Chapter Twenty Two

“Your ‘Only’ Is My Everything”: Mothering Children with Disabilities through COVID-19

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Introduction

In the first few weeks of the COVID-19 pandemic, in the spring of 2020, a meme circulated on Facebook groups for parents of children with disabilities, with the slogan “Your ‘only’ is my everything” superimposed on a child’s picture. The meme’s intended message was to protest the popular rhetoric prevalent at the time that only the already-vulnerable were at risk of COVID-19—a belief that parents of children with disabilities felt denied their children’s value and dismissed them as disposable and expendable.

This chapter examines the experiences of mothers of children with disabilities during the first six months of the COVID-19 pandemic. Although it is increasingly well documented that the COVID-19 pandemic is taking a disproportionate toll on the lives of mothers everywhere, mothers who have children with disabilities face particular challenges. However, many of the COVID-19-related phenomena that the majority of people experience as a profound disruption of their normal live are, in fact, nothing new to these mothers. Paradoxically, they also benefit in unexpected ways from some of the new mechanisms of access and connection that have been widely adopted as a result of COVID-19. The mothers' accounts point to the need to rethink many aspects of our social organization, central among them being the role that carework plays in the functioning of society.

Background

There is mounting evidence that shows women are uniquely affected by the COVID-19 pandemic, due, in part, to the persistence of traditional gender roles, which render them more likely to assume the bulk of unpaid caregiving responsibilities for their family members and/or to be employed in frontline caregiving professions, such as in healthcare, childcare, or education (O'Reilly; Power; Thomason and Macias-Alonso; Johnston, Mohammed, and Linden). Furthermore, gender intersects with other "drivers of vulnerability and marginalisation" (Ryan and El-Ayadi 1405), including age, ethnicity (and racism), indigeneity, socioeconomic status, geography, sexuality, religion, migration/refugee status, disability, and other structural conditions (for example, political and environmental stressors, such as war) (Ryan and El-Ayadi).

Of particular relevance to our focus in this chapter is the intersection between gender and disability in the lives of mothers. Many children with disabilities have underlying medical conditions that place them at a higher risk of COVID-19-related complications (WHO). Moreover, parents of children with disabilities also face a host of additional challenges as a result of COVID-19-related measures. Many of their children require medical procedures, therapies, home-based nurses/personal support workers (PSWs), or school-based supports—many of which were cancelled during the COVID-19 lockdowns and school closures (Lee; Phoenix). The heightened health risks, coupled with loss of supports, created additional logistical and emotional challenges for parents/caregivers (Phoenix; Arim, Findlay, and Kohen; Klass; Reid).

Methods

This article is based on interviews with nine Canadian mothers who have children with disabilities. The interviews were part of a larger study about the needs and supports of people with disabilities and parents/caregivers of people with disabilities during the pandemic, which was led by Olaf Kraus de Camargo—developmental paediatrician at McMaster University and a researcher with the university's CanChild Centre for Childhood Disability Research. The interviews were conducted over the phone or videoconferencing software by Kinga Pozniak, a postdoctoral researcher at CanChild, whose research focuses on the experiences of parents who have children with disabilities. The mothers were recruited through the Centre's parent networks, including its newsletter and Facebook group for parent affiliates. Although the data we present here are drawn from the interviews, the interviews are informed and contextualized by Pozniak's ongoing interactions with parents in a number of different research studies and her regular participation in CanChild's Facebook group for parents. All of the names used in the chapter are pseudonyms.

