

Parenting young children with developmental disabilities: Experiences during the COVID-19 pandemic in the U.S.

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Abstract: High-stress events (e.g., natural disasters, political unrest, disease) significantly impact the lives of children and families. The Coronavirus Disease 2019 (COVID-19) is one event that has brought numerous hardships to families and children with developmental disabilities (DD), likely exacerbating already heightened levels of stress. For this study, we interviewed mothers living in the U.S. (N = 14) of 2- to 8-year-old children with DD about how COVID-19 has affected their family life. The interviews examined how the pandemic impacted (a) their child's educational, therapeutic, and medical services, (b) their stress and resiliency, and (c) their parenting role as an advocate, educator, and interventionist. The results of our thematic analysis of the qualitative data highlight four domains with themes that describe families' experiences as indicated by the mothers interviewed. Voices of families are essential in the delivery of effective and ethical early intervention for young children with disabilities. Based on the data from these interviews with mothers, suggestions for family-focused intervention to support families during high-stress events are discussed. As the long-term effects of the pandemic remain unknown, suggestions for future research to continue to examine the impact of high-stress experiences on young children with DD and their families are also presented.

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Introduction

Early childhood (i.e., infancy through 8 years) represents a particularly critical time for children with developmental disabilities (DD) where early intervention services and supports (e.g., educational, speech-language, occupational, and physical therapy, respite care, social work, service coordination) are critical to promote learning and to enhance positive child and family outcomes. The timing and intensity of early intervention services are essential contributors to positive outcomes. Children receiving appropriate services at an earlier age in conjunction with family support often have more favorable outcomes than those receiving services later (Guralnick, 1997; Nahmias et al., 2019).

During the early responses to coronavirus disease 2019 (COVID-19), parents experienced rapid shifts in their daily life, including delayed early intervention services and the loss of essential supports such as respite care, social networks, and financial stability (Chen et al., 2021; Patrick et al., 2020). COVID-19 restrictions led many parents of children with DD to experience extreme stress, challenging their resiliency due to unexpected changes in routines and daily life (Asbury et al., 2021; Cooke et al., 2020; Gonçalves-Pinho et al., 2021; Iacob et al., 2020; Neece et al., 2020). Parents reported low mood and feeling overwhelmed as they became wholly responsible for their child's early intervention, resulting in feelings of worry for their child's development and future. Many parents of young children with DD described balancing work,

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virtual school, lack of childcare, changes in routine, and family mental health needs as significant burdens (Asbury et al., 2021; Jeste et al., 2020; Neece et al., 2020).

Research suggests that the stress and overall adverse effects of COVID-19 have been high for parents of preschool-aged children with DD (Manning et al., 2020). Indeed, throughout the pandemic, parents have needed to provide direct support and mediate therapies for their young child with DD while carrying the ordinary responsibilities (e.g., managing daily living and responding to challenging behaviors) associated with their child's unique needs and their own (Jeste et al., 2020). Thorell and colleagues (2022) examined parents' experiences in providing education to their children with mental health conditions during COVID-19 restrictions and school closures in several European countries. Parents reported negatives to isolation, including high stress, family discord, and disconnection from support networks. Their findings showed minimal variation across locations, suggesting that the adverse effects of COVID-19 restrictions are not bound by geography .

Changes in Parent Stress, Children's Development, and Support Systems

Evidence suggests a reciprocal relationship between child behavior problems and parenting stress over time in children with DD, with child behavior problems contributing to parenting stress and parenting stress, in turn, contributing to further child behavior problems (Neece et al., 2012; Taylor et al., 2001). Several studies have documented that mental and behavioral health has worsened during the COVID-19 pandemic in school-aged and preschool-aged children with DD (Asbury et al., 2021; Bentenuto et al., 2021; Neece et al., 2020; Nonweiler et al., 2020; Patrick et al., 2020; Schmidt et al., 2021). The pre-existing high parental stress and challenging child behavior were exacerbated to extreme heightened levels by the onset of the pandemic and shutdown in the U.S.

The pandemic eliminated essential therapeutic services (e.g., speech, occupational, physical, and behavioral therapy). In a national U.S. survey, a quarter of families reported losing access to all services, negatively affecting their children's social-emotional development (Jeste et al., 2020). Studies have begun to establish a link between those service deficits and increased challenging behaviors by children with DD (Bentenuto et al., 2021). The increases in challenging behaviors could also be exacerbated by a child's limited ability to understand why changes to routines and services were happening (Asbury et al., 2021).

For children with primary speech and language delays, preschool is a period of significant growth in functional and pragmatic language skills, making it a critical period for intervention (Conti-Ramsden & Durkin, 2012). Jeste and colleagues (2020) report that during the pandemic, up to 52% of children no longer received speech therapy, and 43% lost educational services due to school closures. For children with delays in social reciprocity and communication, such as children experiencing an autism spectrum disorder (ASD), the loss of formal and informal socialization opportunities (e.g., social skills groups, community recreation, in-person preschool) has broadened their developmental differences from their peers.

The rise in behavior challenges and developmental concerns in response to limited services will likely continue to emerge for families with young children with DD. In a recent scoping review of the global impact of service disruption in early education, Kunze and McIntyre (2021) summarized research findings as suggesting that the extent of the disruption caused by COVID-19 will unfold over many years. Such disruption in education and support has exacerbated various risk factors (e.g., geographic isolation, low socioeconomic status, severity of child's behavior) in families with young children who experience DD. Many research outcomes in this review call for systemwide educational change, including the requirement of broader availability of early education and an increase in quality standards for school and therapeutic services to prepare for the unfortunate likelihood of future emergency interruptions.

Positive Outcomes

Despite reporting significant challenges, parents also report positive aspects of receiving early education and therapy in the home during COVID-19 restrictions. For example, 35% of parents of school-age children (as young as age 5) with mental health conditions in Europe reported positive effects on themselves, and 24% reported positive effects on their children during school closures (Thorell et al., 2022).

During the early pandemic response, many parents of preschool children with DD reported that the pandemic had some valuable outcomes, most commonly reported as more time with family and the opportunity to observe their child's developmental gains (Neece et al., 2020). Additional favorable effects of closures were noted in children who felt most comfortable at home due to social anxiety (Asbury et al., 2021). Studies of preschoolers specifically have noted gains in developmental and adaptive skills while receiving telehealth intervention services during COVID-19, especially in those interventions with parent coaching components (Kunze et al., 2021; Neece et al., 2020).

