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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.[2] 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**.

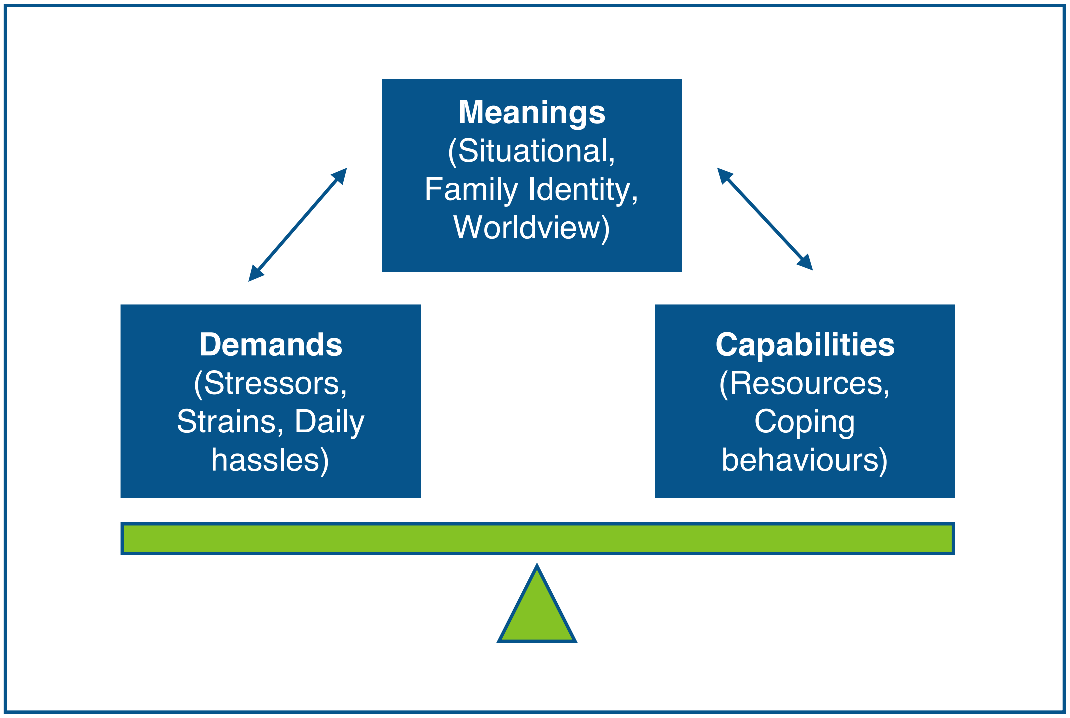
communication/advertisements via social media and our co-investigators and knowledge user networks. We included peer-reviewed published and in press articles from around the world that focused on the experience of parents and caregivers of autistic children and adolescents (below 25 years of age) during 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 c*apabilities*. 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 more 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.

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,[23-25] including their adaptive functioning, academic achievement, self-esteem and friendships.[26] Studies also note bidirectional effects between poor parent mental health, and emotional and behavioural concerns in autistic children.[27-30] Poor family functioning also has significant negative impacts on economic success.[31]

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

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.[32] 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
Target Population	Family, Parent, Sibling, Caregiver	Family, Parent, Caregiver
Diagnosis	"Autism Spectrum Disorder", ASD, Autis*, "Developmental Disabilities"	Autis*, "Developmental Disabilities"
Disease	COVID, Coronavirus	COVID

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), 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.

