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Health and Education Services During the COVID-19 Pandemic Among Young Children with Autism Spectrum Disorder and Other Developmental Disabilities

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Abstract

Objective: Understanding how the COVID-19 pandemic affected children with disabilities is essential for future public health emergencies. We compared children with autism spectrum disorder (ASD) with those with another developmental disability (DD) and from the general population (POP) regarding (1) missed or delayed appointments for regular health/dental services, immunizations, and specialty services; (2) reasons for difficulty accessing care; and (3) use of remote learning and school supports.

Method: Caregivers of children previously enrolled in the Study to Explore Early Development, a case-control study of children with ASD implemented during 2017 to 2020, were recontacted during January–June 2021 to learn about services during March–December 2020. Children were classified as ASD, DD, or POP during the initial study and were aged 3.4 to 7.5 years when their caregivers were recontacted during the pandemic.

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Results: Over half of all children missed or delayed regular health/dental appointments (58.4%–65.2%). More children in the ASD versus DD and POP groups missed or delayed specialty services (75.7%, 58.3%, and 22.8%, respectively) and reported difficulties obtaining care of any type because of issues using telehealth and difficulty wearing a mask. During school closures, a smaller proportion of children with ASD versus another DD were offered live online classes (84.3% vs 91.1%), while a larger proportion had disrupted individualized education programs (50.0% vs 36.2%).

Conclusion: Minimizing service disruptions for all children and ensuring continuity of specialty care for children with ASD is essential for future public health emergencies. Children may need additional services to compensate for disruptions during the pandemic.

Index terms

autism spectrum disorder; developmental disability; special education; individualized education program

Autism spectrum disorder (ASD) is a developmental disability affecting approximately 1 in 36 children aged 8 years in the United States.¹ In addition to condition-specific social, emotional, communication, behavioral, and learning needs, children with ASD have higher rates of co-occurring medical and mental health conditions.^{2–4} Comprehensive support for children with ASD often requires increased health care use and a range of specialty services including behavior therapy, speech or language therapy, physical therapy, occupational therapy, social skills training, and mental health services.^{2–4} This range and intensity of services is needed to improve the health and functioning of children with ASD and reduce their need for services later in life.^{2,4}

Physical distancing and lockdown measures during the COVID-19 pandemic had significant impacts on US health and education systems, resulting in a loss of services for many children.^{5–8} Numerous studies have suggested impacts were more pronounced for children with ASD and other developmental disabilities,^{5,9} with at least some disruption reported by 65%–88% of caregivers and many children experiencing a complete loss of services.^{10–16} The more extreme impact on service access and delivery for children with ASD may be related to their need for comprehensive services to address developmental and co-occurring medical conditions,^{2–4} reliance on specialty services in both clinic settings and school-based programs,^{2,17,18} and potential difficulties using telehealth and remote learning services.^{9,12,14–16} Developing strategies to promote continuity of services during future public health emergencies will require a better understanding of the types of services most affected and the factors associated with disruptions for children with ASD and other developmental disabilities.

We conducted a COVID-19 Impact Assessment of families of young children during January–June 2021 to examine caregiver-reported changes in their child’s health and education services. We asked caregivers about their experiences throughout 2020. This allowed us to include the period just before the COVID-19 pandemic began to severely affect daily life and to then track changes over defined periods (pre-COVID: January–February; spring: March–May; summer: June–August; fall: September–December). Specific

objectives of this analysis were to compare the experiences of children with ASD with the experiences of children with another developmental disability or from the general population as related to (1) missed or delayed appointments for regular health/dental services, immunizations, and specialty services (including behavior therapy, speech or language therapy, physical therapy, occupational therapy, social skills training, and mental health services); (2) reasons for difficulty accessing care; and (3) use of remote learning resources that might have contributed to use of school supports during closures for in-person learning.

