



Health Program

Health Project

America's Long-Term Care Crisis:

Challenges in Financing and Delivery

April 2014



BIPARTISAN POLICY CENTER



Health Program

Health Project

ABOUT BPC

Founded in 2007 by former Senate Majority Leaders Howard Baker, Tom Daschle, Bob Dole, and George Mitchell, the Bipartisan Policy Center (BPC) is a non-profit organization that drives principled solutions through rigorous analysis, reasoned negotiation, and respectful dialogue. With projects in multiple issue areas, BPC combines politically balanced policymaking with strong, proactive advocacy and outreach.

DISCLAIMER

The findings and recommendations expressed herein do not necessarily represent the views or opinions of the Bipartisan Policy Center's founders or its board of directors.

LONG-TERM CARE INITIATIVE

In December 2013, BPC launched a Long-Term Care Initiative under the leadership of former Senate Majority Leaders Tom Daschle (D-SD) and Bill Frist (R-TN), former Congressional Budget Office Director Dr. Alice Rivlin, and former Wisconsin Governor and Secretary of the U.S. Department of Health and Human Services Tommy Thompson. BPC's Long-Term Care Initiative seeks to raise awareness about the importance of finding a sustainable means of financing and delivering long-term services and supports, and, in late 2014, will propose a series of bipartisan policy options to improve the quality and efficiency of publicly and privately financed long-term care.

AUTHORS

This paper was produced by BPC staff, in collaboration with a distinguished group of senior advisors and experts, for the Long-Term Care Initiative. BPC would like to thank Sheila Burke, Chris Jennings, and Tim Westmoreland for providing substantial feedback, support, and direction, and acknowledge BPC staffers Katherine Hayes, Leah Ralph, Brian Collins, Katie Golden, and Kelly Isom for their role in researching and drafting the final paper.

ACKNOWLEDGEMENTS

Supported by a grant from The SCAN Foundation – advancing a coordinated and easily navigated system of high-quality services for older adults that preserve dignity and independence. For more information, visit www.TheSCANFoundation.org.

Table of Contents

Introduction	4
Background	7
Demographic Challenges	7
Political and Fiscal Challenges	7
BPC's Approach.....	9
Medicaid	9
Private Long-Term Care Insurance Market	11
Individual Role in Financing Long-Term Services and Supports	12
Delivery System Reform	14
Background on LTSS.....	15
What are Long-Term Services and Supports?	15
Who Needs Long-Term Services and Supports?	15
Where are Long-Term Services and Supports Delivered?	16
Who Provides Long-Term Services and Supports?	17
Who Pays for Long-Term Services and Supports?	18
Public Financing	18
Private Financing	20
Conclusion and Next Steps.....	25
Technical Appendix: Development of BPC Estimates of National LTSS Spending.....	26
Endnotes	28

Introduction

In December 2013, the Bipartisan Policy Center (BPC) launched a Long-Term Care Initiative under the leadership of the BPC Health Project leaders, former U.S. Senate Majority Leaders Tom Daschle (D-SD) and Bill Frist (R-TN), as well as former Congressional Budget Office Director Alice Rivlin and former Wisconsin Governor and Secretary of the U.S. Department of Health and Human Services Tommy Thompson. The Long-Term Care Initiative will propose a series of bipartisan policy options in late 2014 to assist in the effort to build consensus on how to finance and deliver long-term care—referred to in this paper as long-term services and supports (LTSS)—at a time of political discord and fiscal constraints. The initiative seeks to raise awareness about the importance of the issue, bringing it to the attention of the public, as well as to policymakers, and making a strong case for action. This paper sets the stage for BPC’s recommendations by identifying the major challenges and key questions in the financing and delivery of LTSS for both seniors and individuals under age 65.

BPC leaders recognized the challenges associated with the cost and availability of LTSS while crafting BPC’s 2013 report, *A Bipartisan Rx for Patient-Centered Care and System-Wide Cost Containment*. That report called for an enhanced Medicare system in which incentives encourage both patients and providers to improve care and secure better health outcomes through reforms that would facilitate a transition away from volume-driven fee-for-service medicine and toward more organized systems of care. The report also recommended better integration of Medicare and Medicaid services for people who are dually eligible for both programs, but deferred developing specific policy recommendations to improve the financing and delivery of LTSS until a more focused set of policy options could be produced.

In late 2014, BPC's Long-Term Care Initiative will propose a series of bipartisan policy options to improve the quality and efficiency of publicly and privately financed LTSS at a time of political discord and fiscal constraints.

The number of Americans estimated to need LTSS is expected to more than double, from 12 million in 2010 to 27 million in 2050¹, while the costs of LTSS grow from 1.3 to 3 percent of GDP² and families increasingly struggle to prepare for and afford necessary care. While there is considerable consensus on how LTSS should be delivered—preferably at home and in the community rather than in institutions—there is a deep divide on how to finance LTSS. BPC’s leaders will seek to advance the discussion around LTSS by utilizing the considerable work that has already been done. BPC will draw on the thoughtful work of the 2013 Commission on Long-Term Care,³ and from lessons learned during the 2010 Community

Living Assistance Services and Supports (CLASS) Act debates—and its ultimately unsuccessful implementation in 2011 and 2012.

The financing and delivery of LTSS is an issue with a long and complex history. Public programs spend well over \$100 billion annually on LTSS, and unpaid caregivers, such as family members and friends, contribute services that are worth more than \$450 billion annually.⁴ How we deliver and pay for LTSS is important to many stakeholders, including those needing services (both over and under 65 years of age), their family members and friends, paid caregivers, providers, private insurers, states, and the federal government. Over the past 25 years, a number of proposals have been offered at the federal level to address the financing and delivery of LTSS; some were comprehensive, such as the Pepper Commission Report and the CLASS Act, and others suggested incremental changes in the regulation and tax treatment of private insurance, or provided new state options and demonstrations to expand the availability of home and community-based care through the Medicaid program.

CBO projects that public and private spending on LTSS for the elderly will grow from 1.3 percent of GDP in 2010 to 3 percent of GDP in 2050.⁵

Designing a comprehensive and sustainable system of financing LTSS is a challenging task for many reasons. Challenges include significant diversity in populations needing LTSS, which in turn results in tremendous variation in the level of assistance and types of services required. Significantly, the majority of services are delivered by family members and other unpaid caregivers, often at both personal and financial sacrifice; however, policymakers on both sides of the aisle have historically been unwilling to suggest that the role of the federal government should supplant those services with new federal benefits.

In the delivery of LTSS, there is significant agreement that the current bias toward institutional care under Medicaid should be eliminated. For decades, the Medicaid statute has structurally favored institutional care over home- and community-based care even though beneficiaries have a wide range of needs. Since the early 1980s, many states have taken steps to provide home- and community-based services (HCBS) through waivers for low-income Medicaid-eligible individuals. Likewise, over time, private long-term care insurance has shifted to include coverage of HCBS. Movement toward HCBS was spurred, in part, by the passage of the Americans with Disabilities Act (ADA) and the Supreme Court's 1999 decision in *Olmstead v. L.C.*,⁶ which requires states to make reasonable accommodations to provide services to individuals with disabilities in the most integrated setting appropriate to their needs. Since that time, states have used waivers to adopt innovative approaches to the delivery of LTSS at home and in the community, although in recent years, new state options have also been made available. Despite this effort, there continues to be tremendous variation in the availability of HCBS among states.

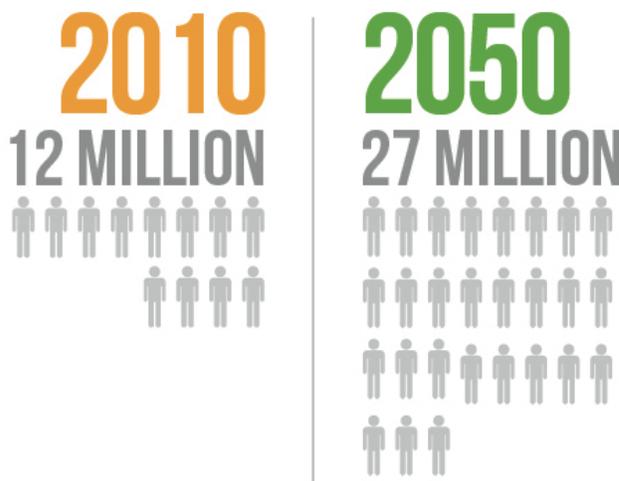
In this paper, BPC seeks to: (1) identify the most pressing problems associated with the current system of providing LTSS in the United States; (2) identify the barriers to finding a sustainable means of financing and delivering LTSS; and (3) outline some of the more critical policy questions that will guide BPC’s work in the coming months. Given the disparate populations in need of LTSS, and the challenges both in terms of politics and budgets, a solution to financing LTSS will likely require a series of policy options—including public and private options as well as long-term and short-term options—and will require legislative and regulatory changes. In the coming months, BPC leaders, staff, and senior advisors will reach out to experts, stakeholders, and policymakers and, later this year, present bipartisan policy approaches that we hope will move the dialogue forward. Importantly, as in *A Bipartisan Rx*, BPC will also work with economists and actuaries to estimate costs and savings associated with these policy solutions. We believe that developing a realistic, politically viable set of policy options is not only achievable, but is also imperative to relieve the pressure on persons who need LTSS, their families and caregivers, and local, state, and federal governments.

