Commentary

Disability—a chronic omission in health equity that must be central to Canada's post-pandemic recovery

Matthew B. Downer, MSc (1); Sara Rotenberg, BS (2)*

This article has been peer reviewed.

▼ Tweet this article

Introduction

As Canada begins to recover and learn from the COVID-19 pandemic, health equity and public health policies must be a central tenet of reform. Recent work has begun to provide guidance on an equitable pandemic recovery in Canada, which highlights many important groups that require specific consideration in recovery policies. There is a key omission in many of these guidelines and, in fact, most health equity efforts—people with disabilities.

Canadians with disabilities make up approximately 22% of the population.2 Globally, people with disabilities have experienced greater risk of SARS-CoV-2 infection and mortality.3,4 A recent retrospective cohort study of 1297 COVID-19 hospital admissions in Ontario, Canada, found that 22.3% of admitted patients had a disability and that this patient population experienced longer hospital stays and higher rates of readmission.5 A pan-Canadian study of 35 519 hospitalizations for COVID-19 found several chronic diseases and disabilities associated with excess risk of death from COVID-19, with people with Down syndrome who were over the age of 50 having 8.5 times higher odds of death from COVID-19.6

Beyond health outcomes, pandemic policies in Canada have overlooked accessibility in public health messaging, testing and vaccination locations, loss of critical services and employment, and effects of prolonged isolation.⁷ However, while some studies have focussed on the impact of COVID-19 on Canadians with disabilities

during the pandemic, little work on postpandemic recovery has focussed on this population.

Considering the evidence that Canadians with disabilities are at higher risk of serious health outcomes from COVID-19 infection and the systemic lack of accessibility and inclusion in Canadian public health policies and practices, it is imperative to centre recovery practices on the needs of people with disabilities for an equitable pandemic recovery. Applying an intersectional and accessibility lens can guide and improve Canada's equitable post-pandemic recovery and devise greater emergency preparedness in the future.

Improving Canada's equitable post-pandemic recovery

Any post-pandemic recovery for Canadian health systems and public health should consider the four key tenets.

- Expand and improve the accessibility of health care services for Canadians with disabilities.
- Improve social determinants of health for Canadians with disabilities.
- Improve representation of people with disabilities in both public health and health systems.
- Include disability as a key priority in pandemic preparedness policies.

Expand and improve the accessibility of health care services for Canadians with disabilities

Several barriers exist for quality, rapid, equitable and affordable care for people

Highlights

- People with disabilities in Canada have experienced excess risk of COVID-19 infections and mortality but have not received adequate policy support throughout the pandemic.
- Canada's post-pandemic recovery for health care and public health must involve and include Canadians with disabilities.
- Any post-pandemic recovery should improve the accessibility of health care, address key social determinants of health for Canadians with disabilities (with an emphasis on housing and employment), increase representation of people with disabilities in health care and public health, and focus on disability considerations in future pandemic preparedness.

Keywords: disability, COVID-19, pandemic recovery, health equity

with disabilities in Canada's universal health system.⁸ Strengthening of health systems post-pandemic must focus on the rights of people with disabilities in order to correct these long-standing inequities. Many of the lessons from the COVID-19 pandemic can help achieve this goal. For instance, messaging on care rationing and mortality risk revealed deeply rooted and problematic assumptions on the value of disabled lives globally⁹—assumptions that

Author references:

1. Nuffield Department of Clinical Neurosciences, University of Oxford, Oxford, United Kingdom

2. Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom

*Both authors contributed equally to this work.

Correspondence: Matthew Downer, Brasenose College, University of Oxford, Oxford OX1 4AJ, United Kingdom; Tel: +44-7367-990222; Email: matthew.downer@bnc.ox.ac.uk

often lead to worse outcomes and poorquality care for people with disabilities. Improving disability training for health workers throughout their curricula can challenge these assumptions.¹⁰

Frameworks for accessible vaccination and testing offer key insights into improved accessibility for health care in general.⁷ This could lead to widespread improvements in accessible communication, appointment booking, physical and environmental accessibility, data collection, specialized clinics and other dimensions.

Investments in new technology and data monitoring can also help make health care more accessible. For instance, the Long-Term In-Home Ventilator Engagement (LIVE) program expanded virtual monitoring during the pandemic. These types of initiatives can be particularly important for stressed health systems with long waiting lists, allowing some care of at-risk populations to be conducted virtually, while simultaneously helping alleviate pressure on health systems.

