









NEW RESEARCH

COVID-19 Pandemic Impacts on Behavioral and Emotional Health of Young Children With Autism

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Objective: To test initial hypotheses that the coronavirus disease 2019 (COVID-19) pandemic was associated with decreases in adaptive behavior and increases in behavioral and emotional problems of children with autism; greater impacts for children who lost specialty services; and greater behavioral and emotional problems for children with autism vs control participants.



Method: Eligible participants (N = 1,158) enrolled in phase 3 of the multisite, case-control Study to Explore Early Development (SEED) before March 31, 2020, were between 2 and 5 years old, and completed follow-up assessments between January and July 2021. Caregivers completed a COVID-19 Impact Assessment Questionnaire, Vineland Adaptive Behavior Scales (VABS), and Child Behavior Checklist (CBCL) for 274 children with autism and 385 control participants.

Results: Mean VABS communication scores of children with autism decreased significantly (mean difference [SD] = -4.2 [10.5]) between pre-pandemic and pandemic periods, while VABS composite ($+2.0$ [9.0]), daily living ($+5.5$ [11.4]), socialization ($+2.3$ [10.0]), and CBCL (-3.2 [8.4]) scores improved. In contrast, CBCL scores worsened in population control participants ($+3.4$ [8.8]). Children with autism who missed specialty appointments scored significantly lower on VABS during the pandemic vs children who did not miss appointments (VABS Composite 70.6; 95% CI 68.8-72.4 vs 74.5; 95% CI 71.8-77.2).

Conclusion: While stay-at-home policies of the COVID-19 pandemic may have beneficially impacted daily living skills, socialization, and behavioral and emotional well-being of children with autism, benefits may have occurred at the cost of communication skills. These findings indicate the need for strategies to maintain therapeutic services in future emergency settings.

Diversity & Inclusion Statement: We worked to ensure sex and gender balance in the recruitment of human participants. We worked to ensure race, ethnic, and/or other types of diversity in the recruitment of human participants. We worked to ensure that the study questionnaires were prepared in an inclusive way. One or more of the authors of this paper self-identifies as a member of one or more historically underrepresented sexual and/or gender groups in science.

Key words: adaptive behavior; ASD; autism spectrum disorder; behavioral and emotional problems; COVID-19

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Public health measures initiated in the spring of 2020 to control the spread of coronavirus disease 2019 (COVID-19) disrupted the lives of children and families. Stay-at-home orders, masking, school closures, quarantining of confirmed cases, and many other measures altered daily routines and contributed to social isolation. Children with autism and other disabilities may have been more severely affected by the pandemic compared with other children, as these measures to control the pandemic interfered with their ability to receive specialty services, which may have adversely affected specific health outcomes.¹ Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by difficulties with

social communication and interaction and restricted or repetitive behaviors or interests.² One characteristic of autism that could have been particularly challenging during the pandemic is a preference for sameness and routines. Abrupt and dramatic changes in daily routines may have adversely affected adaptive functioning and behavioral and emotional health.

Among more than 25 studies published to date from multiple countries (Australia, Belgium, Canada, China, France, India, Israel, Italy, Kazakhstan, Netherlands, United Kingdom, United States) examining the impacts of the COVID-19 pandemic on behavioral and emotional health of children with autism, the findings have been inconsistent.

Most of these studies have entailed cross-sectional online surveys using semistructured interviews or questionnaires not previously validated.^{3–19} A minority of studies were longitudinal and employed standardized instruments both before and during the pandemic to measure autism symptoms, adaptive functioning, or behavioral and emotional health outcomes.^{20–25} Both types of study designs have produced mixed results, with about half of the studies reporting worsening of autism symptoms, adaptive behaviors, or behavioral and emotional health^{3,4,6,11,13–15,17,20,22,25,26} and most of the remaining studies reporting a mix of positive and negative impacts on behavior and functioning.^{5,7–10,16,18,19,23,27,28} For example, parents of children with autism surveyed in Israel reported increases in anxiety, tantrums, and repetitive behaviors and restricted interests of their children during the pandemic.⁵ They also reported improvements in social and communication abilities and family relationships.⁵

Factors reported in previous studies to be associated with worse behavioral outcomes and functioning of children with autism during the pandemic include loss of services,^{17,26} parental anxiety and stress,^{20,22} younger child age,²⁶ and low income.^{11,26} Surveys or questionnaires that were not standardized measures were commonly used in studies reporting a worsening of behavior problems, thus indicating that caregiver stress could be confounding the relation between the COVID-19 pandemic and behavior problems. It has since been predicted that parental stress levels due to the pandemic may have altered parenting behaviors with spillover effects on autism symptoms and behavior of children.²⁹ Inconsistencies in the findings across studies could also be due to geographic variations in the degree and timing of home quarantines, school closures, and disruptions to therapeutic services.³⁰