Background

Demographic Challenges

An estimated 12 million Americans are currently in need of LTSS⁷—defined as institutional or home-based assistance with activities of daily living (ADLs) such as bathing, dressing, or medication management—including both seniors and persons under age 65 living with physical or cognitive limitations. In the next two decades, the U.S. health care system will face a tidal wave of aging baby boomers. This, among many other factors, will create an unsustainable demand for LTSS in the coming years. Fewer family caregivers, increasingly

THE NUMBER OF AMERICANS NEEDING LTSS
IS EXPECTED TO MORE THAN DOUBLE BY 2050



limited personal financial resources, and growing strains on federal, state, and family budgets will further complicate efforts to organize and finance services. Although there is tremendous variation in what is, or will be, needed, fully 70 percent of people who reach the age of 65 will require some form of LTSS at some point in their lives.⁸ As mentioned above, the number of Americans needing LTSS at any one time is expected to more than double from 12 million today to 27 million by 2050.⁹ Indeed, the demand for LTSS will substantially outpace the rate of growth in the U.S. economy over the next decade and drive significant growth in Medicaid spending.

Political and Fiscal Challenges

Potential solutions for the nation's long-term care challenges will be viewed by policymakers in the context of the current political and fiscal environments, which include significant concerns about the long-term cost of major entitlement programs and long-term public debt. The Office of the Actuary of the Centers for Medicare and Medicaid Services (CMS) estimates that Medicaid spending on LTSS will grow by an average of 6 percent annually from 2012 to 2021, far faster than GDP.¹⁰ Notably, the CMS actuaries expect that the baby-boom generation, when they begin to exceed the age of 85 in the 2030s, will start to drive even faster growth in Medicaid LTSS spending. The Congressional Budget Office projects that public and private spending on LTSS for the elderly will grow from 1.3 percent of GDP

in 2010 to 3 percent of GDP in 2050, assuming that the prevalence of obesity and functional limitations does not change.¹¹ If the growth of government spending continues to outpace taxes and other revenues, public debt is on course to grow to levels that are unprecedented in U.S. history. Without changes in policy, the nation faces challenging trade-offs between spending to meet our commitments to older and low-income Americans and investments in the nation's future prosperity. Against this background, policymakers seeking to address the challenge of financing and delivering LTSS for an aging population will be looking for reforms that will reduce the rate of growth in spending over the long term through greater efficiency in public programs for those who need them and an increased reliance on privately funded solutions to constrain the need for publicly funded LTSS.

In the next two decades, an aging population, fewer family caregivers, increasingly limited personal financial resources, and growing strains on federal, state, and family budgets will create an unsustainable demand for LTSS.

Over the years, there have been numerous comprehensive proposals to address the financing of long-term care. However, stumbling blocks have included cost and the partisan divide over the appropriate role of the federal government in the financing of LTSS, particularly for higher-income individuals. As evidenced by the Commission on Long-Term Care report, some believe that LTSS should be provided through a social insurance program such as Medicare, while others believe that the financing of LTSS should be a combination of personal responsibility, through savings and the purchase of private insurance, and a safety-net program, such as Medicaid for those who do not have the resources to pay for LTSS.

Current federal fiscal challenges, combined with partisanship in Congress, make it an especially difficult environment in which to enact comprehensive financing reform of LTSS. That said, given the long-term challenges facing families, states, and the federal government, it is important that policymakers begin to lay the groundwork for action before millions of baby boomers begin to need assistance. Failure to do so will undoubtedly overwhelm the existing structure, which requires those in need of LTSS to rely on individual family resources, family caregivers, and, once private resources are exhausted, the Medicaid program. As such, the looming financing implications for the Medicaid program—and the need for Democrats and Republicans to come together to enact solutions—cannot be overstated.

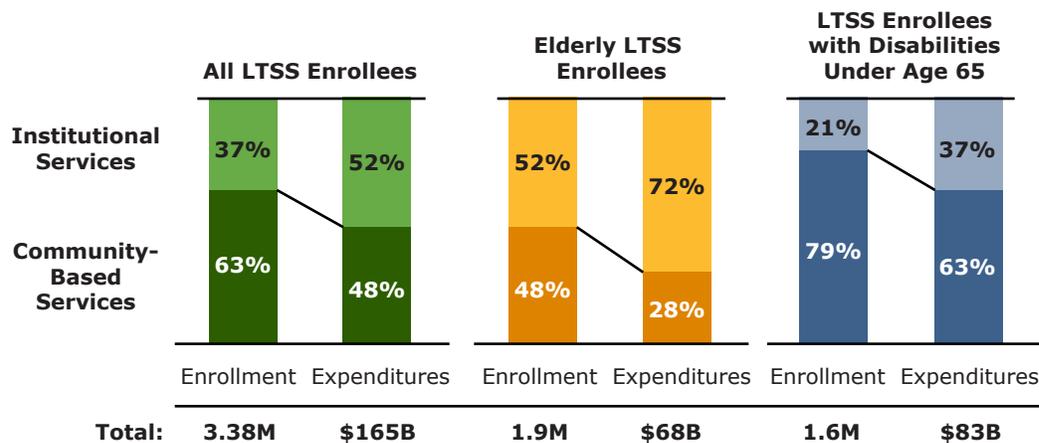
BPC's Approach

While some may believe that a true social insurance option financed through a broad-based tax, similar to the Medicare program, may be the most efficient and equitable means of financing LTSS, the current political and fiscal environment make that solution infeasible for the foreseeable future. As outlined below, BPC's initiative seeks input from experts and stakeholders on how best to craft a series of solutions that include both publicly funded programs, such as Medicaid, and private insurance products. BPC has identified a series of issues with the current system as well as questions that will be explored in the coming months. While BPC does not expect to answer all of the questions raised here, this framework serves as a critical starting point. Further, these issues are not meant to be comprehensive, and BPC welcomes additional questions and guidance from stakeholders and policymakers.

Medicaid

The Medicaid program provides both acute care services and LTSS for a broad range of individuals, including children, pregnant women, and people eligible for cash assistance such as Supplemental Security Income (SSI) and Temporary Assistance for Needy Families (TANF). Under the ACA, and at state option, Medicaid programs may also cover adults without dependent children with incomes below 133 percent of the federal poverty level,¹² as well as certain other low-income populations. The amount and type of income and assets subject to eligibility requirements vary by state. For example, assets typically counted for eligibility include checking and savings accounts, stocks and bonds, real property other than primary residence and motor vehicles other than primary vehicle. Assets not counted for eligibility include primary residence, household belongings, one motor vehicle, life insurance with a face value under \$1,500, up to \$1,500 in funds set aside for burial, and assets held in certain kinds of trusts.¹³ Services are based on "medical necessity," so not all Medicaid-eligible individuals receive LTSS. Although eligibility generally varies by state, Medicaid programs may provide an institutional level of care for individuals with incomes up to 300 percent of SSI income levels.¹⁴ Institutional care includes nursing homes, intermediate care facilities for individuals with mental retardation (ICFs/MR), and other residential facilities.

Distribution of Enrollment and Spending Among Medicaid LTSS Beneficiaries, by Population, 2009



Source: The Kaiser Commission on Medicaid and the Uninsured and Urban Institute estimates based on data from FY 2009 MSIS. Because 2009 data was unavailable, 2008 data was used for Pennsylvania, Utah, and Wisconsin.

Medicaid programs also continue to increase the availability of services in HCBS settings through a variety of waivers and demonstration programs. Experts have suggested that better coordination of services for those with chronic conditions who are eligible for both Medicare and Medicaid could reduce health care expenditures financed under the Medicare program, thus permitting health plans or affiliated provider groups, such as patient-centered medical homes or primary care case management, to use savings to finance improved coordination and availability of LTSS under the Medicaid program. Potential health care savings, however, vary widely from state to state. We look forward to seeing the early results of these demonstrations. We also seek guidance on how the Medicaid program could be improved to provide limited LTSS to individuals whose incomes are above Medicaid-eligibility levels in order to prevent spending down into Medicaid, or to improve existing programs designed to prevent working individuals with disabilities from relinquishing their jobs in order to receive services.

- Presuming that there is agreement that a new public insurance structure is not currently fiscally and politically viable, is there a role for public insurance, apart from the Medicaid program, for those who do not have access to private resources or private long-term care insurance? If so, what is it and how would it be structured in a politically and economically viable fashion?
- What is the appropriate division of responsibility between state and federal programs?
- How could the current delivery system be improved to better coordinate care and improve patient-centeredness and efficiency?

- Should health care services and LTSS be integrated? If so, for all populations, or only for those with chronic health conditions?
- Should integration of health care services and LTSS be left to individuals and families to decide?
- What lessons can be learned from the long history of waivers and demonstration programs?
- What can be learned from other programs and plans such as the Program of All-Inclusive Care for the Elderly (PACE) and Medicare Advantage Special Needs Plans?
- Should states be expected to better coordinate care for Medicaid-covered LTSS? If so, what is the federal role in promoting better coordination?
- What are the pros and cons of proposals that would turn LTSS delivery over to state governments with limits on federal funding, such as a block grant or per capita cap?
- How can lessons learned from public programs be applied to private LTC insurance?

