



## REVIEW ARTICLE

# The impact of COVID-19 on the mental health and wellbeing of caregivers of autistic children and youth: A scoping review

Vivian Lee<sup>1</sup>  | Carly Albaum<sup>2</sup> | Paula Tablon Modica<sup>2</sup> | Farah Ahmad<sup>3</sup> | Jan Willem Gorter<sup>4</sup> | Nazilla Khanlou<sup>5</sup> | Carly McMorris<sup>6</sup>  | Jonathan Lai<sup>7,8</sup> | Cindy Harrison<sup>9</sup> | Teresa Hedley<sup>9</sup> | Pari Johnston<sup>9</sup> | Connie Putterman<sup>9</sup> | Margaret Spoelstra<sup>10</sup> | Jonathan A. Weiss<sup>2</sup>

<sup>1</sup>Department of Psychology, Carleton University, Ottawa, Canada

<sup>2</sup>Department of Psychology, York University, Toronto, Canada

<sup>3</sup>School of Health Policy and Management, York University, Toronto, Canada

<sup>4</sup>Department of Paediatrics, McMaster University, Hamilton, Canada

<sup>5</sup>School of Nursing, York University, Toronto, Canada

<sup>6</sup>Werklund School of Education, University of Calgary, Calgary, Canada

<sup>7</sup>Canadian Autism Spectrum Disorder Alliance, Canada

<sup>8</sup>Dalla Lana School of Public Health, University of Toronto, Toronto, Canada

<sup>9</sup>Canada

<sup>10</sup>Autism Ontario, Toronto, Canada

## Correspondence

Dr Vivian Lee, Carleton University, 1125 Colonel By Drive, Ottawa K1S5B6, Canada.  
Email: vivian.lee4@carleton.ca

## Funding information

York University Research Chair in Autism and Neurodevelopmental Disability Mental Health; McMaster University Sociobank Chair in Child Health Research (Dr. Gorter); Canadian Institutes of Health Research Rapid Knowledge Synthesis Grant

## Abstract

Caregivers and families of autistic people have experienced stress and increase in demands due to the COVID-19 pandemic that may have long-term negative consequences for both their own and their children's mental health. A scoping review was conducted to identify pandemic related demands experienced by caregivers and families of autistic children and youth. The review also consolidated information on coping strategies and parenting-related guidelines that have emerged to help parents meet these demands. Search strategies were approved by a research librarian and were conducted in peer-reviewed and gray literature databases between May 2020 and February 2021. Additional resources were solicited through author networks and social media. All articles were published between December 2019 and February 2021. Article summaries were charted, and a thematic analysis was conducted with confirmation of findings with our knowledge users. Twenty-three published articles and 14 pieces of gray literature were included in the review. The majority of articles characterized and highlighted the increase in demands on caregivers of autistic children and youth during the pandemic globally. Both quantitative and qualitative studies suggest that parents have experienced an increase in stress and mental health-related symptoms during lockdown measures. Findings suggest that families are employing coping strategies, but there no evidence-based supports were identified. The review highlighted the potential long-term impact of prolonged exposure to increasing demands on the mental health and wellbeing of caregivers and families of autistic people, and pointed to a need for the rapid development and evaluation of flexible and timely support programs.

## Lay Summary

Caregivers and families of autistic children and youth have faced increased demands due to pandemic-related lockdown measures. We reviewed the literature to outline sources of stress, links to their influence on caregiver mental health, and if support programs have emerged to help them. Our findings suggest a number of demands have increased caregivers' risk to mental health challenges, and their

[Correction added on 30 October 2021, after first online publication: The copyright line was updated.]

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. *Autism Research* published by International Society for Autism Research and Wiley Periodicals LLC.

potential impact on family wellbeing. Ongoing development of evidence-based supports of all families of autistic children and youth are needed.

#### KEYWORDS

autism, caregivers, COVID, literature review, mental health

## INTRODUCTION

The ongoing COVID-19 pandemic has created new stressors for families of autistic children and youth, and amplified challenges to support their needs. Prior to the COVID-19 pandemic, the existing peer-reviewed literature indicated that parents of autistic children and adolescents can experience considerable mental health problems (Public Health Agency of Canada, 2018) including high rates of distress (Hayes & Watson, 2013; Weiss & Lunskey, 2011), depression and anxiety (Lee et al., 2009; Martin et al., 2019; Vasilopoulou & Nisbet, 2016), financial stress and overall lower rates of quality of life (Heinrich, 2014; Kuhlthau et al., 2014). Family caregivers often experience considerable demands associated with the complex needs of caregiving, which can add to mental health challenges. This includes having to provide ongoing care (Singer, 2006), to act as therapists, advocates, navigators, or teachers in providing supports, and to manage high rates of child and adolescent behavioral difficulties (Lai et al., 2019; Muskens et al., 2017), while balancing their own needs (i.e., career) and family (i.e., siblings and other dependents) responsibilities (Shorey et al., 2020).

Considerations for caregivers' mental health and wellbeing are important because they are reciprocally linked to child mental health and wellbeing, parent-child relationships, and overall family functioning. For example, the Family Systems Theory (Bowen, 1978) illustrates the interconnectivity of family members and the influences of each member's emotional wellbeing and behavior has on each other. This concept has been explored within families of disabled individuals (Taylor et al., 2019). Further, the theory highlights the importance of flexibility between family members and as a unit that impacts their ability to adapt to stress (Brown, 1999). A number of researchers have found transactional relationships between parent stress and child behavioral problems. For example, higher levels of caregiver stress often correlate with higher reports of externalizing (Estes et al., 2013; Herring et al., 2006; Lecavalier et al., 2006) and internalizing behaviors (Hall & Graff, 2012; Hastings et al., 2005; Zaidman-Zait et al., 2011). Within the family context, caregiver mental health and wellbeing can have an impact on autistic children's (and their siblings) general development, including on adaptive functioning, academic achievement, self-esteem and friendships (Haebig et al., 2013; Ruble et al., 2008; Zablotsky et al., 2012). Poor caregiver mental health can also lead to lower levels of marital

satisfaction, which can influence family functioning and can have significant negative impacts on economic success (Bekhet et al., 2012; Benson & Kersh, 2011; Gau et al., 2012; Hartley et al., 2012).

As a result of the pandemic-related social distancing measures (i.e., lockdowns), stressors and poor mental health outcomes in caregivers are likely more prevalent than before the pandemic. The Family Adjustment and Accommodation Resource Model (FAAR Model: Patterson, 1988) is often used as a framework to understand the processes that lead to family outcomes in the face of stressors (Clifford & Dissanayake, 2009), and is relevant in considering the context of family coping during COVID-19. The FAAR model suggests that a response to stressful life events involves the interaction of three domains: *demands*, *capabilities*, and *the family's meaning*. Demands involve the sources of stress, strains, or negative circumstances that persist over time, daily hassles, or other external stressors. The COVID-19 pandemic represents a stark example of an external stressor that can contribute to, and exacerbate, the many demands on caregivers. Studies have documented how around the world families have had to face abrupt changes to their routine, limited access to resources, and for many caregivers, interruptions to financial support (i.e., loss of employment and income). Policies meant to limit the transmission of COVID-19 may have inadvertently exacerbated the difficulties experienced by many families of autistic children, and further expose them to vulnerabilities that may impact caregiver mental health and overall family wellbeing.

When demands increase, families employ their *capabilities*, including external resources (e.g., programs, services, etc.) and internal resources (e.g., coping behaviors) in response to "balance" the new pressures. For example, a family may access new services to address the added pressures related to COVID-19 and thus improve their mental health (i.e., mental health services). Social distancing requirements, however, have halted or significantly altered most in-person social, education, and therapeutic programs (e.g., diagnostic clinics and interventions, day programs, schools, adapted recreation and leisure, etc.), reducing the formal assistance provided outside of the family. Further, families with the same stressors and services may still experience different outcomes as a result of how they perceive these factors; the *meaning* that they make of their experiences (e.g., lessons learned, ways that situations are interpreted). Family outcome is determined by the subjective experience of how well balance is achieved between demands and capabilities.

It is important to support the mental health of caregivers and families with autistic children and understand the services and supports that promote resilience during and after this pandemic. We undertook a scoping review to better understand the mental health concerns and experience of caregivers, including what makes families resilient in the face of stressors, and to identify the evidence-based best practices and service needs to support parents faced with these pandemic-related demands. Using the FAAR model as a framework, we searched for literature that outlined how, as a result of the COVID-19 pandemic, families balanced demands and capabilities, and how they made meaning of this process during this time. The current review aimed to identify and address knowledge gaps and capture evidence for the demands and capabilities of caregivers, as well as how caregivers were making meaning of adversities associated with COVID-19 for caregivers and families of autistic children and youth.

## METHODS

The scoping review was based on the Cochrane Rapid and Scoping Reviews Method Group (Garrity et al., 2020) methodology guide and conducted to examine the extent, range, and nature of research activity in a topic area and to identify research gaps in areas that have yet to receive a comprehensive review (Arksey & O'Malley, 2005). We generated the research question using the FAAR model and asked, "What does the scholarly literature identify as the impact of the pandemic on the mental health and wellbeing of caregivers and families of autistic children and youth, in relation to the demands and capabilities employed by caregivers during this time?" We report select components of the Preferred Reporting Items for Systematic Scoping Reviews and Meta-Analyses (PRISMA-ScR; Tricco et al., 2018). The research team included a group of researchers, clinicians, caregivers, and autism advocates who have an interest in understanding the impact of COVID-19 on the mental health and wellbeing of families with autistic children. Collectively, the team had experience in autism and mental health, community-based mental health care, primary care and health policy for vulnerable populations, and transition services for developmental disabilities. Several research team members also serve as registered healthcare providers in the areas of pediatrics, clinical psychology, nursing, and speech-language pathology. An integrated knowledge translation approach (Gagliardi et al., 2015) was taken, working with knowledge users throughout the process. Knowledge users included representatives from autism advocacy agencies and parents of autistic people.

