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Caregiving in the US

RESEARCH REPORT

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Executive Summary

Caregiving in the US 2025 presents a comprehensive picture of the growing and evolving landscape of family caregiving. In 2025, 63 million American adults provided ongoing care to adults or children with a medical condition or disability–representing almost one-quarter of all adults in the United States. This is a dramatic increase of 45 percent since *Caregiving in the US* was fielded in 2015. Of these 63 million caregivers, 59 million care for an adult with a complex medical condition or disablity.

Family caregivers include parents, friends, neighbors, and even children, and they span across all ages, races and ethnicities, incomes, and communities. They assist care recipients with basic mobility, personal care, financial management, complex medical tasks, and more. This report describes the critical role family caregivers play in supporting the nation's fractured long-term services and supports system and highlights how policies and practices support this essential work and where gaps persist.

What's New for 2025

The 2025 study builds on the last survey in 2020 with the following improvements:

- Addition of state representative caregiver samples for many states (to be summarized in a separate report to be published in November 2025)
- Inclusion of family caregivers participating in caregiver payment programs, such as through Medicaid home and community-based services self-direction waivers, the Department of Veterans Affairs, and state programs
- Use of a four-question summary measure of caregivers' physical and emotional health, the CDC Healthy Days measure
- Inclusion of an expanded Level of Care Index that includes objective and subjective measures of the caregiving experience

Key Findings

Today, roughly one in four American adults (24 percent) is a family caregiver. In addition, 59 million caregivers report caring for adults ages 18 and older, and 4 million report caring for a child under age 18 with an illness or disability. The detailed analysis of this report focuses on the experiences, living situations, and needs of the 59 million family caregivers of adults.

Who the caregivers are. The average caregiver is 51 years old. Women still account for the majority of caregivers (61 percent), and 61 percent of all caregivers identify as non-Hispanic white individuals. Latino/Hispanic caregivers represent 16 percent; African American/Black caregivers 13 percent; and Asian American, Native Hawaiian, and Pacific Islander (AANHPI) caregivers 6 percent. Twenty percent of caregivers live in rural areas, and 24 percent of family caregivers support more than one care recipient. Most are caring for relatives, especially parents or spouses, but 11 percent are caring for nonrelatives such as friends or neighbors. Older caregivers tend to care for spouses, whereas younger ones are more likely to care for older generations.

The care recipients. Care recipients themselves are mostly older adults; nearly half are age 75 or older. Most of these older adults face multiple chronic health conditions. Common primary conditions include age-related decline, Alzheimer's or other dementias, mobility limitations, cancer, and postsurgical recovery. Cognitive issues are prevalent: 27 percent of caregivers report that their care recipient has Alzheimer's, dementia, or another memory-related impairment. Caregivers under 50 are more likely to manage short-term or mental health conditions, whereas older caregivers typically support those with long-term physical health issues. These patterns highlight how the caregiving trajectory differs across the lifespan.

Living arrangements. Most caregivers live with their care recipient (40 percent) or nearby (35 percent), and proximity plays a major role in the intensity and frequency of care provided. Caregivers who live with care recipients provide more care hours and use help less often, whether paid or unpaid, than caregivers who live apart from their care recipients. Lower-income caregivers, men, LGBTQ+ individuals, and caregivers of color are more likely to live with the person they care for. Among caregivers living with care recipients, 22 percent provide more than 21 hours of care weekly. Caregivers who live with their care recipients also less often use either paid (22 percent) or unpaid help (36 percent) than caregivers who live apart from their care recipient.

Among all caregivers, 32 percent use paid help, and 53 percent have unpaid assistance. LGBTQ+ and lower-income caregivers less often have help of any kind. Use of respite care—short-term care that gives caregivers a break from their care responsibilities—is notably low. Although 39 percent of caregivers say respite would be helpful, only 13 percent use it, citing structural and subjective barriers such as lack of trust, shame, or concerns about quality of care.

Nearly one-third of all caregivers care for both an adult with disabilities or complex medical conditions and a child under 18 at home—even more caregivers under age 50 (47 percent) are in this dual role, known as sandwich generation caregiving. African American/Black and Hispanic/Latino caregivers are more often sandwich generation caregivers. Children in a caregiving household may also be care partners. About 4 million children under age 18 assist their families with the care of adults.

What caregivers are doing. Caregiving has become longer term and more intensive. Thirty percent of caregivers provided care for five or more years, a significant increase from 2020. On average, caregivers spend 27 hours per week providing care, and 24 percent provide 40 or more hours per week. Two-thirds of caregivers help with at least one activity of daily living (ADL) like bathing, dressing, toileting, feeding, and mobility. Since 2020, more caregivers are providing some ADL assistance, and more caregivers are providing help with multiple ADLs. Some groups of caregivers are more often engaged in these challenging tasks. Paid family caregivers more often help with any ADLs, whereas more African American/Black and Hispanic/Latino caregivers assist with multiple ADLs. For many, these tasks are physically difficult—23 percent report struggling with these duties.

Instrumental activities of daily living (IADLs)—such as shopping, managing finances, preparing meals, and handling transportation—are common responsibilities. More caregivers are helping with multiple IADLs than in 2015. Just over 8 in 10 caregivers (84 percent) assist with three or more IADLs. Despite the complexity of ADL and IADL tasks, only 11 percent of caregivers received any formal training to prepare them for these tasks.

Many caregivers also handle medical or nursing tasks such as managing catheters, performing injections, or monitoring vital signs. More than half (55 percent) provide these types of tasks, yet only 22 percent received training for this. Training often comes from nurses or doctors when it is available.

Coordination with health care providers is another common care task: 70 percent of caregivers monitor their recipient's health, 64 percent communicate with providers, and 58 percent advocate on behalf of their care recipient. Certain groups of caregivers are more often helping with care coordination tasks, including female caregivers, African American/Black caregivers, and AANHPI caregivers. Younger caregivers less often communicate with health care professionals (57 percent) or advocate on their care recipient's behalf (52 percent).

Technology use among caregivers is growing. Remote monitoring tools, health tracking software, and assistive devices are becoming more common, especially among younger and female caregivers. Remote monitoring, for example, jumped from 13 percent use in 2020 to 25 percent in 2025. These tools help caregivers stay organized and maintain oversight when they are not physically present, and they are increasingly viewed as essential components of modern caregiving.

Working while caregiving. Seven in ten working-age (ages 18 to 64) caregivers are engaged in paid employment. Balancing work and care responsibilities is challenging. Half of all working caregivers experience work impacts such as arriving late, leaving early, or taking time off to meet caregiving obligations. Working caregivers more often feel isolated (25 percent) and face negative financial impacts, including taking on more debt (22 percent), using up short-term savings (31 percent), and leaving bills unpaid or paying bills late (19 percent).

Access to caregiver-friendly workplace benefits has improved since 2015, but access remains uneven. Salaried workers enjoy better access to telecommuting, paid leave, and employee assistance programs than hourly workers. Additionally, many caregivers hesitate to disclose their role—only 49 percent say their supervisor knows they are a caregiver.

Financial impact of caregiving. Nearly half of caregivers report at least one negative financial impact from their caregiving responsibilities. One-third of caregivers have stopped saving money, and 24 percent have used up short-term savings. Others report taking on more debt, delaying retirement, or even facing housing instability. African American/Black, Hispanic/Latino, younger, and lower-income caregivers more often experience negative financial impacts affecting their savings, debt burden, and ability to pay bills and basic expenses. LGBTQ+ caregivers more often report negative financial impacts related to savings and ability to afford basic expenses.

Over the past decade, more family caregivers (28 percent) have had difficulty finding affordable services for their care recipients, like home health aides, transportation, and meal delivery. Caregivers in rural areas (34 percent) more often have difficulty finding affordable services.

Caregiver health. Caregivers may struggle to maintain their own physical and emotional health while caring for someone else. One in five family caregivers rate their health as fair or poor, and nearly a quarter say they have difficulty caring for themselves. Women, LGBTQ+ caregivers, and those living with their care recipient report the worst impacts. Many caregivers experience high emotional stress (64 percent) and physical strain (45 percent). Feelings of isolation have increased since 2020, with 24 percent of caregivers saying they feel alone. Notably, caregivers who report having no choice in becoming a caregiver—56 percent of all respondents—experience significantly worse mental health outcomes, more days of physical strain, and lower perceived purpose in caregiving.

Despite this, there is resilience and meaning in caregiving. More than half of caregivers say that their role gives them a sense of purpose, and this sense is even stronger among Hispanic/Latino caregivers, lower-income caregivers, and those caring for nonrelatives. Purpose, however, is not a substitute for support.

Policy and program supports. Caregivers report that they would benefit from financial support in the form of tax credits (69 percent), direct payment programs (68 percent), or partially paid leave (55 percent). Lower-income caregivers prefer direct payments, whereas higher-income caregivers tend to favor tax credits. Beyond finances, caregivers seek services like respite care, emotional support, and training from health care professionals. They also want help keeping their loved ones safe and managing complex paperwork. Although nearly half have started planning for their future, many report no concrete plans for the person they are caring for—an area ripe for intervention.

Caregiving in the US 2025 offers a comprehensive look at the state of family caregiving in America. The report reveals a growing and diverse population of caregivers, many of whom are strained, under-supported and often invisible in national conversations about health care, aging, and economic policy. These findings are a springboard for action—for families, policymakers, and all who play a role in developing systems to support and sustain the vital contributions of family caregivers.

Introduction

Caregiving in the US 2025: a national portrait

Family caregiving forms the invisible backbone of American communities, providing a critical foundation that sustains our nation's health care system and economy. This vast enterprise spans generations and touches every corner of society. More than 63 million adults provide ongoing care for aging parents, spouses with chronic conditions, or adult children with disabilities and serious illnesses—a staggering 45 percent increase since 2015. Among them, approximately 16 million sandwich generation caregivers balance care for both adults and children simultaneously.

The faces of caregiving are as diverse as America itself. Middle schoolers juggle homework while helping a parent through cancer treatment. Working adults manage careers while caring for aging parents and raising their own children. Retirees dedicate their golden years to supporting adult children with disabilities. College students attend school while helping a parent through cancer treatment. Meanwhile, an estimated 91 million Americans care for children under 18 in their households—these are parents, grandparents, and guardians who often shoulder multiple care responsibilities at once (US Census Bureau 2023b).

Together, this invisible workforce keeps our families strong and our communities functioning, representing an intergenerational network of support that spans the entire spectrum of the human experience. This report focuses on a critical segment of that spectrum: family caregivers of older adults, people with serious illness, and people with disabilities.

The National Alliance for Caregiving (NAC) and AARP are proud to present *Caregiving in the US 2025*, based on comprehensive data collected in 2024. This research continues our longstanding commitment to understanding the evolving landscape of family caregiving that began with our first national profile in 1997 and continued through subsequent editions in 2004, 2009, 2015, and 2020. By iterating and expanding on our established methodology, we can now examine changes in the caregiving experience over the past 15 years.

> ***This research continues our longstanding commitment to understanding the evolving landscape of family caregiving.***

Our research explores multiple dimensions of caregiving, including the prevalence of Americans providing complex care, their demographic characteristics, the nature and intensity of care provided, health and financial impacts on caregivers, workplace challenges and supports, information needs, and the role of technology in caregiving. We pay particular attention to how economic shifts and evolving health trends have reshaped caregiving responsibilities and resources available to families.

This research arrives at an inflection point for care in our nation. Policymakers, employers, and health care leaders are grappling with our nation's growing demand for care and the impacts of that care across society. Americans today face complex decisions—balancing the pressures of family responsibilities and career with the reality of longer-living parents and increasing rates of chronic conditions and disabilities. These trends highlight the need to reconsider cultural attitudes, social obligations, financial impact, and the traditional distribution of caregiving responsibilities.

Caregiving in the US 2025 is a report of empirical survey results that provide a comprehensive description of family caregivers. These findings are a springboard for action for policymakers, advocates, and families—all who develop systems to support and sustain the vital contributions of family caregivers.

What's new for 2025

In 2025, the survey was improved using validated measures of caregiver physical and emotional health and a revised index of caregiving complexity. Unlike in prior years, the 2025 survey includes paid family caregivers, an important addition. For the first time, the survey is designed to generate state-representative caregiver samples for many states.

In recognition of the expansion of programs allowing family caregivers to be compensated for some of their care via Medicaid home and community-based service (HCBS) self-direction waivers, the Department of Veterans Affairs, and other state programs, this year's *Caregiving in the US* survey includes paid family caregivers. The questionnaire includes a validated measure of caregivers' health, the CDC Healthy Days measure, that was not previously included in *Caregiving in the US*. The Healthy Days measure, established in 1993, is a four-question summary measure of global health-related quality of life. The measure assesses perceived physical and mental health over time and is useful for identifying trends in health and well-being among populations (Moriarty et al. 2003).

For the first time, the 2025 administration of the survey includes state-representative samples of family caregivers.

In addition to the Level of Care Index, which is a measure of the intensity or complexity of the caregiving situation that was computed for each administration of *Caregiving in the US* starting in 1997, the 2025 administration of *Caregiving in the US* includes an expanded Level of Care Index. The expanded Level of Care Index includes subjective measures aimed at capturing more of the caregiver experience.

For the first time, the 2025 administration of the survey includes state-representative samples of caregivers. This expansion allows us to estimate the prevalence of caregiving and to describe the characteristics of family caregivers at the state level. State-level results of this survey will be summarized in a separate report to be published in November 2025.

Reading this report

This report draws from a nationally representative online survey completed by 6,858 family caregivers ages 18 and older. This study defines family caregivers as adults providing ongoing care over the past year to adults or children with complex medical conditions or disabilities. In addition, family caregivers have a pre-existing relationship with the care recipient they support, such as a family member (e.g., spouse, parent), friend, or neighbor.

Most family caregivers are not paid for the care they provide. In this study, these are unpaid family caregivers. In limited circumstances, certain Medicaid self-direction or VA caregiver programs provide payments to family caregivers. We consider those receiving payment to be paid family caregivers. Paid family caregivers are not equivalent to professional direct care workers though they may perform similar care tasks.

Throughout this report, arrows or carets in tables indicate statistically significant differences at the 95 percent confidence level. When comparing more than two groups, superscripts show which specific comparisons are statistically significant. All results–including averages, medians, and percentages–have been weighted for accuracy. For complete details about our sampling methodology, survey design, analysis, and weighting, see appendix B.

Detailed findings

A. Prevalence of caregiving

Today, 63 million adults, or almost one-quarter of all American adults, are family caregivers who have provided care to adults or children with a medical condition or disability at some time in the past 12 months.[1] Family caregivers provide support with daily activities like shopping, transportation, and meal preparation; they assist with personal care tasks like bathing and dressing; they help with medical and nursing tasks by giving medications or injections or dressing wounds; and they serve as care coordinators who arrange appointments, monitor the care recipient's condition, and communicate and advocate with care professionals and service providers. Family caregivers are an integral part of the care recipient's care team.

As table 1 shows, the number of family caregivers in the US continues to increase.

Table 1. Estimated Number of Family Caregivers and Prevalence of Family Caregiving by Age of Care Recipient, Trend 2015–2025

Types of Care Recipients	2015	2020	2025
Total Family Caregivers *(of adults or children with medical conditions or disabilities)*	43.5 million *(prevalance: 18.2%)*	53.0 million *(prevalence: 21.3%↑)*	63.0 million *(prevalence: 24.0%↑)*
Family Caregivers of Adults Age 18+	39.8 million *(prevalence: 16.6%)*	47.9 million *(prevalence: 19.2%↑)*	59.0 million *(prevalence: 22.5%↑)*

↑↓ *Significantly higher or lower than prior wave.*

To see detailed prevalence statistics by demographics and for more information about the prevalence increase, see appendix B.

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[1] Of the 21,141 people screened in the online survey, the proportion of initial respondents who had served as caregivers (paid or unpaid) to an adult or child was 24.0 percent. Using a 2024 estimate of 262,083,034 Americans ages 18 and older, the study estimates 63.0 million adults were caregivers to an adult or child in the 12 months prior to the study.

A family caregiver can be anyone, and each caregiving story is unique. The increase in prevalence of caregiving mirrors the face of caregivers. The number of caregivers has increased among all education levels, work statuses, genders, generations, and income levels and nearly all races and ethnicities. A confluence of factors may influence the increase in the prevalence of caregiving in the US, including the aging of the population, a lack of affordable paid long-term services and supports (LTSS), and an increase in the provision of HCBS that enable older adults to age where they overwhelmingly want to: at home (US Census Bureau 2023a; Reinhard et al. 2023; Binette and Farago 2024).

Prevalence of paid family caregiving

For the first time, the 2025 survey includes family caregivers who receive payment for care they provide to an adult family member or friend under Medicaid HCBS self-direction waivers, Veterans Affairs, or other state programs. These family caregivers are distinct from paid professionals, such as home health aides or other direct care workers. This update to the survey screening criteria reflects the shifting policy landscape of caregiving. Several policies have been introduced over the past decade and have accelerated in recent years, allowing family caregivers to receive payment for some of the care they provide. Access to these programs temporarily increased under the COVID-19 public health emergency when the federal government and states developed new flexibilities and mechanisms to support families navigating the pandemic. Although not all states provide the same opportunities for caregivers to receive payment via Medicaid HCBS, most states offer some avenues to payment. See *Medicaid LTSS Programs That Pay Family Caregivers* for more details on self-direction policies allowing family caregivers to be paid.

In total, 11.2 million family caregivers report they were paid for care in 2025. Most of these 11.2 million caregivers indicate they provided both unpaid care and paid care, suggesting that they were paid for only part of the care hours they provided. Only 1.9 million of 59 million caregivers are solely paid family caregivers. For this year, the *Caregiving in the US* total caregiver prevalence includes both paid, as described earlier, and unpaid family caregivers because the share of solely paid family caregivers is relatively small, does not represent a significant change in the prevalence trend for unpaid family caregiving, and is not performing tasks that differ completely from those of unpaid family caregivers.

Table 2. Estimated Number and Prevalence of Family Caregivers of Adults by Paid and Unpaid Status, 2025

	Caregivers of Adults Ages 18+
Unpaid Family Caregivers Only	47.8 million (18.2%)
Paid Family Caregivers Only	1.9 million (0.70%)
Family Caregivers Who Are Both Paid and Unpaid	9.3 million (3.60%)
Total Family Caregivers of Adults Ages 18+	59.0 million (22.5%)

Throughout this report, we include analysis of key differences between unpaid family caregivers and paid family caregivers. Note that these analyses compare family caregivers providing solely unpaid care to family caregivers who provide any paid care (those providing solely paid care and those who provide a mix of paid and unpaid care to a family member or friend). These cross-sectional data cannot be used to draw conclusions about the impact of programs that pay family caregivers on those caregivers, but they provide insights into who is incentivized to pursue programs that pay for care.

Medicaid LTSS programs that pay family caregivers

Medicaid plays a critical role in supporting family caregivers through self-directed long-term services and supports (LTSS) programs that allow them to be paid for their care. As of 2024, 47 states and Washington, DC,* allow payment to family caregivers for personal care services under various LTSS programs (Burns et al. 2025). These services typically include assistance with ADLs, such as bathing, dressing, and eating, and some IADLs, like meal preparation and medication management.

Payments to family caregivers are often authorized through self-directed care models, which are implemented via various Medicaid waivers—such as 1915(c) and 1115—or state plan options. These models allow care recipients to select, train, and manage workers—including friends and family members under some programs—offering both autonomy and flexibility in care delivery. Caregiver-inclusive self-direction programs are allowed for certain groups of LTSS beneficiaries and are most widely available for individuals with intellectual or developmental disabilities (IDD), followed by older adults and people with physical disabilities (National Alliance for Caregiving 2025). Legal requirements for participation as a caregiver differ across programs and are complicated.

The use of self-directed services markedly increased during the COVID-19 pandemic. In response to workforce shortages and safety concerns, the Centers for Medicare & Medicaid Services (CMS) granted states greater flexibility under self-direction waivers, allowing more family caregivers to be paid via these waivers. This allowed more families to safely meet care needs in home and community settings, and many of these flexibilities have remained in place after the pandemic (Burns et al. 2025; Murray et al. 2024).

Protections for the care recipient and family caregiver

Although most states allow payments to family caregivers, 46 states allow legally responsible relatives, such as spouses or parents of minor children, to become paid care workers (Burns et al. 2025). Payments to legally responsible relatives are subject to stricter federal and state regulations to protect the interests of the beneficiary. For example, a legally responsible relative cannot serve as a representative of the beneficiary and self-direct their care while also hiring themselves. Other states have sought to protect paid family caregivers from burnout by implementing recommended limits on the hours of compensated care or offering respite services.

Compensation models

Family caregivers are generally paid hourly wages comparable to those of other direct care workers. Thirteen states,** however, have adopted structured family caregiving programs that offer family caregivers a daily stipend instead. These programs typically involve oversight of family caregivers by provider agencies, which offer training, care coordination, and support. Data on payments in all structured family caregiving programs are not available; however, payments to caregivers in those programs that have shared data range from $40 to $50 per day, depending on the state and program structure (American Council on Aging 2025).

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* Florida, Indiana, and Utah did not respond to the KFF Medicaid HCBS Program Survey 2024, which assessed which states pay family caregivers under any Medicaid HCBS programs.

** California, Georgia, Iowa, Louisiana, Maryland, Missouri, New Mexico, North Carolina, North Dakota, and South Dakota have adopted structured family caregiving programs. Connecticut, Massachusetts, and Rhode Island also have structured family caregiving programs; however, these states use different names for these programs.

B. Who is caregiving?

Key Takeaways

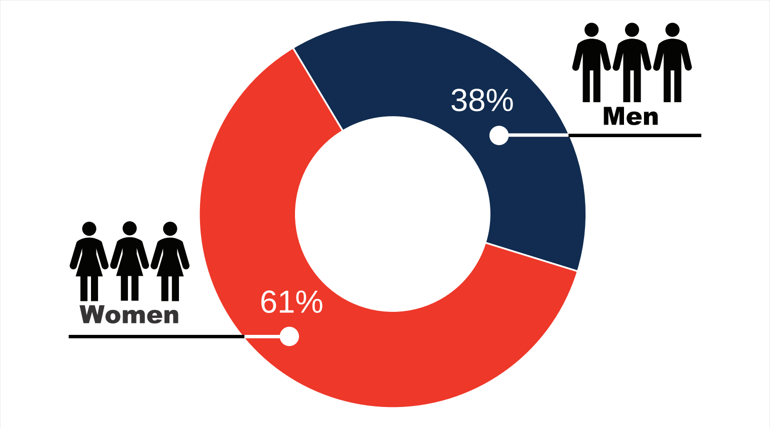
- ✓ Caregivers can be anyone. The average age of a caregiver is 51 years, and 61 percent of caregivers are women.
- ✓ Most caregivers provide care for a relative, whereas 11 percent provide care for a friend or neighbor.
- ✓ Almost one-quarter of caregivers provide care to more than one care recipient at a time.

Caregiving is widespread among all age groups, racial and ethnic groups, income and education levels, family types, gender identities, and sexual orientations. Caregiver demographics in 2025 are similar to those seen in *Caregiving in the US 2020*.

- Three in five caregivers are women (61 percent), and two in five caregivers are men (38 percent).[2]
- On average, caregivers of adults are 50.6 years old.
- Six in 10 caregivers are non-Hispanic white (61 percent), 16 percent are Latino/Hispanic, 13 percent are non-Hispanic African American/Black, 6 percent are Asian American/Native Hawaiian/Pacific Islander (AANHPI), and 6 percent are some other race or ethnicity.
- One in five family caregivers live in rural areas (20 percent).

For the full demographic profile of family caregivers, see appendix C: Demographic Profile and Prevalence.

Figure 1. Caregiver Gender



2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

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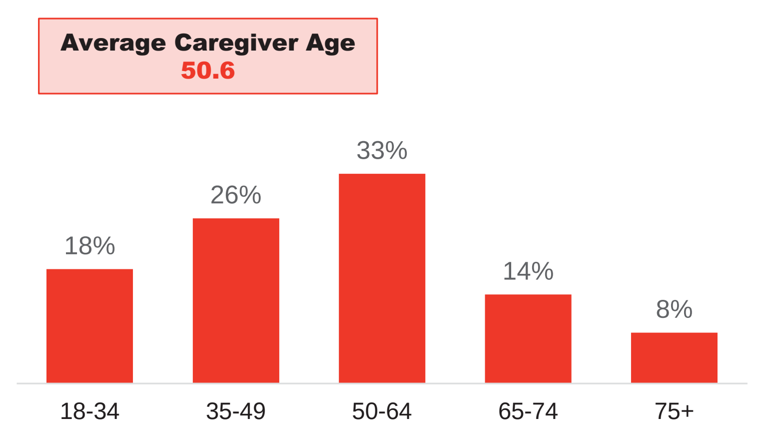
[2] Just under 1 percent of caregivers self-reported their gender identities.

Figure 2. Caregiver Age



2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded; results may not add to 100 percent.*

Who are paid family caregivers?

Paid family caregivers tend to be younger than unpaid caregivers (see table 3). Paid family caregivers tend to be ages 18 to 44 years (52 percent vs. 34 percent of unpaid caregivers) and less often ages 65 and older (14 percent vs. 24 percent of unpaid caregivers). Many of the other demographic differences observed among paid family caregivers tend to correlate with younger ages. Paid family caregivers are more often Hispanic/Latino, Black/African American, or AANHPI and less often have a four-year college degree or have health insurance, compared with unpaid caregivers.[3]

Table 3. Demographic Comparison of Paid Family Caregivers and Unpaid Family Caregivers of Adults

		Paid Family Caregivers (*n* = 1,498)	Unpaid Family Caregivers (*n* = 5,051)
Age (mean)		45.4↓	51.9
Sandwich Generation Family Caregivers (have children)		36%↑	27%
Students		19%↑	7%
Race/Ethnicity	Non-Hispanic white	44%↓	65%
	Hispanic/Latino	23%↑	15%
	Black/African American	21%↑	11%
	Asian American/Native Hawaiian/Pacific Islander	6%↑	4%
Education	High school degree or less	44%↑	32%
	Some college or associate’s degree	31%	33%
	Bachelor’s degree or higher	25%↓	35%
	Have health insurance	83%↓	90%

↑↓ *Significantly higher or lower than unpaid caregivers.*

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[3] For a full comparison of paid family caregivers and unpaid family caregivers, see appendix C: Demographic Profile and Prevalence.

Number of care recipients

The data reveal that although most family caregivers (76 percent) provide care for one person, nearly one-quarter (24 percent) manage care for multiple individuals—with 20 percent caring for two people and 4 percent caring for three or more. This substantial proportion of multiple-recipient caregivers, coupled with the rising prevalence of caregiving overall, reflects a growing culture of Americans who provide critical care support to family members, friends, and neighbors with health or functional needs.

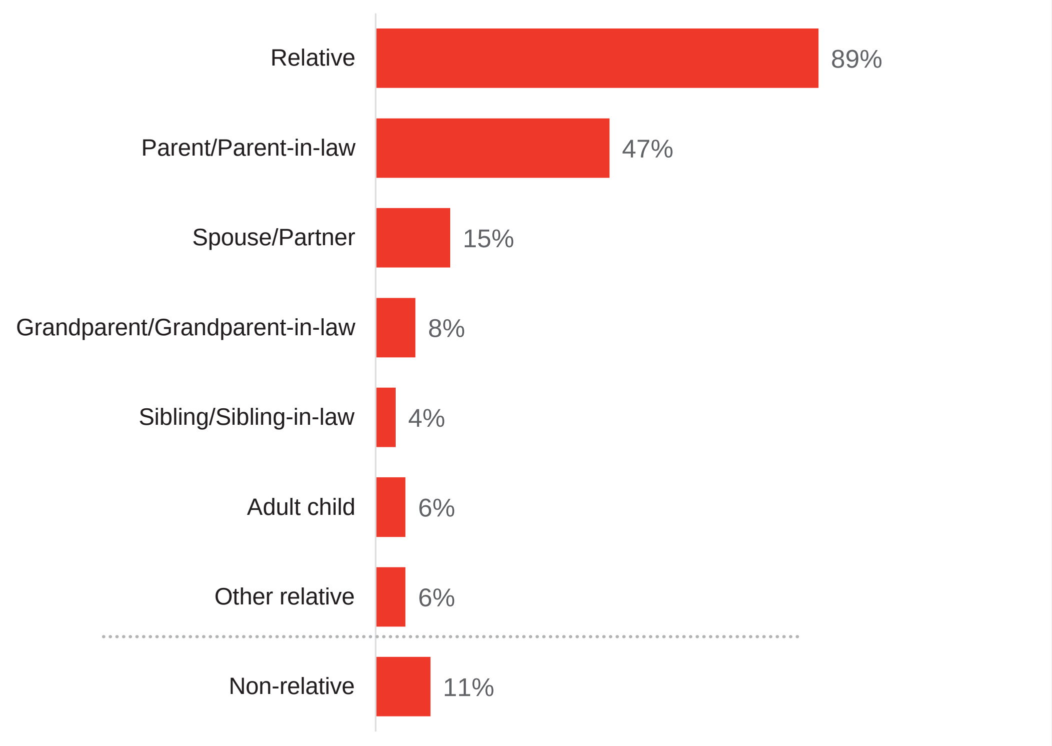
Demographic analysis shows notable patterns: AANHPI caregivers stand out as most likely to care for multiple recipients (31 percent). In comparison, white caregivers (77 percent), African American/Black caregivers (71 percent), those age 65 or older (86 percent), and those caring for spouses or partners (88 percent) typically focus on a single care recipient. These patterns suggest important cultural and situational factors influencing caregiving responsibilities across different populations.

Although some caregivers support multiple adults, respondents were asked to describe the characteristics of the primary adult recipient of care. Findings in this report pertain exclusively to the caregiver's main recipient of care.

Care recipient relationship to caregiver

For most family caregivers, their main care recipient is a relative (89 percent), whereas 11 percent care for a friend, neighbor, or other nonrelative. Most are caring for a parent (40 percent) or parent-in-law (7 percent) or for a spouse or partner (15 percent; see figure 3).

Figure 3. Care Recipient Relation to Caregiver



Q7. Who are you caring/did you care for? Please select one relationship.

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Patterns in caregiver and care recipient relationships are shaped by the caregiver's age. Older caregivers more often care for spouses/partners and siblings, whereas younger caregivers more often care for someone of an older generation, such as parents or grandparents, as is shown in table 4.

Table 4. Care Recipient Relationship to Caregiver by Caregiver Age

	Caregiver Age			
	18–49 (*n* = 2,593)	50–64 (*n* = 2,177)	65–74 (*n* = 1,209)	75+ (*n* = 570)
Care recipient is caregiver's...	A	B	C	D
Parent/Parent-in-law	49%^{CD}	60%^{ACD}	34%^{D}	8%
Grandparent/In-law	18%^{CD}	1%^{C}	0%	0%
Spouse/Partner	7%	12%^{A}	27%^{AB}	48%^{ABC}
Sibling/In-law	4%	6%	11%^{AB}	13%^{AB}
Child	3%	8%^{A}	6%^{A}	9%^{A}
Other Relative	8%^{BC}	5%	6%	7%
Nonrelative	11%^{B}	8%	16%^{AB}	16%^{AB}

Note: *Letters in superscript indicate a percentage is significantly greater than the percentage in the lettered column indicated.*

Women more often care for a non-relative (13 percent) than men (8 percent). Those not working while caregiving are also more often caring for a nonrelative (17 percent vs. 8 percent of employed caregivers).

C. Who are the care recipients?

Key Takeaways

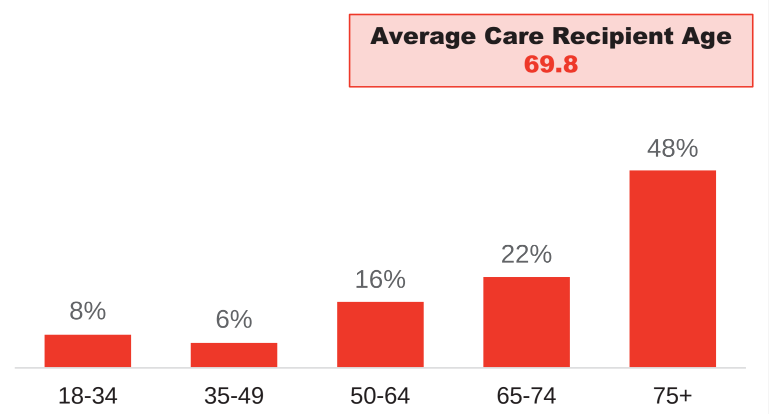
- ✓ Most care recipients face multiple health challenges simultaneously, creating complex caregiving situations that extend well beyond basic physical assistance.
- ✓ Younger caregivers typically manage short-term conditions, whereas older caregivers more often provide sustained care for chronic conditions, reflecting different caregiving journeys across the lifespan.
- ✓ Although "old age" and dementia are primary reasons for care, the broad range of conditions requiring care highlights the varied skills and adaptability family caregivers must develop.

Understanding the profile of care recipients is important for developing effective support systems and policies. Age and gender characteristics not only shape the nature of care needed but also influence relationship dynamics between caregivers and recipients. These factors can significantly affect caregiving intensity, duration, and the specific challenges caregivers face in their roles.

Care recipient age and gender

Family caregivers provide care to family, friends, and relatives across all stages of life. Most family caregivers care for someone in their 70s, as shown in figure 4. Nearly half of all caregivers (48 percent) support individuals ages 75 and older, whereas 38 percent care for those ages 50 to 74. These figures are consistent with 2020 findings.

Figure 4. Care Recipient Age



Q5. How old is/was that adult [at the time you provided care]?

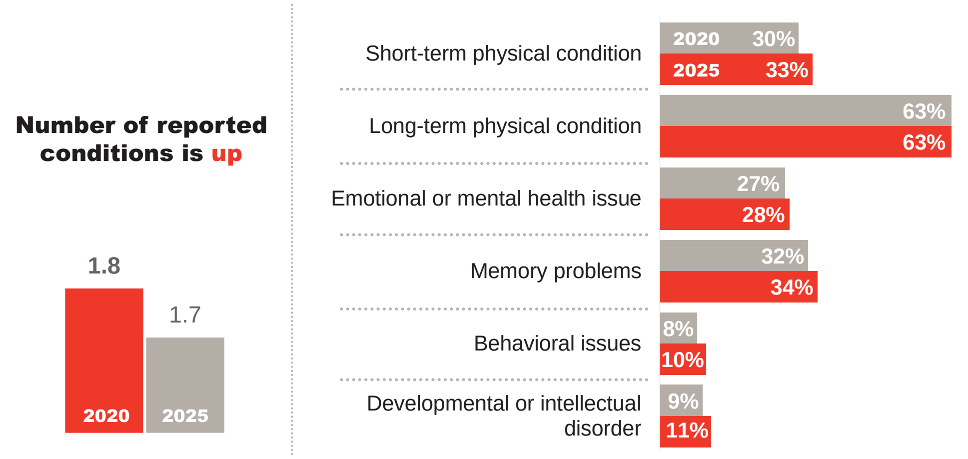
2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,527)

Gender patterns among care recipients track with earlier *Caregiving in the US* findings, with 61 percent of care recipients being women and 38 percent being men. Male care recipients are more often living with their caregiver (47 percent) compared with female recipients (36 percent).

Types of care recipient conditions

Family caregivers provide care for recipients who face complex health conditions, requiring caregivers to learn to assist with varied physical, emotional, and behavioral health needs (see figure 5). More LGBTQ+ caregivers than non-LGBTQ+ caregivers care for someone with an emotional or mental health problem (37 percent) or behavioral issues (13 percent). African American/Black family caregivers more often care for someone with a developmental or intellectual disorder (17 percent), a behavioral issue (15 percent), or a memory problem (39 percent). Nearly three-quarters of their care recipients experience at least two categories of health conditions (73 percent), highlighting the multifaceted nature of caregiving. This complexity has remained consistent since 2020.

Figure 5. Types of Care Recipient Conditions



Q17. Does/Did your [relation] need care because of a …?