It is vital that all technological advances be fully accessible to all health system users, including all providers and patients. The availability of virtual care was a particularly critical accommodation for many people with intellectual and developmental disabilities, who historically have had poor access to health care, ¹² and other people who face barriers in accessing inperson care. Virtual care options must continue to be an available and accessible option for Canadians with disabilities.

Out-of-pocket costs for disability-related health expenses such as assistive technology and prescription drugs are high.¹³ Investing in better access to essential medicines through a national pharmacare program, increased access to rare disease medications and expansion of medical device programs can all improve equity in health systems for Canadians with disabilities.

Together, health systems across Canada recovering and learning from the COVID-19 pandemic must centre accessibility and actively work to dismantle the many barriers that Canadians with disabilities face when interacting with health systems at every level.

Improve social determinants of health for Canadians with disabilities

In addition to improving health systems, there are social interventions, particularly housing and income support or employment that need to address the needs of people with disabilities.

Housing

Over 400 000 Canadian adults with significant disabilities live without adequate, affordable or quality housing.14 This longstanding public health issue has contributed to high rates of homelessness in this population in Canada. Further, many people with a range of various disabilities require supports to be able to live independently at home, but safety is sometimes compromised for affordability and accessibility, leaving people with disabilities at risk of abuse or harm. Investments in affordable housing need to ensure that buildings conform to accessibility standards and provide safer and supported options to address the housing crisis for this population.

Income support and employment

Intrinsically tied to sustainable housing, higher costs of living-medication, devices and transportation, along with housing-contribute to the well-understood link between disability and poverty in Canada. Current disability supports are insufficient to cover many costs-and many people with disabilities reported having their work hours reduced, being furloughed or being laid off during the pandemic.15 Statistics Canada reported that about one-third of the approximately 13000 Canadians with disabilities or chronic health conditions surveyed lost employment, temporarily or permanently, during the first year of the COVID-19 pandemic, and roughly half reported difficulty with at least one essential need or financial obligation.15 Further, media have reported that the Canada Emergency Response Benefit (CERB) and Canada Recovery Benefit (CRB) discriminated against Canadians with disabilities based on eligibility criteria.¹⁶

Any future employment programs must ensure eligibility and support for Canadians living with disabilities, including by expanding remote or virtual work possibilities and accommodations.

Finally, funding for medications and other disability-related health expenses must be available irrespective of work status, to allow people with disabilities to work without fear of losing vital disability-related benefits.

Improve representation of people with disabilities in public health and health systems

"Nothing about us, without us" has been used as a call to action for inclusion of people with disabilities. However, meaningful inclusion—where people with disabilities have an equal voice and are represented in research and on decisionmaking committees-continues to be lacking. Today, even as Canada pushes to administer primary series and subsequent boosters, accessible vaccination locations are limited and the National Advisory Committee on Immunization (NACI) has not adequately recognized the elevated risks of people with disabilities, except for older adults living in congregate settings, despite demonstrated risks.¹⁷ Without the voices of people with a range of intersectional lenses bringing concerns forward, there will continue to be a gap in disability-inclusive policy. Prioritizing the voices of leaders with disabilities in medicine and public health can help address this critical gap. 18

Pandemic preparedness

The impact of the COVID-19 pandemic on people with disabilities has highlighted the need for greater consideration of this population in pandemic preparedness efforts. In the wake of the pandemic, substantial work will be undertaken to review and improve Canada's response to future health emergencies. Having people with disabilities as key stakeholders in this process will help correct for some of the preventable inequities that occurred during this pandemic. For example, when health system capacity surged, news outlets revealed that medical rationing was affecting people with disabilities.^{19,20}

While no analogous work has been conducted in Canada, a Healthwatch England report found several shortcomings in rapidly rolled-out pandemic communications for people with disabilities in the United Kingdom.²¹ These included limited easyto-read information for people with intellectual or developmental disabilities, the widespread use of masks that prevented lipreading, and no sign language interpretation during the initial government briefings, among others.²¹

A 2021 Royal Society of Canada report made several policy recommendations to create a more accessible and disabilityinclusive society for Canadians with intellectual and developmental disabilities for the remainder of the COVID-19 pandemic and the post-pandemic phase.22 However, there are few guidelines for other disability groups, resulting in a gap in learning how to improve preparedness, response and recovery for all Canadians. If Canada had both improved health system preparedness and stringent policies on protecting the rights of people with disabilities during health emergencies, there could have been greater protection of the right to health of people with disabilities. When reviewing Canada's emergency preparedness in the coming years, updated preparedness policies must include revisions for greater health equity for Canadians with disabilities.