### Search terms

A list of search terms was developed in consultation with a reference university librarian and in collaboration with

**TABLE 1** Rapid scoping review search terms

	Research database terms	Gray literature terms
Target population	Family, parent, caregiver	Family, parent, caregiver
Diagnosis	"Autism spectrum disorder", ASD, Autis*, "developmental disability"	Autis*, "developmental"
Disease	COVID, coronavirus	COVID
Mental health	"Mental health", wellbeing	"Mental health", Wellbeing

*Note:* Asterisks (\*) were used for multiple character searching; Quotation marks (") were used for exact phrases.

all members of the research team and knowledge users. Primary search terms included all derivatives of COVID-19, autism, family, and mental health (see Table 1).

### Search strategy

A systematic electronic search for articles were conducted between May 25 and June 12, 2020. A second and third round of searches were done on August 6, 2020 and February 25, 2021 to identify new peer-reviewed articles that were published after the original search time period. The searches were carried out using three strategies.

#### Strategy one

Concurrent searches were conducted of Ovid MEDLINE, PsycINFO, PubMed, CINAHL Plus, Sociological Abstracts, and Social Work Abstracts databases. Restrictions to date of publications varied slightly by database (because of differences in search settings). Searches were limited to include articles published since either December 2019 (i.e., CINAHL Plus, Sociological Abstracts) or January 2020 (i.e., Ovid MEDLINE, PsycINFO, PubMed, Social Work Abstracts), as these were the dates when the first cases of COVID-19 were reported. All databases were searched using the terms "COVID" and "autis\*", and "family" was included as an additional search term for PubMed and PsycINFO (other databases returned less than 10 results when "COVID" and "autis\*" were searched in combination, so the decision was made to not include "family" as an additional term). Searches conducted in PsycINFO, CINAHL Plus, and Sociological Abstracts were also limited to search for terms anywhere except in the full text of articles.

#### Strategy two

A search of Google Scholar articles published since January 2020 was conducted using combinations of

“COVID” or “coronavirus,” and “autism” or “ASD” (See Supplements for exact search terms used in Google Scholar). Searches were first restricted to search article titles only, which yielded few results. A secondary search was completed by including “family” or “parent”, and “wellbeing” or “mental health” in combination with the previously used COVID and autism-related terms, and opening the search up to allow terms to appear anywhere in the text of an article. The resulting titles were screened within Google Scholar, and potentially relevant articles were downloaded for a more thorough review.

### Strategy three

Searches were extended beyond peer-reviewed and empirical databases to include gray literature. Gray literature are nonpeer reviewed products that have been increasingly used by researchers to supplement reviews, contextualize emerging themes and areas of research, as well as to validate or corroborate findings from academic literature (Adams et al., 2016, 2017). Gray literature can consist of a heterogeneous set of materials including books, newspaper articles, government and not-for-profit organizational surveys and reports, and social media posts. Importantly, we only considered gray literature with “known” or “identifiable” sources because of their retrievability from searches and high credibility (Adams et al., 2017). We have included a search of gray literature in the current review to extend and contextualize the scope of our findings in an emerging and dynamic area of research. Newspapers archives were searched for articles published from December 1, 2019 onwards. The Canadian Major Dailies database was searched using the terms “COVID” and “autis\*”, which can be used to identify articles published both nationally and internationally. In addition, an advertisement was shared with service providers, researchers, clinicians, and members of the autism community via email and Twitter, requesting key literature (i.e., peer-reviewed publications, reports, guidelines, newspaper articles) on mental health and wellbeing of caregivers and families of autistic people during the COVID-19 pandemic. We also used hand searching of bibliographies of relevant articles and preprint databases (i.e., PsyArXiv) news articles, newsletters, organizational surveys and reports to find other materials.

### Screening and study selection

We used covidence ([www.covidence.org](http://www.covidence.org)), a systematic review management system to organize articles for our searches. Only peer-reviewed publications were entered in Covidence; all gray literature reports were screened and analyzed separately. Articles identified across the three phases were reviewed and included if the article focused and/or discussed parent and family stressors,

parenting experiences, guidelines for parents of children and youth on the spectrum, mental health and/or wellbeing of parents, caregivers, siblings, or other relatives of autistic children and adolescents (aged 25 years and below), during the COVID-19 pandemic. Articles needed to be published in English to be included.

Given the number of articles and gray literature resources available for the scoping review, two independent reviewers screened all articles by title and abstract for their applicability to the research question. If the article was deemed relevant and appropriate by both reviewers, it was then added to Covidence for a full-text screening. Agreement between the two reviewers was 100% during the screening process. Articles that met eligibility progressed immediately to the next phase of screening. The full-text assessment was completed by two reviewers independently, with discrepancies resolved by the first author.

### Risk of bias appraisal

Gray literature was included in the current review to strengthen our approach and provide contextual information. Given that peer-reviewed literature takes time to reach publication, especially during a pandemic, it was important to consider other forms of information. At the same time, we acknowledged the limits to including gray literature (Adams et al., 2017). Searching gray literature in a systematic way can be onerous and can make results difficult to reproduce. As well, gray literature does not undergo a peer-review process, which may mean substantive variability in the quality of the information available.

### Critical appraisal

Two reviewers used the Critical Appraisal Skills Programme (CASP) Checklists (2018) to determine the quality of empirical data included in the study. The CASP is an appraisal tool used to assess the quality, trustworthiness, relevance, and results of published papers included in literature reviews (Byers & Beaudin, 2001; Dixon-Woods et al., 2007; Katrak et al., 2004). Specifically, each checklist systematically allowed reviewers to assess the validity of the results by determining whether the study stated the purpose clearly, reviewed the relevant background, justified the design of the study, reasonably justified their analysis and results, minimized bias, identified important confounding factors, and so forth. (See Table 2 for CASP Ratings). For quantitative studies, scores ranged between 0 and 12 for CASP Cohort Study checklist, with 12 indicating the highest research quality. For qualitative studies, scores ranged between 0 and 10 using the CASP Qualitative Study checklist, with 10 indicating the highest

TABLE 2 Description of articles from strategy 1 and 2 ( $n = 23$ )

Author(s)	Date published	Country	Title	Journal	Participants	Category	CASP rating
Ameis et al. (2020)	July 22, 2020	Canada	Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond	Molecular Autism	N/A	Commentary	N/A
Cassidy et al. (2020)	May 08, 2020	Multinational (Canada, UK, USA)	An expert discussion on autism in the COVID-19 pandemic	Autism in Adulthood	N/A	Commentary (roundtable)	N/A
Chen et al. (2020)	December 18, 2020	China	Mental Health of Parents of Special Needs Children in China during the COVID-19 Pandemic	International Journal of Environmental Research and Public Health	$N = 1450$ (n = 454 parents of autistic children)	Peer-reviewed, quantitative	10
degli Espinosa et al. (2020)	PrePrint: April 10, 2020 Published June 2, 2020	Italy	A model of support for families of children with autism living in the COVID-19 lockdown: Lessons from Italy	Behavior Analysis in Practice	N/A	Commentary (discussion/review paper)	N/A
Dhiman et al. (2020)	December 2020	India	Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs	Research in Developmental Disabilities	$N = 264$	Peer-reviewed, quantitative	9
Ersoy et al. (2020)	June 15, 2020	Turkey	The comparison of impact of health anxiety on dispositional hope and psychological wellbeing of mothers who have children diagnosed with autism and mothers who have normal children, in Covid-19 pandemic	Social Sciences Research Journal	$N = 126$ ( $n = 60$ mothers with autistic children; $n = 66$ mothers without autistic children)	Peer-reviewed, quantitative	1
Esentürk (2020)	May 22, 2020	Turkey	Parents' perceptions on physical activity for their children with autism spectrum disorders during the novel Coronavirus outbreak	International Journal of Developmental Disabilities	$N = 10$ (60% females; 40% males) Parent Age: 35–54 years old	Peer-reviewed, qualitative	5
Eshraghi et al. (2020)	May 20, 2020	USA	COVID-19: Overcoming the challenges faced by individuals with autism and their families	Lancet Psychiatry	N/A	Commentary (correspondence)	N/A
Lim et al. (2020)	June, 2020	Singapore	Autism spectrum disorder and COVID-19: Helping caregivers navigate the pandemic	Annals, Academy of Medicine Singapore	N/A	Commentary	N/A
Manning et al. (2020)	October 12, 2020	USA	Perceptions of Families on Individuals with Autism Spectrum Disorder during the COVID-19 Crisis	Journal of Autism and Developmental Disorders	$N = 4731$ (gender and age distribution unspecified)	Peer-reviewed, mixed-methods	10

(Continues)



TABLE 2 (Continued)

