



“Caregiving Complexities: The Experiences of Primary Caregivers of Children with Special Needs in the Context of COVID-19”

Letter of Information

Thank you for your interest in this research project! You are being asked to participate in a research study that will be looking at the experiences of primary caregivers of children with special needs during the COVID-19 pandemic.

This research is being conducted by the principal investigator, Dr. Kimberly Hillier from the University of Windsor's Faculty of Education. If you have any questions about the study, please contact Dr. Kimberly Hillier at kimberly.hillier@uwindsor.ca

In order to participate in this study, you must meet the following criteria:

1. You are the primary caregiver of a child with special needs. Within the context of this study, a "primary caregiver" is someone who is the person primarily responsible for the care and upbringing of a child (Government of Ontario, 2020). The Ontario Ministry of Education (2017) identifies "special needs" as exceptionalities that may include: physical, communicational, intellectual, emotional, social, and/or behavioural development, and may require services from multiple sectors and/or professionals.
2. You are a resident of Ontario.
3. You are 18 years of age or older.

PURPOSE OF THE STUDY

The purpose of this study is to learn about the experiences of primary caregivers of children and youth (ages newborn to 16 years) with special needs, during the COVID-19 pandemic. If you volunteer to participate in this study, you will be asked to answer the survey questions that are about your experiences of being a primary caregiver to your child(ren) during the COVID-19 pandemic.

PROCEDURES

If you participate in this research study, you will be asked a series of questions that relate to your experiences of being the primary caregiver of a child with special needs during the COVID-19 pandemic. The questions will ask you about the nature of your caregiving, your child's special needs, the services you have accessed during the pandemic, and your experiences of virtual education during the pandemic.

POTENTIAL RISKS AND DISCOMFORTS

There are no physical risks in completing this survey. There are medium psychological risks and low social and data risks. Given the potential emotional and psychological distress while recalling various experiences pertaining to caregiving during a pandemic, you are encouraged to contact the supporting services and community agencies provided to alleviate any potential distress. An email with supporting services and community agency information will also be given at the end of this survey.

<https://www.ontario.ca/page/covid-19-support-people>

<https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19/resources-parents-children.html>

<https://inclusioncanada.ca/coviddisability-2/>

<https://jmccentre.ca/services/>

CONFIDENTIALITY

The information you share if you consent to participate in this study will be kept confidential. The research findings may be used in future studies, publications, and presentations. All participant information will remain as confidential as possible through the use of pseudonyms and the removal of any information that could potentially identify you.

COMPENSATION

Once you have completed the survey, you may enter your email into a random draw for a \$25 Amazon gift card.

BENEFITS OF PARTICIPATING

Your participation in this research may support research and discussions concerning caregiving, authentic inclusion of children with special needs, social justice, and crisis response planning in education.

PARTICIPATION AND WITHDRAWAL

Your participation in this study is entirely voluntary. You may withdraw at any time without consequence by closing the survey browser tab or swiping up and closing the tab on your cell phone. You may refuse to answer any questions you do not feel comfortable answering. Once you complete the survey, you will no longer be able to withdraw.

FEEDBACK OF THE RESULTS

Results of this study will be made available on the University of Windsor's Scholarship website (<https://scholar.uwindsor.ca>) and a summative report will be emailed to the John McGivney Children's Centre and shared to clients.

YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY

If you have any questions regarding your rights as a participant in this research, please contact the University of Windsor's Research Ethics Coordinator:

Email: ethics@uwindsor.ca

Phone: (519) 253-3000 ext. 3948

If you choose to participate in this research study, please print or save a copy of this letter for your records.