inequities (for example, barriers to accessing timely and appropriate health care) and the socioeconomic consequences of COVID-19 can further exacerbate the severity of adverse health outcomes (United Nations, 2020).

Finally, increased risk can also arise during times of humanitarian crisis, including pandemics, if communication strategies are not fit for purpose. Access to timely, trustworthy, and understandable health and disability information in accessible formats is critical in times of crisis. In the Aotearoa New Zealand COVID-19 response, there were significant challenges in rapidly developing and distributing both general and disability-specific messages in accessible formats (for example, braille, New Zealand Sign Language and Easy Read) in a timely manner. A critical limitation is the likely lack of disability-related capability and capacity across most central government agencies, district health boards, and health practitioners. Without the direct and

proactive collaboration of key disability advocates, academics, and disability support providers, delivery of new or adapted services and facilitation of disability-specific resources would have been limited in Aotearoa New Zealand (Pulman, 2020). However, lessons can still be learned as many disabled people were negatively impacted, often as a result of structural policy decisions. These decisions also created ethical dilemmas for health professionals.

ETHICAL DILEMMAS RELATED TO COVID-19

The extraordinary threat of COVID-19 has raised numerous ethical challenges to those working in the health and disability sector (McGuire et al., 2020). Some of the most publicly contested include (a) professional responsibility to treat people with COVID-19; (b) disclosure of COVID-19 status; (c) allocation of COVID-19 tests when resources are limited; (d) allocation of scarce resources; (e) implications of relaxing research rules and health professional accreditation; and (f) addressing end-of-life issues (Kramer et al., 2020). These areas, and many others, are worthy of reflection (McGuire et al., 2020). However, in this commentary we have space to focus on only two, specifically, professional responsibility and allocation of scarce resources. These two challenges exemplify the implications of decisions in "conventional", "contingency", and "crisis levels of surge capacity"⁴ on the health outcomes of disabled people, especially when decision-making does not include a disability lens.

Professional responsibility

Accounts from Spain of older adults in aged care being abandoned and left to die emerged in March 2020 (British Broadcasting Company, 2020). The newspaper article presents the horror of this event and announces the investigation being launched. Incidents such as these were, and are, occurring in myriads of individual homes and institutional care globally (Pulman, 2020; Webster, 2020). Personal risk of contracting COVID-19 by healthcare professionals and/or caregivers providing personal care and domestic assistance, and meal preparation/delivery when caring for someone with COVID-19, someone with a possible COVID-19 status, or someone at risk of COVID-19 is understandable given the widespread reporting of the death of healthcare professionals from COVID-19. Access to effective personal protective equipment (PPE), and being (up) skilled in the appropriate application and removal (donning and doffing) of PPE should mitigate this risk. But despite many governments' reassurances that there were sufficient supplies of PPE, reporting of on-the-ground shortages was rife, including in Aotearoa New Zealand (Kramer et al., 2020; Pennington, 2020). The ethical dilemma of professional responsibility is particularly pertinent when the institutional or in-home care provided to disabled people is considered.

Most (>94%) in-home caregivers in Aotearoa New Zealand are female with a median age of 49 years, rising up to 64 years (Callister et al., 2014; Ravenswood & Douglas, 2017).

⁴ These capacity terms derive from a taxonomy for health care which delineates, on a continuum, changes to service provision, and thus resource allocation that might occur. Where a facility is on the spectrum is dependent on the onset and scope of the crisis being faced (Hick et al., 2009)

Over 50% are the primary earner and receive approximately \$17.00 per hour (Ravenswood & Douglas, 2017). Many also spend time (up to 30 hours per week) outside work also caring for whānau (Callister et al., 2014). Caregivers are often the interface between the community and the disabled person. They frequently work with several people a day, and care may include exposure to bodily fluids and aerosol generating procedures. Therefore, many caregivers are of an age that puts them at risk; the work they do also puts them at risk, and due to financial circumstances and whānau dependents, they cannot run the risk of becoming sick from COVID-19. Accordingly, the early weeks of Level 4 lockdown saw many caregivers recognise their own "at risk" status and, consequently, stood down from work voluntarily (Radio New Zealand, 2020).

