Therapy service delivery for children with disabilities during COVID-19: Parent perceptions and implementation recommendations

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Abstract
This study identifies challenges and advantages parents faced in navigating therapy service delivery for their child with disabilities during the COVID-19 pandemic. As part of an online survey, 171 parents of children with disabilities answered four, free response questions regarding the therapy services their children received during the pandemic. A grounded theory approach was used to identify top challenges, barriers, advantages, and recommendations. Challenges included children's poor response to telehealth services, lack of parent training, and technological challenges. Advantages included fewer barriers to service access and increased family involvement. Parents largely recommended shorter, more frequent teletherapy sessions, and resuming in-person services. To improve parent engagement in, and the sustainability of, services, parent feedback should inform service delivery design and implementation. Incorporating parent feedback about service delivery can decrease disparities in access and increase parent engagement in child services both generally, and during periods of service disruption.

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1 | INTRODUCTION

Children with disabilities rely on a variety of rehabilitative and habilitative therapy services, such as physical, occupational, speech, or mental health services, to reach their developmental potential. However, the novel Coronavirus Disease 2019 (COVID-19) mitigation efforts suspended access to critical in-person therapies and support for children with disabilities across the world (Bruder et al., 2021; Cacioppo et al., 2020; Eshraghi et al., 2020; Jeste et al., 2020). The potential implications of these service disruptions have worried parents as gaps in services threaten the progress children have made toward their therapeutic goals (Asbury et al., 2021; Cacioppo et al., 2020; Grumi et al., 2021). Parent worry is justified and supported by theory. The theory of developmental cascades posits that environmental and biological factors interact to produce cumulative, long-term consequences on development (Masten & Cicchetti, 2010). Child competencies build on each other, such that early disruptions to services have a larger cumulative impact on developmental outcomes because the disruptions interrupt the progression of competencies. Children with disabilities often require more repetition to build competencies. Thus, gaps in services for children with disabilities can contribute to both an immediate and long-term impact on children’s developmental, behavioral, and academic outcomes (Masten & Cicchetti, 2010). In addition, children with disabilities may have more difficulty catching up after a disruption. Thus, researchers have noted that continuity in service is critical for therapeutic success and to optimize positive developmental cascades for children with developmental or health-related deficits (Aishworiya & Kang, 2021; Masten & Cicchetti, 2010).

Transitioning therapeutic services to remote delivery during pandemic mitigation efforts has placed an inordinate burden on parents as many parents have been tasked with delivering therapeutic interventions in the home or investing significant time and effort into facilitating their children’s telehealth-based services (Cacioppo et al., 2020; Neece et al., 2020). The additional strain of managing their children’s therapies has led many parents to report feeling overwhelmed and even experiencing moderate to severe mental health symptoms (Alhuzimi, 2021; Asbury et al., 2021; Bentenuto et al., 2021; Chan & Fung, 2021; Manning et al., 2020; Masi et al., 2021). These difficulties are exacerbated when telehealth services are not available to the family (Dhiman et al., 2020; White et al., 2021; Willner et al., 2020) and for parents with children with intellectual impairments or challenging behaviors (Alhuzimi, 2021; Manning et al., 2020; Neece et al., 2020). Shifts in service delivery have resulted in high rates of dissatisfaction with the therapies their child[ren] have received during the pandemic, particularly for families only receiving school-based therapies (Masi et al., 2021; Murphy et al., 2021). Parents of young children with developmental delays or autism also reported feeling as if they had to take on the responsibilities of both their child’s service providers and education professionals with little support, resulting in parents feeling like they could not meet the needs of their children at home (Neece et al., 2020). Given the increased burden parents have had to shoulder during the pandemic, it is critical that practitioners better understand the experiences and recommendations of parents to enhance their access to services.

