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The Impact of the Novel Coronavirus Disease 2019 on Therapy Service Delivery for Children with Disabilities

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Objective To assess the impact of the novel coronavirus disease 2019 (COVID-19) pandemic on the delivery of, and parent satisfaction with, therapy services for children with disabilities in early intervention, school, and outpatient settings.

Study design There were 207 parents of children with disabilities who completed a web-based survey about their child[ren]'s access to, and satisfaction with, therapy services during COVID-19. Parents also completed the Family-Provider Partnership Scale and the Telehealth Satisfaction Scale. Satisfaction was compared between families receiving therapies in school, early intervention, outpatient, and multiple settings.

Results Forty-four percent of parents reported low satisfaction with their child[ren]'s therapy services during the pandemic. Access to telehealth positively predicted overall satisfaction and satisfaction with the family-provider partnership, whereas receiving school-based therapies negatively predicted overall satisfaction and satisfaction and satisfaction with the family-provider partnership.

Conclusions School-based therapies are legally mandated for eligible students, free of cost to families, integrated in the academic setting, and less burdensome on parents than other services. Thus, given the disparity in parental satisfaction regarding school-based service delivery, addressing therapy delivery in school-based settings during the duration of COVID-19 is critical for preventing increased disparities and more effectively meeting children's needs. Telehealth seems to be a promising option for continuing high-quality services during the duration of the COVID-19 pandemic and for families who face barriers in accessing services in general. Future studies are warranted with larger and more diverse samples, as well as longitudinal studies that monitor service access and parent satisfaction throughout the remainder of the pandemic. (*J Pediatr 2021;231:168-77*).

ervices such as physical therapy, occupational therapy, psychological services, and speech-language therapies, can help to ameliorate children's functional limitations and promote development.^{1,2} Unfortunately, the novel coronavirus disease 2019 (COVID-19) pandemic has upended service delivery across settings for these children, resulting in decreased access or complete loss of therapy services.³⁻⁵ Gaps in these critical services could result in deficits that ultimately exacerbate the disparities already experienced by these vulnerable children.⁶⁻⁸

Researchers and service providers must better understand the perspectives of parents regarding their children's therapies, because parents have had to take on a significant portion of service delivery during the pandemic. Cacioppo et al⁴ reported that up to 83% of therapies were being delivered by parents during the beginning of stay-at-home orders. Furthermore, parents of children with disabilities have reported even greater levels of stress, mental health symptoms, burnout, and social isolation during COVID-19 than parents of nondisabled children.^{9,10} By better understanding parent perception of services, providers can form more collaborative partnerships with families to ensure that children receive optimal services during the pandemic and during the transition to postpandemic life.¹¹

This study examines how children with disabilities are receiving services and how families are experiencing those services through 3 main research questions. First, how are children receiving therapy services during COVID-19? Given the reduced restrictions on the use of telehealth platforms, we were particularly interested in the use of telehealth services.¹² Second,

how satisfied are parents with service delivery? Understanding parents' satisfaction could identify opportunities for improving service delivery during service disruptions, including pandemics. Third, does satisfaction differ for families receiving services in school, early intervention (EI), outpatient, or multiple settings? Because each setting uses a different model, understanding differences in parents' satisfaction across settings could provide valuable learning opportunities.

COVID-19Novel coronavirus disease 2019ElEarly interventionTSSTelehealth Satisfaction Scale

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Methods

Caregivers of children with disabilities were recruited via Facebook ads and Facebook parent groups, emails from local EI offices, and ResearchMatch.org. Legal guardians of children under the age of 22 years receiving therapy services for disabilities were eligible. Parents completed an open, voluntary REDCap survey regarding parent and child demographics, information on their child[ren]'s services, and measures regarding their current and prior satisfaction with the family-provider partnership. Furthermore, parents completed a measure on their experiences with telehealth services during COVID-19. The study was approved by Northwestern University's Institutional Review Board, and the survey was subsequently marked as exempt because no identifiable information, including IP addresses or cookies, was collected. The survey was tested for usability and accessibility by the research team before being released for public use, and adaptive questioning was used to decrease the number and complexity of the questions each respondent received. Thus, the number of questions and pages varied based on each respondent's response. Parents had the option to change prior answers by using a back button. Parents who completed the survey could opt into receiving the results of the study after completion. The survey took 10-15 minutes to complete. Informed consent detailing the purpose and length of the survey and how data would be stored was obtained from all respondents. Data were collected from May 11 to July 31, 2020. Only completed surveys were analyzed.

Disability Status and Services

For each child with a disability or disabilities in the household, parents indicated which categories, as listed in the Individuals with Disabilities Education Act, applied to the child.¹³ These categories excluded multiple disabilities, because parents could select more than 1 category. In addition, attention deficit/ hyperactivity disorder and sensory processing disorder were added to the list of possible disabilities.

Parents then reported what services each child was receiving at the time of survey completion and in which settings (EI, school, or outpatient) these services were delivered. Service options included physical therapy, occupational therapy, speech-language therapy, psychological services, social work services, behavior therapy (clarified as applied behavior analysis), feeding therapy, and developmental therapy. Parents also had the option to include other therapies; however, this category was excluded from this analysis because most answers either referred to academic interventions or could be recoded into one of the other service types. For each service reported in each setting (eg, physical therapy received in the school setting), parents also reported the modality by which their child received this service during COVID-19 (eg, in person, by telephone, video-based telehealth). Parents could select multiple modalities and write in an "other" option regarding how each service was received. A "not receiving services owing to COVID-19" option was added after data collection started in response to a large number of parents reporting in the other option that their child was not actively receiving a service. During analysis, families whose child[ren] received services in multiple settings (eg, 1 child receiving EI services and a second child receiving school-based therapies, or a child receiving services in 2 settings) were also identified for further comparison against families only receiving services in 1 setting.

