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Barriers Experienced by Children with Disabilities and Caregivers During the First Wave of COVID-19: A Social-Ecological Perspective

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Abstract: This paper examines the results of a Pan-Canadian online survey of caregivers of children with disabilities (n=247) that explored the barriers and unmet needs experienced by children with disabilities and their caregivers during the first wave of school closures during the COVID-19 pandemic. A purposive sample of caregivers of children with disabilities between the ages of 4-21 years were recruited through disability advocacy organisations. A thematic analysis was conducted of caregivers' responses to 3 open-ended survey questions not previously examined. The themes were analysed using Bronfenbrenner's ecological systems framework and revealed attitudinal, structural, and

policy barriers to equity and inclusion for children with disabilities and their caregivers at multiple levels of the social ecology. The themes included the microsystem (Multiple and complex roles for caregivers), Mesosystem (Is anyone out there?), Macrosystem (Disability exclusive decisions), Exosystem (Left behind), and Chronosystem (Stress and giving up). Recommendations for policy and practice include strengthening teacher training in inclusive pedagogies, enacting participatory policy co-design that prioritises the needs of children with disabilities and caregivers, increasing regulation of individualised education planning, and providing supports that address the well-being of children with disabilities and caregivers.

Keywords: COVID-19, disability, school closures, inclusive education, caregivers, children, barriers.

Introduction

In the history of pandemics, few have resulted in worldwide school closures. In 1918, the Spanish Flu led to school closures across the United States, Canada, and Europe (Ibrahim, 2020). In the Canadian context, broad-based school closures also occurred in the mid-1900s to contain the spread of Polio (Cuthbertson, 2020). In 2003, an outbreak of severe acute respiratory syndrome (SARS) caused a brief shutdown of schools in Toronto (Perkins, 2003) and in Mainland China, Hong Kong, and Singapore (The Associated Press, 2003). Two thousand nine school closures also occurred during the A(H1N1) influenza pandemic; however, they were limited and mainly in response to isolated outbreaks in specific settings (Cauchemez et al., 2014). In March 2020, The World Health Organization (WHO) declared COVID-19 a global pandemic and required strategic public health actions and social measures to limit its spread (e.g., handwashing, masking, physical distancing) as well as the shuttering of public spaces, which included school closures when wide-spread public transmission was uncontained (World Health Organization, 2020). Despite the history of pandemics, COVID-19 has been described as one of the deadliest because of the exponential infection rates, high death tolls, and significant social and economic costs (Lele & Goswami, 2024).

Problem Statement

There is much evidence that the impact of crises like the COVID-19 pandemic and consequent school closures were disproportionately experienced by vulnerable groups, including children with disabilities and their parents/caregivers (hereafter referred to as caregivers), given their heightened vulnerabilities (United Nations, 2020). A report, *Children with Disabilities: Ensuring their Inclusion in COVID-19 Response Strategies and Evidence Generation* (United Nations Children's Fund, 2020), found that children with disabilities were 57% less likely to have children's books in their homes, 32% less likely to read books or be read to, and 1.7 times more likely to have acute respiratory symptoms. Research in Canada and internationally has affirmed that during school closures, children with disabilities were acutely at risk of adverse outcomes due to disruptions in routines of daily living, the absence of tailored instruction, and limited access to much-needed specialised services that are accessed through school and community including clinical and therapeutic supports, and medical equipment (Arim et al., 2020; Crawley et al., 2020; Lipkin & Crepeau-Hobson, 2022).

In addition to the barriers experienced by children with disabilities, their caregivers were also adversely affected. Pre-pandemic, it was well-established that caregivers of children with disabilities experience elevated levels of stress and depressive symptoms (Masefield et al., 2020). However, COVID-19 significantly exacerbated the complex psychosocial impacts of caregiving for children with disabilities. A study in the United Kingdom reported that caregivers of individuals with intellectual

disabilities had increased feelings of defeat, anxiety, and depression that were two to three times higher than pre-pandemic levels (Willner et al., 2020). Relatedly, a study conducted in Italy found that parents of children with disabilities experienced elevated levels of burnout due to increased caregiving responsibilities and inadequate support (Fontanesi et al., 2020). These findings are consistent with a survey conducted by Statistics Canada in August 2020, which found that caregivers of children with disabilities reported greater levels of concern about their child's social isolation, academic learning, and mental health, as well as their ability to manage their child's behaviour (Arim et al., 2020). Financial hardships due to increased caregiving responsibilities and the consequent loss or reduction in employment for caregivers of children with disabilities also compounded caregiver strain during this unprecedented time (Representative for Children and Youth, 2020). Given these heightened vulnerabilities, we aimed to examine the barriers and unmet needs experienced by children with disabilities and their caregivers during the first wave of school closures in the Canadian context.

