As part of the American Taxpayer Relief Act of 2012 (ATRA, P.L. 112-240), Congress created a Commission on Long-Term Care that is charged with developing a plan for “the establishment, implementation, and financing of a comprehensive, coordinated, and high-quality system that ensures the availability of long-term services and supports for individuals who need such services and supports, including elderly individuals, individuals with substantial cognitive or functional limitations, other individuals who require assistance to perform activities of daily living, and individuals desiring to plan for future long-term care needs.”

The newly established Commission is the latest federal effort to propose viable options to improve the way long-term services and supports (LTSS) are financed and delivered. Congress’s most recent comprehensive review of financing options was in 1990 by the U.S. Bipartisan Commission on Comprehensive Health Care, known as the Pepper Commission after Rep. Claude Pepper (D-Florida).

**ISSUES BEHIND THE LEGISLATION**

Although debate continues as to whether there is any need for federal policy changes, significant research and advocacy have been devoted to LTSS financing issues and perceived inadequacies of the delivery system over the past several decades. Congress has reviewed many complex LTSS issues and has enacted incremental changes targeted at specific programs and activities (see Time Line). But consensus on which direction to take regarding the overarching issue of financing has remained elusive.

A number of factors continue to concern federal and state policymakers and the advocacy community. Chief among them is the
large personal financial liability some people with LTSS needs face in paying for their care, which can result in impoverishment. Many analysts view the need for LTSS as a financial risk that can be addressed by insurance options, either through public programs and/or private financing. Although some people may never face catastrophic LTSS costs, others risk paying substantial amounts and exhausting their income and assets. One study estimated that, on average, people turning age 65 in 2005 would have needed LTSS for three years. However, it found that the use of services among individuals varied; one-fifth were estimated to have needed care for more than five years and almost one-third to have needed none.³ For those who do face catastrophic costs, there are limited options. The federal-state Medicaid program provides coverage, but only those who have very low income and assets and who meet state-defined functional need criteria qualify, and benefits are unevenly available across states and localities. Others who do not qualify may wish to insure through private insurance but may not be able to afford premiums. In addition, future viability of private long-term care (LTC) insurance is uncertain, as many companies have vacated the market.

Other issues that concern both federal and state policymakers and others include significant public spending largely borne by the Medicaid program; uneven distribution and quality of institutional and home- and community-based services (HCBS) across and within states, resulting in unmet need among some people with disabilities; and the predicted increase in demand for services as a result of population aging. The complex delivery system is difficult for people with disabilities and caregivers to navigate, and this, combined with financing that includes a combination of private resources and support from a myriad of federal, state, and local programs, often results in fragmented and uncoordinated care. In addition, unpaid family caregivers provide most of the care to people with LTSS needs despite significant public and private spending; unpaid caregivers provided an estimated economic value of $234 billion in care in 2011 according to a recent report by the Congressional Budget Office.⁶ The burden on family caregivers has also been well documented over decades of research. Family caregiving often leads to financial and productivity costs for employers and imposes emotional and physical tolls on caregivers themselves.⁷
Time Line, LTSS Financing and Delivery: Selected Major Federal and National Activities, 1965 to Present

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tr>
<td>1965-1970s</td>
<td>Substantial growth of the nursing home industry financed by Medicaid and Medicare. Beginning of awareness that federal policy should give more attention to home and community-based services (HCBS). Senate Special Committee on Aging held a series of 30 hearings on the quality of nursing home care.</td>
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<td>1978</td>
<td>Older Americans Act long-term care ombudsman program to protect the rights of residents in long-term care facilities enacted.</td>
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<td>1980-1986</td>
<td>National Long-Term Care Channeling Demonstration, a major demonstration by the U.S. Department of Health and Human Services (HHS) to test quality and cost-effectiveness of HCBS for the frail elderly, implemented.</td>
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<td>1981</td>
<td>Medicaid section 1915(c) waiver program, allowing states to expand their commitment to HCBS for people with disabilities of all ages, enacted.</td>
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<td>1986</td>
<td>Institute of Medicine (IOM) study, <em>Improving the Quality of Care in Nursing Homes</em>, issued.</td>
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<tr>
<td>1987</td>
<td>Omnibus Reconciliation Act of 1987, nursing home reform requirements and residents’ bill of rights to implement the IOM 1986 recommendations, enacted. The Robert Wood Johnson Foundation (RWJF) began support for long-term care partnership programs in four states to encourage people to purchase long-term care insurance in order to potentially offset their need for care financed by Medicaid.</td>
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<td>1995</td>
<td>IOM study, <em>Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act</em>, issued. The HHS and the RWJF initiated the Cash and Counseling Demonstration (consumer direction), allowing consumers to choose a “cash” option for HCBS in lieu of traditional agency-provided services.</td>
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<td>1996</td>
<td>The Health Insurance Portability and Accountability Act allowed unreimbursed LTSS expenses, including LTC insurance premiums, to be considered as medical expenses that may be deducted from income for federal tax purposes. The Government Accountability Office began an extended and continuing series of reports on the federal and state oversight of nursing home quality.</td>
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*Time Line continued, next page*
CONGRESSIONAL ACTION

