

# Impact of COVID-19 on the Mental Health and Wellbeing of Caregivers and Families of Autistic People

## A Rapid Synthesis Review

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### For

The Canadian Institutes of Health Research

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# Report Notes

## Abbreviations

**COVID-19**                      Coronavirus Disease 2019 (illness)

## Definitions

Term	Definitions
<b>Commentary</b>	An explanation or discussion about an event taking place, a book or articles, or a person. Some may include an opinion. <sup>1</sup>
<b>Editorial</b>	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. <sup>2</sup>
<b>Empirical</b>	A type of research methodology that relies on observation or data collection to arrive at conclusions. Empirical studies can be quantitative (numbers) or qualitative (descriptive) in nature.

## Language

There have been significant changes in recent years that have shaped how autism is discussed, defined, and described. There are some recommendations for identity-first language (e.g., “autistic person”) or for person-first language (e.g., “people with autism”). While traditionally person-first language was the recommended method for describing autism, as part of a broader movement to separate the person from symptoms or traits, many advocates and authors have highlighted the issues with this approach for the autistic community.<sup>1</sup> Many advocates from the autistic community note that identity-first language is the preferred way of talking about autism. Autism is seen as an inseparable part of who autistic people are. Throughout the report, the term “autistic child/person” is used when communicating about autism. We acknowledge that there continue to be disagreements, and our usage of identity-first language is meant to recognize, affirm, and validate the ownership of an identity as an autistic person. The term autistic is not viewed in a negative light.



# Project Summary Description

Autism is a pervasive neurodevelopmental condition and varies in terms of symptom presentation and severity, and autistic people tend to have social communication challenges, sensory sensitivities, and engage in restricted, rigid, and repetitive patterns of behaviour.<sup>2</sup> Given the chronic nature of autism's clinical needs, there is a high degree of demands on caregivers. For example, they must balance their responsibilities in scaffolding the needs of the autistic individual within the broader family context (i.e., responsibilities to their jobs, needs of siblings and other dependents). This difficult balancing act can have a significant impact on their overall mental health and wellbeing. The current project uses a **rapid knowledge review and synthesis**, with an **integrated knowledge translation approach** with knowledge user and expert oversight, to better understand what has been documented regarding the impact of the COVID-19 pandemic on **caregiver and family functioning, and on mental health services response, which have emerged as a result.**



# Lay Summary

**Context:** Before COVID-19, the existing peer-reviewed literature tended to indicate that parents of autistic children and adolescents can experience more mental health problems compared to families without autism and even when compared to caregivers of youth with other brain-based developmental conditions.<sup>3-7</sup> Family caregivers often experience considerable demands and spend an substantial amount of time addressing them, including having to provide around-the-clock care,<sup>8</sup> act as therapists, advocates, navigators, or teachers in providing supports, and manage high rates of child and adolescent difficulties, while balancing their own needs (i.e., career) and their family (i.e., siblings and other dependents) responsibilities.<sup>9</sup>

**The Problem of COVID-19:** As a result of the state of emergency due to COVID-19, stressors and poor mental health outcomes are likely more prevalent than before the pandemic. Distancing requirements have halted all in-person social, education, and therapeutic programs (e.g., diagnostic clinics and interventions, day programs, schools, adapted recreation and leisure, etc.). This means parents have little or no assistance outside of the family. 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 can 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.

**Objectives:** We aimed to identify and address the knowledge gaps and build evidence for the *demands*, *capabilities* and family understanding of their current experiences, which are associated with COVID-19. *Demands* refers to the sources of stress, such as strains or negative circumstances that persist over time, daily hassles, or other external stressors. *Capabilities* refers to the factors that help manage these pressures, such as external (e.g., programs, services, etc.) and internal resources (e.g., coping behaviours). We wanted to provide a summary of the evidence for the mental health needs of caregivers and families of autistic children and adolescents in a short search timeframe, and to describe how these needs relate to caregiver and family mental health response and resilience.

**Methods:** To achieve these objectives, we followed best practices of a rapid knowledge synthesis approach. The initial search terms and strategies for the rapid review were developed and reviewed by a team of researchers, clinicians, caregivers, and knowledge users. Initial searches were performed between May 25, 2020 to June 12, 2020. A second round of searches for published articles within peer-reviewed databases was conducted on August 6, 2020. Our methods included three search strategies: (1) Strategy One – traditional literature search of indexed peer-reviewed databases, (2) Strategy Two – search of peer-reviewed non-indexed literature using Google Scholar, and (3) Strategy



Three – search of grey literature material through newspaper indexes, hand searching using Google, and personal communication/advertisements via social media and our co-investigators and knowledge user networks. We included peer-reviewed published and in press articles from around the world that focused on the experience of parents and caregivers of autistic children and adolescents (below 25 years of age) during the COVID-19 pandemic, as well as relevant published results from organizational reports and surveys, news articles and reports. Information in the report have been verified by all members of the team including our knowledge users.

**Results:** Using Strategy One and Two, we initially identified 210 articles, of which 13 were included in our review. Through Strategy Three, we found 2 organizational reports and 7 newspaper articles or media reports. Of the sources that we reviewed, the majority of the peer-reviewed literature and grey literature focused on the experience of caregivers and families of autistic children during this time, including descriptions of the various *demands* placed on them as a result of isolation policies meant to restrict the spread of COVID-19. The literature and media provided examples of the consequences of increased demands on the wellbeing of caregivers and families as they found ways to cope with these stressors. Some of the literature provided advice in the form of “tips”, opinion pieces, or infographics to help caregivers and families manage their *demands* and to support their *capabilities*. We found limited literature that focused on programs or interventions that supported caregiver and family mental health and wellbeing through the COVID-19 pandemic. Some media reports from the perspective of caregivers underlined the protective effects of connection and close social relationships (via online communications or communities like Facebook groups) in fostering a sense of “togetherness” that helped families find *meaning* during the pandemic. Some reports highlighted 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.

