

Gaps in healthcare policy throughout COVID-19 with respect to disabled individuals: a screener's perspective

Kaitlyn A. Merrill *†‡

Abstract

The medical community holds great responsibility to the public, including that the needs of each patient are met through the tenants of justice, beneficence, non-maleficence and autonomy.¹ Indeed, the balance of ensuring individual health needs are met, while also considering societal health needs is, and always has been, an important component of the healthcare system. This principle was made evident during the COVID-19 pandemic, and achieving this balance was no simple task.

Several blanket policies and recommendations from multiple levels of Canadian government were enacted, adjusted, and upheld throughout the everchanging pandemic.^{2,3} Due to a lack of consideration regarding accessibility during the “one size fits all” governmental policy making, disabled individuals, including people with physical and cognitive disabilities, and their caregivers were left to navigate the healthcare system without their usual, though imperfect, supports. Importantly, pre-pandemic barriers to obtaining proper medical care, including unreliable transportation and stigmatization by healthcare personnel^{4,5}, were both highlighted and exacerbated by new challenges posed by the pandemic. This is cause for concern as, without necessary supports, disabled patients' safety is put at an even higher risk.

Ultimately, this commentary will provide insight to the effect of federal recommendations and provincial healthcare policies on disabled populations in Manitoba. Such insight may help guide responses to the next pandemic. Research into the experiences of disabled individuals, other marginalized, and disenfranchised communities during COVID-19 is sorely needed in order to learn from this pandemic and shape our emergency policies during the next one.

Keywords: COVID-19, disability, essential care partner, policy, restrictions

Conflict of Interest Statement: The authors declare no conflict of interest.

The COVID-19 pandemic introduced many changes and challenges to everyday life. As demonstrated by previous pandemics and crises, vulnerable populations, including disabled people, are disproportionately impacted.⁶ Policies and recommendations were brought forward by the various levels of governments in Canada to minimize the spread of the virus, while mitigating the challenges faced by the public, including specific recommendations regarding disabled people.⁷ These policies were produced quickly, and in hopes of protecting the most people, while ideally posing the fewest issues. Unfortunately, as is the case in many blanket policies, there were disparities, which gave rise to critical health-related problems in the lives of disabled people. My interest in this topic stems from my personal experience as a COVID-19 entry-point screener at a

Winnipeg hospital, and the inequities I witnessed. In this position, I was responsible for upholding current COVID-19 restrictions, which involved communicating with staff to determine who required an essential care partner to remain with them throughout their stay in the department. The purpose of an essential care partner was to ensure specific groups of people, such as those with disabilities, could obtain medical care safely and effectively. Unfortunately, in my experience, the need for this support was often debated, and inconsistently granted. It is known that disabled people seeking medical care are more likely to suffer an adverse medical outcome due to negligence by hospital staff, even prior to COVID-19 when support workers and family members were allowed to be present. Therefore, it is an especially important topic to consider in light of the

*Correspondence to: email@email.email

†Department of Pediatrics and Child Health, Max Rady College of Medicine, Rady Faculty of Health Sciences, University of Manitoba, Winnipeg, Manitoba, Canada

‡Children's Hospital Research Institute of Manitoba, Winnipeg, Manitoba, Canada

COVID-19 pandemic.^{8,9}

First, I would like to draw attention to the cases which initiated the creation of some of the policies specific to disabled people receiving healthcare during the COVID-19 pandemic. At the onset of the pandemic, hospitals and care homes began closing doors to visitors. Therefore, people requiring medical treatment were to go to acute care facilities, clinics, and appointments alone.^{10,11} Since these policies were developed quickly, as necessary by the state of emergency, the policies that generally worked for able-bodied individuals accessing healthcare left gaps for those outside the “norm”. The death of Ariis Knight in April 2020 sparked outrage from the disability community. Knight, a non-verbal woman with cerebral palsy living in British Columbia, was refused the supports she needed to effectively communicate with medical staff, as the policy at the time had no mention of an amendment to allow for support workers. Ariss Knight died alone in hospital without any family or support workers by her side.¹² The lack of consideration of the impact of the “no-visitor” policy on disabled people resulted in trauma for Knight, her family, and the disabled community. After this event, the Government of British Columbia amended the visitation policies to reflect a need for “special consideration to designated representatives” of disabled people.¹³ Despite this amendment, medical staff remained responsible to decide who was essential and who was not, and whether “special considerations” were given.¹³ Along with the ableist history of the Canadian healthcare system^{14,15}, including institutionalization and forced sterilization¹⁶, it seems unlikely that changing the wording of the policy is enough to create substantial change for the disabled community.

