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Financing Long-Term Services and Supports: Continuity and Change

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Abstract

This article provides an overview of financing for long-term services and supports (LTSS) in the United States, paying special attention to how it has changed and not changed over the last 30 years. Although LTSS expenditures have increased greatly (like the rest of health care), the broad outline of the financing system has remained remarkably constant. Medicaid—a means-tested program—continues to dominate LTSS financing, while private long-term care insurance plays a minor role. High out-of-pocket costs and spend-down to Medicaid because of those high costs continue to be hallmarks of the system. Although many major LTSS financing reform proposals were introduced over this period, none was enacted—except the Community Living Assistance Services and Supports Act, which was repealed before implementation because of concerns about adverse selection. The one major change during this time period has been the very large increase in Medicare spending for post-acute services, such as short-term skilled nursing facility and home health care. With the aging of the population, demand for LTSS is likely to increase, placing strain on the existing system.

Introduction

The United States' financing system for long-term services and supports (LTSS), including nursing homes, assisted living facilities, adult day services centers, homemaker services, intermediate care facilities for individuals with intellectual disabilities, and habilitative care, does not meet the needs of older people and younger persons with disabilities. LTSS are expensive and beyond the financial reach of most people. For example, the 2015 median annual private-pay charge for a semiprivate nursing home room was \$80,300 (Genworth Financial, Inc., 2015). Importantly, Medicare provides limited coverage for post-acute nursing home and home health care, but only on a short-term basis. Further, few people have private long-term care (LTC) insurance (National Association of Insurance Commissioners, 2014). Thus, individuals who use LTSS for a sustained period face high out-of-pocket costs.

One study projected that of people who turn 65 between 2015 and 2019, 28 percent will incur LTSS expenses of more than \$100,000 (Favreault & Dey, 2016). Few disabled older adults can afford the catastrophic out-of-pocket expenses associated with LTSS, and many LTSS users spend down to qualify for Medicaid (Coe, 2007; Mehdizadeh, Nelson, & Applebaum, 2006; Spillman & Waidmann, 2014; Waidmann & Liu, 2006; Wiener, Anderson, Khatutsky, Kaganova & O'Keeffe, 2013; Wiener, Sullivan, & Skaggs, 1996).

As the population ages, the demand for LTSS is expected to rise, with projected demand for LTSS expected to roughly double between 2000 and 2040 (Johnson, Toohey & Wiener, 2007). As use of LTSS rises, pressure will increase on private and public LTSS financing sources—including federal, state, and personal budgets—to cover increasing costs.

The LTSS delivery and quality assurance systems have changed substantially since the late 1980s; however, the LTSS financing system has remained roughly stable, although the relative size of the financing sources has changed. The current LTSS system continues to rely heavily on public funding through Medicaid, with minimal coverage offered through private LTC insurance. The major change has been

that Medicare spending for short-term post-acute care services such as skilled nursing facility and home health care has skyrocketed.

In this paper, we review the financing structure for LTSS and how it has (and has not) changed over the past 30 years. After presenting an overview of LTSS expenditures, we analyze the main payers of LTSS in this country—Medicaid, Medicare, private LTC insurance, "other payers" (e.g., Older Americans Act funding and the Department of Veterans Affairs), and out-of-pocket spending—examining public policy initiatives associated with these payers and how expenditures have changed over time. The paper concludes by looking to the future for possible LTSS financing reforms.

Overview of Long-Term Services and Supports Financing

LTSS are provided and paid for by public and private sources. Informal LTSS, which represents more than half of LTSS, includes informal care provided at no paid cost by family members and friends. The Congressional Budget Office (CBO) estimated the value of LTSS informal care in 2011 at approximately \$234 billion (CBO, 2013).