In the context of COVID-19 and other high-stress experiences, research highlights the importance of resiliency and advocacy for parents of young children with DD (Iacob et al., 2020; Patterson, 1991; Rossetti et al., 2021). Resiliency, specific to families with children with DD, as defined by Patterson (1991), is the parent's ability to recover from adversity and adapt to changes caused by hardships. In a crisis, resilient families can reorganize and reconnect with their support systems to withstand the weight of a stressful situation. Advocacy is defined as redirecting adverse thoughts and feelings into constructive actions (Rossetti et al., 2021). This call-to-action mentality speaks to parents' drive and skill set to respond to inequity and injustice, ultimately seeking outcomes advantageous to their needs. The outcomes of family-focused early intervention research suggest that parent empowerment, often achieved through bolstered knowledge of diagnoses and child development, skills in seeking and accessing services, and social resources to build support networks, all improve resiliency and lead to advocacy (Iacob et al., 2020; Patterson, 1991; Rossetti et al., 2021).

Theoretical Framework

Two frameworks are relevant to understanding early intervention and systems of support for families- Bronfenbrenner's Ecological Model (Bronfenbrenner, 1979) and the Transdisciplinary Model (Bricker et al., 2020) are described here. While Bronfenbrenner's (1979) ecological model is not specific to children with DD, the representation of support systems surrounding the child and family are appropriate for this context. Specifically, Bronfenbrenner places the child in the center of a circle which is then surrounded by a support system (e.g., family and educational services). Specifically, this group is called the microsystem, which in the context of early intervention, would provide specific services and supports for the child. When the microsystem is functional, the intervention services (e.g., speech pathologist, behavior therapist), interact with the family to best support the child. The intervention service providers also interact with one another, suggesting a transdisciplinary model. A transdisciplinary model in early intervention allows for goals within various developmental milestones to be practiced in different contexts and repeated with multiple professionals for an increased likelihood of improved skills and familial competency. Promoting the transdisciplinary model can support families with young children in advocating for services as their voice is valued and central to decision-making. (Bricker et al., 2020). Capable professional support systems can act as a buffer for other stressors (Estes et al., 2019).

The COVID-19 pandemic impacted young children with DD and their families at a disproportionately higher level due to an increase in stressors to an already overburdened family unit (Ren et al., 2020). Additionally, the removal of necessary support systems (i.e., intervention services) due to school and business closures, negatively impacted family functioning (Hochman et al., 2022). Figure 1, *The Importance of Service Support*, is based on the ecological and transdisciplinary models as described here. Figure 1 provides a visual model of a functional microsystem with intervention support (i.e., speech therapist, occupational therapist, and Behavior Analyst) and collaboration (i.e., arrows suggesting interaction) in place creating a protective barrier which blocks stress for families. This functional microsystem is compared to a dysfunctional microsystem where supports are removed and the family is exposed to stress depicting the situation for many families during the COVID-19 pandemic.

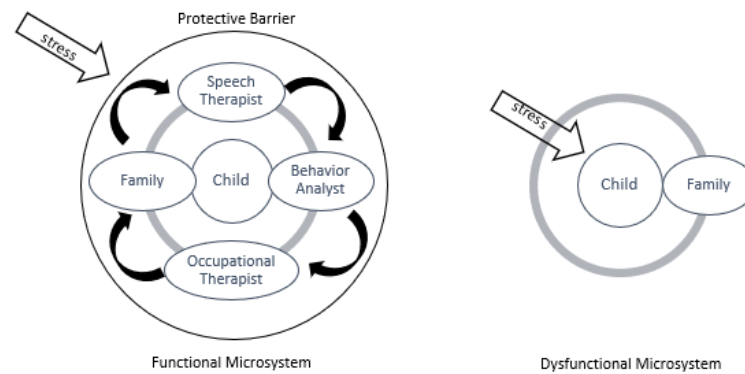


Figure 1. The importance of service support

Current Study

High-stress events (e.g., natural disasters, political unrest, disease) significantly impact the lives of children and families in the U.S. The COVID-19 pandemic is just one example. Thus far, research suggests this event will warrant an increase in mental health, educational, and developmental services for all children, especially those with disabilities, well into the future (Howard-Jones et al., 2022). This study aimed to elucidate how service delivery loss and change affected children, parents, and family units. We conducted qualitative interviews with mothers to answer three research questions about their experiences in the wake of the COVID-19 pandemic. The research questions (RQ) we sought to answer were:

RQ 1: How have changes in educational, therapeutic, and medical services affected families and children with DD?

RQ 2: What effect have COVID-19 restrictions had on parental stress and resiliency toward pandemic challenges (e.g., reduction or loss of employment, limited respite care opportunities, social isolation, and homeschooling)?

RQ 3: How have parental roles (i.e., advocate, educator, and interventionist) been affected by COVID-19 restrictions?

This study followed an initial set of qualitative interviews which examined the impact of Covid-19 on early childhood special education professionals (see Gomez et al., 2021). This study was funded by the National Institute on Disability, Independent Living, and Rehabilitation Research-funded project *Tiered Online Training and Supports*, which also focuses on young children with DD and their families (AWARD # 90DPHF0003).

Method

Participants and Recruitment

Parents were recruited from two geographical regions (mid-west and Pacific north-west) in the US. Participant recruitment was done through outreach to professionals within a children's medical center (e.g., administrative representatives), early childhood special education professionals (e.g., early intervention providers and teachers), and advisors from community organizations (e.g., social workers and case managers). After receiving permission to contact participants, research staff informed parents about study details and collected demographic information before conducting interviews. The participants that agreed to receive a consent form by email identified as mothers, and therefore mothers became the focus of the study.

A research assistant emailed 17 mothers of children with DD. Three mothers did not respond, and the other 14 consented to participate in the interviews. After completing 12 interviews to reach the recommended number for potential saturation of themes (Guest et al., 2006), researchers decided that completing the final two interviews, which were with participants with historically marginalized

racial/ethnic backgrounds, would add unique context and perspective to the study. Children varied in diagnosed disability (e.g., ASD, cerebral palsy). The parents who were interviewed represented a range of educational levels, employment statuses, household incomes, and marital statuses. More than half of the parents had multiple children with a diagnosed disability or delay. Participants each received a \$70 honorarium for their participation. Demographic information for participants is provided in Table 1.

