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**Research Article** 

# The Impact of Covid-19 on Families of Children with Developmental Disabilities in Canada: A Systematic Review on Parental Stress and Coping Strategies

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## **Abstract:**

Background/Aim: Quarantine restrictions and the suspension of in-person learning have posed significant challenges and stress for parents while negatively affecting children's behavioural, social, and emotional development. Parents of children with developmental disabilities (DDs) face additional difficulties across various of developmental domains and often experience heightened strain, low mood, mental health-related symptoms, and distress. During COVID-19, parents of children DDs have reported higher levels of parental stress, anxiety, along with lower levels of psychological well-being than those of children without DDs. The aim of this systematic review was to provide a comprehensive perspective through reviewing the existing literature to explore the parental stress encountered by parents of children with DDs due to COVID-19, and their coping strategies they employed for supporting their children in adapting to ongoing learning activities and addressing social-emotional needs during the COVID-19 crisis.

Materials/Methods: A systematic extensive search was conducted in several databases including PubMed, CINAHL, PsycINFO, ERIC, Google Scholar, and Google internet in English were used for the keywords search (i.e., parental/family stress/challenges, parents/caregivers, child/children with DDs, autism, ADHD, Neurodevelopmental Disorders, coping, strategies, COVID-19, pandemic, Canada), and thirty-one articles (including peer reviewed published articles and graduate school theses (between 2020 and 2024)) were included in the review based on inclusion and exclusion criteria. Two reviewers will independently screen the literature and extract data. A thematic analysis involves reading through the findings and themes was generated and confirmed. Article summaries were charted.

**Results:** Themes of parental stressors were identified include disruptions to daily routines and increased workloads, difficulties in managing children's emotional and behavioural problems leading to parental frustration, limited access to resources and various forms of support, experiences of mental health problems, experiences of social isolation, and reduced self-efficacy. Coping strategies highlighted include fostering family-teacher partnerships and psychological interventions are essential, creating a structured daily schedule, providing support and utilizing new technologies for online learning, promoting self-efficacy and resilience, and ensuring access to protective measures.

**Discussion:** Parents of children with DDs need specific attention and resiliency to face these challenges, family-friendly policies can help parents have a more balanced and adaptable life during the pandemic. More social support from family, friends, school, and the broader community are needed for parents of children with DDs.

Conclusions: Parent stress increased significantly during COVID-19 pandemic when raising children with DDs due to pandemic lockdown measures. The systematic review outlined sources of stress and summarized supportive coping

strategies. Our findings suggest that public health interventions should focus on addressing specific stressors and promoting effective coping strategies while considering the unique needs of these families to mitigate the impacts of pandemic.

**Key words:** developmental disabilities; systematic review; caregiver; stress; coping strategy

#### Introduction

COVID-19 pandemic emerged as a major global crisis, posing a significant threat to public health, and profoundly disrupting daily routines, work, education and social connections worldwide [1,2,3] Quarantine measures, including social distancing, and lockdowns, created unprecedented challenges. These included the closure or suspension of health and social services, schools, and daycares centers. The cessation of in-person learning promoted a swift transition to remote education, significantly altering most in-person social, educational and therapeutic programs [4,1,5,6,7,8] increasing stress levels [9], which let to negative mental health consequences, including psychological distress, depression, and anxiety among parents and caregivers. [10,11,12,13,14,15]. Additionally, children with disabilities experienced significant disruptions affecting their behavioral, social, and emotional development [16,17,18,19,20,21].

Those with developmental disabilities (DDs), particularly children, faced heightened infection risks and struggled to access therapies, maintain physical distancing, and adapt to routine changes [22,23]. Research highlights those individuals with autism faced additional challenges, particularly in accessing essential therapies and coping with disruptions in their daily lives [24]. The global public health emergency significantly heightened mental health risks for families of children with DDs [13,25,26]. Parents of children with DDs faced economic challenges, social marginalization, and elevated stress due to the abrupt disruptions in their routines [27,28,29,21]. Stressors included fears of infection, financial losses, employment insecurity, stigma, and difficulties accessing food, medication, and essential services such as transition to telehealth [1,30,16,31,32,33].

Parental stress, defined as "a state which arises from an actual or perceived demand capability imbalance in the parent's functioning, which is characterized by a multidimensional demand for adjustment or adaptive behavior" [34, pg. 9]. Factors such as limited access to protection materials, inaccessible information, service closures, and disrupted routines, including poor sleep, reduced exercise, and lower diet quality have been shown to negatively affect parental well-being [27,35,29, 36,37,35,29,36,37,33]. Research shows that parents of children with DDs are at a significantly higher risk of depression or other mental health challenges compared to parents of typically developing children in Canada [38,39,40,41,42]. In Canada, one in 16 children is diagnosed with a DD, such as autism, cerebral palsy, ADHD, or metabolic-genetic disorders, which affect cognitive, language motor, and behavioural development [43].

Recent studies indicated that Canadian parents of children with DDs faced heightened concerns and challenges during COVID-19. Key challenges included school closure, shift to remote learning for the educational transitions, concerns about academic success, online safety, lack of accessible information and supports, and disruptions of diagnostic services [1,44,45,35,28,29,46,16], longtime waiting list for children's assessment, managing increased screen time on electronic devices, loneliness due to lack of social connections and being isolated, and reduced physical activity due to insufficient play spaces [1,44,45,28, 46,16,51], eating junk food [45], and struggles with remote learning, nearly half expressing concerns in academic remote learning [45,28]. Especially, racialized families of children with DDs faced different

barriers such as inadequate government funding, inaccessible services, long wait times mental health care, systemic racism, limited school support, inadequate school support, and poor interprofessional collaboration [45,46]. Parents also reported concerns about their children's physical and mental health, caregiver fatigue and exhaustion elevated stress, and anxiety levels [44,45,35,47,29,16,15], lack of social support, worsened financial security, and loss the essential services [35,47,16], limited socialization for children [44,45,47,48,49], difficulties to manage children's behaviours [35,28,46,48,16,49,50], and reduced patience, poor and harsh parenting behaviours, admitted to scolding, or yelling at their children [50]. A recent study [49] used mixed methods found that caregivers of children with disabilities and developmental delays had lower scores in accessing resources and social support, and lower self-care than ones of children without developmental delays in the quantitative study, and also the qualitative results showed that caregivers identified negative impacts from COVID-19, including many disruptions in children's regular daily routine and structures, mental health problems, increased financial burdens, limited access to support services, and interventions.