Prior to Knight’s death, the federal government had established the COVID-19 Disability Advisory Group (CDAG). In fact, the federal government updated their website to include the page regarding the CDAG, on April 10, 2020, just over a week prior to Ariis’s death, with the following description:

“The Government of Canada is taking immediate, significant, and decisive action by announcing the establishment of the COVID-19 Disability Advisory Group (CDAG). The CDAG will advise the Minister on the real-time lived experiences of persons with disabilities during this crisis on disability-specific issues, challenges and systemic gaps and on strategies, measures and steps to be taken.”¹⁷

This indicates the federal government had acknowledged, in writing, the challenges disabled people were facing. Yet, the Government of British Columbia had made no considerations for disabled people in emergency situations. These discrepancies between provincial and federal policies due to a lack of communication between varying levels of government is a serious concern and may have made a difference in the case of Ariis Knight.

Months later, in December 2020 at the Health Science’s Centre in Winnipeg, Cameron Slimmon was de-

nied a caregiver, despite Shared Health stating that decisions regarding support workers and essential care partners would be made on a case-by-case basis.¹⁸ Slimmon was unable to communicate with hospital staff to adequately express his needs, resulting in him discharging himself from the hospital before his condition had improved. He deemed the vulnerability in his position alone at the hospital to be more dangerous than the medical emergency for which he was being treated.¹⁸ The human rights complaint filed by Slimmon generated pressure for Shared Health to create a written policy, which allowed for “essential care partners” deemed necessary by the hospital.¹⁹ This situation was eerily similar to that of Ariis Knight in British Columbia, however, this event took place months later. It appears that the Manitoba Government had not communicated with, nor observed impacts of similar policies in other provinces and the same mistakes were repeated.

Given that provincial governments are largely responsible for healthcare, there is space for variation in policy from province to province.²⁰ Shared Health, Manitoba’s provincial health organization, had set policies which changed frequently and ultimately left all final decisions about COVID-19 restrictions up to the medical personnel in charge of the unit. Provoked by the human rights dispute by Cameron Slimmons, Shared Health created guidelines for the instances in which the province was under Code Red restrictions.^{3,21} People seeking medical attention may have been permitted an “essential care partner”, defined as “those providing physical, psychological and emotional support, as deemed important by the patient.”²¹ In my experience, the determination of essential care partners varied based on which management staff was working that shift; some were more considerate of disabled people, while others immediately rejected support workers.

The procedure went on to state that essential care partner access was exclusive to specific situations and would be supported for patients who “normally have constant care or attendants” or require assistance with “medical history, collateral history, consent and decision making.”²¹ The guidelines stated that ultimately in these circumstances, consultation with the hospital staff was required to determine if the patient would be granted an essential care partner.²¹

The guidelines set by Shared Health were also largely different than the recommendations by the Federal Government. On the Federal Government website, it was stated that:

“Policies and procedures for hospitals, long-term care homes, COVID-19 Assessment Centres, clinics, family practice, other medical facilities and any organization that provide healthcare and supportive services to those with disabilities should provide permission in their directives on the accompaniment of essential supports at all stages of care within the healthcare environment.”⁷