Research Focus and Research Questions

A key strength of this study was its timing – survey data was collected from May until September 2020, which coincided with the extension of COVID-19 school closures. Since this study was conducted during the pandemic's peak, there was slight recall bias because events unfolded in real-time. Examining caregivers' insider perspectives during this critical period is important because it shines a light on the longstanding inequities experienced by children with disabilities and their caregivers and illuminates how specific disability barriers were not considered in emergency education plans. This paper examines the responses to 3 open-ended survey questions not previously examined (Bartlett et al., 2022).

The first open-ended question invited caregivers to describe a situation where their child required support but could not receive it. The second question asked caregivers to identify the most significant unmet need during school closures for children/youth with special education needs/disabilities, while the third question invited caregivers to identify the most significant unmet need for caregivers of children/youth with special education needs/disabilities during this time.

The Canadian Context

The educational context in Canada is unique in that each province and territory has the legislative authority to determine educational programming in its local context. During the first wave of COVID-19, this included determining when schools would close and how education would be delivered. On March 12th, 2020, Ontario was the first province to close publicly funded schools, and by April 21, 2020, all Canadian educational jurisdictions had pivoted to "emergency remote teaching" for kindergarten to grade 12 students (Nielsen, 2020). Even though most media accounts referred to the medium of instruction as "online learning" in the weeks following school closures, the term "emergency remote teaching" or ERT was popularised to characterise what was occurring at all educational levels. According to Hodges et al. (2020), ERT involves a,

> *"temporary shift of instructional delivery to an alternate delivery mode due to crisis circumstances…The primary objective in these circumstances is not to re-create a robust educational ecosystem but rather to provide temporary access to instruction and instructional supports in a manner that is quick to set up and is reliably available during an emergency or crisis" (p. 13).*

Acknowledging that the first wave of COVID-19 was a crisis that necessitated a pivot to ERT, it remains essential to examine the extent to which the needs of children with disabilities and their caregivers were considered in emergency education plans. As outlined in the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Convention on the Rights of the Child (United

Nations, 1989), children with disabilities have the fundamental right to an equitable and inclusive education. These protections also include the right to reasonable accommodations to access learning equitably. The importance of accommodations for students with disabilities must be underscored, as approximately half of the youth with disabilities in Canada require an aid, assistive device or accommodation to access learning, which most often includes additional time for tests, an Individualized Education Plan (IEP), technology with specialised software, and modified or adapted curriculum (Statistics Canada, 2019).

In the spring of 2020, an independent, charitable organisation focused on education and policy began monitoring provincial and territorial ministries of education' school closure dates, learning expectations, resources, grades/reporting practices, and areas of focus (People for Education, 2020a, 2020b, 2020c). Their analysis shows that during the first wave of school closures, there was limited direction regarding the need to provide accommodations for students with disabilities. In March 2020, only the British Columbia Ministry of Education (2020) emphasised the importance of continuity in learning opportunities for students with disabilities or diverse abilities to ensure equitable access to learning. Specifically, Continuity of Learning Plans was required for students with disabilities or diverse abilities that aligned with their Individual Education Plans (IEPs). The accessibility of learning opportunities was also emphasised. The lack of consideration for the needs of students with disabilities throughout most jurisdictions in Canada is consistent with the findings of the United Nations Children's Fund (2020), which noted that this population was largely excluded from emergency education plans.

