**I. Introduction**

Americans are living longer. Population studies report that, from 2005 to 2020, the population age 85 and older will increase by 43 percent.\(^1\) Despite the fact that many of these older people are healthier and more independent, they and other adults with physical disabilities may well need services and supports to help them remain in their homes.

Eighty-four percent of those age 50 and older want to remain in their homes as they age.\(^2\) If they need help with everyday activities such as bathing, dressing and eating, they want to choose who provides that help and control when and how they receive assistance. The way the U.S. long-term care (LTC) system operates today, however, can seriously limit that personal independence.

The primary source of public financing for LTC is Medicaid, which requires coverage for institutional services but permits states to cover home and community-based services (HCBS) through “waivers” that allow them to provide services not usually covered by Medicaid. Consequently, for decades, the bulk of Medicaid funds have been spent on institutional care for people with disabilities and the elderly. Studies show that, on average, Medicaid dollars can support nearly three older people and adults with physical disabilities with HCBS for every person in a nursing home.\(^3\)

A growing number of state policymakers are attempting to address the imbalance between the Medicaid funding for institutional care, such as nursing homes, and HCBS. Still, balancing Medicaid LTC dollars needs to be seen in the context of comprehensive LTC reform that affects people of all incomes and involves both private and public resources. Helping consumers receive services at home or make the transition out of nursing homes, for example, raises questions about adequacy of affordable and accessible housing, transportation, and social and recreational options. Availability of resources to provide consumers with information and assistance in making important decisions regarding service options is also an issue. Medicaid balancing is only one important piece of the LTC reform puzzle.

As the population ages, these issues have become more urgent. Although tough economic times require careful planning by state policymakers, the need to move ahead is no less compelling. As state policymakers look for ways to control state budget growth on health and human services, balancing Medicaid funding can potentially slow the rate of increase in Medicaid LTC spending while serving more people with disabilities who need help. HCBS can be more cost effective and responsive to the preferences of older people and adults with physical disabilities. The situation calls for legislative leadership.

The examples below describe how several states have balanced LTC resources and identify a number of promising strategies. These states have developed long-range plans that allow them to establish priorities, set timelines, and begin the LTC reform process with balancing as a central component.
II. What Is Balancing?

The term “balancing” —or “rebalancing” as it is sometimes called—generally means serving a greater number of people who have LTC needs in their homes and communities rather than in nursing homes, and reallocating LTC funds between institutional and HCBS. Balancing a state LTC system also can encompass:

- Expanded access to a wide variety of services and supports in various settings outside of institutions,
- Ease of locating services and obtaining assistance, and
- Increased support for consumer direction of services and providers.

In FY 2007, 42 percent of Medicaid LTC dollars were spent on home and community-based care, compared to 58 percent for institutional care. When considering only older persons and adults with physical disabilities (excluding people with mental retardation and developmental disabilities who receive Medicaid LTC) the allocations become 27 percent for HCBS and 73 percent for nursing homes.4

Some states have made more progress than others. In 2006, four states—Oregon, New Mexico, Washington and Alaska—spent more than 50 percent of Medicaid LTC dollars on HCBS for older people and adults with physical disabilities. In comparison, Tennessee, Indiana, Utah, and North Dakota spent 5 percent or less on HCBS that year.5

III. Importance of the Issue to Consumers

If they need help with everyday activities, older people and those with disabilities want to decide for themselves where and how they obtain that assistance. Their preference is to remain in their homes or to live in a home-like setting. Moreover, consumers want to be involved and participate in planning public policies that help reshape the environment in which they live and receive services.

Despite their preferences, consumers may be directed toward institutional services because home care services are neither readily available nor easily accessible. They also may be directed to institutional care because it is an easier placement for health care professionals. Some hospital discharge planners and family members may be unaware of many home services in the community or do not trust that supports can be delivered safely at home.

This situation is changing as states shift public dollars to HCBS with the help of consumer input and consumer self-directed services become more of a reality in most states. When consumers direct their own services, they decide which agencies or individuals they will hire to provide those services (and have the authority to fire them if necessary) and when and how the services will be delivered.

IV. Federal Framework: Policies and Programs

The federal government has taken steps in recent years to reverse the institutional bias in the Medicaid program to ensure access to a wider array of services, to use federal dollars more wisely, and to comply with the U.S. Supreme Court’s 1999 Olmstead decision. (This decision requires states to provide services in the most integrated settings appropriate to the needs of persons with disabilities, which gives states a strong impetus to provide community-based services and supports whenever possible.)

