



ASPE ISSUE BRIEF

HHS OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF DISABILITY, AGING AND LONG-TERM CARE POLICY

THE AFFORDABLE CARE ACT AND CAREGIVERS

Informal caregivers, who are caregivers not paid for their assistance, are generally family members or friends of individuals in need of long-term services and supports. They provide the majority of these services and assist in basic activities such as eating and bathing; household management activities such as shopping and meal preparation; other activities such as managing prescribed medications, attending medical encounters; and coordinating financial activities such as handling insurance and bills. Many of these informal caregivers also are often involved in managing complex health care and assistive technology activities at home.¹

Almost 18 million Americans provide care for a chronically ill, disabled or aged family member or friend during any given year.¹ Although informal caregivers are diverse in terms of demographic, socioeconomic, and cultural characteristics, on average they are more likely to be women (62 percent) and middle-aged (50 percent are between 45-64 years). Caregivers provide an average of 75 hours of support per month, but there is great variability depending on the number of caregivers and the older person's level of need. More than half (54 percent) of caregivers spend more than 40 hours per week providing care to their loved ones.¹ Almost two-thirds of people age 65 and older rely exclusively on informal care for their personal care needs. An additional 30 percent use a mix of both paid and unpaid care.

Health Challenges of Informal Caregivers

Providing this assistance can take a toll on caregivers' mental or physical health, which consequently affects their ability to provide care for their loved one. Informal caregivers have a number of risk factors for poor health:

- Family caregivers are at higher risk for stress related illnesses and suffer from depression (13.2 percent) at twice the national rate.²
- 67 percent of unpaid American caregivers said they do not go to the doctor because they put family needs first.³

- Half (51 percent) said they do not have time to take care of themselves and almost half (49 percent) said they are too tired to do so. Just over half (53 percent) of caregivers who said their health had gotten worse due to caregiving also said the decline in their health has affected their ability to provide care.³
- Elderly spouses who reported that caregiving caused an emotional strain had a 63 percent higher mortality rate than older adults whose spouses did not require care.⁴

Caregivers are frequently so engaged in the care of the person they are helping that their own health may not be a top priority. Due to financial or time constraints, informal caregivers may go without health care, or ignore the myriad of physical and mental health concerns they often face.

Informal Caregivers and the Affordable Care Act

As a result of the Affordable Care Act (ACA), health insurance coverage is now more accessible and affordable for millions of Americans who serve as informal caregivers. The ACA invests in prevention and wellness, and provides individuals and families with important protections, such as ensuring that women are not charged higher premiums than men for the same plan and people with pre-existing conditions are not denied coverage.

Because of the availability of affordable, quality health insurance, caregivers will not have to make a choice between their care and that of a loved one due to financial constraints. Health coverage, including mental health coverage, also helps ensure that caregivers have the tools they need to take care of themselves and fight any adverse effects caregiving may have on their health, so they can continue to care for their loved ones for years to come.

Under the ACA, millions of informal caregivers are better able to get affordable, quality health insurance coverage:

- More caregivers are able to get health insurance coverage from private insurance issuers in the Health Insurance Marketplace or as a result of Medicaid expansion.
- Consumers now have access to health insurance through the Marketplace that fits their needs and budget. All plans in the Marketplace cover essential health benefits, pre-existing conditions, recommended preventive care, and more.⁵ Lower income consumers are eligible for financial assistance that make Marketplace plans more affordable.

- Private plans offered in the individual and small group market are required to cover ten essential health benefit categories, including prescription drugs and mental health and substance use disorder services.⁶ For more information on the categories, visit <https://www.healthcare.gov/coverage/what-marketplace-plans-cover/>.
- People who are eligible for Medicaid can enroll in coverage at any time. To date, 29 states and Washington, D.C. have expanded their Medicaid programs pursuant to the ACA to extend eligibility to more individuals. To check to see if you are eligible, visit: <https://www.healthcare.gov/>.
- The ACA has also benefited Medicare recipients, by providing them with improved accessibility of preventive screenings and coordination of care. For more information on the ACA and Medicare, visit <http://www.hhs.gov/healthcare/facts/factsheets/2015/03/affordable-care-act-older-americans.html>.
- For Medicaid beneficiaries, the ACA provided additional opportunities for states to provide home and community-based services. Through the Balancing Incentives Program, for example, 18 states have made structural changes to their home and community-based services systems and are providing new or expanded services in community settings. Through the Community First Choice Program, an enhanced federal Medicaid match incentivizes states to provide more home and community-based attendant services. The Money Follows the Person Rebalancing demonstration, which gives states more options to serve people in the community, was extended and expanded through the ACA. As of December 2013, more than 40,500 individuals with disabilities and chronic conditions have transitioned to the community through the program. To learn more about Medicaid, visit <http://www.medicaid.gov/>.

The ACA provides important tools to help informal caregivers take care of themselves. The new Medicaid community-based support options also create opportunities to better assist informal caregivers. The ACA is an important tool to help informal caregivers care for their own physical and mental health.

- For more information on the Marketplace, Medicaid, and Children's Health Insurance Program, visit <http://www.HealthCare.gov> to learn more. If you have questions or need to find someone who can help you in person, find local help at <http://Localhelp.healthcare.gov/>, or call the Marketplace Call Center at 1-800-318-2596. Translation services are available. TTY users should call 1-855- 889-4325. The call is free.
- For Medicare specific questions or to learn more about Medicare coverage, visit <http://www.Medicare.gov> or call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

Endnotes

1. Spillman B, Woff J, Freedman V, & Kasper J (2014). Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
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2. O'Brien T (2006). The Stress of Family Caregiving: Your Health May Be At Risk. TAKE CARE! Self-Care for the Family Caregiver. Reprint. National Family Caregiver Association. <https://www.caregiver.org/taking-care-you-self-care-family-caregivers>.
3. Center for Disease Control & Prevention (2011). Caregiving: The Facts. Washington, DC: U.S. Department of Health and Human Services.
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4. Schulz R & Beach SR (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Journal of the American Medical Association*, 282(23): 2215-2219.
5. Office of the Assistant Secretary for Public Affairs, Digital Communication Division (2014). The Affordable Care Act and African Americans. Washington, DC: U.S. Department of Health and Human Services.
<http://www.hhs.gov/healthcare/facts/factsheets/2012/04/aca-and-african-americans04122012a.html>.
6. Beronio K, Po R, Skopec L, & Glied S (2013). Affordable Care Act Expands Mental Health and Substance Use Disorder Benefits and Federal Parity Protections for 62 Million Americans. ASPE Issue Brief. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
http://aspe.hhs.gov/health/reports/2013/mental/rb_mental.cfm.

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