2020 Base: Caregivers of Recipient Age 18+ (*n* = 1,392)
2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Respondents may select more than one response; results add to greater than 100 percent.*

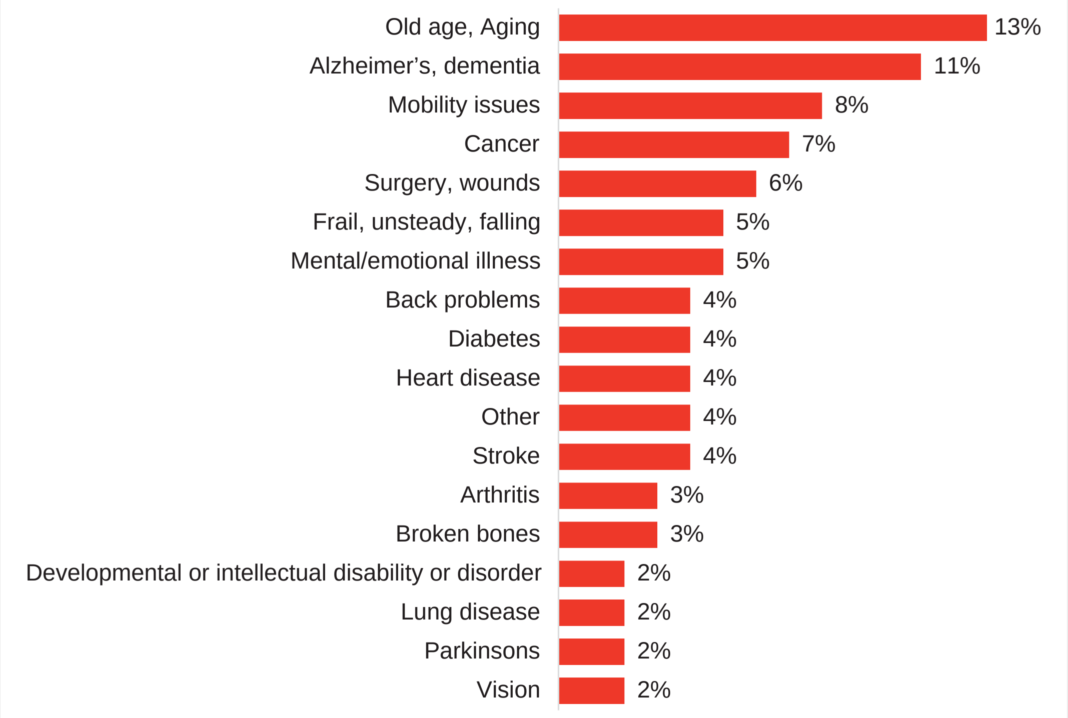
The type of condition managed by family caregivers varies significantly by age. Younger caregivers (ages 18 to 49) more frequently provide care for someone with a short-term physical condition (38 percent) compared with caregivers ages 50 and older (29 percent). Younger caregivers are also more often caring for someone with an emotional or mental health condition (33 percent) than older caregivers (24 percent). Conversely, younger caregivers less often care for someone with a long-term physical condition (59 percent) than their older counterparts (66 percent). This age-related pattern suggests different caregiving trajectories and challenges across the lifespan, with older caregivers more frequently managing chronic conditions requiring sustained care and younger caregivers facing more episodic care.

Care recipient's main condition or illness

When asked to identify the main condition requiring care, family caregivers most commonly cite "old age" or aging (13 percent), followed by Alzheimer's or other dementias (11 percent), mobility issues (8 percent), cancer (7 percent), and surgery or wounds (6 percent). Together, these top five conditions account for nearly half of all primary reasons for care (see figure 6).

Mental or emotional illness ranks seventh at 5 percent, with younger caregivers twice as likely to provide this type of care (7 percent of caregivers under age 50 compared with 4 percent of caregivers age 50 or older). The COVID-19 pandemic has also left its mark on the caregiving landscape, with 1 percent of caregivers reporting it as the main condition necessitating care for their recipient. These caregiver perceptions may differ from clinical diagnoses or population health statistics.[4]

Figure 6. Care Recipient's Main Condition or Illness



Q18. What is/was the <u>main</u> problem or illness your [relation] has/had, for which they need/needed your care?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

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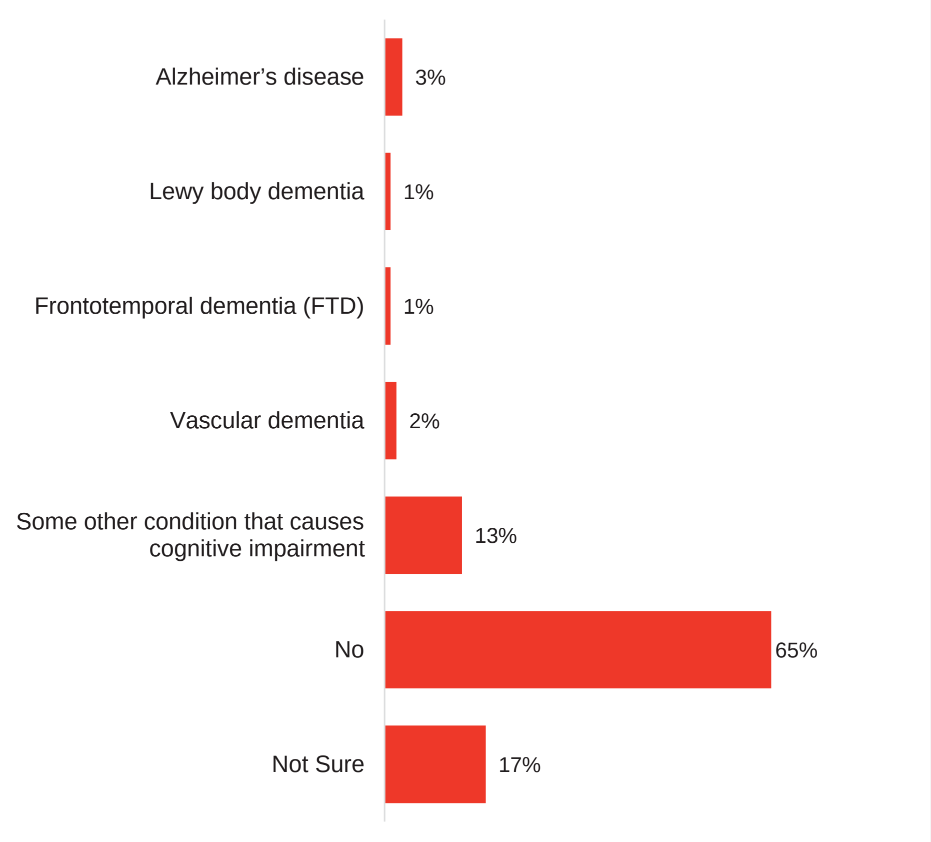
[4] These are self-reports by caregivers about what they perceive their recipient's main problem to be for which they need unpaid care.

Presence of Alzheimer's disease or other dementias

Memory issues and/or dementia among care recipients are reported by more than one-quarter of caregivers: 11 percent cite Alzheimer's or other dementias as the main problem or illness requiring caregiver's help, and an additional 19 percent indicate their care recipient is living with a cognitive impairment. More female family caregivers care for someone with a memory problem (36 percent) than do male family caregivers (32 percent). Notably, 17 percent of caregivers report they are "not sure" whether their care recipient has a memory issue. This high number points to the opportunity for improving clinical detection and communication of specific cognition diagnoses (Burgdorf and Amjad 2023; Liss, 2021).

Figure 7. Alzheimer's Disease and Other Dementias as Secondary Condition



A20a. Is / Was your (...) living with any of the following conditions causing cognitive impairment?

2025 Base: Caregiver of an adult and Alzheimer's not mentioned as a problem (*n* = 5,796)

D. Living situation of family caregiver and care recipient

Key Takeaways

- ✓ Three-quarters of caregivers live with their care recipient or within 20 minutes of them.
- ✓ Caregivers who live with their care recipient have less unpaid family help than caregivers who live apart from their care recipient.
- ✓ Those who care for someone with long-term physical conditions or memory problems more often use paid help.
- ✓ Almost one-third of caregivers live with a child or grandchild under 18 while caring for an adult.
- ✓ Although nearly 4 in 10 caregivers indicate that respite services would be helpful, only 13 percent report using respite services.

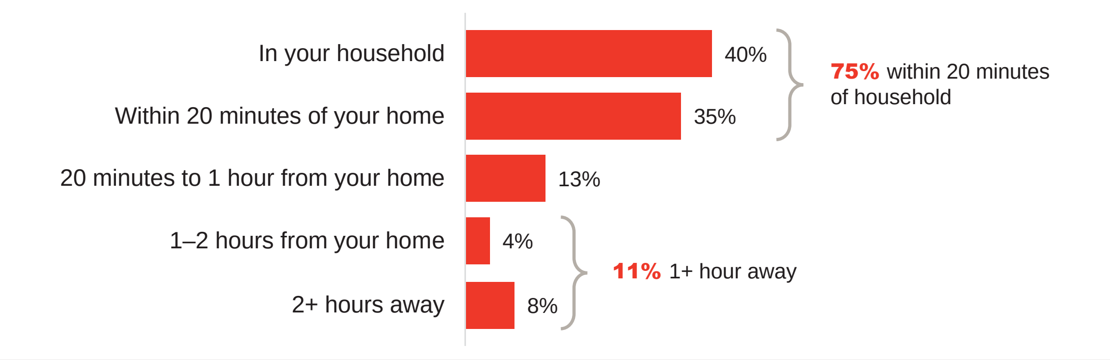
The living situation of family caregivers and those they care for affects caregiving in important ways. Understanding details like whether the caregiver and the care recipient live in the same place or at a distance and whether the care recipient lives alone or with others is critical for understanding caregivers' well-being and their needs for specific services and supports.

Caregiver distance from care recipient

Forty percent of caregivers live with their care recipient (up from 34 percent in 2015), and 35 percent live within 20 minutes of their care recipient. More than 10 percent live an hour or more away from their care recipient. Lower-income caregivers, making $50,000 in annual household income or less, more often live with their care recipients (49 percent) than do higher-income caregivers (36 percent). Caregivers who are men (44 percent compared with 38 percent for women), Hispanic/Latino (45 percent), LGBTQ+ (48 percent), and African American/Black (43 percent) family members and friends also more often live with their care recipients. These findings may be a factor of the intensity of the care recipient's needs, but they also could reflect cultural comfort among African American/Black and Hispanic/Latino families with multigenerational living (Guzman and Skow 2019).

Just over one-fifth of caregivers (22 percent) who live with their care recipients are providing 21 or more hours of care weekly. In comparison, about one-tenth (12 percent) of caregivers who live apart from their care recipients provide the same care hours. In addition to providing more hours of care, caregivers who live with the family member or friend they care for get help less often, whether from unpaid helpers (36 percent compared with 65 percent living apart) or paid helpers (22 percent compared with 39 percent for those living apart).

Figure 8. Caregiver Distance from Care Recipient



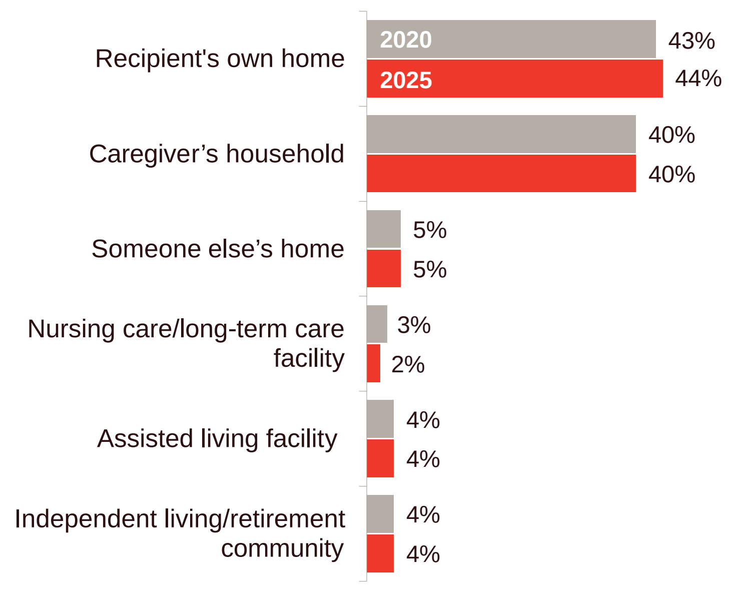
Q11. Where does/did your [relation] live at the time you provided care?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Care recipients living separately from caregivers

Three-quarters of care recipients who do not live with their caregiver live in their own home. Of those, 1 in 10 live in formal long-term care settings like nursing homes or assisted living facilities, similar to findings in 2020; 3 in 10 care recipients who live in a home or community setting live alone.

Figure 9. Where Care Recipient Lives

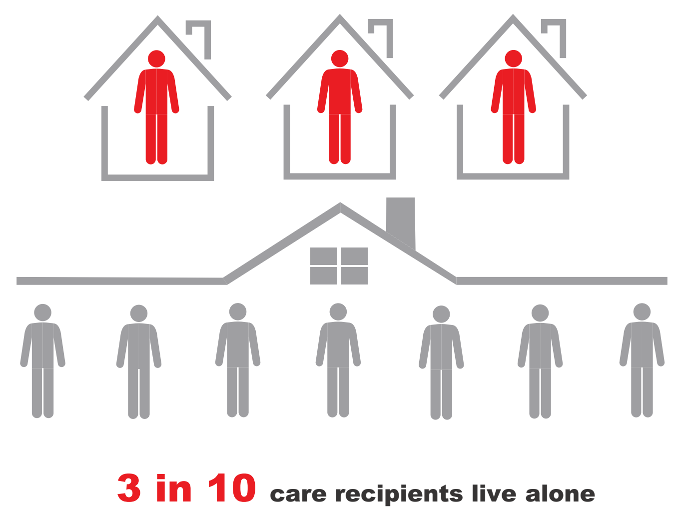


Q13. Which of the following best describes where your [relation] lives/lived at the time you provided care?

2020 Base: Caregivers of Recipient Age 18+ Who Reported Living Arrangement (*n* = 1,389)
2025 Base: Caregivers of Recipient Age 18+ Who Reported Living Arrangement (*n* = 5,358)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Figure 10. Care Recipient Living Alone



Q14c. Does/Did your [relation] live alone at the time you provided care?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 5,363)

Sandwich generation family caregivers

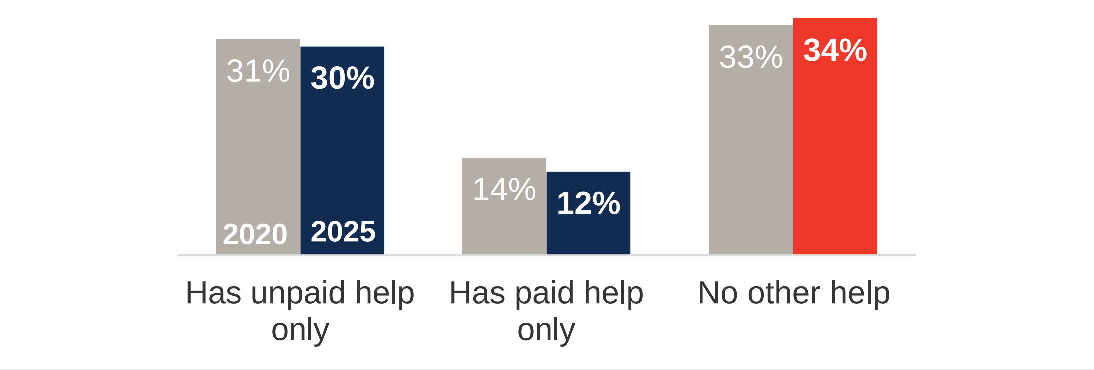
Sandwich generation caregivers care for a child and an older adult at the same time and are sandwiched between these care responsibilities. Almost one-third (29 percent) of all family caregivers have children or grandchildren under 18 living at home while caring for an adult family member or friend. Those under age 50 are more often sandwich generation caregivers than older caregivers (47 percent compared with 14 percent). More African American/Black (36 percent) and Hispanic/Latino family caregivers (43 percent) care for a child who lives in their household and an adult care recipient than overall.

Use of paid help and unpaid help

Some family caregivers include paid or unpaid helpers in their network of support. There are some key differences in which groups of caregivers are more likely to use help that may reflect need, access to help, or family composition.

Paid help. One-third of family caregivers have paid help (32 percent; figure 11). The use of paid help is more common among those with higher incomes (35 percent compared with 24 percent of lower-income caregivers), those with more than $50,000 in annual household income, and working family caregivers (35 percent compared with 27 percent of those not working). Those caring for someone with a long-term physical condition use paid help more often (75 percent compared with 57 percent with no paid help). Caregivers of someone with the following conditions also more often use paid help: memory problem (46 percent compared with 29 percent with no paid help), developmental or intellectual disorder or delay (16 percent compared with 10 percent with no paid help), and behavioral issue (12 percent compared with 9 percent with no paid help).

Figure 11. Use of Paid or Unpaid Help



Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?

Q30. *(If recipient not in nursing home or assisted living)* During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help them?

2025 Base: Caregivers of Recipient Age 18+ Not in Nursing Home or Assisted Living (*n* = 6,549)

Unpaid help. About half of all caregivers (53 percent) include unpaid helpers in their network of support (see figure 11). Some caregivers more often use unpaid help. Men more often have unpaid help (56 percent) than women (51 percent) and report that some other unpaid helper provided most of the care (47 percent of men compared with 42 percent of women). Caregivers who do not live with their care recipient use paid help more often (65 percent) than those who live with their care recipient (36 percent).

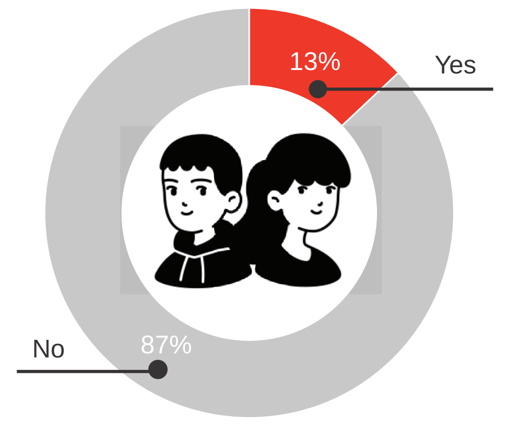
Lower-income family caregivers and LGBTQ+ family caregivers use any help, whether paid or unpaid, less often than their counterparts. Only a quarter (24 percent) of LGBTQ+ caregivers have paid help, and only 43 percent have unpaid help. Among lower-income family caregivers, only 24 percent use paid help, and 42 percent have unpaid help.

Children as part of family caregiving. Children may also assist their families or households with caregiving. Among caregivers who have any unpaid help, 7 percent of all family caregivers include a child under 18 as one of their unpaid helpers. Based on a population of 31 million caregivers of adults who have unpaid help, we estimate 4 million children under 18 in those households provide care to an adult recipient.

> ***"My son has been my caregiver for over 10 years preventing him from gainful employment and obtaining the benefits he rightly deserves. Being a family member he is not entitled to getting any caregiver benefits."***
>
> ***—James, Colorado***
> ***Receiving care from his son***

> ***"I really need to go back to work, especially with two kids going into college…"***
>
> ***—Kaoru, Kansas***
> ***Caregiver to her mother, two children heading into college***

Figure 12. Children as Part of Family Caregiving



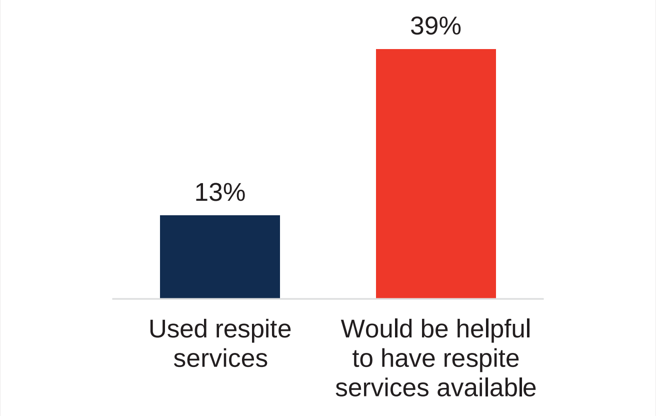
Q29Z. *(If has other unpaid help)* Of all the people who help provide/helped provide care to your [relation], are/were any of them children under the age of 18? They might help or assist/have helped or assisted you with the care you provide/provided. The child(ren) may also help/have helped with things like bringing items to or from your [relation], doing chores or other housework, running errands, or just generally helping watch over your [relation].

2025 Base: Caregivers With Other Unpaid Help for Recipient Age 18+ (*n* = 3,302)

Respite services

Respite care, or care provided to a care recipient so that their family caregiver can get a break from care responsibilities, is widely cited as a helpful support to caregivers (Reinhard, Tilly, and Flinn 2024). Although nearly 4 in 10 caregivers report that respite services would be helpful (see figure 13), only 13 percent of all caregivers use respite services. Other work has identified practical barriers to respite use, like inflexible program design, lack of trained providers, and difficult application processes, and more subjective barriers, such as lack of trust, shame around handing off care to someone else, or uncertainty about the quality of available respite services (Leocadie, Roy, and Rothan-Tondeur 2018; Min, 2021).

Figure 13. Respite Services



Q45. In your experience as a caregiver, have you ever …

N20. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would be/have been helpful to you?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Respite care use is more common among caregivers with paid help (25 percent compared with 8 percent), caregivers providing high hours of care (17 percent compared with 11 percent), and caregivers working full time (17 percent compared with 13%). This suggests that respite care is more often used by those whose care recipients have more needs.

E. What are family caregivers doing?

Key Takeaways

- ✓ Caregiving is long term for many: 30 percent of caregivers have provided care for five years or more, an increase from the proportion providing this duration of care in 2015.
- ✓ Caregiving is time consuming: Nearly one in four caregivers provide 40 hours of care or more per week, and an additional 35 percent of caregivers provide care for more than 20 hours per week.
- ✓ Forty percent of caregivers report providing high-intensity care.
- ✓ More caregivers help with activities of daily living than in 2020, and more caregivers help with three or more activities of daily living than in 2020.
- ✓ Despite the types of care they provide, only 11 percent of caregivers received formal training for this type of care.
- ✓ Most caregivers include health care coordination tasks—such as monitoring care recipients' health conditions and communicating with care recipients' providers—as part of their care responsibilities. However, one-third of caregivers find care coordination challenging.
- ✓ Use of technology to help with caregiving is up compared with 2020.

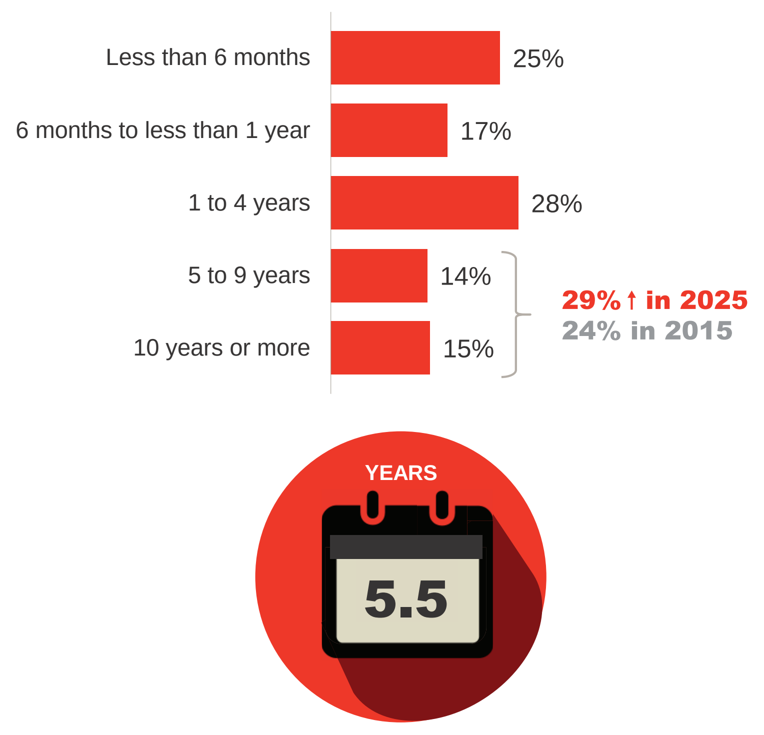
Understanding the scope and intensity of family caregiving requires examining not only who provides care but also what that care involves. Family caregivers perform a range of tasks that vary in complexity, physical demands, and time commitment. This section explores the multifaceted nature of caregiving responsibilities, including the number of hours devoted to care and the specific daily living activities managed by caregivers.

Data from *Caregiving in the US* provide valuable insight into the extensive time commitments caregivers undertake, the personal care tasks they manage, the household and medical responsibilities they handle, and the training they receive. Together, these elements offer a comprehensive picture of the essential, although often unseen, work performed by family caregivers.

Duration of care for recipient

The average duration of caregiving is 5.5 years. Nearly 30 percent of caregivers have provided care for 5 years or more, an increase from 24 percent in 2015.

Figure 14. Duration of Care



Q21. How long have you been providing/did you provide care to your [relation]?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

On average, caregivers spend 27 hours per week providing care (see figure 15).[5] One-third of caregivers provide care for more than 20 hours per week (35 percent), and 24 percent provide care hours equivalent to a full-time job (more than 40 hours of care each week). Women are more likely to provide constant care (22 percent) than men (16 percent). Constant care was defined in the survey as time-intensive care that ranged from on and off around-the-clock care, continuous care with only small sleep breaks, or 24/7 continuous care.

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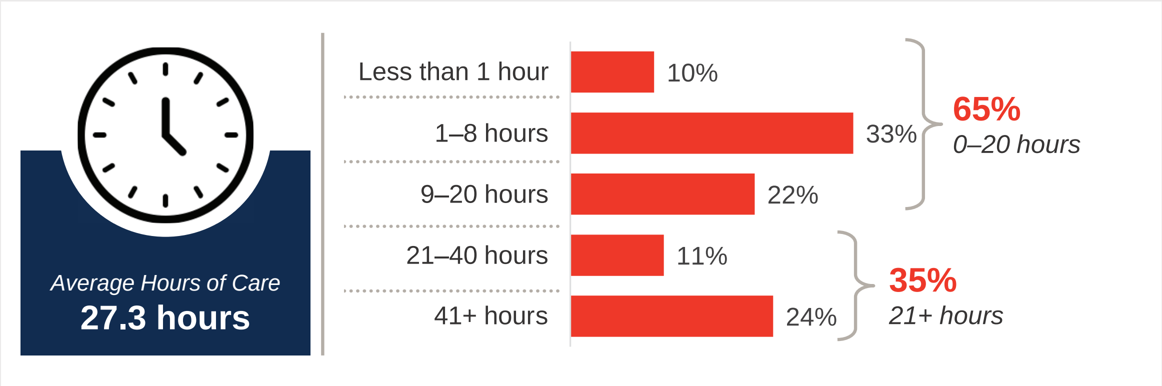
[5] Any caregiver who reported hours of care in excess of 98 hours per week is capped at this level, equivalent to 14 hours per day. We imputed hours of care for caregivers who selected constant care and did not report a numeric response using the range of values reported by all other caregivers and additional information the constant-care caregivers provided about the nature of that constant care. For more details on the imputation model, see appendix B: Detailed Methodology.

Figure 15. Hours of Care Provided



Q25. Thinking now of all the kinds of help you provide/provided for your [relation], about how many hours do/did you spend in an average week helping them?

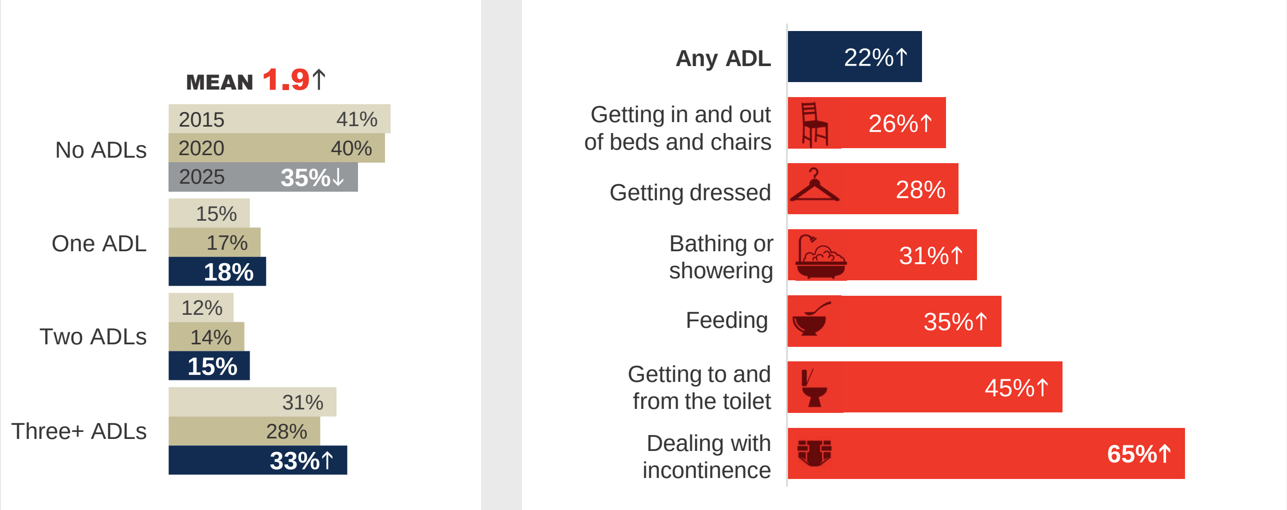
2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Help with activities of daily living

Activities of daily living, or ADLs, are routine tasks that are essential for maintaining personal independence, such as bathing, dressing, feeding oneself, toileting, and transferring from a bed or a chair. Almost two-thirds of caregivers assist their care recipient with at least one ADL. On average, caregivers assist with 1.9 of 6 ADLs. From 2020 to 2025, more caregivers are helping with any ADLs, and more caregivers are helping with three or more ADLs. The most common task is helping recipients get in and out of beds and chairs (45 percent).

Figure 16. Help with Activities of Daily Living (ADLs)



Q22. Which of these do/did you help your [relation] with?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,531)

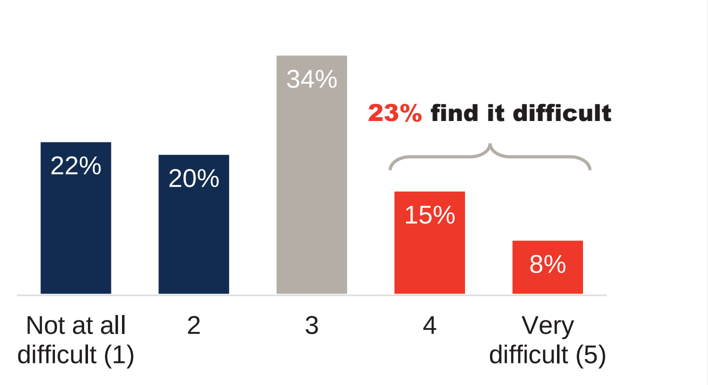
Note: *Respondents may select more than one response; results add to greater than 100 percent.*

Notable differences in ADL help also exist for some groups of caregivers. More paid family caregivers than unpaid family caregivers help with any ADLs (77 percent compared with 63 percent). African American/Black (2.2 ADLs on average) and Hispanic/Latino (2.2 ADLs on average) family caregivers help with more ADLs, on average, than all family caregivers of adults (1.9 ADLs on average).

In terms of gender differences, female family caregivers more often help with dressing (38 percent compared with 30), bathing (34 percent compared with 27 percent), and incontinence management (24 percent compared with 20 percent) than male caregivers. Male family caregivers more often assist with getting in and out of beds and chairs (47 percent compared with 43 percent).

Overall, providing support with ADLs can be taxing for caregivers. Among caregivers performing ADLs, nearly one in four (23 percent) say it is difficult to assist their recipient with these tasks (figure 17).

Figure 17. Difficulty of Helping with ADLs



N1. *(If doing ADLs)* How difficult is/was it for you to help your [relation] with these/those kinds of tasks?

2025 Base: Caregivers who help Recipient Age 18+ with ADLs (*n* = 4,419)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Help with instrumental activities of daily living

Instrumental activities of daily living, or IADLs, are complex tasks necessary for independent living, such as managing finances, preparing hot meals, shopping, housekeeping, and using transportation. Caregivers may help someone with either ADLs or IADLs or a combination of these activities. Caregivers help with an average of 4.5 IADLs (see figure 18). Eighty-four percent of caregivers assist their care recipient with three or more IADLs, up from 77 percent in 2015. More caregivers help with grocery or other shopping (81 percent, up from 78 percent), preparing meals (67 percent, up from 64 percent), and giving medicine, pills, or injections (55 percent, up from 50 percent).[6] More female caregivers assist with shopping (82 percent compared with 78 percent of male caregivers), housework (79 percent compared with 75 percent), and preparing meals (70 percent compared with 63 percent).

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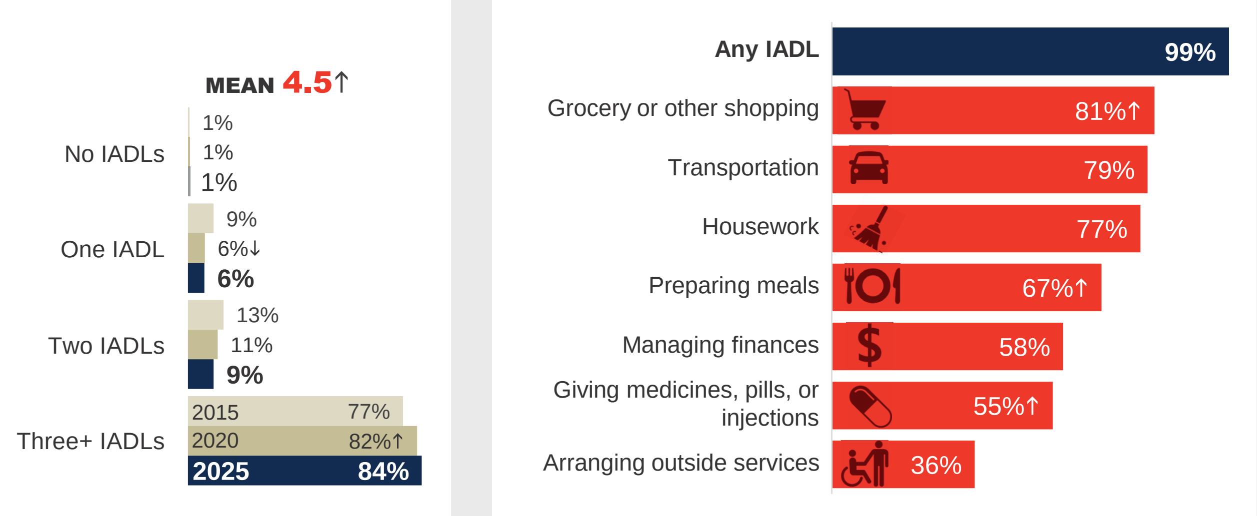
[6] Paid family caregivers are significantly more likely to prepare meals (73 percent vs. 66 percent of unpaid family caregivers) and to give medicines, pills, or injections (64 percent vs. 53 percent).

Figure 18. Help with Instrumental Activities of Daily Living (IADLs)



Q23. Do/Did you provide help to your [relation] with…?

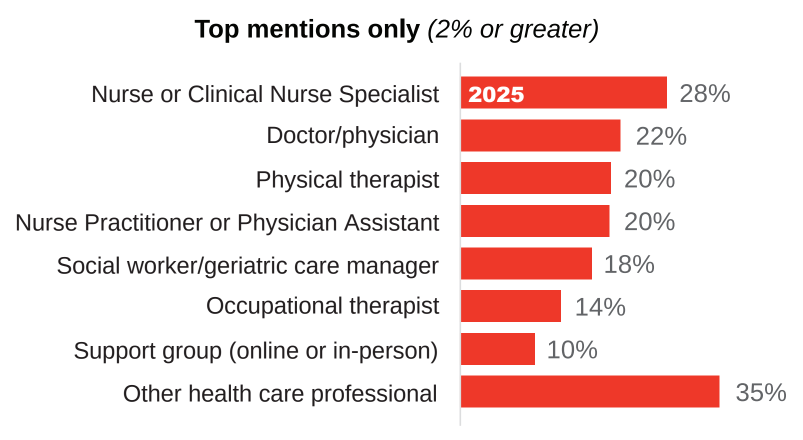
2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Respondents may select more than one response; results add to greater than 100 percent.*

Training for ADL and IADL help

Despite the prevalence of ADL and IADL help, caregivers rarely receive formal training on providing this critical help. Only 11 percent report receiving any training or preparation to assist with ADLs, IADLs, or behavioral management and modification. African American/Black family caregivers are more often trained to assist with ADLs (17 percent) than all caregivers. Those who did report receiving training were trained by a nurse (28 percent), doctor or physician (22 percent), or nurse practitioner or physician's assistant (20 percent; see figure 19). Recently introduced billing codes allow healthcare providers to be paid by Medicare for providing caregivers of Medicare enrollees training on these types of tasks. See *Medicare Caregiver Training Service Billing Codes*. This is just one avenue for offering training to more family caregivers.