Table 1. Participant demographics

Participant Demographics	M (SD) or %	Range or <i>n</i>
Child Age (Years)	4.43 (1.60)	3-6
Child Sex		
Male	--	9
Female	--	4
Child Developmental Disability*		
ASD	57.14%	8
ADHD	14.29%	2
Global Developmental Delay	28.57%	4
Speech Delay	28.57%	4
Genetic Syndrome	14.29%	2
Motor Disorder	21.43%	3
Other Mental/Behavioral	14.29%	2
Multiple Children with a Disability	64.29%	9
Parent Age (Years)	34.50 (7.53)	24-52
Parent Marital Status, Married/Living with Partner	64.29%	9
Parent Ethnicity, Non-Hispanic	85.71%	11
Parent Race		
Latina/o/x	--	1
Black/African American	--	1
Mixed Race	--	1
White/Caucasian	--	11
Parental Education		
Less than HS	7.14%	1
High School/GED	0%	0
Some College/Associate's/Trade School	50%	7
College Degree	28.57%	4
Graduate Degree	14.29%	2
Employment Status		
Full-time	50%	7
Part-time	21.43%	3
Unemployed/Stay at Home	28.57%	4
Geographical Category		
Urban	14.29%	2
Suburban	64.29%	9
Rural	21.43%	3

Note. *Categories are not mutually exclusive. ASD = Autism Spectrum Disorder; ADHD = Attention Deficit Hyperactivity Disorder; GED = General Education Degree

Thirteen of the fourteen participants reported their child attended either a school program or daycare, and ten families participated in outside therapeutic services (e.g., applied behavior analysis, speech, occupational, and alternative) before the COVID-19 pandemic. All families reported an interruption in their child's schooling or therapeutic services once COVID-19 resulted in a national lockdown.

Virtual schooling and therapies were offered to all families. Two families declined to continue school, and four discontinued therapies for their child with a disability via a virtual platform.

Interviews

All authors collaborated to create interview questions that specifically targeted parent experiences. The interview protocol was developed by members of the research team who had experience working with

early childhood special education populations and piloted in previous research (see Gomez et al., 2021). The interview protocol was then reviewed with two 15-member advisory boards (AB), one in the mid-west and one in the pacific northwest. These ABs are an extension of the board serving the NIDLRR-funded parent project (McIntyre et al., 2018). Two-thirds of the AB members are self-advocates and family members, and one-third are professionals in the field of DD. Interview questions and probes aligned with the RQs as shown in Table 2.

Table 2. Study research questions, interview questions, and probes

RQ#	Interview Questions and Probes
1	Question 1
	<ul style="list-style-type: none"> How have services for your child changed during this time? <p><i>Probes:</i> Tell me a little about how services were before COVID compared to now. How do you feel about that? Are you using video conferencing (Zoom, Skype, Facetime) or other ways of connecting with service providers? How has this been working? Is your child being asked to learn things through a virtual environment? How is that going?</p>
	Question 2
2	<ul style="list-style-type: none"> During this time, what are your thoughts about the quality of services you received? <p><i>Probes:</i> Challenges? Positive changes? What are your service providers doing that works well during this time? What could be better to meet your service needs?</p>
	Question 3
	<ul style="list-style-type: none"> If your services were put on pause and then reconvened, how did that look? <p><i>Probes:</i> How many days or weeks were the services put on pause? Which services/evaluations came back for your child? Which ones are you still waiting for? What was communication like with your service provider(s) during the period when they were shut down?</p>
3	Question 4
	<ul style="list-style-type: none"> Have there been benefits or surprising opportunities for you during this pandemic? <p><i>Probes:</i> In this extended time together, have you learned anything new about your child or yourself as a parent?</p>
	Question 5
	<ul style="list-style-type: none"> To what extent have the changes in services affected your family/child? <p><i>Probes:</i> Have you discovered any new strategies that have helped your child/family throughout the day?</p>
	Question 6
Final	<ul style="list-style-type: none"> What coping strategies are you using for yourself during this time?
	Question 7
	<ul style="list-style-type: none"> How do you see the coronavirus pandemic affecting your services/family/child long-term? <p><i>Probes:</i> Have you observed any changes in behavior? How do you feel about those changes?</p>
3	Question 8
	<ul style="list-style-type: none"> How are things going for you since the beginning of the stay-at-home orders, social distancing, and remote services due to COVID-19? <p><i>Probes:</i> What has been most challenging? What is going well? Have your family/child/personal needs shifted due to COVID-19? Have life circumstances changed?</p>
Final	Question 9
	<ul style="list-style-type: none"> Are you being asked to teach your child skills while you are at home? How is that going? <p><i>Probes:</i> Are you getting specific instructions from your provider? How is that working? Could you describe this to me?</p>
Final	Question 10
	<ul style="list-style-type: none"> What are your hopes for the future? Is there anything else you would like tell us?

Note. Each session was scripted to begin with “We want to first acknowledge the extraordinary circumstances we all find ourselves in because of the global pandemic, COVID-19. We would like to ask you some questions about your experience during this difficult time to see how your child and family have been impacted. As always, if there are any questions you don’t want to answer, please tell us you’d like to skip.”

Participants completed interviews using HIPAA-protected Zoom video conferencing technology, which lasted 60–90 minutes. The interviews were conducted by a doctoral researcher trained in early childhood special education and a graduate student with experience interviewing for qualitative research. Both interviewers have extensive experience collecting interview data from parents of children with DD and working with this population in clinical settings. The five-member analysis team consisted of two qualitative research experts, one doctoral researcher with extensive experience working with the population of interest (content expert), and two additional researchers who conducted interviews with the content expert.

Interviewers followed a semi-structured protocol to allow the participants to share their open-ended, nuanced, and salient experiences, which are best captured through interviews. Participants were asked

questions about their family structure, how services have changed during the pandemic, coping strategies, and the potential long-term impact of changes in service delivery. Interviewers followed up questions from the protocol with probes to foster a conversational interview environment and provide more opportunities for detailed responses to protocol questions. To ensure data accuracy, interviewers transcribed and edited their interviews (i.e., adjusted for common homonyms in the English language such as their and there). The analysis team met weekly throughout data collection to review interviews and discuss emerging themes.

Data Analysis

Thematic Analysis, a structured method for rigorously analyzing interview data and identifying salient patterns or themes, was the primary framework for analyzing the data (Braun & Clarke, 2006, 2020). The analysis team used the entirety of the data set to determine organized themes inductively after carefully reading the data and then identifying semantic (as opposed to latent) themes within a critical realist epistemology. We chose a critical realist epistemology because we believe these participants are capable of examining the systems in which they participate, resulting in conclusions about the tangible or material ways they have been affected by COVID-19. Conversely, we also value that, within a critical realist epistemology, we are not required to discount additional causal factors that impact the systems in which our participants operate as a result of COVID-19 (Bhaskar, 1989). Additionally, critical realism provided a framework for the careful analysis of underlying relationships between the events being studied, while still leaving room for the authors to provide strategic recommendations and implications (Fletcher, 2017). Each design decision listed above is essential to a rigorous Thematic Analysis, which was discussed and finalized before the start of the study (Braun & Clarke, 2006).