METHODS

Study Components and Dates

This analysis used data from the Study to Explore Early Development—Phase 3 (SEED3) and the SEED3 COVID-19 Impact Assessment. SEED3 was a multisite case-control study of risk factors, co-occurring conditions, and behavioral phenotypes associated with autism spectrum disorder (ASD) among children aged 2 to 5 years. SEED3 was launched in 2017 at 6 study sites located within communities in different states in the United States. Three groups of children were included: (1) children with ASD, (2) children with another developmental disability (DD), and (3) children from a general population comparison group (POP). A detailed description of SEED, including eligibility criteria, enrollment methods, and data collection can be found in the study of Schendel et al.¹⁹ Study criteria for ASD case classification using the Autism Diagnostic Interview Revised²⁰ and the Autism Diagnostic Observation Schedule²¹ can be found in the study of Wiggins et al.²² Further details on the conditions identified among children in the ASD and the DD group are provided in the study of Wiggins, Levy, et al.²³

The SEED3 COVID-19 Impact Assessment was a caregiver survey designed to learn how the pandemic affected developmental, health care, and school services; child behaviors; and child and family emotional, financial, and physical health, among other outcomes (Supplemental Digital Content 1, <http://links.lww.com/JDBP/A440>). When recruitment and in-person clinic visits for SEED3 were suspended due to community mitigation efforts for the COVID-19 pandemic in March 2020, SEED3 investigators collaboratively developed the COVID-19 Impact Assessment.

Eligible participants (N = 1789) were families who completed SEED3 before March 31, 2020, with a child who received a final study classification of ASD, DD, or POP. Caregivers were surveyed during January–June 2021 and asked to recall their experiences for 2020 overall and during specific periods (pre-COVID: January–February; spring: March–May; summer: June–August; fall: September–December). At most sites, eligible participants first were sent an invitation packet with the survey to complete and return; if no response was received within 3 weeks, study staff called and offered to conduct the survey by phone. At 1 site, participants were first contacted by phone and then given the opportunity to complete the survey by mail if preferred. Of participants invited, 1027 completed the survey (57.4%).

The SEED3 protocol was approved by the Institutional Review Board at CDC and each study site. Caregivers provided verbal informed consent at enrollment for SEED3

and written informed consent during an in-person evaluation of their child. The SEED3 COVID-19 Impact Assessment was developed during April–October 2020 and was approved as an amendment to the SEED3 protocol.

Outcome Measures

Outcome measures were obtained from the SEED3 COVID-19 Impact Assessment. Interruptions to health services were assessed by asking caregivers whether their child missed or delayed any services during 2020 because of the COVID-19 pandemic. Specific services included regular health care/dental visits, immunizations, and specialty services (i.e., behavior therapy, speech or language therapy, physical therapy, occupational therapy, social skills training, and mental health services). All caregivers, including those who did not report missed or delayed services, also were asked about reasons for having trouble getting health care services during 2020. Predefined and “other reason” responses were placed in the following categories: clinic closures/cancellations, avoiding COVID-19 transmission, limited family resources, problems using telehealth, and difficulty wearing a mask.

For school services, caregivers of children attending school before the pandemic were asked whether their child’s school was closed for in-person learning because of COVID-19 at any time from March to December 2020 and during specific periods (spring, summer, and fall). They also were asked whether their school offered remote learning and resources to support that learning, such as providing a computer or digital device. Finally, caregivers of children receiving special education supports before the pandemic through a 504 Plan, Individualized Education Program (IEP), or another provision of the Individuals with Disabilities Education Act (IDEA) were asked about disruptions due to the pandemic.

