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Examining Parental Stress and Autism in the Early Days of the Pandemic: A Mixed-Methods Study

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Abstract: In this convergent parallel mixed-methods study, we investigated the early impact of the COVID-19 stay-at-home mandate in Illinois on 16 caregivers of children with autism. Our goal was to understand contributors to caregivers' stress by integrating qualitative and quantitative data. Through a joint display, we explored the intricate relationship between caregivers' perceptions of their child's needs, the loss of essential services, and stress levels. The caregivers' reported needs, wishes, barriers, and coping strategies informed and corroborated final quantitative results on stress levels. Significant associations were found between stress levels and caregivers' agreement with statements on child supervision, service loss, and perceived level of their child's independence. These findings underscore the importance for robust support systems that enhance family resilience and validate prior research during exceptional circumstances. They offer insights for policymakers and service providers seeking to improve the well-being of families raising children with autism, particularly in times of crisis.

Keywords: COVID-19; autism; caregiver stress; mixed-methods study



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1. Introduction

The COVID-19 pandemic and stay-at-home mandates (i.e., lockdown) profoundly impacted families of children with autism [1] contributing to increased stress levels and a reduced ability to cope with adversity [2–4]. This emotional strain was further compounded by the fear of virus-related mortality, especially when considering the co-occurring medical needs of individuals with developmental disabilities, including autism [5]. Additionally, various economic challenges exacerbated the stressful situation, as pandemic-induced economic downturns affected families globally. These challenges manifested in widespread job losses and the loss of health insurance benefits, critically hindering many families' ability to access essential support and medical care [6].

In light of these challenges, the stay-at-home mandates and social distancing measures not only upended daily schedules and routines but also had profound adverse effects on autistic children and their families [7–9]. The disruption of necessary therapies that are instrumental in enhancing communication skills and managing challenging behavior in children with autism, further complicated an already challenging time [7]. This global disruption extended to education and therapeutic services, which significantly impacted the autistic students' ability to access necessary in-school and in-person therapeutic services in the United States (U.S., [10]). Caregivers of children with autism grappled with heightened concerns about service disruptions, financial challenges, and illness during the pandemic. The shift to online instruction and the sweeping school closures in the U.S. exacerbated the situation, and resulted in learning loss and increased distress, especially for children who had received more frequent and intensive services before the pandemic [11,12].

Furthermore, the social distancing measures altered the frequency, breadth of curriculum, and mode of delivering services for children with autism, including applied behavior

analysis, speech pathology, and occupational therapies. Also, the abrupt shift to telepractice introduced unpredictability and disruptions in routines, further amplifying the adverse effects of the pandemic on the children and their families [13–15]. Therefore, the stay-at-home mandates and social distancing measures not only upended daily schedules and routines, profoundly affecting the wellbeing of autistic children and their families [2], but also disrupted the ability to access support programs, therapeutic services, and education in schools (e.g., [12]), which can typically help foster resilience for autistic children and their families.

1.1. Social Support and Resilience

Social support plays a vital role in promoting positive parental engagement and the overall well-being for both the child and their family [16]. Moreover nurturing relationships within supportive environments can significantly contribute to the positive development of children with autism and other disabilities [17]. By harnessing community resources, these supportive environments can be further strengthened to foster family resilience [18].

Resilience, defined as the ability to thrive in the face of adversity [19], is evident when caregivers experience a sense of control, feelings of self-efficacy, social support, and positive family interactions [20,21]. While research indicates that caregivers of children with autism often experience higher stress levels compared to caregivers of children with other developmental disabilities or no disabilities [22,23], there's evidence of a negative association between family resilience and parenting stress in families of children with autism [24,25]. Studies have shown that parental resilience within families with children with autism can indeed be high (e.g., [26]). Therefore, prioritizing the promotion of family resilience and adopting a strength-based approach (vs. a deficit-based approach) is important for both research and practice. However, it's essential to recognize that factors that could influence resilience levels can vary significantly across studies and countries [26–28]. This underscores the significance of considering diverse contexts and individual family dynamics when addressing resilience in families affected by autism.

At the onset of the COVID-19 pandemic in March 2020 [29], many individuals with autism and their families demonstrated resilience (e.g., [21]). Resilience in caregiving involves recovering from stress and adapting to the care situation [30]. Remarkably, even cultivating a modest level of resilience appeared to serve as a protective factor against anxiety and depression among caregivers of autistic children during the pandemic [31,32]. However, the intermittent inaccessibility of essential support systems due to social distancing and stay-at-home mandates posed a critical challenge for families of autistic children. This loss of access to social connection was particularly significant because poor social connections are mostly linked to poorer well-being for both caregivers and their children with autism [33].

1.2. Stress Mitigation Strategies during the Pandemic

To alleviate caregiver stress, implementing interventions that facilitate the learning and generalization of skills for autistic children within their natural environments can be very helpful [34,35]. However, the national emergency declaration in the U.S. in March 2020 compelled service providers and school districts to close down and reassess their service delivery models [36] further limiting access to needed resources. Respite care, including in-home care, community-based programs, or residential facilities, although often a rare resource was even less available during stay-at-home mandates, significantly contributing to increased stress for caregivers of individuals with autism [37]. Additionally, tensions arose from the novel demands of working from home, homeschooling, the need for enhanced sanitization, unemployment, and political unrest [14].

Moreover, families encountered challenges in accessing the necessary knowledge to effectively support their child with autism and manage stress. This acquisition of knowledge and training can lead to a shift in caregivers' perceptions regarding their capability to assist their children with autism. Such shifts have been associated with increased self-efficacy, decreased stress levels, and heightened motivation to implement

interventions that promote skill development and generalization across various settings [38]. While some families of children with disabilities were able to cultivate self-efficacy and find meaning during the pandemic, which helped strengthen their resilience and maintain their mental well-being [39], others, particularly those with autistic children, faced a prevailing sense of helplessness, especially in the early stages of the pandemic [40].

1.3. Purpose and Research Questions

The abrupt suspension of in-person education, extracurricular activities, social interactions, and routine healthcare during the COVID-19 pandemic significantly impacted the well-being and mental health of families with autistic children [1,7,8,13]. Considering the known bi-directional relation between parental stress and challenging behavior [41,42], caregivers, especially those of autistic children who exhibit challenging behavior, were more likely to have experienced intensified or altered parent-child interactions during stay-at-home mandates.