The present study has built on the existing literature by employing a longitudinal design with a US cohort of children with autism who were administered standardized measures of adaptive behavior^{31,32} and behavioral and emotional health³³ before and during the pandemic. In addition, behavioral and emotional health was evaluated both before and during the pandemic in a group of control children. Our study aimed to understand how the COVID-19 pandemic impacted the adaptive functioning and behavioral and emotional health of children with autism. We initially designed the study to test 3 hypotheses among children with autism, as follows: the COVID-19 pandemic was associated with decreases in adaptive functioning and increases in behavioral and emotional problems; greater impacts for children who lost access to specialty appointments than for children who did not; and (3) greater adverse impacts on the behavioral and emotional health of children

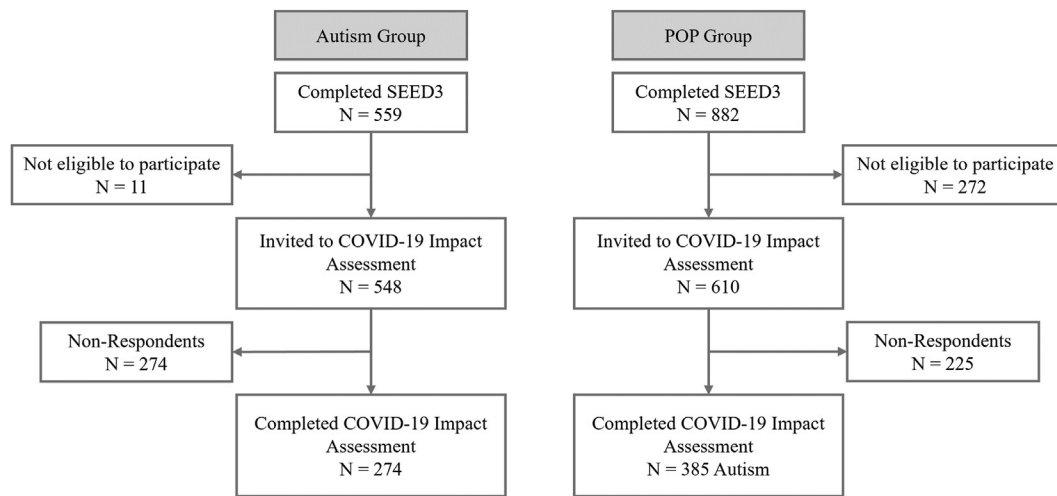
with autism than that of population control participants (POP). Since conducting the study, as mentioned, the literature has demonstrated both positive and negative behavioral and emotional impacts of the pandemic on children with autism. By testing our hypotheses as initially conceived, we hope to contribute to this literature and to improve understanding of the health and development of children with disabilities in public health emergencies.

METHOD

Sample

This study is a subsample from the Study to Explore Early Development, Phase 3 (SEED3) and the subsequent SEED3 COVID-19 Impact Assessment. SEED3 is a population-based, multisite case-control study of risk factors, co-occurring conditions, and behavioral phenotypes of ASD that was launched in 2017 at 6 sites located in Colorado, Georgia, Maryland, Missouri, North Carolina, and Wisconsin. Children were eligible for SEED3 if they were born and resided in the geographical study catchment areas, were between 2 and 5 years old, and lived with the same caregiver consistently from 6 months of age who communicated in English (or English or Spanish at the Colorado site). The present study focuses on 2 SEED3 groups: children with autism and POP. To be included in the study, potential participants with autism had to have received an ASD diagnosis from a clinical provider or received early intervention or special education services for ASD. A final classification of autism was based on the results from the Autism Diagnostic Interview–Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). Alternatively, POP were identified by randomly sampling birth records in the specified birth date range and geographical catchment area at delivery. Detailed descriptions of SEED eligibility criteria, enrollment methods, data collection, and criteria for autism classification using the ADI-R and the ADOS have been published previously.³⁴

The SEED3 COVID-19 Impact Assessment plan was developed between April and October 2020 to evaluate changes in development, health care, and school services before and during the pandemic. Eligible participants (N = 1,158) included families who completed SEED3 before March 31, 2020 (referred to as prepandemic in this article), and received a final study classification of autism or were part of the POP group. Data collection for the follow-up study occurred between January and June 2021 via mail. Eligible participants received a caregiver-report version of the Child Behavior Checklist (CBCL) to measure behavioral and emotional health; the Vineland Adaptive Behavior Scales, Third Edition (VABS-III) to measure adaptive

FIGURE 1 Flowchart of Included Participants of, Study to Explore Early Development (SEED) COVID-19 Impact Assessment

Note: POP = population control participants.

behavior; and the COVID-19 Impact Assessment, a 110-item questionnaire developed to gain insight into how the family was impacted by the pandemic in 2020. Figure 1 is a flowchart of families who were invited to participate in the COVID-19 Impact Assessment and returned all necessary components. Children were not eligible if they did not complete SEED3 before March 20, 2020, or if they did not consent to participate in follow-up.

