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“Falling Off a Cliff”: Mothering Disabled Children through the Pandemic and Beyond

The COVID-19 pandemic has taken a disproportionate toll on the lives of mothers of disabled children. These children have complex needs that require health, educational, and social care support services, but most of these services were cancelled or reduced because of COVID-19-related restrictions. In this article, a group of mother-researchers use a collaborative autoethnographic approach to highlight the essential role that mothers and carework play in social organization; identify gaps in services and systems due to COVID-19 policies; and provide suggestions to transform our social care support systems to better meet the needs of disabled children and their families.

Introduction

The COVID-19 pandemic has taken a disproportionate toll on the lives of mothers. Mothers of disabled children¹ faced additional unique challenges and struggles. These children have complex needs that require health, educational, and social care support services, but most of these services were cancelled or reduced because of COVID-19-related restrictions. For mothers of disabled children, COVID-19 highlighted and accentuated many of the existing cracks in the medical, educational, and social care support systems.

We are a group of mothers and researchers affiliated with a research centre on childhood disability. We are working on a research study to draw on the lessons from the pandemic to identify the services and supports families need moving forwards. In this article, we reflect together (through collaborative autoethnography) on the key themes from our experiences. We will highlight the essential role that mothers and carework play in social organization; identify gaps in services and systems due to COVID-19 policies; and provide

suggestions to transform our social care support systems to better meet the needs of families for a postpandemic recovery. The process of revisiting and recounting our COVID-19 experiences was challenging for us. As one of us put it, “You just don’t want to go back there” (DG). However, we also see value in telling our stories and linking them to what we know of experiences of other mothers who have disabled children because we believe that “You need heart, and you need academia. And you need them to come together to spread this message” (JL).

Background

Disabled children face physical, emotional, and environmental barriers to full participation in everyday activities (Rosenbaum and Gorter). In Canada, 10.6 per cent of children under fifteen years of age have a disability (HRSDC), and this rate rises with age: 13 per cent of children and youth fifteen to twenty-four years of age have a disability (Stats Canada). Disabled children often require the integration of supports and services that meet their medical, social, cognitive, behavioural, physical, educational, and recreational needs and that support their participation in society. This includes medical care, therapeutic supports such as occupational therapy, physiotherapy, speech therapy, behavioral supports, and inclusive educational supports within schools (e.g., resource teachers and aides) (Gardiner et al.). Most of this coordination of everyday support and care is the responsibility of mothers (Blum; Douglas and Klar; Gardiner et al.). During the COVID-19 pandemic, mothers’ care responsibilities rose exponentially in caring for disabled children, and mothers are continuing to experience this in the pandemic’s aftermath (Cacioppo et al.; Houtrow et al.; Rogers et al.).

Mothering and Carework

Mothers are essential to society’s social organization. Carework is disproportionately a labour burden for mothers, as it is gendered and generally the work of women (Charmes). Gendered carework is affected by inequitable social structures, power relations, and social norms that disadvantage women to fulfill carework demands (Dugarova). This labour burden became even more evident and disproportionate during the pandemic, when mothers had even higher responsibility for coordinating most aspects of care for their children (O’Reilly).

Disabled children require additional carework, such as therapies, educational support, and advocacy (Blum; Douglas and Klar). This carework often does not decrease when disabled children grow older; rather, it intensifies (McCann et al.). Mothers are the main caregivers, especially for disabled children

(Douglas et al.). There are moral, social, political, and cultural pressures and expectations that mothers will take care of their children’s physical, emotional, and behavioural needs regardless of the circumstances and that these responsibilities will take precedence over all other forms of work (Knudson-Martin and Silverstein; Runswick-Cole and Ryan). These experiences of caregiving and carework from mothers of disabled children have been largely unknown, hidden, or silenced (Currie and Szabo).