The U.S. Centers for Medicare and Medicaid Services has, for example, supported state LTC reform by implementing more flexible coverage options authorized by the Deficit Reduction Act of 2005. These include increased options for consumer-directed care within home care programs. In addition, an HCBS option within the Medicaid State Plan is offered, with some limitations on income eligibility levels and benefits.

Another federal incentive is seed money provided under the Real Choice Systems Change grant program to help states develop or expand more effective LTC systems. From 2001 to mid-2006, the U.S. Department of Health and Human Services awarded 287 grants to all 50 states, totaling about $280 million. A separate allo-
A $1.4 billion award was made in 2007 to 30 states and the District of Columbia through the Money Follows the Person Rebalancing Demonstration (MFP). The project provides enhanced federal matching funds for HCBS for 12 months for each person moved from an institution to the community during the demonstration period and directs states to sustain support for the services for as long as the person remains eligible. The Real Choice Systems Change grants are aimed at helping states:

- Transform a state’s LTC system by consolidating LTC agencies and services in a single agency;
- Build Aging and Disability Resource Centers to provide information and assistance for those who seek LTC services and supports;
- Transition people from nursing homes to home and community settings; and
- Expand HCBS programs, particularly those that allow people with disabilities to choose their service providers and direct their own services.

**V. What Have States Done to Balance?**

Some states have begun to balance their LTC systems with initiatives that range from expanding HCBS, to creating Aging and Disability Resource Centers that facilitate access to HCBS, to developing “global budgets” that pool LTC funds for institutional care and HCBS in one budget so funds can be allocated more appropriately between the two. The following examples illustrate several strategies that were adopted to meet state needs.

**NEW JERSEY**

On June 21, 2006, Governor Jon S. Corzine signed Public Law 2006, Chap. 23, the “Independence, Dignity, and Choice in Long-Term Care” Act. The legislation says, in part:

“The enactment of this bill will ensure that, in the case of Medicaid-funded LTC services ‘the money follows the person’ to allow maximum flexibility between nursing homes and home and community-based settings … and, in so doing, significantly expands the choices available to consumers of these services and thereby fulfills the goal of personal independence so highly valued by the growing number of older adults and persons with disabilities in this state.”

Goals of the legislation are to expand LTC choices for New Jersey consumers and to create budget mechanisms to ensure those choices are met.

The New Jersey plan is called “Global Options for Long-Term Care” or “GO.” Under the program, the governor has mandated statewide coverage of Aging and Disability Resource Centers (ADRCs), first started in two pilot counties. The goal is to ensure that all consumers are informed about appropriate LTC options and can be counseled on eligibility for various services and supports. Other components include:

- Development of a global budgeting process for expanding HCBS within the existing budget allocation to allow maximum flexibility for consumer choice between nursing homes and home care options;
- Implementation of a fast-track eligibility process under which consumers can receive HCBS for up to 90 days while they are completing the full eligibility process for Medicaid coverage; and
- Creation of a web-based client tracking system that will allow care workers to more efficiently coordinate services and supports.

Since the legislation was enacted, the state has reported the following actions.

- Nearly 1,000 nursing home residents have made the transition to alternative LTC options in the community.
- Three Medicaid waiver programs for HCBS are being consolidated to provide greater consistency of services for consumers and their caregivers.
- Aging and Disability Resource Centers are being developed in five additional counties, and fast-track eligibility became operational statewide in 2008.

A series of federal grants for LTC reform during the last decade has helped New Jersey build its Aging and Disability Resource Centers system and to transition people...
from nursing homes, among other activities. In 2007, the state received a $30.3 million Money Follows the Person Rebalancing Demonstration grant.8

IOWA

In May 2005, the Iowa legislature passed HF 841, the IowaCare Medicaid Reform Act. In addition to expanding Medicaid health care coverage for low-income people, the act mandates fundamental LTC reform under a section of the law called “Rebalancing Long-Term Care.” HF 841 defines the intent of the LTC provisions as:

- Improving access,
- Expanding choices about service delivery, and
- Building the capacity of Iowa communities to sustain independent living for people with disabilities.

The legislation also created a legislative committee, the Medical Assistance Projections and Assessment Council, to oversee all Medicaid reform initiatives established by the legislation. The council will help implement the three core goals noted above and review progress on other initiatives relating to self-direction, quality management and information technology.