Analytic Strategy

For bivariate analyses, Student’s t tests or χ^2 tests were used to examine differences in participant characteristics, interruptions to health services, and school closures and supports by child disability status (ASD, DD, or POP); significance for 2-sided tests was set at $p < 0.05$. In multivariable analyses, child disability status was evaluated as a predictor of missed or delayed health services (regular health/dental, immunization, and specialty services) and reasons for difficulty accessing care. Differences in the reasons caretakers provided for having difficulty accessing services were evaluated for the full population of caregivers who participated in the study and among the subpopulation of caregivers who reported their child actually missed or delayed services. Multicollinearity diagnostic tests first were performed by variance inflation factors, tolerances, and correlation coefficients. Modified Poisson regression was then used to calculate prevalence ratios (aPRs), adjusted for child sex, race-ethnicity, and age; family income relative to the federal poverty threshold; maternal education; SEED study site; and selected household disrupting factors (job loss, difficulty paying bills, lack of private health insurance, or disruptions to coverage).

RESULTS

Sample Characteristics

Participants in the analysis (N = 1027) included 274 caregivers from the autism spectrum disorder (ASD) group, 368 caregivers from the developmental disability (DD) group, and 385 caregivers from the population comparison group (POP) group. At baseline, children in the ASD group were older and less likely to be non-Hispanic White than children in the POP group (Table 1). In comparison with children in both the DD and the POP groups, children in the ASD group were more likely to be male, have a lower household income, and have a mother without a college degree.

Compared with eligible Study to Explore Early Development—Phase 3 participants who did not respond to the COVID-19 Impact Assessment, caregivers who participated had younger children and were more likely to have children who were non-Hispanic White, to have a higher household income relative to the federal poverty threshold, and to report a college degree or higher (Supplemental Digital Content 2, <http://links.lww.com/JDBP/A441>).

In the period just before the COVID-19 pandemic began to severely affect daily life (January–February 2020), caregivers in the ASD group were less likely than those in the DD and POP group to report their child had private health insurance (alone or in combination with public insurance) or had attended private school; caregivers in the ASD group also were less likely than those in the POP group to have a spouse or partner in 2020 (Table 1). During the pandemic (March–December 2020), caregivers in the ASD group were more likely than those in the DD group to report job loss or reduction in hours; they also were more likely than those in the DD and POP group to report difficulty paying bills and to lack private health insurance for their child or experience interruptions to this coverage.

Missed and Delayed Services

Across the 3 study groups, over half of all children missed or delayed appointments for regular health/dental services. The percentage of caregivers reporting interruptions ranged from 65.2% for children in the ASD group to 58.4% among children in both the DD and the POP groups (Table 2) and were somewhat more common for children in the ASD versus the POP group (aPR = 1.16; 95% CI, 1.01–1.32). The percentage reporting missed or delayed appointments for immunization services was lower (10.1%–15.9%) and did not differ significantly by study group. By contrast, interruptions to specialty services differed markedly by study group (22.8%–75.7%)—children in the ASD group were somewhat more likely than children in the DD group (aPR 5 1.30; 95% CI:1.15–1.47) and nearly 3.5 times more likely than children in the POP group (aPR = 3.46; 95% CI, 2.67–4.48) to experience interruptions.

Within the full population, including those who did and did not report missed or delayed appointments, clinic closures/cancellations and avoiding COVID-19 transmission were the reasons reported most commonly for difficulty accessing services across all 3 study groups. Multivariate regression indicated these reasons were somewhat more common for children in the ASD versus the DD and the POP groups (Table 2). The next most common reason across groups was related to problems with telehealth; caregivers in the ASD group were

somewhat more likely than those in the DD group (aPR = 1.58; 95% CI, 1.16–2.14) and 2.5 times more likely than those in the POP group (aPR = 2.51; 95% CI, 1.17–3.68) to report this reason. Caregivers in the ASD group also were 2.5 times more likely than those in the DD group (aPR = 2.50; 95% CI, 1.62–3.86) and 6.5 times more likely than those in the POP group (aPR = 6.53; 95% CI, 3.25–13.14) to report difficulty wearing a mask as a reason their child had difficulty accessing services. Across all 3 groups, <10% of caregivers reported reasons related to limited family resources. Similarly, within the sample of children who actually missed or delayed services, clinic closures/cancellations and avoiding COVID-19 transmission were the reasons caregivers reported most commonly across all 3 study groups. Problems with telehealth were again somewhat more likely to be reported by caregivers in the ASD as compared with the DD and the POP groups, with even greater differences between the ASD as compared with the DD and POP groups with respect to difficulties wearing a mask (Supplemental Digital Content 3, <http://links.lww.com/JDBP/A442>).