**Discussion:** It is important to note that the results in this report are preliminary, and as new peer-reviewed literature is published and indexed, we will be able to provide a broader analysis of the empirical evidence outlining the impact of the COVID-19 pandemic on the mental health and wellbeing of caregivers and families of autistic children, and the supportive programs that have emerged as a result. For example, a number of national and international caregiver-reported surveys (e.g., Families Facing COVID-19; Pandemic Canadian Autism Needs Assessment Survey) have been launched to capture and understand the experience of caregivers of autistic individuals during this time. In the next iteration of this report, we will be able to incorporate findings from these reports into our analysis.





# Background

Before COVID-19, the extant literature suggests that parents of autistic people experience more mental health problems compared to families without autistic family members, even when compared to caregivers of children with other neurodevelopmental disorders, such as intellectual disability.<sup>5-9</sup> Autism varies in terms of symptom presentation and severity, but often involves challenges with social communication and interactions, the presence of restricted, rigid, and repetitive patterns of behaviour or interests, and hypersensitivity or hyposensitivity to environmental stimuli.<sup>2</sup> Many autistic individuals find transitions and changes in their routine difficult.<sup>10</sup> Autism is estimated to be diagnosed in 1 in 66 Canadian children.<sup>3</sup>

The heterogeneous and often chronic nature of autism's clinical needs often contributes to a high degree of demands for caregivers and the broader family context, with the potential to impact mental health and wellbeing. Caregivers may have to provide around-the-clock care,<sup>11</sup> and act as therapists or teachers providing interventions.<sup>12</sup> Self-injurious or aggressive behaviours are common in autistic children, and the onus is often on caregivers to keep themselves, others (i.e., siblings, etc.), and their child safe.<sup>13</sup> Many autistic children have intellectual or physical disabilities,<sup>14-16</sup> or comorbid psychiatric disorders,<sup>17</sup> which can place further strain on the caregiver and family. It is not a surprise that rates of depression and anxiety are higher than in the general population,<sup>18</sup> and that approximately 1 in 10 families report being in crisis at any one moment in time.<sup>19</sup> Parents of autistic children also report high risks of marital discord,<sup>20</sup> unemployment, and financial strain.<sup>21</sup>

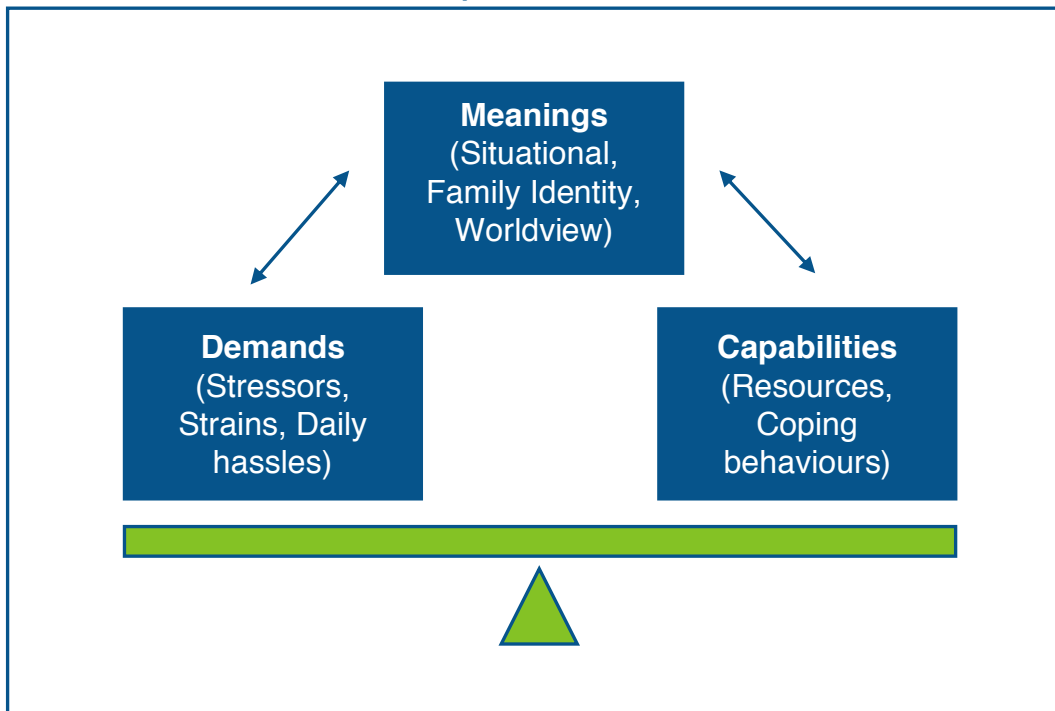
We aimed to better understand the impact of the COVID-19 pandemic on caregiver and family functioning, and the mental health service interventions that have emerged as a result.

## Framework

The *Family Adjustment and Accommodation Resource Model* (FAAR Model) is often used as a framework to understand the processes that lead to family outcomes in the face of stressors.<sup>22</sup> The FAAR model suggests that a response to stressful life events involves the interaction of three domains: demands, capabilities, and the family's meaning (Figure 1). *Demands* involve the sources of stress, such as 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. When *demands* increase, families employ their *capabilities*, including external resources (e.g., programs, services, etc.) and internal resources (e.g., coping behaviours) as 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). However,

two families with the same stressors / 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 therefore determined by the subjective experience of how well balance is achieved between demands and capabilities.

