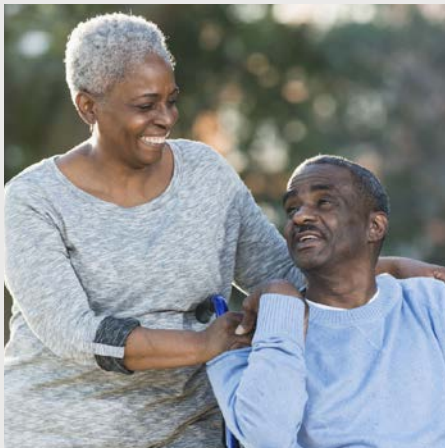


2020 Report

Caregiving in the U.S.



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Executive Summary

Family and friends comprise the most basic unit of any society. For individuals who take on the responsibility of caring for another person through sickness or disability, it can often be challenging to see beyond the individual experience. Yet in the aggregate, family caregivers—whether they be families of kin or families of choice—are woven into the fabric of America’s health, social, economic, and long-term services and supports (LTSS) systems. As the country continues to age, the need to support caregivers as the cornerstone of society will only become more and more important.

Today, more than 1 in 5 Americans (21.3 percent) are caregivers, having provided care to an adult or child with special needs at some time in the past 12 months. This totals an estimated 53.0 million adults in the United States, up from the estimated 43.5 million caregivers in 2015.¹

When looking at caregivers for adults only, the prevalence of caregiving has risen from 16.6 percent in 2015 to 19.2 percent in 2020—an increase of over 8 million adults providing care to a family member or friend age 18 or older, primarily driven by a significant increase in the prevalence of caring for a family member or friend who is age 50 or older. Figure 1 shows the prevalence rate, estimated number of caregivers in the United States, and change in the past five years.

Figure 1. Prevalence of Caregiving by Age of Care Recipient, 2020 Compared to 2015

	2020 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers	2015 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers
Overall	21.3%*	53.0 million	18.2%	43.5 million
Caregivers of recipients ages 0-17	5.7%*	14.1 million	4.3%	10.2 million
Caregivers of recipients ages 18+	19.2%*	47.9 million	16.6%	39.8 million
Caregivers of recipients ages 18-49	2.5%	6.1 million	2.3%	5.6 million
Caregivers of recipients ages 50+	16.8%*	41.8 million	14.3%	34.2 million

* Significantly higher than in 2015.

Compared to 2015, a greater proportion of caregivers of adults are providing care to multiple people now, with 24 percent caring for two or more recipients (up from 18 percent in 2015). This finding, in combination with the increased prevalence of caregiving, suggests a nation of Americans who continue to step up to provide unpaid care to family, friends, and neighbors who might need assistance due to health or functional needs. This increase in prevalence may be due to any of the following:

- The increasingly aging baby boomer population requiring more care
- Limitations or workforce shortages in the health care or long-term services and supports (LTSS) formal care systems
- Increased efforts by states to facilitate home- and community-based services
- Increasing numbers of Americans who are self-identifying that their daily activities, in support of their family members and friends with health or functional limitations, are caregiving
- The confluence of all of these trends

1 As with previous *Caregiving in the U.S.* studies, prevalence estimates include those who have provided care in the 12 months before the time they were surveyed, whether they were a caregiver at the time of survey or had been a caregiver in the prior 12 months but no longer were. With the margin of error, the estimated prevalence of being a caregiver for anyone in 2020 is 20.4 percent to 22.2 percent, which is outside the range estimated in 2015 of 17.3 percent to 19.1 percent.

The demographic characteristics of caregivers remain largely unchanged since 2015: caregiving remains an activity that occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations. The shifts we do see in caregiver demographics reflect general changes in the demographic composition of the U.S. population over the past five years.

Six in 10 caregivers report being non-Hispanic White (61 percent), 17 percent are Hispanic or Latino, 14 percent non-Hispanic African American or Black, 5 percent Asian American and Pacific Islander, and 3 percent some other race/ethnicity, including multiracial. One in 10 is a student enrolled in college or other classes (11 percent), while 9 percent have served on active duty in the U.S. Armed Forces. Eight percent self-identify as lesbian, gay, bisexual, and/or transgender² (LGBTQ).

