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RESEARCH ARTICLE

Analysis of the SPARK study COVID-19 parent survey: Early impact of the pandemic on access to services, child/parent mental health, and benefits of online services

Anjana Bhat^{1,2,3} 💿

¹Department of Physical Therapy, University of Delaware, Newark, Delaware, USA ²Biomechanics & Movement Science Program,

University of Delaware, Newark, Delaware, USA

³Department of Psychological & Brain Sciences, University of Delaware, Newark, Delaware, USA

Correspondence

Anjana Bhat PT, PhD, Associate Professor in Physical Therapy, University of Delaware, Newark, DE 19713. Email: abhat@udel.edu

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Abstract

Children with ASD receive a multitude of educational, medical, and therapeutic services. At the onset of the COVID-19 pandemic, all of these services came to a complete halt following strict lockdowns. Many services have resumed in a hybrid format using face to face and virtual modes of delivery. This study describes findings from the COVID-19 impact survey administered at the onset of the pandemic in a subgroup of families from the SPARK cohort (N = 6393), one of the largest ASD cohorts in the US. The differential early impact of COVID-19 on various subgroups of children with ASD and their families was examined. Caregivers of children and adolescents with ASD between 19 months and 18 years completed an online survey inquiring about the impact of COVID-19 pandemic on access to services, parent concerns about the same, impact on child's ASD-related behaviors, child, and parent mental health, and the benefits/potential benefits of online/ future online services. Analysis revealed that certain demographic (age, income/ SES) and child-related factors (repetitive behaviors, language, functional, cognitive, and motor impairments, and child's understanding), as well as parent's past mental health were associated with/predicted greater service disruptions, greater ASD-related behaviors, and greater negative impact on parent mental health. In conclusion, younger children, children from low-income families, and children with greater impairment severity (more severe repetitive behaviors, language, cognitive, function, language, and motor impairments) were more negatively impacted by the pandemic through service disruptions, increased ASD-related behaviors, parent health/family impact, and found online interactions to be less beneficial.

Lay Summary

The SPARK study impact survey shows that at the onset of the COVID-19 pandemic, parents reported significant service disruptions, negative impact on their child's ASD-related behaviors as well as their own mental health; which was greater in families with younger children, children with greater ASD severity, and children from low-income families. Majority of families did not report significant benefits of online services whereas some families did. Low-income families were hopeful about receiving benefits through future online services. Overall, these findings have important implications for future clinical care delivery and healthcare policies to ensure that healthcare services are not interrupted during a potential resurgence of COVID-19 or other pandemics. A combination of inperson and online healthcare and family support services must be implemented to prevent negative health impacts in the future.

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KEYWORDS

ASD services, Autism Spectrum disorder, child health, COVID-19, online service benefits, parent health, unmet needs

INTRODUCTION

The COVID-19 pandemic has created a social, economic, and public health crisis within the US and throughout the world. In the first several months, parts of the US experienced statewide lockdowns and school, clinic, and workplace shutdowns that suddenly took away the health service and social support systems from parents and families caring for children with autism spectrum disorder (ASD). The school and clinical service shutdowns led to significant loss of services for children with various disabilities including those with ASD. In the subsequent months, Centers for Disease Control and Prevention outlined various best practices to resume social interactions in alternative formats (e.g., online videoconferencing/ telehealth) as well as limited social interactions along with precautionary measures to prevent virus transmission (e.g., mask wearing, social distancing, hand washing, and sanitizing surfaces and touchpoints) (Centers for Disease Prevention, 2020). These alternative methods of social interaction require all individuals including children with ASD to engage in remote/virtual interactions, resulting in reduced direct human contact, and led to drastic changes to daily routines due to restrictions on travel and socialization. These changes to our natural experiences have resulted in negative mental and physical health consequences especially, in families and children with disabilities including children with ASD and their caregivers (Ameis et al., 2020; Colizzi et al., 2020; Spinelli et al., 2020).

The Simons Foundation Powering Autism Research for Knowledge (SPARK) study is one of the largest studies following the development of children and adults with ASD in the US (Feliciano et al., 2018). In mid-March to early April 2020, the SPARK research team completed an online COVID impact survey of families having a child with ASD as well as independent adults with ASD. The survey findings from dependent and independent adults with ASD have been reported by Bal et al., 2021. General findings from the survey in children and adults with ASD have been reported by White et al. (2021). Parental stress measures have been briefly reported recently by Kalb et al. (2021). The goal of the present study was to examine the differential early impact of COVID-19 on subgroups of children with ASD based on various demographic (age, sex, geographic location, etc.), child-related (social communication, language, cognitive, functional, and motor impairments as well as repetitive behavior severity), and parent-related (i.e., parent's past mental health) factors.

The complex, multisystem nature of ASD along with its co-occurring comorbidities requires children with

ASD to access various medical, therapeutic, and mental health services (American Psychiatric Association, 2013; Bhat, 2020, 2021; Bhat et al., 2011, 2018; Shield et al., 2017; van Etten et al., 2017). Children with ASD utilize substantially more healthcare and therapeutic services compared to children with other disabilities or no disabilities. They accessed more physician visits each year for preventive, nonemergency, and emergency care (90%) vs. 12%), utilized more physical, occupational, or speech therapy services (76.0% vs. 6.3%) compared to children without ASD (Gurney et al., 2006). They also received more counseling (75.4% vs. 7.0%) and prescription medications (51.4% vs. 14.5%) for their emotional, developmental, or behavioral problems (Gurney et al., 2006). However, patterns of service utilization by families having a child(ren) with ASD may vary based on demographic, child- or parent-related factors. For example, demographic factors such as race/ethnicity, socioeconomic status (SES), insurance status, and geographic location may hinder their ability to gain knowledge about or utilize certain services (Liptak et al., 2008; Monz et al., 2019; Thomas et al., 2007). On the other hand, certain child-related factors such as ASD/impairment severity (e.g., greater impairments in the social, language, behavioral, or motor domains) or age (e.g., younger children) may be related to greater service needs (Green et al., 2006; Srinivasan, Ekbladh, et al., 2021; White et al., 2006). Taken together, different child and family characteristics will influence service utilization by families of children with ASD.

The caregiving responsibilities for children with ASD are substantially higher compared to children with other disabilities or no disabilities leading to greater parental stress, marital conflicts, and further negative impact on family/sibling dynamics (Schieve et al., 2012; Brown, Ouellette-Kuntz, Hunter, & Kelley, 2010; Brown et al., 2012). More severe impairment is associated with greater parental stress and negative impact on family dynamics (Abbeduto et al., 2004; Bromley et al., 2004). Parent-related factors such as parent's past mental health, their personality, their optimism, and their coping abilities play a significant role in dealing with caregiving stresses (Twoy et al., 2007, Ingersoll & Hambrick, 2011; Baker et al., 2011; Estes et al., 2009). Demographic factors such as minority status and SES or available social support networks (i.e., informal and professional childcare and respite support) also play a significant role in adding or reducing caregiving stresses (Farmer et al., 2004; Bromley et al., 2004; Vasipoulou & Nisbet, 2016; Galpin et al., 2017).