Researchers emphasized the need for practical coping strategies and sufficient support to help families of children with DDs manage challenges and deal with the burden of increased care demands during COVID-19 in Canada [1,29,50]. Many parents actively sought available resources, including school and community tailoring services, ensure continuity of care, rehab, primary care, acute care, mental health support, various therapies and educational assistance, and online social programs and virtual platforms, to help their children to avoid social isolation and maintain a sense of connection [1,47,48,51,52,53]. Parents reported keeping safe during pandemic were essential, educating children with DDs to follow the appropriate requests and measures to avoid the infection from COVID-19 virus [16,49].

Parents and caregivers reported helping their children participate in daily family routines, understand children's needs [48], incorporating regular times for learning, meals, play activities and relaxation time with the family members. They shared activities provided opportunities for communication and strengthened families' cohesion [44,48,16]. Parents created some physical activities, organized children's leisure activities, and arranging virtual meetups with relatives and friends to support their social connections and overall well-being. Moreover, parents used positive reinforcement strategies to provide feedback to children with DDs. This approach encouraged active learning and maintained their children's enthusiasm for exploration, avoiding the stress and overwhelm often associated with setting overly ambitious goals [44,54,55]. Additionally, coping strategies for autistic individuals and their families during the COVID-19 in Canada emphasized the importance of fostering resilience, self-efficacy, acceptance, and positive family function [1,16, 56,51].

Given COVID-19 pandemic presented significant negative impacts on families of children with DDs in Canada, it is important to support their mental health and well-being of parents with children with DDs to deeply understand their challenges and effective coping strategies during and after pandemic. This systematic review aimed to synthesize findings from research on challenges and copings of families of children with DDs,

incorporating commentary, brief report, scoping review, quantitative, qualitative, and mixed-method studies provide a comprehensive perspective to examine existing literature on 1) parental stress as the unique challenges faced by caregivers of children with DDs during COVID-19 and 2) their coping strategies in Canada during pandemic for providing support and assisting their children with DDs in adapting to the continued learning activities and social-emotional needs during or after COVID-19 crisis and to consolidate parenting interventions.

#### **Methods**

A systematic review of the extensive search was conducted, including search strategies, eligibility criteria, what data was extracted from the selected research articles, and what the variables of interest were. Online databases (PsycINFO, CINAHL, PubMed, MEDLINE, EBSCOhost, ERIC, and Google Scholar), the internet (Google) from January 2020 to June 2022 in English were used for the keywords search (i.e., "parental/caregiver/family stress, not (before 2020)", AND "coping,

strategies for parents of child/children (≤12 years old) with developmental disabilities" OR "autism, or ADHD, or neurodevelopmental disorders", AND "COVID-19/coronavirus/pandemic" AND "Canada"). The following eligibility criteria for inclusion were used to select articles for this study: (1) written in English; (2) published after 2020; (3) were full-text articles; (4) identified stressors and coping strategies for parents/caregivers/families of children with DDs (5) Canada. Articles not relevant to the research aims were all excluded from this study. A second round of searches were in September and November 14<sup>th</sup> of 2024 to identify new empirical studies that were published after the original search time period. Exclusion criteria included conference abstracts, published in other languages, guidelines, and syllabus materials. Thirtyone articles (including peer reviewed journal articles, graduate school theses (between 2020 and 2024)) were included in the review based on inclusion and exclusion criteria (see Figure 1).

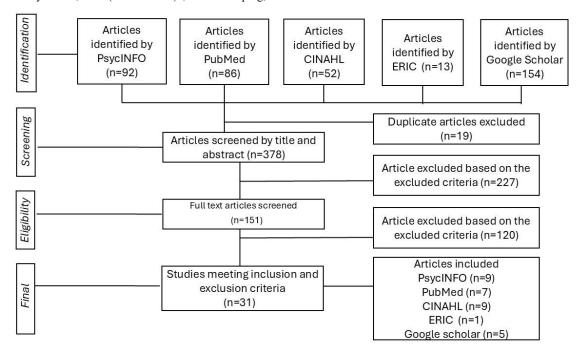


Figure 1: Flow-chart depicting the search strategy in the review.

Two reviewers independently screened the title, abstracts, findings of the articles, read the full texts to assess eligibility and determine if the selected articles met the inclusion criteria, and extracted information from each article and categorized themes related to the impact of COVID-19 on parental stress and coping strategies during the pandemic. Any disagreements regarding the content themes were solved through

discussions. A thematic analysis involves reading through the findings and themes was generated and confirmed. The following data items were extracted for each study, including the authors' name, year of publication, study design, aim of article, main findings, sample characteristics, and method of data collection. Article summaries were organized in a chart format (see Table 1).

No	Author(s) /Date published	Title	Journal	Type of crew of the participants	Categories Peer- reviewed Qualitative Report Editorial	Aim of article	Main findings
1	Ameis, S.H.,	Coping,	Molecula	Autism	Commentar	To foster coping	Regular care systems are
	Lai, M.C.,	fostering	r Autism		у	strategies and enhance	not sufficient to meet the
	Mulsant,	resilience, and				resilience not only for	needs of the autism
	В.Н.,	driving care				both individual with	communities since people
	Szatmari, P.	innovation for				autism and their family,	have shifted to online
	(2020).	autistic people				but also for the autism-	school and increased use

