



Review Essay

What and Who Are “Essential”? A Disability Justice Perspective on COVID-19 Measures and the Diverse Disability Communities in Ontario

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ABSTRACT Central to Ontario’s COVID-19 response was defining, supporting, and protecting essential services and, by extension, essential people – often through decision-making processes that were ad hoc and lacking in meaningful public engagement. This paper examines the Ontario government’s public health responses to the COVID-19 pandemic, from the early steps taken in 2020 by provincial officials to develop a triage protocol for hospitals that would discriminate against those who fall outside of the narrow view of essential people – especially disabled and older people – to the implementation of public health measures that also disadvantaged diverse disability communities in a multitude of settings and far-reaching, multiple, and

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intersecting ways. Selectively drawing on online local and national newspapers across Canada that mentioned COVID-19 and people with disabilities from March 2020 to June 2020, we examined the ways in which disabled people have been rendered invisible, invaluable, disposable, and “non-essential” as they struggle to survive the pandemic largely outside of provincial COVID-19 response frameworks. Through this analysis, we craft a contrasting understanding of “essential” that attends to the principles of disability justice, shifting interdependencies, and the diversity and mutuality of human needs. Drawing on examples of mutual aid and caregiving in diverse disabled communities, we also explore disability justice as an alternative framework that leaves no one behind.

KEYWORDS COVID-19; critical reflection; pandemic; social justice; public health; socioeconomic inequality

Introduction

During the COVID-19 pandemic, official government responses included public health measures to minimize the spread of COVID-19 and the rationing and triaging of supplies and health resources. Years into the pandemic, the politics around who was protected and supported during the pandemic and who was left to languish, and in some cases die, has become more visible, revealing deep-seated racism, ableism, and ageism in our society (Herron et al., 2021; Lagacé et al., 2022). Central to government responses has been the issue of what is essential – and, correspondingly, what is non-essential. We argue here that the essential/non-essential binary that has been employed to determine the pandemic response is a harmful one. The term “essential” as it applies to human needs is inherently subjective, shifting and politically loaded. We argue that, as such, it renders the needs and well-being of those whose needs are deemed “non-essential” or too burdensome to the collective as essentially non-essential people. Indeed, this is reminiscent of Elizabethan Poor Laws, whose legacy still shapes Canadian public health and welfare law in ways that render only some disabled people as deserving of social supports (Withers, 2012). Labelling a service essential implies that it applies to everyone and is equally important to everyone. What have constituted essential services and essential COVID-19 public health interventions, we argue, has been based upon a normative ableist and sanist understanding of who the “normal” or “average” Ontarian is: someone who has a traditional family structure, secure finances, housing, and employment; likely a non-disabled cis-gendered white middle-class man living independently who is urban dwelling with permanent citizenship status. This Ontarian is seen as representing the majority, and the essential voice, experience, and knowledge base that was taken into consideration as the pandemic progressed. In other words, this imagined Ontarian is seen as standing in for and constituting, the essential people in Ontario. Neither the federal nor the provincial government of Ontario

considered the needs of more than 22% of the Canadian population living with disabilities (Statistics Canada, 2022, para. 2) and their families; instead, the majority of COVID-19 stories in Canada did not include the perspectives of disabled people.¹

Disability Justice: Principles and Theory

In this article, we use disability justice principles and theory as a framework that fundamentally challenges the essential/non-essential binary and the corresponding reductionistic, scarcity approach to the COVID-19 pandemic.

A disability justice approach would also frame recommended policies that would be inclusive of the diversity of disability communities. These are briefly described here. Intersectionality (Crenshaw, 1989) is core to a disability justice perspective as systems of oppression are intertwined with each other. For example, ableism is entangled with ageism, heteropatriarchy, white supremacy, colonialism, and capitalism (Berne, 2015; Engelman et al., 2019; Piepzna-Samarasinha, 2018). We see this, for example, in residential facilities that reinforce colonial logic, increasingly exploit racialized, migrant workers, and create care environments that can be hostile to queer or non-binary residents (Fudge Schormans, et al. 2022; Herron, et al., 2021). These intertwining systems of oppression shape people's embodied, diverse, socially located experiences. A disability justice perspective centres anti-capitalist politics, rejecting a profit-based economy and capitalist notions of productivity. It also commits to cross-disability solidarity, honouring all community members, engaging in collective access so all can participate, and taking part in larger cross-movement organizing. In this way, allies and alliances are formed (Berne, 2015). Disability justice collective work aims to organize leadership so those most impacted can draw on their lived experience and knowledge – sometimes referred to as “crip wisdom” (Be[ast] & Harville, 2016) – to make decisions about how to support and meet the needs of others (i.e., interdependency), and recognize the importance of pacing oneself (i.e., sustainability). Disability Justice builds on and challenges the disability rights movement by moving beyond simplistic binaries between embodied impairment and the social discrimination of disabled people, thereby more accurately reflecting the lived experiences of most disabled people (Nishida, 2022). The approach guides us towards a practice of collective liberation, with no body or mind left behind (Berne, 2018). This lens gives rise to two questions that are largely unanswered in the broader public portrayals of the pandemic: how do capitalist structural pandemic responses create privilege (visibility, value, access to resources and opportunities) and oppression (circumstances of

¹ Disabled people, as defined here, are “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006). That said, language about disability and identity is fluid, and we acknowledge that.

invisibility, devaluation, lack of resources or access to them, and limited opportunities), reproducing narratives of who is deserving of care and who gets left behind (Nishida, 2022), and how have diverse disability communities responded to the crisis to support communities deemed non-essential?