The analysis process was iterative. After the conclusion of each interview, the analysis team read the data carefully to identify potential codes or salient ideas. To improve the reliability of the coding process, the analysis team met weekly to discuss their findings and reach a consensus on the salient codes. The consensus was achieved through a three-step process. First, each researcher identified codes they found to be relevant during their analysis. Second, each section of data associated with a specific code was discussed synchronously by the analysis team to determine how each researcher categorized and described the same section. Third, the analysis team came to a consensus about how each example of text would be described and coded in future interviews. Notably, researchers recognized that each of our identities, perspectives, and goals impacted the ways in which we analyzed data. Though we came to consensus we acknowledged that all analysis is affected by inherent biases. After consensus about the unique codes, the qualitative research experts identified themes within the data. The analysis team then met to determine which statements of participants were exemplars of each of the themes. Next, the analysis team finalized, defined, and described each theme. After themes were finalized, domains were created to organize and categorize the themes identified in the data. Codes were initially documented on the transcriptions in Microsoft Word and then were transferred into Dedoose (2019) to document the creation of themes.

An example of the process in its entirety: (a) the analysis team noted that some sections of the data were coded as positive aspects and outcomes of COVID-19. The team came to a consensus determining that these data would be coded as positive outcomes of the pandemic leading to the theme entitled *Future Worries and Positives*, which ultimately fell under the domain of *Effects on Education and School*.

The analysis team used the recommended practices made by Brantlinger and colleagues (2005) throughout the analysis to facilitate a trustworthy and credible qualitative study. Such practices included engaging in investigator triangulation (through coding by consensus), first-level member checking, engaging in collaborative work in each step of the analysis process, debriefing with authors/peers who were not on the analysis team, and creating an extensive audit trail of each decision concerning code, theme, and domain creation. Braun and Clarke (2013) also identified the importance of “dependability” or “trustworthiness” in the analysis process, and engaging in the decision-making process as a function of completing a Thematic Analysis, further echoing Brantlinger and colleagues’ (2005) critical perspective of a trustworthy and credible qualitative study.

Results

Our analysis produced four domains in which families reported significant effects from COVID-19. Each domain contains the research team's frequent and salient themes. The organization of the domains and themes paired with each RQ and the number of participants who discussed those themes can be found in Table 3. Parents reported both positive and negative experiences, including suggestions for remediation. Each domain includes themes specific to participants' resiliency, examples of positive outlook, and coping strategies. The results are presented with participant quotes by domain and theme in relation to the study RQs. Domains 1-3 support findings in response to RQ1 and RQ3. Domain 4 supports findings in response to RQ 2 and RQ 3. Quotes are identified by participant (P) number.

Table 3. Domains and themes

Domain #	Domain Description	Themes and Number of Participants Who Commented
1	Effects on Education and School (RQ 1 and 3)	<ul style="list-style-type: none"> Disparities for children with disabilities ($n = 13$) School and community support ($n = 13$) Importance of communication ($n = 12$) Future worries and positives ($n = 14$)
2	Effects on Therapeutic and Medical Services (RQ 1 and 3)	<ul style="list-style-type: none"> Loss and changes in services ($n = 14$) Navigating the service system ($n = 14$)
3	Effects on Child with Disabilities (RQ 1 and 3)	<ul style="list-style-type: none"> Change in routines and transitions ($n = 14$) Social engagement ($n = 12$) Positive outcomes ($n = 13$)
4	Effects on Parents and Family (RQ 2 and 3)	<ul style="list-style-type: none"> Pre-COVID challenges magnified ($n = 11$) Parent resourcefulness ($n = 14$)

Note. Each participant contributed to each domain. Themes were not mutually exclusive.

Domain 1: Effects on Education and School

To answer RQ 1 and 3, all fourteen participants described positive and negative aspects of how school closures and changes in service delivery affected their child's education and school experiences. Parents' unique experiences with schooling during the pandemic are presented in quotes and summarized as four themes: (a) disparities for children with disabilities, (b) school and community support, (c) importance of communication, and (d) future worries and positives to carry forward. Participant quotes are labeled by Participant (P) number with a description of their child's age and primary diagnosis.

Disparities for Children with Disabilities (n = 13)

Parents identified disparities in how COVID-19 restrictions affected school services for their child with a disability and those without disability. The issue of educational inequity was mentioned across interviews and included concerns about the legality and lack of individualization of their child's education. Parents voiced fears about losing the right to educate their child in public schools. One parent commented:

I think that was a fear for a lot of parents the concern that we were going to lose our rights...making sure that our kids had their services that they were entitled to. Moving forward, just staying hypervigilant and trying to make sure that that doesn't happen. (P5: Mother of twin five-year-old children with ASD)

Individualized learning in hybrid, virtual, or limited in-person sessions was also a concern for parents. A mother of two children with ASD discussed virtual learning for her 3-year-old and said:

I do feel there is a difference with families that have kids with disabilities and those that don't. I stopped doing it. I just didn't feel it was productive enough for us, for me, to sit down and Zoom where I could do something better with those 40 minutes. (P3: Mother of three-year-old with ASD)

One mother described remote learning as having minimal focus on the IEP goals for her daughter: "I tried remote learning with her. But the remote learning the school offered wasn't based on IEPs. So, it made it a lot harder." (P7: Mother of a six-year-old with speech disorder).

Parents discussed specifics about their children's IEPs and special educational needs overall. Exceptions and limits to what schools could provide were an issue for many families. For example, some schools provided limited or no bus service.

My child can't go to school today because they can't get a bus for him to ride? It's in his IEP... that's a service that you're required to provide to him by law. And you're just going to email me in the morning and tell me that you can't do it? It's not acceptable. (P5: Mother of twin five-year-old children with ASD)

Another concern discussed by parents was the limited progress made by children on IEPs during the pandemic.