Most caregivers of adults care for a relative (89 percent), typically a parent or parent-in-law (50 percent), spouse or partner (12 percent), grandparent or grandparent-in-law (8 percent), or adult child (6 percent), though 10 percent provide care to a friend or neighbor. Many caregivers live together with their recipient (40 percent), a proportion that has grown since 2015 (34 percent). As in 2015, older caregivers tend to take care of similar-aged recipients, with 74 percent of caregivers ages 75 and older caring for a recipient age 75 or older, while younger caregivers tend to take care of someone older than themselves (81 percent of caregivers ages 18 to 49 care for someone age 50 or older).

Caregivers report that the adults who receive care (the “care recipient”) have greater health and functional needs than was reported by caregivers in 2015. Compared to 2015, caregivers are more likely to report their adult care recipient needs care because of long-term physical conditions (63 percent, up from 59 percent in 2015), emotional or mental health issues (27 percent, up from 21 percent), and memory problems (32 percent, up from 26 percent), including Alzheimer’s or dementia (26 percent, up from 22 percent in 2015). This increasing comorbidity³ of conditions that require care, with caregivers reporting their recipient has 1.7 conditions categories on average (up from 1.5 in 2015), suggests that not only are more American adults taking on the role of unpaid caregiver, but they are doing so for adult recipients who may have increasingly complex medical or support needs.

The data suggest many caregivers may be taking on this role without adequate and affordable services and supports in place. Despite the increasing complexity of care recipients’ conditions, fewer caregivers report their recipient had been hospitalized overnight (48 percent, down from 53 percent in 2015)⁴ and just 3 in 10 report their recipient has any paid help (31 percent). The health care and LTSS systems in the United States can often be dispersed or fragmented, with many different settings to go to for care, services, or supports,⁵ which can be frustrating, stressful, and costly.⁶ Caregivers navigate this system—and face the choices in where to go for care and the implication it has for costs—along with their recipients. Our data suggest that this journey through the care system may not always be easy as, since 2015, more caregivers say it is difficult to coordinate their recipient’s care across various providers (26 percent, up from 19 percent).⁷ About one in 4 also report it is difficult to get affordable services in their recipient’s area (27 percent).

2 This includes anyone self-identifying as gay or lesbian, bisexual, or some other sexual orientation other than “straight, that is, not gay,” as well as anyone self-identifying as transgender or some other transgender status other than “male” or “female.”

3 Comorbidity is when a person has more than one health issue or condition at the same time.

4 Analysis of trends in hospital inpatient stays suggests this is occurring overall. See R. Sun, Z. Karaca, and H. S. Wong, “Trends in Hospital Inpatients Stays by Age and Payer, 2000–2015,” HCUP Statistical Brief #235, Agency for Healthcare Research and Quality, Rockville, MD, January 2018, www.hcup-us.ahrq.gov/reports/statbriefs/sb235-Inpatient-Stays-Age-Payer-Trends.pdf.

5 For a description of the health care system changes, see Mark Miller, “The Decade in Retirement: Wealthy Americans Moved Further Ahead,” *New York Times*, December 14, 2019, <https://www.nytimes.com/2019/12/14/business/retirement-social-security-recession.html>.

6 National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America* (Washington, DC: The National Academies Press, 2016).

7 Among those who coordinate care, these percentages rise to 31 percent finding it difficult to coordinate care in 2020, up from 23 percent in 2015.

The support and complex care tasks the nation’s caregivers provide are largely unchanged since 2015, with today’s caregivers providing about 24 hours of care each week. As in 2015, nearly all of today’s caregivers help with Instrumental Activities of Daily Living (IADLs; 99 percent), 6 in 10 help with Activities of Daily Living (ADLs; 60 percent), and nearly 6 in 10 help with medical/nursing tasks (58 percent). The Level of Care Index measuring the intensity of the caregiving situation is similar to 2015 (40 percent in a high-intensity care situation⁸).

The impact of disease or disability can ripple beyond the caregiver and recipient. Other members of the family or community, such as children in the home, may be called upon to carry out care tasks. About half of caregivers say there are others who provide unpaid help to their care recipient (53 percent). Among those who report the presence of other unpaid help, 14 percent say *at least* one of those unpaid caregivers is a child under age 18—so out of all caregivers of adults, 7 percent report the presence of a child caregiver. Beyond the estimated 48 million caregivers of adults in the United States, an additional 3.4 million child caregivers may be standing in their shadow.^{9,10,11}

