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Habilitative Teletherapy for Children with Autism Spectrum Disorder: A Survey of Parents

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Abstract

Objective: The purpose of this study was to investigate whether service losses during the coronavirus disease 2019 (COVID-19) pandemic were associated with worsened parent mental health or child behavioral health among families of children with autism spectrum disorder and to identify factors associated with favorable parent appraisals of habilitative teletherapy (applied behavior analysis; speech, occupational, physical therapy) for their child.

Method: This web-based survey study was conducted from May to July 2021 with parents whose children were receiving habilitative therapy for autism from an integrated health system. A total of 322 parents responded to the survey (20% response rate). The outcome variables were pandemic-related parent mental health, pandemic-related child behavioral health, and appraisal of habilitative teletherapy. Predictors were COVID-19–related services changes in health care or child care, COVID-19 history (COVID-19 stress, testing positive for COVID-19), and child autism factors (autistic behaviors, caregiving strain).

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Results: Loss of regular child care was associated with higher odds of worsened parent mental health (odds ratio [OR] = 2.7, 95% confidence interval [CI] = 1.5–4.8); higher levels of caregiving strain were associated with worsened child behavioral health (OR = 2.3, 95% CI = 1.4–3.8). Higher levels of COVID-19 stress were associated with more favorable appraisals of telehealth (β = 0.4, p < 0.01), whereas higher caregiving strain scores were associated with less favorable appraisals of telehealth (β = -0.2, p < 0.01).

Conclusion: During COVID-19, caregiving factors were associated with worsened parent mental health and worsened child behavioral health, and telehealth is not preferred by all families. Policy interventions to support caregivers, such as affordable, high-quality child care and paid family leave, are a high priority.

Keywords

autism spectrum disorder; COVID-19; mental health; parents and caregivers; telehealth

The coronavirus disease 2019 (COVID-19) pandemic has presented unique challenges for families that have a child with autism spectrum disorder (autism). Studies suggest that stay-at-home orders, school closures, economic stressors, and social distancing requirements have disrupted usual support services and routines for these families, leading to increased parent stress and changes to child behavioral function. School closures leading to primary loss of in-person education and secondary loss of school as a potential source of child care for parents may be especially detrimental to families of children with autism. There is also emerging evidence that both adults and children with intellectual or developmental disabilities are at elevated risk for COVID-19 and COVID-19 mortality.

Children with autism often require a complex set of health and social services to support their physical and behavioral health, including habilitative therapy (speech, occupational, or physical therapy), applied behavior analysis, special education, case management, health care visit for comorbid neurological or genetic disorders, respite care, and other family support services. Caring for a child with a developmental disability, such as autism, can be a source of significant stress and strain for parents. Studies suggest that parents of children with autism are at elevated risk for depression, anxiety, and other behavioral health disorders. Parent and family mental well-being and support were identified as priorities for autism research because of significant knowledge and intervention gaps before COVID-19.6 Given the risks of COVID-19 to children with autism and pandemic-related disruptions to usual health and social services, there is substantial concern about the impact of the pandemic on parent and child mental health. However, there is limited empirical research on this phenomenon and whether it is driven by service losses or other pandemic stressors.

There has been a proliferation of research on telehealth as a possible strategy to mitigate in-person service losses for children with autism. ⁹⁻¹¹ Before the pandemic, feasibility and potential efficacy of telehealth interventions have been demonstrated for individuals with ASD in several systematic reviews. ^{12,13} A small telehealth occupation—based coaching intervention study conducted before COVID-19 found significant gains in parent efficacy, in various domains of child participation, and in parent-identified goals postintervention. ¹⁴ Similarly, a small mixed methods study conducted in the Philippines found favorable

parent appraisals of teletherapy for children with disabilities during COVID-19.¹⁵ However, intervention studies of telehealth models for autism care during COVID-19 have generally used small pilot samples with limited generalizability or have not been specific to therapies for autism (e.g., telerehabilitation physical therapy).¹⁶⁻¹⁸ There are multiple studies of telehealth focused on screening, assessment, and diagnosis^{9,10,19} but fewer studies that investigate more hands-on therapies such as applied behavior analysis for autism. Although these existing studies have promising results, parent and family views and preferences around a telehealth format for habilitative therapy specific to autism are not well understood, including whether these views can inform the use of telehealth in the future.