Like all health-related spending, total formal LTSS expenditures have increased dramatically over the last 25 years (Table 1). In 1988, total public and private

Table 1. Financing for long-term services and supports, 1988 and 2013

Financing Source	1988 (\$ billions)	2013 (\$ billions)
Medicaid	24.4	145.9
Medicare	4.8	74.5
Other public payers	0.9	4.9
Out of pocket	15.6	47.7
Private insurance and other private financing	9.0	32.4
Total, excluding Medicare	49.9	230.9
Total, including Medicare	54.7	305.4

Note: Other public payers may include the Department of Defense and Department of Veterans Affairs. Data availability for other public payers, out-of-pocket, and private insurance and other private financing sources is limited to home health and nursing homes expenditures.

Sources: Centers for Medicare & Medicaid Services (2014); 1988 Truven Health Analytics data from S. Eiken, personal communication, July 3, 2003; Eiken, Sredl, Burwell, & Saucier (2015); Medicare Payment Advisory Commission (2015).

LTSS spending, including Medicare expenditures for post-acute care, was \$54.7 billion (9.4 percent of total US personal health care expenditures); in 2013, it was \$305.4 billion (10.6 percent of total US personal health care expenditures) (Centers for Medicare & Medicaid Services [CMS], 2014; 1988 Truven Health Analytics data from S. Eiken, personal communication, July 3, 2003; Eiken, Sredl, Burwell, & Saucier, 2015; MedPAC, 2015). Further, total LTSS spending increased from 1 percent of US gross domestic product (GDP) in 1988 to 1.8 percent of US GDP in 2013.

Medicaid has remained the dominant payer of LTSS expenditures over time. In 1988, Medicaid financed the largest share (about 45 percent) of total LTSS expenditures (including Medicare expenditures). Between 1988 and 2013, Medicaid LTSS spending increased sixfold. In 2013, Medicaid was still the largest payer (about 48 percent) of total LTSS expenditures (including Medicare expenditures). If Medicare spending was excluded from total LTSS expenditures, the Medicaid share of total LTSS expenditures would be even greater: about 49 percent in 1988 and 63 percent in 2013. Medicaid has retained its dominance despite restrictive financial eligibility standards, especially for financial assets.

Although Medicaid has remained the largest LTSS payer over time, the spending levels for the remaining LTSS payers (including Medicare, other public payers, private insurance, and out-of-pocket patient spending) have varied. Between 1988 and 2013, out-of-pocket LTSS expenditures more than tripled, and spending for "other public LTSS payers" (e.g., Department of Veterans Affairs and the Older Americans Act) increased fivefold. Private insurance expenditures for LTSS increased as well, partly because of the uptake in private LTC insurance and the use of private insurance coverage for copayments for Medicare post-acute care services (Cohen, Kaur, & Darnell, 2013).

The largest change in LTSS funding patterns over the period is related to the role of Medicare. Because Medicare does not cover the full scope of traditional LTSS, whether to include its expenditures in calculations of LTSS expenditures is controversial. From 1988 to 2013, Medicare spending dramatically increased, with a more than 15-fold growth, making Medicare LTSS a significant source of spending, not only as a percentage of overall LTSS spending but also as a percentage of total Medicare spending. As a result, the growth in total public and private LTSS expenditures from 1988 to 2013 varies depending on whether Medicare costs are included—558 percent if they are included, and 463 percent if they are not.

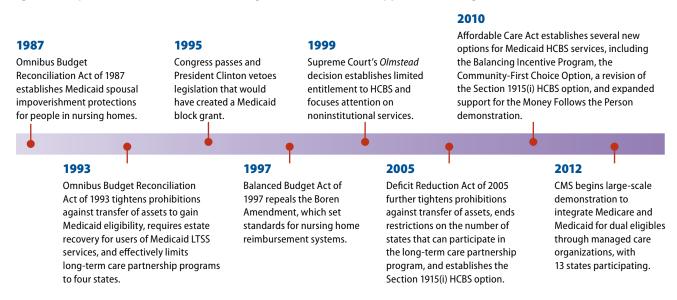
Medicaid

Medicaid is the primary source of LTSS financing in the United States. As mostly an entitlement program, Medicaid coverage is guaranteed to anyone who meets Medicaid eligibility rules. An exception to the entitlement structure of Medicaid are home and community-based services (HCBS) waivers, which allow states to limit the number of beneficiaries and establish waiting lists. Figure 1 summarizes the main events in Medicaid LTSS financing between 1987 and 2012. This history is a mixture of liberalization and restrictions regarding Medicaid eligibility rules and an increase in state flexibility on coverage of HCBS and payment policy.