Figure 19. Sources of Training for ADLs and IADLs for Caregivers Receiving Training



N17. *(if received training)* Who prepared you to assist your [recipient] with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or behavioral management/modification?

2025 Base: Caregivers of Recipient Age 18+ Who Received Training for ADLs or IADLs (*n* = 946)

Medicare caregiver training services billing codes

CMS has implemented payment policies in recent years intended to better support and empower nonprofessional caregivers. In the Calendar Year (CY) 2017 Physician Fee Schedule (PFS), CMS finalized Medicare payment for providers administering caregiver-focused health risk assessments to benefit patients. More recently, the CY 2024 PFS finalized Medicare payment for select family caregiver training services, introducing current procedural terminology (CPT) codes that enable health care providers to receive reimbursement for training furnished to caregivers alongside diagnostic and treatment services for patients, helping caregivers carry out treatment plans.

Caregiver training services (CTS) codes

- **Behavior management/modification training** (96202, 96203)
  - Caregivers are taught by treating practitioners how to structure the patient’s environment to support and reinforce desired patient behaviors, to reduce the negative impacts of the patient’s diagnosis on the patient’s daily life, and to develop highly structured technical skills to manage the patient’s challenging behavior.
- **Education/training for patient self-management** (97550, 97551, 97552)
  - Caregivers are taught by treating practitioners how to facilitate the patient’s ADLs, IADLs, transfers, mobility, communication, swallowing, feeding, safety practices, and problem solving to reduce the negative impacts of the patient’s diagnosis on the patient’s daily life and to help the patient carry out a treatment plan.

Who can bill CTS codes?

Medicare-approved non-physician practitioners (NPPs) can bill for CTS codes. This includes nurse practitioners (NPs), clinical nurse specialists (CNSs), certified nurse-midwives (CNMs), physician assistants (PAs), clinical psychologists (CPs), clinical social workers (CSWs), marriage and family therapists (MFTs), mental health counselors (MHCs), physical therapists (PTs), occupational therapists (OTs), and speech-language pathologists (SLPs). All NPPs must be qualified health care professionals practicing within their license to bill for these codes.

Why use CTS codes?

Caregivers (defined as an adult family member or other individual who assists a patient with a physical or mental limitation) can play a key role in carrying out treatment plans related to physical, occupational, or speech-language therapy as well as other activities. Where the provider believes a caregiver’s involvement is valuable in ensuring a successful treatment plan and the patient agrees to caregiver involvement, caregiver training may be provided.

How CTS codes are used

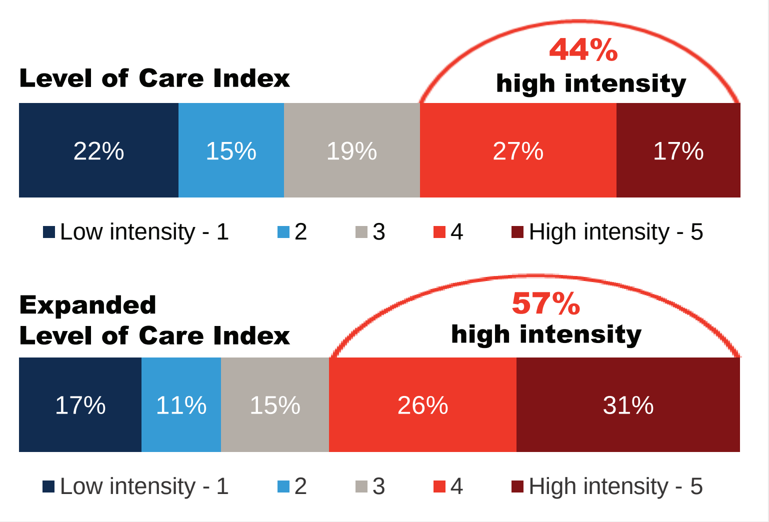
- There is no limit to how many times CTS codes can be billed. The medical necessity should determine the volume and frequency of training (the quantity must be considered reasonable and necessary).
- CTS codes can be furnished in both facility and nonfacility settings.
- CTS codes can be furnished in person or virtually.

Level of Care Index

The Level of Care Index, first developed in the 1997 study *Family Caregiving in the US* (a predecessor to this research) and used in the 2004, 2009, 2015, and 2020 *Caregiving in the US* studies,[7] is replicated in this 2025 study to convey a simple measure of the intensity of the caregiving situation. The index is based on the number of hours of care given as well as the number of ADLs and IADLs performed. The details of index construction are shown in appendix B.

Four in 10 caregivers are in high-intensity situations (44 percent), 19 percent are in medium-intensity situations, and 37 percent are in low-intensity situations (see figure 20). A greater share of African American/Black and Hispanic/Latino caregivers are in the high-intensity index group compared with all caregivers.

Figure 20. Level of Care Indices



2025 Base: Caregivers of Recipient Age 18+ (*n* = 9,549)

Expanded Level of Care Index

The original Level of Care Index measures objective caregiving effort through two equally weighted components: hours spent caregiving and ADL/IADL tasks performed by the caregiver. The original Level of Care Index does not account for the subjective experience of caregiving, an area of growing focus in caregiving research.

For 2025, we have developed a new Expanded Level of Care Index that balances both objective and subjective measures of the caregiving experience with the inclusion of two survey items (in addition to the original metrics): the ease of coordinating care and the availability of other help (paid and unpaid). The details of index construction are shown in appendix B. Figure 20 shows the comparison of how family caregivers are distributed across each level of intensity across the two indices.

---

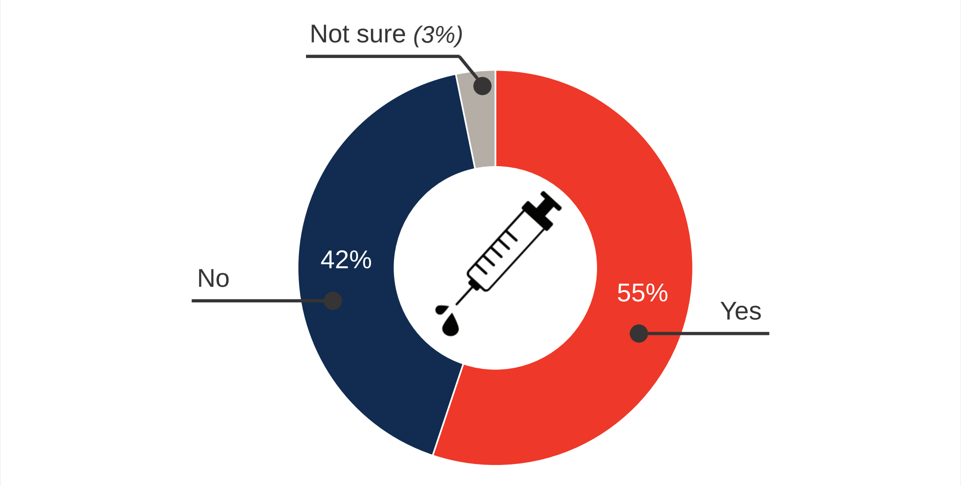
[7] In the 1997, 2004, 2009, and 2015 waves, this index was referred to as the Burden of Care Index, with each level of the index referred to as high, moderate or medium, and low "burden." For the 2020 cycle, the name was adjusted to Level of Care Index, with each level referred to with the word "intensity," as this index is one way to measure the intensity or complexity of the caregiving situation.

Medical and nursing tasks

In addition to ADLs and IADLs, many caregivers take on medical and nursing tasks that are typically handled by health care professionals. These tasks—like administering injections and managing catheters—are performed by 55 percent of caregivers (figure 30), yet only 22 percent receive training, most commonly from medical professionals and personal relationships. Female caregivers more often assist with medical and nursing tasks (58 percent compared with 51 percent of male caregivers). African American/Black family caregivers more often report helping with medical and nursing tasks (62 percent) and are more often trained to do these complex care tasks (27 percent) than all other caregivers.

Nearly one in five caregivers say doing these medical and nursing tasks is difficult (22 percent). A greater share of AANHPI caregivers say doing medical tasks for their care recipient is difficult (27 percent). Lower-income caregivers—those with household incomes of less than $50,000—help with medical and nursing tasks more often (59 percent) and more often report that those tasks were difficult (25 percent) compared with higher-income caregivers.

Figure 21. Assistance with Medical and Nursing Tasks



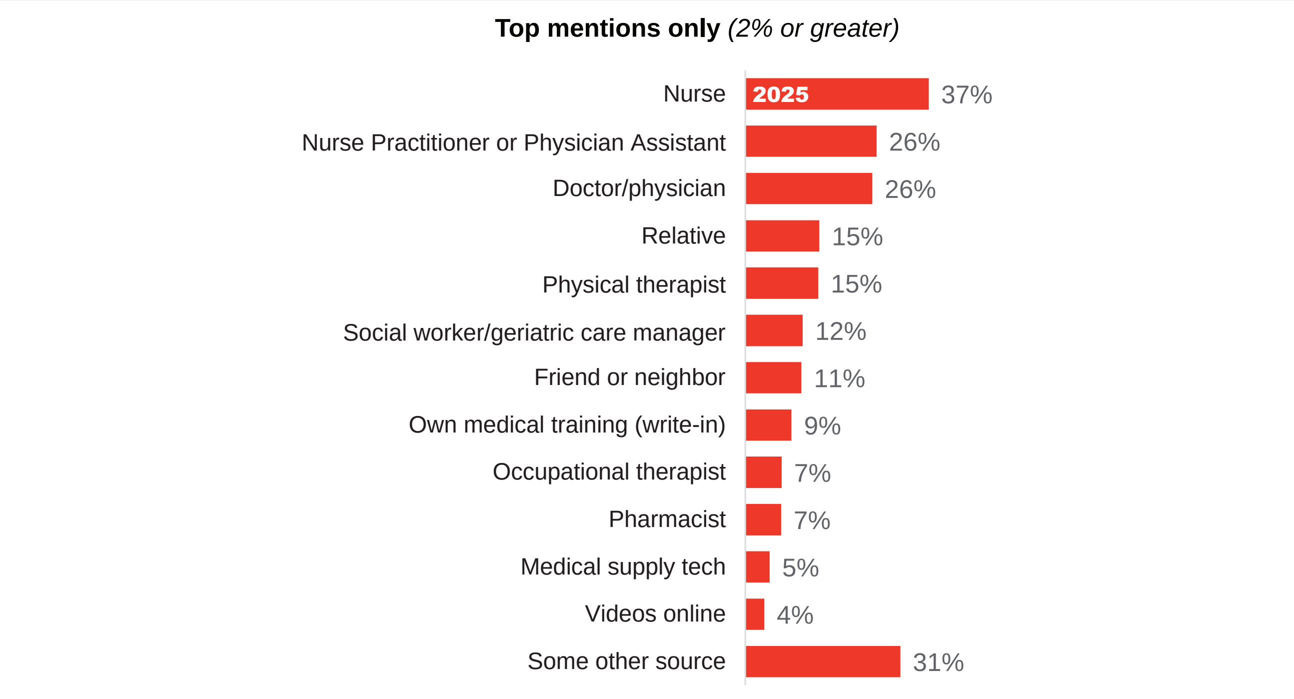
N3. Do/Did you help your [relation] with any medical/nursing tasks? This might include giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, or wound care. You could be monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Among those who received training, nearly all felt the training prepared them to take on these tasks well (96 percent). This highlights the importance of training and preparation for difficult tasks to ensure caregivers' sense of assurance and success.

Figure 22. Sources for Training on Medical/Nursing Tasks for Caregivers Receiving Training



N6. *(if received training)* Who prepared you to do the medical/nursing tasks needed to help your [recipient]?

2025 Base: Caregivers of Recipient Age 18+ Who Received Training for Medical/Nursing Tasks (*n* = 913)

Interactions with health care providers

Caregivers are also key players in managing health care: 70 percent monitor care recipients' health conditions, 64 percent communicate with care recipients' providers, and 58 percent advocate for their care recipients' needs with providers, community services, or government agencies (see figure 23).

Figure 23. Interactions with Health Care Providers

Q23_1. And do/did you provide help to your [relation] by...?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Respondents may select more than one response; results add to greater than 100 percent.*

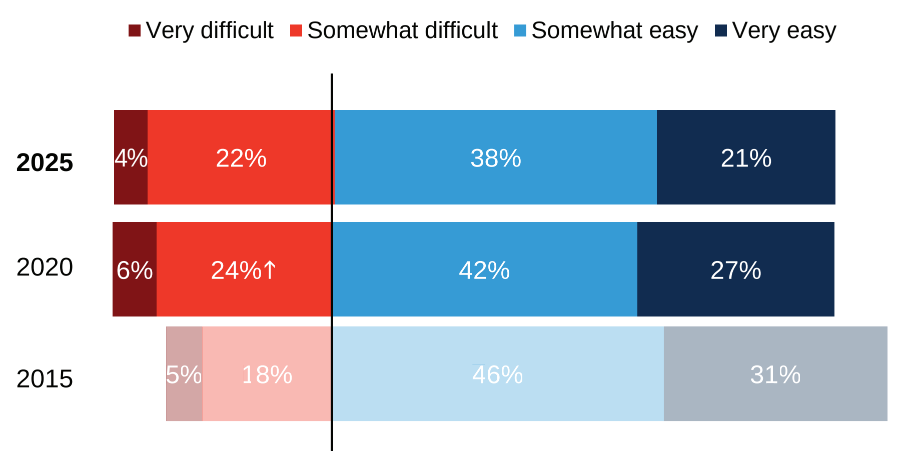
Female family caregivers more often take on these care coordination tasks than do male caregivers. Female caregivers more often report monitoring the severity of the condition (72 percent vs. 67 percent of male family caregivers), communicating with health care providers (67 percent vs. 60 percent), and advocating for their recipient with those providers (61 percent vs. 54 percent). Communicating with providers is more common among African American/Black (70 percent) and AANHPI family caregivers (73 percent), compared with all caregivers, as is advocating on their recipient's behalf (65 percent African American/Black and 69 percent AANHPI). LGTBQ+ caregivers less often report communicating with health care providers (53 percent vs. 65 percent).

Younger family caregivers are less likely to interact with health care professionals. Those ages 18 to 49 are least likely to communicate with providers (57 percent vs. 70 percent of caregivers ages 50 or older) or to advocate on their recipient's behalf (52 percent vs. 63 percent of caregivers ages 50 or older). This is consistent with research that shows younger family caregivers ages 18 to 34 have more difficulty getting in touch with health care providers and are slightly less satisfied with their interactions with health care providers (Raimondi 2024).

Among family caregivers whose care recipient has been in the hospital overnight in the past year, 70 percent said they were included in discussions about their recipient's care. Being included in care conversations during hospitalization episodes is lowest among family caregivers who are ages 18 to 49 (64 percent) and those who identify as LGBTQ+ (60 percent).

Care coordination remains a challenge for many family caregivers; only 6 in 10 report that coordinating care with health professionals is easy (58 percent), continuing a downward trend from 2015 (65 percent) and 2020 (59 percent; see figure 24). One in three AANHPI caregivers (34 percent) report difficulty in coordinating care for their care recipient, a figure that is 7 percentage points higher than that of caregivers overall.

Figure 24. Ease of Coordinating Care



Q38. *(If responsible for coordinating)* Please think about all of the health care professionals or service providers who give/gave care or treatment to your [relation]. How easy or difficult is/was it for you to coordinate care between those providers?

2015 Base: Caregivers Involved in Care Coordination for Recipient Age 18+ (*n* = 1,042)
2020 Base: Caregivers Involved in Care Coordination for Recipient Age 18+ (*n* = 1,200)
2025 Base: Caregivers Involved in Care Coordination for Recipient Age 18+ (*n* = 4,194)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

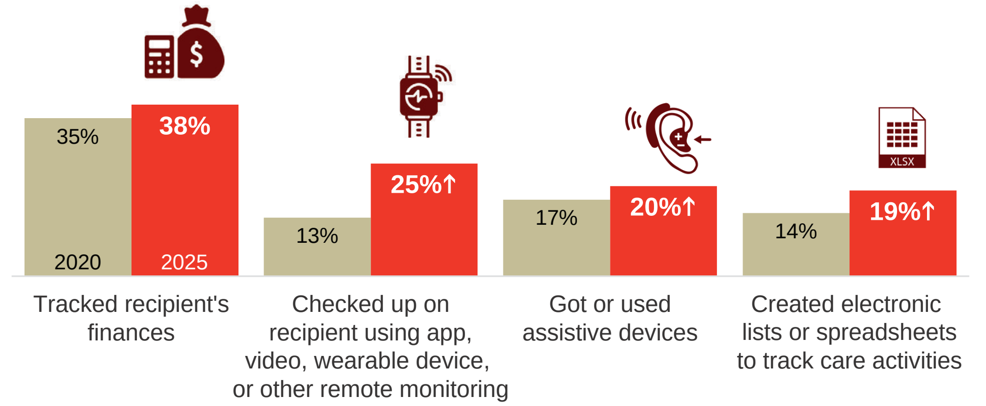
Use of technology to help with tasks

As the nature and complexity of caregiving evolve, family caregivers are increasingly turning to technology solutions to help manage evolving care demands. Thirty-nine percent of caregivers use digital tools to manage care recipients' finances. Even more striking is the rapid adoption of remote monitoring technologies such as apps, video platforms, wearables, and other monitoring systems. This usage has nearly doubled since 2020, with a quarter of caregivers now using these tools to check on care recipients from a distance (25 percent, up from 13 percent in 2020; see figure 25). Four in 10 family caregivers now report using technology or software to track their recipient's personal health records (41 percent, up from 30 percent in 2020), a figure that is higher among female caregivers (43 percent) compared with male caregivers (38 percent).

This technological integration extends to other aspects of caregiving as well. One in five caregivers use assistive devices to support their recipient's independence (20 percent), whereas a similar proportion uses electronic task lists and schedules for care management (19 percent). Younger caregivers, compared with caregivers over 50, more readily embrace technology solutions like remote monitoring (30 percent vs. 22 percent) and digital organizational tools like electronic lists or spreadsheets (22 percent vs. 17 percent).

Among all caregivers, increasing use of technology suggests a shift in caregiving practices, possibly accelerated by the pandemic, the expanding marketplace of digital caregiving solutions, and the aging of digital natives.

Figure 25. Software and Monitoring Solutions



M11. In your experience as a caregiver for your [relation], have you ever done the following things using technology or software?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Respondents may select more than one response; results add to greater than 100 percent.*

Overall, family caregivers report helping with a variety of tasks across a wide spectrum of intensity and difficulty. As caregiving continues to shift in scope, intensity, and complexity–driven by demographic, technological, and health care changes–understanding caregivers' role is essential. Only by recognizing the full picture of caregiving can we begin to provide them with the support they need.

F. Working while caregiving

Key Takeaways

- ✓ Seventy percent of working-age caregivers are employed while also providing care.
- ✓ Balancing paid work and care can be a challenge; half of working family caregivers report going in late, leaving early, or taking time off from work to provide care.
- ✓ Working caregivers more often report feeling alone and facing financial difficulty than nonworking caregivers.
- ✓ Caregivers' access to benefits that might help them balance their responsibilities at work and home is increasing, but access to workplace benefits is higher among salaried workers.

Navigating the dual responsibilities of paid employment and caregiving presents significant challenges for millions of Americans. The intersection of these two demanding roles often requires careful balancing of time, energy, and resources, with implications for both caregivers' economic security and their ability to provide quality care.

This section offers insight into how caregivers manage employment alongside their caregiving duties and the workplace supports available to them. Understanding these realities is essential for developing effective workplace policies and broader social supports that recognize the vital contributions of caregivers while preserving their ability to remain in the workforce.

Seventy percent of working-age caregivers, ages 18 to 64, worked while also caregiving, as shown in figure 26. A small share of caregivers ages 65 and older also engaged in paid employment, bringing the total share of all working caregivers to 60 percent.[8] The proportion of all family caregivers who work is higher among African American/Black family caregivers (66 percent) compared with all family caregivers (57 percent) and among LGBTQ+ caregivers (66 percent) compared with non-LGBTQ+ family caregivers (59 percent). More employed caregivers are paid hourly (53 percent) than salaried (40 percent), in line with the type of employment family caregivers reported in 2020. Rural caregivers less often work full time. Rural caregivers are less often salaried workers (32 percent compared with 39 percent of urban caregivers and 44 percent of suburban caregivers). Male family caregivers more frequently work while also providing care (48 percent compared with

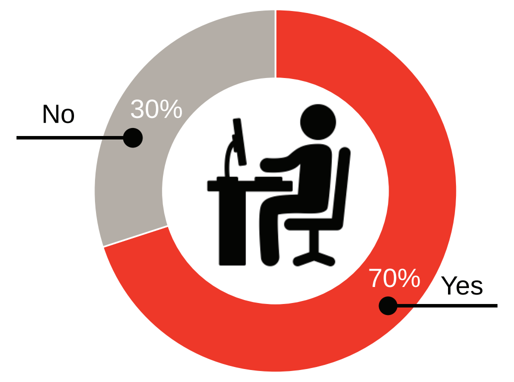
> ***"They needed more time than what I had and I couldn't take any more time off of work…I was working 60 hours a week and coming home and doing everything too… to lose that income, it was a big hit."***
>
> ***—Marci, Kansas***
> ***Caregiver to her mother and her grandson***
> ***Had to leave her job to provide care***

---

[8] Calculated as the share of caregivers in paid employment out of all working-age caregivers (ages 18 to 64). The 2020 report calculated the share of working caregivers out of all caregivers in the survey; for 2025, 60 percent of all caregivers are employed.

40 percent), and they more often are salaried (47 percent compared with 38 percent). More female family caregivers who work are hourly employees (55 percent compared with 47 percent of male family caregivers).

Figure 26. Working while Caregiving

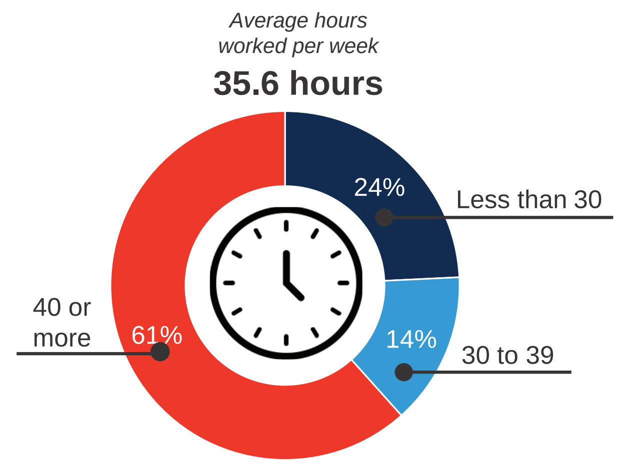


Q32A. Are/Were you currently employed?

Q33. Were you employed at any time in the last year while you were also helping your [relation]?

2025 Base: Caregivers Age 18–64 of Recipients Age 18+ (*n* = 5,074)

Figure 27. Hours Worked among Employed Caregivers



N13. About how many hours a week, on average, do you work?/ When you were last working and helping your [relation], about how many hours a week, on average, did you work?

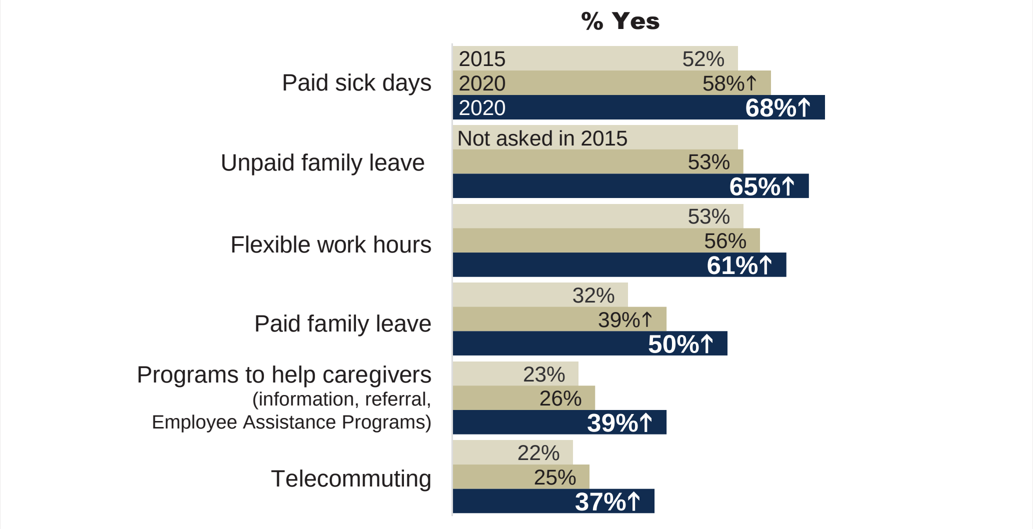
2025 Base: Working Caregivers of Recipient Age 18+ (*n* = 2,463)

Working family caregivers take on many of the same caregiving tasks as nonworking caregivers, with some slight differences. Working caregivers are less likely to help with medical and nursing tasks (50 percent) than family caregivers who do not work (61 percent). However, working family caregivers do more coordination with health care providers (HCPs), such as communicating with HCPs (67 percent compared with 58 percent of nonworking family caregivers) or advocating for their recipient with HCPs (66 percent compared with 48 percent of nonworking family caregivers)–tasks that often must be done during traditional work hours.

Access to caregiver-friendly benefits

Both the public and private sectors recognize the needs of family caregivers. Support for employed family caregivers has evolved significantly in recent years, with 13 states and the District of Columbia offering paid family leave programs. The COVID-19 pandemic (which occurred after data collection for the 2020 study and became endemic before the 2025 data collection period) also spurred employers to offer flexible work hours and teleworking or remote work, benefits most caregivers report as being helpful to them (Pabilonia and Redmond 2024; Cobbe et al. 2024). Access to caregiver-friendly work benefits is increasing, with every benefit more commonly reported by working family caregivers in 2025 than in 2020.

Figure 28. Workplace Benefits for Caregivers



N16. For employees at your work in a similar role or job as yours, which of the following does your employer offer? / At the time when you were last working and providing care for your [relation], for employees at your work in a similar role or job as yours, which of the following did your employer offer?

2015 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (*n* = 587)
2020 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (*n* = 707)
2025 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (*n* = 2,231)

Note: *Respondents may select more than one response; results add to greater than 100 percent.*

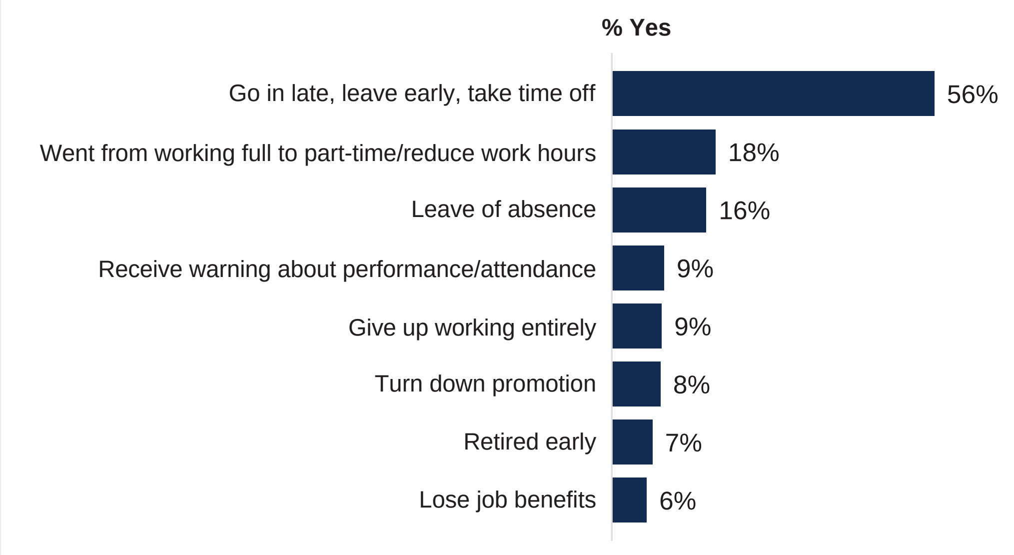
However, access to these benefits is not distributed equally to all workers. A greater share of salaried, working family caregivers has access to all six caregiver-friendly workplace benefits measured in this study than hourly earning caregivers. The starkest differences in access are for telecommuting options (58 percent salaried compared with 23 percent hourly); paid family leave (60 percent salaried compared with 35 percent hourly); paid sick leave (78 percent salaried compared with 55 percent hourly); and information, referrals, counseling, or an employee assistance program (43 percent salaried compared with 27 percent hourly).

Caregivers may not feel comfortable telling their workplace about their caregiving role, which could be a barrier to accessing benefits. Among employed caregivers who are not self-employed, about half report that their supervisor at work is aware of their caregiving responsibility (49 percent). Rural caregivers more often say their supervisor is aware of their caregiving responsibilities (56 percent compared with 49 percent of urban caregivers and 47 percent of suburban caregivers).

Work impacts as a result of caregiving

Although caregiver-friendly workplace benefits are more common, they do not fully meet the needs of family caregivers, as many working caregivers report work impacts. Going in late, leaving early, or taking time off to provide care is the most common work impact, reported by nearly 5 in 10 caregivers (see figure 29).

Figure 29. Work Impacts as a Result of Caregiving



Q34. As a result of caregiving, did you ever experience any of these things at work?

2025 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (*n* = 2,463)

Note: *Respondents may select more than one response; results add to greater than 100 percent.*

More working family caregivers report feeling alone (25 percent) compared with their nonworking counterparts (21 percent), and they experience a variety of financial impacts as a result of caregiving compared with nonworking family caregivers. They report taking on more debt (22 percent compared with 17 percent), using up short-term savings (31 percent compared with 20 percent), leaving bills unpaid or paying them late (19 percent compared with 17 percent), using up long-term savings (17 percent compared with 13 percent), and moving to a less expensive home (9 percent compared with 6 percent). Among working family caregivers, just 10 percent report feeling that their responsibilities as a caregiver led to them being penalized or discriminated against at work.[9]

> ***"I had to end my career as a physician to care for my mother."***
>
> ***—Kaoru, Kansas***
> ***Caregiver to her mother***

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[9] As of December 2024, seven states have expanded statewide employment antidiscrimination laws to include family or caregiving responsibilities as protected classifications. See S. Reinhard et al., "Innovation and Opportunity: A State Scorecard on Long-Term Services and Supports for Older Adults, People With Physical Disabilities, and Family Caregivers, 2023 Edition," Long-Term Services and Supports State Scorecard (AARP, 2023), for more details on these policies.

G. Financial situation of family caregivers

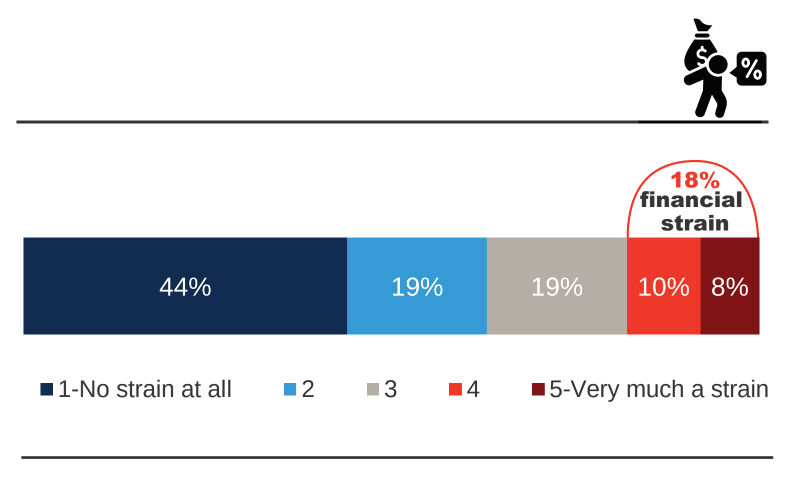
Key Takeaways

- ✓ About half of family caregivers experience at least one negative financial impact due to their care responsibilities.
- ✓ Common negative financial impacts include stopping or using up savings, taking on more debt, and leaving bills unpaid or paying late.
- ✓ Some groups of caregivers disproportionately experience negative financial impacts. These include African American/Black, Hispanic/Latino, lower-income, and younger caregivers.

Financial strain

Family caregiving can result in substantial short-term and long-term financial consequences. About one in five family caregivers report experiencing high financial strain as a result of providing care (18 percent rating 4 or 5 on a 5-point scale; see figure 30). More women than men report caregiving is a financial strain (19 percent vs. 16 percent).

Figure 30. Financial Strain of Caregiving



Q37. How much of a financial strain would you say that caring for your [relation] is/was for you?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

> ***"I had to give up a prosperous career and took jobs to work around their schedule. I took a 90% pay cut and lived out of my savings, which has been depleted."***
>
> ***—Maylia, California***
> ***Caregiver to her father (previously cared for her mother)***

Negative financial impacts

Family caregivers can face some changes to their finances. About half of family caregivers have experienced at least one negative financial impact as a result of caregiving (47 percent), and family caregivers report experiencing about two negative financial impacts (1.8) on average.

A little over a third of family caregivers have stopped saving, 24 percent have used up their personal short-term savings, and 13 percent have used long-term savings (like retirement or education accounts) to pay for other things. Other caregivers report taking on more debt (23 percent) while caring for a family member or friend. Seventeen percent have borrowed money from friends or family. Twenty percent of caregivers have left bills unpaid or have paid them late, whereas 14 percent have been unable to afford basic expenses like food (up from 11 percent in 2020).

Finally, some caregivers attempt to bridge the financial gap through paid work. Eleven percent had to start working, work more, or find a second job due to caregiving's financial impacts, whereas 9 percent put off when they planned to retire or decided to never retire.

Table 5. Negative Financial Impacts as a Result of Caregiving, 2020–2025

		2020 (*n* = 1,392)	2025 (*n* = 6,549)
Saving	Stopped saving	28%	31%
	Used up personal short-term savings	22%	24%
	Used up long-term savings, like retirement or education, to pay for other things	12%	13%
Debt	Took on more debt	23%	23%
	Borrowed money from family or friends	15%	17%
	Missed or was late paying student loan	5%	6%
	Filed for bankruptcy	3%	3%
Bills or Expenses	Left bills unpaid or paid late	19%	20%
	Was unable to afford basic expenses like food	11%	14%↑
Work	Had to start working, work more, or find a second job	11%	11%
	Put off retirement or decided to never retire	9%	9%
Home	Moved to a less expensive home, apartment, or other living arrangement	7%	8%
	Was evicted or had home foreclosed	2%	3%

Note: *↑↓ Result is significantly higher or lower than in prior wave.*

Some groups of caregivers consistently experience more of these negative financial impacts at greater rates than others. African American/Black and Hispanic/Latino caregivers more often experience most of these impacts compared with the total population of family caregivers (see table 6).