It is important to examine parents' perceived unmet needs for health and therapeutic services because they are often charged with the coordination of services for their children and can accurately report the actual barriers to accessing services (Brown et al., 2010). Addressing unmet needs will provide greater assistance to families in hopes of reducing some of their emotional stresses (Bromley et al., 2004). Parents of children with ASD generally express the need for more information on available services, strategies to use with their children, and help coordinating multiple services (Cassidy et al., 2008; Ellis et al., 2002; Krauss et al., 2003; Monz et al., 2019). Compared to parents of children with other disabilities, parents of children with ASD express many more unmet needs, dissatisfaction with services received, and delayed access to services (Kogan et al., 2008). Among demographic factors, belonging to minorities or lower SES were more associated with unmet needs (Farmer et al., 2004; Kogan et al., 2008). Among child-related factors ASD severity, specifically, greater negative behaviors, lower language, functional, and motor abilities were associated with greater perceived unmet needs (Palisano et al., 2010; Douma et al., 2006; Srinivasan et al., 2021).

At the outset of the COVID-19 pandemic, stringent statewide lockdowns of schools, hospitals, clinics, and workplaces took away various healthcare/therapeutic services and social supports for families having children with ASD, leading to increased caregiving burden on families. Initial studies in smaller groups of children with disabilities reported a substantial lack of access to basic educational and therapeutic services with 43%-60% of children losing educational access, 63%-70% losing access to therapeutic services (i.e., physical therapy [PT], occupational therapy [OT], and speech therapy), 53%-73% losing access to behavioral/psychiatric services (i.e., applied behavioral analysis [ABA] therapy, social skills, counseling, psychiatry), and 87%-89% losing access to recreational services that promote physical activity and social connections (Jeste et al., 2020). In Spring 2020, families faced significant challenges due to substantial loss of services, alterations in methods of offering services (telehealth vs. face to face), parents having to play an active role in their child's virtual therapy/ schooling without much support, stresses related to working from home, unemployment, or caring for multiple children. Together, these challenges may have further affected children's and parent's emotional and mental health outcomes (Bellomo et al., 2020; Chen et al., 2020; Kalb et al., 2021; Nonweiler et al., 2020; Spinelli et al., 2020). As clinicians, educators, and researchers started rethinking therapeutic service, learning, and research delivery models including protocols in this author's lab (Bhat et al., 2021; Srinivasan, Su. et al., 2021; Su et al., 2021) many have chosen a hybrid delivery model - a combination of face to face interactions with precautions or a remote/virtual mode of care/ education/research delivery. However, remote/virtual models of care do not work for all subgroups of children

and more systematic studies will be needed to examine the perceived benefits of adding the option of virtual services.

The COVID survey completed by the SPARK study families allows us to stratify the large SPARK sample (N = 6393) based on various demographic, child-related, and parent-related factors. The aim of this study was to identify the subgroups that suffered greatest losses in ASD services and perceived the most negative impact on child and parental emotional and mental health. Parent opinions on benefits of online/potential online services for their child with ASD are also reported. Based on past studies, certain demographic factors such as SES/income and child's age, parent's prior health status, child's understanding of COVID-19 information, and child's ASD severity across different domains will be associated with greater loss of ASD services, more negative impact on their ASD-related behaviors, greater parent concerns, greater negative impact on child and parental mental health, and fewer benefits of online services.

METHODS

Participants

At the onset of the COVID-19 pandemic, around mid-March 2020, a subset of parents of children with ASD from the SPARK cohort were invited to complete the COVID-19 impact survey (N = 9249). In this analysis, the parent survey findings in children and adolescents from 19 months to 18 years of age were examined. For a multiplex family (i.e., family with more than one child with ASD), a single child was selected at random and their issues were reported by the parent completing the survey.

SPARK study original procedures and data access

Families throughout the US with one or more children with ASD have been recruited in the SPARK study through a growing number of sites (i.e., presently 31 clinical sites) across the US using a multi-pronged social media strategy (Feliciano et al., 2018). Families voluntarily signed up for this study by completing the online questionnaires (https://sparkforautism.org/registration/ account_information/) on the SPARK website. They also received information on studies in their nearby community to volunteer for local research studies. This author signed up with the SPARK study to utilize their study recruitment resources (i.e., SPARK Participant Match Resource) for ongoing research studies approved by the University of Delaware (UD)'s Human Subjects Review BHAT

Board. UD also signed an authorization agreement with the Simons Foundation; after which the author was given access to latest versions of the SPARK study database (release date: December 2020).

SPARK forms and measures

- A. The SPARK COVID-19 impact survey included questions about the negative impact of COVID-19 on service-related issues (i.e., service disruptions and parental concerns about the same), negative impact on child's ASD-related symptoms, child's and parent's emotional and mental health, family-related concerns, parental stress, as well as benefits/potential benefits of online services (see complete survey in supplementary data file B). Parents were also asked to report on any past mental health issues and their child's school status and understanding of the COVID-19 information/news. Respondents were asked to select a single best answer on a 4-5-point Likert scale. For example, parents were asked, "In the past week, to what extent have (child's first name)'s ASD services or therapies been disrupted due to COVID-19?" The parent may choose one of the following responses: Severely / Moderately / Minimally / Not at all / Not applicable.
- B. The SPARK team also asked participating families to complete multiple parent questionnaires such as the basic medical screening form, individual data form, and background history form. The basic medical screening form includes demographic information, birth history, professional diagnosis of ASD and other disorders, as well as other general medical conditions. The individual data form provides details on when the ASD diagnosis was made, which professional provided the diagnoses, whether there is a presence of a cognitive impairment, whether there is an Individualized Education Plan (IEP) for the child, and whether the child receives ASD services. The background history form lists the various intervention services received by the child as well as information regarding cognitive, language, and functional age level of each participant (i.e., above, at, slightly below, or significantly below same-age peers) which will be used as a parent-reported outcome for cognitive, language, and functional delay (at or above, slightly below, or significantly below peers). Tables 1 and S1 in supplementary file A summarize the type of SPARK study data used in this analysis.
- C. Additionally, three parent questionnaires including the Social Communication Questionnaire – Lifetime (SCQ, Berument et al., 1999), the Repetitive Behaviors Scale – Revised (RBS-R, Lam & Aman, 2006), and the Developmental Coordination Disorder Questionnaire (DCD-Q, Schoemaker et al., 2006) were analyzed.

