The Future of Long-Term Care Policy: Continuing the Conversation

Statement of

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Before the
Senate Special Committee on Aging

December 18, 2013

Chairman Nelson, Ranking Member Collins, and Members of the Committee, thank you for the opportunity to testify today about the future of long-term care policy.

In 2011, the U.S. paid over $200 billion for long-term care. And yet, the American system is bare-bones. It inadequately protects today's elderly population from the financial devastation of a long-term disabling condition such as Alzheimer's disease or stroke. It leaves children and adults with disabilities with few options for independence. The U.S. long-term care system relies on over $400 billion in estimated economic value of unpaid caregiving to sustain the vast majority of people with long-term care need. So, while at any point in time there are only 11 million people needing long-term care, it has a huge effect on American life, involving a third of all households in caregiving activities.[i]

Families provide this care because the only other option is to pay privately, out-of-pocket for services until they exhaust their resources. When this happens, individuals with long-term care need must rely on Medicaid, which offers few choices other than institutionalization. While only one in five Americans will need help for five years or more, that help will bankrupt those individuals and subsequently force them into a Medicaid nursing home bed, no matter how well they have saved for their retirement.[ii]

In this testimony, I describe the population needing long-term care and how this diverse group of Americans and their families piece together financing and services for long-term care. I briefly discuss the fundamental challenge inherent in rationalizing the financing system.

Population Needing Long-Term Care

The unifying characteristic of the long-term care population is the need for help with highly personal activities that are a basic part of everyday life. Disease, a disabling chronic condition, an accident, a developmental disability, can occur at any age and impair a person's ability to function in every-day activities such as bathing, eating and dressing. A child born with cerebral palsy or mental retardation may need long-term care as could an adult coping with multiple sclerosis or an elderly person with Alzheimer's disease. [iii]

When researchers examine data from national surveys asking people about their level of functioning, they find about 11 million people with some need for assistance with daily activities, broadly defined.[iv] Of this total, 44 percent, almost five million are under age 65 and most of them live in the community. Slightly over six million are elderly and about 1.3 million live in nursing homes. The elderly population needing long-term care tends to be much more comprised of low-income, widowed women than the overall elderly population.[v] In the non-elderly population needing long-term care, only about half are women and the median income is half that of people without long-term care need.[vi]

Service Use

Because long-term care involves providing individuals assistance with basic activities of daily life, the delivery system and its financing are linked inextricably to where these individuals live. The setting in which an individual lives has a significant and varying impact on how much support is provided, what it costs and how it is financed. For any American needing long-term care, the formula each person uses to pay for it will include a combination of three elements: personal financial resources, unpaid caregiving and Medicaid. The contribution of each of these elements depends to a great degree on factors such as the length and severity of functional impairment, family configuration and resources, and geography.

Many of the 1.5 million people who live in a nursing home end up there because supporting them in the community has drained the emotional, physical and/or financial resources of their families. Nursing home residents often begin their long-term care journey in a single-family dwelling, relying on a mix of unpaid family and community-members (e.g., church friends, neighbors) and paid home care. Sometimes simple assistive technology can be helpful in supporting someone's ability to remain at home. Wheelchair ramps, specialized spoons for self-feeding, and bathroom seats can add important support to the work of paid and unpaid caregivers.

Unpaid Help in the Community. The work of providing care to people with long-term care need falls overwhelmingly on unpaid caregivers from family and the community. At most, only just about one-fifth of the long-term care population living in the community reports using paid help.[vii] As a result, ***almost a third*** of all U.S. households reports that at least one person has served as an unpaid family caregiver within the last twelve months.[viii] Spouses, parents and adult children provide care that is intensive in terms of their time and the physical and emotional effort involved. The most common task they perform is helping the care recipient get in and out of beds and chairs, helping with dressing and assisting with bathing or showering. And, they spend an average of 20 hours per week providing this care while most (75 percent) hold down some type of job.[ix]

Paid Help in the Community. Among the community-dwelling long-term care population paying for help, about a quarter funds a portion privately out of their own resources. Those individuals will pay, on average, about $20 per hour, although the rate fluctuates significantly for geography.[x] If a person living at home with long-term care need has low enough income and assets to meet the Medicaid financial requirements, Medicaid may pay for some home care. States offer home and community-based or "personal care" services through Medicaid. States limit these programs -- either through restrictions on the number of people they serve or the amount of services they cover. Of the total Medicaid spends on long-term care for elderly and people with physical disabilities, only 35 percent of spending covers home and non-institutional care.[xi]

Because of the challenges associated with supporting an individual at home through unpaid and paid care, many individuals and families facing a long-term disability find that they have to look to other living options. If resources are already limited, Medicaid coverage of a nursing home stay is almost always the only option. However, if some

personal resources are available, families can consider housing alternatives, such as assisted living.

Housing with Services (Assisted Living). Roughly, about one million people live in some type of housing with services.[xii] An assisted living facility costs about $42,600 per year, on average, and is rarely paid for by Medicaid.[xiii] If the depletion of personal resources begins in the home setting with paid home care, it can accelerate as individuals and family members pay for assisted living. Many senior housing providers report, anecdotally, that their residents often sell their homes to finance senior housing fees. Research shows that private payment for assisted living has displaced some private payment for nursing home care.[xiv] This means that individuals who are in assisted living often stay in this setting until they have run through their home equity and savings, at which point they must move to a nursing home where their care can be financed by Medicaid.