Overall Satisfaction

At the end of the survey, parents rated their overall satisfaction with the services their child[ren] received according to a 3-point rating scale (low, medium, or high) used in a prior research study.¹⁴ These ratings referred to overall satisfaction with all of the services their child[ren] were receiving and not to satisfaction with a specific service.

Parent Satisfaction with the Family-Professional Partnership

The Family-Professional Partnership Scale, developed by the Beach Center on Disability, measures parent satisfaction with how service providers interact with the family.¹⁵ The Family-Provider Partnership Scale consists of 18 statements that parents rated from 1 (very dissatisfied) to 5 (very satisfied). The Family-Provider Partnership Scale has 2 subscales, namely, child-focused relationships and family-focused relationships (both 9 questions). The Family-Provider Partnership Scale does not have clinical cut-off values that determine the clinical significance of a response. Rather, it gives a more general idea of a family's satisfaction and experiences with providers that can be used by clinicians to assess family-provider partnership quality. The internal consistency for the subscales is an α of 0.94 and an α of 0.92, respectively, and an α of 0.96 for the full scale. Parents were asked to complete this measure regarding their general satisfaction with service providers who worked with their child[ren] during COVID-19 and not in terms of any 1 specific provider. In addition, parents were asked to retrospectively report their general satisfaction with the family-provider partnership for their child[ren]'s service providers before the start of the pandemic.

Telehealth Satisfaction

The Telehealth Satisfaction Scale, Telerehabilitation and Televisitation Sessions Version (TSS) was administered to participants who had access to video-based telehealth during COVID-19.¹⁶ The TSS is a 12-item measure that asks respondents to rate various aspects of the telehealth experience on a 4-point scale (poor, fair, good, and excellent, scored 1-4). The TSS also asks if the respondent would use telehealth again and if they would recommend telehealth to another person. Internal consistency is an α of 0.90. Participants responded in reference to their general experience with telehealth and not in regard to 1 specific service.

Statistical Analyses

All analyses were conducted using the programming software R. Descriptive statistics were calculated using the pastecs package.¹⁷ Comparisons between categorical variables, including overall satisfaction ratings, were completed using χ^2 tests.

To control for the retrospective family-provider partnership satisfaction before the pandemic, change scores were calculated for each participant based on the difference between during and pre-COVID-19 family-provider partnership scores. The resulting values violated the assumptions of normality, according to the Shapiro-Wilks normality test (W = .89; P < .001). TSS total scores also were not normally distributed (W = .96; P < .001). Thus, nonparametric tests were used to identify statistical differences between groups for these 2 variables. The Wilcoxon sign rank-sum test was used to identify differences between 2 groups and the Kruskal-Wallace rank-sum test was used to identify differences between 3 or more groups. The *P* value cutoff for statistical significance was designated at .05. Results that trended toward significance (P < .1) are also reported.

Furthermore, to further understand satisfaction with services across settings, analyses were conducted comparing families only receiving services in one setting (school, outpatient, or EI) and families receiving services in multiple settings. Parents were first asked to list all service types each child was receiving (eg, speech therapy, physical therapy) and the setting in which the child typically received these services. Families receiving services in multiple settings were identified during analysis.

Results

Participants

Six hundred sixty-four individuals accessed the survey, 345 (54%) consented to take the survey, and 207 (32%) eligible parents completed it. Respondents were predominantly female (96%) ranging in age from 23 to 70 years (mean, 40 ± 8 years). Parents provided information on 276 children with disabilities ranging from 0 to 21 years (mean, 8 ± 4 years for child ages 0-18 years). Nine children were 19-21 years of age, but their exact ages were not recorded. Parents reported that children fell into an average of 3 ± 2 disability categories. Although the majority of respondents were from the Midwest (115 [56%]), the sample did have some geographic diversity throughout the continental US with 18 respondents (9%) in the Northeast region of the US, 38 (18%) in the South, and 23 (11%) in the West. In addition, 3 respondents (1%) resided outside of the US, and 10 respondents (5%) did not provide their location. Table I describes additional parent and child demographics.

Services Received during COVID-19

Children received an average of 3 ± 1 services. The type of therapies received and the setting in which they were received

during COVID-19 are described in Table II. Video-based telehealth was the most common modality for outpatient and EI service settings, except for outpatient applied behavior analysis, which was most commonly delivered inperson. In contrast, school-based services were most commonly delivered through assignments sent home to either the parent or the child, except for psychological services, which were most commonly delivered via videobased telehealth. School-based speech and language therapy and social work services were also commonly delivered via video-based telehealth. Furthermore, 35% of children who should have been receiving physical therapy, 27% of children who should have been receiving occupational therapy, and 36% of children who should have been receiving applied behavior analysis in the school setting were not receiving these services at the time of survey completion. In the EI setting, 30% of children who should have been receiving occupational therapy and 32% of children who should have been receiving speech and language therapy were not receiving these services at the time of survey completion. Settings where fewer than 10 children of participants were receiving a service are not discussed owing to the limited usefulness of these percentages.

Across all settings, 148 respondents (72%) reported having access to video-based telehealth for their children during COVID-19. Children received an average of 2 ± 1 services (range, 1-5 services) via telehealth. Of the respondents who used telehealth services, 71% used telehealth for speech and language therapies, 45% for occupational therapy, 31% for physical therapy, and 20% for psychological services. Fewer than 15% of respondents accessed social work services, applied behavior analysis, feeding therapy, and developmental therapy via video-based telehealth. Zoom was the most commonly used platform (76%), followed by Google video-based software (26%). Families reported using an average of 2 ± 1 video-based platforms for children with disabilities in their family.

Satisfaction with Services

Respondents were asked, "What is your overall level of satisfaction with the therapeutic services your child[ren] has/have received during the coronavirus pandemic?" Of the 195 parents who responded to this question, 44% reported low satisfaction, 36% reported medium satisfaction, and 21% reported high satisfaction (rounded to the nearest whole). Access to telehealth significantly predicted overall satisfaction, $\chi^2(2) = 39.6$, P < .001, V = 0.45, with 80% of families without telehealth access reporting low satisfaction, as compared with 30% of families with access to telehealth. No significant differences were found in overall satisfaction between income categories, highest household education levels, community settings, number of children in the household with or without a disability, race, number of essential workers in the household, number of employed adults in the household, or marital status.