**Figure 1. The Family Adjustment and Accommodation Resource Model (FAAR Model; Patterson, 1988)**



It is critically important that we support the mental health of parents and families with autistic children and understand responses that promote resilience during and after this pandemic. Within the family context, parental mental health and wellbeing can have an impact on children’s (and siblings’) development,<sup>23-25</sup> including their adaptive functioning, academic achievement, self-esteem and friendships.<sup>26</sup> Studies also note bidirectional effects between poor parent mental health, and emotional and behavioural concerns in autistic children.<sup>27-30</sup> Poor family functioning also has significant negative impacts on economic success.<sup>31</sup>

### The problem of COVID-19

As a result of the COVID-19 state of emergency, these stressors and mental health outcomes are likely more prevalent than before the pandemic. Distancing requirements have halted all in-person social, education, and therapeutic programs (e.g., interventions, day programs, schools, adapted recreation and leisure, etc.). This means parents have little or no assistance outside of the family. 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). Caregivers who were already overburdened with the responsibilities of managing the specific needs of the autistic person and their family have had to very quickly re-establish new norms, and this transition can be emotionally draining for the entire family unit. Policies meant to limit the transmission of COVID-19 have inadvertently exacerbated the difficulties experienced by many families and further exposed them to vulnerabilities that can impact caregiver mental health and overall family wellbeing.

It is essential 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 (i.e., the capabilities) to support parents of autistic children who are faced with these pandemic-related demands. Using the FAAR Model as a framework, the proposed rapid knowledge synthesis review searched for literature that outlines how, as a result of the COVID-19 pandemic, families balance demands and capabilities, and how they make meaning of this process over time.

## Objectives

1. Identify and address knowledge gaps and build evidence for the demands, capabilities and meaning associated with COVID-19 for caregivers and families of autistic people
2. Provide a review of the evidence for the mental health service needs of caregivers and families of autistic children and adolescents in a short timeframe, and
3. Elucidate how these relate to caregiver and family mental health response and resilience.



# Methods

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 (JWG), clinical psychology (JW, CM), nursing (NK), and speech-language pathology (CH). An integrated knowledge translation approach was taken, working with knowledge users throughout the process. Knowledge users included representatives from Canada-wide autism advocacy agencies (Autism Ontario and the Canadian Autism Spectrum Disorder Alliance), and parents of autistic people.

We conducted the rapid review based on the proposed methodology guide of the Cochrane Rapid Reviews Method Group.<sup>32</sup> We report select components of the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA).

## Literature Search

A list of search terms was developed in collaboration with 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). In consultation with a dedicated reference librarian at York University, 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). Ultimately, because of the limited number of returns, the mental health search terms were excluded from the search functions, and instead manually reviewed in each selected output.

**Table 1. Rapid Synthesis Search Terms**

	Research Database Terms	Grey Literature Terms
<b>Target Population</b>	Family, Parent, Sibling, Caregiver	Family, Parent, Caregiver
<b>Diagnosis</b>	“Autism Spectrum Disorder”, ASD, Autis*, “Developmental Disabilities”	Autis*, “Developmental Disabilities”
<b>Disease</b>	COVID, Coronavirus	COVID



<b>Mental Health</b>	“Mental health”, Wellbeing	“Mental health”, Wellbeing
Notes: Asterisks (*) were used for multiple character searching; Quotation marks (“”) were used for exact phrases.		

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

**Strategy One:** First, articles were collected through concurrent searches 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). 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:** For the second strategy, a search of Google Scholar articles published since January 2020 was conducted using combinations of “COVID” or “coronavirus”, and “autism” or “ASD” (See Appendix 1 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” or “sibling”, 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 more thorough review.

**Strategy Three:** In the third strategy, searches were extended beyond peer-reviewed and empirical databases to include other sources and grey literature. 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\*”. In addition, an advertisement was shared with service providers, researchers, clinicians, and members of the autism community via email and Twitter, requesting for 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 pre-print databases (i.e. PsyArXiv) news articles, newsletters, organizational surveys and reports to find relevant materials.



## Study Selection and Extraction

Articles identified across the three phases were reviewed and included if the article focused and/or discussed 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.

We used COVIDENCE ([www.covidence.org](http://www.covidence.org)), a systematic review management system, to organize articles from our searches. Only references from Strategy 1 and Strategy 2 were entered into COVIDENCE, and all grey literature as a result of searches from Strategy 3 and were screened and analyzed separately.

## Risk of Bias Appraisal

Grey literature was included in the current review as it has been suggested that including grey literature in reviews on public health-related topics can reduce publication bias, provide contextual information, and identify all interventions that exist.<sup>33</sup> However, there are clear limits to including grey literature that should be noted: Searching grey literature in a systematic way can be onerous and can make results difficult to reproduce. As well, grey literature does not undergo a peer-review process, which may mean substantive variability in the quality of the information available.

## Synthesis

The data synthesis focused on providing a narrative summary of articles. 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. Our interpretation of the literature have been verified with feedback from our knowledge users including caregivers of autistic children and other knowledge users within the autism community.