Pandemic and Pandemic Restrictions

During the pandemic, families of disabled children lost access to essential supports and services because of government restrictions that aimed to reduce social interaction and physical contact with others in both private and public spaces. In Canada, these restrictions led to reduced access to community-based services, schools, and medical providers (CPHA); disabled children and their families acutely experienced these losses (United Nations). Children experienced reduced access to medical physicians and specialists, therapeutic supports, recreational supports, such as afterschool programs, as well as school and community-based activities (Capioppo et al.), all of which affected their health and development (Shakespeare et al.). With the closure of schools, children lost access to inclusive education, including specialist forms of education (Shakespeare et al.). They also lost routines and structures, which they often require to participate fully in the world (Asbury and Tosseb; Lee et al; Viner et al.). Furthermore, families lost connection to extended family and social networks and access to other sources of help, such as respite or support workers (Currie et al.).

These closures and reductions had a profound impact on disabled children and their families. Children regressed socially and developmentally and experienced increased mental health challenges, such as anxiety (Lee et al.; Masi et al.). This is likely due to the loss of social connections, routines, and the structure provided by school and community activities. (As we write this two and a half years into the pandemic, some accessible or accommodated programs in our communities still have not reopened). Children also lost therapies in schools and home and had medical treatments and procedures postponed or cancelled (Capioppo et al.; Murphy). These challenges affected the entire family (Breux et al.; Gadermann et al.; Guller et al.; Shorey et al.), resulting in increased carework for parents; they also led to adverse health outcomes, including an increase in mental health challenges, anxiety, stress, and burnout (Diskin et al.; Chan et al.; Currie et al.; Lee et al.; Masi et al.; Whitley et al.)

Earlier research studies showed that the pandemic exacerbated pre-existing gaps in care systems affecting families caring for disabled children (Pozniak

and Kraus de Camargo). Further studies could extend an understanding of how these restrictions affected mothers caring for disabled children in Canada, and these maternal experiences could identify supports and strategies needed to assist families in moving forward in recovery.

Methodology

Collaborative autoethnography (CAE) is an approach that explicitly uses the researchers' own experiences and reflections as data and connects these experiences to larger social or cultural phenomena. It "brings together the self-reflection associated with autobiography, the cultural interpretation associated with ethnography, and multi-subjectivity associated with collaboration" (Chang et al., 17). CAE is carried out collectively by a group of researchers who work together to collect, analyze, and interpret their own combined data to gain a meaningful understanding of the phenomena reflected in their individual accounts (Chang et al.). Researchers can interview each other, analyze each other's reflections, or collect archival data about each other. The process is iterative, typically occurring through several sessions of conversations among researchers, with individual and collective meaning making informing each other.

The authors of this article are partners on a research study that grew out of KP's earlier work on the experiences of mothers of disabled children during COVID-19 (Pozniak and Kraus de Camargo). Four of us are parent investigators (GC, JL, ADK, and DG) and partnered with KP, a postdoctoral fellow, and a larger research team to explore the experience of mothers and disabled children during the pandemic.

Our article grew out of a research presentation at the 2021 Learning from the Pandemic conference. At the time, our entire research team brainstormed ideas, and GC and KP presented them on behalf of the team. Following the conference, the five coauthors used these ideas as a springboard for a collective reflection on our shared experiences and wrote them up together. We held three virtual meetings to discuss our experience and establish common themes, and we also worked asynchronously through a Google document. Each of us contributed to sharing our experiences from the pandemic and to writing the chapter. Below are brief biographies of each author.

Biographies of the Mothers

GC is a family partner and nursing researcher. She focuses on the family experience of disease and disability. She lives in Alberta with two boys who have neurodevelopmental disabilities. Her son has a rare disease and has numerous disabilities; he lost access to all his therapeutic supports for one year of the pandemic and in-person and virtual school for four months.

ADK is a parent partner and stay-at-home caregiver to six children ranging from early elementary age to university age. Several of her children have neurodevelopmental disabilities. She lives in Prince Edward Island, where schools were closed for three and a half months in 2020 and again in January of 2022.

JL is a freelance writer, podcaster, reiki healer, and parent partner in research. She lives in Saskatchewan with her husband and two sons. Her journey into childhood disability and family engagement in research was led by her youngest son, with whom she shares a rare genetic disorder diagnosis. While school was out in Saskatchewan for three and a half months, JL became a work-from-home and homeschooler mom. She is a proud advocate for family mental health, rare disorders, and neurodiversity.