Family Systems Theory provides some perspective as to why this sudden change in expectations would cause stress to the family system (Kerr & Bowen, 1988). First, disruption in the child’s services impacted the whole family, as parents were thrust into the roles of therapy service delivery managers and co-therapists. Second, there was no method for returning to homeostasis (a return to customary functioning). Third, there was no parent training or support for parents to build capacity for their new roles. Family Systems Theory views the family as a complex system where members interact to influence one another (Kerr & Bowen, 1988). Thus, to best support children during these service gaps, we must keep in mind how service interruptions impact families and provide parents and families with tools to support new roles and functions.

In-person service disruption during COVID-19 highlighted disparities in service access for vulnerable families and provided insight into alternative ways of providing services. This insight can inform service delivery implementation efforts to reduce disparities and optimize service engagement for the duration of the pandemic and during future periods of service disruption. Most importantly, improved service delivery options can also extend beyond periods of service disruption to improve the standard of care for children with disabilities and families.
This study examined parents’ perceptions of the advantages and challenges of navigating therapies for their child[ren] during COVID-19 as well as recommendations parents have for improving therapy service delivery. The findings identified opportunities for service delivery improvement during periods of service disruption and options for integrating improvements to improve service delivery more generally, that could reduce disparities in service access and engagement.

2 | MATERIALS AND METHODS

2.1 | Author positionality

The authors recognize that they bring their own positions to this study based on their lived experiences. All four authors identify as US-born, White women. The first three authors are in doctoral programs and the final author has their doctorate degree. In addition, the final author is the parent of a child with disabilities who navigated service delivery during COVID-19. We approach the research process as scientific observers with the intention to center parent and family experience to improve service design and delivery. We recognize the importance of a diverse sample with heterogeneous lived-experience and are limited by convenience-sampling methods. We hope this study will provide insight into the importance of funding work like this to support data collection from diverse samples.

2.2 | Study design

As part of an online survey for legal guardians (henceforth referred to as parents) of children with disabilities under the age of 22, US parents answered four free-response questions regarding the therapy services each of their child[ren] with a disability received during the COVID-19 pandemic. These open response questions were delivered via an online survey on REDCap. Survey responses were collected via REDCap between May 11 and July 31, 2020. An interpretative approach of grounded theory (Charmaz & Belgrave, 2007) was used to code all responses across the four questions.

2.3 | Participants

Parents were on average 40 years old (SD = 7.6, range = 23–69) and were predominantly female (96%). About 65% of parents reported being the primary caregiver for their child[ren] with disabilities, and 35% reported parenting equally with their partners. When asked about overall satisfaction with their child’s therapeutic services during COVID-19, 75 (44%) parents reported low satisfaction, 64 (37%) reported medium satisfaction, and 31 (18%) reported high satisfaction.

