

# A New Vision for Long-Term Services and Supports



## A NEW VISION FOR LONG-TERM SERVICES AND SUPPORTS

2519 Connecticut Ave., NW  
Washington, DC 20008-1520  
Phone (202) 783-2242  
Website: [LeadingAge.org](http://LeadingAge.org)  
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### **Report Author**

Aaron Tripp  
*Director, Long-Term Care Policy & Analytics*

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### **About LeadingAge**

The mission of LeadingAge is to be the trusted voice for aging in America. Our 6,000+ members and partners include not-for-profit organizations representing the entire field of aging services, 39 state partners, hundreds of businesses, consumer groups, foundations, and research partners. LeadingAge is also a part of the Global Ageing Network (formerly the International Association of Homes and Services for the Aging), whose membership spans 30 countries. LeadingAge is a 501(c)(3) tax-exempt charitable organization focused on education, advocacy, and applied research.

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# Executive Summary

LeadingAge believes America needs a fairer and more rational financing system to ensure access to quality long-term services and supports (LTSS) for everyone who needs these services.

Americans of all ages use LTSS when functional limitations and chronic illnesses create a need for assistance with routine daily activities like bathing, dressing, preparing meals, and administering medications. Yet, the nation lacks an adequate system to support individuals, including older adults, who have a high need for LTSS.

Our LTSS system is plagued currently by inadequate funding, coordination, and choice. Its current design places enormous pressure on families, and leaves older adults disconnected and depressed. Most alarming, the system is ill prepared to meet the needs of a rapidly growing older population.

America must create a new way of paying for LTSS that infuses the delivery system with funding for high quality, community-based services, and protects families from economic peril.

In this report, LeadingAge recommends a flexible, dignity-driven, and universal LTSS insurance program grounded in the principles of shared risk and consumer flexibility. That system has three essential features:

1. **A universal approach to coverage:** The mandatory program would spread risk over a large population, thus lowering expenses for individuals, and increasing overall funding for LTSS.
2. **A catastrophic benefit period:** The program would finance care for individuals with high needs for LTSS. Benefits would begin after individuals had financed their own care for two years through private long-term care insurance or out-of-pocket spending.
3. **A “managed cash” benefit structure:** Beneficiaries would use a cash payment to purchase services and supports related to an LTSS need. This flexible approach would ensure that services and supports were tailored to individual needs and preferences.

LeadingAge believes an LTSS financing system that promotes consumer choice and flexibility will stimulate and reward innovation, quality improvement, and the development of products and services consumers want and need. This system will promote early health and wellness interventions that can prevent or delay the onset of LTSS need, while helping to reduce and manage lifetime risk. And, most important, it will help us create a society in which all may age with dignity.

# I. Introduction

Physical and/or cognitive impairment will cause about half of all older adults to lose the ability to care for themselves during their lifetimes.<sup>1</sup> These individuals will need daily help with everyday activities like bathing, dressing, preparing meals, and administering medication. About 15% will need daily support for five years or longer.<sup>2</sup>

Despite these sobering statistics, older Americans have a strong desire to live independent and dignified lives. LeadingAge believes strongly that older adults can fulfill this desire if the nation takes deliberate steps today to reform its health care and aging services systems plagued by inadequate funding, poor coordination, and insufficient choice.

This lack of adequate funding, coordination, and choice puts enormous pressure on families, and leaves older adults depressed and disconnected.

Older adults worry that the LTSS system will force them to become a burden on their families, drain life savings and family resources, and ultimately spend their last years either alone at home or in a care setting.

Unpaid family caregivers, on the other hand, provide half of the lifetime care that these older adults receive.<sup>3</sup> Older adults and their families pay for additional care, including community-based services like home care or assisted living, out of their own pockets. They rely on Medicaid only if their savings run out.

LeadingAge believes that America must create a new system of paying for LTSS. It also believes that any discussion about reforming the current system must begin with a clear understanding of the unique nature of LTSS, and a commitment to design and deliver services and supports in a way that advances our vision of an America freed from ageism.

