

It took a pandemic: Perspectives on impact, stress, and telehealth
from caregivers of people with autism

Susan W. White

Laura Stoppelbein

Hunter Scott

Debbie Spain

Deposited 2023-09-27

Citation of published version:

White, S. W., Stoppelbein, L., Scott, H., & Spain, D. (2021). It took a pandemic: Perspectives on impact, stress, and telehealth from caregivers of people with autism. In *Research in Developmental Disabilities* (Vol. 113, p. 103938). Elsevier BV. <https://doi.org/10.1016/j.ridd.2021.103938>



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.



ELSEVIER

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

It took a pandemic: Perspectives on impact, stress, and telehealth from caregivers of people with autism

Susan W. White^{a,*}, Laura Stoppelbein^b, Hunter Scott^c, Debbie Spain^d^a Center for Youth Development and Intervention, The University of Alabama, 200 Hackberry Lane, Suite 101, Tuscaloosa, AL 35487, United States^b Autism Spectrum Disorders Clinic, The University of Alabama, P.O. Box 870161, Tuscaloosa, AL 35487, United States^c Department of Psychology, The University of Alabama, Tuscaloosa, AL 35487, United States^d Institute of Psychiatry, Psychology and Neuroscience, King's College London, de Crespigny Park, Denmark Hill, London SE5 8AF, United Kingdom

ARTICLE INFO

Keywords:

Autism
 COVID-19
 Pandemic
 Stress
 Telehealth

ABSTRACT

Shelter in place mandates due to the COVID-19 pandemic left caregivers to determine how to best meet the therapeutic requirements of their children with autism spectrum disorder (ASD). Understanding the challenges faced by families, and their experiences using telehealth for the first time, may help make services sustainable in future public health emergencies. A sample of 70 caregivers of people with ASD from across the US completed an anonymous online survey. Results indicate that impaired emotion regulation was a primary contributor of parent-reported stress for persons with ASD during the pandemic, while loss of established structure and routine contributed to parental stress. Nearly half the sample reported using telehealth for the first time. Many caregivers were appreciative that telehealth permitted continuation of services, but expressed concerns about limited effectiveness due in part to their children's social communication problems.

What this paper adds

This is the first study, to the authors' knowledge, to examine the experiences and perspectives of telehealth of caregivers of people with autism spectrum disorder (ASD) during the COVID-19 pandemic. This pandemic led to increased stress due, in part, to schedule disruption and emotion regulation problems in affected youth. However, it also resulted in many families trying telehealth for the first time. Most families reported positive telehealth experiences. Results suggest that telehealth may minimize service disruption in the event of future public health emergencies.

Prior to widespread use of vaccinations, major pandemics occurred approximately every 10–30 years (Duszak, 2009). The likelihood of pandemics has increased during the 20th century, due in part to globalization (i.e., increased global travel and integration, urbanization, changes in land use) and greater exploitation of the natural environment (Jones et al., 2008; Morse, 2004). In the past 60 years, the world has seen nine different pandemic outbreaks (Relations, 2020). Continued risk of future pandemics, along with increasing frequency and intensity of natural disasters (Jones et al., 2008; Kelkar & Kumthekar, 2019), will most assuredly continue to interfere with delivery of traditional, in-person social and mental health services. Determining how to sustain supports and services when face-to-face intervention is not possible is of critical importance. In 2020, many disruptions occurred during the COVID-19 pandemic and resulting safety precautions, including shutdowns and restrictions in daily operations across all sectors of society (e.

* Corresponding author.

E-mail addresses: Swwhite1@ua.edu (S.W. White), lastoppelbein@ua.edu (L. Stoppelbein), whscott1@crimson.ua.edu (H. Scott), debbie.spain@kcl.ac.uk (D. Spain).

<https://doi.org/10.1016/j.ridd.2021.103938>

Received 8 November 2020; Received in revised form 7 March 2021; Accepted 10 March 2021

Available online 14 March 2021

0891-4222/© 2021 Elsevier Ltd. All rights reserved.

g., education, finance, business). Additionally, we saw challenges in accessing indispensable mental health services. Given the near certainty of future public health emergencies that will interfere with healthcare delivery, learning what factors influence care sustainability and options for remote service delivery are important.

Continuous access to mental healthcare may be especially important for people with ASD and their families, given the rising population of people diagnosed with ASD (CDC, 2019), pervasiveness and chronicity of the condition (Picci & Scherf, 2015), and high rates of psychiatric comorbidity in this group (Leno & Simonoff, 2020). In addition, youth with ASD and their caregivers may be especially vulnerable to adverse effects from disruptions in daily life and societal changes (Osborne & Reed, 2009). In the April 14th 2020 NIMH Director's Message, Dr. Joshua Gordon remarked, "because autistic people experience social situations and changes in routine differently from many of us, we need to be aware that they may need extra attention and individualized support during this time." Results from a recent survey study of adults in the UK, Belgium, and the Netherlands support this assertion. Investigators found that autistic adults experienced sharper increases in symptoms of anxiety and depression relative to neurotypical adults in response to the pandemic (Oomen et al., 2020).