Over the last 30 years, policymakers have introduced several proposals to address rising Medicaid LTSS expenditures. Presidents Ronald Reagan, George W. Bush, and Donald Trump; presidential candidate Mitt Romney; and conservative congressional leaders have proposed converting Medicaid into a block grant system, under which each state would receive a fixed federal grant based on the state and current federal Medicaid spending in that state (Luthra, 2017). In 1995, Congress passed legislation to convert Medicaid into a block grant, but President Bill Clinton vetoed the legislation, which was not overridden. For their part, over this period, liberal policymakers have focused on replacing or supplementing the Medicaid program with a social insurance program.

¹ This percentage understates the role of Medicaid in LTSS financing because the contribution toward the cost of care by Medicaid nursing home residents is counted as an out-of-pocket expenditure rather than Medicaid spending even though it is on behalf of Medicaid beneficiaries.

Figure 1. Important events in Medicaid long-term services and supports financing, 1987–2012



CMS = Centers for Medicare & Medicaid Policy; HCBS = home and community-based services; LTSS = long-term services and supports.

Between 1988 and 2013, Medicaid LTSS expenditures grew at a 7.4 percent average annual compound rate of increase (Table 2). This rate of increase is lower than that of Medicaid expenditures overall, indicating that other areas of the Medicaid program grew faster than LTSS (Eiken et al., 2015). This lower rate of increase for LTSS is further reflected in the declining proportion of LTSS-related Medicaid expenditures

Table 2. Medicaid expenditures for long-term services and supports, 1988 and 2013

Type of Service	1988 (\$ billions)	2013 (\$ billions)
Non-institutional LTSS	2.4	74.8
Nursing home	14.6	53.2
Intermediate care facilities for individuals with intellectual disabilities	5.9	11.9
Mental health facilities and mental health disproportionate share hospital payments	1.5	5.9
Institutional managed LTSS—unspecified	0.0	0.1
Total LTSS expenditures	24.4	145.9
Total Medicaid expenditures	53.5	429.9

LTSS = long-term services and supports.

Sources: 1988 Truven Health Analytics data from S. Eiken, personal communication, July 3, 2003; Eiken, Sredl, Burwell, & Saucier (2015); Holahan & Liska (1996).

as a percentage of total Medicaid spending. In 1988, LTSS accounted for 45.6 percent of total Medicaid expenditures, whereas in 2013, LTSS accounted for 33.9 percent of total Medicaid expenditures.

Although the debate surrounding the future sustainability of LTSS financing has primarily focused on the aging of the population, most Medicaid LTSS expenditure growth is the result of expenditures for younger individuals with disabilities. For example, between 1995 and 2010, the number of elderly Medicaid nursing home residents declined by about 25 percent (Redfoot, 2013). Indeed, in 2010, nonelderly people with disabilities accounted for 45.3 percent of total (acute and LTSS) Medicaid expenditures (MACPAC, 2013). Further, most Medicaid HCBS waiver-related spending is for individuals with intellectual and developmental disabilities, not for older adults or younger individuals with physical disabilities (Eiken et al., 2015).

Historically, the Medicaid program had an institutional bias, with most expenditures for institutional care rather than HCBS. However, over the last 30 years, federal and state policies have shifted to support the increased use of HCBS (Wenzlow, Eiken, & Sredl, 2016). Important factors contributing

to the expansion of HCBS include the liberalization of Medicaid rules for HCBS waivers, the Supreme Court's *Olmstead v. L.C.* (1999) decision, and expanded coverage options for HCBS provided by the Patient Protection and Affordable Care Act.

Because of federal and state policies focused on increasing HCBS utilization, Medicaid LTSS spending has gradually shifted from institutional care to HCBS. In 1988, HCBS accounted for roughly 10 percent of total Medicaid LTSS expenditures (\$2.4 billion); however, in 2013, HCBS accounted for a majority (51 percent) of total Medicaid LTSS expenditures (\$74.8 billion).

