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Abstract

In the United States, people who need long-term care (LTC) face a system with large gaps in care, which they must rely on friends and family to fill. Medicaid finances the majority of paid LTC, but people must exhaust their resources to qualify. Medicare and private health insurance do not cover LTC, and the private market for long-term care insurance is failing. Unpaid family and friends provide most long-term services, but the value of their services is rarely reflected in debates about LTC financing and delivery. Beyond the value of the services, this system has costs to the economy, as spouses and adult children reduce paid work to care for their loved ones. As the population ages and families are less able to shoulder the burden of LTC, the current system may be unable to meet the growing need without an alternative, sustainable financing mechanism.

Keywords

long-term care, LTC, Medicaid, aging

Disciplines

Geriatrics | Health and Medical Administration | Health Policy | Other Medical Sciences

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LONG-TERM CARE FINANCING IN THE UNITED STATES

Puja Upadhyay and Janet Weiner

In the United States, people who need long-term care (LTC) face a system with large gaps in care, which they must rely on friends and family to fill. Medicaid finances the majority of paid LTC, but people must exhaust their resources to qualify. Medicare and private health insurance do not cover LTC, and the private market for long-term care insurance is failing. Unpaid family and friends provide most long-term services, but the value of their services is rarely reflected in debates about LTC financing and delivery. Beyond the value of the services, this system has costs to the economy, as spouses and adult children reduce paid work to care for their loved ones. As the population ages and families are less able to shoulder the burden of LTC, the current system may be unable to meet the growing need without an alternative, sustainable financing mechanism.

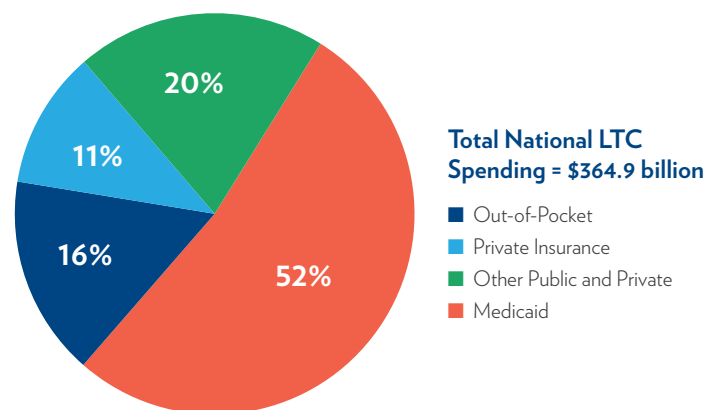
BACKGROUND

Long-term care (LTC), sometimes referred to as long-term services and supports, can be defined as a continuum of medical and social services designed to support individuals who need extended help with “activities of daily living,” such as bathing and dressing. We distinguish LTC from post-acute care, in which similar services are provided on a short-term basis after hospitalization. Although they are often delivered in the same facilities, long-term and post-acute care are financed in very different ways, as shown on page 2.

The current system for financing LTC relies heavily on informal (unpaid) caregivers, many of whom are themselves socioeconomically and medically vulnerable. Medicaid is the primary payer for formal LTC, accounting for over half of national spending in 2017 (Figure 1).

However, Medicaid only becomes available after individuals have exhausted their financial resources. Medicare does not cover LTC, with

Figure 1. LTC spending by payer, 2017.



Source: Kaiser Family Foundation, [Medicaid Home and Community-Based Services Enrollment and Spending \(April 2019\)](#)

Table. Financing and Delivery of Long-Term and Post-Acute Care

	Post-acute care (short-term, rehabilitative)	Long-term care
Payers	Medicare (more than 80%) Other (Medicaid, private insurance, out-of-pocket)	Medicaid Private LTC insurance Out-of-pocket spending Informal, unpaid care
Services/Location of care	LTC hospitals Inpatient rehabilitation Home and community-based services Skilled nursing facilities/nursing homes Assisted living facilities	

most post-acute care limited to less than 100 days. The long-term care insurance market is small and contracting, covering very few Americans at relatively high premiums. Sixteen percent of formal care is paid out-of-pocket. At a median hourly cost of \$22 for a home health aide, and a median annual cost of more than \$100,000 for a private room in a nursing home, most people will not have the resources to self-finance their LTC needs.

This brief reviews how LTC is financed in the U.S. It draws on evidence characterizing the current system, and demonstrates a need for alternative, sustainable solutions to protect against the unpredictable, potentially catastrophic risk of needing LTC.