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		and their families during the COVID-19 pandemic and beyond.				friendly changes in healthcare, social systems, and the broader socio- ecological	of remote delivery of healthcare and autism supports during COVID- 19. Using more telehealth platforms had a positive impact on both care and research and could help to address key priorities for the autism communities.
2	Arim, R., Findlay, L., Kohen, D. (2023)	The impact of the COVID-19 pandemic on Canadian families of children with disabilities.	Gender, Diversity and Inclusion Statistics Hub	84% children with cognitive, behavioural, and emotional problems (such as ADHD).	Report	The purpose of this report was to examine differences in experiences between families of children with and without disabilities during the COVID-19 pandemic as reported by parents or guardians of children aged 0 to 14 years	Crowdsourcing participants' various concerns for their family were similar between parents of children with and without disabilities, a higher proportion of parents of children with disabilities were very or extremely concerned for their children's amount of screen time, loneliness or isolation, general mental health, school year and academic success.
3	Buchanan, T., Phung, N., Hammoud, M., Kjartanson, K., & Friesen, A. (2024).	Parental concerns during the COVID-19 pandemic: Intersections for racialized mothers of children with disabilities.	Journal of Child and Family Studies	Children with disabilities (including special needs)	Quantitativ e study	To examine how parenting as a racialized mother who has a child with a disability (also including ASD) impacted concerns for children and family during the pandemic; and to examine how these experiences depend upon the family life stage of these mothers.	This study emphasizes the importance of intersectional considerations during the early pandemic relating to parenting for racialized mothers of children with disabilities. Parents with only preschool children were less concerned for children but reported slightly higher levels of family concerns.
4	Cardy, R.E., Dupuis, A., Anagnostou, E., Ziolkowski, J., Biddiss, E.A., Monga, S., Brian, J., Penner, M., & Kushki, A. (2021)	Characterizing changes in screen time during the COVID-19 pandemic school closures in Canada and its perceived impact on children with autism spectrum disorder.	Front Psychiatr y	Children with autism spectrum disorder.	Quantitativ e study	To characterize the change in screen time during COVID-19 school closures for children with ASD, and (2) examine the parent perceived impact of screen time on mental health and quality of life of children and their families.	Compared to the community sample, the ASD group had a significantly higher screen time use before and during the COVID-19 pandemic school closures. Gender was a significant predictor of parent perceived mental health and quality of life, with male gender associated with a higher likelihood of negative impact of quality of life and mental health. Parents' most frequently endorsed emotions toward screen time were guilt, frustration, and worry.
5	Colucci, L., Smith, J. A., & Browne, D. T. (2023).	Parenting and pandemic pressures: Examining nuances in parent, child, and family wellbeing concerns during COVID-	Frontiers in Epidemi ology	Children and some children with disabilities (e.g. autism)	Quantitativ e study	To know about the areas of family life parents are most concerned about and how these worries relate to well-being across the family system.	Higher child and family concerns were reported by parents who had not attended university, those who had experienced employment loss or reduced hours, and families with all adults working outside the home.

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		19 in a Canadian Sample. Frontiers in Epidemiology					Parents of children with a disability reported higher concerns across all three domains: child, parenting, and family psychosocial well-being.
6	Currie, G., Finlay, B., Seth, A., Roth, C., Elsabbagh, M., Hudon, A., Zwicker, J. (2022).	Mental health challenges during COVID- 19: perspectives from parents with children with neurodevelopme ntal disabilities.	Internati onal Journal of Qualitati ve Studies on Health and Well- Being	Children with neurodevelopm ental disabilities (NDDs)	Qualitative design	To understand the impacts of these public health measures and restrictions on mental health from the perspective of parents with children with NDDs to inform pathways for public health policies responsive to the needs of this population.	Generic policy measures contributed to many gaps in families' social support systems and contributed to mental health challenges for children and their parents. Four themes emerged: 1) lack of social networks and activities, 2) lack of access to health and social supports, 3) tension in the family unit, and 4) impact on mental health for children and their parents.
7	Currie, G., Materula, D., Gall, N., Lachuk, G., Richard, C., Yohemas, M., Dewan, T., Gibbard, W.B., & Zwicker, J. (2023)	Care coordination of children with neurodevelopme ntal disabilities a nd medical complexity duri ng the COVID- 19 pandemic: Ca regiver experien ces.	Child: Care, Health and Develop ment	Children with n eurodevelopme ntal disabilities	A qualitative descriptive design	To examine the implications of pandemic restrictions on care coordination from caregiver perspectives. These experiences can inform emergency preparedness planning and recovery strategies.	Two themes emerged: (1) disruptions to care coordination from initial COVID-19 restrictions leading to lack of access to supports and services, increasing level of need, and impacts of disruption for caregivers and children; and (2) adaptation and responsiveness to COVID-19 restrictions by advocating for families and managing uncertainties.
8	Deotto, A., Fabiano, F. G., Chung, Y. T. B., Wade, L. S., Anagnostou, E., Crosbie, j., Kelley, E., Nicolson, R., Andrade, F. B., Miller, P. S., Williams, S. T. (2023)	Stepping up to COVID-19: A clinical trial of a telepsychology positive parenting program targeting behavior problems in children with neurological risk.	Journal of Pediatric Psycholo gy	children with neurological risk	Quantitativ e study	To evaluate the feasibility, and preliminary efficacy of a stepped-care parenting program implemented during COVID-19 among families of behaviorally at-risk children with neurological or neurodevelopmental disorders aged 3–9 years.	Parents reported high acceptability, reflected in themes surrounding accessibility, comprehension, effectiveness, and targeted care. Positive parenting skill increases were documented, and robust improvement in child behavior problems was apparent upon Step 3 completion. Stepped care was as effective as traditional delivery, while improving consent and completion rates within a pandemic context.
9	Filler T, Benipal PK, Minhas RS, Suleman S. (2022).	Exploring the impact of COVID-19 on families of children with developmental disabilities: A community-	Paediatri c Child Health	children with developmental disabilities	Qualitative study	This qualitative study was to identify the experiences of families of children with DD during the COVID-19 pandemic.	Families reported difficulty adhering to public health measures leading to isolation and increased parental stress; restricted access to in- person services worsened behaviour and development; and