My kids have fallen behind further than what they were already... it sort of feels like schools are using COVID as an excuse for that, "Don't worry that your son can't write his name anymore, even though he could before. Because all of the kids are falling behind." It feels like it's an excuse... they're not trying as hard as they could. (P6: Mother of a four and six-year-old with ASD)

School and Community Support (n = 13)

Experiences with support varied across families. Supports include respite care, social work, service coordination and therapeutic services (e.g., educational, speech-language, occupational, physical). Some participants indicated that they received support from the school or early childhood programs. A parent provided the following examples:

When we had the toilet paper shortage, Head Start was the ones that actually ordered it. They were ordering hand sanitizer by the gallon and toilet paper and giving it to families that couldn't get it. (P6: Mother of a four and six-year-old with ASD)

Elementary schools were recognized as providing some support as well. Parents said their schools provided activity options, ideas to assist with self-regulation, and visual tools for communication and scheduling. One parent shared that COVID-19 prompted more outreach between school and home:

At first, they kind of pushed the information on me. And then I was like "okay this thing works, so let me ask about this too." They do give really good resources and information. If I need help with something, they're willing to help. (P7: Mother of a six-year-old with speech disorder)

Some mothers found support by reaching out to other families in similar situations and relying on extended family members. For others, COVID-19 eliminated the opportunity to rely on others. For example, some families felt it was not safe to use grandparents in child care as they did prior to the pandemic. Other families created small groups with extended family members to limit exposure with people outside of that designated group. With children out of school, one single Mother had to rely on others for support but found it difficult to get help: "My support system has gone from humongous, down to like 10 people... if I'm lucky." (P2: Mother of three-year-old with ASD, four-year-old with global delay and six-year-old with ADHD).

Importance of Communication (n = 12)

Parents discussed the importance of communication between the school and families and focused on concerns, including variability in the amount of communication (e.g., too much, too little) and mode of communication (e.g., virtual) A parent recounts difficulty navigating virtual communication during IEP meetings.

When we had an IEP virtually I thought "oh, everyone's here!" But then they just leave and didn't even say bye, they just left. I didn't even know that they weren't in the meeting anymore until the end. And I was like, "Wait, we lost the person." It affects the trust. (P5: Mother of twin five-year-old children with ASD)

The content of communication was also addressed. For example, a parent reported receiving limited information about the kindergarten transition: "When he turned five, they cut out his services completely because it rolls over to the elementary school, but schools are closed, so his services have been in limbo" (P1: Mother of five-year-old with speech delay). This parent found that navigating the kindergarten transition without assistance from the school was difficult. "I thought you can sign paperwork, and your kid's in school. And now, I have multiple emails and multiple different contacts, and not even a start date for when they may even have school open for him to begin" (P1).

Another parent described frustration with limited communication about school placements. She questioned the school's plan:

He was supposed to be in a general education class. Nobody said anything to me. Then come to find out... his biggest issue is transitions. They've got him transitioning every half hour [in general education] so then they moved him in with the special education teacher so he wouldn't have a hard time... They just did not say anything to me! (P4: Mother of five-year-old with ASD).

Future Worries and Positives (n = 14)

Parents expressed concern about the future, such as the possibility of schools remaining virtual. They also described the irreversible loss of developmental progress. A Mother expressed her worry:

My fear is for the future. Because he's not prepared for the school system when he gets there, and that's coming. Because if things don't change, how am I going to serve my child? How am I going to make sure that he gets the education he's supposed to get? (P10: Mother of 6-year-old with ODD and ADHD)

Another Mother pointed out the added stress of in-person schooling because she worries about her child's possible exposure to the virus. This Mother detailed her vigilance as part of her role as a mother:

I don't know what the future holds... it's going to be here permanently... I feel more comfortable with them being at home, even if I have to work my butt off and maybe running around crazy, you know, being Wonder Woman, but I rather do that and keep my kiddos safe. (P3: Mother of three-year-old with ASD)

Other positive outcomes of the pandemic identified by parents are smaller class sizes as a result of social distancing and additional online resources that were not previously available. One mother said that, prior to the pandemic, her child was not able to handle the length of the bus ride and the high number of children on the bus:

If not for COVID, we would have been driving my son to school because he couldn't handle a bus ride with 30 or 40 kids. Because of COVID, there's half the kids on there, and the ride is much shorter. (P6: Mother of a 4 and 6-year-old with ASD)

Parents also talked about things that would have improved distance learning and should be implemented in case of future school closures. Those include teaching kids to use technology while in the classroom, standardizing technology platforms in a school district, and allowing usability across devices (e.g., Android and Apple).

Domain 2: Effects on Therapeutic and Medical Services

Continuing to answer RQ 1 and 3, all fourteen participants discussed how COVID-19 affected therapeutic and medical services for their child with DD. These reports were categorized into two themes (a) loss and changes in services and (b) parents' stories of navigating the service system.

Loss and Changes in Services (n = 14)

Beyond school closures due to COVID restrictions, many families experienced changes in therapeutic and medical services. During the pandemic, therapeutic service offerings ranged from limited in-person to virtual-only to suspension. Therapy previously provided in school settings was often canceled due to school closures. As a parent of two children with autism, one in kindergarten and the other in preschool, this mother described her frustration with the school's cancellation of therapy for one of her sons:

I was really bothered that schools weren't trying to offer therapy virtually... Yes, the schools need to close, but only [a few] kids need to have therapy. Why can't they come in one day a week and social distance? Occupational therapy is the major issue [for my son]. Not getting that has really, really hurt him. (P6: Mother of a 4 and 6-year-old with ASD)

Participant 6 continued by describing how the absence of therapeutic services affected her daughter as well.

We tried to get the doctor to refer her out for speech services because that was her biggest delay. The university where we would go to get speech therapy actually closed down. So, there was no option of getting speech around us; we would have to drive about two hours just to go once a week. (P6: Mother of a 4 and 6-year-old with ASD)

Medical services were a stressor for some families. Changes in medical services included delayed

diagnosis, delayed surgery, and canceled intensive interventions in hospital settings. A mother described her family's experience when she recognized that therapy for her son would end very soon due to the pandemic:

We basically were just waiting for them to shut the door on us and sure enough they said everything's canceled. We had to eject from the program early and then went home, and of course school was closed, so in terms of the services that was the big shift, and then also the local outpatient therapies were closed. (P8: Mother of five-year-old with Cerebral Palsy)

Once schools and therapy providers began offering virtual sessions, there was still a delay in services for many. This delay also changed therapy options for some, which added to frustration of parents. For example, a parent of kindergartener with developmental delays said: "So he's missed a lot. He's only been to a therapy session three times since his IEP services started in early November [six months prior]. He was supposed to have 45–60 minutes per week" (P10: Mother of six-year-old with ODD and ADHD).

Similarly, the mode of delivery for therapy was difficult for families, and the changes in delivery were noted in delayed development and skills. A mother recounts their experience:

She has OT virtually. And that's one of the hardest ones to do virtually, because I don't know how to teach her how to write, and it just does not translate over the computer. I think they realized that she has missed out on a lot. [If she was]in the classroom, she would have been working on writing and getting that extra support, which she is not getting at home. (P17: Mother of three-year-old with Down's syndrome)

Navigating the Service System (n = 14)

The unforeseen barriers to getting therapy prompted many parents to become advocates for their child with DD. Identifying services and getting their therapy and medical needs met was difficult. One parent discussed her challenges in getting her child's medication needed for various complications with his syndrome.

