The Role of States in Supporting Family Caregivers

By Audrey Wall [1]
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Family caregivers are the backbone of our nation’s system of long-term services and supports for older adults and people with disabilities. The economic value of their contributions is estimated at $450 billion per year. It is critical that states support the efforts of these caregivers, to help them avoid burn out and protect their own health.

About the Author

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Introduction

It’s larger than total Medicaid spending—both state and federal. It’s bigger than the combined sales of the three largest publicly held auto companies—Toyota, Ford and Daimler. It amounts to almost $1,500 for every man, woman and child in the United States. What is this behemoth? It’s the economic value of unpaid contributions made by family caregivers who help an adult with limitations in daily activities in the U.S.1

Across the nation, states are transforming their systems for delivering long-term services and supports, also known as long-term care, to older adults and people with disabilities. Policymakers engaged in this issue know our nation’s primary source of payment for long-term care is Medicaid—a program designed for people with low incomes and few assets. But the high cost of long-term care often results in making Medicaid the default program of last resort for middle class Americans, many of whom spend down their life savings paying for care when they or a spouse grow ill, frail or acquire a disability.

But many do not realize that an even more extensive foundation for our nation’s long-term care system is built upon the often-unseen efforts of family caregivers. The importance of family caregivers as an integral element of the long-term care system was recognized in the development of the first Long-Term Services and Supports Scorecard (See the 2012 Book of the States for a description of this project).2 Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers3 ranked the 50 states and the District of Columbia on the performance of their long-term care systems—overall and along key dimensions. One of these dimensions was support for family caregivers, broadly defined as any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or other adult with a chronic or disabling condition.4
The Role of Family Caregivers in Providing Long-Term Services and Supports

More than ever, people with disabilities are remaining in their own homes, even as they experience levels of disability that, 20 years ago, would likely have resulted in nursing home placement. This is a public policy success story, a positive response to the strong preference of most people to remain in the comfortable and familiar surroundings of home. Yet many policymakers may be unaware that a large part of this success depends on the voluntary contributions of family caregivers. Fully two-thirds of older people with disabilities who receive long-term care at home get all their care from family caregivers, generally wives and adult daughters. One in four uses a combination of family care and paid help; less than one in 10 relies on only paid help.

The Economic Value of Family Caregiving

In 2009, more than 42 million family caregivers in the United States assisted an adult with limitations in activities of daily living at any given point in time. Researchers at the AARP Public Policy Institute estimated the economic value of family caregiving based on caregivers providing, on average, 18.4 hours of care per week to individuals age 18 or older. Using an average wage for home care workers of $11.16 per hour, the national estimate of the economic value of this care amounted to $450 billion in 2009—a staggering amount.

The economic value of family caregiving also was estimated for every state and the District of Columbia. Because average wages for home care workers vary by state, the state-level estimates reflect these differences. Table A illustrates the economic value of family caregiving, by state, in 2009.

To place the value of family caregiving in context, AARP researchers compared it with three measures of Medicaid spending, nationally and in each state: total Medicaid spending; Medicaid spending on all long-term care, including nursing homes; and Medicaid spending on home and community-based services. The economic value of family caregiving exceeded Medicaid long-term care spending in every state, and was more than three times as great in 42 states. Even more dramatic, the value of caregiving dwarfs Medicaid spending on home and community-based services; it was at least twice as great in every state and was more than six times as great in 40 states. These findings are illustrated in Table B.

Profile of Family Caregivers

The typical caregiver is a 49-year-old woman who works outside the home and provides, on average, nearly 20 hours of care per week to her mother for an average of five years. More than eight in 10 caregivers provide help to a friend or relative age 50 or older.

Every caregiving situation is unique, but caregivers generally help with household tasks like shopping for and preparing meals, handling bills and insurance forms, and providing transportation for medical and social purposes. Many provide aid with personal care, such as bathing and dressing, and help coordinate health care and other services. Increasingly, family caregivers are called upon to assist with complex medical tasks.

A recent report by the AARP Public Policy Institute and the United Hospital Fund found that almost half of family caregivers now perform medical or nursing tasks, often with little or no training. For example, among caregivers who perform such tasks, three-fourths managed medications, including administering intravenous fluids and injections. Commonly, these caregivers were responsible for managing five to nine medications. More than a third of caregivers engaged in medical tasks were responsible for wound care—a task that many found stressful and difficult—often fearing they would make a mistake and cause harm to their loved one.

Impact of Family Caregiving

While most family caregivers undertake their role willingly, they can suffer negative effects that result from the strains of providing care. Caregiving can be physically and emotionally demanding. Caregivers often find themselves pressed for time, as they balance managing their own lives and immediate families, their jobs and the needs of the care recipient. Social isolation can result from a lack of free time for social interaction and leisure activities.

A body of research literature documents that many caregivers suffer from depression and experience less robust health than noncaregivers. The strain can be particularly severe when caring for an individual with Alzheimer’s disease or...
other form of dementia. But these physical and psychological effects are just half the story.