This research, part of a broader investigation, aimed to understand the challenges faced by families with young autistic children during the early stages of stay-at-home mandates. Aligned with the goal of producing context-specific evidence [43], this study sought to create an understanding that could inform state legislatures and local service providers when they address the needs, wants, and beneficial strategies that can promote the well-being of families with autistic children in future emergencies. This study centered on two key research questions: (1) How did the loss of services and caregivers' perception of their child's needs impact their stress levels? and (2) What were the caregivers' needs and obstacles in accessing stress-alleviating support?

2. Materials and Methods

2.1. Procedures and Design

After obtaining approval from the Institutional Review Board of the University of Illinois Urbana Champaign, and conducting a pilot study with two caregivers of children with disabilities, we employed purposive participant selection from a single state to ensure their adherence to similar mandated stay-at-home guidelines. This unique sample was recruited during the initial wave of the virus and the early stages of the stay-at-home mandate enforced by Illinois from 29 April to 16 June 2020. In an effort to broaden the scope of our investigation, leverage the strengths of both methodologies [44], enhance this study's validity, and substantiate our findings [45,46], we employed a convergent parallel mixed-methods approach that integrated both qualitative and quantitative data.

To gain quantitative insights, we utilized the Parenting Stress Index, Fourth Edition-Short Form (PSI-4-SF; [31]) and administered a demographic questionnaire. Additionally, with the same caregivers, we followed a protocol (see Supplementary File S1) for semi-structured interviews to obtain complementary qualitative data. During the interpretation phase, the results from both types of data were compared, contrasted, and confirmed, aligning quantitative findings with qualitative insights. The procedural diagram (see Figure 1) illustrates the implementation of a one-phase and convergent parallel design [47], where the qualitative and quantitative components were conducted independently. The results of both were integrated to support a deeper understanding of the experiences within the small sample obtained during the extenuating circumstances of a global shutdown.

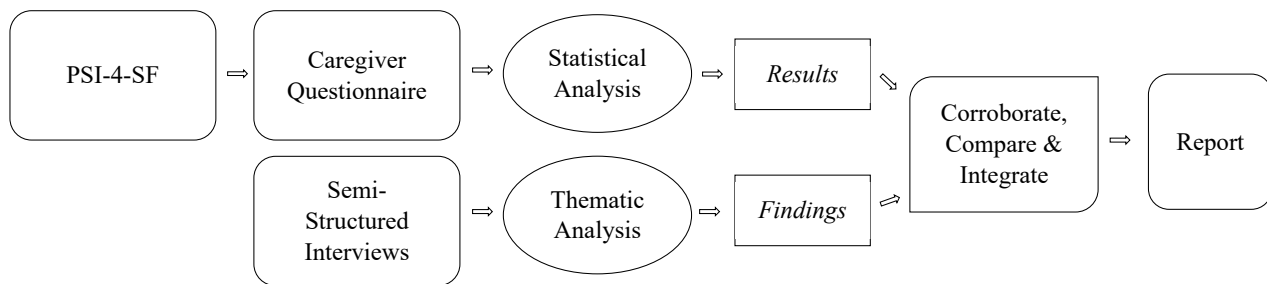


Figure 1. Triangulation Design: Convergent Parallel Model.

2.2. Participants

To obtain in-depth insights from a potentially homogeneous group of participants, we initiated recruitment using purposive sampling [46], followed by criterion sampling [48]. Participants were recruited through social media and targeted email blasts to engage autism parent groups and service providers. The respondents were then required to complete a pre-screening form to qualify for this study. The eligibility criteria for this study required participants to be (a) 18 years or older, (b) residents of Illinois, (c) primary caregivers of a 2 to an 8-year-old child diagnosed with autism, and (d) practicing social distancing as defined by Illinois' stay-at-home mandate. A total of 16 participants who met these criteria completed all aspects of this study (see Table 1). Among them, 13 out of 16 caregivers were women, and 12 out of 16 identified as White, with an average age of 37. Children with autism in this study were mainly boys ($n = 13$) and White ($n = 12$), with an average age of 5.25 and an average age of diagnosis of 2.68. During this study in Illinois, all participants ($n = 16$) confirmed adherence to the stay-at-home mandate. Caregivers left their homes only for essential activities such as shopping, exercising, and seeking medical services. One participant, an essential worker, left home for work while their child with autism attended a respite childcare setting without special services. Of the remaining participants, two were stay-at-home caregivers, six lost their jobs due to the pandemic, and eight were employed in different fields. Among the employed participants, four had to leave their homes for work, while the rest were able to work remotely. Among the six caregivers who lost their jobs, two had a working spouse. The remaining participants were single caregivers.

Table 1. Demographic Information of Caregivers and Children with Autism.

Caregiver				
Age	M = 37	Range (23–51)		
Gender	Female 13 (81%)	Male 3 (19%)		
Race	White 12 (75%)	Black 3 (19%)	Other 1 (6%)	
Marital Status	Married 10 (63%)	Divorced 2 (13%)	Single 4 (25%)	
Education	BA 6 (38%)	AA 4 (25%)	CCr 4 (25%)	HS 2 (13%)
Occupation	Stay-at-home 2 (13%)	Unemployed 6 (38%)	Employed 8 (50%)	
Work Remotely	Yes 5 (31%)	No 11 (69%)		

Table 1. Cont.

Caregiver				
Income/mos.	\$6–8 K 3 (19%)	\$2–4 K 6 (38%)	\$4–6 K 5 (31%)	
Child				
Age	M = 5.25	Range (3–8)		
Age of Diagnosis	M = 2.68	Range (1.5–5)		
Gender	Male 13 (81%)	Female 3 (19%)		
Race	White 12 (75%)	Other 1 (6%)		
Level of Support	Level 1 4 (25%)	Level 2 Substantial 6 (38%)	Level 3 Very Substantial 4 (25%)	Unknown 2 (13%)
Service Hours/week before Mandate	More than 20 11 (69%)	5–10 4 (25%)	Less than 1 1 (6%)	

Notes: BA = Bachelor's, AA = Associate's, CCr = College credits, and HS = High school. Percentages may not add up to 100% due to rounding. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) categorizes Autism into three levels, indicating the varying support needs in communication, social interactions, and self-care tasks compared to neurotypical individuals.