School Closures, Supports, and Disruptions to Special Education Programs and Accommodations

Before the onset of the COVID-19 pandemic, approximately 90% of children across the 3 study groups attended school (Table 3). Children in the ASD versus the DD and the POP group were more likely to have had special education supports under a 504 Plan/IEP or other IDEA accommodations.

Among those attending school, approximately 95% of children across the 3 study groups experienced closures for in-person learning during the COVID-19 pandemic (Table 3), with the percentage exceeding 90% across all 6 study sites (91.3%–99.2%). In the fall, more variation existed by study site and group (50.0%–91.7%), and closures for in-person learning were somewhat more common for children in the ASD (82.5%) versus the DD group (75.8%, $p = 0.05$) and significantly more common for children in the ASD versus the POP group (71.5%, $p = 0.002$).

During school closures, most caregivers reported their children were offered some type of support for remote learning, including live online classes, assignments to complete online, and/or assignments printed and sent home (Table 3). Although there was variation by study site and group in the types of support (live online classes: 68.1%–98.2%; assignments to complete online: 56.8%–94.6%; printed assignments sent home: 56.1%–86.1%), across sites children in the ASD group were less likely than children in the DD group to be offered live online classes (84.3% vs 91.1%, $p = 0.01$). Among children across the 3 groups offered online classes, 76.7% always had access to a computer or digital device; this proportion was higher when this equipment was provided by their school (85.1%) than when it was not (70.5%, $p < 0.001$; data not shown). Of children offered online classes, 80.4% always had internet access supporting video; only 3% of caregivers reported their school provided internet access (data not shown).

Among children who had an IEP/504 Plan or received IDEA accommodations before the pandemic, those in the ASD versus the DD group were more likely to report disruptions (50.0% vs 36.2%, $p = 0.009$; Table 3). The proportion of children with a greatly decreased

ability to receive IDEA accommodations was similar in the ASD (66.7%) and the DD (63.6%) group.

DISCUSSION

This analysis documents substantial interruptions to health and education services for all children during the COVID-19 pandemic. It further highlights aspects of service interruptions that were more common among children with autism spectrum disorder (ASD) than others, along with some of the reasons for those differences. More than half of children (regardless of disability status) experienced disruptions to regular health/dental services, with clinic closures and avoiding COVID-19 infection noted as the most common reasons. However, the burden of disruptions to specialty services and special education supports fell disproportionately on children with ASD, who were also more likely to struggle with telehealth, remote learning, and wearing a mask. Overall, these findings highlight the need in future public health emergencies to minimize interruptions to services for all children, proactively consider the needs and best modes of delivery for children with developmental disabilities, and assess the need for additional services to compensate for disruptions that children already experienced during the COVID-19 pandemic.

Children with ASD may have experienced more interruptions not only because of their need for services to address specific skills and symptoms but also because of their greater overall health care utilization, including services used by children with and without developmental disabilities.²⁻⁴ This likely was reflected in the patterns we observed for interruptions to general health/dental services, which were common for all children but somewhat more common for children in the ASD group. Given that clinic closures and avoiding COVID-19 infection were the barriers to care endorsed most often by caregivers in all 3 study groups, adaptations to service delivery systems that could be implemented during future public health emergencies to ensure continuity of care for all children might be particularly beneficial for children with ASD.

