



“It’s been a hard year”: How families who have children with disabilities and chronic health conditions experience the COVID-19 pandemic

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ABSTRACT

Background: Families of children with disabilities and chronic health conditions experience unique challenges associated with school, therapies, and social supports. However, little is known about the COVID-19 pandemic’s influence on these families.

Aims: To understand the lived experiences of families with children with disabilities and chronic health conditions during the COVID-19 pandemic.

Methods and Procedures: We gathered narrative accounts from 25 mothers of children with disabilities and chronic health conditions using individual interviews (n = 19) and one focus group (n = 6). A phenomenological approach was used to analyze the data.

Outcomes and Results: Three overarching themes were identified: isolation, connection, and thriving. Families experienced isolation due to the pandemic causing stress and poor mental health; maintained social connections with other family members, friends, and care providers using virtual platforms; and discovered unexpected benefits from the pandemic including a better understanding of their children and a slower pace of life.

Conclusions and Implications: Therapy and support for children with disabilities and their families should prioritize reducing everyday stress, developing social connections that leverage existing networks and identify potential new ones, implementing approaches that build on children’s strengths, and maintaining choice in delivery of professional and peer-led support.

What this paper adds

Families who care for children with disabilities and chronic health conditions rely on a complex network of support to provide an optimal level of care for these children. The COVID-19 pandemic disrupted this care and required families to be nimble in how they adapted to and addressed the needs of their children. We conducted qualitative interviews with 25 mothers to understand how the COVID-19 pandemic affected their families’ lives and the lives of their children who have a disability or chronic health condition. Our findings highlighted some of the negative consequences of the pandemic, e.g., breakdowns in services and routines, parental and intrafamilial stress, declines in mental health for the parent and child. However, we also pinpointed areas of resilience and innovation. For example, some mothers reported that the pandemic brought their families closer together and inspired them to take a strengths-based approach when thinking about their children. There was

greater awareness of the child’s capacities and personhood rather than a primary focus on their deficits and diagnoses. Also, technology (e.g., online games, Zoom) allowed children to stay connected with peers and maintain a sense of normalcy during rather atypical times, and it fostered equity by providing families with access to supports or activities that were previously inaccessible due to distance or an inability to travel.

1. Introduction

The COVID-19 pandemic has changed many aspects of everyday life for people around the globe, creating unique stresses and some unforeseen benefits for families and children. These negative and positive outcomes associated with the pandemic are particularly salient for families who have children with disabilities and chronic health conditions.

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1.1. Negative outcomes associated with COVID-19

Children with disabilities and their parents have reported decreased well-being (Yates & Dickinson, 2021), and parents of children with intellectual disability had greater feelings of defeat and entrapment during COVID than prior to the pandemic (Willner et al., 2020). COVID-19-related stresses included families having to re-organize their lives (Kong, 2020), worries of contracting the virus and loss of finances (Faccioli et al., 2021), fears of children falling behind in skills (Asbury et al., 2021), and concerns of who would look after the children if parents died from COVID-19 (Asbury et al., 2021).

Children's stress has been reported to often manifest itself in greater intensity and frequency of behaviors that caregivers find challenging to manage (Asbury et al., 2021; Neece et al., 2020; Shorey et al., 2021). For example, children did not understand the broad social and health consequences of the COVID-19 pandemic (Asbury et al., 2021), and routines were upended in a population that often benefits from structured routines (Shorey et al., 2021). The literature recommended behavioral strategies such as using tokens to receive rewards and reinforcement systems to support family coping (Neece et al., 2020; Shorey et al., 2021). However, compliance-based behavioral systems are in direct opposition to neurodiversity affirming supports and can cause post-traumatic stress disorder (Kupferstein, 2018).

Families who were already feeling isolated due to environmental challenges such as disability stigma (Mitter et al., 2019) and a lack of participation supports have reported being more isolated during the pandemic (Kong, 2020; Patel, 2020), which negatively affects children's emotions, mood, sleep, and mental well-being (Patel, 2020). They also experienced a loss of supports, social connection, structure, specialist input, and routines (Asbury et al., 2021; Kong, 2020; Neece et al., 2020; Shorey et al., 2021). Parents of children with challenging behavior felt less social support than parents of children with solely intellectual or physical disability (Provenzi et al., 2021; Willner et al., 2020). Further, parents experienced increased caregiver burden due to greater care demands and loss of supports from developmental therapies and school (Faccioli et al., 2021; Kong, 2020; Neece et al., 2020). Thus, the nascent literature suggests that parents' loss of supports and overall family stress had negatively influenced family well-being.