# Results

## Literature Search

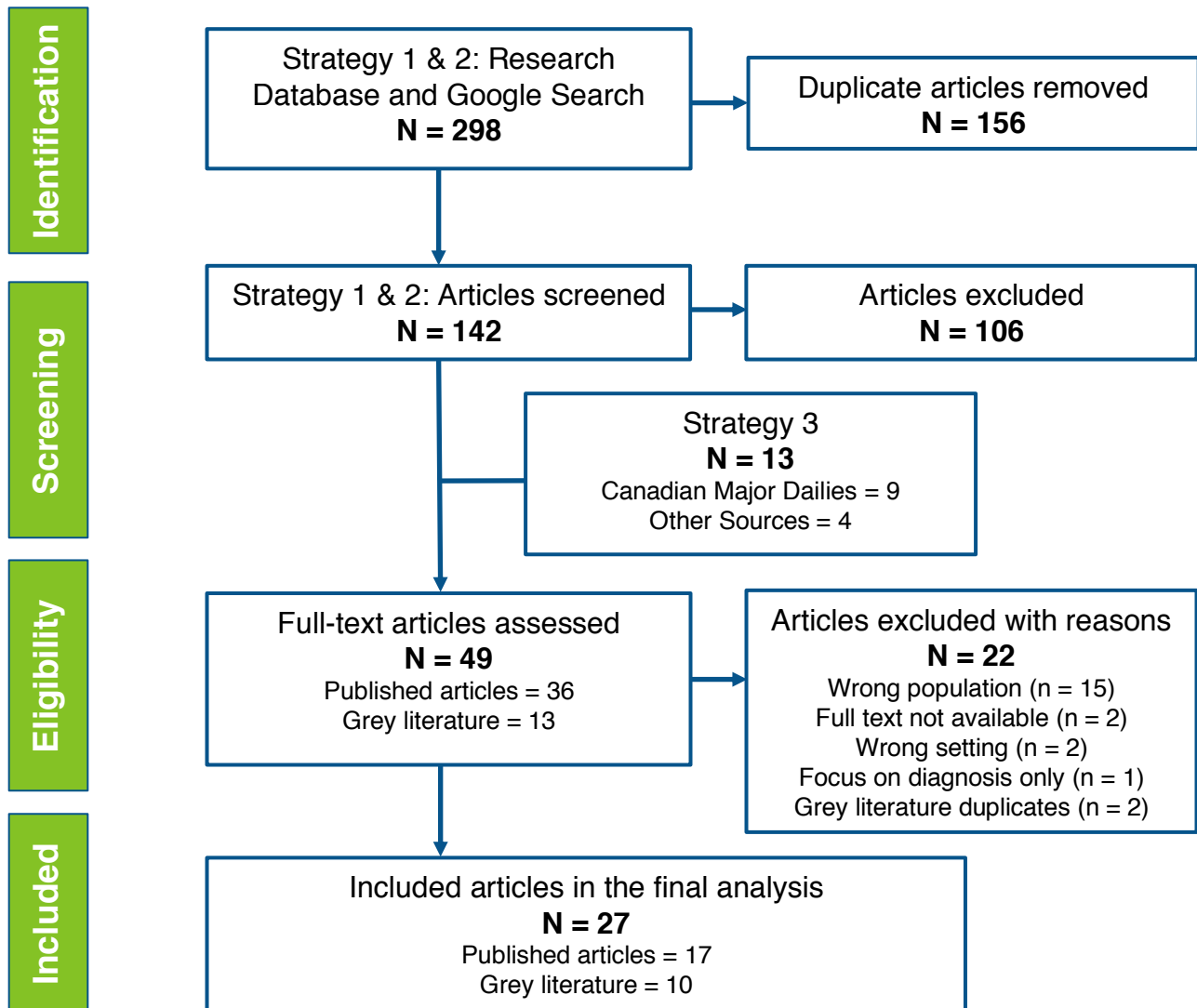
Using Strategy One and Two, we identified 209 articles (see Figure 2). Through COVIDENCE, 111 duplicate articles were removed. After a preliminary screening of abstracts (VL and CA), 106 additional articles were marked as irrelevant using predetermined criteria (articles must include reference to caregivers, parents, autism, developmental disability, and COVID-19) and were removed. From these articles, 36 received full text reviews and 20 were excluded (i.e., 15 were wrong patient population, 2 full-text were not available, 2 had irrelevant context, and 1 focused only on autism diagnosis). Four additional articles were sent to our team for review as a result of our

request for related materials by co-investigators and their networks, and only one was accepted. In total, 17 published articles were included in our review. See Table 2 for a description of included literature.

Through Strategy Three, we were able to three organizational reports and found ten newspaper articles or media reports (See Figure 2). The full text of all news and media articles, and organizational reports were screened by a single reviewer for relevance to our objectives. From these articles, three were excluded (i.e., 2 were duplicates, 1 was the wrong patient population). In total, two organizational reports, one non-peer reviewed published report, and seven newspaper articles/media reports were included in our review. See Table 3 for a description of included literature.



**Figure 2. Study Flow Diagram**



## Characteristics of Included Articles

Of the 17 published articles included in our review, 11 articles were categorized as editorials or commentaries written by clinicians or researchers in the field of autism, which were published in peer-reviewed journals. Three articles were published in peer-reviewed journals; one used qualitative (i.e., interview) methods and two used quantitative (i.e., survey) methods to capture caregivers' perspectives on their experiences during the COVID-19 pandemic. Two articles were pre-print manuscripts of empirical studies, which had not undergone peer-review, and the remaining article was a pre-print technical guide for applied behaviour analysis (ABA) providers. See Table 2 for characteristics of published articles. Articles represented editorials and studies from various countries



including Canada, United States, United Kingdom, Italy, China, Turkey, Serbia, and Singapore.