Table 6. Negative Financial Impacts by Race/Ethnicity of Caregiver

		Total (*n* = 6,549)	Non-Hispanic white (*n* = 801)	African American (*n* = 197)	Hispanic (*n* = 199)	AANHPI (*n* = 205)
		A	B	C	D	E
Saving	Stopped saving	31%	28%	36%↑	40%↑	19%
	Used up personal short-term savings	24%	21%	29%↑	31%↑	17%
	Used up long-term savings, like retirement or education, to pay for other things	13%	11%	16%	18%↑	10%
Debt	Took on more debt	23%	19%	27%↑	31%↑	17%
	Borrowed money from family or friends	17%	13%	24%↑	24%↑	6%
	Missed or was late paying student loan	6%	13%	24%↑	24%↑	6%
	Filed for bankruptcy	3%	2%	4%	6%↑	1%
Bills or Expenses	Left bills unpaid or paid late	20%	17%	29%↑	24%↑	7%
	Was unable to afford basic expenses like food	14%	11%	18%↑	20%↑	5%
Work	Had to start working, work more, or find a second job	11%	8%	17%↑	16%↑	11%
	Put off retirement or decided to never retire	9%	8%	10%	11%	8%
Home	Moved to a less expensive home, apartment, or other living arrangement	8%	6%	14%↑	10%	5%
	Was evicted or had home foreclosed	3%	2%	6%↑	4%	1%

Note: ↑ *indicates a figure is significantly higher than the total population of caregivers.*

Lower-income caregivers, those with less than $50,000 in household income, are more often hit by these negative financial impacts. Lower-income caregivers are more likely to be unable to afford basic expenses (28 percent compared with 8 percent). Notably, lower-income caregivers more often report disruptions to savings (45 percent stopped saving, 35 percent used up personal short-term savings, and 19 percent used long-term savings). These caregivers are already less likely to have sufficient savings to weather financial storms.

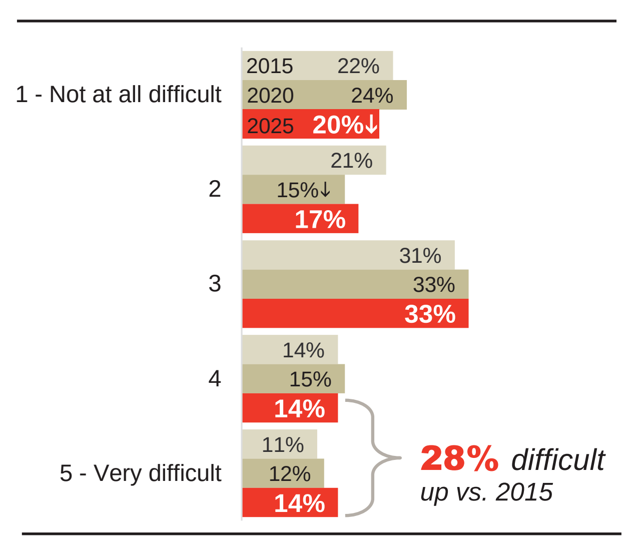
More caregivers under age 50 experience many of these negative impacts than older caregivers do. Impacts like taking on more debt (27 percent compared with 19 percent), stopping savings (35 percent compared with 28 percent), or using up personal savings (30 percent compared with 20 percent) can set back a young family caregiver's future financial security. Taking on more debt (27 percent compared with 19 percent), paying bills late or leaving them unpaid (26 percent compared with 15 percent), and experiencing an eviction or foreclosure (5 percent compared with 1 percent) can negatively affect their credit scores.

Compared with non-LGBTQ+ caregivers, LGBTQ+ caregivers more often experience several negative financial impacts, especially around saving (44 percent have stopped saving compared with 29 percent) and not being able to afford basic expenses (27 percent compared with 12 percent).

Affordability of services

Since 2015, more family caregivers have had difficulty finding affordable services for their care recipient, with 28 percent having difficulty finding services like delivered meals, transportation, or in-home health services (see figure 31). Caregivers living in rural areas more often say it is very difficult to get affordable services in their local area or community (34 percent), compared with urban (27 percent) and suburban (26 percent) caregivers.

Figure 31. Affordability of Services



N19. How difficult is/was it to get affordable services in your [relation]'s local area or community that could help/would have helped you care for your [relation], like delivered meals, transportation, or in-home health services?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,594,)
2020 Base: Caregivers of Recipient Age 18+ (*n* = 1,392)
Base: Caregivers of Recipient Age 18+ (*n* = 1,248)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

> ***"We [caregivers] are under-rated, and I think the world has no idea what we do. Being a caregiver is the hardest role. It's nothing like babysitting. You are playing three or more roles: taking care of your family members, the house, yourself, your job…"***
>
> ***—Maylia, California***
> ***Caregiver to her father (previously cared for her mother)***

H. Well-being of family caregivers

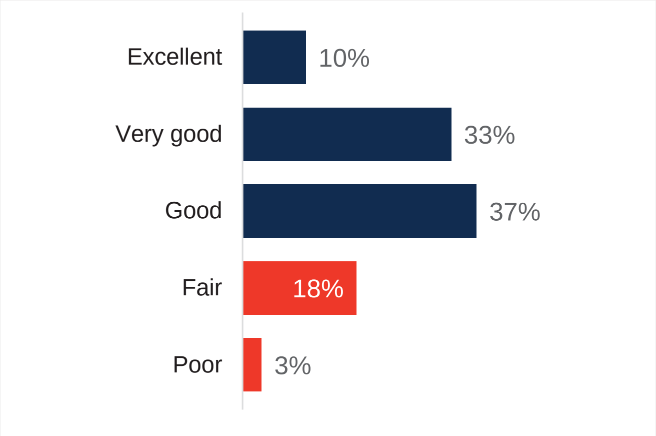
Key Takeaways

- ✓ Twenty percent of caregivers report their health as fair or poor, and caregivers who live with their care recipient report poorer health than other caregivers.
- ✓ Nearly 25 percent of caregivers indicate difficulty in caring for themselves because of caregiving.
- ✓ More female than male caregivers report poor health and physical and emotional strain.
- ✓ Feelings of isolation are common for caregivers. More caregivers now report feeling alone (nearly one in four) compared with those in 2020.
- ✓ For half of caregivers, caregiving provides a sense of purpose or meaning in life.

Caregiver health

Caregivers face the challenge of taking care of their own health as they focus on their care recipient's well-being. In 2025, one in five caregivers report fair or poor health, similar to findings from 2020. Caregivers who live with their care recipient more often report fair or poor health (26 percent).

Figure 32. Caregiver Self-Rated Health



D1. How would you describe your own health? / When you were last caregiving, was your health …?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

This year's survey included the CDC Healthy Days measure, a series of four questions assessing perceived physical and mental health of the caregiver over the past 30 days (Moriarty et al. 2003). On average, caregivers report having four days per month where poor mental or physical health kept them from doing their usual activities (see figure 33), which can make completing their caregiving duties difficult. Nearly 20 percent of caregivers report having a disability that prevented their full participation in work, school, housework, or other activities.

Some caregivers report more poor health days than others. Caregivers under age 50 and those who live with their care recipient report more poor mental health days than the total population of caregivers. LGBTQ+ caregivers and lower-income caregivers are more likely to report their health as fair or poor (28 percent and 32 percent, respectively).

Figure 33. CDC Healthy Days Measure

H1. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

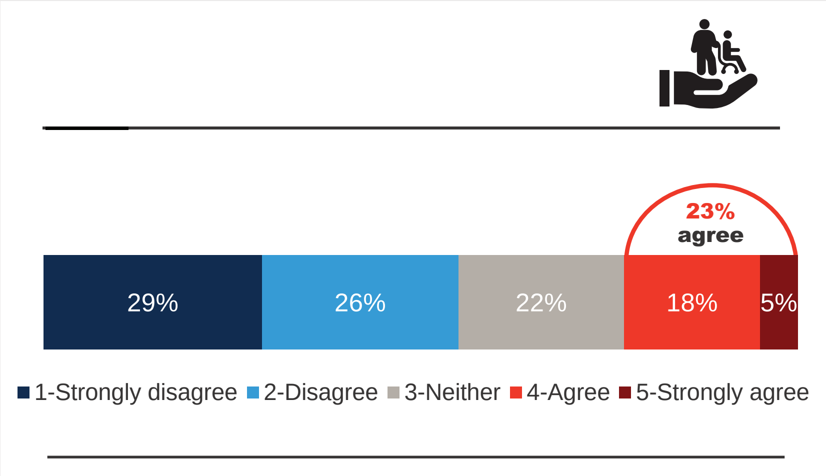
H2. Now thinking about your mental health, which includes stress, depression, and problems with emotions,

H3. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Twenty-three percent of caregivers report difficulty in caring for their own health as a result of their caregiving (see figure 34), a figure that is higher among female caregivers (26 percent), LGBTQ+ caregivers (33 percent), Hispanic/Latino caregivers (27 percent), and lower-income caregivers (31 percent).

Figure 34. Difficulty Caring for Own Health

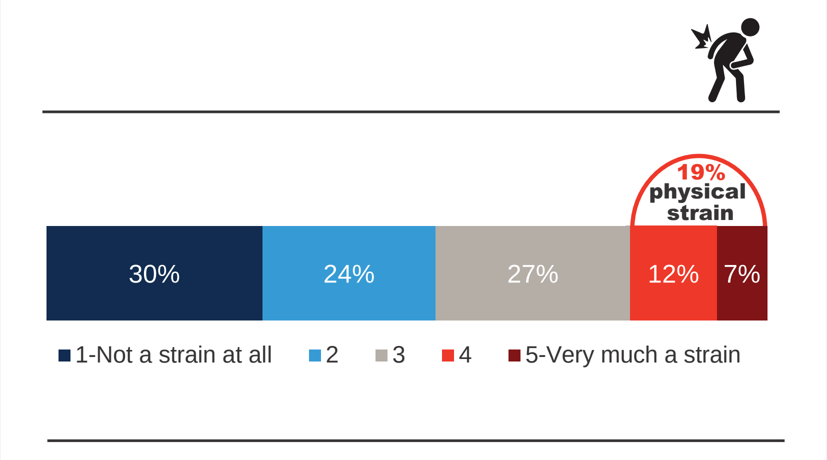


M5_2. How much do you agree or disagree with each statement below about being a caregiver for your [relation]? "I find/found it difficult to take care of my own health."

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Figure 35. Physical Strain of Caregiving



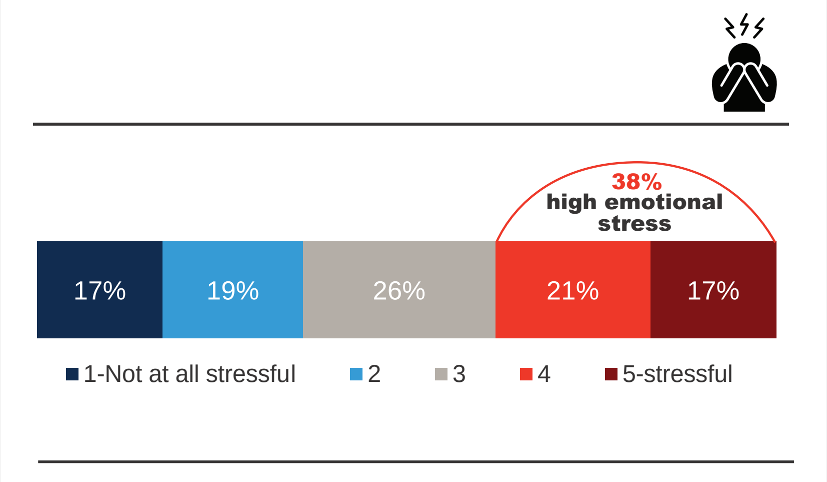
Q35. How much of a physical strain would you say that caring for your [relation] is/was for you?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Caregiving can affect both physical and emotional health. Nearly two-thirds of caregivers report moderate or high emotional stress, and 45 percent of caregivers experience moderate or high physical strain. More women than men report physical strain (21 percent and 16 percent, respectively) and emotional strain (41 percent and 33 percent, respectively). Hispanic/Latino caregivers more often report physical strain (28 percent) than other caregivers (19 percent).

Figure 36. Emotional Stress of Caregiving



Q36. How emotionally stressful would you say that caring for your [relation] is/was for you?

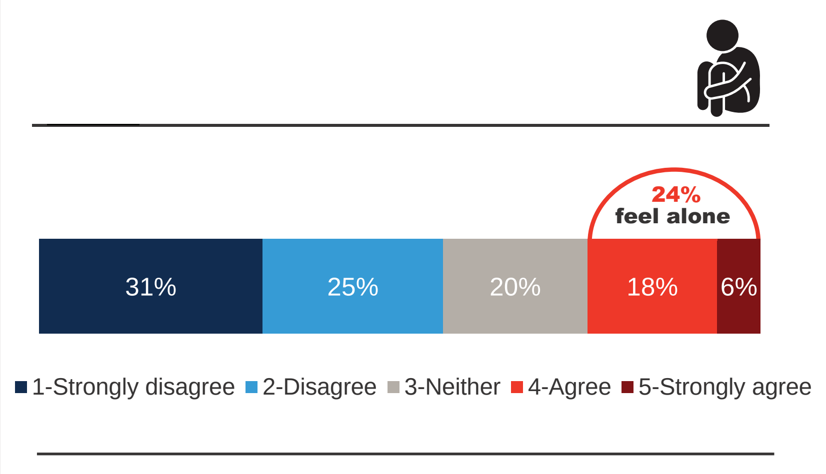
2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

> ***"I miss my own home, my grandchildren and my financial freedom, but am fully willing to do this for my parents so they can enjoy their last years."***
>
> ***—Cindy, California***
> ***Caregiver to her parents***

In addition to emotional strain, nearly one in four caregivers (24 percent) report feeling alone, a slight increase from 2020 (21 percent). More female (26 percent compared with 20 percent of male) and LGBTQ+ caregivers (32 percent compared with 23 percent of non-LGBTQ) report feeling alone compared with other caregivers.

Figure 37. Feeling Alone



M5_3. How much do you agree or disagree with each statement below about being a caregiver for your [relation]? “I feel/felt alone”

2025 Base: Caregivers of Recipient Age 18+ (*n* = 9,549)

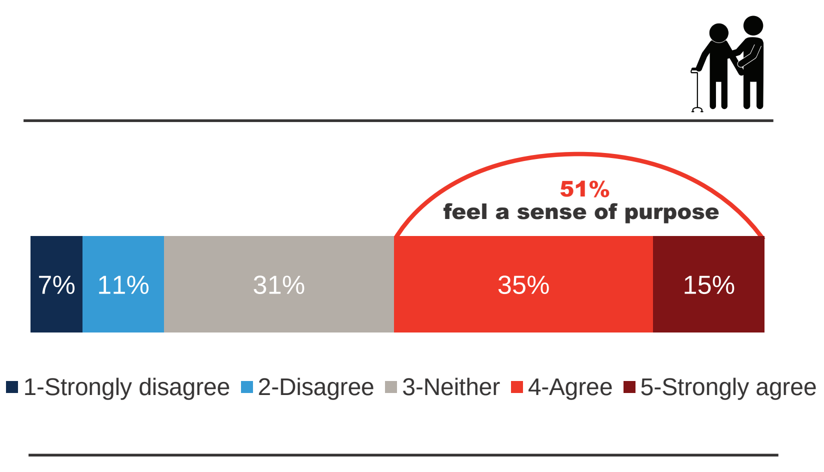
Note: *Results are rounded and don’t know/refused responses are not shown; results may not add to 100 percent.*

Sense of purpose

For caregivers, positive emotions often coexist with feelings of isolation, stress, or strain. Half of caregivers report that their role as a caregiver gives them a sense of purpose or meaning in life (51 percent; see figure 38).

Compared with the total population of caregivers, Hispanic/Latino caregivers are more likely to agree that their role gives them a sense of purpose (58 percent), as are lower-income caregivers (56 percent), those who provide more hours of care (57 percent), and those caring for a nonrelative (63 percent).

Figure 38. Sense of Purpose



M5_1. How much do you agree or disagree with each statement below about being a caregiver for your [relation]? "My role as a caregiver gives/gave me a sense of purpose or meaning in my life"

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Note: *Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

Choice in caregiving

Previous *Caregiving in the US* research indicates that the choice—or lack thereof—in becoming a family caregiver significantly affects well-being. This finding remains true in 2025. Over half of family caregivers (56 percent) felt they had no choice in taking on their caregiving role, with profound consequences for their health and outlook. African American/Black family caregivers are the most likely to say they had a choice in becoming a caregiver (52 percent).

The physical and mental health disparities are quantifiable: Caregivers who felt they had no choice have more poor physical health days (5.8 days on average vs. 4.6 days), nearly twice as many poor mental health days (8 vs. 4.5), and more days when health issues disrupted their normal activities (4.6 vs. 3.2).

The psychological impact is equally striking: Only 42 percent of involuntary caregivers find purpose in their role versus 62 percent of those who felt they had a choice.

Support networks also differ significantly. Caregivers who felt they did not have a choice less often have unpaid help (51 percent vs. 56 percent), and nearly three times more experience feelings of isolation (34 percent vs. 12 percent).

I. Policy and program support for family caregivers

Key Takeaways

- ✓ Caregivers across different income levels show varied preferences for financial support policies—higher-income caregivers favor tax credits (71 percent), whereas lower-income caregivers prioritize direct payment programs (71 percent).
- ✓ Caregivers value support beyond finances, such as respite services (39 percent), professional assessment of their needs (33 percent), and emotional support (30 percent), alongside practical assistance with care recipient safety (27 percent) and paperwork management (26 percent).
- ✓ Although 47 percent of caregivers now have plans for their own futures, 38 percent report no comprehensive plans exist for managing their care recipients' affairs.

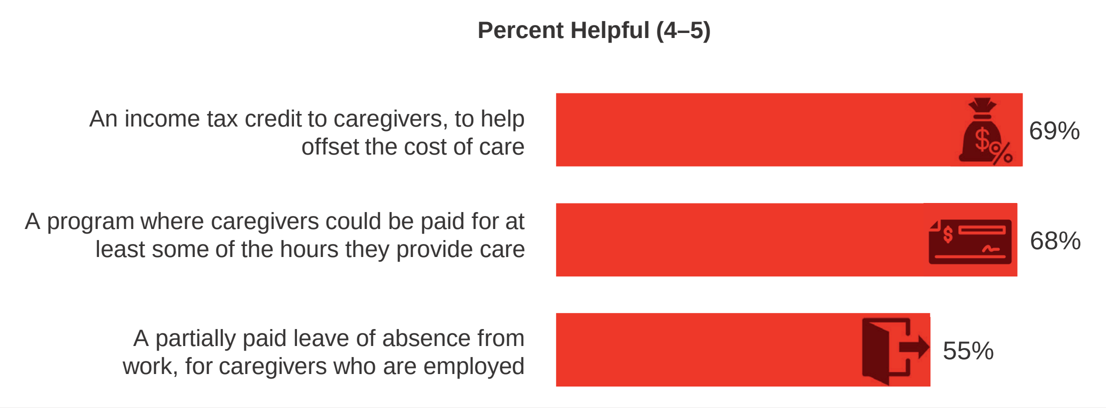
Family caregivers provide billions of hours of unpaid care annually while facing substantial personal and financial challenges. As caregiving demands grow with an aging population, targeted policy solutions become more essential. This section examines caregivers' preferences for financial support, programs, and planning tools to inform comprehensive policy development.

Financial support policies

The economic impact of caregiving extends far beyond immediate out-of-pocket expenses. Many caregivers reduce work hours, pass up promotions, or leave the workforce entirely, resulting in lost wages, reduced retirement savings, and diminished Social Security benefits. These career sacrifices can amount to hundreds of thousands of dollars in lifetime earnings losses. To address these substantial financial challenges, caregivers seek policy solutions that provide meaningful relief.

Most family caregivers think tax credits, paid leave, and programs that provide pay for caregiving would be financially helpful, consistent with sentiments toward these same policies in 2020. This strong support reflects the significant financial challenge that caregiving places on families across America. According to the data, 69 percent would find an income tax credit helpful, 68 percent consider caregiver payment programs helpful, and 55 percent view partially paid leaves of absence as helpful.

Figure 39. Reaction to Financial Support Policies



M9. Below are some ways that people are proposing to help caregivers financially. How helpful would you find/have found each?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

> ***“They need to make it clear what people are entitled to. After 7 years of paying everything for my mother…this year I was told she could get assistance. I did not know. I bet there are plenty of people like myself out there that have no idea.”***
>
> ***—Ana, Florida***
> ***Caregiver to her mother***

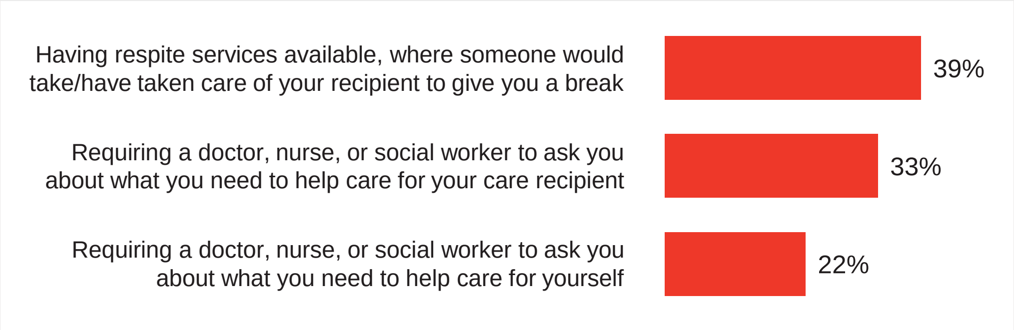
Family caregivers across income levels express different preferences for financial support mechanisms, reflecting their unique economic circumstances. Those with household incomes below $50,000 are more likely to find direct payment programs valuable (71 percent compared with 67 percent of higher-income caregivers). Meanwhile, caregivers earning $50,000 or more tend to prefer income tax credits (71 percent vs. 64 percent of lower-income caregivers). These divergent preferences underscore the importance of developing diverse financial support policies that address the varied needs of family caregivers.

Caregiver support and training policies

Family caregivers express clear preferences regarding supportive programs and services that address their multifaceted needs. The highest demand is for respite services, with 39 percent valuing programs that provide temporary relief and breaks from caregiving. Additionally, one-third of caregivers (33 percent) want policies requiring health care professionals to assess their needs as caregivers to better support their care recipients.

Caregivers increasingly recognize their own well-being as essential, with 3 in 10 seeking more help or information to manage their emotional or physical stress. Meanwhile, 22 percent would find conversations with health care professionals about addressing their self-care needs beneficial. Practical support remains important as well, with 27 percent of caregivers seeking assistance in keeping care recipients safe at home, whereas 26 percent need help managing paperwork or navigating eligibility requirements for services. These findings highlight the importance of developing comprehensive support systems that recognize caregivers not only as providers of care but as individuals with distinct needs requiring attention and resources to sustain that care.

Figure 40. Reaction to Caregiver Support Policies



N20. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would be / have been helpful to you?

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

> ***"The hardest part for me is you really do become a tech in a way. You have to do things like the port, and I deal with things like the dosage of the medication, and it wasn't easy."***
>
> ***—Nancy, New Jersey***
> ***Caregiver to her husband, who has a stem cell transplant***

Figure 41. Training and Information Needs of Caregivers

Q48. Which of the following topics do you feel you need/needed more help or information? Select all that apply.

2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

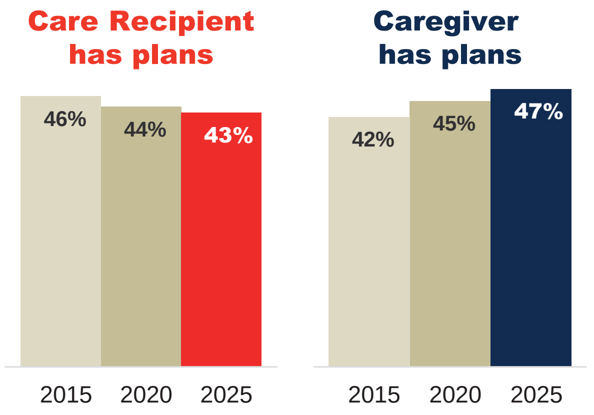
Note: *Respondents may select more than one response; results add to greater than 100 percent.*

Long-range planning

The implementation of comprehensive care plans represents a critical component in supporting family caregivers, yet significant gaps remain. Despite their importance for managing financial matters, health care decisions, and living arrangements, 38 percent of caregivers report that no established plans exist, whereas an additional 19 percent are uncertain whether such plans are in place. Encouragingly, progress has been made since 2015, with 47 percent of family caregivers now reporting they have implemented long-range plans for their own futures.

This growing emphasis on future planning could reflect an increasing awareness of the need for structured support systems that address both immediate caregiving responsibilities and long-term personal well-being through clearly defined instructions for financial management, health care choices, and residential considerations.

Figure 42. Future Care Plans



N22. Do you have your own plans for your own future care, such as handling financial matters, health care decisions, or living arrangements?

N21. Does/did your [relation] have plans in place for his/her future care, such as instructions for handling financial matters, health care decisions, or living arrangements?

2015 Base: Caregivers of Recipient Age 18+ (*n* = 1,248)
2020 Base: Caregivers of Recipient Age 18+ (*n* = 1,392)
2025 Base: Caregivers of Recipient Age 18+ (*n* = 6,549)

Conclusion

Over the past decade, family caregiving has become an increasingly prevalent experience. In 2015, 18 percent of all American adults (44 million) were caring for an adult or child with a disability or serious medical condition. By 2025, those numbers had risen to 24 percent of all Americans, or 63 million adults. While there are inherent similarities across caregiving experiences, each situation is also unique.

> ***“Caring for your aging parents is not something easily prepared for, but it is a relief to know that there are ways doctors can be of more help. The patients must come first, and by educating caregivers by giving us more information on how to continue putting them first, we can work together both meaningfully and more successfully.”***
>
> ***—Rachel, New York***
> ***Caregiver to her mother, who has dementia***

Caregivers come from all backgrounds. Although the average caregiver age is 51, just over 40 percent are between ages 18 and 50. Most are caring for a relative facing multiple, complex health conditions that demand a wide range of skills and adaptability on the caregiver's part. Caregivers help with medical and nursing tasks, ADLs, management of their care recipient's finances, coordination of health care and social services, and countless other functions.

The intensity and duration of caregiving are increasing. Thirty percent of caregivers have been caregiving for five years or more, and more caregivers than ever are assisting with ADLs. More than half of caregivers balance these extensive responsibilities with employment and often face work disruptions because of care demands. Financial strain is common, especially among African American/Black, Hispanic/Latino, lower-income, and younger caregivers. Additionally, caregiving takes a toll on personal health: 20 percent report fair or poor health, and nearly a quarter struggle to care for themselves.

As caregiving continues to shift in scope, intensity, and complexity—driven by demographic, technological, and health care changes—it is crucial to understand the vital role of caregivers in our health and social systems. Only by recognizing the full picture of caregivers, and the range of roles they perform, can we begin to ensure the support they need.

Appendix A. Questionnaires

This appendix provides the full annotate English- and Spanish-language versions of the survey fielded for *Caregiving in the US 2025*.

A. English Language Version

Caregiving in the US 2025 Survey

Prefer_Lang [S]
¿Prefiere llenar sus encuestas en español o en inglés?
Do you prefer to do surveys in Spanish or English?

1. Español
2. English

Informed Consent

You are invited to participate in a research study about family caregivers across the United States. The goal of this research study is to understand your experiences with caregiving.

This study is being conducted by the National Alliance for Caregiving (NAC) and AARP.

Please note: You must be 18 or older to participate in this study.

Participation in this study is voluntary. Your responses remain confidential and will be used for research purposes only. This survey will take approximately 20 minutes. The interview includes questions about your caregiving characteristics such as general information about you, the person you provide care for, your caregiving situation, caregiving activities, and well-being.

Participating in this study may not benefit you directly, but it will help us inform policy, practice, and research recommendations. You may find some questions to be sensitive, but we expect that this would not be different from the kinds of things you discuss with family or friends. You may skip any questions you don’t want to answer, and you may withdraw from the interview at any time.

The information you will share with us if you participate in this study will be kept completely confidential to the full extent of the law.

The study staff understands that the security of online transmissions is not guaranteed due to the risk of interception by third parties, or the possibility of monitoring software installed on research participants’ electronic devices. Your answers will be combined with everyone else’s and shared with NAC/AARP. We will not share your name or personal identifiable information with NAC/AARP, without your consent. Your answers could be used for future research studies or distributed to another investigator for future research studies without additional informed consent. If that happens, all identifiable private information will be removed before your answers are shared. Your identity will not be known in the results of the study. Data will not be analyzed or reported in such a way that it will be possible to identify any individual participant. This study is for research purposes only.

No individually identifiable information will be collected. Your responses to questions will be recorded and data will be stored electronically with Ipsos.

Deidentified data is retained by NAC and AARP and archived with the Roper Center (Ipoll) at Cornell University.

If you have any questions about this study, please contact Dr. Fawn Cothran, 202-918-1021, fawn@caregiving.org or Dr. George Kueppers, 202-918-1021, george@caregiving.org. If you have any questions or complaints, you may contact a person not on the research team at the Biomedical Research Alliance of New York Institutional Review Board at (516) 318-6877 or at www.branyirb.com/concerns-about-research.

Do you agree to participate in this study?

[Programming: If yes, continue; if no, stop]

[ALL RESPONDENTS]
[SP; PROMPT TWICE]

SC1a. At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?

This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult does not need to live with you.

Yes, I have provided care to an adult in the last year 1
Someone else in my household has provided care (not me) 2
No...3

SC1d. At any time in the last 12 months, has anyone in your household gotten paid to provide care to a relative or friend 18 years or older to help them take care of themselves?

This may include helping with personal needs or household chores. It might be managing a person’s finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.

Yes, I have provided paid care to an adult in the last year...................... 1
Someone else in my household has provided paid care (not me)............... 2
No.. 3

[Programmer: please create hover pop-up over words “paid care”: Paid care includes payments to caregivers through self-directed programs under Medicaid, Veteran’s Affairs, or other state programs. Paid care does not include those employed full-time as direct care workers, such as home health aides or assistants, in a home or community-based settings or facility setting.]

[SP; PROMPT ONCE]
[IF SC1A=1 OR 2]
SC1c. Were any of the adults that **[if SC1a=1, insert:** you / **IF SC1a=2, insert:** someone in your household**]** cared for age 50 or older?

Yes 1
No..2

[ALL RESPONDENTS]
[SP; PROMPT TWICE]
SC1b. In the last 12 months, has anyone in your household provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability?

This kind of unpaid care is <u>more than the normal care</u> required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.

Yes, I have provided care to a child in the last year 1
Someone else in my household has provided care (not me) 2
No..3

[ALL RESPONDENTS]
[DISPLAY]
This is an important study and to be sure we talk to a variety of people, we need to ask you some basic questions about you and your household.

[ALL RESPONDENTS]
[NUMBERBOX, RANGE 1-30; PROMPT ONCE]
SC6. How many people, including children, live in your household?

Please include yourself.

____ **[RANGE 1 - 30]**

[NUMBER BOX, RANGE 0-97; PROMPT ONCE]
2. **[IF CGTYPEF=1 OR 2]:** How many adults did you care for in the past 12 months?

[IF CGTYPEF=3]: How many children under the age of 18 did you care for in the past 12 months, because that child or children had some sort of medical, behavioral, or other condition or disability?
___ **[RANGE 0-97]**

IF Q2=0 OR REFUSED, TERMINATE AND INSERT STANDARD CLOSE.

[IF Q2 GE 5]
[SP; PROMPT ONCE]

3. Were all of these **[IF CGTYPEF=1 or 2, INSERT:** adults / **IF CGTYPEF=3, INSERT:** children**]** together in an institutional or group setting, like a nursing home, senior center, daycare, group home, or school where you work or volunteer?

Yes	1
No	2

IF Q3=1 OR REFUSED, TERMINATE AND INSERT STANDARD CLOSE.

[IF Q2 GE 5]
[SP; PROMPT ONCE]

4. How many of the **[IF CGTYPEF=1 or 2, INSERT:** adults / **IF CGTYPEF=3, INSERT:** children**]** you helped care for had some sort of special need that was the reason for their care?

A special need could be an illness, injury, disability, or mental health problem.

All	1	**SKIP TO TEXT AFTER Q2B**
Some	2	
None	3	

IF Q4=3 OR REFUSED, TERMINATE AND INSERT STANDARD CLOSE.

[IF Q4=2]
[NUMBER BOX, RANGE 0-Q2 ANSWER; PROMPT ONCE]

2b. **[IF CGTYPEF=1 OR 2], SHOW:** How many adults with some sort of special need did you provide care for in the past 12 months?

[IF CGTYPEF=3], SHOW: How many children with some sort of special need did you provide care for in the past 12 months?

___ **[RANGE 0-Q2 ANSWER]**

IF Q2B=0 OR REFUSED, TERMINATE AND INSERT STANDARD CLOSE.

PROGRAMMING NOTE: DISPLAY EITHER DISPLAY_2 OR DISPLAY_3 ON SAME PAGE AS Q1.

[Q2=1 OR Q2B=1]
[DISPLAY_2]
Now, we would like to get some information about the **[IF CGTYPEF=1 or 2, INSERT:** adult / **IF CGTYPEF=3, INSERT:** child**]** for whom you provided care.

[IF Q2=2 THRU 97 OR Q2B=2 THRU 97]
[DISPLAY_3]
For the next set of questions, please think about the **[IF CGTYPEF=1 or 2, INSERT:** adult / **IF CGTYPEF=3, INSERT:** child**]** for whom you provided the <u>most</u> assistance in the past year.**]**

[IF CGTYPEF=1,2,3]
[SP; PROMPT TWICE]

1. Are you <u>currently</u> providing unpaid help to **[IF CGTYPEF=1 or 2, INSERT:** that adult relative or friend / **IF CGTYPEF=3, INSERT:** that child**]**, or was this something you did in the past 12 months and are no longer doing?

Currently	1
Past 12 months but not currently	2

[IF CGTYPEF=1,2,3]
[NUMBER BOX, 0-130]

5. How old **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** that **[IF CGTYPEF=1 or 2, INSERT:** adult / **IF CGTYPEF=3, INSERT:** child**] [IF Q1=2 OR REFUSED:** at the time you provided care]?

Your best estimate is fine. **IF CGTYPEF=3, SHOW:** *If the child is less than 1 year old, please enter '0'.*

___ years old **[RANGE 0 - 130]**

[IF CGTYPEF=1,2,3]
[SP; PROMPT TWICE]

9. And **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** the person you **[IF Q1=1, INSERT:** care / **IF Q1=2 OR REFUSED, INSERT:** cared**]** for…

Male	1
Female	2
Non-Binary	3

PROGRAMMING NOTE: USE GENDER NEUTRAL PRONOUNS THROUGHOUT IRRESPECTIVE OF ANSWER TO Q9 (1, 2, 3, OR REFUSED) "THEY/THEIRS/THEM".

PROGRAMMING NOTE FOR Q7, IF Q9=3 OR REFUSED, SHOW BOTH COLUMNS ON SAME SCREEN; ALSO, FOR Q9=REFUSED CASES: IF ANY OPTION FROM LEFT COLUMN SELECTED UNDER 'RELATIVE', RE-PUNCH Q9=1. IF ANY OPTION FROM RIGHT SIDE OF THE COLUMN OF Q7 SELECTED UNDER 'RELATIVE', RE-PUNCH Q9=2. IF ANY OPTION UNDER NON-RELATIVE IS SELECTED, KEEP Q9 PUNCHES AS REFUSED.

[IF CGTYPEF=1,2,3]
[SHOW Q7 AND GRID BELOW ON SAME SCREEN; IF Q9=REFUSED, SHOW ALL OPTIONS ON ONE SCREEN LISTED IN TWO COLUMNS; RESPONSE OPTIONS SHOULD ALWAYS DISPLAY AS SHOWN BELOW WITH CODE 22 AT BOTTOM]
[SP; SUPPRESS DEFAULT INSTRUCTIONS; PROMPT TWICE]

7. Who **[IF Q1=1, INSERT:** are you caring **/ IF Q1=2 OR REFUSED, INSERT:** did you care] for?

Please select one relationship.