Children with disabilities were on average 7.7 years old (SD = 4.8, range = 1–18). Six children with disabilities were between the ages of 19 and 21, but their exact ages were not recorded. Children with disabilities had an average of 3.2 (SD = 2.0, range = 1–11) disability types and received 2.5 different types of therapy services (SD = 1.4, range = 1–7). Seventy-eight (33%) children received services in multiple settings (e.g., school, early intervention [EI], and/or outpatient settings). Most children received speech/language therapy (67%), occupational therapy (55%), physical therapy (35%), and psychological services (22%). Respondents also reported that children frequently received social work services (19%), applied behavior analysis (16%), developmental therapy (12%), feeding therapy (9%), and other therapies not specified (9%). Additional details on parent and child demographics can be found in Table 1.
| Household (N = 171) | n  | %  | Children (N = 236) | n  | %  |
|---------------------|-----|-----|---------------------|-----|-----|
| Respondent race/ethnicity |     |     | Race/ethnicity |     |     |
| American Indian/Alaskan Native | 2  | 1   | American Indian/Alaskan Native | 4  | 2   |
| Asian | 3  | 2   | Asian | 5  | 2   |
| Black or African American | 14 | 8   | Black or African American | 34 | 14  |
| Hispanic or Latino | 15 | 9   | Hispanic or Latino | 29 | 12  |
| White | 133 | 78  | Native Hawaiian | 1  | <1  |
| Other/prefer not to say | 11 | 6   | White | 173 | 73  |
| Relationship status |     |     | Disability type |     |     |
| Single | 22 | 13  | ADHD | 77 | 33  |
| Living with a partner | 7  | 4   | Autism spectrum disorder | 91 | 39  |
| Married | 131 | 77  | Cognitive impairment | 46 | 19  |
| Divorced/separated | 11 | 6   | Hearing impairment | 20 | 8   |
| Highest household education |     |     | Developmental delay | 107 | 45  |
| High school/GED | 7  | 4   | Emotional/behavioral disorder | 56 | 24  |
| Some college | 13 | 8   | Motor/physical disability | 48 | 20  |
| Associate degree or vocational program | 16 | 9   | Medical disability | 43 | 18  |
| Bachelor's degree | 44 | 26  | Specific learning disability | 39 | 17  |
| Master's degree | 67 | 39  | Speech/language impairment | 43 | 18  |
| Advanced degree | 24 | 14  | Traumatic brain injury | 13 | 6   |
| Number of employed adults |     |     | Visual impairment | 20 | 8   |
| 0 | 28 | 16  | Sensory processing disorder | 69 | 29  |
| 1 | 80 | 47  | Other | 30 | 13  |
| 2 | 62 | 36  | Grade level |     |     |
| 3 | 1  | <1  | Has not started school | 48 | 20  |
| Number of essential workers |     |     | Prekindergarten | 46 | 19  |
| 0 | 86 | 50  | K-5 | 73 | 31  |
| 1 | 71 | 42  | 6th–8th grade | 40 | 17  |
| Income |     |     | High school | 27 | 11  |
| Below $50,000 | 33 | 19  | Prefer not to say | 2  | <1  |
| $50,000–$99,999 | 48 | 28  | School type |     |     |
| $100,000–$149,999 | 34 | 20  | Public neighborhood | 114 | 48  |
| $150,000 and above | 39 | 23  | Charter school | 11 | 5   |
| Prefer not to say | 17 | 10  | Private | 16 | 7   |
**2.4 | Procedure**

As part of an online survey for parents with children with disabilities under the age of 22, 171 US parents answered four free-response questions regarding the therapy services their child[ren] with disabilities received during the COVID-19 pandemic. Participants were recruited through Facebook ads, Facebook groups for parents of children with disabilities, and through emails from local EI offices. Six hundred and forty-four individuals accessed the survey, 345 (54%) consented to take the survey, and 171 (27%) eligible parents completed the qualitative portion of the survey. The survey was tested for usability and accessibility before being disseminated to the public. In total, the survey took about 10 to 15 min to complete and included a demographic questionnaire about the parent and child[ren] with a disability, multiple quantitative measures, and a qualitative measure developed for this study, as described below. Only qualitative findings will be reported here. The quantitative results and more details about the survey can be found in Murphy et al. (2021).

**2.5 | Open-ended questions**

After reviewing relevant quantitative and qualitative literature, the authors identified constructs that they would like to hear more about that were not covered in the previously mentioned quantitative measures. While much of the literature discusses the hardships parents faced in supporting children with disabilities during the pandemic, no study to our knowledge directly asked parents to identify the barriers they faced when navigating therapy services or recommendations to combat these barriers. In addition, Neece et al. (2020) appear to be the first and only study—at the time our survey was designed—that asked about positive changes or “silver linings” that had resulted from COVID-19 (p. 3). The authors chose to ask about barriers, recommendations, and benefits as these were seen as being useful and relevant to service providers. Furthermore, the authors wanted to ensure that parents had the opportunity to share any other aspects of the service navigation experience that were not encompassed in these open-response items. Thus, the authors included a question to add any comments not otherwise covered in the other open-response items.

As a result, the following four open-ended items were included in the survey: (1) What barriers has/have your child[ren] faced in receiving therapeutic services during the coronavirus pandemic? Do these barriers differ from
before the coronavirus pandemic? (2) What benefits has/have your child[ren] experienced in receiving therapeutic services during the coronavirus pandemic? Do these benefits differ from before the coronavirus pandemic? (3) Do you have any recommendations to improve the delivery of therapeutic services for children with disabilities during the coronavirus pandemic? (4) Do you have any other comments regarding your child’s/children’s therapeutic services during the coronavirus pandemic? Even though these items asked participants about their experiences before COVID, the majority of parents answered solely about their experiences during COVID. Thus, we will be reporting mostly on parent experiences during the pandemic.