As a part of the mandated school closures, there was limited direction from provincial and territorial educational jurisdictions in Canada regarding the amount of instructional time and methods of instruction (e.g., synchronous or asynchronous) that teachers were expected to provide (People for Education 2020a, 2020b, 2020c). By May 6, 2020, 8 provinces/territories provided recommendations regarding "learning time" as opposed to "instructional time", which typically included 5 hours per week for students in kindergarten to grades 3-6, 10 hours per week for students in Grade 7 to 9, and 3 hours per week for each course for students in grades 10-12 (People for Education 2020b). The limited guidance regarding instructional time and the need for real-time, synchronous instruction disadvantaged students with disabilities, as research affirms the critical role of teacher presence in an online environment (Morrison & Jacobsen, 2023). The focus on learning time instead of instructional time appeared to be directed toward caregivers as a metric they should use in setting expectations for their children's home learning, which also disproportionately increased the pressure on caregivers of children with disabilities as their children may be less independent with learning tasks. These examples illustrate how the needs of children with disabilities and caregivers were not prioritised during the first wave of school closures in Canada. Given these inequities, it was essential to obtain the insider perspectives of caregivers of children with disabilities during school closures to illuminate the barriers and unmet needs they experienced during this time.

Theoretical Framework

The barriers and unmet needs experienced by caregivers of children with disabilities and their children during the first wave of school closures were examined by applying an ecological systems perspective comprised of five interrelated systems, including the micro-, meso-, exo-, macro, and chronosystems (Bronfenbrenner 1979). Bronfenbrenner's (1979) ecological theory provides a holistic framework to examine the complex interplay between the multiple nested environments within which one exists. Applying an ecological systems framework to the experiences of children with disabilities and their caregivers during school closures facilitates an in-depth understanding of the multi-dimensional, contextual factors that impact these vulnerable populations (Shogren et al., 2014).

Methods

After institutional ethical approval, an online anonymous survey was administered to caregivers of school-age children with disabilities between the ages of 4-21 from across Canada. Recruitment occurred through disability advocacy organisations and service providers for children with disabilities (Bartlett et al., 2022).

Sample and Participants

A purposive sample of caregivers (n = 247) of school-age children with disabilities completed the survey. The mean age of caregivers' children was 11.2 years. All provinces and territories except for Nunavut were represented. Most participants (33.2%) were from Ontario, followed by (22.27%) from Manitoba, 15% from British Columbia, 7% from Saskatchewan, 6% from Alberta, 6% from New Brunswick, and 6% from Newfoundland. Prince Edward Island, Nova Scotia, Quebec, and the territories comprised 5% of the total participants (Bartlett et al., 2022).

Caregivers were invited to identify their child's disability and could identify more than one. Therefore, the percentages of reported disabilities do not equal 100 per cent. The most frequently cited disabilities included learning disability (47.37%), autism spectrum disorder (ASD) (36.06%), and attention deficit hyperactivity disorder (ADHD) (34.01%), mental health condition (21.05%), physical disability (14.57%), Deaf/hard of hearing (4.05%), blind/visually impaired (4.05%), Fetal Alcohol Spectrum Disorder (3.64%), no diagnosis/label (2.43%), and other (18.22%) (Bartlett et al., 2022).

Instrument and Procedures

The survey was administered through SurveyMonkey during the months of June-September 2020. The survey comprised 29 questions, including demographic and single-choice, multiple-choice, Likert scale, and open-ended response options. See Appendix A (Bartlett et al., 2022). This paper focuses on the responses to the three open-ended questions, which invited participants to respond freely, all with a response rate > 99%.

Data Analysis

Applying Braun and Clarke's (2006) 6 phases of thematic analysis, two research team members analysed the anonymised open-ended survey data for the three questions of interest using NVivo, which involved reading and coding the data. The researchers' conceptualisation of the barriers and unmet needs during COVID-19 school closures as a social-ecological phenomenon evolved throughout the analysis. While this framework informed the analysis, it did not predetermine it. After the initial set of codes were generated, the codes were analysed, and the themes and subthemes were jointly identified and mapped to the ecological system they best represented. After reviewing and naming the themes, the frequency of sub-themes was determined to reveal the commonness of the perspective among the participants.

Results

Five overarching themes were identified within the social ecology, and they included:

1) Microsystem: Multiple, Complex Roles - which involved the pressure to perform specialised functions, adapt instruction and materials, and balance multiple life demands.

2) Mesosystem: Is anyone out there? – which included a lack of direct, synchronous instruction, feelings of isolation, and limited communication

3) Exosystem: Disability exclusive decisions – which included reductions in or the elimination of disability-related services from clinicians, educational assistants, and respite.

4) Macrosystem: Left behind – which included individualised educational needs not being attended to and feeling uncared for and forgotten by the services charged with providing support.

5) Chronosystem: Hopelessness and giving up – which included significant stress and caregivers expecting less from their children.