The SEED3 protocol was approved by the Centers for Disease Control and Prevention (CDC) Institutional Review Board and institutional review boards at each study site. The SEED3 COVID-19 Impact Assessment was approved as an amendment to the SEED3 protocol in December 2020. This study followed the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) reporting guidelines.³⁵

Outcome Measures

Vineland Adaptive Behavior Scale. The VABS, Second Edition (VABS-II) Survey Interview Form was administered in person to the child's caregiver during the SEED3 clinic visit. VABS-II measures adaptive behaviors, including the ability to cope with environmental changes, learn new skills, and demonstrate independence.³¹ It is a semistructured interview consisting of 3-point scale items (from 0 = never to 2 = usually or often). For children younger than 6 years, VABS-II comprises 4 domains: communication, daily living, socialization, and motor skills. A composite score of overall adaptive behavior is derived from the summation of domain scores. Scores for each domain range from 20 to 160 (mean [SD] = 100 [15]) with higher scores indicating higher adaptive functioning. The VABS, Third Edition

(VABS-III) is an updated version of VABS-II that includes parent-report questionnaires in addition to semistructured interviews.³² A study of concordance between VABS versions found that VABS-III produces lower scores than VABS-II in individuals with intellectual and developmental disabilities.³⁶ The Domain-Level Parent/Caregiver Form is a briefer version of the semistructured interview that incorporates updated skill examples and simpler wording and does not include the Motor Skills domain in composite score calculation. This form was mailed with the SEED3 COVID-19 Impact Assessments for caregivers to complete and return. While the caregiver-reported method of data collection could induce bias, the pandemic restricted alternative methods of data collection. VABS scores are derived based on age norms, therefore controlling for the expected maturation with age between SEED3 and the SEED3 COVID-19 Impact Assessment.

Child Behavior Checklist. The CBCL is a standardized caregiver-administered questionnaire that assesses behavioral and emotional problems in young children on a 3-point scale (from 0 = absent to 2 = occurs often).³³ Caregivers first completed the CBCL at the SEED3 clinic visit. For the SEED3 COVID-19 Impact Assessment, caregivers were mailed CBCL forms to fill out along with the COVID-19 Impact Assessment questionnaire. Due to the nature of the pandemic, an in-person interview could not be conducted, so the questionnaire format was required. The CBCL includes 2 domains: externalizing and internalizing behaviors. T scores from each domain and a Total Problems score were collected, with a score ≥ 60 indicating borderline to clinically significant behavioral and emotional problems.

Covariates

SEED3 COVID-19 Impact Assessment Questions. Caregivers were asked: “In 2020, due to changes related to COVID, did the study child miss or delay any specialty appointments or referral visits such as behavior therapy, speech or language therapy, physical therapy, occupational therapy, social skills training, or mental health services?” Response options were “Yes,” “No,” or “Not Applicable.” For analytical purposes, the latter 2 categories were combined. Hereinafter this variable will be referred to as missed specialty appointments, though a child could have missed or delayed a specialty appointment or referral visit. Caregivers were also asked to give a numeric response to the following question: “In January or February of 2020, about how many hours per week on average did the study child receive any of these services from a professional provider, such as from school, a clinic, or another source?” Finally, receiving telehealth services was a binary variable in which children were coded as receiving said services if any of their therapies were conducted remotely at some point during the pandemic.

