



# INITIAL IMPACT OF COVID-19 ON THE WELL-BEING OF CAREGIVERS OF CHILDREN WITH AND WITHOUT DISABILITIES

A CSCH Brief by Sandra M. Chafouleas and Emily A. Iovino

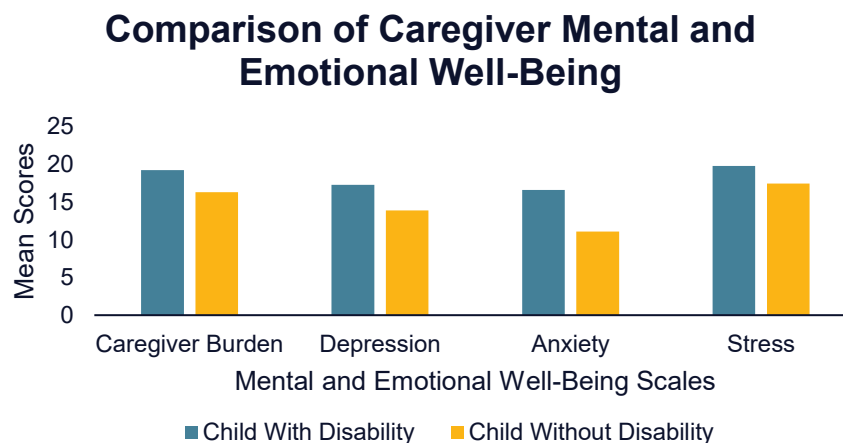
## Background

The COVID-19 pandemic has created unprecedented challenges for families.<sup>1</sup> Preliminary reports suggest that family caregivers of children and adolescents are experiencing increased stress, poorer mental health, and reduced income as a result of COVID-19.<sup>2,3</sup> However, challenges for caregivers of children with developmental disabilities (DD) may be even greater.<sup>4</sup> Maintaining health and well-being has shown to be challenging for these caregivers given additional stressors involved with caregiving activities.<sup>5</sup> In addition to the usual responsibilities associated with caring for a child with DD, caregivers have been tasked with special education teacher and related service provider roles during school closures. In April 2020, we surveyed 407 caregivers of children with and without DD across the United States to explore their mental and emotional well-being resulting from COVID-19.<sup>6,7</sup>

## Key Findings

### Mental and Emotional Well-Being of Caregivers:

- **All caregivers** indicated that their **psychological worry increased** and **opportunity to engage in self-care decreased** at least somewhat as a result of COVID-19.
- **Caregivers of typically developing children** reported a greater impact with regard to their typical **inability to see friends or family**.
- **Caregivers of children with DD** indicated experiencing **significantly higher caregiver burden, depression, anxiety, and stress**.



Average scores on mental and emotional well-being measures by caregiver type

## Exposure to COVID-19:

- **32% of all caregivers indicated no known exposure**; 6% of participants indicated that they or a family member living in the home had been infected.
- 40% indicated that a friend or neighbor had been infected, 19% indicated a family member not living in the home had been infected, and **12% of all caregivers said that a loved one had died** due to COVID-19.
- 29% of all caregivers indicated a **community-wide outbreak**; 48% indicated a **state-wide outbreak**.

## School and Family Impact of COVID-19:

- 95% of all caregivers indicated their child's school building was closed, and **90% held primary responsibility for facilitating remote learning**.
- Caregivers of children with DD reported a significantly greater impact on **available supports for their child's specialized educational goals, resources to assist with childcare, and increased financial strain**.

## Implications

Initial findings confirmed that all caregivers are experiencing challenges as a result of COVID-19, and likely need support for their own well-being as the pandemic continues. However, the **negative impact of COVID-19 on caregivers of children with DD is significantly greater**. Given that the response and well-being of caregivers largely determines child outcomes following a crisis,<sup>8,9</sup> schools must prioritize supporting their caregivers of children with disabilities in order to promote positive outcomes for those children.

## 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.

### NCTSN Parent/Caregiver Guide

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

<sup>1</sup> Cluver, L., Lachman, J.M., Sherr, L., Wessels, I., 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).

<sup>2</sup> 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

<sup>3</sup> 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>

<sup>4</sup> Center on the Developing Child. (2020, March). Stress, hope, and the role of science: Responding to the coronavirus pandemic. Retrieved from: <https://mailchi.mp/harvard/the-center-on-the-developing-child-statement-separating-families-647053?e=55f76154cd>

<sup>5</sup> Chafouleas, S.M., Iovino, E.A., & Koriakin, T.A. (2020). Caregivers of children with developmental disabilities: Exploring perceptions of health-promoting self-care. *Journal of Developmental and Physical Disabilities*, <https://doi.org/10.1007/s10882-019-09724-x>.

<sup>6</sup> 36% of participants were from states in the Northeast, 24% were from states in the South, 12% were from states in the Midwest, and 27% were from states in the West.

<sup>7</sup> 460 caregivers were interviewed. Of the surveyed individuals, 278 were the primary caregiver of a child with DD and 182 were the primary caregiver of a child without DD.

<sup>8</sup> 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>

<sup>9</sup> 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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