1.2. Positive outcomes associated with COVID-19

In contrast to the negative outcomes associated with COVID-19, some families also experienced unforeseen benefits from pandemic-related changes. These benefits included decreased demands on parents and children due to a slower pace of life (Embregts et al., 2021; Neece et al., 2020; Rosenbaum et al., 2021); increased quality family time that supported parents understanding of family members and positive family relationships (Meral, 2021; Neece et al., 2020; Rosenbaum et al., 2021); a shift to more positive social interactions between children with disability and their neurotypical siblings (Embregts et al., 2021); and the child with disabilities demonstrating increased skills, especially with self-care (Meral, 2021).

1.3. Study rationale

A scoping review on the mental health of children with disabilities and their families during COVID-19 revealed that the current literature base on the COVID-19 experience of families of children with disabilities is understandably limited (Asbury et al., 2021). The literature includes predominately expert opinion, rather than empirical studies. The empirical studies tend to be surveys where the COVID-19 experience of families was not the focus of the research, or qualitative interviews that had very small sample sizes. There is an important need to understand the lived experience of families of children with disabilities and chronic health conditions as their experience with the pandemic evolved. Throughout the pandemic, parents had had to balance their children's

well-being in doing activities and keeping them safe from increased vulnerability to COVID-19 complications (Embregts et al., 2021).

1.4. Current study

The aim of this study was to understand the social-emotional well-being of families who have children with disabilities and chronic health conditions during the COVID-19 pandemic. Specifically, the research question that framed this investigation was: How did the COVID-19 pandemic affect the everyday lived experience of families who care for children with disabilities and chronic health conditions? This exploratory study adds to the literature by including diverse families in terms of children's age, children's diagnosis, parent disability, family's race and ethnicity, family's living situation including rural and urban, and families' COVID-19-related decision making.

2. Materials and methods

2.1. Study design

The investigators used a phenomenological research design to understand the meaning participants derived from their experience of the COVID-19 pandemic. Specifically, this approach was used to describe rather than explain participants' lived experience through fresh, complex, and rich descriptions of the phenomenon (Finlay, 2013).

2.2. Study site

The participants were recruited from a Midwestern state in the United States that declared a peacetime emergency in mid-March 2020 and followed the Center for Disease Control and Prevention's (CDC) guidance for COVID-19 restrictions. The state's policies were consistent with other U.S. states that enforced CDC guidance including: schools shifting to online delivery until January 2021; nurseries, playgrounds, and indoor public spaces closed for at least 3 months with gradual re-opening; mask requirements in public locations starting in summer 2020; many appointments shifting to online through 2020; social distancing; and imposing reductions in the number of people in venues when they opened. The state eased and tightened restrictions based on the prevalence of disease, and hospital capacity. Data collection for this study took place in Spring 2021, with the participants reflecting on their experiences during the first year of the COVID-19 pandemic.

2.3. Participants

The research team used purposive sampling to recruit participants through online parent groups for children with disabilities (e.g., a group for parents who have children on a disability waiver, and a group for parents of Autistic children). Snowball sampling was subsequently used after initial contacts were made from the online parent groups. We also recruited participants through contact with an advocacy group for parents of Autistic children to increase the racial and ethnic diversity of our sample. The advocacy group representative recommended that some families would be most comfortable talking in a group, thus we conducted one focus group to facilitate the interview process.

Participants included 25 mothers of children with a disability and/or chronic health conditions, i.e., 19 individual interview participants and 6 focus group participants. Approximately two-thirds (68 %, $n = 17$) of the participants identified as white or white/Jewish, 28 % ($n = 7$) identified as Black/Somali, and 4 % ($n = 1$) as Native American. The age range of participants who provided data was 30–51 years old ($M=40.3$, $SD=5.9$, $n = 19$). Of the 21 participants who reported their geographic location, 4 (19.1 %) lived in a rural community, 15 (71.4 %) suburban, and 2 (9.5 %) urban. The mothers described the disabilities and chronic health conditions for a total of 35 children. The most common diagnosis was Autism (51 %), followed by global developmental delay (28 %),

Table 1
Participant and Child Characteristics.

