



# STRESS: FAMILY CAREGIVERS OF CHILDREN WITH DISABILITIES

A CSCH Brief by Emily Auerbach, MA, Hannah Perry, BA, & Sandra M. Chafouleas, PhD

## 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). In the U.S., the prevalence of children aged 3–17 years diagnosed with a developmental disability increased by 9.5% between 2009 and 2017.<sup>1</sup> Just under 17 million family caregivers provide care to children with DD under the age of 18, with over half providing care for their own children.<sup>2</sup> Further, compared to non-caregivers, family caregivers are at increased risk for adverse physical and psychological health outcomes related to chronic stress.<sup>3,4,5,6</sup> As such, 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.

“A [family] caregiver—sometimes called an informal caregiver—is an unpaid individual...involved in assisting others with activities of daily living and/or medical tasks.”

— Family Caregiver Alliance (2016)

## How do Family Caregivers Experience Stress?

Family caregivers have commonly identified time commitments associated with caregiving demands as a source of stress.<sup>7,8</sup> In addition, dealing with child behavioral challenges and/or medical needs frequently leads to stress among family caregivers.<sup>8,9,10,11</sup> 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.<sup>7,12,13</sup>

## 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,”**<sup>14</sup> can lead to negative outcomes related to *physical health* as well as *mental and emotional health*.

## Physical Health Outcomes

Family caregivers of children with DD tend to report poor physical health at a higher rate than non-caregivers,<sup>3,13</sup> and have shown to experience physical strain from caregiving more often than those caring for adults.<sup>2</sup> Further, family caregivers have frequently reported chronic fatigue and poor sleep as a result of stress associated with caregiving responsibilities.<sup>13,15</sup>

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.<sup>3,12</sup> Health problems associated with stress may be exacerbated by family caregivers' low prioritization of their health and well-being.<sup>6,13</sup> Further, family caregivers report that current services provide inadequate support for the physical demands of life-long caregiving.<sup>13</sup>

## 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,<sup>12,13</sup> 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.<sup>5,7,13</sup> 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).<sup>16</sup> 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.<sup>8,12</sup> 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.<sup>13</sup>

## 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.<sup>16</sup> 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.<sup>12,16,17,18</sup>

**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.”<sup>19</sup>

**Support Groups.** Interventions aimed to promote greater social support can help reduce stress in caregivers of children with DD.<sup>12,18</sup> Effective interventions have included parent caregivers engaging with other parent caregivers through an in-person or social media-based support group.<sup>16</sup>

**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.<sup>12,16</sup>

## 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.

### 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.

<sup>1</sup> Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the united states: 2009-2017. *Pediatrics*, 144 doi:10.1542/peds.2019-0811

<sup>2</sup> National Alliance for Caregiving and AARP. (2009). *Caregivers of children: A focused look at those caring for a child with special needs under the age of 18*. Available from: [http://www.caregiving.org/pdf/research/Report\\_Caregivers\\_of\\_Children\\_11-12-09.pdf](http://www.caregiving.org/pdf/research/Report_Caregivers_of_Children_11-12-09.pdf).

<sup>3</sup> Gallagher, S. & Whiteley, J. (2012). Social support is associated with blood pressure responses in parents caring for children with developmental disabilities. *Research in Developmental Disabilities*, 33, 2099-2105.

<sup>4</sup> Miodrag, M., N., & Hodapp, M., R. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinion in Psychiatry*, 23, 407-411. doi:10.1097/YCO.0b013e32833a8796

<sup>5</sup> Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS ONE*, 14(7), e0219888. doi:10.1371/journal.pone.0219888

<sup>6</sup> Schulz, R., & Sherwood, P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108, 27.

<sup>7</sup> Goudie, A., Nacisse, M., Hall, D.E., & Kuo, D.Z. (2014). Financial and psychological stressors associated with caring for children with disability. *Families, Systems, and Health*, 32, 280-290.

<sup>8</sup> Ritzema A., & Sladeczek I. (2011). Stress in parents of children with developmental disabilities over time. *Journal on Developmental Disabilities*, 17, 21-34.

<sup>9</sup> Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230.

<sup>10</sup> Hsiao, Y. (2018). Parental stress in families of children with disabilities. *Intervention in School and Clinic*, 53, 201.

<sup>11</sup> Woodman, A. C., Mawdsley, H. P., & Hauser-Cram, P. (2015). Parenting stress and child behavior problems within families of children with developmental disabilities: Transactional relations across 15 years. *Research in Developmental Disabilities*, 36, 264.

<sup>12</sup> Lindo, E. J., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations*, 65, 207-224.

<sup>13</sup> Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2006). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, 33, 180-187.

<sup>14</sup> Pearlin, L. I. (1989). The sociological study of stress. *Journal of Health and Social Behavior*, 30, 241-256.

<sup>15</sup> Micsinszki, S. K., Ballantyne, M., Cleverley, K., Green, P., & Stremier, R. (2018). Sleep outcomes for parents of children with neurodevelopmental disabilities: A systematic review. *Journal of Family Nursing*, 24, 217-249.

<sup>16</sup> Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental health interventions for parent carers of children with autistic spectrum disorder: Practice guidelines for a critical interpretive synthesis (CIS) systematic review. *International Journal of Environmental Research and Public Health*, 15, doi:10.3390/ijerph15020341

<sup>17</sup> Frantz, R., Hansen, S., & Machalick, W. (2018). Interventions to promote well-being in parents of children with autism: A systematic review. *Review Journal of Autism and Developmental Disorders*, 5, 58-77.

<sup>18</sup> Sohmaran, C. D., & Shorey, S. (2019). Psychological interventions in reducing stress, depression and anxiety among parents of children and adolescents with developmental disabilities: A systematic review and meta-analysis. *Journal of Advanced Nursing*, doi:10.1111/jan.14166

<sup>19</sup> Lifespan Respite Care Act, H.R. 3248, 109<sup>th</sup> Cong. (2006).