2.6 | Ethics

This study was reviewed by the Northwestern University’s Institutional Review Board and marked exempt since no identifying information, including IP addresses or cookies, was recorded. Regardless, participants completed an informed consent form before accessing the survey.

2.7 | Data analysis

While participants were asked about different constructs (benefits, challenges, and recommendations), many respondents answered all the open-response questions with a similar theme, regardless of what the question was asking. Thus, to identify these overarching themes, in addition to themes regarding overall benefits, barriers, and recommendations, responses were coded across questions. Responses were analyzed using an interpretative grounded theory approach (Charmaz & Belgrave, 2007) that involved several iterative rounds of open and closed coding. Verbatim responses were extracted from the survey and open coded in NVivo by the first author. The first author was not involved in the process of developing the survey questions and therefore had no expectations for the responses. Open codes emerged from the responses to indicate shared experiences among parents. A second round of open coding was completed by an additional author to ensure that all concepts were accounted for. The initial codes and notes from these two rounds of open coding were aggregated and synthesized to identify 10 main codes. Frequency counts were calculated, and the codes were refined into emerging themes based on commonalities, resulting in a final coding scheme of six major themes. The frequency calculations also helped to identify the most common barriers, benefits, and recommendations across the responses. The first and second authors then independently coded all responses using the main coding scheme. The interrater reliability between the two coders was excellent, they agreed on 92.3% of all codes. All discrepancies between the two coders were resolved by the third author.

In addition, all responses were close coded to indicate whether they included a negative and/or positive response and if their comment pertained to a specific service setting (i.e., school, EI, or outpatient). The frequency of positive and negative comments by setting was calculated and compared to determine if parents felt differently about the services, they received during COVID-19 by setting.

3 | RESULTS

3.1 | Overall qualitative trends

Qualitative analysis of the parents’ responses revealed six major themes: (1) increased family involvement, (2) fewer barriers to access, (3) child not responding well to telehealth, (4) parents feeling unprepared or ill-equipped, (5)
technological challenges, and (6) hoping for in-person services. Frequencies for each theme reported as a percentage of the total codes can be found in Table 2. Two of the themes were related to the benefits of telehealth: increased family involvement and less barriers to access. Three themes related to the challenges of service delivery during COVID-19: the individual child not responding well, parents feeling unprepared or unable to serve as the home “therapist,” and technological challenges. The final code was neither a benefit nor difficulty but, rather, parents stating a need for in-person services.

3.2 | Challenges

3.2.1 | Technical challenges

When asked about the barriers to receiving services during the pandemic, 54% of parents reported technological challenges, many stating that telehealth does not work for children with disabilities for a variety of reasons explored below. Parents also reported that they had difficulties with internet connectivity.

3.2.2 | Child challenges

About 42% of parents reported that their child struggled to effectively interact with telehealth services. Difficulty to engage with telehealth was largely a result of a child’s young age or specific needs. For instance, a White, mother who is married and living with a disability stated, “My son has low core strength so sitting at a computer without being held is a challenge. He gets bored more easily without an actual therapist here and sometimes refuses to participate, something he doesn’t normally do.” Parents also reported children being unable to engage with e-learning due to being unfamiliar with the platform.