In the early stages of the COVID-19 stay-at-home mandate, all participants reported that their children with autism lost access to academic and therapeutic services for at least four weeks. The closure of public schools resulted in the loss of specialized instruction and related services for children receiving special education. Paid childcare services, feeding therapy, physical therapy, respite care, and play therapy were no longer available. Only 31% of families received synchronous virtual services, and 50% had no alternative modes of service delivery. Three families accepted telepractice services, but the number of service hours significantly reduced (from 32, 37, and 20 h or more per week to 3, 5, and 0.5 virtual hours per week, respectively). The data reported by the caregivers suggest that the stay-at-home mandate had a significant impact on the availability of support services for children with autism.

2.3. Data Sources

2.3.1. Caregiver Questionnaire (CQ)

Caregivers filled out a three-part online questionnaire. The first section gathered demographic information about the caregivers and their family. The second section used a Likert-type scale to assess the supports the family received, with statements exploring the caregiver's perceptions of their child's support needs (e.g., "For their safety, my child requires the undivided attention of an adult during waking hours"). The third section comprised yes/no questions and inquired about the children with autism, the services they received, and those lost due to the pandemic.

2.3.2. Parenting Stress Index, Fourth Edition-Short Form

(PSI-4-SF, [31]). The PSI-4-SF is a self-reporting tool designed to identify various sources and types of stress associated with parenting children aged 0–12. It consists of a 36-item questionnaire that takes less than 10 min to complete. The tool generates scores for three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). Additionally, a Total Stress (TS) score is generated to indicate the overall level of stress experienced by the caregiver in their role as a parent [49].

2.3.3. Semi-Structured Interview

Qualitative data for this study were exclusively analyzed based on responses to two questions: (a) What strategies, information, or skills have proven helpful in supporting you, your child, or your family during the pandemic? and (b) What support do you wish you had for yourself, your family, and your child? The first question explored

helpful approaches and sources of support utilized by caregivers during the stay-at-home mandate, while the second inquired about support they wished they had. The interviews were conducted between 29 April and 16 June 2020, with a total duration of 533 min ($M = 33.31$ min per interview, $\text{Range} = 23\text{--}48$). Following the interviews, participants received a summary via email, allowing them to review and make any necessary changes (member checking). Audio recordings were transcribed and reviewed for accuracy.

2.4. Data Analysis

The research team was composed of an advanced doctoral student and a faculty member, both identify as Women, non-Hispanic. Qualitative and quantitative data were separately analyzed. The caregiver questionnaire generated numeric, categorical, and Likert-type responses, which were statistically analyzed alongside subscales of the PSI-4-SF. The qualitative data analysis was guided by predefined a priori themes derived from the research questions. The researchers systematically and iteratively analyzed the interview data, drawing inspiration from Brawn & Clark's approach [50]. In the initial phase, they applied deductive coding to break down the data into smaller units based on preselected a priori themes. During the second coding cycle, the researchers reached a consensus on the significance of transcript units, leading to the creation of a thematic map and a codebook (See Supplementary File S2). To ensure consistency, they used this codebook to re-code all the data. This a priori coding approach enhanced rigor and transparency in reporting qualitative data, providing a structured framework while remaining receptive to enriching insights from participants. The researchers utilized Dedoose, a web-based application for qualitative and mixed-methods research, to organize, analyze, and visualize their data. To improve the credibility and trustworthiness of the qualitative findings, contextual nuances were considered in the analysis, and member checking allowed for alignment with participants' experiences, providing an opportunity for participants to correct or confirm the record. Thematic and qualitative findings from semi-structured interviews were corroborated with quantitative results and finally presented using a joint display.

Three a priori themes guided the thematic analysis of the semi-structured interview (see Figure 2). The first theme focused on the caregivers' expressed wants and needs, the second theme explored barriers hindering caregivers from fulfilling those needs, and the third theme delved into strategies that proved effective for caregivers in navigating challenges during the early stages of the pandemic.

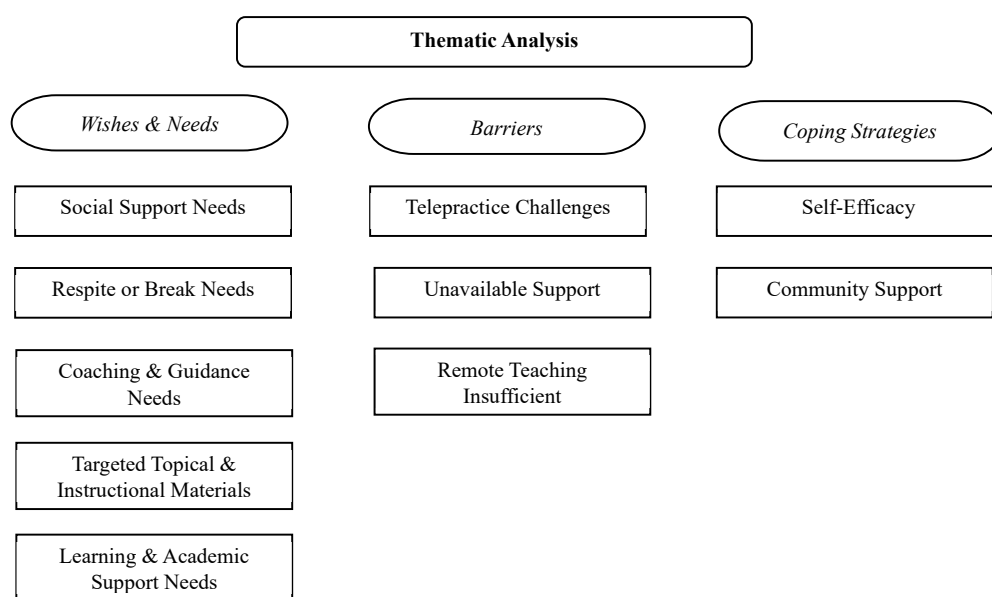


Figure 2. Themes and Subthemes Generated from the Interview Questions.

3. Results

3.1. Quantitative Data

3.1.1. Caregiver Questionnaire

Participants expressed their agreement levels on four Likert-type statements, providing ratings that reflected their perceptions of their child's level of independence (see Table 2). Nearly 90% of participants either agreed or strongly agreed with Statement 1 (St1), where they believed that they needed to give their child undivided attention for safety. Regarding Statement 2 (St2), about 56% of participants either disagreed or strongly disagreed with the idea that their child was independent and could entertain themselves. For Statement 3 (St3), about 44% of participants expressed their agreement (agreed and strongly agreed), indicating that they were not concerned about their children with autism's safety when left alone in a room. Conversely, almost 44% either strongly disagreed or disagreed with Statement 3. Finally, 68.75% of participants strongly agreed with Statement 4 (St4), affirming that they used the time their children with autism received services to catch up on running errands and chores.

