



A Guide to Long-Term Care for State Policy Makers

THE STATE OF LONG-TERM CARE

America's long-term care (LTC) system has been described as fragmented and complex, relying mainly on institutional care for frail elders and others with disabilities. Individuals who want to remain in their homes and communities often have few choices or have difficulty in learning about available supports other than costly nursing home care unless their families can support them in their homes. Each state has its own eligibility rules for publicly funded services and a maze of different agency programs.

These circumstances have been difficult not only for those with disabilities of all ages but also for state policymakers who are attempting to provide the best options for their constituents and to control escalating public costs for institutional services that often are not appropriate or desirable for many people. Spurred by judicial rulings, buttressed by federal grant monies, and encouraged by consumer advocacy, states now have more options to address these LTC issues.

What are some of the new developments in LTC reform that are now available to state policymakers? How should lawmakers assess these options and evaluate their effectiveness in helping vulnerable people with disabilities gain the services they need in the most cost-effective manner possible? What, then, are these initiatives?

Key Components of a Rebalanced LTC System

- *Consolidated state agencies:* A single state agency for both institutional and community services with coordinated policies and budgets.
- *Single access points:* Access to a wide variety of community supports in one location or single website.
- *Controls on supply of institutional beds:* Limits or reduces institutional beds through mechanisms such as Certificate of Need requirements.
- *Transitions from institutions:* Assistance in helping institutional residents to move back to the community.
- *Continuum of residential options:* Support services in a variety of settings from single-family homes to apartments or group settings.
- *Provider recruitment and training:* Developing a sufficient supply of providers who have the necessary skills and knowledge
- *Consumer direction:* Primary decision-making authority over direct care workers and delivery of services
- *Quality management:* Measuring whether system achieves desired outcomes, meets program requirements, and identifies strategies for improvement.

Source: Thomson Medstat. December 2006



- **Rebalancing a state's long-term care system**

The term “rebalancing” refers to shifting a state’s LTC resources from institutional care to home and community-based services (HCBS). For many years, public funding (mainly from Medicaid) has been allocated overwhelmingly to institutional care. In 1987, for example, more than 90 percent of total Medicaid LTC spending went to institutional care and only 10 percent went to HCBS. The institutional share dropped to about 76 percent in 1997 and then to 63 percent in 2006; only 37 percent of Medicaid funding remains for home and community services and support.

The elderly and people with disabilities rarely want to enter a nursing home, but if they have limited funds and little family support, that may be their only choice. They have an “entitlement” to publicly funded care in a nursing home through the Medicaid program if they meet a state’s financial and functional eligibility standards; access to publicly funded home or community care is more limited.

Under judicial pressure and through new funding mechanisms and increased federal flexibility, however, many states have attempted to rebalance their LTC systems to offer consumers more options to remain in their homes and communities.

- **The *Olmstead* Supreme Court decision.** This 1999 ruling increased state responsibility to provide a range of HCBS options. The Court ruled that states must provide services in the most integrated setting appropriate to the needs and wishes of people with disabilities. Failure to provide people with disabilities with community rather than institutional services could constitute discrimination under the Americans with Disabilities Act.
- **The federal Real Choice Systems Change grant program.** The Systems Change grants have provided \$240 million since 2001 through more than 300 separate state grants. These grants have helped states set up Aging and Disability Resource Centers, design Nursing Home Transition and Money Follows the Person programs, and develop person-centered and self-directed home and community services and supports, including initiatives through the Independence Plus Initiative.
- **The Deficit Reduction Act of 2005.** This act allows states to offer home and community-based services as a Medicaid State Plan optional benefit for qualified individuals with incomes below 150 percent of the federal poverty level. This provision gives states greater flexibility than can be exercised with Medicaid waiver programs that require federal approval whenever states change services or other options under the waiver. The DRA also eliminates a requirement under waiver programs that eligible individuals be shown at risk for institutionalization to be eligible for HCBS. These DRA provisions could help states expand the number of people receiving home and community services and supports.
- **Money Follows the Person.** These programs give nursing home residents the option to move from an institution to a community setting; the public funds used for their nursing home care are transferred to their community care. The concept involves public funds moving with the individual to the most appropriate setting as the individual’s needs and preferences change.

- **Nursing Home Transition.** These programs also have been adopted by many states, with special funds authorized by state legislatures to assist in the transitions, including money that can be used for security deposits, utility hookups and furniture.