Due to the social distancing requirements associated with COVID-19, access to healthcare, including mental health services, changed abruptly in March 2020 across the United States, giving rise to concerns about how to adapt and provide sustained medical and mental health services. Telehealth became the delivery method of choice for many, but not everyone (Ameis et al., 2020), and parents began serving as at-home coaches for their children via remote services (Samadi et al., 2020). During the COVID-19 crisis, many people with no prior telehealth experience began utilizing these platforms for medical and mental healthcare needs. According to the U.S. Department of Health and Human Services, rates of telehealth delivery for primary care increased sharply. In February of 2020, prior to wide-scale COVID-19 shut-downs, telehealth appointments constituted less than 1% of billed services for Medicare. By April 2020, use had dramatically increased and constituted 44 % of billed services for Medicare patients (HHS Press Office, 2020). The extension of health insurance coverage to include reimbursement for many telehealth services not previously reimbursable contributed to the increased use of telehealth and assisted providers with maintaining some continuity of care.

In addition to concerns regarding how mental health services can be sustained during public health emergencies, there is concern for the parents of people with ASD during service interruptions. A rich body of research indicates that parents of people with ASD experience higher levels of stress than parents of neurotypical children and children with other types of developmental disabilities (Hayes & Watson, 2013; Osborne & Reed, 2009; Van Steijn et al., 2014). Caregivers and parents (hereafter referred to as caregivers) of children with ASD appear to experience a unique pattern of stressors related to their child with ASD due, in part, to specific behavioral concerns [e.g., impulsive behaviors, verbal outbursts, problems with social communication/perspective taking, behavioral and cognitive rigidity, and sensory concerns; (Mount & Dillon, 2014)]. Caregivers also experience adverse effects (e.g., lower marital/relationship quality, work/income concerns) secondary to heightened stress (Hoogsteen & Woodgate, 2013; Mount & Dillon, 2014; Sullivan, 2017).

There have been a handful of published survey studies of the concerns and challenges associated with COVID-19 among people with ASD and their caregivers. These studies show that disruption of services and education has been both common and challenging, coping with uncertainty and loss of routine has proven difficult for many, parents have experienced heightened stress due to the pandemic, as well as problems among their children with ASD (Colizzi et al., 2020; Manning et al., 2020; Nonweiler et al., 2020; White et al., 2021).

Colizzi and colleagues assessed the impact of the pandemic on wellbeing and needs related to managing during the pandemic among 529 caregivers of individuals with ASD in Italy. They found that most caregivers (93.9 %) experienced heightened difficulties with managing daily activities/structure and behavior problems were commonplace (Colizzi et al., 2020). In a survey conducted by SPARK in the early days of the pandemic, 84 % of a large, nationwide sample of parents of persons with ASD reported that school services or therapies were disrupted and 52 % reported that clinical services were disrupted (SPARK, 2020). This finding is especially concerning since many individuals with ASD receive needed mental health services within schools or community-based clinics (e.g., mental health services, speech therapy, social skills training, applied behavior analysis).

In early spring of 2020, when most schools in the US moved to distance learning, therapeutic services were reduced or terminated due to inadequate time to prepare for the transition to virtual delivery. The burden, quite suddenly, fell to the students' untrained caregivers to try to implement programs (Aman & Pearson, 2020). Many caregivers were simultaneously faced with job loss or reduced hours (and pay) at work and economic uncertainty alongside the stress directly associated with mass illness and contagion fears. It is reasonable to assume that stress increased for most families but perhaps especially so for those with members with ASD or related conditions. The goal of this study was to identify the challenges experienced by caregivers raising children with ASD during the COVID-19 pandemic and ascertain parental perspectives on service disruptions and use of/access to, telehealth during local and broad 'shut-down' and 'shelter in place' orders.

1. Methods

An anonymous online survey was used to collect data from self-identified caregivers of people with ASD. We sought to identify the relative impact and stress experienced by people with ASD, as reported by parents, related to pandemic factors and gain insight into the lived experiences of caregivers in their own words. Additionally, we hoped to include a diverse sample that was not geographically restricted. Therefore, we determined an online survey with both rank choice and open-text answers would be most appropriate to yield quantitative and qualitative data, respectively. The survey was created by the authors, and is available upon request. Two adults with ASD reviewed and provided feedback on content and structure. The final survey had a 7th grade readability level. Following demographic questions (e.g., family composition, age of child), the survey contained four questions with quantitative responses, including two questions about the child's stress and disruption (rated on a 5-point Likert scale) as perceived by the caregiver, one

question about use of telehealth, and one question about degree of parental satisfaction (rated on 4-point scale) if the respondent indicated they had telehealth experience. Seven free-text response questions (e.g., challenges, personal experiences with telehealth) were also included as a part of the survey. Data were collected between June and early July of 2020, approximately 10 weeks after physical distancing orders were mandated and most schools in the U.S. were temporarily shut down. We selected this relatively brief time-frame in order to capture data following the peak of first-wave shutdowns. Caregivers were identified via multiple sources including two university-affiliated clinics working with children and adults with ASD, social media postings, and word of mouth. Participants were offered a small cash incentive (\$20) for participation. To protect anonymity, participants were directed to a separate link (decoupled from the survey) upon completion of the primary survey, which asked only for the email address of where to send the incentive electronically.