Table 2. Percentage Distribution of Responses for Four Likert-Type Rating Statements (1–4).

Statement	SD	D	NN	A	SA
	N (%)				
(St1) For safety, my child needs constant adult supervision during waking hours.	-	-	2 (12.5%)	6 (37.5%)	8 (50%)
(St2) My child is independent and can entertain themselves during the day.	4 (25%)	5 (31.25%)	1 (6.75%)	6 (37.5%)	-
(St3) I can leave my child in a room by themselves without worrying that they might get hurt.	4 (25%)	3 (18.72%)	2 (12.5%)	6 (37.5%)	1 (6.75%)
(St4) Time that my child spends in school or therapy is when I catch up on running errands and doing chores.	1 (6.7%)	-	1 (6.75%)	3 (18.75)	11 (68.75%)

Notes: Participants rated their agreement with the statements on a 5-point Likert-type scale, ranging from Strongly Disagree (SD) to Strongly Agree (SA), with the intermediate options including Disagree (D), Neither Agree nor Disagree (NN), and Agree (A).

3.1.2. PSI-4-SF

The interpretive report (see Table 3) provides percentile profiles for independent and cumulative domain scores of the PSI-4-SF. Scores falling between the 15th and 80th percentile are deemed typical, those in the 81st–89th percentile are considered high, and scores at or above the 90th percentile are classified as clinically significant. In this study, participants displayed an average Total Stress score (TS) of $M = 79$, ranging from 55 to the ≤ 99 th percentile. Overall, 69% of participants ($n = 11$) scored within the normal range on the Total Stress (TS) scale, while 31% ($n = 5$) fell in the clinically significant range (see Table 3). Elevated scores were more prevalent across participants when analyzing individual domains of the PSI-4-SF. On the Difficult Child (DC) subscale, 56% of participants ($n = 9$) had a clinically significant elevated stress range, 25% ($n = 4$) fell within the high stress range, while the remaining caregivers fell within the typical range. On the Parent-Child Dysfunctional Interaction (P-DCI) subscale, 31% of caregivers ($n = 5$) placed in the clinically significant range and 19% ($n = 3$) fell within the high-stress range. Additionally, 12.5% of caregivers ($n = 2$) were in the clinically significant range on the Parental Distress (PD) subscale, and another 12.5% ($n = 2$) placed in the high range on this subscale.

Table 3. PSI-4-SF Interpretive Report Summary.

Participant	TS	PD	PCDI	DC
A	97 **	62	95 **	≤99 **
B	≤99 **	≤99 **	≤99 **	≤99 **
C	77	76	59	96 **
D	79	73	73	95 **
E	76	50	83 *	91 **
F	76	78	92 **	52
G	94 **	82 *	90 **	98 **
H	69	59	63	81 *
I	92 **	85 *	86 *	96 **
J	79	76	82 *	83 *
K	74	76	55	83 *
L	57	23	59	76
M	76	64	70	95 **
N	68	64	63	73
O	98 **	92 **	≤99 **	93 **
P	73	68	55	86 *

Notes: The numbers reported are percentile placement for TS = Total Stress Score, PD = Parental Distress Score, PCDI = Parent Child Dysfunctional Interaction Score, DC = Difficult Child Score. * Denotes high score and ** clinically significant.

3.1.3. Linear Regression

A linear regression analysis was performed to examine the influence of demographic variables on the TS percentile score. None of the following variables: age of diagnosis, parent gender, race, child's gender, parent's level of education, and number of people living in the household were significant predictors to the model. A regression model showed that listed demographic variables explained a non-significant 23.91% of the variable in the TS of caregivers ($F = 0.11$, $p = 1$, $R^2 = 0.24$).

3.1.4. Pearson's Correlations

To detect the direction and strength of the relations between the variables derived from the PSI-4-SF scores and the remaining caregiver responses to Likert-type statements and close-ended questions on the CQ, a Pearson's correlation was performed to indicate the direction and strength of the significant associations between the percentile placements of the PSI-4-SF subscales (TS, PD, PCDI, and DC) and nine questionnaire responses that included demographic information, agreement to statements on a Likert type scale, and other numerical and categorical responses (see Table 4).

Table 4. Correlation Coefficient (r) for PSI-4 Subscale Raw Scores and Caregiver Questionnaire Responses.

	1	2	3	4	5	6	7	8	9	10
TS	1.00									
PD	0.82 *	1.00								
PCDI	0.92 *	0.72 *	1.00							
DC	0.77 **	0.39	0.55 *	1.00						
St1	0.62 *	0.52	0.7 *	0.26	1.00					
St2	−0.58 *	−0.25	−0.78 **	−0.65 *	0.46	1.00				
St3	−0.81 **	−0.61 *	−0.67 *	−0.63 **	0.14	0.24	1.00			
St4	−0.2	−0.11	0.02	0.3	0.23	0.69	0.03	1.00		
St5	−0.36	0.05	0.29	0.26	0.12	0.21	0.44	−	1.00	
St6	−0.03	−0.2	0.39	0.12	0.32	0.13	0.17	0.23	0.17	1.00

Notes: TS = Total Stress Score; PD = Parental Distress Stresses Score; PCDI = Parent Child Interaction Stress Score; DC = Difficult Child Score. (St1–St4) 5-point Likert Type scale from Strongly disagree to Strongly agree. (St1) Statement 1 (St1): For their safety, my child requires the undivided attention of an adult during waking hours. Statement 2 (St2): My child is independent and can entertain themselves during the day. Statement 3 (St3): I can leave my child in a room by themselves without worrying that they might get hurt. (St4) Statement 4: Time that my child spends in school or therapy is when I catch up on errands or chores. Close ended question (St5): I can work from home. Close ended question (St6): Number of lost hours of service after the stay-at-home mandate. Strength of correlation (r): < 0.1: no correlation, 0.1 to <0.3: low correlation, 0.3 to <0.5: medium correlation, 0.5 to <0.7: high correlation, 0.7 to <1: very high correlation. Significant p -values: ($p \leq 0.05$) *; ($p < 0.001$) **.

