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What we did and why we did it

Past emergency reports and after-the-fact research have noted that persons with disabilities are particularly vulnerable during emergencies. They have specific access and functional needs and can face increased risks and vulnerabilities that are often overlooked in advance of an emergency.

The MacEachen Institute has authored a report entitled "Environmental Scan: Emergency Management Policies and Programs for People with Disabilities in Canada". Kaitlynne Lowe, co-author of the report and Research Assistant with the MacEachen Institute, presented findings from this research (slides available).

On March 25, 12 invited participants met online. They represented public agencies, non-profit groups that represent persons with disabilities, and academics.

Invitations to attend the webinar were sent to partners that collaborated on a funding application the MacEachen Institute submitted to Accessibility Standards Canada in February 2020.

Following the presentation, participants discussed the issues raised and their perspective on them from their professional and personal experiences. Their comments are summarized below but not attributed.

Contact

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MIPP COVID-19 RESEARCH BRIEFING



COVID-19 and People with Disabilities: Roundtable Discussion

Presentation

Past emergencies like SARS and H1N1 highlighted several key issues for persons with disabilities including access to medications and assistive devices, accessible information and services, disruption to care and personal assistance, increased stigma and marginalization, and questions surrounding service or guide animals. To understand our ability to control an emergency response, it is helpful to understand the three elements of a control mechanism. Cybernetic control is defined as our ability to gather information, set standards and change behaviour, and this was used as the framing device to analyze research results.

Key demographic information was presented using data from the 2017 Canadian Survey on Disability (CSD). The survey reports that 22% of Canadians over the age of 15 report having at least one disability, with higher rates among seniors and a high correlation between severe disabilities and poverty. It is important to note that the CSD does not include data from persons living in institutions, on Canadian Armed Forces bases, and on First Nations reserves. This is notable because First Nations peoples are nearly twice as likely to have a disability as non-Indigenous Canadians, according to the Assembly of First Nations (2017). It is also important to consider the needs of persons with disabilities in both the community and institutional contexts.

There are also numerous international and domestic frameworks and standards to support persons with disabilities during an emergency and improve accessibility across society. A few notable examples include the Sendai Framework and the Dhaka Declaration, both of which highlight an inclusive, people-centred approach to emergency management. Canada supports the implementation of the Sendai Framework through the United Nations. Canada is also a signatory to the United Nations Convention on the Rights of Persons with Disabilities, in which Article 11 asserts the importance of emergency management policies and programs to support persons with disabilities during an emergency.

Presentation continued

The <u>Canadian Charter of Rights and Freedoms</u>, the <u>Accessible Canada Act</u>, and provincial/territorial legislation and strategies also act as standard-setting frameworks to address accessibility issues.

Research has shown that the field of emergency management and persons with disabilities is rapidly growing nationally and internationally. The implementation of the United Nations Sendai Framework demonstrates an international commitment to advance disaster risk reduction (DRR) that is centred on and led by persons with disabilities. In Canada, particularly over the past five to ten years, there have been Federal and Provincial/Territorial accessibility legislation and frameworks. Many of the jurisdictions studied have created guides and resources that focus specifically on the needs of persons with disabilities in the emergency management context. Information-gathering and standard-setting efforts have increased in recent years. Behaviour change has often taken the form of training and educational initiatives. Reducing stigma is a key area to address. Challenges can arise with coordination and information-sharing, especially with the involvement of many jurisdictions and levels of government in emergency planning and response.

What we Discussed

The post-presentation discussion focused on limitations of the CSD data, in particular the exclusion of persons living in institutions and on First Nations reserves. Participants suggested that this represents a significant gap in policy and protocol for the COVID-19 pandemic as congregate living environments are more susceptible to outbreaks. Additionally, participants emphasized the importance of disaggregated data to address the disproportionate impact of disasters on gender and additional intersectional identities (e.g. race, Indigeneity, religion, sexual orientation, and socio-economic status). Recent examples of gendered differences in the current pandemic include higher levels of concern among women, who are often responsible for health care and caregiving, and the relationship between domestic violence and self-isolation.