Some medications with the pandemic were harder to attain or, if not completely sold out. And so, it's a constant phone call to either the doctor or the pharmacies. And then you go from having one pharmacy to three pharmacies, just so you can make sure you can get the different medications that he needs to be in a good health status. (P11: Mother of six-year-old with ASD and Charge Syndrome)

While the mothers interviewed were persistent in successfully navigating the service system, it was a trying, multifaceted task. Advocacy was challenged by the barriers of the pandemic. One mother whose child was newly diagnosed with ASD and also had medical complications during COVID-19 provides details of her situation:

The problem that I'm going to have is that I need to call the hospital for this. We're doing all these alternative tests, and I would love to meet a dietitian that specializes in autism, because I have no clue what I'm doing. ...unfortunately this past year has put everything on hold. Her diagnosis was over Zoom; I dropped the ball on referrals..... I mean, I need to make dental appointments, and I have no idea what to do. (P12: Mother of three-year-old with ASD)

Delays in diagnostic appointments required additional navigation by a parent. One mother reports the trouble she had in getting her child diagnosed with ASD during the pandemic:

The doctor, [told] me it would be a month before the specialist was going to call me. Then two months later, I finally called them and they said, "oh, we're just now getting to referrals from January, so it's still going to be another month or two before they call you". COVID had everything all backed up... their wait times are ridiculously long anyway, but COVID added a significant amount of time. (P4: Mother of 5-year-old with ASD).

During the pandemic, it became more difficult to get prescriptions filled and arrange for in-home services and appointments for children with disabilities. Nonetheless, parents demonstrated resourcefulness during this challenging time. One parent describes her perseverance in maintaining routines and appointments, "We have to stay on top of it... we have to make profound decisions that would work for us because we can't miss a beat" (P14: Mother of six-year-old with ASD). Another mother relied on resources for help:

I went directly to the special education director, and she helped me navigate what I needed to. She sat in with me in meetings, which was very useful and helpful because I wouldn't have known to do this or do that. I'm 52 years old and never had a child. Now I've got a child, and I'm trying to navigate all these things that I'm supposed to do for

him. (P10: Mother of six-year-old with ODD and ADHD)

Navigating these systems requires parents to be advocates. One mother, whose kindergarten-aged son experienced severe medical complications said,

I-f I don't get the answer I like from one person... I'll call again just to make sure that I actually get them thinking about this outside the box. I think if the child's parent isn't like that, it is a lot harder to get what you need... (P8: Mother of five-year-old with Cerebral Palsy)

Domain 3: Effects on Child with Developmental Disabilities

In support of RQ 1 and 3, participating mothers reported the effects of COVID-19 on their families overall. This domain highlights the specific effects on their child with DD. This domain is presented in three themes: (a) changes in routines and transitions, (b) social engagement, and (c) positive outcomes.

Change in Routines and Transitions (n = 14)

Various participants described the difficulties their children have with changes in routine and unexpected transitions and noted that the restrictions implemented by state governments were unpredictable. One mother said, "you're always trying to explain it, [but really just] say "I don't even know what to tell you" because in an hour, the governor could tell us something completely different is about to happen" (P13: Mother of four-year-old with Global Delay). The mothers recounted that the abruptness of the COVID restrictions, followed by continued uncertainty, made things even harder for their children to regulate.

Once hybrid school opened again, unpredictable transitions and routines continued. One mother described how the issue of school personnel being out affected her twins with ASD in multiple ways:

For the girls, it's the change in routine, and I have noticed when those schedule changes happen — it affects a little bit of their behavior at home, especially with sleep patterns. Also, their self-stimulation and repetitive behaviors have increased. (P5: Mother of twin five-year-old children with ASD)

A single mother of three children under the age of six with various disabilities has seen several changes in behavior due to routine and schedule changes. Here, she describes what it has been like for her toddler, who was recently diagnosed with ASD and experiences several other health impairments:

They can't come in and do home visits. School is not open. We get phone calls, but the phone calls don't help. There are virtual story times, but there's no in-person services. We relied on those! They came in, and they worked with her when she wasn't at school. And now we're not getting anything, and I feel like... we're definitely.... we're having more meltdowns, we're having more issues. (P2: Mother of three-year-old with ASD, four-year-old with global delay and six-year-old with ADHD)

Social Engagement (n = 12)

A common theme was concern about the limited opportunities for social engagement due to COVID restrictions. For many children, social engagement was an area of focus or a goal in their IEP. Due to the limited exposure to people beyond the immediate family, mothers were concerned that their children would make limited gains in social-emotional development and possibly experience social skill regression. One mother commented, "Thinking about it, really the social piece was probably the biggest thing that she's missing out on. She was really starting to click at Head Start, knowing other kids' names" (P6: Mother of four and six-year-olds with ASD).

Another parent said of her child's social connections:

I think he does miss being around other kids because he is a social kid. ...And a lot of his IEP goals are social-emotional, which is really hard to work on when you're not around other kids. (P17: Mother of three-year-old with Down's syndrome)

One mother said that even though she tries, she feels that the social opportunities available during the pandemic are not enough for her son:

I mean, I still feel that [I'm not enough] in some sense, with like the social piece; those types of skills are what I get nervous about — those little things that I can't teach them. It's something that they learn and they observe and those

are the things that I think that make me worry. He needs that social piece.. (P13: Mother of four-year-old with Global Delay)

Positive Outcomes (n = 13)

Despite school and community routines being interrupted, some families found that home routines were strengthened, which decreased child anxiety and facilitated progress in skills on which the parents could focus in some cases. One mother described their experience:

I think because of the pandemic, everything was sort of simplified. We've established more family routines in terms of eating at similar times now and establishing a morning routine like sitting on the couch and reading books. (P8: Mother of five-year-old with Cerebral Palsy)

Another mother shared,

It's nice, especially for my daughter with anxiety, it's nice to not have that pressure of constantly running around and being on time for things. Not having to be in a certain place at a certain time and navigating and juggling their different therapies. We're still juggling them, but it's a lot easier when you can just open up your computer.(P17: Mother of three-year-old with Down's syndrome)

Some families described progress in their child's development when they were expecting regression. Parents reported an increase in their child's vocalizations (P13: Mother of four-year-old with Global Delay) and more reciprocal interactions with family members (P3: Mother of three-year-old with ASD) and pets (P12: Mother of three-year-old with ASD). Family experiences of child progress varied across participants. One mother described how she carried on in the unpredictable journey of raising her son with ASD:

If you work with people and maintain good relationships with them, I think you can make anything happen. If this [therapist] can't identify that barrier or wall and they can't get to your child, there is going to be another specialist out there that probably is going to get to your child. It's just a patience game. And then, when you run out of patience, you have a higher being you could talk to...or you vent a little and cry a bunch. And then you reset. (P14: Mother of six-year-old with ASD)

Domain 4: Effects on Parents and Family

To answer RQ 2 and contribute to RQ 3, this domain summarized how the COVID-19 pandemic has affected parents and family members of children with disabilities beyond the changes to schooling and therapeutic and medical services. Parents describe the loss of seeing extended family for visits, as well as the loss of their assistance providing care. Families miss routine breaks, such as family vacations, holidays, and spousal date nights. Parents also describe a sense of loss for neuro-typical siblings in the family whose activities and celebrations (e.g., birthdays, community outings) have also been limited. All participants agreed that COVID-19 had both positive and negative effects on family life. Their experiences are explained here using unique quotes and stories in two themes: pre-COVID challenges magnified and parent resourcefulness.