ID	Participant	Participant's race/ethnicity	Child's age/gender/primary diagnosis
Individual Interview			
FAM01	Mother	White	17 years old/ female/Autism
FAM02	Mother	White	9 years old/ female/ Autism
			11 years old/ male/Autism
			13 years old/ male/ADHD
FAM03	Mother	Black/Somali	7 years old/ male/ Autism
FAM04	Mother	Naive American	7 years old/ female/Autism
			15 years old/ male/Autism
			17 years old/ male/ Autism
FAM05	Mother	White/Jewish	7 years old/ female/ Autism
FAM06	Mother	White	2 years old/ female/Down syndrome
FAM07	Mother	White	12 years old/ female/ Down syndrome
			12 years old/male/ Leg amputation
			14 years old/ female/Tourette's syndrome
FAM08	Mother	White	20 months/ female/ Down syndrome
FAM09	Mother	White	4 years old/ male/ Down syndrome
FAM10	Mother	White	14 years old/ female/ Global developmental delay
FAM11	Mother	White	12 years old/ female/ Global developmental delay
			15 years old/ female/ Global developmental delay
FAM12	Mother	White	21 months/ female/ Down syndrome
FAM13	Mother	White	8 years old / female/ Down syndrome
FAM14	Mother	White/Jewish	11 years old/ male/ Autism
			11 years old/ male/ Autism
FAM15	Mother	White	5 years old/ male/Global developmental delay
			6 years old/ male/ Global developmental delay
			17 years old/ male/Autism
FAM16	Mother	White	4 years old/ male/ Quadriplegic cerebral palsy
FAM17	Mother	White	7 years old/ male/Global developmental delay
FAM18	Mother	White	10 years old/ female/Infantile Batten Disease
FAM19	Mother	White	6 years old/ male /Autism
Focus Group			
FG1	Mother	Black/Somali	14 years old/ male/ Autism
FG2	Mother	Black/Somali	11 years old/ female/ Autism
FG3	Mother	Black/Somali	6 years old/ male/ Autism
FG4	Mother	Black/Somali	7 years old/ male/ Autism
FG5	Mother	Black/Somali	8 years old/ male/ Autism
FG6	Mother	Black/Somali	15 years old/ male/ Autism

attention-deficit/hyperactive disorder (25 %), and Down syndrome (17 %). The majority (76 %) of children had more than one diagnosis. A summary of participant and child characteristics is provided in [Table 1](#).

2.4. Ethics

The University of Minnesota Institutional Review Board granted approval for this study (STUDY00010953). All participants received a written description of the investigation and had an opportunity to ask questions about the research study before agreeing to take part in a recorded interview. A \$40 electronic gift card was provided to each participant.

2.5. Data collection

Individual and focus group participants were informed of the nature

of the study and provided an opportunity to ask questions before commencing the interview. The majority of the interviews were conducted via Zoom (individual participants, n = 17; focus group participants, n = 6) and two were completed by phone. Interviews lasted between 45 and 70 min (M=54). The current study analyzed responses to the following questions: (1) What has it been like for you and your family to deal with COVID-19? (2) What ongoing routines do you engage in to keep your family safe? and (3) How else has your daily life changed due to COVID-19? All interviews were recorded and transcribed verbatim.

2.6. Data analysis

The researchers began data reduction and analysis by importing the transcripts into NVivo ([NVivo Qualitative Data Analysis Software, 2015](#)) and coding the data into broad categories (e.g., COVID has been hard emotionally, parental fears). Data were coded line by line to capture what the research participants were describing related to their COVID-19 social-emotional experience. Similar codes were grouped and organized into categories (e.g., virtual connection is not as good, learned about the child). The first author engaged in peer debriefing with the research team, consolidating and re-organizing the categories, until the final three major themes were identified: isolation, connection, and thriving. In accordance with phenomenological approaches (Finlay, 2013), and especially important given the shared and differing experience worldwide of the COVID-19 pandemic, the researchers bracketed their own experiences and previous knowledge when engaging with the data and participants. Trustworthiness of data analysis was maintained in a number of ways: credibility was supported through the use of in-depth interviews, transferability through the use of thick description and a table of family characteristics, dependability through an audit trail, and reflexivity through peer debriefing and using a diary throughout the research process ([Korstjens & Moser, 2018](#)).

3. Results

Findings from our analysis of the interview data were organized into three substantive themes: isolation, connection, and thriving. These themes articulate the challenges and benefits families derived from their experience of managing the COVID-19 pandemic.