The national picture of Medicaid HCBS spending masks the wide variation across states and subpopulations that use LTSS. In 2013, HCBS as a percentage of total Medicaid LTSS spending by state ranged from 25.5 percent in Mississippi to 78.9 percent in Oregon. At the same time, HCBS accounted for 72 percent of national Medicaid LTSS spending for individuals with developmental disabilities and 40 percent of national Medicaid LTSS spending for older adults and younger individuals with physical disabilities (Eiken et al., 2015). Within the subpopulation of older adults and younger individuals with physical disabilities for which data are reported, most Medicaid HCBS spending is for younger individuals with physical disabilities rather than older people (Borck, Peebles, Miller, & Schmitz, 2014).

LTSS has historically been provided almost entirely through a fee-for-service system, but the use of capitated managed care organizations is growing rapidly. As of 2016, at least 19 states had a managed LTSS system in which managed care organizations were responsible for Medicaid services (Ensslin & Kruse, 2016). In addition, CMS is currently conducting the Financial Alignment Initiative in 13 states, which will integrate Medicare and Medicaid spending primarily through managed care organizations (Chepaitis et al., 2015; Musumeci, 2015; Walsh et al., 2016). The policy hypothesis of the Initiative is that better integration of care will result in better care coordination, improved quality of care, and higher participant satisfaction, along with lower

costs and less cost-shifting between public financing programs.

Medicare

Historically, Medicare has played a very limited role in LTSS financing. Medicare was created to cover acute and post-acute care for individuals age 65 or older and younger individuals who qualify for Social Security Disability Insurance, but not LTSS. Medicare does provide coverage for some LTSS-type services (e.g., skilled nursing facility services, home health services, inpatient rehabilitation facility services, LTC hospital services and hospice), but Medicare coverage is generally on a short-term basis and services are more focused on medical and skilled care than Medicaid-covered services. For example, although there are no limits on the length of stay for Medicaid nursing home benefits, Medicare's skilled nursing facility benefit is limited. Medicare will cover up to 100 days of post-hospital care for people needing continuous skilled nursing or rehabilitation services on a daily basis; the average length of a Medicarecovered stay is only 27.1 days (Colello, Mulvey, & Talaga, 2013). The rationale for including Medicare LTSS-type services in an analysis of LTSS financing is that these Medicare services assist people with functional impairments, and some of the providers (especially nursing homes, home health agencies, and hospice) also provide what are clearly LTSS services. Figure 2 catalogs the main events in Medicare postacute care financing over the last 30 years.

Between 1988 and 2013, Medicare expenditures for post-acute care increased dramatically from \$4.8 billion to \$74.5 billion, an increase of 1,552 percent (Table 3). With this growth in spending, post-acute care costs changed from a "rounding error" to about 13 percent of total Medicare expenditures (Medicare Payment Advisory Commission [MedPAC], 2015). Medicare skilled nursing facility expenditures were \$1.0 billion in 1988 and \$28.7 billion in 2013; home health expenditures were \$2.0 billion in 1988 and \$18.7 billion in 2013.

Two court cases sparked the increase in Medicare skilled nursing facility and home health expenditures: *Fox v. Bowen* (1986) and *Duggan v. Bowen* (1988)

Figure 2. Key events in Medicare post-acute care financing, 1988–2015

1986 and 1988

The court cases *Duggan v*.

Bowen and Fox v. Bowen result in rulings that liberalize the Medicare definition of skilled care, opening the way for much greater Medicare coverage.

1997

Balanced Budget Act of 1997 enacts prospective payment systems for Medicare skilled nursing facilities and home health agencies, with the goal of reining in the rate of increase in expenditures.

2013

Settlement agreement in court case of *Jimmo v. Sebelius* establishes that Medicare can no longer require improvement as part of its coverage decisions for skilled care.

2014

Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014 requires the reporting of standardized patient assessment data by post-acute care providers with regard to quality measures, resource use, and other measures.

