



Understanding and Navigating the Caregiver Shortage

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The shortage of qualified caregivers is of no surprise to care partners, including people with disabilities, older adults, and those in their circle of support. Headlines such as “Nationwide Caregiver Shortage Felt By Older Adults” or “The Talent Shortage And The Caregiving Crisis” fills the airways heightening the anxiety of people who need assistance and those currently supporting their loved ones. In light of the shortage of additional supports for care partners, let alone quality care, many questions surface, including – how did we get here? And what can you do if you need caregiving help?

How DID We Get Here?

The United States is facing a demographic shift. The number of people living with disabilities continues to increase. Moreover, for the first time in its history, older adults are outnumbering the young due to the large numbers of aging “baby boomers” (those born between 1946 to 1964). We are living longer and with more chronic conditions due to the significant advances in healthcare over the last century. This translates into a greater likelihood of needing additional supports and services for people with disabilities and older adults.

Those available to provide support to the growing number of people with disabilities and older adults, however, are trending downward. In part, the numbers of individuals born after the baby boomer generation are significantly fewer. This results in a shrinking pool of natural supports for people with disabilities and older adults.

According to the [U.S. Bureau of Labor Statistics \(BLS\)](#), “Employment of home health and personal care aides is projected to grow 25 percent from 2021 to 2031, much faster than the average for all occupations.” In addition, retention of home care workers has consistently been a challenge: the median caregiver turnover rate in 2021 was 64%, [according to the preliminary Home Care Pulse findings](#). With so many employment opportunities available now and into the future, why are these positions not being readily filled? [PHI, an organization that promotes quality direct care jobs as the foundation for quality care](#), cites the following challenges in recruiting and retaining direct care workers:

- **Low pay.** The median wage for direct care workers was just \$14.27 per hour in 2021, with variability by occupational role and geographic location (among other factors), and median earnings were only \$21,700 per year in 2020. As a result, 40 percent of this workforce lives in or near poverty, and 43 percent rely on public assistance programs to make ends meet.
- **Demanding work.** Beyond low wages, direct care jobs are physically and emotionally demanding and often characterized by heavy workloads, scheduling challenges, inadequate supervision, and limited training and career advancement prospects.

Other barriers or challenges may include the view that direct care is “low status” work, in part related to the marginalization of people with disabilities and older adults and minimal growth potential for career advancement.

Because of the shortage, the responsibility of care typically falls to natural, unpaid supports, including family members and friends. The [National Alliance for Caregiving and AARP](#) cite that approximately 43.5 million caregivers have provided unpaid care to an adult or child in the last twelve months. Therefore, not surprisingly, a [Gallup study](#) found that more than 1 in 6 Americans who work full or part-time also assist with caring for an elderly or disabled family member, relative, or friend. The [Kaiser Family Foundation](#) also noted the [COVID-19 pandemic](#) has magnified the unmet need for home and community-based services (HCBS) among older adults and people with disabilities, where Medicaid is often the primary payer of these services.

All of these issues have contributed to the caregiving crises we see today, which have significantly impacted the quality of care and life for people with disabilities and older adults. The shortage of supports also has impacted the access by people with disabilities and older adults to home and community-based services, at times having to resort to more restrictive living settings. [A family caregiver survey published by the ARC of the United States in 2017](#) identified the extent of the financial, emotional, physical, and psychological impact on family caregivers. Finding assistance in providing care is imperative to improving the health and well-being of all care partners.

Finding Caregiving Assistance

While finding caregiving assistance can feel daunting, here are some tips and resources to help you navigate finding caregiving services.

- **Seek Referrals**

Actively ask for referrals. Be open and talk to friends, family, and co-workers to see if they have any referrals for caregivers in your area. Explore social media groups, particularly Facebook groups, to see if people you know have direct referrals of qualified individuals who may be available to provide care or indirect referrals for other places to contact for care assistance. Contact local advocacy organizations, such as the local ARC organization or Area Agency on Aging (AAA), for referrals as well.

- **Create a Care Cohort or Co-Op**

If the caregiving services you seek are for respite or part-time care, creating a care cohort can be a great way to get help. A care cohort is when multiple families share a caregiver and the cost of the services. Some families may also be able to assist each other by taking turns providing care themselves.

- **Get Paid to Care for a Family Member**

Beginning as a pilot Medicaid program in fifteen states, “cash and counseling” programs started with the objective of increasing participants’ control over their care services and providers. According to the organization [Paying for Senior Care](#), “Currently forty-nine states offer consumer direction in their Medicaid programs, twenty-nine states have consumer direction in non-Medicaid or non-profit assistance programs, forty-two states allow for some veterans’ care services to be self-directed, and life and long-term care insurance policy conversion programs are available in all 50 states.”

- **Additional Research Options Via the Web**

For additional resources available in your state, visit the Family Caregiver Alliance’s website. It has a robust interactive tool designed to help you find family caregiver services available by state: <https://www.caregiver.org/connecting-caregivers/services-by-state/>

Taking Action

Reading the list of reasons why it is difficult to find qualified caregivers can feel daunting, but there are things you can do to help facilitate meaningful change. First, you can research the efforts of organizations advocating for caregiver support. A great starting resource is the [2022 National Strategy to Support Family Caregivers](#). Developed by the U.S.

Department of Health and Human Services, the strategy details more than 350 federal actions and 150 measures that state and local governments, public health departments, philanthropies, and community-based, faith-based, and nonprofit organizations can take immediately to support the United States’ caregivers. You can then contact your local, state, and federal representatives to let them know how they can help to support caregivers in your community and nationwide. If you are unsure who your representatives are and how

to contact them, Common Cause has an easy resource to help you find that information [here](#). Simply enter your address, and all the names you need will be at your fingertips.

Conclusion

It “takes a village” to support an individual with disabilities or an older adult. Quality of life and care can be greatly impacted based on the availability of unpaid and paid supports. As care partners navigate through a widening void of support during this caregiving crisis, there is no single solution to this challenge. It will involve multiple sources of assistance, culture, policy changes in the provision of care, and creative thinking from those impacted by this unmet need. The more we can raise awareness and continue the conversation, the more solutions we may be able to identify tomorrow.

If you need help finding assistance and guidance, please check out the resource links below or search for an attorney in your area to guide you through the [Special Needs Alliance](#). Be sure to also follow the efforts of the Special Needs Alliance’s [Public Policy Committee](#) on these and other issues.

[National Family Caregiver Support Program](#)

[Veteran Directed Care](#)

[Family Caregiver Alliance CareNav](#) – a secure online service for quality information, support, and resources for family caregivers

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