Long-Term Services and Supports:
Changes and Challenges in Financing and Delivery

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The aging of the baby boomers and the increase in the number of old-old persons (those 85 and older) are predictors for the increasing need for long-term services and supports (LTSS). Among persons age 65 and over, an estimated 70 percent will use LTSS. Persons age 85 and over are four times more likely to need LTSS than persons age 65 to 84.[1] The number of Americans needing LTSS is projected to more than double, to 27 million by 2050,[2] when one-fifth of the total U.S. population will be 65 or older. This is a significant increase from 12 percent in 2000 and 8 percent in 1950.[3]

LTSS covers a broad range of services in a variety of settings for people of all ages requiring assistance with activities of daily living (ADLs), such as eating, bathing, dressing and toileting over a long period. It includes services for persons over 65 with chronic illness, ADL dependence, dementia and other frailties of aging, as well as for people of all ages with physical, intellectual and developmental disabilities who might need lifelong supportive services. They may receive care in institutional settings, such as nursing homes and intermediate care facilities, or in community-based settings that range from assisted living residences to adult day care services at a local center or at home. In recent years there has been a movement away from institutional care towards greater use of home- and community-based services (HCBS), for which consumers can have their health and personal needs met while aging in place.

The Coming Callenge

As the population continues to age, the number of elderly people with functional or cognitive limitations, and thus the need for assistance, is projected to increase sharply.[4] This will result in a substantial rise in expenditures for these services.

National expenditures for LTSS totaled $368 billion in 2012,[5] and that only accounts for about half of all LTSS services provided. Unpaid caregivers, such as family and friends, make up the rest. The Congressional Budget Office (CBO) estimates that the value of support provided by family caregivers to elderly people with functional limitations living in the community totaled approximately $234 billion in 2011. The value of this care in terms of lost wages could be even higher.[6]

The high cost of formal LTSS makes it unaffordable for many families. At 2012 prices, nursing home care averaged over $90,000 per year; home health totaled $20,000 per year, at $21 per hour for only 20 hours per week; and adult day care cost $18,000 per year at an average of $70 per day for five days per week.[7]

Who Pays?

In 2012, the largest single payer for LTSS was Medicaid, at 40 percent of the total spend.[8] Though eligibility varies somewhat by state, subject to federal minimum requirements, individuals qualify for Medicaid based on income and/or functional status. Medicaid coverage of LTSS is provided to low-income persons and those whose financial resources have been depleted, largely by out-of-pocket expenses on health and LTSS.

Though private long-term care insurance has been available for three decades, its market share has remained below 10 percent.[9] Most people list premium unaffordability as a key reason for not purchasing it.[10]

The Affordable Care Act included a plan to enhance the private market with a

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national voluntary insurance program. The Community Living Assistance Services and Supports (CLASS) Act, was intended to be self-sustaining, funded by purchasers of the private insurance. However, after studying various formulas and methods, the secretary of the Department of Health and Human Services (HHS) announced that the plan was actuarially unsound and could not be implemented. Congress later repealed the CLASS Act.

Medicaid, State Budgets, and Managed LTSS

With Medicaid's provision of LTSS weighing heavily on state budgets, states are increasingly seeking ways to contain costs and reduce their Medicaid burden while maintaining or improving the quality of the program. In the last few years, states have been turning to Medicaid managed care to control costs, provide required basic health care services and, more recently, to provide LTSS.[11]

Provisions in the ACA support integrated care, including the integration of health and LTSS, and thereby the movement to managed LTSS. HHS's Administration for Community Living has funded several initiatives to help increase the capacity of state and community-based aging and disability organizations to participate in the design and delivery of Medicare-Medicaid managed long-term services and supports (MLTSS) in their states.[12] These initiatives include the Community-based Care Transitions Program, which aims to improve Medicare patients' transitions from in-hospital care to other care settings and reduce readmissions to the hospital. [13] Another initiative, the Business Acumen Learning Collaboratives, aims to assist community based organizations in marketing, contracting and pricing the LTSS services they provide.[14]

The ACA provides states that spent less than half of Medicaid LTSS dollars on community-based care as of 2009 with a financial incentive to rebalance, i.e., change the ratio of institutional care to home and community bases services (HCBS). Up to September 2015, states may access federal funding of up to $3 billion to enhance the matching rates for spending on HCBS.[15] States spending less than half of their Medicaid LTSS budget on HCBS are eligible for a 2 percent increase in matching funds, called the federal medical assistance percentage (FMAP). They are required to increase their HCBS Medicaid spending to half by September 30, 2015. Thirty-six states are eligible for the increased 2 percent.[16]

The number of states with MLTSS programs increased from 8 in 2004 to 16 in 2012. The number of persons receiving care under these programs increased from 105,000 to 389,000.[17] There continues to be increasing interest from states to participate in these programs. Twenty-six states were projected to have MLTSS programs in 2014.[18]

Dual Eligible Beneficiaries and HCBS

Although Medicaid is the primary public program financing LTSS, Medicare, which covers persons 65 and older and those with disabilities, provides limited coverage for LTSS. Yet, 20 percent of Medicare beneficiaries are eligible for both programs, often confusing consumers and complicating the coordination of care.