Although we did not collect demographic information on the mothers, we sketch out some trends relevant to the discussion that will follow. Five of the mothers were residing in Ontario, whereas two lived in Alberta and two lived in Saskatchewan. All spoke English with nativelike proficiency, although one mother was born outside of Canada (in the United States), and English was not her first language. We did not ask the mothers about their ethnic backgrounds or about whether they identified as members of any visible minority groups, and none of the mothers made any reference to this. The mothers' ages ranged from early forties to early sixties, and their children ranged in ages from four to thirty-two. All of the mothers had at least one child (sometimes more) with a medical diagnosis, and the diagnoses included cerebral palsy, autism spectrum disorder, and rare conditions. All of the mothers were primary caregivers to their children before COVID-19, which they combined with a variety of work and volunteering arrangements. Giselle was a nurse pursuing her PhD and teaching at the university level. Janelle had her own part-time housekeeping business. Maria was a business analyst for a government health agency. Valerie taught English as a second language online to international students. Cathleen had a home daycare. Diana was a public speaker, writer, and activist. Jackie worked part-time for a national disability advocacy organization and volunteered as president of her local branch. Kate had quit her job a few years ago when her son graduated high school, and Tammy was home full-time looking after her four children, all with different diagnoses and needs. All the mothers continued to be the primary caregivers to their children during the COVID-19 lockdown period, the only exception being Maria, who had maintained her job due to her need of its healthcare benefits while her freelance contractor husband looked after their three children. Although we did not probe into the mothers' family composition or relationship status beyond what they themselves volunteered in the interviews, all of the mothers alluded in some way to having a spouse or partner, eight of whom were male, and one was female. In all, the mothers occupied relatively secure socioeconomic locations; they were all able to provide an adequate standard of living for their children, and many were involved in various advocacy or research activities related to their children's diagnoses.

Results and Discussion

In what follows, we present the complex, and sometimes unexpected, ways that mothers of children with disabilities were affected by the COVID-19 pandemic. While they, their children, and their families were particularly affected by COVID-19-related public health measures, their experiences also show preexisting vulnerabilities resulting from structural cracks in the system that have always marginalized them. The silver lining of COVID-19 may be that it forced the mainstream society to create certain accommodations from which these families are poised to benefit.

Disability Exacerbates the Toll of COVID-19, and COVID-19 Exacerbates the Challenges Posed by Disability

As exemplified by the "Your 'only' is my everything" slogan, people with disabilities face an increased risk of adverse health outcomes related to COVID-19. Furthermore, in addition to being more medically vulnerable, children with disabilities and their families are affected in multiple other ways by COVID-19-related restrictions.

These children often require frequent medical or therapy appointments, the majority of which were cancelled or postponed during the lockdown. For example, at the beginning of the lockdown, Tammy was worried about the cancellation of her teenage daughter's scheduled corrective surgery, which needed to be done before her daughter's growth-plates closed. She told Pozniak that delaying the surgery by even a few months could affect her daughter's future ability to walk.

Parents with adult-age children who reside in care homes were often shut out of their children's care, resulting not only in potential isolation and trauma to both parents and children, but also in potential medical complications. Diana, a mother of an adult son with cerebral palsy who was living in a residential care home, told Pozniak that because of COVID-19, all of her son's standing appointments at a pain clinic were cancelled, and as a result, his implanted pain pump did not get refilled. Since she was not allowed inside the care home to visit her son, she was not aware of the cancelled appointment, nor did she realize that the care home did not reschedule it. Her son went into life-threatening withdrawal and ended up in the emergency room, where she was also not allowed to be present. Summing up her story, Diana said the following: "COVID made it very difficult to look after somebody in long-term care.... Normally we would have a clear role as an advocate, as a backstop for medical error, and for making sure that everything is fine. We simply aren't there, and we don't know what's going on day to day."

Another issue that frequently surfaced in mothers' accounts was schooling. Although many parents struggled with supporting their children's learning during school closures, mothers of children with disabilities faced additional issues. Many of these children lost their school-based supports, such as therapies as well as the help of support workers and learning aides. Furthermore, for children with sensory or emotional difficulties, school offers routine and structure. For these children, virtual learning is often a mixed experience. Some of the mothers reported that their children, in fact, did quite well learning from home; for other children, virtual learning did not work at all, since they were unable to regulate themselves, concentrate, and follow a virtual interaction. Even when the virtual format worked for the children, mothers reported spending significant time and energy on supporting their children’s learning by adapting the material, troubleshooting technology glitches, and liaising with teachers. Although some mothers found this process altogether manageable, others described it as a “shit show” and as a “nightmare.”