Within the grey literature, we reviewed two organizational reports, one magazine article, one blog post, one non-peer reviewed published report, and five newspaper articles. Of the organizational reports, we included Autism Ontario's survey report, which was based on a brief survey that they sent to caregivers and autistic individuals in March 2020 to determine the needs of families, and autistic people during this time and what services they could offer to help. The second was a preliminary report from the Pandemic Canadian Autism Needs Assessment survey report. This report was sent to caregivers, families, and autistic individuals in partnership with McMaster Autism Research Team, the Canadian Autism Spectrum Disorder Alliance, and Autism Speaks. The survey aimed to understand how the autism community was being impacted by the COVID-19 pandemic. Finally, the seven newspaper articles included media reports of the experience of caregivers of autistic children through the COVID-19 pandemic from Canada, USA, and Israel.

A single reviewer (PTM) used the Critical Appraisal Skills Programme (CASP) Checklists<sup>34</sup> to determine the quality of empirical data included in the study. For quantitative studies, scores ranged between 0-12 for CASP Cohort Study checklist, with 12 indicating the highest quantitative research quality. For qualitative studies, scores ranged between 0-10 using the CASP Qualitative checklist, with 10 indicating the highest qualitative research quality. Four of the empirical studies included in the rapid systematic review were assessed: three (Ersoy et al., 2020; Pavlopoulou et al., 2020; Stankovic, 2020) used the CASP Cohort Study checklist, and one (Esentürk, 2020) used the CASP Qualitative checklist. The CASP rating scores for the three studies are indicated below in Table 2. In general, the quality was assessed as low for the four peer-reviewed articles.

**Table 2. Description of Articles from Strategy 1 and 2 (n = 17)**

Author(s)	Date published	Country	Title	Journal	Participants	Category	CASP Rating
Ameis et al.	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.	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
degli Espinosa et al.	Pre-Print: 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
Ersoy et al.	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	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	<b>N = 10</b> (60% females; 40% males) <b>Parent Age:</b> 35-54 years old	Peer-reviewed, qualitative	5
Eshraghi et al.	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.	June, 2020	Singapore	Autism spectrum disorder and COVID-19: Helping caregivers navigate the pandemic	Annals, Academy of Medicine Singapore	N/A	Commentary	N/A
Narzisi	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
Parentau et al.	July 23, 2020	USA	The experience of parents of children with autism spectrum disorder during COVID-19 pandemic: A qualitative analysis	N/A (available through Research Square)	<b>N = 15</b> (gender and age distribution unspecified) <b>Child Age:</b> 11 to 21 years	Pre-print, qualitative	4

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Pavlopoulou et al.	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)	<b>N</b> = 449 (n = 401 mothers; n = 35 fathers; n = 13 carers [including siblings]; Age range unspecified)	Pre-print, quantitative	4
Rose et al.	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	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.	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	<b>N</b> = 85 (74% mothers; 22% fathers; 4% other relatives)	Peer-reviewed, quantitative	1



Szabo et al.	April 23, 2020	USA	From helpless to hero: Promoting values-based behaviour and positive family interaction in the midst of COVID-19	Behavioural Analysis in Practice	N/A	Technical guide	N/A
Wang	July 26, 2020	China	The impact of COVID-19 on autism research: Reflections from China	Autism Research	N/A	Commentary (letter)	N/A
Yarımkaya & Esentürk	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	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	Pre-print, technical guide	N/A

Notes: 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 0-12 for the CASP Cohort Study checklist, with 12 indicating the highest quantitative research quality and scores range between 0-10 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; Pre-print- a empirical paper that has not yet gone under peer-review; Technical Guide- written document to guide clinicians in their practice; N – Total number; N/A – Not Available; UK – United Kingdom; USA – United States of America.



**Table 3. Description Grey Literature articles (n = 10)**

Author(s)	Date published	Country	Title	Source	Participants	Category
Autism Ontario	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
PanCANS (partnership between Autism Speaks Canada, McMaster ART, and CASDA)	July 16, 2020	Canada	Pandemic Canadian Autism Needs Assessment (PanCANS) Results	<a href="https://www.autismspeaks.ca/siteAssets/Files/Press%20Releases/pancans-survey_16July2020.pdf">https://www.autismspeaks.ca/siteAssets/Files/Press%20Releases/pancans-survey_16July2020.pdf</a>	N = 1066	Organizational Report
Brown	April 01, 2020	Israel	A plea for solutions for people with autism during the crisis	Jerusalem Post	N/A	Newspaper
Hawkins	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 isn't their 'norm to sit at the kitchen table'	Wall Street Journal	N/A	Newspaper
Laucius	June 01, 2020	Canada	A summer without camp: families of autistic children lose respite	Ottawa Citizen	N/A	Newspaper

MacDonald	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
Pellicano et al.	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>	<b>N = 131</b> (n = 80 parents of autistic children; n = 35 autistic adults; n = 16 young autistic people, 12-18 years old)	Other report
Picon	May 04, 2020	USA	Six ways to support autism and special needs families during the Coronavirus pandemic	Exceptional Parent Magazine	N/A	Magazine
Schuck	May 05, 2020	Canada	Why community matters more than ever for parents of kids with special needs	CBC News	N/A	Blogpost
Yogaretnam	March 30, 2020	Canada	Touched by autism, families ‘in crisis’	Ottawa Citizen	N/A	Newspaper
Notes: 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.						



## General Themes

Our rapid search of the literature found 13 published peer-reviewed articles and 9 grey literature pieces related to the impact of COVID-19 on the daily lives of caregivers and families of autistic children. A limited number (2 peer-reviewed articles and 1 grey literature) focused specifically on the *mental health* and *wellbeing* of caregivers and families, while the remaining literature reported more broadly on relevant topics. We anticipate that in the following months, a number of studies and reports that focus on the perspectives of caregivers and families, including validated measures of their mental health and wellbeing, will emerge. The synthesis is limited by the number of high-quality articles within our rapid search, but we are optimistic that as more data is collected by research groups and organizations from around the world and published in peer-reviewed journals and online, we will be able to provide a broader analysis of the scope and impact of COVID-19 on the mental health and wellbeing of caregivers and families of autistic children.