## *The Unique Nature of LTSS*

Unlike medical care, which focuses on curing disease, LTSS are function-based and holistic in nature. The prolonged duration and personal nature of LTSS makes them an integral part of a person's daily life, not the temporary disruption that acute care often represents. Within the world of the LTSS recipient, there are few boundaries between medical care services, non-medical social services, and supports provided by family and friends.

LeadingAge members work in a variety of care settings around the country to help older adults and their families coordinate long-term services and supports with the acute-care medical services that individuals need. Our members pursue integrated service models that rely on accurate and timely communication across service settings and providers. Despite their best efforts, however, our members recognize that the current system leaves many individuals with unmet LTSS needs.

This recognition was the catalyst for LeadingAge's work to reform LTSS financing so it promotes a system of services and settings that is responsive to the needs and preferences that we all share.

## *An America Freed from Ageism*

The Frameworks Institute<sup>4</sup> has begun to focus on creating a better public understanding of older adults' needs and contributions to society—and subsequently to improve the lives of all people as they age. It recommended new ways of thinking about aging that are consistent with developing an aging services infrastructure we need and the financing to support it.<sup>5</sup> For example:

1. **Aging is not synonymous with functional decline.** We all face the risk that we will eventually need LTSS, and this risk increases with age. But we can manage risk by developing a system that protects us all by allowing all to share that risk.
2. **Older adults are not “those” people.** We are *all* aging, and we all want to continue participating fully in society as we age. We can achieve this goal by developing strategies that ensure we can all access the services and supports we desire should we develop LTSS needs.
3. **Development of LTSS needs is not always the result of individual lifestyle choices.** The need for LTSS can be attributed to a confluence of social determinants, including genetics, geography, socio-economic factors, and personal decisions. We must develop and strengthen policies that support individuals from birth through death and allow all people to develop and grow older with dignity and independence.

Any organizing structure for service delivery should support these shifts in our perception of aging. This organizing structure must be community-based and should engage older adults, their families, and their neighbors in making sure that communities around the nation are livable for all ages: the youngest and oldest, as well as those in the middle who are providing care.

### *Ongoing Work to Reform LTSS*

The following pages outline LeadingAge's call for a fairer, more rational, and more coordinated delivery system for the range of medical care and LTSS required by older adults with a high level of need. This report calls for a coherent financing mechanism for LTSS grounded in the principles of shared risk and consumer flexibility, and achieves twin goals:

- Infusing the delivery system with adequate funding to support high-quality, community-based services that promote dignity and independence; and
- Protecting families from economic peril.

Our research, discussions, and modeling work, conducted over the past 12 years, illustrates that workable solutions can be developed to reach these goals.<sup>6</sup> This work culminated in 2016 with a series of reports from the Urban Institute,<sup>7</sup> the Bipartisan Policy Center,<sup>8</sup> the Long-Term Care Financing Collaborative,<sup>9</sup> and LeadingAge.<sup>10</sup>

The current report builds on this work by providing further analysis of the research, funded by LeadingAge, The SCAN Foundation, and AARP, that was described in the 2016 LeadingAge report, “Perspectives on the Challenges of Financing Long-Term Services and Supports.” This report offers more details about the key elements of the LTSS financing mechanism that LeadingAge recommended in the 2016 report.

## *Essential Elements of a Reformed LTSS System*

This report focuses on LeadingAge's longstanding call for an LTSS insurance program featuring:

1. **A universal approach to coverage:** The mandatory program would spread risk over a large population, thus lowering expenses for individuals and increasing overall funding for LTSS.
2. **A catastrophic benefit period:** The program would finance care for individuals with high needs for LTSS. Benefits would begin after individuals had financed their own care for two years through private long-term care insurance or out-of-pocket spending.
3. **A “managed cash” benefit structure:** Beneficiaries would use a cash payment to purchase services and supports related to an LTSS need. This flexible approach would ensure that services and supports were tailored to individual needs and preferences.