DG is an IT professional and a mother of two young men (one of whom lives with cerebral palsy). She is also an advocate and research partner on numerous studies in childhood disability. She lives in Ontario.

KP is a sociocultural anthropologist and postdoctoral researcher at CanChild Centre for Childhood Disability Research as well as a mother of two elementary school-age boys, one of whom has cerebral palsy. She lives in Ontario, the Canadian province that experienced one of the longest school closures in the world (a total of twenty weeks from March 2020 until May 2021).

Pandemic Impacts on Mothers

Each of us was impacted differently by pandemic-related restrictions due to diverse policies across provinces, length of school closures, and how restrictions were enacted; nonetheless, we identified many shared themes across our experiences that we describe below. All of us are primary caregivers to our children and this continued throughout the pandemic. As mothers, we experienced many gaps in support (e.g., emotional, respite, financial, behavioral, and extended family) and schooling for our disabled children. These gaps were accentuated and amplified with pandemic restrictions and as mothers we were left to fill them.

Missing Out on Learning

As federal and provincial governments implemented policies to curb the transmission of COVID-19, education and learning for children became sidelined. Much is written about the adverse impact of school closures on children (Chaabane et al.; Vaillancourt et al.; Whitley et al.). Although these closures affected all children, for disabled children, they both revealed and magnified pre-existing gaps in access to an inclusive education. During the pandemic, there was a sense that education for children with disabilities was

not as important. When schools moved to online learning, some of our children received no schooling at all for a significant period of time; others received online instruction but not the additional supports they needed to learn (e.g., education assistants). GC, whose son did not receive any schooling at all for the first four months of the pandemic, reflected:

I felt like my son wasn't important enough to provide support for online schooling. I had to insist the teacher call him three times a week for fifteen minutes just so he felt connected to something beyond home during the lockdown. Other children in the public system were receiving online instruction on a regular basis in my province but not special needs children unless you were in a private school. This sent a message that he was not as important because he was disabled.

ADK also shared the variability in terms of virtual learning experiences among children:

Initially we were sent home with a schedule with videos and activities for the children to do.... This juggling of multiple children was very difficult as I spent lots of time with Z and Q, and B [pseudonyms] was not completing the expected work. In January 2022, there was some instruction in the morning with children being expected to complete work independently after that. Again, [Z] required lots of support, [B] needed lots of prompting, and [Q] needed some guidance.

While online learning was a mixed experience for students, for children with disabilities, virtual solutions presented particular challenges. Many of these children could not sit in a chair for long or concentrate on a computer screen. Learning materials were often inaccessible or inappropriate for children's learning requirements. Children could not stay focused on teachers even during virtual class time and would fidget or occupy themselves with something else (e.g., an online game), which was perceived by some teachers as disruptive. This is how JL described it: "[My son] was not cooperative with his EA [educational assistant] virtually. He was labeled 'disruptive.' There was a sense that 'We are not all in this together' [yet] it did not feel like his teacher was on his team and his teacher was just trying to get through the year."

At various stages across Canada, many schools reopened in-person for children who were deemed to need it most acutely, including many disabled children. However, many parents were not informed that their children qualified for in-person attendance, and those who did found that there was still little focus on learning. ADK reflected: "Not every family was able to get schooling, eventually children who qualified for EAs [educational assistants] were allowed into the school system, but it was all play based—no emphasis on

education." DG similarly noted that her son's EAs focused on the routine care tasks—stretching, feeding, and changing—but were not able to help with academics.

Some children made good academic progress at home, provided they received appropriate intense support from caregivers. DG, for instance, noted that before her son returned to in-person schooling, she spent a lot of time reading with him at home, since her son's EA was not allowed to assist during virtual learning. However, the support parents provided during virtual learning came at a great cost. DG, for instance, reported that she only got five hours of sleep at night as she was also working remotely at the time. In reflection, schools might not have been providing individual intense supports before the pandemic, and they might have been inadequate in meeting the needs of some children to begin with.

