

Caregiver Focus: Disabilities

A look at caregivers for people with disabilities — who they are, how they can get support, and ways they can advocate for the people they love.

Disabilities affect many of us, whether we have one ourselves or know someone who does. The Centers for Disease Control and Prevention (CDC) reports that “at some point in their lives, most people will either have a disability or know someone who has one.” In fact, one in four U.S. adults has a disability that impacts major life activities. The CDC tracks U.S. adults across six disability types:



If you're a caregiver for someone with a disability, you might deal with any number of the above at the same time. You might be helping a family member, friend or child living at home. Whatever your circumstances are, you should know there are support and advocacy resources for you to help care for someone with a disability. Read on to become a more informed and empowered disability caregiver.

A Demanding Role

When it comes to providing care for someone with a disability, everyone's experience comes with its own set of rewards and challenges. One thing most disability caregivers have in common, however, is the sheer amount of time they commit to the role. According to national advocacy organization The ARC, families are the primary source of support for older adults and people with disabilities in the U.S., and on average, these family caregivers spend more than 57 hours a week caring for someone with disabilities. That adds up to more than eight hours a day. Add that on top of other responsibilities, like a part or full-time job, family obligations and more — and it's easy to see why many caregivers can feel overwhelmed.



Getting Support

While you're caring for someone with a disability, it might feel like the last thing you have time for is to research the support available to you. But often, one phone call can put you in touch with a resource that ends up saving you time, energy and perhaps even money down the line. If you haven't looked at any of these resources before, make it a goal to contact one of them every week. (Or better yet, have another friend or family member take on this task for you!)

Disability-specific organizations

If the person you're caring for has a specific condition (Parkinson's disease, for example), see what resources are available at the local and national level.

Caregiver Action Network 855-CARE-640	This excellent resource hub is filled with information and educational materials designed to support family caregivers.
Family Caregiver Alliance 800-445-8106	One of many helpful resources at FCA is the organization's "Family Care Navigator," a list of services by state.
ARCH National Respite Network archrespite.org	This site lists financial assistance resources for family caregivers.
Family Voices familyvoices.org	Focuses on advocacy and support for caregivers of children and youth with special needs

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Ways to Advocate

Make your voice heard! Join other disability caregivers in advocating for improvement in public policies both nationally and locally. The following organizations make it easier to get involved, whether it's by simply adding your name to email lists to stay informed on legislation or finding ways to get involved at a grassroots level in your community.

National Alliance for Caregiving
800-222-2225

This coalition of national organizations does research and tracks legislation that affects caregivers and the people they care for. The NAC advocates for expanded caregiver supports and services, protection of financial security for caregivers, and more.

The Arc
800-433-5255

The Arc is dedicated to seeking full inclusion in the community for people with intellectual and developmental disabilities. The “advocacy” portion of their site lets you to sign up for emails, find your local and state elected officials and track legislation.

Sources:

1 in 4 U.S. adults live with a disability

<https://www.cdc.gov/media/releases/2018/p0816-disability.html>

Caregiving and planning for the future for people with disabilities

<http://thearc.org/wp-content/uploads/2019/07/18-115-FINDS-CFP-Materials-for-National-Caregiver-Week-v2.pdf>

ACL: Support to caregivers

<https://acl.gov/programs/support-caregivers>

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