LeadingAge believes that an LTSS financing system that promotes consumer choice and flexibility will stimulate and reward innovation, quality improvement, and the development of products and services consumers want and need. This new system would promote early health and wellness interventions that can prevent or delay the onset of LTSS need, while helping to reduce and manage lifetime risk. And, most important, it would help us create a society that meets the needs of older adults and persons with disabilities so they will be able to age with dignity.

## II. The Challenge

Americans fear losing their ability to care for themselves. This fear is rooted partly in the high value our society places on independence and self-reliance. But fear of dependence is also related to the dread that many Americans associate with entering the U.S. system of caring for older adults.

This sense of dread should not surprise us. The American system has failed older adults in two important ways.

### **1. The U.S. lacks a rational, coordinated delivery system for the range of medical care and LTSS required by older adults with a high level of need.**

On a societal level, this lack of coordination leaves our nation woefully unprepared to serve a growing population of older adults. On an individual level, it leaves families, older adults, and caregivers alone as they attempt to coordinate, navigate, and manage a complex system of fragmented medical care and LTSS. Inevitably, this lack of support results in unmet needs and poor outcomes.

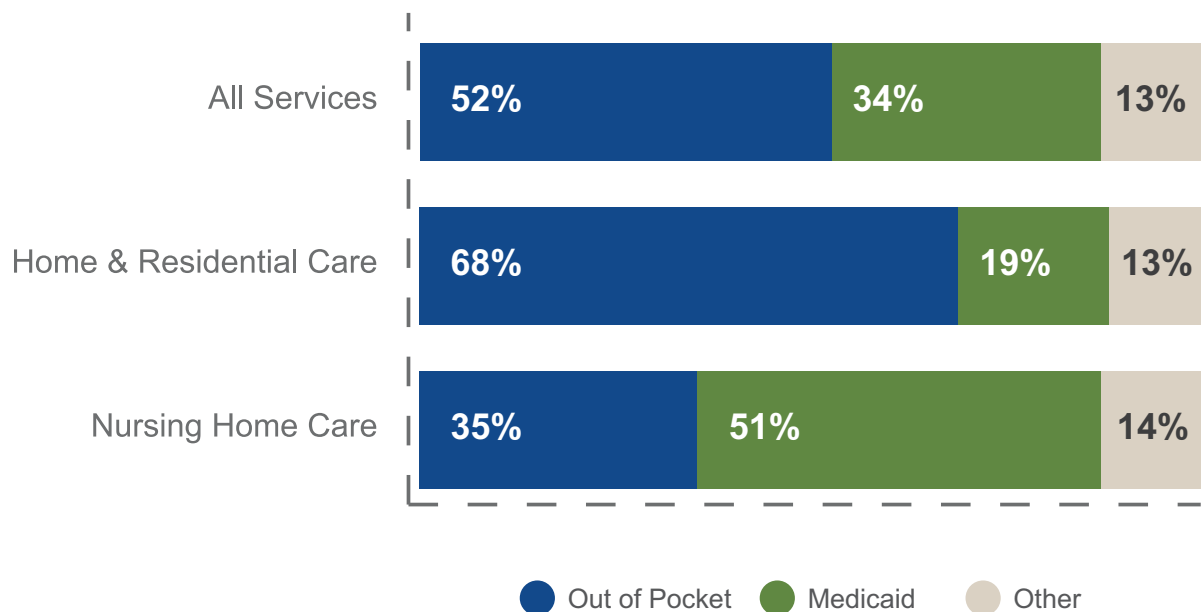
Today, families shoulder the responsibility for organizing medical care and LTSS across an uncoordinated system. These families have no place to turn for help in identifying high-quality providers or managing the multiple and often-complex medical needs of a family member. They often carry out these tasks without any information, training, or tools, and often without services or products they can trust to meet their loved one's needs.

The design of our current LTSS system is based on policies that place extreme burdens on families, and funnel individuals into high-cost institutional settings. We need a new set of policies and incentives that give families what they want and need: high quality and affordable community-based services that support aging in place.