TABLE 1 SPARK study demographic information for the sample used in this analysis

Sample size and inclusion/exclusion criteria						
Original dataset	9249					
Inclusion/exclusion	Form completed: 9027,					
criteria	Age ≤ 18 years: 7889,					
	SCQ score nonblank: 7796,					
	SCQ score ≥ 12: 6393					
Final dataset	6393 included (total excluded = 2856 [30.9%])					
Demographics						
Sex	Female: 1235 (19.3%),					
	Male: 5158 (80.7%)					
Race/ethnicity	Non-White (More than one: 1507 [23.6%]					
	Asian: 104 [1.6%],					
	African American: 248 [3.9%],					
	Native American: 20 [0.31%],					
	Native Hawaiian: 3 [0.05%],					
	Hispanic: 6 [0.09%],					
	Other: 50 [0.8%]),					
	White (4191 [65.6%]),					
	Missing: 264 (4.1%)					
Annual household	≤20 K: 627 (9.8%),					
income (\$)	21–35 K: 782 (12.2%),					
	36–50 K: 729 (11.4%),					
	51–65 K: 608 (9.5%),					
	66–80 K: 667 (10.4%),					
	81–100 K: 667 (10.4%),					
	101–130 K: 657 (10.3%),					
	131–160 K: 362 (5.7%),					
	≥161 K: 576 (9.0%),					
	Missing: 718 (11.2%)					
Geographic location	Urban (Large central metro: 1121 [17.5%					
	Large fringe metro: 1543 [24.1%],					
	Medium metro: 1079 [16.9%],					
	Small metro: 543 [8.5%]),					
	Rural (micropolitan: 462 [7.2%],					
	Noncore: 294 [4.6%]),					
	Missing: 1351 (21.1%)					
Age A (years)	A ≤ 3: 89 (1.4%),					
	3 < A ≤ 6: 1136 (17.8%),					
	6 < A ≤ 9: 1548 (24.2%),					
	9 < A ≤ 12: 1447 (22.6%),					
	12 < A ≤ 15: 1236 (19.3%),					
	15 < A ≤ 18: 937 (14.7%)					

i. Social Communication Questionnaire (SCQ) is a widely used parent questionnaire (Yes/No format) to screen for autistic traits in children above 4 years of age with a mental age of at least 2 years (Berument et al., 1999). It is based on a well-validated diagnostic interview, the Autism Diagnostic Interview-Revised (ADI-R). The SCQ has two versions – lifetime, which is used to support a diagnosis and - current, which is used to support an evaluation of current difficulties. The Lifetime version provides a total SCQ score and a total score \geq 12 is indicative of a social communication delay and higher likelihood to be on the autism spectrum. The 12-point cutoff used in this study is a research recommended, more sensitive cutoff score (Lee et al., 2010; Daniels et al., 2011; Zwaigenbaum et al., 2015; Marvin et al., 2017).

- ii. Repetitive behaviors scale-revised or the RBS-R is a widely used, parent report measure to characterize the repetitive behaviors of children with ASDs. It has high internal consistency and medium reliability (Lam & Aman, 2006). It has six subscales to assess the child's stereotyped (I), self-injurious (II), compulsive (III), ritualistic (IV), and sameness behaviors (V), as well as restricted interests (VI). Each item/ question is scored on a 4-point scale: 0 (no such behavior), 1 (mild problem), 2 (moderate problem), and 3 (severe problem). Therefore the total score ranges between 0 and 129 with higher score indicating more repetitive behavior.
- iii. The Developmental Coordination Disorder Questionnaire (DCD-Q) is a parent questionnaire used to assess a child's gross- and fine-motor coordination during everyday functional/play skills within their natural environment (Schoemaker et al., 2006). It focuses on various motor skills such as ball skills (e.g., hitting or catching a ball), complex body coordination skills (e.g., jumping, running), fine motor skills (e.g., writing, cutting.), and general motor control abilities (e.g., quickness, clumsiness, fatigability). The total final score is calculated as a sum of the individual subscale scores with higher scores indicating better motor coordination/functioning. Further details on DCD-Q performance in the SPARK sample can be obtained from Bhat, 2020, 2021.

Inclusion/exclusion criteria

Out of the 9249 families contacted, 9027 respondents completed the COVID-19 survey form. Only one child with ASD was allowed as a participant from each family, that is, if a family had more than one child with ASD registered in SPARK, one of the children was randomly selected as a participant for this survey. Table 1 shows the subsequent filters applied to ensure inclusion/ exclusion based on robust criteria. Participants above 18 years of age were excluded, resulting in 7889 children. Only participants who met the SCQ cutoff of \geq 12 were included (Lee et al., 2010; Daniels et al., 2011), which reduced the final sample to 6393 children. These samples were cross-referenced for additional questionnaire and participant data from the SPARK dataset version 5 to extract the details not provided in the COVID-19 impact survey data, including certain details on demographic information from the standard SPARK forms, and standard questionnaire data - SCQ, RBS-R, and DCD-Q.

Demographics of this population sample are also presented in Table 1. Key demographics for this sample are as follows: ~81% are males, ~66% are Caucasian, ~24% are multi-racial, there is a fairly equal distribution of income from ≤ 20 K to ≥ 161 K USD, ~42% are from large metro areas, and there is a fairly equal distribution of age from 19 months to 18 years. Most of the missing data was for information on geographic location (~21%), income (~11%), and race/ethnicity (~4%). Information extracted from SPARK forms and standard questionnaires is presented in Table S1 in supplementary file A.

Subgrouping analysis

Similar to the approach in Bhat, 2021, the questionnaire data were divided into five subgroups based on the different ranges for SCQ scores, RBS-R scores, and DCD-Q scores using each measure's sample mean and standard deviations (see Table S1 in supplementary file A and details in Bhat, 2021). Accordingly, the entire sample was divided into five subgroups ranging from very low, low, high, very high, and extremely high social communication impairments or motor impairments or repetitive behavior severity. Consistent with previous results in Bhat, 2020 and 2021, this sample also presents with 87.4% of the children reporting motor impairments based on their DCD-Q performance. Missing data for information on scores was $\sim 10\%$ for the RBS-R and $\sim 22\%$ for the DCD-Q scores, but no data was missing for SCQ scores because presence of the SCQ score was a key inclusion criterion.

Data extracted from parent reported levels of cognitive, functional, and language delays are presented in Table S1 in supplementary file A. Similar to the approach in Bhat, 2021, the parent-reported outcome data were divided into three subgroups based on the reported level of cognitive, functional, and language delay compared to peers (i.e., at or above, slightly below, or significantly below peers). Missing data on impairment levels was $\sim 12\%$ for cognitive, $\sim 10\%$ for functional, and $\sim 10\%$ for language delays.