In light of these gaps in knowledge about parent mental health during COVID-19 and their views of telehealth, our study leveraged a sample of parents from an autism registry from a large, diverse integrated health system to (1) investigate whether service losses during COVID-19 were associated with worsened parent or child behavioral health during the pandemic and (2) identify factors associated with favorable parent appraisals of habilitative teletherapy (applied behavior analysis, speech therapy, occupational therapy, physical therapy) for their child with autism.

METHODS

Design and Setting

This survey study was conducted in a large integrated health system in Southern California from May to July 2021. We surveyed a sample of parents of children with autism who were members of the integrated health system and whose children were currently receiving habilitative therapy for autism (applied behavior analysis, speech therapy, occupational therapy, or physical therapy) from the health system. The health system contains 15 hospitals and more than 200 clinics across 7 counties in Southern California. This study was approved by the Institutional Review Board at Kaiser Permanente Southern California.

Sample

We randomly selected 2000 children who had a diagnosis of autism from the health system autism registry and contacted their parents. Parents were eligible to participate in the survey if they had at least 1 child with a diagnosis of autism and at least 1 autism-related therapy referral (behavioral therapy, speech therapy, occupational therapy, physical therapy) in 2020. Three hundred seventy-six parents were ineligible for the survey because they did not meet the above inclusion criteria for current habilitative therapy. There were 1624 eligible parents who were contacted about the survey with a baseline letter and e-mail. Assuming 95% confidence and a 5% margin of error, the minimum sample size needed to reflect this population in a survey was 311 participants.²⁰ Then, parents received phone, text, or e-mail reminders about the survey twice after the baseline contact. All parents provided informed consent to participate in the study, and parents who had more than 1 child with autism had the option to complete the survey for each child. Surveys were only available in English. A \$30 cheque was offered to parents as a survey incentive.

Measures

Outcomes—The primary outcome variables were pandemic-related parent mental health, pandemic-related child behavioral health, and parent appraisal of telehealth therapy.

Pandemic-Related Parent Mental Health and Child Behavioral Health—Parents responded to 2 global pandemic-related behavioral health assessment questions for themselves and their child with autism: "Since the start of the COVID-19 pandemic, has the behavioral health of your child with autism spectrum disorder gotten: better, worse, or stayed the same? Has your own mental health gotten: better, worse, or stayed the same?" Responses of "better" and "stayed the same" were collapsed into a single response category for both items for a binary variable of "worse" versus "better/same" indicators of parent mental health and child behavioral health. We used the term "behavioral health" for children and "mental health" for parents because of the behavioral nature of autism and associated symptoms.

Telehealth Appraisal—A 7-item measure of parent appraisals of telehealth for their child (Table 1) was developed for this survey, with items rated on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree). One item was reverse coded. Items were averaged for a total score range of 1 to 5, with higher scores denoting more favorable appraisals of telehealth. The internal consistency reliability for this measure was high in our sample (Cronbach's alpha = 0.90, 95% confidence interval = 0.88–0.92). Parents also reported on whether their child had received any of the following therapies (yes/no) in telehealth format: applied behavior analysis, speech therapy, occupational therapy, and psychotherapy. Parents who responded "yes" were then asked to rate whether a telehealth format was better, worse, or the same compared with an in-person format.

Predictors—The primary predictor was COVID-19–related service losses. We also examined child autistic behavior and associated symptoms, parent COVID-19 stress, and demographic covariates.

COVID-19 Service Changes—Parents reported whether their child with autism had any lost or delayed health care because of the pandemic. Parents could select one or more of the following health care types: well-child health visits or vaccine, sick or chronic condition visits, specialist visits, surgery/procedures/diagnostics, therapy (behavioral, speech, occupational, physical), mental health, or other. We also assessed loss or cancellation of regular child care (yes/no).