Author(s)	Date published	Country	Title	Journal	Participants	Category	CASP rating
Narzisi (2020)	April 01, 2020	Italy	Handle the autism spectrum condition during Coronavirus (COVID-19) <i>Stay at Home</i> period: Ten tips for helping parents and caregivers of young children	Brain Science	N/A	Editorial	N/A
Neece et al. (2020)	October, 2020	USA	Examining the impact of COVID-19 in the ethnically diverse families with young children with intellectual and developmental disabilities	Journal of Intellectual Disability Research	N = 77	Peer-reviewed, Qualitative	10
Parentau et al. (2020)	July 23, 2020	USA	The experience of parents of children with autism spectrum disorder during COVID-19 pandemic: A qualitative analysis	Journal of America Academy of Child and Adolescent Psychiatry	N = 15 (gender and age distribution unspecified) Child Age: 11 to 21 years	Peer-reviewed, qualitative	5
Pavlopoulou et al. (2020)	June, 2020	UK	Impact of COVID-19 on the experience of parents and family carers of autistic children and young people in the UK	N/A (available through University College London online repository)	N = 449 ( <i>n</i> = 401 mothers; <i>n</i> = 35 fathers; <i>n</i> = 13 carers; Age range unspecified)	Nonpeer reviewed technical report, quantitative	4
Rose et al. (2020)	May 15, 2020	UK	The effect on and experience of families with a member who has intellectual and developmental disabilities of the COVID-19 pandemic in the UK: developing an investigation	International Journal of Developmental Disabilities	N/A	Editorial	N/A
Smile (2020)	May 25, 2020	Canada	Supporting children with autism spectrum disorder in the face of the COVID-19 pandemic	Canadian Medical Association Journal	N/A	Commentary (letter)	N/A
Stankovic et al. (2020)	May 12, 2020	Serbia	The Serbian experience of challenges of parenting children with autism spectrum disorders during the COVID-19 pandemic and the State of Emergency with the police lockdown	The Lancet Child and Adolescent Health	N = 85 (74% mothers; 22% fathers; 4% other relatives)	Peer-reviewed, quantitative	1
Szabo et al. (2020)	April 23, 2020	USA	From helpless to hero: Promoting values-based behavior and positive family interaction in the midst of COVID-19	Behavioral Analysis in Practice	N/A	Technical guide	N/A
Ueda et al. (2021)	February 15, 2021	Japan	The quality of life of children with neurodevelopmental disorders and their parents during the Coronavirus disease 19 emergency in Japan	Nature Scientific Reports	N = 152 (86% mothers)	Peer-reviewed, quantitative	10
Wang	July 26, 2020	China	The impact of COVID-19 on autism research: Reflections from China	Autism Research	N/A	Commentary (letter)	N/A

(Continues)

TABLE 2 (Continued)

Author(s)	Date published	Country	Title	Journal	Participants	Category	CASP rating
White et al. (2021)	January 2, 2021	USA	Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from the SPARK Cohort	Journal of Autism and Developmental Disorders	<i>N</i> = 4369 (93% mothers)	Peer-reviewed, Quantitative	10
Yarımkaaya & Esentürk (2020)	April 22, 2020	Turkey	Promoting physical activity for children with autism spectrum disorders during Coronavirus outbreak: Benefits, strategies, and examples	International Journal of Developmental Disabilities	N/A	Commentary (parent guide)	N/A
Yi & Dixon (2020)	April 23, 2020	USA	Developing and enhancing adherence to a telehealth ABA parent training curriculum for caregivers of children with autism	N/A (available through PsyArXiv)	N/A	Nonpeer reviewed, technical guide	N/A

Abbreviations: N, total number; N/A, not available; UK, United Kingdom; USA, United States of America.

Note: CASP – Critical appraisal skills Programme checklist (2018), a study appraisal tool used to determine the quality of empirical data included in the study (scores range between 0 and 12 for the CASP cohort/quantitative study checklist, with 12 indicating the highest quantitative research quality and scores range between 0 and 10 for the CASP qualitative checklist, with 10 indicating the highest qualitative research quality); COVID-19 – Coronavirus disease 2019; commentary – An explanation or discussion about an event taking place, a book or articles, or a person; editorial – A brief article that expresses an opinion and balances an analysis of evidence, often written by a senior editorial staff or publisher about the topics discussed in a publication issue; preprint – a empirical paper that has not yet gone under peer-review; technical guide – written document to guide clinicians in their practice.

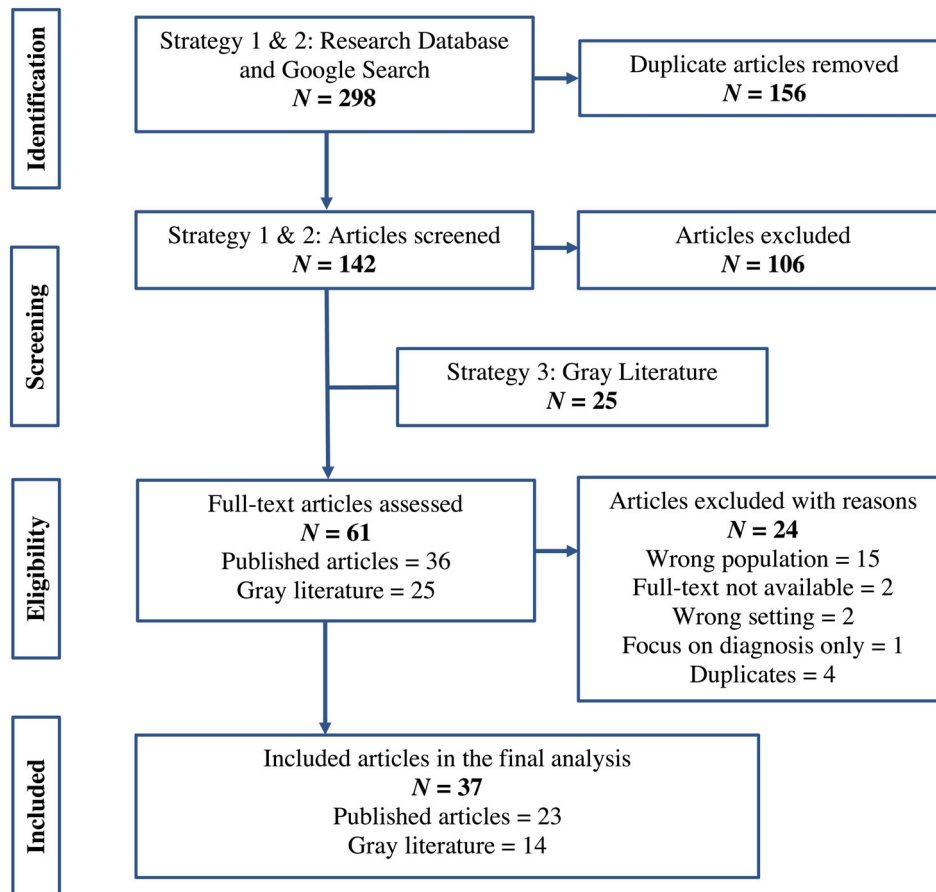
qualitative research quality. To ensure high interrater agreement, we used a calibration exercise with both reviewers using the standardized CASP checklists and discussions were held to clarify issues. Scores on the checklists were calculated for each reviewed publication by both reviewers and agreement was determined when both members reached an acceptable percent agreement (i.e., 70% or more for scoping reviews; see Prime et al., 2020) on the publication. The overall reliability on all reviewed articles was 90%.

## Charting the data

Article characteristics including the authors' name, year, country of origin, publication type, aim of article, sample characteristics, method of data collection, outcome measures (if applicable), and the main findings were organized in a chart format and was constantly modified as new evidence emerged through searches. This technique has been used in other scoping reviews to help reviewers synthesize findings from a multitude of resources into a succinct narrative (Prime et al., 2021; Shorey et al., 2020). The chart was used by both reviewers and discrepancies were clarified with the research team and knowledge users.

## Synthesis of results

The data synthesis focused on providing a narrative summary of published articles and gray literature. Two reviewers extracted information from each article, grouped and labeled findings, categorized themes, and summarized general trends on the impact of COVID-19 on the mental health and wellbeing of caregivers. Our interpretations of the findings were reviewed and verified by our knowledge users (e.g., caregivers of autistic individuals) through a series of group meetings that followed best practice guidelines for engaging knowledge users in research (Brown et al., 2018). The meetings were led by the first author and a knowledge user to ensure applicability of the content and whether the themes resonated with all knowledge users' lived experience. All knowledge users provided context and a qualitative review of information extracted from gray literature. Disagreements in interpretation of content themes were resolved by consensus through discussions with all knowledge users. Knowledge users also had the opportunity to include additional themes, and these were also discussed as a group before inclusion. These findings were incorporated into the final synthesis. Findings were framed within the FAAR Model, highlighting the demands, capabilities, and meaning that have been described within the context of the COVID-19 pandemic.



**FIGURE 1** Preferred reporting items for systematic scoping reviews and meta-analyses (PRISMA-ScR) diagram

## RESULTS

Reporting of the three searches and data collection process can be found in the PRISMA-ScR flow diagram in Figure 1. In Strategies 1 and 2, 142 published articles were identified after removal of duplicates. Of the identified articles, 106 were excluded based on a review of the titles and/or abstracts. In Strategy 3, 25 gray literature were identified. Full-text assessment for eligibility were completed on 61 published articles and gray literature. Based on the eligibility criteria, 24 were excluded for the following reasons: different population focus, text was not available, different setting, diagnosis focus, and identified duplicates. A total of 37 articles were included in the final analysis, 23 of which were published articles in academic journals and 14 were gray literature reports. Further article characteristics will be described below.

As shown in Table 2, 11 studies were assessed out of the original 23 published articles: eight (Chen et al., 2020; Dhiman et al., 2020; Ersoy et al., 2020; Manning et al., 2020; Pavlopoulou et al., 2020; Stan-kovic et al., 2020; Ueda et al., 2021; White et al., 2021) with the CASP Study checklists, and three (Esentürk, 2020; Neece et al., 2020; Parentau et al., 2020) with the CASP Qualitative checklist. The remaining 12 published articles included editorials, commentaries, special reviews, and letters to the editor that

were not critically appraised. In general, the quality of the published articles was variable, as determined by assessments using the CASP checklists.

## Study characteristics

Of the 23 published articles included in our review, two were technical reports and 10 articles included letters to the editor, editorials, or commentaries written by clinicians or researchers in the field of autism, which were published in peer-reviewed journals. Eleven articles included data collection during the early stages of the pandemic; two used qualitative (i.e., interview) methods, eight used quantitative (i.e., survey) methods, and one used mixed-methods (i.e., frequency count and analysis of free form texts) to capture caregivers' perspectives on their experiences during the COVID-19 pandemic. The majority of the articles were published in 2020 and early 2021 representing countries from Europe (Turkey, Serbia, United Kingdom, Italy), Asia (China, Singapore, and India), and North America (Canada and United States).