COVID-19 related restrictions also meant the loss of essential supports to parents whose children need constant care and who rely on the help of nurses, PSWs, or respite workers. Because these workers usually rotate between multiple homes in any given day, many parents cancelled their services due to risk of transmission. However, this left them without respite, leading to burnout and stress. Giselle, a mother of a teenage boy with a rare condition who required 24/7 supervision, decided to keep her nanny during the COVID-19 lockdown to help care for her son, as she herself was working and pursuing a PhD. However, the nanny got COVID-19 and eventually infected her son. Fortunately, her son was able to recover at home, but Giselle lost her son’s entire support team, which consisted of a nanny, a behavioural aide, respite workers, a physiotherapist, an occupational therapist, and a speech therapist. She reflected on her experience in these terms:

> Society expects mothers to be superheroes when you have a child with disabilities, and I think it’s because no one knows how to help you or no one knows what to do. No one really wants to burden themselves. There’s not enough money. There’s not enough help. And so, if you want your child to live with you and to have a certain quality of life; then, you have to sacrifice yourself. And there’s no empathy about that.… It’s just you’re supposed to do it.… So, I think COVID would just magnify that a whole lot more. Because, again, parents are in their home trying to homeschool, trying to find medical care, behavioural care, trying to provide therapy, with no supports to help them.

Giselle’s quote illustrates that although COVID-19 has presented some unique challenges, the underlying structures of marginalization were present in mothers’ lives long before the pandemic—a theme to which we now turn.

"Nothing New": COVID-19 Exposes and Magnifies Existing Cracks in the System

For the majority of society, COVID-19 imposed restrictions represented a profound disruption of normal life. However, many mothers of children with disabilities never had the luxury of living a normal life. Many were already feeling isolated, overwhelmed, and marginalized. Many of them had children who regularly missed school for prolonged periods of time due to sickness. Although the disastrous impact of COVID-19 on mothers' paid employment is making headlines (Ruppanner, Collins; and Scarborough; Linden), many mothers of children with disabilities were forced to leave the paid workforce long before the pandemic because they have never been able to secure adequate supports and funding to allow them to combine caregiving with paid employment. Kate—a mother of an adult son who quit her job four years ago because her son aged out of school and she was not able to secure adequate care for him—told Pozniak that "nothing has changed":

> Things aren't very different; he and I are at home. We're not really missing out on anything that we would have had before.… This is where we were at anyway. And I'm hearing that from a lot of parents and a lot of families, saying, "Well, we were already isolated. We already were stuck at home with no way to get out or [with] no meaningful activities for us".… So, for a lot of families, nothing has changed in a way.

A theme that came up in a number of conversations is that for these mothers, COVID-19 is, indeed, nothing new. Although there are undeniably at least some unprecedented things about the pandemic, this statement is meant to draw attention to the fact that missing out on important life experiences (such as school, social connections, or recreational opportunities) is only seen as a problem when it affects the able-bodied population. The fact that for mothers of children with disabilities the isolation is nothing new exposes the cracks in the system that people with disabilities and their parents/caregivers have always fallen through.

The Silver Lining: New Ways of Access and Connection

The pandemic forced mainstream society to rethink existing ways of living, leading to new ways of accessing schools, healthcare, and workplaces as well as new ways of making social and community connections. Paradoxically, for families of children of disabilities, these coping measures constitute the silver lining of COVID-19, since they create new possibilities that were hitherto not available when it was only the disabled population who needed to be accommodated. For example, a few of the mothers noted that their children, in fact, did well with virtual learning, since they were able to proceed on their own terms and pace. Many mothers also positively commented on the possibility to access at least some of their medical appointments virtually instead of in person. This was especially the case for mothers whose children see a multitude of specialists, some of whom may be based at hospitals located hours away. As Tammy put it: “Some stuff you need to see the doctor for. You can’t get Botox injections [to relieve muscle spasticity in people with cerebral palsy] over the Internet. For some of the other stuff, where you’re just checking in, you don’t need my kid’s body.”

Lastly, mothers also remarked on the availability of other online supports that were previously not open to people with disabilities and their caregivers. Kate, who quit her job when her son aged out of the school system, told Pozniak that even prior to COVID-19, she had difficulty finding programs for her son and support networks for herself. However, the pandemic-imposed lockdowns resulted in many programs switching to virtual delivery formats. Mothers commented on the availability of online recreation (e.g., free yoga videos), mental health supports (e.g., mindfulness apps and virtual therapy), and opportunities for networking and connecting (e.g., virtual caregiver group meetings, music therapy for children, and church services). Importantly, they noted that these only became possible when the mainstream, able-bodied population began to need them. As Kate put it: “Many people with disabilities, any kind of disability at all, adult or child, whether it’s intellectual or physical, they’re all saying ‘We’ve been asking for this for decades. Why can’t we have had this online stuff before.’ And everybody kept telling us we couldn’t. And then, boom. Once all the able[-bodied people] ... needed this, suddenly they can do it.”