Private Long-Term Care Insurance Market

No one would argue that the private long-term care insurance (LTCI) market, as currently structured, is a viable solution to address the needs of the diverse population in need of LTSS. Among other financial challenges, such as the current low-interest-rate environment, LTCI has struggled to find a viable risk pool. As with traditional health insurance coverage, the current voluntary system for private long-term care insurance has encountered adverse selection, driving up premium costs, and resulting in strict medical underwriting by insurers. The Affordable Care Act (ACA) addressed medical underwriting in the health insurance market by requiring individuals without other qualified coverage to purchase coverage or pay an assessment to assure a viable risk pool. While a potential policy approach for LTC, BPC does not believe that guaranteed issue paired with a requirement to purchase coverage is a solution that can be pursued in the post-ACA political environment. Likewise, recent experience with the enactment and repeal of the CLASS Act might suggest that a voluntary public option would have little support among policymakers in the current environment. However, a reformed private long-term care insurance market can be part of the solution in financing LTSS, and BPC seeks input on how to restructure the market.

- What is the role of the private long-term care insurance market?
- What reforms should be enacted to encourage carriers to remain in the market and encourage additional carriers to enter?
- How should products be structured to achieve this goal?

- Should products be structured and regulated similar to Medigap, with limited choices, or should the market be left flexible to address purchaser choice and market innovation?
- How should products be made available to individuals? Through the current system of brokers and sales representatives, through employers, through retirement (IRA, 401[k], etc.) account servicers, through health insurance exchanges, or through other options?
- Should LTC insurers be expected to better manage services, similar to health insurers, as opposed to paying claims or establishing per-diem payments?
- Could a non-insurer provider-sponsored model work for LTSS, and if so, how could solvency issues be assured?
- Are additional consumer protections needed, and if so, what would they include?
- What impact has existing consumer protections had on product design, availability, and affordability?
- In a political environment that is trending toward fewer deductions and preferential tax treatment, can or should the current structure of state regulation with certain federal minimum standards for tax-preferred policies be maintained?
- Would a voluntary structure work if framed to be similar to employer-sponsored retirement-savings options and disability insurance (i.e., auto-enrollment with an opt-out)?
- If so, how would one address the issue of affordability for those who cannot afford coverage?
- Could some form of reinsurance improve the viability of the LTCI market, in general, and the viability of policies with catastrophic (lifetime) coverage, in particular?
- How could reforms that increase the role of private LTCI in financing LTSS reduce the incidence of spending down to Medicaid eligibility for individuals and families and reduce public spending on Medicaid?

Individual Role in Financing Long-Term Services and Supports

Individual and family contributions to the cost of LTSS are difficult to estimate accurately. The majority of LTSS is provided by unpaid family members and friends, creating a fundamental challenge with designing public approaches to financing LTSS. Historically, one reason that policymakers have been reluctant to address LTSS is a concern that any solution that calls for greater involvement of government programs would supplant—rather than supplement—private spending, adding significantly to federal costs.

At the same time, experts recognize the economic cost in lost productivity as family caregivers are called upon to provide care to family members, or when working-age individuals with disabilities opt not to work because an increase in income would jeopardize eligibility for LTSS. Given the cost of financing LTSS, and the lack of private savings relative to the cost of care, most experts would agree that none but the highest-income individuals could pay for LTSS solely out-of-pocket. This is especially true for working adults who may need personal assistance or adaptive technology, those who need LTSS for an extended period of time, or those who are living on Social Security and retirement savings. Yet given current fiscal and political challenges, we recognize that some level of personal responsibility is needed from those who have adequate resources. Unfortunately, personal savings for retirement needs of all kinds, including general living expenses and out-of-pocket health care expenses, are lacking among most Americans. In 2005, only one-third of Americans age 65 and over had at least \$70,000 in assets (excluding a home), which is about the cost of a one-year stay in a nursing home.¹⁵ Further, 65 percent of Americans over 40 have done little to no planning for living expenses in retirement.¹⁶ While some people will experience catastrophic LTSS costs that would be impossible for most Americans to realistically meet with savings, many, if not a majority, of retirees should be able to meet some LTSS costs out-of-pocket. For example, in a cohort of 65-year-olds, 42 percent will ultimately have no spending on LTSS and 30 percent will ultimately spend something, but less than \$25,000.¹⁷

In 2005, only one-third of Americans age 65 and over had at least \$70,000 in assets, which is about the cost of a one-year stay in a nursing home. Sixty-five percent of Americans over 40 have done little to no planning for living expenses in retirement.^{18,19}

If Americans had more savings for retirement, the nation would be better able to handle the costs of less-intensive LTSS. To address this challenge, BPC's Economic Policy Project will launch a Personal Savings and Financial Security Initiative (PSFSI), which will explore potential policy solutions and recommendations for increasing private savings over the next year. BPC's Long-Term Care Initiative will collaborate with PSFSI, where appropriate, on proposals that could improve both retirement savings and families' preparedness for LTSS expenses.

- If problems associated with stability and affordability in the private long-term care insurance market could be addressed, would it be reasonable to expect that more individuals could afford to pay private long-term care insurance premiums?
- A number of tax benefits currently exist to encourage personal savings and the purchase of private long-term care insurance. In light of tax reforms, will these tax benefits continue, and if so, how could these and other incentives be better targeted?

- What is the best means of empowering and encouraging individuals to make arrangements to self-finance LTSS? To what extent is an educational component needed to inform the public of this impending need?
- How can the nation best support family caregivers without supplanting private spending?
- Can technology play a role in reducing costs by allowing individuals to remain at home and in the community?

Delivery System Reform

Historically, states and the federal government have limited utilization of Medicaid-funded LTSS by restricting eligibility for services and by providing care primarily in institutional settings. As a result, fewer people are eligible for services, and those who are eligible receive them in the most costly settings. Over the past decades, states have used waivers and state plan options to make care available at home and in other settings, such as small group homes, but the structure of waivers and the costs of expansion have resulted in a slower transition from institutional to home and community-based settings. While the Deficit Reduction Act of 2005 and the ACA made more options available, the full potential of these options has not been realized, in part because of limited resources. Policymakers have learned much about the importance of delivery system reform in recent years with respect to the delivery of acute care services. Likewise, a handful of states have been leaders in the integration of health and long-term care services in improving patient care, while others have been more focused on assuring efficient utilization of services. While this is related to Medicaid, BPC will explore whether individuals with private insurance and Medicare coverage might buy-in to an integrated delivery system for LTSS. For example, a Medicare beneficiary may choose to utilize the provider network in place for an individual who receives both acute care and LTSS as an individual dually eligible for Medicare and Medicaid.

- How critical is delivery system reform to the financing of LTSS, particularly for those who receive care through Medicaid?
- What lessons learned about care coordination and integration of services can be applied to the private insurance market?
- Should there be better coordination and integration of acute health care delivery system reforms in Medicare with LTSS? If so, what services and how?

Background on LTSS

What are Long-Term Services and Supports?

LTSS includes a broad range of health-related and social services that assist individuals who have limitations in their ability to perform self-care due to a physical, cognitive, developmental, or other chronic health condition that is expected to continue for an extended period of time (usually 90 days or more).²⁰ These services include assistance with activities of daily living (ADLs), such as bathing, dressing, eating, transferring, and walking,²¹ and instrumental activities of daily living (IADLs), such as meal preparation, money management, house cleaning, medication management, and transportation.²² Importantly, LTSS does not include medical or nursing services needed to manage an individual's underlying health condition. Defining ADLs and IADLs, and determining the number of functional limitations in performing these tasks, has important policy implications, because it determines eligibility for LTSS benefits in both public and private insurance programs.²³ Federal and state LTSS programs—and often private long-term care insurance—typically base eligibility and benefits on needing assistance with two or more ADLs; this population is roughly 3.2 million people.²⁴ This compares with a more broadly defined LTSS population of 12 million who need assistance with one or more ADLs or IADLs.²⁵

Who Needs Long-Term Services and Supports?

Individuals who use LTSS may have very different needs depending on age, health status, employment status, and the presence of intellectual and/or developmental disabilities.²⁶ For example, a senior citizen with Alzheimer's disease may need constant supervision and assistance with ADLs, while an adult with physical disabilities may only require personal care assistance to permit them to work. Of the 12 million Americans in need of LTSS, approximately 50 percent are adults over age 65, 47 percent are adults between the ages of 19 and 65, and 3 percent are children under the age of 18.²⁷

Some individuals who utilize LTSS may have very few health care needs. For example, a young person with developmental disabilities may have no more than routine interactions with the health care system, such as the occasional office visit. Others who need LTSS have significant coexisting health conditions that may require extensive use of the health care system, or a significant medical event may have triggered the need for LTSS. This is particularly common among older Americans who use LTSS.²⁸ For these individuals, better coordination among LTSS providers and health care providers may improve quality and lower costs. Some programs already attempt to better integrate health care and LTSS payment and delivery, such as PACE and State Demonstrations to Integrate Care for Dual Eligible Individuals, both run by the CMS Medicare-Medicaid Coordination Office in

partnership with states.²⁹ Today, this kind of integration is rare, mainly occurs where explicit funding exists for LTSS through Medicaid, and is especially unusual for services funded by private LTC insurance. Proposals to improve the financing and delivery of LTSS must address the need to integrate LTSS with health care services across settings and include solutions that are targeted to the varying needs—and the disparate nature—of different populations.

