Including People with Developmental Disabilities as a Priority Group in Canada's COVID- 19 Vaccination Program: Key Considerations: Part 2

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1. Purpose and Background

This document builds on our previous report, Including People with Developmental Disabilities as a Priority Group in Canada's COVID-19 Vaccination Program: Key Considerations, by presenting updated evidence on the impacts of the COVID-19 pandemic on people with developmental disabilities and the urgent need to prioritize this group for vaccination. The purpose of this report is to examine Canada's vaccine rollout strategy, identify gaps in distribution and administration of vaccines to this group, and delve further into developing an equitable vaccination strategy specific to the people with developmental disabilities.

COVID-19 Related Morbidity and Mortality and Impacts of Pandemic Restrictions on Developmental Disabilities: Updates to the Evidence-Base

Since releasing our January 2021 report in which we discuss mortality risks and the impacts of pandemic restrictions on the health of people with developmental disabilities, further evidence has emerged. Two large-scale studies were published on mortality: the National Office of Statistics in the UK[1] reported that men and women with intellectual disabilities were 3.7 times more likely to die than other adults, in both the first and second waves of the pandemic. One of the strongest predictors of mortality was living in a congregate setting, and even after adjusting for a host of clinical and demographic variables, death was 1.7 times as common; a US-based study published in the New England Journal of Medicine Catalyst reported that having an intellectual disability was the strongest predictor of mortality in a large national cohort of adults, besides age.[2] One key contributor to mortality was the high prevalence of comorbid conditions amongst this population. Additional research has also been published regarding unique risks of COVID-19 to people with Down syndrome based on an international cohort.[3] A summary of issues on COVID-19 and Down syndrome, including important information with regard to vaccinations can be found here.

With regard to the impact of pandemic restrictions, two Canadian studies were published on challenges accessing health care,[4] and impacts on mental health according to adults with developmental disabilities.[5] In addition, a large study from the UK[6] included 621 adults with intellectual disabilities and 378 family caregivers or paid staff and found that less than 50% had seen their doctor since lockdown started and more were feeling lonely, as activities, jobs, and other social opportunities were limited with the pandemic restrictions. Two thirds of adults had felt angry or frustrated, sad or down, and worried or anxious at least some of the time in the four weeks before they were interviewed. Carers reported that their health had been affected by their caring role in the four weeks prior, most commonly disturbed sleep (57%), feeling tired (64%) and feeling stressed (65%).

As our understanding evolves, it is becoming increasingly evident that age is not the sole determinant of poor COVID-19 outcomes; disability status, place of residence and comorbid health

conditions are also powerful determinants for who is most at risk for contracting COVID-19, being hospitalized, and dying. Furthermore, pandemic restrictions have disproportionate impacts on certain marginalized individuals. International research clearly indicates that adults with developmental disabilities are a very high-risk group and should be prioritized for vaccination.

2. Key Messages

1. There is increasingly strong evidence that all people with developmental disabilities need to be prioritized for the vaccine. However, we need clear and inclusive language to ensure no one is left behind based on residence, diagnosis, access to care, or severity of disability.
2. Provinces and territories should adapt existing processes and provide more specialized services to improve the overall accessibility to the vaccination process, including access to information, booking processes, and vaccination clinics.
3. Public health units should provide targeted support/programs to reach people with developmental disabilities and engage with the different sectors/agencies serving them.
4. Home and mobile clinics are necessary to reach people with developmental disabilities who might not otherwise be able to access public vaccination clinics or smaller, more specialized clinics.

3. Adapting Canada's COVID-19 Vaccination Program

Throughout the pandemic, global policy responses[7], including Canada's,[8] have largely overlooked people with disabilities, with advocates calling for a disability lens to be applied to policy-making.[9] Vaccination plans continue to highlight how people with disabilities are often forgotten in Canada's health care system, and the severity of this negligence has even led to a Charter of Rights challenge over equity in Ontario's vaccine rollout.[11,12] Similar disputes over vaccine-related equity challenges for adults with Down syndrome have arisen in Manitoba,[13] along with a Human Rights complaint in British Columbia.[14] Evidently, Canada must position equity as a driving force in public health policies, one in which produces equitable response, ensuring that information and vaccination environments are accessible to people with disabilities.

