Disability Related Barriers to COVID-19 Vaccines:

# Highlights From the COVID-19 Vaccination Accessibility Survey 2021

**June 2022**

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**This Report is available in French translation.**

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# Information icon in a navy background with the letter i in white in the middle. Executive Summary

In June 2021, Independent Living Canada and ARCH Disability Law Centre launched a survey asking about COVID-19 vaccination hesitancy and barriers to getting the vaccination. This report provides an overview of all data gathered in the survey.

Five hundred and ninety-two (592) respondents living with a disability responded to the survey, from every province and territory except Nunavut.

Eighty-nine percent (89%) of all respondents reported having received at least one dose of a COVID-19 vaccine prior to completing the survey (527 respondents - the “Vaccinated” group). Eleven percent (11%) of all respondents reported not having received a COVID-19 vaccination at the time they completed the survey (65 respondents - the “Not Vaccinated” group).

Sixty-two percent (62%) of all respondents have more than one disability (368 respondents) and 69% of respondents who answered this question reported feeling the impact of their disability “most” or “all” of the time (404 respondents). The most common disabilities reported include mobility, pain, mental health/depression/anxiety, and a chronic condition such as diabetes, heart, or lung disease, while other disabilities represented include agility/flexibility/dexterity, brain injury, communication, developmental, environmental sensitivity, hearing, learning, memory/focusing/ concentration, and seeing. More than half (approximately 58%) of the 520 respondents who answered this question identify with at least one other equity-seeking group. The other equity-seeking groups include low income (60% of the 303 respondents who identified with another equity-seeking group), Indigenous (7%), LGBTQ2S+ (23%), cultural (14%) or language minority (11%), racialized (8%), immigrant/ refugee/migrant (8%).

Demographic information from all respondents shows that most identify as female (63%) or male (24%), with a small number reporting their gender as non-binary/nonbinary, transgender, gender queer, or gender fluid, while some respondents preferred not to answer. Approximately two-thirds (68%) of all respondents who answered this question are under 60 years of age. One-third (34%) who answered this question live alone in a privately owned or rented home, while most of the remaining respondents live with others (in a privately owned or rented home, or a congregate facility or group home). The highest numbers of respondents report living in Ontario, British Columbia, Quebec, and Alberta, with 92% of respondents who provided a postal code classified as living in urban areas.

## Concerns raised by Participants

Concerns with COVID-19 vaccinations were reported by those in both the Vaccinated and Not Vaccinated groups in relation to:

* mandatory requirements;
* safety and efficacy of vaccines;
* possible short and longer-term side effects, especially regarding chronic conditions;
* allergic reactions to vaccines;
* travel to, and accessibility of, vaccination/clinic sites;
* interactions with other medications;
* additional expenses; and
* and intimidation of others.

## Accessibility Barriers

Accessibility challenges or barriers were identified in relation to:

* Information about vaccinations:
* access to information on government websites and elsewhere;
* alternate formats such as ASL/Braille or electronic format not available, and clarity of available information to designated priority groups;
* booking appointments;
* transportation and travel to appointments;
* availability of support persons; and
* vaccination sites – location, barriers, wait times, vaccination consent forms; and expenses, mostly related to transportation.

Vaccination hesitancy was reported by some respondents in the “Not Vaccinated” group, while others had been advised not to get the vaccination due to their underlying health conditions.

Please note that select detailed responses to survey questions are available throughout this report.

This report identifies several recommended areas of improvement based on the survey responses:

* increased disability and rights awareness;
* enhanced support;
* enhanced information accessibility;
* disability-informed policies and booking systems;
* increased accessible transportation;
* accessible vaccination/ clinic sites; and
* further medical research.

IL Canada and ARCH Disability Law Centre extend thanks to all who participated in the survey for enhancing our knowledge and awareness of accessibility issues in Canada in relation to COVID-19 information, vaccines, and vaccinations.

# Introduction

It is indisputable that persons with disabilities have been disproportionately impacted by the COVID-19 pandemic, and by the corresponding policy and legal responses attempting to contain it.[[1]](#footnote-1) The impacts on persons with disabilities, and those with intersecting identities with other marginalized and equity-seeking groups, have been as complex as they have been devastating. This health crisis has impacted and isolated persons with disabilities differently and profoundly, in a variety of ways. One of the most significant failures since the onset of this pandemic has been the lack of disability-informed legal and policy responses. These responses have had wide-ranging impacts, including restrictions on access to communication supports and other accommodations in hospitals which are vital to accessing health care, and an exacerbation of isolation with restrictive bans denying persons with disabilities living in congregate care access to their family, friends, and other supports.

With the approval of vaccines as the most significant development throughout the pandemic, persons with disabilities have been, once again, challenged to fight for their own prioritization and access to vaccines, and for the removal of barriers and inaccessibility. In response to the countless complaints to Independent Living Canada (IL Canada) and ARCH Disability Law Centre (ARCH) regarding access to vaccines and lack of accessibility, and because vaccinations will continue to be an important ongoing response to the pandemic, our organizations launched a survey in June 2021 to better understand the experiences of persons with disabilities across Canada. In particular, the survey asked about COVID-19 vaccination hesitancy and barriers to getting the vaccination.

This report highlights some of the key findings from the 2021 survey.

In 2020, IL Canada conducted a survey of people with disabilities, staff, and volunteers of the 24 Independent Living Centres across Canada, exploring the concerns of respondents regarding the risk and impacts of COVID-19 infection. Results from this survey, available on the IL Canada website[[2]](#footnote-2), further encouraged IL Canada to collaborate with ARCH Disability Law Centre to conduct the 2021 survey.

This report reviews and offers the information respondents shared with us so that we can all learn from these experiences. IL Canada and ARCH hope that, by facilitating expression of some of the respondents’ experiences and concerns, we can help to encourage government and other bodies to implement needed changes and continue to bring improvements in accessibility of information and access to COVID-19 vaccinations for people living with disabilities across Canada.

We sincerely thank every individual who took the time to complete the survey, and for sharing some of their experiences with us. We know that there are challenges for people with disabilities in relation to accessibility of information about COVID-19, and to accessibility of vaccinations. The shared experiences and perspectives collected through this survey will be an important resource for efforts to improve accessibility in this regard.

## Illustrated icon of a clipboard.Methodology

During the summer of 2021, the survey was distributed as an online link through partner organizations of IL Canada and ARCH, and was available on the IL Canada and ARCH websites. The online survey stayed active for several months, into the early fall.

## Technical Notes

The survey data are not representative of the general population.

This report will highlight some interesting information from the survey responses of two groups - those who had, and those who had not, received at least one dose of a COVID-19 vaccine at the time they completed the survey (with the groups identified as “Vaccinated”, and “Not Vaccinated”, respectively). A small number of those who had not received a vaccination indicated that, at the time they completed the survey, they had a vaccination appointment scheduled.

