NATIONAL HEALTH POLICY
FORUM

THE BASICS

The Commission on Long-Term Care:
Background Behind the Mission

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As part of the American Taxpayer Relief Act of 2012 (ATRA, P.L. 112-240), Congress created a Commission on Long-Term Care[1] 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."[2] The Commission issued its report[3] on September 30, 2013, containing recommendations in two of three major areas: service delivery and workforce. In the third major area, financing, Commission members did not reach agreement and therefore did not issue any recommendations. How to improve long-term services and supports (LTSS)[4] financing across multiple populations remains an intractable policy issue. Before the Commission's efforts, Congress's last comprehensive review of financing options was conducted in 1990 by the U.S. Bipartisan Commission on Comprehensive Health Care, known as the Pepper Commission after Rep. Claude Pepper (D-FL).[5]

ISSUES BEHIND THE LEGISLATION

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, pp. 3–4). But

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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.[6] 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 for people age 65 and over in 2011 according to a report by the Congressional

Time Line, LTSS Financing and Delivery: Selected Major Federal and National Activities, 1965 to Present

1965	Medicare and Medicaid programs, including coverage of skilled nursing home care for eligible beneficiaries, enacted.
1965-1970s	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.
1978	Older Americans Act long-term care ombudsman program to protect the rights of residents in long-term care facilities enacted.
1980-1986	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.
1981	Medicaid section 1915(c) waiver program, allowing states to expand their commitment to HCBS for people with disabilities of all ages, enacted.
1982	First National Long-Term Care Survey (NLTCS), a longitudinal study of frail Medicare beneficiaries living in the community, implemented by HHS (subsequent surveys in 1984, 1989, 1994, 1999, 2004).
1986	Institute of Medicine (IOM) study, *Improving the Quality of Care in Nursing Homes*, issued.
1987	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.
1990	U.S. Bipartisan Committee on Comprehensive Health Care, known as the Pepper Commission, issued report on LTSS financing options. Americans with Disabilities Act of 1990 (ADA) enacted.
1995	IOM study, *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*, 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.
1996	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.

Time Line, LTSS Financing and Delivery, continued

1999	In *Olmstead* vs. *L.C.* the Supreme Court affirmed the rights of people with disabilities to live in community settings and held that unnecessary institutional segregation constitutes a violation of the ADA.
2000	Older Americans Act Caregiver Program, authorizing grants to states for caregiver support and services, enacted.
2001	New Freedom Initiative to remove barriers to community living for people with disabilities established. Real Choice Systems Changes grants: the Center for Medicare & Medicaid Services and Administration on Aging (AoA, now the Administration for Community Living, ACL) initiated a series of grants to states and non-profit agencies to develop integrated LTSS systems.
2005	Deficit Reduction Act of 2005 allowed all states the option to implement long-term care insurance partnership policies; enacted provisions allowing states to develop consumer direction options in Medicaid HCBS programs; authorized the Money Follows the Person (MFP) Rebalancing demonstration program; and allowed states to add an optional Medicaid state plan benefit for HCBS.
2006	Reauthorization of the Older Americans Act added requirements that the AoA (now the ACL) establish Aging and Disability Resource Centers in all states.
2008	IOM study, *Retooling for an Aging America, Building the Health Care Workforce*, issued. Included analysis and recommendations regarding the LTSS workforce and family caregivers.
2010	The Patient Protection and Affordable Care Act of 2010 (ACA) enacted provisions under the Medicaid program to give states incentive to improve their LTSS infrastructures and expand HCBS. Provisions included the Balancing Incentive Program, the Community First Choice state plan option, an MFP extension, among others. The Community Living Assistance Services and Supports (CLASS) Act enacted.
2013	The American Taxpayer Relief Act of 2012 (ATRA) repealed the CLASS Act and established the Commission on Long-Term Care. The Commission on Long-Term Care issued a report reviewing LTSS policy and program issues. The report made recommendations regarding service delivery and workforce. No agreement on financing recommendations was reached; instead the report put forward financing approaches suggested by members.

Budget Office.[7] 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.[8]

CONGRESSIONAL ACTION

Policymakers have taken limited actions 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.[9]

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,[10] the ATRA repealed the CLASS Act and established the Commission on Long-Term Care.

Congress charged the Commission with making recommendations regarding LTSS policy. The Commission issued its report in September 2013. The Commission was composed of 15 members appointed by the President, the House of Representatives, and the Senate.[11] The Commission was 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; and (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.

COMMISSION REPORT

The Commission produced a report containing multiple recommendations related to service delivery and the LTSS workforce. With respect to LTSS financing, the Commission did not reach agreement on recommendations but offered two different approaches suggested by its members to illustrate ways Congress could restructure financing and improve financial protection for individuals and families from risks of LTSS expenses.

Service Delivery

The Commission's vision regarding service delivery is to create a more responsive, integrated person-centered, and fiscally sustainable LTSS delivery system to ensure that people can access quality services in settings of their choice. The Commission called for a number of actions, including more emphasis on creating a balanced array of services that would prioritize access to HCBS. It also recommended more emphasis on care integration, such as establishing a single point of contact for individuals and their families, and aligning incentives to integrate LTSS with health care services in a person- and family-centered approach. It recommended the creation of a standard assessment mechanism across care settings; the expansion of a "no wrong door" approach that would include improved access to services; and creation of models for public payment for post-acute care and LTSS based on services needed by individuals rather than settings, among other things.