A significant and high positive correlation was found between PDCI and St1 ($r = 0.7$, $p = 0.003$), a highly significant and very strong negative correlation between the PDCI scale and St2 ($r = -0.78$, $p < 0.001$), and a significant and high negative association between the PDCI percentile placement and St 3 ($r = -0.67$, $p = 0.004$). Additionally, for St 2, there were significant negative associations with medium strength between caregivers' responses and their Total Score percentile placement ($r = -0.55$, $p = 0.02$). Finally, the level of agreement with St3 was significantly associated with all percentile placements of caregivers on the three stress subscales and the total stress score.

The correlation coefficients r with magnitudes greater or equal to (± 0.5) across variables were identified and further analyzed. In each case, we confirmed a 95% or more degree of confidence ($p < 0.05$) for the existence of a relationships between the nine listed variables (see Supplementary File S3). Caregivers were asked if they were able to perform their work duties from home and they answered with yes (1) or no (0), as well as to whether their children with autism has lost any of the services that they normally received prior to the stay-at-home mandates. These two questions had a positive correlation with the raw scores from the caregivers' PSI-4-SF subscale, Difficult Child (DC) where the direction of their correlation increased and decreased in tandem with the caregivers' responses to whether the caregivers were able to work from home (St5) and whether they lost therapeutic services (St6); ($r = 0.52$ and $r = 0.514$), respectively.

A significant and very strong negative correlation was identified between TS and St3 ($r = -0.81$, $p < 0.001$). The effect size of this correlation was very high and negative ($r = -0.81$). This robust negative association reveals that higher TS scores for caregivers are strongly linked to reduced confidence in leaving their child unattended while they remain safe from harm. This consistent pattern is further evidenced by examining the correlations between DC subscale scores and St3, yielding a substantial negative correlation of -0.63 ($p < 0.001$). Similarly, PD scores and St3 demonstrated a substantial negative correlation of -0.67 ($p = 0.004$). These findings underscore a robust association between caregivers' stress levels and their confidence in their child's ability to avoid potential harm. The identified strong relationships prompted a more detailed investigation.

3.1.5. Multiple Linear Regression Analysis to Identify Influencing Factors on Total Stress Score

A multiple linear regression analysis of the variables on the levels of agreement on a 5 point-Likert scale ranging from (strongly disagree to strongly agree) on St3: I can leave my child alone in a room without worrying they might get hurt explained a large and significant 78.38% variance in the TS ($F [5, 6.98] = 7.25$, $p = 0.001$, $R^2 = 0.78$). According to the regression analysis, standardized coefficients beta were used to determine the independent contribution of each variable to the dependent variable, with values ranging from -1 to 1 . In this model, the variable response disagree has the most influence on the TS ($\beta = 0.77$, $p = 0.001$, 95% CI = [11.46, 35.2]). (See Supplementary File S4).

A multiple linear regression analysis was conducted to assess the impact of different ranges of lost service hours (More than 20 h, 5–10 h, and 1–5 h) on the Total Stress Raw Score variable. The regression model revealed that the variables More than 20 h, 5–10 h, and 1–5 h collectively accounted for a large and significant 65.47% in variance in the Total Stress Raw Score ($F [3, 18.42] = 7.58$, $p = 0.002$, and $R^2 = 0.65$). According to the regression analysis, standardized coefficients beta were used to determine the independent contribution of each variable to the dependent variable with values ranging from -1 to 1 . In this model, the variable response 5–10 h has the most influence on the TS ($\beta = 0.77$, $p = 0.001$, 95% CI = [42.86, 123.14]). (See Supplementary File S5).

3.2. Qualitative Data

3.2.1. Wishes and Needs

Social Support Needs

Caregivers highlighted the limitations in social support, expressing the need for an expanded social circle and the challenges of being separated from extended family and important social connections. One caregiver emphasized the difficulty saying, “Any human. I would take just somebody who is only near us. We don’t have any family here. So that is exceptionally hard”. Another caregiver shared the impact on their child, stating, “My daughter is very close to her grandparents; she’s not able to see them”.

Respite or Break Needs

Caregivers expressed a desire for respite or breaks, emphasizing the need for help and support with childcare to allow time for work, self-care, or a break from teaching responsibilities. One caregiver expressed a wish for someone else to engage with the children, saying, “I would like someone to play with the kids that is not me”. Others articulated the need for childcare to destress or work, such as “I wish I had some type of childcare so I could work and be able to get some things that he needs at home”.

Coaching and Guidance Needs

Caregivers expressed a need for coaching and guidance on coping with the challenges of homeschooling a child with autism. They sought advice on managing special education, dealing with their child’s anxiety, and effective homeschooling strategies. A caregiver voiced their struggle, saying, “I wish I had someone to help me help her. I wish that someone had been there just to be like, this is what you do, this is what I want you to do with her”.

Targeted Topical Instructional Materials

Most caregivers conferred that it would be helpful to receive targeted parental instruction, a single father wished he knew how to provide instruction for his autistic child and said, “I wish that someone could teach me how to kindergarten; how to home-school an autistic kid”. Other caregivers mentioned coaching in addition to the written or video materials on how to respond specifically to their child and their challenging behavior, feeding struggles, potty training, and communication. Caregivers identified specific informational needs and expressed the desire for targeted instructional materials on topics like communication skills, structured physical activities, toilet training, social skills, occupational therapy, selective eating, and dealing with emotional meltdowns. One caregiver stated, “We’re always interested in any information about toilet training”. Another emphasized the need for effective ways to handle tantrums.

Learning and Academic Support Needs

Caregivers expressed concerns about the lack of support from schools, the desire for progress on Individualized Education Program (IEP) goals, and the need for access to therapy and one-on-one support for their children. One caregiver expressed their wish for more school support, saying, “I wish I had more support from the school”. Another emphasized the importance of in-person services, stating, “I think for the kids, and for us, it’s just more beneficial to have at least some time in the clinic working on the skills they need to work on, which also allows us to have a little break”. Most caregivers also wished for in-person at home or in-clinic services. A mother of twin autistic boys with very substantial support needs said, “I wish that we had more hands-on assistance. We should have been protecting them (her children). They should not have been just thrown out. I’m thinking of all the children in this community with no services”.