Disruptions to services during the COVID-19 pandemic also may have been more common for children with ASD because of their more frequent use of school-based programs to address specialty service needs,^{2,17,18} many of which were disrupted by the rapid closing of schools and shift to remote learning.^{5,6,10,14,24} Special education supports from the public school system often function as a central source of services for children with disabilities: they can be accessed without costs or other barriers, may be the only source of developmental and behavioral supports for some children,^{2,17,18,25} and are more commonly used by children with ASD as compared to children with most other developmental disabilities (DDs).² However, in spite of the importance of school-based services for children with ASD, other studies have found that interruptions during COVID-19 were more common for services delivered through schools versus clinic-based settings.^{10,25} In our study, we also found children in the ASD group were more likely than children in the other groups to continue experiencing school closures for in-person learning into the fall and more likely than children in the DD group to experience disruptions to their IEP/504 Plans. Potentially this might have reflected shortages in staff and other resources schools could provide to support the learning needs of children with ASD, in addition to the

burden of implementing strategies to minimize COVID-19 transmission for all children. This highlights the importance of considering the capacity schools would need to have to provide ongoing support.

Difficulties using remote services also likely contributed to our finding that service disruptions were most pronounced for children in the ASD group. In many studies, caregivers of children with disabilities have reported challenges with delivery and low perceived benefits from remote services, particularly for services commonly used by children with ASD and for those who are younger and have greater behavioral impairments.^{5,7,10,12,16,26,27} Consistent with these studies, we found that children in our ASD versus our DD group were less likely to be offered live classes online. Providing services remotely to expand access and ensure continuity of care may require prioritizing use of in-person services to therapies that are less effective when delivered remotely and for children who have greater difficulties with remote delivery, along with training of both caregivers and providers on specific procedures.^{26–30} Indeed, the Society for Developmental and Behavioral Pediatrics recently highlighted the importance of considering which services can most effectively be delivered online, drawing lessons from guidelines developed by related health care fields for provider training, and conducting further research to inform condition-specific guidelines for providers to deliver developmental and behavioral pediatric services.³⁰

In addition to providing training and prioritization of certain services for remote and in-person delivery, it is important to ensure that families have the necessary technological resources. Previous studies found lower income families more likely to report disruptions to services and less likely to receive remote care during the COVID-19 pandemic, particularly if lacking access to an electronic device, such as a computer, smartphone, or tablet.^{5,7,10,29} In our analysis, we found families were more likely to report they always had access to a digital device when this equipment was provided by schools. Hence, while telehealth can reduce disparities in access by bridging geographic distances to care and increasing flexibility, it can also widen disparities for families without efforts to ensure access to technological resources.^{15,27,29,30}

There are limitations to this study. While we observed that difficulty using telehealth was a common reason for missed or delayed appointments, we were not able to determine the extent to which these difficulties were related to limitations in family resources, child characteristics and behavioral skills, or other factors. Similarly, while we found children with ASD were more likely than those with another DD to have disruptions to their IEP/504 Plans and less likely to attend online classes, we did not have information on the reasons for these patterns, which may have differed widely across the DD group because of the heterogeneity of children and conditions included. In addition, some caregivers who reported their child did not miss or delay specialty services may not have had their child use these services before the pandemic, although they were provided the option to indicate the question was not applicable versus responding no to the question. Recall bias may also have been a limitation because caregivers were surveyed during January to June 2021, which was up to a year after the experiences they were asked to recall and at a time when the COVID-19 pandemic was continuing to have pronounced impacts on daily life. Finally,

compared with nonresponders, Study to Explore Early Development—Phase 3 participants who participated tended to have higher income and education and were more likely to be non-Hispanic White; if low income, low education, and other race-ethnicity families had been better represented, impacts of the pandemic might have seemed even greater.