To address Objective 1, we identified and summarized the findings from our rapid review and categorized them into the three domains of the FAAR Model. Specifically, we described and built evidence from documented examples in the literature that provide examples of the types of *demands* (i.e., stressors, strains, and daily hassles) that have been put on caregivers and families and the consequences of prolonged exposure to these demands. It should be noted that these demands may not be unique experiences for caregivers and families of autistic children. But given their vulnerability to mental health problems, the increased intensity and frequency of these demands as a result of social distancing measures due to COVID-19 amplifies their risk even further. To address Objective 2, we provide a review of the evidence for mental health and wellbeing related services identified, including the *capabilities* (i.e., mental health and wellbeing resources, programs, supports, ways of coping) that have been reported. To address Objective 3, we reference reports that capture information on caregivers' and families' perspectives on *meaning* (i.e., beliefs, identity, community, family culture) that relate to how their understanding of events related to COVID-19 shape their ability to remain resilient through adversity. See a summary of the general themes in Table 4.

**Objective 1: Summary of Demands.** Twelve out of 13 published literature and 9 grey literature reports focused on the experience of caregivers and families of autistic people including descriptions of the various *demands* placed on them as a result of isolation policies meant to restrict the spread of COVID-19. In five empirical (pre-print and published) articles included in our review (Ersoy et al., 2020; Esentürk, 2020; Pavlopoulou et al., 2020; Stankovic et al., 2020; Parentau et al., 2020), researchers reported 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. School closures resulted in a loss of not only educational





supports, but behavioural therapies and programs for autistic children (i.e., one-on-one support, trained teachers, educational assistants, behavioural interventions, specialists, clinicians, therapists), and these same parents also reported an increase in challenging behaviours (i.e., frustrations, aggression and violence towards self and others, outbursts), increased parenting-related workloads (i.e., “round-the-clock” care), disruptions to their daily routines, loss of respite (i.e., social distancing have limited access to support workers as well as grandparents and extended family), and loss of recreational and community-based opportunities. It should be noted that none of the studies analyzed how caregiver mental health and family wellbeing may be associated with the intersectional factors, such as social economic status, gender, racialized and cultural differences.

The peer-reviewed literature and media reported similar consequences of increased demands on the mental health and wellbeing of caregivers’ and families. For example, 59% of parents reported feelings of helplessness (Stankovic et al., 2020). Mothers of autistic children in one Turkish study reported higher levels of anxiety, and lower feelings of dispositional hope and psychological wellbeing when compared to mothers of neurotypical children (Ersoy et al., 2020). Preliminary survey results from the PanCANS report indicated that many Canadian parents note being “very stressed” (43%), and that 24% report “coping poorly” to changes related to COVID-19 (PanCANS Survey, 2020). In the same survey, 67% of parents responded that COVID-19 had negatively impacted their autistic child’s emotional and mental health. Parents reported experiencing feelings of worry (85%), anxiousness (86%), stress (86.1%), depression (58%), and isolation (77%).

Media reports have highlighted the struggle of caregivers and families of autistic children as they attempt to balance demands. For example, a parent in the Ottawa Citizen said, “Now with kids home, private therapy centres closed, and no respite for families, it’s been a struggle to keep my family safe and functioning”, and others parents reported that “The pandemic has been hard enough to understand for most people, it’s even harder to grasp for people with autism”. It is possible that quotes from media reports may have focused on highlighting the extremes in negative outcomes for families.

### Caregiver comments on demands:

“Now with kids home, private therapy centres closed, and no respite for families, it’s been a struggle to keep my family safe and functioning” – Laucius, *Ottawa Citizen*, March 30, 2020

“The pandemic has been hard enough to understand for most people, it’s even harder to grasp for people with autism” – Yogaretnam, *Ottawa Citizen*, June 1, 2020

“Without access to therapies and supports for our son, his behaviour has regressed and his meltdowns and tantrums has become more frequent, and any of the tools he learned previously to help with his emotional regulation have been forgotten and he no longer uses them”

**Objective 2: Summary of Capabilities.** There were no published empirical articles investigating the effectiveness of interventions or support programs addressing the mental health and wellbeing needs of caregivers and families of autistic children at this time. Seven published articles, and one grey literature report included editorials or guidelines that provided therapists, or caregivers and families with advice or “tips” to help them manage their *demands* and to support their *capabilities* during the pandemic. For example, two editorials (Narzisi, 2020; di Espinosa et al., 2020) provided an advice list to help families, especially those with children who have social communication challenges and stereotypical behaviours, manage their time during the pandemic. These lists provided generic recommendations to parents which included creating a daily schedule to re-establish a routine, create a visual schedule, use warm tone of voice to communicate, share special interests with their children, provide physical activities for their children, etc. None of the reports focused on advice or suggestions for caregivers or families as they face their own potential mental health challenges. One blogpost (Schuck, May 5, 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.”

