

Supporting People with Developmental Disabilities: The Importance of Caring for the Country's Caregivers



Background

“There are only four kinds of people in the world: those that have been caregivers, those that are caregivers, those who will be caregivers, and those who will need caregivers.”— Rosalyn Carter¹

Family caregivers provide necessary support for older adults and adults with chronic conditions or other disabilities.² Developmental disabilities are chronic disabilities that may be intellectual, physical, or both. They are diagnosed before age 22 and may include visual or hearing impairments, Fragile X syndrome, and cerebral palsy.³ Individuals with developmental disabilities requiring higher levels of support often place greater demands on caregivers to manage their daily activities and communication needs.⁴

Based on 2015 data, 71% of individuals with developmental disabilities resided with a family caregiver, and 24% of these caregivers were 60 years old or older.⁵ Given increased longevity among people with developmental disabilities and aging concerns amongst their caregivers, it is important to acknowledge caregivers’ physical, mental, and social health outcomes to understand the current strengths and limitations of services for people with developmental disabilities, future directions and service models, and ways that Local Health Departments (LHDs) may support caregivers to better serve those with developmental disabilities.

As such, caregivers often suffer from muscle strain and injury from caregiving activities as well as neglect of their own health, such as maintaining a healthy diet and physical activity.⁸ According to the AARP Public Policy Institute,⁹ family caregivers provided 36 billion hours of unpaid care in 2021, equivalent to a value of \$600 billion.



LHD Resources to Support Caregivers’ Physical Health Outcomes

Making Caregiver Safety a Priority

Adaptiveequipmentcorner.com¹⁰ is a website devoted to making caregiving safer and easier via instructional videos on a variety of topics like shower safety and product demonstrations. LHDs may also consider the development of programs including occupation therapists and physical therapists to help demonstrate safety techniques for supporting people with developmental disabilities.

Promote Caregiver Self-Directed Services

Self-directed services may provide a caregiver with personal choice and control over the delivery of services that their state plan provides. For example, caregivers may train and supervise staff they hire, often other family members, to assist with daily caregiving activities and recreational supports for individuals with developmental disabilities. A service plan, including a budget, is determined, and a support broker oversees the financial aspects of paying for this care.¹¹

Caregiver Physical Health Outcomes

One-quarter of all caregivers report that being a caregiver worsens their health.⁶ Individuals with more severe disabilities and motor difficulties also have significantly low bone quality,⁷ and may require greater caregiver support.

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Caregiver Mental Health Outcomes

Parents of adults with developmental disabilities must sometimes provide caregiving for one or more additional family members. This compounded caregiving may increase a caregiver's stress, particularly with the perception of their ability to provide adequate care.¹² Caregivers are diagnosed with depression more frequently than non-caregivers, with female caregivers reporting more depression than male caregivers.¹³ Caregiver stress is often increased due to greater health needs among people with developmental disabilities as they age. For example, Alzheimer's dementia is common in older adults with Down syndrome.¹⁴ Caregivers are at risk for mental distress, including anxiety that can be greater than that experienced by their loved ones.¹⁵



LHD Resources to Support Caregivers' Mental Health Outcomes

Charting the LifeCourse

Charting the LifeCourse is a series of tools from the LifeCourse Nexus Training and Technical Assistance Center through the University of Missouri. People with developmental disabilities, caregivers, and referral staff may use these tools to articulate needs by exploring supports and services, sharing ideas, problem solving, and accomplishing goals.¹⁶

Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers

This guidebook was created by The National Down Syndrome Society, in partnership with The National Task Group on Intellectual Disabilities and Dementia Practices and the Alzheimer's Association. It provides education on the progression of Alzheimer's disease and what to expect, community resources, how to engage as a caregiver at the early, middle, and late-stage progression of this disease, and preservation of a caregiver's own self-care.¹⁴

Family Caregiver Support Programs


The National Family Caregiver Support Program (NFCSP) provides grants to states and territories to pay for services that assist caregivers caring for older adults in their homes. Services include counseling and training to reduce caregiver stress, anxiety, and depression.¹⁷

Caregiver Mental Health Pulse Check Campaign

The National Alliance for Caregiving is examining the mental health of family caregivers to facilitate policy efforts to support family caregivers. Family caregivers are encouraged to share their experiences by calling the number provided within the campaign site. Crisis counselors are also available by texting TOUGH to 741741.¹⁸

Caregiver Social Health Outcomes

When looking at family caregivers of children with autism, family caregivers report less time spent with family, friends, and spouses.¹⁹ Increased levels of social support are associated with higher resilience, which helps to reduce mental health symptoms.²⁰ It is also important to note the positive effects of caregiving. For many caregivers, supporting or assisting others may be as beneficial to health as receiving support.²¹



LHD Resources to Support Caregivers' Social Health Outcomes

Assist Caregivers in Locating Support Groups

- Caregivers Connect: In this support group, members often post useful resources for caregivers caring for people with a variety of disabilities.²²
- Working Daughter: This support group consists of a community of women that are balancing a career with caregiving responsibilities.²³
- Alzheimer's and Dementia Caregiving Center: Here you can find supports that are the closest in proximity to where you live. Support groups are available for both caregivers caring for people with Alzheimer's dementia as well as those who have this disease.²⁴
- The Sibling Leadership Network: This network provides siblings of individuals with developmental disabilities information to support their loved ones. They have chapters in many states under a variety of individualized names. For example, the Florida chapter is known as the Florida Sibling Alliance and the New York chapter is referred to as Sibs NY.²⁵

- Faith-Based Community Networks: Many caregivers receive a variety of supports within churches and other faith-based communities.

Encourage Workplace Flexibility for Caregivers

Encouraging workplace flexibility for caregivers is a benefit for both caregivers and employers given the increases in labor shortages. It assists caregivers in managing financial responsibilities and allows for the socialization that comes with working with others. The New York State Office for the Aging (NYSOFA) and the New York State Department of Labor (DOL) developed the Caregiver Guide for Businesses based on the Minnesota Board on Aging's Resource Guide for Employers.²⁶

Promote Attainment of Caregiver Goals

Continuing education is a goal of many caregivers. Cariloop's Caregiver Scholarship supports primary caregivers with low incomes who wish to pursue higher education and serve their communities.²⁷

Caregivers have an enormous impact on the health of people with disabilities and other health conditions. Healthy People 2030 focuses on methods that parents and caregivers can utilize to keep the people they provide care and support for and themselves healthy.²⁸ LHDs and other service providers should consider caregivers' physical, mental, and social health outcomes as they may have a direct impact on the care and quality of life of individuals with developmental disabilities. LHDs and other service providers may incorporate the resources provided within this discussion to support caregivers within their caregiving journeys.

Additional Resources

[Home and Community-Based Services](#)
[Positive Aspects of Caregiving: Rounding out the Caregiver Experience](#)
[15 Best Books for Caregivers](#)

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FOR MORE INFORMATION

To learn more about NACCHO's health and disability program, visit <https://www.naccho.org/programs/community-health/disability>.

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