The inability to source PPE also created increased risk of exposure for disabled people. Caregivers, for the same reasons alluded to above, put disabled people at greater risk of contracting COVID-19. In Aotearoa New Zealand, disabled people reported waiting times of several weeks or even months for PPE, resulting in many sewing their own masks from old clothes (Pulman, 2020). Many disabled people required support, but due to staff shortages, they were left without care (Radio New Zealand, 2020). Other disabled people made the difficult decision to cancel their formal care supports, and only received support from whānau during lockdown (Parahi, 2020). The extent of physical and psychosocial impacts due to disruption of usual supports for disabled people and their whānau is yet unknown (Hole & Stainton, 2020)

Allocation of scare resources with contingency and crisis capacity

Health is a basic human right for all, even during a pandemic. Thus, allocation of resources became a fiercely contentious issue (Pring, 2020) when the National Institute for Health and Care Excellence (NICE) published guidelines on 29 March 2020 recommending that the provision of critical care be determined by a clinical frailty score (NICE Guidelines, 2020). It recommended use of this score when surge capacity forced deployment of "crisis capacity"⁵ healthcare provision (Nelson et al., 2020). The guideline, and others like it, was intended to provide advice on managing health and safety of staff, management of non-finite healthcare resources (such as ventilators and ICU beds), and maximise patient safety (Kramer et al., 2020; McGuire et al., 2020; Nelson et al., 2020; NICE Guidelines, 2020; Scully, 2020). However, it resulted in cries of discrimination⁶ by disabled people and disabled persons organisations (McGuire et al., 2020; Pring, 2020; Webster, 2020). In essence, the guideline recommended that anyone with a frailty score of 5 or above should not be offered ventilator support (NICE Guidelines, 2020). A 5 is someone with evident slowing, requiring help with high-order activities of daily living (finance, transportation, and heavy housework). Thus, many disabled people, but not necessarily frail people, would find themselves meeting this threshold.

These guidelines were subsequently amended (29 April 2020) to clarify that the frailty score does not apply to "people with stable long-term disability ... learning disability or autism" and that the frailty score should not be the sole assessment of frailty (NICE Guidelines, 2020, p.6). The amended guidelines now recommend that individual patient assessment should be performed but, in all cases, taking comorbidities and underlying health conditions into consideration (NICE Guidelines, 2020). Furthermore, the guidelines remind health professionals of the need to exercise their clinical judgement while taking the guidelines fully into account (NICE Guidelines, 2020).

But the guidelines, including amendments, do not necessarily relieve anxieties for disabled people (Pring, 2020). This is because up to 50% of people with disability have secondary health conditions and comorbidities (Battalio et al., 2019). In addition, the subjective decision-making required by health professionals, pressured by health system population level guidelines, is considered suspect and untrustworthy, arguably due to the longstanding structural bias and racism resulting in health inequities, as discussed earlier in the paper (Berger & Miller, 2020; McGuire et al., 2020). Assumptions about quality of life and social utility are frequently made by health professionals with respect to disabled people (McGuire et al., 2020; Scully, 2020). This is especially true for people with a learning (intellectual) disability or cognitive impairment who traditionally face extreme discrimination and have higher rates of do-not-resuscitate orders (McGuire et al., 2020; Nelson et al., 2020; Parsons & Johal, 2020).

Conversely, many individual health professionals found population-related "crisis" capacity recommendations morally distressing (McGuire et al., 2020). This is because they forced health professionals to work from a "best interests" perspective (Parsons & Johal, 2020). A best interests perspective undermines standards of professional practices, such as gaining of informed consent, facilitating supported decision-making to ensure will and preferences, maintaining autonomy, and respecting patient well-being (Wicclair, 2020). Furthermore, value-based decisions based on lives and life-years saved can be conscientiously objectionable, as they unjustly disadvantage disabled people (Berger & Miller, 2020; McGuire et al., 2020; Nelson et al., 2020; Wicclair, 2020) whose health status is attributable to determinants largely outside their control (Marmot et al., 2008; Whitehead & Dahlgren, 1991).

Fortunately, in Aotearoa New Zealand as in other parts of the world, "crisis capacity" has remained mostly theoretical or of limited duration. Instead, a prolonged period of "contingency capacity" has been in place. At contingency capacity, rehabilitation beds, post-anaesthesia care rooms, and other patient areas are modified to increase ICU capacity

⁵ "Crisis capacity is when non-traditional spaces are used for patient care so that ICU capacity can expand by up to 200%. Staff may practice outside of their usual expertise and there may be insufficient staff to deal with the volume of patients. Critical supplies are often limited, leading to higher risk reuse, such as reusing usually sterile supplies. Uniquely, crisis capacity involves taking treatments, such as ventilators, from one patient to give to another due to a shortage of supplies." (Nelson et al., 2020 p. 2)

⁶ Publication of discriminatory guidelines as part of COVID-19 crisis management are not isolated to the United Kingdom. Similar examples can be found in the United States and elsewhere (McGuire et al., 2020).