2. Sample

A total of 70 caregivers completed the survey, 34 men and 36 women. Table 1 provides descriptive information on the sample. Caregivers came from 18 different states in the U.S., although the majority of the sample resided in Alabama (38.6 %) and California (21.4 %). The caregiver sample was predominantly white (82.9 %). Half of the sample (50.0 %) reported caring for a person with autism who was school-age (i.e., 5–12 yrs.), 22 respondents (31.4 % of sample) cared for adolescents with ASD (12–17 yrs.), nine (12.9 %) for children under age five, and four (5.7 %) for adults with ASD. With respect to the estimated functioning level of the individuals with ASD, most caregivers reported their child to be either minimally verbal (48.6 %) or verbal (38.6 %), with only 9 caregivers (12.9 %) indicating their child was nonverbal. Of note, although the sample gender composition was nearly even, communication level of child differed by gender of respondent (χ square = 9.02, p = .003). Men were more likely to report their child with ASD either minimally verbal or nonverbal. Among male caregivers, 79 % of the children were minimally verbal or nonverbal; among women, this proportion was 44 %.

3. Data analysis

Qualitative data were analyzed using an inductive approach to thematic analysis. Thematic analysis is a well-accepted means of analyzing qualitative data that includes six steps: (1) becoming familiar with the data; (2) developing initial codes; (3 and 4) generating and reviewing themes; (5) naming themes; and (6) summarizing the data (see Braun, & Clarke, 2006). The transcript for each open-ended question of the survey was reviewed by (omitted for peer review) several times and steps 1–6 were completed. Once all steps were completed, the entire transcript was re-reviewed to establish if any codes or categories had not been adequately described by tentative themes. Reliability of the themes was addressed by having a second reviewer, complete a review of 30 % of the

Table 1
Demographic Data of Sample ($n = 70$).

| Variable | N (%) |
|---|---------------|
| Gender | |
| Woman | 36 (51.4) |
| Man | 34 (48.6) |
| Race* | |
| Asian | 2 (2.9) |
| Black or African American | 10 (14.3) |
| White | 58 (82.9) |
| Age of Child(ren) with Autism | |
| Young (i.e. have not entered school yet) | 9 (12.9) |
| School-age, but not adolescents (i.e. 5–12 years) | 35 (50.0) |
| Adolescents (i.e. 12–17 years) | 22 (31.4) |
| Adults (i.e. 18+ years) | 4 (5.7) |
| Household Composition | |
| Single-parent, single child | 4 (5.7) |
| Single-parent, multiple children | 4 (5.7) |
| Dual-parent, single child | 26 (37.1) |
| Dual-parent, multiple children | 35 (50.0) |
| Other | 1 (1.4) |
| Communication Level | |
| Verbal | 27 (38.6) |
| Minimally Verbal | 34 (48.6) |
| Nonverbal | 9 (12.9) |
| Functional Level | |
| Very Little Support | 18 (25.7) |
| Moderate Support | 41 (58.6) |
| Considerable Support | 11 (15.7) |
| Age of Caregiver | M (SD) |
| | 39.67 (6.752) |

*No participants indicated Latinx ethnicity.

data and the consistency between themes and sub-themes compared. In terms of authors' positionality, we approached the data from a clinical science and humanistic lens based on our collective prior training and focus on evidence-based healthcare as well as experiencing living through pandemic-related upheaval along with study participants. Quantitative data were analyzed descriptively, as there were no a priori hypotheses. Because the survey questions asking for rankings (quantitative data) focused primarily on challenges and degree of disruption related to the pandemic and the open-ended questions (qualitative data) focused on personal experiences with telehealth and resilience, no attempt was made to integrate the qualitative and quantitative data.

4. Results

4.1. Challenges & unearthed resiliency

Caregivers ranked the degree to which various factors contributed to heightened stress related to COVID-19 in their children with ASD, on a 5-point scale (1 = not at all, 3 = a bit, 5 = quite a lot). Fig. 1 presents the breakdown of responses across factors. The highest rated factor (i.e., strongest contributor of stress and adversity) was "problems with emotion regulation and coping with stress." Caregivers provided statements such as, "At first he had a lot of anxiety, which caused me (caregiver) anxiety," or "Temperaments have flared, nerves have been on edge and irritation levels have been high." The lowest ranked factor was "physical health problems." Of note, impaired emotion regulation was the only factor that no one ranked as 1 (i.e., not at all a contributor to stress) (see Fig. 2). Qualitatively, a common theme across all responses to open-ended questions included either concerns or importance of having a regular routine and structure for their child with ASD. This theme permeated throughout all but one (telehealth services) of the open-ended survey responses. Caregiver responses included comments such as, "The change in schedule really threw my son off," and "Creating structure for the day and sticking with it consistently have been a major challenge."