In this report, we make five key recommendations to ensure equitable and accessible access to the COVID-19 vaccine for people with developmental disabilities. Implementing these recommendations requires the cooperation and collaboration of all health and social service sectors, particularly the organizations that support people with developmental disabilities:

1. **Explicit vaccine prioritization language**: vaccine rollout programs/policies must include adults with developmental disabilities explicitly and should not select subgroups based only on residence, diagnosis or severity of their disability;
2. **Accessible information**: ensuring people with developmental disabilities and those who support them have access to accessible information about the COVID-19 vaccine;
3. **Accessible booking process**: provide resources and assign staff to support the vaccination booking process;
4. **Accessible vaccination clinics**: adapt the physical and sensory environment of vaccine clinics;
5. **Targeted vaccination clinics**: Offer specialized clinics and also make mobile and home vaccinations available.

1. Explicit Vaccine Prioritization Language: The Need for Clear Policy Definitions

Across the country, there are discrepancies in the definitions used to classify individuals with developmental disabilities when they are included within high-risk condition groups. These inconsistencies in definitions across the country can lead to confusion concerning vaccination prioritization and may wrongfully exclude certain people. To mitigate the implications of unclear and inconsistent definitions, vaccination rollout plans should explicitly state adults with developmental disabilities' without adding a degree of severity to the defining term. In addition, vaccine prioritization language should <u>not</u> select subgroups based only on residence, diagnosis or severity of disability. Proof of disability should also be avoided. There are different ways disability is determined ranging from self-report, to documentation from health care providers, to notification from the health provider or health system, or being a recipient of a certain category of disability services. "Proving" a diagnosis can be an additional barrier for certain individuals.

At the time of finalizing this report, Ontario's [15] vaccination plan uses the term "individuals with high-risk conditions" and classifies "intellectual and developmental disabilities" as a high-risk category in Phase 2 of the plan. In contrast, British Columbia's[16] Phase 3 plan identifies "people who are clinically extremely vulnerable" and lists "adults with very significant developmental disabilities that increase risk", with eligibility based on service receipt. Similar phrasing is used in Saskatchewan, Prince Edward Island and in Newfoundland and Labrador. However, Newfoundland and Labrador[17] operationalized this group with further limiting language, stating "adults with very significant developmental disabilities who cannot perform most activities of daily living (e.g. dressing, grooming, toileting, feeding, etc.)". Alberta,[18] in their Stage 2B (high-risk conditions) identifies "people with severe or profound learning disabilities or severe developmental delay", including individuals with Down syndrome, fetal alcohol spectrum disorder, cerebral palsy, autism spectrum disorder and others. Some of the syndromes listed include a range of cognitive functioning (not just severe developmental delay) leaving it unclear whether individuals with mild to moderate intellectual disability qualify. As a priority item, vaccine prioritization language must be consistent across the country and must explicitly include all adults with developmental disabilities, not just select subgroups.

2. Accessible Information and Conversations

Accessible information is necessary to develop an understanding of public health emergencies amongst people with disabilities, and ultimately, to protect these marginalized groups.[19,20] Providing accessible health information specifically tailored to people with developmental disabilities can promote protective practices and increase participation in health-related behaviours.[21-26] Thus, to ensure health equity for all, public health communications, messaging, and technologies must be accessible to all populations,[27] by considering the unique circumstances of people with developmental disabilities.

In order for people to make informed decisions about vaccinations, communication strategies must adhere to accessibility standards; both to help individuals with developmental disabilities understand the material, and to help caregivers to more easily explain this information to them. The failure to develop and communicate accessible vaccine information increases fear and creates significant barriers for adults with developmental disabilities to protect themselves from the virus.

An inclusive disability approach requires public health authorities to both disseminate and ensure equitable access to public health messaging, such as easy read information on the importance of being vaccinated, how to register for a vaccination appointment, and how to access support to assist with the vaccination process. Vaccine information must use clear, jargon-free language that is specifically tailored to meet the health information needs for people with developmental disabilities.[26,28]

There are several strategies and resources available to create more accessible and effective COVID-19 vaccine information, including: [21, 23, 24, 25, 26, 27, 28, 29]

- Simplified language/"easy read" formats;
- Use of photos with text to illustrate concepts and ideas;
- Audio and video formats for non-readers;
- Braille and American Sign Language (ASL) translations;
- Closed captioning for videos, public service announcements, etc.
- Narrative health information/story-telling;
- Relay services (to support communication by phone between hearing people and people who are deaf, deafened, hard of hearing, or those with speech disabilities. Professionally trained operators act as intermediaries to facilitate the call);[30]
- Enhanced colour contrast of text (i.e., use of colour contrast analyzer tools), readable font style, large font size;
- Compatibility with assistive technologies (I.e., text-to-speech reading software) and compliance with Web Content Accessibility Guidelines (WCAG 2.1).