Where are Long-Term Services and Supports Delivered?

LTSS are generally provided in three types of settings—nursing care facilities, home care, and residential facilities³⁰—and are often divided into two broad categories: institutional and HCBS. HCBS are defined as those services delivered outside of an institutional setting, which could include the beneficiary’s home, a caregiver’s home, or an assisted living facility.³¹

While the majority of LTSS has been, and continues to be, unpaid and delivered in the home, paid LTSS has historically focused on institutional care. State Medicaid programs are required to cover nursing-facility services, while coverage for HCBS remains optional, creating a bias toward institutional care. Originally, Medicaid and private insurance paid exclusively for nursing home care. Coverage has significantly shifted away from institutional care in favor of HCBS in recent years; today, roughly half of LTSS Medicaid spending is for HCBS, and at least one major private LTC insurance issuer has also seen claims shift toward HCBS.³² Several authorities allow states to offer HCBS through Medicaid waivers or state plan options. There have been several statutory changes in the last 30 years to provide increased federal incentives, and flexibility, to states to broaden beneficiary access to HCBS.^{33,34} Now only about 1.5 million of the nation’s LTSS recipients live in nursing homes.³⁵ This shift has had the most impact on the under-65 Medicaid LTSS population, of which nearly 80 percent are using community-based services (among the over-65 population, it’s less than 50 percent).³⁶ While this is a notable, and laudable, shift, much remains to be done in the movement to de-institutionalize LTSS.

The financing and delivery of LTSS are highly fragmented, lacking in coordination across services and providers, and is often provided in ways that can be inefficient, expensive, and not meeting the needs of the patient.

LTSS is highly fragmented, lacking in coordination across services and providers, and often provided in ways that can be inefficient, expensive, and not meeting the needs of—or ensuring the best outcome for—the patient.³⁷ The planning and organization of LTSS is often handled separately from health care planning, so that when a patient is transitioning from acute or post-acute care to an LTC setting, few incentives are in place for health care

providers to integrate LTSS in their plan for a patient. Access to services is also often determined by the funding stream, creating an approach to LTSS that is provider- or setting-focused, rather than patient-focused.³⁸ A number of initiatives to test new payment and delivery models could assist in integrating health care and long-term care services by building in the necessary financial incentives to achieve patient-centered health outcomes and a seamless continuum of care.

Who Provides Long-Term Services and Supports?

The LTSS workforce includes, but is not limited to, nursing home and assisted living administrators, physicians, nurses, social workers, physical and occupational therapists, aides, and ancillary staff who may be employees of home health agencies, nursing homes, or assisted living facilities.^{39,40} However, a majority of LTSS is provided by informal caregivers, such as friends or family members, providing assistance on an unpaid basis to a person in the home with functional limitations. In 2009, about 66 million Americans provided unpaid care to family members and friends, almost one-third of the U.S. adult population.⁴¹ Caregiving often causes financial, physical, and emotional hardship; caregivers have little to no training for the duties they are expected to perform and have little access to information or support in navigating the LTSS system.⁴² Caregivers who are also employed cost U.S. employers up to \$34 billion annually in lost productivity from reduced hours, absenteeism, and workday distractions.⁴³

In 2009, about 66 million Americans provided unpaid care to family members and friends, almost one-third of the U.S. adult population.

Families pay a high price, too. Although not included in formal cost estimates for LTSS, a range of studies estimate the value of informal caregiver services—costs to families and businesses—at hundreds of billions of dollars.⁴⁴ Informal caregiving was estimated to be valued upwards of \$450 billion in unpaid services in 2009.⁴⁵ One survey found the average annual out-of-pocket expense for caregiving families is \$5,531, more than 10 percent of the median household income in 2007.⁴⁶ Informal caregivers also often forgo income-generating opportunities, further complicating efforts to save for their own retirement and any future LTSS needs.

LTSS faces a range of workforce challenges, including an emerging “care gap,” particularly as the population in need of LTSS continues to grow with an aging baby-boomer population. Declining birth rates in the last 50 years means there will be fewer family members to care for aging parents or relatives in the coming years.⁴⁷ Over the next 20 years, the caregiver support ratio is projected to drop from seven (in 2010) potential caregivers for every person over 80 to four (in 2030),⁴⁸ and demand for direct-care workers—nursing, home health, and personal care aides—is expected to increase by 48 percent in the next decade.⁴⁹

Historically, policymakers have raised the concern that approaches to financing LTSS would ultimately have the effect of supplanting—rather than supplementing—the assistance

provided by unpaid family members and other caregivers, adding exponentially to the cost of LTC. Ultimately, any policy approach to address challenges in LTC workforce and delivery must consider how to build upon and strengthen, rather than replace, existing family caregiver support. Further, policymakers must consider ways to optimize the LTC workforce to ensure safe, high-quality care at the lowest cost.

Who Pays for Long-Term Services and Supports?

Complexity in the delivery of LTSS is mirrored by complexity in the financing system. LTSS is financed through a range of public and private sources, including Medicaid and a variety of smaller public programs, private long-term care insurance, and personal savings. Public spending on LTSS is well over \$100 billion annually, most of which is Medicaid spending; in 2012, private LTCI paid for about \$7 billion of LTSS, and out-of-pocket spending by individuals and families accounted for tens of billions more.⁵⁰ Exact numbers on LTSS spending, whether private or public, are unknown due to limitations in the available data; for now, policymakers must rely on estimates. LTSS spending is hard to gauge because LTSS providers (such as skilled nursing facilities and home health providers) also deliver post-acute care (rehabilitative) services, and this spending is commingled with LTSS spending in much of the available data. However, it is clear that Medicaid is by far the major LTSS payer, paying for two-thirds or more, with private savings and private LTCI rounding out the rest. Private LTCI likely accounts for less than 5 percent of total spending on LTSS.

Public spending on LTSS is well over \$100 billion annually, most of which is Medicaid spending; in 2012, private LTCI paid for about \$7 billion of LTSS, and out-of-pocket spending by individuals and families accounted for tens of billions more.⁵¹

There are public sources other than Medicaid that pay for LTSS, but they often limit assistance to small, specific populations and cover only limited services. For example, the Older Americans Act, directed by the Administration on Aging, offers LTSS to older individuals who are low-income, minority, have limited English proficiency, live in rural areas, and are at risk for institutional placement.⁵² The Veterans Health Administration covers some LTSS benefits for veterans, but coverage varies considerably based on location, income, availability, and disability.⁵³

PUBLIC FINANCING

Medicare

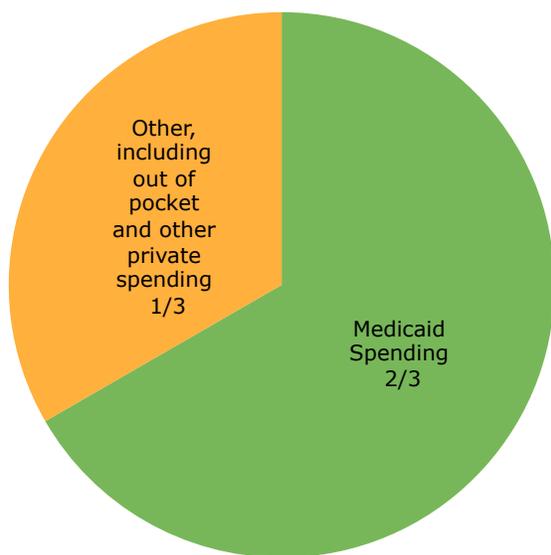
Medicare does not cover long-term services and supports. Benefits are limited to acute care health services—including, among other acute services, hospital stays, post-acute care, and physician visits—and prescription drugs for the elderly and certain individuals with disabilities.⁵⁴ As a result, Medicare only covers skilled nursing facility (SNF) care or rehabilitation services following a three-day hospital inpatient stay, within 30 days of

hospitalization, and only for up to 100 days per benefit period.⁵⁵ Medicare also covers medically necessary, intermittent home health services (60 days per episode) and physical, speech, or occupational-therapy services, as well as medical supplies and durable medical equipment such as wheelchairs, hospital beds, oxygen, and walkers.⁵⁶ After rehabilitation is complete, if the beneficiary’s functional status indicates that personal care services are needed on a long-term basis, the continued use of skilled services would not be covered by Medicare.

