Long-Term Care Financing Collaborative
A project of Convergence Center for Policy Resolution

February 2016

A Consensus Framework for Long-Term Care Financing Reform

In 2012, a uniquely diverse group of policy experts and senior-level decision makers representing a wide range of interests and ideological views created The Long-Term Care Financing Collaborative. Our goal was to develop pragmatic, consensus-driven recommendations for a sustainable and affordable, public and private insurance-based financing system that better enables people of all incomes to receive high quality long-term services and supports. Our approach aims to enhance the independence and choice of those receiving care and support the family members and communities that assist them. This is the Collaborative's final report.

EXECUTIVE SUMMARY

The Long-Term Care Financing Collaborative is recommending a series of reforms aimed at expanding access to long-term services and supports (LTSS) for people of all incomes. We believe the current system of financing LTSS is inadequate, especially for those with high levels of need. It puts an enormous burden on family members and friends, often results in poor care, and frequently causes preventable harm that endangers recipients of care and their caregivers, and increases medical costs.

Today, more than 6 million older adults need this high level of care, a number expected to increase to nearly 16 million within a half-century. Millions of middle-income Americans drain their financial resources, place enormous burdens on family caregivers, and eventually turn to Medicaid for assistance. We believe the United States can do far better.

In July 2015, we released our principles for financing LTSS. Our goal was to create a system that would allow older Americans and younger people with disabilities to live as independently as possible, and with maximum autonomy and choice in the services they receive and the setting in which they receive them.[1]

The Collaborative seeks to improve financing to better support family caregivers, integrate health care with person- and family-centered services and supports, and increase access

to insurance while improving safety net programs. We believe these solutions must be fiscally sustainable. We aim to improve mechanisms for people with sufficient assets and income to save for and insure against LTSS needs and risks, and we recognize the importance of increasing public awareness about the need to prepare for LTSS costs.

In July 2015, we recommended ways to better support the families and communities that provide LTSS.[2] We proposed better integration of LTSS and medical care, greater support for paid caregivers and families, and enhanced support for communities and employers of caregivers.

In our final report, we make the following additional recommendations:

- A universal catastrophic insurance program aimed at providing financial support to those with high levels of care needs over a long period of time.

- A series of private sector initiatives and public policies aimed at revitalizing the long-term care insurance market to help address non-catastrophic LTSS risk. We also support efforts to encourage retirement savings and develop more efficient and innovative use of home equity to assist middle-and upper-income families finance LTSS needs for those risks that are not covered by catastrophic insurance benefits.

- A modernized Medicaid LTSS safety net for those with limited lifetime incomes who are not able to save for these care needs, as well as for those who deplete their assets paying for medical and long-term care costs. This includes more flexible public programs that can deliver care in the setting most appropriate to the needs of individuals.

- Stronger support for families and communities that are the bedrock for people receiving care at home and better integration of medical treatment and personal assistance. We described these two recommendations in our July 2015 report, Vision of a Better Future for People Needing Long-Term Services and Supports.

There is no single solution to the challenges we face. We believe that this package of reforms best fits those of all ages who need supports and services. It also best targets public resources to those who most need assistance—people with chronic conditions who face very long and costly periods of LTSS need.

Our proposals are primarily focused on assisting older adults with LTSS needs. However, we believe that any reform must also serve the needs of younger people with disabilities. We also believe transitions between insurance and safety-net programs must be seamless and must not leave middle-income people without access to either.

Recent research shows that about half of all seniors will need a high level of personal assistance before they die. They typically will need this care for two years at an average cost of nearly $140,000. However, behind the averages is wide variation: One in five older adults will need this high level of personal assistance for less than one year while 14 percent will need it for more than five years. For about 10 percent of older adults, the total cost of paid care will be less than $25,000, but for 15 percent the cost of care will exceed $250,000.

This pattern of risk is ideally addressed through insurance. Few Americans can save for catastrophic LTSS costs, nor should they. Yet, the current private insurance market has been unable to create a product that is priced to attract a meaningful number of middle-income consumers.

After careful consideration, we concluded that no voluntary insurance program is broadly affordable. Thus we recommend a universal catastrophic insurance program. One benefit of such a program is that it is likely to significantly reduce Medicaid's LTSS expenditures for older adults.

We recognize that such a catastrophic program has limitations. It does not finance care in the first years of need, which can be costly. Nor would the limited daily benefit we contemplate cover all lifetime costs for those with very high care needs. However, we expect that middle- and upper-income families will supplement this insurance with private savings, better use of home equity, and private long-term care insurance, which could be sold to supplement catastrophic coverage. Lower-income people will have access to improved Medicaid.

The Collaborative also acknowledges that there are many unanswered questions when it comes to LTSS financing. As a result, it recommends further research to better support stakeholder agreement and informed policy making.

MEMBERS OF THE COLLABORATIVE

Gretchen Alkema, The SCAN Foundation+

Robert Blancato, Elder Justice Coalition

* Sheila Burke, Harvard Kennedy School; Strategic Advisor, Baker, Donelson, Bearman, Caldwell & Berkowitz

* Stuart Butler, The Brookings Institution+

* Marc Cohen, LifePlans, Inc.

Susan Coronel, America's Health Insurance Plans (AHIP)

John Erickson, Erickson Living

Mike Fogarty, former CEO, Oklahoma Health Care Authority

William Galston, The Brookings Institution+

* Howard Gleckman, Urban Institute+

Lee Goldberg, The Pew Charitable Trusts+

Jennie Chin Hansen, immediate past CEO, American Geriatrics Society+

Ron Pollack, Families USA

* Don Redfoot, Consultant

John Rother, National Coalition on Healthcare

Nelson Sabatini, The Artemis Group

Dennis G. Smith, Dentons US LLP

Ron Soloway, UJA-Federation of New York (retired)

Richard Teske (1949-2014) Former U.S. Health and Human Services Official

Benjamin Veghte, National Academy of Social Insurance+

Paul Van de Water, Center on Budget & Policy Priorities (CBPP)+

Audrey Weiner, Jewish Home Lifecare, immediate past Chair, LeadingAge

* Jonathan Westin, The Jewish Federations of North America (JFNA)

Gail Wilensky, Project HOPE

Caryn Hederman, Project Director, Convergence Center for Policy Resolution

Allen Schmitz, Technical Advisor to the Collaborative, Milliman, Inc.+

+ Collaborative members have joined in their individual capacities with institutional affiliations provided for identification purposes only.

* Jonathan Westin, Stuart Butler, and Howard Gleckman founded the Collaborative in 2012. Collaborative Steering Committee members include Sheila Burke, Stuart Butler, Marc Cohen, Howard Gleckman, Don Redfoot, and Jonathan Westin.

INTRODUCTION

"Long-term care has been America's denial issue for too long. It has long been apparent that a genuine public/private approach is needed. The Collaborative mirrored in its work its belief that it will take consumers, providers, insurers and government working together to design a first time LTSS system that delivers and finances services. The diverse backgrounds and views of the members of the Collaborative provided the right ingredients for our principles to be presented. The Collaborative wanted to be more than just a new voice—it wants to be the catalyst that drives the issue of LTSS to the forefront of the American policy and political agenda where it belongs."

-Bob Blancato, National Coordinator, Elder Justice Coalition

Members of the Long-Term Care Financing Collaborative ("Collaborative") include policy experts, consumer advocates, and representatives from service providers and the insurance industry. We are former senior executive branch officials in both Democratic and Republican administrations, former congressional aides, and former top state health officials. Our goal is to offer an expanded vision of a better future for people who need LTSS and recommend paths toward LTSS financing policies that empower that future.