Other major legislation enacted in April 2007—HF 451—calls for development of a single point of entry long-term living resources system, considered by state policymakers to be a key component of the state’s LTC reforms. This is envisioned as an integrated system that will help Iowans navigate a variety of private and public LTC resources. The project is being developed by a team of state agency representatives, legislators, consumers, advocates and providers.

The Iowa program also has moved on several other fronts.

- In October 2006, Iowa launched a new Cash-and-Counseling program, “Consumer Choice Option,” in a 12-county north central area of the state. The program, to be expanded statewide gradually, allows waiver participants to direct their own services.
- In April 2007, Iowa became the first state to use the Deficit Reduction Act authority to receive federal approval to add HCBS to its Medicaid State Plan, instead of using the Medicaid waiver system. Iowa’s new benefit will provide statewide home and community-based case management services and habilitation services at home or in day treatment programs.
- Iowa received a $51 million Money Follows the Person Rebalancing Demonstration grant in 2007 and a $2.3 million Real Choice Systems Transformation grant in 2005 to improve information and access, streamline the eligibility and assessment process, and develop a plan to expand HCBS.
- In August 2008, the Single Point of Entry Resource Team issued eight recommendations for the 2009 legislative session to strengthen the initiative, including a proposal for increased funding to expand the program.

Iowa demonstrates how state legislative initiatives can be combined with federal legislation and grant programs to achieve LTC reforms, starting with key components such as a single point of entry and self direction of services.

MINNESOTA

In 2001, the Minnesota Legislature enacted comprehensive legislation (S.F. 4, 1st Special Session) to rebalance the state’s LTC system, building on the recommendations of a Long-Term Care Task Force. The task force was composed of 12 legislators and the commissioners of several state agencies. This legislation continues to serve as the framework for the balancing initiative. It established four benchmarks aimed primarily at reducing nursing home utilization, and mandated a biennial update to the Legislature.

Minnesota’s nursing home utilization rate was one of the nation’s highest in the 1990s—84 beds per 1,000 people age 65 and older in 1993—despite a statewide moratorium on new nursing facility construction since 1984. Through a number of other initiatives such as a voluntary program under which the state provides fa-
cilities with financial incentives for closing beds, the ratio of beds to 1,000 people age 65 and older dropped to 56 in 2008. This compares to a national average of 45 beds per 1,000 people age 65 and older in 2007.

Other indicators of progress in LTC reform include the following.

- In 2001, Minnesota allocated about 82 percent of Medicaid LTC dollars for nursing home care. By 2006, that had dropped to about 60 percent.

- Spending on home and community-based care more than doubled between FY 2001 and FY 2006, from $209 million to $566 million, while spending on nursing homes decreased from $901 million to $853 million.

- The state provides LTC consultation services to help consumers and their families choose LTC services that reflect their needs and preferences. Services are available locally from county teams of social workers and public health nurses.

- Minnesota was one of 10 states to receive a $500,000 grant in 2007 from the Centers for Medicare and Medicaid Services to use a new State Profile tool developed to access its LTC system and to explore the development of prototype LTC balancing indicators.

OHIO

For years, Ohio's PASSPORT program has been one of the nation's largest Medicaid HCBS. Now, the state hopes to build on that initiative by developing an ambitious, long-range plan for comprehensive LTC reform.

In the 2007-2008 budget bill (HB 119), the legislature authorized a unified LTC budget that consolidates policymaking authority and budgeting in a single entity, and provides consumers with choice and a continuum of services. An Implementation Committee is composed of state legislators, advocates, consumers and providers.

In its May 30, 2008, report, the committee adopted mission and vision statements, the key components of which are consumer choice, flexibility, and transparency. The committee also recommended a multi-phase approach for project implementation, starting in FY 2009. For example, priorities for the “near or short term” (SFY 2009) include deciding on financing and service delivery structures (Medicaid waivers, state plan options, etc.); developing information and assistance tools; and establishing an interagency expenditure and caseload forecasting process.

Other steps Ohio has taken to meet its LTC reform goals include the following.

- Issuance of a March 2007 directive from Governor Ted Strickland for the Department of Aging to expand access to PASSPORT services for 1,100 people on a waiting list;

- Passage by the legislature of a provision in the 2008-2009 biennium budget bill to add 5,600 more slots to PASSPORT over the biennium.

- Receipt of a five-year, $101 million Money Follows the Person Rebalancing Demonstration grant from CMS in 2007 to expand HCBS.

Ohio is building on the broad base of the PASSPORT program to create an even more comprehensive LTC system. The state's multi-phased approach to LTC reform will help demonstrate that careful planning can proceed and progress can be made in the face of poor economic conditions.