The Medicare-Medicaid Coordination Office established under the ACA is working with states to develop and replicate new models for integrating the delivery and financing of Medicare and Medicaid benefits with the goals of reducing costs, maintaining or improving quality and better coordinating the care that dually eligible beneficiaries receive. The financial alignment demonstration is designed to enroll more dual eligibles into managed care models and to improve the level of integration those models offer. Ten states (California, Illinois, Massachusetts, Michigan, New York, Ohio, South Carolina, Texas, Virginia, and Washington) have a capitated model for serving this population. Eight of the 10 states include Medicaid HCBS waiver services as well as nursing facility services. Only California and Massachusetts exclude HCBS waiver services.[19]

Working Toward Solutions

When Congress repealed the CLASS Act, it created the Long-Term Care Commission. Its objective in the short term was to develop a plan for the establishment, implementation and financing of "a comprehensive, coordinated, and high-quality system" that ensures the availability of LTSS for individuals who need them.[20] The president and leaders of the House and Senate appointed a fifteen-member commission, as required by statute. The commission met in September 2013 and submitted a report to Congress[21] that outlined several policy recommendations in the areas of LTSS service delivery, workforce, and financing. Examples include establishing integrated care teams, using technology-enhanced data sharing across settings and providers, training family caregivers, and finding a sustainable balance of public and private financing. Five of the 15 members of the commission issued an independent minority report that outlined alternative recommendations for LTSS reform.[22]

Meanwhile, a number of policymakers, advocates and analysts have been working on various proposals to find a financing solution for LTSS. The

Bipartisan Policy Center's Long-Term Care Initiative and the Long Term Care Financing Collaborative are two such groups.

Leading Age, a membership association of not-for-profit providers of care and services, has proposed a framework to guide the work of solution development. The goals and guiding principles include sustainability, better public awareness and information, meaningful choice in LTSS, improved quality, the encouragement of cost-effective services, plus building fiscal responsibility and stewardship of public resources. The framework identifies a spectrum of options that rely both on private markets and public programs.[23]

States continue to implement MLTSS programs in hopes that they can reduce costs and improve quality and consumer satisfaction. Stakeholders contend that further development of MLTSS quality measures is needed, such as those related to quality of life, LTSS rebalancing, and community integration. Evidence on these measures would provide policymakers and other stakeholders needed information to oversee and evaluate these programs.

Questions Moving Forward

Though this toolkit limited its scope to the aging of the population and current and future financing of LTSS, there are other issues with which policymakers and stakeholders contend in the field of LTSS.

- LTSS Workforce. Personal care aides and home care aides will be the fastest growing occupational categories in the country between now and 2020. Are we prepared to fill the need with properly-trained workers?
- Quality of care. The Centers for Medicare & Medicaid Services (CMS) are attempting to improve Nursing Home Compare's 5-star rating system to make better information available to the public. Will this information be adequate to inform decision making? What are the appropriate measures to capture quality of life, quality of care and consumer satisfaction?
- Home Health Care. What policy levers are available to improve the delivery of home health and contain costs?

Suggested Reading

The Basics

Rising Demand for Long-Term Services and Supports for Elderly People
Congressional Budget Office. June 26, 2013
http://goo.gl/7smRv1
This report provides demographic information about the aging of the American population and how that correlates with the need for long-term services and supports (LTSS). It also provides the current financing picture of LTSS and concerns about future prices and demands for services.

National Spending for Long Term Services and Supports 2012
National Health Policy Forum. March 2014
http://goo.gl/3BIiej
This issue brief provides data about LTSS spending ($219.9 billion in 2012, representing 9.3 percent of all personal health care spending), and breaks down public and private funding sources.

Medicaid and Long-Term Services and Supports: A Primer
Reaves, Erica and Musumeci, MaryBeth, Kaiser Family Foundation. July 30, 2014
http://goo.gl/cAYQrn
This report describes the what, where and how of LTSS, and also the providers and financial challenges.

Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community
National Council on Disability. February 2015
http://goo.gl/SS8Bcn
The National Council on Disability reviews the research on outcomes since the 1999 Olmstead Supreme Court Decision, which established that people with disabilities who could live in the community – rather than in institutions – should. The report finds that smaller, more dispersed and individualized community settings further integration and positive outcomes for individuals with disabilities. Specifically, greater individual choice, satisfaction, housing stability, and higher levels of adaptive behavior and community participation are associated with living in residential settings of smaller size.

National Study of Long Term Care Providers
Centers for Disease Control and Prevention. 2014
http://www.cdc.gov/nchs/nsltcp.htm
The biennial study monitors trends in the major sectors of paid, regulated LTSS. It uses data from surveys of residential care communities and adult day services centers and administrative data on home health agencies, nursing homes and hospices. It provides statistical information to inform policymaking.