3.2.3 | Parent challenges

About 27% of parents reported feeling unprepared for and unsupported in the level of expected involvement in their child’s therapeutic services during the pandemic. One respondent, a White, single mother who was currently unemployed wrote, “I think it is just harder as a parent to deliver these services when you’re so used to having a professional do these things with your child. I also think that it’s much harder to play the mom role as well as the therapist role and the teacher role.” While some parents expressed more comfort or ability to engage in their

| Theme                                      | n  | %   |
|--------------------------------------------|----|-----|
| Increased family involvement               | 28 | 7.4 |
| Less barriers to access                    | 13 | 3.5 |
| Child not responding well to telehealth    | 72 | 19.1|
| Parents feeling unprepared or ill-equipped | 46 | 12.2|
| Technological challenges                   | 92 | 24.5|
| Hoping for in-person                       | 41 | 10.9|

Note: N = 376. Frequency of codes by major themes is reported as a percentage of the total number of coding instances.
children’s treatment than others, it was apparent that doing so required significant time and effort from each parent. This added responsibilities to the parent’s day, making other tasks like parenting other children or job responsibilities difficult. In fact, some parents reported that they were no longer engaging in services because they could not keep up with the demands while maintaining their responsibilities at home and work. In total, 39% of parents reported that their children were receiving lower-quality services during the pandemic.

3.3 | Benefits

When asked about the benefits of telehealth, 22% of parents noted that telehealth-based services were working well for their families. There were two main benefits indicated by parents. First, 14% of parents reported that having their children receive services via telehealth had increased their family’s involvement in, and their knowledge of, their child’s therapies. One White, single, and self-employed mother stated, “It’s given me a good indication of how to work with my children and where they are at. That was something I wasn’t as tuned into before.” Second, 8% of parents endorsed that they were experiencing less barriers to accessing services than they had before the pandemic. As another White, mother who self-identified as an individual with a disability that hindered employment said, “My child has been able to make more rapid progress in her therapies since [COVID-19 mitigation strategies]. More time and energy can be spent on therapeutic exercises when we are not driving 60–90 min each way to our clinics, and not attending school (though we do have online school.) [Stay-at-home protocols have] actually been a great thing for my child.”

3.4 | Parent recommendations for improving services

Several common recommendations for improving services emerged. Many parents (24%) reported that their children needed in-person services. They suggested that children with disabilities be the first group allowed to resume in-person services or that providers receive special permission to do home visits. Parents even stated in this early stage of the pandemic that they would feel comfortable bringing their child into the service setting if all parties were masked. In addition, 6% of parents mentioned having shorter, more frequent telehealth sessions to improve service delivery while mitigation efforts prevent in-person services. Several parents (4%) also mentioned a need for one-on-one instruction for both parents and children, which was frequently lost as providers switched to telehealth. This recommendation and the call for instructional tips and at-home materials for navigating telehealth platforms have implications for telehealth services that extend beyond the COVID-19 pandemic. Overall, parents highlighted that children with disabilities have different needs than typically developing children when accessing telehealth-based services and, in many cases, recommended suggestions that alleviated the burden of telehealth-based services on parents and caregivers at home.

3.5 | Setting specific findings

Analysis of setting-specific responses found that 16% of all parents surveyed mentioned positive experiences with outpatient services as compared to 4% of parents mentioning positive experiences with EI and 2% of parents mentioning positive experiences in school settings, suggesting higher satisfaction with services delivered in the outpatient setting. Of the 37 specific instances where parents had positive accolades for their child[ren]’s service delivery during COVID-19, 73% of comments referenced services received in the outpatient setting, 16% referenced EI, and 11% referenced school-based services. In addition, 36% of all parents surveyed specifically reported dissatisfaction with telehealth services delivered by, and at times “abandonment” from, school-sponsored
services and providers. Parents pointed to a “lack of communication” or “no outreach or plan from the school” as the main reasons for disappointment. In contrast, only 9% of comments mentioned negative experiences with outpatient and only 9% with EI services. In fact, one female married parent (unidentified race) stated that “Outpatient services have been helpful. School based [services] are atrocious.” Notably, this patient indicated they lived in a rural area and had three children living in the home with a disability.

4 | DISCUSSION

Our findings indicate that towards the beginning of the COVID-19 pandemic, many parents reported increased barriers to accessing services for their children with disabilities. Our results highlight the need for additional training and support to access or optimize the therapy services their children received. However, some parents also noted the opportunity that the remote service delivery model provided for parents to better understand their child’s therapeutic goals and better engage with therapeutic interventions.