Statistical analysis

Statistical analyses were conducted using JMP Pro 15.0 (JMP, Inc). Descriptive analyses were conducted to report mean and standard deviation for each demographic and child–/parent-related characteristics as well as proportions of different responses for the COVID-impact survey questions. Spearman correlation coefficients were used for

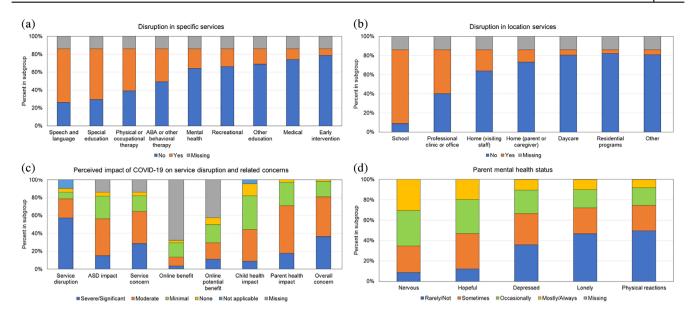


FIGURE 1 Disruption explained by service type (panel a), location (panel b), proportion of responses regarding service impact, concerns, health impact, ASD related behaviors, family concerns, and online/potential online benefits (panel c), and parent mental health status (panel d)

ordinal or continuous data. Ordinal logistic regression analyses were used to predict the impact on ASD symptoms, child and parent health impact, and online benefits using various demographic, child-/parent-related factors. The rationale for the independent variables used was based on past literature confirming important factors which impact health service access and unmet needs, for example, age, sex (male, female), minority status (White, non-White), geographic location (rural, urban), SES (nine income levels), child's ASD severity based on various measures (cognitive, functional or language delay levels, SCQ, DCD-Q, RBS-R scoring levels), parent's past mental health (affected, not affected), and child's ability to understand COVID-19 information (four levels - completely, moderately, minimally, or not at all). For regression analyses, Pearson's correlations were used to rule out multicollinearity between independent variables (r < 0.6). If an independent variable was moderately correlated with another then only one of those two variables was used within the regression analysis. The Wald test's chi-square values and its significance levels were used to assess which independent variable/coefficients significantly contribute to a given model and to compare contributions of coefficients across models. Statistical significance was set at p < 0.05. Bonferroni corrections were used when multiple correlations were performed.

RESULTS

Service disruptions due to the COVID-19 pandemic

Overall disruption in types of services ranged from 7.3% to 59.8% (Figure 1a). In descending order, disruptions

were reported for speech-language therapies (59.8%), special education (56.7%), physical/occupational therapy (46.8%), ABA/behavioral therapies (36.8%), mental health (21.9%), recreational therapies (19.9%), other educational services (17.1%), medical (12.1%), and early intervention (EI, 7.3%). In 14% of the sample had missing data, hence, the reported percentages for disruptions and no disruptions sum to 86% for each service.

80.5% of families reported that their child's school was closed during the pandemic (78.9% due to COVID-19 and 1.6% due to spring break or other reason). Overall disruptions in service locations ranged from 4.0% to 77.1% (Figure 1b). In descending order, disruptions were reported at school (77.1%), professional clinic/office (45.9%), home-based through visiting staff (22.0%), home-based through parent/caregiver (12.9%), daycare (5.5%), and residential programs (4.0%). Services that were most often accessed through schools and clinics (i.e., speech, special education, and physical/occupational therapies) were more disrupted than others.

Impact of COVID-19 on service access, concerns about disruptions, ASD-related behaviors, child and parent health impact, and overall family concern

Figure 1c shows the proportions of different responses provided for each question. The 80.5% reported school closure. The 78.5% reported moderate to severe disruptions in services as a result of the pandemic. The 64.6% expressed moderate to severe concern about feeling stressed or overwhelmed by the service disruptions. The 56.2% reported moderate to severe negative impact on

	Impact on services (service disruption)	Impact on ASD behavior/ symptoms (due to service disruption)	Parent's concern regarding service disruption	Negative impact on child's mental health	Parent's overall concern about family	Negative impact on parent's mental health	Online benefit (perceived benefit from online services)	Online potential benefit (not receiving online services)
Sex	NS	NS	NS	-0.038	NS	NS	NS	NS
Age	0.216	0.070	0.128	-0.097	0.043	0.062	-0.142	-0.094
Minority status	0.062	0.044	0.040	NS	0.036	NS	NS	0.057
Income	NS	0.162	0.093	0.062	NS	NS	NS	0.115
Location	NS	NS	NS	NS	-0.056	-0.053	NS	NS
Parent's past mental health	NS	-0.051	-0.084	-0.085	-0.042	-0.173	NS	-0.063
Child understands	-0.256	-0.153	-0.198	0.164	NS	-0.066	0.252	0.180
Cognitive delay	-0.158	-0.141	-0.130	NS	-0.037	NS	0.135	0.050
Functional delay	-0.162	-0.159	-0.133	NS	-0.090	-0.089	0.129	0.098
Language delay	-0.283	-0.104	-0.155	0.135	-0.054	-0.060	0.211	0.144
SCI level	-0.088	-0.175	-0.106	-0.094	-0.043	NS	0.068	NS
RB level	-0.119	-0.334	-0.232	-0.223	-0.097	-0.107	NS	-0.126
MI level	-0.149	-0.166	-0.145	-0.043	-0.069	-0.072	0.153	NS

TABLE 2 Spearman correlations between demographic (rows 1–5), parent-related (row 6), and child-related factors (rows 7–13) and parent-reported impact of COVID-19 (columns 2–7) and online/potential service benefits (columns 8–9)

Abbreviations: MI, motor impairment; RB, repetitive behaviors; SCI, social communication impairment.

Note: Correlations with p < 0.00625 after Bonferroni corrections are shown below, correlations ≥ 0.1 or ≤ -0.1 are highlighted, and NS indicates not significant.

ASD-related symptoms. The 44.1% expressed moderate to severe impact on their child's emotional or mental health due to pandemic-related concerns. The 80.7% expressed moderate to extreme concern about the impact of the pandemic on their family or household. The 71.1% expressed moderate to severe impact on their own emotional or mental health due to the pandemic and 49.8% parents said yes to having past mental health issues.

Figure 1d shows the proportion of different responses for questions related to parent's mental state. The 65.4% reported feeling mostly or moderately anxious/nervous, 53.0% reported feeling mostly or moderately hopeful, 33.3% reported feeling mostly or moderately depressed, 27.9% reported feeling mostly or moderately lonely, and 25.2% reported physical reactions to the ongoing experiences mostly or moderately.