Missing Out on Therapies and Supports

For disabled children, school is about more than academics, as these children often receive multiple educational and therapeutic supports at school. Children who receive educational supports (e.g., education assistants and resource teachers) either did not have access to them during the school closures or were only able to work with them virtually and for limited periods of time. JL, for instance, noted that when her son lost his EA support, she was forced to assume that role, in effect becoming "on a first name basis with his teacher." Children who received therapies (e.g., speech, behavioural, occupational, and physical) at school similarly did not receive these supports for the duration of school closures and often not after schools reopened. For instance, while ADK's daughter had been referred to be seen and assessed by a school speech pathologist, this did not happen due to COVID-19. The family eventually was able to find one private SLP speech language pathologist (SLP) to assess and work with their daughter. GC's son lost his entire team of therapists—occupational therapy (OT), physical therapy (PT), speech therapy (ST), and behavioural—and it took over a year to get them in a virtual format. Furthermore, neither the parents nor outside supports (e.g., physiotherapists) were allowed into the school to help troubleshoot any issues that arose. DG noted that her son's stander device broke, but neither she nor her son's physiotherapist were allowed into the school to fix it. In effect, her son was not able to use his equipment for months, which he required for physical wellbeing.

Children who received therapy services in the community were no better off, as these services were also initially cancelled and then moved to teletherapy or a virtual platform. Some children were delayed with diagnosis or treatment. For example, when DG's son's wheelchair broke, the physiotherapist who previously used to come in person to check and adjust the equipment was not able to do so. In effect, DG was forced to fix it herself using duct tape and

screws. GC's son struggled with interacting with his therapists over a screen and became easily distracted and then frustrated: "My son did not understand how to connect with his speech or occupational therapist over a computer screen. He would start disengaging during sessions and picking his skin in frustration during these appointments." ADK's son lost one of his specialists who retired because of COVID-19. Prior to the onset of the pandemic, her son was in the process of getting a formal diagnosis, which delayed the process and the support that came with it. Since ADK's province has a shortage of specialists, she was forced to travel out of province for specialist appointments. This became an ordeal due to pandemic travel restrictions, which required her to make the return trip on the same day, without making any stops along the way to break up the journey for her son.

Missing Out on Connections

Pandemic restrictions demonstrated that attending school is also about social dimensions as well as physical and social interactions. Losing these connections affected children's development and wellbeing. As GC explained: "My son regressed socially, as he already has no friends outside of school. He relies on his connections with peers and adults at school to socialize and interact with others outside the home. We had to reteach him how to ask questions and wait for cues from others."

Pandemic restrictions also affected children's ability to have physical contact with important people in their lives, including family members or respite workers. The loss of these connections was difficult for children and deprived mothers of others' support and help. As GC reflected: "You have no one outside of your family, and you're caring for that family." Due to physical distancing requirements or concerns children did not have physical contact with family members, such as grandparents or older siblings who lived away from home. Respite workers were harder to access and more likely to cancel. Pandemic policies and realities also made it more difficult to receive support from live-in partners. For example, ADK's husband had to work from home more intensively than before COVID-19, making it a challenge for her to support her children's online learning by herself while also protecting his workspace from distractions. DG's husband, who travels out of the country for work, ended up getting stuck abroad for two months due to a series of positive COVID-19 tests, leaving her alone to look after her son.

Finally, children lost access to after-school recreational activities, which they needed for physical health and for socialization. For example, DG's son stopped horseback riding and soccer, activities which he had done for ten years and which provided opportunities for both essential exercise and socialization. ADK's son had been in gymnastics for both therapeutic reasons and because he socialized better with his gymnastics group than with his classmates at

school. Instead of gymnastics he did modified soccer but found that the focus on drills and the lack of social interaction was “more of a chore than fun for him” (ADK) and consequently never went back.

Mothers Filled the Gaps

When children lost their education and health supports, mothers had no choice but to step up and fill in the gaps. As a result, many mothers fulfilled multiple roles during the pandemic. Mothers were caregivers to all family members; they became teachers, teacher aides, medical caregivers, behavioural managers, and therapists—often while still working at their own paid jobs. Mothers had to learn new skills and technologies, such as using education platforms for their children’s online instruction. JL summed it up in these words: “You’re mom PT, you’re mom OT, you’re mom SLP, you’re mom tutor.... Mothers are expected to just carry the backpack.”