Participatory approaches must guide the development of public health information resources. This requires working in direct consultation and collaboration with adults with developmental disabilities to create vaccine-related resources, while ensuring accessibility, inclusivity, and universal design are guiding principles.[29]

Accessibility can also be supported by encouraging educational conversations about vaccines between healthcare providers and people with developmental disabilities, and offering tools and resources to support these conversations. For instance, individuals who are concerned about vaccination need guidance to explain issues, answer questions, and foster vaccine confidence. Knowing reasons behind vaccine reluctance is crucial. For example, some individuals may not get vaccinated because they cannot navigate the process. Some may be frightened of needles, while others may be concerned about going into a public setting that is unfamiliar and stressful to them, especially after so much time in isolation. Others may have concerns about vaccine side effects and risks to immunocompromised individuals. The Health Care Access Research and Developmental Disabilities Program (H-CARDD)[31] has worked together with self-advocates to learn about common concerns and develop resources to address them, including easy read tools, and an informational video available here.

H-CARDD has also worked with the Surrey Place Developmental Disability Primary Care Program[32] to develop resources for families.[33] Accessible information and communication strategies should also apply to family members and other caregivers that support people with developmental disabilities.[27,34] Often, people with developmental disabilities have limited health literacy, thus they may depend on the support of caregivers and health care providers.[22] Moreover, it is important to consider the unique concerns and information needs of families of people with developmental disabilities, based on their knowledge of their loved one's health history, as well as the unique needs of the many workers in the sector who provide essential in-person care.[33]

It is crucial that there be rapid ways to exchange information and ideas on how to help with this decision-making across the country, and that unique concerns in different cultural and regional groups also be identified and addressed.

3. Accessible Vaccine Booking Process

The Need for Intersectoral Collaboration

To achieve accessible and equitable access to vaccines for people with developmental disabilities, governments will need to embrace intersectoral collaboration and communication. Intersectoral collaboration helps meet the needs of an individual's current, emerging, and future needs by engaging health and other government sectors, along with organizations from the private, voluntary, and non-profit sectors.[37,38,39] These collaborative efforts across organizations strive to improve the health and well-being of specific populations.[38,39] Moreover, intersectoral collaboration can strengthen vaccination scenario planning, which requires the engagement of the various organizations that support people with disabilities to ensure that their needs are both considered and attended to.[35-38] By collaborating and communicating across sectors, the unique circumstance to this population can be identified and appropriate responses can be developed accordingly. Together, the sectors can forecast the number of individuals and design accessible solutions to registering for and distributing vaccines.

Recommendations for Booking and Preparing for Vaccination

To streamline this process for individuals with developmental disabilities and provide the necessary support and accommodations, intersectoral collaboration is needed between regional public health units and the organizations who regularly interact with this population. Organizations who actively engage in the developmental services sector play an important role in contacting eligible individuals and arranging support for them. Intersectoral collaboration leverages the expertise that already exists across different groups and organizations. Such organizations already have prior experience navigating COVID-19 testing for this population, not to mention rolling out seasonal flu vaccination with this group. As well, many have developed strong relationships with local public health units and primary care providers. These organizations, working together with self-advocates and families, understand the needs of people with developmental disabilities and can provide recommendations on how to reduce vaccine hesitancy and improve access.

Recommendations include:

- Clear communication on vaccination procedures (how, when, where) and helping people know what to expect at the appointment so they can prepare (e.g., social stories, videos);
- Appointment booking support for different environments (group homes, independent living, assisted living, living with family), including someone to speak with who is familiar with disability issues if there are challenges encountered with standard online booking processes, and a way to book a group of individuals at one time from the same household;
- Ensuring that staff booking appointments by telephone understand eligibility requirements and can support someone with a developmental disability to book an appointment or direct them to someone who can address their unique concerns;
- Involve both public and private organizations to support vaccination processes when there are barriers;
- Offer alternative vaccination options for people whose needs cannot be easily accommodated in existing clinics.

When developing policy responses to public health emergencies, it is critical to apply the best available evidence quickly and proactively. While circumstances vary between the two groups, the

COVID immunization rollout for older adults offers lessons learned and reveals strategies to inform immunization programmes for adults with developmental disabilities. For instance, Toronto-based initiatives include mapping of naturally occurring retirement communities to launch mobile vaccination sites,[41,42] and Toronto Public Library staff assisting older adults to sign up for their vaccine via telephone calls.[43,44] In addition, the City has launched a program to arrange accessible transportation[56] for people who cannot get to vaccination sites. Individuals in older age cohorts have encountered a number of barriers, including lack of Internet access, difficulty navigating online sites and phone lines, living in isolation and not having the appropriate supports, limited time slots, mobility restrictions and getting transportation to and from vaccine clinics, as well as way-finding at the sites themselves.[45,46,47] By recognizing and addressing these challenges, public health units can prevent the same issues from arising amongst other at-risk groups, such as adults with developmental disabilities.