We attempt to answer these questions in the paper, first by exploring the framing of essential services in terms of official government definitions and categories, the often-unstated corollaries—the non-essential services and the implications this has for people who require these services who, we argue, are rendered non-essential people. Second, we reviewed the literature (academic and public sources) from and about diverse disability communities, highlighting their shifting needs and desires and how they have been excluded by official pandemic responses. A list of the public media sources we reviewed in this paper is provided in Appendix A. Finally, we conclude by discussing a few initiatives developed by these diverse disability communities to support themselves, despite their knowledge and required services being deemed non-essential. These endeavours are good examples of mutual aid, which can be the basis for supportive alternative policies for local diverse disability communities in a post-pandemic society. They demonstrate the necessity of disabled people’s knowledge in both post-pandemic recovery planning and social, health, and economic policy planning moving forward.

Essential Services

Federal and Provincial Government Definitions of Essential Services

The federal government’s *National Strategy for Critical Infrastructure* defines essential services and functions in Canada during the COVID-19 pandemic (Government of Canada, 2022). Critical infrastructure is defined as “the processes, systems, facilities, technologies, networks, assets, and services essential to the health, safety, security or economic well-being of Canadians and the effective functioning of government” (p. 2). The strategy classifies 10 critical infrastructure sectors: energy and utilities, information and communication technologies, finance, health, food, water, transportation, safety, and government and manufacturing. According to the website, this framework is intended to help provinces and territories, Indigenous communities, and municipalities protect their communities while ensuring that critical infrastructure operations and services continue to support the physical, social, and economic well-being of the population (Government of Canada, 2022).

There is not, however, a universal, Canada-wide understanding or consensus of what is (and is not) an essential service. The federal government’s framework and principles may not necessarily be reflected in provincial government policies. Given that certain sectors, such as healthcare, are the

responsibility of provincial governments, we found varying definitions on the government website of what constitutes essential services. Considering this disparity, we focus on Ontario. As Ontario-based critical disability studies scholars, we are affected by the consequences of the Ontario government's articulation of what essential services are, and by the government's apparent lack of understanding of the consequences to various segments of Ontario's diverse disability communities during the COVID-19 crisis.

Ontario's Definition of Essential Service

In 2021, Ontario invoked the *Emergency Measures Act*, which meant that what is considered essential services within the province could be altered as needed (Ontario Office of the Premier, 2021a). Ontario chose to provide a list of services, which allowed the government to add or take away services as it deemed fit (Toronto Star Staff, 2020; Village Media, 2020). This shifting list of services meant that there was not a comprehensive sense of who was affected by the mandatory closure of non-essential services, nor of how the interconnection of lost services poses untenable consequences for segments of the Ontario population in need of attention and support. These lost services and lack of support that disabled people were experiencing resulted in cumulative effects of isolation, fear, uncertainty, and feelings of being devalued and disposable (Linton, 2020; Rankin, 2020; Shingler & Stevenson, 2020; Spagnuolo & Orsini, 2020; Vigliotti, 2020).

Public health, medicine, and their related disciplines have been dominant players in the determination of essential services. Their experience and knowledge are understood to be “essential knowledge” in decision-making regarding pandemic responses and planning. In other words, medical knowledge is considered the authority and expert on disability, rather than disabled people themselves, who were generally not consulted about public health measures. Medical authorities' configuration of who needs help, and what that help should be, operates from a medical model of disability, premised on the assumption that disability must be eliminated, “fixed,” or cured, often with the goal of managing risk and safety, rather than quality of life (Shakespeare, 2006). The federal and provincial governments are similarly positioned as essential voices with essential knowledge – while at times working in concert with public health and medicine; it has become clear that they also operate from their own agendas in ways that sometimes override or contradict what medical “experts” are advising as the best course of action (Merrifield, 2021). Thus, decision-making and policies are ad hoc and shifting. With the power of decision-making limited to these players, many communities – and the knowledge, experience, and perspectives they could bring to pandemic planning – are ignored and not regarded as essential or worthy of seeking out. Ultimately, despite mounting knowledge about how to make government pandemic responses equitable, there is little incentive to

challenge the status quo. Such a limited focus has consequences for many diverse disability communities (Adjekum, 2020; Kassam, 2020; Uyede-Kai, 2021). For example, keeping as many people as possible at home isolating and physically distanced from others, with only very specific essential services, has revealed the ableist, sanist, classist, and ageist ways in which essential services have been created and constructed for an ideal population (Spagnuolo & Orsini, 2020).