Convergence Center for Policy Resolution was selected to convene the Collaborative and facilitated our efforts to build trust, identify solutions, and form alliances for action. Convergence offered a neutral place for dialogue and effective, nonpartisan leadership to help us better understand each other's personal and professional interests and values. We reached consensus on a shared vision of a better future for people who need LTSS and principles to guide financing reforms. We coordinated with other LTSS financing initiatives to support new research that begins to answer key questions about LTSS financing. By agreeing to a vision, principles for reform, and shared facts, we have been able to push through long-standing ideological differences and come to consensus on recommendations in this report.

The Collaborative believes we need 21st Century financing for 21st Century lives. We are living longer and our preferences for how we receive services and supports are changing. Yet, our financing options remain stuck in the last century. Many Americans, including those who were solidly middle-income until they faced long-term chronic illness or injury, turn to Medicaid, a public safety net program. State governments, which share responsibility for Medicaid with the Federal government, are scrambling to meet Medicaid's expanding costs and address the policy implications of its huge share of state budgets.

This approach fails to protect middle income families from financial impoverishment. It discourages younger adults with disabilities from working, locking them into a lifetime of poverty. It precludes autonomy and choice of services. Its perverse financial incentives create obstacles to appropriate and coordinated health and LTSS care. Our current policies foreclose, for many, an option large numbers of Americans prefer: living independently in one's home and community as long as possible.

Few Americans are prepared for the risks of LTSS. Without financial resources, the burden of caregiving often falls on spouses or adult children, often daughters. There is an alternative: advance planning and prefunding, either by individuals or society, through some form of insurance or saving.

The Collaborative supports a hybrid public/private insurance approach to protect Americans against the risks of catastrophic LTSS costs. While we recognize there is no single "magic bullet" solution, a well-designed package of financing tools can better protect millions of us from the risk of impoverishment due to costs of meeting high-level LTSS needs.

We believe such a system should prevent gaps between Medicaid and private market insurance for those with middle-incomes. Insurance should mesh seamlessly with a strong safety net for low-income families.

In July 2015, we published *Principles for Improving Financing and Delivery of Long-Term Services and Supports*. We imagined a model that would shift to a financially-sustainable insurance-based system built on a framework of private and public reforms. Middle-income people could provide for their LTSS needs without impoverishment. Working-age people with disabilities could earn income and acquire savings without jeopardizing the services and supports they need.

This new design would support autonomy, choice of services, and the ability to live independently in one's home and community while receiving LTSS. It would make meaningful employment possible for working-age people living with disabilities, and would better integrate medical care with person-centered supports and services.

Our recommendations are based on this shared vision as well as on the best research available on long-term services and supports, including both data on current programs and economic modeling of potential alternatives.

THE PROBLEM

"America faces an enormous challenge in figuring out how to address and pay for the long-term needs of aging Baby Boomers and the generations that will follow them. We need to imagine ways to shift from a more welfare-based financing system to a primarily insurance-based system that meets the needs of individuals and their caregivers. We need to have an honest discussion of the obligations we have to each other."

-Stuart Butler, The Brookings Institution

More than two-thirds of older adults will need some personal assistance before they die, and nearly half will have a high enough level of need that they would be eligible for private long-term care insurance or Medicaid.[3] More than 6 million older adults need that level of care today, and nearly 16 million will need this assistance in 50 years.

We pay for much of that care "out of pocket" from savings and retirement income and help from families. By mid-century, such spending will more than double as a share of the economy.[4] Yet these costs are far beyond the reach of most Americans and will result in increasing numbers turning to Medicaid for financial assistance.

Out of pocket spending for paid care is high, but it is dwarfed by the economic value of unpaid LTSS provided by families and communities. In 2013 alone, family and friends provided an estimated 37 billion hours of uncompensated LTSS for adults, worth up to $470 billion. This level of uncompensated care was more than three times what Medicaid spent on LTSS in 2013.[5,6]

The majority of unpaid family caregivers report having to reduce work hours or take unpaid leave.[7] A woman in her 50s who leaves a job to care for aging parents loses an average of $300,000 in lifetime income.[8] Unpaid family caregivers lose an estimated $3 trillion in lost lifetime wages and benefits.[9]

Unpaid caregiving costs employers, too. Estimates of lost productivity from absenteeism alone range from $17.1 billion to $33 billion annually.[10] Costs of turnover and schedule adjustments for caregiving workers add an additional $17.7 billion in costs.[11]

Women and LTSS

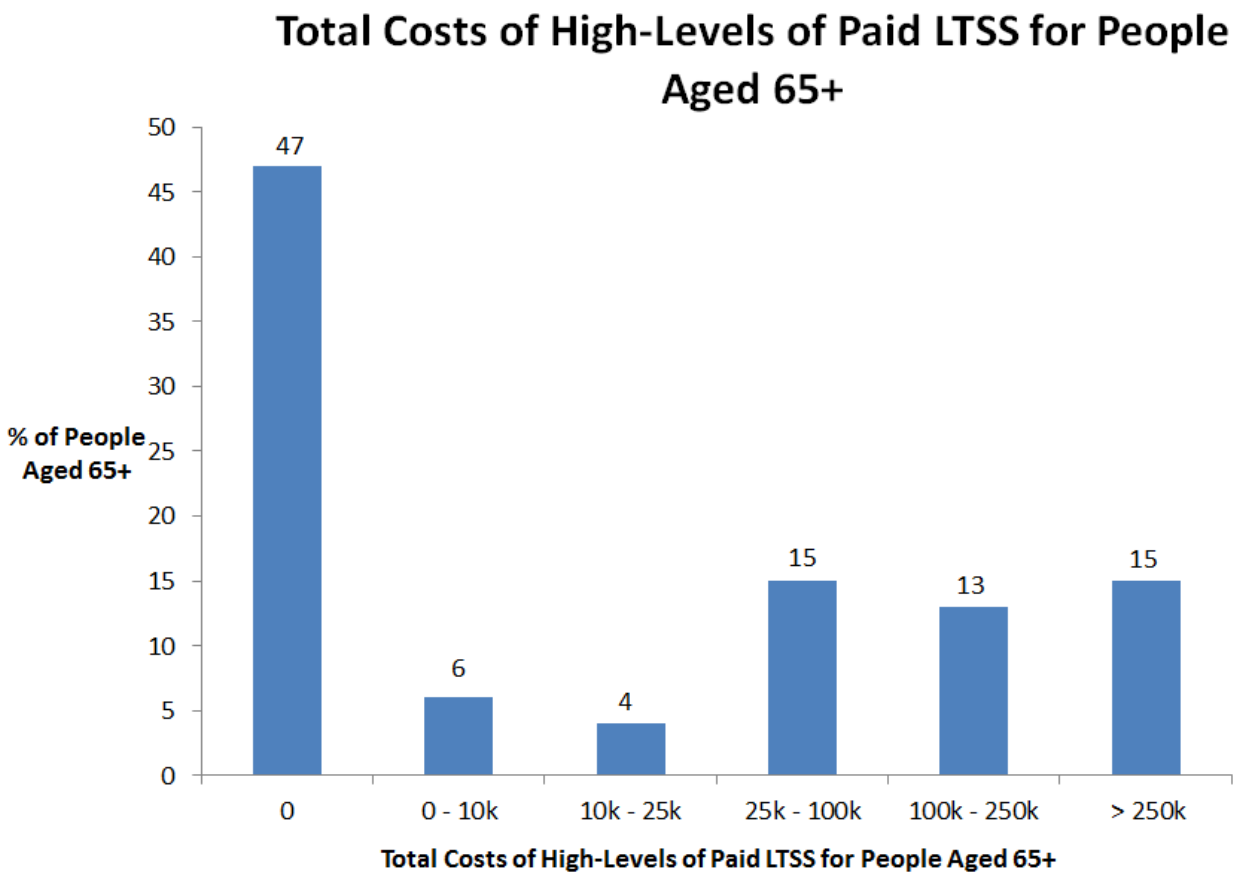
Whether they are receiving care or providing it, women are hardest hit by LTSS need and least likely to have the financial resources to pay for that care.