### **2. The U.S. lacks a coherent financing mechanism for LTSS.**

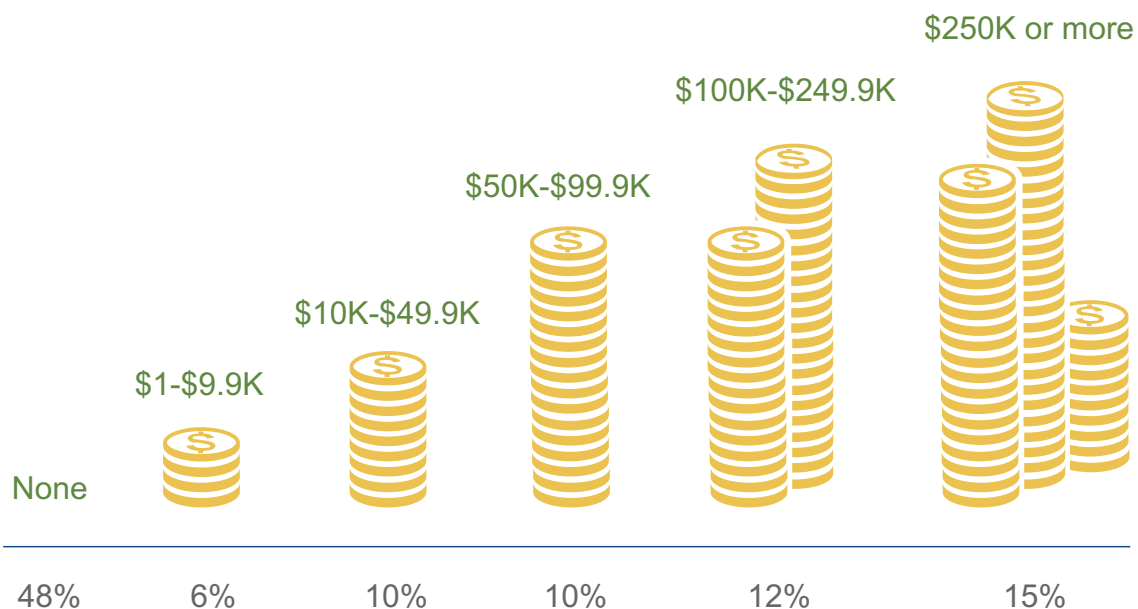
The current financing system offers no protection against the severe economic consequences associated with a high need for expensive services and supports, particularly over long periods.

Only 11% of older adults had private long-term care insurance in 2014.<sup>11</sup> This leaves personal savings and Medicaid to cover most of America's LTSS costs, which average \$138,000 over an older adult's lifetime. About half (52%) of these lifetime costs are financed, on average, through out-of-pocket payments, with Medicaid paying 34% and other sources covering the rest.<sup>12</sup>



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A smaller percentage of older adults experience financially catastrophic LTSS needs. The Urban Institute estimates that about 15% of the older adult population will face lifetime LTSS costs of \$250,000 or more.<sup>14</sup>



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Family-provided care is another form of LTSS financing. Many families provide care to relatives because paid home care is expensive, and because families want to avoid the nursing home care often financed by Medicaid. About 75% of older adults who receive care in the community report that this care comes exclusively from unpaid family caregivers.<sup>16</sup>

Many families are stretched thin as they attempt to meet the needs of aging parents and young children, while following the financial imperative to work. Many of these caregivers sacrifice wages, retirement savings and, in some cases, their own health in order to support aging relatives.<sup>17</sup>



### *Related Failures—and a Call to Action*

The two systems failures described above—lack of coordination and lack of coherent financing -- are related.

On the one hand, a fragmented and inefficient health care delivery system wastes resources. Those wasted resources would be much better spent, and would create much more value for older adults and their families, if they were deployed in ways that prevented and managed LTSS needs.

Conversely, the lack of a functioning LTSS insurance system contributes to inadequacies in delivery, and hinders investment in the infrastructure and innovation we need to support older adults and their families.