Within the gray literature, shown in Table 3, we reviewed four organizational reports mainly from North America and Europe (Autism Ontario *Supporting Our Community Report*, April 2020; National Autistic



TABLE 3 Description of Gray literature articles ( $n = 14$ )

Author(s)	Date published	Country	Title	Source	Participants	Category
Autism Ontario (2020)	April, 2020	Canada	Supporting our community	<a href="https://www.autismontario.com/news/supporting-our-community">https://www.autismontario.com/news/supporting-our-community</a>	$N = 182$	Organizational Report
Brown (2020)	April 01, 2020	Israel	A plea for solutions for people with autism during the crisis	Jerusalem Post	N/A	Newspaper
Coteau (2020)	June 29, 2020	Canada	Crisis in the Autism Community	<a href="https://michaelcoteau.onmpp.ca/coteau-releases-report-on-autism-services-during-covid-19-pandemic/">https://michaelcoteau.onmpp.ca/coteau-releases-report-on-autism-services-during-covid-19-pandemic/</a>	$N = 70-105$	Provincial Government Report
Hawkins (2020)	April 25, 2020	USA	One New York special-needs school is ahead of the curve with remote learning; systems already in place for autistic students help them adapt since it is not their 'norm to sit at the kitchen table'	Wall Street Journal	N/A	Newspaper
Laucius (2020)	June 01, 2020	Canada	A summer without camp: families of autistic children lose respite	Ottawa Citizen	N/A	Newspaper
MacDonald (2020)	April 21, 2020	USA	For people with autism, lockdowns shatter routine, heighten anxiety: The coronavirus pandemic has disrupted the reliable pace and structure of life essential to many people with autism	Wall Street Journal	N/A	Newspaper
National Autistic Society (2020)	September 07, 2020	United Kingdom	Left stranded: The impact of coronavirus on autistic people and their families in the UK	<a href="https://www.autism.org.uk/what-we-do/news/coronavirus-report">https://www.autism.org.uk/what-we-do/news/coronavirus-report</a>	$N = 4323$ ( $n = 2422$ family member of autistic people)	Organizational Report
Pellicano et al. (2020)	August 16, 2020	Australia	'I want to see my friends': The everyday experiences of autistic people and their families during COVID-19	<a href="https://www.sydney.edu.au/content/dam/corporate/documents/sydney-policy-lab/everyday-experiences-of-autistic-people-during-covid-19-report-july-2020.pdf">https://www.sydney.edu.au/content/dam/corporate/documents/sydney-policy-lab/everyday-experiences-of-autistic-people-during-covid-19-report-july-2020.pdf</a>	$N = 131$ ( $n = 80$ parents of autistic children; $n = 35$ autistic adults; $n = 16$ young autistic people, 12-18 years old)	Other report
Picon (2020)	May 04, 2020	USA	Six ways to support autism and special needs families during the Coronavirus pandemic	Exceptional Parent Magazine	N/A	Magazine
Salt et al. (2020)	July 16, 2020	Canada	Pandemic Canadian Autism Needs Assessment (PanCANS) Survey	<a href="https://www.autismspeaks.ca/siteAutismCaEN/assets/File/Press%20Releases/pancans-survey_16July2020.pdf">https://www.autismspeaks.ca/siteAutismCaEN/assets/File/Press%20Releases/pancans-survey_16July2020.pdf</a>	$N = 1066$	Organizational Report

(Continues)

TABLE 3 (Continued)

Author(s)	Date published	Country	Title	Source	Participants	Category
Schuck (2020)	May 05, 2020	Canada	Why community matters more than ever for parents of kids with special needs	CBC News	N/A	Blogpost
SPARK: Simon Foundation Powering Autism Research for Knowledge (2020)	April 3, 2020	USA	Impact of COVID-19 on Families and Children with Autism	<a href="https://sparkforautism.org/discover_article/covid-19-impact-asd/">https://sparkforautism.org/discover_article/covid-19-impact-asd/</a>	N/A	Organizational Report
Vandinter (2020)	April 23, 2020	Canada	COVID-19 pandemic taking harder toll on parents, families taking care of children living with autism	CTV News	N/A	News Report
Yogaretnam (2020)	March 30, 2020	Canada	Touched by autism, families 'in crisis'	Ottawa Citizen	N/A	Newspaper

Abbreviations: N, total number; N/A, not available; McMaster ART, autism research team; CASDA, Canadian autism spectrum disorder alliance; PanCANS, Pandemic Canadian autism needs survey; USA, United States of America.

Society: *Left Stranded Report*, September 2020; Pandemic Canadian Autism Needs Assessment Survey, October 2020; and SPARK: Simon Foundation Powering Autism Research for Knowledge, April 2020) one government report (Coteau, 2020), one magazine article, one blog post, one nonpeer-reviewed published report, one news report, and five newspaper articles. The remaining sources included a policy report and media reports of the experience of caregivers of autistic children through the COVID-19 pandemic. Gray literature articles were from Canada, Australia, the USA, and Israel.

## Pandemic-related demands

Twenty out of the 23 published articles in peer-reviewed journals and 11 of our gray literature reports from Europe, Asia, and North America included descriptions of the various *demands* placed on caregivers and families as a result of isolation policies meant to restrict the spread of COVID-19.

## School and service closures

Parents reported on the increased demands for caregivers due to school closures, which resulted in a loss or reduction of prepandemic educational services, childcare support, behavioral therapies and programs for autistic children (i.e., one-on-one support, trained teachers, educational assistants, behavioral interventions, specialists, clinicians, therapists). This resulted in parents and caregivers having to take-up these additional roles (i.e., increased parenting-related workloads or “round-the-clock” care) alongside existing family obligations and responsibilities (Dhiman et al., 2020; Manning et al., 2020; Parentau et al., 2020; Pellican et al., 2020; Stankovic et al., 2020; Ueda et al., 2021; White et al., 2021), and reports of feeling inadequate prepared to meet their child educational and developmental needs (Neece et al., 2020).

## Increase in challenging behaviors and parental stressors

Parents also indicated an increase in challenging behaviors (i.e., frustrations, aggression and violence towards self and others, outbursts), and concerns with increased family conflict (Ueda et al., 2020). Additional stressors were also noted due to abrupt and unpredictable disruptions to the child, caregiver, and family daily routines (White et al., 2021), loss of respite (i.e., limited or no access to support workers as well as grandparents and extended family), loss of caregiver employment leading to financial instability (Manning et al., 2020; National Autistic Society Report, 2020; Neece et al., 2020; White

et al., 2021), and loss of recreational and community-based opportunities (Yarımkaya & Esentürk, 2020).

### Increased vulnerability to mental health challenges

The findings indicated that self-isolation measures had heightened levels of psychological distress in parents (i.e., anxiety, stress, distress, helplessness, psychological wellbeing) and parents reported experiencing anxiety related to safety (i.e., how to protect their child and family from infection when communication about the virus with their child is difficult), loss of income, and high financial strain. The prevalence of depression, anxiety, and symptoms of stress were high within a sample of parents of children with autism and cerebral palsy in India, and levels of strain was significantly higher during the pandemic compared to before (Dhiman et al., 2020), and when compared to mothers of neurotypical children in a Turkish sample (Ersoy et al., 2020). Child maladaptive behaviors were associated with parental self-reported levels of stress (Ueda et al., 2021). American parents with younger autistic children and those with more complex needs reported higher levels of stress and concern during the early stages of the pandemic (Manning et al., 2020). Findings from organization reports from Canada, UK, and the US indicate that parents are “very stressed” and “coping poorly” with reports of feeling worried, anxious, isolated, and depressed. In the U.S.-based SPARK report, 97% of parents or caregivers indicated feeling stressed or overwhelmed due to disruptions in autism-specific services or therapies, and 95% of parents reported that COVID-19 had negatively impacted their mental health.

### Long-term impact of isolation and future needs

Seven articles and three gray literature reports (Ameis et al., 2020; Cassidy et al., 2020; Coteau, 2020; degli Espinosa et al., 2020; National Autistic Society Report, 2020; Neece et al., 2020; Rose et al., 2020; SPARK Report, 2020; Stankovic et al., 2020; White et al., 2021) discussed the potential long-term impact of prolonged exposure to increasing demands on the mental health and wellbeing of caregivers and families of autistic children and alluded to the need for the rapid development and evaluation of flexible, timely, and web-based support programs. For example, Cassidy et al. (2020) wrote that given the long-term uncertainty of the pandemic, caregivers and families are repeatedly faced with financial instability, unpredictable situations, and outcomes. They noted that therapists, clinicians, and educators have mobilized quickly to adapt their services or programs for online platforms, but the impact of these changes need to be tested and investigation into

whether these new delivery models are effective is warranted.

### Capabilities during the pandemic

Researchers and clinicians published a number of letters to editors, editorials, commentary, and technical guidelines that provided advice on how caregivers can manage their *demands* by increasing their *capabilities* during the pandemic. Ten publications and gray literature pieces (Ameis et al., 2020; Brown, 2020; Cassidy et al., 2020; degli Espinosa et al., 2020; Eshraghi et al., 2020; Lim et al., 2020; Manning et al., 2020; Narzisi, 2020; National Autistic Society Report, 2020; Neece et al., 2020; Pellicano et al., 2020; Smile, 2020; SPARK Report 2020; Szabo et al., 2020) either provided or highlighted clinician’s advice to help families, especially those with autistic children with higher levels of social communication challenges and repetitive stereotypical behaviors, to manage their time during the pandemic. Recommendations to parents included re-establishing a “new normal” by reinstating a daily or bedtime routine, giving attention to sensory stimulation, creating visual schedules, allowing adequate but limited exposure to media and regulated screen time, attention to personal and family healthy behaviors (i.e., regular hygiene, daily exercise, and sleep), using communication strategies, sharing special interests with their children, and providing physical activities for their children. One blogpost (Schuck, 2020) highlighted the importance of “personal time” for a single mother of an autistic daughter: “I’ve resorted to just escaping to a hot shower to cry when I’m at my breaking point.”