3.2.2. Barriers Telepractice Challenges

While communication with support teams was positively received, many caregivers expressed dissatisfaction with telepractice services. Several caregivers expressed difficulties with telepractice, citing issues such as technology challenges, lack of engagement, and remote delivery being considered inappropriate for their child's needs. One caregiver stated, "But when you do it (ABA) on the computer, it does not work". Another caregiver mentioned, "the tele-health, I felt like it was just a waste of our time. I didn't feel like it was a very good setup for the kids". Some caregivers found the online format overwhelming, with one sharing, "He was getting speech therapy. They tried doing video therapy. We tried that twice, and it was just too overwhelming for him. Too much". A common thread among these quotes was the notion that remote sessions were not effective for their children, as illustrated by a caregiver's remark, "It's really just more the way he's wired. It does not work for him".

Caregivers highlighted the challenges they faced, emphasizing the tiring and difficult nature of therapy sessions. One caregiver expressed exhaustion, stating, "I felt like I really couldn't do much. Literally exhausted after the hour of telemedicine therapy session that they had because it's a lot of work". This sentiment was echoed by others, such as "Doing Zoom classes was horrible for her" and "My son who is autistic is not really into adult-directed activity". The struggle was further emphasized by a caregiver who said, "the video thing . . . doesn't work for him", highlighting the additional burden placed on caregivers during remote sessions.

Unavailable Support

Another prominent theme revolved around the lack of adequate support from providers, including the loss of communication with schools and providers, service disruptions, and a lack of individualized attention. Caregivers expressed frustration at the absence of support, with one saying, "Every service that they could use was closed". Another caregiver noted, "They do not do one-on-one sessions and especially occupational therapy". Additionally, the absence of communication was underscored by a caregiver's surprise at not receiving a check-in call, stating, "Someone would need to call and say, 'How is he doing?' I'm shocked that I didn't get that call". Finally, the loss of therapeutic services was elemental in feeling unsupported among caregivers; a mother stated, "I feel that lack of services has affected every single minute of our day. And I feel like if I had maybe a stronger routine with the services that maybe that would help make it a little bit more tolerable".

Remote Teaching Insufficient

Caregivers reported limited or generic support from schools and a lack of individualized attention or guidance from teachers or experts. A caregiver mentioned, "Limited capacity from the school, so consultative call for half an hour per week", highlighting the insufficient support provided. Another caregiver expressed frustration with remote learning materials, stating, "The school's remote learning is mostly delivered to us as material, and we have to take care of it". These quotes collectively reveal the challenges faced by caregivers in navigating remote teaching, underscoring the need for more personalized and supportive approaches.

3.2.3. Coping Strategies Self-Efficacy

Caregivers discussed personal coping styles unique to being a caregiver of a child with autism. One caregiver acknowledged the challenges of dealing with autism, stating, "I mean, with autism, it's really a lot to deal with period". Despite facing significant upheavals, this caregiver highlighted a coping strategy rooted in self-efficacy, noting, "This big change didn't seem probably as big to us as it would to people that don't deal with these types of upheavals on a daily basis". The resilience of adapting to disruptions and

adjusting to changes reflected a coping mechanism developed through the daily experiences of caregiving a child with autism.

Community Support

Caregivers discussed the importance of prioritizing and managing access to necessary services and support within their community. One caregiver shared how they utilized respite services, illustrating a proactive approach to self-care and support. The caregiver stated, “We get respite services, but I give those hours to my sister for helping when I’m at the grocery store or if I just need some time to myself”. This exemplifies a coping strategy that involves leveraging community support and services to enhance their ability to manage daily tasks and find moments of respite. These coping strategies underscore the resourcefulness and adaptability of caregivers of children with autism, demonstrating how they draw upon both personal resilience and community support to navigate the unique challenges they face.

3.3. Joint Display: Data Converging and Mixing

Data from qualitative and quantitative sources were integrated to deepen the understanding of factors contributing to caregivers’ stress (see Table 5). The strongest predictor for TS was the combined impact of Difficult Child stress sub-score and the Likert-type questions that had the caregivers rate their perception on their child’s level of autonomy and safety (St3 + Difficult Child). The statistical findings were further supported by the information analyzed from the semi-structured interviews. Themes and sub-themes emerged, listing the needs and wishes of caregivers to help them feel more supported and better equipped to respond to their child’s needs. The robust evidence derived from Themes 1 and 2 underscores how the identified parental perception and stress can significantly contribute to the overall parental total stress score.

Table 5. Joint Display: Interplay of Contributing Factors in Stress Domains During the Lockdown.

TS ↔ St3 ↔ DC ↔ PD ↔ Theme 1 ↔ Theme 2
Total Stress Scores correlate with Difficult Child and Parental Distress scores and is highly influenced by caregivers’ confidence in their child’s ability to remain safe if left unattended (St3). Themes from interviews, including wishes, needs, and barriers, shed light on the link between caregiver stress, their perception of their child’s ability to remain safe when unattended, their level of perceived autonomy to entertain themselves while remaining unharmed.
PD ↔ St3 ↔ Theme 1 ↔ Theme 2 ↔ Theme 3
Parental Distress Stress is related to caregivers’ confidence in their child’s ability to remain safe if left unattended (St3). Caregiver confidence and self-efficacy are influenced by their perceptions of their child’s support and supervision needs for safety. Caregivers highlight that access to social support, respite, and coaching can alleviate this stress, but the stay-at-home mandate restricts previously obtained support.
DC ↔ St2 ↔ St3 ↔ St4 ↔ Remote work ↔ Hours of Service lost ↔ Theme 1 ↔ Theme 2
Difficult Child Stress is linked to caregivers’ confidence in their child’s ability to remain safe if left unattended (St3) and perceptions of the child’s independence and ability to entertain themselves (St2). Additional stressors include increased time demands, remote work, and a loss of 5–10 h services for children with autism. Caregivers also faced a reduction in respite time and time for errands, impacting their life balance (St4). Expressing a need for social support, respite, coaching, and relevant instructional materials was associated with dissatisfaction with telepractice implementation and the importance of a higher level of community and social support.
PDCI ↔ St1 ↔ St2 ↔ St3 ↔ Theme 1
Parent Child Dysfunctional Interaction correlates with caregivers’ confidence in their child’s ability to remain safe if left unattended (St3) and their perceptions of the child’s independence and ability to entertain themselves (St2), and the level of support and undivided attention their child needs during the day (St1), respectively. Caregivers expressed a need for additional coaching and targeted instructional materials to respond positively to their children with autism.