Review of Literature

In this section, we examine articles (academic and public sources) published between March 2020 to June 2020. These articles specifically discussed COVID-19 and its impact on people with disabilities within Canada. Key terms we used to find these articles included “COVID-19 and people with disabilities,” and “disabled people’s experiences during COVID-19.” Given that most papers we found were written within an Ontario context, we focus predominantly on the experiences of people living in Ontario. Our methodology for analyzing these articles was rooted in discourse analysis, allowing us to explore the interplay of power and relationships, discern patterns, and delve into both political and philosophical underpinnings present in written text. Here we adopted a macro-level approach emphasizing the critical examination of language and ideologies within societal contexts. According to Shaw and Bailey (2009), this approach enables researchers to dissect and challenge assumptions, providing insights into how these assumptions influence individual narratives and broader societal norms. We endeavoured to provide a thorough and insightful analysis that not only highlights the specific challenges faced by individuals with disabilities during the COVID-19 pandemic but also contributes to a broader understanding of societal attitudes towards disabled people. We speak to our analysis within four encompassing and related themes: 1) Triage and Scarcity; 2) Disabled People and Services in the Community; 3) Experiences of People labelled/with Intellectual Disabilities; and 4) People Living and Working in Continuing Care Systems.

Triage and Scarcity

As early COVID-19 waves began to challenge the healthcare system, especially intensive care units (ICUs), the Ontario government’s emergency powers directed a bioethics table to develop a triage protocol for hospitals. This protocol would determine who would be given care if the health care or hospital system became unable to provide care to all. It was based on a fragility scale used to assess the elderly and identify the level of care they would need.

The scale would give lower scores to people who required care or support from others (Advocacy Resource Centre for the Handicapped [ARCH] Disability Law Centre, 2020). ARCH Disability Law Centre is a legal clinic that is a leader in disability rights advocacy in Ontario, Canada. ARCH Disability Law Centre (2020) argued that the scale's metrics, and the interpretation of the metrics, would discriminate against disabled people who required any type of care or support. The triage protocol is an extreme example of the ableist and sanist actions of the provincial government.

Disabled advocacy organizations, disabled activists, and allies protested the use of this triage protocol and organized widespread support (ARCH Disability Law Centre, 2020; Dubinsky, et al., 2021). The government eventually withdrew the original protocol. However, while no other public version of the triage protocol was released, it remained the cornerstone document. It should be noted that the hospital system in Ontario coordinated its ICU beds so that COVID-19 patients received intensive care (Critical Care Services Ontario, 2019). While controversial, this effort also helped to prevent the implementation of the triage protocol across the province.

Despite vaccination efforts, ICUs remain stretched beyond capacity, in part, because hospital workers are burnt out from the intensity of COVID-19 and compounding staffing shortages and have left or are leaving the profession (Giacomo et al., 2021; Mulligan & Bond, 2022) or working for private agencies (Laucius, 2022). In both situations, the lack of nurses and continuity of care means longer wait times in emergency wards for transfer to nurse-staffed beds and decreased quality of care. This continuing health care crisis in the Ontario health care system continues to disadvantage disabled people, especially those who are poor, without permanent resident status, racialized, or unfamiliar with the health care system (i.e., newcomers to Canada) (Forman & Jackson, 2023; Ma et al., 2022). We need to critically explore the implication of this triage and scarcity approach for diverse disability communities.

Disabled People and Services in the Community

Many diverse disability communities who receive services in the community were adversely affected by pandemic public health guidelines to isolate and maintain physical and social distance from each other during the early onset of COVID-19 (Cooper et al., 2020). Isolation is difficult and sometimes impossible for diverse disability communities who require access to services from others as an essential part of their everyday lives. People who use care workers such as attendants daily to assist with transfers, bathing, dressing, and eating view these services as essential to their survival (Galloway, 2020; Goldman, 2020; Mustafa 2020). People using attendants worried about attendants coming to work and whether they were protected during travel. Attendants also worried about their safety (Porch et al., 2021). Isolation guidelines extended to potential hospital visits. People who have attendants

accompanying them to the hospital were now told that attendants were prohibited from accompanying them into the hospital (Malhotra & Johnson, 2020). This situation meant that disabled people were “choosing” to avoid hospitals because of this pandemic measure. Similarly, older adults were also not able to have a partner or support person accompany them to the hospital. Older adults may require supports to navigate the hospital and understand tests and physician communication. This is further complicated if English is not the person’s first language of communication, cultural differences or if the person is a newcomer to the country.

People who were using services related to the training of guide dogs or were learning how to navigate the environment due to sight loss did not have these essential services available to them during the early part of the pandemic (ABC 17 News, 2021). These services were essential for enabling them to get around in their everyday lives. Similarly, people who required assistive devices such as mobility aides (e.g., wheelchairs, scooters) and other devices or supplies funded by the Assistive Devices Program (ADP) were not able to access them as they were deemed to be non-essential services (Monsebraaten, 2020). This isolation also made it difficult for people to provide for themselves. Many people could not get out for food without putting themselves at risk, and grocery delivery services were prohibitively expensive. For those who can afford it, many services leave the food at the door to comply with “physical distancing guidelines.” However, due to mobility or other issues, many people cannot pick up the groceries and bring them into their homes.