Qualitatively, when asked about the biggest challenges faced, the primary theme identified by nearly half of the participants included disruption/lack of structure and routine in their child's day-to-day life. Subthemes included challenges related to difficulty with completing assigned schoolwork and structuring work/learning routines via an online platform as well as being able to provide the necessary support for their child while balancing other demands (e.g., work; "It was difficult to work from home while providing appropriate support to my children for school"). Many caregivers (30 %) highlighted a strong realization of the importance of relationships/family in their/their child's life, while just over one fourth of respondents talked about the strain placed on them due to social isolation from others. Other concerns noted included those related to school and community based supports (e.g., effectiveness, difficulty accessing; 23 %).

Most caregivers indicated that they had been able to adapt, at least to some degree, by doing things such as providing visual supports, giving their child choices, and changing their expectations of the situation/their child (e.g., pace of in-school work). For example, caregivers made statements such as, "We organized our spaces to help us keep more organized minds," and "We used a block schedule which gives us a predictable schedule throughout the day." They also indicated that they were able to provide more effective behavior management/support strategies for their child at this time. Nearly 25 % indicated gaining a better understanding of their

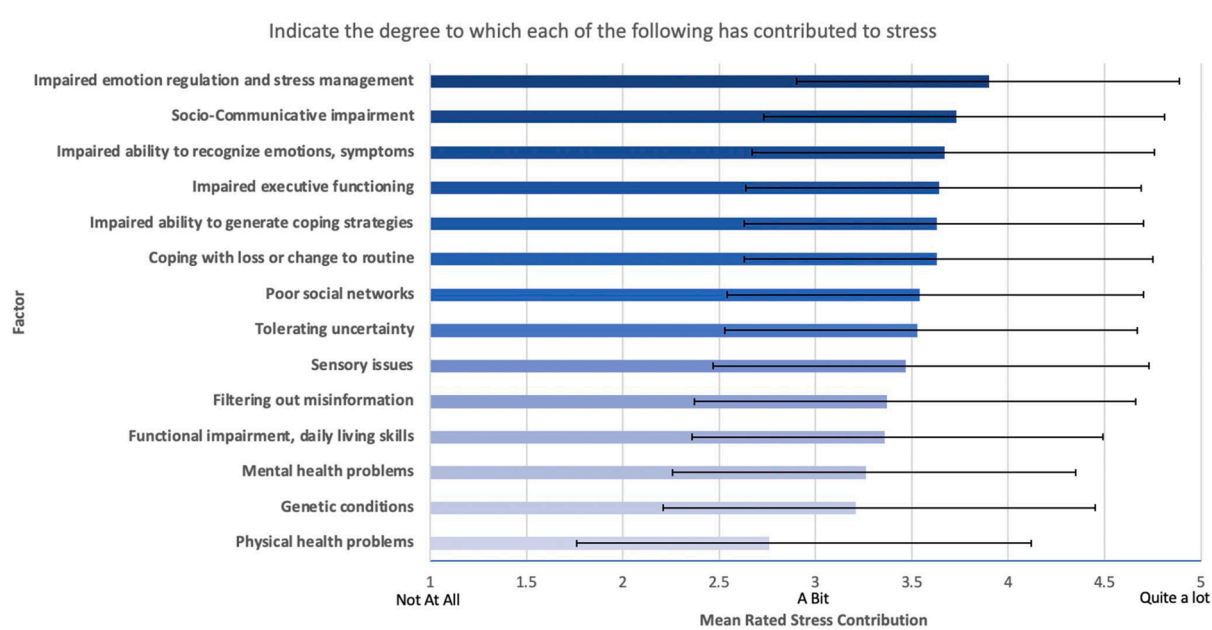


Fig. 1. Bar plot showing mean and standard deviation (SD) for each factor contributing to felt stress, ordered from greatest mean stress contribution to least mean stress contribution.