Aging and Disability Services Need—and Deserve—Support
O'Brien-Suric, Nora, The John A. Hartford Foundation. February 2015
http://goo.gl/HTPJx8
This author touts the importance of community-based agencies in developing initiatives for aging and disability services. It notes provisions in the ACA that are particularly relevant to the integration of health and long-term services and supports.

Long Term Care Insurance

The Long Term Care Financing Crisis
Calmus, Diane, The Heritage Foundation. February 2013
http://goo.gl/hhfBa
This paper provides an overview of who needs long-term services and supports (LTSS) and the challenges in financing. It reviews issues pertaining to long-term care insurance, what prevents people from buying the available products, the tax incentives to encourage purchasing insurance and why the incentives have failed to increase market penetration.

Needing Help: Long-Term Care Risk
Collins, Brian, Bipartisan Policy Center. October 2014
http://goo.gl/nCi9zr
This blog post explains the challenges to preparing for the financial burden of long-term care (LTC). It notes that LTC is an insurable risk and outlines the barriers that prevent Americans from buying this product.

Prospective Solutions

'Milestone' Rules Would Limit Profits, Score Quality for Private Medicaid Plans.
Hancock, Jay, Kaiser Health News. May 26, 2015
http://goo.gl/zg5nSX.
The article describes major proposals to create profit guidelines for private Medicaid plans. The rules also would establish standards for provider networks and rules to coordinate Medicaid insurance more closely with other coverage.

Consumer Choices and Continuity of Care in Managed Long-Term Services and Supports: Emerging Practices and Lessons
Saucier, Paul and Burwell, Brian, AARP Public Policy Institute. August 2013
http://goo.gl/7RUkr8
This report studies managed care transitions in Kansas, New York and Wisconsin. It examines how the program addressed consumer choices and continuity of care during implementation, and found that little changed for consumers during the transition period, and that there was no disruption of services.

Financing Long-Term Services and Supports
LeadingAge. March 2014
http://goo.gl/RjKsNt
In this brief, LeadingAge outlines its framework for developing solutions to the challenges in LTSS financing.

Key Themes in Capitated Medicaid Managed Long-Term Services and Supports Waivers
Musumeci, MaryBeth, AARP Public Policy Institute. November 2014
http://goo.gl/NzlPdD
This issue brief examines key themes in 19 capitated Medicaid managed long-term services and supports (MLTSS) waivers approved to date by the Centers for Medicare and Medicaid Services (CMS). Most waivers include provisions to increase access to home- and community-based services.

Long-Term Services and Supports: Balancing Incentive Program
Community Catalyst. 2015
http://goo.gl/s0Wutr
This policy brief describes the Balancing Incentive Program provided for in the ACA. The incentive aims to help states move away from a bias on institutional care to favor more community-based care. The brief provides some early evidence of Medicaid savings and improved consumer satisfaction when people move from institutional to community-based care.

On the Verge: The Transformation of Long Term Services and Supports
Cheek, Mike, et al., AARP Public Policy Institute. February 2012
http://goo.gl/7ygsYA
This report presents findings from a 2011 state survey finding that many states are transforming the financing and delivery of LTSS and that many are moving to managed-LTSS in their Medicaid programs and in their programs for beneficiaries dually eligible for Medicaid and Medicare.

Study Finds States Moving to Managed Care for Older Americans Who Need Long-Term Services and Supports
AARP. February 2012
http://goo.gl/y39lru
This article summarizes the findings in an AARP report of a state survey of state LTSS restructuring. It notes that a number of states either have implemented Medicaid Managed LTSS, or plan to do so, and that a majority of states report focusing on better integrating Medicare and Medicaid services for their dual eligible population.

Experts

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Websites

AARP Public Policy Institute
www.aarp.org/research/ppi

Administration on Aging, HHS
www.aoa.gov

Alzheimer's Association
www.alz.org

American Association of People with Disabilities
www.aapd–dc.org

American Institutes for Research
www.air.org

Center for Health Care Strategies
www.chcs.org

Center on an Aging Society, Georgetown University
http://ihcrp.georgetown.edu/agingsociety

Consortium for Citizens with Disabilities
www.c–c–d.org

Disability Policy Collaboration (The Arc of the United States/United Cerebral Palsy)
www.thearc.org

Federal Long Term Care Insurance Program
www.ltcfeds.com/index.html

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http://gppi.georgetown.edu

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www.genworth.com

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http://www.jhartfound.org

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www.hebrewrehab.org

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www.kff.org

Leading Age
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www.milbank.org

National Academy for State Health Policy
www.nashp.org

National Academy of Social Insurance
www.nasi.org

National Association for Homecare and Hospice
www.nahc.org

National Association of States United for Aging and Disabilities
www.nasuad.org

National Center for Assisted Living
www.ncal.org

Family Caregiver Alliance, National Center on Caregiving
www.caregiver.org

National Council on Aging
www.ncoa.org

National PACE Association
www.npaonline.org

The National Consumer Voice for Quality Long–Term Care
www.theconsumervoice.org

Robert Wood Johnson Foundation
www.rwjf.org

RTI International
www.rti.org

The SCAN Foundation
www.thescanfoundation.org

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www.seiu.org

ENDNOTES

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