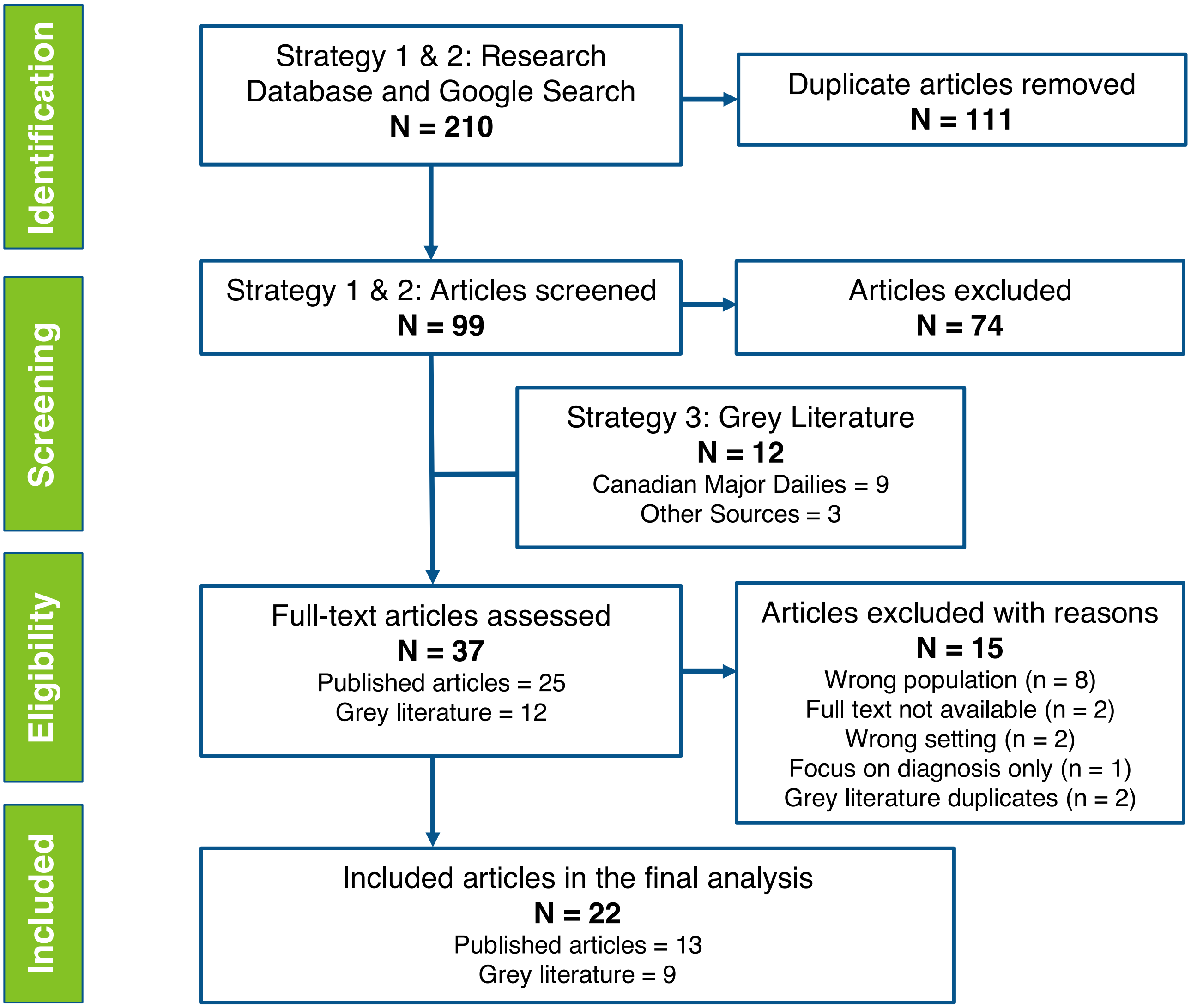
Risk of Bias Appraisal

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.[33] 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.

Figure 2. Study Flow Diagram



Characteristics of Included Articles

Of the 13 published articles included in our review, nine articles were categorized as editorials or commentaries by clinicians or researchers in the field of autism that were published in peer-reviewed journals. Of the four remaining articles, one used qualitative methods and three used quantitative (i.e., survey) methods to capture the caregivers' perspective on their experiences during the COVID-19 pandemic. See Table 2 for characteristics of published articles. Articles represented editorials and studies from various countries including Turkey, United Kingdom, Serbia, United States, Canada, and Italy.

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	N/A
Narzisi	April 01, 2020	Italy	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	N/A	Editorial	N/A
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	Editorial	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	**N** = 85 (74% mothers; 22% fathers; 4% other relatives)	Empirical Article – Quantitative	1

Table 3. Description Grey Literature articles (n = 9)

Author(s)	Date published	Country	Title	Publication	Participants	Category
Autism Ontario	April, 2020	Canada	Supporting our community	https://www.autismontario.com/news/supporting-our-community	**N** = 182	Organizational Report
PanCANS	Pre-print	Canada	Pandemic Canadian Autism Needs Assessment Survey	N/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
Picon	May 04, 2020	USA	Six ways to support autism and special needs families during the Coronavirus pandemic	Exceptional Parent Magazine	N/A	Magazine

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.

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"

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.

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 resources 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).

	- No studies were found that investigated the effectiveness of programs meant to support the mental health and wellbeing of caregivers and families.
Meaning - **Family Resilience** including beliefs and family culture	- 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.

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-children 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, “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

Macdonald, A. (2020, April 21). *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

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PanCANS (Pre-print). *Pandemic Canadian Autism Needs Assessment Survey .*

Pavlopoulou, G., Wood, R., & Papadopoilos, 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*

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