



IMPACT OF COVID-19 ON CAREGIVERS OF CHILDREN WITH AND WITHOUT DISABILITIES: A SIX-MONTH FOLLOW-UP

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Background

The COVID-19 pandemic continues to present substantial challenges for families, including increased stress, poorer mental health, and reduced income as a result of COVID-19.^{1,2,3} In particular, for family caregivers of school-age children, caregiving demands have increased dramatically; this has been especially true for caregivers of children with developmental disabilities (DD), such as autism and attention-deficit/hyperactivity disorder (ADHD).⁴ In April 2020, [we surveyed family caregivers](#) of children with and without DD across the United States to explore their mental and emotional well-being resulting from COVID-19. All caregivers indicated increased psychological distress and decreased ability to engage in self-care as a result of the pandemic.⁵ Significantly greater challenges were reported among caregivers of children with DD, with many noting a substantial impact on their child's specialized support services amid school closures in the spring of 2020.⁵ In October, 2020, we conducted a 6-month follow-up to further explore and compare caregiver burden and psychological distress among caregivers of children with and without DD during the COVID-19 pandemic.^{6,7}

Although caregiving demands have increased for all, family caregivers of children with DD are struggling to a greater degree.

Key Findings

Mental and Emotional Well-Being of Caregivers:

- All caregivers continued to report heightened psychological distress and decreased ability to engage in self-care as a result of COVID-19.
 - Caregivers of children with DD continued to experience significantly higher caregiver burden, depression, anxiety, and stress overall.
 - For caregivers of typically developing children, decreased opportunities for self-care were also associated with significantly higher depression, anxiety, and stress.
 - Caregivers who reported fewer opportunities for self-care due to COVID-19 also reported higher caregiver burden.

Exposure to COVID-19:

- 9.5% of all participants indicated that they or a family member living in the home had been infected, up from 6% at the time of the initial survey.
- 25.5% of participants indicated a family member not living in the home had been infected, a 6.5% increase from April 2020 survey responses.
- 14.5% of all caregivers said that a loved one had died due to COVID-19 compared to 12% reported in the initial survey.

Between April and October 2020, COVID-19 infections and deaths of loved ones increased for all participants.

Factors Associated with COVID-19 Impact:

- The following factors were associated with a greater negative impact of COVID-19 on the individual or their family:
- Having a child with DD with moderate to severe behavioral challenges
 - Being the sole provider of care
 - Lower education levels or household income, increased financial strain, or loss of employment due to the pandemic
 - Inability to see friends or family
 - Community-wide outbreak or COVID-19 infection in the home
 - Decreased opportunities for self-care
 - Reduced childcare resources
 - Reduced supports for child's specialized educational goals

Implications

All caregivers continued to experience challenges six months into the COVID-19 pandemic. However, the **negative impact of COVID-19 on caregivers of children with DD remained significantly greater** at follow-up. Findings reaffirm the importance of supporting caregivers' mental health and well-being, particularly among those caring for a child with DD. Results provide directions for change; notably, addressing caregiver self-care may serve to support caregivers' psychological health throughout the pandemic, which can significantly impact child outcomes.⁸

Additional Resources

Alliance for a Healthier Generation Parent Resource Center

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

NASP Care for Caregivers: Tips for Families and Educators

List of strategies to support caregiver self-care.

Responding to COVID-19: Simple Strategies Anyone Can Use to Foster an Emotionally Safe School Environment

CSCH Brief that contains strategies for fostering an emotionally safe environment for children, families, and schools.

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 Brown, S.M., Doom, J.R., Lechuga-Peña, S., Watamura, S.E., & Koppels, T. (2020). Stress and parenting during the global COVID-19 pandemic. *Child Abuse & Neglect*, doi: 10.31234/osf.io/ucezm

³ Ananat, E., & Gassman-Pines, A. (2020, April 2). *Snapshot of the COVID crisis impact on working families*. EconoFact. <https://econofact.org/snapshot-of-the-covid-crisis-impact-on-working-families>

⁴ Garbe, A., Ogurlu, U., Logan, N., & Cook, P. (2020). COVID-19 and remote learning: Experiences of parents with children during the pandemic. *American Journal of Qualitative Research*, 4, 45-65.

⁵ Chafouleas, S.M., & Iovino, E.A. (in press). Comparing the initial impact of COVID-19 on burden and psychological distress among family caregivers of children with and without developmental disabilities. *School Psychology*.

⁶ Final sample included 337 participants that completed the 6-month follow-up. 189 were the primary caregiver of a child with DD and 148 were the primary caregiver of a child without DD.

⁷ Participants resided in 40 US states, 23% lived in Connecticut, 15% in California, 10% in Florida, and between 4% and 0.3% in the other states.

⁸ 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>

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