**THE BURDEN OF IMPOSSIBLE CHOICES DURING TIMES OF A PANDEMIC: A LONGITUDINAL STUDY OF PARENTAL CAREGIVING EXPERIENCES OF CHILDREN WITH COMPLEX NEEDS DURING QUARANTINE AND SOCIAL ISOLATION POLICIES**

**Michelle Janzen, Ph.D. Candidate, Department of Child and Youth Studies, Brock University**

**Correspondence:** Michelle Janzen, Department of Child and Youth Studies, Brock University, [mjanzen@brocku.ca](mailto:mjanzen@brocku.ca)

**1: Objective:** The study's purpose is to investigate through human rights and critical disability lens, the impact of Governmental policy and practices resulting from the Pandemic on parents' caregiving experiences for children experiencing disability with complex caregiving needs living within Southern Ontario.

**2: Method:** Through a phenomenological approach, the research involves a longitudinal qualitative study that interviewed 11 parents (10 mothers and one father) between the ages of 32 to 58 and asked open-ended questions virtually or by phone about how Covid-19 has impacted their caregiving experiences. Diagnoses of participant's children varied, including Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, Cerebral Palsy, Cardiofaciocutaneous Syndrome, Charge Syndrome, PANS, and EDF3 Genetic Disorder. The ages of the participants children ranged from 6 to 24, all of whom experienced mild to profound intellectual and developmental impairments.Parents were recruited through advertisements in family support groups on Facebook, word of mouth, and emailed to parents through two community service agencies located within two different Southern Ontario regions. The Interviewing began at the initial stages of the Pandemic, with follow-up interviews to commence in April, approximately one year after initial interviews were completed. Interviews were recorded and transcribed and used a content analysis approach within the transcripts' preliminary data analysis. Once the study is complete, a more robust comparative analysis of the participants' experiences based on the initial experience, and one year after the Pandemic began, will be analyzed through content, inductive and deductive approaches.

**3: Results:** The study is not yet complete, but preliminary results indicate that due to restrictions on services and social isolation policies and practices that limit the spread of Covid-19, the theme of impossible choices emerges as a dominant pattern, in which parents express being forced to make impossible decisions about their personal lives, and their children's. Impossible choices include risking the family's health and safety by choosing to abide or not by social isolation protocols, choosing between working and childcare, and discussing whether marriages will survive if COVID-19 is brought into the home. Preliminary analysis also suggests that both parents and children experienced significant declines in physical, mental health and well-being due to a lack of available support and services with an increase in the use of substances as coping mechanisms.

**4: Discussion:** Preliminary findings suggest that initial quarantine and social isolation practices implemented by the Government failed to consider that many community services and supports dependent on families with children with complex needs are essential. Parents report feeling the Government has forgotten about them, and the lack of recognized services as essential forced many families into decision making that placed them at risk for adverse financial, legal, medical, and health outcomes. Preliminary implications suggest that in future emergent states, Ontario must ensure that the planning includes their most vulnerable families and citizens' needs.