As a result, mothers were pulled in multiple directions and exhausted. Some mothers experienced mental health challenges from the stress and anxiety of being responsible for everyone. The additional roles imposed took a toll on our mental wellbeing. We felt “lonely and alone” (DG). We felt that we had “lost ourselves” (JL), as we had no time to recharge and to build our own capacities as women outside of being caregivers, teachers, and therapists. Many of us worried that we were never “getting enough done to support” our children (ADK), and we felt guilty that we were not able to devote more time to them. We asked ourselves: “Am I enough? Am I doing enough? Will my kids forgive me? Have I damaged them?” (JL).

The imperative to be teachers and therapists also affected our sense of identity as mothers. We felt that with the additional roles we had to take on, we were not able to be mothers. As JL put it: “I didn’t know where mom ended, and JL began.... I didn’t feel like I had an identity.” ADK added: “You could be mom until 9:00 a.m., until you started schoolwork, and then you were mom again putting them to bed if you managed to get everything else done.” This situation, in turn, affected our relationship with our children, who needed us to be their mothers. JL said that her son would hug her and say, “I just want mom. I don’t want a teacher.”

Lastly, the additional responsibilities also took a toll on our professional lives and commitments from which we are still recovering. For example, GC and KP scaled back on their research work; ADK had hoped to look for a job outside the home but was not able to do so. DG also struggled to balance her work with her caregiving obligations: “I slept less than five hours a day. I just couldn’t keep up with all of it.... My work is my escape from reality; it’s my passion. But there were times when it was a burden as well. I was forgetting stuff and falling behind” (DG).

What Mothers Need (Discussion)

In our discussions, we noted that although mothers are used to having experts, such as clinicians and educators, tell us what we need (and what we need to do for our children!), we usually do not have the ability to ask for what *we* feel we need. We are simply expected to “carry the backpack” (JL). In what follows, we outline some areas of support that we identified through our discussions.

Children Need to Inform Policy

There needs to be consultation with mothers and caregivers as well as the children themselves about the impact of restrictions and supports on families (Krahn; Subramaniam and Villeneuve). Governments can utilize disability advisory committees and virtual support groups across the country to inform policy recommendations. This may require modifying the ways we ask for feedback from children, youth, and families (Abbott; Pluqualiec; Whitney-Mitchell and Evans). For example, disabled children can provide input into important questions for inquiry, interventions under development, and how to learn about the experiences of other children (Ibrahim et al.; Vasalou et al.). Children know what is important to them (Rosenbaum and Gorter). They were not considered when restrictions were implemented, but their voices need to be considered in the “back to better” policies with pandemic recovery.

Offer Flexible Solutions

We must modify policy restrictions for disabled children by extending what has worked well and changing what was not effective. While considering what worked well, all of us identified having access to more hybrid and flexible approaches in healthcare and education. These include virtual medical appointments (e.g., for prescription renewals, general check-ins, and some forms of therapy) and some virtual learning (e.g., when a child is sick and needs to stay home). We noted that virtual appointments reduced time lost due to travel time or waiting for appointments and reduced stress on children from missing school. However, virtual solutions (e.g., virtual appointments and online learning) may offer new possibilities but are not a catch all. For example, we found that virtual appointments were suitable for chronic health situations but difficult when a child needed to be seen for an acute illness. Virtual school curricula required aides and supports for learning, which alienated many disabled children (Bakaniene et al.). These nuanced experiences illustrate that there is no-one-size-fits-all solution. Policy measures must respond to family needs and consider the possibility of both in-person and virtual schooling and therapies, with appropriate supports, depending on the child’s and family’s needs. As ADK put it: “We need flexible solutions so that kids can be there [in person] when they can be there and still feel connected when they cannot.”