by 100%. Typically, one staff member will care for a larger group of patients, and supplies are conserved or re-used (when considered low risk) (Negrini et al., 2020; Nelson et al., 2020). The redeployment of staff and repurposing of beds results in shorter stays and fewer admissions (Negrini et al., 2020; Nelson et al., 2020). Also, many "non-essential" services, which disabled people rely upon, either cease or are delivered less regularly (Parahi, 2020; United Nations, 2020; Webster, 2020). These services include, but are not limited to, outpatient appointments; delivery of health and/or essential supplies, for example, podiatry and incontinence items; community care, including day and respite services; and home and personal support. Furthermore, contingency capacity with COVID-19 has seen many hospitals and institutions (aged care and supported living homes) maintain no visitor policies in the "best interests" of the people being cared for (Hancock, 2020; Nelson et al., 2020).

Negative experiences with service delivery, including no visitor policies, at both crisis and contingency capacity phases of the ongoing COVID-19 response, are widespread for disabled people in Aotearoa New Zealand and internationally (Armitage & Nellums, 2020; Parahi, 2020). The impact on the health of disabled people by the (delayed) designation of some services (for example, home support, physiotherapy, and podiatry) may never be fully known. Similarly, aside from the emotional trauma a no visitor policy can inflict (Hole & Stainton, 2020; Nelson et al., 2020), loss of face-to-face contact can significantly exacerbate existing conditions (for example, depression and anxiety, or physical health deterioration due to a decrease in oversight), and this cost is also yet unknown (McGuire et al., 2020). Furthermore, it is unlikely that new provisions that arose during crisis capacity for disabled people will have mitigated the negative impacts of the COVID-19 response. These provisions included fully subsidised taxi fares to New Zealand Total Mobility customers from March until the 30 June (Metlink, 2020). This provision was put in place following the realisation that the COVID-19 public transport safety measures limited disabled people from being able to use these services. Thus, whilst the public transport changes were discriminatory, their implementation led to the provision of a different service which alleviated the risk of contracting COVID-19 on public transport, reduced health-related expenditure and, likely, provided some biopsychosocial benefits.

In almost all of the above examples of crisis and contingency capacity, changes to the allocation of resources, a loss of opportunity for enhancing, maintaining, or slowing loss of function is represented (Negrini et al., 2020; Nelson et al., 2020). Interestingly, it is entirely possible that the ongoing impact of contingency capacity is likely to pose a greater risk to disabled people than crisis capacity (McGuire et al., 2020; Nelson et al., 2020; Pulman, 2020). Estimates across 35 countries in Europe suggest this collateral damage is affecting up to 2.2 million people every day (Negrini et al., 2020). Thus, crisis or contingency capacity policy (as well as education, transport, and employment decisions) which are made at the population level can inadvertently disadvantage disabled people who may already face precarity⁷, and will have morbidity and mortality implications (Hole & Stainton, 2020; United Nations, 2020). Consequently, the Chair of the United Nations Committee on the Rights of Persons with Disabilities, on behalf of the Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, issued a statement reminding member states, of which Aotearoa New Zealand is one, of their obligations. Included in this statement was specific reference to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 11 "Situations of risk and humanitarian emergencies":

States parties shall take all possible measures to ensure the protection and safety of persons with disabilities in the national response to situations of risk and humanitarian emergencies. This comprises measures in all areas of life of persons with disabilities, including the protection of their access to the highest attainable standard of health without discrimination, general wellbeing and prevention of infectious diseases, and measures to ensure protection against negative attitudes, isolation, and stigmatization that may arise in the midst of the crisis. (Basharu & Cisternas Reyes, 2020)

WHAT IS THE IMPACT OF COVID-19 ON DISABLED PEOPLE TO DATE?

Due to previously existing drivers of health inequity, disabled people are likely to have a higher COVID-19-related morbidity and mortality. Excess deaths are a means of exploring the impact of COVID-19 on mortality. In Aotearoa New Zealand, an excess mortality rate has not been observed (Stats New Zealand, 2020a). However, other countries have not been so fortunate. Between 1 March and 1 August 2020, approximately 200,000 people, which represents a 20% increase, died in the United States of America. Interestingly, COVID-19 was reported as the cause of death in only 67% of these excess deaths. Remaining deaths were attributed to heart disease and dementia (Woolf et al., 2020). However, this would represent a highly unusual increase in the baseline death rate of people with heart disease and dementia for this period of 2020 (Woolf et al., 2020). This trend is similarly observed in the United Kingdom, with higher excess mortality in adults over the age of 85 years (Sinnathamby et al., 2020). Therefore, these examples likely reflect underreporting due to unrecognised or undocumented infection in the disability community.