Child Autistic Behavior—The Autism Behavior Inventory-Short Form (ABI-S) was used to assess 5 domains of core autistic behaviors and associated symptoms (social communication, restrictive behaviors, mood and anxiety, self-regulation, challenging behavior).²¹ The ABI-S contains 36 items assessing the frequency of symptoms or quality (e.g., independence) of behaviors and is completed by parents or caregivers. Items used 4-point Likert scales for frequency (0 = never, 3 = very often) and quality (e.g., independence; 0 = not at all, 3 = without help) of symptoms/behaviors. We examined overall ABI-S scores by averaging all items, with possible scores ranging from 0 to 3 and with higher scores

denoting more autistic behaviors/associated symptoms. In addition, we examined caregiving strain related to caring for a child with autism using the Caregiver Strain Questionnaire, a 21-item measure of strain experienced by caregivers of youth with emotional problems.²² Items were reported on 5-point Likert scales (1 = not at all, 5 = very much) and averaged for a total score range of 1 to 5 with higher scores denoting more caregiving strain.

COVID-19 History—Parents reported whether they or their child with autism had ever tested positive for COVID-19 (yes/no). We also measured COVID-19—related stress with the COVID Stress Scale (CSS), a 36-item measure of 5 domains of COVID-19—related stress (danger and contamination fears, fears about economic consequences, xenophobia, compulsive checking and reassurance seeking, traumatic stress symptoms).²³ Items were reported on 4-point Likert scales (1 = not at all, 4 = extremely) and averaged for a total score range of 1 to 4 with higher scores denoting more COVID-19—related stress.

Covariates—We examined sex (boy, girl, other), child age (2–4 years, 5–7 years, 8–12 years, 13–17 years), race/ethnicity (White, Black/African-American, Hispanic/Latinx, Asian, Other), insurance type (Commercial, Medi-Cal, other), whether the child had siblings with autism (yes/no), parent marital status (married/partnered, unpartnered), and parent employment status (employed full-time/parttime, other). Pandemic-related covariates included history of COVID-19 infection by parent or child, child behavioral health, and parent mental health. We also measured parent depression risk with the 8-item version of the Patient Health Questionnaire. Items used 0 to 3 Likert scales (0 = not at all, 1 = several days, 2 = more than half the days, 3 = nearly every day) to measure the frequency of depressive symptoms; scores of 10 or greater were considered probable depression.

Analysis—Descriptive statistics were used to characterize the sample on demographic variables. We used χ^2 tests to compare survey responders versus nonresponders on demographic characteristics (child age, sex, race/ethnicity, insurance type) and to compare favorable versus unfavorable appraisals of telehealth by demographic characteristics. Multiple logistic regression models were used to examine whether service losses (health care, child care), child autism factors (Autism Behavior Inventory-Short Form score, Caregiver Strain Questionnaire score), or COVID-19 history (COVID-19 stress, COVID-19 infection) were associated with worsened pandemic-related child behavioral health and parent mental health in separate models. Then, we used multiple linear regression modeling to identify correlates of favorable parent appraisals of telehealth using the same set of predictor variables. All models were adjusted for demographic covariates (child sex, age, race/ethnicity, parent employment, parent marital status, parent depression, and whether the household had more than 1 child with autism).

RESULTS

Sample Description

A total of 322 parents responded to the survey (20% response rate). The sample was predominantly parents of boys with autism (n = 272, 84.5%) (Table 1), and there was slight over-representation of boys among survey responders (84.5%/N = 272 of responders

compared with 75.9%/N = 1035 of nonresponders, p = 0.031). No other significant demographic differences between survey responders and nonresponders were observed. The sample was 40.4% (n = 130) parents who identified their child's race/ethnicity as Hispanic, 22.7% (n = 73) White, and 16.5% (n = 53) Asian. Approximately one-quarter of families (24.2%, n = 78) reported having more than 1 child with autism. Most responding parents were married or partnered (92.9%, n = 267) and employed full-time or part-time (76.7%, n = 247).

Fifteen percent of parents (n = 49) reported a history of testing positive for COVID-19; 6% of parents (n = 20) reported that their child with autism had a history of testing positive for COVID-19. Service losses or delays were common, with 54.3% of the sample (n = 175) reporting loss of regular child care and 48.4% of the sample (n = 156) reporting loss or delay of at least 1 health-related service for their child (Fig. 1).