Mullen Scales of Early Learning. The Mullen Scales of Early Learning (MSEL) is an instrument used to measure cognitive ability in children up to 68 months of age.³⁷ It is a clinician-administered interactive assessment that yields a standard score (mean [SD] = 100 [15]) and comprises a Gross-Motor Scale and 4 Cognitive Scales: Visual Reception, Fine-Motor, Receptive Language, and Expressive Language. The Visual Reception t score (mean [SD] = 50 [10]) from the in-person SEED3 clinic visit was used as an index of nonverbal cognition to avoid underestimating cognitive ability in children with language delays as a function of their young age.³⁸

Additional Covariates. Other covariates were reported during the SEED3 caregiver interview. Household income relative to the federal poverty level used the ratio of caregiver-reported household income in the 12 months before the interview and the federal poverty level, with $\leq 100\%$ representing below the poverty threshold. The mother was asked about the highest grade or year of school/college completed. If this question was missing, maternal education was extrapolated from birth record data. Child sex, age, race, and ethnicity were reported by the caregiver. SEED study site was the geographic state where the family participated. Time between assessments was calculated as the difference between the dates of the SEED3 COVID-19 Impact Assessment and the SEED3 clinic visit.

Statistical Analysis

Likelihood ratio χ^2 tests were performed to determine differences between autism and POP groups for nominal

descriptive variables, Mantel-Haenszel χ^2 tests were performed for the ordinal variables, and independent sample t tests with pooled standard deviations were performed for continuous variables. Paired t tests were used to compare the means of the SEED3 and SEED3 COVID-19 Impact Assessment VABS and CBCL scores. VABS measures were available from SEED3 only for the autism group, so analyses in the POP group were limited to the CBCL outcome. McNemar tests were used to compare the proportions of children who had borderline to clinical behavioral and emotional problems before the onset of the pandemic compared with during the pandemic.

Multiple linear regression models were built to estimate VABS and CBCL least-squares means measured during the pandemic, adjusting for the respective SEED3 domain score, sex, race, ethnicity, study site, age at clinic visit, MSEL Visual Reception score, time between studies, receipt of telehealth services, and having missed a specialty appointment during the pandemic. Additionally, VABS models were adjusted for average weekly hours of specialty services received before COVID. Least-squares means are computed based on linear models and are used to control for the potential effects of confounders, portraying comparisons of children with autism who did and did not miss a specialty appointment during the pandemic. Regression model coefficients are documented in Table S2, available online.

A sensitivity analysis was conducted to compare the complete case analysis with an analysis applying multiple imputation by chained equations to impute data nonrespondents to the SEED3 COVID-19 Impact Assessment. Missing data were imputed using the mice R package.³⁹ We included all variables listed in the main analysis in the imputation model and performed 50 imputations with 200 iterations each to impute missingness in covariates as well as the VABS and CBCL scores of the nonrespondents.

All tests of statistical significance were 2-sided, and a p value $< .05$ was considered significant. Statistical analyses for complete case analysis and analysis of the imputed data were conducted using SAS 9.4,⁴⁰ and multiple imputation was conducted using R Version 4.2.2.⁴¹

RESULTS

Baseline participant characteristics for the autism and POP groups are shown in Table 1. A total of 274 children with autism and 385 POP completed the VABS and/or CBCL in both SEED3 and the SEED3 COVID-19 Impact Assessment. Compared with POP, children with autism were more likely to be male ($p < .0001$), from a racial and ethnic minority group ($p = .0001$), and from lower-income

TABLE 1 Characteristics of Study Participants Who Completed Study to Explore Early Development, Phase 3 (SEED3) and SEED3 COVID-19 Impact Assessment

Characteristic	Autism (n = 274)		POP (n = 385)		p ^a
	n	%	n	%	
Study site					.2710
Wisconsin	63	23.0	90	23.4	
Missouri	59	21.5	82	21.3	
North Carolina	43	15.7	59	15.3	
Colorado	39	14.2	79	20.5	
Maryland	39	14.2	40	10.4	
Georgia	31	11.3	35	9.1	
Child sex					<.0001
Male	217	79.2	200	52.0	
Female	57	20.8	185	48.1	
Child race ^b					.0001
Black, non-Hispanic	41	15.0	24	6.2	
Hispanic	35	12.8	39	10.1	
White, non-Hispanic	158	57.7	278	72.2	
Household income relative to federal poverty level					<.0001
≤100%	56	20.4	17	4.4	
>100% to ≤200%	52	19.0	49	12.7	
>200% to ≤300%	42	15.3	67	17.4	
>300% to <400%	64	23.4	84	21.8	
≥400%	54	19.7	163	42.3	
Missing	6	2.2	5	1.3	
Maternal education					<.0001
Without high school diploma	8	2.9	3	0.8	
High school graduate without college education	43	15.7	13	3.4	
Some college education	81	29.6	61	15.8	
Degree from 4-y college or more	141	51.5	307	79.7	
Missing	1	0.4	1	0.3	
	Mean	SD	Mean	SD	
Age at clinic visit, mo	47.2	8.8	44.3	8.1	<.0001
Time between parent reports	26.3	7.9	29.2	5.8	<.0001
Mullen scores					
Early learning composite	64.9	19.5	104.8	16.6	<.0001
Visual reception	33.5	15.2	56.8	10.9	<.0001
	n	%	n	%	
Received telehealth services during pandemic	194	70.8	24	6.2	<.0001
Specialty appointments disrupted during pandemic					<.0001
Yes	199	72.6	50	13.0	
No	64	23.4	169	43.9	
Not applicable	11	4.0	165	42.9	
Missing	0	0.0	1	0.3	