Table I. Demographics of respondents and their children with disabilities*					
Household demographics (n = 207)		Children demographics (n = 276)			
Respondent race/ethnicity		Race/ethnicity			
American Indian/Alaskan Native	2 (1%)	American Indian/Alaskan Native	4 (2%)		
Asian	3 (1%)	Asian	6 (2%)		
Black or African American	20 (10%)	Black or African American	41 (15%)		
Hispanic or Latino	18 (9%)	Hispanic or Latino	35 (13%)		
Native Hawaiian	0 (0%)	Native Hawaiian	1 (<1%)		
White	160 (77%)	White	200 (7.3%)		
Other	0 (0%)	Other	12 (4%)		
Prefer not to say	8 (4%)	Prefer not to say	8 (3%)		
Marital status	0 (170)	Diagnoses	0 (0,0)		
Single	29 (14%)	Attention deficit/hyperactivity disorder	92 (33%)		
Living with a partner	10 (5%)	Autism spectrum disorder	108 (39%)		
Married	153 (74%)	Cognitive impairment	58 (21%)		
Divorced/separated	15 (7%)	Hearing impairment	27 (10%)		
Highest household education		Developmental delav	124 (45%)		
High school/GED	8 (4%)	Emotional/behavioral disorder	69 (25%)		
Some college	18 (9%)	Motor/physical disability	53 (19%)		
Associate degree or vocational program	25 (12%)	Medical disability	50 (18%)		
Bachelor's degree	53 (26%)	Specific learning disability	45 (16%)		
Master's degree	75 (36%)	Speech/language impairment	49 (18%)		
Advanced degree	28 (14%)	Traumatic brain injury	13 (5%)		
No. of employed adults	20 (11/0)	Visual impairment	24 (9%)		
	34 (16 4%)	Sensory processing disorder	81 (29%)		
1	96 (46%)	Other	40 (15%)		
2	77 (37%)	Grade level	10 (1070)		
No. of essential workers		Has not started school	56 (20%)		
	100 (48%)	Pre-Kindergarten	51 (19%)		
1	85 (41%)	K-5	89 (32%)		
2	22 (11%)	6th-8th grade	42 (15%)		
Income	== (1173)	High school	39 (14%)		
<\$50,000	48 (23%)	Prefer not to say	9 (3%)		
\$50,000-\$99,999	56 (27%)	School type	0 (070)		
\$100 000-\$149 999	39 (19%)	Public neighborhood school	136 (49%)		
>\$150,000	45 (22%)	Charter school	13 (5%)		
Prefer not to say	19 (9%)	Private, religion-based school	7 (3%)		
Community setting		Private, non-religion-based school	9 (3%)		
Rural	26 (13%)	Therapeutic day school	20 (7%)		
Suburban	145 (70%)	Residential program	1 (<1%)		
Urban	35 (17%)	Head Start program	1 (<1%)		
orban.	00 (11 /0)	Pre-Kindergarten program	7 (3%)		
Children per household (mean)	2.1 (1.0)	Homeschooled	10 (4%)		
	()	Does not vet attend school	48 (17%)		
Total children with a disability		Other	18 (7%)		
1	153 (74%)	Prefer not to say	6 (2%)		
2	41 (20%)	Intervention setting	0 (270)		
3	11 (5%)	School	124 (45%)		
4	2 (1%)	Outpatient	123 (45%)		
	. ,	EI	49 (18%)		
			()		

GED, General educational development.

*Percentages for race/ethnicity, diagnoses, and intervention setting do not add up to 100% because respondents could indicate that multiple categories applied.

Respondents reported, on average, feeling neutral trending toward somewhat satisfied with the family-professional partnership during COVID-19. In contrast, respondents reported being somewhat satisfied with the family-provider partnership before the start of the pandemic. Items focused on the child-provider relationship had an average satisfaction rating of neutral trending toward somewhat dissatisfied during COVID-19 and somewhat satisfied before the pandemic. Additionally, family-focused scores had an average rating of neutral trending toward somewhat satisfied during the pandemic and somewhat satisfied before the start of the pandemic. Exact family-provider partnership averages are reported in **Table III**. The differences between before and during the COVID-19 pandemic Family-Provider Partnership Scores and family-focused subscale scores are not likely clinically significant, because both before and during COVID-19, ratings decreased within 0.3 points of the somewhat satisfied benchmark. However, because scores on the child-focused subscale shifted from somewhat satisfied toward the dissatisfaction range, it is likely that there is a clinically significant difference in satisfaction regarding items related to child-provider interactions.

During the pandemic, parents reported being most satisfied with providers' friendliness (mean, 4.2 ± 0.9), protection of family privacy (mean, 4.2 ± 1.0), use of understandable language (mean, 4.2 ± 1.0), and showing respect for their family's values and beliefs (mean, 4.1 ± 1.1). Parents reported being dissatisfied with providers providing services