“COVID-19 vaccine” may have included any of the available vaccine options available at the time respondents completed the survey and are referred to as “the vaccine” (or “vaccination”) for the purposes of this report.

Within the survey, there were various skip patterns for respondents who answered “yes” or “no” to certain questions, and therefore, not every question was asked of both groups (Vaccinated or Not Vaccinated). The Overview section of this report pertains to all respondents, reviewing information from both the Vaccinated and Not Vaccinated groups, while two other sections review the Vaccinated and the Not Vaccinated groups separately. Not all respondents answered each question asked of their group. Percentages are calculated using the number who did answer the question rather than the total number of respondents included in the survey data or those in either of the groups. Where appropriate, percentages are calculated using the total number of respondents included in the survey data (n=592), the total in the Vaccinated group (n=527), or the total in the Not Vaccinated group (n=65), as applicable.

Canada Post identifies “rural” postal codes as those with the number “0” as the second character of the postal code. This is the basis upon which we classified postal codes to determine if respondents live in “rural” or “urban” settings.[[3]](#footnote-3)

We have added many direct quotations from respondents, in their own words, to allow their perspectives to be shared (with minor editing for clarity in spelling and grammar). Sections of quotations [in square brackets] indicate an edited section for clarification or to ensure anonymity of respondents. We would like to emphasize that the responses by respondents may or may not be factual but represent their own belief and understanding.

# Overview

**682 responses were received from across Canada, with representation from each of the provinces and territories – except Nunavut.**

We asked only those living with a disability to complete the survey and to let us know if they had received at least one dose of a COVID-19 vaccination, or not. Only those respondents who self-identified as living with a disability are included in this report. Ninety (90) people who opened the survey were excluded as they indicated they were not a person living with a disability.

| **Vaccinated**  **89%**  **of survey respondents had received at least one dose of a COVID-19 vaccine at the time they completed the survey**  **(527 respondents).** | **Not Vaccinated**  **11%**  **of survey respondents had not received at least one dose of a COVID-19 vaccine at the time they completed the survey**  **(65 respondents).** |
| --- | --- |

**592 responses from those who declared a disability are included in the survey data (referred to as “respondents”).**

We asked respondents who had received at least one dose of a COVID-19 vaccine (the Vaccinated group) to tell us about their experiences, including any barriers they encountered when scheduling an appointment to get a vaccination, getting to the vaccination clinic/site, or receiving the vaccination. We asked all respondents to share their concerns regarding COVID-19 vaccines in relation to their disability/disabilities, and to identify some of the reasons why they had not received a vaccination if that was the case (for those in the Not Vaccinated group).

The survey questions that were asked of both groups include:

* Demographic information (age, gender, geographic location);
* Nature and impact of disability/disabilities; and
* Concerns about the COVID-19 vaccines.

## Demographics

Survey questions about some basic demographic information were asked of all respondents, and this section provides those details for both groups.

### Gender

IL Canada and ARCH respect the feedback given by some respondents on the survey question asking about gender and acknowledge that the response options given may have been inappropriately polarized. To the extent that these responses can be categorized without identifying individuals, we note that the largest numbers of respondents self-identified as female (63%) or male (24%). Other respondents reported a gender identification not specifically male or female - for example, non-binary/nonbinary, transgender, gender queer, or gender fluid, and some respondents preferred not to answer this question.

### Age

Of those in the Vaccinated group who responded to the question regarding age, the median age group was in the 50’s range, while for those in the Not Vaccinated group, it was in the 40’s. This means that half of the respondents in each group fell in this age range or younger, and the other half fell in this age range or older. Just over two-thirds (68%) of respondents who answered this question were under 60 years of age.

### Equity-seeking Group in addition to Disability

We asked respondents to let us know if they identify with any other equity-seeking group(s), in addition to their stated disability/disabilities. A total of 520 respondents answered this question (461 in the Vaccinated group and 59 in the Not Vaccinated group). Of those who answered this question, many do not identify with another equity-seeking group (approximately 42%, or 217 respondents). However, the majority, 303 respondents, reported that they do identify with at least one other equity-seeking group (258 respondents in the Vaccinated group and 45 respondents in the Not Vaccinated group).

Overall, 58% of respondents who answered this question self-identify with at least one other equity-seeking group. More specifically, this is 56% of those in the Vaccinated group and 76% of those in the Not Vaccinated group who do identify with another equity-seeking group.

Overall, amongst the 303 respondents who do identify with another equity-seeking group, the largest group is “low income” with 60% of these respondents identifying with this group. More specifically, 57% of the Vaccinated group and 73% of the Not Vaccinated group identify with “low income”. The other equity-seeking groups identified include Indigenous (7%), LGBTQ2S+ (23%), cultural (14%) or language minority (11%), racialized (8%), and immigrant/refugee/migrant (8%). Further exploration on the impacts of intersecting identities is warranted, particularly amongst those in the Not Vaccinated group, given the compounding and complex impacts and barriers that arise while living in a “low income” bracket, and/or identifying as part of other marginalized groups.

### Living Arrangements

In both the Vaccinated and Not Vaccinated groups, approximately one-third of those who answered this question live alone in a privately owned or rented home, while most of the remaining respondents live with others (in a privately owned or rented home, or a congregate facility or group home). A small number of respondents identified as “homeless” and some preferred not to answer this question. Thirty-four percent (34%) of all respondents who answered this question reported living alone in a privately owned or rented home (155 respondents in Vaccinated group and 20 respondents in Not Vaccinated group), while 55% who answered reported living with others in a privately owned or rented home (256 respondents in Vaccinated group and 32 respondents in Not Vaccinated group). Less than 5% of all respondents reported living with others in a congregate facility or group home. Of the 9% of respondents who answered this question and indicated “other” as their living arrangement, most reported living with roommate(s) or family (parent(s), spouse, child(ren)). It is notable that a few respondents indicated that their current living arrangements are temporary (mostly due to being ill themselves, or caring for a parent or a child, in relation to COVID-19 complications).

## Geographic Location

Province/Territory: Survey respondents live in all provinces/territories of Canada except for Nunavut, with the highest number of respondents located in Ontario, and the second highest number in British Columbia. Thirteen percent (13%) of all respondents are located in British Columbia, 14% in Alberta/Saskatchewan/Manitoba, 45% in Ontario/Quebec, and 20% in Nova Scotia/New Brunswick/Prince Edward Island/Newfoundland and Labrador. Eight percent (8%, or 45 respondents) did not indicate a response to this question.