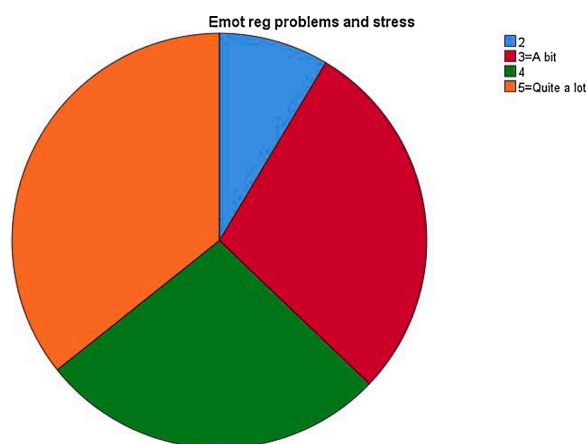


Fig. 2. Proportion of responses in each category to the question about degree to which difficulties with emotion regulation and coping with stress have contributed to stress and adversity related to COVID-19 and shelter in place mandates.

child's unique strengths and limitations/better perspective on understanding neurodiversity. Using qualitative statements to exemplify this, one parent said that they learned their child "really" wants to learn while others described gaining an enhanced understanding of how to "read" their child's emotions and needs. A number of parents noted how well their child had learned to adapt and how resilient they had become (e.g., "He is adaptable, surprisingly adaptable!"). Structure and routine were again prominent in answers to questions regarding what caregivers had learned and how they would address similar situations in the future. For example, 30 % of caregivers indicated that, in the future, they would address structure/routine for their child.

4.2. Service disruption & telehealth experience

There was tremendous variability in responses in relation to service disruption. A sizeable number of caregivers reported a complete loss of services (13.1 %) whereas several others reported no disruption (17.9 %). Although men reported slightly less disruption ($M = 2.26$, $SD = 1.05$) than did women ($M = 2.69$, $SD = 1.09$), the difference was not statistically significant ($t = 1.68$, $p = .099$). Only one respondent had prior experience with telehealth. The majority of caregivers ($n = 40$, 57.1 %) reported still not using telehealth, and 29 caregivers (41.4 %) reported using telehealth as a result of the pandemic. In the group of caregivers that used telehealth due to COVID-19, 14 (48.3 %) had no preference for in-person versus telehealth, 8 (27.6 %) preferred in-person services, and 5 (17.2 %) preferred telehealth ($n = 2$ indicated NA). None of the caregivers first using telehealth as a result of COVID-19 were raising nonverbal children.

Qualitatively, of the 29 caregivers who reported using telehealth, responses indicated both positive and negative experiences. Two positive themes emerged: caregivers were thankful their child was able to continue receiving services (4 responses) (e.g., "We were able to start therapy without losing valuable time because we could meet via telehealth") and services and treatments received were perceived as helpful (3 responses). Eleven caregivers indicated negative telehealth experiences suggesting that telehealth was less effective than in-person services (6 responses), difficulties with social communication hampered the impact of telehealth (5 responses; e.g., "Telehealth just doesn't work for my son. He is such a visual learner and literal processor"), and the child did not like telehealth even if the caregiver was fine with it (4 responses; e.g., "My son does not feel satisfied by it"). Of the 11 negative experiences, none of the comments reflected it was due to household composition (e.g., single parent managing other duties); the comments seemed more reflective of the affected child's direct experience with telehealth.

5. Discussion

This survey study was undertaken to identify challenges related to the COVID-19 pandemic and experiences with telehealth of caregivers of people with ASD as a way to inform practices that might minimize disruption in mental healthcare when faced with future large-scale public health emergencies. Caregivers noted difficulty with emotion regulation in their child, and loss of structure and routine as key challenges. Sustained healthcare was also identified as a challenge. In general, telehealth may not be preferred by most families, but it appears viable when face-to-face service is not an option. For some families, such as those living in remote areas or those with members more susceptible to infection, telehealth may be the only, if not the preferred, method for healthcare delivery.

The COVID-19 pandemic has resulted in major disruptions to people's routines and lives from the mundane (e.g., grocery shopping) to the substantial (e.g., loss of outside employment). People with ASD, by and large, thrive on routine, consistency, and structure. The need to establish new routines and provide predictability for individuals with ASD was noted as one way to cope with the impact of the pandemic. Use of routines is considered a protective factor against stress in daily living (Bridley & Jordan, 2012) and during major life events (e.g., chronic illness; Fiese & Wamboldt, 2000). Research suggests that, for children with ASD and/or with other neurodevelopmental disorders, establishment and maintenance of routines may be especially important for decreasing risk of emotional and

behavioral symptoms (Harris et al., 2014; McRae et al., 2019, 2020; Stoppelbein et al., 2016). Thus, if caregivers can develop new routines and try to structure daily activities, the negative impact on the person with ASD, and the whole family, may be minimized.