Nearly 60 percent of those who receive paid care are women.[12] Seventy percent of people receiving any assistance with activities of daily living are female. Two-thirds of long-stay nursing home residents are women, as are more than 60 percent of those receiving LTSS home health.[13]

Women live longer than men, and women's greater longevity means a greater chance of living some portion of life with disability. Overall, older women are likely to need high-levels of care far longer than men (2.5 years versus 1.5 years on average) and they are twice as likely to need it for five years or more (nearly 18 percent versus less than 10 percent).[14] Average total lifetime LTSS spending for older women is also double that for men ($182,000 versus $91,000). Low-income women are most likely to need high levels of care.[15]

At the same time, both unpaid and paid caregivers are likely to be women. Approximately 88 percent of direct care workers are female, with most serving as nursing aides, orderlies, and attendants.[16] While men increasingly provide unpaid LTSS to family members and friends, female caregivers usually perform the most difficult work, such as bathing and dressing, as well as medical and nursing tasks.[17] Women spend more time providing unpaid care and suffer the greatest economic loss, often reducing paid work hours or even quitting their jobs.[18]

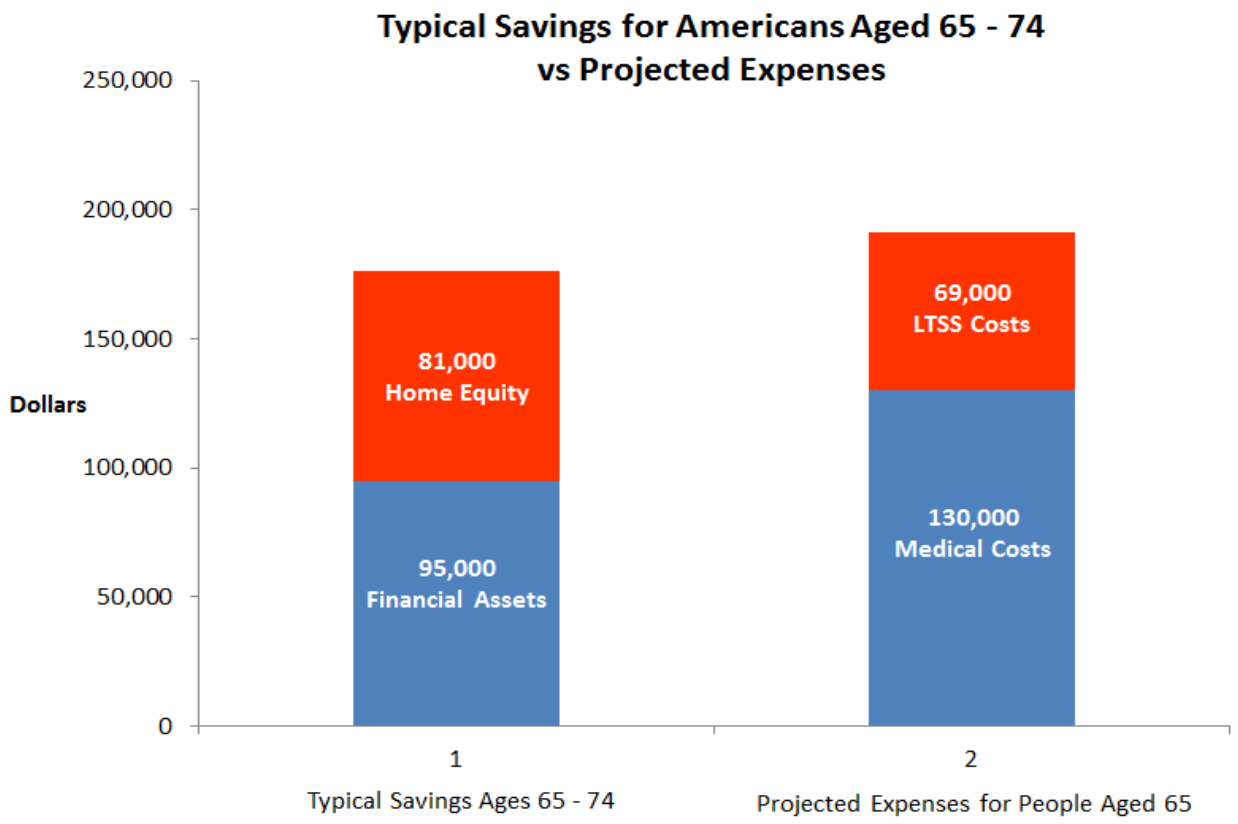
It is very difficult for a given individual to predict LTSS need after age 65, though we know that low-income people are more likely to have long spells of need than those with higher incomes. Half of those aged 65 or older will never have a high level of need for this care. One in five older adults will need this high level of personal assistance for less than one year while 14 percent will need it for more than five years. For about 10 percent of older adults, the total cost of this high-level of paid care will be between $1 and $25,000, but for 15 percent the cost of care will exceed $250,000.[19]



Individuals and Medicaid pay for most spending on high levels of LTSS. Individuals pay about 55 percent of these costs out-of-pocket, while Medicaid pays about 37 percent. Private LTSS insurance pays less than 5 percent. The likelihood of using Medicaid LTSS benefits falls sharply as income rises, as does the average amount of Medicaid benefits.

Private long-term care insurance plays a small role in financing LTSS. Many carriers have exited the market over the past decade and currently fewer than a dozen sell a meaningful number of policies. Sales of individual policies have fallen by 80 percent. Few private carriers will insure against risks of 10 years or more and increasingly are capping their risk at five years.

Similarly, few Americans have saved sufficiently for the costs of retirement. A typical American aged 65-74 has financial assets of $95,000 and home equity of $81,000[20], but retirement savings across all Americans varies widely. Someone turning 65 today would need to have saved about $130,000 to have a 90 percent chance of paying for all lifetime medical expenses (including Medicare premiums and out-of-pocket costs) plus an additional $69,500 for LTSS costs.[21,22] Thus, an average older adult can expect to spend his or her entire nest egg—and then some—to pay for only medical and LTSS expenses.



For those who can afford long term care insurance but do not choose to purchase it – generally Americans in the top three income deciles - savings is currently the primary vehicle for financing LTSS.[23] Yet only the most affluent Americans can afford to self-finance the costs of catastrophic levels of LTSS.[24]

LTSS FINANCING RECOMMENDATIONS

"Our families and our nation face a long journey that will test us in many ways. Any long journey requires a good map. That is what the Collaborative has provided. Members from different vantage points, diverse backgrounds, and with strong opinions have contributed their knowledge and mutual commitment to offering solutions to the problem of financing a system of long-term services and supports. These valuable guides should encourage opinion leaders and policymakers across the country to elevate LTSS financing as a priority."

-Dennis G. Smith, Dentons US LLP

The Collaborative has agreed on five key recommendations. They include:

- A universal catastrophic insurance program aimed at providing financial support to those with high levels of LTSS care needs over a long period of time.

- A series of private market initiatives and public policies aimed at revitalizing the long-term care insurance market to help address non-catastrophic LTSS risk. We also support efforts to increase retirement savings and more efficient and innovative use of home equity to assist middle-and upper-income families to finance LTSS needs that are not covered by catastrophic insurance benefits.

- An enhanced Medicaid LTSS safety net for those with limited lifetime incomes who are not able to save for their care needs and for those who impoverish themselves paying for medical and long term care needs. This includes more flexible public programs that can deliver an appropriate suite of services to those receiving care at home, and equal access to care in the setting most appropriate given individual needs, whether at home or in a care facility.

- Stronger support for families and communities that are the bedrock for people receiving care at home and better integration of medical treatment and personal assistance. We described these two recommendations in our July 2015 report we issued in our July 2015 report, Vision of a Better Future for People Needing Long Term Services and Supports.