As Kate underscores, new accommodations became possible only when they were needed by the able-bodied population. However, this silver lining of COVID-19 can serve as an impetus for the mainstream society to reconsider some of the values we live by and their accompanying social arrangements.

Towards a New Normal: Rethinking the Value of Caregiving

The COVID-19 pandemic created a renewed impetus to recognize the essential nature of the care economy to the functioning of society as well as the interrelated networks of carework that compose it. Mothers of children with disabilities are particularly attune to this interrelated nature of carework, since they often have more complex and longer-lasting caregiving responsibilities than the average mother. Furthermore, their children also require a more extensive network of careworkers, often including nurses, PSWs, and respite workers.

All of the mothers in our study were primary caregivers to their children before COVID-19, and most of them continued in this role throughout the pandemic-related closures of schools, day programs, therapy, and respite support. The case of Diana, the mother who was shut out of her adult son's care—with near-disastrous consequences—poignantly illustrates the essential role of caregivers and what happens when suddenly their presence disappears.

The mothers' stories expose the intertwined systemic inequities that characterize the lives of mothers and other careworkers, making them particularly vulnerable at times of crisis, such as COVID-19. All of the mothers in our study reported a lack of adequate support with their caregiving responsibilities. Insufficient funding was a common theme running through the mothers' stories. Even when funding was available and supports existed in theory, they were described as inadequate, boggled down by red tape, and not flexible enough to meet each family's unique circumstances. Kate, for instance, noted that while she was very fortunate to have funding for caregivers, the high turnover rate in the profession meant that she was unable to keep any respite worker for longer than a few months, in effect rendering her unable to hold down a job.

Furthermore, people who perform carework for wages are often poorly compensated, making both themselves and those for whom they care more vulnerable. This is why Tammy, Maria, and Kate decided to cancel their respite workers due to the heightened risk to their children. Giselle was the only mother in the study who decided to keep her nanny (because she was still working full-time). She paid dearly for this decision when her nanny—an immigrant woman who lived in shared accommodations with several other people who worked in long-term care homes—got COVID-19 and infected her son. In telling her story, Giselle explicitly underscored the interconnected nature of carework and the need for systemic change:

> So, it becomes that those that are vulnerable become more vulnerable because they expose other people…. I was like "of course she got COVID because she's living with people who work in long term care." And so, it's just like this pattern, this algorithm you can expect is going happen because we're all drawing from the same pool of people who are low-income service workers who are taking the jobs that other people don't want. So … again, these systemic inequities … are leading to problems for seniors [and] problems for children with disabilities.

Taken together, these stories point to the need to fundamentally reorganize social arrangements to recognize the true value of carework. In a recent policy brief about carework, Kate Power outlines a "5-R" framework for revaluing the care economy. This framework recommends that unpaid carework be recognized, reduced (through public investment in infrastructure), and redistributed (among different institutions), whereas caregivers need to be represented in decision making and appropriately rewarded for their labour (Waring; Bjornholt and McKay).

The mothers' stories contained a number of suggestions for bringing this about. These start with the explicit recognition of the essential role played by mothers in their children's education, healthcare, and day-to-day life, whether these children are young or grown up, and regardless of whether they live at home or in residential care. Institutions, such as hospitals or care homes, need to implement concrete mechanisms for incorporating caregivers (Thomson). The mothers' stories also highlight the need for varied and flexible financial and other supports that meet each family's unique situation. For example, both Tammy and Maria positively commented on the expansion of certain disability funding schemes to support the purchase of at-home recreation and therapy equipment, such as sensory toys or an above-ground pool. Other strategies that alleviated the caregiving burden include the possibility of virtual healthcare appointments for children as well as virtual mental health supports for parents. Finally, mothers recognized the fact that all carework is intertwined. While outlining their own needs for support, they underscored the fact that those employed in caregiving occupations (e.g., health workers, PSWs, and respite workers) also need to be properly compensated.

