

Mothers of Disabled Children Faced Numerous Challenges During the COVID-19 Pandemic

Amy Lutz, Sujung (Crystal) Lee, and Baurzhan Bokayev

KEY FINDINGS

- Mothers of disabled children often worked closely with their children during COVID-19 school closures because previously available services were often not available during the pandemic.
- Meeting children's educational needs made it difficult for some mothers to manage paid employment during the COVID-19 pandemic.
- Some families with disabled children had multiple family members engaged with their child's education.

The COVID-19 pandemic changed life dramatically for most families, but particularly for families with a disabled child. Mothers of disabled children faced increased difficulties during the early months of COVID-19 compared to other families. According to research, many parents of children with intellectual and developmental disabilities reported a reduction in services offered to their child.^{1,3} Without these services, caregivers of disabled children felt overwhelmed with having to provide these services on their own, especially if they were also working while overseeing their child's education.²

Caregivers of disabled children also experienced greater depression during COVID-19 school closures and service disruptions.⁴ Parents of disabled children are at higher risk of parenting-related exhaustion.⁵ They may also have faced greater difficulties balancing their work and overseeing their children's education, as they may have needed to spend more time than other parents working closely with their child to do schoolwork. Many students were unable to fully participate in remote schooling and were left at risk of falling behind academically.⁶ Parents experienced anxiety, stress, and difficulties with helping their children to adjust in remote schooling.

In this brief we summarize results from our [recently published study](#) on the challenges that COVID-19 and its related school closures brought for mothers of disabled children. Our findings are based on interview data we collected from 65 parents (mostly mothers) in central New York State when schools were closed in the Spring of 2020.

Lauren's Story: Carving Out Time to Work with Her Daughter

Mothers of disabled children reported that their children had a particularly difficult time adapting to remote education. Some were unable to get equivalent school-based services during remote education. Thus, they had to work closely with children in a way that was often incompatible with their own work. Lauren's 5th grade daughter, Melissa, has ADHD and was receiving services through school. Lauren said:

So, Melissa has an IEP (Individualized Education Program). She has ADHD, and she has a very tough time focusing. And having her now move her education to the home and have me be the teacher is the worst possible situation she could be in for her learning disability. She just wants to quickly rush through and get it done, just pick any answer so she can move on and go outside, play, hang out, whatever. It was very difficult in the beginning because I was getting frustrated.

Lauren, an engineer who was working from home, found that she could not work while her daughter was doing her schoolwork:

I would not have her do schoolwork when I was working because she always needs me. I tried. I said, "Go up in your room. Go take your computer to your desk and try it on your own." "I can't. I can't do it. I need you." So, I gave up on that and I said, "Fine. Just go do whatever you want for an hour. This is your break." And then I would be able to get back to it. But she would take the laptop and keep coming in the office. "What about this? What about this? What about ..." It was just constant, constant, constant.

As a way to manage the conflict between her own work and the extra work that teaching her disabled daughter entailed, Lauren decided that she would dedicate every day from noon until 2 p.m. working closely with her daughter and spend the rest of the day on her own work. This worked out well and over time her daughter started becoming more independent:

And as it's gone on, even with this week, she's gotten way more independent and doing much better, and actually doing her math on her own where I don't even have to go in there. Not that she's getting it right, but she's trying. To the point where she got an email from her resource teacher and her school teacher commending her, saying, "This is an amazing ..." She wrote a paragraph all on her own. I wasn't even aware of it. Submitted it and, "This is amazing. You're doing so great. You're one of the best distance learners. And you're trying so hard, and we're so proud of you." So, that was really nice to see that we're making progress. I was stressing out over it all day long because it was a lot of work for her.

Lauren's story illustrates that she, as a parent, had to come up with a plan of action for overseeing her daughter's education, rather than having a cohesive plan in place at the school level. While Lauren's daughter, Melissa, made progress using the system she developed, many parents have had to put in long hours working with children with disabilities such as ADHD.

Melanie's Story: Bringing in Grandma to Help with the Schoolwork

In some cases, multiple family members were involved in overseeing the education of a disabled child. Melanie is a research analyst, with two children, one of whom is a twelve-year-old boy with dyslexia with a 3rd grade reading level who "has difficulty reading for

long periods of time.” Her son, Ryan, needed to be read to in order to do each assignment. The family split up this work among Melanie, her husband, and her mother, who lives in Florida and reads to Ryan over WebEx. About the arrangement with her mother, Melanie said:

My mother's been helping my son because of his disability for years now. She offered him a tutor years ago and I said, "No." I said, "If you're going to help my son, you're going to get on this WebEx with them and you're going to read with him." So, she's been doing that for multiple years now. I think it's going on three years that they've been doing that. They just upped the schedule. They're doing it daily now instead of once a week.

Melanie's husband had to shut down his business due to COVID-19, so he was also helping their son with his work during the pandemic. Despite her mother's and husband's help, Melanie still spent a lot of time helping her son with his assignments. She estimated that she spent at least 3 hours a day working with him on his schoolwork, in addition to working full time as a research analyst. She said:

My son takes a really long time to do his work. So I can give him an assignment, read to him what he needs to do and then he can sit on the computer trying to read it for literally hours.

In addition, Ryan sometimes got tired of doing his work and started to play video games, so Melanie had to keep checking to make sure he is doing his work, which interrupted the flow of her own work. She said:

I have to keep going back very frequently and interrupting my day, whereas I could get more done in my day if I didn't have those interruptions.

Melanie's interactions with Ryan's teachers were also challenging. She said:

The stressful part of overseeing that is finding out what the teachers are doing and sometimes the attitudes of the teachers come through. That's not a fun part. If a teacher emails me and says, "I haven't seen anything from your son in three weeks," it's very accusing. Like, why are you not doing it? And I had to write back and say, "He's done every assignment. We've put it here. We've put it there." They just really have to find it. So that and trying to get the communication with the teachers in a way that was conducive to working together, I think was the hardest part.

Melanie said that she feels that her son has benefitted from all the one-on-one attention he received from family members during remote education, but that she “wouldn't want to do it forever.” She said, “I'm glad that my kids are home and they're safe, but it is stressful.”

Being Prepared for the Next Pandemic

Mothers of disabled children found that the teaching role intensified their mothering, often leading to conflicts with their employment, which many mothers were doing from home during the pandemic.⁷ They put in extra time and effort to meet their children's educational needs during the pandemic. In many cases the primary caregiver took on that responsibility, but in other cases, such as Melanie's, multiple family members shared the work of educating her son.

The experiences from the COVID-19 pandemic suggest that schools were not prepared to adequately address the educational needs of children, especially in the case of disabled students who received services such as special education. As a result, parents had to take on extreme educational oversight for their children's education. Given that future pandemics may impact schooling, now is the time to plan for future emergency situations in public schools. In addition to the possibility of future health emergencies, climate change may result in the localities having to rapidly switch to online education due to flooding and other natural disasters. Thus, schools should be prepared to rapidly transition to online education with short notice. To prepare, schools should be proactively developing emergency plans to meet the educational needs of all students, but particularly disabled students. Students receiving specialized instruction should not be disadvantaged in instances when it is necessary for schools to transition to online learning. Failure to adequately prepare for these events risks increasing harm to all students, but particularly to disabled students and their families.

Data and Methods

This research is based on 65 interviews with parents (mostly mothers) who were living with school-age children between April and June of 2020. We conducted semi-structured telephone interviews while school was operating remotely in the Syracuse, NY area. Most participants were working during this time while also overseeing children's remote education. Only 7 parents (11%) were not working. For additional findings and methodological details, see the [published study](#).⁸

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