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		based formative study.					worsened household financial security in already marginalized families. Public health restrictions have impaired the daily lives of these families of children with DDs.			
10	Friesen, K. A., Weiss, J. A., Howe, S. J., Kerns, C. M., & McMorris, C. A. (2022).	Mental health and resilient coping in caregivers of autistic individuals during the COVID-19 pandemic: findings from the families facing COVID study.	Journal of autism and develop mental disorders	Autism	Quantitativ e study	To characterize caregiver stress, anxiety, and resilient coping during COVID-19 and investigated the impact of COVID-19 disruptions, demographic variables, and resilient coping on mental health.	Most of the caregivers reported some degree of disruption associated with COVID-19, and more than half reported moderate levels of stress and high anxiety. Resilient coping did not emerge as a moderator between COVID-19 disruptions and caregiver mental health, but instead had a direct effect on outcomes.			
11	Gonzalez, M., Zeidan, J., Lai, J. et al. (2022).	Socio- demographic disparities in receipt of clinical health care services during the COVID-19 pandemic for Canadian children with disability.	BMC Health Service Research	children with developmental disabilities and delays	Quantitativ e study	To need for tailoring services for families of children with disabilities, particularly low socioeconomic status families, to ensure continuity of care during public health emergencies.	The needs for tailoring services for families of children with disabilities are essential, particularly low socioeconomic status families, to ensure continuity of care during public health emergencies. Being a single parent, having low educational attainment, having low income, working less than full time, as well as male gender and older age of the child with disability were factors associated with decreased likelihood of receiving services.			
12	Gowans, L., Ritchie, T., Rogers, M. A., Jiang, Y., Climie, E. A., Mah, J. W. T., Corkum, P., Krause, A., & Parvanova, M. (2024).	The association between the impact of covid-19 and internalizing problems among children and adolescents with ADHD: The moderating role of parental anxiety.	Child Psychiatr y and Human Develop ment.	Children and adolescents with ADHD	Quantitativ e study	To assess whether the impact of COVID-19 was associated with internalizing problems in children and adolescents with ADHD during pandemic, and whether parental anxiety moderated this relationship over time.	The results indicated that the impact of COVID-19 on children at T1 (Spring 2021) was a unique predictor of child internalizing problems at T1 but not at T2 (Fall/Winter 2022). While parental anxiety did not moderate this association cross-sectionally, it was a significant moderator longitudinally. More specifically, low parental anxiety at T1 positively moderated the association between the COVID-19 impact on children at T1 and child internalizing problems at T2.			
13	Jacques, C., Saulnier, G., Éthier, A., & Soulières, I. (2021).	Experience of autistic children and their families during the pandemic: from	Journal Autism Develop ment Disorder	Autistic children	Mixed methods design (both quantitative and	To need to consider the child's autistic characteristics and interests to implement emergency	Parents reported the concerns about their child with DDs and difficulties managing their child's behaviors before and during pandemic were			

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		distress to coping strategies.			qualitative study)	accommodations and services.	significantly associated. Parents identified maintaining social relationships and implementing appropriate interventions to their child's characteristics as facilitators during the pandemic.
14	Katalifos, A. (2023).	Alignment of Canada's COVID-19 policy response with barriers and facilitators for coping reported by caregivers of children and youth with developmental disabilities, delays and disorders.	ProQuest Dissertat ions & Theses Global	Children with developmental delays, disorders, and disabilities (DDDs)	Qualitative study	The aim was increasing awareness, compiling data, proving guidance for policy and programming, and engaging international-level partners on understanding and improving the conditions of children and youth with disabilities around the globe.	Prioritizing needs of families of youths with DDDs during a public health emergency can significantly impact their experiences and mental health. Barriers to coping at the individual level were family mental health complications, concerns about regression of the child's condition, along with challenges involving the child's online schooling, insufficient play spaces, and managing physical health in quarantine. Environmental barrier included the worsening of families' finances, loss of public services, and experiencing stigma.
15	Kingsbury, M., Arim, R., & Findlay, L. (2023).	Parenting concerns during the COVID-19 pandemic: Results from a Canadian crowdsource sample.	Journal of Family Issues	Family with children with disability	Quantitativ e study	To examine parents' concerns regarding their own parenting behaviour during the pandemic and to explore the characteristics of families who may be particularly vulnerable to parenting concerns, and to identify families (e.g., parents with disabilities) that may be more at risk of increased parenting concerns during the pandemic	Many parents were very or extremely concerned about managing child behaviour and having less patience with, scolding, or yelling at their children.
16	Lamptey, D., McIsaac, D, MacQuarrie, M., Cummings, R., Rossiter, D. M., Janus, M., & Turner, J. (2024).	Relationship between childhood disability or developmental delay and COVID-19 Pandemic Impacts on Families across the Canadian Maritime Provinces	Journal of Child and Family Studies	childhood disability or developmental delay	Mixed methods design (both quantitative and qualitative study)	To examine the early impacts of the COVID-19 pandemic on family environments that influenced early childhood development of children with disability and developmental delays and health in the Maritime provinces of Canada	The study findings indicate that the early impacts of the pandemic on family environments that influenced early childhood development and health of children with disabilities or developmental delays were mixed and context specific. The study findings inform the development of context-specific policies and programs to adequately support families of