Medicaid

Medicaid is the primary LTSS payer, generating two-thirds or more of the total payments for LTSS.⁵⁷ In 2011, the CMS Office of the Actuary estimated Medicaid LTSS spending at \$114 billion, while an analysis by Mathematica Policy Research arrived at an estimate of \$136 billion.⁵⁸ LTSS accounts for at least one-quarter, and possibly almost a third, of total Medicaid spending (\$432 billion in 2011);⁵⁹ however, only a small fraction (6.7 percent or 4.2 million in 2009) of Medicaid beneficiaries received LTSS and/or post-acute care.⁶⁰ Eligibility for the elderly and persons with disabilities is subject to categorical and financial eligibility standards. In most states, Medicaid-eligible individuals who qualify for cash assistance under the SSI program (i.e., have incomes below 74 percent of the federal poverty level and meet other requirements relating to resources and level of disability) are eligible for the full range of Medicaid services.⁶¹

Medicaid Pays for the Vast Majority of LTSS Spending



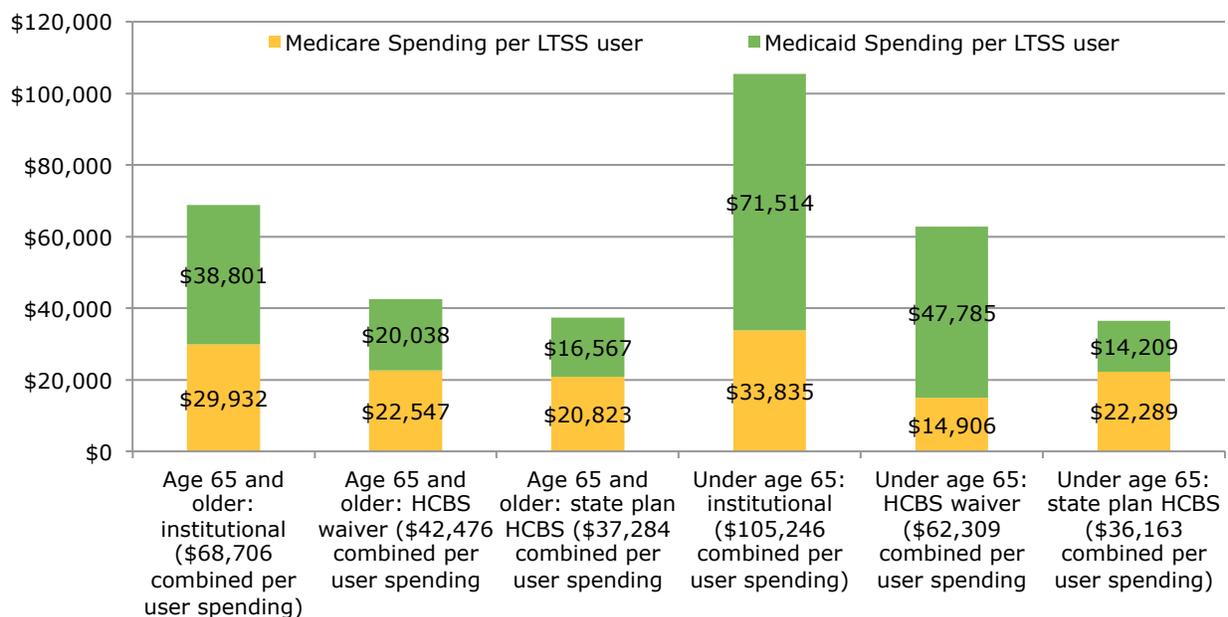
Source: BPC Analysis, informed by the National Health Policy Forum’s National Spending for Long-Term Services and Supports and the Centers for Medicare and Medicaid Services’ 2012 Actuarial Report on the Financial Outlook for Medicaid. See Technical Appendix for more on BPC’s analysis of national spending on LTSS.

When an individual has too much income to qualify for Medicaid under the SSI pathway, but faces catastrophic LTSS and health care costs that he or she cannot meet, it is possible to qualify for Medicaid through a “spend down” process.⁶² Most individuals over the age of 65 who qualify for Medicaid do so by spending down.⁶³ The details of this process vary by state, but individuals typically must exhaust almost all of their savings (an exception allows Medicaid beneficiaries to keep a home, within certain limits) and spend a substantial portion of their income on health care and LTSS expenses before they can qualify. Once a person has qualified for Medicaid coverage of LTSS, they could be required to contribute most of their remaining income to the cost of services used. There are exceptions to protect spouses who live in the community, and beneficiaries who are receiving HCBS,

who need to cover basic living and home-maintenance expenses.

For dual-eligible individuals (those eligible for both Medicare and Medicaid), Medicare covers the cost of acute and post-acute care services, such as short-term stays in skilled nursing facilities or inpatient rehabilitation facilities following hospitalizations. Medicaid pays for medically necessary acute care services covered by the state—but not covered by Medicare—as well as LTSS. It is important to note that only institutional LTSS coverage is universal in Medicaid. Coverage of HCBS remains optional for states; some do not cover it at all, and many restrict HCBS coverage to certain regions and/or a subset of Medicaid beneficiaries.

Per User Medicare and Medicaid Spending on Fee-For-Service Full-Benefit Dual-Eligible Medicaid LTSS Users By Age, 2009



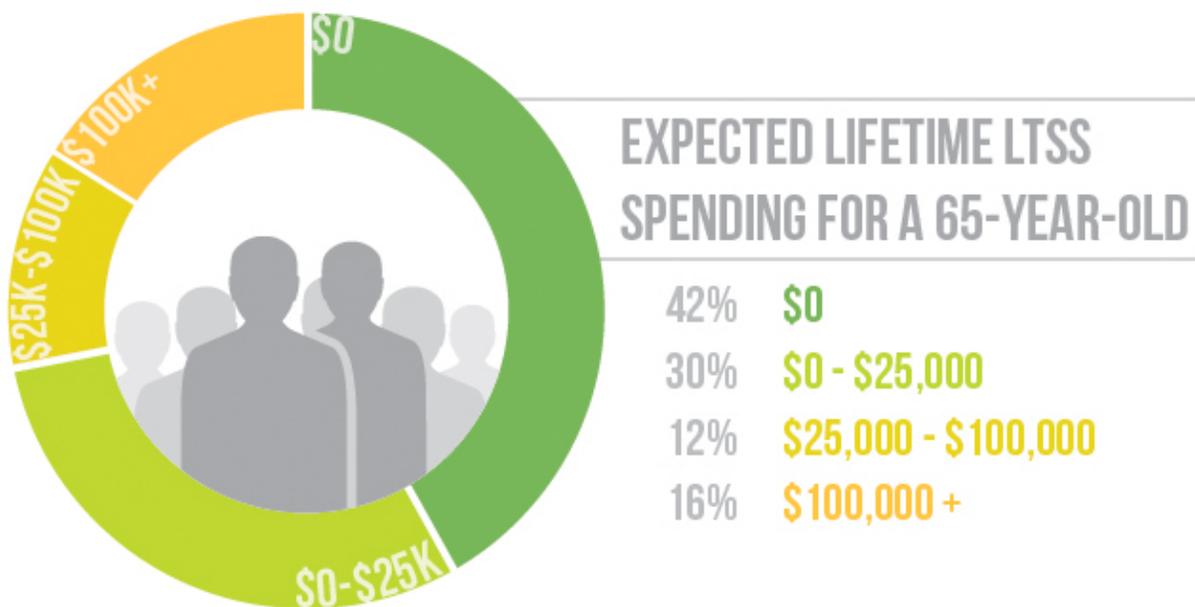
Source: Medicare Payment Advisory Commission (MedPAC) and Medicaid and CHIP Payment and Access Commission (MACPAC). Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid. Dec 2013. P. 61. Available at: http://www.medpac.gov/documents/Dec13_Duals_DataBook.pdf

PRIVATE FINANCING

Private LTC Insurance

Long-term services and supports are expensive, especially when they are needed for long periods of time.⁶⁴ Of a cohort of 65-year-old Americans, a large portion (42 percent) will have no spending on LTSS for the rest of their lives, either because they will not need LTSS or they will rely on unpaid assistance from family and friends. A small group (16 percent) will ultimately use more than \$100,000 in services, with the rest spending more than zero but less than \$100,000.⁶⁵ Because a small number of people will have substantial needs that are unlikely to be met solely through personal savings, insurance would seem to be an

ideal mechanism to finance these needs. Yet, the private LTCI market has struggled in recent years and currently plays a minor role in the financing of LTSS.⁶⁶ After several years of strong growth in private LTCI coverage in the late 1990s and early 2000s, the number of insured lives has been virtually unchanged since 2005, and sales of individual-market policies have dropped by two-thirds from their peak in 2002.⁶⁷ Growth has focused on the group market, while the individual market (two-thirds of the total) has declined.⁶⁸ About 8.2 million lives are covered by private LTCI,⁶⁹ representing fewer than 6 percent of Americans over the age of 40.⁷⁰ Of those over 65 with annual incomes above \$20,000, only 16 percent carry private LTCI.⁷¹ In 2012, LTCI policyholders paid more than \$11 billion in premiums.⁷² Cash payments to policyholders (or LTSS providers) from private LTCI claims totaled about \$7 billion in 2012,⁷³ funding less than 5 percent of total spending on LTSS.⁷⁴



Private LTCI is typically purchased when the buyer is middle-aged and, if needed, used in very old age. The policy parameters are fixed at purchase, as are the premiums, which are set based on age at purchase and are intended to remain level after purchase (they can and often do increase in certain circumstances described below). Private LTCI works somewhat like a high-deductible health plan. But rather than a dollar-amount deductible, the policyholder is responsible for paying the cost of all LTSS used during an initial elimination period, which is usually for 30, 60, or 90 days. After the elimination period has expired, the LTCI policy covers all costs up to a daily benefit amount for a maximum period (usually three to five years). Inflation protection is an option for all private LTCI policies, and it was included in 74 percent of policies sold in 2010.⁷⁵ Since it is not uncommon for decades to pass between when policies are purchased and when they are used, inflation protection is an important feature to ensure that the benefit will keep up with the rising cost of LTSS, but some do not include it because it adds significantly to the premium.⁷⁶ Partnership programs,

which are offered by most states, allow holders of private LTCI policies to shield additional assets from spend-down requirements, should they exhaust their private policies and need assistance from Medicaid.⁷⁷ The average LTCI policy purchased in 2010 had a premium of \$2,283 and would cover almost five years of nursing home care at \$153 per day after a 90-day elimination period.⁷⁸ The average age of purchasers in 2010 was 59 years.⁷⁹ Even if such a policy had been purchased with a 5 percent annual inflation adjustment, it would still be about \$50 per day short of covering the national median daily rate for a private room in a nursing home in 2013.⁸⁰