(continued)

TABLE 1 Continued

Characteristic	Autism (n = 274)		POP (n = 385)		p ^a
	n	%	n	%	
	Mean	SD	Mean	SD	
Average weekly hours of specialty services, prepandemic	12.4	12.1	1.8	2.6	<.0001

Note: POP = population control participants.

^aLikelihood ratio χ^2 tests were used to calculate p values for nominal descriptive variables; Mantel-Haenszel χ^2 tests were used for ordinal variables; independent sample t tests with pooled standard deviations were used for continuous variables; and paired t tests were for differences between the SEED3 and SEED3 COVID-19 Impact Assessment Vineland Adaptive Behavior Scale and Child Behavior Checklist scores.

^bDue to small sample sizes, American Indian/Alaska Native, Asian, Native Hawaiian or other Pacific Islander, multiple races, or those reporting other race were not included in this table.

household ($p < .0001$). Among children with autism, 72.6% missed specialty appointments, and 70.8% received some appointments via telehealth due to the pandemic. In the POP group, only 13.0% of children missed specialty appointments, though few of these children had regularly scheduled appointments before the pandemic, and 6.2% were able to continue to receive services via telehealth during the pandemic.

Of the 1,158 families enrolled in SEED3, 56.9% of participants responded to the SEED3 COVID-19 Impact Assessment. Respondents were more likely to be non-Hispanic White, of higher income, and higher maternal education compared to non-respondents, regardless of group status (Table S1, available online). In the autism group, SEED3 VABS and CBCL scores were similar in respondents and nonrespondents, although individuals who participated in the follow-up assessments had higher MSEL and VABS communication scores on average ($p = .04$) than those who did not participate in follow-up. Children of respondents in the POP group scored higher on MSEL at baseline and had better behavioral and emotional health as documented by the CBCL. Eligible participants may not have responded to the SEED3 COVID-19 Impact Assessment due to the amount of time it would take to complete the measures, particularly if families were experiencing additional stressors related to the pandemic.

Changes in Adaptive Functioning and Behavioral and Emotional Problems

VABS communication domain scores of children with autism declined significantly from before to during the

TABLE 2 Vineland Adaptive Behavior Scale (VABS) and Child Behavior Checklist (CBCL) Score Changes From Prepandemic to During Pandemic

	Prepandemic, September 2017 to March 2020			During pandemic, January 2021 to July 2021			Mean difference			<i>p</i> ^a
	n	Mean	SD	n	Mean	SD	n	Mean	SD	
Autism group										
VABS composite	273	71.5	11.8	271	73.5	12.6	270	+2.0	9.0	.0002
VABS communication	274	76.1	17.0	272	71.8	17.4	272	-4.2	10.5	<.0001
VABS daily living	274	72.5	13.3	272	78.0	14.5	272	+5.5	11.4	<.0001
VABS socialization	274	71.2	10.5	272	73.4	12.7	272	+2.3	10.0	.0002
CBCL total score	273	64.3	10.8	274	61.1	9.9	273	-3.2	8.4	<.0001
CBCL internalizing	273	63.2	9.6	274	57.8	10.3	273	-5.5	9.0	<.0001
CBCL externalizing	273	61.0	11.2	274	57.7	10.7	273	-3.2	9.1	<.0001
POP										
CBCL total score	384	42.2	9.3	385	45.6	11.0	384	+3.4	8.8	<.0001
CBCL internalizing	384	41.6	9.2	385	45.6	10.1	384	+3.9	9.7	<.0001
CBCL externalizing	384	43.2	9.8	385	46.9	10.9	384	+3.6	9.5	<.0001

Note: POP = population control participants.