"The Collaborative's catastrophic insurance concept meets several key policy objectives – most importantly that Americans would have some shelter from a core risk threatening their retirement and overall economic security. Addressing this "back end" risk would also provide needed relief to states by reducing Medicaid expenditures while leaving room for growth in the private insurance market to address front end needs in an affordable way. Clearly, when compared to a number of alternatives considered, the catastrophic insurance design -- which is both affordable and fiscally sustainable – met the greatest number of policy goals on which there was a consensus."

–Marc Cohen, LifePlans, Inc.

Expanding Access to Catastrophic LTSS Insurance

The Collaborative supports a strong government role in expanding protection against catastrophic risk. Such a proposal might require consumers to pay for the first two or three years, after which they'd receive a limited daily benefit for life. While this benefit would not likely cover all LTSS costs for those with very high levels of care needs, it would provide a solid base to help pay these expenses.

We recommend that the definition of "catastrophic risk" should be tied to an individual's lifetime income, and that eligibility thresholds be designed to avoid creating disincentives to saving. In such a model those with lower lifetime incomes would be eligible for catastrophic benefits sooner than those with higher incomes. Research exploring such a phased catastrophic insurance appears promising, though the concept remains at an early stage of development.

The benefit should offer a choice between discounted cash or services.

We reviewed two possible alternatives for financing catastrophic LTSS insurance, including a universal design and a voluntary alternative. Universal catastrophic insurance produces the greatest increase in enrollment, provides new resources to replace or add to out-of-pocket spending, and reduces Medicaid LTSS spending relative to the current baseline obligations.[25] The amount of high-level LTSS need over long durations will continue to grow. We believe LTSS expenditures made within an insurance framework will provide better outcomes for people who need LTSS. A universal catastrophic design is also the design that is most likely to meet the test of fiscal sustainability.

Because universal insurance spreads risk across the entire population, it avoids the challenges of adverse selection, where consumers who are likely to claim benefits also are more likely to purchase coverage, thus driving up premiums. As a result, universal insurance appears to offer broad-based insurance at a comparatively low lifetime cost.

America's most expensive option is doing nothing.

-Gretchen Alkema,
The SCAN Foundation

Voluntary catastrophic insurance, by contrast, presents major technical challenges. Because of the risk of adverse selection, premiums would remain quite high, thus severely limiting enrollment. It is possible that a strong set of incentives could encourage wider participation, but research to date has not yet identified those incentives, and most agree that it would be difficult to make such a program work.

In our view, the most promising approach is a universal catastrophic program fully financed by a dedicated revenue source.

Such a plan raises several key design issues:

Financing: A program could be financed with a payroll tax, an income tax, a new tax such as a Value-Added Tax, premiums, or some combination. Each has advantages and disadvantages.

A traditional payroll tax is the mechanism the United States uses to fund Social Security and some of Medicare. However, it would apply to many lower-paid individuals for whom Medicaid already provides a form of catastrophic protection. This problem could be addressed if the payroll tax is applied only to incomes *above* a certain level. This would contrast with today's Social Security payroll tax that is applied only to incomes *below* a designated level.

An explicit income tax surcharge or other dedicated tax is another financing option. There are many possible versions of a dedicated tax. One would be a tax imposed on a broader income base (all income rather than just wages), which would be more progressive.

Structure: Another issue is the structure of the program itself. It could be designed as an open-ended entitlement, a "capped" entitlement, or as appropriated funding. Many members of the Collaborative are concerned about the risk to future deficits and debt of an open-ended entitlement. Thus, a more promising approach would be to set a budget for a fixed amount of time, perhaps two or three decades, with appropriate adjustments at designated intervals. In Germany, for instance, universal LTSS insurance is designed as a capped entitlement. Benefits are not increased with inflation, but are reviewed every five years. If the government chooses to boost benefits, it also raises taxes to fund the extra assistance.

As recent research indicates, Medicaid would be a "beneficiary" of a public catastrophic program, with the federal government and the states seeing reductions in their Medicaid expenses for LTSS costs.[26] A significant amount of any savings to states will, however, be offset by increasing Medicaid LTSS eligibility with the intent of closing any gap in access to services for people of different income levels, as recommended later in this report. Nevertheless, we encourage states and the federal government to explore ways to use potential Medicaid savings, if and when they materialize, for "front-end" community-based services.

Catastrophic insurance could be offered through a public/private partnership, such as Medicare Part D, Medicare Advantage, or through a new program. The plan design could be structured many different ways, but the goal should be to create broad access to affordable catastrophic insurance, while encouraging individuals to plan for and protect against uncovered need, either through savings or through purchase of private long-term insurance in the context of a revitalized market.

Paying for Care Before Receiving Catastrophic Insurance Benefits

The Collaborative supports reforms to help cover costs that are not covered by the new daily benefit of a universal catastrophic program. These include stronger supports for family caregivers and communities, increased retirement savings, more efficient and innovative use of home equity, and private long-term care insurance. By combining these resources, more people ought to be able to pay for those first years of care, as well as costs that exceed the daily benefit of a catastrophic plan.

Revitalizing the Private Insurance Market

One resource is private long-term care insurance (LTCi). The insurance industry, employers, and policymakers could expand the market for private insurance by adopting new initiatives aimed at lowering costs and encouraging consumers to purchase coverage. The combination of price reductions and greater consumer confidence in the product's value could lead to a meaningful increase in the purchase of LTCi.

For example, employers could add LTCi to their benefits packages as an opt-out benefit. In this model, employees would be automatically enrolled unless they choose to reject coverage. While such an opt-out design has successfully increased participation in 401(k) plans, little is known about how workers would respond to a similar incentive for long-term care insurance. At the same time, such a model would have to overcome the reluctance of employers to participate. One such challenge is finding mechanisms to defray employers' administrative costs.

We also recommend future research on whether tax incentives or other subsidies could encourage participation in LTCi for uncovered risks, in the presence of a universal program covering the catastrophic risk.

Other cost-saving tools could include improved policy designs, some of which would require regulatory changes. For example, benefits could be more standardized. Policies could be designed so premiums and benefits increase over time, or to allow for small annual premium increases, which would make coverage less costly at younger ages. Carriers could sell through an electronic marketplace (similar to Medicare Supplement or Medicare Part D insurance). They could sell jointly with Medicare Advantage plan offerings, Medigap policies, or traditional fee-for-service Medicare. Regulators could take steps to reduce the costs of getting products approved for sale across the country.

In addition, state and federal policymakers should continue to support efforts by carriers to experiment with hybrid products that combine LTCi with other insurance, such as annuities, life insurance, or disability insurance. In addition to improving public education, policymakers may also want to examine protections for the insurance industry, as a whole, in cases where factors outside of the control of individual companies affect the financial stability of products and the solvency of carriers. These unpredictable shocks may include public policies designed to reduce long-term interest rates or sudden changes in disease morbidity, which are neither manageable nor predictable but affect the entire marketplace. Such a protection might be accomplished through state or multi-state reinsurance arrangements that cap industry losses for those companies that adhere to a common set of industry practice standards.

Finally, to improve consumer perception of the value of LTCi, policymakers should continue to work with the insurance industry to strengthen consumer protections and enhance product information for prospective buyers. For example, consumers need to better understand that premiums are not necessarily fixed throughout the life of the policy, what the practical implications of benefit eligibility standards are, and what they can expect from their insurance company at claim time.

Encourage Increased Savings for Retirement

While we do not believe savings can fully address the risk of extended high-level LTSS needs, increased individual savings would help many consumers pay for their preferred form of care. Additional savings could also help consumers purchase long-term care insurance and reduce the number of middle-income Americans who are driven to Medicaid.

Tools for increasing private savings include employer-based auto-enrollment in retirement plans, expanded use of existing retirement vehicles, new forms of targeted tax subsidies for retirement savings, stronger public outreach and education efforts, and even savers' lotteries.