While many caregivers feel their role has given them a sense of purpose or meaning (51 percent), these positive emotions often coexist with feelings of stress or strain. Caregivers report physical, emotional, and financial strain, with 2 in 10 reporting they feel alone (21 percent). When compared to 2015, fewer caregivers report their health status as excellent or very good (41 percent, down from 48 percent in 2015) and a greater proportion report being in fair or poor health (21 percent, up from 17 percent in 2015). One in 4 find it difficult to take care of their own health (23 percent) and a similar proportion report caregiving has made their own health worse (23 percent). This decline in caregiver self-reported health is concerning, as the stress associated with caregiving may exacerbate declines in health that occur with age. This means that supports for caregivers and their recipients will be even more critical if this trend in declining caregiver health continues to hold. From a policy perspective, the strain of disease or disability on a family unit can endanger larger system goals to improve health care and



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- 8 The Level of Care Index, first developed in the 1997 study *Family Caregiving in the U.S.* (a predecessor to this research) and used in the 2004, 2009, and 2015 *Caregiving in the U.S.* studies, is replicated to convey the intensity or complexity of the caregiving situation. This index provides one way to articulate the impact of a disease or disability on the people who care for a patient during the caregiver journey. The index is based on the number of hours of care given as well as the number of ADLs and IADLs performed. High intensity is scoring a 4 or 5 on the 5-level index. The details of index construction are shown in appendix B.
- 9 This may be an underestimate as the literature shows that adults are often hesitant to say that children are providing care. See C. Levine, “More Than 1 Million Young Caregivers Live in the United States, but Policies Supporting Them Are Still ‘Emerging,’” *Health Affairs Blog*, August 7, 2017, <https://www.healthaffairs.org/doi/10.1377/hblog20170807.061390/full/>.
- 10 For comparison, 11.2 percent of caregivers of adults report living with their care recipient and there being children or grandchildren under the age of 18 also living in the same home at the time of care. This would project out 5.4 million child caregivers providing care to an adult, if at least one child in each of these households provided care.
- 11 Past estimates of the number of child caregivers in the United States placed the estimate at 1.3 million children. See G. Hunt, C. Levine, and L. Naiditch, “Young Caregivers in the U.S.: Report of Findings,” National Alliance for Caregiving and United Hospital Fund, New York, NY, September 2005, <https://www.caregiving.org/wp-content/uploads/2020/05/youngcaregivers.pdf>.

reduce overall costs in an increasingly strained system. Caregivers who cannot care for themselves may become unavailable to care for others; likewise, caregivers have their own financial, health, and wellness needs, which begs the question, “Who will care for the caregivers?”

The shift in health care to community-based settings rather than traditional residential care settings¹² puts additional pressure on families to fill the gaps in LTSS. Caregivers increasingly provide and monitor complex care at home, navigating the care system, advocating for their care recipient, and paying for services to help the person with care needs.¹³ While many caregivers rely on health care professionals (such as doctors, nurses, or social workers) as a source of information about providing care (55 percent), very few report having conversations with them about what they need to care for their recipient (29 percent) or to support their own well-being (13 percent).

The economic effects of family caregiving can result in financial strain with substantial financial consequences. One in 5 caregivers report high financial strain as a result of caregiving (18 percent). Four in 10 have experienced at least one financial impact as a result of their caregiving (45 percent). Most commonly, 3 in 10 have stopped saving (28 percent) and 1 in 4 have taken on more debt (23 percent), both of which could have longer-term repercussions on caregivers’ financial security into the future, especially if the caregiving situation lasts a long time. Caregivers of adults find themselves providing care for 4.5 years, on average, and an increasing proportion have been providing care for 5 years or longer (29 percent, up from 24 percent in 2015).

In fact, caregivers’ savings are eroding, with 22 percent who used up personal short-term savings and 12 percent who used up long-term savings (for things like retirement or education). Two in 10 have left bills unpaid or paid them late (19 percent), while another 15 percent borrowed money from family or friends. One in 10 have been unable to afford basic expenses like food (11 percent).

Six in 10 caregivers report working while caregiving (61 percent) and the majority have experienced at least one work-related impact (61 percent). As in 2015, most working caregivers report going in late, leaving early, or taking time off to accommodate care (53 percent). One in 10 working caregivers have had to give up work entirely or retire early (10 percent). When this happens, caregivers more often face financial impacts (2.9 on average) and are twice as likely to report high financial strain (35 percent). Employers appear to be taking note of the challenges facing caregivers in the workforce. Caregivers more often report having workplace benefits such as paid family leave (39 percent, up from 32 percent) and paid sick days (58 percent, up from 52 percent) than in 2015, likely an effect of a greater number of large employers and state and local governments taking action on paid leave. Despite this progress, most caregivers (61 percent) still report having no paid family leave at their workplace.