WHO BEARS THE RISK FOR LONG-TERM CARE?

While individuals of all ages are at risk for needing LTC, this need grows with age. By 2055, nearly [90 million people](#) in the U.S. will be aged 65 and older, and the population aged 85 and older will more than double! The number of older Americans with severe LTC needs is estimated to increase [140 percent](#) between 2015 and 2055, reaching 15.1 million.²

But this risk is [not distributed equally](#), even among people 65 and over.³ One-third of them may never need LTC, while a fifth will need it for more than five years. Need also varies by subpopulation; for example, women need care longer (3.7 years on average) than men (2.2 years).

However, in our present system, the financial and physical risks families face is not only a function of needing LTC, but also of needing to provide care.⁴ [Hoffman](#) (2016) points out that current LTC policy fails to account for the risk of becoming responsible for someone else’s care, which she terms “next-friend” risk. Next-friends, or those who directly provide or arrange LTC, take on responsibilities that may threaten their own long-term health and financial security. Even more troubling is that informal caregivers tend to be those already more vulnerable: caregiving responsibilities are heavily borne by [women, certain minorities, and the poor](#).⁵ Hoffman argues that social policy has expanded next-friend risk by reinforcing a structure of long-term care that relies on informal caregiving. Although people have long relied on family members for care, current LTC policy has intensified and cemented this role.

MEDICAID IS THE PRIMARY PAYER FOR LONG-TERM CARE

Because long-term care is not considered “medical care” as defined in federal legislation, neither Medicare nor private health insurance cover LTC. Although not intended to be a long-term care program, Medicaid finances 52 percent of all paid LTC, and functions as a critical safety net when long-term disabilities occur. However, this coverage is limited, ultimately falling short for people who need LTC. Coverage and spending [vary significantly](#) by state, with the highest-spending states averaging six times more than the lowest spending states (\$3,000 vs. \$500 per low-income resident).⁶

Hoffman ([2015](#); [2016](#)) details how Medicaid emerged as the primary payer of LTC, and how its design affects the way care is financed and delivered.^{4,7} For instance, to qualify for Medicaid, individuals must have low income and limited savings, or exhaust almost all of their resources until they qualify. As a result, only the poorest Americans have LTC coverage, except for the relatively limited number who have private policies.

Initially, Medicaid had an “institutional bias” – favoring the provision of LTC in licensed nursing homes (a mandatory benefit that states must cover to receive federal matching funds) over home care (an optional benefit). This structure incentivized long-term institutional care, and set the stage for the current patchwork coverage for home and community-based care. Nonetheless, Hoffman explains, this relieved some of the burden on family and friends. In a recent study of the effects of expanding Medicaid eligibility by changing “spend-down” provisions, [Mommaerts](#) (2018) found that fewer elderly beneficiaries resided with their children, and more resided in nursing homes.⁸ This effect was concentrated among individuals aged 80 and older, with lower income, and those who have difficulty caring for themselves. A subpopulation of moderate-income people may have moved away from coresidence and into independent home care, but the study was not designed to assess changes in home and community-based care.

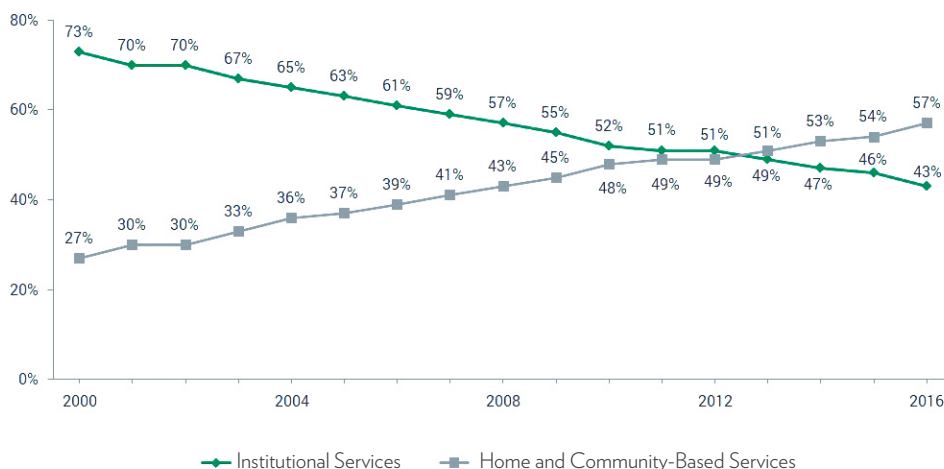
In recent decades, Medicaid has “rebalanced” its services away from institutions and toward home and community-based services. This shift reflects patients’ preference to remain at home, as well as the