In my experience, staff tended to attempt to find a reason for refusal of a partner, as their role was to uphold the visitation restrictions, which were both

important and necessary to minimize transmission of COVID-19, especially in hospital, where there is an increased risk of severe outcomes for certain patient populations.²² That being said, in my experience, given that the recommendations and policies left room for interpretation, inconsistent decision making of the staff took place. The Federal Government recommendation was often ignored at our emergency department, as well as in the cases of disabled people attending appointments within the hospital. The Shared Health policy was also often ignored, aside from the line stating that medical staff of the site will have final say in these decisions. It has also been reported that variation between facilities also occurred in the case of a dementia patient.²³ I have been instructed to refuse a care partner for a disabled person who was both deaf and blind, and unable to communicate with medical personnel. A similar case in which a mother was refused to visit her non-verbal son was also reported on early in the pandemic.²⁴ I have also been instructed to refuse care partners for people amid mental breakdowns, while there has been a suicide attempt in the emergency room washroom and studies have since shown the importance of caregivers to the mental health of patients.²⁵ There were also instances in which once the patient was denied a care partner, they left the facility rather than being treated. Ultimately, the refusal of support for disabled patients leads to poorer health outcomes²⁶, demonstrating the dire need of these supports.

Over time, the pandemic phased out of a state of emergency, rules and regulations lessened, and more patients were permitted to obtain their necessary supports. At the time of policy development, we were living through an unprecedented global health emergency. Unfortunately, like many other public health policies developed during our pandemic response, it is impossible to know how many lives were saved through strict visitation policies in hospital. However, we do know that many disabled individuals unduly suffered at the hands of said policies. In my opinion, the “essential care partner” designation was an important component of these policies, and in theory well-defined, but when it came to real life practice, the role faltered and was inconsistently regulated. As stated previously, there were many cases in which the individual safety of disabled patients was compromised, due to rigid and inconsistently enforced policies. As medical professionals, we are well-versed in following procedural policies, which is of great importance, but it is also important to ensure humanity remains in the system when making decisions for all patients, and especially vulnerable ones. Though policymakers are responsible for creating safe procedures, medical professionals also hold a responsibility to advocate for their patients, as outlined by the Royal College of Physicians and Surgeons of Canada under the CanMEDS framework. Looking onward to the next public health emergency, it is important to reflect on our pandemic response, and seeking out the lived-experiences of vulnerable populations is key to consistent and systemic improvement.

References

- [1] Framework for Ethical Deliberation and Decision-Making in Public Health: A Tool for Public Health Practitioners, Policy Makers and Decision-Makers. Government of Canada; 2017. Available from: <https://www.canada.ca/content/dam/phac-aspc/documents/corporate/transparency/corporate-management-reporting/internal-audits/audit-reports/framework-ethical-deliberation-decision-making/pub-eng.pdf>.
- [2] Protecting Public Safety and the Well-Being of Canadians: Legislative and Other Measures +Coronavirus Disease (COVID-19). Government of Canada; 2022. Available from: <https://www.justice.gc.ca/eng/csj-sjc/covid.html>.
- [3] Manitoba SH. Latest News; 2023. Available from: <https://sharedhealthmb.ca/category/covid-19/>.
- [4] Drainoni ML, Lee-Hood E, Tobias C, Bachman SS, Andrew J, Maisels L. Cross-disability experiences of barriers to health-care access: consumer perspectives. *Journal of Disability Policy Studies*. 2006;17(2):101-15.
- [5] Kelsall D. Doing the right thing for our patients with disabilities. *CMAJ*. 2016;118(14):993.
- [6] for the Coordination of Humanitarian Affairs UNO. The Pandemic Disproportionately Impacts People with Disabilities; 2020. Available from: <https://reliefweb.int/report/world/pandemic-disproportionately-impacts-people-disabilities>.
- [7] COVID-19 and People with Disabilities in Canada. Government of Canada; 2023. Available from: <https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/guidance-documents/people-with-disabilities.html>.
- [8] Krahn GL, Walker DK, Correa-De-Araujo R. Persons With Disabilities as an Unrecognized Health Disparity Population. *American Journal of Public Health*. 2015;105(S2):S198-206.
- [9] Tuffrey-Wijne I, L LG, Gordon V. The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study. *BMC Health Services Research*. 2014;14(1):432.
- [10] Golding L, MacRae S. Canadian Health Sector: Weekly COVID-19 Update. FASKEN; 2020. Available from: <https://www.fasken.com/en/knowledge/2020/04/20-canadian-health-sector-weekly-covid-19-update/>.
- [11] Munshi L, Evans G, Razak F. The case for relaxing no-visitor policies in hospitals during the