Rural vs. Urban: Seventy-four percent (74%) of all respondents provided a postal code (438 of the 592 respondents). Of those respondents who provided a postal code, 92% are classified by Canada Post as living in an “urban” area of Canada, with the other 8% classified as living in a “rural” area, based on their postal code. However, 26% of all respondents did not provide their postal code which means we cannot classify them as living in an “urban” or “rural” part of Canada. We know that rural areas can present additional challenges and barriers, especially for those living with disabilities, and we are interested in further exploration of the relationship of living with a disability in a rural area of Canada and the access and accessibility to information and COVID-19 vaccines.

## Nature and Impact of Disability

**61% of the Vaccinated group reported having more than one disability, and the following table shows the highest reported categories of disability by respondents in the Vaccinated group, along with the prevalence in reported disabilities.**

| **Mobility (47%)** | **Pain (31%)** | **Mental Health, Depression or Anxiety (30%)** |
| --- | --- | --- |
| **These three categories account for**  **42% of all responses** | | |

We can see that almost half of those in the Vaccinated group are living with a mobility challenge (47%); and about one-third experience pain (31%) and/or mental health, depression or anxiety (30%). These three types of disability account for almost half of all responses in the Vaccinated group. Respondents could choose multiple responses, as the reality is that most (61%) of those in the Vaccinated group are living with more than one disability (319 respondents). The impact of these disabilities was noted as limiting everyday activities “most” or “all” of the time for 68% of those in the Vaccinated group.

**75% of the Not Vaccinated group reported having more than one disability.**

|  |  |  |
| --- | --- | --- |
| **Pain (46%)** | **Chronic Condition (43%)** | **Mental Health, Depression or Anxiety (43%)** |
| **These three categories account for**  **39% of all responses** | | |

Eighty-three percent (83%) of respondents who had not received at least one dose of a COVID-19 vaccine at the time they completed the survey indicated that their disability impacts them “most” or “all” of the time.

The most reported types of disabilities for all respondents include mobility, pain, chronic condition, and mental health/ depression/ anxiety, although other disabilities were also mentioned by various respondents, including agility/ flexibility/ dexterity, brain injury, communication, developmental, environmental sensitivity, hearing, seeing, learning, and memory/ focusing/ concentration.



## RECOMMENDED AREA OF IMPROVEMENT: Disability and Human Rights Awareness

There can be multiple complicating factors inhibiting people with disabilities from receiving a COVID-19 vaccination. We can begin to piece together stories from some of the survey respondents, showing how there is not usually only “one” complicating factor for them in relation to getting a COVID-19 vaccination.

Sixty-two percent (62%) of all respondents in this survey indicated they have more than one disability, and 69% of those who answered this question reported feeling the impact of their disability/disabilities most or all the time. There can be compounded impacts of geographic location (urban vs. rural), living alone/no support worker, poverty/financial hardship, nature/impact of disability, and any other combination of realities faced by those living with disabilities in Canada. It is important not to view people who live with disabilities as the sum of their individual characteristics. Combined impacts of a variety of circumstances can result in complex realities that make navigating information about, and access to, COVID-19 vaccinations very difficult.

Our organizations, IL Canada and ARCH, and others work to support and advocate on behalf of, those with disabilities living in Canada, regardless of their individual choices regarding COVID-19 vaccinations, or any other matter. The work of individuals and organizations like ours needs continued support to ensure that awareness about the complexities of life for those living with a disability is factored into such things as public health responses to pandemics such as COVID-19, and to ensure that accessibility challenges do not interfere with ensuring human rights are recognized and protected for individuals living with a disability.

## Concerns about COVID-19 Vaccinations

### Vaccinated Group

***“I have severe pain and allodynia in both arms, and unfortunately the vaccines are only approved for injection into the deltoid muscles. I was also worried about having a flare-up of my chronic conditions. Indeed, both of these occurred, but I still had both doses of the vaccine.”***

***“Blood clots as I have a history and was only offered Astra Zeneca when I was first eligible, despite my concerns.”***

**39% of respondents in the Vaccinated group reported that they had concerns about getting a COVID-19 vaccination (205 respondents).**

Concerns ranged from:

* “possible side effects” (72%)
* “allergic reactions” (37%)
* “accessibility of the vaccination site” (33%)
* “interactions with other medications” (31%)

Respondents were asked to indicate as many concerns as applicable. These top four concerns account for 72% of all responses to this question by those in the Vaccinated group. Additionally, respondents indicated concerns relating to intimidation from others, logistics of vaccination clinics (required travel, waiting in lines, parking, others not wearing masks), fear of needles, vaccine safety and efficacy, conflicting or lack of information or research on COVID-19 vaccines/virus, and side effects from their first dose.

For more examples of what respondents from the Vaccinated group indicated as their concerns, please go to pages 20 - 33 and 43 - 46.

### Not Vaccinated Group

***“As a person with an autoimmune disorder, I am extremely worried that I will experience negative physical effects. In the past (and recently), I have experienced extreme neurological tics, anxiety, and OCD, as well as disrupted sleep and difficulty with movement control. Reassuring me will not really help with the symptoms I have previously experienced, particularly as these symptoms have lasted typically longer than 18 months.”***

***“Lack of evidence on people with disabilities or autoimmune diseases– it would be nice to see what the effects are (short term and long term) on people with certain health conditions/disabilities in order to help with the anxiety and hesitancy about getting it.”***

In the Not Vaccinated group, some of the concerns about COVID-19 vaccines include the following:

* possible side effects (23% of respondents in this group);
* allergic reactions (14%);
* interactions with other medications (13%); and
* intimidation from others (8%).

These top four concerns account for 46% of all responses to this question for those in this group. No respondent in this group indicated a concern with “accessibility of the vaccination site”.

For more examples of what respondents from the Not Vaccinated group indicated as their concerns, please go to pages 34 – 38.

# Vaccinated Group

In the following section, we will outline information from the questions specifically directed to those in the group of respondents who had received at least one dose of a COVID-19 vaccine at the time they completed the survey (89% of all respondents living with a disability). We will then review the questions specific to the Not Vaccinated group–- those who had not received at least one dose of a COVID-19 vaccine at the time they completed the survey (11% of all respondents living with a disability).

## Illustrated icon of stethoscope.Info**rmation about COVID-19 Vaccines/Vaccinations**

Respondents in the Vaccinated group reported using a variety of sources to obtain information about COVID-19 vaccines or vaccinations, including the following:

| Government Website  63% | Internet  48% | Television  34% |
| --- | --- | --- |
| Social Media  34% | Radio  15% | Newspaper  14% |
| Doctor  29% | Pharmacist  16% | Service Provider  12% |
| Family  31% | Friend  21% | Other\*  11% |

\*Percentages in this table are of those who answered this question. Of those who indicated “other” (that they used another source for information), the responses indicated include non-profit organizations supporting those with disabilities (such as Empower: The Disability Resource Centre in Newfoundland and Labrador) or research and advocacy organizations specific to their disability (such as Muscular Dystrophy Canada). Some indicated they accessed scientific journals, or talked to those at their school or workplace, or called the government information line.