[SHOW IF Q9=1]:		**[SHOW IF Q9=2]:**	
RELATIVE:		**RELATIVE:**	
Brother	2	Aunt	1
Brother-In-Law	3	Companion/Partner	4
Companion/Partner	4	Daughter	5
Father	6	Granddaughter	8
Father-In-Law	7	Grandmother	10
Grandfather	9	Grandmother-In-Law	11
Grandfather-In-Law	11	Mother	13
Grandson	12	Mother-In-Law	14
Husband	20	Niece	16
Nephew	15	Same-sex partner	30
Same-sex partner	30	Sister	17
Son	19	Sister-In-Law	18
Uncle	21	Wife	20
NON-RELATIVE:		**NON-RELATIVE:**	
Foster child	23	Foster child	23
Friend	24	Friend	24
Neighbor	26	Neighbor	26
Other (Specify) **[textbox]**	22	Other (Specify) **[textbox]**	22

PROGRAMMING NOTE: CREATE DOV_CODE THAT HOLDS Q7 RESPONSES. FOR DOV_CODE:

IF Q7=4 OR 30 [USE "partner**"]**
IF Q7=22 OR REFUSED [USE "care recipient**"]**
IF Q7=ANY OTHER RESPONSE NOT EQUAL TO THE ABOVE, INSERT THAT RESPONSE (FROM Q7)

FOR DOV_CODE, ALWAYS UN-CAPITALIZE FIRST LETTER OF INSERT (E.G., sister**), UNLESS OTHERWISE SPECIFIED.**

[IF CGTYPEF=1,2,3]
[SP]

11. Where **[IF Q1=1, INSERT:** does / **IF Q1=2 OR REFUSED, INSERT:** did**]** your **[DOV_CODE]** live [**IF Q1=2 OR REFUSED, INSERT:** at the time you provided care**]**?

In your household..........1 **[SKIP TO Q15]**
Within twenty minutes of your home..........2
Between twenty minutes and an hour from your home..........3
One to two hours from your home..........4
More than two hours away..........5

[IF Q11=2-5 OR REFUSED]
[SP]

13. Which of the following best describes where your **[DOV_CODE] [IF Q1=1, INSERT:** lives / **IF Q1=2 OR REFUSED, INSERT:** lived at the time you provided care**]**?

Their own home **[IF CGTYPEF=3:** (with parent or guardian)**]**..........1
Someone else's home..........2
IF CGTYPEF=1 or 2, SHOW: An independent living or retirement community..........3
IF CGTYPEF=1 or 2, SHOW: In an assisted living facility where some care may be provided..........4
A nursing care or long-term care facility..........5
IF CGTYPEF=3, SHOW: A group home..........10
IF CGTYPEF=3, SHOW: Foster care..........11
Or somewhere else? (Specify) **[TEXTBOX]**..........6

PROGRAMMING NOTE: IF (Q13=2 OR 4 OR 5 OR 10 OR 11) OR (CGTYPEF=3), SKIP TO Q15.

[IF (CGTYPEF=1 OR 2) AND (Q13=1 OR 3 OR 6 OR REFUSED)]
[SP]

14c. **[IF Q1=1, INSERT:** Does / **IF Q1=2 OR REFUSED, INSERT:** Did**]** your **[DOV_CODE]** live alone [**IF Q1=2 OR REFUSED, INSERT:** at the time you provided care**]**?

Yes..........1
No..........2

[IF CGTYPEF=1,2,3]
[SP]

15. **[IF Q1=1, INSERT:** Does / **IF Q1=2 OR REFUSED, INSERT:** Did**]** your **[DOV_CODE]** live in a rural area [**IF Q1=2 OR REFUSED, INSERT:** at the time you provided care**]**?

Yes	3
No	6

CHARACTERISTICS OF RECIPIENT

[IF CGTYPEF=1,2,3]
[GRID, SP ACROSS, DISPLAY IN ORDER AS SHOWN A-G]

17. **[IF Q1=1, INSERT:** Does / **IF Q1=2 OR REFUSED, INSERT:** Did**]** your **[DOV_CODE]** need care because of a…?

a. **SHORT-TERM PHYSICAL CONDITION**
b. **LONG-TERM PHYSICAL CONDITION**
c. **EMOTIONAL OR MENTAL HEALTH PROBLEM**
d. Developmental or intellectual disorder or delay
e. **BEHAVIORAL ISSUE**
f. **MEMORY PROBLEM**

CATEGORIES

1. YES
2. NO

[IF CGTYPEF=1,2,3
[SP; DISPLAY OPTIONS ON THE SAME SCREEN IN TWO COLUMNS]

18. What **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** the <u>main</u> problem or illness your **[DOV_CODE] [IF Q1=1, INSERT:** has / **IF Q1=2 OR REFUSED, INSERT:** had**],** for which they **[IF Q1=1, INSERT:** need / **IF Q1=2 OR REFUSED, INSERT:** needed**]** your care?

IF CGTYPEF=3, SHOW: ADD, ADHD, Attention deficit disorder	1
IF CGTYPEF=1 or 2	
Alzheimer's, dementia	3
IF CGTYPEF=1 or 2, SHOW: Arthritis	5
IF CGTYPEF=3, SHOW: Asthma	6
Autism or Autism Spectrum Disorder	7
IF CGTYPEF=1 or 2, SHOW: Back problems	8
IF CGTYPEF=1 or 2, SHOW: Blood pressure, hypertension	11
Brain damage (e.g., tumor, encephalitis)	38
Brain injury (e.g., TBI, concussion)	39
Broken bones	13
Cancer	14
Developmental or intellectual disorder or disability	21
Diabetes	16
IF CGTYPEF=1 or 2, SHOW: Frail, unsteady, falling	18
IF CGTYPEF=1 or 2, SHOW: Hearing loss, deafness	15
IF CGTYPEF=1 or 2, SHOW: Heart disease, heart attack	19
IF CGTYPEF=1 or 2, SHOW: HIV/AIDS	36
IF CGTYPEF=1 or 2, SHOW: Lung disease, emphysema, COPD	20
Mental illness, emotional illness, depression	22
Mobility problem, can't get around	23
IF CGTYPEF=1 or 2, SHOW: Old age, Aging	24
IF CGTYPEF=1 or 2, SHOW: Parkinson's	27
IF CGTYPEF=1 or 2, SHOW: Stroke	30
Substance, drug, alcohol use disorder	31
Surgery, wounds	32
Transplant	35
COVID-19	37
IF CGTYPEF=1 or 2, SHOW: Vision loss, blindness, can't see well	10
Other (Specify) **[TEXT BOX – PROMPT TWICE]**	33
Not sure	34

[IF CGTYPEF=3]
[SP]

19. As a result of your **[DOV_CODE]**'s condition **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** your **[DOV_CODE]** limited in any way in their ability to do the things that most children of the same age do?

Yes	1
No	2

[IF CGTYPEF=3 AND NO LIMIT (Q19=2) AND NO CONDITIONS (Q17A=2 AND Q17B=2 AND Q17C=2 AND Q17D=2 AND Q17E=2 AND Q17F=2), TERMINATE.]

20a. [IF CARES FOR ADULT CGTYPEF=1 or 2 AND ALZHEIMER’S NOT MENTIONED (Q18≠3)] { **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** your **[Q7 CODE]** living with any of the following conditions causing cognitive impairment? [check all that apply]

Alzheimer’s disease	1
Lewy body dementia	2
Frontotemporal dementia (FTD)	3
Vascular dementia	4
Some other condition that causes cognitive impairment	5
No	6 [exclusive]
Not sure	7[exclusive]

LENGTH OF CARE AND TASKS

[IF CGTYPEF=1,2,3]
[NUMBER BOX, RANGE 1-93]

21. **IF CGTYPEF=1 OR 2, SHOW:** How long **[IF Q1=1, INSERT:** have you been providing / **IF Q1=2 OR REFUSED, INSERT:** did you provide] care to your **[DOV_CODE]?**

IF CGTYPEF=3: How long **[IF Q1=1, INSERT:** have you been providing / **IF Q1=2 OR REFUSED, INSERT:** did you provide**]** care to your **[DOV_CODE]**, over and above normal childcare needs?

Your best estimate is fine.

___ years **[range 1-93]**

Less than six months	96
Six months to one year	95
All their life	94

[IF CGTYPEF=1,2,3]
[GRID, SP ACROSS; RANDOMIZE A-F, ANCHOR G]

22. **IF CGTYPEF=1 or 2, SHOW:** Which of these **[IF Q1=1, INSERT:** do / **IF Q1=2 OR REFUSED, INSERT:** did] you help your **[DOV_CODE]** with?

    IF CGTYPEF=3, SHOW: Which of these **[IF Q1=1, INSERT:** do / **IF Q1=2 OR REFUSED, INSERT:** did**]** you help your **[DOV_CODE]** with, because they **[IF Q1=1, INSERT:** are / **IF Q1=2 OR REFUSED, INSERT:** were**]** less able to do this task than children of the same age without their condition?

a. **IF Q5>2: GETTING IN AND OUT OF BEDS AND CHAIRS**
b. **IF Q5>3: GETTING DRESSED**
c. **IF Q5>3: GETTING TO AND FROM THE TOILET**
d. **IF Q5>5: BATHING OR SHOWERING**
e. **IF Q5>3: BY DEALING WITH INCONTINENCE OR DIAPERS**
f. **IF Q5>2: BY FEEDING THEM**
g. **BY GIVING MEDICINES, LIKE PILLS, EYE DROPS, OR INJECTIONS FOR THEIR CONDITION**

CATEGORIES

1. Yes
2. No

[IF ANY RESPONSES OF 22A THRU 22F =1; REVERSE GRID OPTIONS (1-5/5-1)]
[IF Q22A THRU F =2 OR REFUSED AND Q22G=1, SKIP N1]
[GRID, SP ACROSS]

N1. How difficult **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was] it for you to help your **[DOV_CODE]** with **[IF Q1=1,** insert: these / **IF Q1=2 OR REFUSED,** insert: those] kinds of tasks?

1 - Not at all difficult..1
2 2
3 3
4 4
5 – Very difficult...5

[IF CGTYPEF=1,2,3]
[GRID, SP ACROSS; RANDOMIZE A-F]

23. **[IF Q1=1, INSERT:** Do / **IF Q1=2 OR REFUSED, INSERT:** Did] you provide help to your **[DOV_CODE]** with…

		Yes	No
a.	Managing finances, such as paying bills or filling out insurance claims	1	2
b.	**IF CGTYPEF=1 OR 2, SHOW:** Grocery or other shopping	1	2
c.	**IF CGTYPEF=1 OR 2, SHOW:** Housework, such as doing dishes, laundry, or straightening up	1	2
d.	**IF CGTYPEF=1 OR 2, SHOW:** Preparing meals	1	2
e.	**IF CGTYPEF=1 OR 2, SHOW:** Transportation, either by driving them, or helping them get transportation	1	2
f.	Arranging outside services, such as nurses, home care aides, or meals-on-wheels	1	2

[IF CGTYPEF=1,2,3]
[GRID, SP ACROSS]
[RANDOMIZE ITEMS A-C]

23_1. And **[IF Q1=1, INSERT:** do / **IF Q1=2 OR REFUSED, INSERT:** did] you provide help to your **[DOV_CODE]** by…

		Yes	No
a.	Advocating for them with health care providers, community services, **[IF CGTYPEF=3, INSERT:** schools,**]** or government agencies	1	2
b.	Monitoring the severity of their condition so that you **[IF Q1=1, INSERT:** can / **IF Q1=2, INSERT:** could] adjust care accordingly	1	2
c.	Communicating with health care professionals like doctors, nurses, or social workers about their care	1	2

[IF CGTYPEF=1,2,3]
[NUMBER BOX; RANGE 1-168]
[SP]

25. Thinking now of all the kinds of help you **[IF Q1=1, INSERT:** provide / **IF Q1=2 OR REFUSED, INSERT:** provided**]** for your **[DOV_CODE]**, about how many hours **[IF Q1=1, INSERT:** do / **IF Q1=2 OR REFUSED, INSERT:** did**]** you spend in an average week helping them?

___ hours **[RANGE 1-168]**

Less than 1 hour per week **[SP]** 169
Constant care **[SP]**..170

[IF Q25=168 OR 170]

25Z. We would like to understand a little bit more about people like you who have {to provide/provided} constant care.

Which of the following best describes how much care or help you {have to give/gave} your **[dov_code]**, because of their condition(s) in a normal week? {Do/Did} you provide care…

All the time: 24 hours a day, 7 days a week..................................1
Almost all the time, with only small breaks here or there 2
Almost all the time, with just breaks to sleep 3
On and off around the clock..4
Other **(SPECIFY) [Textbox]** 5

[IF CGTYPEF=1,2,3]
[SP]

N3. **[IF Q1=1, INSERT:** Do / **IF Q1=2 OR REFUSED, INSERT:** Did**]** you help your **[DOV_CODE]** with any medical/nursing tasks?

This might include giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, or wound care. You could be monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

Yes 1
No 2
Not sure..3

IF (CGTYPEF=1 OR 2) AND (ALL Q22A THRU G = 2 OR REFUSED) AND (ALL Q23A THRU F =2 OR REFUSED) AND N3=2, 3 OR REFUSED, TERMINATE AND INSERT STANDARD CLOSE.

QFLAG INSTRUCTIONS:
IF (CGTYPEF=3) OR [(CGTYPEF=1 OR 2) AND (Q22A=1 OR Q22B=1 OR Q22C=1 OR Q22D=1 OR Q22E=1 OR Q22F=1 OR Q22G=1 OR Q23A=1 OR Q23B=1 OR Q23C=1 OR Q23D=1 OR Q23E=1 OR Q23F=1 OR N3=1), QFLAG=1 QUALIFIED.
ELSE QFLAG=2 NON-QUALIFIED.

[IF DOES M/N TASKS (N3=1)]

N4. How easy or difficult **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** it for you to do the medical/nursing tasks that {**[IF Q1=1, INSERT:** are / **IF Q1=2 OR REFUSED, INSERT:** were**]** } required to help your [Q7 CODE]? [ROTATE 1-5/5-1]

HOVER DEFINITION FOR UNDERLINED TEXT ABOVE: Medical/nursing tasks include: giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, wound care, monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

Very easy	1
Somewhat easy	2
Neither easy nor difficult	3
Somewhat difficult	4
Very difficult	5

[IF DOES M/N TASKS (N3=1)]

N5. Did anyone prepare you to do these tasks?

Yes	1
No	2 [SKIP TO N11]
Not sure	3 [SKIP TO N11]

[IF PREPARED (N5=1)]

N6. Who prepared you to do the medical/nursing tasks needed to help your [Q7 CODE]? [select all who helped]

2. Doctor/physician
3. Nurse Practitioner or Physician Assistant
4. Nurse
5. Social worker/geriatric care manager
6. Physical therapist
7. Occupational therapist
8. Pharmacist
9. Medical supply technician
10. Friend or neighbor
11. Videos online (e.g., YouTube)
12. Support group (includes online or in person)
13. Other [SPECIFY]

[IF PREPARED (N5=1)]

N7. How well do you feel that training prepared you to take on these medical/nursing tasks? [ROTATE 1-3/3-1]

Very well 1
Somewhat well 2
Not well 3
Not sure 4

[IF CGTYPEF=1,2,3]

N11. Did you receive any training or preparation to assist with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or behavioral management/modification for your [Q7 CODE]?

Yes 1
No .... 2 [SKIP TO N9]
Not sure .... 3 [SKIP TO N9]

Programmer please create Hover pop-up on ”activities of daily living: Assistance with activities of daily living includes assistance helping someone with bathing, dressing, eating, walking, and using the toilet.

Programmer please create Hover pop-up on “instrumental activities of daily living”: Assistance with instrumental activities of daily living includes helping someone with cooking, shopping for groceries, transportation, housework, managing medications and managing finances.

[IF PREPARED (N11=1)]

N17. Who prepared you to assist your [Q7 CODE] with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or behavioral management/modification? [select all who helped]

2. Doctor/physician
3. Nurse Practitioner or Physician Assistant
4. Nurse or Clinical Nurse Specialist
5. Social worker/geriatric care manager
6. Physical therapists
7. Occupational therapist
8. Pharmacist
9. Medical supply technician
10. Support group (includes online or in person)
11. Clinical psychologist
12. Speech language pathologist
13. Other health care professional

Programmer please create Hover pop-up on ”activities of daily living: Assistance with activities of daily living includes assistance helping someone with bathing, dressing, eating, walking, and using the toilet.

Programmer please create Hover pop-up on “instrumental activities of daily living”: Assistance with instrumental activities of daily living includes helping someone with cooking, shopping for groceries, transportation, housework, managing medications and managing finances.

[IF CGTYPEF=1,2,3]
[SP]
N9. In the last 12 months **[IF Q1=2 OR REFUSED, INSERT**: that you were caring for them, how many times was your **[DOV_CODE]** hospitalized overnight?

None	1
One time	2
2 times	3
3 or more times	4
Not sure	5

[IF HOSPITAL (N9=2, 3. OR 4)]:
N10. When your [Q7 CODE] was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about your [Q7 CODE]’s care, such as discussions about discharge planning, or in-hospital care plans?

Yes	1
No	2
Not sure	3

OTHER CAREGIVER SUPPORT

[IF CGTYPEF=1,2,3]
[SP]
28. Has anyone else provided <u>unpaid</u> help to your **[DOV_CODE]** during the last 12 months?

Yes	1
No	2

IF Q28=2 OR REFUSED, SKIP TO Q30.

[IF Q28=1]
[SP]
29. Who would you consider to be the person who **[IF Q1=1, INSERT:** provides/**IF Q1=2 OR REFUSED, INSERT:** provided] <u>most</u> of the unpaid care for your **[DOV_CODE]**?

You (yourself)	1
Someone else	2
We split it evenly	3

[IF Q28=1]
[SP]

29Z. Of all the people who {help provide/provided} care to your **[DOV_CODE]**, **[IF Q1=1, INSERT**: are / **IF Q1=2 OR REFUSED, INSERT:** were**]** any of them children under the age of 18?

They might **[IF Q1=1, INSERT**: help or assist / **IF Q1=2 OR REFUSED, INSERT:** have helped or assisted**]** <u>you</u> with the care you **[IF Q1=1, INSERT**: provide / **IF Q1=2 OR REFUSED, INSERT:** provided**]**. The child(ren) may also **[IF Q1=1, INSERT**: help / **IF Q1=2 OR REFUSED, INSERT:** have helped**]** with things like bringing items to or from your **[DOV_CODE]**, doing chores or other housework, running errands, or just generally helping watch over your **[DOV_CODE]**.

Yes 1
No..2

[IF CGTYPEF=1,2,3]
[SP]

30. During the last 12 months, did your **[DOV_CODE]** receive <u>paid</u> help from any aides, housekeepers, or other people who were paid to help them?

Yes 1
No..2

[IF CGTYPEF=1,2,3]
[SP; REVERSE ORDER OF RESPONSE OPTIONS 1-4/4-1]

38. Please think about all of the health care professionals or service providers who **[IF Q1=1, INSERT:** give/ **IF Q1=2 OR REFUSED, INSERT:** gave**]** care or treatment to your **[DOV_CODE]**. How easy or difficult **[IF Q1=1, INSERT:** is **/ IF Q1=2 OR REFUSED, INSERT:** was] it for you to coordinate care between those providers?

Very easy 1
Somewhat easy..2
Somewhat difficult 3
Very difficult...4
[IF Q28=1, DISPLAY: Not applicable: someone else **[Q1=1, INSERT:** does / **IF Q1=2 OR REFUSED, INSERT:** did**]** this**]**...7

PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING

[IF CGTYPEF=1,2,3]
[SP; REVERSE RESPONSE OPTIONS 1-5/5-1]
35. How much of a physical strain would you say that caring for your **[DOV_CODE] [if q1=1, insert:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** for you?

1 - Not a strain at all 1
2 2
3 3
4 4
5 – Very much a strain 5

[IF CGTYPEF=1,2,3]
[SP; REVERSE RESPONSE OPTIONS 1-5/5-1]
36.How emotionally stressful would you say that caring for your **[DOV_CODE] [IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** for you?

1 - Not at all stressful 1
2 2
3 3
4 4
5 – Very stressful 5

[IF CGTYPEF=1,2,3]
[SP; REVERSE RESPONSE OPTIONS 1-5/5-1]
37B. How much of a financial strain would you say that caring for your **[DOV_CODE] [IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was] for you?

1 - Not a strain at all 1
2 2
3 3
4 4
5 – Very much a strain 5

IF CGTYPEF=1,2,3
[SP]
D1. **[IF Q1=1, INSERT:** How would you describe your own health? / **IF Q1=2 OR REFUSED, INSERT:** When you were last caregiving, was your health…?**]**

Excellent 5
Very good 4
Good 3
Fair 2
Poor 1

[IF CGTYPEF=1,2,3]

H1. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? Your best guess is fine. [number of days]

______ Number of days [range 0-30]

[IF CGTYPEF=1,2,3]

H2. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? Your best guess is fine. [number of days]

______ Number of days [range 0-30]

[IF CGTYPEF=1,2,3]

H3. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? Your best guess is fine. [number of days]

______ Number of days [range 0-30]

[IF CGTYPEF=1,2,3]
[SP]

39. Do you feel you had a choice in taking on this responsibility for caring for your **[DOV_CODE]**?

Yes 1
No 2

[IF CGTYPEF=1,2,3]
[GRID, SP ACROSS]
[RANDOMIZE ITEMS A-C]
M5. How much do you agree or disagree with each statement below about being a caregiver for your **[DOV_CODE]**?

		Strongly disagree	Disagree	Neither	Agree	Strongly agree
a.	My role as a caregiver **[IF Q1=1, INSERT: GIVES / IF Q1=2 OR REFUSED, INSERT:** gave] me a sense of purpose or meaning in my life	1	2	3	4	5
b.	I **[IF Q1=1, INSERT: FIND / IF Q1=2 OR REFUSED, INSERT:** found] it difficult to take care of my own health	1	2	3	4	5
c.	I **[IF Q1=1, INSERT: FEEL / IF Q1=2 OR REFUSED, INSERT:** felt] alone	1	2	3	4	5

WORKING CAREGIVERS

[IF CGTYPEF=1,2,3]
[SP]
32A.Now we have some questions about you.

Are you currently employed?

Yes 1
No..2

IF (Q1=1 AND Q32A=1), SKIP TO N13.

[SP] [IF CGTYPEF=1,2,3]
33. **[IF Q1=1, INSERT:** Have you been / **IF Q1=2 OR REFUSED, INSERT:** Were you**]** employed at any time in the last year while you were also helping your **[DOV_CODE]**?

Yes 1
No..2

IF Q33=2 OR REFUSED, SKIP TO M2.

PROGRAMMING NOTE: PUT DISPLAY AND QUESTION N13/N13_1 ON THE SAME SCREEN.
[DISPLAY]
[IF Q33=1]: For the next few questions, please think about the most recent time in the last year when you were working and providing care to your **[DOV_CODE].**

[Q1=1 AND Q32A=1]
[NUMBOX, RANGE [1-80]]
N13. About how many hours a week, on average, do you work?

___ hours a week

[IF Q33=1]
[NUMBOX, RANGE [1-80]]
N13_1. When you were last working and helping your **[DOV_CODE]**, about how many hours a week, on average, did you work?

___ hours a week **[RANGE 1-80]**

[Q1=1 AND Q32A=1]
33Z. Are you…?

[IF Q33=1]
33Z_1. Were you…?

Paid a salary 1
Paid hourly for the time you work......................................2
Some other arrangement (SPECIFY) **[TEXTBOX]**................3

[IF Q32A=1 OR Q33=1]
[SP]
N14_1. **[IF Q32A=1, INSERT:** Does / **IF Q33=1, INSERT:** Did**]** your supervisor know that you were caring for your **[DOV_CODE]**?

Yes 1
No..2
Not sure...3
N/A, I am self-employed... 4[exclusive]

[IF Q1=1 AND Q32A=1 AND N14_1 =1,2, OR 3]
[GRID, SP ACROSS; RANDOMIZE ITEMS A-C, KEEP E-D-F LAST AND IN THAT ORDER]

N16. For employees at your work in a similar role or job as yours, which of the following does your employer offer?

		Yes	No
a.	Flexible work hours	1	2
b.	Telecommuting or working from home	1	2
c.	Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	1	2
d.	Paid family leave, where you could take extended paid time off from work (in weeks) to care for an ill family member	1	2
e.	Paid sick days, where you can take limited paid hours or days off from work to care for or go to appointments with an ill family member	1	2
f.	Unpaid family leave, where you could take extended time off (in weeks) without pay to care for an ill family member	1	2

[IF Q33=1 AND N14_1 =1, 2, 0R 3]
[GRID, SP ACROSS; RANDOMIZE ITEMS A-C~~,~~ KEEP E-D-F LAST AND IN THAT ORDER]

N16_1. At the time when you were last working and providing care for your **[DOV_CODE]**, for employees at your work in a similar role or job as yours, which of the following did your employer offer?

		Yes	No
a.	Flexible work hours	1	2
b.	Telecommuting or working from home	1	2
c.	Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	1	2
d.	Paid family leave, where you could take extended paid time off from work (in weeks) to care for an ill family member	1	2
e.	Paid sick days, where you can take limited paid hours or days off from work to care for or go to appointments with an ill family member	1	2
f.	Unpaid family leave, where you could take extended time off (in weeks) without pay to care for an ill family member	1	2

[IF Q32A=1 OR Q33=1]
[GRID, SP ACROSS; RANDOMIZE ITEMS A-H]
34. As a result of caregiving, did you ever experience any of these things at work?

		Yes	**No**
a.	Went in late, left early, or took time off during the day to provide care	1	2
b.	Took a leave of absence	1	2
c.	Went from working full-time to part-time, or cut back your hours	1	2
d.	Turned down a promotion	1	2
e.	Lost any of your job benefits	1	2
f.	Gave up working entirely	1	2
g.	Retired early	1	2
h.	Received a warning about your performance or attendance at work	1	2

[IF Q33=2 OR REFUSED]
[SP]
M2. At <u>any time</u> while you **[IF Q1=1, INSERT:** have been providing / **IF Q1=2 OR REFUSED, INSERT:** provided] care to your **[DOV_CODE]**, have you worked or had a job?

Yes 1
No 2

[IF Q34B=1 OR Q34F=1 OR Q34G=1 OR M2=1)]
[MP; RANDOMIZE ITEMS 1-4]
N15. Why did you leave your job, take a leave of absence, or otherwise decide to not work while also providing care?

Needed more time to care for your **[dov_code]** 1
Could not afford paid help for your **[dov_code]**... 2
Job did not allow flexible work hours... 3
Job did not allow time off with pay 4
Other reason (Specify) **[TEXTBOX]**.. 5

IF CGTYPEF=1,2,3]
M3. Have you ever felt that your responsibilities as a caregiver led to you being penalized or discriminated against at work?

Yes.. 1
No 2
Not sure... 3

INFORMATION, SUPPORT, PLANNING, TECH and FINANCE

IF CGTYPEF=1,2,3]

[GRID, SP ACROSS; RANDOMIZE ORDER A-F]

45. In your experience as a caregiver, have you ever....

		Yes	No
a.	Requested information about how to get financial help for your **[DOV_CODE]**?	1	2
b.	Used respite services where someone would take care of your **[DOV_CODE]** to give you a break?	1	2
c.	Had an outside service provide transportation for your **[DOV_CODE]** instead of you providing the transportation?	1	2
d.	Had modifications made in the house or apartment where your **[DOV_CODE] [IF Q1=1, INSERT:** lives/ **IF Q1=2 OR REFUSED, INSERT:** lived**]** to make things easier for them?	1	2
e.	Had a doctor, nurse, or social worker ask you about what you **[IF Q1=1, INSERT:** need / **IF Q1=2 OR REFUSED, INSERT:** needed**]** to help care for your **[DOV_CODE]**?	1	2
f.	Had a doctor, nurse, or social worker ask you what you **[IF Q1=1, INSERT:** need / **IF Q1=2 OR REFUSED, INSERT:** needed**]** to take care of <u>yourself</u>?	1	2

IF CGTYPEF=1,2,3]

[SP; REVERSE RESPONSE OPTIONS 1-5/5-1]

N19. How difficult **[IF Q1=1, INSERT:** is / **IF Q1=2 OR REFUSED, INSERT:** was**]** it to get affordable services in your **[dov_codes]**'s local area or community that **[IF Q1=1, INSERT:** could help / **IF Q1=2 OR REFUSED, INSERT:** would have helped] you care for your **[dov_code]**, like delivered meals, transportation, or in-home health services?

1 – Not at all difficult..1
2 2
3 3
4 4
5 – Very difficult...5

IF CGTYPEF=1,2,3]

[MP; RANDOMIZE ITEMS 4-6]

N20. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would **[IF Q1=1, INSERT:** be / **IF Q1=2 OR REFUSED, INSERT:** have been**]** helpful to you?

Having respite services available, where someone would **[IF Q1=1, INSERT:** take / **IF Q1=2 OR REFUSED, INSERT:** have taken**]** care of your **[dov_codes]** to give you a break.. 4
Requiring a doctor, nurse, or social worker to ask you about what you **[IF Q1=1, INSERT:** need / **IF Q1=2 OR REFUSED, INSERT:** needed**]** to help care for your **[dov_codes]**.. 5
Requiring a doctor, nurse, or social worker to ask you what you **[IF Q1=1, INSERT:** need / **IF Q1=2 OR REFUSED, INSERT:** needed**]** to take care of <u>yourself</u>... 6
None of the above...7

IF CGTYPEF=1,2,3]

[GRID; SP ACROSS; RANDOMIZE ORDER OF ITEMS A-E]

M11. In your experience as a caregiver for your **[Q7 CODE]**, have you ever done the following things using technology or software?

		Yes	No	Not Applicable
a.	Created electronic lists or spreadsheets to track activities related to providing care for your **[DOV_CODE]**	1	2	3
b.	Checked up on your **[DOV_CODE]** using an app, video, wearable device, or other remote monitoring	1	2	3
c.	Tracked your **[DOV_CODE]**’s personal health records	1	2	3
d.	Tracked your **[DOV_CODE]**’s finances	1	2	3
e.	Got or used assistive devices for things like your **[DOV_CODE]**’s low vision or hearing problems	1	2	3

IF CGTYPEF=1,2,3]

[MP; RANDOMIZE ITEMS 1-10; KEEP RESPONSES 98 AND 99 LOCKED AT BOTTOM]

48. Which of the following topics do you feel you **[IF Q1=1, INSERT:** need / **IF Q1=2 OR REFUSED, INSERT:** needed**]** more help or information? Select all that apply.

Keeping your **[DOV_CODE]** safe at home	1
Managing your **[DOV_CODE]**’s challenging behaviors, such as wandering	2
Activities you **[IF Q1=1, INSERT:** could do / **IF Q1=2 OR REFUSED, INSERT:** could have done**]** with your **[DOV_CODE]**	3
Choosing a home care agency, assisted living facility or nursing home	4
Managing your emotional or physical stress	5
Making end-of-life decisions	6
Finding non-English language educational materials	7
Figuring out forms, paperwork, or eligibility for services or support for your **[DOV_CODE]**	8
Managing or handling your own personal finances	9
Using technology to care for your **[DOV_CODE]**	10
Something else (SPECIFY) **[Textbox]**	98
None of the above	99

[SP] IF CGTYPEF=1,2,3]

N21. **IF CGTYPEF=1 OR 2, SHOW: [IF Q1=1, INSERT:** Does / **IF Q1=2 OR REFUSED, INSERT:** Did**]** your **[DOV_CODE]** have plans in place for their future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?

IF (CGTYPEF=3) AND (Q7 NE 5 AND Q7 NE 19), SHOW: [IF Q1=1, INSERT: Does / **IF Q1=2 OR REFUSED, INSERT:** Did**]** your **[DOV_CODE]**'s family have plans in place for their future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?

IF (CGTYPEF=3) AND (Q7=5 OR Q7=19), SHOW: [IF Q1=1, INSERT: Do / **IF Q1=2 OR REFUSED, INSERT:** Did**]** you have plans in place for your **[DOV_CODE]**'s future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?

Yes 1
No 2
Not sure...3

[SP] IF CGTYPEF=1,2,3]

N22. Do you have your <u>own</u> plans for your own future care, such as handling financial matters, healthcare decisions, or living arrangements?

Yes 1
No 2

IF CGTYPEF=1,2,3]

[GRID; SP ACROSS; KEEP ORDER OF ITEMS A-M AS SHOWN]

M6. As a result of providing care to your **[DOV_CODE]**, have <u>you</u> ever experienced any of these financial things?

		Yes	**No**	**Not Applicable**
a.	Took on more debt (credit cards, loans, lines of credit)	1	2	3
b.	Missed or was late paying for a student loan	1	2	3
c.	Borrowed money from family or friends	1	2	3
d.	Filed for bankruptcy (medical or personal)	1	2	3
e.	Been unable to afford basic expenses like food	1	2	3
f.	Left your bills unpaid or paid them late	1	2	3
g.	Used up your personal short-term savings	1	2	3
h.	Used long-term savings, like retirement or education, to pay for other things	1	2	3
i.	Stopped saving	1	2	3
j.	Moved to a less expensive home, apartment, or other living arrangement	1	2	3
k.	Was evicted or had a home foreclosed	1	2	3
l.	Put off when you planned to retire or decided to never retire	1	2	3
m.	Had to start working, work more, or find a second job	1	2	3

IF CGTYPEF=1,2,3]

[GRID; SP ACROSS; RANDOMIZE ORDER OF ITEMS A-C]

M9. Below are some ways that people are proposing to help caregivers financially. How helpful would you **[IF Q1=1, INSERT:** find / **IF Q1=2 OR REFUSED, INSERT:** have found**]** each?

		Very helpful				Not at all helpful
a.	An income tax credit to caregivers, to help offset the cost of care	5	4	3	2	1
b.	A partially paid leave of absence from work, for caregivers who are employed	5	4	3	2	1
c.	A program where caregivers could be paid for at least some of the hours they provide care	5	4	3	2	1

PROGRAMMING NOTE: CREATE A COUNT VARIABLE COUNTM9 OF ALL MENTIONS IN M9 WHERE ITEM IS 3 OR HIGHER.

DEMOGRAPHICS

PROGRAMMING NOTE: SHOW DISPLAY_D AND QUESTION M10 ON SAME SCREEN.

IF CGTYPEF=1,2,3]

[DISPLAY_D]

And finally, we have just a few questions for classification purposes only. [FOR KNOWLEDGEPANEL RESPONDENTS, ADD] These questions are to make sure our information is up to date, even though you may have answered some of the questions before.

[SP] IF CGTYPEF=1,2,3]

M10. At any time in the past year <u>while you were providing care</u> to your **[DOV_CODE]**, were you also a student, either full-time or part-time?

Yes 1
No.. 2

[SP] IF CGTYPEF=1,2,3]

M12. **[IF Q1=1, INSERT:** Are you, yourself, currently / **IF Q1=2 OR REFUSED, INSERT:** At the time you last provided care, were you, yourself**]** covered by any form of health insurance or a health plan?

Yes 1
No 2

[IF M12=1]
[SP] IF CGTYPEF=1,2,3]

M13. What type of health insurance or health coverage **[IF Q1=1, INSERT:** do / **IF Q1=2 OR REFUSED, INSERT:** did**]** you have? Please select your main source of health insurance.

An employer plan (yours or a family member's)	1
Plan bought directly (from an insurance company, using an agent, or using an exchange/marketplace)	2
Medicare (standard, supplemental, and/or Medicare Advantage)	3
Medicaid coverage provided by your state	4
Military health care (Tricare, VA, Champ)	5
Some other type of coverage (SPECIFY) **[TEXTBOX]**	6
Not sure	7
No health insurance	8

[SP] IF CGTYPEF=1,2,3]

D3. **[IF Q1=1, INSERT:** Are you currently / **IF Q1=2 OR REFUSED, INSERT:** When you were last caregiving, were you]…

Married	1
Living with a partner	2
Widowed	3
Separated	4
Divorced	5
Single, never married	6
Decline to respond	8

[SP] IF CGTYPEF=1,2,3]

D6. **[IF Q1=1, INSERT:** Are / **IF Q1=2 OR REFUSED, INSERT:** When you were last caregiving, were**]** there any children or grandchildren living in your household under 18 years of age **[IF CGTYPEF=3 AND Q11=1, INSERT:** in addition to your **[DOV_CODE]]**?

Yes	1
No	2
Decline to respond	4

[IF CGTYPEF=1,2,3]

D4. Did you ever serve on active duty in the US Armed Forces?

This includes Army, Navy, Air Force, Marines, Coast Guard, or Women's Armed Forces, Space Force, National Guard, or Reserves.

Yes	1
No	2
Don't know	3

[IF CGTYPEF=1,2,3]

D6B. When you were last caregiving, did you have internet access of any kind in your home? Please include dial-up, broadband, cable, or internet access via smartphone.