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							children with disabilities or developmental delays in public health crises similar to the pandemic.
17	Laughlin, E. (2022)	Leisure as a Coping Resource for Parent Caregivers of Children Living with Autism	Honor thesis, Broke Universit y	Children living with autism	Qualitative study	To explore the lived experiences of life challenges and leisure as a stress coping resources among parent caregiver of children living with autism.	These parent's caregivers face a number of barriers related to their leisure participation in four areas: (a) caregiving responsibilities and demands, (b) COVID-19 related barriers (c) timerelated barrier and (d) interpersonal barrier. The findings also revealed that leisure was used as a stress-coping resource in four ways: (1) rejuvenation through leisure, (2) mood enhancement through leisure, (3) distance from stressors through leisure, and (4) social experiences through leisure.
18	Lee, V., Albaum, C., Tablon Modica, P., Ahmad, F., Gorter, J.W., Khanlou , N., McMorris, C., Lai, J., Harrison, C., Hedley, T., Johnston, P., Putterman, C., Spoelstra, M., & Weiss, J.A. (2021).	The impact of COVID-19 on the mental health and wellbeing of caregivers of autistic children and youth: A scoping review.	Autism Research	Autism	A scoping review	To identify pandemic related demands experienced and coping strategies by caregivers and families of autistic children and youth.	Our findings suggest a number of demands have increased caregivers' risk to mental health challenges, and their potential impact on family wellbeing. Ongoing development of evidence-based supports of all families of autistic children and youth are needed.
19	MacSorley, C. A. (2022).	The lived experience of parental stress of fathers of a child with autism spectrum disorder.	A Thesis of Master of Social Work. Universit y of Regina	Autism	Qualitative study	To expand the current understanding of father parental stress through an interpretive phenomenological analysis of fathers of children with autism spectrum disorder's lived experience.	Five superordinate themes were identified, including Covid-19 pandemic, isolation, self-efficacy, stressors, and coping. Participants highlighted the breakdown of their limited supports during the global pandemic, and the sense of loss, isolation, and frustration created. Participants also identified negative perceptions of their self-efficacy and lack of dedicated supports for fathers.
20	Majnemer, A., McGrath, J. P., Baumbusch,J. , Camden,C., Fallon, B., Lunsky, Y.,	Time to be counted: COVID-19 and intellectual and developmental disabilities-an	FACETS	Intellectual and developmental disabilities (IDDs)	Policy Briefing report	To examine the risks and recommendations of mental health issues due to COVID-19 pandemic for persons with IDDs.	Not only do people with IDD have a greater risk of severe complications and death from the virus as shown in large-scale studies, but they also face significant short- and

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	Steven P. Miller, S. P., Sansone, G., Stainton, T., Sumarah, J, Thomson, J., & Zwicker, J. (2021).	RSC Policy Briefing.					long-term consequences of COVID-related public health measures on their mental health and wellbeing.			
21	Myers, M. (2021)	The experiences of co-parents raising children with autism spectrum disorders during the COVID-19 pandemic.	Master Degree Thesis in Universit y of Guelph,	Children with autism spectrum disorders	Mixed methods design (both quantitative and qualitative study)	To explore the experiences of caregivers coparenting a child with ASD during the COVID-19 pandemic. Caregivers have an essential part in maintaining the family system. Children with ASD may be particularly vulnerable to the effects of the COVID-19 pandemic, including social isolation, disruptions to structure and routine and lack of therapies and schooling available, especially considering need for routine and sameness are characteristics of ASD.	The main themes which emerged from the data included caregiver's concerns regarding their own wellbeing due to increased caregiver demands and confinement related stressors, their child's adjustment to a lack of structure and routine, relational functioning due to negotiating time together, and family resilience in the face of adversity. An illustration of the centrality of the coparenting relationship in supporting child adjustment is provided.			
22	Osman L, & Whitley J. (2024)	Parent perceptions of social well- being in children with special educational needs during COVID-19: A mixed-methods analysis.	Child Care Health	Children with special educational needs	Quantitativ e and qualitative study	To analyse impacts of these changes on social well-being, with limited studies placing an emphasis on the experiences of students with special educational needs (SENs). This article focusses on parent perspectives regarding impacts of school closures on social well-being in Canadian children with SENs.	The majority of parents expressed concern for their child's social well-being during the Spring 2020 school closures, with increased concerns for younger children.  According to parents, children experienced communication barriers to peer interaction and many experienced emotional difficulties as a result.  Technology was described as critical for some in maintaining social connections. Parents raised concerns about the impact of limited peer interaction on broader social skill development, in the short and long term.			
23	Pizzo, A., Keys E, Corkum P. (2023)	Parental perceptions of the impact of the COVID-19 pandemic on the sleep of children with neurodevelopme ntal Disorders.	Journal Pediatric Health Care.	Children with neurodevelopm ental Disorders.	Quantitativ e study	To determine and describe the impact of the COVID-19 pandemic; To identify and describe contributing factors.	Most parents (66%) reported the pandemic did not worsen their child's sleep, 30% stated their child's sleep had worsened, and 4% reported an improvement. Stress and anxiety about the pandemic, disrupted routines, and increased screen time were common parent-identified contributing factors.			

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24	Schmidt, M. & Bronw, M. Š.I. (2023)	Parents helping a child with disability learn at home during COVID-19: Experiences from Slovenia and Canada	Journal of Policy and Practice in Intellectu al Disabiliti es	Canadian child with disability (ASD, ADHD, some in ASD learning programs); Slovenian sample with special education needs (ASD, ADHD)	Mixed methods design (both quantitative and qualitative study)	The specific research questions were: (1) Did the Slovenian and Canadian parents differ in their perceived workload—assisting their children with remote learning? (2) Did the Slovenian and Canadian parents differ according to the support and resources received from schools and teachers? and (3) Did the Slovenian and Canadian parents differ according to their satisfaction with homeschooling their children with SEN and disabilities?	Parents in both countries (Slovenia and Canada) identified several specific advantages and disadvantages to learning remotely from home. The Slovenian children spent more hours per day at their lessons and attended more lessons than the Canadian children.
25	Seth, Ash et al. (2022).	Impacts of the COVID-19 pandemic: Pan-Canadian perspectives from parents and caregivers of youth with neurodevelopme ntal disabilities.	Journal of Pediatric Health Care	Qualitative study	Children and youth with neurodevel opmental disabilities	To understand the experiences and perspectives of parents and caregivers of youth with NDD across Canada in accessing services and their mental health needs during the COVID-19 pandemic; To explore the impacts of COVID-19 on parents, caregivers, and youth with NDD and identified recommendations for disability-inclusive policy planning and development.	The results enabled us to understand the impact of service disruptions in significant areas of life, including health, education, employment, and risk mitigation.
26	Smile, S.C. (2020).	Supporting children with autism spectrum disorder in the face of the COVID-19 pandemic.	Canadian Medical Associati on Journal	Autism	Commentar y (letter)	To address the mental distress of autistic children and children who are quarantined, to emphasis on designing diverse, sociocultural appropriate programs to address mental distress and provide mental health care and psychosocial supports	The consequences of a pandemic and the measures decrease transmission of coronavirus COVID-19, which have affected children and youth with autism spectrum disorder and their families, including siblings. parental anxiety around job loss, economic uncertainty, lack of access to health care facilities and treatment centres, and extension of waitlists for early intervention programs
27	Swansburg, R., Hai, T., MacMaster, F.P., & Lemay, J.F. (2021).	Impact of COVID-19 on lifestyle habits and mental health symptoms in children with	Paediatri c Child Health.	Children with attention- deficit/hyperact ivity disorder	Quantitativ e study	To investigate the impact of COVID-19 on lifestyle habits and mental health symptoms in paediatric attention-deficit/ hyperactivity	17.4% and 14.1% of children met criteria for moderately severe to severe depression and anxiety symptoms respectively. Children met SNAP-IV cut-off scores