Parent/Child Behavioral Health

In adjusted models, loss or delays of health care were not associated with worsened parent mental health or child behavioral health (Table 2), nor were parent or child history of testing positive for COVID-19. However, loss of regular child care was associated with higher odds of worsened parent mental health (odds ratio [OR] = 2.7, 95% confidence interval [CI] = 1.5–4.8). There was also an association between higher caregiving strain scores and worsened child behavioral health (OR = 2.3, 95% CI = 1.4–3.8).

Appraisal of Telehealth Therapy

Parents of older children, Asian children, and with more than 1 child with autism generally had more favorable appraisals of telehealth compared with others, although telehealth receipt overall was relatively low (Supplemental Digital Content 1, http://links.lww.com/ JDBP/A365). In adjusted models examining telehealth appraisal scores (Table 3), higher caregiving strain scores were associated with less favorable appraisals of telehealth (β = -0.2, p < 0.01). Higher levels of COVID-19 stress were associated with more favorable appraisals of telehealth (β = 0.4, p < 0.01). Parent and child history of testing positive for COVID-19 were not significantly associated with telehealth appraisal scores. Among parents who reported their child had received a habilitative therapy through telehealth, most of the parents felt that telehealth was worse for their family compared with an in-person format (Supplemental Digital Content 1 and 2, http://links.lww.com/JDBP/A365, and http://links.lww.com/JDBP/A366).

DISCUSSION

This survey of parents with children with autism found that caregiving factors had an association with worsened parent mental health and child behavioral health during COVID-19, whereas service losses and even testing positive for COVID-19 did not. Loss of regular child care was associated with worsened parent mental health, whereas higher levels of caregiving strain among parents was associated with worsened child behavioral health. This relationship may be bidirectional. Parents who chose telehealth for their child's therapy during the pandemic generally perceived this format to be worse for their child

compared with an in-person format, although there was an association between higher levels of COVID-19 stress and more favorable appraisals of telehealth. We also observed some demographic differences in telehealth appraisal, for which parents of older children, Asian children, and families with more than 1 child with autism had more favorable appraisals of telehealth. Age-related differences may have been because of a greater potential ability for older children to participate in therapy independently, whereas telehealth may have been a more convenient modality for parents who had more than 1 child with autism and thus multiple appointments or sessions. Our findings related to race/ethnicity align with a recent study during COVID-19 suggesting demographic differences in preferences for telehealth.²⁵ Younger age, higher income, and higher educational attainment were associated with a preference for telehealth, whereas identification of one's race/ethnicity as Black/African-American or Hispanic/Latino was associated with a preference for in-person care. This study did not disaggregate results for individuals who identified as Asian, so findings cannot be compared directly, but other demographic factors (e.g., younger age, higher income, higher educational attainment) associated with a preference for telehealth may be present among Asian families in our study.²⁵

These findings suggest that reliable child care, inside or outside of school systems, and caregiver support are a high priority for families who have a child with autism as we move forward from the COVID-19 pandemic and consider new models of health care, such as telehealth. Previous studies have demonstrated that disruptive behavior, oppositionality, and hyperactivity among children with autism are associated with higher levels of caregiving strain. ²⁶ In the context of COVID-19, our study, too, found that caregiving strain was associated with reports of worsened child behavior. Given this association, it is unsurprising that loss of child care was significantly associated with worsened parent mental health. Child care is an essential service for many families with a child with autism, but up to 60% of parents report unmet child care needs. ²⁷ These families report that child care access has a strong effect on their employment decisions and that high-quality child care is a major concern and source of stress for parents. ²⁸

Parents have cited challenges with finances, a lack of respite from responsibilities, inadequate rest or sleep, trouble remaining hopeful about the future, and a lack of information about support resources as contributors to stress associated with autism care.²⁹ Health care organizations should prioritize caregivers' mental health needs because they are essential players in the success of their child's therapy. They may also consider strategies such as care management or peer support groups to address autism-related stressors. Care management has been implemented across different populations and different specialties, and a growing body of research supports the use of this evidence-based intervention to lower distress levels in caregivers experiencing life-changing diagnoses by providing families with an advocate.³⁰ Similarly, there is early evidence of benefit for parents of a child with autism from peer support groups.³¹ Although health care systems have opportunity to improve individual-level and family-level support services for parents, gaps in child care and caregiving strain may ultimately require policy intervention. The primary federal legislation support autism services and research is the newly reauthorized Autism Collaboration, Accountability, Research, Education, and Support Act of 2019.³² This legislation mentions caregiver mental health as an area of need but does not specifically address child care or

caregiving strain. Recent federal policy proposals for paid parental leave, child care support, and permanent establishment of child tax credits are important policy changes that could support the needs of this population of families.³³