Beyond the pandemic, we need to overhaul our definition of health equity in Canada to consistently include people with disabilities. While medicine has long had a problem with ableism, research has repeatedly demonstrated inequities in care quality, treatment and outcomes among Canadians with disabilities23 as well as accessibility issues, most recently during public health campaigns throughout the COVID-19 pandemic.7 As Canadian health care and public health move beyond pandemic response, recovery must be rooted in initiatives that improve the accessibility, availability, acceptability and quality of care for people with disabilities. We must normalize disability within all our health equity work-anything short of concerted efforts to include people with disabilities will perpetuate inequity.

Conclusion

People with disabilities have faced higher rates of COVID-19 infections and mortality, yet these inequities and lack of policy supports received inadequate attention and action during the pandemic. To that end, any post-pandemic recovery for Canadian health systems and public health should consider the following four key tenets. First, we must expand and improve the accessibility of health care for all Canadians with disabilities, and address barriers to health care and public health, several of which were identified and exacerbated throughout the COVID-19 pandemic.

Second, health-focussed post-pandemic recovery must address key social determinants of health for people with disabilities, particularly housing and income support or employment. Third, both public health and health systems must increase representation of persons with disabilities in Canada. Centring of disabled voices is also closely linked to the final tenet, that future pandemic-preparedness policies that arise must include disability as a key priority.

Acknowledgements

There was no funding for this research project.

Conflicts of interest

MBD receives PhD funding from the Rhodes Trust, the Clarendon Fund at the University of Oxford and the Canadian Institutes of Health Research (DFD-175796) and receives compensation for work at the National Institute on Ageing at Toronto Metropolitan University. SR receives PhD funding from the Rhodes Trust and consulting fees from the Clinton Health Access Initiative. Funders had no role in the conceptualization or writing of this commentary or the decision to submit it for publication.

Authors' contributions and statement

Both authors contributed equally to the conceptualization of this manuscript as well as to the writing of the original draft and the review and editing.

The content and views expressed herein are those of the authors and do not necessarily reflect those of the Government of Canada.

References

- 1. Persaud N, Woods H, Workentin A, et al. Recommendations for equitable COVID-19 pandemic recovery in Canada. CMAJ. 2021;193(49):E1878-88. https://doi.org/10.1503/cmaj.210904
- Morris S, Fawcett G, Brisebois L, Hughes J; Canadian Survey on Disability Reports. A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017 [Internet]. Ottawa (ON): Statistics

- Canada; 2018 Nov 28 [cited 2023 Jan 15]. Available from: https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654
 -x2018002-eng.htm
- 3. Bosworth ML, Ayoubkhani D, Nafilyan V, et al. Deaths involving COVID-19 by self-reported disability status during the first two waves of the COVID-19 pandemic in England: a retrospective, population-based cohort study. Lancet Public Health. 2021; 6(11):e817-25.
- 4. Salter A, Fox RJ, Newsome SD, et al. Outcomes and risk factors associated with SARS-CoV-2 infection in a North American registry of patients with multiple sclerosis. JAMA Neurol. 2021; 78(6):699-708. https://doi.org/10.1001/jamaneurol.2021.0688
- 5. Brown HK, Saha S, Chan TC, et al. Outcomes in patients with and without disability admitted to hospital with COVID-19: a retrospective cohort study. CMAJ. 2022;194(4):E112-21. https://doi.org/10.1503/cmaj.211277
- Zakaria D, Aziz S, Bartholomew S, Park SB, Robitaille C, Weeks M. Associations between chronic conditions and death in hospital among adults (aged 20+ years) during first acute care hospitalizations with a confirmed or suspected COVID-19 diagnosis in Canada. PLoS ONE. 2023;18(1):e0280050. https://doi.org /10.1371/journal.pone.0280050
- 7. Rotenberg S, Downer MB, Brown H, et al. COVID-19 vaccination for people with disabilities. Science Briefs of the Ontario COVID-19 Science Advisory Table. 2021;2(35):1-22. https://doi.org/10.47326/ocsat.2021.02.35.1.0
- 8. Casey R. Disability and unmet health care needs in Canada: a longitudinal analysis. Disabil Health J. 2015:8(2): 173-81. https://doi.org/10.1016/j.dhjo.2014.09.010
- Chen B, McNamara DM. Disability discrimination, medical rationing and COVID-19. Asian Bioeth Rev. 2020; 12(4):511-8. https://doi.org/10.1007/s41649-020-00147-x