Only 39.8% felt their child moderately understands the information and news, whereas 60.2% felt that their child had minimal to no understanding. In terms of benefits of online service delivery, only 13.5% were moderately or significantly benefited whereas the remaining 18.8% were minimally or not benefited (only 32.3% responded to this question). In terms of potential benefits of online service delivery, only 29.5% thought their child would be moderately or significantly benefited whereas the remaining 28.0% thought that there would be minimal or no benefits (only 57.5% responded to this question).

Associations between demographic factors and parent-related factors and COVID impact on service access and concerns

Table 2 shows correlations between demographic, childand parent-related factors and impact of COVID-19 on service access, negative impacts, and online benefits. Among demographic factors, age correlated with COVID impact on services ($\rho = 0.22$, p < 0.0001) and parent concerns about disruptions ($\rho = 0.13$, p < 0.0001) indicating that younger children were facing greater service disruptions and their parents were expressing greater concerns about such disruptions. Age also correlated with parent's perception of benefits from online services ($\rho = -0.14$, p < 0.0001) indicating that younger children were minimally benefited from online services compared to the older children.

Household income correlated with negative impact on a child's ASD-related symptoms ($\rho = 0.16$, p < 0.0001) such that lower income families reported a greater negative impact of the pandemic on their child's

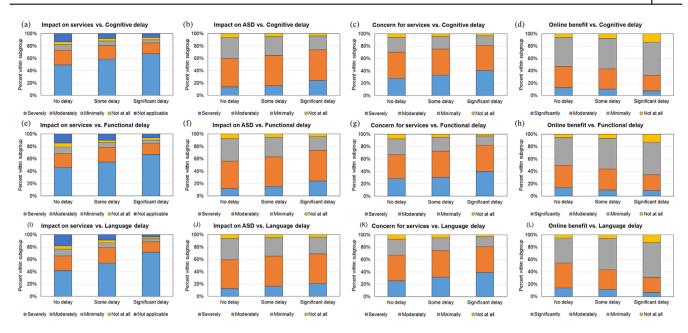


FIGURE 2 Impact on services/concerns, ASD-related behaviors, and online benefits as a function of - cognitive delay (panels a–d), functional delay (panels e–h), and language delay (panels i–l). Negative impacts (severe and moderate) increased and online benefits reduced with increasing delay from left to right

ASD-related behaviors. Income also correlated with parent's perception of potential online benefits with lower income families perceiving greater benefit of accessing online services in the future ($\rho = 0.11$, p < 0.0001) compared to higher income families.

Parent's past mental health correlated with parent health impact ($\rho = -0.17$, p < 0.0001) such that majority of the parents who reported past mental health issues were more likely to have a greater negative impact on their current emotional or mental health. Lastly, a child's understanding of the COVID-19 pandemic correlated with multiple negative impacts including impact on service access ($\rho = -0.26$, p < 0.0001), ASD-related behaviors ($\rho = -0.15$, p < 0.0001), parent concerns about services ($\rho = -0.20$, p < 0.0001), and benefits of online/ potential online services (online: $\rho = 0.25$, p < 0.0001, potential online: $\rho = 0.18$, p < 0.0001) with children who understood less having more negative impact on their services, ASD-related symptoms, and parents noting that online/potential services were/would be less beneficial to them. However, one unexpected finding was that child's understanding of COVID-19 information correlated with the child's emotional and mental health ($\rho = 0.16$, p < 0.0001) with less understanding about the pandemic associated with less impact on their emotional and mental health.

COVID-19 as a function of cognitive delay

In terms of child-related factors, the severity of cognitive delays correlated with impact on services $(\rho = -0.16, p < 0.0001)$, ASD-related symptoms $(\rho = -0.14, p < 0.0001)$, and parent concerns about service disruptions $(\rho = -0.13, p < 0.0001)$ indicating that parents of children with greater cognitive delays reported greater COVID-related service disruptions and concerns about the same as well as greater negative impact on their child's ASD-related behaviors (Table 2, Figure 2a–d). Additionally, the severity of cognitive delays correlated with perceived benefits of online services ($\rho = 0.14, p < 0.0001$) indicating that parents of children with greater cognitive delays were reporting lower benefits from online services.

COVID-19 impact as a function of functional delay

The severity of functional delays correlated with impact on services ($\rho = -0.16$, p < 0.0001), ASD-related symptoms ($\rho = -0.16$, p < 0.0001), and parent concerns about service disruptions ($\rho = -0.13$, p < 0.0001) indicating that parents of children with greater functional delays reported greater COVID-related service disruptions and concerns about the same as well as greater negative impact on their child's ASD-related behaviors (Table 2, Figure 2e–h). Additionally, the severity of functional delays correlated with the benefits of online services ($\rho = 0.13$, p < 0.0001) indicating that parents of children with greater functional delays were reporting lower benefits from online services.

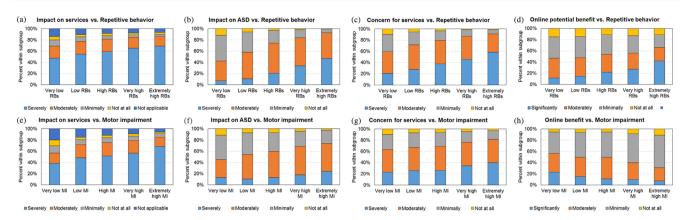


FIGURE 3 Impact on services/concerns, ASD-related behaviors, and online/potential benefits as a function of repetitive behavior severity (panels a–d) and motor delay (panels e–h). Negative impacts (severe and moderate) increased with increasing repetitive behavior or motor impairment from left to right (panels a–c, e–g). Parents of children with more repetitive behaviors were hopeful about potential online benefits (panel d). But, parents of children with greater motor impairments perceived less benefit of current online services (panel h)

COVID-19 impact as a function of language delay

The severity of language delays correlated with impact on services ($\rho = -0.28$, p < 0.0001), ASD-related symptoms ($\rho = -0.10$, p < 0.0001), and parent concerns about service disruptions ($\rho = -0.15$, p < 0.0001) indicating that parents of children with greater language delays reported greater COVID-related service disruptions and concerns about the same as well as greater negative impact on their child's ASD-related behaviors (Table 2, Figure 2i-l). Additionally, the severity of language delays correlated with the benefits of online services ($\rho = 0.21$, p < 0.0001) as well as potential benefits of online services ($\rho = 0.14$, p < 0.0001) indicating that parents of children with greater language delays were reporting lower benefits from online services and felt less confident about benefiting from online services in the future. Language delay correlated with parent's perception of their child's emotional and mental health $(\rho = 0.14, p < 0.0001)$ such that greater language delay was associated with less perceived impact on child's emotional and mental health.

COVID-19 impact as a function of social communication impairment

Categories of social communication impairment correlated with impact on ASD-related behaviors ($\rho = -0.17$, p < 0.0001) and parent's concern about service disruptions ($\rho = -0.11$, p < 0.0001) indicating that parents of children with greater social communication impairments expressed greater concerns about service disruptions and reported greater negative impact on their child's ASD-related behaviors (Table 2).