People receiving financial support through the Ontario Disability Support Program (ODSP) did not receive additional monies to pay for protective equipment from the Ontario government. People often had to pay for it out of their monthly ODSP payment, which was an issue as monthly ODSP payments pre-pandemic barely covered both rent and food each month (Ozga & Smith, 2023). People laid off from work were able to access CERB (Canada Emergency Response Benefit), which was significantly more money than the ODSP payments. The ODSP community rallied to push the government to increase ODSP payments given COVID-19 and the need for continued use of protective equipment. Recently, the Ontario government increased ODSP payments by five percent, which amounted to an additional paltry \$58 a month (DeClerq, 2022, para. 3).

Mask mandates when outside of personal residences also created challenges for some disability communities. While mask-wearing is important, there was a lack of understanding that many people may not be able to comply with this requirement due to respiratory conditions. People who are D/deaf or hard of hearing may struggle to hear others, and for those who communicate using Sign Language, mask-wearing presents a significant barrier to communication. (M. Aguayo, personal communication, 2021).

The inaccessibility of the vaccine rollout, booking, and communication related to the pandemic was another barrier to the safety of diverse disability

communities (Rotenberg et al., 2021). Online vaccine booking processes were not accessible, as they assumed people had computers with updated software. The geographic and physical locations for public vaccine delivery were also inaccessible. Accommodations for people who required an attendant, caregiver or support person, and ASL or Braille were not routinely possible (Rotenberg et al., 2021). These impacts were further compounded for people in diverse communities – diverse in terms of race, sexual orientation, gender, age, class, geographic location, and status (Aknin et al., 2022; Canadian Research Institute for the Advancement of Women, 2021; Kemei et al., 2023).

Experiences of People Labelled with Intellectual Disabilities

The pandemic has “brought to the surface, and intensified, the countless struggles that have long persisted for people labelled/with intellectual disabilities,” a group long made vulnerable by oppressive ableist practices that have only been disadvantaged even further due to COVID-19 (Fudge Schormans et al., 2021, p. 83). This group is disproportionately impacted by the virus itself, public health restrictions, and exclusion from pandemic planning and decision-making.

People labelled/with intellectual disabilities are at greater risk of COVID-19 infection due in part to an increased likelihood of other health conditions, and more likely to be hospitalized, experience severe symptoms, and die from the virus (Heslop et al., 2021; Majnemer et al., 2021; Public Health England, 2020). This increased risk, however, cannot be attributed solely to “intellectual disability” or pre-existing health concerns; many other factors increased their vulnerability during the pandemic (Courtenay & Cooper, 2021). For example, despite knowledge of the increased risk, neither people labelled/with intellectual disabilities nor their families or support persons were prioritized in vaccination programs. Many people labelled/with intellectual disabilities live in congregate care settings (e.g., nursing homes, institutions, group homes) with increased exposure to numbers of staff coming in and out of their homes – both situations linked to higher infection rates (Hakim, 2020; Landes et al., 2020). The failure to provide information about the virus, safety protocols, and vaccinations in plain language and alternative formats further increased their risks (Hewitt et al., 2022; Majnemer et al., 2021). For those requiring hospitalization for COVID-19, family or support persons often were not allowed to accompany them. Combined with the lack of training that medical practitioners receive in working with people labelled/with intellectual disabilities, this increased the risk that individual ways of communicating, and needs for support in understanding what was being said, would not be attended to (Fudge Schormans et al., 2021; Majnemer et al., 2021). Particularly alarming are risks posed by pandemic triage protocols to guide medical decision-making, which reveal discriminatory bias and a lack of knowledge of intellectual disability (Fudge Schormans et al., 2021; Majnemer et al., 2021).

Access to life-saving treatment has been denied to this group (Saia et al., 2021) using do-not-resuscitate orders for people labelled/with intellectual disabilities hospitalized with COVID-19 in the UK – a decision of which families were not always aware (Das, 2022; Heslop et al., 2021).

Public health restrictions have had significant short- and long-term consequences on the mental health and well-being of people labelled/with intellectual disabilities (Courtenay & Cooper, 2021; Majnemer et al., 2021; Scherer et al., 2022). For those in independent or supported living arrangements, limited access to support workers has resulted in food insecurity and a lack of daily living supports (e.g., eating, dressing, bathing, toileting, communication) (Hewitt et al., 2022). For those living with families, lockdowns and safety protocols created challenges that included loss of in-person support from workers providing a range of supports impacting health, well-being, and learning. Without access to respite, family members are providing support on a full-time basis (Majnemer et al., 2021). For older adults labelled/with intellectual disabilities, long-standing shortages of adult residential and supported independent living programs (Dubé, 2016) have meant aging parents (themselves at increased risk of contracting the virus) providing support to adult sons and daughters with even fewer supports than they had before the pandemic (Hewitt et al., 2022).