Supreme Court’s decision in *Olmstead v. L.C.* (1999) that avoidable institutionalization of persons with disabilities violates the Americans with Disabilities Act.⁷ Subsequently, the share of Medicaid LTC spending on home and community-based services has consistently increased since the 1980s, surpassing institutional care in 2013 (Figure 2).⁹ The Affordable Care Act included financial incentives for states to expand Medicaid coverage of community LTC, and between 2011 and 2015, 18 states received more than \$2.4 billion in enhanced federal funding.¹⁰ In 2016, home and community-based services were 57 percent of total LTC expenditures. However, coverage of these services remains optional, and funding varies significantly by state.

As a result, most people receiving LTC live in private homes or community settings, including many individuals with severe functional limitations.¹¹ While the shift to home offers considerable benefits to care-recipients, Hoffman explains, rebalancing has cemented the obligations of friends and family to fill in gaps in care, often with little support to do so.⁴

Recently, some states have experimented with using Medicaid funds more flexibly to pay for family members to provide care. Coe and colleagues (2019) studied a demonstration program that gave Medicaid beneficiaries an allowance equal to the cost of home health agency care, with a choice of paying for agency care or paying family members to provide care.¹² They found that family involvement in home care significantly decreased inpatient health care utilization and Medicaid spending on inpatient care. They also found improvements in health outcomes, including significant decreases in infection rates and development of bed sores and shortness of breath. These findings suggest paid family care could both increase beneficiary health while lowering utilization and costs.

Figure 2. Proportion of Total Medicaid LTC Spending on Institutional Services and Home and Community-Based Services, 2000–2016



Source: MACPAC, [Home and Community Based Services](#)

THE MARKET FOR PRIVATE LONG-TERM CARE INSURANCE IS FAILING

Private LTC insurance has been available since the 1980s, but the market is relatively small and contracting. In 2014, 7.2 million people were covered by private LTC insurance, about 5 million of whom were 65 and older (11 percent of all elderly adults).^{13,14} Wealthier people are more likely to be covered, but the coverage rate among the wealthy is still fairly low; in 2014, only a quarter of adults 65 and older with at least \$1 million in household wealth were covered. By contrast, only 8 percent of older adults with wealth between \$100,000 and \$500,000 had coverage.

The private market for LTC insurance has unraveled in recent years. Despite the growing need, the number of new stand-alone individual LTC insurance policies has fallen from 372,000 in 2004 to just under 70,000 in 2017. Likewise, the number of insurers offering the coverage has diminished from slightly over 100 to about a dozen. Premium rates for newly issued policies have risen as the remaining insurers adjust their pricing.^{15,16}

Surveys indicate that people are often reluctant to purchase LTC insurance because they underestimate their future LTC needs, mistakenly believe Medicare or private health insurance will cover their LTC expenses, have concerns about insurer solvency, and/or believe premiums are too high.¹⁷ Even at actuarially fair prices, Pauly (1990) notes that risk-averse buyers who are rational and well-informed may still choose not to purchase LTC insurance, if they view family members as an alternative source of care.¹⁸ Demand may be low, Pauly argues, because the main consequence of LTC insurance is to enhance the expected value of a buyer’s estate.

But LTC insurance may have other intergenerational benefits. Coe and colleagues (2015) found that people with LTC insurance use less informal caregiving.¹⁹ Adult children are less likely to live with or near parents with LTC insurance and more likely to work full-time, suggesting that economic gains from private LTC insurance could accrue to the younger generation.

WHY ARE LONG-TERM CARE INSURANCE COVERAGE RATES SO LOW?