- Rotenberg S, Rodríguez Gatta D, Wahedi A, Loo R, McFadden E, Ryan S. Disability training for health workers: a global evidence synthesis. Disabil Health J. 2022;15(2):101260. https://doi.org/10.1016/j.dhjo.2021 .101260
- Amin R, Pizzuti R, Buchanan F, Rose L. A virtual care innovation for home mechanical ventilation. CMAJ. 2021: 193(17):E607-11. https://doi.org/10.1503/cmaj.202584
- Selick A, Durbin J, Hamdani Y, Rayner J, Lunsky Y. Accessibility of virtual primary care for adults with intellectual and developmental disabilities during the COVID-19 pandemic: qualitative study. JMIR Form Res. 2022:6(8):e38916. https://doi.org /10.2196/38916
- 13. McColl MA, Schaub M. The lifetime costs associated with living with a disability [Internet]. Canadian Disability Policy Alliance; 2016 [cited 2023 Jan 15]. Available from: https://www.disabilitypolicyalliance.ca/wp-content/uploads/2016/02/CDSP-270116-1.pdf
- 14. Alzheimer Society of Canada, ARCH Disability Law Centre, Canadian Association for Community Living, et al. Meeting Canada's obligations to affordable housing and supports for people with disabilities to live independently in the community. Under Articles 19 and 28, Convention on the Rights of Persons with Disabilities and Under Articles 2 and 11, International Covenant on Economic, Social and Cultural Rights. Report to UN Special Rapporteur on the Right to Housing [Internet]. Geneva (CH): OHCHR; 2017 May 15 [cited 2023 Jan 15]. Available from: https://www.ohchr .org/sites/default/files/Documents /Issues/Housing/Disabilities /CivilSociety/Canada-ARCHDisability LawCenter.pdf
- 15. Statistics Canada. The daily impacts of COVID-19 on persons with disabilities [Internet]. The Daily. 2020 Aug 27 [cited 2023 Jan 15]. Available from: https://www150.statcan.gc.ca/n1/en/daily-quotidien/200827/dq200827c-eng.pdf?st=Zsgc1u7M

- 16. Saba R. CERB and CRB discriminated against Canadians with disabilities, new Charter challenge claims [Internet]. Toronto Star. 2021 Nov 26 [updated 2022 Jun 30; cited 2023 Jan 15]. Available from: https://www.thestar.com/business/2021/11/26/cerb-and-crb-discriminated-against-canadians-with-disabilities-new-charter-challenge-claims.html
- 17. National Advisory Committee on Immunization. Guidance on the prioritization of key populations for COVID-19 immunization [Internet]. Ottawa (ON): NACI; 2021 [cited 2023 Jan 15]. Available from: https://www.canada.ca/en/public-health/services/immunization/national-advisory-committee-on-immunization-naci/guidance-prioritization-key-populations-COVID-19-vaccination.html
- 18. Rotenberg S. Integral to inclusion: amplifying public health leaders with disabilities. Lancet Public Health. 2021: 6(8):e543. https://doi.org/10.1016/S2468-2667(21)00141-18
- 19. Hansen N. Who gets medical care during the coronavirus pandemic and what does that mean for people with disabilities? [Internet]. CBC News (Manitoba Ed.). 2020 Apr 05 [cited 2023 Jan 15]. Available from: https://www.cbc.ca/news/canada/manitoba/manitobans-disability-health-care-coronavirus-1.5520589
- 20. Accessibility for Ontarians with Disabilities Act Alliance. A deeply troubling issue of life and death — an independent report on Ontario's seriously-flawed plans for rationing or "triage" of critical medical care if COVID-19 overwhelms Ontario hospitals [Internet]. AODA Alliance; 2021 Feb 25 [cited 2023 Jan 15]. Available from: https://www.aodaalliance.org /whats-new/a-deeply-troubling-issue -of-life-and-death-an-independent -report-on-ontarios-seriously-flawed -plans-for-rationing-or-triage-of-critical -medical-care-if-covid-19-overwhelms -ontario-hospitals/
- 21. Healthwatch. Healthwatch England Report: Are people getting their right to accessible information? Kingston Upon Thames (UK): Healthwatch Kingston Upon Thames; 2022 Sep 08 [cited 2023

- Jan 15]. Available from: https://www.healthwatchkingston.org.uk/report/2022-09-08/healthwatch-england-report-are-people-getting-their-right-accessible-information
- 22. Majnemer A, McGrath PJ, Baumbusch J, et al.; RSC Task Force on COVID-19. Time to be counted: COVID-19 and intellectual and developmental disabilities. Facets. 2021;6(1). https://doi.org/10.1139/facets-2021-0038
- 23. Janz HL. Ableism: the undiagnosed malady afflicting medicine. CMAJ. 2019; 191(17):E478-9. https://doi.org/10.1503/cmaj.180903