These two failures will become even more catastrophic in the coming years, as more Americans manage multiple chronic conditions that lead to LTSS needs, and while LTSS providers find themselves meeting new care delivery expectations. Now is the time to recognize and adopt a new approach for care delivery so we can ensure that:

- Older adults have the supports they need to manage their care at a cost they, their loved ones, and society can afford; and
- Delivered services are coordinated and seamless so people do not fall through the gaps in our current fragmented delivery and payment systems.<sup>18</sup>

# III. A Financing System that Supports our Vision

There are two opportunities to create a system supporting the LeadingAge vision for an ageism-free society that delivers and integrates care for all.

1. **Redirect health and long-term care dollars already in the system.** The LTSS system should spend less on high-cost institutional services like hospitals and nursing homes, and more on care coordination, management, integration activities, and home and community-based services.<sup>19</sup>
2. **Create a dedicated LTSS insurance program that covers most people.** LeadingAge recommends a national, universal financing program that insures against the risk of long periods of high need and greatly diminished independence. This program would provide new funding to meet care needs, and would stimulate service delivery innovation.

## *Designing a National LTSS Insurance Program: A Roadmap for Policy Makers*

LeadingAge believes that three key design elements of a national LTSS insurance program are most consistent with our vision for a better LTSS service delivery system:

- A universal approach to coverage: The mandatory program would spread risk over a large population, thus lowering expenses for individuals and increasing overall funding for LTSS.
- A catastrophic benefit period: The program would finance care for individuals with high needs for LTSS. Benefits would begin after individuals had financed their own care for two years through private long-term care insurance or out-of-pocket spending.
- A cash payment: The program would make cash payments to beneficiaries so they would have maximum flexibility in the use of benefits. This payment would also incentivize service delivery innovation.

## *A Universal Approach to Coverage*

One of the most important features of any insurance program is its ability to spread risk over a large population and to avoid enrolling a population that is more likely than the average beneficiary to need benefits. Private long-term care insurance addresses this challenge through a process called underwriting, which evaluates individuals for risk in advance of selling them a policy. In this way, insurers avoid selling policies to individuals who are already in need of benefits.

Insurance programs can also enhance their financial sustainability by requiring participation from everyone who meets certain enrollment criteria. This universal or “mandatory” approach allows a large group of individuals to share an average level of overall risk.

In 2016, the Urban Institute modeled several types of universal insurance for LTSS that were similar to Medicare: working individuals would enroll and pay into the system, and would receive benefits after they reached age 65 and developed significant disabilities.

Urban Institute researchers compared the efficacy of this “Medicare-like” LTSS universal coverage to a “voluntary” approach that would give individuals strong incentives to enroll in the insurance program but would not require them to participate.

The research yielded two important findings:

- **Lower individual and Medicaid expenses:** The universal approach would be less expensive for individuals than the voluntary approach, and would save much more in Medicaid and out-of-pocket spending. By 2050, annual Medicaid and out-of-pocket spending would drop 27% under universal insurance, compared to 4% for voluntary subsidized insurance, and 1% for voluntary unsubsidized insurance.<sup>20</sup>
- **More overall funding:** When everyone is insured, there is more overall funding available to spend on LTSS. Even though insured individuals would spend fewer Medicaid and out-of-pocket dollars, they would spend more money overall because they would have access to insurance. Total system-wide spending would rise to \$147,900 per beneficiary under a mandatory catastrophic insurance program, compared to \$138,000 per beneficiary if there was no change in law. Private insurance would pay 30% of the total cost, compared to 3% under current law.<sup>21</sup>



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Individual contributions are much lower in the universal insurance scenario because risk spreads over a much larger group of people. The Urban Institute research priced voluntary insurance between \$1,210 and \$7,480 per year, depending on the beneficiary's age and type of coverage. The payroll tax rate ranged from 0.6% for a two-year, time-limited option, to 1.35% for a comprehensive, universal approach. A universal approach covering only catastrophic costs would require an average payroll tax rate of 0.75%.