COVID-19, as reported by parents at the time of survey completion*						
Types of services	Total children receiving service, n	Video-based telehealth, n (%)	In person, n (%)	Over the phone, n (%)	Send home assignments, n (%)	Not receiving service, n (%)
Physical therapy						
School	43	10 (23)	1 (2)	1 (2)	18 (42)	15 (35)
Outpatient	37	18 (49)	12 (32)	2 (5)	5 (14)	6 (16)
El	26	19 (73)	2 (8)	1 (4)	2 (8)	4 (15)
Occupational therapy		. ,				
School	82	25 (30)	2 (2)	2 (2)	42 (51)	22 (27)
Outpatient	64	45 (70)	13 (20)	2 (3)	14 (22)	8 (13)
El	27	13 (48)	2 (7)	2 (7)	4 (15)	8 (30)
Psychological services						
School	21	11 (52)	0 (0)	2 (10)	6 (29)	3 (14)
Outpatient	47	35 (74)	3 (9)	12 (26)	8 (17)	5 (11)
El	0	-	-	-	-	-
Speech/language therapy						
School	121	56 (46)	3 (2)	5 (4)	58 (48)	18 (15)
Outpatient	65	46 (71)	10 (15)	1 (2)	10 (15)	9 (14)
El	37	21 (57)	1 (3)	1 (3)	3 (8)	12 (32)
Social work						
School	38	17 (45)	1 (3)	8 (21)	19 (50)	4 (11)
Outpatient	19	10 (53)	3 (16)	8 (42)	5 (26)	2 (11)
El	2	0 (0)	0 (0)	1 (50)	0 (0)	1 (50)
Applied behavior analysis						
School	11	3 (27)	2 (18)	1 (9)	2 (18)	4 (36)
Outpatient	38	16 (42)	23 (61)	4 (11)	5 (13)	3 (8)
EI	4	2 (50)	2 (50)	0 (0)	0 (0)	0 (0)
Feeding therapy						
School	3	0 (0)	0 (0)	0 (0)	1 (33)	2 (67)
Outpatient	15	8 (53)	1 (7)	0 (0)	4 (27)	3 (20)
EI	8	1 (13)	3 (38)	0 (0)	1 (13)	3 (38)
Developmental therapy						
School	11	1 (18)	0 (0)	2 (18)	5 (45)	5 (45)
Outpatient	3	1 (33)	1 (33)	0 (0)	1 (33)	1 (33)
Ы	19	14 (74)	0 (0)	1 (5)	1 (5)	3 (16)

Table II. The number of children receiving, or who should be receiving, common forms of therapy by setting during

*Total children receiving a service refers to the total number of children receiving a specific service in a specific setting (school, El, or outpatient). Percentages of children receiving a service with a specific modality (eg, video-based telehealth, in-person) were calculated by dividing the number of children receiving a service via a specific modality in a specific setting (eg, a child receiving school-based physical therapy in-person) by the total number of children receiving that service in that setting (children receiving a service school-based physical therapy). The "not receiving a service" column refers to children not receiving a service at the time of survey completion in a specific setting but who should be receiving that service. For example, a child who should be receiving physical therapy in school, according to his or her individualized education program, but who is not receiving the service during the pandemic would be indicated by this category. Percentages do not add up to 100 because children could receive services in multiple settings and could also receive each service through multiple modalities (eg, receiving outpatient physical therapy through both telehealth and in-person).

Table III. Family-Provider Partnership Scale scores						
Variables	Overall	School	EI	Outpatient	Multiple	
Overall						
Before	4.2 (0.8)	4.0 (0.9)	4.6 (0.4)	4.2 (0.8)	4.3 (0.8)	
During	3.7 (1.0)	3.2 (1.1)	4.2 (0.7)	3.6 (0.9)	3.7 (1.0)	
Difference	0.5	0.8	0.4	0.6	0.6	
Child-focused subscale						
Before	4.2 (0.8)	3.9 (1.0)	4.6 (0.4)	4.0 (0.9)	4.2 (0.8)	
During	3.4 (1.1)	2.8 (1.1)	4.0 (0.8)	3.6 (1.0)	3.4 (1.1)	
Difference	0.6	1.1	0.6	0.4	0.8	
Family-focused subscale						
Before	4.3 (0.8)	4.1 (0.8)	4.7 (0.4)	4.3 (0.9)	4.3 (0.7)	
During	3.9 (1.0)	3.4 (1.1)	4.4 (0.6)	4.0 (1.0)	3.9 (1.0)	
Difference	0.4	0.7	0.3	0.3	0.4	

Each item of the family-provider partnership was rated on a five-point Likert Scale from 1 (dissatisfied) to 5 (satisfied) and then averaged together to calculate mean family-provider partnership scores and subscale scores. Before refers to retrospective reports of mean satisfaction before the onset of COVID-19, and during refers to satisfaction scores during COVID-19. Values are mean (SD).

that met the child[ren]'s individual needs (mean, 2.7 ± 1.4). The average satisfaction scores for each item both before and during the pandemic are reported in **Table IV** (available at www.jpeds.com).

Using family-provider partnership change scores, further analyses were conducted to see how different demographic factors influenced satisfaction. The number of children with a disability in the household significantly influenced family-provider partnership scores, *Kruskal-Wallace* χ^2 (2) = 9.4, P = .009, $\eta^2[H] = .04$, with families with 2 children with a disability experiencing a significantly greater change from the before to during COVID-19 Family-Provider Partnership Scores (mean, -0.8 ± 0.7 ; median, -0.7) than families with 1 child with a disability (mean, -0.5 ± 0.8 ; median, -0.4) (Dunn statistic = 2.7, P = .02). Differences between families with 1 child with a disability and 3 or more children with a disability (mean, -1.1 ± 1.1 ; median, -1.2) were marginally significant (Dunn statistic = 1.86, P = .06). Additionally, telehealth access resulted in significant differences in family-provider partnership scores (W = 3073.5, P = .002, $\eta^2[H] = 0.22$). Families without telehealth access experienced a median change of -0.9 in family-provider partnership satisfaction and families with telehealth access reported a median change of -0.4. The number of caregivers who served as essential workers was also significantly associated with Family-Provider Partnership Scores, *Kruskal-Wallace* χ^2 (2) = 6.3, P = .04, $\eta^2 [H] = 0.02$; however, no significant pairwise comparisons between having zero (mean, -0.4 ± 0.8 ; median, -0.4), 1 (mean, -0.7 ± 0.8 ; median, -0.6), or 2 (mean, -0.8 ± 0.9 ; median, -0.5) essential workers in the home were found. No significant differences were found between income categories, highest household education, community settings, number of employed adults in the household, marital status, or race.

