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

A CSCH Brief by Hannah Y. Perry, Emily A. Iovino, Jacqueline M. Caemmerer, and Sandra M. Chafouleas

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. 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). 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. 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. 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.

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.
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.¹

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.

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.

This study is funded by a seed grant from the University of Connecticut’s Institute for Collaboration on Health, Intervention, and Policy (InCHIP) to examine social and behavioral implications of COVID-19.