^a*p* value calculated using paired samples *t* tests.

pandemic, with mean scores measured during the pandemic 4.2 (SD = 10.5) points lower on average than prepandemic scores (Table 2). In contrast, mean scores improved significantly for the composite, daily living, and socialization domains during the pandemic compared to the prepandemic period with largest improvements in daily living (mean [SD] = 5.5 [11.4] points), followed by socialization (2.3 [10.0]) and the composite score (2.0 [9.0]). All differences were statistically significant ($p < .05$) (Table 2). After imputing the nonrespondent and covariate data, the mean differences between VABS and CBCL scores before and during the pandemic were similar to complete case analyses, though slightly attenuated (Table S3, available online). In the imputed analysis, all scores obtained during the pandemic were statistically significantly different from the prepandemic scores except for the VABS socialization domain. In the autism group, the VABS composite and daily living scores improved, while the VABS communication score declined.

Contrary to our hypothesis, CBCL scores of children with autism improved significantly from before to during the pandemic (mean difference [SD] = -5.5 [9.0] for internalizing behavior problems and -3.2 [9.1] for externalizing problems), indicating fewer behavioral and emotional problems during the pandemic compared with before the pandemic (Table 2). The same pattern occurred for multiply imputed CBCL scores (Table S3, available online). Before the pandemic, 67.5% of children with autism had borderline to clinically significant behavioral and

emotional problems compared with 58.8% during the pandemic ($p = .0088$); the largest decrease was in the internalizing domain with a 24.1% reduction in the proportion of children with borderline to clinically significant problems compared with a 10.6% reduction in the externalizing domain (Table 3). In contrast, 5.5% of children in the POP group had borderline to clinically significant behavior problems before the pandemic compared with 10.9% during the pandemic ($p = .0003$).

Limited sample sizes restricted our ability to analyze the outcomes by individual predictors, as it would have resulted in an underpowered analysis. However, similar patterns were observed before and during the pandemic, regardless of sex, race or ethnicity, age, or the amount of time that passed between assessments.

Missed Specialty Appointments in Children With Autism

When stratifying the SEED3 COVID-19 Impact Assessment VABS scores by children with autism who did and did not miss specialty appointments during the pandemic, children who did not miss specialty appointments scored higher on average (Table 4). However, mean VABS composite and daily living domain scores were statistically significantly higher. After adjustment for covariates, the difference in scores between children who did and did not miss specialty appointments also became statistically significant for the communication domain. The largest difference in VABS scores between children who did and did not miss specialty appointments was in the daily living skills

TABLE 3 Proportion of Borderline to Clinically Significant Child Behavior Checklist (CBCL) Scores^a

	Prepandemic		During pandemic		<i>p</i> ^b
	n	%	n	%	
Autism group (n = 274)					
Total score	185	67.5	161	58.8	.0088
Internalizing behaviors	192	70.1	126	46.0	<.0001
Externalizing behaviors	152	55.5	123	44.9	.0017
POP group (n = 385)					
Total score	21	5.5	42	10.9	.0003
Internalizing behaviors	17	4.4	34	8.8	.0052
Externalizing behaviors	25	6.5	47	12.2	.0012

Note: POP = population control participants.

^aBorderline to clinically significant CBCL score ≥ 60 .

^b*p* value calculated using McNemar test.

domain, followed by the composite, communication domain, and socialization domain. In the stratified analysis of CBCL scores, children who missed specialty appointments scored slightly higher, suggesting worse behavioral and emotional health for these children, though these differences were not statistically significant. In the adjusted CBCL models, the conclusions remain the same. Missing specialty appointments appeared to have little association with CBCL scores during the pandemic after adjustment. Least-squares means from multiply imputed data were similar to complete case analysis of children with autism who did and did not miss specialty appointments during the pandemic (Table S4, available online).

DISCUSSION

Limited longitudinal evidence exists demonstrating the impacts of the COVID-19 pandemic on children with autism, and results are conflicting.⁴² We hypothesized that major disruptions during the COVID-19 pandemic that affected many aspects of children's lives would have adverse impacts on adaptive behavior and behavioral and emotional health. Additionally, we hypothesized that these adverse impacts would be worse for children who lost specialty services and worse for children with autism compared with the POP group.

Our initial hypothesis was partially supported, with adverse impacts particularly on communication scores for young children with autism. The 4.2-point decline in communication scores that we observed was above the threshold for clinically significant differences of VABS communication scores, which ranges from 2.0 to 3.2 points based on method and individual IQ.⁴³ This finding is consistent with some,^{9,22,26} though not all,^{9,28,30} findings from previous studies of impacts of the pandemic on the

communication skills of children with autism. Longitudinal decreases in communication scores during the pandemic could be related to public health measures taken to control the spread of the coronavirus, as social distancing measures limited the opportunities to practice and further develop communication skills.⁴⁴ However, inconsistencies in study methods and the directionality of findings preclude firm conclusions about the impacts of the pandemic on communication of children with autism.