On the TSS, respondents rated their average overall experience using telehealth between fair and good (mean, 2.7 ± 1.0). Respondents rated the following items at or above good: (1) how well their family's privacy was respected (mean, 3.6 ± 0.6), (2) the courtesy, respect, sensitivity, and friendliness of the clinicians (mean, 3.4 ± 0.7), (3) how well clinicians answered their questions about the telehealth technologies they used (mean, 3.2 ± 0.8), (4) the thoroughness, carefulness, and skillfulness of the clinicians (mean, 3.0 ± 0.9), (5) the voice quality of the equipment (mean, 3.0 \pm 0.8), and (6) the visual quality of the equipment (mean, 3.0 ± 0.7). Respondents rated the following statements as less than good: (1) personal comfort with their families using telehealth (mean, 2.9 ± 1.0), (2) the explanation of their child[ren]'s services by clinicians (mean, 2.9 ± 0.9), and (3) the length of time their families spent with clinicians (mean, 2.8 \pm 1.1). Overall, the average score on the TSS was 31.0 ± 6.4 (range, 10-40), suggesting that respondents considered their overall experience with telehealth as good. A slight majority of respondents indicated they would use telehealth again for their child[ren]'s services (55%) and would recommend telehealth to another family (62%). Income categories, highest household education, community settings,

number of essential workers in the household, number of employed adults in the household, marital status, and race were not significantly associated with total TSS scores.

Comparing Satisfaction Across Settings

Of the 207 families, 44 received services solely in the school setting, 37 received services solely in an outpatient setting, 32 received services solely in an EI setting, and 94 received services in multiple settings. Families who received only school-based services reported low satisfaction about twice as frequently (73%) as compared with families who received outpatient services (29%), EI services (29%), and services in multiple settings (41%). Overall satisfaction ratings were significantly associated with setting, $\chi^2(6) = 29.37$, P < .001, V = 0.27. Complete satisfaction ratings by setting are reported in the Figure.

Furthermore, access to telehealth was significantly associated with setting, $\chi^2(3) = 15.8$, P = .001, V = 0.27. Families who received school-based services reported less access to telehealth (48%) than families who received services in outpatient settings (76%), EI settings (81%), and in multiple settings (78%). In terms of telehealth satisfaction, families receiving services in EI (mean, 33 ± 6), outpatient (mean, 31 ± 6), or multiple settings (mean, 30 ± 6) reported TSS scores in the good range and families receiving schoolbased services (mean, 28 ± 6) reported average TSS scores in the fair range. Given that all 4 groups had scores in or near the good rating, it is likely that there are no clinically significant differences in telehealth satisfaction scores across settings. Furthermore, no statistically significant differences were found between the groups.

In terms of family-provider partnership satisfaction before the pandemic, parents in all 4 groups retrospectively reported being somewhat satisfied, with the satisfaction scores in families receiving only EI services trending toward satisfied. However, during the pandemic, families who received school-based therapies reported average family-provider partnership scores that were neutral, trending toward somewhat dissatisfied, and families in the outpatient and multiple settings groups reported satisfaction scores trending toward somewhat satisfied. Families receiving EI services had an average rating in the somewhat satisfied range. This finding suggests clinically significant changes in parent satisfaction with the family-provider partnership in the school-based setting as satisfaction moved from somewhat satisfied before COVID-19 to neutral trending toward somewhat dissatisfied during COVID-19.

On the child-focused relationships subscale, families who received school-based services were somewhat dissatisfied with the provider's child-focused supports and families who received outpatient services and EI services were somewhat satisfied. Families who received therapies in multiple settings reported neutral satisfaction with child-focused skills that trended toward somewhat dissatisfied. Differences in satisfaction between school-based services (somewhat dissatisfied) and EI services (somewhat satisfied) suggest clinical significance by setting that likely reflects meaningful differences in satisfaction with child-focused supports offered in the school and EI settings. Before the pandemic, parents whose children received therapies in outpatient and multiple settings were somewhat satisfied with providers' interactions with their children. Families who received EI therapies trended toward satisfied, whereas families who received school-based therapies trended toward somewhat satisfied. Differences in satisfaction by time for school-based settings shows that before the pandemic, parents were somewhat satisfied. However, during the pandemic, parents were somewhat dissatisfied. These results suggest clinical significance by time that likely reflects meaningful decreases in satisfaction with child-focused supports offered in school-based settings.

On the family-focused relationship subscale, families who received EI and outpatient services reported being somewhat satisfied with the provider's focus on the family during COVID-19. Families who received multiple services reported neutral satisfaction trending toward being somewhat satisfied. Families receiving school-based services reported neutral satisfaction with the provider's family focus trending toward somewhat dissatisfied during COVID-19. In contrast, all families reported being somewhat satisfied before the pandemic with families who received EI services trending toward satisfied. These results likely represent a clinically significant decrease in satisfaction in schoolbased settings after the pandemic, relative to the other settings.

Discussion

Overall, access to telehealth significantly predicted overall satisfaction and satisfaction with the family-provider partnership. Conversely, receipt of solely school-based services negatively predicted overall satisfaction and familyprovider partnership satisfaction.

Telehealth has allowed continuing care for children with disabilities during COVID-19.¹⁸ This modality provides many benefits, including a lower cost of care, fewer transportation barriers, and limited exposure of immunocompromised children to others. Our study suggests that, overall, respondents had positive experiences with the services they received via video-based telehealth. In addition, these results suggest that access to telehealth plays a large role in predicting parent satisfaction with services and could be a promising tool in service delivery both during and after the pandemic.