1988

Medicare Catastrophic Coverage Act of 1988 changes the Medicare skilled nursing facility benefit to provide slightly more days of coverage, eliminate the prior hospitalization requirement, and change the copayment. The Act was repealed in 1989.

2012

CMS begins large-scale demonstration to integrate Medicare and Medicaid for dual eligibles through managed care organizations, with 13 states participating.

2014

Protecting Access to Medicare (PAMA) Act of 2014 establishes a value-based purchasing reimbursement system for Medicare skilled nursing facilities services, built on the skilled nursing facility 30-day all-cause readmission quality measure.

Table 3. Medicare expenditures for post-acute care, 1988 and 2013

Type of Service	1988 (\$ billions)	2013 (\$ billions)
Skilled nursing facilities	1.0	28.7
Home health	2.0	18.3
Hospice	0.4	15.1
Inpatient rehabilitation facilities	1.2	6.9
Long-term care hospitals	0.2	5.5
Total LTSS expenditures	4.8	74.5

LTSS = long-term services and supports.

Sources: Congressional Budget Office (1990); Centers for Medicare & Medicaid Services (2001); Newhouse & Young (1997); Liu, Baseggio, Wissoker, Maxwell, Haley, & Long (2001); Medicare Payment Advisory Commission (2015).

clarified the definition of "skilled care" in such a way that many additional individuals qualified for Medicare benefits (Liu, Gage, Harvell, Stevenson, & Brennan, 1999). Government policymakers expected this change in eligibility to have a relatively small impact on overall Medicare post-acute care expenses. However, because Medicare payment rates are much higher than Medicaid rates, providers seek Medicare over Medicaid and even private-pay residents.

Following the policy change on Medicare, expenditures exploded from 1989 through 1997. Medicare skilled nursing facility expenditures increased from \$1.0 billion in 1988 to \$11.2 billion in 1997. Similarly, Medicare home health expenditures increased from \$2.0 billion in 1988 to \$16.7 billion in 1997 (CMS, 2013b; 1988 Truven Health Analytics data from S. Eiken, personal communication, July 3, 2003).

In 1997, amid concern over Medicare post-acute care expenditures and fear that Medicare was becoming an LTSS program, Congress passed the Balanced Budget Act of 1997. The legislation reined in Medicare spending mostly through reimbursement-related reforms rather than explicit changes in coverage. Immediately following the implementation of the Balanced Budget Act, expenditures fell sharply; however, expenditures gradually increased again as providers became familiar with the new system (McCall, Komisar, Petersons, & Moore, 2001; Spector, Cohen, & Pesis-Katz, 2004).

An additional coverage issue may also result in an increase in expenditures. Historically, Medicare has only covered "skilled care," such as therapies and skilled nursing, when it was likely that the services would result in an improvement in an individual's condition or functional status. However, in 2013, the US District Court for the District of Vermont ruled that this was an illegally narrow coverage definition. The Court approved a settlement in *Jimmo v. Sebelius*

(2011) requiring CMS to clarify that Medicare beneficiaries who require a covered skilled care cannot be denied services if their health will not be restored or improved by the service (CMS, 2013a). As a result of the court decision, a Medicare beneficiary may receive covered skilled services to prevent further deterioration or to preserve current functional status. More recently, the Court has found CMS's implementation of this change to be inadequate and has ordered that CMS take additional steps to clarify the new Medicare coverage policy (Center for Medicare Advocacy, 2017).

Over time, Medicare coverage changes and payment rates higher than Medicaid and private pay have changed the dynamics of the nursing home and home health agency industries, as providers seek to maximize Medicare utilization and revenue. A substantial portion of nursing homes and home health agencies are more highly attuned to Medicare than Medicaid policy. On the government side, the substantial increase in Medicare services utilization and expenditures for post-acute care has made Medicare a major player in nursing home policy, which it was not earlier. In addition, Medicare payments, quality measures, and other operational requirements play major roles in other post-acute care providers, including inpatient rehabilitation facilities, LTC hospitals, and hospices, where Medicaid payments are a small part of total revenues.