Contrary to our initial hypothesis, there were significant improvements in the daily living and socialization adaptive behavior domains. Daily living skills increased by an average of 5.5 points, indicating the acquisition of important life activities, as this average increase is both clinically and statistically significant.⁴³ Improvements in adaptive behavior in children with autism could have resulted from reduced exposure to stressors associated with school routines⁴² and the increased opportunities of parents to spend time with their children to support daily living and social skills, which could be reflected in improved VABS scores.^{10,24} A study of 33 Italian preschool-age children with autism also found increases in conceptual and practical measures of adaptive behavior when comparing measures taken after the COVID-19 lockdown with measures taken before the pandemic.²⁴ However, that study saw a decrease in the socialization domain early in the pandemic, potentially due to the stricter lockdown procedures that occurred in Italy compared with the United States.

The COVID-19 pandemic brought about additional challenges for families of children with disabilities in accessing specialty services. We hypothesized that children who were able to continue to receive services throughout the pandemic would fare better. After accounting for covariates, children with autism who missed specialty appointments due to closures during the pandemic had a

TABLE 4 Assessments Measured During COVID-19 Pandemic Stratified by Missed Specialty Appointments and Multivariate Linear Regression for Covariate-Adjusted Assessment Scores in Autism Group

	Prepandemic score ^a		Mean score during pandemic ^b				<i>p</i> ^c	Covariate adjusted models ^d				
	Mean	SD	Did not miss specialty appointments		Missed specialty appointments			Did not miss specialty appointments		Missed specialty appointments		<i>p</i> ^c
			Mean	SD	Mean	SD		LS mean	(95% CI)	LS mean	(95% CI)	
VABS												
Composite	71.5	11.8	76.2	14.2	72.2	11.8	.0464	74.5	(71.8, 77.2)	70.6	(68.8, 72.4)	.0035
Communication	76.1	17.0	74.0	17.5	70.4	17.2	.1571	72.9	(69.7, 76.1)	68.7	(66.5, 70.9)	.0070
Daily living	72.5	13.3	82.2	15.1	76.3	14.2	.0074	80.2	(76.8, 83.6)	74.6	(72.3, 76.9)	.0006
Socialization	71.2	10.5	75.6	15.4	72.4	11.7	.1265	73.6	(70.3, 76.8)	70.9	(68.7, 73.1)	.0857
CBCL												
Total score	64.3	10.8	60.0	10.4	61.9	9.7	.2039	61.3	(58.8, 63.7)	63.0	(61.3, 64.6)	.1490
Internalizing	63.2	9.6	56.7	11.1	58.4	10.0	.2873	58.4	(55.8, 61.1)	59.8	(58.0, 61.6)	.2680
Externalizing	61.0	11.2	57.3	10.6	58.1	10.8	.6183	58.9	(56.2, 61.5)	59.4	(57.6, 61.2)	.6576

Note: CBCL = Child Behavior Checklist; LS mean = least-squares mean; MSEL = Mullen Scales of Early Learning; SEED3 = Study to Explore Early Development, Phase 3; VABS = Vineland Adaptive Behavior Scale.

^aAt baseline, the sample size for the VABS composite score and CBCL total score, internalizing, and externalizing scores was $n = 273$. For the VABS communication, daily living, and socialization domains, the sample size was $n = 274$.

^bFor children who did not miss specialty appointments, the sample size was $n = 62$ for each VABS domain and $n = 64$ for each CBCL score. The sample size for children who missed specialty appointments during the COVID-19 pandemic was $n = 198$ for the VABS composite and $n = 199$ for every other domain in the VABS and CBCL.

^c*p* values indicate the comparison between the mean scores of children who did and did not miss specialty appointments during the pandemic.

^dAdjusted for child sex, child race/ethnicity, child age at clinic visit, study site, MSEL Visual Reception score, respective SEED3 domain score, average pre-COVID weekly hours of specialty services, months between SEED3 and SEED3 COVID-19 Impact Assessment, whether specialty appointments were missed during the pandemic, and whether the child had telehealth services during the pandemic.

decline of 7.4 points in the communication domain compared with a 3.2-point average decline in children who did not miss appointments, indicating the importance of receiving services. A meta-analysis by Sandbank *et al.*⁴⁵ found that speech and language therapies facilitate statistically significant improvements in language outcomes for young children with autism, particularly when implemented by clinicians or a combination of clinicians and caregivers. Our results suggest that in preparing for future service disruptions associated with public health emergencies, ensuring continuity of language and communication therapies using telehealth and other modalities may help prevent language regression. Despite emerging evidence supporting telehealth-based adaptations of social communication interventions, proven programs are not yet widely available.^{27,46–48} The natural experiment opportunity provided by the COVID-19 pandemic emphasized the importance of receiving services for the communication skills of young children with autism.