3.1. Isolation

Families described in detail actions they took to keep their vulnerable family members safe and avoid being infected with COVID-19. For them, isolation was perceived to be far greater than that of other members of the public, which placed additional strain on the whole family. Mothers, especially sole parents, worried about what would happen to their children if the children's primary guardian or caregiver contracted COVID-19. "If I get sick, I have no one to care for my kids and I can't rely on [others] to care for my medical kids. Will the hospital take them because they're hospital-level care and, if so, how do I get them there?" (FAM15). The worry of what would happen if they, as their child's primary caregiver, died had a profound impact on their everyday decision making during the pandemic, often increasing their isolation. When asked about keeping her family safe one participant said:

I think pretty much just staying home and judging people who make unsafe decisions. And I don't know if that helps anything. But I do it anyway because it makes me feel good. I'm in a high-risk group. And as the only parent of three disabled Black children, I can't die. They'll go into foster care and foster care isn't good for disabled Black children. (FAM04)

Families found it challenging to lose supports that they relied on previously. For example, one family member stated, "When it happened, she was under a year old, and her diagnosis was still fresh for me. The

hardest part was being cut off from everybody when I needed support on how to help her, and emotional support for me” (FAM08). Families described how the pandemic deepened isolation that they were already experiencing, but some tried to find humor in the situation:

COVID has really taken its toll because we feel pretty isolated as it is. Then you add another layer on top of it, to the point where I was FaceTiming with my best friend and she was like, “[younger child’s name], what do you want for Christmas?” And [younger child] goes, “I just want to go to Walmart.” I’m like, that is the most pathetic, sad thing I’ve ever heard in my life (laughs). (FAM11)

The need for the whole family to isolate to protect vulnerable family members made it challenging for families with immunocompromised children. One family described how some of their family members previously had to isolate due to their child’s health conditions; however, “the COVID isolation has been much harder than it was the first time around just because of health. I think the reason is because it’s impacting all the other kids, too” (FAM13). Some families became frustrated with extended family or community members whose actions put their family at greater risk of contracting COVID-19, which in turn increased their isolation.

It makes me feel very lonely as far as who can I reach out to that respects COVID restrictions and generally practices them. Who can I call that wears a mask when they go out and generally believes [that COVID is a serious condition]? I can’t really call anyone in to help me in my home, which I definitely would have done in other circumstances. (FAM16)

Some mothers, especially those with children who are immunocompromised, described breaking ties with family members and friends who did not respect their child enough to try to keep them safe from COVID-19. They also expressed uncertainty about whether they would return to those relationships post-pandemic.

3.1.1. Depression, anxiety, and “behaviors”

Many families described increased depression and anxiety in their children as well as increased frequency and intensity of challenging behaviors, indicating that their children were stressed. One focus group participant described her Autistic child’s hospitalization due to depression, which she attributed to isolation and lack of communication for him. Another family described the isolation increasing her children’s behaviors, “I’ve noticed, especially in [younger child], a ramp up with behavioral problems because she’s not interacting with many people. She doesn’t have her same routine” (FAM11). Mothers attributed some of the mental health challenges to children with disabilities and their siblings experiencing stricter isolation than in many other households during COVID. As one mother stated, “There has been a lot more mental health supports that they needed. Two of our kids have been receiving mental health treatment, because the isolation that our family has had to endure looks really very different than most people” (FAM13). The isolation of COVID and loss of valued routines caused anxiety and stress for the entire family. One mother described the challenges of routine disruption as follows:

For us, it was very bad. My daughter who is on the [autism] spectrum, she used to go for activities seven days a week. But she’s not doing it. We gained weight a lot. In my house, I used to invite people every weekend or every other weekend. We eat together with friends. We didn’t have that or school. It was terrible last year... She didn’t know what to do, and it affected me. When her dad comes home from work, people are crying. The little one who was doing her work is crying too. (FG2)

Parents also experienced depression and anxiety due to the pressures of the pandemic. Many of the focus group families described deaths of close friends and loss of bereavement rituals. “I lost a lot of friends and family. It was really hard for us not seeing loved ones. Traditionally, we

visit the sick. We help whoever needs, even if you give birth to a baby. All that was not there” (FG2).

Parents tried to protect their children from the pervasive human toll of the pandemic: “I am shielding my children from the suffering. I don’t necessarily want them to be aware of the scale of grief that is ongoing in our society right now, because we already came out of a diaspora like that” (FAM02). However, this protecting of children may have created a greater emotional burden on the parents, especially when they already felt isolated.