Caregivers of adults have information and training needs to support their daily life. Increasingly, caregivers are recognizing that some services and supports, like respite care, would be helpful to their own situation, though actual use of supports and services remains low. Just 14 percent report having used respite, though 38 percent feel it would be helpful (up from 33 percent in 2015). The most common information and support needs are related to keeping their care recipient safe at home (26 percent); managing their own (the caregiver’s) stress (26 percent); and navigating forms, paperwork, and eligibility for services (25 percent). The majority of caregivers—about two in three for each—feel an income tax credit (68 percent) or program to pay caregivers to provide care (65 percent) would be helpful to defray the financial costs of care.

Some experts hope that technology might help support caregivers, but only about half of caregivers report using software or other technological tools to help them (53 percent), most commonly, tracking

12 J. E. Gaugler, “Innovations in Long-Term Care,” in *Handbook of Aging and the Social Sciences*, edited by L. K. George and K. F. Ferraro (London, UK: Academic Press, 2016), 419–39.

13 See S. C. Reinhard et al., *Home Alone Revisited: Family Caregivers Doing Complex Care* (Washington, DC: AARP Public Policy Institute, 2019); see also C. G. Whiting, N. Boice, and L. Weber-Raley, “Rare Disease Caregiving in America,” National Alliance for Caregiving in partnership with Global Genes, Washington, DC, February 2018.

their care recipient's finances (35 percent). Despite how connected and smartphone-centric society is,¹⁴ only 6 in 10 caregivers report going online to do something to help support care (60 percent). Caregivers most commonly go online to find more actual, hands-on help: searching for services, aides, facilities, or other help (32 percent). This may change in the future as millennial and generation X caregivers, who use these online tools more often, could drive continued advancement of and education about these online and technology support tools.

When it comes to looking forward, many caregivers are not preparing for their own or their care recipient's future needs. About half of caregivers expect to be caring for someone in the next five years (54 percent). However, making plans for future care, such as instructions for handling financial matters, health care decisions, or living arrangements, is still not the norm among caregivers: just 44 percent report their recipient has these plans in place and 45 percent of caregivers have their own future care plans in place.

Ultimately, caregivers are us, with one out of every five American adults providing care in a given year—from all walks of life and backgrounds. This research highlights the varied experiences and situations of caregivers in the United States and points to the impacts many caregivers face as a result of their stepping up to help family and friends. Unpaid caregiving is increasing in prevalence and the U.S. population continues to age and live longer with more complex and chronic conditions. Caregivers feel the push and pull of providing care on their time, their financial well-being, their health, their family, their work, and their own personal well-being. They may find themselves in need of information, resources, benefits, or programs—but these things are often difficult to find or access, or too expensive to afford. Unpaid caregivers are serving as a core piece of the health and LTSS systems, as well as the main source for long-term care for adults living at home and in the community.

Of key concern for policy makers and other stakeholders is whether this arrangement is sustainable with the care gap looming on the horizon, as more people need care and fewer potential family members are available to provide that everyday help.^{15,16} Without greater explicit support for family caregivers in coordination among the public and private sectors and across multiple disciplines, overall care responsibilities will likely intensify and place greater pressures on individuals within families, especially as baby boomers move into old age. In addition, the caregivers *themselves* require support to ensure they do not suffer deteriorating health effects, financial insecurity, or a combination of these negative impacts. There is an opportunity for public health experts, policy makers, health and social providers, researchers, employers, financial institutions, and other stakeholders to work together to improve the health care and LTSS systems so they better address the needs of caregivers. Together, we can develop and enact solutions to support family caregivers and to improve their well-being and the well-being of those for whom they provide care.

14 The Pew Research Center “Mobile Fact Sheet” indicates that 81 percent of Americans own smartphones (see “Mobile Fact Sheet,” Pew Research Center, June 12, 2019, <https://www.pewresearch.org/internet/fact-sheet/mobile/>).

15 D. Redfoot, L. Feinberg, and A. Houser, “The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers,” AARP Public Policy Institute, Washington, DC, 2013, <https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html>.

16 J. E. Gaugler and R. L. Kane, eds., *Family Caregiving in the New Normal* (San Diego, CA: Academic Press, 2015).

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