While the Collaborative does not endorse any specific proposals, we support efforts to increase savings, and urge a stronger public policy emphasis in this area.

Home Equity for LTSS Financing

Home equity comprises a significant portion of personal assets for many Americans, particularly those who may be at risk for needing LTSS care. Housing wealth is particularly important for middle income Americans. More than half of those over 55 without retirement savings are homeowners and rates of home ownership are particularly high among those 65 and older. Many older adults lost their home equity in the recent recession and found themselves without resources just when they needed them. But over the long run, home equity can be a valuable resource for those needing to finance LTSS.

While homeowners say they are reluctant to use home equity for LTSS care, the reality is that many of those who need assistance in old age sell their homes, take out home equity loans, or turn to reverse mortgages. About half of those who reside in a nursing home for six months or longer spend down all of their assets, including their home equity.[27]

As a result, we believe that policymakers should explore more efficient uses of home equity to support LTSS. This resource could also help pay for the early stages of care, especially capital costs associated with home modifications and specialized mobility equipment that are generally not covered by insurance or Medicaid. While the Collaborative does not take a position on any specific approach to tapping home equity, policymakers could consider several options including:

- Deferred payment loans from public agencies, such as those used in England, Ireland, and New Zealand. In this model, those needing LTSS receive services in exchange for an explicit lien against their home equity. When they sell their home or they and their spouse die, this government loan is repaid from the proceeds of the home sale.

- Less expensive reverse mortgages, perhaps through public subsidies, to allow homeowners needing LTSS to tap their assets.

Other Considerations

The Collaborative also considered a limited "front-end" insurance program that would cover the first year or so of LTSS need. Such a model has important advantages. For instance, it would fit easily with Medicare's current post-acute care benefit and eliminate

many of the (often artificial) distinctions between that benefit and long-term supports and services. Front-end insurance would also benefit many more individuals than catastrophic coverage.

However, the Collaborative felt that, given limited resources and cost constraints, a universal program should focus on truly catastrophic costs that far exceed the financial resources of nearly all Americans. In addition, we felt that improved private insurance, sold to supplement a catastrophic program, could protect many consumers against a front-end risk. Private catastrophic insurance, in contrast, is not currently a viable product.

The Collaborative also acknowledges that many individuals require lower levels of personal care, often for years, which would not trigger long-term care insurance benefits. Much of this care is provided by family members or is financed privately and, thus, is not well understood. This lower level of care also requires careful financial planning and pre-funding.

> *"I praise [Convergence and the Collaborative] in seeing that this crucial issue of great complexity can be discussed, debated and evolved with the greatest of respect of understandable divergent perspectives and recognition of how important this matter is to the country's national policy direction. It is rarified air in which this civility and intellectual rigor comes together in such skilled guidance and respect."*
>
> -Jennie Chin Hansen, immediate past CEO, American Geriatrics Society

Greater Support for the Families and Communities that Provide Care

The Collaborative recommends that LTSS reform begin with stronger support for family caregivers. Increasingly, Americans prefer to receive LTSS in their homes and communities. However, this will put more caregiving responsibility on families and communities. The Collaborative's July 2015 report, Vision of a Better Future for People Needing Long Term Services and Supports, suggests ways to improve the delivery of services by giving families and communities the tools and support they need and by eliminating legal obstacles that prevent more effective use of community resources.

We believe that LTSS and medical care can be better integrated by redesigning delivery systems and payment models to effectively meet person- and family-centered choices. We support efforts by state governments to break down barriers between Medicaid and non-Medicaid services such as housing, transportation, and information-and-referral. We recommend revising payment and licensing systems to support the growing use of services

such as telehealth and monitoring and assistive technologies that promote more affordable and better-coordinated care.

We also recommend stronger support for paid caregivers. This includes changing scope of practice rules and state licensing laws to allow health care professionals and direct care workers to "work to the top of their skills." We support expanding competency-based training and opportunities for promotion for direct care workers, and advanced training for medical and health professionals in geriatrics and the care of patients with functional and cognitive limitations or other complex care needs. Better training and higher pay will result in better care.

We endorse broader supports for family caregivers, including opportunities for better training. We encourage the creation of care teams that include health professionals, direct care workers, and family caregivers, with the permission of those receiving care. Plans of care should acknowledge the central role of family caregivers. Discharge and care plans should assess and address their needs as well as the availability of community supports. With permission, family caregivers should have access to a care recipient's medical records.

We also recognize the importance of cultural competency in planning, training, and delivery of long-term care services to reduce disparities in the quality of care, improve access, and enhance independence and quality of life.

To refocus the delivery of medical care and LTSS, we recommend that government and the private sector develop a national strategy to support family caregivers that is similar in scope to the government's initiative aimed at preventing and treating Alzheimer's disease and other forms of dementia.

We recommend stronger supports for community caregivers, including recognition that friends and neighbors often serve roles once played by relatives. We also endorse modifying local regulations that impede new forms of community, such as zoning laws that limit the number of unrelated people who may share a home, and liability and licensing rules that constrain ride-sharing. With proper support, existing institutions such as faith communities, hospitals, and schools can serve as portals to and providers of care, especially for low-income communities.

We encourage employers to voluntarily create "family-friendly" flexible workplaces that make it possible for family members to remain employed while doing the hard work of caregiving.

Modernize Medicaid Financing and Eligibility to Better Support 21st Century LTSS Needs and Preferences

Retain and Strengthen Medicaid LTSS

While encouraging personal responsibility and reforming the private market are important, they will not be sufficient to protect all Americans from catastrophic LTSS costs. Working age people with lifelong disabilities need known levels of LTSS, triggering high levels of projectable costs. Their needs are not a risk, which insurance is designed to spread, but a certainty, for which a rational LTSS financing system must systematically provide.

People who encounter LTSS needs at older ages have more time to plan by saving and insuring over their working lives. But individuals with modest incomes are not likely to have saved enough to provide for their LTSS needs or to have sufficient disposable income to purchase private insurance.

The majority of Americans who require LTSS, including many individuals with intellectual and developmental disabilities (ID/DD), a majority of people receiving nursing center care, and about a fifth of all assisted living residents, rely on Medicaid to pay for their care each day. There will continue to be a need for Medicaid to provide access to LTSS.[28]

Medicaid and LTSS

Medicaid funds 37 percent of all paid LTSS and is by far the largest single public payer for supports and services.[29] In 2013, Medicaid spent $146 billion—34 percent of its budget—on LTSS for older adults and younger people with disabilities.[30]

Beneficiaries are subject to strict eligibility rules. While these vary from state to state and differ by care setting, they typically limit beneficiaries to $2,000 in financial assets and $723 per month in income (the monthly benefit level for the Supplemental Security Income program). As a result, millions of middle-income families who face catastrophic LTSS costs must impoverish themselves before receiving public support.

The few high-income people who do qualify for Medicaid generally do so after many years of high LTSS need. As a result, a universal catastrophic insurance program could significantly reduce Medicaid LTSS spending, including spending

for middle- and upper-income individuals who would otherwise become impoverished over time due to high medical and LTSS expenses.

Older adults with low incomes are more likely to experience a high level of disability, for a longer period of time, and incur greater LTSS costs than those with higher incomes. Because those with lower incomes are also least likely to be able to save or insure, they are at the highest risk of needing Medicaid assistance.

While some wealthy individuals transfer assets to children or other relatives to qualify for Medicaid, the federal government and states have become more aggressive in closing loopholes. More often, wealth transfers go the other way: By paying for the LTSS costs of their parents, children often transfer some of their wealth to their older relatives.