Other private funding options include hybrid insurance products (a combination of life insurance and LTCI or an annuity and LTCI), personal savings (including savings in tax-advantaged accounts, such as 401(k)s, Individual Retirement Accounts, and Health Savings Accounts), and home equity, which can be used to pay for LTSS through the sale of a residence or a reverse mortgage. Hybrid products—which combine LTSS benefits with life insurance, an annuity, or both—are a newer option and are less common than traditional LTCI. Hybrid products may be more attractive to consumers than traditional LTCI policies, because there is a guaranteed cash payout at some point. For example, in a hybrid annuity/LTCI policy, if LTSS benefits are never utilized, the policyholder will still receive regular annuity payments. Additionally, premiums can never go up⁸¹ and there is favorable tax treatment under the Pension Protection Act of 2006.⁸² This law states that payouts used for LTSS are not taxable; whereas, payouts from life insurance or annuity products are sometimes considered taxable income.⁸³

About 8.2 million lives are covered by private LTCI,⁸⁴ representing fewer than 6 percent of Americans over the age of 40.⁸⁵ Of those over 65 with annual incomes above \$20,000, only 16 percent carry private LTCI.⁸⁶

While many policymakers hoped that private LTCI products would cover a growing portion of Americans, provide greater financial protection for the middle class, and reduce the burden on public programs and family members, a variety of challenges have kept this product from assuming a larger role. These challenges include high costs, adverse selection, and insufficient planning on the part of many individuals and families for potential costs during retirement, including LTSS needs. Insurers have been exiting the market (from more than 100 issuers in 2002 to about a dozen now in the individual market, and fewer than eight currently issuing new coverage in the group market).^{87,88} Those remaining have been increasing premiums, if justified and approved by state insurance regulators, when claims are higher than expected, investment returns are lower than expected, and fewer subscribers let their policies lapse than expected.⁸⁹ These increases have made it challenging for some elderly policyholders to maintain coverage. Sales and underwriting costs are high, which reduces the value of the product for the price paid.

Private LTCI is also vulnerable to adverse selection. Even though the product is underwritten, buyers will always know more about their potential future health status than insurers. As such, people who are more likely to need LTSS are more likely to buy insurance, which results in higher premiums and discourages those of average or lower-than-average risk of needing LTSS from purchasing coverage.^{90,91} Finding more viable risk pools for LTCI is a major challenge that must be met in order for the product to play a larger role in LTSS financing. More effective risk pools could help to address adverse selection, high sales and administrative costs, and the propensity of Americans to avoid planning for potential living needs in old age.

Even without adverse selection, it is not clear that consumer demand for private LTCI would be strong. Most Americans are not especially interested in or motivated to purchase private LTCI. Many do not plan for LTSS costs, and, as noted above, 65 percent of Americans over 40 have done little to no planning for any sort of living expenses for when they are older.⁹² Many think that they won't need LTSS (70 percent of those over 65 will need some LTSS, whether paid or unpaid, but just over half say that they are at risk of needing LTSS), and most of those who do realize they are at risk of needing LTSS think that someone else will bear the cost.⁹³ For those who are interested in LTCI or on the fence, high premiums and underwriting discourage or prevent many from purchasing coverage. Some assume that Medicare will cover LTSS; it doesn't. As discussed above, Medicaid will pay for LTSS, but only for people who have very low incomes and assets to begin with or who have spent down most income and non-housing assets on LTSS.

Personal Savings

Personal savings is an important source of financing for LTSS. But, because these services can be very expensive, savings cannot be the only source of payment for most people who need LTSS. Savings are also a complement to private LTCI. Since LTCI is typically purchased at working age, when incomes are typically higher, policyholders must be able to continue to afford premium payments during their retirement years, as well as pay for out-of-pocket LTSS costs during the policy-elimination period, should the need for LTSS arise. Personal savings for retirement are one way of meeting these costs. However, around half of Americans have insufficient savings for general living needs in retirement, let alone enough to cover potential costs related to LTSS.⁹⁴ Increased savings for retirement could make private LTCI more viable, helping more Americans afford premiums and related out-of-pocket costs.

For LTCI purchased in 2010, the average buyer was 59 years old at purchase and the average annual premium was \$2,283 (the parameters of the average policy are described earlier).⁹⁵ In that same year, the median household income of Americans age 65 and up was \$31,408.⁹⁶ In such a household, the average private LTCI premium for two persons would consume almost 15 percent of household income. It is unlikely that median income for retirement-age Americans would increase enough in the next few years to significantly change this analysis. Clearly, this is a major expense, which savings could help to meet.

The larger problem is that most Americans do not have sufficient savings to preserve their standard of living in retirement, let alone to pay for LTSS. Only about half of Americans participate in some kind of a workplace retirement plan, such as a defined benefit pension or defined contribution account, like a 401(k).⁹⁷ Those between the ages of 55 and 64 who do participate in an employer-based retirement plan have a median defined contribution account balance of \$100,000.⁹⁸ The National Retirement Risk Index, which incorporates factors other than retirement accounts (such as home equity and Social Security) into an assessment of national retirement preparedness, estimates that 53 percent of households are at risk of not being able to maintain their standard of living when they are no longer working.⁹⁹ Individuals who are unprepared for retirement in general are not likely to take steps to prepare for potential costs related to LTSS needs.¹⁰⁰

Conclusion and Next Steps

The financing and delivery of LTSS is a complex issue, and policymakers have struggled for decades to improve the quality and delivery of these services in a cost-effective way. As the demand for LTSS more than doubles over the next 35 years, current funding sources will quickly become unsustainable and this population growth will only exacerbate the fragmented way in which these services are delivered. Due to both the diversity of the LTSS population and the current political environment, it is extremely unlikely that a single solution will adequately address these challenges. For this reason, BPC's Long-Term Care Initiative plans to produce a set of recommendations that weave together the approaches of publicly funded programs, such as Medicaid, with private insurance products to control costs, while also improving the efficiency and quality of LTSS. Senator Daschle, Senator Frist, Dr. Rivlin, and Governor Thompson plan to build upon the considerable work being done in this area, particularly by the recent Commission on Long-Term Care, and welcome comments and guidance from stakeholders and policymakers as the initiative progresses.

Technical Appendix: Development of BPC Estimates of National LTSS Spending

National spending on LTSS is difficult to estimate because the available data sources generally commingle LTSS and post-acute care (PAC) spending. PAC includes rehabilitative services that are used on a short-term basis after an acute medical issue.¹⁰¹ An example of PAC would be rehabilitative services delivered by a skilled nursing facility (SNF) or a home health agency (HHA) for a few weeks after knee-replacement surgery. Medically-necessary PAC is covered by Medicare and private health insurance. LTSS, as described in the report, includes services to assist individuals with functional limitations with ADLs and IADLs on a long-term basis. In many cases, for PAC and LTSS, the same kinds of services are delivered by the same providers (SNFs and HHAs). As such, economic data that focuses on providers, such as the National Health Expenditure Accounts (NHEA), mix this spending together. This creates major challenges for estimating LTSS spending, for which there are not perfect solutions.

The federal Commission on Long-Term Care relied on a National Health Policy Forum (NHPF) analysis of NHEA data for LTSS spending estimates.¹⁰² The NHEA data is not segmented by service type (PAC vs. LTSS), but it is segmented by payer, such as Medicare, Medicaid, and out-of-pocket, among other categories. Because Medicare does not pay for LTSS, payments to SNFs and HHAs that originate from Medicare are assumed to be for PAC and can be eliminated from the analysis; using this methodology, NHPF estimated total LTSS spending of \$210.9 billion for 2011. The advantage to this approach is that it is a broad measure that is likely to capture most LTSS spending (with the exception of assisted-living and certain social services, which are not included). The disadvantage is that the \$210.9 billion estimate also includes a substantial amount of PAC spending from private insurance, Medicaid, and out-of-pocket.

For this white paper, BPC used an alternative approach to estimate LTSS spending, examining data from major LTSS payers in order to exclude as much PAC as possible. Essentially, the BPC approach trades precision for accuracy.

Medicaid and Other Public Spending

Medicaid is clearly the largest LTSS payer, and data on program spending is available to the public. The CMS Actuary reported that federal and state outlays for LTSS under the Medicaid program totaled \$114.3 billion in fiscal year (FY) 2011.¹⁰³ A study from Mathematica Policy Research estimated 2011 Medicaid spending on LTSS to be \$136.2 billion.¹⁰⁴ Both amounts include an unknown amount of PAC. However, the amount of PAC spending included is likely relatively low for two reasons. First, for dual-eligibles, Medicare is paying for any PAC services. Second, about half of Medicaid beneficiaries are enrolled in managed-care plans; capitated payments to these plans, which pay for any PAC needed by their beneficiaries, are accounted for separately and are not included in the \$114.3 billion figure. The CMS estimate (\$114.3 billion) does not include LTSS paid for by managed-care plans. The vast majority of capitation payments are for acute care, but some states provide at least some LTSS through capitated plans. The Mathematica estimate includes some data on Medicaid managed-care spending on LTSS, which was collected through a survey. The CMS and Mathematica estimates use different definitions of LTSS in other respects, as well. While they differ, they provide a realistic “ballpark” sense of Medicaid spending on LTSS; it is probably well over \$100 billion annually.