Conclusion

Mothers' accounts reveal the compounded challenges of mothering a child with a medical condition during the COVID-19 pandemic, which has highlighted and exacerbated the struggles that have always characterized their lives. The fact that the new challenges imposed by COVID-19 are seen by some mothers as nothing new reveals the profound failure of the system to meet the needs of these families in the first place. Paradoxically, COVID-19 has also forced society to adopt measures that benefit these families, such as virtual services, supports, and community-building opportunities. The silver lining of COVID-19 may be that it presents an opportunity to rethink existing social arrangements and rebuild a more equitable postpandemic society.

Works Cited

Arim, Rubab, Leanne Findlay and Dafna Kohen. "The Impact of the COVID-19 Pandemic on Canadian Families of Children with Disabilities." *Statistics Canada*, 27 Aug. 2020, www150.statcan.gc.ca/n1/pub/45-28-0001/2020001/article/00066-eng.htm. Accessed 10 Jan. 2020.

Bjornholt, Margunn, and Ailsa McKay. *Counting on Marilyn Waring. New Advances in Feminist Economics.* 2nd ed. Demeter Press, 2014.

Johnston, R., A. Mohammed, and C. van der Linden "Evidence of Exacerbated Gender Inequality in Child Care Obligations in Canada and Australia During the COVID-19 Pandemic." *Politics & Gender*, vol. 16, no. 4, 2020, pp. 1131-41.

Klass, Perri. "The Pandemic's Toll on Children With Special Needs and Their Parents." *New York Times* 27 July 2020, www.nytimes.com/2020/07/27/well/family/children-special-needs-pandemic.html. Accessed 10 Jan. 2021.

Lee, Joyce. "Mental Health Effects of School Closures during COVID-19." *The Lancet*, vol. 4, no. 6, 2020, p. 421.

Nessa E. Ryan, and Alison M. El Ayadi. "A Call for a Gender-Responsive, Intersectional Approach to Address COVID-19." *Global Public Health*, vol. 15, no. 9, 2020, pp. 1404-12.

O'Reilly, Andrea. "'Trying to Function in the Unfunctionable': Mothers and COVID-19." *Journal of the Motherhood Initiative*, vol. 11, no. 1, 2020, pp. 7-24.

Phoenix, Michelle. "Children with Disabilities Face Health Risks, Disruption and Marginalization under Coronavirus." *The Conversation*, 11 May 2020, theconversation.com/children-with-disabilities-face-health-risks-disruption-and-marginalization-under-coronavirus-137115. Accessed 10 Jan. 2021.

Power, Kate. "The COVID-19 Pandemic Has Increased the Care Burden of Women and Families." *Sustainability: Science, Practice and Policy*, vol. 16, no. 1, 2020, pp. 67-73.

Ruppanner, Leah, Kaitlyn Collins, and William Scarborough. "COVID-19 Is a Disaster for Mothers' Employment. And no, Working from Home Is Not the Solution." *The Conversation*, 20 July 2020, theconversation.com/covid-19-is-a-disaster-for-mothers-employment-and-no-working-from-home-is-not-the-solution-142650. Accessed 10 Jan. 2021.

Reid, T. "Canadians with Disabilities Left with Few Alternatives amid COVID-19 Shutdowns." *CBC News*, 19 Apr. 2020, www.cbc.ca/news/health/covid-19-impact-on-canadians-with-disabilities-1.5525332. Accessed 10 Jan. 2021.

Thomason, B, and I. Macias-Alonso. "COVID-19 and Raising the Value of Care." *Gender Work Organisation* 27, 2020, pp. 705–8.

Thomson, Donna. "Now Is the Time for More, Not Less, Caregiver Partnership." *National News Watch*, 12 May 2020, www.nationalnewswatch.com/2020/05/12/now-is-the-time-for-more-not-less-caregiver-partnership/#.X_sXNtg3nIU. Accessed 10 Jan. 2021.

Linden, Clinton van der. "The Moms Are Not Alright: How Coronavirus Pandemic Policies Penalize Mothers." *McMaster University*, 3 Sept. 2020. brighterworld.mcmaster.ca/articles/the-moms-are-not-alright-how-coronavirus-pandemic-policies-penalize-mothers/. Accessed 10 Jan. 2021.

Waring, Marilyn. *If Women Counted: A New Feminist Economics.* HarperCollins, 1988.

World Health Organization. "Disability Considerations during the COVID-19 Outbreak." WHO, 26 Mar., www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1. Accessed 10 Jan. 2021.