Parents offer one of the biggest opportunities to help children meet therapeutic goals—therapy tasks and activities can be integrated into the child’s daily routine, greatly increasing the amount of time the child practices these skills. This highlights the importance of engaging parents early in the child’s treatment and building parent capacity to identify where they can implement therapy practice in activities of daily living. Improved parent capacity will also provide continuity for the child during periods of service disruption, helping to ameliorate the challenges seen during the COVID-19 pandemic. Providers should aim to partner with each family to understand their individual needs (Asbury et al., 2021; Dhiman et al., 2020; Murphy & Risser, 2022), as well as to empower parents to make their needs or concerns known to the providers in order that they may more fully participate in therapy skill implementation. Providers may also want to leverage additional aides to assist families with both navigating the telehealth platform as well as supporting the delivery of services within the home (Jeste et al., 2020). Ultimately, tailoring services to each family, including building parent capacity to engage with services, can allow families to integrate therapy more fully into their daily lives, thereby making the services more effective.

Different service settings present different models for interacting with and supporting families. An examination of setting-specific needs during the pandemic demonstrated that families reported high levels of satisfaction in the outpatient setting and high levels of dissatisfaction in school settings. Some parents even reported supplementing the school services with outpatient services to fill in the gaps in service delivery offered by the schools. These differences are likely driven by several factors. The outpatient setting may allow for more individualized services, more frequent communication with families about therapeutic goals and progress, and may provide additional support or training to parents to implement therapy exercises at home. These features of the outpatient setting may have allowed providers to adapt to each individual family’s capacity for remote service delivery more effectively. In addition, as reported in the quantitative findings previously published by the authors, when therapeutic services switched to online service delivery, families who received services through the school and EI settings reported more low-tech, “hands-off” approaches, such as sending asynchronous assignments for the child to do on their own time (Murphy et al., 2021). It seems that outpatient services settings were able to transition to telehealth service delivery much faster than school and EI settings, perhaps due to outpatient settings having more resources available to facilitate the switch to telehealth. Not all families can pay for outpatient services, however, and Medicaid services can be limited due to long waitlists and limited providers taking that form of coverage. One way that schools and EI settings could improve flexibility in service provision is to consider alternative payment models like those used in other healthcare settings, such as group-based service delivery that allows more frequent sessions for shorter periods of time and adding a parent training component to assist parents in supporting treatment goals in their daily routine. These shifts could be supported by already existing legislation, the Individuals With Disabilities Education Act (2004), which states that parent participation is a critical part of EI and special education services, and that parent training is a potential related service to improve student outcomes in special education.
As we begin to resume in-person activities, providers can support families by strengthening family–provider partnerships and communication about how the transition will be handled as well as giving parents the space to express concerns about any regressions their children experienced during the pandemic. Providers should empower parents to pursue service modalities that are best suited for their family—whether that be continuing telehealth, in-person services, or a hybrid of the two. Policymakers can also continue to support these families by advocating for continued reimbursement for telehealth services. Our results indicate that continuing to offer this option for families with children with disabilities may increase access and support improved outcomes for some children.

In spaces where telehealth will still be used, care should be taken to fit the telehealth expectations and demands to the abilities and needs of each family. For these families, instructional materials and assistive resources that facilitate telehealth engagement could support parent capacity to use technologies and to build child stamina to use telehealth services for longer periods of time. For example, a visual schedule that provides pictures of each activity that will be completed during the session could help the parent and child remain on task while allowing the child to feel successful when crossing off each task that has been completed. A parent could also use a visual timer on a separate device or in the corner of their screen to show the amount of time remaining to help children engage with the sessions. These visual strategies can keep the children's attention and help build their tolerance for working with screen-based services. In addition, better communication between service providers and parents is critical to ensuring that providers can teach therapeutic strategies to parents in an efficient manner that reduces parental strain (Dhiman et al., 2020). Instructional materials could also support the transition back to in-person services. It will be important that providers offer some explanation about how in-person services may be different than they were pre-pandemic. Providers may also need to create channels for parents to provide feedback after return to in-person service delivery, as parents have adjusted to playing a larger role in therapy delivery.

