



STRESS: FAMILY CAREGIVERS OF CHILDREN WITH DISABILITIES

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Why Focus on Family Caregivers?

Family caregivers play an essential role within the national health care system, particularly as a resource for children with developmental disabilities (DD). One in six children aged 3-17 years old has been diagnosed with a developmental disability.¹ These children often need additional support with academic, social, emotional, behavioral, or physical development, and caregivers are key in providing and coordinating this care. This caregiving can lead to chronic stress and increased risk for adverse physical and psychological health outcomes.^{2,3,4,5} This brief reviews a) how family caregivers experience stress, b) outcomes associated with chronic family caregiver stress, and c) evidence-informed strategies family caregivers of children with disabilities can use to combat chronic stress.

Caregiving can lead to chronic stress and increased risk for negative physical and mental health outcomes.

How do Family Caregivers Experience Stress?

Family caregivers have commonly identified time commitments associated with caregiving demands as a source of stress.^{6,7} In addition, dealing with child behavioral challenges and/or medical needs frequently leads to stress among family caregivers.^{7,8,9,10} Other factors related to stress among family caregivers include financial burden, relationship strain, employment/activity constraints, low self-efficacy, physical demands of caregiving, concerns about the future, and perceived social isolation.^{6,11,12}

Outcomes Associated with Chronic Stress

Among family caregivers of children with disabilities, chronic stress, defined as stress stemming from **“relatively enduring problems, conflicts, and threats that many people face in their daily lives,”**¹³ can lead to negative outcomes related to *physical health* as well as *mental and emotional health*. In a recent national survey, only 44% of mothers and 52% of fathers of children with special needs reported being in excellent or very good physical and mental health (compared to 63% of mothers and 67% of fathers of children without special needs).¹⁴

Physical Health Outcomes

Family caregivers of children with DD tend to report poor physical health at a higher rate than non-caregivers,^{2,12} and have shown to experience physical strain from caregiving more often than those caring for adults.² Further, family caregivers have frequently reported chronic fatigue and poor sleep as a result of stress associated with caregiving responsibilities.^{12,15}

Chronic stress related to the daily, long-term challenges faced by family caregivers of children with DD has been linked to increased risk of heart disease, cancer, gastrointestinal disorders, high blood pressure, overweight/obesity, asthma, and reduced immune functioning.^{2,11} Health problems associated with stress may be exacerbated by family caregivers' low prioritization of their health and well-being.^{5,12} Further, family caregivers report that current services provide inadequate support for the physical demands of life-long caregiving.¹²

Mental and Emotional Health Outcomes

Although many family caregivers report that caring for a child with DD has had a positive impact on their lives,^{11,12} caregivers also report negative mental/emotional health outcomes due to chronic stress. Specifically, caregivers of children with DD have shown to report persistent feelings of anxiety, depression, guilt, and overall psychological distress at a higher rate than non-caregivers.^{4,6,12} Family caregivers also experience higher levels of stress, depression, and anxiety when the children they care for exhibits challenging behaviors (e.g., aggression, defiance, hyperactivity).¹⁶ Child disability diagnosis, severity, and age, along with the age of the caregiver, have shown to impact negative psychological outcomes for caregivers of children with DD.^{6,10} Overall, caregivers of children with DD have identified the need for improved mental and emotional supports, and report concerns that their worsening psychological well-being might interfere with the ability to meet the long-term needs of their children.¹¹

Supporting Stress Reduction for Family Caregivers

Given the well-documented physical and psychological health risks associated with caregiving stress, it is critical to support caregivers in reducing stress and improving overall well-being. The following strategies have been shown to reduce negative outcomes among family caregivers of children with DD.

Stress-Reduction Activities. Several strategies can be used by caregivers of children with DD to reduce stress and improve their health and well-being - specifically healthy eating, maintenance of a restful sleep cycle, meditation, and regular exercise.¹⁶ In addition, coping skill-building, mindfulness, and cognitive behaviorally based therapy (CBT) have been found to be effective as a means to reduce stress in family caregivers.^{11,16,17,18}

Respite Care. Another strategy caregivers can use to reduce stress involves respite care, defined by the Lifespan Respite Care Act (2006) as “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.”¹⁹

Support Groups. Interventions aimed to promote greater social support can help reduce stress in caregivers of children with DD.^{11,18} Effective interventions have included parent caregivers engaging with other parent caregivers through an in-person or social media-based support group.¹⁶

Parent Training. Given that caregivers often report that their child's behavioral problems impact their stress levels, interventions that teach caregivers how to manage problematic behavior at home and in the community have also found to be beneficial to caregivers.^{11,16}

Additional Resources

Online/National Sources

Benefits for Children with Disabilities

Provides an overview of Social Security services and benefits for children with disabilities.

Caregiver Guide for Special Needs

Gives information and advice to help caregivers overcome challenges and understand the unique needs of people with disabilities.

Caregiving Tips for Families of People with Disabilities

Provides helpful tips for family caregivers of people with disabilities.

Center for Parent Information and Resources

Lists articles and information about disabilities; provides resources, support groups, and services.

Respite: A Child/Adolescent Guide for Families and Caregivers

Guidebook for communicating with respite care providers.

Grand Resources: A Grandparent's and Other Relative's Guide to Raising Children with Disabilities

Provides grandparent caregivers with information on how to access services for children with disabilities.

ARCH National Respite Network

Helps caregivers locate respite providers including visiting nurses, childcare centers, and sleepaway camps.

Support for Families

Provides resources for families of children with disabilities.

State-Specific Sources

Resources for Your Child's Care: Connecticut Edition

Directions helps Connecticut caregivers plan and coordinate care for children with special health care needs, including ways to organize the child's health information.

- [English Version](#)
- [Spanish Version](#)

Connecticut Medical Home Initiative at FAVOR, Inc.

Provides information on respite funds and services in Connecticut. Call [860-436-6544](tel:860-436-6544) or toll free at [1-855-436-6544](tel:1-855-436-6544).

Connecticut Parent Advocacy Center, Inc. (CPAC)

- Statewide nonprofit organization in Connecticut that offers information and support to family caregivers of children with disabilities.

Resource Guide for Families of Children with Disabilities or Developmental Delays: 2016

Provides family caregivers in the State of New York with information and resources about caring for a child with DD.

Parent-to-Parent Initiative

Statewide program in Tennessee where caregivers can serve as a mentor or be matched with a parent mentor who has a child with disabilities.

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