**Caregiver comment on capabilities:**

“I’ve resorted to just escaping to a hot shower to cry when I’m at my breaking point.” – Schuck, *CBC*, May 05, 2020

Seven published articles (Cassidy et al., 2020; degli Espinosa et al., 2020; Esentürk, 2020; Narzisi, 2020; Pavlopoulou et al.; 2020, Szabo et al., 2020, & Yi & Dixon, 2020), see Table 2 for details) highlighted the importance for caregivers and families to remain connected to educational services (i.e., teachers, educational assistants, special education resource teachers), behavioural therapists, and community resources during the pandemic. For example, the published reports noted that some families have maintained consistent contact with teachers and school administrators either through phone or online meetings (Narzisi, 2020), and some teachers had the capacity to continue consulting with parents on how best to provide at-home education to their autistic child (Stankovic et al., 2020). Educational professionals were able to adapt their lessons via online tools and continued to provide modified educational experiences for families, but the effectiveness of these changes in mitigating behavioural challenges were not measured. There were examples of behavioural therapists who adapted their behavioural interventions or curriculums so that parents could deliver the program at home (degli Espinosa et al., 2020), and those who provided online consultations with parents (Narzisi, 2020; Szabo et al., 2020). In a qualitative study by Parentau et al, (pre-print, 2020), researchers asked parents to list coping responses to COVID-19. In the report, parents listed activities such as 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 coping with stresses in response to self-isolation measures. In the same study, parents noted positive outcomes due to self-isolation measures. For example, some parents reported that school

closures meant that their child’s school curriculum refocused from building new academic skills (i.e. reading, writing, and math skills), to strengthening daily living skills (i.e. self-help) that benefits the wellbeing of both the child and their caregiver (i.e. child has developed some independent adaptive skills).

Commentary from Cassidy et al. (2020) suggested that parents should seek organizations in their community that could provide resources and support during this time. For example, one author suggested organizations, such as “*Parents Helping Parents*”, who support lower income families who might not have space or enough resources to self-isolate, or internet access to connect with services. Autism Ontario encouraged parents to contact their *service navigators* during the COVID-19 pandemic, a program with trained professionals who could help direct them to services or online resources. However, none of these programs or adaptations have been tested empirically.

Preliminary results from both organizational surveys (Autism Ontario and PanCANS) have indicated that parents recognize that one consequence of having to balance increased demands during the pandemic may leave them and their families vulnerable to mental health challenges. For example, results from the Autism Ontario “Supporting our community” report indicated that 17% of parent respondents wanted help addressing increased personal anxiety, 11% wanted respite, and 13% wanted help addressing increased anxiety and long-term impacts of their children’s behaviours. From the PanCANS survey, 14% of caregivers reported being able to access mental health supports during COVID-19, and 43% noted that they would like to access mental health services during isolation, but were unable to do so.

Four reports (Cassidy et al., 2020; degli Espinosa et al., 2020; Rose et al., 2020 & Stankovic et al., 2020) highlighted 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 entire situation, caregivers and families are repeatedly faced with 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.

**Objective 3: Summary of Meaning.** Media reports from the perspective of caregivers of autistic children underline 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 the CBC blog post, “*Why Community Matters More Than Ever For Parents Of Kids With Special Needs*” (Schuck, May 5, 2020), some parents have found Facebook communities or parent support groups a vital resource during the pandemic. Parents of children with special needs rely on these online communities for support,



especially when they own personal communities (i.e., extended family, supportive neighbours and friends) are unable to help them due to self-isolation guidelines. Some families have reported that supportive relationships and positive socially distant interactions with family members (i.e., reading stories together on their phone or even daily text check-ins) have been helpful in maintaining feelings of normalcy during this time (personal communications).

**Table 4. General Summary of Themes**

FAAR Model Domains	Thematic Synthesis
<p><b>Demands</b></p> <ul style="list-style-type: none"> <li>• <b>Social Disruptions</b> including job loss, financial insecurities, social distancing, and confinement</li> <li>• <b>Caregiver Wellbeing</b> including psychological distress, parenting stress, and mental health symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• 11 articles published in research journals outlined the increase of social disruptions (i.e., loss of job, change of job/job disruption, increased marital conflict, financial instability) and parenting demands (i.e., “round-the-clock” care, homeschooling).</li> <li>• Published and grey literature indicated that parents reported an increase in behavioural challenges leading to problematic interactions between parent and child, and strains in the parent-child-family relationships.</li> <li>• Published and grey literature indicated that parents experienced increased levels of anxiety and stress, <i>and</i> identified a high need for support.</li> <li>• One out of 3 empirical studies measured psychological distress, wellbeing, and mental health challenges in caregivers and families during COVID-19.</li> </ul>
<p><b>Capabilities</b></p> <ul style="list-style-type: none"> <li>• <b>Caregiver Coping Skills</b> including stress response, physiological and psychological</li> <li>• <b>Family Resources</b></li> <li>• <b>Family Routines</b></li> <li>• <b>External Resources</b> including services and support programs</li> </ul>	<ul style="list-style-type: none"> <li>• All empirical articles suggested that caregivers and families are struggling to manage their demands.</li> <li>• Published and grey literature suggest that caregivers use routines, structure, and schedules to cope, but continue to struggle with child anxiety and challenging behaviours.</li> </ul>

	<ul style="list-style-type: none"> <li>• Published and grey literature suggested that families are able to utilize phone or web-based technology to access child services (i.e., behavioural supports) but very little is available that support caregiver needs (i.e., respite, mental health services).</li> <li>• No studies were found that investigated the effectiveness of programs meant to support the mental health and wellbeing of caregivers and families.</li> </ul>
<p><b>Meaning</b></p> <ul style="list-style-type: none"> <li>• <b>Family Resilience</b> including beliefs and family culture</li> </ul>	<ul style="list-style-type: none"> <li>• One grey literature article reported that caregivers find staying connected with the autism community via social media (i.e., Facebook groups and chats) have been instrumental in helping them feel less alone when facing the increased demands due to COVID-19.</li> </ul>



# Discussion

Our rapid search for literature and resources during a short time frame yielded a limited number of high-quality published and grey literature articles. From our data synthesis, this report indicates that there is a knowledge gap regarding the impact of COVID-19 on the mental health and wellbeing of caregivers and families of autistic children, including strong empirical studies that capture the toll of self-isolation measures on caregiver and family mental health, and on our understanding of best practices and programs that would best support the mental health needs of caregivers and families during this time.