### Remote services and telehealth

Nine published articles (Ameis et al., 2020; Chen et al., 2020; Cassidy et al., 2020; Dhiman et al., 2020; degli Espinosa et al., 2020; Esentürk, 2020; Narzisi, 2020; Pavlopoulou et al., 2020; Szabo et al., 2020; Yi & Dixon, 2020) and one published report (Pellicano et al., 2020) highlighted the importance of how caregivers and families remained connected to educational services (i.e., teachers, educational assistants, special education resource teachers), behavior therapists, and community resources during the pandemic. For example, some families maintained consistent contact with teachers and school administrators either through phone or online meetings (Chen et al., 2020; Dhiman et al., 2020; Narzisi, 2020; Neece et al., 2020; White et al., 2021), and some teachers had the capacity to continue consulting with parents on how best to provide at-home education to their autistic children (Chen et al., 2020; Dhiman et al., 2020; Neece et al., 2020; Stankovic et al., 2020; White et al., 2021). Some argued that telehealth adaptations should remain even after stay-at-home measures are

lifted, especially if adequate alternative forms of care for this vulnerable population is unavailable (Pellicano et al., 2020). Educational professionals were able to adapt their lessons via online virtual platforms and continued to provide modified educational experiences for families, but the effectiveness of these changes in mitigating behavioral challenges were not measured. There were examples of behavior therapists who adapted their interventions or curriculums so that parents could deliver programs at home (Chen et al., 2020; degli Espinosa et al., 2020; Dhiman et al., 2020; White et al., 2021; Yi & Dixon, 2020), and who provided online consultations with parents (Narzisi, 2020; Szabo et al., 2020). It should be noted, however, that access to online or virtual support was provided inconsistently and was only moderately beneficial (White et al., 2021). Although some families were able to connect with existing services via online platforms, especially mental health services which were well suited for online adaption (White et al., 2020), others noted geographical, cultural, and financial barriers that limited access (Dhiman et al., 2020; White et al., 2021), and that services received online may not work well for minimally verbal children or those with complex needs (Ameis et al., 2020).

### Coping strategies

In a qualitative study by Parentau et al. (2020), researchers asked parents to list coping responses to lockdown measures imposed by the pandemic. In the report, parents listed exercising, attending virtual groups to connect with their community, spending time on self-care (i.e., taking a bath, online shopping), and getting creative with time away from their partners and children, as ways to cope with the stressors of isolation. In the same study, parents noted positive outcomes due to self-isolation measures. Some parents reported that school closures meant that their child's school curriculum refocused from academics (i.e., reading, writing, and math skills) to daily living skills (i.e., self-help) that benefited the wellbeing of both the child and their caregiver (i.e., child has developed some independent adaptive skills). Similarly, Neece et al. (2020) noted that parents coped by implementing behavioral strategies, re-establishing routines, practicing meditation, providing space for family members to decompress and taking breaks from each other, and 92% of parents reported being able to manage their circumstance related to the pandemic. A small handful of parents also noted the helpfulness of receiving government financial aid. Organizational surveys and reports indicated that parents recognized that efforts to balance increased demands during the pandemic could leave them and their families vulnerable to mental health challenges (Autism Ontario, National Autistic Society, Coteau, SPARK, and PanCANS). Some parent respondents noted wanting help addressing increased personal anxiety

(Autism Ontario, 2020) and that while they would like to access mental health services during isolation, were unable to do so (PanCANS, 2020).

### Caregiver making meaning of their pandemic experience

There was relatively little scholarship related to how caregivers made sense of their pandemic experiences. Media reports from the perspective of caregivers of autistic children highlighted the protective effects of connection and close social relationships (via online communications or communities like Facebook groups) in fostering a sense of "togetherness" that has helped families find *meaning* during the pandemic. From one blog post, "*Why Community Matters More Than Ever For Parents Of Kids With Special Needs*" (Schuck, 2020), some parents reported finding Facebook communities or parent support groups a vital resource during the pandemic. In Neece et al. (2020), a handful of ethnically and linguistically diverse parents noted enjoying seeing communities come together to support each other during the pandemic. Parents of children with disabilities relied on these online communities for support, especially when their own personal communities (i.e., extended family, supportive neighbors, and friends) were unable to help them due to isolation guidelines. Some families reported that supportive relationships and positive socially distanced interactions with family members (i.e., reading stories together on their phone or even daily text check-ins) were helpful in maintaining feelings of normalcy during this time (personal communications). Supporting caregiver and family cultures was an emerging theme within gray literature that spoke to the attitudes towards family cohesiveness and culture that led to caregiver and family resilience.

### DISCUSSION

The current scoping review identified the demands, capabilities, and how families were making meaning of their experience through the COVID-19 pandemic across a number of evidence-based and gray literature sources. The synthesis reveals that caregivers of autistic children and youth are facing increased demands and external stressors that are having an impact on their mental health and wellbeing. Families have experience abrupt changes to their routines, have limited access to or lost their autism-based supports (i.e., interventions, therapists, respite, schools and other professionals), and are struggling with the pressures of confinement. While families are engaging internal and external resources to cope with the abrupt changes and disruption in their lives as a result of the pandemic, there is also a reduction in

existing resources, impacting the ability to balance the new stressors. Reported family outcomes have been variable, with some families coping and have experienced positives during the pandemic, while others have experienced crisis (Friesen et al., n.d. submitted). Knowledge users confirmed themes derived from the literature that describe the importance of a family's belief system and how they make meaning of adversity on building resilience. There is a need for longitudinal surveillance of caregiver mental health and wellbeing as the pandemic progresses, and to address the research gaps in reports that assess evidence-based programs to support caregivers. The following are key themes synthesized from the scoping review.

### **Caregiver mental health and wellbeing**

Although there has been an increasing number of published reports outlining the demands of the pandemic on families and the potential impact on their mental health and family functioning, (Prime et al., 2020; Wade et al., 2020), there are a limited number of reports focused on potential mental health outcomes for caregivers and families of autistic people. Given the vulnerability to existing mental health concerns in caregivers of autistic people (Martin et al., 2019), it is important for researchers, clinicians, key-decision makers, and policymakers to consider the unfolding impact of the unpredictable demands of the pandemic coupled with pre-existing stressors associated with the care of autistic children and youth on caregivers and families. A host of parent-focused surveys were launched in the first wave of the pandemic aimed to better capture the information about the mental health challenges in caregivers and families (i.e., siblings), though final results of these surveys have yet to be made available. While data from these surveys will provide useful information about family experiences, collaborations will be important to avoid duplication of efforts. As evident from our review, it will be crucial for future work to include considerations of cultural and regional variations in COVID-19-related response that may impact caregiver mental health and family outcomes, as well as validated measures of mental health that can properly quantify and describe symptoms, including how they change over time in terms of their intensity and frequency (Lai et al., 2019).

### **Considerations for caregivers from marginalized and linguistically diverse communities**

There are several gaps in the extant literature. Perhaps most critical to the systemic nature of the pandemic are the many inequities that have been brought to light regarding access to health, educational, and social

services by many different marginalized communities (Khanlou, 2021; Khanlou et al., 2020; Pellicano & Stears, 2020). For example, reports have emerged highlighting how women, especially those from ethnically and linguistically diverse populations, have experienced higher levels of financial burden and loss of employment (Khanlou et al., 2020), and mothers have reported high levels of anxiety, depression, and stress due to the pandemic (Racine et al., 2021). Outside of the pandemic, work has been done demonstrating how these intersections are critical considerations for families of autistic people (Escarce & Kapur, 2006; Liptak et al., 2008; Nguyen et al., 2016; Zuckerman et al., 2017). To date though, no published work that we have located has applied an intersectionality-informed lens in explicating the heightened marginalization of racialized families in relation to coping with the demands of the pandemic, disparities in the social determinants of health, and the specific supports they require to ensure equitable care. There is evidence from prepandemic work to suggest that healthcare systems do not adequately meet the needs of ethnically and linguistically diverse, and marginalized communities. This includes reports of disparities in access to timely diagnosis and developmental interventions (Liptak et al., 2008; Nguyen et al., 2016; Zuckerman et al., 2017) that are associated with language barriers and socioeconomic status (Escarce & Kapur, 2006; Stahmer et al., 2019), and mental health literacy, stigma, and discrimination (DeFreitas et al., 2018). The demands associated with caring for an autistic individual, especially those with complex needs (i.e., age of child, intellectual disabilities), may be compounded by these socio-contextual variables, which may make caregivers and families increasingly vulnerable to the impact of the pandemic.

### **Changing parent-child relationships and dynamics**

The extant publications also do not consider how the heightened levels of psychological distress might impact the quality of relationships among caregivers (i.e., marital/partners), parents and their autistic children, and siblings. Considering the impact of caregivers' on the developmental outcomes of their children (Developmental Systems Theory; Griffiths & Hochman, 2015), and coupled with the difficulties that autistic people may experience adjusting to extreme changes in routine (Ameis et al., 2020; Chen et al., 2020), and strict social distancing regulations, these demands pose a significant risk for the emotional adjustment of all children, and as some editorials have mentioned, will likely manifest as behavioral challenges (i.e., aggression, tantrums, emotional outbursts, self-harm, difficulties with transitions, etc.). Ample evidence supports that lockdown measures have had a negative impact on the mental



health and wellbeing of autistic children and youth (Ameis et al., 2020; Asbury et al., 2020; Colizzi et al., 2020; Kong, 2021; Shorey et al., 2020) and adults with intellectual and developmental disabilities (Lake et al., 2021). Given the bidirectional nature of heightened parenting stress and child challenging behaviors (Neece et al., 2012; Zaidman-Zait et al., 2014), it is plausible that within a family unit, hardships experienced during the pandemic have intensified or changed family dynamics and parent-child interactions. Future research is warranted in understanding the unique challenges posed by the pandemic on autistic people and their families, and how this may be addressed by supports that target child emotional development and mental health, promote positive interpersonal connections, parent-child relationships, and family wellbeing.