Private Long-Term Care Insurance

Historically, LTSS were largely thought to be uninsurable, in part because individuals have great control over the use of services. However, starting in the 1980s, private LTC insurance emerged as an option for individuals to pay for LTSS. Early private LTC insurance policies in the 1980s only covered nursing home care and required a prior hospitalization. Over time, policy coverage gradually changed to include home care services, assisted living, adult day care, and other community-based care options (Cohen et al., 2013). Figure 3 summarizes the key events affecting private LTC insurance over the last 30 years.

By the mid-to-late 1990s, more than 100 insurance companies sold individual LTC policies and LTC policies for individuals in group settings (i.e., employer markets). Annual sales increased throughout the next decade. In 1990, insurance companies sold 380,000 individual LTC policies; in 2002, at the height of the market, insurance companies sold 755,000 individual LTC policies (Cohen et al., 2013). In 2002, the market started to unravel as LTC insurance sales plummeted and companies stopped selling policies. After a steady increase in the number of LTC insurance policies in force between 1992 and 2005, the number of insured lives remained relatively flat—at about

Figure 3. Key events in private long-term care insurance, 1988–2015

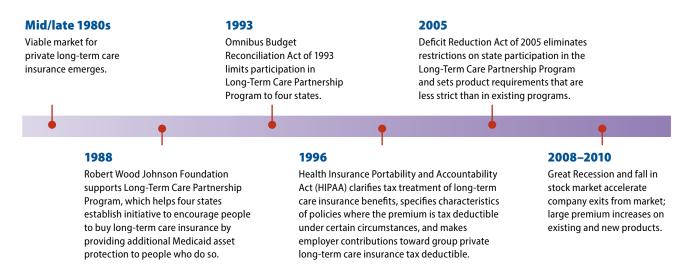
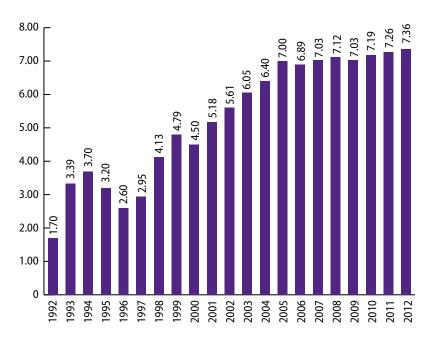
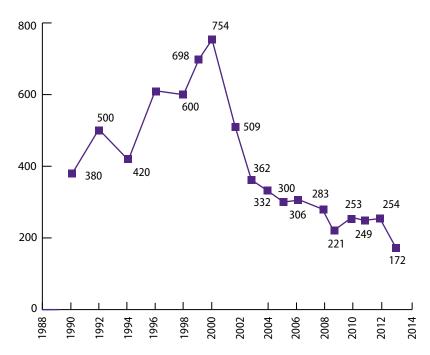


Figure 4. Number of people in United States with private long-term care insurance, 1992–2012 (in millions)



Source: National Association of Insurance Commissioners (2014).

Figure 5. Annual sales (units) of individual long-term care insurance policies, 1990–2013 (in thousands)



Note: LifePlans analysis based on America's Health Insurance Plans, Life Insurance Marketing Research Association, and LifePlans sales surveys, 1990–2013. Beginning in 2009, Long-Term Care Partners data for annuitants are included in counts.

Sources: National Association of Insurance Commissioners (2014); Life Insurance Marketing Research Association (2014); LifePlans, Inc. (2014).

7.1 million between 2004 and 2012 (National Association of Insurance Commissioners, 2014) (Figure 4). Additionally, new sales fell precipitously; in 2013, only 172,000 new LTC policies were sold (Life Insurance Marketing Research Association, 2014; LifePlans, Inc., 2014; National Association of Insurance Commissioners, 2014) (Figure 5). Although 125 companies competed in the private LTC insurance market in 2000, by 2012, fewer than 15 insurance companies remained that actively sold stand-alone LTC insurance policies that were not combined with other products, such as life insurance or annuities (Cohen et al., 2013).

