NATIONAL ACADEMY OF SOCIAL INSURANCE

Long-term Services and Supports

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A key source of insecurity and anguish in the United States is the lack of a well-functioning system for financing and delivering long-term services and supports (LTSS) – the services and supports used by individuals of all ages with functional limitations and chronic illnesses who need assistance to perform routine daily activities. The country needs an LTSS system that is affordable, meets the needs of those requiring support, and preserves the independence and autonomy of frail older adults and working-age individuals with disabilities. Long-term care (LTC) is currently delivered in a piecemeal and costly fashion that prevents many from getting the support they need within their community, while placing a heavy financial, emotional, and physical burden on their families who assist them.

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This vast unmet need and lack of coordination of supportive services results in preventable harm to those in need of care, which in turn often results in costly acute medical episodes, including hospitalizations. Aside from the harm to individuals, this inappropriate and unnecessary health care spending increases the financial burden on both Medicare and state Medicaid programs. As the Boomer generation ages, the population at risk for LTSS needs is growing rapidly, while the younger generation of potential caregivers is growing more slowly. The U.S. thus faces a looming crisis in providing and financing sufficient care.

While these challenges seem daunting, it is possible to design a financing system for LTSS that can promote effeciency in medical service delivery and provide important protections against catastrophic costs that far exceed the resources of most American families.

Background

What are long-term services and supports and why are they important?
The fundamental goal of long-term services and supports is to help individuals with functional limitations live their daily lives safely while maintaining quality of life and

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maximizing independence in their preferred community setting. With access to care and supports, seniors and individuals with disabilities are better able to make choices about where they live and how they spend their time. Devastating and costly health incidents – such as falls and malnutrition – can often be prevented with proper services and supports such as personal assistance, home modifications for mobility impairments, and home meal delivery programs. But without access to appropriate, high-quality care, individuals with functional limitations may suffer further health deterioration, which in turn causes unnecessary health care spending.

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Status quo is costly and unsustainable

Over half of all seniors are expected to experience a high need for LTSS assistance before they die,[1] and many individuals with disabilities rely on these services throughout their lives. But for both older and younger people with LTSS needs, costs are unpredictable and varied. About one in six seniors and their families will spend over $100,000 out-of-pocket for long-term care before they die.[2] For over 15 percent of seniors above the age of 65, the total cost of long-term services and supports across all payers will exceed $250,000, and for 9 percent, out-of-pocket costs alone will exceed that amount.[3] While this problem has been growing quietly for decades, it is becoming ever more severe as the private insurance market shrinks, high and rising costs make private long-term care insurance coverage unattainable for most people,[4] and the caregiver gap continues to widen.[5]

Burden on states

As the Boomers get older and frailer, our current system of relying heavily on Medicaid to finance long-term services and supports will overburden states, likely at the expense of pursuing other critical budget priorities. In addition, increased need for Medicaid LTSS will put substantial strain on the program's ability to provide other forms of much-needed basic health care coverage for low-income individuals and families.

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[1] Melissa Favreault and Judith Dey. 2015. Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief. Office of the Assistant Secretary of Planning and Evaluation. https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief.
[2] Ibid.
[3] Ibid.
[4] National Association of Insurance Commissioner (NAIC) and The Center for Insurance Policy and Research (CIPR), 2016, The State of Long-Term Care Insurance: The Market, Challenges and Future Innovations, http://www.naic.org/documents/cipr_current_study_160519_ltc_insurance.pdf.
[5] Donald Redfoot, Lynn Feinberg, and Ari Houser, 2013, The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers, AARP Public Policy Institute, Insight on the Issues: 85, http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf

Burden on Medicare

Financial strain also extends to the Medicare program when seniors and individuals with disabilities develop or exacerbate illnesses and injuries – particularly acute medical episodes such as falls or infections – due to a lack of appropriate, high-quality services and supports. The 15 percent of Medicare beneficiaries with chronic conditions who also have functional limitations, and therefore require long-term services and supports, account for almost one-third of all Medicare spending.[6]

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Toll on families

Many families are forced to make significant personal sacrifices to care for an aging loved one, taking away from their own financial security and health and often interrupting professional advancement.[7] This is especially true for women, who are most likely to be the caregivers. While individuals have a personal responsibility to plan for their own future needs, and while families are responsible for caring for their loved ones, the financial, emotional, and physical burdens of prolonged LTSS need far exceed the capacity of many families. Private long-term care insurers have tried and failed to alleviate this burden, but are leaving the market given the challenge of the task.

Clearly, our current system of long-term care – or lack thereof – has become a substantial burden on the federal budget, state economies, and most importantly on the health and financial stability of countless individuals and families.