## Access to Information

While most respondents who answered this question indicated that they were able to get “all” (47%) or “some” (34%) of the information they needed about COVID-19 vaccines/vaccinations from their province’s/ territory’s website, it is notable that approximately 20% indicated “no”, that they had not been able to get the information they needed from the government website, or that they “did not try”. Of concern are situations where people do not get the information they are seeking, or do not bother trying due to the realities of living with a disability, the lack of information that appropriately reflects or considers disability, or the inaccessibility of the information.

## Alternate Format of Information

**17% of those in the Vaccinated group who answered this question indicated that they needed COVID-19 vaccine/vaccination information in an “alternate format” (84 respondents).**



## A green checkmark with a navy blue background. RECOMMENDED AREA OF IMPROVEMENT: Information

Respondents in this survey indicated a need for clearer and more precise information, in fully accessible formats (such as information provided through a government website for appointment booking, but also to enhance an individual’s knowledge regarding the COVID-19 virus and vaccination information). Almost one in five respondents in this survey reported not being able to navigate their province’s government website to find information about COVID-19 or the vaccines/vaccinations, or not even trying to find such information. While it is admirable that some do attempt to find information on their own, it is important that we recognize this is not possible for everyone, and further support is required. Sixteen percent (16%) of respondents reported needing this information in an alternate format, and almost half (43%) of those respondents reported that the alternate format was not available to them. Almost half of the survey respondents indicated that, when they could find information about when they would qualify for a COVID-19 vaccination, it was only somewhat clear, or not at all clear. We need to do a better job of ensuring that information is available and clear for those living with disabilities.

Respondents were asked if they required an “alternate format” to access information about COVID-19 vaccines/ vaccinations. Although most respondents who answered this question (83%, or 419 respondents) indicated that they did not need an alternate format, our attention is drawn to the fact that 84 respondents (17% of the Vaccinated group who answered this question) indicated that they did need an alternate format – and of these, 48 respondents (57% of those who needed an alternate format) were provided with the format they needed, while the remaining 36 respondents (43% of those who needed an alternate format) were not provided with the alternate format they needed. Of those who did need an alternate format, the top three most common formats needed include: “electronic” (32%), “easy to read and understand” (29%), and “large print” (26%). Other formats that respondents indicated they would need include audio, video, Braille, Language other than English or French, Closed Captioning, and American Sign Language.

## Clarity of Information

***“The government website contradicted the government’s media statements about vaccine availability, eligible demographics, and participating locations. Some of the media statements were also contradictory. The information on the government website contradicted the information on the hospital website. Necessary accessibility information was unavailable on both the hospital and government websites.”***

***“Did my disabilities make me eligible under ‘medical condition’ eligibility. Would I be able to access vaccines somewhere other than a mass vaccination centre.”***

Respondents were asked if they found the information on their government’s website “clear” about when they would qualify for a COVID-19 vaccination. While just over half of those who answered this question (53%) indicated that the information was “very clear” to them, most of the other half indicated it was “only somewhat clear” or “not at all clear” about when they would become eligible to receive a COVID-19 vaccination.

In relation to the lack of clarity regarding when they would qualify for a COVID-19 vaccination, respondents who answered this question and indicated it was “only somewhat clear” or “not at all clear” (47%, or 238 respondents), had a variety of things to say about “what information was missing”:

* Information not compatible with their screen reader;
* General information about COVID-19 vaccines was unclear (e.g., side effects);
* Unclear how to book a vaccination appointment;
* Eligibility information was not clear (where and when they would get a COVID-19 vaccination); and
* Accessibility of vaccination sites not specified.

For more examples of what respondents told us about clarity of information, please go to pages 43 – 46.

## A green checkmark with a navy blue background. RECOMMENDED AREA OF IMPROVEMENT: Policies

Fifteen percent (15%) of those in the Vaccinated group who answered this question indicated that they had been denied a vaccination appointment (74 respondents), and almost one in five of them (19%) did not know why this was the case. Some examples of reasons provided by those who reported not being able to get an appointment included that they were not medically eligible, were “not clinically vulnerable”, or there was a misunderstanding surrounding the letter of eligibility from home care. Even amongst those who had attended a vaccination appointment, 15% who indicated needing a support person to accompany them were not permitted to have that person be present with them throughout their appointment. We believe the survey data show that we need more inclusive, disability- informed, policies, and communication regarding same, for vaccine distribution and priority/eligibility by age, health condition, living arrangements, accessible booking systems and vaccination sites. The survey data support a concerning trend of failure to adhere to human rights obligations to accommodate persons with disabilities regardless of province or territory of residence.

## Designated Priority Groups

Fifty-six percent (56%) of those in the Vaccinated group who answered this question indicated that they believed they were a member of a designated priority group to receive a COVID-19 vaccination (260 respondents). Almost half (47%) of those who answered “yes” to this question indicated they were in a priority group due to “underlying health condition(s)” (121 respondents). Seventeen percent (17%) who answered “yes” to this question indicated that the priority group was related to age. Others thought the priority group was related to their living arrangement (7%) or employment (11%), or another reason (such as being Indigenous or living in a designated “hot spot”).

## Denied a Vaccination Appointment

***“Was told that I was not deemed clinically vulnerable [CV] (despite my medical history that shows otherwise), and the guidelines changed depending on whom I talked to when trying to make an appointment. Then GP refused to help me get letter to qualify me as CV.”***

***“Visual impairment was not acknowledged as a priority group although I was putting others who assist me at risk due to the necessity for being in close proximity in order to receive care/assistance.”***

15% of those in the Vaccinated group who answered this question reported that they had been denied a vaccination appointment at some point.

## A green checkmark with a navy blue background. RECOMMENDED AREA OF IMPROVEMENT: Booking Systems

Twenty-three percent (23%) of respondents in the Vaccinated group who answered this question were unable to book their appointment on their own – they needed assistance to do this, which was provided by family, friends, a support person, or a medical professional. Some respondents have reminded us that not everyone has access to such support. Most respondents who had received at least one dose of a COVID-19 vaccine at the time they completed the survey booked their appointment online, and over half (54%) of all in the Vaccinated group who answered this question had to try more than once to book their appointment. Not everyone has access to a computer, or the internet, and there can be technical issues with an online booking system. As noted elsewhere, alternate formats of information are required, but not always available. We need more accessible and efficient booking systems for vaccination appointments to ensure that this part of the process does not become more of a burden for those living with disabilities, acting as a discouragement for those who wish, or need, to receive a COVID-19 vaccination. Accessible booking systems are an important cornerstone in ensuring equal access to health care, such as the provision of COVID-19 vaccinations, for those living with disabilities in Canada.