### *LeadingAge Recommends a Universal Approach to Coverage.*

The universal approach significantly reduces out-of-pocket and Medicaid spending and increases overall spending on LTSS, thereby creating an influx of needed funds into the marketplace. A universal approach succeeds at a lower individual price than voluntary options. If families and older adults have more money to spend on services, organizations and providers that invest in innovation are more likely to be rewarded by the marketplace.

## Benefit Period and Structure

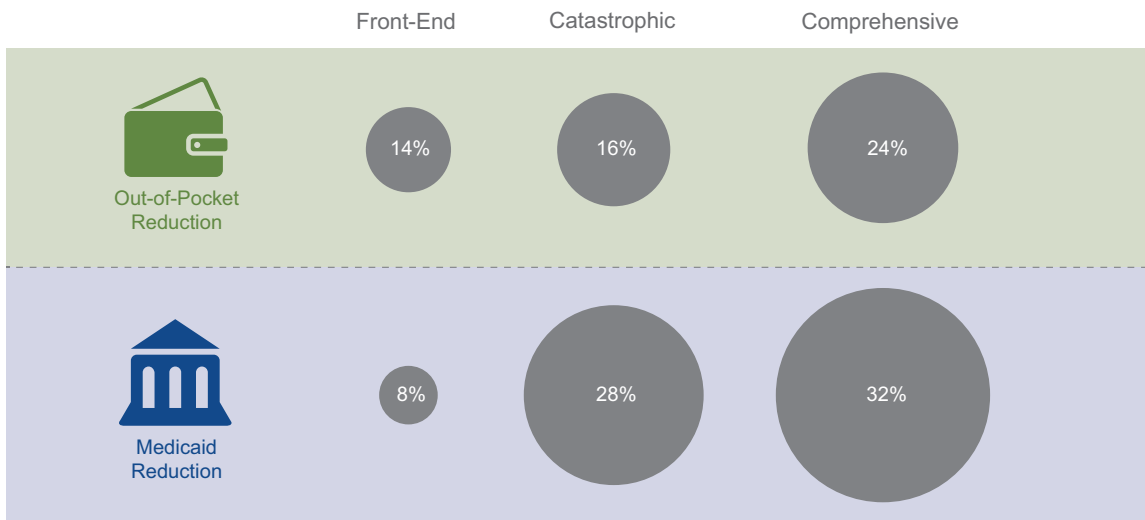
Long-term care insurance pays benefits for all, or some part, of an individual's lifetime need for LTSS. In the private market, many individuals purchase time-limited policies that pay a limited amount of daily benefits (e.g. \$100, \$150, or \$200) over a period of about two-to-three years. The policies typically reimburse up to the daily benefit amount for services provided by qualified providers in the typical LTSS service categories, including home care, assisted living, and nursing home care. If the entire daily benefit is not used, which is often the case; the remaining amount can be used to extend the life of the policy.

**Please note:** The 2016 Urban Institute model used a daily benefit amount of \$100 per day. That value can be adjusted up or down to balance competing concerns about the adequacy of benefits to pay for the most expensive services, and the need to keep premiums and/or taxes as low as possible. Determining an optimal benefit level that meets pricing goals is an area for further research. LeadingAge does not currently have a recommendation related to benefit level or pricing.

### A Catastrophic Benefit Period

The period of risk targeted by the benefits for a LTSS insurance program is a key element of program design. The Urban Institute modeled three options:

1. **A front-end benefit** provides benefits immediately when the beneficiary meets a predetermined level of need, but only provides benefits for a finite period. That period was two years in the Urban Institute model. Assuming a \$100-per-day front-end mandatory benefit, the model projects these national outcomes for 2050:
  - \$508.6 billion in Medicaid expenditures, down from \$555.3 billion.
  - \$685.7 billion in out-of-pocket expenditures, down from \$794 billion.
  - A 4.3% reduction in adults receiving LTSS Medicaid benefits.
  - 3.4 million people receiving benefits from this scenario's new insurance program.
  - \$259 billion paid out in benefits at a cost of a 0.6% payroll tax.<sup>23</sup>
2. **A back-end or catastrophic benefit** would pay benefits only to people whose care had already lasted for more than two years. Those benefits would continue for the remaining period of need. Assuming a \$100-per-day benefit, the model projects these national outcomes for 2050:
  - \$401.2 billion in Medicaid expenditures, down from \$555.3 billion.
  - \$664 billion in out-of-pocket expenditures, down from \$794 billion.
  - A 4% reduction in adults receiving LTSS Medicaid benefits.
  - 5 million people receiving benefits from this scenario's new insurance program.
  - \$410.9 billion paid out in benefits at a cost of a 0.75% payroll tax.<sup>24</sup>
3. **A comprehensive benefit** would cover the entire period of an individual's LTSS needs. Assuming a \$100-per-day benefit, the model projects these national outcomes for 2050:
  - \$377.4 billion in Medicaid expenditures, down from \$555.3 billion.
  - \$604.4 billion in out-of-pocket expenditures, down from \$794.0 billion.
  - A 3.9% reduction in adults receiving LTSS Medicaid benefits.
  - 6.2 million people receiving benefits from this scenario's new insurance program.
  - \$572.4 billion paid out in benefits at a cost of a 1.35% payroll tax.<sup>25</sup>



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### *LeadingAge Recommends a Catastrophic Benefit Period*

Urban Institute models indicate that the catastrophic approach offers more value than the other benefit options, as defined by out-of-pocket and Medicaid offsets divided by price. We believe that a catastrophic insurance program could:

- Raise national savings to pay for future LTSS expenditures.
- Provide families with stronger incentives to save, by reducing reliance on Medicaid.<sup>27</sup>
- Serve as a catalyst for innovation in a reinvigorated private long-term care insurance market.
- Make premiums for a front-end private insurance market more affordable for a greater portion of the population.
- Allow individuals to contribute to coverage for their potential risk through a tax mechanism.
- Encourage further personal responsibility by making private insurance for LTSS needs more attainable.

### *A Managed Cash Benefit Structure*

Most private long-term care insurance policies require that the policyholder purchase a covered service from a qualified provider in order to draw down the daily benefit amount. In a departure from this traditional approach, the Urban Institute simulation model assumed beneficiaries would receive a “cash benefit” that would provide more flexibility in the types of services they could purchase and the types of people who could provide those services. For example, a beneficiary might choose to purchase home modifications, transportation, or meals provided by a neighbor or friend.

LeadingAge believes that investments in new and better forms of service delivery and infrastructure will be stimulated when consumers have more dollars to spend, more flexibility in how they use these dollars, and the navigational support and information they need to find appropriate services.

LeadingAge explored three types of benefit structures before making a recommendation.

1. **Service Reimbursement:** Medicare and most private long-term care insurance products currently use a service reimbursement benefit structure. Under this design, the insurer pays up to the daily benefit only for a specific set of services, which usually include nursing home, assisted living, home care, respite care, and some family care. In order to qualify for payment, service providers must be certified in some manner. Nearly all LTSS are reimbursed currently through service reimbursement. However, prevailing trends are moving LTSS and health care spending from a fee-for-service payment system to more value-driven approaches.
2. **Unrestricted Cash:** Social Security uses an unrestricted cash approach. This structure bases its benefits only on whether an individual meets certain qualifications, including age and disability. Benefit payments are not contingent on how the money is used. In pure economic terms, this approach might be the most efficient and simplest to administer. However, it does not target LTSS needs, since unrestricted cash could be used to pay a variety of retirement expenses.
3. **Managed Cash:** This benefit structure is most like the Medicaid Cash and Counseling Demonstration, which requires that funds pay for services and supports related to an LTSS need. Unlike that demonstration, however, this structure allows flexibility in the use of funds and does not narrowly prescribe the types of services or the organizations providing the service. A managed cash structure gives people with LTSS needs the option to manage a budget and decide what mix of goods and services best meet their goals. Individuals may use their benefit to hire personal care workers, purchase items, and make home modifications that help them live independently.