It is also important that people whom the individual is reliant upon for care have the option to receive the vaccine simultaneously so they can continue with their caring duties. This includes situations where more than one person with a disability is from the same household. Distribution plans should explicitly name these essential paid workers and family caregivers in their plans and booking systems should facilitate/accommodate these situations.

4. Adapting Vaccination Clinics

To ensure adults with developmental disabilities have equitable access to the COVID-19 vaccine, there must be adaptations made to general vaccine clinics. Canada's vaccination program should consider the following adaptations: [48-53]

- Vaccine clinics must be accessible (e.g., parking, drop off points, clear signage, ramps, lifts, doors, lighting and noise);
- Availability of vaccine administrators and staff with experience and/or training on providing care to people with developmental disabilities;
- Modifications to time of day, wait time, and length of immunization session should be permitted;
- Allowance for a support person (or in some cases two support people) and/or animal to be present;
- Flexibility in mask requirements for certain individuals (it can be hard for some people to change their mask upon entry, and hard for others to wear a mask at all);
- Designated time slots during which rules are more flexible, and fewer people are present, with support from specialized staff;
- Additional aids and activities available to soothe or distract the person who needs such supports to participate;
- The option to carry out the 15 minute wait following the vaccine in a different way (e.g., in a waiting area where one can move about while observed);
- Specialized clinics should be an alternative for those who require additional accommodations.

5. Equitable Vaccine Access Requires Tailored Vaccination Clinics and Home Vaccination

Consistent with our earlier report, the location and set-up of vaccination sites is an important element in ensuring equitable access for people with developmental disabilities. Although some individuals will be able to travel to and attend mainstream vaccine clinics, there are many individuals who will not, due to challenges with adopting public health measures (e.g., wearing a mask, maintaining physical distance), mobility issues, lack of access to transportation, or extreme anxiety in unfamiliar/noisy settings. Thus, local public health units, in collaboration with developmental disability organizations, must provide accessible vaccination locations for people who cannot manage at the larger vaccination sites. In keeping with federal guidance on accessibility of health care for people with disabilities during COVID-19 and strategies to adapt COVID-19 testing procedures,[54] similar efforts are required to ensure that vaccination clinics and processes are accessible. This will include specialized sites,[55] which are more familiar and/or private, or drive-in locations where the individual does not have to leave their vehicle. Targeted vaccine locations can be selected by mapping areas,[41] similar to what has been done with older adults in Toronto. For those individuals who cannot go to a specialized or drive-in vaccination clinic or to a familiar setting like their family doctor's office, in-home vaccination should be made available.

4. Conclusion

The evidence is clear that people with developmental disabilities are a high-risk group and should be prioritized in Canada's vaccination planning. To date, there have been limited considerations to ensure people with developmental disabilities are fully included, either because of burdens of proof, qualifiers on disability status, residence, and/or inaccessible environments and information. Governments need to make concerted efforts to include this at-risk population, especially as many people with developmental disabilities become eligible for their shot across the country in the coming weeks.

To make sure the vaccine rollout is fully accessible to this group, it requires planning and collaboration with a disability lens approach. This involves not only meeting basic accessibility standards, but also being adaptable, responsive, and active in reaching people with developmental disabilities to ensure they can book appointments and be vaccinated in ways and places that are most accessible to these individuals.

Canada's pandemic response has often overlooked the rights and needs of people with developmental disabilities. Failing to prepare for accessible, appropriate, and timely vaccination will ultimately result in preventable morbidity and mortality for people with developmental disabilities. Therefore, governments have a moral and legal obligation to improve their vaccination plans to meet the needs of this at-risk population.

For more information on topics covered in this report:

Two organizations are tracking and monitoring Canadian vaccine distribution policies for people with developmental disabilities:

- Inclusion Canada
- Ready for My Shot

Other Canadian resources to support vaccination for people with developmental disabilities:

- H-CARDD COVID webpage
- Surrey Place Developmental Disability Primary Care Program

Case examples of specialized vaccination clinics for people with developmental disabilities:

In Canada:

- KW Habilitation Pop Up Clinic, Ontario, Canada
- Ongwanada Clinic, Ontario, Canada

In UK:

- Primary Care Wirral, UK
- James Paget NHS Clinic, UK
- Midlands clinics, UK
- Central Liverpool GP Network

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