We expected that pandemic-related disruptions in routines and access to services would have a greater impact on behavioral and emotional problems for children with autism than for POP but found instead that children in the POP group reported an increase in behavioral and emotional problems as reported by the CBCL. Siracusano *et al.*²⁴ also found improvements in CBCL scores of children with autism after the onset of pandemic lockdown procedures in Italy. It is possible that the stay-at-home period was less stressful for children with autism than in-person classes and intensive therapy regimens, and this could have resulted in improvements in behavior. However, other studies have reported increases in behavioral and emotional problems of children with autism during the pandemic.^{3,6,49} Rather than reporting changes in pre-post scores from validated and standardized tools, such as the CBCL used in this study, previous studies reporting adverse behavioral impacts were based on parent impressions reported in questionnaires developed during the pandemic and may not have accurately measured behavioral changes.^{3,5,9,17} Location-specific differences in lockdown policies and disruptions in which these studies were conducted could contribute to the differing results as well.

With respect to other aspects of adaptive behavior and behavioral and emotional problems, our findings of improvements among children with autism during the pandemic may indicate the need for further research into potential stress or other adverse impacts for children receiving specialized services. A recent survey of health care professionals in England concluded that the COVID-19 pandemic revealed a pressing need for improvements in

services to reduce stresses and better accommodate individuals with autism and their families.⁵⁰ Understanding why children with autism may have improved in certain areas of adaptive functioning as well as behavioral and emotional health during the COVID-19 pandemic is important in planning for how services should be delivered in the future.

The observational nature of this study is a limitation. However, the availability of measures of adaptive behavior and behavioral and emotional health both before and during the pandemic and the inclusion of a control group allowed us to make robust pre-post comparisons, evaluate changes over time, and compare impacts on children with autism and POP. Another important strength of this study is the inclusion of a diverse, population-based sample. The POP group was selected to be representative of the geographically defined communities where the children identified as having autism resided, while the autism group was intended to be representative of children with autism in those communities. However, families enrolled in the SEED POP group are less diverse and more highly educated than families in the respective community populations.⁵¹ These findings could suggest selection bias because families who consented to participate may not represent all those with a child with autism or the general population, potentially limiting the generalizability of the results. While correlated with direct observation of the child's behavior or assessment of their abilities, parent responses to the VABS and CBCL are potentially influenced by unmeasured factors that may contribute to changes observed during the pandemic, including the amount of time caregivers spent with the child or caregiver stress related to the pandemic. Another limitation is that the prepandemic adaptive behavior scores were captured using the VABS-II, while follow-up measures were documented using the VABS-III. However, a study of the concordance of the 2 editions found that among individuals with intellectual and developmental disabilities, the VABS-III produces lower scores than the VABS-II,³⁶ indicating that the improvements we observed in VABS domains may underestimate actual improvements. Additionally, the decrease we observed in the communication domain may have been a function of the different version of the tests, and this decline may not have been as substantial. The changes we observed were relatively short-term. Additional research is needed to determine whether these changes persist over a longer period.

In conclusion, we found significant declines in the communication scores of young children with autism during the pandemic, while daily living skills, socialization skills, and behavioral and emotional health improved during this time based on measures taken during the COVID-19

pandemic compared with those taken before. Children who missed specialty appointments during the pandemic saw greater declines in communication relative to children who did not miss appointments, supporting the need for equitable and accessible delivery of care. In contrast to the POP group, children with autism experienced improvements in behavioral and emotional health. This, combined with their improvements in daily living and other adaptive skills, may point to the need for therapeutic interventions that are less stressful for children with autism.

CRedit authorship contribution statement

Olivia M. Pokoski: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Hayley M. Crain:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Sarah M. Furnier:** Writing – review & editing, Validation, Methodology, Investigation, Formal analysis, Conceptualization. **Ronald E. Gangnon:** Writing – review & editing, Methodology, Investigation, Formal analysis. **Cy Nadler:** Writing – review & editing, Methodology, Investigation, Data curation. **Eric J. Moody:** Investigation, Data curation. **Karen Pazol:** Writing – review & editing, Methodology, Investigation, Formal analysis, Data curation. **Maria A. Stanley:** Writing – review & editing, Investigation. **Lisa D. Wiggins:** Writing – review & editing, Methodology, Investigation, Formal analysis, Data curation. **Maureen S. Durkin:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – original draft, Writing – review & editing.

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