The degree of disruption caused by the pandemic, as perceived by caregivers in this sample, varied. Research with neurotypical children/adolescents and their families following disasters has revealed that disruption to daily life and structure is a predictor of negative outcomes (Furr et al., 2010; Pfefferbaum et al., 2015). It may be that factors such as economic advantage, availability of social support, and general parenting styles/behaviors impact the amount of disruption experienced by families following disasters such as the COVID-19 pandemic. It has been proposed that primary contextual determinants of child adjustment post-disaster include parental psychopathology and parental distress (Cobham et al., 2016). It is feasible that caregivers of children with ASD who experienced more stress prior to the pandemic or struggled with mental health problems may be less effective in garnering resources for their child's care, or less adept at using necessary supports (e.g., behavioral management techniques, establishing routines). Indeed, a recent study found that autistic children's response and health in relation to pandemic lockdown was directly related to how well the parents were able to cope (Latzer et al., 2021). In addition to individual factors, the role of community resilience and preparedness may have also impacted the level of disruption felt by families recently. Community resilience is the capacity of communities to identify, account for, and develop capabilities to address their vulnerabilities to disasters and disaster-related outcomes. A community's capacity to respond in a resilient manner is dependent upon its access to human, economic, political, and social capital (Chandra et al., 2018). Norris and colleagues suggest that community resiliency increases capacity of the system to adapt and recover from unexpected events that impact multiple systems (Norris et al., 2002). Thus, families residing in communities that lack resilience may experience greater disruption following disasters and have less access to needed resources as a result (Abramson et al., 2014).

This survey study did not, unfortunately, measure factors such as familial or community resilience, or assess caregiver mental health. As such, we cannot make inferences about the reasons for the observed variability in degree of disruption or perceptions of telehealth. Ideally, this pilot study will be followed by in-depth qualitative research that will provide more robust findings. Related to this, although two adults with ASD provided feedback on survey development, it would have been ideal to also have input from caregivers as it is possible they would have suggested additional areas of inquiry. Other limitations of this study include a fairly small and non-diverse sample. Although respondents were drawn from several states across the country, there are state-based differences in access to in-person care and telehealth which existed prior to and during the pandemic. The sample is neither large nor diverse enough (e.g., sample as a whole is predominantly white and we did not collect data on socio-economic status) to examine the influence of state policy, race, or SES on degree of disruption and access to services among families. Prior research has shown that being in a racial minority or in lower socioeconomic status compounds risks associated with ASD (Bishop-Fitzpatrick & Kind, 2017). Response bias (convenience sample) must also be considered. In addition, the survey questions were not specific to mental health services; therefore, responses may reflect a broad array of telehealth options (e.g., primary care, psychiatry). Finally, caregivers reported on their perceptions of what has been challenging or stressful for their child. Although caregiver as proxy is viable when using online survey methodology, it is not the firsthand experience of the child.

In conclusion, the central challenges faced by families affected by ASD during this pandemic may be due, in part, to the nature of ASD itself, specifically the high need for consistency and structure (Losh et al., 2008; O'Nions et al., 2018) and heightened emotion dysregulation (Mazefsky et al., 2013). Arguably, the pandemic has been characterized by uncertainty on most fronts including mistrust of science (e.g., prevalence, transmission, symptoms, and effective prevention), sociopolitical upheaval (e.g., care access and social justice), and debate (e.g., mask ordinances). When both caregivers and their children must manage the reality of tremendous uncertainty, instilling a sense of calmness and maintaining structure is extremely challenging.

Firm conclusions cannot be drawn from a pilot study such as this. However, results do suggest certain clinical implications. The pandemic appears to have been the impetus for at least some families to try telehealth for the first time. Experiences for first-time users were generally positive, even if in-person services are still preferred by most. However, the majority of the sample (60 %) reported not ever using telehealth, even several months into the lockdown, and several caregivers reported primarily negative telehealth experiences. Given this variability in subjective experiences, and the very limited research base suggesting clinical efficacy of telehealth for children with ASD (e.g., Gerow et al., 2021), clinicians and implementation scientists should consider strategies to promote usability and effectiveness of telehealth, including for individuals who have social communication impairment, and broaden access to sustained services for families who may be most vulnerable to disrupted mental healthcare. Given that none of the children switching to telehealth in this study were nonverbal, results may suggest inequities in coverage for families of children who have severe verbal or cognitive impairment. Moreover, we need further research to understand predictors of positive telehealth experiences with the hopes of informing more personalized approaches to ensure that all families' needs are met, perhaps considering other avenues of service delivery.

Credit author statement

Susan W. White, Laura Stoppelbein, Debbie Spain - Conceived of the concept for the paper and study design.

Susan W. White, Laura Stoppelbein, Hunter Scott - Were involved in data collection and analysis.

All authors contributed to writing and review of the manuscript.