Family caregivers often experience financial hardships for a variety of reasons. Many caregivers reduce their work hours or quit their jobs to care for a loved one. These losses of income affect caregivers’ present lives and also potentially imperil their future financial security. They lose out not only on wages, but also on contributions to pension plans and Social Security. They may lose health insurance coverage. The lifetime income-related losses for a family caregiver average $303,880, according to one analysis. Moreover, caregivers typically spend money out of their own pockets incurring expenses on behalf of the person for whom they provide care. Several studies found that typical out-of-pocket expenses exceed $5,000 per year.

Why States Should Help Family Caregivers
Many family caregivers do not even identify with the word caregiver. They simply see what they do as an expected part of caring for a parent, spouse, grandparent or someone else with whom they are close. Yet the public system of providing long-term care depends on the availability of family caregivers to prevent, delay or substitute for publicly funded services. If caregivers are overstressed and burn out, the result may be higher demand for public services.

When family caregivers are overburdened, their productivity at work declines and their health and financial security are negatively affected. By providing support to caregivers, states can help them take care of their own health, remain productive and control the demand for public services. It is critically important that public programs that provide long-term care not simply assume that family members will provide services as part of an individual’s care plan. Instead, these programs should assess the needs and abilities of family caregivers and determine what forms of support are most needed to help the caregiver.

The Impact of Population Aging
People age 85 and older are the population most likely to need long-term care. This cohort is projected to increase 69 percent over the next 20 years and more than triple by 2050. The population is projected to more than quadruple in seven states—Alaska, Nevada, Georgia, Colorado, Utah, Texas and Virginia. A basic measure of the availability of family caregivers is the ratio of the population in the average caregiving range—50 to 64—to the population age 85 and over. In 1990, the ratio was 11-to-1. By 2050, it will be only 4-to-1.

As a result of these trends, more employees are likely to have family caregiving responsibilities that will necessitate taking time off from work. Absent workplace supports, working family caregivers may be compelled to reduce the number of hours they work, change jobs or leave the workforce altogether, especially if they do not have the means to pay for outside help. In a recent national survey, one in five retirees left the workforce earlier than planned to care for an ill spouse or other family member. Almost 70 percent of caregivers reported making work accommodations to address caregiving needs. Family caregivers with the most intense level of caregiving—those who provide 21 hours or more of care each week or those who live with their care recipient—are especially likely to report having to make workplace adjustments.

How Can States Support Family Caregivers?
The good news is that many forms of support for family caregivers do not require public expenditure of scarce funds. For example, the Long-Term Services and Supports Scorecard recommended that states allow nurses to delegate a range of health maintenance tasks to home care workers. This action can relieve many working caregivers of the burden of having to run home at lunch or leave work early to perform tasks that a home care worker could be trained to safely perform. Changing nurse delegation laws does not cost the state money.

Changing laws to protect working caregivers from discrimination in the workplace also does not require public expenditure of funds, yet it can help caregivers retain the important link to employment. Working caregivers may need some flexibility in work schedules or use of leave. Often, the need to provide care cannot be scheduled in advance if there is a health crisis or emergency that requires immediate attention. Caregivers will experience less stress if they do not have to shoulder the additional burden of fearing they will face retaliation at work, or loss of their job, if they need to take off time.

The number one need of family caregivers is to get a break. Respite care often is used to provide caregivers temporary relief from their responsibilities and is available in all 50 states. Although respite services are funded with federal, state and general revenue funds, the amount and type of respite offered varies widely across states and among programs within states. The definition of respite also varies widely across states.

State Innovations in Caregiver Support
Several states have developed innovative laws and public policies that establish a framework for workplace policies that recognize and accommodate working caregiver needs.

**FMLA Expansion**—The federal Family Medical Leave Act guidelines allow workers in firms with 50 or more employees to take up to 12 weeks of unpaid, job-protected leave to care for a spouse, parent or child with a serious health condition. Expanding on FMLA guidelines can enable employed family caregivers to address a more diverse range of caregiving responsibilities and care for a broader definition of family members. The District of Columbia, Hawaii, Oregon and Vermont all have expanded the federal FMLA. States also can extend FMLA protections to employers with fewer than 50 workers.

**Paid Family Leave**—Two states—California and New Jersey—have implemented innovative state-wide paid family leave programs that offer wage replacement during periods of absence to care for a family member with a serious health condition. Both programs are fully funded by a small employee tax with no direct costs to the state or to employers. Table C illustrates examples of innovative statewide laws and policies addressing caregiver supports.

Table C: Examples of Innovative Statewide Caregiver Supports

**Conclusion**

It is imperative that states implement strategies to support the family caregivers who play an important role in our nation’s long-term care system. Establishing effective policies now will help prevent a greater crisis that is looming in the next 20 years. As the baby boom generation ages, large numbers of older individuals will develop disabilities and chronic conditions and need assistance. Yet this cohort will have fewer potential caregivers than previous generations because of smaller families and greater mobility. Those caregivers who are available will need support, and both current and future caregivers also need more options for public services, access to respite care and better alternatives to help families pay for long-term care. Providing support for family caregivers is not only the compassionate thing to do, it also is the fiscally sound action for states to take given the economic value of family caregivers’ contributions.

**Notes**

4. Ibid
7. Ibid
8. Ibid
10. Ibid
13. Ibid
16. AARP Public Policy Institute calculations from REMI (Regional Economic Models, Inc.) 2012 baseline demographic projections.
17. Ibid

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