CONCLUSION

We found missed and delayed appointments for general health/dental services were common for all children, while disruptions to specialty services were most pronounced among children with autism spectrum disorder, who also experienced difficulties with telehealth, remote learning, and wearing a mask. These findings suggest that some children may need additional services to compensate for the disruptions that occurred during the COVID-19 pandemic and that it will be important to consider strategies to minimize service disruptions during future public health emergencies that account for the special service needs of children with developmental disabilities. Potential strategies include adapting remote services for use by children with disabilities when feasible and prioritizing in-person delivery for children and services that cannot be delivered remotely, implementing parent and provider training, considering the capacity schools would need to provide ongoing support for children with developmental disabilities, and ensuring that all families have the necessary technological resources for remote service utilization.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1. Selected Child and Family Characteristics Before the COVID-19 Pandemic and Potential Disruptive Events During the Pandemic (March–December 2020)

Characteristic	ASD		DD		POP		<i>p</i> ^d ASD vs. DD	<i>p</i> ^d ASD vs. POP
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)		
Total, N 5 1027 (%) ^b	274 (26.7)	368 (35.8)	385 (37.5)				N/A	N/A
Baseline characteristics ascertained during SEED Phase 3								
Child age at SEED clinic assessment (mo), mean (SD)	46.8 (8.8)	48.1 (9.4)	43.9 (8.2)				0.06	< 0.001
Child sex ^c								
Male	217 (79.2)	232 (63.0)	200 (52.0)				< 0.001	< 0.001
Female	57 (20.8)	136 (37.0)	185 (48.1)					
Child race-ethnicity ^c								
Hispanic	35 (12.8)	42 (11.4)	39 (10.1)				0.17	< 0.001
Non-Hispanic White	158 (57.7)	243 (66.0)	278 (72.2)					
Non-Hispanic Black	41 (15.0)	43 (11.7)	24 (6.2)					
Non-Hispanic other or multiracial	40 (14.6)	40 (10.9)	44 (11.4)					
Household income, relative to federal poverty threshold ^c								
100%	33 (12.3)	25 (7.0)	8 (2.1)				< 0.001	< 0.001
101%–200%	58 (21.6)	51 (14.3)	43 (11.3)					
201%–300%	44 (16.4)	45 (12.6)	59 (15.5)					
301%–399%	47 (17.5)	63 (17.7)	64 (16.8)					
400%	86 (32.1)	172 (48.3)	206 (54.2)					
Maternal education ^c								
High school or less	51 (18.7)	36 (9.8)	16 (4.2)				< 0.001	< 0.001
Some college	81 (29.7)	63 (17.2)	61 (15.9)					
College graduate/advanced degree	141 (51.6)	268 (73.0)	307 (79.9)					
Study site ^c								
Colorado	39 (14.2)	52 (14.1)	79 (20.5)				0.07	0.28
Georgia	31 (11.3)	59 (16.0)	35 (9.1)					
Maryland	39 (14.2)	35 (9.5)	40 (10.4)					