Fewer than one-half of children receiving school-based therapies had access to telehealth (47%), which likely played into the overall dissatisfaction parents expressed with school-based services. Telehealth could serve as a tool for school-based providers during the pandemic, particularly with the reduced restrictions providers currently face in using telehealth platforms.¹² Although privacy protection when using telehealth has been a major concern in the past, families reported feeling comfortable with privacy protection across service settings.¹⁹





Despite these benefits, children with disabilities face unique barriers to fully accessing telehealth services. When using typical telehealth services, children with disabilities might require adaptations (eg, captions, magnification, enhanced contrast) or modified content to accommodate visual, cognitive, and communication impairments.²⁰ Although the Americans with Disabilities Act in principle applies to virtual spaces, web-based services are not required to provide the accommodations expected in a physical space.²¹ Thus, caregivers likely shoulder the increased burden of supporting their children during telehealth visits, likely contributing to the 44% of respondents who reported that they would not choose to use telehealth again for their children. For families who do not have a parent available to assist with telehealth services, children may receive inaccessible or less effective services. The results of this study indicate that there is a need for clinicians to orient families to new technologies and how the technologies will be used for a child's services as well as to ensure telehealth technologies meet the needs of the child and family.

School, EI, and outpatient services operate on different models that can differentially influence satisfaction both during and before COVID-19. Outpatient services operate on a consumer model, where families pay for services through insurance or out of pocket. Thus, in theory, families have a choice in provider and can switch providers if they are dissatisfied with services. Provider choice, in addition to the increased focus on family-centered care in outpatient therapy settings, likely plays a role in the higher levels of overall satisfaction and provider satisfaction reported for outpatient services both before and during the COVID-19 pandemic.^{22,23} However, outpatient services can be inaccessible to many families as a result of prescription or referral requirements, limited sessions insurance coverage, and a lack of disability-specific training for providers.^{1,24,25} Although Medicaid services cover necessary therapies through the Early and Periodic Screening, Diagnosis, and Treatment benefit, families receiving Medicaid benefits can also face barriers with transportation, childcare, and access to providers who take Medicaid that are likely exacerbated by COVID-19 and its mitigation efforts.^{26,27} Thus, although outpatient services seem to be perceived favorably during COVID-19, attention must be given to service settings that can be more equitably accessed by families.

In contrast, school-based services provide therapies free of charge to children ages 3-21 years for "developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education."³ In theory, any child with an Individualized Education Program who demonstrates need in a certain domain (eg, motor impairments), can access therapy services to help address those concerns, as long as the service supports their academic progress. Although school-based services are a more widely available and equitable modality of service delivery than outpatient services, with 13.7% of children ages 3-21

receiving special education services through Part B of the Individuals with Disabilities Education Act, the focus on supporting the academic curriculum means providers are not necessarily focused on complete rehabilitation of the child's nonacademic needs.^{13,28} Thus, in light of the strain COVID-19 mitigation efforts have put on schools, providers likely had to focus their attention on meeting children's academic needs during the period in which this data were collected, resulting in therapeutic needs being less of a priority.

Limited school resources often impact the ability of school providers to adopt new technologies, such as telehealth services. Special education services are already costly to school districts; although the Individuals with Disabilities Education Act claims to cover 40% of special education costs, in reality it covers less than 20%, leaving large gaps in funding that the state and local school district have to cover.²⁹ In the context of the COVID-19 pandemic, schools likely did not have the same financial, training, and time resources as outpatient services to shift to remote delivery. Furthermore, the sudden onset of COVID-19 likely resulted in a shift in services based on school resource capacity and may not have factored in family needs and priorities. These constraints in adaptation likely played a role in the dissatisfaction with school-based services reported by our survey respondents.

Unlike school-based services, which focus more on the child's access to the academic curriculum, EI services focus on the family's goals for their child's development. Children under age 3 years with, or at risk for, a developmental delay can access government-subsidized EI services. The goal of EI is to minimize the impact of a child's disability as early as possible to enhance future developmental outcomes while delivering services in the family's "natural environment."¹³ Services are adapted to fit the family and are designed to empower caregivers to support their child[ren]'s development within the family's daily routine.^{30,31} Of the 3 service delivery modalities, EI services had the highest overall satisfaction and family-provider partnership satisfaction within our sample. Given the main difference in this service setting is its unique focus on the family's routines and goals for the child, it is likely that the continued attention on the family's needs during COVID-19 played a key role in the high level of reported satisfaction with EI. These results suggest that increasing the planning around, and the involvement of, the family could be a key strategy in improving satisfaction with school-based therapies during the remainder of COVID-19. Furthermore, bolstering the family-provider partnership could increase continuity of care, help protect against deterioration of skills, and promote maintenance and generalization of skills in school-based therapies during the duration of the COVID-19 pandemic and during postpandemic life.

This study has several potential limitations. The reported number of children not receiving services during COVID-19 is possibly underestimated, given that this response option was added after data collection began. However, because all responses that initially indicated not receiving services in the "other" service modality option were recoded to be included in the no service modality option, we expect our estimate to be fairly accurate. Furthermore, although parents could indicate if their child was not receiving a service during COVID-19, the reasons behind the change in service delivery, in addition to changes in service delivery not related to the pandemic, were not collected. Given the short time span between when the pandemic mitigation measures began and the time at which participants took the survey (approximately 2-4 months), we believe it is unlikely that changes reported in services or service delivery that were unrelated to the pandemic occurred for many of the children. Nonetheless, we would suggest that future studies allow for further elaboration on how services were disrupted and why.

Given that this study was created in response to COVID-19, participants completed the survey at a single time point and could only retrospectively report on their satisfaction with their family-provider partnerships before the start of the pandemic. Asking parents to retrospectively report their satisfaction could result in biased responses, particularly for parents who have strong feelings, both positive and negative, about the services their child[ren] receive during the pandemic. For example, if a respondent feels that their child is not receiving quality services during the pandemic, these impressions could lead to lower ratings of pre-COVID-19 family-provider partnership satisfaction than would have been obtained in a survey done before the start of the pandemic. Furthermore, the rapid changes in mitigation strategies during the course of the pandemic could have resulted in differences in satisfaction between participants who completed the survey at different points during the data collection period. Although researchers cannot currently gather data on satisfaction before the pandemic without possible recall bias, longitudinal studies throughout the course of the pandemic are recommended to more fully understand the influence of the different stages of the pandemic on disability-related therapies.