OTHER STATE INITIATIVES

The following states have made significant strides towards balanced LTC systems. In Washington, progress has taken many years. The state has expanded HCBS annually since the 1980s. It has consolidated LTC management in a single agency and funding for LTC in a single appropriation for years. Vermont has set specific goals for LTC reform since 1996 that have been successfully met. New Mexico ranked second among the states in FY 2006 in the percentage of Medicaid LTC expenditures that went to HCBS (67 percent for all Medicaid beneficiaries; 54 percent when counting only older people and adults with physical disabilities). Massachu-
setts adopted a “Community First” policy in 2003 to emphasize its intent to give consumers as many options as possible to remain in their communities.

Washington has one of the nation’s most balanced LTC systems for older people and adults with physical disabilities. It is one of the few states that spend more on HCBS than on nursing homes—in 2006, 54 percent of Medicaid LTC dollars were allocated to HCBS. From FY 2001 to FY 2006, Medicaid spending on HCBS increased significantly from $439 billion to $642 million, while spending on nursing homes decreased from $614 million to $558 million.

Faster, more efficient access to HCBS is available through the following:

- Single state agency administering and funding for institutional and HCBS;
- Presumptive Medicaid financial eligibility process that allows a caseworker to approve and begin services while detailed paperwork proceeds;
- Expedited eligibility determination process; and
- Computerized assessment tool used to determine functional eligibility and development of care plans.

Vermont illustrates a state that is balancing its LTC system by combining nursing home and HCBS funds into a “global budget” to fund a consumer’s entitlement to either nursing home or home and community care. The state implemented “Choices for Care” program in October 2005. Before program implementation, 2,286 people were in nursing homes, 1,207 were receiving home and community based services, and 207 were on a waiting list. As of December 2007, the number of nursing home residents had dropped to 2,070, while the number of people receiving HCBS had increased to 1,875. As of April 2008, 31 people were on a waiting list for services.

In 1996, the Vermont legislature enacted Act 160, which required the state to shift dollars saved from reduced Medicaid nursing home utilization to HCBS. The original goal was to serve a minimum of 40 Medicaid home and community-based clients for each 60 Medicaid-funded nursing home residents per county. In 2008, the state set a new target of 50-50. When Act 160 was passed, 88 percent of Medicaid LTC dollars were allocated to nursing home care and 12 percent to HCBS. In 2008, the allocation is 62 percent for nursing homes and 38 percent for HCBS.

New Mexico is implementing a coordinated, managed LTC program—“Coordination of Long-Term Services,” or “CoLTS”—for up to 38,000 Medicaid-eligible individuals, including those who have dual eligibility for Medicare and Medicaid, those who need a nursing facility level of care, and those who participate in the state’s disabled and elderly waiver program or receive services under the Medicaid State Plan personal care option.

CoLTS began July 1, 2008, in selected counties and will provide primary, acute, and LTC services in one integrated program. CoLTS provides an example of a state teaming up with Medicare health plans to develop a coordinated system.

Massachusetts spent more than five years developing its “Community First” LTC policy, which is grounded in the People’s Plan, an Olmstead plan developed by a group of consumer advocates in 2002. That plan provided the starting point for discussion of an Olmstead Planning Committee convened in late fall 2007. The committee reviewed prior and current initiatives designed to achieve Olmstead objectives and identified gaps in needed services. The outcome is a “Community First Olmstead Plan” announced in the fall of 2008.

The plan outlines the state’s short-term (18 month) strategic plans for regulatory, fiscal and program development to facilitate the growth of a more flexible community-based services delivery system. Goals include:

- Helping individuals transition from institutions into the community,
- Expanding access to community-based long-term supports,
- Improving the capacity and quality of such community supports, and
- Expanding access to affordable and accessible housing and supports.
Specific timetables set for individual projects include:

- Implementing a Long-Term Options Counseling process to help people who are making the transition from nursing homes to the community (end of 2008),
- Developing recruitment and retention strategies to expand the LTC workforce (June 2009), and
- Analyzing options for supporting caregivers, such as paying spouses (September 2010).

VI. HOW CAN LEGISLATORS APPROACH LONG-TERM CARE REFORM?

The state examples described here illustrate various strategies states have adopted to meet unique LTC needs. No one formula will fit every state due to various economic constraints and the state’s unique accomplishments to date in revamping and reforming its LTC system.