Characteristic	ASD		DD		POP		p^d ASD vs. DD	p^d ASD vs. POP
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)		
Missouri	59 (21.5)	61 (16.6)	82 (21.3)					
North Carolina	43 (15.7)	78 (21.2)	59 (15.3)					
Wisconsin	63 (23.0)	83 (22.6)	90 (23.4)					
Characteristics ascertained during COVID-19 Impact Assessment								
Child age at time of COVID-19 Impact Assessment (mo), mean (SD)	73.1 (9.4)	74.2 (9.5)	73.0 (8.9)	0.13				0.96
Child health insurance before COVID (January–February 2020) ^c								
Private	106 (38.8)	258 (70.1)	315 (81.8)	<0.001				<0.001
Public	103 (37.7)	72 (19.6)	58 (15.1)					
Both	60 (22.0)	32 (8.7)	7 (1.8)					
Uninsured	4 (1.5)	6 (1.6)	5 (1.3)					
Child school attendance before COVID (January–February 2020) ^c								
Did not attend school	29 (10.6)	26 (7.1)	32 (8.3)	<0.001				<0.001
Attended public school	210 (76.9)	237 (64.6)	198 (51.4)					
Attended private school	34 (12.5)	104 (28.3)	155 (40.3)					
Caretakers with a spouse or partner during 2020 (vs no spouse or partner in 2020) ^d	233 (85.0)	325 (88.3)	365 (94.8)	0.22				<0.001
Household disruptions during the COVID-19 pandemic, March–December 2020								
Percentage with job loss (permanent or temporary) or reduction in hours—self or spouse/partner ^d	122 (44.7)	130 (35.5)	158 (41.0)	0.02				0.35
Percentage reducing work hours for childcare—self or spouse/partner ^d	91 (33.2)	128 (34.9)	119 (30.9)	0.66				0.53
Percentage reporting divorce, separation, or death of spouse/partner ^d	15 (5.5)	11 (3.0)	15 (3.9)	0.11				0.34
Percentage reporting difficulty paying bills during COVID ^d								
Any time March–December 2020	51 (18.6)	35 (9.5)	18 (4.7)	<0.001				<0.001
Spring (March–May) 2020	38 (13.9)	27 (7.3)	15 (3.9)	0.007				<0.001
Summer (June–August) 2020	45 (16.5)	27 (7.3)	14 (3.6)	<0.001				<0.001
Fall (September–December) 2020	44 (16.1)	29 (7.9)	11 (2.9)	0.001				<0.001
Percentage reporting child lacked private health insurance in 2020 or experienced disruptions to this coverage during COVID-19 (March–December) ^{d,e}	112 (41.0)	82 (22.3)	75 (19.5)	<0.001				<0.001

Items in bold are significant at a value of $p < 0.05$. ASD, autism spectrum disorder; DD, developmental disability; POP, population comparison group; SEED, Study to Explore Early Development.

^a p -value is for the χ^2 test of differences, for all variables but child age at clinic assessment and at time of the COVID-19 Impact Assessment, which are based on Student's t test.

^b Row percentage.

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^cColumn percentage.

^dPercentage with affirmative response.

^eThis group was selected for comparison with children who had continuous coverage with private health insurance given findings that children from the Study to Explore Early Development with public insurance only or no insurance were less likely to receive certain services (Rubenstein et al.³¹).

Table 2. Caregivers Reporting Missed or Delayed Service Appointments Because of the COVID-19 Pandemic and Reasons for Experiencing Difficulties Accessing Services During 2020

Type of Missed or Delayed Service/Reason for Interruption	ASD, No. (%)	DD, No. (%)	POP, No. (%)	aPR ^d ASD vs DD	aPR ^d ASD vs POP
Type of missed or delayed services					
Regular health/dental ^b	178 (65.2)	215 (58.4)	225 (58.4)	1.14 (1.00–1.29)	1.16 (1.01–1.32)
Immunization ^b	40 (15.9)	35 (10.1)	46 (13.0)	1.18 (0.75–1.87)	0.88 (0.56–1.37)
Specialty services ^{b,c}	199 (75.7)	166 (58.3)	50 (22.8)	1.30 (1.15–1.47)	3.46 (2.67–4.48)
Reasons for having difficulties accessing services ^d					
Clinic closures/cancellations ^e	157 (57.3)	168 (45.7)	132 (34.3)	1.21 (1.03–1.42)	1.66 (1.38–2.00)
Avoiding COVID-19 transmission ^f	160 (58.4)	150 (40.8)	136 (35.3)	1.41 (1.20–1.65)	1.57 (1.31–1.88)
Limited family resources ^g	19 (7.0)	26 (7.1)	14 (3.6)	0.77 (0.41–1.43)	1.06 (0.51–2.21)
Problems using telehealth ^h	80 (29.4)	61 (16.7)	41 (10.8)	1.58 (1.16–2.14)	2.51 (1.71–3.68)
Difficulty wearing a mask	65 (23.8)	28 (7.6)	11 (2.9)	2.50 (1.62–3.86)	6.53 (3.25–13.14)

Confidence interval does not overlap 1 for items in bold. aPR, adjusted prevalence ratio; ASD, autism spectrum disorder; DD, developmental disability; POP, population comparison group.