Telehealth has been widely discussed as a promising innovation in delivery of health care, especially mental health care, arising from the COVID-19 pandemic. ¹⁰ There have been several recent studies of telehealth and digital approaches to autism care that are similarly optimistic about this approach for families with autistic children. ^{16,17} However, because evidence about telehealth for this population is still emerging, ¹⁹ caution should be used before fully implementing telehealth models of care. The few existing studies of telehealth models for autism care have small pilot samples that limit generalizability and limited representation of families of color. ^{16,17} Our study of predominantly non-White families who used telehealth suggested that telehealth was not a preferred modality for delivery of autism therapy, although parents with high levels of COVID-19 stress had more favorable appraisals of telehealth, which is likely because of concerns about safety. Availability of the required technology for telehealth and digital literacy may be barriers to accessing health care virtually, particularly among economically disadvantaged populations. In California, expansion of telehealth laws and reimbursement policies has made this evidence-based delivery model increasingly possible. 10,16 As such, additional research is needed to understand which aspects of autism care can be successfully delivered through telehealth (e.g., screening and diagnosis) and which families can benefit from this modality, while retaining in-person and hybrid models of care for families who prefer for their child to receive therapy in-person.

Strengths

There are strengths and limitations to consider in interpreting the findings of this study. We used a representative, random sample of a population of families with a child with autism in Southern California. The sample was racially/ethnically diverse, which is an important strength of this study given that much prior research on autism has used majority White samples with limited representation of racial/ethnic minority groups whose perspectives and experiences may differ. Our survey response rate was adequate, and we had multiple measures of pandemic variables (e.g., COVID-19 history, COVID-19 stress) to understand the unique impact of COVID-19.

Limitations

Limitations of this study were under-representation of girls with autism, use of a cross-sectional sample from a single institution, and relying on parent-reported data. Parents may have been subject to reporting bias based on their pandemic experiences and their child's past experiences with therapy, including length of time in therapy, which was not assessed. The survey was only available in English, and families who did not speak English as a primary language may have opted not to participate. Although our sample was representative of the population demographically, it is possible that parents with negative pandemic experiences or child telehealth experiences may have been more motivated to respond to the survey. Alternatively, parents who were frequent engagers with autism services/resources

and receiving therapy through the health care system may have been more willing to respond to a survey, potentially missing families who were even more stressed.^{34,35}

We did not have detailed measures of school experiences during COVID-19 nor school-based or community-based services families may have been receiving virtually outside of the health system, including virtual services received in the past. Parents of children with autism may see school as a source of child care, and thus, responses of loss of child care may be conflated with school closures during the pandemic. There is a need for future studies to identify strategies for recruiting families of girls with autism and other under-represented demographic groups in survey research and research generally.³⁶

CONCLUSION

During COVID-19, caregiving factors (caregiving strain, loss of child care) were associated with worsened parent mental health and child behavioral health among families with a child with autism. Although telehealth is a promising service delivery model for behavioral health, our survey with a racially diverse sample of families in Southern California suggested that telehealth is not preferred for receiving therapy for autism. Policy interventions to support caregivers, such as affordable, high-quality child care and paid family leave, are a high priority in the aftermath of COVID-19. Such policies are likely to have outsized benefit to families of children with autism because caregiving and child care are core needs that local health care and social service systems are not equipped to provide comprehensively. Similarly, because health systems and providers consider the promise of telehealth for delivery of behavioral health care in the aftermath of COVID-19, it is important to ensure that the option for in-person therapy is retained and that the needs and preferences of diverse families for autism services are explored further in research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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The authors are grateful to the parents and families who shared their personal experience of COVID-19 for this survey. The authors use person-centered language to describe autism spectrum disorder in this paper because this is the standard in the scientific and clinical literature. However, the authors acknowledge that such language is not preferred by all individuals in the disability community and that there is heterogeneity in how individuals with autistic traits and their families prefer to identify themselves. Clinicians should always refer to patients with the language the patient prefers.