Rethink What Constitutes Essential Service

The pandemic sharply illustrated that carework is one of the few truly essential societal activities that does not stop even when the rest of the world shuts down. However, the pandemic’s immense toll on mothers and other caregivers highlighted the need to redefine as essential the activities that directly or indirectly support carework. For disabled children and their families, therapy supports—in a format that works for the family—are needed to allow children to maximize their potential. What mothers need moving forward in “building back better” are hybrid approaches in which therapy formats can be virtual when needed (Camden et al.; White et al.), and providers can also provide regular check-in points by phone, text, email, or home visits so that families can feel connected to support systems (Tosseb and Asbury). If there is a public health emergency, therapists and educational assistants can travel to visit a cohort of families to provide connection and support but still keep the risk of exposure to families low. Finally, at-home supports, such as nursing or respite for family members, are also essential supports, particularly during a time of uncertainty when most services were delayed or cancelled to rebuild parental capacity for caring for their children with complex needs (Colizzi et al.; Edelstein et al.; Nonweiler et al.). Moving forward, respite and support workers need to be properly compensated to reduce turnover and absenteeism and receive proper protective equipment to protect themselves as well as the individuals for whom they provide care.

Sectors Need to Work Together

The experience of the pandemic has also shown us that sectors that are typically seen as separate—including but not limited to healthcare and education—are in fact intertwined. For example, disabled children receive many health supports and therapies at school. Therefore, education and health sectors need to work together with a shared plan at both the provincial and federal level. Providers on the ground often want to work together but are hampered by organizational/structural bureaucracies. For example, when schools closed in-person learning, support was required in the home for education and for therapy that was previously offered in schools. This required recognizing the needs of these children and adapting how support was provided. Families would have benefited from ongoing support and check-ins from school therapists, teachers, family physicians, and community support workers (Fazzi and Galli; Murphy et al.; Narzisi). Moving forwards, measures must be put in place to enable children to catch up on learning and curriculum missed during the pandemic (Shakespeare et al.). For example, therapeutic support, such as physiotherapy as well as speech and occupational therapy, needs to be enhanced to support children who have regressed developmentally during the pandemic (Shakespeare et al.)

Collective Problems Need Collective Solutions

The pandemic highlighted and exacerbated many existing societal challenges. However, for the most part, the responsibility to cope with these challenges has been downloaded onto individuals. In our case, mothers of disabled children have been expected to cope with school and daycare closures as well as the cancellations of healthcare services and other medical, social, and behavioral supports our children need on a regular basis. Our experience of the pandemic highlighted that collective problems need collective solutions.

There needs to be recognition that children's health and wellbeing are a collective societal issue. Children and families need an infrastructure of supports, informed by public policies which are responsive and adaptable for families (Leonardi et al.; Nuri et al.; Schiarit). On the contrary, during the pandemic mothers' existing support structures (e.g., teachers and respite workers) were taken away, creating an untenable situation. GC noted that "These are such unrealistic expectations that these are your children and you're supposed to do it all," with ADK adding: "But how do you do it[carework], if you don't get a break?" To prevent health challenges for vulnerable populations (such as disabled children and their families), essential services and support must be maintained always and further increased during public health emergencies.

Equitable Policies

Finally, the pandemic highlighted existing health and social inequities for priority populations (including but not limited to disabled people), and a health and social system ill equipped to reduce these inequities (Ndumbe-Eyoh et al.). As we emerge from the pandemic, policies assume that "we are all in the same boat" and ignore existing inequities and vulnerabilities. When rebuilding, we need policies and solutions that aim for equity (i.e., giving everyone what they need) rather than equality (i.e., treating everyone the same) (Jesus et al). In effect, equitable solutions will end up benefiting everyone. For example, when the needs of children with disabilities are considered, this benefits everyone, since the same solutions that are good for children with disabilities (e.g., flexibility and individualized supports) are good for all children.

Conclusion

The COVID-19 pandemic illuminated many pre-existing cracks in the support system for disabled children and their families. However, we experienced living through the pandemic as "more than falling through the cracks—it was falling off a cliff" (DG). As the world returns to normal, the everyday for families like ours is not normal: at best, we would call it a "semi-typical

situation” (JL). For disabled children and their families, normal policies were never inclusive to begin with. We need to “build back fairer” (Marmot et al.) and develop equitable inclusive policies for children with disabilities, recognizing key areas for support and transforming policies that were never inclusive to begin with.

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Endnotes

1. As we wrote this article, we grappled with the debates around using person-first versus identity-first language (e.g., Best et al.; Ferrigon and Tucker). We decided to use identity-first language of “disabled” child or children, as that is consistent with the social model of disability, which recognizes the role of societal structures and attitudes in making people “disabled.”

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