Yes	1
No	2

[IF CGTYPEF=1 or 2]
[SP]
D5.Did your **[DOV_CODE]** ever serve in the US Armed Forces?

This includes Army, Air Force, Marines, Coast Guard, or Woman's Armed Forces, Space Force, National Guard or Reserves.

Yes	1
No	2
Not sure	3

[IF CGTYPEF=1,2,3]

D14. Does any disability or handicap keep you from participating fully in work, school, housework, or other activities?

Yes	1
No	2

Base: [CGTYPEF=1, 2,3, 4 and dov_sample=2,3]
[PPINCIMP]
QINC [S]
How much is the combined income of all members of YOUR HOUSEHOLD for the PAST 12 MONTHS?
[SPACE]
Please include your income PLUS the income of all members living in your household (including cohabiting partners and armed forces members living at home). Please count income BEFORE TAXES and from all sources (such as wages, salaries, tips, net income from a business, interest, dividends, child support, alimony, and Social Security, public assistance, pensions, or retirement benefits).

Select one answer only.

1. Below $50,000
2. $50,000 or more
3. Don't know

[PROMPT]
Your answer will help represent the entire U.S. population and will be kept confidential. Thank you!

Base: respondents with household income below $50,000 (QINC=1)
QINC2 [S]
We would like to get a better estimate of your total HOUSEHOLD income in the past 12 months before taxes. Was it...

[PROMPT]
Your answer will help represent the entire U.S. population and will be kept confidential. Thank you!

Select one answer only.

1. Less than $5,000
2. $5,000 to $7,499
3. $7,500 to $9,999
4. $10,000 to $12,499
5. $12,500 to $14,999
6. $15,000 to $19,999
7. $20,000 to $24,999
8. $25,000 to $29,999
9. $30,000 to $34,999
10. $35,000 to $39,999
11. $40,000 to $49,999

Base: respondents with household income of $50,000 or more (QINC=2)
QINC3 [S]
We would like to get a better estimate of your total HOUSEHOLD income in the past 12 months before taxes. Was it...

[PROMPT]
Your answer will help represent the entire U.S. population and will be kept confidential. Thank you!

Select one answer only.

3. $50,000 to $59,999
4. $60,000 to $74,999
5. $75,000 to $84,999
6. $85,000 to $99,999
7. $100,000 to $124,999
8. $125,000 to $149,999
9. $150,000 to $174,999
10. $175,000 to $199,999
11. $200,000 to $249,999
12. $250,000 or more

Base: IF [CGTYPEF=1, 2, 3, 4 AND dov_sample=2, 3] OR [Dov_sample=1 and respondents with XCP0003=99]

NOTE: ITEM USED FOR CURRENT CALIBRATION APPROACH - CALIBRATION 3.0.

QCP0003 [Q]
Approximately, how many hours of television do you watch on an average day?

Type in the number for the answer.

Base: IF [CGTYPEF=1, 2,3,4 AND dov_sample=2, 3] or [Dov_sample=1 and respondents with XCP0005=999]

NOTE: ITEM USED FOR CURRENT CALIBRATION APPROACH - CALIBRATION 3.0.
QCP0005 [Q]
In a typical week, about how many hours do you spend on the Internet for personal use? If none, enter "0". If less than an hour in a week, enter "1".

Type in the number for the answer.

Base: IF [CGTYPEF=1, 2,3,4 AND dov_sample=2, 3] or [Dov_sample=1 and respondents with XCP0005=999]

NOTE: ITEM USED FOR CURRENT CALIBRATION APPROACH - CALIBRATION 3.0.
QCP0007 [S]
How often, if at all, have you used the Internet to express your opinions about POLITICAL or COMMUNITY issues within the last 12 months?

Select one answer only.

1. Basically every day
2. A few times a week
3. A few times a month
4. Once a month
5. Less than once a month
6. Not at all

Base IF [CGTYPEF=1, 2,3,4 AND dov_sample=2, 3] or [Dov_sample=1 and respondents with XCP0005=999]

NOTE: ITEM USED FOR CURRENT CALIBRATION APPROACH - CALIBRATION 3.0. IF YOUR PROJECT REQUIRES THAT YOU INCLUDE QADOPT1-QADOPT5, DO NOT ALSO INCLUDE QCP0017 (QCP0017 IS THE SAME AS QADOPT1. QCP0017 IS A STANDALONE QUESTION, WHEREAS QADOPT1 IS PART OF A GRID).
QCP0017 [S]
How much does the following statement describe you?

Select one answer only.

Statement in row:
1. I usually try new products before other people.

Answers in column:
1. Not at all
2. Somewhat
3. A lot
4. Completely

Base: IF CGTYPEF=1, 2,3,4 AND dov_sample=2, 3 and ppethm=4 Hispanic respondents

[ACSLANG/XACSLANG – ASKED OF HISPANICS ONLY]

QACSLAN1 [S]
Do you speak a language other than English at home?

Select one answer only.

1. Yes
2. No

Base: Hispanic respondents who speak a language other than English at home ((QACSLAN1=1)

QACSLAN2 [M]
What language do you speak at home other than English?

Select all answers that apply.

1. Spanish
2. Chinese (any dialect)
3. Tagalog
4. Vietnamese
5. French
6. German
7. Another language

Base: Hispanic respondents who speak a language other than English at home (QACSLAN1=1)

QACSLAN3 [S]
How well do you speak English?

Select one answer only.

1. Very well
2. Well
3. Not well
4. Not at all

IF DOV_SAMPLE=2,3 AND CGTYPEF=4 – SHOW STANDARD TERMINATION CLOSE]

[KP RESPONDENTS ONLY DOV_SAMPLE=1]
[SP]

D10. If the situation arose, would you be interested in participating in future research on caregivers?

By agreeing to be contacted, Ipsos will provide your name, email address, as well as some of your responses connected to this survey to AARP and the National Alliance for Caregiving, who may contact you if and when they undertake follow-up research about caregiving. It is completely optional.

Yes 1
No/Decline...2

[KP RESPONDENTS ONLY DOV_SAMPLE=1]
[SP]

D11. The results of this survey are totally confidential. However, if a reporter writing a story about the results of the survey wanted to interview you for a news story, would you be willing or not?

By agreeing to be contacted, Ipsos will provide your name, email address, as well as some of your responses connected to this survey to AARP and the National Alliance for Caregiving, if and when they have a reporter looking to speak with a caregiver. It is completely optional.

Yes	1
No/Decline	2

[CGTYUPEF=1,2,3 THANKYOU_DISPLAY]

Thank you very much for your time. Your responses have been very helpful to this research. The results of this research should be released to the public in spring 2025 on both caregiving.org and aarp.org, if you are interested in seeing the results.

[INSERT STANDARD CLOSE]

B. Spanish Language Version

SCREENER

Prefer_Lang. ¿Prefiere llenar sus encuestas en español o en inglés?
Do you prefer to do surveys in Spanish or English?

Español 1
English... 2

Informed Consent. Se le invita a participar en un estudio de investigación sobre personas que brindan cuidados familiares en los Estados Unidos. El propósito de este estudio de investigación es entender sus experiencias al brindar cuidados.

Este estudio está siendo llevado a cabo por la Alianza Nacional para la Prestación de Cuidado (National Alliance for Caregiving) y AARP.

Por favor tome en cuenta: Usted debe tener 18 años o más para participar en este estudio.

La participación en este estudio es voluntaria. Sus respuestas se mantendrán de manera confidencial y se usarán solo con fines de investigación. Esta encuesta le tomará alrededor de 20 minutos. La encuesta incluye preguntas sobre sus características al brindar cuidados, tales como información general sobre usted, la persona a la cual le brinda cuidados, su situación al brindar cuidados, actividades al brindar cuidados y bienestar.

El participar en este estudio puede que no le beneficie a usted directamente, pero nos ayudará para informar sobre recomendaciones de políticas, prácticas y de investigaciones. Usted puede encontrar algunas de las preguntas delicadas, pero esperamos que esto no sea diferente a los tipos de cosas que usted platica con familia o amigos. Usted puede omitir cualquier pregunta que usted no quiera responder y puede dejar la encuesta en cualquier momento.

La información que usted compartirá con nosotros, si es que usted participa en este estudio, se mantendrá completamente confidencial conforme a la ley.

El personal del estudio entiende que la seguridad en el intercambio de información en línea no está garantizada debido al riesgo de que la información sea interceptada por terceras partes o la posibilidad de software de monitoreo instalado en los dispositivos electrónicos de los participantes en la investigación. Sus respuestas se combinarán con las de todos los otros participantes y se compartirán con la NAC/AARP. No compartiremos su nombre o información personal con NAC/AARP, sin su consentimiento. Sus respuestas se podrían usar en futuros estudios de investigación o distribuidas a otros investigadores para futuros estudios de investigación sin consentimiento informado adicional. Si esto sucede, toda la información personal privada será removida antes de que las respuestas sean compartidas. Su identidad no será conocida en los resultados del estudio. Los datos no serán analizados de manera alguna que sea posible identificar a cualquier participante individual. Este estudio es solo con fines de investigación.

Ninguna información personal será recolectada. Sus respuestas a las preguntas serán recolectadas y los datos serán guardados de manera electrónica con Ipsos.

Datos sin identificación serán conservados por la NAC y AARP y archivados en el Roper Center (Ipoll) en la Universidad Cornell.

Si usted tiene alguna pregunta sobre este estudio, por favor póngase en contacto con la Dra. Fawn Cothran, al 202-918-1021, fawn@caregiving.org o con el Dr. George Kueppers, al 202-918-1021, george@caregiving.org. Si tiene preguntas o quejas, puede contactar a una persona que no se encuentra en el equipo de investigación que es parte de la Junta de Revisión Institucional Biomedical Research Alliance of New York al (516) 318-6877 o en www.branyirb.com/concerns-about-research.

¿Está usted de acuerdo en participar en este estudio?

Si	1
No	2

[Programming: If Sí, continue; if no, stop]

Gracias por tomarse el tiempo de participar en este importante estudio nacional. Esta encuesta se llevará a cabo solo una vez y le tomará 20 minutos de su tiempo.

[ALL RESPONDENTS]

SC1a. En cualquier momento durante los últimos 12 meses, ¿alguna persona en su hogar ha cuidado gratuitamente a un familiar o amigo de 18 años o más para ayudarle a cuidar de sí mismo?

El cuidado gratuito puede incluir ayudar a una persona con sus necesidades personales o tareas de la casa. Puede ser ayudar a alguien con el manejo de sus finanzas, conseguirle servicios de otros, o visitarle regularmente para saber cómo está. La persona no necesariamente vive en su casa.

Sí, he brindado cuidado a un adulto durante el último año	1
Alguien más en mi hogar ha brindado cuidado	2
No	3

SC1d. En cualquier momento durante los últimos 12 meses, ¿alguna persona en su hogar ha recibido un pago para proporcionar cuidados a un familiar o amigo de 18 años o más para ayudarle a cuidar de sí mismo?

Esto puede incluir ayudar a una persona con sus necesidades personales o tareas de la casa. Puede ser ayudar a alguien con el manejo de sus finanzas, conseguirle servicios de otros, o visitarle regularmente para saber cómo está. La persona no necesariamente vive en su casa.

Sí, he proporcionado cuidado pagado a un adulto durante el último año1
Alguien más en mi hogar ha brindado cuidado pagado (no yo).... 2
No 3

[Hover pop-up over words "cuidado pagado": Cuidado pagado incluye pagos a brindadores de cuidados a través de programas auto dirigidos por parte de Medicaid, Asuntos de los Veteranos (Veteran's Affairs) u otros programas del estado. El cuidado pagado no incluye a aquellos empleados a tiempo completo como trabajadores de cuidado directo, tales como asistentes de salud a domicilio o en lugares basados en comunidad/hogar o en establecimientos.]

[if SC1a=1 or 2]
SC1c. ¿Alguno de los adultos a quien **[IF SC1a=1, insert**: usted / **IF SC1a=2, insert**: alguien en su hogar] brindó cuidado tenía 50 años de edad o mayor?

Sí 1
No 2

[ALL RESPONDENTS]
SC1b. Durante los últimos 12 meses, ¿alguna persona en su hogar ha brindado cuidado gratuito a algún menor de 18 años debido a una afección médica, un problema de comportamiento o algún otro padecimiento o discapacidad?

Esta clase de cuidado gratuito es más que el cuidado normal necesario para un menor de esa edad. Esto puede incluir el cuidado de una afección médica en curso, enfermedad seria de corto plazo, problemas emocionales o del comportamiento, o problemas del desarrollo.

Sí, he brindado cuidado a un menor durante el último año.......... 1
Alguien más en mi hogar ha brindado cuidado 2
No.. 3

[ALL RESPONDENTS]
Este es un estudio importante y para estar seguro de que hablemos con una variedad de personas, tenemos que hacer algunas preguntas básicas acerca de usted y de su hogar.

SC6. ¿Cuántas personas, incluyendo menores, viven en su casa?

Por favor inclúyase a usted mismo/a.

____ **[RANGE 1 - 30]**

CHECKPOINT: CLASSIFY TYPE OF HOUSEHOLD AND INDIVIDUAL

COMPUTE CGHHf "Caregiver in Household Field Version"
1 = "Caregiver of adult only in HH" [(IF (SC1A=1 OR 2 OR SC1D=1 OR 2) AND (SC1B=3 OR REFUSED))]
2 = "Caregiver of adult and Caregiver of child in HH" (if (sc1a=1 or 2 OR SC1D=1 OR 2) and (sc1b=1 or 2))
3 = "Caregiver of child only in HH" (if (sc1a=3 or refused and sc1d=3 or refused) and (sc1b=1 or 2))
4 = "No caregivers in HH" (if (sc1a=3 or refused and SC1d=3 OR REFUSED) and (sc1b=3 or refused))

COMPUTE CGTYPEf "Caregiver Type Field Version"
1 = "Caregiver of adult only" [(if sc1a=1 or sc1d=1 and (sc1b=2 or 3 or refused))]
2 = "Caregiver of adult and child" (if sc1a=1 OR SC1D=1 and sc1b=1)
3 = "Caregiver of child only" (if (sc1a=2 or 3 or refused AND SC1D=2 OR 3 or refused) and sc1b=1)
4 = "Not a caregiver" (if (sc1a=2 or 3 or refused AND SC1D=2 or 3 OR REFUSED) and (sc1b=2 or 3 or refused))

IF RESPONDENT IS NOT CAREGIVER (CGTYPEf=4): TERMINATE.

C.CHARACTERISTICS OF THE RELATIONSHIP

Esta encuesta es parte de un importante estudio a nivel nacional realizado por la Alianza Nacional para la Prestación de Cuidado (National Alliance for Caregiving) y AARP. Le agradecemos mucho su participación.

[If CARES FOR ADULT AND CHILD]
Para el resto de esta encuesta, por favor solo piense en las personas adultas de 18 años o más a quienes usted brindó cuidado sin remuneración durante los últimos 12 meses.

2. **IF CARES FOR ADULT:** ¿A cuántos adultos ha brindado cuidado en los últimos 12 meses?

IF CARES FOR CHILD ONLY: ¿A cuántos menores bajo la edad de 18 años ha brindado cuidado en los últimos 12 meses, debido a que ese menor o menores tuvieron algún tipo de afección médica, un problema de comportamiento o algún otro padecimiento o discapacidad?

____________ **[ALLOW 0-97; TERMINATE IF 0 or REFUSED]**

FOR THE FEW RESPONDENTS WHO SAY THEY ARE CAREGIVERS TO 5+ PEOPLE, WE WILL DOUBLE CHECK THAT THEY ARE TRULY CAREGIVERS – THEY CAN'T BE IN AN INSTITUTIONAL SETTING AND THEY MUST BE CARING FOR RECIPIENTS WHO DO HAVE SPECIAL NEEDS.

3. **[IF Q2 >= 5]** ¿Estaban todos estos **[IF CGTYPEF=1 or 2, INSERT:** adultos / **IF CGTYPEF=3, INSERT:** menores**]** juntos en un entorno institucional o de grupo, como un asilo de ancianos, un centro de ancianos, una guardería, un hogar de grupo o una escuela donde trabaja o es voluntario?

   Si.. 1 **TERMINATE**
   No.. 2

IF REFUSES (Q3=missing), TERMINATE.

4. **[IF Q2 >= 5]** ¿Cuántos de los [**IF CARES FOR ADULT**, INSERT: adultos / **IF CARES FOR CHILD ONLY**: menores] a los que usted ayudó a cuidar tenían algún tipo de necesidad especial por la que recibieron cuidados?

   Una necesidad especial puede ser una enfermedad, lesión, discapacidad o problema de salud mental.

   Todos ....1 **SKIP TO TEXT AFTER Q2B**
   Algunos...2
   Ninguno 3

IF REFUSES (Q4=missing), TERMINATE.

2b. **IF CARES FOR ADULT:** ¿A cuántos adultos con algún tipo de necesidad especial brindó cuidado en los últimos 12 meses?

IF CARES FOR CHILD ONLY: ¿A cuántos menores con algún tipo de necesidad especial brindó cuidado en los últimos 12 meses?

____________ **[ALLOW 0 thru Q2(answer); TERMINATE IF 0]**

IF REFUSES (Q2B=missing), TERMINATE.

[IF ONE PERSON (Q2=1 OR Q2B=1): Ahora nos gustaría obtener alguna información sobre el **[IF CARES FOR ADULT**: adulto / **IF CARES FOR CHILD ONLY**: menor**]** a quien brindó cuidado.

[IF MORE THAN ONE (Q2=2 thru 97 OR Q2b=2 thru 97): Para el siguiente grupo de preguntas, por favor piense en el **[IF CARES FOR ADULT**: ese familiar o amigo adulto/ **IF CARES FOR CHILD ONLY**: ese menor**]**, a quien usted brindó más atención en el último año.**]**

1. ¿Está usted actualmente proporcionando asistencia no remunerada a **[IF CARES FOR ADULT**: adulto / **IF CARES FOR CHILD ONLY**: menor**]**, o fue algo que hizo en los últimos 12 meses y ya no está haciendo?

   Actualmente 1
   En los últimos 12 meses pero no actualmente 1

WORDING NOTE 1:
IF CURRENTLY (Q1=1): USE PRESENT TENSE, first verb in {BRACKETS}
IF PAST 12 MONTHS (Q1=2 or REFUSED): USE PAST TENSE, second verb in {BRACKETS}

5. ¿Qué edad {tiene/ tenía} ese **[IF CARES FOR ADULT**: adulto / **IF CARES FOR CHILD ONLY**: menor**] [IF Q1=2 or REFUSED:** en el momento en que usted le brindó cuidado]?

Su mejor estimación está bien. **[IF CARES FOR CHILD ONLY**: *Si el menor tiene menos de un año, por favor escriba ‘0’.*

___ ___ ___ años de edad **[RECORD AGE IN YEARS; ALLOW 0 - 130]**

9. Y la persona que usted {cuida es/cuidaba era} …

Masculino	1
Femenino	2
Otro tipo de identidad	3

PROGRAMMING NOTE: Use Gender neutral pronouns throughout irrespective of answer to Q9 (1,2,3, OR REFUSED) “they/theirs/them”.

7. ¿A quién {está cuidando usted/ cuidaba usted}?

Por favor seleccione un parentesco.

[SHOW IF Q9=1]:	[SHOW IF Q9=2]:
PARIENTE:	PARIENTE:
Hermano2	Tía1
Cuñado3	Compañera / Pareja4
Compañero / Pareja4	Hija5
Padre6	Nieta8
Suegro7	Abuela10
Abuelo9	Abuela de su esposo/a11
Abuelo de su esposo/a 11	Madre13
Nieto12	Suegra14
Esposo20	Sobrina16
Sobrino15	Pareja del mismo sexo30
Pareja del mismo sexo30	Hermana17
Hijo19	Cuñada18
Tío21	Esposa20
NO PARIENTE:	NO PARIENTE:
Hijo adoptivo temporal (foster)23	Hija adoptiva temporal (foster)23
Amigo24	Amiga24
Vecino26	Vecina26
Otro [ESPECIFICAR___]22	Otro [ESPECIFICAR___]22

INSERT RESPONSE FROM Q7 ANYWHERE IT SAYS [Q7 CODE], EXCEPT FOR:
IF Q7=4 or 30 [Use "partner**"]**
IF Q7=22 OR REFUSED [Use "care recipient**"]**

11. ¿Dónde {vive/ vivía} su **[Q7 CODE]** live **[IF Q1=2 or REFUSED:** en el momento en que le brindaba los cuidados**]**?

En la casa de usted.. 1 **[SKIP TO Q15]**
A veinte minutos de su casa 2
Entre veinte minutos y una hora de su casa 3
De una a dos horas de su casa 4
A más de dos horas de su casa.. 5

13. **[IF NOT IN HOUSEHOLD (Q11=2 thru 5 OR REFUSED)]:** ¿Cuál de las siguientes mejor describe dónde su **[Q7 CODE]** {vive/vivía} en el momento en que le brindaba los cuidados?

En su propio hogar 1
En la casa de otra persona .... 2 **[SKIP TO Q15]**
IF CARES FOR ADULT: En una comunidad de vida
independiente o de retiro 3
IF CARES FOR ADULT: En un centro de residencia
donde se brindan algunos cuidados .... 4 **[SKIP TO Q15]**
En una institución de cuidado de enfermería o
de cuidados a largo plazo.. 5 **[SKIP TO Q15]**
IF CARES FOR CHILD ONLY: Un hogar grupal .... 10 **[SKIP TO Q15]**
IF CARES FOR CHILD ONLY: Hogar de acogida (Orfanato/Casa hogar/Foster)11 **[SKIP TO Q15]**
En algún otro lugar **[ESPECIFICAR ________]**.. 6

IF CARES FOR CHILD ONLY, SKIP TO Q15.

14c. **IF CARES FOR ADULT RECIPIENT AND IN OWN HOME, INDEPENDENT LIVING, ELSE, REFUSED (Q13: 1 OR 3 OR 6 OR REFUSED0, ASK:** ¿Su **[Q7 CODE]** {vive solo/a/vivía solo} **[IF Q1=2 or REFUSED:** a en el momento en que le brindaba los cuidados**]**?

Sí 1
No 2

15. ¿Su **[Q7 CODE]** vive en un área rural? **[IF Q1=2 or REFUSED:** vivía en un área rural en el momento en que le brindaba los cuidados?**]**?

Sí 1
No 2

D. CHARACTERISTICS OF RECIPIENT

17. ¿Diría usted que su **[Q7 CODE]** {necesita/necesitaba} cuidados debido a uno de los siguientes problemas…? **[MAINTAIN ORDER A-G]**

		Sí	**No**
a.	Afección física a corto plazo	1	2
b.	Afección física a largo plazo	1	2
c.	Problema de salud emocional o mental	1	2
d.	Desorden o retraso del desarrollo o intelectual	1	2
f.	Problema de comportamiento	1	2
g.	Problema de memoria	1	2

18. ¿Cuál {es/era} el principal problema o enfermedad que su **[Q7 CODE]** {tiene/tenía}, por el cual {necesita/necesitaba} su cuidado?

IF CARES FOR CHILD ONLY: ADD por sus siglas en inglés,
ADHD por sus siglas en inglés, trastorno de déficit de atención................ 1
IF CARES FOR ADULT: Alzheimer, demencia 3
IF CARES FOR ADULT: Artritis 5
IF CARES FOR CHILD ONLY: Asma 6
Autismo o trastorno de espectro autista 7
IF CARES FOR ADULT: Problemas de espalda 8
IF CARES FOR ADULT: Presión arterial, hipertensión......................................11
Daño cerebral (por ejemplo, tumor, encefalitis) 38
Lesión cerebral (por ejemplo, TCE, contusión)…………………………….…39
Huesos rotos o fracturados 13
Cáncer.. 14
Afección o discapacidad intelectual o de desarrollo..21
Diabetes 16
IF CARES FOR ADULT: Debilidad, inestabilidad, caídas 18
IF CARES FOR ADULT: Pérdida de capacidad auditiva, sordera.......................15
IF CARES FOR ADULT: Cardiopatía, ataque cardiaco.......................................19
IF CARES FOR ADULT: Enfermedad pulmonar, enfisema, COPD......................20
Enfermedad mental, enfermedad emocional, depresión 22
IF CARES FOR ADULT: VIH/SIDA 36
IF CARES FOR ADULT: Problema de movilidad, no puede moverse solo/a... 23
IF CARES FOR ADULT: Vejez, envejecimiento...24
IF CARES FOR ADULT: Parkinson 27
IF CARES FOR ADULT: Derrame cerebral 30
Trastornos de uso de sustancias 31
Cirugía, lesiones 32
Transplante………………………………………………………………….…..35
COVID-19…………………………………………………………………………37
IF CARES FOR ADULT: Pérdida de visión, ceguera, no puede ver bien.............10
Other **[SPECIFY REQUIRED:__________________]** 33
No estoy seguro/a...34

19. **[IF CARES FOR CHILD ONLY, ASK]:** ¿Como resultado de la afección de su **[Q7 CODE]**’s {se limita/se limitó} **[Q7 CODE]** en cualquier manera la capacidad de su **[Q7 CODE]** para hacer las cosas que hace la mayoría de los niños de la misma edad?

Sí 1
No 2

[IF CARES FOR CHILD ONLY AND NO LIMIT (Q19=2) AND NO CONDITIONS (Q17A=2 AND Q17B=2 AND Q17C=2 AND Q17D=2 AND Q17E=2 AND Q17F=2), TERMINATE.]

20a**.** **[IF CARES FOR ADULT AND ALZHEIMER’S NOT MENTIONED (Q18≠3)]** {¿Está /Estaba} su **[Q7 CODE]** viviendo con alguna de las siguientes condiciones que causan deterioro cognitivo? [Seleccione todas las que apliquen]

Enfermedad de Alzheimer 1
Demencia con cuerpos de Lewy 2
Demencia Frontotemporal (FTD, por sus siglas en inglés)..................... 3
Demencia vascular 4
Alguna otra condición que causa deterioro cognitivo 5
No 6 [exclusive]
No estoy seguro/a.. 7 [exclusive]

E. LENGTH OF CARE AND TASKS

21. **IF CARES FOR ADULT**: ¿Por cuánto tiempo {ha estado usted brindando cuidados /brindó cuidados] a su **[Q7 CODE]?**

IF CARES FOR CHILD ONLY: ¿Por cuánto tiempo {ha estado usted brindando cuidados/brindó cuidados} a su **[Q7 CODE]**, que supera las necesidades normales de atención para menores?

Su mejor estimación está bien.

___ ___ años **[ALLOW 1 - 93]**

Menos de seis meses... 96
De seis meses a un año 95
Toda su vida.. 94

22. **IF CARES FOR ADULT**: ¿Con cuál de estos usted {ayuda/ayudaba} a su **[Q7 CODE]** ?

IF CHILD RECIPIENT (IF CARES FOR CHILD ONLY): ¿Con cuál de estos usted {ayuda/ayudaba} a su **[Q7 CODE]** debido a que ellos {son/eran} menos aptos para realizar esta tarea que menores de la misma edad que no tienen esa afección?

[RANDOMIZE A-F ORDER; ALWAYS SHOW G LAST]

	ADL list	**Sí**	**No**
a.	**[IF CARE RECIPIENT IS 3+ YEARS (Q5>2):** Acostarse y levantarse de la cama, sentarse y levantarse de sillas	1	2
b.	**[IF CARE RECIPIENT IS 4+ YEARS (Q5>3):** Vestirse	1	2
c.	**[IF CARE RECIPIENT IS 4+ YEARS (Q5>3):** Movilización al y del inodoro	1	2
d.	**[IF CARE RECIPIENT IS 6+ YEARS (Q5>5):** Bañarse o ducharse	1	2
e.	**[IF CARE RECIPIENT IS 4+ YEARS (Q5>3):** Lidiar con incontinencia o pañales	1	2
f.	**[IF CARE RECIPIENT IS 3+ YEARS (Q5>2):** Proceso de alimentación	1	2
g.	Proceso de alimentación	1	2

N1. **[IF DOES ADLS (ANY Q22a thru Q22f = 1)]:** ¿Qué tan difícil {es/fue} para usted ayudar a su **[Q7 CODE]** con {estas/aquellas} clases de tareas?? **[ROTATE 1-5/5-1]**

1 - Nada difícil ....
2.. 2
3.. 3
4.. 4
5 – Muy dificil.. 5

23. Usted {ayuda/ayudaba} a su **[Q7 CODE]** con…**[RANDOMIZE ITEMS A-F]**

		Sí	**No**
a.	La administración de las finanzas, tales como pagar facturas o completar formularios de seguro	1	2
b.	**IF CARES FOR ADULT:** Hacer las compras de alimentos y artículos para la casa	1	2
c.	**IF CARES FOR ADULT:** Tareas de la casa, tales como lavar los platos, la ropa, o arreglar la casa	1	2
d.	**IF CARES FOR ADULT:** Preparación de las comidas	1	2
e.	**IF CARES FOR ADULT:** Transporte, llevándolos en un automóvil, o ayudándolos a obtener transporte	1	2
f.	La coordinación de servicios de agencias, tales como enfermeras o ayudantes de cuidado en casa, o “Meals on Wheels”	1	2

23_1.Y usted {ayuda/ayudaba} a su **[Q7 CODE]** al…**[RANDOMIZE ITEMS A-C]**

		Sí	**No**
a.	Abogar por ellos con prestadores de servicios de salud, servicios comunitarios, **[IF CARES FOR CHILD ONLY**: escuelas,**]** o agencias gubernamentales	1	2
b.	Seguir de cerca la gravedad de la afección para que usted {pueda/pudiera} hacer los ajustes correspondientes a los cuidados	1	2
c.	Comunicarse con profesionales de la salud, tales como doctores, enfermeras o trabajadores sociales acerca de su cuidado	1	2

25. Teniendo en cuenta todas las clases de ayuda que usted {brinda/ brindó} a su **[Q7 CODE]**, ¿aproximadamente cuántas horas {pasa/pasaba} ayudándolos en una semana promedio?

___ ___ ___ horas **[ALLOW 1-168]**

Menos de 1 hora por semana..169
Cuidado constante 170

25Z. **[IF CONSTANT CARE (Q25=168 or 170), ASK]:** Quisiéramos entender un poco más a gente como usted que {tiene que brindar/brindó} cuidado constante.

¿Cuál de las siguientes declaraciones describe de mejor forma el cuidado o la ayuda que usted {tiene que brindar/brindó} a su **[Q7 CODE]**, debido a sus afecciones en una semana normal? {Presta/prestó} cuidados…

Todo el tiempo: 24 horas al día, 7 días a la semana..............................1
Casi todo el tiempo, descansando de vez en cuando 2
Casi todo el tiempo, descansando para dormir 3
Intermitentemente durante todo el día..4
Otro **(ESPECIFIQUE) [Textbox]**..5

N3. ¿Usted {Ayuda/ayudaba} a su **[Q7 CODE]** con cualquier tarea médica/de enfermería?

Tareas medicas/de enfermería: Esto puede incluir dando medicinas tales como pastillas, gotas de ojos, o inyecciones, preparando comida para dietas especiales, alimentaciones por tubo, o cuidado de lesiones. Usted podría estar monitoreando cosas tales como presión arterial o azúcar en la sangre, ayudando con incontinencia, u equipo operativo como camas de hospital, sillas de ruedas, tanques de oxígeno, nebulizadores o manga de succión.

Sí 1
No 2
No estoy seguro/a.. 3

IF CARES FOR ADULT AND NO/DK/REF TO ADLS (ALL Q22a thru f > 1) AND IADLS (Q22G>1 and ALL Q23a thru f > 1) AND Medical/Nursing (N3>1), THEN TERMINATE AS NON CAREGIVER.

N4. ¿Qué tan fácil o difícil {es/fue} para usted realizar las tareas médicas/de enfermería que {son/eran} necesarias para ayudar a su **[Q7 CODE]? [ROTATE 1-5/5-1]**

[HOVER DEFINITION FOR UNDERLINED TEXT ABOVE] Tareas médicas/de enfermería incluyen: dar medicinas tales como pastillas, gotas de ojos, o inyecciones, preparar comida para dietas especiales, alimentaciones por tubo, o cuidado de lesiones, monitorear cosas tales como presión arterial o azúcar en la sangre, ayudando con incontinencia, u equipo operativo como camas de hospital, sillas de ruedas, tanques de oxígeno, nebulizadores o manga de succión.

Muy fácil	1
Algo fácil	2
Ni fácil ni difícil	3
Algo difícil	4
Muy difícil	5

IF DOES MEDICAL/NURSING TASK (N3=1)

N5. ¿Alguien lo/a entrenó para hacer estas tareas?

Sí	1
No	2 **[SKIP TO N11]**
No estoy seguro/a	3 **[SKIP TO N11]**

IF SOMEONE PREPARED FOR TASKS (N5=1)

N6. ¿Quién lo/a entrenó para hacer las tareas necesarias para ayudar a su **[Q7 CODE]?** [Seleccione a todos los que ayudaron]

Doctor/médico	2
Enfermero/a practicante o Asistente Médico	3
Enfermero/a	4
Trabajador social / administrador de cuidados geriátricos	5
Terapeuta físico	6
Terapeuta ocupacional	7
Farmacéutico	8
Técnico/a de suministros médicos	9
Amigo/a o vecino/a	10
Videos en línea (*por ejemplo, YouTube)	11
Grupo de apoyo (incluye en línea o en persona)	12
Otro [ESPECIFIQUE]	13

IF SOMEONE PREPARED CAREGIVER FOR MEDICAL/NURSING TASKS (N5=1)

N7. ¿Qué tan bien siente usted que el entrenamiento lo/a preparó para hacer estas tareas médicas/de enfermería? **[ROTATE 1-3/3-1]**

Muy bien.. 1
Algo bien 2
No muy bien.. 3
No estoy seguro/a... 4

N11. ¿Recibió algún entrenamiento o preparación para asistir con actividades de la vida diaria (ADL, por sus siglas en inglés), actividades instrumentales de la vida diaria (IADL, por sus siglas en inglés) o manejo/modificación del comportamiento para su **[Q7 CODE]?**

Sí 1
No 2 **[SKIP TO N9]**
No estoy seguro .... 3 **[SKIP TO N9]**

[HOVER DEFINITION FOR UNDERLINED TEXT ABOVE] "activities of daily living:" Asistencia con actividades de la vida diaria incluye asistencia en ayudar a alguien con tomar un baño, vestirse, comer, caminar y usar el sanitario.

"instrumental activities of daily living": Asistencia con actividades instrumentales de la vida diaria incluye ayudar a alguien a cocinar, comprar abarrotes, transportarse, trabajo en el hogar, manejar los medicamentos y las finanzas.

IF SOMEONE PREPARED CAREGIVER FOR ADL/IADL TASKS (N11=1)

N17. ¿Quién lo preparó para asistir a su [Q7 CODE] con actividades de la vida diaria (ADL, por sus siglas en inglés), actividades instrumentales de la vida diaria (IADL, por sus siglas en inglés) o manejo/modificación del comportamiento? [Seleccione a todos los que ayudaron]

Doctor/médico …………………………………………………….2

Enfermero/a practicante o Asistente Médico... 3
Enfermero/a o Especialista en Enfermería Clínica 4
Trabajador social / administrador de cuidados geriátricos....................... 5
Terapeuta físico.. 6
Terapeuta ocupacional.. 7
Farmacéutico.. 8
Técnico/a de suministros médicos... 9
Grupo de apoyo (incluye en línea o en persona)................................. 10
Psicólogo/a clínico.. 11
Patólogo de habla/lenguaje 12
Otro profesional de la salud 13

[HOVER DEFINITION FOR UNDERLINED TEXT ABOVE] “activities of daily living:” Asistencia con actividades de la vida diaria incluye asistencia en ayudar a alguien con tomar un baño, vestirse, comer, caminar y usar el sanitario.

“instrumental activities of daily living”: Asistencia con actividades instrumentales de la vida diaria incluye ayudar a alguien a cocinar, comprar abarrotes, transportarse, trabajo en el hogar, manejar los medicamentos y las finanzas.

N9. En los últimos 12 meses **[IF Q1=2 or refused:** en los que estaba cuidando de él/ella**]**, ¿cuántas veces su **[Q7 CODE]** pasó la noche hospitalizado/a?