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REFERENCES

- 1. Vasa RA, Singh V, Holingue C, et al. Psychiatric problems during the COVID-19 pandemic in children with autism spectrum disorder. Autism Res. 2021;14:2113–2119. [PubMed: 34231323]
- 2. White SW, Scahill L, Klin A, et al. Educational placements and service use patterns of individuals with autism spectrum disorders. J Autism Dev Disord. 2007;37:1403–1412. [PubMed: 17082975]
- Turk MA, Landes SD, Formica MK, et al. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. Disabil Health J. 2020;13:100942. [PubMed: 32473875]

4. Becerra TA, Massolo ML, Yau VM, et al. A survey of parents with children on the autism spectrum: experience with services and treatments. Perm J. 2017;21:16–25.

- Schnabel A, Youssef GJ, Hallford DJ, et al. Psychopathology in parents of children with autism spectrum disorder: a systematic review and meta-analysis of prevalence. Autism. 2020;24:26–40. [PubMed: 31070044]
- Clark M, Adams D. Listening to parents to understand their priorities for autism research. PLoS One. 2020;15:e0237376. [PubMed: 32790720]
- Kalb LG, Badillo-Goicoechea E, Holingue C, et al. Psychological distress among caregivers raising a child with autism spectrum disorder during the COVID-19 pandemic. Autism Res. 2021;14: 2183–2188. [PubMed: 34363330]
- 8. Nadler C, Godwin DL, Dempsey J, et al. Autism and access to care during the COVID-19 crisis. J Dev Behav Pediatr. 2021;42:73–75. [PubMed: 33229969]
- Dow D, Holbrook A, Toolan C, et al. The brief observation of symptoms of autism (BOSA): development of a new adapted assessment measure for remote telehealth administration through COVID-19 and beyond. J Autism Dev Disord. 2021;16:1–2.
- Dahiya AV, McDonnell C, DeLucia E, et al. A systematic review of remote telehealth assessments for early signs of autism spectrum disorder: video and mobile applications. Pract Innov. 2020;5:150–164.
- 11. Keder RD, Mittal S, Stringer K, et al. Society for developmental and behavioral pediatrics position statement on telehealth. J Dev Behav Pediatr. 2022;43:55–59. [PubMed: 34855691]
- 12. Sutherland R, Trembath D, Roberts J. Telehealth and autism: a systematic search and review of the literature. Int J Speech Lang Pathol. 2018;20:324–336. [PubMed: 29709201]
- 13. Knutsen J, Wolfe A, Burke BL, et al. A systematic review of telemedicine in autism spectrum disorders. Rev J Autism Dev Disord. 2016;3:330–344.
- 14. Little LM, Wallisch A, Pope E, et al. Acceptability and cost comparison of a telehealth intervention for families of children with autism. Infants Young Child. 2018;31:275–286.
- 15. Eguia K. Teletherapy for children with developmental disorders during the COVID-19 pandemic in the Philippines: a mixed-methods evaluation from the perspectives of parents and therapists. Child Care Heal Dev. 2022;12.
- 16. Wallisch A, Little L, Pope E, et al. Parent perspectives of an occupational therapy telehealth intervention. Int J Telerehabilitation. 2019;11:15.
- 17. Vismara LA, McCormick C, Young GS, et al. Preliminary findings of a telehealth approach to parent training in autism. J Autism Dev Disord. 2013;43:2953–2969. [PubMed: 23677382]
- 18. Alonazi A. Effectiveness and acceptability of telerehabilitation in physical therapy during COVID-19 in children: findings of a systematic review. Child. 2021;8:1101.
- Gibbs V, Cai RY, Aldridge F, et al. Autism assessment via telehealth during the Covid 19 pandemic: experiences and perspectives of autistic adults, parents/carers and clinicians. Res Autism Spectr Disord. 2021;88:101859. [PubMed: 34512797]
- 20. Fox N, Hunn A, Mathers N. Sampling and Sample Size Calculation. 2007. Available at: www.rds-yh.nihr.ac.uk. Accessed March 1, 2022.
- Bangerter A, Ness S, Aman M, et al. Autism behavior inventory: a novel tool for assessing core and associated symptoms of autism spectrum disorder. J Child Adolesc Psychopharmacol. 2017;27:814–822. [PubMed: 28498053]
- 22. Brannan AM, Heflinger CA, Bickman L. The caregiver strain questionnaire: measuring the impact on the family of living with a child with serious emotional disturbance. J Emot Behav Disord. 2016;5:212–222.
- 23. Taylor S, Landry CA, Paluszek MM, et al. Development and initial validation of the COVID stress scales. J Anxiety Disord. 2020;72:102232. [PubMed: 32408047]
- 24. Kroenke K, Strine TW, Spitzer RL, et al. The PHQ-8 as a measure of current depression in the general population. J Affect Disord. 2009; 114:163–173. [PubMed: 18752852]
- 25. Predmore ZS, Roth E, Breslau J, et al. Assessment of patient preferences for telehealth in post—COVID-19 pandemic health care. JAMA Netw Open. 2021;4:e2136405. [PubMed: 34851400]