### Considerations for remote services and telehealth

Reports suggest that educators and therapists have adapted some school lessons and interventions for online platforms, and have been able to continue providing modified programming to autistic children (i.e., consultations over the phone, adaptations to virtual delivery, dropping off physical kits to parents, meeting in parks, etc.). However, few adaptations have been systematic or strategic, and none have yet to be tested for their effectiveness or efficacy. Rather, the literature suggests that most have been adapted as urgent family needs arise. Previous work has indicated that there are benefits to participating in online interventions for caregivers of autistic children (Blackman et al., 2020; Hermaszewska & Sin, 2020; Simacek et al., 2020), and autistic adults (Lunsky et al., 2021), but none within the context of a global pandemic. There is ample opportunity to continue investigating the effectiveness of adapted and web-based curricula and interventions on the targeted needs of autistic children during the pandemic, including the impact of participation in online programs on the wellbeing of the children and their caregivers and family.

### Limitations

It is important to note that this review included mostly research and articles from the first wave of the pandemic which limits the scope of our interpretation. Yet, there is value in reviewing, synthesizing, and documenting the published and gray literature as they emerge in order to capture the full extent of the demands and capabilities that families have experienced throughout the duration of an ongoing pandemic. As the pandemic continues to evolve and the international community continues to adapt, new evidence may provide more insight into the lived experience of caregivers and families of autistic people and illuminate ways in which mental health and wellbeing has been put at risk or have been supported. The majority of articles included in the review varied in quality and the

results should be interpreted with caution. Reviewing themes and validating them with our knowledge users (e.g., parents of autistic individuals, community-based advocates) was undertaken to help mitigate this limitation. Moreover, we consolidated information from the English-only literature on families of children and youth, and responders were mostly mothers which limits the scope of our interpretations. We did not include literature on the mental health and wellbeing of caregivers for adults on the spectrum or those with more complex needs, which limits the scope of the review and generalizability of the findings.

### CONCLUSIONS

There is growing awareness of the pandemic's impact and the increase in stressors and demands placed on caregivers of autistic children and youth. Ongoing surveillance of caregiver mental health and wellbeing throughout and beyond the pandemic is needed, especially research that examines changes in family dynamics, the effectiveness of adapted virtual services and interventions, factors that contribute to resilience and growth, and the experiences of families who live at the intersections of autism and sociodemographic inequities and marginalization. It would be interesting to conduct an analysis of cross regional responses to limiting the spread of COVID-19, and their impact on caregiver mental health and wellbeing, but this would be beyond the scope of this review. Doing so will continue to further our understanding of how the pandemic has changed caregiver and child behaviors and family relationships, and will help service providers and policymakers to continue to adapt to their needs. However, surveillance should be coupled with equity-informed and specific actions, so that needs of caregivers are responded to in a timely and family-focused manner, and not just reported on.

### ACKNOWLEDGMENTS

The author(s) disclose receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by the 2020 Canadian Institutes of Health Research Rapid Knowledge Synthesis Grant, and by the York Research Chair in Autism and Neurodevelopmental Disability Mental Health. Dr. Gorter is supported by the McMaster University University Scotiabank Chair in Child Health Research.

### ETHICS STATEMENT

The current manuscript reviewed and synthesized findings from previously published empirical articles. This type of research does not require an ethics committee approval at our institution.

### ORCID

Vivian Lee  <https://orcid.org/0000-0002-8686-6264>

Carly McMorris  <https://orcid.org/0000-0002-5164-6210>

## REFERENCES

- Adams, J., Hillier-Brown, F. C., Moore, H. J., Lake, A. A., Araujo-Souares, V., White, M., & Summerbell, C. (2016). Searching and synthesising 'grey literature' and 'grey information' in public health: Critical reflections on three case studies. *Systematic Reviews*, 5(1), 164. <https://doi.org/10.1186/s13643-016-0337-y>
- Adams, R. J., Smart, P., & Huff, A. S. (2017). Shades of grey: Guidelines for working with grey literature in systematic reviews for management and organizational studies. *International Journal of Management Reviews*, 19(4), 432–454. <https://doi.org/10.1111/ijmr.12102>
- Amies, S. H., Lai, M. C., Mulsant, B. H., & Szatmari, P. (2020). Coping, fostering resilience, and driving care innovation for autistic people and their families during COVID-19 pandemic and beyond. *Molecular Autism*, 11, 61. <https://doi.org/10.1186/s13229-020-00365-y#citeas>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Asbury, K., Fox, L., Deniz, E., Code, A., & Toseeb, U. (2020). How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families. *Journal of Autism and Developmental Disorders*, 51(5), 1–9. <https://doi.org/10.1007/s10803-020-04577-2>
- Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). Resilience in family members of persons with autism spectrum disorder: A review of the literature. *Issues in Mental Health Nursing*, 33(10), 650–656.
- Benson, P., & Kersh, J. (2011). Martial quality and psychological adjustment among mothers of children with ASD: Cross-sectional and longitudinal relationships. *Journal of Autism and Developmental Disorders*, 41, 1675–1685.
- Blackman, A. L., Jimenez-Gomez, C., & Shvarts, S. (2020). Comparison of the efficacy of online versus in-vivo behavior analytic training for parents of children with autism spectrum disorder. *Behavior Analysis: Research and Practice*, 20(1), 13–23. <https://doi.org/10.1037/bar0000163>
- Bowen, M. (1978). *Family theory in clinical practice*. Jason Aronson.
- Brown, A., Strain, K., Wallsworth, C., Charlton, S. G., Chang, W., McNamee, K., & Hamilton, C. (2018). What constitutes meaningful engagement for patients and families as partners on research teams? *Journal of Health Services Research & Policy*, 23(3), 158–167. <https://doi.org/10.1177/1355819618762960>
- Brown, H. (2020). A plea for solutions for people with autism. *Jerusalem Post*. <https://www.jpost.com/opinion/coronavirus-a-plea-for-humane-solutions-for-people-with-autism-623243>
- Brown, J. (1999). Bowen family systems theory and practice: Illustration and critique. *Australian & New Zealand Journal of Family Therapy*, 20(2), 94–103. <https://doi.org/10.1002/j.1467-8438.1999.tb00363.x>
- Byers, J. F., & Beaudin, C. L. (2001). Critical Appraisal Tools Facilitate the Work of the Quality Professional. *Journal For Healthcare Quality*, 23(5), 35–43. <http://dx.doi.org/10.1111/j.1945-1474.2001.tb00374.x>
- Cassidy, S. A., Nicolaidis, C., Davies, B., Des Roches Rosa, S., Eisenman, D., Giwa Onaiwu, M., Kapp, S. K., Kripke, C. C., Rodgers, J., & Waisman, T. C. (2020). An expert discussion on autism in the COVID-19 pandemic. *Autism in Adulthood*, 2(2), 106–117. <https://doi.org/10.1089/aut.2020.29013.sjc>
- Chen, S.-Q., Chen, S.-D., Li, X.-K., & Ren, J. (2020). Mental health of parents of special needs children in China during the COVID-19 pandemic. *International Journal of Environmental Research and Public Health*, 17(24), 9519. <https://doi.org/10.3390/2fijerph17249519>
- Clifford, S., & Dissanayake, C. (2009). Dyadic and triadic behaviours in infancy as precursors to later social responsiveness in young children with autistic disorder. *Journal of Autism and Developmental Disorders*, 39, 1369–1380. <https://doi.org/10.1007/s10803-009-0748-x>
- Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zocante, L. (2020). Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: An online parent survey. *Brain Sciences*, 10(6), 341. <https://doi.org/10.3390/brainsci10060341>
- Coteau, M. (2020). *Crisis in the autism community: Challenges from COVID-19 and the changes in the OAP*. Office of Michael Coteau <https://michaelcoteau.onmpp.ca/coteau-releases-report-on-autism-services-during-covid-19-pandemic/>
- Critical Appraisal Skills Programme (2018). CASP (Cohort Study and Qualitative) Checklist. <https://casp-uk.net/casp-tools-checklists/>
- DeFreitas, S. C., Crone, T., DeLeon, M., & Ajayi, A. (2018). Perceived and personal mental health stigma in Latino and African American college students. *Frontiers in Public Health*, 6, 49 <https://doi.org/10.3389/fpubh.2018.00049>
- Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Research in Developmental Disabilities*, 107, 103790. <http://dx.doi.org/10.1016/j.ridd.2020.103790>
- Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of covid-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Research in Developmental Disabilities*, 107, 103790. <https://doi.org/10.1016/j.ridd.2020.103790>
- Dixon-Woods, M. A., Sutton, A., Shaw, R., Miller, T., Smith, T., Smith, J., Young, B., Booth, A., & Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Services Research and Policy*, 12(1), 42–47. <https://doi.org/10.1258/135581907779497486>
- Ersoy, K., Altun, B., Sankaya, B., & Özkardaş, O. (2020). The comparison of impact of health anxiety on dispositional hope and psychological well-being of mothers who have children diagnosed with autism and mothers who have normal children, in Covid-19 pandemic. *Social Sciences Research Journal*, 9(2), 117–126 <https://dergipark.org.tr/en/pub/ssrj/issue/54392/737630>
- Escarce, J. J., & Kapur, K. (2006). Access to and quality of health care. In M. Tienda & F. Mitchell (Eds.), *National Research Council (US) panel on Hispanics in the United States*. Hispanics and the Future of America. National Academies Press (US) <https://www.ncbi.nlm.nih.gov/books/NBK19910/>
- Esentürk, O. K. (2020). Parents' perceptions on physical activity for their children with autism spectrum disorders during the novel coronavirus outbreak. *International Journal of Developmental Disabilities*. <https://doi.org/10.1080/20473869.2020.176933>
- Eshraghi, A. A., Li, C., Alessandri, M., Messinger, D. S., Eshraghi, R. S., Mittal, R., & Armstrong, F. D. (2020). COVID-19: Overcoming the challenges faced by individuals with autism and their families. *Lancet Psychiatry*, 7(6), 481–483. <https://doi.org/10.1016/s2215-0366>
- Degli Espinosa, Metko, A., Raimondi, M., Impenna, M., & Scognamiglio, E. (2020). A model for support for families of children with autism living in the COVID-19 lockdown: Lessons from Italy <https://doi.org/10.31234/osf.io/48cme>
- Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., & Munson, J. (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain Development*, 35(2), 133–138 <https://doi.org/10.1016/j.braindev.2012.10.004>
- Friesen, K., Weiss, J.A., Howe, S., Kerns, C., & McMorris, C.A. Mental health and resilience in caregivers of autistic individuals during the COVID-19 pandemic: Findings from the families facing COVID study.
- Gagliardi, A. R., Berta, W., Kothari, A., Boyko, J., & Urquhart, R. (2015). Integrated knowledge translation (IKT) in health care: A scoping review. *Implementation Science*, 11(1), 38. <https://doi.org/10.1186/s13012-016-0399-1>
- Garrity, C., Gartlehner, G., Kamel, C., King, V. J., Nussbaumer-Streit, B., Stevens, A., Hamel, C., & Affengruber, L. (2020).