Most of the insurers that remained in the market have substantially increased their premiums, including for existing policyholders. A doubling in premiums from one year to the next has not been uncommon. Further, LTC insurers have tightened their underwriting while reducing benefits, making it less beneficial for people interested in private LTC insurance to buy policies (Ujvari, 2012). A recent study estimated that 40 percent of the general population aged 50-71 could not pass the medical underwriting for LTC insurance (Cornell, Grabowski, Cohen, Shi, & Stevenson, 2016).

Although the decline in the private LTC insurance market began in 2002, the more recent collapse of the LTC insurance market can be traced to the Great Recession of 2008–2010 (O'Leary, 2012). Because of low interest rates since the recession, the returns on reserves held by insurers fell well below the actuarial assumptions used to determine initial premiums. Thus, the reserves were inadequate to cover both actual and

expected claims. Furthermore, the lapse rate—the proportion of individuals who discontinue their insurance—was lower than actuarial predictions, which meant that companies were required to pay claims on policies they had not expected to be in force. The ensuing rise in premiums engendered bad publicity and hard feelings toward many insurance companies.

Social Insurance

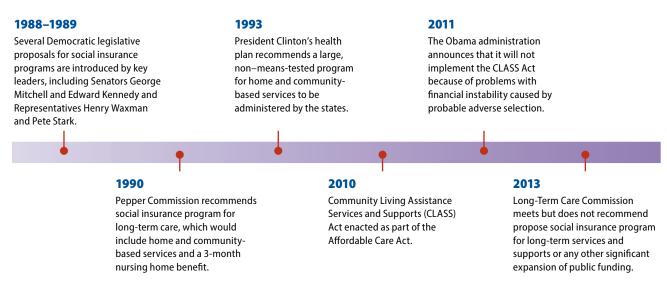
Although LTSS financing in the United States is dominated by means-tested financing, several other countries—including Germany, Japan, the Netherlands, all Scandinavian countries, and South Korea—have universal social insurance programs or non-means-tested programs for LTSS (Campbell et al., 2010; Colombo et al., 2011; Rhee et al., 2015). For example, in 1995, Germany implemented a universal social insurance program for LTSS (Soziale Pflegeversicherung). Funded by mandatory payroll and pensioner premiums, the program is administered by nonprofit, nongovernmental organizations that are heavily regulated by the government and covers nonskilled home care and institutional care. Similarly, in 2000, Japan implemented mandatory public LTC insurance (Kaigo Hoken). Financed by a combination of general tax revenues and premiums, the program is

administered by the municipalities, under direction of the central government.

US policymakers have debated various social insurance options for LTSS financing reform over the last 30 years; however, only one was enacted and none were implemented. Figure 6 lists the key events that occurred in the United States related to social insurance for LTSS financing. In 1988 and 1989, several Democratic legislative proposals were introduced to create a social insurance program for LTC (University of Massachusetts Boston Gerontology Institute & OMB Watch, 1990). In 1990, the US Bipartisan Commission on Comprehensive Health Care, more popularly known as the Pepper Commission, proposed establishing a social insurance program covering HCBS and the first 90 days of nursing home care as well as measures to promote private LTC insurance (US Bipartisan Commission on Comprehensive Health Care, 1990). In 1993, President Clinton's health plan included a provision for a new, large non-means-tested program for HCBS, which would have given states great flexibility in administering the program (Wiener, Estes, Goldenson, & Goldberg, 2001).

In 2010, Congress passed the Community Living Assistance Services and Supports (CLASS) Act as part of the Affordable Care Act. The program would have been a government-run, voluntary LTC insurance

Figure 6. Key events in social insurance for long-term services and supports, 1988–2015



program completely funded by enrollee premiums; the program would have provided a modest amount of benefits, primarily for HCBS. However, after the US Department of Health and Human Services determined that the program was not actuarially sound because of the risk of adverse selection, the Obama Administration did not implement the program. The CLASS Act was repealed in 2013, and the Commission on Long-Term Care was established in its stead (American Taxpayer Relief Act of 2012 [P.L.112-240]). The Commission was charged by Congress to make policy recommendations regarding LTSS. Although the Commission's subsequent recommendations addressed many aspects of LTSS in the United States, the Commission was unable to come to consensus on LTSS financing reform proposals and did not make any significant recommendations in that area (Commission on Long-Term Care, 2013).