Each theme and associated sub-themes will be described, and illustrative quotes will be provided to capture the caregivers' perspectives that were obtained. See Table 1.

Table 1

Themes/Sub-Themes, Occurrence and Illustrative Quotes

Themes Sub-Themes	n – 223–234	%	Illustrative Quotes
Microsystem: Multiple and Complex Roles			
Pressure to perform specialised roles	44	19.13	I don't know what my son needs. I'm not an educational specialist!
Having to adapt instruction/materials	42	18.26	Kids were given a novel study – no audio format, questions written above academic abilities, and no adaptations or modifications.
Balancing multiple demands	28	12.17	Assuming we can and have the time and ability to teach, work, parent and care for our needs. My own needs have been severely neglected…
Mesosystem: Is anyone out there?			
Lack of direct synchronous instruction	92	40	There was NO teaching done in this period. It was all self-learning, and for a kid with LD and ASD, this is overwhelming.
Feelings of isolation	72	31.30	Complete isolation from peers. Friendships are already a struggle, and the minimal Zoom meetings were with large groups of kids with minimal interaction.
Limited communication	33	14.34	I had reached out to all of her teachers to express the need for additional support or teaching opportunities but received nothing in return.
Exosystem: Disability-exclusive decision			
No specialist support	57	24.78	My child had direct access to OT, PT and SLP at school, and I haven't heard anything at all from these resources. He has severe oral motor skill deficits and moderate gross motor planning deficits.
Cuts to respite	38	16.52	Respite! No respite whatsoever from 100% caregiving for my 3 children under the age of 10, the 5 yr. old with Down syndrome.

Themes Sub-Themes	n – 223–234	%	Illustrative Quotes
Limited educational Assistant Support	29	12.60	I spent many weeks waiting for the EAs to be "trained" on Microsoft Teams, and then they were laid off a few weeks later.
Macrosystem: Left behind			
Individualised education needs not. attended to	114	49.56	The school closure put a stop to my child getting his IEP. I asked for a copy of his IEP and never got one; I asked for individualised work and never received it; the teacher never reviewed the work we did complete.
Feeling uncared for	73	31.73	No one cares.
Feeling forgotten	44	19.13	We were forgotten about during the last 3-4 months.
Chronosystem: Hopelessness and giving up			
Increased/significant stress	92	40	The loss of multiple supports for special needs children resulted in a significant increase in stress in what was already a very trying situation. This, combined with the loss of opportunities for self. Care made it difficult for parents to maintain good mental health during this time. My child was experiencing overwhelming anxiety.
Accepting less from the child	10	4.34	When online learning began, I emailed several times to figure out where the learning was taking place, but her learning needs weren't met. Then, we gave up because it wasn't worth the added stress. We were told we are getting all there is.

Source: Authors' development.

Microsystem

Theme: Multiple, Complex Roles. The microsystem includes patterns of activities and interpersonal relations in the most immediate environmental setting, including the relationships between a caregiver and child.

Subtheme – Pressure to Perform Specialist Responsibilities. In addition to balancing multiple demands, parents described the need to take on what they characterised as "specialist" responsibilities to accommodate their child's diverse needs, which resulted in a significant shift in the parent-child relationship.

I don't know what my son needs. I'm not an educational specialist!

Subtheme – Having to Adapt Instruction/Materials. The need to be a "specialist" was attributed to what parents described as a "one size fits all" approach to instruction and a lack of differentiation and adaptation of instructional material provided by teachers.

Kids were given a novel study – no audio format, questions written above academic abilities, and no adaptations or modifications.

Subtheme – Balancing Multiple Demands. During school closures, caregivers reported that they were required to balance multiple demands beyond their parenting role in addition to parenting.

Assuming we can and have the time and ability to teach, work, parent and care for our needs. My own needs have been severely neglected…

Mesosystem

Theme: Is anyone out there?. The mesosystem includes the interactions between an individual's microsystems (e.g., caregiver-school, children-school, children-peers).

Subtheme: Lack of Direct Synchronous Instruction. One of the most frequently cited barriers and unmet needs for children and caregivers was the absence of synchronous, direct instruction.

There was NO teaching done in this period. It was all self-learning, and for a kid with LD and ASD, this is overwhelming.

Subtheme: Limited Communication. In addition to limited synchronous instruction, infrequent communication with school personnel was also reported as a barrier and unmet need for caregivers and children.