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		attention- deficit/hyperacti vity disorder in Canada.				disorder (ADHD) in Canada.	for inattention, hyperactivity/ impulsivity, and oppositional defiant disorder behaviours. Caregivers reported changes in sleep, eating, exercise, and screen use in their ADHD child, greatly impacting youth. The COVID-19 pandemic has resulted in less healthy lifestyle habits and increased mental health symptoms in Canadian children with ADHD.
28	Wendel, M., Ritchie, T., Rogers, M. A., Ogg, J. A., Santuzzi, A. M., Shelleby, E. C., & Menter, K. (2020).	The association between child ADHD symptoms and changes in parental involvement in kindergarten children's learning during COVID-19	School Psycholo gy Review	Child with ADHD symptoms	Longitudin al research	To examine the changes to parent and child behavior due to COVID-19 among 4- and 5-year-old children and their parents. Changes in attention deficit hyperactivity disorder (ADHD) symptoms and levels of parental involvement in children's learning were examined. ADHD symptoms were also examined as a moderator of changes in parent involvement.	The mean levels of ADHD symptoms fell at the midpoint between never (1) and sometimes (2). To gain insight into the frequency of clinical levels of ADHD symptoms, we also examined the number of child participants at each time point who had parent-rated ADHD symptoms above the 90th percentile. Correlations between key variables in the spring showed that parent beliefs were positively associated with each other. Home-based involvement was also associated with all parental involvement beliefs. Child levels of inattention showed a significant and negative association with parental self-efficacy and knowledge and skills. Child levels of hyperactivity/impulsivity were negatively associated with all parental involvement beliefs.
29	Williams, T.S., Burek, B., Deotto, A., Ford, M.K., Green, R., & Wade, S.L. (2022)	Pandemic perils and promise: Implementation of a virtual parenting intervention during COVID- 19 among children with early neurological conditions.	Develop mental Neuroreh abilitatio n.	Children with early neurological conditions.	Mixed methods design (both quantitative and qualitative study)	To examine feasibility, acceptability, and preliminary efficacy of a tele-psychological positive parenting intervention	Parents reported strong therapeutic alliance and programme acceptability with barriers due to competing time demands. Therapists reported high acceptability but perceived parental burnout.  Parenting confidence, and child behavior improved following the intervention.
30	Williams, T. S., Deotto, A., Roberts, S. D., Ford, M. K., Désiré,	COVID-19 mental health impact among children with early brain	Child Neurops ychology	Children with early brain injury and associated conditions	Mixed methods design (both quantitative	To describe the mental health impact of COVID-19 among a clinical research sample of parents with children	Over 40% of parents described moderate to extreme influence of COVID-19 on their child's mental health.

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	N., &	injury and			and	diagnosed with early	Common child stressors
	Cunningham,	associated			qualitative	brain injury and/or	reported included
	S. (2021).	conditions.			study)	associated conditions	restrictions on leaving the
						impacting brain	home and social isolation.
						development; To	Among parents, the most
						examine risk factors for	common stress reported
						elevated mental health	was caring for their child's
						impact by child factors	education and daily
						including age, sex,	activities. Some COVID-
						brain injury severity,	19 positives were
						intellectual/global	identified, namely
						functioning, and	increased quality family
						comorbid ADHD and	time. Findings reflect the
						intellectual diagnoses,	significant pandemic
						as well as salient	mental health impact.
						psychosocial contextual	mentar nearth impact.
						factors.	
31	Winfield, A.,	The impact of	PLoS	Children with	Qualitative	To examine 1) the	Content analysis revealed
31	Sugar, C., &	the COVID-19	ONE	ADHD	study	unique ways that the	that the most frequently
	Fenesi, B.	pandemic on the	18(3):	ADIID	study	COVID-19 pandemic	identified mental health
	(2023)	mental health of	e028322			affected their mental	effects for families were
	(2023)	families dealing	7.			health and 2) the	increased child anxiety
		with attention-	7.			,	3
						specific barriers these	and disconnectedness, as
		deficit				families faced to	well as deteriorating
		hyperactivity				maintaining optimal	parental mental health.
		disorder.				mental wellbeing.	The most frequently
							identified barriers to
							maintaining optimal
							mental wellbeing were
							lack of routine, lack of
							social interaction and
							social supports, and
							uncertainty and fear.

 Table 1: Parental stress and coping strategies based on characteristics of children

# **Results**

The systematic review design was used in this literature study.

#### Disruptions to daily routines, and increased workloads.

In March and April 2020, Canada implemented schools and daycare closures, among other measures, to prevent the spread of Covid-19. These shutdowns negatively impacted student learning and socializations. Parents struggled with online learning, faced challenges keeping up with school assignments, and expressed heightened concerns about the future academic developments of children with DDs [1,44,45,35,28,29,46,48, 16,50,53,54,55]. A scoping review [15] on mental health and well-being of autistic children and youth highlighted several challenges faced by parents and caregivers, including school, campus program, and service closures resulted in loss of essential services, which increased unpredictability [35,44,47,16,48,50,54]. Additionally, parents were required to take on extra roles, such as managing children's daily schedules while continuing their own work, leading to increased workloads. Many were overwhelmed by the demands of caring for their children without the daily support of specialists, coupled with other obligations and responsibilities [47,16,54].

