# Respecting the Needs and Rights of Persons with Disabilities in Receiving and Providing Care in a Post-Pandemic World

# Consent Form

## **Date:** November to December 2021

## Study Name: Respecting the Needs and Rights of Persons with Disabilities in Receiving and Providing Care in a Post-Pandemic World

## Researchers:

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## Purpose of the Research:

In Canada, the COVID-19 pandemic has led to the implementation of numerous laws, policies and guidelines in all levels of government, but how do these affect people with disabilities? This mixed methods project will critically analyze the impact of relevant laws, policies and guidelines related to care and caregiving on the needs and rights of people with disabilities in Ontario. It seeks to incorporate the lived experience of persons with disabilities into the analysis.

Parts of the research may be published (e.g., conference papers, journal articles or articles in policy magazines).

The aggregate results may be used in future funding applications for a larger study.

## What You Will Be Asked to Do in the Research:

Complete an anonymous on-line questionnaire. The questionnaire will take about 20 to 30 mins to complete.

**Benefits of the Research and Benefits to You**:

The findings from this research will advance knowledge about the impact of COVID-19 on people with disabilities in Ontario in the area of receiving and providing care.

**Risks and Discomforts**:

There are only minimal foreseeable risks to participants. The questions ask about help or care you may have received for a long-term health condition, a physical, mental or episodic disability or problems related to aging. The questions also ask about help or care you may have provided to another person, for example, a family member. Some questions may bring stress or discomfort as you recall barriers, difficulties, challenges or discrimination you encountered.

**Resources:**

Government of Canada: “COVID-19 and people with disabilities in Canada” (<https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/guidance-documents/people-with-disabilities.html>)

Government of Ontario: “COVID-19: Support for people” (<https://www.ontario.ca/page/covid-19-support-people>.

Canadian Mental Health Association: “Provincial Mental Health Supports” (<https://ontario.cmha.ca/provincial-mental-health-supports/>)

**Do not disclose any personal health information that you do not want to share.**

**Voluntary Participation and Withdrawal**:

Your participation in the study is completely voluntary and you may choose to stop participating at any time. Feel free to speak to people you trust before you participate.

To discontinue the questionnaire, you can simply close the browser.

Once the questionnaire is complete and submitted, the researcher will not be able to remove your answers from the study.

Your decision not to volunteer, to stop participating, or to refuse to answer particular questions will not influence the nature of your relationship with York University either now, or in the future.

## Confidentiality:

All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. The data will be destroyed by November 2023*.* Confidentiality will be provided to the fullest extent possible by law.

The data collected in this research project may be used – in an anonymized form - by members of the research team in subsequent research investigations exploring similar lines of inquiry if other research staff are hired for this project. Such projects will still undergo ethics review by the HPRC, our institutional REB. Any secondary use of anonymized data by the research team will be treated with the same degree of confidentiality and anonymity as in the original research project.

The researcher acknowledges that the host of the online survey (e.g., Qualtrics, Survey Monkey etc.) may automatically collect participant data without their knowledge (i.e., IP addresses.) Although this information may be provided or made accessible to the researchers, it will not be used or saved without participant’s consent on the researcher’s system. Further, because this project employs e-based collection techniques, data may be subject to access by third parties as a result of various security legislation now in place in many countries and thus the confidentiality and privacy of data cannot be guaranteed during web-based transmission.

## Questions About the Research?

If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Poland Lai either by telephone at (416)736-5210 or by e-mail (poland.lai@yorku.ca). This research has received ethics review and approval by the Human Participants Review Sub-Committee, York University’s Ethics Review Board (Certificate # e2021-289) and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of

Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

This questionnaire is administered by the Institute for Social Research, York University.

\_\_\_ I consent to participate in Respecting the Needs and Rights of Persons with Disabilities in Receiving and Providing Care in a Post-Pandemic World conducted by Poland Lai. I have understood the nature of this project and wish to participate.

# Screening questions

## **Screening Question 1**

I am (select one):

* Under the age of 18
* 18 or older

## Screening Question 2

I live in Ontario (select one).

* Yes
* No

## Screening Question 3

Do you identify as a person with a disability?