### *LeadingAge Strongly Recommends a Managed Cash Benefit Structure*

A managed cash approach holds promise for both cost control and support for people with LTSS needs and their families because it aligns financing with high-quality, innovative service delivery.

Evaluations of this approach show that participants are more likely to receive paid care, have greater satisfaction with their care, and experience fewer unmet needs.<sup>28</sup> Additional research suggests that the ability to fund family caregivers' efforts can lead to improved health outcomes for those in need of LTSS. These findings suggest that family involvement in home care can substitute for hospital care,<sup>29</sup> and that lower emergency department and inpatient utilization can achieve cost savings.

The managed cash structure is a better match for LTSS needs than either the unmanaged cash or services reimbursement options. Social Security uses the unmanaged cash structure to fulfill a recipient's need for income security, while Medicare uses the services reimbursement model to fulfill the need for medical care. However, neither of these benefit structures is a perfect match for LTSS because the need for income security or medical care is not the same as the need for LTSS.

If you need medical care, you have little choice but to fulfill that need by visiting a doctor or a physician-equivalent like a nurse practitioner. LTSS needs, on the other hand, can be met in a number of different ways and by a variety of skill sets. Therefore, a reimbursement structure designed for medical care is inappropriate.

In the same way, an unmanaged cash benefit works well for individuals purchasing items that are well understood and accessed, including food, rent, and clothing. However, LTSS services can be hard to access and coordinate with other services and needs. Benefit management can make the cash benefit more effective and meaningful for the individual who needs LTSS, and his or her family.

Finally, the managed cash approach helps to deliver optimal person- and family-centered care by offering two important features that successful delivery systems possess:

- **Flexibility** makes it possible to tailor services to an individual's needs and preferences.
- **Navigation/coordination of services and supports** helps individuals manage the managed case benefit's flexibility. Individuals do well when a service navigator or care coordinator can help them define the scope of available services and supports, and offer guidance regarding how those services and supports can be coordinated to support unique situations and goals.

## IV. Conclusion

LeadingAge believes strongly in the need to find new ways to finance LTSS, integrate care delivery, end care silos, and encourage innovation across aging services.

Given our experience delivering services and housing to older adults, and buoyed by recent research, LeadingAge recommends a universal, catastrophic insurance approach to finance adequately the care needs of people who require long-term services and supports. It is our belief that a “managed cash” benefit design will stimulate high quality, innovative service delivery.

These remaining questions require exploration and careful consideration:

- Is there an optimal benefit level that balances needs with the appropriate financing approach?
- How can we maximize efficiencies as this new approach takes its place alongside existing Medicare and Medicaid benefits?
- Can we design a program that provides new support for people and families while simultaneously reinvigorating the private long-term care insurance market?

LeadingAge recognizes that a universal, catastrophic insurance approach might not be accepted readily in today’s budgetary and political environment. However, given projected demographic trends, we are confident that the need for reform of the LTSS system will not disappear. Rather, the magnitude of the challenges outlined in this report promise to grow more serious with each year that those challenges go unaddressed.

Modeling results shared in this report show that our recommendation for a universal, catastrophic insurance approach is the most effective strategy for meeting our goal to create a society in which older adults and persons with disabilities can age with dignity. A recent report from the Bipartisan Policy Center<sup>30</sup> and a forthcoming LeadingAge paper<sup>31</sup> offer many well-researched recommendations for improving policy and removing regulatory barriers so our delivery system can move in the direction that LeadingAge recommends.

Clearly, it is time to look to the future.

The programs that define our financing and delivery systems—Medicare, Medicaid, and the Older Americans Act—were created in the 1960s. As we prepare for the next generation of older adults, we must improve these vital programs, and achieve greater alignment between public and private resources devoted to the medical and non-medical needs of people as they age.

Efficiencies can and should be sought within and across existing programs. But additional capital will also be needed to foster innovation within the fragmented service delivery system so our LTSS infrastructure can successfully support the aging population of the 21st century.



# Endnotes

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