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[6] Harriet L. Komisar and Judy Feder, 2011, Transforming Care for Medicare Beneficiaries with Chronic Conditions and Long-Term Care Needs: Coordinating Care Across All Services, Georgetown University, http://www.thescanfoundation.org/sites/default/files/Georgetown_Trnsfrming_Care.pdf.

[7] National Academies of Sciences, Engineering, and Medicine, 2016, Families Caring for an Aging America, Washington, DC: The National Academies Press, https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america.

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Working toward policies that improve access to LTSS will therefore be both a critical step towards improving health outcomes and a key strategy for reducing unnecessary health care spending. Many of the policy options suggested in this *Report* will require some level of investment – but those investments will yield significant benefits for the health and financial security of our nation's most vulnerable populations, and may reduce other government spending. Every family in America faces the risk of caring for a loved one at some point in time, and most will struggle to make ends meet in doing so. There are many opportunities for cost-savings through more effective implementation of long-term care, as well, but investing in the financial security and health of American families is a worthy cause in and of itself – one that touches all and so one around which we all should be able to rally.

Policy Challenges

Expensive, fragmented LTSS financing

Today's system of LTSS financing is complicated, fragmented, inefficient, and expensive. Medicaid serves as the primary public payer, covering roughly one-third to half of all spending, but is available only on a means-tested, asset-tested basis for those at a certain threshold of financial and/or medical need.

The rest of LTSS financing comes from a variety of sources. Contrary to popular belief, Medicare does not cover LTSS services; rather, Medicare covers only post-acute care, focusing primarily on short-term needs. Private insurance, in turn, finances less than one-tenth of LTSS spending.[8] Family out-of-pocket spending pays for as much as 40 percent of all paid care. The rest is funded by myriad sources, including the Veterans Health Administration, temporary disability insurance, and charity.[9] The reality of LTSS costs to families extends beyond direct out-of-pocket spending on health services. This array of funding sources for LTSS leads not only to confusion, but also to inefficiencies in the coordination of care that likely elevate costs significantly.

[8] Erica L. Reaves and MaryBeth Musumeci, 2015, Medicaid and Long-Term Services and Supports: A Primer, The Kaiser Commission on Medicaid and the Uninsured: The Henry J. Kaiser Family Foundation, http://kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/.

[9] Kirsten J. Colello and Scott R. Talaga, 2015, Who Pays for Long-Term Services and Supports? A Fact Sheet, Congressional Research Service, https://fas.org/sgp/crs/misc/R43483.pdf.

Family caregivers suffer adverse health, financial, and professional consequences

Without a coordinated and efficient system of long-term services and supports, much of the responsibility for caregiving has fallen on family members and loved ones. Estimating the number of caregivers is a challenging undertaking, but research suggests that at least 17.7 million Americans are providing care to an aging loved one coping with functional limitations.[10] While many of these family caregivers gladly give this care, they also face many challenges with, at best, exceedingly limited help. Most caregivers provide this assistance without any paid support. Family caregivers experience generally poorer health outcomes than their peers, and those health outcomes worsen as the intensity of their caregiving responsibilities increases.[11] In addition, many caregivers spend a substantial amount out-of-pocket to support their loved ones. For women in their 50s who leave the workforce to care for an aging family member, the average lifetime loss in earnings exceeds $300,000.[12] These expenditures and disruptions in employment will inevitably affect their own long-term economic stability, in addition to any health consequences they suffer as a result of their caregiving work.

Private LTC insurance market failure

A private long-term care insurance market has operated for several decades, but has generally failed to make a sufficient dent in tackling the large-scale issue of financing long-term services and supports. Over the past decade, the market for traditional policies has collapsed, with substantial declines in sales of policies and the number of carriers offering coverage.[13] Carriers have been discouraged by such things as low interest rates on their reserves, higher-than-expected policy retention rates, and high and unpredictable payouts. Meanwhile, Americans generally do not appreciate the risk of needing LTC. The result is that premiums for private policies are unaffordable for most American families, while the coverage offered under the available plans is not sufficient to cover the risk of true catastrophic LTSS need. As a result, consumers recognize that purchasing coverage is often not worth the investment for the level of protection they would receive, further driving up the cost of private plans as only the consumers most at risk for using LTSS services decide to purchase plans.

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[10] National Academies of Sciences, Engineering, and Medicine, 2016.
[11] Ibid.
[12] MetLife Mature Market Institute, National Alliance for Caregiving, and Center for Long Term Care Research and Policy, New York Medical College. 2011. The MetLife Study of Caregiving Costs to Working Caregivers:
Double Jeopardy for Baby Boomers Caring for Their Parents. http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf.
[13] NAIC and CIPR, 2016.