I had reached out to all of her teachers to express the need for additional support or teaching opportunities but received nothing in return.

Subtheme: Feelings of Isolation. Limited synchronous instruction and infrequent communication with school personnel were further described as contributing to feelings of isolation from critical social networks for both caregivers and children.

Complete isolation from peers. Friendships are already a struggle, and the minimal Zoom meetings were with large groups of kids with minimal interaction.

Exosystem

Theme: Disability Exclusive Decisions. The exosystem includes the environments in which an individual may not directly interact but affect them (e.g., school district and social service policies).

Subtheme: No Specialist Support. When identifying barriers and unmet needs, caregivers described reductions and, in some cases, eliminating specialised academic, social-emotional, clinical, and therapeutic support.

My child had direct access to OT, PT and SLP at school, and I haven't heard anything at all from these resources. He has severe oral motor skill deficits and moderate gross motor planning deficits.

Subtheme: Limited Educational Assistant Support. Parents also described how access to educational assistants was severely curtailed, which some attributed to layoffs by school districts.

I spent many weeks waiting for the EAs to be "trained" on Microsoft Teams, and then they were laid off a few weeks later.

Subtheme: Cuts to Respite. In addition to reductions in the support provided by the school system, the cancellation of respite support by other social service providers was also cited as a barrier and unmet need.

> *Respite! No respite whatsoever from 100% caregiving for my 3 children under the age of 10 and the 5 yr. old with Down syndrome.*

Macrosystem

Theme: Left Behind. The macrosystem includes broader societal attitudes, ideologies, and norms in which the individual is immersed (e.g., attitudes toward disability). During school closures, this includes normative beliefs and practices that reflect what and who are valued.

Subtheme: Individualized Educational Needs not Attended to. Overwhelmingly, caregivers indicated that their children's individualised educational needs were not considered.

> *The school closure put a stop to my child getting his IEP. I asked for a copy of his IEP and never got one; I asked for individualised work and never received it; the teacher never reviewed the work we did complete.*

Subtheme: Feeling Uncared for. Consequently, parents expressed that they and their children felt no one cared about them and their needs.

> *No one cares. They learn differently, so it's too much work to try to accommodate them.*

Subtheme: Feeling Forgotten. Caregivers also described how they felt that the school system and service providers had forgotten them and their children.

> *We were forgotten about during the last 3-4 months.*

Chronosystem

Theme: Hopelessness and Giving Up. The chronosystem refers to environmental and sociocultural events and their impact over time (e.g., the prolonged effect of COVID-19 on all systems).

Subtheme: Increased/Significant Stress. Due to the complex, multi-faceted barriers influencing all ecological systems (e.g., increased demands, insufficient and inadequate support, isolation), many parents reported that they were experiencing stress and anxiety and that their children were experiencing similar feelings that often manifested in social, emotional, and behavioural challenges.

> *The loss of multiple supports for special needs children resulted in a significant increase in stress in what was already a very trying situation. This, combined with the loss of opportunities for self. Care made it difficult for parents to maintain good mental health during this time.*

Subtheme: Accepting Less from the Child. Feelings of defeat and despair also arose, and some parents indicated that they eventually gave up advocating for support as a form of self-preservation.

> *When online learning began, I emailed several times to figure out where the learning was taking place, but her learning needs weren't met. Then, we gave up because it wasn't worth the added stress.*

Discussion and Recommendations

Our findings demonstrate that the need for parents to adapt materials and take on specialised roles is a unique experience within the parent-child microsystem for families of children with disabilities, which created increased tensions within this relationship. Similar findings regarding the need for caregivers of children with disabilities to adapt instructional materials and attempt to differentiate instruction during the first wave of school closures have also been noted in other contexts (Asbury et al., 2020; Neece et al., 2020; Representative for Children and Youth, 2020; Vaterlaus, 2021). The lack of accessibility of instruction illuminates the need for enhanced teacher training in areas such as differentiation (D'Intino & Wang, 2021) and Universal Design for Learning (UDL) (Rusconi & Squillaci, 2023). Our findings also illustrate the need for enhanced teacher training in online pedagogies, as research affirms that pre-service and in-service teacher training in Canada has not prioritised the development of these skills (Archibald et al., 2020). While concerns regarding the need for enhanced teacher training in inclusive pedagogical practices are longstanding in Canada (Massouti, 2021; McCrimmon, 2015), the failure of schools to provide appropriate educational programming for students with disabilities during COVID-19 reveals the pervasiveness of this issue.