3.1.2. Child regression

Several mothers described their children regressing in skills such as toilet learning or communication due to the isolation of COVID-19, including the loss of supports: “It’s been really hard because we’ve been isolated. And my son has regressed, unfortunately. But at least he doesn’t have COVID, and we don’t have COVID, (laughs). It’s been hard, and we’re getting antsy” (FAM03). One family described toileting regression specifically, “[My child] is not toilet trained. He was, and then regressed with COVID, which is kind of typical. We’re experiencing losses with skills that have already been gained. He wasn’t fully trained, but now he’s all in pull-ups” (FAM14). Families also described regression in emotional well-being within the family due to competing demands of parents during the first part of the pandemic. One mother stated,

When COVID hit and we couldn’t have any PCA’s (personal care assistant) in our house and both of us were trying to work and kids were trying to do school. He did a lot of sitting and hanging on his own near us, but not being held. He regressed a lot and he was not as happy and he would complain more often, just ‘cause nobody had as much time or he didn’t have the one-on-one attention as he was used to getting. (FAM17)

Families also worried about how the isolation due to the pandemic would affect their children’s future skills and development. “I worry about her development because all she knows of the world at 20-months-old is our house, our four walls, and daycare’s four walls. I worry about the future. Am I stifling that super important stage in her life?” (FAM08).

Families of children with disabilities perceived their isolation due to the COVID-19 pandemic to be greater than families that only had typically developing children in their house. Due to this isolation, there was decreased well-being across children with disabilities, parents, and siblings, and parents worried about current or potential skill regression in their children.

3.2. Connection

The COVID-19 pandemic disrupted routines and social connections for families who have children with disabilities and chronic health conditions, while simultaneously offering alternative ways of communicating and staying in touch. For example, families tried to foster or maintain social connections during the pandemic by embracing video technology.

I come from a big family. And on top of that, our culture, we’re very family oriented. We’re used to going to people’s homes. And you don’t call someone if you want to know their wellbeing, you go and see them. So it’s been kinda difficult. But I still make an effort to make that connection and call them via FaceTime or, just giving them a phone call, so it’s a new thing for us, and I’m sure for everybody, with COVID. (FAM03)

Some families with strong ties previously found it easier to maintain relationships with distance. “We go to a church that has a lot of close relationships. During this past year, those are the people, generally, we’re calling and checking in on. We email, call, and send cards” (FAM07). While many parents found the switch to virtual interactions

limiting, some families embraced the increased opportunities for community connection that it created.

Now that everybody has to do virtual things, stuff that I'd been begging to have as options pre-COVID [became standard]. For example, a lot of the [State] Down Syndrome Association activities are all up in the [city location]. We never got to go to anything because [my child] was sick, or things would be going on. Whereas now it's like, okay, we're logging in via Zoom. And so is everybody else. The playing field has been leveled and you're able to get in on so many more things that would be more difficult previously. (FAM06)

Parents sought out virtual opportunities to maintain social connection for their children during this time of isolation. "I signed him up for a weekly social group that they talk about Roblox (online game) on, 'cause that's his special interest. That's his big outlet for social stuff, and then he has a friend that they Zoom with all the time" (FAM14). Five families talked about online gaming as an important social interaction for their children. An Autistic parent of three Autistic children described how in the past they would engage in parallel play with homeschooling through outings to places such as children's museums. Now, however, all her children use online gaming to interact with peers.

My boys have X-Box parties, where they'll talk to friends while they're playing video games. My youngest plays Warlocks and she has friends who are daughters of my friends. And they're all Autistic (laughs). It's a group of girls and they chat while they're playing Roblox. It's kind of parallel play but they're still interacting. (FAM04)

Families implemented creative ways to maintain current connections and develop new connections through digital methods. These methods were sufficient to reduce isolation for some families and had distinct advantages to traditional social connection for other families, such as bridging geographic distances.

3.3. Thriving

Many families experienced neutral or positive changes due to the pandemic. They described components that supported their resilience such as already homeschooling their children, having older children who could provide assistance, being able to work virtually, and maintaining existing social connections such as through faith and disability communities. Considerations of their privilege in relation to others inspired some families to be appreciative of their position.