Additionally, the completion rate for the participants who accessed the survey was relatively low (32%) and does not account for the large group of parents who received notification of the study through Facebook groups or Facebook ads but chose not to participate. Thus, the parents who completed the survey may differ from the general population. In addition, parents who belong to Facebook support groups might differ from the overall population of parents of children with disabilities. To identify trends in service delivery and parent satisfaction throughout the pandemic that can be generalized to a broader group of parents, further work is needed using a larger, nationally representative sample of parents.

This study did not take into account how demographic factors interact to influence satisfaction and perception of services. To better inform treatment planning and delivery, further studies are needed looking at how parent and child factors interact to meaningfully impact service perception and satisfaction.

Finally, although the states in which respondents resided were included, data were not collected regarding their specific location within states, so the severity of the COVID-19 outbreak in the respondents' communities, as well as the required mitigation efforts put in place, are not known. It is likely that respondents living in areas with high rates of COVID-19 would respond differently than respondents who reside in regions where COVID-19 rates were lower. These geographical differences could also influence the sophistication of service delivery modalities available to families. Furthermore, different perceptions of COVID-19 and mandated mitigation strategies could influence respondent satisfaction and how respondents perceived the Facebook recruitment materials used in this study. To more fully understand parent perception of services during COVID-19, further research is needed to examine how the views of respondents regarding the pandemic influence satisfaction with and perception of service delivery during COVID-19.

To optimize successful and effective parent involvement in services, providers must understand the barriers parents are facing during COVID-19 and adjust services to the family's needs. In addition to these adjustments to services, including an increased focus on family goals in the school setting and the availability of adapted telehealth materials throughout all settings, family navigation and parent coaching services could be useful tools to augment service delivery. Family navigation services could support families in finding appropriate services and locating service providers who can effectively support their child[ren] during COVID-19. In addition, parent coaching services could support families in using new technologies and building capacity to support their child[ren]'s therapeutic interventions for the remainder of the pandemic. Together, these services could be a costeffective solution to extending the therapeutic services offered in school, EI, and outpatient settings by training parents to implement therapy goals during their daily routine, to advocate for services that adequately address their child [ren]'s needs during periods of service disruption, and to increase parent activation about and engagement in services.

Furthermore, ensuring access to mental health services for children with disabilities is of particular importance during COVID-19, because mitigation strategies have widely impacted the social, emotional, and behavioral health of children with disabilities and their families.^{10,32,33} Change in routine, a lack of appropriate support from providers, and increased social isolation can lead to behavioral and emotional challenges as children attempt to manage their environment, which can in turn put intense strain on the rest of the family.^{34,35}

Determining how different service modalities, such as telehealth and in-person services, compare in terms of helping children reach therapeutic goals is critical for supporting children and families in navigating periods of service disruption, such as a pandemic. Similarly, follow-up research is needed to determine how service delivery has been experienced by providers during the pandemic. By better understanding both parent and provider perception, more strategic efforts can be made to enhance family-provider partnerships during the disruption of service delivery. ■

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References

- 1. Houtrow A, Murphy N, COUNCIL ON CHILDREN WITH DISABIL-ITIES. Prescribing physical, occupational, and speech therapy services for children with disabilities. Pediatrics 2019;143:e20190285.
- 2. Stineman MG, Streim JE. The biopsycho-ecological paradigm: a foundational theory for medicine. PM R 2010;2:1035-45.
- Armitage R, Nellums LB. The COVID-19 response must be disability inclusive. Lancet Public Health 2020;5:e257.
- 4. Cacioppo M, Bouvier S, Bailly R, Houx L, Lemperuer M, Mensah-Gourmel J, et al. Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: The ECHO French survey. Ann Phys Rehabil Med 2020 [Epub ahead of print].
- Jeste S, Hyde C, Distefano C, Halladay A, Ray S, Porath M, et al. Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. J Intellect Disabil Res 2020 [Epub ahead of print].
- **6**. Eshraghi AA, Li C, Alessandri M, Messinger DS, Eshragi RS, Mittal R, et al. COVID-19: overcoming the challenges faced by individuals with autism and their families. Lancet Psychiatry 2020;7:481-3.
- Fung A, Ricci M. Rethinking 'essential' and 'nonessential': the developmental paediatrician's COVID-19 response. Paediatr Child Health 2020;25:265-7.
- 8. Sholas M. The actual and potential impact of the novel 2019 coronavirus on pediatric rehabilitation: a commentary and review of its effects and potential disparate influence on Black, Latinx and Native American marginalized populations in the United States. J Pediatr Rehabil Med 2020;13:339-44.
- **9.** Fontanesi L, Marchetti D, Mazza C, Di Giandomenico S, Roma P, Verrocchio M. The effect of the COVID-19 lockdown on parents: a call to adopt urgent measures. Psychol Trauma 2020;12:79-81.
- Willner P, Rose J, Krose BS, Murphy GH, Langdon PE, Clifford C, et al. Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. J Appl Res Intellect Disabil 2020;33:1523-33.
- 11. Neese C, McIntyre LL, Fenning R. Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. J Intellect Disabil Res 2020;64:739-49.
- Department of Health and Human Services. Notification of enforcement discretion for telehealth remote communications during the COVID-19 nationwide public health emergency. Fed Reg 2020;85:22024-5.
- 13. Individuals with Disabilities Education Act of 2004, S 300.34-300.8 Stat. 20U.S.C.
- 14. Spann SJ, Kohler FW, Soenksen D. Examining parents' involvement in and perceptions of special education services: an interview with families in a parent support group. Focus Autism Other Dev Disabil 2003;18:228-37.