Other Programs

In addition to funding from Medicaid and Medicare, LTSS are financed by a range of other small, appropriated programs, including Title III of the Older Americans Act, Title 20 of the Social Security Act, state programs for HCBS, and the Department of Veterans Affairs. Total expenditures for this category grew from \$0.9 billion in 1988 to \$4.9 billion in 2013 but declined from about 1.7 percent of expenditures in 1988 to about 1.6 percent of expenditures in 2013.

Out-of-Pocket Costs

Because of the lack of insurance coverage for LTSS, individuals who need care but do not qualify for Medicaid or who need services not covered by Medicare must either pay out of pocket or go without the services. Because there are no government program expenses to monitor, calculating out-of-pocket LTSS expenses is difficult. In 1988, approximately \$15.6 billion was spent out of pocket for nursing home care and home health care; estimates are not available for HCBS. By 2013, out-of-pocket expenses for nursing home care and home health care had grown to \$47.7 billion; again, estimates are not available for HCBS. Out-of-pocket

spending fell from 29 percent of total LTSS spending in 1988 to 16 percent of total spending in 2013, although part of the decline is probably an artifact of the lack of data for HCBS.

LTSS Financing in the Future

Except for Medicare's significant increase in the financing of LTSS-like services, the broad contours of LTSS financing have remained the same over the last 30 years. Medicaid continues to dominate LTSS financing, while private insurance continues to play a minor role. High out-of-pocket costs and impoverishment continue to be the key characteristics of the system. Although many LTSS financing reform proposals were introduced during this time, none was enacted—except the CLASS Act, which was repealed before implementation.

Why is LTSS financing so hard to reform? Although there are many answers, a major one is that LTSS financing reform is essentially about the role of government in American society, a topic on which there is little consensus. People are divided between those who believe LTSS is a private responsibility in which the government should only play a role when people can no longer afford to care for themselves, and those who believe LTSS is a societal/communal responsibility in which the government should play a key role (Rivlin & Wiener, 1988; Wiener, Illston, & Hanley, 1994).

Moreover, Americans strongly prefer financing options in which participation is not mandatory, such as voluntary private and public LTC insurance. Despite these preferences, few people have private LTC insurance and the market is rapidly deteriorating (Wiener et al., 2013). Moreover, microsimulation analyses consistently find low uptake for voluntary LTC insurance policy options, leaving most people uninsured and benefits primarily serving the upperincome population (Favreault, Gleckman, & Johnson, 2015; Wiener et al., 1994).

Despite the problems of Medicaid and the limited potential of private LTC insurance, public opinion survey evidence suggests that few Americans support a mandatory public LTC insurance program; indeed, in a recent survey only 18 percent of respondents

aged 40–70 favored such a program (Wiener, Khatutsky, Thach, & Greene, 2016). This opposition is despite the fact that a mandatory program will provide coverage for almost all people and substantially reduce Medicaid spending (Favreault et al., 2015; Wiener et al., 1994).

At the other end of the political spectrum, President Trump and others in Congress have proposed converting the Medicaid program from an openended entitlement program (with certain exceptions for Medicaid HCBS waivers) to a block grant, indexed at substantially less than expected spending. Such a change would be a major change in LTSS financing and would likely have a profound impact on LTSS service delivery and perhaps quality of care. A key

question is whether states would be able to achieve efficiencies without reducing benefits and coverage (Wiener, 1996).

With the aging of the population and the growing number of younger people with disabilities, the demand for LTSS services will continue to increase over time. The question now is whether LTSS financing will be reformed so that a better LTSS financing system will be put in place that can better meet the needs of older people and younger individuals with disabilities at a price that people are willing to pay. The issue of LTSS financing reform will not go away because the problems of the current financing system are likely to get worse rather than better.

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