- Cochrane rapid reviews. *Interim Guidance from the Cochrane Rapid Reviews Methods Group*.
- Gau, S. S. F., Chou, M. C., Chiang, H. L., Lee, J. C., Wong, C. C., Chou, W. J., & Wu, Y.-Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders, 6*, 263–270. <https://doi.org/10.1016/j.rasd.2011.05.007>
- Griffiths, P. E., & Hochman, A. (2015). *Developmental Systems Theory*. John Wiley & Sons. Ltd.
- Haebig, E., McDuffie, A., & Ellis Weismer, S. (2013). Brief report: Parent verbal responsiveness and language development in toddlers on the autism spectrum. *Journal of Autism and Developmental Disorders, 43*, 2218–2227. <https://doi.org/10.1007/s10803-013-1763-5>
- Hall, H. R., & Graff, J. C. (2012). Maladaptive behaviors of children with autism: Parent support, stress, and coping. *Issues in Comprehensive Pediatric Nursing, 35*(3–4), 194–214. <https://doi.org/10.3109/01460862.2012.734210>
- Hartley, S. L., Barker, E. T., Baker, J. K., Seltzer, M. M., & Greenberg, J. S. (2012). Marital satisfaction and life circumstances of grown children with autism across 7 years. *Journal of Family Psychology, 26*(5), 688–697. <https://doi.org/10.1037/a0029354>
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*(4), 377–391. <https://doi.org/10.1177/1362361305056078>
- Hawkins, L. (2020). One New York special-needs school is ahead of the curve with remote learning; systems already in place for autistic students help them adapt since it isn't their 'norm to sit at the kitchen table'. Wall Street Journal. <https://www.wsj.com/articles/one-new-york-special-needs-school-is-ahead-of-the-curve-with-remote-learning-11587823201>
- Hayes, S., & Watson, S. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 629–642. <https://doi.org/10.1007/s10803-012-1604-y>
- Heinrich, C. J. (2014). Parents' employment and children's wellbeing. *The Future of Children, 24*(1), 121–146. <http://doi.org/10.1353/foc.2014.0000>
- Hermaszewska, S., & Sin, J. (2020). End-user perspectives on the development of an online intervention for parents of children on the autism spectrum. *Autism, 25*(5), 1234–1245. <https://doi.org/10.1177/1362361320984895>
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disabilities Research, 50*(Pt 12), 874–882. <https://doi.org/10.1111/j.1365-2788.2006.00904.x>
- Katrak, P., Bialocerkowski, A. E., Massy-Westropp, N., Kumar, V. S., & Grimmer, K. A. (2004). A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology, 4*(1), 1–11. <http://dx.doi.org/10.1186/1471-2288-4-22>
- Khanlou, N. (2021). Year 2020: How will it impact identities of children and youth over time? *International Journal of Mental Health and Addiction, 1*–3. <https://doi.org/10.1007/s1007%2Fs11469-021-00484-4>
- Khanlou, N., Ssawe, A., Vazquez, L. M., Pashang, S., Connolly, J. A., Bohr, Y., Epstein, I., Zahraei, S., Ahmad, F., Mgwigwi, T., & Alamdar, N. (2020). *COVID-19 pandemic guidelines for mental health support of racialized women at risk of gender-based violence: Knowledge synthesis report*. Funded by Canadian Institutes of Health Research (CIHR) Operating Grant: Knowledge Synthesis: COVID-19 in Mental Health & Substance Use. York university: <https://cihr-irsc.gc.ca/e/52062.html>
- Kong, M. (2021). What COVID-19 means for non-neurotypical children and their families. *Pediatric Research, 89*, 396–397. <https://doi.org/10.1038/s41390-020-0913-7>
- Kuhlthau, K., Payakachat, N., Delahaye, J., Hurson, J., Pyne, J. M., Kovacs, E., & Tilford, J. M. (2014). Quality of life for parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 8*(10), 1339–1350. <https://doi.org/10.1016/j.rasd.2014.07.002>
- Lai, J., Klag, M., & Shikako-Thomas, K. (2019). Designing a program evaluation for a medical-dental service for adults with autism and intellectual disabilities using the RE-AIM framework. *Learning Health Systems, 3*(3), e10192. <https://doi.org/10.1002%2Flrh2.10192>
- Lai, M. C., Kasse, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry, 6*(10), 819–829. <https://doi.org/10.1016/s2215-0366>
- Lake, J. K., Jachyra, P., Volpe, T., Lunsy, Y., Magnacca, C., Marcinkiewicz, A., & Hamdani, Y. (2021). The wellbeing and mental health experiences of adults with intellectual and developmental disabilities during COVID-19. *Journal of Mental Health Research in Intellectual Disabilities, 14*(3), 285–300. <https://doi.org/10.1080/19315864.2021.1892890>
- Laucius, J. (2020). A summer without camps: Families of autistic children lose respite. Ottawa Citizen, <https://www.pressreader.com/canada/ottawa-citizen/20200601/281505048436560>
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 3*, 172–183. <https://doi.org/10.1111/j.1365-2788.2005.00732.x>
- Lee, G. K., Lopata, C., Volker, M. A., Thomeer, M. L., Nida, R. E., Toomey, J. A., Chow, S. Y., & Smerbeck, A. M. (2009). Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on autism and other developmental disabilities, 24*(4), 227–239. <https://doi.org/10.1177%2F1088357609347371>
- Lim, T., Tan, M. Y., Aishworiya, R., & Kang, Y. Q. (2020). Autism spectrum disorder and COVID-19: Helping caregivers navigate the pandemic. *Annals of Academy of Medicine Singapore, 49*(6), 384–386.
- Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nola, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children's health. *Journal of Developmental and Behavioral Pediatrics, 29*(3), 152–160. <https://doi.org/10.1097/dbp.0b013e318165c7a0>
- Lunsy, Y., Albaum, C., Baskin, A., Hastings, R. P., Sue, H., Steel, L., Wang, W., & Weiss, J. (2021). Group virtual mindfulness-based intervention for parents of autistic adolescents and adults. *Journal of Autism and Developmental Disorders, 51*(8), 2920–2928. <https://doi.org/10.1007/s10803-020-04835-3>
- Macdonald, A. (2020). For people with autism, lockdowns shatter routine, heighten anxiety: The coronavirus pandemic has disrupted the reliable pace and structure of life essential to many people with autism. Wall Street Journal. <https://www.wsj.com/articles/for-people-with-autism-lockdowns-shatter-routine-heighten-anxiety-11587480231>
- Manning, J., Billian, J., Matson, J., Allen, C., & Soares, N. (2020). Perceptions of families of individuals with autism Spectrum disorder during the COVID-19 crisis. *Journal of Autism and Developmental Disorders, 51*(8), 2920–2928. <https://doi.org/10.1007/s10803-020-04750-5>
- Martin, C. A., Papadopoulou, N., Chellew, T., Rinehart, N. J., & Sciberras, E. (2019). Associations between parenting stress, parent mental health and child sleep problems for children with ADHD and ASD: Systematic review. *Research in Developmental Disabilities, 93*, 103463. <https://doi.org/10.1016/j.ridd.2019.103463>
- Muskens, J. B., Velders, F. P., & Staal, V. G. (2017). Medical comorbidities in children and adolescents with autism spectrum disorders and attention deficit hyperactivity disorders: A systematic