Nursing Home Care. The benefit of nursing home care is that Medicaid will pay for it when an individual depletes all other means of private payment. In some cases, individuals will pay privately for nursing home care when the care needs are so significant that even the most robust community-based services can no longer support an individual safely. Like assisted living residents, private pay nursing home residents are also in the process of depleting their personal assets due to costs that run between $81,030 and $90,520 per year.[xv]

Financing Sources

Of the formal sources of financing, not including the value of unpaid caregiving, Medicaid has played a key role, with a $136 billion contribution in 2011. However, the inability to accurately measure private out-of-pocket contributions makes it difficult for analysts to know the relative role of private spending and Medicaid. The result may be a skewed view of the degree to which Medicaid coverage of nursing home care is seen by most Americans as a last resort rather than an opportunity to protect wealth.

Private Out-of-Pocket. Private out-of-pocket spending is challenging to assess because much of what individuals spend on these services is not captured in the national health expenditure data. The spending that is captured amounts to only between $45 and $53 billion in 2011, depending on the service categories included.[xvi] And, this likely represents an underestimation of what individuals and families are spending on these settings and services. When researchers attempt to quantify the value of unpaid caregiving, it increases this amount by over $400 billion per year.[xvii]

Medicaid. Medicaid spending is available because states report their expenditures by service category. The federal government and states spent $136 billion on long-term care in 2011.[xviii] More importantly, the average annual growth in spending from FY 2006 to FY 2011 was 4.8 percent compared to 6.3 percent for the total Medicaid program – thereby reducing the share of Medicaid that is spent on long-term care to 33.1 percent – the lowest it has been in two decades and the continuation of a downward trend. Over this time, the mix of spending between institutional and non-

institutional has also shifted from an institutional, non-institutional spending ratio of 63 to 37 percent in FY 2006 to a 53 to 47 percent mix in FY 2011.[xix]

While the shift in resources towards non-institutional care demonstrates progress towards providing people services they prefer, the Medicaid program will face enormous pressure from budget challenges, competing health care priorities and a growing population of very old. These pressures will require Medicaid to reduce the number of people who receive long-term care services and the amount spent per person – regardless of setting. And, in fact, we see that reflected already in the growing interest among states in shifting from fee-for-service long-term care programs to capitated arrangements with managed care plans.[xx] These trends point to the possibility of a growing gap between public program financing and the need for financing.

Medicare. Medicare comes up frequently in discussions about long-term care even though it does not pay for long-term care. Medicare beneficiaries with long-term care needs use much more health care than Medicare beneficiaries without long-term care needs, even when we control for the presence of chronic illness. In other words, a Medicare beneficiary with chronic illness is much more likely to have very high health care spending if he or she also has a significant need for long-term care. Avalere research found that Medicare spent about 50 percent or $11,000 more per year for seniors with any chronic condition and functional impairment compared to seniors with any chronic condition and no functional impairment.[xxi]

The long-term care population uses significant amounts of hospital and post-hospital care. Spending on post-acute services such as skilled nursing facilities and home health agencies is the most variable, indicating a great deal of inefficiency in this area of the health care system. Accountable care organizations and bundled payment participants have significant opportunities provide better post-acute care at a lower cost.[xxii] To do so, they will need to integrate acute-post-acute and long-term care for the long-term care population.

Private Long-Term Care Insurance. Even more difficult than assessing the financial contribution of out-of-pocket payments is quantifying the role of private long-term care insurance in paying for long-term care. Currently, 7 to 7.7 million individuals have coverage, translating into about 12.4 percent of the population over age 65.[xxiii] [xxiv] Again, the national health expenditure data that we rely on to capture payments made by insurance is not sufficient to give us a good picture of the contribution of this type of financing. It does not disaggregate payments made by private long-term care insurance from those made by private supplemental health insurance policies that pay for skilled nursing facility copayments during the post-acute episode. Further, long-term care insurance claimants report using their insurance to pay for assisted living facility care, which as stated above, is not captured in the data. With these limitations in mind, the private insurance payments attributable to home health and nursing home care equal about $17 billion in 2011.[xxv]

Implications and Considerations

Over the next 20 to 25 years, the percentage of the population age 65 and older is going to increase dramatically with a substantial bump in the percentage over age 85. Avalere projects that the number of individuals needing long-term care will increase with this trend, growing to 14.6 million by 2040.[xxvi]

Despite many years debating and considering long-term care policies aimed at increasing the number of people covered by some type of insurance coverage, the U.S. remains a nation almost entirely dependent on Medicaid, personal savings and unpaid family caregivers for long-term care. At this juncture, in the wake of CLASS' repeal, policymakers could continue to debate the merits of increasing coverage under the existing private insurance market or under some type of social insurance, but that debate – while very important – must also consider whether any effort, public or private, is sufficient without some component that requires everyone to contribute to a risk pool.

Having analyzed the budgetary impact of both a private/public partnership with a federal catastrophic benefit, and the CLASS Act and similar social insurance options, my experience suggests that, in either case, the challenge lies chiefly in the question of persuading individuals to enroll in an insurance program that they do not know they need and won't use for up to 30 or 40 years. Research suggests that, without sufficient participation, any program – whether private or public – will fail to fill the financing gaps in our current system. As challenging as it may seem in the current policy and political environment, some type of mandatory approach to insurance appears to be the only way to protect most Americans from the financial devastation of long-term care need.[xxvii]

Endnotes

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