**Persons with disabilities** include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

See the United Nations Convention on the Rights of Persons with Disabilities: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Select one

* Yes
* No

## Screening Question 4

Do you have a long-term health condition, or a physical, mental or episodic disability?

**A long-term health condition** is one that has lasted or is expected to last 6 months or longer.

**Disability** is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

**Episodic disabilities** are the result of medical conditions or diseases that are prolonged and often lifelong but have unpredictable episodes of illness and disability. These episodes of disability can vary in severity and duration and are often followed by periods of wellness. Examples of chronic conditions and diseases that are episodically disabling include: arthritis, Crohn’s and colitis, HIV/AIDS, mental illness, multiple sclerosis, as well as some forms of cancer and rare diseases. See the Report of the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities entitled: “[Taking Action: Improving the Lives of Canadians Living with Episodic Disabilities](https://www.ourcommons.ca/DocumentViewer/en/42-1/HUMA/report-15)”: <https://www.ourcommons.ca/DocumentViewer/en/42-1/HUMA/report-15/>

Select one:

* Yes
* No

## Screening Question 5

Do you have problems related to aging? Select one.

* Yes
* No

# Part 1 Health and disability questions

## **Introduction**

The following question is about difficulties you may have doing certain activities. Only difficulties or long-term conditions that have lasted or are expected to last for six months or more should be considered.

## Question 1 Do you have any of the following difficulties?

(Please select all that apply)

* Difficulty walking, using stairs, using my hands or fingers or doing other physical activities
* Difficulty learning, remembering or concentrating
* Emotional, psychological or mental health conditions e.g., anxiety, depression, bipolar disorder, substance use or addiction, anorexia
* Difficulty seeing even when wearing glasses or contact lenses
* Difficulty hearing even when using a hearing aid or cochlear implant
* Other health problem or long-term condition that has lasted or is expected to last for six or more months
* I do not have any difficulty or long-term condition that has lasted or is expected to last for six or more months

## Introduction

The following questions are about pain due to a long-term condition or disability that has lasted or is expected to last for six months or more.

## Question 2 Do you have pain that is always present?

* Yes
* No
* Don't know
* Prefer not to answer

## Question 3 Do you have periods of pain that reoccur from time to time?

* Yes
* No
* Don't know
* Prefer not to answer

## Question 4 How often does this pain limit your daily activities?

If your pain is controlled by medication or therapy, please answer this question based on when you are using your medication or therapy. If you have more than one pain problem, please refer to the pain that bothers you the most.

* Never
* Rarely
* Sometimes
* Often
* Always
* Don't know
* Prefer not to answer

## Introduction

The following questions are about other disabilities you may identify.

## Question 5 Do you consider yourself to be:

* Blind
* Legally blind
* Deaf-Blind
* None of the above
* Prefer not to answer

## Question 6 Do you consider yourself to be:

* Deaf (use sign language to communicate)
* Hard of hearing
* Oral deaf
* None of the above
* Prefer not to answer

# Part 2 Care received by respondent

## Introduction

The next few questions ask about:

* medical care, therapies, treatments and other services provided by health care providers (e.g. doctors, nurses, physiotherapists, occupational therapists, chiropractors) and other regulated professionals (e.g., social workers)
* help or care you may have received for a long-term health condition, a physical, mental or episodic disability or problems related to aging. This help may come from family, friends, neighbours, paid workers or organizations (e.g. health charities). It may include help with driving, shopping, housework, personal care or anything else.

A long-term health condition is one that has lasted or is expected to last 6 months or longer.

Help or care include:

* indoor household chores e.g., cleaning, washing or ironing
* outdoor chores e.g., cutting grass, shoveling or home repairs
* driving to appointments or to do errands or shopping
* banking or financing
* coordinating care needs
* navigating the health care system
* administering medication
* helping with personal care e.g., bathing or cutting nails
* any other activity you received help with.

## Introduction

On July 16, 2021, Ontario entered Step Three of the Roadmap to Reopen.  The following questions ask about your experience **between mid-July 2021 and mid-November 2021**.
Step 3 focused on the resumption of additional indoor services with larger numbers of people and restrictions in place. See: <https://www.ontario.ca/page/reopening-ontario>

## Question 7 Between mid-July 2021 and mid-November 2021, were there times when you did not go to the hospital or to see a doctor even though you needed to?