Regardless of how families choose to engage with therapies after the end of the pandemic, parents and children will need space to process the stress and anxiety brought about by the past year of service disruptions. Providers and communities can help by creating specific resources for parents that discuss how to handle the transition to in-person services. Providers could also provide referrals to mental health services, support groups, and parenting skills interventions to begin to address the mental health needs that have arisen in both parents and children during the pandemic (Alhuzimi, 2021; Asbury et al., 2021; Chan & Fung, 2021; Jeste et al., 2020; Manning et al., 2020; Masi et al., 2021). It will be critical to the long-term development of children to not only restore their services and meet their mental health needs, but also empower their parents to once again function at their best.

During the COVID-19 pandemic, children with disabilities and their families faced unprecedented gaps in therapy services that could lead to long-term consequences on children's development. Without the appropriate resources, parents became responsible for ensuring the delivery of therapies. The findings of this study provide insight into parents' experience of navigating service disruption during the COVID-19 and actionable recommendations, most notably building parent capacity, to improve service delivery during future periods of disruptions and during the transition into in-person services.

5 | LIMITATIONS

There are several potential limitations to our findings. First, the survey completion rate was low. Of the parents who accessed the survey, only 27% completed the qualitative portion of the survey. It is possible that the parents who completed the survey may have different experiences than the general population of parents of children with disabilities. For instance, those parents that felt strongly about the services their children received, either positively or negatively, may have been more likely to complete the survey. Future studies should aim to reach a larger, more diverse group of parents to increase generalizability. Furthermore, given that the sample was majority White and married, increasing the diversity of the sample is warranted to allow future research to examine differences in access by demographic group. Second, the findings presented are based on responses to four free-response
questions. We suggest that future research use interviews or focus groups to gather richer, more in-depth data on how parents of children with disabilities received services during COVID-19 and how that compares to pre-pandemic services. Third, this study was started in response to COVID-19; therefore, parents had to retrospectively report on how the services they were receiving had changed since the pandemic. While in many cases the difference was clear and parents would explicitly state if the problems were the same as pre-pandemic (communication, needs not being met, etc.), it is possible that using a recall methodology may have biased responses. Fourth, we do not have specific data on COVID-19 severity or mitigation strategies employed in each family’s specific location, so it is possible that parents’ responses are impacted by the severity of disease in their area as this may result in more restrictive policies than in areas with lower community spread. Studies that examine parental responses in the context of geographic information regarding COVID-19 could address this limitation.

6 | CONCLUSIONS

The novel coronavirus (COVID-19) has drastically interrupted therapy service delivery for children with disabilities, resulting in service disruptions that may impact their development and functioning long term (Cacioppo et al., 2020; Eshraghi et al., 2020; Jeste et al., 2020). These disruptions have also placed a large burden on parents, as parents have often been expected to take on managing, coordinating, and delivering their children’s therapeutic interventions. This service disruption epidemic, in conjunction with the COVID-19 pandemic, has exacerbated pre-existing disparities that children with disabilities and their families face, further marginalizing individuals with disabilities who face stark inequities in access to services and community participation. To combat this marginalization and ensure that children with disabilities and their families receive both the tools and the services they need to successfully navigate their environments, policymakers, service providers, and communities must understand the barriers families face while also considering their recommendations to rectify these inequities. In addition, it is important that parents are viewed as an equal part of their child’s service team. Parents’ perspectives, coupled with provider knowledge, should be used to determine service planning.

Our findings support previous research showing that parents have taken on a significant burden during COVID-19 to ensure that their children with disabilities receive services (Cacioppo et al., 2020; Dhiman et al., 2020; Neece et al., 2020; Willner et al., 2020). As services transition to in-person or remain remote, it is critical that service providers partner with families to better understand how lessons learned during this period can be used to improve service delivery overall, and during future periods of service disruption. Communities may also consider creating support groups for parents and targeted outreach that teaches parents specific skills and therapeutic strategies that are relevant to service delivery to help reduce parent strain.

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