- **Innovative Service Delivery Models**

The nation’s Aging Network—including state and Area Agencies on Aging and the Disability Network and Centers for Independent Living—have long provided information and assistance to people with disabilities who are trying to find the resources they need for LTC. Too few people know about these supports, however, and the fragmentation of LTC services and funding among so many local and state agencies and organizations has made the process challenging for all those with disabilities and their families. Even if they can remain at home, they often are frustrated by as they attempt to understand and access appropriate home and community supports. Several initiatives are addressing these concerns:

- **Aging and Disability Resource Centers (ADRCs).** Federal grants are helping spur the development of these centers as physical or virtual (Internet or telephone) locations where people of all ages and disabilities can obtain information about and assistance with public and private LTC services. The goal is for these centers to develop the capacity to provide one-stop access to all publicly funded services, particularly HCBS, and to make speedy determination of Medicaid eligibility for such services.

Since 2003, the U.S. Administration on Aging and the U.S. Centers for Medicare and Medicaid Services have partnered to provide grants to states to develop the ADRCs and to help expand their capacity. Forty-three states have received funding to date and are demonstrating the ADRC model through more than 100 pilot sites.

- **Consumer-Directed Care.** With Robert Wood Johnson demonstration funds, several states have pioneered a consumer-directed model of care—Cash and Counseling¹—that has allowed those who are receiving LTC services at home to hire and fire their workers, direct their own services, and pay the aides through a budget they control. Some self-directed care programs allow beneficiaries to hire family members as their caregivers.

Other states have developed this concept for the delivery of services under the Medicaid waiver or Personal Care Option programs. The DRA now allows states to offer a state plan benefit for self-directed personal care services without a waiver.

- **Financial and Funding Innovations**

- **Long-Term Care Partnership Program.** The Deficit Reduction Act allows states to create this program, which couples the purchase of LTC insurance

¹ There are now 15 “Cash and Counseling” demonstration states—the original three states (Arkansas, Florida and New Jersey) plus 12 replication states funded in 2004.

with eligibility for Medicaid coverage of LTC services. With the purchase of a partnership policy, a consumer can become eligible for Medicaid coverage after using up the insurance benefits without having to exhaust his or her own assets to qualify for such coverage. The protected assets also are exempt from the Medicaid estate recovery provisions.

By encouraging people to purchase LTC insurance with this added incentive, states hope to limit the number of people who “spend down” their own assets for costly nursing home care and then turn to Medicaid for assistance. It is believed that purchasing the partnership insurance will delay or eliminate access to Medicaid by many of these individuals.

- **Global Budgeting.** Several states have adopted this concept for long-term care. State and federal funds for various LTC services such as nursing home care and HCBS are pooled in one budget (generally under a cap on total spending) rather than being allocated among different budget lines and state agencies. In several states, this also has involved consolidating LTC programs and budgets into a single state agency where the administrator has the flexibility to move funds among the various LTC services to provide the most appropriate services for each consumer—whether that be nursing home or home care—and also control caseloads and costs.
- **Other Programs.** States also are adopting various strategies to encourage Americans to assume greater personal responsibility for planning for their potential need for LTC services and supports. Through a Department of Health and Human Services (DHHS) pilot program, “Own Your Future,” 15 states have received grants for public awareness campaigns about LTC planning. In these states, campaigns are launched by the governor, who sends a letter to all households that include members between the ages of 45 and 65, directing them to resources that can help them plan for future long-term care needs. In a related effort to encourage people to consider such LTC planning, the DRA funded DHHS to launch the National Clearinghouse for Long-Term Care Information.

Nebraska, one of the Own Your Future states, passed a 2006 law (the Nebraska Long-Term Care Savings Plan Act), that make taxpayers eligible to claim state income tax deductions for contributions they make to a savings plan to be used for long-term care expenses of older people or certain people with disabilities.

The Challenge for State Policymakers

The current LTC environment continues to present many challenges for state policymakers whose support is essential to the process of reforming the system. No entitlement to community care exists, and caps remain on HCBS caseloads. Most public funding still continues to go to institutional rather than community care. Nonetheless, state policymakers have some additional tools that can help provide greater access to LTC services and supports for consumers. State legislators are in a position to authorize new services, appropriate funds to sustain LTC reform programs, and oversee executive branch implementation of these efforts.

Some state executive branches and legislatures have been engaged in systemic long-term care reform, using Systems Change grants to help support components of the overall reform effort. Other state legislatures have authorized new LTC service models, such as consumer direction, for HCBS programs that the federal grant funds then helped to implement. State policymakers can make best use of these opportunities within the framework of each state's environment for change and the unique needs of its diverse populations of people with disabilities.

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Funding for this project was made possible through funding from the U.S. Administration on Aging. The views expressed in written materials or publications do not necessarily reflect the official policies of the Department of Health and Human Services nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.