Pre-COVID Challenges Magnified (n = 11)

Challenges that were already part of these families' lives pre-COVID became more difficult during the pandemic. For one family, health issues became extremely difficult to navigate due to trips to the hospital for spousal health problems during COVID restrictions and limited child care: "So it was like almost juggling knives at this point with just, the amount of [stress]...I don't know where we're going to go from here" (P11).

Additional perspectives from parents describe the limitations of living with a child with a disability, pre-COVID.

So, we were going to the hospital a lot. And so that was like we were already kind of going through our own pandemic. I think the hard thing is we've just felt like we've been living in a pandemic since our son was born, and that's been a lot of trauma. There's been a lot of acute issues from infantile spasms to unexpected issues; he's going to have major hip surgery in the spring. All of that's not even related to COVID. I remember my sister-in-law saying, "oh, my family is just not used to not being able to do what we want to do," and I just thought, "well, welcome to our world, pandemic aside!" (P8: Mother of five-year-old with Cerebral Palsy)

Homeschooling multiple children during COVID is difficult. When the children have a disability

and difficulty learning, the challenge is magnified. One mother with two children with disabilities describes her experience:

You know bouncing back and forth between two kiddos and sometimes.... Yeah, I do feel pressure because I feel like I'm not giving one enough, I'm not giving the other one enough...there's just one of me. So yes, it can be challenging.
(P3: Mother of three-year-old with ASD)

Parent Resourcefulness (n = 14)

Similar to past themes, mothers described examples of their resourcefulness. A mother who was furloughed for three months during the pandemic used that time to focus on her family.

It was like vacation. I got to grow with my older daughter, I got to grow with my nine-year-old. I spent time with my dogs and trained them better. I mean, I just had the time. And then school and everything was going great, and I was home if one of the kids had to be quarantined for any reason. I was hoping they'd fire me, but they didn't. That was my little secret [laughter]. (P14: Mother of six-year-old with ASD)

In addition to resourcefulness, mothers shared means of coping during the pandemic. One Mother said about her own self-care, "Let me push the reset button and figure out what needs to happen from here. So, I made an appointment with a doctor, went in, and now just try to be vigilant with my own mental health" (P11). Maintaining a positive outlook was a coping strategy for some mothers. For example:

We have really tried to be super positive and look at how fortunate we are. We've been healthy, and we haven't had any major issues with this whole situation. Yes, we've been inconvenienced, and that is super frustrating. But in the grand scheme of things, it could be way worse. . (P13: Mother of four-year-old with Global Delay)

Other mothers described self-care opportunities. One mother said she "takes some time in the morning to walk or run or whatever, whereas usually, we were running out the door. I've been able to read more and meditate more" (P17: Mother of three-year-old with Down's syndrome)

Discussion

The current study aimed to elucidate some of the impacts of the COVID-19 pandemic on family life for parents and young children experiencing DD. Qualitative interviews with mothers were used to measure the influence of this unpredictable event. Overall, the results indicate that events (e.g., school closures, loss of therapeutic services) in response to the COVID-19 outbreak negatively affected families and children with DD and these changes in daily life were described as stressful by Mothers Results further highlighted that despite many negative reports (e.g., limited support systems, increase in child-rearing responsibilities), some parents spoke of positive outcomes, their increased resiliency, and advocacy actions. This discussion will summarize participant voices in response to the research questions targeted in this study. Implications for practice, future research, and limitations are described.

Impact of Changes in Educational, Therapeutic, and Medical Services (RQ1)

Early intervention and early childhood special education services for young children with DD provide necessary developmental support and services (Warren & Stone, 2011; Zwaigenbaum, et al., 2015). Delays or lack of access to early intervention services negatively impact a child's growth trajectory and can result in a limited gain or loss of skills, thus increasing the disparities between children with DD and their typically developing peers. Some mothers in this study suggested that limited social opportunities due to isolation, as required to decrease exposure and spread of COVID-19, stunted their child's social-emotional development. Similarly, parents discussed significant concerns about academic performance (i.e., writing, reading, and math). These mothers hypothesized that their child's disability, combined with the interruption in education, caused their child's academic progress to be minuscule compared to a typically developing peer despite all children being denied educational opportunities. The examples listed here are supported by other literature about parenting experiences during COVID-19 (Hochman et al., 2022, Neece et al., 2020; Ren et al., 2020). However, the perspectives included in the current study are unique as they are results of direct quotes from the participants, rather than cumulation of survey data.

Implication for Practice

Eliminating service disruptions may decrease further disparities due to lack of availability. Training professionals to coach parents and deliver interventions or academic lessons virtually allows skill development to continue despite extenuating circumstances (Kunze et al., 2021; Lerman et al., 2020). Virtual interventions have been explored in addressing disparities in rural communities and may have similar positive impacts on families who experience isolation under various circumstances. Due to COVID-19, professional training protocols have become more available based on the demand for guidance on how to deliver virtual intervention (see Poole et al., 2020).

Evidence-based training and practices for professionals in the delivery of effective virtual interventions are still evolving and have yet to become a standard part of pre-training and in-service education for early intervention providers and educators. Further research is necessary to test the fidelity of virtual intervention delivery, the efficacy of parent-mediated technologies delivered via distance, and the efficacy of training protocols to prepare professionals to deliver such services.

Additionally, the positive influences of the Covid-19 shutdown should be considered in practice and policy. Some mothers shared that the shutdown put a temporary stop to constant therapeutic and educational appointments leading to feelings of being overscheduled. They found that spending time at home was a welcomed break. As these interviews represent one snapshot in time, the next steps in understanding the impact of Covid-19 on families should consider the family's view of scheduling, commitment, and breaks from back-to-back appointments. Because early intervention is family-focused, it is vital to consider both social validity and usability of parent-mediated interventions delivered via distance, which decreases a family's commitment to appointments outside of the home.