Ninguna.. 1
Una vez 2
2 veces... 3
3 o más veces.. 4
No estoy seguro/a.. 5

IF HOSPITALIZED OVERNIGHT (N9=2, 3, OR 4)

N10.Cuando su **[Q7 CODE]** estaba en el hospital, ¿fue incluido/a por los trabajadores de la salud, como enfermeros/as, doctores, trabajadores sociales, en discusiones sobre el cuidado de su **[Q7 CODE],** tales como discusiones sobre darlo(a) de alta, planeaciones o planes de cuidado dentro del hospital?

Sí…………………………………………………………………1

No 2
No estoy Seguro/a 3

F.OTHER CAREGIVER SUPPORT

28. ¿Alguien más le ha brindado ayuda gratuita a su **[Q7 CODE]** durante los últimos doce meses?

Sí ………………………………………………………………………..1

No.. 2 **[SKIP TO Q30]**

29. **IF HAS OTHER UNPAID HELP (Q28=1):** ¿Quién considera usted que ha sido la persona que {brinda/ brindó} la mayoría de los cuidados gratuitos a su **[Q7 CODE]**?

Yo (mismo/a) 1
Alguna otra persona.. 2
Lo repartimos igualmente 3

29Z. **IF HAS OTHER UNPAID HELP (Q28=1):** ¿ De toda las personas que {ayudan a brindar/brindaron} atención para su **[Q7 CODE]**, {son/eran} algunos de ellos menores bajo la edad de 18 años?

Ellos podrían {ayudarle o darle asistencia/haberle ayudado o haberle dado asistencia} a usted con el cuidado que usted {brinda/brindaba**}**. Los menores también podrían {ayudar/haber ayudado**}** con cosas tales como traer cosas de o a su **[Q7 CODE]**, hacer tareas u otros trabajos del hogar, hacer mandados, o en general, ayudar a cuidar a su **[Q7 CODE]**.

Sí	1
No	2

30. Durante los últimos doce meses, ¿su **[Q7 code]** recibió ayuda <u>pagada</u> de parte de algún ayudante, ama de llaves u otras personas que recibieron dinero por ayudarle?

Sí	1
No	2

38. Piense en todos los profesionales o proveedores de servicios de salud que {dan/dieron} cuidado o tratamiento a su **[Q7 CODE]**. ¿Qué tan fácil o difícil {es/fue} para usted coordinar el cuidado entre esos proveedores? **[ROTATE 1-4/4-1]**

Muy fácil	1
Algo fácil	2
Algo difícil	3
Muy difícil	4
[IF Q28=1: No aplicable: alguien más lo {hace/hizo} this**]**	7

G. PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING

35. ¿Qué tanta <u>tensión física</u> diría que usted {sufre/ sufrió} a causa de cuidar a su **[Q7 CODE]**? **[ROTATE 1-5/5-1]**

1 - Nada de tensión	1
2	2
3	3
4	4
5 – Mucha tensión	5

36. ¿Qué tanta <u>tensión emocional</u> diría que usted {sufre/ sufrió} a causa de cuidar a su **[Q7 CODE]**?

1 - Nada de tensión	1
2	2
3	3
4	4
5 – Mucha tensión	5

37B. ¿Qué tanta tensión financiera diría usted que {tiene/ tenía} a causa de cuidar a su **[Q7 CODE]** ? **[ROTATE 1-5/5-1]**

1 - Nada de tensión	1
2	2
3	3
4	4
5 – Mucha tensión	5

D1. {¿Cómo describiría usted su propio estado de salud?**/**Cuando estaba brindado cuidado la última vez, ¿su propio estado de salud era…}?

Excelente	5
Muy bueno	4
Bueno	3
Regular	2
Malo	1

H1. Ahora pensando en su salud física, lo cual incluye enfermedad física y lesiones, ¿por cuantos días durante los últimos 30 días, su salud física no fue buena? Su mejor estimado está bien. [Número de días].

____________ Número de días **[range 0-30]**

H2. Ahora pensando en su salud mental, lo cual incluye estrés, depresión y problemas con sus emociones, ¿por cuantos días durante los últimos 30 días, si salud mental no fue buena? Su mejor estimado está bien. [Número de días].

____________ Número de días **[range 0-30]**

H3. Durante los últimos 30 días, ¿por alrededor de cuantos días su mala salud física o mental evitó que usted hiciera sus actividades usuales, como cuidado propio, trabajo o recreación? Su mejor estimado está bien. [Número de días].

____________ Número de días **[range 0-30]**

39.¿ Ahora tenemos algunas preguntas sobre usted. ¿Está actualmente empleado?**[Q7 CODE]**?

Sí	1
No	2

M5. ¿En qué medida usted está de acuerdo o en desacuerdo con cada una de las siguientes declaraciones en referencia a ser la persona que brinda cuidado para su **[Q7 CODE]**? **[RANDOMIZE ORDER OF ITEMS A-C]**

		En desacuerdo fuertemente	En desacuerdo	Ninguno	De acuerdo	De acuerdo fuertemente
a.	Mi rol como persona que brinda cuidado {da/dio} un sentido de propósito y significado a mi vida	1	2	3	4	5
b.	{Me parece/Me pareció} difícil cuidar de mi propia salud	1	2	3	4	5
c.	{Me siento/Me sentí} solo	1	2	3	4	5

H.WORKING CAREGIVERS

32A.Ahora tenemos algunas preguntas sobre usted. ¿Está actualmente empleado?

Sí 1
No 2

IF CURRENT CG (Q1=1) AND CURRENTLY WORKING (Q32A=1), SKIP TO N13.

33. {¿Ha estado/¿Estaba**]** trabajando en cualquier momento durante el último año mientras ayudaba a su **[Q7 CODE]**?

Sí 1
No .... 2 **[SKIP TO M2]**

[IF Q33=1]: Para las siguientes preguntas, por favor piense acerca del momento más reciente durante el último año cuando usted estaba trabajando y brindando cuidado a su **[Q7 CODE].**

N13. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]:** ¿Alrededor de cuántas horas a la semana, en promedio, trabaja usted?

___ horas a la semana

N13_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]:** La última vez que estaba trabajando y ayudando a su [**Q7 CODE**], ¿alrededor de cuántas horas a la semana, en promedio, trabajó usted?

___ horas a la semana **[RANGE 1-80]**

33Z. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]:** ¿Recibe usted?

33Z_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]:** ¿Recibió usted?

Un salario..1
Una tarifa por hora por el tiempo que usted trabajó..........2
Algún otro beneficio (ESPECIFIQUE) **[TEXTBOX]**...........3

N14. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1):** En ese momento, ¿su supervisor sabía que usted estaba brindando cuidado a su **[Q7 CODE]**?

N14_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1):** En ese momento, ¿su supervisor sabía que usted estaba brindando cuidado a su **[Q7 CODE]**?

Sí	1
No	2
No estoy seguro/a	3
N/A, trabajo por mi propia cuenta	4

N16. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1):** ¿Cuál de las siguientes opciones ofrece su empleador para empleados en su trabajo en posiciones o roles similares al suyo?

[RANDOMIZE ITEMS A-C; KEEP E-D-F LAST AND IN THAT ORDER]

		Sí	**No**
a.	Horas de trabajo flexibles	1	2
b.	Trabajando a distancia o de casa	1	2
c.	Programas tales como información, referencia, terapia o un programa de asistencia al empleado, para ayudar a personas que brindan cuidados como usted	1	2
d.	Permiso remunerado para ausentarse para estar con su familia, mediante el cual usted puede tomar un descanso extendido de su trabajo (durante semanas) para cuidar a un familiar enfermo	1	2
e.	Días remunerados de descanso por enfermedad, mediante los cuales usted puede descansar de su trabajo con una remuneración por horas o días para brindar cuidado o para ir a citas médicas con un familiar enfermo	1	2
f.	Permiso no remunerado para estar con su familia, mediante los cuales usted puede tomar períodos de descanso extendidos (durante semanas) sin ninguna remuneración para brindar cuidado a un familiar enfermo	1	2

N16_1. La última vez que estuvo trabajando y brindando cuidado a su **[Q7 CODE]**, para empleados en su trabajo con posiciones o roles similares al suyo, ¿cuál de los siguientes ofreció su empleador?

		Sí	**No**
a.	Horas de trabajo flexibles	1	2
b.	Trabajando a distancia o de casa	1	2
c.	Programas tales como información, referencia, terapia o un programa de asistencia al empleado, para ayudar a personas que brindan cuidados como usted	1	2
d.	Permiso remunerado para ausentarse para estar con su familia, mediante el cual usted puede tomar un descanso <u>extendido</u> de su trabajo (durante semanas) para cuidar a un familiar enfermo	1	2
e.	Días remunerados de descanso por enfermedad, mediante los cuales usted puede descansar de su trabajo con una remuneración por horas o días para brindar cuidado o para ir a citas médicas con un familiar enfermo	1	2
f.	Permiso no remunerado para estar con su familia, mediante los cuales usted puede tomar períodos de descanso extendidos (durante semanas) sin ninguna remuneración para brindar cuidado a un familiar enfermo	1	2

34. **[IF WORKING CAREGIVER (Q32A=1 OR Q33=1), ASK]:** As a result of caregiving, did you ever experience any of these things at work? **[RANDOMIZE ITEMS A-I]**

		Sí	**No**
a.	Ha tenido que llegar al trabajo tarde, salir más temprano, o pedir permiso durante el día para brindar cuidado	1	2
b.	Ha pedido permiso o licencia en el trabajo para estar ausente	1	2
c.	Ha tenido que cambiar de un trabajo de tiempo completo a uno de tiempo parcial, o ha tenido que reducir las horas de trabajo	1	2
d.	Ha rechazado un ascenso o una promoción	1	2
e.	Ha perdido cualquiera de los beneficios otorgados por su empleo	1	2
f.	Ha tenido que dejar de trabajar completamente	1	2
g.	Se ha retirado anticipadamente	1	2
h.	Ha recibido una advertencia acerca de su desempeño o asistencia al trabajo	1	2

M2. **[IF NOT WORKING OR NOT WORKED IN PAST YEAR (Q33 NE 1)]:** ¿Estuvo trabajando o tuvo un trabajo <u>durante cualquier período de tiempo</u> en que usted **{**ha estado brindando/ brindaba} cuidado a su?

Sí 1
No 2

N15. **[IF LEFT (Q34b=1 OR Q34f=1 OR Q34g=1)] OR HAD A JOB AT SOME POINT IN THE FAR PAST (M2=1):** ¿Por qué dejó su empleo, se tomó un permiso de ausencia o decidió no trabajar de cualquier otra forma, mientras brindaba cuidado? **[RANDOMIZE ITEMS 1-4; ALLOW MULTIPLE RESPONSE]**

Select all answers that apply.

Necesitaba más tiempo para cuidar a su **[Q7 code]** 1
No podía pagar por cuidado para su **[Q7 code]** 2
El empleo no le permitía horas de trabajo flexibles 3
El empleo no le permitía tomar tiempo con sueldo pagado 4
Otra razón **[ESPECIFICAR:________________________]** 5

M3. ¿Sintió alguna vez que sus responsabilidades como persona que brinda cuidado conllevaron a que se le penalice o discrimine en el trabajo?

Sí 1
No 2
No estoy seguro 3

I.INFORMATION/SERVICES/POLICY

45. En su experiencia como persona que brinda cuidados, ¿alguna vez...? **[RANDOMIZE ORDER A-F]**

		Sí	**No**
a.	Ha pedido información sobre cómo obtener ayuda financiera para su **[Q7 CODE]**	1	2
b.	Ha usado un servicio de relevo o de acompañante para cuidar de su **[Q7 CODE]** para tomar un descanso	1	2
c.	Ha utilizado un servicio externo que transporte a su **[Q7 CODE]** en vez de transportarlo/la usted mismo/a	1	2
d.	Hizo modificaciones en la casa o departamento en donde su **[Q7 CODE]** {vive/vivía} para facilitarle las cosas	1	2
e.	Un doctor, enfermera o trabajador social le preguntó lo que usted {necesita/necesitaba} para ayudarle a brindar cuidado a **[Q7 CODE]**	1	2
f.	Un doctor, enfermera o trabajador social le preguntó lo que usted **[IF Q1=1, INSERT:** necesita / **IF Q1=2 OR REFUSED, INSERT:** necesitaba**]** para cuidarse a usted mismo/a	1	2

N19. ¿Qué tan difícil {es/fue} obtener servicios al alcance del bolsillo en el área o comunidad local de su **[Q7 CODE]** que le {ayuden/hubieran ayudado} a cuidar a su **[Q7 CODE]**, como comidas entregadas, transportación o servicios de salud en casa? **[ROTATE 1-5/5-1]**

1 – Nada difícil.. 1
2... 2
3... 3
4... 4
5 – Muy difícil 5

N20. Distintas organizaciones están pensando acerca de las maneras de ayudar a personas que brindan cuidados como usted. ¿Cuál de las siguientes considera que {sería/ hubiera sido} de ayuda para usted? **[RANDOMIZE ITEMS 4-6; ALLOW MULTIPLE RESPONSE]**

Select all answers that apply.

Tener servicios de relevo disponibles, donde alguien {cuide/hubiera cuidado} de su **[Q7 code]** para darle a usted un descanso..4
Exigir a un doctor, enfermera o trabajador social preguntarle acerca de lo que {necesita/necesitaba**}** para cuidar de su **[Q7 code]**.................................5
Exigir a un doctor, enfermera o trabajador social preguntarle lo que usted **{**necesita/necesitaba**}** para cuidarse a sí mismo/a....................................6
Ninguno de los anteriores 7

M11. En su experiencia como persona que brinda cuidados para su [**Q7 CODE]**, ¿alguna vez realizó alguna de las siguientes actividades utilizando tecnología o software?

[RANDOMIZE ITEMS A-E]

		Sí	**No**	**Not Aplica**
a.	Creó listas electrónicas u hojas de cálculo para monitorear las actividades relacionadas con proporcionar cuidado para su **[Q7 CODE]**	1	2	3
b.	Monitoreó a su **[Q7 CODE]** utilizando una aplicación, sistemas de vídeo, dispositivos portátiles que pueden usarse como artículo de vestir, u otro tipo de monitoreo remoto	1	2	3
c.	Monitoreó los registros médicos personales de su **[Q7 CODE]**	1	2	3
d.	Monitoreó las finanzas de su **[Q7 CODE]**	1	2	3
e.	Obtuvo o utilizó dispositivos de asistencia para cosas tales como problemas visuales o auditivos de su **[Q7 CODE]**	1	2	3

48. ¿De cuál de los siguientes temas siente usted que {necesita/necesitaba**}** más ayuda o información? ? **[RANDOMIZE ITEMS A-Q]**

Select all that apply.

		Sí
a.	Mantener a su **[Q7 CODE]** seguro en el hogar	1
b.	Manejar comportamientos difíciles de su **[Q7 CODE]**, tales como deambular	1
c.	Actividades que usted {podría realizar/pudo haber realizado} con su **[Q7 CODE]**	1
r.	Escoger una agencia de atención en el hogar, un centro de vida asistida o un asilo de ancianos	1
l.	Manejar su estrés emocional o físico	1
m.	Tomar decisiones relacionadas con el final de la vida	1
n.	Encontrar materiales educacionales en otros idiomas aparte del inglés	1
o.	Descifrar el funcionamiento de formularios, trámites o servicios de elegibilidad o de apoyo para su **[Q7 CODE]**	1
p.	Administrar o manejar sus propias finanzas personales	1
q.	Usar la tecnología para proveer cuidado a su **[Q7 CODE]**	1
s.	Otro tema (ESPECIFICAR)	1
t.	Ninguna de las opciones anteriores	1

N21. **IF CARES FOR ADULT**: {¿Tiene/¿Tenía} su **[Q7 CODE]** planes determinados para su cuidado futuro, tales como instrucciones para el manejo de asuntos financieros, decisiones de salud, o lugares dónde residir?

IF CARES FOR CHILD ONLY BUT NOT CARING FOR OWN CHILD (Q7 NE 5 AND Q7 NE 19): {¿Tiene/¿Tenía} la familia de su **[Q7 CODE]** planes para su cuidado futuro, tales como instrucciones para administrar asuntos financieros, decisiones de atención médica, o lugares dónde residir?

IF CARES FOR CHILD ONLY AND CARING FOR OWN CHILD (Q7=5 OR Q7=19): {¿Tiene/¿Tenía} usted planes para el cuidado de su **[Q7 CODE]** en el futuro, tales como instrucciones para administrar asuntos financieros, decisiones de atención médica, o lugares dónde residi?

Sí 1
No 2
No estoy seguro/a.. 3

N22. ¿Tiene usted sus <u>propios</u> planes para su propio cuidado futuro, tales como manejo de asuntos financieros, decisiones de salud o lugares dónde residir?

Sí 1
No 2

M6. ¿Experimentó usted en alguna ocasión cualquiera de las siguientes situaciones financieras como resultado del cuidado brindado a su **[Q7 CODE]**? **[KEEP ORDER AS SHOWN]**

		Sí	**No**	**Not Aplica**
a.	Incurrió en más deudas (tarjetas de crédito, préstamos, líneas de crédito)	1	2	3
b.	No pudo pagar o pago retrasadamente un préstamo estudiantil	1	2	3
c.	Pidió dinero prestado de familiares o amigos	1	2	3
d.	Se declaró en bancarrota (médica o personal)	1	2	3
e.	No pudo pagar gastos básicos tales como comida	1	2	3
f.	No pudo pagar sus cuentas o las pagó tarde	1	2	3
g.	Utilizó sus ahorros personales a corto plazo	1	2	3
h.	Utilizó sus ahorros a largo plazo, tales como de retiro o de educación, para pagar por otras cosas	1	2	3
i.	Dejó de ahorrar	1	2	3
j.	Se mudó a un hogar, departamento u otro tipo de residencia de menor costo	1	2	3
k.	Fue desalojado o ejecutaron la hipoteca de uno de sus hogares	1	2	3
l.	Pospuso sus planes para retirarse o decidió no retirarse nunca	1	2	3
m.	Tuvo que empezar a trabajar, tuvo que trabajar más, o tuvo que encontrar un segundo empleo	1	2	3

M9. A continuación hay algunas maneras que personas están proponiendo para ayudar financieramente a personas que brindan cuidados. ¿Cuán útil {le parecería/le hubiera parecido } cada una? **[RANDOMIZE ORDER OF ITEMS A-C]**

		Muy útil				**Nada útil**
a.	Un crédito sobre el impuesto de la renta para personas que brindan cuidados, para ayudar a compensar el costo de los cuidados	5	4	3	2	1
b.	Un permiso de ausencia laboral parcialmente pagada, para personas que brindan cuidados que se encuentren empleadas	5	4	3	2	1
c.	Un programa donde las personas que brindan cuidados puedan recibir pago por lo menos respecto a algunas de las horas por las cuales brindan cuidado	5	4	3	2	1

PROGRAMMING NOTE: CREATE A COUNT VARIABLE COUNTM9 OF ALL MENTIONS IN M9 WHERE ITEM IS 3 OR HIGHER.

J.DEMOGRAPHICS

Y finalmente, tenemos unas cuantas preguntas únicamente para cuestiones de clasificación. [**FOR KNOWLEDGEPANEL RESPONDENTS, ADD]** Estas preguntas son para asegurarnos que tenemos nuestra información actualizada, aunque puede ser que ya haya respondido algunas de estas preguntas anteriormente.

M10. Estas preguntas son para asegurarnos que tenemos nuestra información actualizada, aunque puede ser que ya haya respondido algunas de estas preguntas anteriormente. **[Q7 CODE]**, ¿era usted también estudiante, a tiempo completo o parcial?

Sí……………………………………………………………………………….1

No 2

M12. {Tiene usted actualmente/Tenía usted en el momento en que brindó cuidado,} algún tipo de cobertura de seguro o plan médico?

Sí……………………………………………………………………………….1

No 2

M13. **[IF SÍ (M12=1)]:** ¿Qué tipo de seguro o cobertura médica {tiene/tenía}? Por favor seleccione su fuente principal de seguro médico.

Un plan de un empleador (suyo o de un familiar) 1
Un plan comprado directamente (de una compañía de seguros, utilizando un agente, o
por medio de un mercado)...2
Medicare (estándar, suplementaria y/o Medicare Advantage) 3
Cobertura de Medicaid facilitada por su estado..4
Atención médica militar (Tricare, VA, Champ)..5
Otro tipo de cobertura (ESPECIFICAR) **[TEXTBOX]**...................................... 6
No estoy seguro... 7
No tengo seguro médico..8

D3.{¿Está usted actualmente…?/Cuando usted estaba brindando cuidados, ¿estaba usted…?}

Casado/a 1
Viviendo con una pareja 2
Viudo/a 3
Separado/a 4
Divorciado/a 5
Soltero/a, nunca casado/a 6
Prefiero no responder.. 8

D6. {¿Hay niños o nietos menores de 18 años de edad que viven en su hogar/ La última vez que estaba brindando cuidados, ¿había niños o nietos menores de 18 años de edad que vivían en su hogar} **[IF CARING FOR CHILD LIVING IN CG’S HOME (Q11=1), INSERT:** además de su **[Q7 CODE]]**?

Sí 1
No 2
Prefiero no responder.. 4

D4. ¿Alguna vez sirvió en servicio active en las Fuerzas Armadas de los Estados Unidos?

Esto incluye Ejército (Army), Marina (Navy), Fuerza Aérea (Air Force), Infantería de Marina (Marines), Guardacostas (Coast Guard), Fuerzas Armadas de Mujeres (Women's Armed Forces), Fuerza Espacial (Space Force), Guardia Nacional (National Guard) o Reservas.

Sí 1
No 2
No sé 3

D6b. Cuando estaba brindado cuidados, ¿tenía acceso a internet de cualquier tipo en su hogar? Por favor incluya dial-up, banda ancha cable o acceso a internet a través de un teléfono inteligente (smartphone).

Sí………………………………………………………………………1

No 2

D5. **IF CARES FOR ADULT**: ¿Su **[Q7 CODE]** ha servido alguna vez en las Fuerzas Armadas de los EEUU?

Esto incluye Ejército (Army), Marina (Navy), Fuerza Aérea (Air Force), Infantería de Marina (Marines), Guardacostas (Coast Guard), Fuerzas Armadas de Mujeres (Women's Armed Forces), Fuerza Espacial (Space Force), Guardia Nacional (National Guard) o Reservas.

Sí 1
No 2
No estoy seguro/a 3

D14. ¿Alguna discapacidad o minusvalía evita que usted participe completamente en el trabajo, escuela, tareas del hogar u otras actividades?
Sí 1
No 2

D10. Si se presenta la oportunidad, ¿estaría interesado en participar en futuras investigaciones acerca de las personas que brindan cuidados?

Si usted acepta que lo contacten, Ipsos facilitará su nombre, dirección de correo electrónico, así como algunas de sus respuestas referentes a esta encuesta con AARP y la Alianza Nacional para la Prestación de Cuidado (National Alliance for Caregiving), que pueden ponerse en contacto con usted si es que y cuando realicen seguimiento a la investigación sobre la prestación de cuidados. Esto es completamente opcional.

Sí 1
No/Se niega 2

Appendix B. Detailed methodology

The *Caregiving in the US 2025* report is based on the 2025 cycle of the repeated, cross-sectional *Caregiving in the US* survey. The *Caregiving in the US* study began in 1997 and, since 2004, the survey has been fielded every five years with a new sample of family caregivers. This study of family caregivers of adults and children with disabilities or serious health conditions was fielded with adults ages 18 and older, using Ipsos' national, probability-based online KnowledgePanel as well as an opt-in sample. The final study includes 6,858 completed surveys, 5,106 from KnowledgePanel® and 1,752 opt-in respondents.

The following sections describe the *Caregiving in the US 2025* study's research and sample design, weighting, response rate, and sample demographics.

A. Research design

The design of this study aims to estimate the prevalence of family caregiving for children and adults with disabilities or serious medical conditions in the US and to describe the characteristics, roles, and needs of family caregivers. For the purposes of this survey, family caregiving is defined as providing ongoing supports and management of complex care tasks for children and adults with chronic, disabling, or serious health conditions.

All respondents are screened for their age and eligible family caregiver status. This allows estimation of the national prevalence of caregiving for persons of any age (children and/or adults with disabilities or serious medical conditions) among adults in the US. Respondents who indicate they are age 18 or older and provide regular caregiving, in line with the definition above, then respond to the full survey online.

In previous cycles of this survey, survey respondents had to be unpaid family caregivers. In recognition of the expanded availability of programs allowing family caregivers to receive some form of payment for their care, the *Caregiving in the US 2025* survey expanded the eligibility criteria to include family caregivers of adults who were receiving payment for care.[1,2] Payments to family caregivers could include those received from self-directed programs under Medicaid, Veterans Affairs, or other state programs. Paid family caregivers do not include professional paid caregivers–those employed full time as direct care workers, such as home health aides or assistants, in home or community-based settings or in facility settings.

Areas of focus for the 2025 iteration of *Caregiving in the US* include training and preparation for caregiving tasks, physical and mental health of the caregiver, support and service needs, financial impacts of caregiving, and issues faced by working caregivers.

The 2025 administration of *Caregiving in the US* was submitted for Institutional Review Board review with BRANY IRB and received an exempt determination.

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[1] Priya Chidambaram and Alice Burns, "How Many People Use Medicaid Long-Term Services and Supports and How Much Does Medicaid Spend on Those People?," Kaiser Family Foundation, August 14, 2023, https://www.kff.org/medicaid/issue-brief/how-many-people-use-medicaid-long-term-services-and-supports-and-how-much-does-medicaid-spend-on-those-people/.

[2] S. Reinhard et al., "Innovation and Opportunity: A State Scorecard on Long-Term Services and Supports for Older Adults, People With Physical Disabilities, and Family Caregivers, 2023 Edition," AARP, 2023, https://doi.org/10.26419/ppi.00203.001.

B. Questionnaire design

The 2025 questionnaire is based on the *Caregiving in the US 2020* questionnaire. Most of the questions from prior administrations of this survey were maintained to show changes in the caregiver population over time. The 2025 questionnaire is shown in appendix A.

First, respondents had to agree to participate in this study. They were presented with an informed consent statement before the start of the survey. The informed consent statement outlined information about the study, including sponsorship, benefits to participating, ability to skip or withdraw, confidentiality, and data use. It also provided points of contact for both National Alliance for Caregiving and the Biomedical Research Alliance of New York Institutional Review Board.

The screener establishes whether a respondent is an unpaid family caregiver for an adult, a paid family caregiver of an adult, a family caregiver of a child under age 18 with disabilities or serious medical conditions, or not a caregiver. The screening questions used to identify the status of a family caregiver are as follows:

To identify the unpaid family caregiver of an adult:

> *At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?*
>
> *This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult does not need to live with you.*

To identify the family caregiver of an adult who receives some form of payment:

> *At any time in the last 12 months, has anyone in your household gotten paid to provide care to a relative or friend 18 years or older to help them take care of themselves?*
>
> *This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.*
>
> *Hover-over definition for "paid to provide care": Paid care includes payments to caregivers through self-directed programs under Medicaid, Veteran's Affairs, or other state programs. Paid care does not include those employed full-time as direct care workers, such as home health aides or assistants, in a home or community-based settings or facility setting.*

To identify those caring for a child with disabilities or a serious medical condition:

> *In the last 12 months, has anyone in your household provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability?*
>
> *This kind of unpaid care is more than the normal care required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.*

If the respondent reported they were not a caregiver but reported that someone else in the household was a caregiver, the survey ended after obtaining the demographic data (if the respondent was part of the opt-in sample and not in the KnowledgePanel®). If the respondent was a family caregiver of an adult or a family caregiver of both an adult and a child, the respondent was administered the questionnaire about their caregiving experience for the adult. If the respondent was a family caregiver of a child only, they were administered the questionnaire about their caregiving experience for the child. Only one family caregiver per household was surveyed.

Respondents who self-identified as a family caregiver (paid or unpaid) were validated as being a caregiver of an adult if they report providing help with at least one activity of daily living (ADL), instrumental activity of daily living (IADL), or medical or nursing task. Validated caregivers go on to complete the full survey. Caregivers who are not validated are terminated from the survey at the point of response that disqualifies them as a family caregiver. To be validated as a family caregiver of a child only and complete the full survey, all self-identified caregivers of children had to confirm that the child had at least one condition for which they required care or that the child was limited in their ability to do "things most children of the same age do." Nonvalidated family caregivers of children are terminated from the survey at the point of response that disqualifies them as a family caregiver.

The questionnaire asks for demographic data for all screened respondents regardless of caregiver status such as race, ethnicity, gender, education, state of residence, and age. Ipsos provided the following additional appended variables for KnowledgePanel® respondents: rurality, residence type, employment status, household income, marital status, metropolitan area, and home ownership.

Ipsos programmed the questionnaire into a computer-aided web interviewing system (CAWI) and administered the survey to their KnowledgePanel® in both English and Spanish. The Spanish-language version was professionally translated from English.

C. Sample

The *Caregiving in the US 2025* survey uses KnowledgePanel®, the largest online panel in the United States that relies on probability-based sampling methods for recruitment to provide a representative sampling frame of adults in the US. This is the same national, probability-based online panel used for previous administrations of the *Caregiving in the US* survey. Ipsos selects panelists to join KnowledgePanel® via random selection of residential addresses, known as address-based sampling (ABS). People in selected households are invited by mail[3] to participate in the web-enabled KnowledgePanel®. Ipsos provides a web-enabled device and internet service at no cost to respondents who agree to participate and who do not already have internet access. People who already have devices and internet service participate in the panel using their own equipment.

Panelists receive notification emails inviting them to complete active surveys and reminder emails at a regular cadence. All panel members are provided with privacy and confidentiality protections. Ipsos also operates an ongoing modest incentive program to encourage participation and create member loyalty. The incentive program includes special raffles and sweepstakes with both cash rewards and other prizes. KnowledgePanel® respondents receive an incentive based on a points structure. Reward points can be redeemed for cash, games, gift cards, or merchandise.

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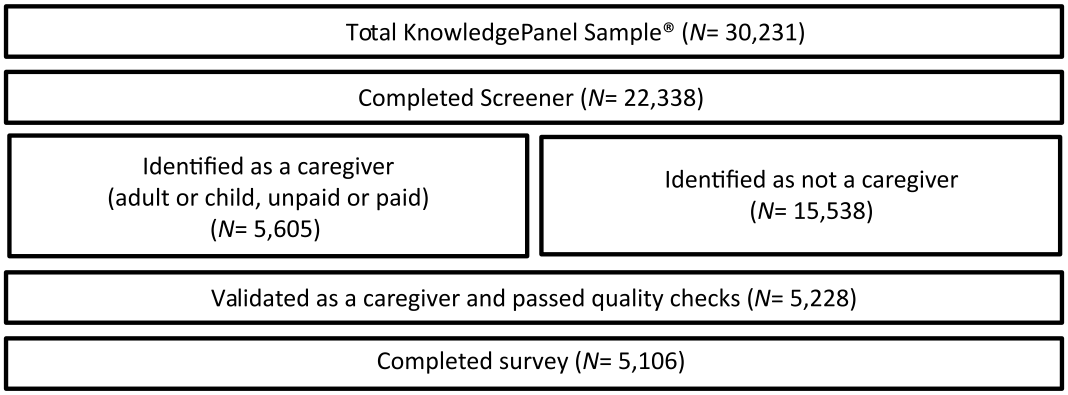
[3] Adults from sampled households are invited to join KnowledgePanel® through a series of mailings, including an initial invitation letter, a reminder postcard, and a subsequent follow-up letter. Moreover, telephone refusal-conversion calls are made to nonresponding households for which a telephone number could be matched to a physical address. Invited households can join by completing and mailing back a paper form in a postage-paid envelope, calling a toll-free hotline maintained by Ipsos, or going to a designated Ipsos website and completing the recruitment form online.

The target population for the *Caregiving in the US 2025* survey includes noninstitutionalized adults ages 18 and older residing in the United States. In addition to the general population sample, KnowledgePanel® recruited supplemental samples of Black/African Americans, Hispanics, Asian Americans (inclusive of Pacific Islanders and Native Hawaiians and referred to as AANHPI), residents of certain states, persons ages 75 and older, and persons ages 18 to 27 to improve inferences about caregivers within those populations.[4]

The survey was fielded with 30,231 KnowledgePanel® respondents, 22,338 of whom completed at least the screener. The final sample includes 6,858 completed surveys, 5,106 from KnowledgePanel® and 1,752 opt-in respondents from select states where the KnowledgePanel® sample was small.



Interpreting the inclusion of paid family caregivers

The inclusion of paid family caregivers in the *Caregiving in the US* sample is new in 2025. Payments to family caregivers include those received from self-directed programs under Medicaid, Veterans Affairs, or other state programs.[5] Paid family caregivers do not include those employed full time as direct care workers, such as home health aides or assistants, in home or community-based settings or in a facility setting.

The number of paid family caregivers in the United States in 2025 is 11.2 million, most of whom indicated they also provide unpaid care.[6] Because most paid family caregivers in the 2025 study also report being unpaid caregivers[7] and the prevalence of paid-only family caregiving is so low (0.7 percent), we present results for 2025 across the full spectrum of caregivers of adults (paid and unpaid) and compare them to 2020 results (unpaid caregivers of adults). For additional details about the prevalence of paid family caregiving, see the following Prevalence section. For information about who paid family caregivers are, see section B of the main report.

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[4] Due to the small sample size of American Indian/Alaska Native respondents, findings cannot be reliably generalized to this population, representing a limitation of this study.

[5] As of 2024, 47 states and Washington, DC, allow payment to family caregivers for personal care services under various LTSS programs, according to the KFF Medicaid HCBS Program Survey 2024 (Burns et al. 2025). In that survey, Florida, Indiana, and Utah did not respond to questions assessing which states pay family caregivers under any Medicaid HCBS programs.

[6] Just 0.71 percent of Americans surveyed reported being paid family caregivers only (prevalence of paid-only family caregiving among adults living in the US), or approximately 1.9 million caregivers. The remaining 9.3 million paid family caregivers also reported being an unpaid caregiver to either an adult or a child, suggesting that caregivers view these payment programs as supplemental or cover only part of the care hours provided.

[7] Among the family caregivers who identified as receiving payments for some portion of the care they provide, 83 percent said they provide unpaid care to an adult.

D. Field methodology

Ipsos invited one adult per household in a representative sample of households to participate in the *Caregiving in the US 2025* study. Selected panel members received an email invitation to complete the survey and were asked to do so at their earliest convenience. All randomly selected respondents began with the screener; only randomly selected respondents who identified as family caregivers proceeded to the substantive portion of the questionnaire.

The survey was fielded August 6 through October 14, 2024. KnowledgePanel® respondents had the option of conducting the survey in Spanish or English. Five percent of qualified respondents took the survey in Spanish.

Email reminders were sent to nonresponders on Day 3 of the field period. Additional reminders were sent to any remaining nonresponders on days 7, 10, and 14 of the field period.

The median completion time of the survey was 21 minutes. See appendix A for full questionnaires in both English and Spanish with all instructions.

Data quality checks

Ipsos, NAC, and AARP conducted data quality checks on KnowledgePanel® and the opt-in sample. Respondents were unable to complete the survey more than once; after completing the survey one time, respondents no longer had access to the survey.

Opt-in cases received an additional open-ended question that asked them to describe their caregiving tasks to detect any bots or noncaregivers. This open-ended question was manually checked for quality.

A total of 183 respondents were removed from the final data. These included 157 cases for not passing Ipsos technical and survey-based quality control checks, such as having an age mismatch of +/- two years between this survey and panel data. Twenty-six were removed by NAC and AARP after quality checks. Reasons for removal of these 26 cases include indicating they were a professional or volunteer caregiver, nonsensical answers in open-ended questions, speeding through the survey, and providing less than one hour of care a week.

E. Weighting

Multiple weights were created to aid in analysis for the data. This section provides an overview of the multipart weighting process.