Limits to any voluntary insurance approach to LTSS due to cost, underestimation of risk

There are a variety of reasons why individuals and families struggle to save for future LTSS needs. First, at younger ages, people have more immediate financial concerns, such as the need to pay off college loans, raise a child, buy a home, or purchase health insurance. Second, the need for long-term services and supports is unpleasant to consider, and many underestimate the likelihood of requiring it. Moreover, even those who are aware of the need for LTSS coverage and turn to the private LTC insurance market often opt against purchasing coverage due to the lack of availability of affordable policies with stable premiums.[14]

The risk of needing care is unpredictable and can become catastrophic. While it is possible to use personal savings to cover some level of future care needs, most Americans cannot afford to fully self-insure against such a substantial risk. And it is virtually impossible to purchase a plan on the private market that covers extreme catastrophic risk, as an overwhelming majority of plans only cover up to five years of LTSS needs. This is the very reason that social insurance exists – to spread risk widely enough to provide adequate protection for the smaller proportion of individuals for whom the expensive, insurable event transpires.

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Working-age people with disabilities have needs that are distinct from those of elderly

Younger adults who experience a lifelong need for LTSS have fundamentally different needs from seniors. Most notably, many are seeking supports that enable them to participate in the workforce. Some public policy options that might help address the needs of seniors are not well-suited to addressing those of working-age people with disabilities. For example, a universal social insurance program that requires many years of vesting does not meet their needs. Additionally, Medicaid waiver programs are not working well for people with disabilities; there are long waiting lists for people with intellectual disabilities in most states. Given past experience, any effort to render Medicaid more state-based is likely, especially in light of many states' balanced budget requirements, to fail to address the needs of working-age people with disabilities.

[14] Diane R. Calmus, 2013, The Long-Term Care Financing Crisis, The Heritage Foundation: Center for Policy Innovation, No. 07, http://www.heritage.org/research/reports/2013/02/the-long-term-care-financing-crisis.

Policy Options

Develop a public, universal long-term care insurance program

The key to any effective insurance program is spreading risk as broadly as possible, and there is no more effective way to spread risk than through a universal program. Therefore, one model for addressing our current fractured system would be to develop a universal, catastrophic LTSS insurance program.

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Such a system could be designed in a variety of ways.[15] Financing could come from a variety of potential sources, such as new payroll contributions (as for Social Security and Medicare Hospital Insurance), an income or other dedicated tax, general revenues, or some other kind of new levy. These taxes could potentially be paired with premiums paid by beneficiaries, as in Medicare Parts B and D. It may be possible to cover some costs through savings from Medicaid as well as lower Medicare health expenditures.

Eligibility thresholds could match those used for the Medicare program, applying to all seniors as well as individuals with disabilities who are either receiving benefits under Social Security or one of a few other public programs. Policymakers could consider more relaxed vesting periods and eligibility criteria for working-age people with disabilities requiring LTSS to participate in the labor market. Alternatively, however, the program could apply only to seniors. In some models, all Americans would be eligible for at least some catastrophic benefit as long as they worked for some period of time, much like Medicare Part A. Catastrophic coverage could kick in either after a period of time and/or a fixed amount of out-of-pocket LTSS spending. However eligibility thresholds are defined, they should be developed with caution to assure people of all incomes have adequate protection and do not discourage people from saving for retirement or other personal needs.

Another important subject to consider is how benefits would be delivered and what benefits would be covered. Benefits could be based on those currently covered under Medicaid, on an assessment of what is typically covered under private long-term care insurance plans, or an entirely new list of benefits could be developed.

[15] For a detailed, bipartisan discussion of possible approaches to achieving a universal long-term care insurance program, please see: Long-Term Care Financing Collaborative, 2016, A Consensus Framework for Long-Term Care Financing Reform, http://www.convergencepolicy.org/wp-content/uploads/2016/02/LTCFC-FINAL-REPORT-Feb-2016.pdf.

Revitalize the private long-term care market for non-catastrophic risk

The private market alone will not be able to come anywhere close to addressing the need for LTSS across the nation. That said, the creation of a catastrophic universal public plan, for instance, could create a framework within which private front-end LTSS insurance plans could play a meaningful role, while ensuring that the highest risk and costliest individuals could still obtain affordable coverage. Some other reforms that could rekindle the private insurance market include:

- Encouraging employers to add LTC coverage to their employee benefits packages;
- Refundable tax benefits or subsidies for individuals to purchase private coverage;
- Increasing standardization of benefits;
- Setting premiums and benefits to slowly increase over time, making LTC insurance more affordable for individuals who purchase coverage at a younger age;
- Experimenting with hybrid products combining LTC insurance with other policies (e.g., life insurance, disability);
- Strengthening consumer protections to improve public perception of the private market.[16]

Create a federal reinsurance mechanism for private LTSS plans

An alternative to an individual catastrophic benefit would be federal reinsurance or stop-loss insurance for LTSS coverage offered by private plans. This approach would resemble Medicare Part D, which provides federal catastrophic insurance that caps private prescription drug benefits and individual out-of-pocket drug expenses. Stop-loss insurance would pay for LTSS expenses after a plan reaches some predefined amount. Reinsurance would spread the excess LTSS expenses among participating plans, and could include a provision that would cap private insurers, with the federal government paying annual losses for expenses in excess of the cap. This approach to catastrophic insurance would operate in the background to lower the cost and improve the benefits that would otherwise be available through private coverage.