* Yes
* No
* Don't remember
* Prefer not to answer

## Question 7a What were the reasons you did not go to the hospital or to see a doctor even though you needed to?

(Please select all that apply)

* Fear of coming into contact with people who may have COVID-19
* Fear of physical or emotional discomfort
* Did not want to learn about chronic or serious illness
* Difficulty finding transportation
* Cannot afford the cost of transportation
* No one to accompany me
* The hospital or doctor could not accommodate my disability. Please explain: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Accessibility barriers (e.g. such as lack of interpreters)
* My employer or school did not allow me to take time off to go to the hospital or to see a doctor
* Could not find another paid or unpaid carer to help with my caregiving responsibilities
* Could not afford to pay another carer to help with my caregiving responsibilities
* Others, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

## Question 8 Between mid-July 2021 and mid-November 2021, did you need any of the following therapies, treatments or services for a long-term condition, physical, mental or episodic disability, or problems related to aging, but did not receive it?

(Please select all that apply)

* Physiotherapy, massage therapy or chiropractic treatments
* Speech therapy
* Occupational therapy
* Counselling services from a psychologist, psychiatrist, psychotherapist or social worker
* Professional nursing care at home e.g., injections, catheter or colostomy care, wound care or tube feeding
* Support group services, drop-in centre, telephone information or support lines, peer support (in person or on-line)
* Regular medical testing for issues unrelated to COVID-19 e.g., blood work, X-ray, CT scan, MRI, colonoscopy, biopsy
* Regular medical or dental treatments or appointments for issues unrelated to COVID-19
* Surgery
* Other therapies or services
* I did not need any of the above therapies, treatments or services
* I received the therapies or services that I required
* Don’t remember

## Question 8a What were the reasons you did not receive any of the therapies, treatments or services for a long-term condition, physical, mental or episodic disability, or problems related to aging, that you needed?

(Please select all that apply).

* In-person service was not available
* I was placed on a wait list for the therapies, treatments or services I required
* Fear of coming into contact with people who may have COVID-19
* Fear of physical or emotional discomfort
* Did not want to learn about chronic or serious illness
* I was able to do more activities during some periods but fewer activities during other periods due to my episodic disability
* Difficulty finding transportation
* Could not afford the cost of transportation
* No one to accompany me
* The facility, clinic or health care provider could not accommodate my disability. Please explain: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Accessibility barriers (e.g. such as lack of interpreters)
* My employer or school did not allow me to take time off to receive the treatment, therapies or services that I required
* Could not find another paid or unpaid carer to help with caregiving responsibilities
* Could not afford to pay another carer to help with caregiving responsibilities
* Did not know how to find or arrange the help or care that I required
* Others, please specify:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

## Question 9 Between mid-July 2021 and mid-November 2021, did you need any of the following services for a long-term condition, physical, mental or episodic disability, or problems related to aging, but did not receive it?

(Please select all that apply).

* Transportation (e.g., to do shopping, errands, get to medical appointments, social events, or for any other reason)
* Meal preparation, meal clean-up, house cleaning, laundry or sewing
* House maintenance or outdoor work (e.g., painting walls, repairing cupboards, replacing flooring, lawn maintenance, gardening, snow shoveling, outside wall painting)
* Personal care provided by a personal support worker (e.g., bathing, dressing, toileting, hair care, or care of nails)
* Scheduling or coordinating care-related tasks (e.g., organizing care schedule, making appointments, hiring professional help, filling out medical history, applications)
* Managing my finances (e.g., banking, bill paying or managing health insurance claims)
* Replacing or repairing an equipment that I need for my long-term care condition or disability, for example, a wheelchair or other assistive devices
* Navigation support provided by health charities or disability advocacy groups
* Others, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* I did not need any of the above services
* I received the services that I required
* Prefer not to answer

## Question 9a [If did not get at least one of the above] what were the reasons? Select all that apply.

* Fear of coming into contact with people who may have COVID-19
* Did not know if people who provided the service were fully vaccinated or not
* I was placed on a wait list for the service I required
* I was able to do more activities during some periods but fewer activities during other periods due to my episodic disability
* Could not find a personal support worker who was willing and able to come to my home
* Could not afford to pay for the services I need
* Not eligible for services provided by Home and Community Care Support Services (formerly known as Local Health Integration Networks)
* I was not fully vaccinated (i.e., did not have two doses of the COVID-19 vaccines)
* Did not know how to find or arrange the help or care that I required
* I moved
* The person(s) who normally provided care has moved, become ill or has died
* The service provider (e.g. paid workers, government agencies or voluntary organizations) could not accommodate my disability
* Others, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to answer