Findings from this study demonstrate that the interactions within the mesosystem were infrequent and often inaccessible for students with disabilities and their caregivers, which exacerbated disengagement with learning and feelings of social isolation. Related research involving parents of children with disabilities in the United States during COVID-19 school closures reported similar concerns. It emphasised the importance of explicit instruction for students with disabilities (Kim & Fienup, 2021) and regular communication with caregivers (Lipkin & Crepeau-Hobson, 2022). The limited provincial/territorial guidance from ministries of education regarding teaching/learning expectations (e.g., number of minutes of instruction, modality) and communication with caregivers disadvantaged students with disabilities and their families. In an examination of the effects of COVID-19 on the early childhood experiences of caregivers of children with disabilities in Canada, Underwood et al. (2021) noted similar examples of procedural biases within the educational system and other services that "centred non-disabled experiences (i.e.., ableism)" (p. 18) and contributed to the exclusion of children with disabilities and their families.

The gaps in access to school-based supports (e.g., school psychologists, speech and language therapists, occupational therapists, physiotherapists, educational assistants) as well as respite and day programming that were reported in this study provide further evidence of what Guidry-Grimes et al. (2020) describe as, "structural disability bias that may distort how crisis standards of care are put into practice" (p. 28). These discriminatory policy decisions within the exosystem revealed deep structural inequities in the provision of support for persons with disabilities. As the pandemic progressed, some jurisdictions made provisions for students with disabilities to return to school to access disability-related supports and some disability-related services, including respite, resumed (Manitoba, 2022). However, research indicates that the learning loss and skill regression that resulted from lapses in support were significant for marginalised groups, and the long-term implications of these discriminatory practices are still unfolding (Gallagher-Mackay et al., 2021). In an evaluation of responses to COVID-19 for persons with disabilities in Canada, Seth et al. (2022) recommended the engagement of persons with disabilities and community organisations in a process of participatory policy co-design to identify shortcomings and re-envision policy responses to crises in the future. Given the local autonomy of school districts across Canada, school districts should similarly engage students with disabilities and caregivers to obtain their perspectives and enlist their leadership in critical policy decisions instead of employing top-down approaches like those enacted during the pandemic.

The macrosystem comprises a society's values and laws and reflects what and who is valued. The reported lack of consideration for the individualised educational needs of children with disabilities in this study raises significant concerns about the institutionalised norms of exclusion that are evident within the macro system. Affirming our findings, similar studies in Canada during the pandemic highlighted the lack of attention to the individualised educational needs of this population and the need to improve oversight at the local and provincial levels (Rolland, 2020).

Our findings also indicate that the pandemic constituted a significant adverse life event in the chronosystem for children with disabilities and caregivers as the intersectional barriers that they experienced compounded over time. Caregivers in our study reported high levels of caregiver strain and heightened emotional and behavioural challenges for their children, consistent with other research (Arim, 2020; Representative for Children and Youth, 2020). The compounding effects of the pandemic also contributed to some parents giving up and accepting less for their children over time. Research conducted in the Netherlands also noted a reduction in parental advocacy when caring for a child with disabilities during the pandemic (Embregts et al., 2021). This finding is important to highlight as parental advocacy has been critical in securing the rights of children with disabilities to equity, inclusion, and protection from discrimination (Hutchinson et al., 2014). Social support for children with disabilities and their caregivers during the pandemic through peer mentorship and parent-peer support partners contributed to improved psychological well-being (Rakap et al., 2022; Smith et al., The importance of social support must be underscored as social connectedness may buffer parenting stress, improve family functioning, and enhance mental health and quality of life, and as such should be prioritised, particularly during times of crisis.

Limitations

Our study has several limitations that must be discussed. First, the respondents were likely from households with greater levels of health consciousness, health literacy, and resources, thus limiting the generalizability of the results to all caregivers of children with disabilities. Second, since the survey was online, respondents had access to technology. Therefore, the results do not reflect the perspectives of those experiencing digital exclusion due to older age, higher support needs, and lower socioeconomic status (Chadwick et al., 2022). Third, given the self-report nature of the survey, it may be subject to social desirability bias. Finally, not all provinces/territories were equally represented, so the views expressed do not reflect all regions in Canada to the same extent.