As with many of the questions in this survey, it is heartening to learn that many respondents did not experience difficulties in accessing a vaccination appointment or information about COVID-19 vaccines. This is valuable information and helps us understand and highlight what is going well to support those with disabilities if it is their desire or a necessity to receive the vaccination. The flip side of the coin is also apparent, and responses that indicate difficulties with access help us learn more about that experience. For example, while 85% of respondents in the Vaccinated group who answered this question indicated that they had not ever been denied a vaccination appointment (412 respondents), 15% reported that they had been denied an appointment (74 respondents). Nineteen percent (19%) of those who answered this question and reported that they had been denied an appointment indicated that they did not know why they had been denied an appointment (14 respondents). Others listed some reasons why they thought they had been denied an appointment which many included: their age, their disability was not part of a designated priority group at that time, and no available appointments at that time. However, there were also various other reasons respondents reported for being denied a vaccination appointment.

## Booking Vaccination Appointments

Twenty-three percent (23%) of those in the Vaccinated group who answered this question indicated that they had someone help them book their appointment(s) (112 respondents), and 67% of those respondents indicated they were assisted by “family” or a “friend”. Respondents who needed help booking an appointment also relied upon their “service provider” (19%) or a health care provider, doctor, or pharmacist (12%).

The majority (66%) of respondents in the Vaccinated group indicated that their appointment was booked “online”, while 32% indicated their appointment had been booked by “telephone”.

**54% of those in the Vaccinated group who answered this question indicated that they had to make more than 1 try before they successfully booked a vaccination appointment (238 respondents).**

Compared to those respondents who were able to book their appointment on their first or second try, the 143 respondents who said it took them three or more tries to book their appointment were more likely to be 60 years or older, and more likely to experience limitation in their activity most or all of the time.

While many indicated it took only minutes to book a vaccination appointment, it is important to note that for some, it was a more difficult process – involving several tries (over 3 tries for almost 1 in 5 people) and anywhere from 1 to 5 or more hours before they successfully booked an appointment.

## Transportation and Travel to Vaccination Appointment(s)

***“I'm a motorized wheelchair user, don't drive, have chemical sensitivities and minimal income so cabs were inaccessible for me, and don't have many folks in my life who drive or can accommodate me in my wheelchair.”***

***“I could not get a ride from my co-habitant and did not feel safe taking a bus (due to COVID), so I needed to book a cab.”***



**Fifteen percent (15%) of those in the Vaccinated group who answered this question indicated that they had difficulty arranging for transportation to get them to the vaccination site.**

For more examples of what respondents told us about transportation and travel to vaccination appointments, please go to 43 – 46.

## A green checkmark with a navy blue background. RECOMMENDED AREA OF IMPROVEMENT: Transportation

Some survey respondents indicated that they were able to receive their vaccination at home. However, this was a very small number of those in the Vaccinated group. Some respondents indicated they had not known about this option, or perhaps it was not made available to them. The majority of those who received a vaccination had to travel to a vaccination site, where we know that, from respondents in this survey who did receive a vaccination, barriers exist. Survey respondents indicated that travel can be difficult for those with a disability, and sometimes accessible transportation is difficult to find, or is too expensive for those who have low income. Further exploration and consideration is needed for access to at-home vaccinations for those who need or want a COVID-19 vaccination and prefer, or need, to receive it at home due to disability. In addition, increased options for funded, accessible transportation, and more accessible and local vaccination sites, are needed to ensure those living with disabilities can have easier access to the vaccination.

## Travel

Eighteen percent (18%) of respondents in the Vaccinated group who answered this question reported that they had to travel out of town to get to the vaccination site. The number of kilometers to the site ranged from 5 to 75, with a median reported distance of approximately 30 kilometers.

## Support Person

Half (50%, or 239 respondents) of those in the Vaccinated group who answered this question needed someone to go with them to the vaccination site. Of those, 16% (38 respondents) had difficulty finding someone to go with them, and approximately 15% (35 respondents) were not able to have the person with them when they entered the vaccination site. As respondents indicated, they often needed a support person to attend the vaccination appointment with them due to lack of accessibility at the vaccination site. Luckily, of those who needed someone to accompany them, 85% were able to have that person with them when they entered the vaccination site. This is clearly a factor in the success of those who wanted or needed to get a vaccination and were able to accomplish that goal.

## Vaccination Sites

### **Location**

Respondents in this group who answered this question indicated that they had received their vaccination(s) at a “provincial/territorial health unit” (31%), a “mobile vaccination unit/pop-up site/drive through” (25%), a “pharmacy” (13%) or a “doctor’s office/walk-in clinic” (9%).



Less than 5% of those who had received at least one dose of a COVID-19 vaccine at the time they completed the survey indicated that they had received it at home. This represents a very small number of the 592 people who reported living with disabilities and completed this survey. Even fewer respondents indicated they had received a vaccination at a special clinic set up for people with disabilities. A small percentage (19%) indicated that another type of vaccination site was where they receieved their vaccination, with most of those respondents indicating the vaccination site was a clinic that had been set up by their city.

### **Barriers**

***“When I booked the appt, they were not clear how long I needed to be there & I needed that info for [accessible transportation service provider].”***

***“Location was not set up for wheelchairs. Ended up in a crammed and unsafe position. Also, the location took people in order of arrival instead of appointment time but didn’t bother to inform anyone of that*** ***unwritten policy. This meant that I needlessly froze outside in the wind trying to dodge panhandlers when I could have gone inside for the shot.”***

Twenty-six percent (26%) of those in the Vaccinated group who answered this question indicated that they had encountered barriers at the vaccination site (123 respondents), including: “no accessible parking spaces or not enough accessible parking spaces” (18% of those who encountered barriers), “no ASL interpreter available” (16%) and “noise problems – had difficulty hearing instructions, etc.” (16%). Other barriers mentioned included:

* No ramp or not enough ramps;
* No accessible washroom on site;
* Unable to speak in the language of my choice;
* Not enough signs;
* Size of print on signs too small;
* Written material not in plain language (or Braille); and
* Lack of seating/too much standing required.

For more examples of what respondents told us about barriers at the vaccination sites, please go to pages 43 – 46.

### **Wait Time**

In addition to finding information about the vaccine/vaccinations, getting an appointment booked, finding a way there and someone to go with, and overcoming any barriers encountered at the actual physical vaccination site, respondents were also asked about wait times at the clinic. Wait times can prove to be a significant barrier for some people. Of those in the Vaccinated group who answered this question, 79% indicated it was not a long wait. However, 21% (102 respondents) did find it to be a long wait at the vaccination site/clinic. Of those, 79% (81 respondents) reported that they found the wait “somewhat” or “very” difficult.