There are other public programs that pay for LTSS, such as Veterans Affairs and Older Americans Act programs. These are included in NHPF’s \$9.7 billion total for Other Public Spending, based on NHEA data.

Private Spending: LTCI and Out-of-Pocket

Private spending on LTSS is even more difficult to estimate than public spending. The NHPF analysis of NHEA data shows a total of almost \$70 billion out-of-pocket and other private (including insurance) spending on LTSS in 2011 (not including assisted living), but this figure includes a substantial amount of PAC spending. Additionally, some spending that originated from private LTCI is reported as out-of-pocket because it is common for LTCI to pay policyholders directly, who then in turn pay LTSS providers. This figure also leaves out spending on assisted living, and probably does not include a substantial amount of gray-market home care, but it likely includes all nursing-home out-of-pocket spending, which is the most expensive form of LTSS. Because we have no sense of how much of the \$70 billion figure is for out-of-pocket and health insurance payments for PAC, the true out-of-pocket LTSS spending figure (not including assisted living) is likely somewhere well above zero and well below \$70 billion. Hence, a precise estimate is not possible; the best we can say is that tens of billions are likely spent out-of-pocket on LTSS annually, excluding assisted living.

The situation is different for private LTCI. While LTCI issuers do not report the exact amount of cash paid to policyholders and LTSS providers each year based on claims, the data available can be used to estimate annual cash payments from claims. At the request of BPC, LifePlans reviewed data collected by the National Association of Insurance Commissioners and estimated that private LTCI paid out about \$7 billion on claims in 2012.

Endnotes

- ¹ Department of Health and Human Services (2003) *The Future Supply of Long-Term Care Workers in relation to The Aging Baby Boom Generation*, Report to Congress. Available at: <http://aspe.hhs.gov/daltcp/reports/ltcwork.htm#section1>.
- ² Congressional Budget Office (2013) *Rising Demand for Long-Term Services and Supports for Elderly People*. June, p. 33. Available at: <http://www.cbo.gov/publication/44363>. Note: In this analysis, the Congressional Budget Office includes Medicare spending for post-acute care in its LTSS spending statistics. In BPC estimates of LTSS spending elsewhere in the report, we have attempted to exclude spending on post-acute care, to the extent possible.
- ³ Available at: <http://ltccommission.org/>.
- ⁴ See Technical Appendix for BPC's analysis of public LTSS spending. For an estimate of the economic value of unpaid LTSS, see: L. Feinberg, S. Reinhard, A. Houser, R. Choula (2011) *Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving*. AARP Public Policy Institute.
- ⁵ Congressional Budget Office (2013) *Rising Demand for Long-Term Services and Supports for Elderly People*. June, p. 33. Available at: <http://www.cbo.gov/publication/44363>. Note: In this analysis, the Congressional Budget Office includes Medicare spending for post-acute care in its LTSS spending statistics. In BPC estimates of LTSS spending elsewhere in the report, we have attempted to exclude spending on post-acute care, to the extent possible.
- ⁶ 527 U.S. 581 (1999). In *Olmstead*, the Supreme Court overturned a decision by the state of Georgia that denied requests by plaintiffs with intellectual disabilities to be moved from a state hospital to an available community-based setting. The Court held that such "unjustified isolation" violated Title II of the American's with Disabilities Act, which prohibits discrimination based on disability by public entities, such as states and local governments.
- ⁷ Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1): 11-21.
- ⁸ Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1):98.
- ⁹ Department of Health and Human Services (2003) *The Future Supply of Long-Term Care Workers in relation to The Aging Baby Boom Generation*, Report to Congress. Available at: <http://aspe.hhs.gov/daltcp/reports/ltcwork.htm#section1>.
- ¹⁰ Office of the Actuary, Centers for Medicare and Medicaid Services (2012) *2012 Actuarial Report on the Financial Outlook for Medicaid*, p. 27. Available at: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Downloads/medicaid-actuarial-report-2012.pdf>.
- ¹¹ Congressional Budget Office (2013) *Rising Demand for Long-Term Services and Supports for Elderly People*. June, p. 33. Available at: <http://www.cbo.gov/publication/44363>. Note: In this analysis, the Congressional Budget Office includes Medicare spending for post-acute care in its LTSS spending statistics. In BPC estimates of LTSS spending elsewhere in the report, we have attempted to exclude spending on post-acute care, to the extent possible.
- ¹² In 2014, 133 percent of the federal poverty level is \$15,521 for an individual and \$20,921 for a couple.
- ¹³ Department of Health and Human Services. Available at: www.longtermcare.gov
- ¹⁴ In 2014, 300 percent of the maximum annual SSI benefit is \$25,956 for an individual and \$38,952 for a couple.
- ¹⁵ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 25.
- ¹⁶ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 26.
- ¹⁷ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 23-24.
- ¹⁸ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 25.
- ¹⁹ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 26.
- ²⁰ Alkema, G.E. (2013) *Current Issues and Potential Solutions for Addressing America's Long-Term Care Financing Crisis*. The SCAN Foundation, March.
- ²¹ Index of ADLs. S. Katz, et al. (1970) "Progress in the development of the index of ADL." *The Gerontologist* 10: 20-30.
- ²² Index of IADLs. M. Lawton and E. Brody (1969) "Assessment of older people: self-maintaining and instrumental activities of daily living." *The Gerontologist* 9: 179-186.

- ²³ Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service, April 4.
- ²⁴ Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1): 14.
- ²⁵ Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1): 98.
- ²⁶ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 22-23.
- ²⁷ Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1):11-21.
- ²⁸ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 14-15.
- ²⁹ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 17.
- ³⁰ Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service. April 4.
- ³¹ Available at: <https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider#h-9>.
- ³² Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service. April 4; claims data provided by Genworth.
- ³³ Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service. April 4.
- ³⁴ Waiver and state plan authority for HCBS are authorized through Title XIX of the Social Security Act and include 1915(c) home- and community-based waivers, 1915(i) state plan home- and community-based services, 1915(j) state plan self-directed personal-assistance services, and 1915(k) Community First Choice.
- ³⁵ Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1):19.
- ³⁶ Rowland, D. (2013) Testimony to the Commission on Long-Term Care. August 1. (Commission report p. 10.)
- ³⁷ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 36.
- ³⁸ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 35.
- ³⁹ Institute of Medicine and National Research Council (2013) *Financing long-term services and supports for individuals with disabilities and older adults: Workshop summary*. Washington, DC: The National Academies Press.
- ⁴⁰ Eldercare Workforce Alliance (2014) *Geriatrics Workforce Shortage: A Looming Crisis for Our Families*. Washington, DC: Eldercare Workforce Alliance. Available at: <http://www.eldercareworkforce.org/research/issue-briefs/research:geriatrics-workforce-shortage-a-looming-crisis-for-our-families/>.
- ⁴¹ National Alliance for Caregiving and AARP (2009) "Caregiving in the U.S. 2009." November.. Available at: http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.
- ⁴² Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 49.
- ⁴³ MetLife Mature Market Institute and National Alliance for Caregiving (2006) *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*, July, p. 4. Available at: http://www.caregiving.org/data/Caregiver_percent20Cost_percent20Study.pdf.
- ⁴⁴ Institute of Medicine and National Research Council (2013) *Financing long-term services and supports for individuals with disabilities and older adults: Workshop summary*. Washington, DC: The National Academies Press.
- ⁴⁵ Feinberg, L., S. Reinhard, A. Houser, R. Choula (2011) *Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving*. AARP Public Policy Institute.
- ⁴⁶ Evercare and National Alliance for Caregiving (2007) *Family Caregivers: What They Spend, What They Sacrifice; The Personal Financial Toll of Caring for a Loved One*. Minnetonka, MN: Evercare, and Bethesda, MD: NAC. See also: IOM p. 3-5 and Feinberg, p. 6.
- ⁴⁷ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 49.
- ⁴⁸ Redfoot, D., L. Feinberg, and A. Houser (2013) *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers*. AARP Public Policy Institute, August.
- ⁴⁹ National Center for Health Workforce Analysis (2004) Commission report, p. 19.
- ⁵⁰ BPC Analysis, consulting O'Shaughnessy, Carol (2013) "National Spending for Long-Term Services and Supports." National Health Policy Forum, 1. See also: Centers for Medicare and Medicaid Services Office of the Actuary (2012) *2012 Actuarial Report on the Financial Outlook for Medicaid*. February, p. 13. Available at: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and->

[Reimbursement/Downloads/medicaid-actuarial-report-2012.pdf](#). See also: Eiken, et. al. (2013) *Medicaid Expenditures for Long Term Services and Supports in 2011*. Mathematica Policy Research. October. Available at: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Downloads/LTSS-Expenditure-Narr-2011.pdf>. See also: LifePlans analysis of NAIC data. See also: Technical Appendix for more on BPC's analysis of national spending on LTSS.