Our synthesis indicated that caregivers and families of autistic children have experienced increased demands (i.e., caregiver and family-related stressors and external stressors) due to the social distancing and self-isolation measures put in place to contain COVID-19. These demands have been compounded by the pressure of managing the needs of their autistic child and their struggles to maintain balance using their capabilities. However, our findings indicated that there were limited published peer-reviewed research articles that properly surveyed (using standardized and validated questionnaires) the intensity, frequency, and level of distress, stress, anxiety, and general mental health and wellbeing challenges as experienced by caregivers and family members during the pandemic. No considerations for the unique experiences of racialized or minority populations with caregivers and families of autistic children were found. A number of parent-focused surveys have been employed across Canada and internationally, aimed to better capture the information about the mental health challenges in caregivers and families (i.e., siblings), and the results of these surveys should be available in the next few months. While data from these surveys will be timely and provide useful information about experience of all caregiver and families of autistic children, it speaks to the need to develop an evidence base to collect and capture all available survey data, and allow for collaborations and to avoid duplications of efforts.

The literature also does 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. Coupled with the difficulties that autistic people may experience adjusting to extreme changes in routine, and the 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 behavioural challenges (i.e., aggression, self-harm, etc.). Future research is warranted in understanding the unique challenges posed by the pandemic on autistic people and their families, and how this translated into supports that promote positive interpersonal connections, parent-child relationships, and family wellbeing. 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. However, few of the adaptations have been systematic or strategic. Rather, the literature suggests that most have been adapted as urgent family needs arise. There is





ample opportunity here 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 (i.e., do online behavioural interventions lower behavioural difficulties? What is the impact of web-based interventions on parent-child relationship during the pandemic?).

Reports point to the importance for caregivers and families to stay connected to community-based resources, as well as with other parents during the pandemic. No research to date exists showing ways of improving the mental health of caregivers during COVID-19 or considerations for long-term effects on mental health, and this kind of rapid research is needed, with a particular focus on scalable and feasible interventions. Focused considerations on the mental health and wellbeing of caregivers and family members are warranted, given the demands and the struggles to maintain their capabilities as reported from our synthesis.

## Limitations

It is important to note that the results in this report are preliminary and as new peer-reviewed literature is published and indexed, we will be able to provide a more complete summary of the experiences of caregivers and families and provide more empirical evidence outlining the impact of the COVID-19 pandemic on the mental health and wellbeing of caregivers and families of autistic children, and the supportive programs that have emerged as a result. For example, although most of the reports have highlighted the struggles and difficulties experienced by caregivers and families of autistic individuals, knowledge users have noted that there are a number benefits to staying at home, including more time to focus on family relationships and a decrease in unpredictable daily hassles associated with attending school. In the next iteration of this report, we will be able to incorporate findings from currently ongoing studies into our analysis.

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# Appendix 1. Search Strategy Summary

Database	Search terms	Additional search criteria	Number of results returned
PubMed	COVID, autis*, family, caregiver, parent Developmental disability	2020 to current	11
PsycINFO	COVID, autis*, family, caregiver, parent Developmental disability	January 1, 2020 to current, anywhere except full text	5
CINAHL Plus	COVID, autis*, family, caregiver, parent Developmental disability	December 2019 to current, anywhere except full text	4
Sociological Abstracts	COVID, autis*	December 1, 2019 to current, anywhere except full text	0
Social Work Abstracts	COVID, autis*	2020 to current	0
MedLine	COVID, autis* family, caregiver, parent Developmental disability	2020 to current, in title only	3
Google Scholar	COVID, autism	2020 to current, in title only	12
	COVID, ASD	2020 to current, in title only	0
	Corona, autism	2020 to current, in title only	0
	Corona, ASD	2020 to current, in title only	0
	Coronavirus, autism	2020 to current, in title only	4
	Coronavirus, ASD	2020 to current, in title only	0
	COVID, autism, family, wellbeing	2020 to current, anywhere	265
	COVID, autism, parent, wellbeing	2020 to current, anywhere	212

	COVID, autism, family, “mental health”	2020 to current, anywhere	340
	COVID, autism, parent, “mental health”	2020 to current, anywhere	291
	COVID, autism, sibling, wellbeing	2020 to current, anywhere	65
	COVID, autism, sibling, “mental health”	2020 to current, anywhere	73
Canadian Major Dailies	COVID, autis*	March 1, 2020 to current, anywhere except full text	20
	COVID, autis*, family	March 1, 2020 to current, anywhere except full text	6
	COVID, autis*, parent	March 1, 2020 to current, anywhere except full text	2
	COVID, autis*, caregiver	March 1, 2020 to current, anywhere except full text	2
	COVID, autis*, mental health	March 1, 2020 to current, anywhere except full text	0
	COVID, autis*, wellbeing	March 1, 2020 to current, anywhere except full text	0
	COVID, “development disability”	March 1, 2020 to current, anywhere except full text	20
	COVID, “development disability”, family	March 1, 2020 to current, anywhere except full text	6
	COVID, “development disability”, parent	March 1, 2020 to current, anywhere except full text	2
	COVID, “development disability”, caregiver	March 1, 2020 to current, anywhere except full text	2

	COVID, “development disability”, mental health	March 1, 2020 to current, anywhere except full text	0
	COVID, “development disability”, wellbeing	March 1, 2020 to current, anywhere except full text	0

## Appendix 2. References for Included Articles

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