People often attribute low purchase rates of private LTC insurance to a reduced demand because of the availability of Medicaid coverage. While this so-called “crowd out” occurs, evidence suggests that it has only a modest impact on demand. For example, Brown, Coe,

[and Finkelstein](#) (2007) estimated that even the most stringent state Medicaid eligibility requirements, applied nationally, would only increase the demand for private LTC insurance from 9.1 percent to 11.8 percent. The authors conclude, “The vast majority of households would still find it unattractive to purchase private insurance.”²⁰ A more recent study by [Kim](#) (2017) modeled the decision to purchase LTC insurance and found that eliminating Medicaid would increase demand only slightly (by 5.3 percent), but would have a larger effect on savings, increasing median assets by 15.3 percent.²¹

Medical underwriting by insurers may also contribute to low coverage rates. In any voluntary market, insurers use underwriting to price risks accordingly and to avoid adverse selection. One [study](#) of two LTC insurers found that they denied up to 24 percent of applications based on medical underwriting; a simulation of underwriting estimated that 40 percent of the general target population would be denied.²² Rapid advances in predictive testing and changes in health technology (for example, [biomarkers](#) that can predict risk of developing Alzheimer’s up to 20 years before symptoms) may enhance underwriting that could narrow the LTC insurance market even further.¹⁶

There may be an even more important reason for low LTC insurance purchase rates: the behavioral economic principle of “narrow framing,” or the tendency to make decisions in isolation. [Gottlieb and Mitchell](#) (2019) found that, all else being equal, individuals who are subject to narrow framing are between 25 and 66 percent less likely to buy LTC insurance than average.²³

INFORMAL CAREGIVERS PROVIDE THE BULK OF LONG-TERM CARE, AT AN ENORMOUS COST

Absent public and private coverage, most people needing LTC rely solely on informal caregivers (unpaid friends and family members) rather than on paid services. The risk taken on by loved ones caring for a friend or relative intensifies the scale of the LTC problem in the U.S. In 2013, the estimated value of these unpaid, often unnoticed contributions was about [\\$470 billion](#), based on caregivers providing 18 hours of care per week at an average wage of \$12.51 per hour.²⁴ Other estimates, which differ based on methodology and definitions, include [\\$199 billion](#) (2009), [\\$234 billion](#) (2011), and [\\$522 billion](#) (2011-2012).^{25,26,27}

The range of estimates reflects the difficult and complicated task of placing a value on informal caregiving. Most estimates rely on straightforward methods such as multiplying the hours of informal care provided by the wage of a formal home health worker. However, monetary losses are just the beginning. [Informal caregiving today](#) is more complex, costly, stressful, and demanding than ever.²⁵ Although caregiving can be an enriching, meaningful experience, informal caregivers often experience permanent harm to their health, careers, and relationships.

[Coe, Skira, and Larson](#) (2018) estimate a more comprehensive cost to an individual caregiver that accounts for the value of lost leisure time, potential impacts on future employability and wages, and any intrinsic benefits such as fulfilling a familial duty.

The authors find that the cost to a daughter caring for her elderly mother for two years ranges from \$144,000 to \$200,000, depending on the mother’s health. The median cost was \$180,000, seven times the estimate that only considers foregone wages. This suggests that the costs of providing informal care to a daughter’s well-being are about the same as the cost of a semi-private bed in a nursing home (about \$170,000 for two years in 2017). As Medicaid programs continue shifting LTC to home and community-based services, with variable coverage and waiting lists, people may need to rely more on informal supports, at great cost to families.

Relying on families to “pick up the slack” presupposes that informal care can substitute for formal care, which has been found in a number of studies.^{29,30,31} However, formal care can also complement informal care, especially in low-income populations. In a study of Medicaid beneficiaries in Texas, [Moudini and colleagues](#) (2012) found that more formal home care hours were not associated with fewer informal care hours; in fact, the hours of informal care increased as the number of formal care hours increased.³² The authors suggest that the need for care may drive both forms of care. Formal home care may allow informal caregivers to focus on different tasks that need attention as the beneficiary’s needs change.

CONCLUSION

America’s LTC problem might be hidden from public eye, but it affects all of us, and significantly impacts how public dollars are spent. As the population ages and rates of disability rise, the current system’s failure to meet the needs of those who require LTC, and their loved ones, will only intensify.

In the absence of other viable public or private options, Medicaid will continue to be the major mechanism for financing LTC for millions of Americans. As Medicaid continues rebalancing its services, the focus should be on streamlining access to home and community-based care, supporting informal caregivers including with pay, and addressing gaps in coverage through comprehensive or incremental reforms. Private insurance can and will likely play a complementary role, but even proponents of private options admit that building future policy around a private market will [leave most Americans unprotected](#).³³

The lack of protections for individuals who need and provide LTC, combined with demographic trajectories and projected needs, point to the urgency around pursuing policies more sensitive to the risks and financial insecurity individuals and families face. In the end, each of us, or the people we love, will need LTC, and creating a sustainable financial solution to this problem will benefit all.

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