Increase federal financing of state Medicaid programs for LTSS

States already bear a heavy burden when it comes to financing long-term care, and this burden will only increase as the Boomers become older and frailer. The burden will be spread unevenly across the country, as some states face larger populations of aging adults than others. Furthermore, there is tremendous variation among states in how many individuals who require LTSS receive them through the Medicaid program. On average, only about

[16] Ibid.

half of low-income adults with long-term care needs actually receive support from Medicaid or other public assistance with LTSS costs.[17]

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With such substantial rates of unmet need, the problem is not exclusively – or even primarily – one of issues with Medicare or Medicaid, but rather of insufficient investment in LTSS. In addition to creating a new social insurance program, there are two possible avenues for addressing the impending surge in state burden for Medicaid long-term services and supports:

1. Establish a nationally uniform minimum benefit for low-income populations – namely those dually eligible for Medicare and Medicaid – through federal financing, which states could then enhance as needed by contributing their own funds to be matched by federal funds.
2. Enhance the federal Medicaid matching rate based on the proportion of a state's population that is represented by low-income seniors.[18]

Pursue a public/private partnership

Another option would be some form of public/private partnership, either added on to an existing program, such as Medicare Advantage, or through an entirely new partnership program.[19] In this option, LTSS services could be included in the package of Medicare Advantage services, which would blend LTSS services more efficiently and seamlessly with medical services.

Strengthen access to LTSS for working-age people with disabilities through Medicaid buy-in programs

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Many working-age people with disabilities could increase their labor-market participation if they received the necessary supports. For example, some SSDI beneficiaries also receive Medicaid, which funds the long-term services and

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[17] Included population is low-income adults above the age of 21 and below 250% of the federal poverty level with an activities of daily living (ADL) disability; Susan C. Reinhard, Enid Kassner, Ari Houser, Kathleen Ujvari, Robert Mollica, and Leslie Hendrickson, 2014, Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers (Second Edition), AARP, The Commonwealth Fund, and The SCAN Foundation, http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf.
[18] For a detailed description and analysis of both options, see: Judy Feder and Harriet L. Komisar, 2012, The Importance of Federal Financing to the Nation's Long-Term Care Safety Net, Georgetown University, http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf.
[19] Long-Term Care Financing Collaborative, 2016.

supports they need to engage in employment. Reentering the workforce may cause them to lose these supports in some states, or they may choose to suppress their earnings so as not to lose access to Medicaid LTSS. These are both untenable outcomes and formidable work disincentives. Medicaid Buy-In programs can, if properly designed, provide critical LTSS supports to working-age people with disabilities without the fear of losing access to them because of their assets or earnings.[20,21]

Strengthen family supports

In order to provide the care that their loved ones need, family caregivers need greater protections both inside and outside of the workforce. Those who leave the workforce to care for a family member miss out not only on income and benefits, but also on contributing to critical protection programs such as Social Security. For those who do remain in the workforce, many face substantial barriers in terms of scheduling and workplace flexibility. (For an extensive discussion of policy options to protect and support caregivers, please see Section 5 of this *Report* on Caregiving.)

[20] Bipartisan Policy Center, 2015, "Improve the SSDI Program and Address the Impending Trust Fund Depletion August 2015 Consensus Recommendations of BPC's Disability Insurance Working Group," August. http://bipartisanpolicy.org/wp-content/uploads/2015/08/BPC-Economy-SSDI-Program.pdf

[21] Jack Gettens, Denise Hoffman, and Alexis Henry, 2015, "Wraparound Health Insurance Cost and Utilization among Employed People with Disabilities," Mathematica Center for Studying Disability Policy.

Conclusion

The lack of an efficiently financed, well-functioning, and broadly accessible system of long-term services and supports is heavily burdening American families, state and federal budgets, and the economy as a whole. These problems will only worsen in the coming decades as the Boomers age into their 80s and beyond. At the same time, the economic contributions and quality of life of working-age people with disabilities remain unnecessarily limited. Congress has a range of policy options at its disposal to address the LTSS needs of seniors and working-age people with disabilities.

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