Workforce

The Commission's vision regarding the LTSS workforce is to support family caregivers and attract and retain a competent and adequate workforce capable of providing high-quality, person- and family-centered care across all settings. Among the Commission's recommendations are to promote ways to support family caregivers, such as including family caregiver needs in care teams and care plans, and encouraging caregiver interventions, such as respite care programs. With respect to the paid workforce, the Commission recommended that scope of practice be revised to broaden opportunities for professional and direct care workers, that the federal government work with states to use national

criminal background checks for the LTSS workforce, that career ladders for direct care workers be encouraged, and that efforts be made to encourage states to establish certification procedures for home care workers.

Financing

The Commission suggested two alternative approaches to address financing. In developing its approaches, the Commission's vision was to provide individuals with the tools to better prepare themselves to finance their LTSS needs, and to ensure that those without the resources to cover the cost of care have access to high-quality services and supports. Similar to past policy reviews of LTSS financing, Commission members differed on how responsibility for financial should be apportioned between the public and private sectors.

The first approach suggested by some Commission members is to strengthen LTSS financing through private options for financial protection. The Commissioners suggested various ways to provide new market incentives, recognizing that fewer people are now purchasing LTC insurance and fewer companies are offering policies. Many people do not understand their risk of needing LTSS, and for many the cost of purchasing policies is prohibitive. Commissioners listed 12 options that could create new market incentives for personal protection, including providing tax preferences for LTC insurance policies through retirement and health accounts by allowing withdrawals from existing accounts to pay for premiums, supporting life care annuities, continuing support for Long-Term Care Partnership Programs, allowing insurance carriers more flexibility in pricing and product design, providing catastrophic protection for the relatively small proportion of people who experience need for services over an extended period of time, and strengthening eligibility requirements and asset recovery procedures under Medicaid, among others.

The second approach suggested by some Commissioners is to finance LTSS through social insurance and to spread risk broadly among the government, participants, and/or employers and employees. As put forward by the Commissioners, a social insurance approach could cover either comprehensive benefits under Medicare Part A or more limited benefits under Medicare or a new

public program. Under the comprehensive approach, the benefit would be triggered when an individual meets certain functional criteria and would be financed through a combination of a Medicare payroll tax increase and a new Part A premium. The limited benefit approach would insure only catastrophic costs for individuals who establish eligibility after a waiting period and would cover specified dollar amounts that would vary with levels of impairment. Benefits could be financed through a combination of Medicaid savings and increased taxes. The Commissioners indicated that both of these approaches would include a role for private insurance.

ENDNOTES

1. American Taxpayer Relief Act of 2012 (ATRA), P.L. 112-240, section 643, http://beta.congress.gov/112/plaws/publ240/112publ240.pdf.

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

3. Commission on Long-Term Care, "Report to the Congress," September 30, 2013, www.ltccommission.senate.gov/Commission%20on%20Long-Term%20Care-%20Final%20Report%209-26-13.pdf.

4. 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.

5. The Pepper Commission, U.S. Bipartisan Commission on Comprehensive Health Care, "A Call for Action," Final Report, September 1990, www.allhealth.org/publications/Uninsured/Pepper_Commission_Final_Report_Executive_Summary_72.pdf.

6. Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry*, 42, no. 4 (Winter 2005–2006): pp. 335–350, www.inquiryjournalonline.org/doi/abs/10.5034/ inquiryjrnl_42.4.335.

7. Congressional Budget Office, "Rising Demand for Long-Term Services and Supports for Elderly People," June 2013, www.cbo.gov/sites/default/files/cbofiles/attachments/44363-LTC.pdf.

8. Carol V. O'Shaughnessy, "Family Caregivers: The Primary Providers of Assistance to People with Functional Limitations and Chronic Impairments," National Health Policy Forum, Background Paper No. 84, January 11, 2013, www.nhpf.org/library/details.cfm/2900.

9. Carol V. O'Shaughnessy, "National Spending for Long-Term Services and Supports (LTSS), 2011," National Health Policy Forum, The Basics, February 1, 2013, www.nhpf.org/library/details.cfm/2783.

10. Sherry Glied, Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, testimony on the CLASS Act before the Committee on Energy and Commerce, Subcommittee on Oversight and Investigations and Subcommittee on Health, United States House of Representatives, October 26, 2011, www.hhs.gov/asl/testify/2011/10/t20111026a.html.

11. Commission on Long-Term Care, "Commissioners," www.ltccommission.senate.gov/commissioners.cfm.

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Selected Forum Materials on LTSS Financing and Delivery

- "National Spending for Long-Term Services and Supports, 2011" (The Basics, February 1, 2013), www.nhpf.org/library/details.cfm/2783
- "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
- "Health Policy Essentials, Medicaid, CHIP, and Long-Term Services and Supports" (Fundamentals Briefing, March 15, 2013), www.nhpf.org/library/details.cfm/2918
- "Private Long-Term Care Insurance: Where Is the Market Heading?" (Forum Session, April 15, 2011), www.nhpf.org/library/details.cfm/2855
- "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
- "The Community Living Assistance Services and Supports (CLASS) Act: Major Legislative Provisions" (The Basics, January 3, 2013), www.nhpf.org/library/details.cfm/2790
- "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