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Summary of Findings

The purpose of this video is to provide a summary of my research project about the care experiences of people living with the effects of disability, ageing and other social locations (such as gender) during the COVID-19 pandemic. While we all need care, some people with disabilities and older adults are perceived to be a “burden of care”. At the same time, people with disabilities, regardless of age, may be overlooked as caregivers in scholarly and public policy debates. Similarly, many older adults also provide care to their spouses, grandchildren and so on.

The results describe why people with disabilities and older people were not able to access the care that they needed during a period when economic and social activities began to resume and how their caring relationships had been disrupted. Disruptions include: delays in seeking care; avoiding tests, treatments and other types of care; not receiving care needed for self-care or for care of others; and not being able to support others. I focused on Ontario, Canada.

The findings have been published in an article in the *International Journal of Care and Caring* in 2024. The article is entitled “Disruptions in care among disabled people and older adults during the COVID-19 pandemic: evidence from Ontario, Canada.” You can find the link to the article on my website. Or you can send me an email and I will be happy to send you a copy.

This study was designed as a two-phase pilot project. The first phase, conducted from April to August 2021, consisted of interviews with groups that represented the families of care recipients, disability advocacy organisations, health charities and lawyers with expertise in disability law and/or elder law.

The second phase involved an online, anonymous survey. The data-collection period was from 22 November to 23 December 2021. The data set contained data from 36 respondents; however, respondents did not necessarily answer all of the questions.

The majority of survey respondents self-identified as female and 55 years of age or older. More than one third of respondents were from Toronto, and the rest were from cities and towns of various sizes in Ontario. Respondents reported a wide range of physical, mental and sensory disabilities, as well as pain and other health problems or long-term conditions.

The analysis of the results is based on the idea that people with disabilities and older adults may be involved in many caring relationships concurrently. They may provide different types of care and support to multiple people (for example, aging parents and children) and receive care (for example, from personal support workers) for their own needs and the needs of their loved ones. Therefore, they may experience disruptions in their multiple care relationships.

There are three main findings from the interviews and survey responses. First, unmet needs were common due to disrupted access to care, which was exacerbated by the barriers encountered by

people with disabilities and older adults. Second, disability shapes one's care decisions in relation to the care of others and self-care. Public policy is not well equipped to recognise, value and support multiple parties in caring relationships. Third, the rights of disabled people and older adults were not respected like the rights of other people during the pandemic.

While disruptions to care were common for everyone, the impact of such disruptions on disabled people and older adults was amplified by three key factors. First, the care needs of disabled people and older adults are not well understood because they tend to be relegated to mere recipients of care. When additional care responsibilities arise (for example, due to homeschooling), the accommodation needs of people with disabilities who provide care are an afterthought. Second, disabled people and older adults' rights to care are more likely to be undermined by ableism and ageism because protective measures can be introduced in the name of their safety or protection, as they are deemed to be particularly 'vulnerable'. Further, the harm of such measures is shared by others related to people with disabilities and older adults. Third and relatedly, non-discrimination was rarely addressed in mitigating the impact of disruptions in care for multiple parties. The concept of disability discrimination should not be limited to those who are identified as disabled. Rather, disability discrimination also impacts those in caring relationships.

Many thanks to the key informant interviewees and the organisations that they represented, as well as the survey respondents. I acknowledge the support of organisations and colleagues who assisted with the promotion of the survey.

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If you have any question, please do not hesitate to contact me. Thank you for watching this video.