# Part 3 Care Giving by respondent questions

The next questions ask about help or care you may have given to your children, grandchildren, family, friends or neighbours for a long-term health condition, physical, mental or episodic disability, or problem relate to aging. This help may include driving them, shopping with or for them, helping with housework, personal care or anything else. Exclude any assistance you provided as part of a volunteer organization or paid job.

## Question 10 Do you have any children?

* Yes
* No
* Prefer not to answer

## Question 10a Does any of your children have a long-term health condition, or a physical, mental or episodic disability?

* Yes
* No
* Prefer not to answer

## Question 10b Between mid-July, 2021 and mid-November 2021, did you help or care for your children?

* Yes
* No
* Prefer not to answer

## Question 11 Between mid-July, 2021 and mid-November 2021, did you help or care for someone with a long-term health condition, a physical, mental or episodic disability or problems related to aging (in addition to any children identified in question 10)?

* Yes
* No
* Prefer not to answer

## Introduction

The next few questions ask you about your caregiving experience between mid-July 2021 and mid-November 2021.

## Question 12 How much of an impact did the COVID-19 pandemic have on your ability to meet your current caregiving responsibilities?

* Major impact
* Moderate impact
* Minor impact
* No impact
* Don't know
* Prefer not to answer

## Question 12a Please tell us why the COVID-19 pandemic had an impact on your ability to meet your current caregiving responsibilities.

## Question 13 To accommodate your caregiving duties, has any of the following support been provided to you between mid-July 2021 and mid-November 2021?

(Please check all that apply)

* Accommodation at work or school, such as working or learning from home, flexible schedule
* Spouse or partner modified their life and work arrangements
* My children and extended family members provided me with help
* Close friends or neighbours provided me with help
* Community, spiritual community, or cultural or ethnic groups provided me with help
* Health charities or disability advocacy groups provided me with help
* Occasional relief or respite care (Respite care is temporary care of a few hours or weeks for a sick or disabled person to provide a break or relief to the regular caregiver)
* Adult or Seniors Day programs for the person(s) I cared for (in-person or virtual)
* Money or tax credits from the government (e.g., caregiver tax credit, infirm dependent tax credit, medical expense tax credit)
* Child care arrangements (e.g. daycare centre, preschool, nanny, before or after school program)
* Other support or help. Please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* I have not received any help between mid-July 2021 and mid-November 2021

## Question 14 Between mid-July 2021 and mid-November 2021, how often can you meet all of your caregiving responsibilities?

* All of the time
* Most of the time
* Some of the time
* Rarely or never
* Do not know or do not remember
* Prefer not to answer

## Question 15 Thinking about your own caregiving experience between mid-July 2021 and mid-November 2021, please explain any barriers or challenges you may have encountered.

## Question 16 Are you the substitute decision maker or an attorney acting under a power of attorney for decisions related to personal care, health care or admission to long-term care (nursing homes) for another person (e.g. grandparents, parents, siblings etc)?

Where a decision is necessary and an individual has been found legally incapable with respect to that decision or that type of decision, a substitute, such as a guardian, person acting under a power of attorney or a substitute decision-maker under the Health Care Consent Act will make that decision. See the Law Commission of Ontario’s 2017 Final Report on Legal Capacity, Decision-making and Guardianship: <http://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/final-report/2-overview-of-legal-capacity-decision-making-and-guardianship-in-ontario/>

* Yes
* No
* Do not know
* Prefer not to answer

## Question 16a Please explain any difficulties or challenges you may have experienced in relation to your role as the substitute decision maker or attorney under a power of attorney between mid- July 2021 and mid- 2021.

If none, please indicate none.

## Question 16b Did these difficulties or challenges exist before the COVID-19 pandemic (March 2020)?

# Part 4 Technology

## Introduction

The next question is about the use of technology in receiving or providing care between mid-July 2021 and mid-November  2021.