It is imperative that COVID-19 data for disabled people are collected and published (McGuire et al., 2020; Reed et al., 2020; Sabatello et al., 2020; United Nations, 2020). Without disability data, health inequities and social injustice are perpetuated (Reed et al., 2020; Sabatello et al., 2020), and disabled people will continue to be excluded from policy decisions which affect their health and well-being (Armitage & Nellums, 2020; Reed et al., 2020; Sabatello et al., 2020; United Nations, 2020). Lamentably, there is a paucity of this type of analysis to date

⁷ "Precarity is the politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence and death" (Butler cited in McNeilly, 2015, p.150)

(Reed et al., 2020; Sabatello et al., 2020). Yet the disability data that exist are alarming (Turk & McDermott, 2020). Data from the United Kingdom exploring known or reported COVID-19 related deaths demonstrate that disabled people account for 60% of all deaths. Moreover, the age standardised mortality rate was statistically significantly higher for disabled people than the general population (Office for National Statistics, 2020). Furthermore, mortality is higher in those with learning (intellectual) disability and developmental disability (Landes et al., 2020), and this group is dying younger (Turk et al., 2020).

IMPLICATIONS FOR PHYSIOTHERAPISTS AS HEALTH PROFESSIONALS

While some disabled people might be more at risk of COVID-19, "vulnerability" arises from the continuation and exacerbation of discriminatory policies, including health professionals' conscious and unconscious biases. There are numerous strategies by which physiotherapists can help address inequities; the following are suggestions that could be easily integrated into clinical practice or could be advocated for collectively as a profession.

As per ethnicity, physiotherapists are professionally and ethically obliged to individually and collectively consider their role in perpetuating health inequities for other identities too. Conscious reflection upon their own practice, consideration of institutional bias, and determining areas of professional development may be required. To gain some understanding of the discrimination disabled people experience might require reading about models of disability; the UNCRPD; current government strategy documents, such as the New Zealand Disability Strategy (Office for Disability Issues, 2017) and Whāia Te Ao Mārama 2018 to 2022 (MoH, 2018); and about the lived experiences of disabled people within the health system, including experiences with inclusive and supported decision-making. New knowledge and reflection on one's own experiences may enhance a deeper and more nuanced understanding of the impact of systemic bias resulting in long-standing health inequities.

Unless disability specific data are collected and disaggregated, the full impact of COVID-19 on the morbidity and mortality of disabled people will never be known. The paucity of these data is testimony to the ongoing systematic and systemic discrimination of disabled people. To help put this issue in perspective, it is only since ethnicity data was routinely collected by health services in Aotearoa New Zealand that the extent of Māori health inequities have been revealed. At present, disability identity is not routinely collected by health services in Aotearoa New Zealand. Physiotherapists should consider how disability identity might be sensitively collected in their area of practice and query the routine inclusion of disability identity as part of demographic data collection in larger organisations. They could also advocate for the routine disaggregation of disability data in their area of practice.

Finally, physiotherapists could advocate for better inclusion of disabled people within the wider health sector. Employing disabled people within the health and disability system is one mechanism for reducing discrimination. As per ethnicity, employment of disabled people provides a mirror on society, and a unique and valuable perspective on decisions made at a micro level. Certainly, this will then require the explicit inclusion into and support of disabled people within health professional programmes; physiotherapists in academia may wish to consider how they might advocate for this change. Furthermore, collection and analysis of disabled physiotherapists within the health workforce demographic will be required to determine if representation improves over time. Physiotherapists working in policy development (meso and macro) should expect meaningful inclusion of disabled people in the co-development of acts, standards, and guidelines, rather than obligatory consultation. They could query the process when the former "ideal" process is not attained. When disabled people are not included in national and local structural policy decisions, bias is perpetuated.

Admittedly, some of these strategies might feel confrontational to some physiotherapists. A growing awareness of the concept of silence being considered as complicit might help all physiotherapists find the confidence to challenge interpersonal, internalised, and institutional bias when it is observed.

KEY POINTS

What is already known

 Society, including health professionals, is complicit in the perpetuation of health inequities in disabled people. Systemic bias is highlighted by the lack or limited inclusion of disabled people in the response planning for humanitarian emergencies and when a crisis event, such as COVID-19, arises.

What this paper adds

- 1. This commentary highlights the health inequities disabled people experience in Aotearoa New Zealand (and internationally) and explains why these are exacerbated in times of crisis, such as the COVID-19 pandemic.
- 2. A case is made for physiotherapists to reflect upon their knowledge of the health inequities disabled people experience.
- Strategies physiotherapists might adopt to challenge interpersonal, internalised, and institutional bias are presented

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PERMISSIONS

None.

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