26. Bradshaw J, Gillespie S, McCracken C, et al. Predictors of caregiver strain for parents of children with autism spectrum disorder. J Autism Dev Disord. 2021;51:3039–3049. [PubMed: 33151499]

- 27. Hodgetts S, Zwaigenbaum L, Nicholas D. Profile and predictors of service needs for families of children with autism spectrum disorders. Autism. 2015;19:673–683. [PubMed: 25073749]
- 28. Mereoiu M, Bland C, Dobbins N, et al. Exploring perspectives on child care with families of children with autism. Early Child Res Pract. 2015;17:13.
- 29. Kiami SR, Goodgold S. Support needs and coping strategies as predictors of stress level among mothers of children with autism spectrum disorder. Autism Res Treat. 2017:1–10.
- 30. Golfenshtein N, Srulovici E, Medoff-Cooper B. Investigating parenting stress across pediatric health conditions—a systematic review. Compr Child Adolesc Nurs. 2015;39:41–79.
- 31. Clifford T, Minnes P. Logging on: evaluating an online support group for parents of children with autism spectrum disorders. J Autism Dev Disord. 2012;43:1662–1675.
- 32. Interagency Autism Coordinating Committee. Autism Collaboration, Accountability, Research, Education, and Support Act of 2019. US Department of Health and Human Services. 2019. Available at: https://iacc.hhs.gov/about-iacc/legislation/autism/cares-act-2019/. Accessed December 8, 2021.
- DeLauro RL. Why we need a permanent expanded and improved child tax credit. Acad Pediatr. 2021;21:S90–S91. [PubMed: 34740433]
- 34. Saberi P. Research in the time of Coronavirus: continuing ongoing studies in the midst of the COVID-19 pandemic. AIDS Behav. 2020; 24:2232–2235. [PubMed: 32303924]
- 35. Cardel MI, Manasse S, Krukowski RA, et al. COVID-19 impacts mental health outcomes and ability/desire to participate in research among current research participants. Obesity. 2020; 28:2272–2281. [PubMed: 32845582]
- 36. Mademtzi M, Singh P, Shic F, et al. Challenges of females with autism: a parental perspective. J Autism Dev Disord. 2018;48: 1301–1310. [PubMed: 29022174]

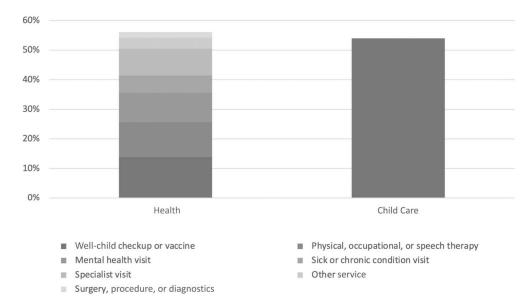


Figure 1. Service losses: Cancellations or delays of child care and health care during COVID-19 among children with autism. Parent report of service cancellations/delays for their child with autism during COVID-19 (N=322) in a survey conducted from May to July 2021. Parents could select any items that applied to their child; gradient bars represent the specific health care services parents reported being cancelled/delayed.