The switch to online learning, socializing, and delivery of medical and other supports was especially challenging. Technology and virtual learning increased access for some; for others, it increased existing education, health, and social inequities. Differing access needs, training, and comfort with technology, differential access to technology and support to learn how to use it, and unequal funds to pay for technology and the internet excluded many from engagement with others virtually (Canadian Press Staff, 2020; Rushowy & Teotonio, 2020). The heavy reliance by governments, service providers, and organizations on the provision of information online disadvantages many people labelled/with intellectual disabilities who experience a great deal of frustration in trying to access support via telephone. This matters a great deal when one is seeking support from Ontario Disability Support Programs, medical professionals, and others (Majnemer et al., 2021; Santinele Martino et al., 2020; Scherer et al., 2022).

In addition to lockdowns, developmental services agencies followed public health protocols and implemented strict visitation bans for residential programs. Visitation bans proved particularly disruptive, exacerbating the social isolation already common to many people labelled/with intellectual disabilities. Combined with the loss of access to formal and informal community programs, settings, and activities, some people labelled/with intellectual disabilities have extremely limited contact with others, sometimes limited to a worker who stops by (but does not go into) their apartment once or twice a week to bring groceries or check-in. Unable to visit agencies, community drop-ins and food programs, or meet with family or other support

persons many needs were unmet (Linton, 2020; MacLean, 2020). The loss of important social connections and relationships that nurture and sustain them was especially difficult for people labelled/with intellectual disabilities (Majnemer et al., 2021; Santinele Martino et al., 2020; Scherer et al., 2022).

People Living and Working in Continuing Care Systems

Older adults with disabilities relying on formal continuing care services, such as those provided through residential long-term care (LTC) facilities, have been among those most disproportionately impacted by the pandemic. In the first wave of the pandemic, deaths in residential care facilities accounted for more than 80% of COVID-19 deaths in Canada (Stall et al., 2020) – the largest proportion of LTC deaths per capita in the Organization for Economic Cooperation and Development [OECD] countries (OECD, 2021). At a crisis point, military personnel were called into LTC facilities in Ontario and Quebec to help and their reports documented horrific conditions of neglect, including residents dying alone from starvation and dehydration after being forcibly confined to their rooms for days on end (Malek, 2020).

Numerous studies, editorials, and reports analyzing the impacts of the pandemic on people living in LTC (Armstrong & Cohen, 2020; Estabrooks & Keefe, 2020; Jama et al., 2020; Jones et al., 2021) have pointed to limitations of the continuing care system, such as massive long-standing staffing shortages that predated the pandemic, shared bedrooms and bathrooms that make physical distancing challenging, top-down decision-making, and an over-emphasis on “safety and security” to the detriment of a fulsome quality of life for LTC residents. Intimately interrelated with these challenges are the notoriously poor and often disabling working conditions for LTC workers, where 88% to 90% of direct care workers (typically referred to as personal support workers or PSWs in Ontario) experience some form of violence (Banerjee et al., 2012; Canadian Union of Public Employees Ontario, 2019) and suffer disproportionate rates of COVID-19 and other infectious diseases (Gregor et al., 2020). While Ontario’s PSWs provide essential services during the pandemic, living wages, job security, guaranteed vacation time and benefits continue to be out of reach for many workers (Hapsari et al., 2022), particularly racialized immigrant women (Lightman, 2021) and those working in the home care sector (Noorsumar, 2020). The PSW turnover rate and massive disabling burn-out that workers experience (Agrba, 2021; Payne, 2022) indicate how profoundly underserved these workers are, even despite their essential status (Bouka, 2021). Such trends make clear that it is human-made systems that intentionally and systemically exclude large numbers of people from decent work and living conditions, and that put people at risk in a pandemic, rather than mere health status alone.

In the first year of the pandemic, the numerous media accounts highlighting the horrific state of continuing care services gave some hope that these long-

standing issues might finally get addressed. In most provinces, vaccinations were prioritized for those living and working in LTC facilities and national standards were drafted to improve the state of LTC in Canada (Health Standards Organization, 2021). Calls to deinstitutionalize (Herron et al., 2021) or even abolish LTC (Fritsch & Shanouda, 2022) have become more widespread. Yet, several years after the pandemic began, changes that tackle these systemic issues remain scarce. Instead, the Ontario government continues to make cuts to desperately needed healthcare services and privatize LTC facilities (and many other health services) (Olivieri et al., 2022), despite evidence that privately owned and operated LTC facilities are considered among the most dangerous places to work and live in Ontario (McGregor & Harrington, 2020).

While most people living in LTC are over 65 years old, these issues affect a wide diversity of people. Continuing care systems are complex, including a small but mighty population of younger disabled people living in LTC (Gillmore, 2021), a growing majority of racialized immigrant women who provide direct care (Chamberlain et al., 2019), as well as vast networks of informal and unpaid caregivers – usually women (Estabrooks & Keefe, 2020) – who are also disabled by the violence and inadequacies of these systems (Bouka, 2021). Provincial protocols and policies that continue to ignore and even exacerbate these issues demonstrate how deep-seated and intersecting ableism, ageism, sexism, and racism make it possible to dismiss and endanger the knowledge, concerns, and basic well-being of this vast diversity of people living in Ontario.