^a Adjusted for child sex, child race-ethnicity, child age at COVID-19 Impact Assessment, household income as a percentage of the federal poverty threshold, maternal education, SEED study site, job loss or reduced hours during COVID (March–December 2020), difficulty paying bills during COVID, and child health insurance status.

^b Estimates include 1026 (ASD: N = 273; DD: N = 368; POP: N = 385), 953 (ASD: N = 252; DD: N = 347; POP: N = 354), and 767 (ASD: N = 263; DD: N = 285; POP: N = 219) caregivers for regular health/dental, immunizations, and specialty services, respectively, because of missing and not applicable responses.

^c Specialty services were defined as specialty appointments or referral visits including behavior therapy, speech or language therapy, physical therapy, occupational therapy, social skills training, and mental health services.

^d All caregivers were asked to report whether they experienced difficulties, including those who did or did not miss services or experience delays.

^e Clinic was closed due to the COVID-19 pandemic, or the clinic or provider canceled an appointment due to the COVID-19 pandemic.

^f Caregiver or child had to stay home because of COVID-19 symptoms or infection, or caregiver canceled an appointment to avoid being around others or was concerned about the safety of public transportation.

^g Caregiver unable to pay for services or did not have transportation or childcare for siblings who were not allowed at appointment.

^h Caregiver did not want to use telehealth or was unable to use telehealth for an appointment, or child was unable to interact with a computer or was reported as too young.

Table 3. School Closures for In-Person Learning and Support Provided for Families Because of the COVID-19 Pandemic During 2020

Characteristic	ASD		DD		POP		p ASD vs. POP ^d
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	
School attendance and program participation before the COVID-19 pandemic							
Children attending school	245 (89.4)	342 (92.9)	353 (91.7)		0.12		0.32
Children with IEP/504 Plan	215 (87.8)	149 (43.7)	28 (7.9)		< 0.001		< 0.001
Children with IDEA accommodations	138 (56.3)	77 (22.6)	11 (3.1)		< 0.001		< 0.001
School closures ^b							
Child experiencing school closures for in-person learning at any time	236 (96.3)	327 (95.9)	333 (94.3)		0.79		0.26
Children experiencing school closures for in-person learning, spring (March-May 2020)	219 (89.4)	317 (93.0)	311 (88.4)		0.13		0.69
Children experiencing school closures for in-person learning, fall (September-December 2020)	202 (82.5)	257 (75.8)	248 (71.5)		0.05		0.002
Resources provided by schools to support learning during school closures ^c							
Children offered live classes to attend online	199 (84.3)	298 (91.1)	272 (82.2)		0.01		0.50
Children had assignments to complete online	181 (76.7)	267 (81.7)	247 (74.6)		0.15		0.57
Children had printed assignments sent home	184 (78.0)	268 (82.0)	246 (74.3)		0.24		0.32
Disruptions to special education plans and school-based accommodations ^d							
Individual special education disrupted greatly ^e	107 (50.0)	54 (36.2)	_{-g}		0.009		N/A
Ability to receive school-based accommodations decreased ^f	92 (66.7)	49 (63.6)	_{-g}		0.65		N/A

Items in bold are significant at a value of $p < 0.05$. ASD, autism spectrum disorder; DD, developmental disability; IDEA, Individuals with Disabilities Education Act; IEP, individualized education program; POP, population comparison group.

^a p -value is for the χ^2 test of differences.

^b Among children attending school pre-COVID pandemic (January–February 2020).

^c Among children experiencing school closures for in-person learning.

^d Among children with IEP/504 Plans and IDEA accommodations before the COVID-19 pandemic.

^e Disrupted greatly in comparison with all other response options (disrupted somewhat, no effect, improved somewhat, or improved greatly); includes IEPs and 504 plans.

^f Decreased greatly in comparison with all other response options (increased, increased and decreased at different times, or stayed the same); includes accommodations through the IDEA.

^g Not reported because of small sample size.