

CAREGIVER VOICES: THE INITIAL IMPACT OF COVID-19 ON CAREGIVERS OF CHILDREN WITH AND WITHOUT DISABILITIES



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Background

Families across the nation are facing unprecedented challenges as a result of the COVID-19 pandemic.¹ In April 2020, we surveyed caregivers of children with and without developmental disabilities (DD) across the United States to explore their well-being as a result of these challenges.² Our survey findings found that although all caregivers are experiencing increased stress and well-being challenges, this was especially true for caregivers of children with DD.² To gain further insight into the impact of COVID-19 on caregiver stress and well-being, we interviewed 30 caregivers of children with and without DD.³

Key Findings

Caregiving Stress

- The majority of caregivers indicated that **supporting their child's education and schooling from home has been their greatest source of stress**, which has influenced various aspects of their personal and professional life including work, leisure activities, relationships, and sleep.
- Caregivers of typically developing children reported a **greater impact on capacity to support their child based upon the school's expectations for digital learning**, and a greater impact on ability to balance work obligations, and inability to see friends or family.

"...the requirements and expectations for distance learning have been a big stressor, just in terms of juggling, being her teacher at home and having to jump into a lot of content that I don't know... when she had spring break, and we didn't have distance learning, it was a lot less stressful for everybody in the household."

- Caregivers of children with DD reported that **one of their greatest sources of stress was replicating special education services at home**, which impacted their ability to balance work obligations, as well as care for their own physical and mental/emotional needs.

"Trying to replicate any kind of special ed programming in the home has been the most difficult...that's the biggest stressor."

"This definitely had a negative impact on my work performance. Because my mind is now in 15 different places and not the usual five that I could concentrate on."

"I feel like all of the things that I do have been doing in my life for the past, you know, 15 to 20 years to keep myself mentally and physically healthy have been taken away."

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Self-Care

- The majority of caregivers reported engaging in various self-care behaviors such as exercise, social relationships, leisure activities, and time for self but **indicated that their ability to engage in self-care behaviors has changed** at least somewhat as a result of COVID-19, and reported needing virtual and/or physical supports to engage in self-care.
- Caregivers of typically developing children **reported greater impact on their inability to access self-care resources in the community** like gyms and salons and their inability to see friends or family and reported needing virtual or physical supports to engage in self-care behaviors.

“I mean, I can't go to a gym. I can't just go out to a park any day anytime walk. So, I would say all of the self-care activities have probably gone by the wayside. There just isn't access.”

“I think we need childcare. And whether that's for me to spend time by myself or me to spend time with my husband or me to call a friend and just have like a long phone conversation.”

- Caregivers of children with DD remarked that they **struggled to engage in self-care behaviors both before and during COVID-19**. Some also reported a change in their ability to engage socially or access self-care resources in the community.

“There was no extra time to have done things back then either. I had problems with self-care before this happened.”

“I think the biggest issue is just not being able to get out, either with the family or on my own, to spend time with other people, or go out to dinner, or the kinds of things that we would do that were enjoyable. For me, it's been just kind of a non-stop long stretch of taking care of everybody.”

“For me, it's been...a non-stop long stretch of taking care of everybody.”

Support Needs

- All caregivers expressed the **need for school-related preparedness supports**. They indicated that schools should provide these resources, and that resources specific to schooling and digital learning would have helped.

“I'd probably feel better about what I'm doing if I had a little more guidance.”

“I think if I would have had an opportunity to work with the school or the classroom teachers to say, ‘give us an idea of what we should be expecting or what should a day look like...’”

“It certainly would have been helpful if the schools had a plan in place for doing [distance learning]. And the parents had been provided, you know, some training or some knowledge of it because they ended up kind of developing it on the fly. If they'd had a plan in place...then maybe they could have handled that transition differently.”

- Caregivers of typically developing children provided mixed responses, with some indicating that they needed informational and emotional resources about supporting their child's schooling and routines at home and others reporting that they had sufficient resources.

“I think that the hardest thing for me is maintaining a consistent schedule for the girls have...routine also helps delineate and start them on their day. And so, getting the kids to actually focus and provide a solid routine for them is really hard.”

- **Caregivers of children with DD overwhelmingly expressed the need for respite** and indicated the need for emotional support, support around implementing special education and related service supports from home.

“But also, emotional support for us...there really is not a lot of emotional support out there. And then now it just kind of even widens that gap even more of having really no resources for emotional support. Especially during these times because it's so uncertain...it's a lot, it's draining, and to not really have free time, kind of being the caregiver 24/7, and being the educator 24/7, and trying to just find a balance of homeschool, fun.”