- Summers JA, Hoffman L, Marquis J, Turnbull A, Poston D, Nelson LL. Measuring the quality of family-professional partnerships in special education services. Except Child 2005;72:65-81.
- 16. Morgan DG, Kosteniuk J, Stewart N, O'Connell ME, Karunanayake C, Beever R. The Telehealth Satisfaction Scale: reliability, validity, and satisfaction with telehealth in a rural memory clinic population. Telemed J E Health 2014;20:997-1003.
- Grosjean P, Ibanez F. pastecs: Package for Analysis of Space-Time Ecological Series. R package version 1.3.21. 2018. Accessed December 15, 2020. Available at: https://CRAN.R-project.org/package=pastecs
- Camden C, Silva M. Pediatric telehealth: opportunities created by the COVID-19 and suggestions to sustain its use to support families of children with disabilities. Phys Occup Ther Pediatr 2020;41:1-17.
- Hale TM, Kvedar JC. Privacy and security concerns in telehealth. AMA J Ethics 2014;16:981-5.
- 20. Courtenay K, Perera B. COVID-19 and people with intellectual disability: impacts of a pandemic. Ir J Psychol Med 2020;37:231-6.
- Annaswamy TM, Verduzco-Gutierrez M, Frieden L. Telemedicine barriers and challenges for persons with disabilities: Covid-19 and beyond. Disabil Health J 2020;13:100973.
- 22. Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient-and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. Pediatrics 2014;133:e1451-60.
- 23. Kuhlthau K, Bloom S, Van Cleave J, Knapp A, Romm D, Klatka K, et al. Evidence for family-centered care for children with special health care needs: a systematic review. Acad Pediatr 2011;11:136-43.
- 24. Warfield ME, Gulley S. Unmet need and problems accessing specialty medical and related services among children with special health care needs. Matern Child Health J 2006;10:201-16.
- 25. Chiri G, Warfield ME. Unmet need and problems accessing core health care services for children with autism spectrum disorder. Matern Child Health J 2012;16:1081-91.
- **26.** Rosenbaum S. When old is new: Medicaid's EPSDT benefit at fifty, and the future of child health policy. Milbank Q 2016;94:716-9.
- 27. Social Security Amendments of 1967. P.L. No. 90-248, S 505 (a)Stat. 81.
- National Center for Education Statistics. The condition of education: students with disabilities. Institute of Education Sciences. 2020. Accessed October 1, 2020. Available at: https://nces.ed.gov/programs/coe/indi cator_cgg.asp/
- **29.** Dragoo KE. The individuals with disabilities education act (IDEA) funding: a primer. CRS 20181-34.
- **30.** Moes DR, Frea WD. Contextualized behavior support in EI for children with autism and their families. J Autism Dev Disord 2002;32:519-33.
- Hwang AW, Chao MY, Liu SW. A randomized controlled trial of routines-based EI for children with or at risk for developmental delay. Res Dev Disabil 2013;3:3112-23.
- **32.** Asbury K, Fox L, Deniz E, Code A, Toseeb U. How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? J Autism Dev Disord 2020 [Epub ahead of print].
- 33. Bartlett JD, Griffin J, Thomson D. Resources for supporting children's emotional wellbeing during the COVID-19 pandemic. Child Trends. 2020 [Cited 2020 Oct 12]. Accessed October 12, 2020. Available at: www.childtrends.org/publications/resources-for-supporting-childrensemotional-well-being-during-the-covid-19-pandemic
- 34. Dhiman S, Sahu PK, Reed WR, Ganesh GS, Goyal RK, Jain S. Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. Res Dev Disabil 2020;107: 103790.
- **35.** Fegert JM, Vitiello B, Plener PL, Clemens V. Challenges and burden of the coronavirus 2019 (COVID-19) pandemic for child and adolescent mental health: a narrative review to highlight clinical and research needs in the acute phase and the long return to normality. Child Adolesc Psychiatry Ment Health 2020;14:20.

Table IV. Average satisfaction scores			
How satisfied are you that your child's service providers	Before COVID-19	During COVID-19	Difference
Child-focused relationship subscale average	4.16 (0.8)	3.42 (1.1)	0.74
Helps you gain skills or information to get what your child needs.	4.03 (1.0)	3.15 (1.4)	0.88
Has the skills to help your child succeed.	4.08 (1.0)	3.19 (1.4)	0.89
Provides services that meet the individual needs of your child.	3.97 (1.1)	2.72 (1.4)	1.25
Speaks up for your child's best interests when working with other service providers.	3.98 (1.0)	3.33 (1.3)	0.65
Lets you know about the good things your child does.	4.24 (0.9)	3.58 (1.3)	0.66
Treats your child with dignity.	4.43 (0.8)	4.00 (1.1)	0.43
Builds on your child's strengths.	4.19 (0.9)	3.49 (1.3)	0.7
Values your opinion about your child's needs.	4.17 (1.0)	3.74 (1.2)	0.43
Keeps your child safe when your child is in his/her care.	4.43 (0.9)	3.59 (1.1)	0.84
Family-focused relationship subscale average	4.32 (0.8)	3.89 (1.0)	0.43
Is available when you need them.	4.09 (1.0)	3.30 (1.4)	0.79
Is honest, even when there is bad news to give.	4.25 (0.9)	3.79 (1.1)	0.46
Uses words that you understand.	4.43 (0.9)	4.16 (1.0)	0.27
Protects your family's privacy.	4.49 (0.9)	4.18 (1.0)	0.31
Shows respect for your family's values and beliefs.	4.39 (0.9)	4.06 (1.1)	0.33
Listens without judging your child or family.	4.31 (0.9)	3.96 (1.1)	0.35
Is a person you can depend on and trust.	4.23 (1.0)	3.73 (1.3)	0.5
Pays attention to what you have to say.	4.25 (1.0)	3.73 (1.3)	0.52
Is friendly.	4.47 (0.7)	4.20 (0.9)	0.27
Average family-provider partnership Score (per person)	4.24 (0.8)	3.65 (1.0)	0.59

Values are mean (SD).