Medicaid's strict eligibility rules also prevent working age disabled individuals from maintaining employment while continuing to receive LTSS benefits. While the Achieving a Better Life Experience (ABLE) Act and other programs are modest steps to address this problem, challenges to maintaining employment and coverage remain.[31]

Medicaid continues to provide unequal access to care settings. Basic program rules entitle beneficiaries only to LTSS in institutional settings. Home and community based care (HCBS) is available through complex waiver programs or state plan amendments. Gradually, Medicaid is shifting to an HCBS benefit. However, in many states, beneficiaries are still likely to receive care in a care facility, though HCBS care can be less costly, and provide greater autonomy, independence, and choice.

New research suggests that broad insurance coverage against catastrophic risks could reduce some of the burden on Medicaid.[32] However, this would only slow the rise in future costs, rather than reducing expenditures in absolute terms. A well-designed insurance-based system for financing LTSS needs for middle income families will still require a significant commitment from the federal government and states to provide LTSS to those whom insurance systems do not reach.

Financing

The Collaborative recommends a federal statutory change that would set all LTSS on an equal basis, whether provided through an institution or in the community. States would be required to provide the LTSS benefit. The new LTSS benefit would consist of all LTSS services currently allowable through institutional and non-institutional settings. The outdated distinction between mandatory and optional services would be eliminated. Eligibility for the LTSS benefit would no longer be based on an institutional level of care, but would be based on a functional assessment and a needs assessment, using tools designed with federal, state and consumer input. This recommendation is made with the objective of promoting access to care in the setting most appropriate given individual needs and preferences (whether in community or institutional settings).

We acknowledge that this recommendation may increase Medicaid expenditures and will have federal and state level policy implications. Although a universal catastrophic LTSS insurance program could provide Medicaid savings, they may be offset by the expected cost of our Medicaid LTSS recommendations. As we recommend later in this report, research regarding the costs of these Medicaid recommendations is needed. The additional costs of increased Medicaid expenditures must be considered in the overall design for LTSS financing.

State Medicaid programs are required to provide reimbursement for certain care provided in institutional settings, such as hospitals, nursing homes, intermediate care facilities for people with intellectual disabilities, and, for people 65 years or older, institutions for mental illnesses. State Medicaid programs may currently elect to provide some LTSS through state plan amendments. They may choose to offer a broader array of LTSS through time-limited HCBS waivers, if approved by the federal government as cost effective.

Since 2013, HCBS has accounted for a majority of Medicaid LTSS expenditures, due to an increase in HCBS expenditures and a decline in spending for LTSS in institutional settings. States and the federal government spent $146 billion—34 percent of all Medicaid spending—on Medicaid LTSS across all care settings and populations.[33] HCBS accounted for 72 percent of spending for people with developmental disabilities, 40 percent of spending for older people or people with physical disabilities, and 36 percent of spending for people with serious mental illness or serious emotional disturbances. While progress has been made toward more person-centered financing, the federal framework of optional and mandatory services is in itself a barrier to state innovation.

In a recent rulemaking, the Centers for Medicare and Medicaid Services (CMS) acknowledged that LTSS is non-medical in nature, even though people with LTSS needs frequently require extensive healthcare and other services as well. We encourage greater authority for states to coordinate, and in some cases, provide health-related, housing-related services and social supports in HCBS settings. The Collaborative recommends additional changes in Medicaid reimbursement that promote community integration for individuals with disabilities and older adults needing LTSS.

Eligibility

Our recommendation to expand Medicaid eligibility does not come easily or lightly. However, as a part of the overall package, we concluded it is necessary to ensure that all Americans have a viable option for protection against financial disaster. It would be fundamentally inequitable to leave lower-income Americans who have worked all their lives, without an affordable means to protect themselves, and in many cases their children, against impoverishment.

HCBS waivers currently require that an individual meet an institutional level of care. The Collaborative seeks to change this antiquated requirement, to allow states to serve people before they reach the very high levels of need that is currently characteristic of people receiving institutional services. Specifically, the Collaborative would:

- Shift LTSS eligibility from the outdated institutional level of care to a functional assessment and a needs assessment, using tools designed with federal, state and consumer input.

- Redesign Medicaid's LTSS component with a sliding scale based on income and assets with income-based cost sharing. This would modestly expand eligibility and eliminate the eligibility cliffs between the safety net and the primary insurance and private market options for LTSS financing.

Traditional Medicaid gives states three basic choices for creating savings or greater efficiencies in the program: cut eligibility, cut benefits, or cut provider payments. To shift away from these current "big three" choices and to improve outcomes, the Collaborative agrees that the federal government needs to provide stronger financial supports and incentives for LTSS delivery innovations. States, which provide approximately 43 percent of Medicaid LTSS expenditures, face enormous fiscal liabilities in the current program. Because financial burdens on individuals and families are also likely to grow, shifting additional costs to consumers is not viable. Providers routinely contend that Medicaid reimbursement rates

are below the cost of providing high quality services, so it is not likely that many states can enact further payment reductions.

Expanded eligibility for Medicaid LTSS should be combined with improved delivery systems that do a better job integrating LTSS, healthcare, and social services to both improve lives for the individuals being served and promote fiscal responsibility. States have often been the leaders in promoting innovation in LTSS delivery, but more should be done to support state initiatives. With so much at stake, any transition to a new Medicaid payment and delivery system needs to be gradual and allow for adequate consumer and provider input on the implementation process.

Catastrophic insurance would generate savings to the Medicaid program.[34] In such a context, the Collaborative agrees that Medicaid funding should remain mandatory spending and that expanded Medicaid LTSS eligibility should be accompanied by incentives for states to share in any savings from greater efficiencies and innovations in the delivery of LTSS delivery, especially those savings that might accrue to Medicare from more effective LTSS. We also recognize that expanding eligibility will introduce additional costs beyond the current baseline and must be factored into the overall design and financing of the new LTSS system so that the Medicaid program itself is sustainable.

Savings for Working Age People with Disabilities

The Collaborative recommends that Medicaid LTSS eligibility across the states allow working-aged people who are living with disabilities to work and build assets, while continuing to receive the services and supports they need.

Although the ABLE Act and other modest legislative and regulatory initiatives acknowledged the importance of this goal and raised political awareness of the need for policy to support it, the effect of these programs is expected to be very small.[35]

Another Possibility: Financing Integrated Medical Care and LTSS

Most LTSS financing reform is focused on improving stand-alone long-term care insurance: that is, insurance that provides benefits for only LTSS. However, the Collaborative also recognizes that it may be possible to create an LTSS benefit within a framework of health insurance.

Today, consumers face a bifurcated care system. Care is delivered separately and is rarely coordinated. Health care comes from doctors, hospitals, and other medical providers, while LTSS often is delivered by home care aides and providers of social services such transportation, home-delivered meals, and the like. This disorganized care is driven in large part by a divided payment system. Medicare or private medical insurance pays for health care, the Older Americans Act finances certain social supports, while Medicaid, long-term care insurance, and out-of-pocket spending fund personal assistance and other services.

The consequences of this split delivery system are serious. It increases medical risk for those older adults with both multiple chronic conditions and high levels of need for personal assistance. This population also incurs extremely high medical costs—two times greater than for those with multiple chronic conditions alone.[36]

The Collaborative believes that by better managing and coordinating the health and personal care needs of these older adults, it is possible to both improve their quality of life and reduce the growth in medical spending. Designing a single payment stream could enhance delivery of such integrated care by aligning financial incentives for both medical and LTSS spending. It may reduce hospitalizations and nursing home admissions.[37]

However, fully integrating care delivery is difficult as long as it is financed by two separate payment streams. This is especially challenging because the LTSS costs are borne by the LTSS insurer, while any medical savings are reaped by the health care insurer.

Several care models are attempting to fully integrate medical care with LTSS. The Program of All-Inclusive Care for the Elderly (PACE) program and certain Medicare Special Needs Plans such as the Commonwealth Care Alliance have been delivering such integrated care for many years. In addition, with the encouragement of the U.S. Department of Health and Human Services, two dozen states are experimenting with combined medical and LTSS services through managed care in demonstration programs for older adults and younger people with disabilities who are eligible for both Medicare and Medicaid (known as the "dual eligibles").