Essential Services Must be Determined by Essential Knowledges of Diverse Disability Communities

The previous section details the affects and effects of the Ontario provincial government’s response to COVID-19 and the public health measures to control the spread of the virus and its impact on diverse disability communities. The government and public health experts’ view of essential services, described above, has been framed as a kind of “essential knowledge” that should be trusted and relied upon during the pandemic. Correspondingly, the knowledge of diverse disability communities and their needs were not deemed essential and when communities shared stories, they remained largely unheard throughout the pandemic, as evidenced by the scarcity of these accounts in the media we reviewed. Yet such official and expert knowledge was insufficient to provide the “essential needs” of the diverse disability communities we discussed in Ontario (Enns, 2021; Linton, 2020; Vigliotti, 2020). We argue that going forward diverse disability communities, their knowledges, and experiences are essential for developing an equitable and effective pandemic response. This means that governments and public health bodies need to seek

out and incorporate this knowledge into future pandemic and disaster planning and recovery strategies. We articulate diverse disability communities' knowledge as *crip* or *disability wisdom*. The idea of *crip wisdom* has emerged from a series of interviews with the Disability Visibility Project (Be(ast) & Harville, 2016). The central idea is that *crip* or *disabled wisdom* emerges from the lived experience of disability. The varying embodied nature of living with diverse disabilities, in a world that largely does not account or truly value for those embodied differences, means many things. It means an abundance of knowledge, deep understanding, great intelligence, and an astuteness of being. It means having a reflexive stance and connecting with self, others, and the world around you. Given this, the essential knowledge of the diverse disability communities outlined in this paper demonstrates this disability or *crip wisdom* on how the pandemic has affected people's lives. In the next section, we detail how this *crip wisdom*, which is synergistic with disability justice, is essential to informing current and future planning related to the pandemic, broader disaster planning, and social and economic (e.g., housing and transportation) planning in general.

*Using Disability Justice and Crip Wisdom to Inform Future Planning:
Examples of Disability Justice in Action*

In this section, we briefly describe two examples of how diverse disability communities organized to support their communities during COVID-19. These examples clearly demonstrate the mutual aid among diverse disabled communities, and consequently their knowledge and experience, their capacity to lead, and their commitment to collective access for all.

Care and Food Sharing or Mongering. In March 2020, Hamilton, Ontario organizers came together led by the Disability Justice Network of Ontario, the Hamilton Centre for Civic Inclusion, the Hamilton Student Mobilization Network, and Erich's Cupboard to create CareMongering HamOnt, "a mutual aid service meant to deliver food to people's doorstep during the COVID-19 outbreak" (Disability Justice Network of Ontario, 2020, para. 1). Using a Facebook group, people were able to post the types of supports they needed for those who reside in Hamilton, Ontario. The organizers wanted to ensure that they were prioritizing racialized and disabled residents in Ontario, so they created a centralized system with a phone number and a result form. Flyers were also created and translated into Spanish, Polish, French, and Arabic. In April 2020, organizers had more than 200 volunteers sign up who helped with delivery, flyer drop-offs, restocking inventory, and office supplies. Since the start of the program, they estimate that over 500 people have been fed (Moro, 2020). This has been a critical service, especially during times when public health requires the isolation of people.

The Accessibility Task Force on COVID-19 Vaccines. The Accessibility Task Force (ATF), a collective of mainly cross-disability consumer-led community organizations, came together when it became clear that the City of Toronto was not identifying disabled people as a priority for vaccination rollout during the COVID-19 crisis. With the increased risk of the Ontario Critical Care Triage Protocol being invoked and to avoid potential hospital and critical care admission, the ATF made urgent recommendations to the city for the vaccination of disabled people (City of Toronto, 2021):

1. A simplified, centralized vaccine booking process that includes disability-related priority groups and navigation support for disabled people.
2. Accessibility and accommodations training for staff at vaccine clinics to appropriately provide accommodations and care from a human rights perspective.
3. Accessible clinic locations that include private, quiet spaces for those who require this as an accommodation, and other accommodations as requested
4. Disability-specific clinics such as mobile, drive-through, and pop-up community clinics are appropriately resourced to ensure these options are offered in a timely fashion.
5. Prioritized access to in-home vaccination through existing mobile vaccination outreach methods, including emergency medical services and Ontario Health Teams-mediated mobile vaccination efforts.
6. Clear communications and navigation resources (in accessible formats such as Braille, plain language, ASL) specific to people with disabilities to access information about their eligibility and how to access vaccines.