## Question 17 Between mid-July 2021 and mid-November 2021, which of the following have you experienced?

(Please select all that apply)

* I did not have regular access to computer or high-speed internet in order to have a virtual medical appointment for myself or the person I helped or cared for
* I did not know how to use technology (e.g. video conferencing services such as Zoom, Microsoft Teams etc) in order to have a virtual medical appointment for myself or the person I helped or cared for
* I did not know how to use technology (e.g. internet, on-line appointment booking system) in order to arrange care for myself or the person I helped or cared for
* I did not have regular access to computer or high-speed internet in order arrange care for myself or the person I helped or cared for
* I did not have problems with using technology to arrange care for myself or the person I helped or cared for
* I was able to find someone who can help me with using technology to arrange care for myself or the person I helped or cared for
* None of the above

# Part 5 Discrimination

## Introduction

The next questions are about your experience with discrimination between mid-July 2021 and mid-November 2021 in Ontario.

## Question 18 Between mid-July 2021 and mid-November 2021, did you experience discrimination or were treated unfairly by others while receiving treatments, therapies or other services in a health care setting such as hospitals, doctor offices, pharmacies, clinics … etc?

* Yes
* No
* Don’t remember
* Prefer not to answer

## Between mid-July 2021 and mid-November 2021, did you experience discrimination or were treated unfairly by others while receiving care or help in your own home?

* Yes
* No
* Don’t remember
* Prefer not to answer

## Between mid-July 2021 and mid-November 2021, did you experience discrimination or were treated unfairly by others while receiving care or help in other settings (e.g. community centres, health charities)?

* Yes
* No
* Don’t remember
* Prefer not to answer

## Question 18a You have experienced discrimination or been treated unfairly by others in Ontario because of any of the following:

(Please select all that apply)

* Disability
* Age
* Indigenous identity
* Ethnicity or culture
* Race or skin colour
* Religion
* Sex (Sex refers to sex assigned at birth.)
* Sexual orientation (e.g., heterosexual, lesbian, gay, bisexual)
* Gender identity or expression (Include gender diverse identities such as two-spirit or non-binary.)
* Family status (e.g. being a parent)
* Other, please specify:

# Demographics Questions

## Introduction

The next few questions collect information about socio-demographic data, such as age, gender and cultural backgrounds, of research participants. Data can be further broken down so that we understand better how specific segments of the population are experiencing impacts of the COVID-19 pandemic.

## Question 19 What is your gender?

Gender refers to current gender which may be different from sex assigned at birth and may be different from what is indicated on legal documents.

Please select one.

* Male
* Female
* Non-binary
* Other
* Prefer not to answer

## Question 20 What is your age? Please select one.

* 17 and younger
* 18 to 24 years
* 25 to 34 years
* 35 to 44 years
* 45 to 54 years
* 55 to 64 years
* 65 to 74 years
* 75 and older
* Prefer not to answer

## Question 21 Are you First Nations, Métis or Inuk (Inuit)?

* No
* Yes, First Nations
* Yes, Métis
* Yes, Inuk (Inuit)
* Prefer not to answer

## Question 22 Are you:

(Please select all that apply)

* White
* South Asian (e.g., East Indian, Pakistani, Sri Lankan)
* Chinese
* Black
* Filipino
* Arab
* Latin American
* Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai)
* West Asian (e.g., Iranian, Afghan)
* Korean
* Japanese
* Other: Please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to answer

## Question 23 Between March 2020 and November 2021, how has your overall household monthly income from all sources changed? Include income from all household members before taxes and deductions. Select one.

* Stayed about the same as before the COVID-19 pandemic
* Increased since before the COVID-19 pandemic
* Decreased since before the COVID-19 pandemic
* Don’t know / Don’t remember
* Prefer not to answer

## Question 24 Where do you live?

* Please name the town or city where you normally reside: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to answer

# Thank you for taking part in this study!

You have completed the survey of the project " Respecting the Needs and Rights of Persons with Disabilities in Receiving and Providing Care in a Post-Pandemic World". The results of the study will be available on the researcher’s website. If you have any questions, please contact the principal investigator at: [Poland.lai@yorku.ca](Poland.lai%40yorku.ca)

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