This delivery system has great benefits. However, financing models remain undeveloped. The idea of an insurance program that covers both health care and long-term services and supports raises many unresolved design and actuarial issues. While we are unable to put forward a specific integrated financing model at this time, we believe this concept has promise and should be explored by policymakers and insurers. We encourage experiments in integrating medical and long-term care coverage through both traditional fee-for-service Medicare and Medicare Advantage as well as through commercial insurance for working-age people.

"In an era characterized by sharp partisan differences in health care, the work of the Long Term Care Financing Collaborative stands out as a notable exception. The Collaborative is taking on the next "big challenge in health care"—designing a sustainable and affordable system of long term care. Resolving financing issues in a way that crosses the political spectrum remains an enormous challenge, but the Collaborative deserves credit for attempting it. Those of us involved fervently hope these efforts will be successful."

-Gail Wilensky, Project HOPE

Increase Public Education Around Catastrophic LTSS Risks and Costs

Any long-term care financing recommendations must acknowledge challenging and conflicting public attitudes about aging, savings, and insurance. Surveys of American perceptions of long-term care show a widespread lack of understanding of the likely need for LTSS and the costs of those services. Similarly, consumers frequently are unaware of their financial needs in retirement, including LTSS, and have not sufficiently prepared for their lives in old age.

Consumers fear loss of independence and becoming a burden on family members. Research indicates conceptual support for insuring against long-term care risks, but a general unwillingness to pay more than nominal premiums for extensive coverage. Consumers are skeptical of mandatory insurance, but have been unwilling to buy voluntary insurance.

Changing perceptions and encouraging planning will require an aggressive education campaign to go along with the proposals the Collaborative is making regarding the sharing of risk. As a result, the Collaborative recommends coordinated public outreach by insurers, government, medical providers, and financial professionals to raise awareness of LTSS risks and the need to prepare for those risks. If a new program is enacted to cover income-related catastrophic risks, then consumers will have to be periodically informed about their estimated responsibility to provide for the remaining upfront costs and how they might do so through insurance and/or savings.

One way to provide such information may be through regular Social Security statements that include not only a record of earnings history and estimated Social Security benefits, but also an estimate of the individual's responsibility for meeting their needs for long-term services and supports. Medical professionals, service providers, and financial professionals

should take advantage of "educable moments" in life, such as when family caregivers are supporting aging parents, to provide useful information about preparing for their own future needs.

Public education efforts tied to more specific, individualized estimates of risk, and more timely provision of such information are more likely to be successful in encouraging preparation for future LTSS needs than have past public education efforts tied to general information about the risk and costs associated with LTSS.

RECOMMENDED FUTURE RESEARCH AREAS

"Long-term care financing and delivery are critically important to the well-being of older Americans, young people living with disabilities, and those families' members who help care for them. Yet few public policy issues are more complex and controversial. The Long-Term Care Financing Collaborative has tackled these challenges head on and is helping guide the nation toward workable, consensus solutions."

-Howard Gleckman, Urban Institute

We found many unanswered questions concerning LTSS financing and delivery. To further refine policy solutions, the Collaborative recommends future research in the following areas:

- Effects of LTSS financing reform on working age adults.
- Incomes, health status, and employment of working-age people living with disabilities.
- Total lifetime risks and costs of LTSS, including lower levels of needs that are not covered by insurance or Medicaid; the current and projected ability of families to finance these lower-level LTSS needs; and the value and opportunity costs of unpaid caregiving.
- How to better apply lessons from behavioral economics to LTSS delivery and finance.
- Effects of enhanced retirement savings on LTSS financing.
- Costs to employers resulting from caregiving responsibilities of their employees.
- Effects of proposed Medicaid reforms on overall costs and beneficiary's quality of life.
- How to create a seamless transition between Medicaid and LTSS insurance.
- Effects of integrating financing and delivery of healthcare and LTSS.
- Effects of LTSS costs by race and ethnicity.

ACKNOWLEDGMENTS

The Collaborative's work builds upon other major initiatives, and in particular, actuarial and microsimulation research on LTSS financing options released this year by Milliman, Inc. and the Urban Institute, the LeadingAge Pathways initiatives, 2013 Congressional Commission on Long Term Care, 2013 SCAN Foundation LTC Financing Research Series, 2005 Georgetown University/Robert Wood Johnson Foundation LTC Financing Project, 2000 U.S. Department of Labor Working Group on Long Term Care, 1990 U.S. Bipartisan Commission on Comprehensive Health Care (aka Pepper Commission), and 1988 Catholic Health Association Task Force on Long Term Care Policy. Links to the Milliman and Urban Institute research and the LeadingAge Pathways and 2013 Congressional Commission on Long Term Care reports and others on long term care financing may be found here: http://www.thescanfoundation.org/ltc-financing-initiative.

Support for the Long Term Care Financing Collaborative has been provided by AARP, American Health Care Association/National Center for Assisted Living (AHCA/NCAL), America's Health Insurance Plans (AHIP), Akin Gump Strauss Hauer & Feld LLP, Convergence Center for Policy Resolution, Dennis Passis, The John A. Hartford Foundation, Hederman Consulting LLC, The Jewish Federations of North America (JFNA), Jewish Healthcare Foundation, LeadingAge, Maja Kristin, Mt. Sinai Health Care Foundation, The SCAN Foundation, and the Urban Institute. Support for the Collaborative does not constitute endorsement of any of the specific policy recommendations made in this report.

Convergence Center for Policy Resolution was founded in 2009 to offer an alternative solution for addressing urgent social and policy issues that were bogged down in disagreement and discord. Drawing from decades of experience solving difficult policy issues, Convergence was formed to use dialogue and collaboration to generate breakthrough solutions to important yet intractable problems. Convergence uses structured, facilitated dialogue and long-term relationship building to build trust and understanding and to create a renewed sense of what is possible through shared goals and long-term cooperation. Convergence does not take positions on issues. The views expressed in this report are those of the members of the Collaborative and should not be attributed to Convergence Center for Policy Resolution, its Board of Trustees, or its funders.

The members of the Long-Term Care Financing Collaborative were aided and honored by the friendship, wisdom, insights and policy contributions of Richard Teske (1949-2014). Debra Whitman provided support and encouragement at crucial stages throughout the Collaborative's efforts. Lisa Ekman contributed a wealth of expertise and leadership on

several key issues. We thank the researchers and project coordinators involved in the LTSS financing research conducted in partnership by Urban Institute and Milliman; in particular, we thank Melissa Favreault, Chris Giese, Howard Gleckman, Rich Johnson, Al Schmitz, Anne Tumlinson, and Gretchen Alkema for sharing their time and talents far above and beyond the scope of their work.

We are deeply grateful to Maja Kristin for her generous support, and to Thomas Risberg and the wonderful Convergence Center for Policy Resolution interns, Evelyn Chuang, Brittany Dougall, Vivian Nguyen, Ross Fishbein, Jamie Kendall, and Ashleigh Allen for their research and support of the Collaborative's efforts.