The City of Toronto requested support from diverse disability communities to enact some of the recommendations. Given this, the Accessibility Cluster Vaccine Equity Team (ACVET) was formed consisting of community-based organizations that spanned the diversity of disability communities (e.g., the Centre for Independent Living in Toronto, the Ethno-Racial Coalition of Ontario, Deaf Spectrum, Balance for Blind Adults, Autistics for Autistics). The ACVET represents cross-disability solidarity working towards vaccination for all disabled people in a manner that reflects collective access. The ACVET supported six super support clinics between November 2021 and January 2022 (City of Toronto, 2022). Communication on vaccine information and support at these clinics was led by paid disabled and deaf ambassadors. In this way, those impacted by COVID-19 were supported by peers. Everyone’s access needs, regardless of disability, were meaningfully considered if not fully met. For example, COVID-19 information and vaccines were translated into American Sign Language (ASL), and d/Deaf ambassadors were engaged in outreach and explaining in ASL the risks, benefits, consent and process of getting vaccinated. The ACVET was also committed to teaching a broader perspective of accessibility to Toronto’s 150 equity teams and providing resources on this topic. In this way, the group was committing to informing others of the effects of disability and the ableism that existed within the initial

vaccine rollout. These two examples show the importance of disabled people being an essential part of any pandemic planning or recovery process.

Conclusion

In this paper, we have demonstrated the broad implications of Ontario's pandemic response and public health interventions, which largely overlooked the needs of diverse disability communities. Through a disability justice perspective, we have highlighted how these communities mobilized to address their needs during the pandemic. However, relying solely on mutual aid from disability communities is not sustainable. Governments and public health departments must integrate lessons from disabled people into future policies for pandemics, disasters, and recovery efforts. An intersectional framework is crucial, benefiting not only disabled individuals but also non-disabled people who needed additional support during the pandemic. The disability or crip wisdom must also be considered essential knowledge and inform other policies related to healthcare, poverty, food insecurity, and under or unemployment. This perspective and meaningful input from diverse disability communities will support people so that no one is left behind.

As the pandemic progressed beyond 2020, significant changes occurred in services available to disabled people. Ontario made substantial investments to increase hospital capacity and address staffing shortages, which helped manage patient loads more effectively during subsequent waves of the virus (Ontario Office of the Premier, 2021b). Additionally, the expansion of telehealth services provided a critical lifeline for many disabled individuals, allowing them to access healthcare remotely and reduce their risk of exposure.

Despite these improvements, systemic issues persisted. Efforts to make public health information and vaccine rollout more accessible were not always consistently implemented. Disability justice initiatives, such as mutual aid networks and advocacy for accessible vaccine clinics, showcased the resilience and adaptability of disabled communities. However, the fundamental inequities in the healthcare system continued to disproportionately affect disabled people. While there were notable improvements, many initial challenges faced by disabled communities remained. The pandemic underscored the need for a more inclusive and equitable approach to public health and emergency preparedness, fully integrating the voices and needs of disabled individuals in all aspects of planning and response. Future efforts must build on lessons learned to ensure no one is left behind.

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Appendix A: List of Articles the Authors Read to Inform the Discussion in this Paper

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Appendix B: March 2020 List of Ontario's Essential Services

Domain	Services
Supply chains	<ul style="list-style-type: none"> • Businesses that supply other essential businesses or essential services within Ontario, or that supply businesses or services that have been declared essential in a jurisdiction outside of Ontario, with the support, products, supplies, systems, or services, including processing, packaging, warehousing, distribution, delivery, and maintenance necessary to operate.
Food	<ul style="list-style-type: none"> • Businesses that primarily sell food, beverages and consumer products necessary to maintain households and businesses including: <ul style="list-style-type: none"> • Supermarkets and grocery stores • Convenience stores • Discount and big box retailers selling groceries • Restaurants (take-out, drive-through and delivery service only) • Beer and wine and liquor stores.
Services	<ul style="list-style-type: none"> • Pharmacies • Gas stations and other fuel suppliers • Laundromats and dry cleaners • Security services for residences, businesses and other properties • Vehicle and equipment repair and essential maintenance and vehicle and equipment rental services • Courier, postal, shipping, moving and delivery services • Funeral and related services • Staffing services including providing temporary help • Veterinary services (urgent care only) and other businesses that provide for the health and welfare of animals, including farms, boarding kennels, stables, animal shelters, zoos, aquariums and research facilities • Home childcare services of up to six children as permitted under the Child Care and Early Years Act, 2014, and child care centres for essential workers authorized to operate in accordance with Ontario Regulation 51/20 (Order Under Subsection 7.0.2 (4) of the Act - Closure of Establishments) made under the Act • Hotels, motels, and other shared rental accommodation including student residences, except for seasonal campgrounds and any pools, fitness centres, meeting rooms and other recreational facilities that may be part of the operations of these businesses • Cheque cashing services • Services to the public that are restricted to alternative methods of sale • Stores that sell any of the following items and provide them to the customer only through an alternative method of sale such as curb side pick-up or delivery, except in exceptional circumstances: Hardware products, vehicle parts and supplies, pet and animal supplies, office supplies and computer products including computer repair, safety supplies.