“It's a lot, it's draining, and to not really have free time, kind of being the caregiver and educator 24/7, and trying to just find a balance.”

“The educational piece is sort of the most confusing, particularly because she's in a self-contained class...other than her IEP goals, it's not like there's a set curriculum she was supposed to learn.”

“I think where I'm coming up short... I really think that if there were some sort of respite available... any kind of respite that would get me out of the house for a little while or something, would be very, very valuable.”

- **Caregivers of children with DD indicated the need for resources to prepare them for the delivery of related services from home and increased home-school communication.**

“I have been...left, in a sense, to try and meet all of those professionals' needs, including occupational therapists, physical therapists, speech therapists, school psychologists. So, I think now that's where the current issue is, whereas before...I did have support.”

“I think the school should have provided more supports for families. I think they should have asked what we needed...should have been responsive based on feedback that was specifically solicited, instead of acting so quickly... I think that the school mental health providers should be holding more regular meetings and office hours with families to call in and say, ‘How's it going?’ ‘What are your needs?’”

Additional Sources of Impact:

- **All caregivers reported worrying about the negative impact that the COVID-19 pandemic will have on children's wellbeing.**

“I think that all of these things will have some kind of long-term effect on him. And whatever I can do now, to prevent there being too much scarring or whatever. I'd like to know what that is that we can do for the kids”

“I do think that being confined much more than not...has created some mental health issues for the kids...I can't see how this could be good for them. It's necessary, but it's not good for them.”

“Whatever I can do now to prevent too much scarring, I'd like to know what we can do for the kids.”

- **Caregivers of children with DD emphasized the impact of caregiver burden and the lack of caregiver supports.**

“I think that, again, caregivers at home aren't given any support really. So, I feel maybe going on in the future, caregivers in general would get a little bit more resources...where to go if you need help...I think just kind of stepping up our level of empathy and encouragement for caregivers.”

Implications

Interview responses suggested that all caregivers are experiencing challenges as a result of COVID-19, and likely need support to reduce stress and improve personal well-being during and following the immediate threat of the pandemic. Interview findings were consistent with survey results indicating that **the initial impact of COVID-19 has had a greater negative impact on the personal well-being of caregivers of children with DD as compared to caregivers of typically developing children.**² Given that the response and well-being of caregivers significantly influences child outcomes following a crisis,^{4,5} schools should be particularly cognizant of providing support to caregivers of children with DD in order to reduce the risk of negative outcomes for children with disabilities.

Additional Resources

[Alliance for a Healthier Generation Parent Resource Center](#)

Includes resources for parents to support both their children and their own self-care.

[NASP Care for Caregivers: Tips for Families and Educators](#)

List of strategies to support caregiver self-care.

[CSCH Brief: Stress in Family Caregivers of Children with Disabilities](#)

Brief that contains information/resources about stress for caregivers of children with disabilities.

[NCTSN Parent/Caregiver Guide](#)

Resource guide for caregivers to support their own health and well-being along with that of their child.

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¹ Cluver, L., Lachman, J.M., Sherr, L., Wessels, I., Krug, E., Rakotomalala, S., Blight, S., Hillis, S., Bachman, G., Green, O., Butchart, A., Tomlinson, M., Ward, C.L., Doubt, J., & McDonald, K. (2020). Parenting in a time of COVID-19. *The Lancet*, 4, 395, [https://doi.org/10.1016/S0140-6736\(20\)30736-4](https://doi.org/10.1016/S0140-6736(20)30736-4).

² Chafouleas, S.M. & Iovino, E.A. (2020, July). *Initial Impact of COVID-19 on the Well-being of Caregivers of Children with and without Developmental Disabilities*. Storrs, CT: UConn Collaboratory on School and Child Health. Available from: <http://csch.uconn.edu/>.

³ Of the 30 interviewed, 13 were caregivers of children with disabilities and 17 were caregivers of typically developing children.

⁴ Prime, H., Wade, M., & Browne, D. T. (2020). Risk and resilience in family well-being during the COVID-19 pandemic. *American Psychologist*. <http://dx.doi.org/10.1037/amp0000660>

⁵ Rowe, C. L., & Liddle, H. A. (2008). When the levee breaks: Treating adolescents and families in the aftermath of Hurricane Katrina. *Journal of Marital and Family Therapy*, 34, 132-148.

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