I just kept saying we were fine, but I could just only imagine how much worse if you had the stressor of— if have you just lost your job or you worked in an hourly job somewhere at a restaurant and you could no longer work. There were just so many levels of stress on top of families. So, we were fine. We had jobs and we could all be safe at our nice newly remodeled home. We just had to keep having that viewpoint that we are in a much better place than a large population. And so, I don't complain. (FAM17)

Families described that with intense time spent together away from the fast pace of pre-pandemic life, they learned more about their child (ren) with disabilities. "Everywhere you go, we learn about our children's deficits. Now I can tell you what are his skills. What can he do? He can dress himself. He can go and get his own milk" (FG5). One family used the changes due to the pandemic as an opportunity for developing her parenting and advocacy skills.

I've had some awesome things that happened during COVID. I did a fellowship. I did a policy advocacy program and without COVID, I wouldn't be able to do that 'cause they were all online. I learned how to really appreciate my son as an individual, not as the diagnosis, but as [child's name]. What does he like? What does he not like? Who is he? I learned the importance of self-advocacy and encourage him to

be a self-advocate. [Without COVID] I don't know if I would be able to take part of these programs and really learn those things so that I could apply it in my life so that my son could benefit from that. So, no, it hasn't all been doom and gloom. We've actually thrived as well. (FG4)

Positive changes within the family unit that mothers saw included older siblings stepping up with caregiving, partners understanding the care coordination mothers do every day, life slowing down, increased family connection, and the child with a disability happier at home with their family. Just slowing down the pace of life was something many families appreciated. "Being home together was nice. We took advantage of the time. We did games, theme nights for dinner, just stuff that we normally wouldn't do. Just slowing everything down, 'cause we're pretty busy" (FAM19). Working from home with children present was challenging for many families, but some saw unexpected benefits as well.

Being home together they have all stepped up in the caregiving. Like, 'Mom's in a meeting. Dad's in a meeting. Okay, I got [child with a disability], Mom. I'll go do whatever with her.' I talk about the resentment, but I'm also seeing more willingness to do what needs to be done for us to still function as a family and the pride and taking ownership in that. [Child with a disability] is just kinda sick of us being the only ones taking care of her at this point, so sometimes the kids can convince her to do something if my husband and I can't, and that makes them really proud. (FAM13)

One mother described how the pandemic supported a re-prioritization for their family, and described COVID-19 as, "A blessing in disguise because I get to spend so much time with my son. He had spent so many years in therapies, been out of the house. I learned to appreciate little things and let unnecessary things go" (FG5).

4. Discussion

The study findings align with and expand previously published research. Similar to other studies, the mothers and families in this investigation felt very isolated during the COVID-19 pandemic. This isolation negatively affected their children's mood and well-being (Kong 2020; Patel 2020), and was exacerbated by a loss of supports (Asbury et al., 2021; Kong, 2020; Neece et al., 2020; Shorey et al., 2021). In the current study, families lost the support of school, early intervention, and personal care assistants, which increased parent and child stress. This stress and isolation resulting from the pandemic negatively impacted family mental health, causing some children to require hospitalization. There was a great fear of what would happen if the parent could no longer take care of the children due to COVID-19, or if immunocompromised children contracted COVID-19 and become very ill or died. Parents had to weigh the competing threats of COVID-19 illness, and poor mental well-being due to isolation including anxiety, depression, and skill regression.

The unexpected benefits of COVID-19 for families also aligned with the literature, including decreased outside demands on families (Embregts et al., 2021; Neece et al., 2020; Rosenbaum et al., 2021), greater quality family time (Meral, 2021; Neece et al., 2020; Rosenbaum et al., 2021), and neurotypical siblings helping more within the families (Embregts et al., 2021). The families with greater social supports and less change in daily activities, often reflecting their privileged socioeconomic status, appeared to have less stress during the pandemic. Single mothers and families in which both parents were engaged in paid work while trying to take care of their child(ren) often described greater stress. Additionally, families who had to take greater caution with COVID-19, increasing their isolation, described more difficulty coping with the challenges of the pandemic. This stress and isolation was exacerbated by family and friends who did not follow safety protocols. For some participants, strong community connections supported

resilience, while for others the inability to come together socially to give and receive support from members of the community exacerbated isolation. Some families who already confronted challenges due to mental or physical health, experienced greater challenges due to COVID-19 restrictions or precautions, such as mental health crises, developmental regression, or social isolation. Previous literature described parents better understanding their family members due to the pandemic (Meral, 2021; Neece et al., 2020; Rosenbaum et al., 2021), which was echoed and expanded in the current study. Many focus group participants described that before the pandemic their children were in intensive behavioral interventions, and that being home during the pandemic allowed them to learn more about their children's strengths and limitations, be better advocates on their children's behalf, and teach their children to advocate for themselves.