Conclusions

The COVID-19 pandemic and school closures illuminated the complex, intersectional ways that “marginalisation creates vulnerability” (United Nations, 2020, p. 11). Specifically, our findings indicate the detrimental effects on children with disabilities and caregivers when barriers are experienced at multiple levels of the social ecology. While one of the UN’s Universal Values is “Leave no One Behind” (United Nations Sustainable Development Group, 2022), the insights gained from this research have illuminated the longstanding attitudinal, structural, and policy barriers to equity and inclusion for children with disabilities and their caregivers in the Canadian context. Since the study was conducted during the pandemic's peak, it provides key insights into the perspectives of caregivers of children with disabilities during this unprecedented time. The findings further illustrate the need to disrupt discriminatory attitudes and practices on multiple fronts and across multiple systems to ensure equity and inclusion for all. A multi-faceted and integrated approach is needed, one that ensures uninterrupted access to inclusive, equitable education, access to disability-related services for both children with disabilities and caregivers at all times, including during crises, and prioritising the voices of persons with disabilities and caregivers in policymaking.

Suggestions for Future Research

Future research should revisit the perspectives of Canadian caregivers of children with disabilities to determine whether the gaps and unmet needs that were experienced during the pandemic have been remedied. This should also include an examination of the substantive policies that have been enacted to address the needs of children with disabilities and their caregivers. Each Canadian province and territory has jurisdiction over education. Therefore, this will require an examination at the local level. Given the ongoing threat of another pandemic, it is essential to reflect on past practices and the lessons learned to ensure that proactive measures are taken to protect persons with disabilities from future injustice.

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Conflict of Interest

None.

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Appendix A – Survey Questions

SC = single choice

MC = multiple choice

OE = open ended

* = allows for "Other" (free answer)

1. In what province/territory do you live? (SC)
2. Please identify your caregiving role. (SC*)
3. What is your child /youth's living situation? (SC*)
4. In addition to you, who is currently available to help meet your child/youth's needs in the home? (MC*)
5. What is the age of your child/youth with special education needs? (SC)
6. If your child has a diagnosis, please identify their special education need? (MC*)
7. In what areas does your child/youth require support? (MC*)
8. Of the needs you identified, how well would you say the school is addressing your child's needs during the school closure? (SC)
9. Has an Individualized Education Plan – IEP been developed to support the academic, behavior, social and/or emotional, physical, health, and life skills needs of your child/youth while learning at home? (SC)
10. If yes, how satisfied are you with the plan (IEP) that has been developed for implementation at home? (SC)
11. If an Individualized Education Plan (IEP) has been developed has there been a formal review meeting with all support providers to assess your child's progress and review goals since the school closure occurred? (SC)
12. What impact has the school closure had on your child/youth? (MC*)
13. Please provide an example of the impact of school closure on your child. (OE)
14. What impact has the school closure had on you as a parent/guardian? (MC*)
15. How many minutes/hours on average per day is your child receiving remote instruction/support from a teacher (e.g., classroom teacher, resource teacher, special education teacher)? (SC*)
16. How many minutes/hours on average per day is your child receiving remote instruction/support from other school services (e.g., speech and language, occupational therapy, physiotherapy, psychology, social work)? (SC*)
17. Is the remote instructional time that your child/youth is receiving sufficient to address their needs? (SC)
18. Do you have sufficient technological resources to support your child's learning (e.g., Wi-Fi, laptop, scanner, printer, communication devices)? (SC)
19. If you answered no, have you been offered additional resources from the school division/district or school? (SC)

20. How confident do you feel to support your child's learning at home? (SC)

21. How satisfied are you with the support your child has received from their school to use technology (class apps, websites, communication tools etc.) at home? (SC)

22. How confident do you feel in your child's ability to use and benefit from remote learning? (Apps, websites, communication devices, etc.) (SC)

23. What supports from the school has your child found most helpful? (MC*)

24. What support does your child require from the school that they have not received? (MC*)

25. Please provide an example of a situation where your child required support but was unable to receive it. (OE)

26. What supports from the school have you as a parent/guardian found most helpful? (MC*)

27. What supports from the school do you need as a parent of child with special education needs during school closure? (MC*)

28. What would you identify as the most significant unmet need for children/youth with special education needs during school closures? (OE)

29. What would you identify as the most significant unmet need for parents/guardians of students with special education needs during school closures? (OE)