REFERENCES

1 Long Term Care Financing Collaborative, *Principles for Improving Financing and Delivery of Long-Term Services and Supports* (July 2015). http://www.convergencepolicy.org/wp-content/uploads/2015/07/LTCFC-Foundational-Principles-Final-070215.pdf

2 Long Term Care Financing Collaborative, *Vision of a Better Future for People Needing Long Term Services and Supports* (July 2015). http://www.convergencepolicy.org/wp-content/uploads/2015/07/LTCFC-Vision-070215.pdf

3 Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, *Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?*, Inquiry, 42(4): 335-350. http://www.allhealth.org/briefingmaterials/Long-TermCareOveranUncertainFuture-WhatCanCurrentRetireesExpect-461.pdf

4 Melissa Favreault and Judith Dey, *Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief*, Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (July 2015). http://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief

5 Susan C. Reinhard, Lynn, F. Feinberg, Rita Choula, and Ari Houser, *Valuing the Invaluable: 2015 Update: Undeniable Progress, but Big Gaps Remain*, p. 3, AARP Public Policy Institute (July 2015). http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf

6 Susan C. Reinhard, Lynn, F. Feinberg, Rita Choula, and Ari Houser, *Valuing the Invaluable: 2015 Update: Undeniable Progress, but Big Gaps Remain*, p. 3, AARP Public Policy Institute (July 2015). http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf

7 AARP Public Policy Institute, *Valuing the Invaluable: 2011 Update, The Economic Value of Family Caregiving*. https://www.caregiver.org/selected-caregiver-statistics; National Alliance for Caregiving and AARP, *Caregiving in the U.S.: A Focused Look at Those Caring for Someone Age 50 or Older* (2009). https://www.caregiver.org/selected-caregiver-statistics

8 Lynn Feinberg and Rita Choula, *AARP Public Policy Institute Fact Sheet 271: Understanding the Impact of Family Caregiving on Work* (October 2012). http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc

[9] Susan Reinhard, Lynn Feinberg, Rita Choula, Ari Houser, *Valuing the Invaluable 2015 Update: Undeniable Progress, But Big Gaps Remain,* AARP Public Policy Institute (July 2015). http://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html

[10] Dan Witters, *Caregiving Costs U.S. Economy $25.2 Billion in Lost Productivity*, Gallup Wellbeing (July 2011). http://www.gallup.com/poll/148670/caregiving-costs-economy-billion-lost-productivity.aspx

[11] Metlife, *MetLife Study of Working Caregivers and Employer Health Costs*, pp. 4, 7 (February 2010). https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working-caregivers-employers-health-care-costs.pdf

[12] Susan Reinhard, Carol Levine, and Sarah Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care*, p. 13, AARP Public Policy Institute (October 2012). http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

[13] Centers for Disease Control and Prevention, *Long Term Care Services in the United States: 2013 Overview*, Vital and Health Statistics, 3(37): 33 (2013). http://www.cdc.gov/nchs/data/nsltcp/long_term_care_services_2013.pdf

[14] M. Favreault and J. Dey (July 2015).

[15] M. Favreault and J. Dey (July 2015).

[16] Carla Washington, Presentation at WV Partnership for Elder Living 2013 Summit, *Direct Care Workers: Essential to Quality Long Term Care*, p. 6, Direct Care Alliance, Inc. (2013). http://www.wvpel.org/summit4Pres/WVPEL_Carla.pdf

[17] National Alliance for Caregiving and AARP Public Policy Institute, *Caregiving in the U.S.*, p. 40 (June 2015). http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

[18] MetLife Mature Market Institute, *The MetLife Study of Caregiving Costs to Working Caregivers Double Jeopardy for Baby Boomers Caring for Their Parents*, p. 2 (June 2011). http://www.aarp.org/relationships/caregiving/info-11-2008/i13_caregiving.htm

[19] Note: These are total expenses, which include government expenses. M. Favreault and J. Dey (2015).

[20] This is a measure of median financial assets, not income. Financial assets include retirement accounts, taxable savings accounts, stocks, and bonds. Gretchen Jacobson, Christina Swoope, Tricia Neuman, and Karen Smith, *Income and Assets of Medicare Beneficiaries 2014-2030*, Henry J. Kaiser Family Foundation (2015). http://kff.org/medicare/issue-brief/income-and-assets-of-medicare-beneficiaries-2014-2030/

[21] Employee Benefit Research Institute Notes October 2015, *Amount of Savings Needed for Health Expenses for People Eligible for Medicare: Unlike the Last Few Years, the News Is Not Good*. https://www.ebri.org/publications/notes/index.cfm?fa=notesDisp&content_id=3284.

[22] M. Favreault and J. Dey (July 2015).

[23] America's Health Insurance Plans, *Who Buys Long Term Care Insurance in 2010-2011? A Twenty Year Study of Buyers and Non-Buyers (in the Individual Market)* (March 2012). https://www.ahip.org/WhoBuysLTCInsurance2010-2011/

[24] M. Favreault and J. Dey (July 2015).

[25] Melissa M. Favreault and Richard W. Johnson, *Microsimulation Analysis of Financing Options for Long Term Services and Supports*, pp. 25-26, Urban Institute (November 2015). http://www.thescanfoundation.org/sites/default/files/nov_20_revised_final_microsimulation_analysis_of_ltss_report.pdf; Melissa M. Favreault, Howard Gleckman, and Richard W. Johnson, *Financing Long Term Services and Supports: Options Reflect Trade-Offs for Older Americans and Federal Spending*, Health Affairs Vol. 34 No. 12 (December 2015). http://content.healthaffairs.org/content/early/2015/11/13/hlthaff.2015.1226.full.pdf+html

[26] M. Favreault and R. Johnson (November 2015).

[27] S. Banerjee, EBRI Issue Brief No. 372, *Effects of Nursing Home Stays on Household Portfolios*, p.11 (June 2012). http://www.ebri.org/pdf/briefspdf/EBRI_IB_06-2012_No372_NrsHmStys.pdf

[28] This is true for costs associated with LTSS needs for all age groups. For older persons (ages 65 years and older), out-of-pocket expenditures are substantially higher than Medicaid expenditures. Researchers project that older persons will pay out pocket for more than half of their LTSS expenditures, with insurance carriers paying a small amount in addition. M. Favreault and R. Johnson (November 2015).

[29] M. Favreault and J. Dey (July 2015).

[30] Steve Eiken, Kate Sredl, Brian Burwell, and Paul Saucier, *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013: Home and Community-Based Services were a Majority of LTSS Spending*, Centers for Medicare & Medicaid Services and Mathematica Policy Research (June 30, 2015). http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf

[31] ABLE Act of 2014, H.R. Res. 647, 113th Congress (2014) (enacted). Following enactment at the federal level, most states passed state ABLE Acts to establish state ABLE programs for their residents. The ABLE Act limits eligibility to individuals with significant disabilities that arose prior to age 26, and limits total annual contributions, including from friends and family, to $14,000.

[32] M. Favreault and R. Johnson (November 2015).

[33] S. Eiken, K. Sredl, B. Burwell, and P. Saucier (June 2015).

[34] M. Favreault and R. Johnson (November 2015).

[35] ABLE Act of 2014. The ABLE Act of 2014 created tax-advantaged savings accounts for individuals with disabilities and their families, but it is a limited mechanism, e.g. eligibility requires an onset of disability prior to age 26. This program is also only a realistic option for those with significant resources that allow them to make such savings contributions.

[36] Harriet L. Komisar and Judy Feder, *Transforming Care for Medicare Beneficiaries with Chronic Conditions and Long-Term Care Needs: Coordinating Care Across All Services*, The SCAN Foundation (October 2011). http://www.thescanfoundation.org/sites/default/files/Georgetown_Trnsfrming_Care.pdf

[37] Health Affairs. *THE CARE SPAN: Strong Social Support Services, Such As Transportation And Help For Caregivers, Can Lead To Lower Health Care Use And Costs*. Vol. 32 pp. 3544-551 (March 2013). http://content.healthaffairs.org/content/32/3/544.full.pdf+html; Harris Meyer, A New Care Paradigm Slashes Hospital Use And Nursing Home Stays For The Elderly And The Physically And Mentally Disabled, Health Affairs Vol. 30, No.3 pp. 412-415 (2011). http://content.healthaffairs.org/content/30/3/412.full.pdf+html

[38] Commonwealth Care Alliance, http://commonwealthcaresco.org/