Table 1.

Sample Description

	n (%)
Sex	322 (100%)
Boy	272 (84.5%)
Girl	48 (14.9%)
Other	2 (0.6%)
Age	
2–4 yr	86 (26.7%)
5–7 yr	110 (34.2%)
8–12 yr	78 (24.2%)
13–17 yr	47 (14.6%)
Race/ethnicity	
White	73 (22.7%)
Black	25 (7.8%)
Hispanic	130 (40.4%)
Asian	53 (16.5%)
Other	44 (13.7%)
Insurance type	
Commercial	181 (56.2%)
Medicaid	98 (30.4%)
Both	17 (5.3%)
Other	26 (8.1%)
Sibling with autism	78 (24.2%)
Parent married or partnered	267 (82.9%)
Parent employed full-time or part-time	247 (76.7%)
History of COVID-19 (parent)	49 (15.2%)
History of COVID-19 (child)	20 (6.2%)
Parent depression (PHQ-9 10)	61 (18.9%)
Child pandemic behavioral health	
Better/same	165 (51.2%)
Worse	157 (48.8%)
Parent pandemic mental health	
Better/same	154 (47.8%)
Worse	168 (52.2%)

Sample demographic characteristics from a survey of parents of children with autism spectrum disorder (N = 322) conducted from May to July 2021. PHQ-9, Patient Health Questionnaire (9-item version).

Table 2.

Association Between Service Losses, Child Autistic Behavior, COVID-19 History, and Worsened Parent Mental Health or Child Behavioral Health During the COVID-19 Pandemic

	Worsened Child Behavioral Health	Worsened Parent Mental Health	
Predictors	aOR (95% CI)	aOR (95% CI)	
Child care loss	1.15 (0.67–2.00)	2.67 (1.5–4.76)	
Health care loss	1.45 (0.86–2.44)	0.91 (0.53-1.57)	
ABI-S score	1.49 (0.49-4.56)	2.41 (0.8–7.28)	
CGSQ score	2.3 (1.39–3.80)	1.26 (0.82–1.92)	
COVID Stress score	0.98 (0.91-1.06)	1.04 (0.96–1.12)	
Parent had COVID-19	1.59 (0.67–3.81)	0.24 (0.09-0.67)	
Child had COVID-19	0.38 (0.11–1.36)	2.44 (0.65–9.13)	

Two multivariate logistic regression models estimating odds of worsened parent mental health and child behavioral health. Higher COVID Stress scores represent more COVID-related stress. Models are adjusted for child sex, age, race/ethnicity, parent employment, parent marital status, parent depression, and whether the household had more than 1 child with autism. ABI-S, Autism Behavior Inventory-Short Form (higher scores represent more autistic behaviors/symptoms); aOR, adjusted odds ratio; CGSQ, Caregiver Strain Questionnaire (higher scores represent more strain in caring for a child with behavioral/emotional disorder); CI, confidence interval.

Table 3.

Association Between Service Losses, Child Autistic Behavior, COVID-19 History, and Telehealth Appraisal Scores During the COVID-19 Pandemic

Predictor	β	SE	p
Child care loss	-0.15	0.13	0.249
Health care loss	0.02	0.12	0.873
ABI score	0.12	0.22	0.585
CGSQ score	-0.23	0.08	0.004
COVID Stress score	0.44	0.10	< 0.001
Parent had COVID-19	0.10	0.21	0.634
Child had COVID-19	0.03	0.28	0.929

Multiple linear regression model predicting telehealth appraisal scores (score range 1-5, higher scores represent more favorable appraisal) with a sample of parents of children with autism spectrum disorder (N=322). This model is adjusted for child age, sex, race/ethnicity, parent employment status, parent marital status, parent depression, and whether the household had more than 1 child with autism. Higher COVID Stress scores represent more COVID-19–related stress. ABI-S, Autism Behavior Inventory-Short Form (higher scores represent more autistic behaviors/symptoms); CGSQ, Caregiver Strain Questionnaire (higher scores represent more strain in caring for a child with behavioral/emotional disorder); SE, standard error.