COVID-19 impact as a function of repetitive behaviors

Categories of repetitive behavior severity correlated with impact on services ($\rho = -0.12$, p < 0.0001), ASD-related behaviors ($\rho = -0.33$, p < 0.0001), and parent concerns about service disruptions ($\rho = -0.23$, p < 0.0001) indicating that parents of children with greater repetitive behavior severity reported greater COVID-related service disruptions and concerns about the same as well as greater negative impact on their child's ASD-related behaviors (Table 2, Figure 3a-d). Surprisingly, repetitive behavior severity correlated with potential benefits of online services ($\rho = -0.13$, p < 0.0001) indicating that parents of children with greater repetitive behavior severity expressed some confidence about benefiting from online services in the future. Lastly, repetitive behavior severity also correlated with their child's emotional and mental health ($\rho = -0.22$, p < 0.0001), as well as their own emotional and mental health ($\rho = -0.11$, p < 0.0001) such that parents of children with greater repetitive behavior severity reported a greater negative impact on their child's and their own emotional and mental health.

COVID-19 impact as a function of motor impairment

The severity of motor impairment correlated with impact on services ($\rho = -0.15$, p < 0.0001), ASD-related behaviors ($\rho = -0.17$, p < 0.0001), and parent concerns about service disruptions ($\rho = -0.14$, p < 0.0001) indicating that parents of children with greater motor impairment reported greater COVID-related service disruptions and concerns about the same as well as greater negative impact on their child's ASD-related behaviors (Table 2, Figure 3(e)-3(h)). Additionally, the severity of motor impairment correlated with the benefits of online services ($\rho = 0.15$, p < 0.0001) indicating that

TABLE 3 Results from ordinal logistic regression analyses. Goodness of fit and statistical significance for the whole model is provided for each dependent variable

	N R2 Probability > chi- square for the whole model		Impact on services	Impact on AS behavior/ symptoms	service disrupt	Concern for service disruption 3961 0.044 <0.0001		Overall family concern	Parent health impact 3822 0.027 <0.0001	Online benefit 1549 0.032 <0.0001	Online potential benefit 3162 0.028 <0.0001
			4659	3989				4399			
			0.054	0.067	0.044			0.013			
Wald chi-square			<0.0001	<0.0001	<0.000			<0.0001			
Demographic	Sex			5.57			12.23				
factors	Age		109.71	15.40	34.69		29.57	5.70	14.09	9.32	21.11
	Incom	ie	27.10	21.87	15.96			22.24	24.73		22.21
	Locat	ion					•	16.04	16.03		
	Minor	rity status	5.72					4.40		-	15.23
Parent-related Parent's past factor mental health		1			29.49		9.47	5.01	104.96	7.25	
Child-related	Cognitive delay		18.17	10.00	10.84						
factors	Functional delay		6.42	7.18	6.33			24.79	17.61		16.63
	Language delay SCQ level RBS-R level - RBs		99.94		16.65		96.34			26.17	37.37
				5.51				_			6.02
			29.54	263.17	118.06		365.88	37.15	13.00		73.76
DCD-Q level Motor		-	14.52	9.09	10.40				4.28	16.44	
Probability > chi	-square	;									
Demographic factors		Sex		NS	0.0182	NS	0.0005	NS	NS	NS	NS
		Age		< 0.0001	< 0.0001	< 0.0001	< 0.000	0.0169	0.0002	0.0023	< 0.000
		Income		0.0007	0.0052	0.0430	NS	0.0045	0.0017	NS	0.0045
		Location		NS	NS	NS	NS	< 0.0001	< 0.0001	NS	NS
		Minority Statu	15	0.0168	NS	NS	NS	0.0359	NS	NS	< 0.000
Parent-related factor P		Parent's past r	nental healt	h NS	NS	< 0.0001	0.0021	0.0252	< 0.0001	NS	NS
Funct Langu SCQ I RBS-1		Cognitive delay		0.0001	0.0067	0.0044	NS	NS	NS	0.0266	NS
		Functional delay Language delay SCQ level		0.0404	0.0276	0.0422	NS	< 0.0001	0.0001	NS	0.0002
				< 0.0001	NS	0.0002	< 0.000	01 NS	NS	< 0.0001	< 0.000
				NS	0.0189	NS	NS	NS	NS	NS	0.0142
		RBS-R level -	RBs	< 0.0001	< 0.0001	< 0.0001	< 0.000	01 <0.0001	0.0003	NS	< 0.000
		DCD-Q level	- Motor	0.0001	0.0026	0.0013	NS	NS	0.0385	< 0.0001	NS

Abbreviations: DCD-Q, developmental coordination disorder questionnaire; NS, not significant; RBs, repetitive behaviors; RBS-R, repetitive behaviors scale-revised; SCQ, social communication questionnaire.

Note: Highlighted cells indicate a substantial contribution based on Wald chi-square (>10).

parents of children with greater motor impairment were reporting lower benefits from online services.

Predicting impact on services, ASD-related behaviors, child and parent health impact, overall concern, and online/potential online benefit using demographics and child—/parent-related factors

Ordinal logistic regression analyses were used to predict COVID-19 impact using various demographic, child- and parent-related factors. Statistical significance of the predictors was assessed using Wald chisquare values (Table 3). Upon correlating the independent variables, only "child's understanding of COVID-19 information" moderately correlated with language delay ($\rho = 0.62$, p < 0.0001); hence, only language delay was included within the regression analysis and child's understanding was excluded. No other correlations were above 0.6.

For the impact on services model, in the order of most to least importance, child's age, language delay,

RBS-R scores, income level, cognitive delay, and DCD-Q scores were the significant contributors to the model. For the impact on ASD-related behaviors model, child's RBS-R scores, income level, age, and cognitive delay were the significant contributors to the model. For service-related concerns model, child's RBS-R scores, age, parent's past mental health, language delay, income, cognitive delay and DCD-Q scores were the significant contributors to the model. For the child health impact model, child's RBS-R scores, language delay, age, and sex were the significant contributors to the model. For the overall family concern model, child's RBS-R scores, functional delay, income, and location were the significant contributors to the model. For the parent health impact model, parent's past mental health, income, functional delay, location, age, and RBS-R scores were the significant contributors to the model. For online service benefits model, language delay and DCD-Q scores were the significant contributors to the model. For potential online service benefits model, child's RBS-R scores, language delay, income, age, functional delay, and minority status were the significant contributors to the model.