# Difficulties in managing children's emotional and behavioural problems leading to parental frustrations.

Restricted access to in-person services significantly worsened behaviour and development in children with DDs due to a loss of stability, and predictability, negatively affected the function of the family unit [35,47, 28,46,48,16,50,49]. Children with DDs experienced drastically altered

routines, leading to increase their anxiety, frustration, tension, aggression and rigidity [44,47,50]. Some children with autism and other neurodevelopmental disorder struggled to comply with certain public health measures, some children with sensory disorders were sensitive to the touch and smell of masks and hand sanitizers caused parents anxiety [47,54,55]. Additionally, some autistic children displayed greater physically aggression and volatility [44,16,59], further escalating parental stress and frustration. These challenges heightened emotional strains and behavioural difficulties for parents, who often reported feeling frustrated, exhausted, overwhelmed, and even aggressive, which sometimes led to harsh parenting practices [50,49]. The increased demands of addressing their children's emotional and academic needs contributed to an authoritarian parenting style, escalated family tensions, and even violent behaviours within some households [47,50].

#### Limited access to resources, services, and various forms of support.

In March and April 2020, Canada shut down schools and daycare centers as part of measure to prevent the spread of Covid-19, leading to a significant disruption in the educational system [47,15,55]. Parents reported receiving insufficient support from government. They faced a lack of external resources, such as programs for youth and children, closed schools and community services, limited access to healthcare facilities and treatment centres, lack of therapeutic supports in the schools, delayed therapeutic services or shifting health services to virtual mode, and extension of wait-lists for early intervention programs and reduced access to essential therapy hours (e.g., speech and language therapy, behavioural therapy, and occupational therapy) critical for their children [1,44,45,35,47,28,29,46,16,55,53,54]Parents also reported the challenges

related to the absence of in-person assessment tools necessary for diagnosing children with specific needs [46,33]. The reliance on telehealth posed significant obstacles, preventing children and families from receiving the care they needed due to concerns about the COVID-19 infection, and difficulties accessing appropriate interventions [15,16, 49,51] Additionally, families required internal resources such as user skills, reliable internet connections, effective coping strategies to adapt to these new pressures. Furthermore, one recent research [46] indicated that low-income families and single parent of children with disabilities decreased likelihood of receiving services.

Parents of children with DDs experienced social and economic marginalization during the pandemic COVID-19 [28]. Caregivers reported insufficient medical support [47], limited social networks, and activities [47], increased financial insecurity [28,16], and interruptions to financial assistance, making it challenging to secure funding [28]. They also faced a lack of connection with family and friends, as well as insufficient dedicated support for parents [45,51]. These factors were compounded by job losses and reduced income, further exacerbating the stress and challenges faced by these families.

# Experiences of mental health problems.

Parents caring for children with DDs during the COVID-19 pandemic have experienced significant deficits and delays in various areas of development, as well as unique additional strains. These include low mood (e.g., depression, anxiety, suicidal ideation, and distress), and other mental health-related symptoms such as frustration, increased vulnerability, isolation, sense of loss, anger, fears, exhaustion, burnout, shame, and guilt over difficulties managing their children's behaviour. Other challenges include cultural stigma and discrimination, concerns about children's online safety, mood disturbance, and a perceived failure in fulfilling their parental role. Parental anxiety related to job loss, economic uncertainty further heightened their vulnerability and negatively affected their well-being [44,45,35,47,28,29,15,6,46,15,51,52, 54,81,83,84]. Furthermore, parents exhibited lower levels of resilient coping [29]. Limited access to wellness services exacerbated these challenges, significantly impacting the mental health of both parents and their children with DDs [55].

# Experiences of social isolation and reduced self-efficacy.

The COVID-19 pandemic has presented unique challenges for families and caregivers of children with DDs. Both parents and children identified lack of socialization, limited social engagement, restricted access to spaces for physical activities and increased social isolation as significant challenges. These issues were compounded by increased screen time and reliance on electronic devices [1,44,45,35,47,28,48,49,52,51,53]. Prolonged home isolation has been linked to potential long-term negative consequences for the psychological wellbeing of both children and caregivers. Parents reported difficulties adhering to public health measures, which contributed to isolation and elevated stress levels4 [35, 28,16,54]. A recent study focusing on Canadian fathers of children between the ages of six and 12 with autism spectrum disorder experienced social isolation, neglected their children's needs, and highlighted a negative perception of their self-efficacy and lack of social support for fathers [51].

# Coping strategies for parents of children with DDs under COVID-19 Fostering family-teacher partnerships and providing psychological interventions are essential.

Parents often reach out to schools and teachers for receiving additional support and services. Through these interactions, parents can become

more familiar with school policies regarding children with special needs. Schools can play a critical role by offering essential resources such as daily necessities, educational services, rehabilitation programs within the school settings. Additionally, schools can provide basic food and welfare support for children with developmental disabilities and families [1,21,48]. Access to psychological interventions should also be prioritized to help alleviate mental health challenges faced by parents with developmental disabilities [48].

#### Creating a structured daily schedule.

Creating a structured daily schedule has been an effective strategy for parents and caregivers helped children with DDs. They implemented various methods to help their families cope with stressors, such as organizing leisure activities, engaging in media entertainment, and exploring hobbies like baking, gardening, painting, meditation, and so on. Parents also incorporated physical activities and exercises into their routines [1,44,28,16,51] stories daily, shows, videos games, and enhancing quality family time through reinforcement system for establishing appropriate behaviours during the challengeable pandemic [44,56,51,54]

# Providing resources and services and utilizing new technologies to provide support.

The COVID-19 pandemic necessitated the use of technology to offer a broader range of care options and better address the diverse needs of children with DDs and their parents or caregivers, who often experienced heightened anxiety and frustration [1,47,28]. It is crucial for parents to maintain and strengthen social relationships while supporting their children' mental health, and social connections. For instance, families spent more time together, and parents arranged online interactions with relatives to foster social engagement [1,16,17]. Financial resources provided to families played a vital role in facilitating access to in-home and community-based services, programs, and interventions [17,53,21, 50,82,83]. Support from extended family and community or organizations also proved invaluable [1,15,52]. Additionally, telehealth has emerged as an effective tool for education and therapy within autism communities. It can help address long waitlists for assessment and care, improve access to services in remote locations, and accommodate restricted service hours. However, parents and their children with DDs require adequate support to enhance accessibility and fully maximize its benefits [1,16,52].