Policymakers have taken limited action regarding the financing of care, including expansion of HCBS through the Medicaid program, as well as exemption of qualified LTSS expenses, including LTC insurance premiums, from federal taxation under certain circumstances. Broader policy options often discussed include an expanded social insurance program for all Americans; support for private financing, such as expanding tax incentives for the purchase of LTC insurance; and hybrid approaches that would
combine elements of both public and private financing. However, to date, the nation lacks a comprehensive policy regarding the financing of care even though significant amounts of public and private dollars are spent on LTSS. By default, the federal-state Medicaid program finances about two-thirds of national spending on LTSS (about $210 billion in 2011). Slightly more than one-fifth of spending comes from individuals and families out-of-pocket.8

Twenty years after the Pepper Commission made its recommendations, Congress attempted to address the issue of financing and enacted the Community Living Assistance Services and Supports (CLASS) Act as part of the Patient Protection and Affordable Care Act of 2010 (ACA, P.L. 111-148). Unlike other federal LTSS programs, CLASS program benefits would have been financed entirely by individuals’ age-adjusted premiums. After the U.S. Department of Health and Human Services (HHS) found that the program was not actuarially sound, the ATRA repealed the CLASS Act and established the Commission on Long-Term Care.9

With the repeal of the CLASS Act, Congress charged the Commission with making recommendations regarding LTSS policy. The Commission is composed of 15 members appointed by the President, the House of Representatives, and the Senate.10 The Commission is required to provide recommendations that (i) address the interaction of LTSS with existing programs including Medicare, Medicaid and private long-term care insurance; (ii) improve health care programs necessary to ensure the availability of LTSS; (iii) address issues related to the LTSS workforce, including its adequacy and capacity to deliver high-quality services, the development of entities able to serve as employers and fiscal agents, and gaps in the LTSS infrastructure that prevent delivery of high-quality services.

The Commission must produce a report that contains recommendations or proposals for legislative or administrative actions, including proposed legislative language, referred to in the law as the Commission bill. The bill is required to have the approval of a majority of its members, and must be voted on by September 12, 2013. If approved by its members, the Commission must submit its bill to the President, the Vice President, and Congress, and the Commission bill is to be introduced to the full Congress. The bill must also be made public, along with a record of the votes by Commission members.
ENDNOTES


2. ATRA, section 643(b)(1).

3. In recent years, terminology referring to the services and infrastructure to help frail older people and younger people with disabilities remain independent has been changing. The term long-term services and supports (LTSS) has gained wider use than long-term care (LTC) and appears to be more descriptive of the services needed by people with disabilities in their daily lives. The term is used in P.L. 111-148, the Patient Protection and Affordable Care Act of 2010 (ACA), to refer to a range of supportive services for these populations. Both LTSS and LTC terminology are used by ATRA. The term LTC is generally applied when referring to long-term care insurance.


Selected Forum Materials on LTSS Financing and Delivery


- “Family Caregivers: The Primary Providers of Assistance to People with Functional Limitations and Chronic Impairments” (Background Paper No. 84, January 11, 2013), www.nhpf.org/library/details.cfm/2900


- “State Variation in Long-Term Services and Supports: Location, Location, Location” (Forum Session, July 13, 2013), www.nhpf.org/library/details.cfm/2934

- “Medicaid Managed Long-Term Services and Supports (MMLTSS): Increasing State Interest and Implications for Consumers, Quality of Care, Providers, and Costs” (Forum Session, May 11, 2012), www.nhpf.org/library/details.cfm/2894


- “Money Follows the Person Rebalancing Program (MFP): A Work in Progress” (Background Paper No. 85, May 10, 2013), www.nhpf.org/library/details.cfm/2927

- “Aging and Disability Resource Centers (ADRCs): Federal and State Efforts to Guide Consumers Through the Long-Term Services and Supports Maze” (Background Paper No. 81, November 19, 2010), www.nhpf.org/library/details.cfm/2835