- review. *European Child and Adolescent Psychiatry*, 26(9), 1093–1103. <https://doi.org/10.1007/s00787-017-1020-0>
- Narzisi, A. (2020). Handle the autism spectrum condition during coronavirus (COVID-19) stay at home period: Ten tips for helping parents and caregivers of young children. *Brain Science*, 10(4), 207. <https://doi.org/10.3390/brainsci10040207>
- National Autistic Society (2020). *Left stranded: The impact of coronavirus on autistic people and their families in the UK*. <https://s4.chorus-mk.thirdlight.com/file/1573224908/63117952292/width=-1/height=-1/format=-1/fit=scale/t=444295/e=never/k=da5c189a/LeftStranded%20Report.pdf>
- Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: a transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities*, 117, 48–66.
- Neece, C., McIntyre, L. L., & Fenning, R. (2020). Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*. <http://dx.doi.org/10.1111/jir.12769>
- Nguyen, C. T., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K. (2016). Sociodemographic disparities in intervention service utilization in families of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(12), 3729–3738. <https://doi.org/10.1007/s10803-016-2913-3>
- Autism Ontario (2020). *Supporting our community*. <https://www.autismontario.com/news/supporting-our-community>
- Parenteau, C., Bent, S., Hendren, R. L., Hossain, B., Chen, Y., Widjaja, F., & Breard, M. (2020). A qualitative analysis: The experience of parents of children with autism Spectrum disorder during the COVID-19 pandemic. *Journal of American Academy of Child and Adolescent Psychiatry*, 59(10), S251. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7567555/>
- Patterson, J. (1988). Families experiencing stress: The family adjustment and adaptation response model. *Family Systems Medicine*, 6(2), 202–237. <https://doi.org/10.1037/h0089739>
- Pavlopoulou, G., Wood, R., & Papadopoulos, C. (2020). Impact of Covid-19 on the experiences of parents and family carers of autistic children and youth people in the UK. *UCL Research Briefing, ID: 4992C01D-4415-480D-8088-341CF13EE1EB*
- Pellicano, E., & Stears, M. (2020). The hidden inequities of COVID-19. *Autism*, 24(6), 1309–1310. <https://doi.org/10.1177/1362361320927590>
- Picon, D. (2020, May 4). Six ways to support autism & special needs families during the coronavirus pandemic. *Exceptional Parent Magazine*, 50(5), 40–41.
- Prime, H., Andrews, K., McTavish, J., Harris, M., Janus, M., Bennett, T., & Gonzalez, A. (2021). The application of positive parenting interventions to academic school readiness: A scoping review. *Child: Care, Health and Development*, 47(1), 1–14. <https://doi.org/10.1111/cch.12810>
- Prime, H., Wade, M., & Browne, D. T. (2020). Risk and resilience in family well-being during the COVID-19 pandemic. *American Psychologist*, 75(5), 631–643.
- Public Health Agency of Canada. (2018). *Autism Spectrum Disorder among Children and Youth in Canada 2018: A report of the National Autism Spectrum Disorder Surveillance System*. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html>
- Racine, N., Hetherington, E., McArthur, B. A., McDonald, S., Edwards, S., Tough, S., & Madigan, S. (2021). Maternal depressive and anxiety symptoms before and during the COVID-19 pandemic in Canada: A longitudinal analysis. *The Lancet Psychiatry*, 8(5), 405–415. [https://doi.org/10.1016/S2215-0366\(21\)00074-2](https://doi.org/10.1016/S2215-0366(21)00074-2)
- Rose, J., Willner, P., Cooper, V., Langdon, P. E., Murphy, G. H., & Kroese, B. S. (2020). The effect on and experience of families with a member who has intellectual and developmental disabilities of the COVID-19 pandemic in the UK: Development an investigation. *International Journal of Developmental Disabilities*. <https://doi.org/10.1080/20473869.2020.1764257>
- Ruble, L., McDuffie, A., King, A. S., & Lorenz, D. (2008). Caregiver responsiveness and social interaction behaviors of young children with autism. *Topics in Early Childhood Special Education*, 28, 158–170. <https://doi.org/10.1177%2F0271121408323009>
- Salt, M., Soliman, P., & Kata, A. (2020). Pandemic Canadian autism needs assessment survey [report v.1.0]. Autism Speaks Canada.
- Schuck, P. (2020). *Why community matters more than ever for parents of kids with special needs*. Canada: The Canadian Broadcasting Corporation. <https://www.cbc.ca/parents/learning/view/why-community-matters-more-than-ever-for-parents-of-kids-with-special-needs>
- Shorey, S., Ng, E. D., Haugan, G., & Law, E. (2020). The parenting experiences and needs of Asian primary caregivers of children with autism: A meta-synthesis. *Autism*, 24(3), 591–604. <https://doi.org/10.1177/1362361319886513>
- Simacek, J., Elmquist, M., Dimian, A. F., & Reichle, J. (2020). Current trends in telehealth applications to deliver social communication interventions for young children with or at risk for autism spectrum disorder. *Current Developmental Disorders Reports*, 8, 15–23. <https://doi.org/10.1007/s40474-020-00214-w>
- Singer, G. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, 111, 155–169. <https://doi.org/10.1352/0895-8017>
- Smile, S. C. (2020). Supporting children with autism spectrum disorder in the face of the COVID-19 pandemic. *Canadian Medical Association Journal*, 192(21), E587. <https://doi.org/10.1503/cmaj.75399>
- SPARK: Simons Powering Autism Research. (2020). *Impact of COVID-19 on families and children with autism*. [https://sparkforautism.org/discover\\_article/covid-19-impact-asd/](https://sparkforautism.org/discover_article/covid-19-impact-asd/)
- Stahmer, A. C., Dababnah, S., & Rieth, S. R. (2019). Considerations in implementing evidence-based early autism spectrum disorder interventions in community settings. *Pediatric Medicine*, 2, 18. <https://doi.org/10.21037%2Fpm.2019.05.01>
- Stankovic, M., Jelena, S., Stankovic, M., Shih, A., Stanjanovic, A., & Stankovic, S. (2020). The Serbian experience of challenges of parenting children with autism spectrum disorders during the COVID-19 pandemic and the state of emergency with the police lockdown. *The Lancet Child and Adolescent Health*. <https://doi.org/10.2139/ssrn.3582788>
- Szabo, T. G., Richling, S., Embry, D. D., Biglan, A., & Wilson, K. G. (2020). From helpless to hero: Promoting values-based behaviour and positive family interaction in the midst of COVID-19. In *Behaviour analysis in practice* (pp. 1–9). Advanced online Publication.
- Taylor, W. D., Cobigo, V., & Ouellette-Kuntz, H. (2019). A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(5), 1116–1128. <https://doi.org/10.1111/jar.12601>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. <https://doi.org/10.7326/m18-0850>
- Ueda, R., Okada, T., Kita, Y., Ozawa, Y., Inoue, H., Shioda, M., Kono, Y., Kono, C., Nakamura, Y., Amemiya, K., Ito, A., Suguira, N., Matsuoka, Y., Kaiga, C., Kubota, M., & Ozawa, H. (2021). The quality of life of children with neurodevelopmental disorders and their parents during the coronavirus disease 19 emergency in Japan. *Scientific Reports*, 11(1), 1–8. <https://doi.org/10.1038/s41598-021-82743-x>
- Vandinter, J. (2020). COVID-19 pandemic taking harder roll on parents, families, taking care of children living with autism. CTV Coronavirus News.

- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders, 23*, 36–49. <https://doi.org/10.1016/j.rasd.2015.11.008>
- Wade, M., Prime, H., & Browne, D. T. (2020). Why we need longitudinal mental health research with children and youth during (and after) the COVID-19 pandemic. *Psychiatry Research, 290*, 113143. <https://doi.org/10.1016/j.psychres.2020.113143>
- Weiss, J. A., & Lunsky, Y. (2011). The brief family distress scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. *Journal of Child and Family Studies, 20*(4), 521–528. <https://doi.org/10.13072/midss.110>
- White, L. C., Law, J. K., Daniels, A. M., Toroney, J., Vernioia, B., Xiao, S., The SPARK Consortium, Feliciano, P., & Chung, W. K. (2021). Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from SPARK Cohort.
- Yarimkaya, E., & Esentürk, O. K. (2020). Promoting physical activity for children with autism spectrum disorders during coronavirus outbreak: Benefits, strategies, and examples. *International Journal of Developmental Disabilities, 2020*. <https://doi.org/10.1080/20473869.2020.1756115>
- Yi, Z., & Dixon, M. R. (2020). Developing and enhancing adherence to a telehealth ABA parent training curriculum for caregivers of children with autism. <https://doi.org/10.31234/osf.io/sc7br>
- Yogaretnam, S. (2020). *Touched by autism, families 'in crisis.'* Ottawa Citizen, <https://www.pressreader.com/canada/ottawa-citizen/20200330/281522228187720>
- Zablotsky, B., Boswell, K., & Smith, C. (2012). An evaluation of school involvement and satisfaction of parents of children with autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities, 117*(4), 316–330. <https://doi.org/10.1352/1944-7558-117.4.316>
- Zaidman-Zait, A., Mirenda, P., Duku, E., Szatmari Georgiades, S., Volden, J., Zwaigenbaum, L., Vaillancourt, T., Bryson, S., Smith, I., Fombonne, E., Roberts, W., Waddell, C., Thompson, A., & The Pathways in ASD Study Team. (2014). Examination of bidirectional relationships between parent stress and two types of problem behavior in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*, 1908–1917. <https://doi.org/10.1007/s10803-014-2064-3>
- Zaidman-Zait, A., Mirenda, P., Zumbo, B. D., Georgiades, S., Szatmari, P., Bryson, S., Fombonne, E., Roberts, W., Smith, I., Vaillancourt, T., Volden Waddell, C., Zwaigenbaum, L., Duku, E., Thompson, A., & Pathways in ASD Study Team. (2011). Factor analysis of the parent stress index-short form with parents of young children with autism spectrum disorders. *Autism Research, 4*(5), 336–346. <https://doi.org/10.1002/aur.213>
- Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in diagnosis and treatment of autism in Latino and non-Latino families. *Pediatrics, 139*(5), e20163010. <https://doi.org/10.1542/peds.2016-3010>

## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

**How to cite this article:** 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, 14*(12), 2477–2494. <https://doi.org/10.1002/aur.2616>