- ongoing COVID-19 pandemic. *CMAJ*. 2021;193(4):E135.
- [12] Hua J. B.C. Woman with Disability Dies Alone in Hospital Due to COVID-19 Visitor Restrictions. *Global News*; 2020. Available from: <https://globalnews.ca/news/6866586/bc-woman-disability-dies-covid-19/>.
 - [13] of CBC News E. B.C. Updates Policy on Hospital Visitors after Outcry over Disabled Woman's Death. *CBC News*; 2020. Available from: <https://www.cbc.ca/news/canada/british-columbia/b-c-updates-policy-on-hospital-visitors-after-outcry-over-disabled-woman-s-death-1.5576316>.
 - [14] Janz HL. Ableism: the undiagnosed malady afflicting medicine. *CMAJ*. 2019;191(17):E478-9.
 - [15] Neilson S. Ableism in the medical profession. *CMAJ*. 2020;192(15):E411-2.
 - [16] Brown I, Radford JP. The Growth and Decline of Institutions for People with Developmental Disabilities in Ontario: 1876-2009. *Journal on Developmental Disabilities*. 2015;21(2):7-27.
 - [17] Backgrounder: COVID-19 Disability Advisory Group. Government of Canada; 2020. Available from: <https://www.canada.ca/en/employment-social-development/news/2020/04/backgrounder--covid-19-disability-advisory-group.html>.
 - [18] McKendrick D. Human Rights Complaint Filed by Winnipeg Man after Caregivers Not Allowed to Stay in Hospital. *CTV News*; 2020. Available from: <https://winnipeg.ctvnews.ca/human-rights-complaint-filed-by-winnipeg-man-after-caregivers-not-allowed-to-stay-in-hospital-1.5224712>.
 - [19] Unger D. Change to Manitoba Hospital Visitation "Good News" Says MaRn Who Filed Human Rights Complaint against HSC. *CTV News*; 2020. Available from: <https://winnipeg.ctvnews.ca/changes-to-manitoba-hospital-visitation-good-news-says-man-who-filed-human-rights-complaint-against-hsc-1.5241842>.
 - [20] Canada's Health Care System. Government of Canada; 2019. Available from: <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/health-care-system/canada.html#a5>.
 - [21] Manitoba SH. COVID-19 Essential Care Partner and Visitor Guidelines for Acute Care—Provincial Response Level Red; 2021. Available from: <https://sharedhealthmb.ca/files/covid-19-inpatient-visit-principles-level-red.pdf>.
 - [22] for Disease Control C, Prevention. Underlying Medical Conditions Associated with Higher Risk for Severe COVID-19: Information for Healthcare Professionals; 2023. Available from: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/underlyingconditions.html>.
 - [23] Froese I. Family of Dementia Patient Puzzled by COVID Rules Denying Entry at 1 Winnipeg Hospital, but Not Another. *CBC News*; 2022. Available from: <https://www.cbc.ca/news/canada/manitoba/family-dementia-patient-covid-visitation-rules-winnipeg-1.6475835>.
 - [24] News C. "Unjust" COVID Restrictions Keeping Winnipeg Mom from Seeing Her Nonverbal Son in Hospital; 2020. Available from: <https://www.cbc.ca/news/canada/manitoba/winnipeg-mother-hospital-covid-19-1.5818713>.
 - [25] Montesanti S, MacKean G, Fitzpatrick KM, Fancott C. Family caregivers as essential partners in care: examining the impacts of restrictive acute care visiting policies during the COVID-19 pandemic in Canada. *BMC Health Serv Res*. 2023;23(1):320.
 - [26] Stangl AL, Earnshaw VA, Logie CH. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*. 2019;17(1):31.