⁵¹ BPC Analysis, consulting O'Shaughnessy, Carol (2013) "National Spending for Long-Term Services and Supports." National Health Policy Forum, 1. See also: Centers for Medicare and Medicaid Services Office of the Actuary (2012) *2012 Actuarial Report on the Financial Outlook for Medicaid*. February, p. 13. Available at: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Downloads/medicaid-actuarial-report-2012.pdf>. See also: Eiken, et. al. (2013) *Medicaid Expenditures for Long Term Services and Supports in 2011*. Mathematica Policy Research. October. Available at: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Downloads/LTSS-Expenditure-Narr-2011.pdf>. See also: LifePlans analysis of NAIC data. See also: Technical Appendix for more on BPC's analysis of national spending on LTSS.

⁵² Stone, J. (2012) "Long-Term Care (LTC): Financing Overview and Issues for Congress." Congressional Research Services, p. 5-6.

⁵³ Tell, E. (2013) "Overview of Current Long-Term Care Financing Options." The SCAN Foundation, March, p. 6.

⁵⁴ O'Shaughnessy, C. (2013) "The Basics: National Spending for Long-Term Services and Supports (LTSS), 2011." National Health Policy Forum, February.

⁵⁵ O'Shaughnessy, C. (2013) "The Basics: National Spending for Long-Term Services and Supports (LTSS), 2011." National Health Policy Forum, February.

⁵⁶ Department of Health and Human Services. Available at: www.longtermcare.gov

⁵⁷ BPC calculation. See Technical Appendix for more on BPC analysis of LTSS spending.

⁵⁸ Centers for Medicare and Medicaid Services Office of the Actuary (2013) *2012 Actuarial Report on the Financial Outlook for Medicaid*. February, p. 13. Available at: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Downloads/medicaid-actuarial-report-2012.pdf>. See also: Eiken, et. al. (2013) *Medicaid Expenditures for Long Term Services and Supports in 2011*. Mathematica Policy Research, October. Available at: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Downloads/LTSS-Expenditure-Narr-2011.pdf>.

⁵⁹ Centers for Medicare and Medicaid Services Office of the Actuary (2013) *2012 Actuarial Report on the Financial Outlook for Medicaid*. February, p. 13. Available at: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Downloads/medicaid-actuarial-report-2012.pdf>. (BPC calculation.)

⁶⁰ MACPAC (2013) "Overview of Medicaid and CHIP." January. Available at: <http://www.macpac.gov/publications/MACPAC-Overview-2013-01.pdf?attredirects=0&d=1>.

⁶¹ 42 U.S.C. §1396a(a)(10)(A)(i)(II)(aa) (2012).

⁶² For more information on Medicaid qualification pathways, see: Kaiser Family Foundation (2010) *Medicaid Financial Eligibility: Primary Pathways for the Elderly and People with Disabilities* February. Available at: <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8048.pdf>. See also: AARP Public Policy Institute (2010) *Access to Long-Term Services and Supports: A 50-State Survey of Medicaid Financial Eligibility Standards*. September. Available at: http://assets.aarp.org/rgcenter/ppi/ltc/i44-access-ltss_revised.pdf.

⁶³ Wiener, et. al. and RTI International (2013) *Medicaid Spend Down: New Estimates and Implications for Long-Term Services and Supports Financing Reform*, March. Available at: <http://thescanfoundation.org/rti-international-medicaid-spend-down-new-estimates-and-implications-long-term-services-and-supports>.

⁶⁴ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 22.

⁶⁵ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 23-24.

⁶⁶ Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1): 97.

⁶⁷ Cohen, M. (2013) "The Current State of the Private Long-Term Care Insurance Industry." Presentation to the Commission on Long-Term Care, June.

⁶⁸ Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1): 97.

⁶⁹ Tell, E. (2013) "Overview of Current Long-Term Care Financing Options." The SCAN Foundation, March, p. 3.

⁷⁰ 2011 American Community Survey. (BPC calculation.)

⁷¹ Cohen, M. (2013) "The Current State of the Private Long-Term Care Insurance Industry." Presentation to the Commission on Long-Term Care, June.

- ⁷² National Association of Insurance Commissioners (2013) *Long-Term Care Insurance Experience Reports for 2012*.
- ⁷³ LifePlans analysis of NAIC data.
- ⁷⁴ BPC analysis.
- ⁷⁵ America's Health Insurance Plans (2011) *Who Buys Long-Term Care Insurance in 2010-2011?* p. 22. Available at: <http://www.ahip.org/WhoBuysLTCInsurance2010-2011/>.
- ⁷⁶ Keen, M. (2011) "Funding Long-Term Care." *NARFE Magazine* 87(4): 2, 24-25.
- ⁷⁷ Tell, E. (2013) "Overview of Current Long-Term Care Financing Options." The SCAN Foundation, March, p. 3.
- ⁷⁸ In 2010, the average cost for a semi-private room in a nursing home was \$205 per day; for a private room, the cost was \$229 per day. Available at: www.longtermcare.gov.
- ⁷⁹ America's Health Insurance Plans (2011) *Who Buys Long-Term Care Insurance in 2010-2011?* p. 22. Available at: <http://www.ahip.org/WhoBuysLTCInsurance2010-2011/>.
- ⁸⁰ BPC calculation, based on data from the *Genworth 2013 Cost of Care Survey*. Available at: https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/131168_031813_Executive%20Summary.pdf.
- ⁸¹ Keen, M. (2011) "Funding Long-Term Care." *NARFE Magazine* 87(4): 2, 24-25.
- ⁸² Tell, E. (2013) "Overview of Current Long-Term Care Financing Options." The SCAN Foundation, March, p. 4.
- ⁸³ Tell, E. (2013) "Overview of Current Long-Term Care Financing Options." The SCAN Foundation, March, p. 4.
- ⁸⁴ Tell, E. (2013) "Overview of Current Long-Term Care Financing Options." The SCAN Foundation, March, p. 3.
- ⁸⁵ 2011 American Community Survey. (BPC calculation.)
- ⁸⁶ Cohen, M. (2013) "The Current State of the Private Long-Term Care Insurance Industry." Presentation to the Commission on Long-Term Care, June.
- ⁸⁷ Cohen, M. (2013) "The Current State of the Private Long-Term Care Insurance Industry." Presentation to the Commission on Long-Term Care, June.
- ⁸⁸ Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 27.
- ⁸⁹ AARP Public Policy Institute (2012) *Long-Term Care Insurance: 2012 Update*. June, p. 2. Available at: http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/ltc-insurance-2012-update-AARP-ppi-ltc.pdf.
- ⁹⁰ Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1): 98.
- ⁹¹ Cohen, M. (2013) "The Current State of the Private Long-Term Care Insurance Industry." Presentation to the Commission on Long-Term Care, June.
- ⁹² Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 26.
- ⁹³ Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1): 98.
- ⁹⁴ See estimates from Center for Retirement Research at Boston College (2012). Available at: <http://crr.bc.edu/special-projects/national-retirement-risk-index/>. See also: Employee Benefit Research Institute (2014) *What Causes EBRI Retirement Readiness Ratings to Vary: Results from the 2014 Retirement Security Projection Model*. February. Available at: http://www.ebri.org/pdf/briefspdf/EBRI_IB_396_Feb14.RRRs.pdf.
- ⁹⁵ America's Health Insurance Plans (2011) *Who Buys Long-Term Care Insurance in 2010-2011?* p. 22. Available at: <http://www.ahip.org/WhoBuysLTCInsurance2010-2011/>.
- ⁹⁶ U.S. Census Bureau (2011) *Income, Poverty, and Health Insurance Coverage in the United States: 2010*. September, p. 6. Available at: <http://www.census.gov/prod/2011pubs/p60-239.pdf>.
- ⁹⁷ National Institute on Retirement Security (2013). Available at: http://www.nirsonline.org/index.php?option=com_content&task=view&id=774&Itemid=190.
- ⁹⁸ National Institute on Retirement Security (2013). Available at: http://www.nirsonline.org/index.php?option=com_content&task=view&id=781&Itemid=190.
- ⁹⁹ Center for Retirement Research at Boston College (2012). Available at: <http://crr.bc.edu/special-projects/national-retirement-risk-index/>.
- ¹⁰⁰ BPC's separate Personal Savings and Financial Security Initiative will address these retirement-savings challenges over the next year and will collaborate with the Long-Term Care Initiative.

¹⁰¹ PAC has its own financial and quality challenges, which are beyond the scope of this report. For a perspective on reforms related to PAC spending, see: Mechanic, R. (2014) "Post-Acute Care: The Next Frontier for Controlling Medicare Spending." *New England Journal of Medicine*. February. Available at: <http://www.nejm.org/doi/full/10.1056/NEJMp1315607>.

¹⁰² O'Shaughnessy, C. (2013) *National Spending for Long-Term Services and Supports (LTSS), 2011*. National Health Policy Forum. February, p. 4. Available at: http://www.nhpf.org/library/the-basics/Basics_LTSS_02-01-13.pdf.

¹⁰³ Centers for Medicare and Medicaid Services Office of the Actuary (2013) *2012 Actuarial Report on the Financial Outlook for Medicaid*. February, 13. Available at: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Downloads/medicaid-actuarial-report-2012.pdf>.

¹⁰⁴ Eiken, et. al. (2013) *Medicaid Expenditures for Long Term Services and Supports in 2011*. Mathematica Policy Research. October. Available at: <http://www.medicicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Downloads/LTSS-Expenditure-Narr-2011.pdf>.