Vaccine/Vaccination Information and Consent Form Respondents were asked how they felt about information they had received about the vaccine/vaccination, including a consent form. Eighty-nine percent (89%) of those who answered this question indicated that they understood the information and felt it was enough for them to agree to have the vaccination (425 respondents). As with a few other areas covered in the survey, it is good to know that there have been some positive experiences in relation to the vaccination for some people living with disabilities. It is clear that some things work well, and we should keep ensuring that we can provide these kinds of supports.

On the other hand, others have had less success, for a variety of reasons. Approximately 11% of respondents reported either not receiving a consent form or feeling that they had not received enough information, or did not understand the information provided, but stated that they agreed to go ahead anyway because they wanted the vaccination. Among the 51 respondents who reported some issues with the information provided at the vaccination site, the majority indicated that they had either a communication, or a mental health/memory, disability.

## A green checkmark with a navy blue background. RECOMMENDED AREA OF IMPROVEMENT: Vaccination Sites

As survey respondents indicated, COVID-19 vaccinations may be accessed by people living with disabilities at any of the available vaccination sites, including: pharmacies, doctors’ offices/clinics, mobile/pop-up/drive-through vaccination clinics, in-patient/hospital units, at home, or any other site approved by the government. Therefore, provisions for extra staff, information in alternate formats, or other accessibility features may be required at such sites to ensure that communication, mobility, and other needs of people with disabilities must be taken into consideration. People visiting a vaccination site, especially those with compromised immune systems, should be able to expect that there is adherence to COVID-19 restrictions such as masking and distancing. Masks with a transparent window can help enhance communication for those with hearing difficulties.

As respondents have indicated, there is also a need to ensure accommodations can be made for those who are unable to tolerate wearing a mask or standing, or even sitting still, in such an environment for an extended time. In addition, designated staff/volunteers at any of the vaccination sites may be required to respond to needs regarding mobility, environmental and noise sensitivities, or other needs, when someone with a disability arrives, accompanied or unaccompanied, by a support person. Relevant information (including signage) may need to be available in “alternate formats” at the site (such as ASL, large print, Braille, electronic/audio/video, easy to understand, or other accessible formats). Reduced travel time, particularly for those in rural settings, can make a significant difference for many people living with disabilities. In addition, further exploration is recommended to determine the potential for increasing partnerships with trusted and accessible community-based organizations to host vaccine clinics.

## Expenses

***“Rental of a folding wheelchair that would fit in standard car, so I didn’t have to take mobility taxi with stranger”***

***“I also had to pay for someone to stay with me for 24 hours in case of a flare of my regular health issues (which did occur). So, pay for their food etc.”***

Seventy-three percent (73%) of those in the Vaccinated group who answered this question indicated that they did not have any out-of-pocket expenses relating to getting their vaccination (344 respondents); however, 24% of respondents indicated that they had expenses relating to transportation, paying someone to come with them (4%), or other expenses. Amongst those respondents who reported having out-of-pocket expenses, the cost of transportation, by far, was the most common expense. For more examples of what respondents told us about expenses, please see page 44 - 46.

# Not Vaccinated Group

This group represents those who had not received at least one dose of a COVID-19 vaccine at the time they completed the survey.

**65 respondents had not received at least one dose of a COVID-19 vaccine at the time they completed the survey (11% of all respondents).**

This group represents only a small number of survey respondents, but the responses nonetheless help us highlight why some people with disabilities have not received a COVID-19 vaccination. There is less to say specifically about this group, because of the nature of the skip question patterns within the survey, but the information they have shared generates a lot of questions and can help us learn more about experiences of people living with a disability in relation to accessibility of COVID-19 vaccinations.

Not all questions in the survey were applicable to those who had not received at least one dose of a COVID-19 vaccine. However, the opinions and concerns expressed by this group are very important to note, as these respondents are amongst the most vulnerable in our population and are those who had chosen (or been advised) not to receive the COVID-19 vaccination at the time they completed the survey. The other 89% of respondents in the survey (the Vaccinated group) also expressed concerns, had various difficulties in accessing the vaccination or required information, or experienced barriers at the vaccination site – all important pieces of the puzzle in helping us understand the complicated relationship to COVID-19 vaccines for those living with a disability in Canada.

As previously indicated, the questions applicable to both groups were discussed earlier in the report, and include:

* Nature and impact of disability;
* Concerns about COVID-19 vaccines; and
* Demographics.

This section of the report will highlight information gleaned from the responses of those in the Not Vaccinated group.

## A green checkmark with a navy blue background. RECOMMENDED AREA OF IMPROVEMENT: Medical Research

As some respondents have commented, further research would be helpful in increasing knowledge about any potential severe and life-threatening side effects of COVID-19 vaccines for those with certain disabilities, what can be done about disabilities where there are no known vaccination risks, broader communication and circulation of any such research to the general public and to health care providers, and an identification of necessary areas of further research/communication. More information could, perhaps, allay some fears that are represented by those reporting “vaccination hesitancy”.

In addition to potentially helping to provide more information, enhanced medical research could help identify specific disability characteristics that make getting the vaccination difficult or impossible. Respondents in this survey, people living with disabilities, are the experts in their own lived experiences. They are not a combination of “characteristics”. When we consider the nature of a person’s disability (or multiple disabilities), we can appreciate that there are many factors complicating the decisions surrounding getting a vaccination, or not getting it, where and when to access a vaccination, and several of the other questions explored in this survey. For example, respondents have pointed out the issue of requirement of a deltoid muscle as injection site for Covid-19 vaccines, which is not a possibility for some people. Is there any research being conducted that explores alternate vaccine delivery for those who cannot have the vaccine injected in this way? Others know, or fear, that the vaccine may interact negatively with their medications – what can be done to increase knowledge about such interactions? The impact of getting a vaccination may increase anxiety and negatively impact mental health for those already living with these realities. Some people living with disabilities are already at risk of blood clots or seizures, which may be a side effect of some vaccines. The impact of COVID-19 vaccines may be largely unknown on some rare and severely debilitating conditions. We need to know more. Some disabilities may limit a person’s ability to travel to the site of a vaccination clinic, and so perhaps more availability in-home vaccination would be helpful. Further research can help address some of the issues reported by survey respondents.

## Vaccination Hesitancy

***“[I am] scared of reactions, and illness intensified because of having it. I live alone, with no supports. I have had horrific reactions to vaccinations and drugs in the past.”***

***“My risk of mortality and morbidity of the Covid-19 vaccine are higher than my risk of mortality and morbidity of the virus itself.”***

Twenty-eight percent (28%) of those in the Not Vaccinated group who answered this question indicated that they were hesitant to receive a COVID-19 vaccination although they were eligible (17 respondents).