DISCUSSION

The present study examined the differential impact of COVID-19 in Spring 2020 on a large group of families of children with ASD from the national SPARK study. Most service disruptions occurred for school- and clinic-based services. A large proportion of families, specifically, families with younger children, from lowincome families, and those having children with various delays (cognitive, social communication, language, functional, or motor) as well as greater repetitive behavior severity were expressing significant concerns about the service disruptions and reporting a greater negative impact on their child's ASD-related symptoms. Majority of the parents who reported past mental health issues were more likely to report a greater negative impact on their current emotional or mental health. Parents of children with greater repetitive behavior severity reported greater negative impact on their child's and their own emotional and mental health. However, parents felt that children with greater language delays and less COVID-19 understanding were less negatively impacted in their emotional or mental health. Families of younger children and those with cognitive/language/functional/motor delays expressed lower benefits of online services. In contrast, low-income families and parents of children with greater repetitive behavior severity were not receiving access to online services at the time and were more hopeful about its future benefits. Next, the significance of these findings and recommendations for the future will be discussed.

School and clinic-based services for children with ASD have a greater risk for disruption in a future pandemic

Majority of the service disruptions in Spring 2020 were for school and clinic-based services that children with ASD often receive such as speech-language therapies, physical/ occupational therapies, and ABA/behavioral therapies (Brown et al., 2010; Chiri & Warfield, 2011; Farmer et al., 2013; Karpur et al., 2018). Interestingly, EI, mental health, medical, and recreational services were not reported disrupted to the same extent. When strict lockdowns were imposed to prevent transmission of COVID-19, schools, businesses, and hospitals were closed and not offering outpatient therapeutic services. As a result, it is not surprising that a range of therapies came to a halt for several months before clinical and educational sites reopened or reinvented their modes of care/educational delivery. One of the initial reports from parents of children with intellectual and developmental disabilities found that 74% of the parents reported loss of access to at least one therapeutic or educational service following the onset of the pandemic (Jeste et al., 2020). The reported percentages are similar to the 79% of the SPARK families who expressed moderate to severe disruptions in service access with 65% expressing moderate to severe concerns about the service disruptions. Along these lines, Neece et al. (2020) reported parents feeling concerned about loss of services for their children with developmental disabilities and the long-term impact of prolonged lack of services for their children. Lack of access to services meant that the parents were responsible for providing care and services to their child with ASD without any professional support. At the time, there were multiple calls for providing alternative means to access healthcare/therapeutic services through safe reopening of schools as well as virtual/remote interventions, both of which have been implemented over the last year (Aishworiya & Kang, 2021; Dibner et al., 2020; Fontanesi et al., 2020). During potential future lockdowns, it will be important to consider continuing safe methods of service delivery through in-person interactions with proper precautions or meaningful virtual/remote methods to avoid large gaps in access to services.

Even so, certain service types such as EI, mental health, medical, and recreational services as well as service locations (i.e., home-based, daycare, and residential) were not reported as disrupted to the same extent with only 4%–22% reporting disruptions. It is unclear if the families did not access certain services often before the pandemic and hence, did not report concerns (e.g., annual physician visits) or perhaps these services were deemed essential at the time and were not closed, or their occurrence was determined by the individual facility, family, or clinician involved and hence, still continued. Certain types of services or formats of care may be more resilient and/or less affected by nationwide lockdowns. More research is needed to evaluate the differential nature of the pandemic's effects on various types of services.

Various subgroups of children with ASD faced significant service disruptions and worsened ASD-related symptoms

Seventy-nine percent of the families were facing moderate to severe service disruptions and 65% were moderate to severely concerned about the disruption. Eighty-six percent of the families reported moderate to severe negative impact on their child's ASD-related behaviors and 44% reported moderate to significant negative impact on their child's emotional and mental health. There have been multiple reports on the lack of access to services for children with developmental disabilities including children with ASD for smaller samples (Jeste et al., 2020; Neece et al., 2020; Spinelli et al., 2020). Parents have also reported an increase in challenging / negative behaviors and the need for further coaching/training to better handle their child's increased negative behaviors due to loss of structure of a regular school day (Ameis et al., 2020; Chen et al., 2020; Colizzi et al., 2020; Nonweiler et al., 2020). A child's language abilities and their ability to understand the COVID-19 crisis played a major role in negatively impacting their emotional and mental health and those two issues were found to be related in this analysis. Only 44% of surveyed parents of children with ASD reported negative impact on their child's emotional and mental health. It is possible that parents may not be accurately reporting on the emotional health of their low to nonverbal children with ASD. More importantly, the severity of service-related concerns or negative impact on ASD-related behaviors increased in younger children and in those with increasing autism severity including worsening cognitive, language, functional, and motor impairments as well as repetitive behavior severity. Families with younger children, children with greater impairments, and low income families reported greater loss in services, concerns about the same, and greater negative impact on ASD-related behaviors. This is not surprising because even before the pandemic, such healthcare inequalities impacted the families of children with greater autism severity, poor adaptive functioning, and low-income families the most (Brown et al., 2010, 2012; White et al., 2021). The COVID-19 pandemic further laid bare the pre-existing healthcare inequalities and continues to highlight the greater service needs of families of children in the aforementioned subgroups.

COVID-19 had a negative impact on parent's emotional and mental health and led to greater family concerns

The COVID crisis significantly increased the parent's caregiver burden due to loss of services, having to adapt to the altered methods of offering services (telehealth vs. face to face), parents having to play an active role in their child's virtual therapy/schooling, family stressors of

working from home, job loss, or caring for multiple children, loss of access to peer/expert interactions, and the loss of the daily structure of a school day (Ameis et al., 2020; Bellomo et al., 2020; degli Espinosa et al., 2020; Manning et al., 2021). Parents of children with disabilities including ASD were reporting increased anxiety, depression, and stress due to their caregiving burden increased ASD-related negative behaviors of their child during the pandemic and challenges they face while managing their child's behaviors (Chen et al., 2020; Dhiman et al., 2020; Spinelli et al., 2020). Parents of children with ASD with greater ASD severity as seen by greater functional delays and repetitive behavior severity, and poor understanding about COVID-19, families with younger children, low income were reporting the greater negative health impact on themselves and concerns about their families. It has been well-established that caregiving stresses are much greater in parents of children with ASD with greater repetitive behaviors, language delays, and functional dependence and need more family supports (Srinivasan et al., 2021; Abbeduto et al., 2004, Bromley et al., 2004; Brown et al., 2010). There are a few reports on how family supports such as respite care were not operational during the initial months of the pandemic (Chen et al., 2020; Spinelli et al., 2020). In fact, parents were expressing need for more respite care services during the initial months of the pandemic due to school closures and all the caregiving burden placed on them. In the future, it would be important to also consider the needs of families of children with ASD and other disabilities when imposing lockdowns in response to resurgence of COVID-19 or other future pandemics and to have important family support services in place to support parents and caregivers.