Additionally, the Parental Distress (PD) stress score was also directly and strongly related to (St3). These stress scores connected the caregiver's confidence and self-efficacy to how they perceived their child's support and supervision needs to remain safe. While caregivers knew that access to social support, respite, and coaching can mitigate this stress, the stay-at-home mandate has restricted their access to previously obtained support.

Several factors contributed and impacted the Difficult Child (DC) stress subscale which measures parental stress associated with challenging behavior and the perceived difficulty of managing a child with autism. It focuses on aspects of parenting related to the child's temperament and behavior that contribute to the overall stress experienced by the parent. The mix of generated data indicated that the parental perception about their autistic child's autonomy and their ability to independently entertain themselves (St2), played a significant role in impacting their DC scores. Naturally, the increased time demands induced by the need to work remotely, losing the ability to attend to their daily maintenance life tasks (St4) and the loss of services specifically, 5–10 h had a significant impact on the parental DC scores. Additionally, the factors that influenced the DC scores were corroborated by the generated themes and subthemes from the listed needs and barriers extracted from the semi-structured interviews.

Finally, the perception of the caregiver autistic child's autonomy and their ability to independently entertain themselves (St2) had a significant relationship with the Parent-Child Dysfunctional Interaction (P-CDI) stress score which was further communicated and explained by the caregiver responses and expressed need for additional coaching and targeted instructional materials to better respond positively to their children with autism. Finally, as this exploration delved into the primary contributors to elevated stress levels, a deeper understanding emerged through the caregivers' expressions of anxiety and stress in their interview responses. These expressions were clustered into wishes and needs (Theme 1) and barriers (Theme 2) and encompassed desires for social support, respite care, coaching on effective child interaction, and targeted instructional materials, all aimed at addressing gaps in support or inadequate services.

In essence, our study uncovers a complex network of interconnected factors that influenced parental stress amid challenging circumstances. This network, derived from a diverse range of data sources, enhances our understanding of the relationships within our dataset. As such, the alignment of the autistic children's caregiver needs and wishes with explicit barriers and strategies gave a deeper understanding for the final quantitative results on stress levels.

4. Discussion

As part of a broader initiative to explore the parenting experience during the early stages of the stay-at-home mandate in Illinois, this convergent parallel mixed-methods study investigated how parental perceptions, loss of support services, increased time demands, and isolation influenced stress levels among caregivers of young children with autism. Our findings unravel a complex network of interconnected relations, drawing insights from three sources: PSI-4-SF and its subscales, caregiver questionnaires, and semi-structured interviews. TS scores served as the central node in this study's network of variables, with caregivers' responses to questions about their child's autonomy and safety, along with Difficult Child (DC) subscale scores, strongly predicting TS scores. Particularly, concerns about the child's safety and ability to be left unattended were significant factors.

Heightened concerns about injury and the stress of providing constant supervision for autistic children may stem from various factors. By experiencing routine disruptions, fears of illness, and economic uncertainties [9,51,52], caregivers of autistic children may have felt the need to be more hypervigilant to reduce the need to seek medical attention during the pandemic. Also, autistic children frequently engage in risk-taking behaviors which can lead to more frequent and severe injuries. The severity of autism symptoms was found to positively correlate with risk-taking behavior and the frequency of injury [53]. This suggests that prevention and treatment of childhood injury may require more intensive

services and supervision, which were highly reduced during the pandemic and added stressors for the caregivers (e.g., [14,40]). Social distancing measures have led to a rise in challenging behavior among autistic children [1,7], potentially increasing the risk of injury. Injuries, in turn, may necessitate hospitalization, posing a heightened risk of virus exposure for autistic children who are more vulnerable due to frequently occurring co-occurring medical conditions [5,54,55]. Furthermore, adding to caregivers' worries about injuries and safety, specifically the preference to avoid the necessity of medical interventions during the pandemic may have been exacerbated by suboptimal past experiences with healthcare institutions which are traditionally ill-prepared to address their children's unique needs in previous medical crises [56]. This convergence of risk-taking behavior, injury prevalence, and pandemic-related challenges emphasizes the urgent need for targeted interventions and support systems for children with autism and their caregivers, which were voiced as contributing factors to caregiver stress when they expressed their needs and wishes in the semi-structured interviews.

The findings from this study indicated that there is a significant link between caregivers' confidence in the child's ability to remain safe without supervision and TS which emphasizes the stress associated with perceiving a child with autism as difficult to parent (DC). This, in turn, can create a feedback loop where high caregiver stress correlate with increased challenging behaviors [57] which can be exacerbated by loss of support due to stay-at-home mandates, limited opportunities for self-care, and diminished access to social support [14] which can detrimentally affect their effectiveness as caregivers [58].

Surprisingly, our data analysis revealed no significant impact on Total Stress (TS) scores for caregivers whose children lost more than 20 h of service per week due to the stay-at-home mandate. However, a robust and statistically significant association emerged between TS scores and children losing 5–10 h of services weekly during the shutdown. Although this finding is intriguing, we lack sufficient information to pinpoint the significant predictors influencing this variable, further investigation is warranted to explore additional variables that may contribute to this finding such as family dynamics, child characteristics, caregivers' prior knowledge, and access to parental training opportunities.

In grappling with the challenges posed by their child's challenging behavior, the stress scores related to PDCI subscale reflected the caregiver's anxiety about how they perceive their child's ability to have impulse and emotional control, and overall behavior regulation. This correlation aligns with previous research conducted during the COVID-19 pandemic, which identified widespread feelings of helplessness among caregivers of autistic children [40]. Unfortunately, such sentiments can potentially hinder the development of family resilience, which is contingent upon caregivers fostering self-efficacy, positive social interactions, and a general sense of control over their lives, e.g., [59].

Moreover, the well-documented bidirectional relation between caregiver stress and challenging behavior in children with autism [41,42] reinforces our findings. The Difficult Child (DC) subscale emerged as one of the top contributors to parental Total Stress (TS), emphasizing the intricate connections between caregiver stress and perceptions related to their child's challenging behavior. These insights underscore the complex interplay between caregiver stress, perceptions, and the unique challenges faced during the pandemic, as highlighted by the PDCI and DC subscale scores.