***“Severe and life-threatening side effects from regular vaccine and I would not be able to get the medical attention these days that would be required to save my life. 50% of Canadians with M.E. [Myalgic Encephalomyelitis] cannot take the vaccine, the other that have taken the vaccine have had severe and life-threatening side effects.”***

***“I have been advised by Covid hotlines & some doctors, including pharmacists at the vaccine site, that I cannot get it without clearance & approval from my specialist for these conditions who is too busy under the pandemic changes to reply to their requests for a response; therefore, they have refused me getting it. Knowing of this current refusal from those specializing in the vaccine & what to do also has me a bit concerned about how it will affect me with my conditions. Of note, other doctors for other conditions/ailments have stated they'd refuse to see me if I didn't get it, essentially because they were scared. I'm stuck between a rock & a hard place that's not in my control.”***

For more examples of what respondents told us about their reluctance to receive the vaccination, please go to pages 44 - 45.

## Advised Not to Get Vaccination due to Underlying Health Condition(s)

Twenty-one percent (21%) of those in the Not Vaccinated group who answered this question had not received at least one dose of a COVID-19 vaccine at the time they completed the survey because they had been advised not to get it due to their underlying health condition(s) (13 respondents).

For more examples of what respondents told us about being advised not to get the vaccination, please go to pages 45 - 46.

### 

### Other Reasons for Not Getting Vaccinated

***“temporary illness”***

***“housebound”***

***“can’t afford to travel”***



Fifty-one percent (51%) of those in the Not Vaccinated group who answered this question indicated “other” reasons why they had not received a COVID-19 vaccination at the time they completed the survey, including:

* had their first vaccination appointment booked for a future date;
* felt COVID-19 vaccines were too risky and they were not going to get vaccinated, or they were unsure about getting vaccinated, or had delayed getting vaccinated, at the time they completed the survey; and
* another reason not specific to COVID-19 vaccines.

Most respondents in the Not Vaccinated group (except for the small number who had an appointment booked in the near future) were definitely sure they were not going to get the vaccination because of the perceived risk to themselves personally, given the nature and severity of their disability, or because they felt the COVID-19 vaccines were too risky in general for anyone.

# Discussion

We know that there is not one profile of people living with disabilities in Canada. These survey data show the complexities of life for the respondents – there are multiple factors that impact each person’s relationship with COVID-19 and the available vaccines, the booking systems, the priority groups and availability of vaccines/vaccination appointments, the vaccination sites, and the impacts of the vaccine on their health and well-being. Considering and addressing each of the stated reasons drawn from the survey data regarding why those with a disability would choose not (or were unable) to get a vaccination, and reflecting on the difficulties encountered by those who had received at least one dose of a COVID-19 vaccine at the time they completed the survey, helps us highlight some of the issues that need to be addressed by government decision- and policy-makers, health care providers, research funding agencies/donors, pharmaceutical companies, and others.

As noted throughout the report, we have highlighted some “recommended areas for improvement” based on the survey data that we believe could help ensure better support for those living with disabilities in Canada, and protection of their human rights. These areas include access to information in the format they need; supporting better access to appointment booking systems and information/communication at vaccination sites; and allowing those living with disabilities to generally be as independent as possible and able to make informed choices. As with other aspects of everyday life for those who live with disabilities in Canada, we need to ensure better access to information, and to COVID-19 vaccinations, from a human rights perspective and to protect and respect the dignity of everyone.

The recommended areas for improvement, previously discussed in more detail, are listed briefly in this final section. For more examples of what respondents told us in the study, please review the Appendix.

We welcome further discussion of the results from this survey, along with further research to explore these and other related issues of concern in relation to COVID-19 and people living with disabilities in Canada.

## A green checkmark with a navy blue background. Recommended Areas of Improvemen**t**

|  |  |
| --- | --- |
| Disability and Human Rights Awareness | Need increased attention to, and support of, the complexities of “disability” in relation to the COVID-19 virus and available vaccines.  Need more rights-based information made available to persons with disabilities to facilitate better access to supports and accommodations for vaccine access, and increased direction to ensure government policy-makers, health care providers, and others, fulfill human rights obligations toward persons living with disabilities. |
| Information | Need clearer and more precise information, in fully accessible formats such as ASL, Braille, easy to understand, and large print. |
| Policies | Need more inclusive, disability-informed, policies regarding vaccine distribution and priority groups. |
| Booking Systems | Need more accessible and efficient booking systems for vaccination appointments. |
| Transportation | Need enhanced accessible transportation options to vaccination sites and increased options for at-home vaccinations for those who need them. |
| Vaccination Sites | Need enhanced capabilities to respond to disability issues at vaccination sites (communication, mobility, environmental and noise sensitivity, need for “alternate formats” of information and navigation signs at the site, alternate types of PPE such as masks with a transparent window), and exploration of the potential for increasing partnerships with trusted and accessible community-based organizations to host vaccine clinics. |
| Medical Research | Need more information about the medical impacts of COVID-19 vaccines on specific disabilities, and more exploration of characteristics of specific disabilities that make getting the vaccination difficult or impossible, and wider communication of this information. |



# Conclusion

Respondents in this study have helped us to highlight many accessibility issues related to COVID-19 – information regarding the virus and vaccinations, and access to the vaccine. We are grateful to the respondents of this survey for taking the time to share their experiences with us. This information allows us to know more about the experiences of people living with disabilities in Canada as they have attempted to access appropriate information about the virus and vaccinations, and to access vaccinations.

There are other stories not told here. There is more research to be done. There are more questions to ask and more answers to find. There are more barriers to accessibility that exist, or that have yet to be experienced, than those outlined here by survey respondents. As we continue to grapple with COVID-19 around the world, we will learn more, and if we focus resources on removing the various barriers identified in this report, we will become better at addressing the needs and rights of those living with disabilities. Moreover, as vaccines continue to be the primary response and more vaccinations/boosters are required, additional information is critical to the ongoing efforts to contain this health crisis and increase safety for all, including those living with disabilities.

In conclusion, it is evident from the stories told in this report that, even if we remove many, or all, of the barriers to accessibility, there will still be people living with disabilities who will be unable to get vaccinated, due to a variety of reasons, including pre-existing underlying health conditions that make it impossible to receive this vaccination. However, to the extent that we can remove as many barriers as possible, such as those mentioned by respondents to this survey – barriers to information, barriers to booking vaccination appointments, barriers to transportation to the vaccination site, and barriers experienced at the vaccination site - we will increase the number of people living with disabilities who will be able to access a COVID-19 vaccination and thus better serving their health and human rights. We encourage all of those with a part to play in this to take action and take direct action to help remove these barriers.

# Appendix

## Select Respondents’ Closing Statements

Survey respondents were asked if they had any other comments or concerns they wished to share, and we will let their statements speak for themselves in this closing section. It is notable that there are some success stories, and those comments help to highlight what is needed to ensure people living with disabilities do not face accessibility issues in relation to COVID-19 vaccinations. Those who have concerns and experienced difficulties in accessibility highlight the difficult questions and areas for improvement.