National screened respondent weight

A total screened respondent weight was created for estimates of incidence of caregiving, which included data from all samples in the study, regardless of caregiver status. This screened respondent weight (n = 21,143) involved two steps:

1. Design weights for KnowledgePanel® assignees were computed to reflect their selection probabilities. This involved all samples, including the general population sample plus the supplemental samples for Hispanics, non-Hispanic Black/African Americans, non-Hispanic Asians/Native Hawaiians/Pacific Islanders (AANHPI), some state-specific samples, those ages 75 and older, and those ages 18 to 27.
2. Design weights were adjusted to the geodemographic distribution of the 18-and-over US population by controlling demographics within race/ethnicity (Hispanics, non-Hispanic Black/African Americans, AANHPI, and all else) through nested targets to account for the

oversampling of those racial/ethnic categories. Benchmarks for targets were obtained from the 2022 American Community Survey. Benchmarks included age by gender, census region, education, household income, language dominance, Hispanic origin, and state.

The resulting weight was trimmed and scaled to the number of screened respondents and labeled as "*KP_screen_wt*." This weight was used to generate national caregiver incidence rates and state-level incidence rates, except in those states that had sufficient sample size to create state-specific screened respondent weights.

National caregiver weight

For states with at least 100 KnowledgePanel® caregiver responses, the resulting weights were trimmed and scaled to sum to the number of qualified respondents (*n* = 5,106) who were caregivers. This weight is labeled as "*KP_qualified_wt*" and used for all national analyses of caregivers presented in this report.

For states with fewer than 100 KnowledgePanel® caregiver responses, opt-in sample supplemented the number of caregivers who completed the survey. These states included:

> Alaska, Arkansas, Delaware, Hawaii, Idaho, Maine, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Rhode Island, South Dakota, Utah, Vermont, Washington DC, West Virginia, and Wyoming.

Design weights for opt-in sample caregivers were created by weighting these opt-in respondents to the geodemographic characteristics of the 18-and-older caregiver population within these states as generated using the *KP_screen_wt* and an additional bias-correction factor of four variables. The targets included age by gender, race/ethnicity, education, household income, language dominance, census region, and the four-variable correction for opt-in based on media and psychographic metrics. The resulting weights for these states was scaled to sum to the number of qualified respondents (*n* = 1,752) and labeled as "*Optin_qualified_wt*."

Finally, the two weights of "*KP_qualified_wt*" and "*Optin_qualified_wt*" were combined to create "*overall_wt*" for the full population of caregivers surveyed (*n* = 6,858).

Estimation of millions of caregivers for any result

To project results in this report to the US population, multiply any percentages by the estimated 59.0 million US adults estimated to be caring for an adult, as the report focuses on results for caregivers of adults.

F. Margin of error and response rate

The margin of sampling error at the 95 percent confidence level for the total sample, inclusive of all respondents (screened, dropped off, terminates, or completes) is +/-0.9 percentage points, assuming a 50 percent result. The margin of sampling error at the 95 percent confidence level for the sample of qualified completes (family caregivers) is +/-1.8 percentage points, assuming a 50 percent result. The margin of error will be larger for subgroups within each sample.

The cumulative response rate for the study was 4.2 percent.[8]

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[8] The cumulative response rate considers panel recruitment rates, household profile rates, retention rate, and study-specific response and completion. M. Callegaro and C. DiSogra, "Computing Response Metrics for Online Panels," *Public Opinion Quarterly* 72, no. 5 (2008): 1008–32.

G. Estimating prevalence of caregiving

We took the following steps to estimate the prevalence of caregiving. These steps remain the same as in 2020 and 2015 to maintain consistency in reporting. All cases are weighted using the screened respondent weight for prevalence calculations.

1. Designate respondents who indicated they are a caregiver in the screener and assist with an ADL, IADL, or medical or nursing task as validated caregivers.
2. Designate respondents who indicated they are a caregiver in the screener but did not assist with an ADL, IADL, or medical or nursing task, or did not complete enough of the survey to indicate whether they assisted with these tasks as nonvalidated caregivers.
3. Adjust nonvalidated caregivers as follows: 94.85 percent of respondents who reported being a caregiver in the screener are validated caregivers. Multiply this percentage by nonvalidated caregivers as an adjustment.
4. Add the number of validated caregivers and adjusted nonvalidated caregivers.
5. Divide by the total number of adults age 18+ according to US Census data

$$\text{Prevalence} = \frac{\text{Validated caregivers} + \text{Adjusted nonvalidated caregivers}}{\text{Number of Adults Ages 18+ in the US}}$$

The prevalence of each type of family caregiver is shown in table B1. Some family caregivers care for multiple people and are counted in multiple prevalence categories. Categories are not mutually exclusive because of this and cannot be summed.

Table B1. 2025 Population Prevalence by Family Caregiver Type

Family Caregiver Type	Prevalence	Number of Adults Ages 18+ in the United States*	Estimated Number of US Adults Who Are Family Caregivers
Total Caregiving (any)	24.03%	262,083,034	63.0 million
Caregiver of an Adult or Child (unpaid)	23.32%	262,083,034	61.1 million
Caregiver of an Adult (unpaid or paid)	22.51%	262,083,034	59.0 million
Caregiver of an Adult (unpaid)	21.74%	262,083,034	57.0 million
Caregiver of an Adult (paid)	4.27%	262,083,034	11.2 million

** Population estimate from US Census Bureau, Population Division, "Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, Regions, States, District of Columbia, and Puerto Rico: July 1, 2023 (SCPRC-EST2023-18+POP)," https://www.census.gov/data/tables/time-series/demo/popest/2020s-national-detail.html.*

Prevalence of paid family caregiving

The 2025 *Caregiving in the US* survey also included paid family caregivers. As shown in table B1, 4.27 percent of adults in the US say they are a family caregiver who receives some payment for providing care. Many of the caregivers who indicate they are paid family caregivers respond that they also provide unpaid care to a care recipient. This suggests that for many family caregivers, payment for caregiving does not cover all the hours of care provided. To estimate the number of adults who are exclusively paid family caregivers, we subtract the prevalence of unpaid family caregiving from total caregiving prevalence, shown in table B2.

Table B2. 2025 Population Prevalence by Family Caregiver Type

Family Caregiver Type	Prevalence	Number of Adults Ages 18+ in the United States	Estimated Number of US Adults Who Are Family Caregivers
Total Caregiving (any)	24.03%	262,083,034	63.0 million
Caregiver of an Adult or Child (unpaid)	23.32%	262,083,034	61.1 million
Exclusive Caregiver of an Adult (paid)	0.71%	262,083,034	1.9 million

H. Level of Care Index

Original Level of Care Index

The Level of Care Index, first developed in the 1997 study *Family Caregiving in the US* (a predecessor to this research) and used in the 2004, 2009, 2015, and 2020 *Caregiving in the US* studies,[9] is replicated in this study to convey a simple measure of 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 an individual during the caregiver journey. The index is based on the number of hours of care given and the number of ADLs and IADLs performed.

For caregivers, the calculation of the Level of Care Index begins by assigning points for the number of hours of care, as follows:

Hours of Care per Week	Points
0 to 8 Hours	1 point
9 to 20 Hours	2 points
21 to 40 Hours	3 points
41 or more Hours	4 points

Points are then assigned for the number of ADLs and IADLs performed:

Types of Care Provided	Points
0 ADLs, 1 IADL	1 point
0 ADLs, 2+ IADLS	2 points
1 ADL, Any Number of IADLs	3 points
2+ ADLs, Any Number of IADLs	4 points

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[9] In the 1997, 2004, 2009, and 2015 waves of this study, this index was referred to as the Burden of Care Index, with each level of the index referred to as high, moderate or medium, and low "burden." For the 2020 cycle, the name was changed to Level of Care Index, with each level of the index referred to with the word "intensity," as this index is one way to measure the intensity or complexity of the caregiving situation.

Then, the total number of points is consolidated into five levels of care. In this report, analysis often further collapses the five levels into three categories of intensity, with "high intensity" equating to levels 4 to 5, "medium intensity" corresponding to level 3, and "low intensity" equating to levels 1 and 2.

Consolidating points into five levels of care and three intensity categories

Points	Level	Intensity
2 to 3 points	Level 1	Low intensity
4 points	Level 2	
5 points	Level 3	Medium intensity
6 to 7 points	Level 4	High intensity
8 points	Level 5	

Expanded Level of Care Index

The Level of Care Index, as described earlier, measures the caregiving experience objectively through two equally weighted components: hours spent caregiving and the numbers of ADLs and IADLs the caregiver performs. The Level of Care Index does not account for the subjective experience of caregiving, an area of growing focus in caregiving research. To address these developments, *Caregiving in the US 2025* includes an Expanded Level of Care Index that incorporates subjective measures of the caregiving experience. The expanded index adds two components to the Level of Care Index–a measure of the ease of coordinating care between health care and other service providers and a measure of paid and/or unpaid caregiving help–to capture objective and subjective aspects of the caregiving experience:

Ease of care coordination component*

	Coordination Component	Points
Ease of Care	No coordination of care (not a function the caregiver has)	1 points
	Care coordination is easy	2 points
	Care coordination is somewhat difficult	3 points
	Care coordination is very difficult	4 points
Presence of Other Paid/Unpaid Help*	Has both unpaid and paid help	1 points
	Has only paid help or shares unpaid caregiving equally with others	2 points
	Has no paid help and has some unpaid help but is the primary unpaid caregiver	3 points
	Has neither paid nor unpaid help (is the sole caregiver)	4 points

** Based on Q28 (unpaid help) and Q30 (paid help)*

The points from the four components of the Expanded Level of Care Index are summed and then scaled into five levels ranging from low complexity to high complexity:

Consolidating points into five levels of care and three complexity categories

Points	Level	Intensity
4 to 7 points	Level 1	Low complexity
8 points	Level 2	
9 points	Level 3	Medium complexity
10 to 11 points	Level 4	High complexity
12 or more points	Level 5	

Table B3 shows a comparison of the Level of Care Index and the Expanded Level of Care Index for 2020 and 2025.

Table B3. Level of Care Index and Expanded Level of Care Index Comparison, 2020 and 2025

Category (level)	2020 Level of Care	2025 Level of Care	2020 Expanded Level of Care	2025 Expanded Level of Care
Low (1)	27%	22%	18%	17%
Low (2)	16%	15%	14%	11%
Medium (3)	16%	19%	16%	15%
High (4)	27%	27%	26%	26%
High (5)	14%	18%	26%	31%

I. Data manipulations and cleaning

Imputation of hours of care values

The *Caregiving in the US 2025* questionnaire asks how many hours per week one spends on caregiving duties as a numeric value (e.g., 24 hours per week). Caregivers could alternatively select from two categorical values, "less than one hour per week" or "providing constant care," as follows.

> Q25. Thinking now of all the kinds of help you provided for your…, about how many hours did you spend in an average week helping them?
>
> *Hours [open-end numeric value]*
> *Less than 1 hour per week*
> *Constant care*

The 2015 and 2020 *Caregiving in the US* analyses imputed a fixed value for all respondents who reported providing constant care using four predictors: employment while caregiving, co-residence of the care recipient in the caregiver's home, number of ADLs caregiver helps with, number of IADLs caregiver helps with, and the presence of other unpaid caregivers. Constant care responses were validated against a follow-up question asking caregivers who provided constant care to describe their hours of care. The 2015 and 2020 *Caregiving in the US* analyses imputed 77 hours of care for all caregivers reporting constant care. Benchmarks from the 2020 American Time Use survey and the Guardian Life Insurance study validate the average hours of care imputed in 2015 and 2020.[10] These benchmarks find that caregivers provide an average of 24 hours of care per week. Other measures in the 2025 *Caregiving in the US* survey, such as the share of respondents reporting constant care hours and the relationship of the 2020 care hour imputation model measures to each other, demonstrate consistent relationships to those seen in 2020. This indicates that it remains appropriate to use the 2020 benchmarks in 2025 in the absence of more recent benchmarks.

Q25Z. We would like to understand a little bit more about people like you who have provided constant care. Which of the following best describes how much care or help you gave} your… because of their condition(s) in a normal week? Did you provide care…

All the time: 24 hours a day, 7 days a week
Almost all the time, with only small breaks here or there
Almost all the time, with just breaks to sleep
On and off around the clock
Other [SPECIFY:_______________]

Imputed hour values with a normal distribution are necessary for some analyses, such as determining means or conducting differences tests. To impute numeric caregiving hour values that can be used for any analytical purpose, we generated a distribution for constant care hours as described as follows. Respondents who select constant care receive a follow-up question to describe what they mean by constant care. We use this follow-up question as additional information to impute hour values for caregivers who indicated they provide constant care.

Q25Z. We would like to understand a little bit more about people like you who have provided constant care. Which of the following best describes how much care or help you gave} your… because of their condition(s) in a normal week? Did you provide care…

All the time: 24 hours a day, 7 days a week
Almost all the time, with only small breaks here or there
Almost all the time, with just breaks to sleep
On and off around the clock
Other [SPECIFY:_______________]

Approximately 7 in 10 respondents reported a numeric caregiving hours value that did not require imputation. Caregivers reporting less than one hour per week of time caregiving were assigned a fixed value of 0.5 hours. To impute values for caregivers reporting constant care, we took the following steps.

1. **Set floor and ceiling values for constant care**: First, the few (i.e., .5 percent) caregivers who typed in a numeric value of 98 or more hours of care per week (indicative of constant care) were given an upper-bound value of 98 hours. This approach aims to limit skew and follows what was done in prior years. We expect those reporting constant care to report a high number of caregiving hours. As such, cases with an estimated imputed value of fewer than 41 hours were manually set to a value of 41; however, no cases fell into this category. Respondents reporting constant care receive imputed values ranging from a low of 41 hours and a maximum of 168 hours.

   About 7 percent of cases reporting constant care did not report a follow-up level of constant care value (e.g., "providing care all the time, 24 hours a day, 7 days a week") but provided a verbatim description of what constant care entailed. Review of these verbatims (and hot-deck

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[10] *Standing Up and Stepping In: A Modern Look at Caregivers in the US*, Guardian Life Insurance Company of America, 2023. https://www.guardianlife.com/reports/caregiving-in-america.

imputation for 16 cases for which no verbatims were provided) resulted in level of constant care values for all cases. This manual review was new to the 2025 imputation and had a minimal impact on the overall share of caregivers reporting differing levels of constant care. As with the method described previously (using 2020 data), imputed caregiving hour values were dispersed around the mean of each of the four levels of constant care.

2. **Determine the sources of variability in care hours for caregivers not reporting constant care**: Four binary measures were the basis for previous imputations. All combinations of these four binary measures result in 16 possible combination categories. For those not reporting constant care, hours of care were computed for each combination category. For those who report constant care, the share of caregivers in each of the 16 combination categories is calculated and compared with each of the four levels of constant care defined in follow-up question Q25Z. Imputed hours of care are then calculated as a percentage of the mean hours of caregivers who report care hours, and variation around these new means is determined using the share of caregivers providing constant care who are within the relatively time-intensive (or less time-intensive) of the 16 combination categories.

   The hours spent by caregivers in each of the 16 conditions is expressed, and variation around constant care means can be produced using the share of caregivers providing constant care who are within the relatively time-intensive (or less time-intensive) of the 16 combination categories. This imputation assumes that time-intensive conditions for those reporting numeric caregiving values are also time-intensive conditions and reporting the categorical response of “providing constant care.”

3. **Value estimation and adjustments**: Values for cases reporting constant care were estimated and assigned based on the variability determined for cases with known hours. Out-of-range estimates (those exceeding 168 hours) were rare (i.e., 0.48 percent of constant care hours). Estimates exceeding 168 were set to exactly 168, and the excess hours beyond 168 were distributed proportionally among the remaining combination categories to avoid bias in the distribution.

4. **Summary of caregiving hourly values**

Category	Categorical Value	2025 CGUS Survey
Reported Hours (83.4% of values)		Mean = 13.8 hours (80.6% of values)
Imputed Constant Care Hours	Constant care = “All the time- 24 hours a day, 7 days a week”	Mean = 89.5 hours (this value may be trimmed but share is the same) (21.6% of constant care values)
	Constant care = “Almost all the time with only small breaks here or there”	Mean = 80.2 hours (25.4% of constant care values)
	Constant care = “Almost all the time with just breaks to sleep”	Mean = 71.5 hours (16.4% of constant care values)
	Constant care = “On and off around the clock”	Mean = 74.4 hours (36.6% of constant care values)

J. Analysis of variable definitions

The following chart shows definitions and unweighted sample sizes for key subpopulation variables used in the *Caregiving in the US 2025* report. Analysts used statistical testing between groups at the 95 percent confidence interval.

Main Report: Caregivers of Recipients 18+

For all analysis, Weight by: Overall_wt. Select cases where Complete_status=qualified & Care recipient is age 18+ (CGTYPEF=1 or CGTYPEF=2) & QFLAG=1

Analysis Variable	Definition	*N* (unweighted)
Paid Family Caregiver	Sc1d=1	1,498
Unpaid Family Caregiver	Sc1d NE 1	5,051
Caregiver Gender: Male	Ppgender3=1	2,367
Caregiver Gender: Female	Ppgender3=2	4,143
Caregiver Age: 18–49	Ppage=<50	2,593
Caregiver Age: 50–64	Ppage=50-64	2,177
Caregiver Age: 65–74	Ppage=65-74	1,209
Caregiver Age: 75+	Ppage=75+	570
Caregiver Race: white, non-Hispanic	Ppethm=1	4,472
Caregiver Race: African American/Black, non-Hispanic	Ppethm=2	734
Caregiver Race: Hispanic/Latino	Ppethm=4	750
Caregiver Race: Asian American/Native Hawaiian/Pacific Islander, non-Hispanic	ppethm=3 & ppracem=4 & 5	261
Caregiver Household Income <$50,000	Ppinc7=1, 2, or 3	2,482
Caregiver Household Income $50,000+	Ppinc7= 4, 5, 6, or 7	4,067
Had a Choice to Be a Caregiver	Q39=1	3,069
No Choice to Be a Caregiver	Q39=2	3,446
Caregiver Lives in a Rural Area	Xurbanicity=2	1,558
Caregiver Lives in an Urban Area	Xurbanicity=1	2,496
Caregiver Lives in a Suburban Area	Xurbanicity=3	2,448
Caregiver is LGBTQ+	Lgbtq=1	398
Caregiver is Not LGBTQ+	Lgbtq=0	4,479
Caregiver’s Job is Paid Hourly	Q33=2 OR Q33Z_1=2	1,434
Caregiver’s Job is Salaried	Q33=1 OR Q33Z_1=1	2,017
Employed while Caregiving	Q1=1 & Q32a=1 OR Q1=1 & Q32a>1 & Q33=1	3,754
Not Employed while Caregiving	Q1=1 & Q32a>1 & Q33>1	2,771

K. Advisory board

The *Caregiving in the US 2025* survey and report development was guided by a group of scientific experts across various subfields of caregiving research. The steering committee met several times per year to provide guidance on multiple aspects of the survey and provided guidance via email and individual meetings. Steering Committee meeting dates and membership are listed as follows:

CGUS steering committee meetings

- April 10, 2024
- December 10, 2024
- February 28, 2025
- June 3, 2025

CGUS steering committee members

- Dr. Maggie Ornstein, PhD, MPH, Guest Faculty, Sarah Lawrence College
- Dr. Ranak Trivedi, PhD, Investigator, Health Services Research & Development Center for Innovation to Implementation, VA Palo Alto
- Dr. Courtney Van Houtven, PhD, Professor, Department of Population Health Science, Duke University
- Dr. Maria Aranda, PhD, MSW, MPA, LCSW, Professor of Social Work and Gerontology, University of Southern California
- Dr. Donna Benton, PhD, Research Associate, Professor of Gerontology, University of Southern California
- Dr. J. Nicholas Dionne-Odom, PhD, RN, Associate Professor, School of Nursing, University of Alabama at Birmingham
- Dr. Regina Shih, PhD, Professor, School of Public Health, Emory University
- Dr. Fayron Epps, PhD, RN, FGSA, FAAN, Professor, Karen and Ron Hermann Endowed Chair in Caregiver Research, UT Health San Antonio
- Dr. Debra Lerner, PhD, MS, Professor, School of Medicine, Tufts University
- Dr. Leanne Clark-Shirley, PhD, President & CEO, American Society on Aging
- Didier Trinh, National Director, Diverse Elders Coalition

Appendix C. Demographic profile and prevalence by demographics

This appendix provides the demographic profile for respondents in the *Caregiving in the US 2025* study who care for someone age 18 or older. Figure C3 of this appendix shows the prevalence of caregiving for adults and children by caregiver demographics over time.

Caregiver demographic profile

Caregivers reflect the general US population and on the whole look similar to caregivers in 2020 (see figure C1). Six in 10 are women and 4 in 10 are men; the average age is 50.6 years, 6 in 10 are white, and about half are married.

Figure C1. Demographic Summary of Caregivers of Adults, Trend 2015–2025

Demographic	2025 (*n* = 6,549)	2020 (*n* = 1,392)	2015 (*n* = 1,248)
Caregiver Gender			
Man	38%	39%	40%
Woman	61%	61%	60%
Age of Caregiver			
18–34	18%↓	24%	24%
35–49	26%↑	23%	23%
50–64	33%	35%	34%
65–74	14%	12%	12%
75+	8%	7%	7%
Mean age	*50.6↑*	*49.4*	*49.2*
Median age	*49.6*	*51.0*	*51.0*
Race/Ethnicity of Caregiver			
Non-Hispanic white	61%	61%	62%
African American/Black	13%	14%	13%
Hispanic/Latino	16%	17%	17%
Asian American/Native Hawaiian/Pacific Islander	6%	5%	6%
American Indian, Alaska Native, or multiracial*	7%	3%	2%
Caregiver Education			
Less than high school	9%↑	6%	8%
High school graduate	26%	26%	28%
Some college or associate's degree	33%	33%↑	29%
Bachelor's degree	18%↓	21%	20%
Master's degree or above	15%	14%	15%
Caregiver Marital Status			
Married	54%	54%	57%
Living with a partner	10%↑	7%	8%
Widowed	4%	4%	5%
Separated	2%	3%↑	1%
Divorced	8%	8%	8%
Single, never married	21%	21%	19%

↑↓ *Result is significantly higher or lower than in prior wave.*

** Methodological difference from 2025 to 2020; no statistical testing applied.*

Household incomes for family caregivers are higher in 2025 than in 2020, although this change may be due to both changed measurement and general wage change over the past five years.[11] Thirty percent of caregivers have a child or grandchild living in their home at the time of care, and 20 percent live in a rural area, up from 2020.[12] Sixty percent are employed while providing care, whereas 10 percent are students while caregiving.

Figure C1. Demographic Summary of Caregivers of Adults, Trend 2015–2025 *(continued)*

Demographic	2025 (*n* = 6,549)	2020 (*n* = 1,392)	2015 (*n* = 1,248)
***Caregiver Household Income (unadjusted)**			
Less than $50,000 (net)	30%	36%	47%
Less than $10,000	5%	n/a	n/a
Less than $15,000	n/a	8%	12%
$10,000–$24,999	8%	n/a	n/a
$15,000–$29,999	n/a	13%	16%
$25,000–$49,999	16%	n/a	n/a
$30,000–$49,999	n/a	15%	18%
$50,000 or More (net)	70%	64%	53%
$50,000–$74,999	17%	18%	17%
$75,000–$99,999	12%	14%	13%
$100,000+	41%	33%	23%
Median household income (unadjusted)	***$68,770***	***$70,200***	***$54,700***
Children/Grandchildren in Caregiver's Household			
Yes	29%	30%	28%
No	70%	68%	70%
Caregiver Location			
Not rural (net)*	79%	88%	84%
Urban	35%	n/a	n/a
Suburban	44%	n/a	n/a
Rural*	20%	12%	16%
Caregiver Employment Status			
Employed in past year while caregiving	60%	61%	60%
Not employed	40%	39%	40%
Caregiver Student Status			
Yes	9%	11%	n/a
No	90%	89%	n/a
Caregiver Disability Status			
Yes	18%	n/a	n/a
No	82%	n/a	n/a

↑↓ *Result is significantly higher or lower than in prior wave.*

* *Results not tested for significant change wave over wave due to methodological differences.*

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[11] See *Caregiving in the US 2020, Appendix B: Detailed Methodology* for documentation on inflation and the comparison of scales for household income used in 2020 and 2015.

[12] In 2015 and 2020, caregivers were asked to self-report their location as rural vs. not rural. Beginning in 2025, profile information from the Ipsos panel was used to classify caregivers as living in an urban, rural, or suburban locations.

Most caregivers have health insurance, usually through an employer. National estimates of insurance coverage indicate that 11.5 percent of Americans ages 18 to 64 do not have health insurance.[13] Among caregivers ages 18 to 64, 13.5 percent report they do not have health insurance, suggesting that caregivers are more likely than general Americans to lack health insurance. Just 8 percent have served in the US armed forces (down from 2020), and 8 percent self-identify as LGBTQ. One in three report their recipient lives in a rural area, and 12 percent say their recipient is a veteran (also down from 2020).

Figure C1. Demographic Summary of Caregivers of Adults, Trend 2015–2025 *(continued)*

Demographic	2025 (*n* = 6,549)	2020 (*n* = 1,392)	2015 (*n* = 1,248)
Caregiver Has Health Insurance			
Yes	89%	87%	n/a
No	11%	13%	n/a
Caregiver Source of Health Insurance			
Employer sponsored	50%↓	56%	n/a
Medicare	24%↑	20%	n/a
Medicaid	13%↑	9%	n/a
Direct purchase	6%	8%	n/a
Military/veterans	3%	4%	n/a
Caregiver Service in Armed Forces			
Served on active duty	8%	9%	10%
Did not ever serve	92%	91%	89%
Caregiver LGBTQ+ Status			
Yes	9%	8%	9%
No	87%	91%	91%
Care Recipient Location			
Urban/suburban	67%	69%	71%
Rural	33%	31%	28%
Care Recipient Service in Armed Forces			
Served on active duty	12%↓	14%	14%
Did not serve	86%↑	83%	85%

↑↓ *Result is significantly higher or lower than in prior wave.*

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[13] “National Uninsured Rate at 8.2 Percent in the First Quarter of 2024 (Issue Brief No. HP-2024-17),” Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services, August 2024, https://aspe.hhs.gov/sites/default/files/documents/ee0475e44e27daef00155e95a24fd023/nhis-q1-2024-datapoint.pdf.

Demographic profile of family caregivers (paid vs. unpaid)

Paid family caregivers are younger than unpaid family caregivers by 5.5 years, on average. They are more often African American, Hispanic/Latino, Asian American, Native Hawaiian, or Pacific Islander. They are more often living with a partner, single, or separated than unpaid family caregivers and are less often to have a college degree (see figure C2).

Figure C2. Demographic Summary by Paid vs. Unpaid Family Caregiver Status, Caregivers of Adults

Demographic	Paid Family Caregivers (*n* = 1,498)	Unpaid Family Caregivers (*n* = 5,051)
Caregiver Gender		
Man	40%	38%
Woman	59%	61%
Age of Caregiver		
18–34	29%↑	16%
35–49	32%↑	25%
50–64	25%↓	35%
65–74	10%↓	16%
75+	4%↓	8%
Mean age	*45.4*↓	*51.9*
Race/Ethnicity of Caregiver		
Non-Hispanic white	44%↓	65%
African American/Black	21%↑	11%
Hispanic/Latino	23%↑	15%
Asian American/Native Hawaiian/Pacific Islander	8%↑	6%
American Indian, Alaska Native, or multiracial	8%	7%
Caregiver Education		
Less than high school	15%↑	7%
High school graduate	29%↑	25%
Some college or associate's degree	31%	33%
Bachelor's degree	14%↓	18%
Master's degree or above	10%↓	16%
Caregiver Marital Status		
Married	41%↓	57%
Living with a partner	13%↑	10%
Widowed	4%	4%
Separated	4%↑	1%
Divorced	7%	8%
Single, never married	28%↑	19%

↑↓ *Result is significantly higher or lower than unpaid family caregivers.*

Paid family caregivers have lower household incomes than unpaid family caregivers, more often have children living in their household, and more often live in an urban area. Paid family caregivers are more often students than unpaid family caregivers, perhaps related to their younger age.

Figure C2. Demographic Summary by Paid vs. Unpaid Family Caregiver Status, Caregivers of Adults *(continued)*

Demographic	Paid Family Caregivers (*n* = 1,498)	Unpaid Family Caregivers (*n* = 5,051)
Caregiver Household Income		
Less than $50,000 (net)	40%↑	27%
Less than $10,000	10%↑	4%
$10,000–$24,999	11%↑	7%
$25,000–$49,999	20%↑	16%
$50,000 or more (net)	60%↓	73%
$50,000–$74,999	16%	18%
$75,000–$99,999	12%	13%
$100,000–$149,999	14%↓	19%
$150,000 or more	17%↓	24%
Median household income	***$52,110***	***$73,520***
Children/Grandchildren in Caregiver's Household		
Yes	36%↑	27%
No	60%↓	72%
Caregiver Location		
Urban	44%↑	33%
Rural	16%↓	22%
Suburban	40%	45%
Caregiver Employment Status		
Employed in past year while caregiving	68%↑	58%
Not employed	32%↓	42%
Caregiver Student Status		
Yes	19%↑	7%
No	81%↓	93%
Caregiver Disability Status		
Yes	19%	17%
No	80%	82%

↑↓ *Result is significantly higher or lower than unpaid family caregivers.*

Paid family caregivers less often have health insurance coverage, and when they do, it is more often through Medicaid rather than employer-based coverage or Medicare. Their care recipients more often live in a rural area.

Figure C2. Demographic Summary by Paid vs. Unpaid Family Caregiver Status, Caregivers of Adults *(continued)*

Demographic	Paid Family Caregivers (*n* = 1,498)	Unpaid Family Caregivers (*n* = 5,051)
Caregiver Has Health Insurance		
Yes	83%↓	90%
No	17%↑	10%
Caregiver Source of Health Insurance	**(*n* = 1,244)**	**(*n* = 4,645)**
Employer sponsored	46%↓	51%
Medicare	18%↓	26%
Medicaid	23%↑	11%
Direct purchase	7%	6%
Military/veterans	4%	3%
Caregiver Service in Armed Forces		
Served on active duty	9%	7%
Did not ever serve	90%	92%
Caregiver LGBTQ+ Status		
Yes	10%	10%
No	90%	90%
Care Recipient Location is Rural		
Rural	39%↑	31%
Not	61%↓	68%
Care Recipient Service in Armed Forces		
Served on active duty	11%	12%
Did not serve	86%	86%

↑↓ *Result is significantly higher or lower than unpaid family caregivers.*

Prevalence of caregiving by demographics

The prevalence of caregiving for adults and children with disabilities or serious medical conditions has increased among most demographic groups compared with prevalence estimates from 2020. Table C3 summarizes prevalence changes by caregivers' race/ethnicity, gender, education, employment, and age group.

Table C3. Total Prevalence of Family Caregiving by Select Demographics, Trend 2015–2025

	2025 Prevalence*	2020 Prevalence	2015 Prevalence
Race/Ethnicity			
Non-Hispanic white	23.2%↑	19.8%↑	16.9%
African American/Black	27.9%	28.1%↑	20.3%
Asian American/Native Hawaiian/Pacific Islander	19.9%	19.2%	19.7%
Hispanic/Latino	24.6%↑	21.9%	21.0%
Other	28.3%	28.2%↑	21.3%
Gender			
Men	19.1%↑	17.5%↑	15.0%
Women	28.5%↑	24.8%↑	21.1%
Education			
Less than high school	25.6%↑	20.1%	16.4%
High school graduate or equivalent	23.0%↑	20.0%↑	17.5%
Some college, trade school	26.4%↑	23.8%↑	18.7%
Bachelor's degree or higher	22.4%↑	20.4%	18.8%
Employment Status			
Employed	23.9%↑	21.8%↑	17.9%
Not employed	24.3%↑	20.3%	18.6%
Age			
18–34	18.7%	19.2%↑	15.3%
35–44	25.5%↑	20.8%↑	17.4%
45–54	27.4%↑	25.0%↑	21.8%
55–64	30.6%↑	26.1%↑	21.3%
65–74	23.5%↑	19.0%	18.0%
75 or older	18.5%↑	15.5%	16.4%

↑↓ *Result is significantly higher or lower than prior wave.*

** Total population prevalence for 2025 includes family caregivers who indicated they receive some form of payment for their care, whereas 2020 and 2015 did not include or measure the prevalence of this type of caregiving.*

Appendix D. Family caregiver data sources and definitions

Survey	Definition of Caregiver	Inclusion Criteria	Screening/Inclusion Questions—Detailed	Fielding Frequency	Methodology	Referent Period
CGUS 2025	Providing ongoing supports and management of complex care tasks for children and adults with chronic, disabling, or serious health conditions.	Answered yes to 1 question identifying caregivers and to 1 of 3 questions about ADL, IADL, or medical and nursing task-related care provided.	At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult does not need to live with you. AND: At any time in the last 12 months, has anyone in your household gotten paid to provide care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.	5 years	Nationally representative (web) survey of the US population (using KnowledgePanel®) conducted in 2024	12 months
National Study of Caregiving (NSOC)	The NSOC, conducted as part of the National Health and Aging Trends Study (NHATS), defines a *caregiver* as someone who provides help to an NHATS respondent (age 65+) with activities such as personal care, mobility, household tasks, transportation, or managing finances and medications.	Periodically, caregivers of NHATS participants are interviewed in the supplemental NSOC. Interviews are conducted with family and unpaid helpers to NHATS participants who report receiving assistance with self-care, mobility, medical or household activities.	[From NHATS] Eligible sample persons reported receiving help with mobility activities (getting around inside or outside, getting out of bed), self-care activities (eating, bathing, using the toilet, dressing), or household activities for health or functioning reasons (laundry, shopping, preparing hot meals, paying bills and banking, keeping track of medications). Helpers of eligible sample persons are eligible for NSOC if: 1) they were either related to the sample person or unrelated and not paid to help, and 2) they helped with mobility activities (getting around inside or outside, getting out of bed), self-care activities (eating, bathing, using the toilet, dressing), household activities for any reasons (laundry, shopping, preparing hot meals, paying bills and banking, keeping track of medications), or other activities (other money matters, medical activities, transportation).	Annually	Nationally representative (in-person and telephone) survey of Medicare beneficiaries 65 and older.	N/A

Survey	Definition of Caregiver	Inclusion Criteria	Screening/Inclusion Questions—Detailed	Fielding Frequency	Methodology	Referent Period
American Time Use Survey (ATUS)	The ATUS Well-Being Module considers someone a *caregiver* if they provide unpaid care to an adult (age 18+) due to a health condition, disability, or aging-related needs.	Answered yes to 1 question as part of the “eldercare” module of the ATUS questionnaire.	Not including financial assistance or help you provided as part of your paid job, [in the past 3 months], have you provided any care or assistance for an adult who needed help because of a condition related to aging?	Monthly	Nationally representative (computer-assisted telephone interview) survey of the US population.	3 months
Behavioral Risk Factor Surveillance Survey (BRFSS)	The BRFSS defines a *caregiver* as an individual who has provided care or assistance to a friend or family member in the past 30 days due to a health problem or disability.	Answered yes to 1 question as part of the caregiving module of the BRFSS questionnaire.	During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?	Monthly	Nationally representative (telephone) survey of the US population.	30 days
2023 RAND Caregiving Survey	The RAND Corporation defines a *caregiver* as an individual who provides unpaid assistance to someone with a wound, illness, injury, or other condition requiring support. According to a recent RAND study, over 40% of American adults, representing approximately 105.6 million people, fulfill caregiving roles.	Answered yes to 1 of 8 prompts from RAND 2023 Caregiving Survey.	The prompts are (1) Personal care (for example, bathing, dressing, or feeding); (2) Giving medicines or treatments; (3) Helping someone remember things that, due to a condition like a brain injury or dementia, they may be prone to forget; (4) Helping someone manage symptoms of psychological disorders (for example, depression, anxiety, or posttraumatic stress disorder); (5) Helping arrange for medical or psychological services (for example, finding appropriate providers or making appointments); (6) Providing transportation to medical or mental health appointments; (7) Helping getting in and out of beds and chairs; (8) Helping with other tasks that people with wounds, illness, or injuries may have difficulty performing themselves; (9) I do not currently provide any of these types of assistance, but I have in the past; (10) I have never provided any of these types of assistance to someone else.	Once	Nationally representative (web + phone) survey of the US population conducted in 2023 (using the AmeriSpeak panel).	30 days

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