Parents were divided about the benefits of online services

Only a small proportion of families responded to benefits of online services and about equal numbers found it highly beneficial (14%) or not beneficial (19%). Lowincome families expressed potential benefits from online services in the future suggesting that those subgroups were most negatively impacted in the initial months and were hoping services could be resumed in an online format. Most importantly, with increasing autism severity including poor child understanding of COVID-19, worsening cognitive, language, functional and motor delays, there was less online benefit perceived. Similarly, parents of younger children reported fewer benefits of online services than older children. Both of these trends are plausible in that younger children and children with greater ASD severity may not be able to attend to the computer screen for a prolonged period or may not perceive the verbal cues or demonstrations presented to them making it difficult for them to engage with online therapist-child

interactions. As a result, the parent will need to play an active role in explaining, prompting, and reinforcing their child or learn the principles from the expert to implement throughout the day without any professional support. In both cases, the caregiving burden falls on the parent entirely and managing their child's care on their own could easily contribute to parent anxiety and stress. In the future, clinicians must recognize the characteristics of the child and family unit. For some children, virtual/ remote services may not be beneficial and they will need continued professional support in-home or in-clinic to facilitate age-appropriate skills. Effective approaches that allow face-to-face interactions with precautions such as wearing masks, social distancing, limiting the number of people present, and sanitizing surfaces and toys will need to be implemented.

At the same time, there was a subgroup of families $(\sim 14\%)$ that found online services to be significantly beneficial, specifically, families with older children and children with low ASD severity. There was also a nonintuitive finding of a subgroup of families of children with greater repetitive behavior severity reporting greater potential benefits of online services. From a family's perspective, virtual/remote therapies reduce the burden of traveling to the therapy location and online interactions are more distant/disconnected and hence, less socially intense and stressful for the child. Even before the pandemic, there was a body of literature including multiple systematic reviews on the efficacy of telehealth to provide a variety of health services to families living in remote and rural areas (Knutsen et al., 2016; Ferguson et al., 2018; Sutherland et al., 2018). Telehealth services can be provided through live synchronous interactions or asynchronous content that is shared through audio, video, or written formats (Samadi et al., 2020). However, face to face or in-person interactions have always been the mainstay of pediatric clinical practice. The pandemic has clearly accelerated the implementation of telehealth approaches in pediatric practice with the availability of videoconferencing technologies such as HIPAA enabled-Zoom, transition to online/hybrid education, and the acceptance of remote videoconferencing among service providers as well as families. A range of therapeutic services are being provided virtually including ABA, speechlanguage, physical and occupational therapies using direct child interactions as well as via caregiver training (Simacek. et al., 2020; Tenforde et al., 2020; Tomlinson et al., 2018; Tohidast et al., 2020). This author has modified an ongoing movement intervention clinical trial involving face-to-face interventions to a hybrid format wherein families are able to choose between in-person vs. online/telehealth visits to complete testing and interventions as outlined in recent publications (Su et al., 2021; Bhat et al., 2021; Srinivasan et al., 2021). Allowing families to choose their preferred mode of clinical trial delivery has made it feasible to conduct the study in spite of hesitancy among families to participate in

nonessential clinical interactions such as participating in a research study during the pandemic.

LIMITATIONS

Reliance on parent report questionnaires is a clear limitation of this study. Parent reports of their child's abilities could be influenced by reporting biases such as the Horn effect, i.e., parents of children with greater ASD severity may have rated higher scores for negative impact. For example, parents may not accurately perceive the emotional health of their child with language delays. Nevertheless, parent reports as opposed to parent interviews or child assessments are the best way to obtain information from a large group of families. In spite of the large sample size, there could still be an ascertainment bias due to the online nature of the study and inclusion of participants from large autism centers in the US. The COVID-19 impact survey developed by the SPARK study team is not a validated measure; however, it was a very timely effort to document the service challenges and human impact of the pandemic on families of children with ASD. Another detail to note is the potentially problematic use of the term "Early intervention" as a type of service because parents may know that their child receives speech therapy but may not know that it is through EIbased programming or may associate EI with a different name (e.g., Child Development Watch in Delaware) and hence, may not accurately respond to the question. Last but not the least, the SPARK study sample is currently biased toward a larger proportion of Caucasian and urban families.

Implications for clinical practice and healthcare policy

In the future, during a potential resurgence of the COVID-19 or other pandemics, it would be important to continue access to healthcare services to children with ASD and other developmental disabilities because access to care was significantly reduced at the outset of the COVID-19 pandemic. Researchers need to systematically study the short-term and long-term impact of this pandemic on the future outcomes of children with ASD and disabilities. Families have been informing other researchers such as this author that their child with ASD has lost skills over the last 1 year due to a complete lack of or inconsistent access to services they urgently need. With more sites and schools providing hybrid methods for delivering care and instruction, it is important to provide services based on family preference and child needs to ensure optimal care. This may require giving families the option of in-person services with appropriate precautions or telehealth services for both, healthcare and family support services. Lastly, parents burdened with the

care of their child with ASD are in urgent need of respite care and other related family support services often not capitalized upon by parents. Family support services need to be better developed, promoted, covered through insurance and Medicaid programs and made accessible to all families of children with ASD, but especially those having younger children, children with greater severity of ASD or other impairments as seen by greater repetitive behaviors, language, functional, and/or motor delays, as well as low-income families that may not have access to personal childcare/home care networks.

CONCLUSIONS

The present study examined the findings from the SPARK study COVID-19 impact parent survey. A large proportion of parents reported significant service disruptions and concerns about the same. They also reported a substantial negative impact of the pandemic and related lockdowns on the ASD-related behaviors of their child. The negative impact of the service disruption on their child's ASD-related behaviors and their emotional or mental health increased with increasing ASD severity including increasing cognitive, language, functional, and motor impairments as well as repetitive behavior severity. A small proportion of families reported minimal to no benefits from online services whereas another small percentage reported significant benefits. More importantly, younger children with ASD and children with greater ASD severity were less benefited by online services. Lowincome families were hopeful about receiving some benefits through online services. Overall, these findings have important implications for clinical care delivery and future healthcare policies to ensure that healthcare services are not interrupted during potential resurgence of COVID-19 or other pandemics. Hybrid healthcare delivery models inclusive of face to face and/or telehealth services must be offered to families based on their preferences and needs. More needs to be done for parents with greater caregiving burden to improve knowledge about, accessibility to, and private insurance/Medicaid coverage for family support services including respite care, childcare, and home-based care, specifically for, parents of younger children, children with greater ASD severity, and those belonging to low-income families.

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CONFLICT OF INTEREST

There are no conflicts of interest to report.

ORCID

Anjana Bhat D https://orcid.org/0000-0002-0771-0967

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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