* *“The entire process was a complete debacle. Because of the homecare letter issue, I had to wait several months to get the first shot and only got it when my age category came up in my area. All the other people with disabilities that I know had similar problems. Not one of us got a shot with the first eligible group we were supposed to; we saw health care workers and hospital workers that weren’t front line workers get their shots while we couldn’t get access. All of us tried to apply for the shots that could be administered at your home but those services were exceedingly limited and confined to just a handful of buildings in [our local area]. Because I couldn’t access that service, I sustained injuries trying to access the hospital site (I was so exhausted and stiff from the cold that I fell when trying to transfer when I got home). It was clear from the lack of resources and the administrative and systemic barriers in place that not only were people with disabilities not prioritized, but that they considered us to be expendable. Far more resources and vaccination opportunities were made available to low-risk able-bodied people who were prioritized.”*
* *“I happen to live with my 79-year-old mother; while she does not consider herself disabled, nor do many of the older people in this apt building, I know for a fact she would not have been able to navigate the internet to register on her own, and she would have required a taxi to drive her back and forth for both shots; she also would likely never know to claim those as medical expenses. I would imagine the* *same is true of the 60 to 70 % of people who managed to take themselves to be immunized and are single seniors in this building. It seems to me that the government could have served the people of [our province], who were disabled or infirm or elderly, with small mobile units travelling throughout the areas in each municipality, in conjunction with the mass inoculation sites which were risky for some individuals to even be exposed to. I realize there were issues with maintaining temp[erature]s of vaccines, but it seems a poor excuse when I know my father in LTC [long term care] in [another province] was vaccinated … as they did the entire building in one day (maybe two), then returned approx. 6-8 weeks and gave second doses way back in Feb[ruary] timeframe. Seems a mobile unit could have actively been doing similar work at ap[artmen]t blocks etc.”*
* *“I think the process of getting both of my vaccines was extremely well organized both getting my vaccine in my home and in the community. I would have liked a clear message when my first attempt to book my second appointment failed. The message said my numbers didn't match when it sounds like it should have said, "System is busy. Please try again later." I also would have liked to have been more clear about whether I needed to be registered for my second vaccine when my first one was in home. As for the community vaccine set up sites, I went on my own and managed but was nervous as I did not know how accessible the site was or what to expect. I would have liked this to be more clear prior to going so I would be more sure I could manage it on my own. The community site was very accessible however with very helpful people to assist me. Thank you.”*
* *“As I was trying to help others with disabilities, I got a sense of the many challenges, (besides my own). There were many barriers. Having a mostly online system and phone line where no one answered, was very challenging for those without email. The information was fragmented and very inaccessible. Also, a number of people I assisted did not have rides and had to pay money they didn't have. More needs to be done to make it accessible!!! Additionally, the public-private partnerships which are now being formed during a Pandemic are alarming. We have not signed up for a privatized* *model of vaccine and health delivery. There has been little to no transparency around this. The collaboration/partnership model is Privatization at its worst. This is happening while we are trying to survive Covid-19.”*
* *“Horrendous, health-killing, exhausting experience for weeks trying to get this arranged after GP said unable to get vaccine to come to home after weeks of promise. (family of 3 disabled adults - all very fatigued)”*
* *“I don't appreciate it being used as a political issue re mandatory vs. choice.”*
* *“I am housebound and in bed for 22hours daily. My public health unit was accommodating on site, but still the whole endeavour of getting me to and from the clinic was a lot, and also required a lot of recovery and a caregiver for a week after. Option for in home vaccination would have saved me a lot of extra illness and effort. (Still, I am very grateful to have access to vaccine. Gearing up to do this all over again for my second dose)”*
* *“poor/marginalized citizens cannot afford the cellphone & internet-email connectivity the government expects & essentially demands that we have to access the most basic services. nor do many of us have the family or family-dr. supports they expect of us as substitutes for the digital access.”*
* *“Lack of evidence on people with disabilities or autoimmune diseases - it would be nice to see what the effects are (short term and long term) on people with certain health conditions/disabilities in order to help with the anxiety and hesitancy about getting it.”*
* *“I have an intellectual disability and cannot get my vaccine through clinics or pharmacies. It's not offered at my doctor's office. I don't understand what is happening, can't sit still, and can't wear a mask. I cannot wait quietly. I finally got my first dose at home. Now my caregiver is fighting for the 2nd dose. I'm supposed to get it at home* *but they have NO IDEA when it might happen, but said it will be weeks for sure. I am prioritized due to high risk, yet for both doses, I have been vaccinated after eligibility opened to the general population. Maybe if there was a sensory-friendly site that could accommodate me without a mask, I might be able to go get my vaccine that way. I heard there is one an hour out of town but that is a long way (and I live in a major city). There have been no accommodations for people with disabilities like mine.”*
* *“\*\*NO\*\* accessibility for people who are deaf or hard of hearing. NONE AT ALL.”*
* *“It’s way more difficult for a PWD [person with disabilities] to access services in Canada if you don’t have internet, phone or transportation and money to pay for these services.’*
* *“I chose my vaccination site based on accessibility. When I arrived with my walker, I was immediately directed to a special area for people with reduced mobility and did not have to wait in line. The area was close to the door (the shortest possible walk.) I was very pleased with how good the accessibility was.”*
* *“I believed my high-level spinal cord injury should have put me in a priority group since our diaphragms and lungs don't work the same for coughing. Every time I get a cold, I develop pneumonia.”*
* *“I only accidentally stumbled upon the information that i COULD request a home visit from mobile clinic so I wish that option would have been made AS available as the rest and not an after thought.”*
* *“Public health policies need to consider rare conditions when addressing vaccination protocols and need to allow flexibility for treating clinicians to recommend at-risk patients for vaccinations on a case-by-case basis.”*

1. Hilary K. Brown, Sudipta Saha, Timothy C.Y. Chan, Angela M. Cheung, Michael Fralick, Marzyeh Ghassemi, Margaret Herridge, Janice Kwan, Shail Rawal, Laura Rosella, Terence Tang, Adina Weinerman, Yona Lunsky, Fahad Razak and Amol A. Verma, “Outcomes in patients with and without disability admitted to hospital with COVID-19: a retrospective cohort study” CMAJ January 31, 2022 194 (4) E112-E121, online at <https://doi.org/10.1503/cmaj.211277> [↑](#footnote-ref-1)
2. Independent Living Canada, online: https://www.ilc-vac.ca/covid-19/ [↑](#footnote-ref-2)
3. Canada Post, online: <https://www.canadapost-postescanada.ca/cpc/en/support/articles/addressing-guidelines/postal-codes.page> [↑](#footnote-ref-3)