## Promoting self-efficacy and resilience

Parents who foster self-efficacy and resilience can help reduce children's negative emotional responses [1,16,51,52,74,77,82]. Building resilience involves adopting strategies such as problem-focused coping, maintaining optimism and hope, fostering a sense of control, enhancing self-efficacy and acceptance. It also includes developing a sense of coherence, promoting positive family functioning, and enhancing care and psychosocial supports to mitigate the effects of prolonged isolation on children [1,48,51,74,77].

# **Ensuing access to protective measures**

Parents trained their children with DDs to properly use preventative measures such as wearing masks, practicing social distancing, and self-isolating when necessary, and safely using hand sanitizer [1,16,9]. Parents reported that children with intellectual developmental delay highlighted the need for robust public health measures to mitigate the risk of transmission [52].

#### **Discussions**

The findings revealed that the COVID-19 pandemic had a significant impact on parents and their children with developmental disabilities (DDs). Globally, both groups faced substantial challenges during this period, making them particularly vulnerable. Thematic analyses of parental stressors highlighted disruptions to children's daily routines, concerns about the closures of schools, daycares, and social services [1,47,28,29,48,54,55,72,78,79,81], which aligned with recent studies [52,57;56;57]. Many parents had to adjust their work schedules to care for their children due to these closures [54] while also experiencing increased workloads from juggling multiple family roles [1,45,16]. The shutdown of schools and services deprived children of accessing the essential programs and resources, exacerbating parental stress [58,9,33,52,55]. Similarly to the findings of [6], parents also struggled with supporting their children's transition to online learning, which added to the challenges of remote learning [1,44,45,56,80].

Parental stress during pandemic included drastically disturbed the routines of children with DDs, leading to increased stress, anxiety, aggression and behavioural issues in children, which heightened parental concerns [44,35,47,28,29,48,16,50,49,78], which was consistent with the studies by [59,60,17]; [50] reported many parents experienced reduced patience, and increased scolding and yelling at their children during COVID-19, which was consistent with the previous studies [61,62]. Moreover, parental stressors compassed concerns about their children's health, mental health and well-being. A study [63,84] showed individuals with Down syndrome experienced a higher susceptibility to COVID-19 infection and more severe diseases, as some parents experienced depression, anxiety and psychological distress, consistent with findings from some recent studies [16,61,64,65]. Parents expressed significant concerns about their children's socialization, lack of social networks and activities, excessive screen time and social isolation [1,44,35,47,48,51,72, 75,78,79,81,84], alongside financial difficulties and burdens [28,49,55], and limited access to educational resources and support services [45,47,15,51], especially low income families, and single parent have decreased likelihood of receiving services [46]. These challenges were consistent with findings from [66], and [6].

Parents and caregivers with DDs sought support from schools and teachers to access effective academic assistance for their children, as noted by [1,44,35,52,53]. In particular, parents played a vital role in supporting their children's online learning [80]. They also reached out to various services, including educational, recreational, community-based programs, counselling interventions, telehealth, and rehabilitation services, to help improve their children's emotional, social and behavioural adjustments during the COVID-19 pandemic [1,44,16,52,21,74,77]. These efforts were necessitated by quarantine measures such as social distancing, lockdowns, and the closure or suspension of health and social services, schools, and daycares, which created unprecedented challenges for raising children with DDs [1,44,48,49,53], these aligned with some recent studies [6,58,57,65,67,21,56,32,73].

Some parents created structured daily schedules to provide needed routines for their children with DDs, including physical activities and exercises, leisure activities to maintain children's social connections with their friend and relatives [1,44,16,76], these findings were aligned with studies [19,9]. Additionally, parents implemented various effective coping strategies, such as reinforcement techniques, to enhance their children's social and behavioural skills and improve emotional regulation [56,54].

The results revealed that parents provided various forms of support, including financial assistance, verbal and non-verbal information, advice, tangible aid, emotional, and instrumental support. These supports significantly benefited both parents' and children's mental health and well-being. This finding aligns with previous studies [41,42], which showed that social support could mitigate stressors and enhance mental health and well-being in families with DDs before pandemic. Additionally, a prior study found that parents who received psychiatric help experienced lower levels of anxiety and employed more coping strategies, such as seeking support [68].

This systematic review, however, had some limitations. For instance, the electronic database searches were restricted to peer-reviewed academic articles and graduate school theses with full text available from 2020 to 2024, excluding gray literatures. The review was also limited to studies published in English, thereby excluding potentially relevant research in other languages. Moreover, the review did not focus on assessing the quality of the selected articles, as highlighted by [69]. Future study should prioritize quality assessments and emphasize robust methodological designs and practical implications [70,71]. To support the mental health and well-being of these parents, and caregivers, it is crucial to develop more supportive healthcare, social educational services, and community-based interventions, and in-home activities tailored for children with developmental disabilities.

## **Conclusion**

This systematic review provided a comprehensive overview of the challenges and stressors faced by parents and caregivers of children with developmental disabilities (DDs) during the COVID-19 pandemic. It also highlights the effective coping strategies they implemented to navigate these difficulties. The findings underscore a significant increase in parental stress during the pandemic, emphasizing the urgent need for targeted attention and resilience-building initiatives. Enhanced mental health resources and support system for parents and caregivers are essential. Greater social support from family, friends, schools, and the broader community is critical to helping parents of children with DDs lead more balanced and adaptable lives during or after pandemic. Public health interventions should prioritize addressing parenting-specific stressors, developing context-specific policies and programs to support these families, and promoting effective coping strategies. These measures should consider the unique needs of these families raising children with DDs to mitigate the long-term impacts of the COVID-19 pandemic.

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