Effects on Parental Stress and Resiliency (RQ2)

Our findings suggest that COVID-19 has increased parental stress, which aligns with other pandemic research (Asbury et al., 2021; Cooke et al., 2020; Gonçalves-Pinho et al., 2021; Howard-Jones et al., 2022). At the same time, participants' descriptions of their pandemic experiences also highlighted their resiliency. Some mothers described their connection with their spouse, spiritual practices, and social supports may have acted as protective factors for their mental health. For example, participant 11 described an experience of reaching her "breaking point" and using her resources (i.e., medical doctor, spouse) to support her recovery, preventing further stress-induced mental breakdowns. In addition to external support, parents reported using a positive outlook, patience, prayer, and emotional outlets to cope.

Implications for Practice

The results of this study highlight the critical role of support systems in the lives of families with young children experiencing DD. Professional support in therapeutic and educational services can provide mental health guidance for families through referrals and social networking suggestions (Bronfenbrenner, 1979). Professionals can prepare the families they serve for interruptions in services due to unexpected high-stress events by assisting families in identifying their strengths and resources. Established strategies such as Routines-Based Interviews (RBI)(McWilliam et al., 2009), ecological-mapping (Eco-maps)(McCormick et al., 2008), and motivational interviewing (MI)(Williams, & Wright, 2014) demonstrate promising outcomes in early intervention. These strategies can assist families in establishing healthy routines, identifying supports, and following through on goal setting to increase family resiliency in response to disruptions, ultimately protecting families from the negative impacts of unforeseen stressors. Research specific to parental stress and the use of established strategies (e.g., RBI, Eco-maps, MI) is necessary to better understand the role of support systems in high-stress events. Additionally, future research and practice should consider each families' unique experiences during COVID-19. Because many parents were left without support systems (e.g., missing therapists, professionals, and teachers from Microsystem; Bronfenbrenner, 1979), parents were able to experience what providers and services were most essential. This increase in understanding of the necessary interventions for their child may have been amplified by an increase in parental awareness resulting from time with their child. This informed and

critical viewpoint possibly highlighted who is important and what services are not.

Multiple Parental Roles and Responsibilities (RQ3)

Mothers described the difficulty they had in taking on additional roles as a result of COVID-19 restrictions. Parents were left to take on the many roles previously filled by various professionals (e.g., teacher, behavior analyst, physical therapist). This lack of educational and therapeutic support for children was also heard in the legal concerns posed by parents: school and therapy closures affected children with disabilities to the point of decreasing their quality of life and producing inequity in education. Ultimately, COVID-19 isolation contradicts both the purpose (i.e., to promote progress) and urgency (i.e., more developmental gains are made when access is early) of early childhood intervention (McIntyre et al., 2021)

Implications for Practice

Parents emphasized difficulty fulfilling and navigating services between schools, therapists, and service providers. Being the go-between for schools and professionals was perceived as a burden by the parents in this study. Early childhood practitioners are uniquely positioned to provide this link by, for example, facilitating communication between a clinic and school. Mothers interviewed in this study emphasized their need for a professional to assume the role of “parent educator” and “family supporter” (P10) and to “think outside the box” (P8) in their practice with families. These findings echo parents’ need for help with disability education, system navigation, and advocacy.

Using a transdisciplinary model, commonly cited as a best practice for early intervention, is one option to support families using special education services during early intervention and through their time in school (Bricker et al., 2020). However, this delivery model, where the family is central to intervention delivery, goal-setting, and choice-making for their child, is typically only used in early childhood education, under age five. In these initial years of identification and vital intervention, families have a team of professionals that provide services, collaborating with one another to increase the amount of opportunities for a child to succeed in their milestone achievement. However, once children with DD move into a school system (e.g., kindergarten and beyond), the services often become isolated rather than collaborative. It is likely that due to the distance of professionals from one another and from the family, service delivery did not follow the suggested transdisciplinary model during the early part of the pandemic and became isolated rather than remaining collaborative.

Limitations

There are several limitations to note within this research. First, parents’ responses were likely linked to their child’s disability severity (e.g., disability severity influenced parents’ perspective of their effectiveness in caring for their child). While disability information was collected, the severity of the disability was not measured. Second, spousal and partner support was a topic volunteered by participants in several interviews; however, the quality of those relationships was not measured. Additional questionnaires could have been used to measure whether familial relationships moderate stress levels and the participants’ capacity to handle the additional burdens set forth by the pandemic. Third, the variation among the participants was minimal; thus, broad generalizations to diverse populations are cautioned. The sample overall was small, generally middle to higher SES with minimal representation from Black or Hispanic families. Fourth, details on stopping and starting therapies and in-person education were collected in an interview format, which relied on parents to recall their child’s experiences retrospectively. The participant experiences presented here were drawn from parent reports and represent individual experiences and should be interpreted with caution beyond those of each family. Last, the timing of the interviews, each family’s geographic location, and SES likely impacted the family’s experiences. The variability between these differences may hinder the opportunity to draw broad conclusions, especially considering the ongoing pandemic.

Conclusion

Early childhood intervention is crucial in supporting child development and family well-being (Zwaigenbaum et al., 2015). COVID-19 has drastically altered education, intervention, and services for families with young children, and the effects of those service changes for young children with DD and their families continue to unfold. This study examined a snapshot in time during the onset of COVID-19, capturing the stories of the families' experiences to better understand its impact on their family life. The voices presented here suggest valuable lessons to prevent future educational and therapeutic disparities, provide family support in schools and communities, and hold on to hope for the future. The findings of this study are in line with research suggesting that families with children with DD have higher levels of stress than other families, and COVID-19 restrictions may exacerbate that disparity. The findings from this study are uniquely framed in the theoretical framework of Bronfenbrenner's Ecological Model (1979) and the transdisciplinary model (Bricker et al., 2020) used in early intervention. These models are used to highlight the importance of service support systems for families. Intervention providers can act as a protective barrier preventing some stressors from impacting a family unit. When such supports are unavailable, families become vulnerable- allowing for an opportunity for additional stressors to negatively impact their family.

The unfortunate fact that COVID-19 will remain with us, and that future high-stress events may lead to service and school interruptions, makes further research necessary. Understanding family experiences during high-stress events, such as COVID-19, will highlight individual support needs by suggesting modifications and adaptations increase equity and quality in service delivery at times of unprecedented challenges (Lerman et al., 2020). Future research should work to identify post-pandemic needs, including systematic response to crises, the efficacy of virtual education, essential support systems for families, and the impact of service interruption during vital windows of opportunity in the development of young children.

Declarations

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