Participants identified challenges caused by the siloed nature of government departments and the top-down flow of information. Organizations involved in caregiving emphasized challenges with coordination between relevant government departments, such as those responsible for public health and social services. This has been highlighted especially with respect to COVID-19 as the messages to communicate have been rapidly changing and evolving. The volume and pace of change of information is a unique aspect of the current pandemic, and it has caused confusion. System-wide standardization of emergency management policies (e.g. screening) among institutionalized facilities (e.g. long-term care) and other provincially funded facilities for people with disabilities (e.g. group homes) do not appear to be the norm. This emphasizes the importance of coordinated emergency management policy formulation and distribution within government-funded and -regulated congregate living facilities. A recent article (published after this meeting) raises this issue and emphasizes the need for accountability.

Information flows directly from press conferences, meaning both organizations and ground-level government officials are adapting to policy change with no preparation and little detailed knowledge. This has demonstrated the need to ensure a cross-sectoral approach to emergency management that considers all aspects of care and the disproportionate effect of gendered differences and the rural/urban divide.

Another challenge raised in the discussion was the logistics of minimizing the risk of transmission while continuing to deliver the same level of services. Residents in collective living environments are at a higher risk of contracting the virus if an outbreak were to occur within the institution, yet persons with disabilities living in the community are facing the loss of critical services that are being cut back due to capacity challenges and to minimize the number of interactions that could transmit the virus. Needs of people providing care in institutions and in the community should be considered to ensure care services can be delivered effectively and in a manner that protects both the recipient and the caregiver.

The support of staff was highlighted as especially critical during emergencies. Participants recommended that institutions review and update some of their policies before problems arise. These include Occupational Health and Safety policies, especially the right to refuse unsafe work, labour policies for dealing with staffing shortages and critical components, and various financial and communications-related policies and protocols. The mental and emotional well-being of staff and volunteers was underlined as being of critical concern.

Ableism was also expressed as a problem that persons with disabilities face during emergencies. Participants felt that the most vulnerable people (e.g. persons with disabilities, women, seniors, low-income and unhoused populations) should be central to government planning and response. They highlighted the need to coordinate emergency response with the protection of human rights and to ensure that persons with disabilities are included in the planning and decision-making processes as equal partners. Reports from the United Nations indicate that persons with disabilities generally feel excluded from emergency preparedness initiatives.

The importance of transparency was a recurring theme during the discussion. Organizations that provide support for persons with disabilities must be as transparent as possible about the measures being put in place to protect their residents. This is especially true as protective measures increasingly limit opportunities for face-to-face contact between residents of support homes and their families.

Looking forward, it is clear that coordination is a key consideration in emergency preparation for persons with disabilities. The participants regretted that there is often insufficient interest in spending the time doing so with no imminent threat, but that table-top exercises and discussions when there is not an emergency in progress are helpful.

What we recommend

- Involvement of persons with disabilities in policies and planning that affect persons with disabilities. Ensure engagement with diverse populations and persons with intersectional identities (e.g. race, indigeneity, age, disability, gender, sexual orientation, religion, and low income)
- Stronger coordination between public agencies and all organizations with responsibility for persons during emergencies
- Careful monitoring of resources at institutions to ensure they can provide care (1) within their institutions and (2) to clients outside the institutions
- Emphasize qualities necessary for trustworthiness: openness, knowledge and concern
- Recognize that the flow of information is so fast from Public Health that it presents challenges for managers to operationalize plans in a consistent manner

What we recommend continued

• In the medium term, enhance commitment to emergency response exercises that include those with responsibility for persons with disabilities during emergencies and those with lived experience.

About the MacEachen Institute

The MacEachen Institute for Public Policy and Governance at Dalhousie University is a nationally focused, non-partisan, interdisciplinary institute designed to support the development of progressive public policy and to encourage greater citizen engagement.

More from the MacEachen Institute

The Institute is working to create resources and policy discussion around the COVID-19 crisis. These include briefing notes like this one as well as panel discussions, videos and media commentary. You can find all resources related to COVID-19 on our website.

Other briefing notes in this series

- Quarantine and COVID-19
- Labour issues and COVID-19

This briefing note was prepared by MacEachen Institute Research Assistants Kaitlynne Lowe and Mary Macgowan.