Additionally, the insights retrieved from the caregiver questionnaire provide contextual information on how the caregiver's perception of their role as a parent and of their child's independence heavily relates to all stress subscales. A way to enhance this perception is by increasing both the child's and the caregiver's self-efficacy. Caregivers pointedly asked for support, guidance, and coaching on how to respond to their child's needs during the lockdown, which are, incidentally, the main ingredients in building family resilience [20,21]. Caregivers' perception of their role as caregivers and their child's positive development can contribute to building resilience, acting as an antidote to stress [24,25]. To thrive in the face of adversity, families of children with autism require specific skills and support, including the ability to see their child learn and generalize skills in natural

environments [34,35]. Unfortunately, this was not available to the participants in this study. As a result, caregivers listed their need for support, coaching, respite care, and advice on specific topics that pertain to their families and their child's specific needs.

Finally, to prioritize the well-being of children with autism and their families, creating sustainable and practical support initiatives, is essential for systematically building resilience. For instance, respite care, as highlighted by Manning et al. [12] and requested by the caregivers in this study, can positively impact the mental health and well-being of caregivers of children with autism. Considering respite care as an essential service can provide caregivers with the space for self-care and time to manage other life demands [60].

4.1. Limitations

This study acknowledges several notable limitations. While purposive sampling was employed, concerns arose regarding the generalizability of findings due to the restricted sample size and regional focus. Despite utilizing interviews to contextualize self-reported stress responses, the reliance on self-report tools and interviews introduces susceptibility to response and interpretation biases. When individuals self-report on stress levels, various factors, including self-perception, confidence, personal biases, and the accuracy of memory recall, can influence the information provided [61]. To bolster the trustworthiness and credibility of our findings, we incorporated methodological strengths, such as triangulation, member checks [43], and validation through existing research [40].

Additionally, the impact of the lockdown itself imposed limitations on accessing a larger pool of participants. Caregivers faced resource constraints that affected our sampling, as the stay-at-home mandate influenced their capacity to allocate time for participation and their ability to maintain reliable internet connections for video interviews and completing the measures informing our study. The limited sampling in Illinois and other social factors may have influenced the depth of responses [62]. The consequences of stay-at-home mandates during the pandemic might extend beyond its duration, depending on the family's existing characteristics and their levels of financial, social, and emotional support [63]. The increased demand for caregivers' resources and their reduced capacity for self-care activities may adversely affect both their effectiveness as caregivers and their perception of their ability to respond to their child's needs [58].

Furthermore, this study spanned eight weeks during the early stages of the stay-at-home mandate in Illinois, potentially leading to varying perspectives among early and later interviewees. It is important to recognize this temporal constraint and how it may affect the caregivers' responses, particularly acknowledging that people may have experienced job losses and reduced access to healthcare services at a disparate rate based on ethnicity, e.g., [64], and socioeconomic status during that period. This disparity is especially pertinent for historically marginalized groups who, even before the pandemic, faced unequal access to timely diagnoses and interventions [65,66]. The COVID-19 pandemic has exacerbated these existing inequalities, significantly impacting access to healthcare, academic resources, and social services, particularly for these communities [67]. Further research is warranted to comprehensively understand the impact of the pandemic on caregivers of children with autism, specifically those belonging to historically marginalized groups. Apart from geographical and temporal constraints, social factors, including ethnic background, the presence of others during the interview, and the established rapport with the interviewer, could have influenced the extent and depth of participant responses to specific questions [68]. It is important to recognize and acknowledge these influences on this study's outcomes and offer room for future insights to shed light on these influences.

4.2. Implications

To alleviate parental stress, enhance self-efficacy, and foster resilience, comprehensive and innovative approaches are necessary. The findings from our study underscore the importance of proactive measures and continuous support for caregivers of children with autism. In addition to offering actionable insights for immediate support for families

during times of crisis, creating a long-term plan to sustain community-based initiatives, respite care services, and coaching programs can support family resilience and future positive outcomes for the child and their family, e.g., [20,59]. Additionally, establishing more inclusive cultures in medical institutions for patients with diverse communication needs aligns with caregivers' expressed wishes for expanded support. This approach can help build reliable community support systems that cultivate satisfaction and minimize adverse effects on the family [18,32]. Moreover, improving telepractice services [69] and providing tailored online instructional materials [70,71] offer effective and feasible ways to provide parental training and support.

Looking ahead, future research should focus on creating feasible and proactive systems to engage families of young children with autism, where they can foster reliable connections within their communities and where they consistently rely on the support of their services providers and educational. Research, e.g., [69,72,73] shows that using affordable online methods effectively provides training and support to caregivers. Encouraging initiatives that advocate for therapeutic services and educational support providers to plan ahead and adopt targeted and responsive online practices can empower caregivers to acquire sustainable strategies that extend and persist beyond crisis situations.

The challenges and stress contributing factors in this study reveal issues related to availability, appropriateness, accessibility, and sufficiency of support services during the rapid transition to remote delivery. To leverage existing infrastructure, researchers can explore effective virtual training and support methods for caregivers. This includes establishing regular, sustained, and frequent online visits from community members, support service providers and educational institutions to aid them build their sense of self-efficacy and resilience among the caregivers of autistic children. These strategic interventions, based on our findings, are needed not just for relieving immediate stress but also for protecting caregivers from the potential impact of future challenges or disasters.

5. Conclusions

Our study delves into the complex dynamics of stress experienced by caregivers of young children with autism during the early stages of the stay-at-home mandate in Illinois. We employed a convergent parallel mixed-methods approach and identified a multifaceted network of interconnected factors that influence parental stress levels. The factors include parental perceptions, loss of support services, increased time demands, and isolation, with concerns regarding child safety and autonomy emerging as significant predictors of stress. The pandemic's impact on the infrastructure providing interventions and support for families of children with autism emphasizes the necessity for sustained community-based initiatives, respite care services, and coaching programs to bolster family resilience. Additionally, enhancing telepractice services and offering tailored online resources can empower caregivers and extend support beyond crisis situations. Future research should prioritize the development of feasible systems to effectively engage families and leverage virtual platforms for ongoing training and support, with the ultimate goal of safeguarding caregivers and mitigating the adverse effects of future crises on families of children with autism.

Supplementary Materials: The following supporting information can be downloaded at: <https://www.mdpi.com/article/10.3390/disabilities4010010/s1>, File S1: Interview Protocol; File S2: Codebook—Qualitative Analysis; File S3: Pearson Correlation of PSI-4-SF Subscale—Percentiles and Questionnaire Responses; File S4: Multiple Regression Statement 3 (St3) on Total Stress Score; File S5: Multiple Regression of Number of Hours of Services Lost on Total Stress Score.

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