References

- Abramson, D. M., Grattan, L. M., Mayer, B., Colten, C. E., Arosemena, F. A., Bedimo-Rung, A., et al. (2014). The resilience activation framework: A conceptual model of how access to social resources promotes adaptation and rapid recovery in post-disaster settings. *The Journal of Behavioral Health Services & Research*, 42(1), 42–57. <https://doi.org/10.1007/s11414-014-9410-2>.
- Aman, M. G., & Pearson, D. A. (2020). Challenges for child and adolescent psychiatric research in the era of COVID-19. *Journal of Child and Adolescent Psychopharmacology*, 30(5), 280–284. <https://doi.org/10.1089/cap.2020.0081>.
- Ameis, 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 the COVID-19 pandemic and beyond. *Molecular Autism*, 11(1), 1–9. <https://doi.org/10.1186/s13229-020-00365-y>.
- Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A scoping review of health disparities in autism Spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(11), 3380–3391. <https://doi.org/10.1007/s10803-017-3251-9>.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <https://doi.org/10.1191/1478088706q0630a>.
- Bridley, A., & Jordan, S. S. (2012). Child routines moderate daily hassles and children's psychological adjustment. *Children's Health Care: Journal of the Association for the Care of Children's Health*, 41(2), 129–144. <https://doi.org/10.1080/02739615.2012.657040>.
- CDC, U. (2019). *National center on birth defects and developmental disabilities*. Centers for Disease Control and Prevention. <https://www.cdc.gov/childrensmentalhealth/stateprofiles-providers/alabama/index.html>.
- Chandra, A., Acosta, J., Meredith, L., Sanches, K., Howard, S., Uscher-Pines, L., et al. (2018). Understanding Community resilience in the context of national health security: A literature review. *Understanding community resilience in the context of national health security: A literature review, February 2010*. <https://doi.org/10.7249/wr737>.
- Cobham, V. E., McDermott, B., Haslam, D., & Sanders, M. R. (2016). The role of parents, parenting and the family environment in children's post-disaster mental health. *Current Psychiatry Reports*, 18(6). <https://doi.org/10.1007/s11920-016-0691-4>.
- 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), 1–14. <https://doi.org/10.3390/brainsci10060341>.
- Duszak, R. S. (2009). Congenital rubella syndrome-major review. *Optometry*, 80(1), 36–43. <https://doi.org/10.1016/j.optm.2008.03.006>.
- Fiese, B. H., & Wamboldt, F. S. (2000). Family routines, rituals, and asthma management: A proposal for family-based strategies to increase treatment adherence. *Families Systems & Health*, 18(4), 405–418. <https://doi.org/10.1037/h0091864>.
- Furr, J. M., Comer, J. S., Edmunds, J. M., & Kendall, P. C. (2010). Disasters and youth: A meta-analytic examination of posttraumatic stress. *Journal of Consulting and Clinical Psychology*, 78(6), 765–780. <https://doi.org/10.1037/a0021482>.
- Gerow, S., Radhakrishnan, S., Akers, J., McGinnis, K., & Swensson, R. (2021). Telehealth parent coaching to improve daily living skills for children with ASD. *Journal of Applied Behavior Analysis*, 9999(9999), 1–16. <https://doi.org/10.1002/jaba.813>.
- Harris, A. N., Stoppelbein, L., Greening, L., Becker, S. P., Luebbe, A., & Fite, P. (2014). Child routines and parental adjustment as correlates of internalizing and externalizing symptoms in children diagnosed with ADHD. *Child Psychiatry and Human Development*, 45(2), 243–253. <https://doi.org/10.1007/s10578-013-0396-4>.
- Hayes, S. A., & Watson, S. L. (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(3), 629–642. <https://doi.org/10.1007/s10803-012-1604-y>.
- HHS Press Office. (2020). *HHA issues new report highlighting dramatic trends in medicare beneficiary telehealth utilization amid COVID-19*. <https://www.hhs.gov/about/news/2020/07/28/hhs-issues-new-report-highlighting-dramatic-trends-in-medicare-beneficiary-telehealth-utilization-amid-covid-19.html>.
- Hoogsteen, L., & Woodgate, R. L. (2013). Embracing autism in Canadian rural communities. *The Australian Journal of Rural Health*, 21(3), 178–182. <https://doi.org/10.1111/ajr.12030>.
- Jones, K. E., Patel, N. G., Levy, M. A., Storeygard, A., Balk, D., Gittleman, J. L., et al. (2008). Global trends in emerging infectious diseases. *Nature*, 451(7181), 990–993. <https://doi.org/10.1038/nature06536>.
- Kelkar, S., & Kumthekar, M. B. (2019). Need of sustainable planning and development against natural disaster resulting because of climate change and human intervention. *SSRN Electronic Journal*. <https://doi.org/10.2139/ssrn.3366750>.
- Latzer, I. T., Leitner, Y., & Karnieli-Miller, O. (2021). Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism*.
- Leno, V. C., & Simonoff, E. (2020). ASD and Co-occurring psychiatric conditions: A conceptual framework. In C. A. M. S. W. White, & B. M. Maddox (Eds.), *The Oxford handbook of autism and Co-occurring psychiatric conditions*. Oxford University Press.