Financial services	<ul style="list-style-type: none"> • Businesses that provide the following financial services: Capital markets and related securities trading and advisory services, banking/credit union activities including credit intermediation, insurance, land registration services, real estate agent services, pension and benefits payment services, financial services including payroll and payment processing and accounting and tax services.
Telecommunications and IT infrastructure/ service providers	<ul style="list-style-type: none"> • Information Technology (IT) services, including online services, software products and the facilities necessary for their operation and delivery • Telecommunications providers and services (phone, internet, radio, cell phones etc.) and facilities necessary for their operation and delivery • Newspapers, radio and television broadcasting.
Maintenance	<ul style="list-style-type: none"> • Maintenance, repair and property management services strictly necessary to manage and maintain the safety, security, sanitation and essential operation of institutional, commercial, industrial and residential properties and buildings • Transportation services • Businesses and facilities that provide transportation services, including, transportation services provided by air, water, road, and rail, including taxis and other private transportation providers, and support services for transportation services, including, logistical support, distribution services, warehousing and storage, truck stops and tow operators, services that support the operations and safety of transportation systems including maintenance and repairs, and marinas, but only to the extent that the marina is necessary to enable individuals to access their primary place of residence • Businesses that provide and support online retail, including by providing warehousing, storage and distribution of goods that are ordered online.
Manufacturing	<ul style="list-style-type: none"> • Businesses that extract, manufacture, process and distribute goods, products, equipment and materials, including businesses that manufacture inputs to other manufacturers, (e.g. primary metal/ steel, blow molding, component manufacturers, chemicals, etc. that feed the end-product manufacturer), regardless of whether those other manufacturers are inside or outside of Ontario, together with businesses that support and facilitate the movement of goods within integrated North American and global supply chains.
Agriculture and food production	<ul style="list-style-type: none"> • Businesses that produce food and beverages, and agricultural products including plants, including by farming, harvesting, aquaculture, hunting and fishing • Businesses that process, manufacture or distribute food, beverages, crops, agricultural products, animal products and by-products • Businesses that support the food or agricultural products supply chains and the health and safety of food, animals and plants.

Construction	<ul style="list-style-type: none"> • Construction projects and services associated with the healthcare sector, including new facilities, expansions, renovations and conversion of spaces that could be repurposed for health care space • Construction projects and services required to ensure safe and reliable operations of, or to provide new capacity in, critical provincial infrastructure, including transit, transportation, energy and justice sectors beyond the day-to-day maintenance • Critical industrial construction activities required for, the maintenance and operations of petrochemical plants and refineries, significant industrial petrochemical projects where preliminary work has already commenced, industrial construction and modifications to existing industrial structures limited solely to work necessary for the production, maintenance, and/or enhancement of Personal Protective Equipment, medical devices (such as ventilators), and other identified products directly related to combatting the COVID-19 pandemic • Residential construction projects where, a footing permit has been granted for single family, semi-detached and townhomes, an above grade structural permit has been granted for condominiums, mixed use and other buildings, or the project involves renovations to residential properties and construction work was started before April 4, 2020 • Construction and maintenance activities necessary to temporarily close construction sites that have paused or are not active and to ensure ongoing public safety.
Resources and energy	<ul style="list-style-type: none"> • Businesses that provide and ensure the domestic and global continuity of supply of resources, including mining, forestry, aggregates, petroleum, petroleum by-products and chemicals • Electricity generation, transmission, distribution and storage and natural gas distribution, transmission and storage.
Community services	<ul style="list-style-type: none"> • Businesses that deliver or support the delivery of services including: Sewage treatment and disposal, collecting, transporting, storing, processing, disposing or recycling of any type of waste, potable drinking water, critical infrastructure repair and maintenance including roads, dams, bridges etc., environmental rehabilitation, management and monitoring, and spill clean up and response, administrative authorities that regulate and inspect businesses, professional and social services that support the legal and justice system • Government services including but not limited to policing and law enforcement, fire and emergency services, paramedics, coroner and pathology services, corrections and court services, licences and permits.

Research	<ul style="list-style-type: none">• Businesses and organizations that maintain research facilities and engage in research, including medical research and other research and development activities• Health care and social services• Organizations and providers that deliver home care services or personal support services to seniors and persons with disabilities• Businesses that sell, rent or repair assistive/mobility/medical devices, aids and/or supplies• Regulated health professionals (urgent care only) including dentists, optometrists, chiropractic services, ophthalmologists, physical and occupational therapists and podiatrists• Organizations that provide health care including retirement homes, hospitals, clinics, long-term care facilities, independent health facilities and mental health and addictions counselling supports• Laboratories and specimen collection centres• Manufacturers, wholesalers, distributors and retailers of pharmaceutical products and medical supplies, including medications, medical isotopes, vaccines and antivirals, medical devices and medical supplies• Manufacturers, distributors and businesses that provide logistical support of or for products and/or services that support the delivery of health care in all locations• Not-for-profit organizations that provide critical personal support services in home or residential services for individuals with physical disabilities• Not-for profit organizations that support the provision of food, shelter, safety or protection, and/or social services and other necessities of life to economically disadvantaged and other vulnerable individuals.
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Note: List is available online at CTV News Staff (2020).