This current study has several limitations that need to be considered when interpreting the findings. First, interviews were conducted during the COVID-19 pandemic when family and caregiving demands may have been higher than during pre-pandemic times. As such, the participants in this investigation could represent individuals who are highly motivated to participate in research and share their experiences. Second, this study was conducted in one US state and may not represent the experiences of families in other geographic regions in the US with different social and health care resources. Third, only mothers of children with disabilities or chronic health conditions participated in the individual interviews and focus group, therefore, our findings do not reflect the perspectives of fathers or male-identified guardians.

How families of children with disabilities developed connections during the pandemic is a previously unexplored topic in the literature. In the current study, families maintained their social networks through virtual connections, and even expanded some networks through video calls and online gaming to connect geographically distant people. These newly established means of personal and social engagement allowed families to overcome barriers using digital technology.

4.1. Implications

The unusual nature of life during the COVID-19 pandemic can teach important lessons about how to support families during non-pandemic times. Parents described valuing the additional time with their family members and having a break from constant activity. Families should be encouraged to reflect on their values and consider prioritizing certain activities or therapies and allow plenty of down time or family time to support the well-being of the whole family. Families should prioritize therapies that are strengths-based and identity affirming, as well as ones that affirm (a) the family to know their child and their capabilities, and (b) current child and family needs. The child's well-being should be prioritized along with their development (Scottish Government, 2016). The more the family understands the child's interests, values, and capabilities, the better they will be able to engage in collaborative partnerships with providers (e.g., physicians, social workers, occupational therapists).

Video connection supported families in several ways and maintaining these virtual options should be encouraged post-pandemic. Many families lost therapy support during the pandemic. Telehealth can provide continuity of care and support child development and well-being during times of disruption (Provenzi et al., 2021), but may be beneficial to maintain as an option post-pandemic—e.g., if a family member is ill or the family is unable to travel to an appointment. Disability support groups can increase equity by having hybrid gatherings instead of in-person only events as one way to include families who may not have or cannot afford transportation, may live far away from the in-person event, or have a child who may be too ill or require constant supervision. In addition, children who benefit from consistency of routines may feel more comfortable joining from the comfort of their home rather than having to transition to a new location. Additionally, many children in this study enjoyed the social interaction of connecting virtually

through video games, texting, and video calls. Children should be encouraged to have social connections in the way that they feel comfortable—virtual, in-person, or both—and virtual interactions should be viewed as a valid method of social connection for children with disabilities.

Families can be encouraged to leverage their own sources of resilience in times of stress (e.g., being grateful for the resources they have, using humor, developing and maintaining connections with others) to support posttraumatic growth to integrate the experience into their life story (Tedeschi & Calhoun, 2004). For immunocompromised children who may have to isolate during non-pandemic times, therapists can support families to continue previous social connections, establish new connections to reduce feelings of isolation, and problem solve with families to maintain engagement in school, therapies, and community activities. To support future resilience, providers should also support families' networks in non-crisis times by listening and encouraging naturally occurring networks and recommending other ways for them to develop community connections.

5. Conclusions

The COVID-19 pandemic has had a profound influence on families who care for children with disabilities and chronic health conditions. It has increased the stress some families experience in their day-to-day lives, tested the strength of interpersonal relationships and social supports, and adversely affected the mental health of parents and children. The pandemic has also inspired families to be creative in how to maintain and expand social interactions, focus on individual and collective strengths rather than deficits, and take the time to get to know their child(ren) at a more nuanced level. The lessons learned from this study are essential because they can be used to inform how medical and social service providers can adopt a holistic approach when providing care to families with children who have disabilities or chronic health conditions. In a time of a global public health crisis, it is incumbent upon care providers to think and act creatively in the best interests of their patients and clients, and to acknowledge and harness the strengths and resilience that families manifest as a means to improve their overall well-being.

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CRediT authorship contribution statement

Julia Sterman: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Supervision, Project administration, Funding acquisition. **Joseph Merighi:** Methodology, Investigation, Writing – review & editing, Project administration, Funding acquisition.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

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