- Losh, M., Childress, D., Lam, K., & Piven, J. (2008). Defining key features of the broad autism phenotype: A comparison across parents of multiple- and single-incidence autism families. *American Journal of Medical Genetics Part B Neuropsychiatric Genetics*, 147(4), 424–433. <https://doi.org/10.1002/ajmg.b.30612>.
- 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*. Article 0123456789. <https://doi.org/10.1007/s10803-020-04760-5>.
- Mazefsky, C. A., Herrington, J., Siegel, M., Scarpa, A., Maddox, B. B., Scahill, L., et al. (2013). The role of emotion regulation in autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52(7), 679–688. <https://doi.org/10.1016/j.jaac.2013.05.006>.
- McRae, E. M., Stoppelbein, L., O'Kelley, S. E., Fite, P., & Greening, L. (2019). Predicting child behavior: A comparative analysis between autism spectrum disorder and attention deficit/hyperactivity disorder. *Journal of Child and Family Studies*, 28(3), 668–683. <https://doi.org/10.1007/s10826-018-1299-6>.
- McRae, E. M., Stoppelbein, L., O'Kelley, S., Fite, P., & Smith, S. (2020). Comorbid internalizing and externalizing symptoms among children with ADHD: The influence of parental distress, parenting practices, and child routines. *Child Psychiatry and Human Development*. <https://doi.org/10.1007/s10578-020-01019-z>, 0123456789.
- Morse, S. S. (2004). Factors and determinants of disease emergence. *OIE Revue Scientifique et Technique*, 23(2), 443–451. <https://doi.org/10.20506/rst.23.2.1494>.
- Mount, N., & Dillon, G. (2014). Parents' experiences of living with an adolescent diagnosed with an autism spectrum disorder. *Educational and Child Psychology*, 31(4), 72–81.
- Nonweiler, J., Rattray, F., Baulcomb, J., Happé, F., & Absoud, M. (2020). Prevalence and associated factors of emotional and behavioural difficulties during COVID-19 pandemic in children with neurodevelopmental disorders. *Children*, 7(9), 128. <https://doi.org/10.3390/children7090128>.
- Norris, F. H., Byrne, C. M., Diaz, E., Friedman, M. J., Watson, P. J., & Kaniasty, K. (2002). 60,000 disaster victims speak: Part I. An empirical review of the empirical literature, 1981–2001. *Psychiatry*, 65(3), 1981–2001.
- O'Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2018). How do parents manage irritability, challenging behaviour, non-compliance and anxiety in children with autism spectrum disorders? A Meta-Synthesis. *Journal of Autism and Developmental Disorders*, 48(4), 1272–1286. <https://doi.org/10.1007/s10803-017-3361-4>.
- Oomen, D., Nijhof, A., & Wiersema, R. (2020). *The impact of the COVID-19 pandemic on autistic adults*.
- Osborne, L., & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autistic spectrum disorders. *Exceptional Children*, 76(1), 54–73. <https://doi.org/10.1177/001440290907600103>.
- Pfefferbaum, B., Jacobs, A. K., Griffin, N., & Houston, J. B. (2015). Children's disaster reactions: The influence of exposure and personal characteristics. *Current Psychiatry Reports*, 17(7). <https://doi.org/10.1007/s11920-015-0598-5>.
- Picci, G., & Scherf, K. S. (2015). A two-hit model of autism: Adolescence as the second hit. *Clinical Psychological Science*, 3(3), 349–371. <https://doi.org/10.1177/2167702614540646>.
- Relations, C. on F. (2020). *Major epidemics of the modern era 1899-2020*. <https://www.cfr.org/timeline/major-epidemics-modern-era>.
- Samadi, S. A., Bakhshalizadeh-Moradi, S., Khandani, F., Foadgar, M., Poursaid-Mohammad, M., & McConkey, R. (2020). Using hybrid telepractice for supporting parents of children with asd during the COVID-19 lockdown: A feasibility study in Iran. *Brain Sciences*, 10(11), 1–14. <https://doi.org/10.3390/brainsci10110892>.
- SPARK. (2020). *Impact of COVID-19 on families and children with autism*.
- Stoppelbein, L., Biasini, F., Pennick, M., & Greening, L. (2016). Predicting internalizing and externalizing symptoms among children diagnosed with an autism spectrum disorder: The role of routines. *Journal of Child and Family Studies*, 25(1), 251–261. <https://doi.org/10.1007/s10826-015-0218-3>.

- Sullivan, R. (2017). Lived experiences of low-income parents raising children with autism. *ProQuest Dissertations and Theses*, 14(1), 210. <https://doi.org/10.5590/JSBHS.2020.14.1.14>.
- Van Steijn, D. J., Oerlemans, A. M., Van Aken, M. A. G., Buitelaar, J. K., & Rommelse, N. N. J. (2014). The reciprocal relationship of ASD, ADHD, depressive symptoms and stress in parents of children with ASD and/or ADHD. *Journal of Autism and Developmental Disorders*, 44(5), 1064–1076. <https://doi.org/10.1007/s10803-013-1958-9>.
- White, L. C., Law, J. K., Daniels, A. M., Toroney, J., Vernioia, B., Xiao, S., et al. (2021). 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*. <https://doi.org/10.1007/s10803-020-04816-6>, 0123456789.