Still, major change can come from political leadership in every state. Legislators can be leaders in identifying the issue of LTC system reform in their state and in supplying the vision of major systemic change. They can help state agencies find the resources to develop changes and engage other policymakers and stakeholders. They can initiate an assessment of the status of LTC services and the possible gaps in service delivery and funding, possibly using task forces or work groups to bring more stakeholders into the process.

THE INITIAL ASSESSMENT

Legislators can use a variety of steps to begin. These steps can be a logical outgrowth of committee work or could be undertaken with other legislators who also want to advance the LTC reform agenda. Planning could involve the following initiatives:

- Determine the appropriate executive branch officials with whom to engage;
- Build coalitions with consumers, families, advocates and providers;
- Develop a comprehensive state LTC strategy;
- Set priorities and timetables;
- Require periodic updates from the lead agency responsible for LTC initiatives that include goals and measurements of progress in meeting the goals.

FEDERAL RESOURCES TO GET STARTED

According to the Centers for Medicare and Medicaid Services, researchers have identified eight system components associated with comprehensive LTC reform and balancing: a consolidated state agency, single access points, institutional supply controls, transition from institutions, continuum of residential options, HCBS infrastructure development, participant direction, and quality management.

For states that are considering balancing initiatives, technical tools are available from the federal government and reports from other states can help develop a planning process, administrative and/or budgetary reorganization steps, an implementation plan, and evaluation measures. For example, the Centers for Medicare and Medicaid Services developed a Technical Assistance Guide and State Profile Tool that can help legislators to develop and policymakers implement LTC planning and strategy.

The federal agency developed a model profile of Pennsylvania’s LTC system that other states can replicate. States can use the profile to identify service gaps and opportunities for improved coordination among long-term support programs and with other health and social services. The Technical Assistance Guide provides questions related to each of eight components that policymakers can use to assess their state LTC system’s strengths and weaknesses. In 2007, the Centers for Medicare and Medicaid Services awarded grants of approximately $500,000 each to 10 states (including Iowa and Minnesota) to use the model to develop a state LTC profile.14
EVALUATING PROGRESS

Policymakers also can use several approaches to evaluate progress toward balancing. These include calculating:

- The percentage of total Medicaid LTC spending that goes toward HCBS over time and compared to other states.

- Increases in the percentage of Medicaid LTC spending on HCBS (although if spending has historically been low, the percentage increases can be misleading).

- Changes in the number of Medicaid beneficiaries who receive HCBS and dollar changes in expenditure amounts. Using data points, such as changes over a five-year period, can be helpful.

It is equally important for a state to determine progress in reforming LTC services and supports by developing and using measures of consumer satisfaction with the services received and the choices available.

VII. MOVING FORWARD

Although Medicaid is the major financer of publicly funded LTC, problems with LTC services and supports involve much more than Medicaid. Fixing LTC also means looking at improving Medicare, which has a key role in promoting person-centered services due to its coverage for preventive services, drugs and post-acute care. Many critical services such as housing and transportation are not covered by Medicaid. Beyond both Medicare and Medicaid, other solutions could involve tax credits and public/private partnerships. Future papers in this series will discuss these LTC financing strategies and other LTC issues such as support for family caregivers and improved conditions for the direct care workforce.

Whatever a state’s circumstances, strong leadership and political will are crucial to meeting the desire of senior citizens and people with disabilities to live independent lives of choice and dignity. This challenge is made even more daunting because of the difficult economic conditions states face today. Progress has been made, however, in states that had the vision and courage to make major systemic changes to LTC delivery and financing systems, and their initiatives can be guideposts for action.
VIII. FOR FURTHER INFORMATION

Information on the CMS technical assistance tools described above and state reports that describe LTC reform initiatives can be found at the following sites.

The Model State Profile for Assessing a State Long-Term System and the Technical Assistance Guide to Assessing a State Long-Term Care System are available on the CMS website at: www.cms.hhs.gov/NewFreedomInitiative/037_StateProfiles.asp

For case studies of the activities of eight states in balancing their LTC systems, see the University of Minnesota Long-Term Care Resource Center: www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/Rebalancing_state_ltc_systems_case_studies.htm

For publications of the AARP Public Policy Institute on LTC balancing, see:


STATE REPORTS


NOTES


6. For the first time in State FY 2006, $30 million in state and federal funds were allocated to rebalance the Medicaid long-term care budget to more equitably distribute funds between nursing homes and HCBS. The state budget now includes a line item dedicated to the global budget initiative.

7. A “fast-track process” helps to ensure that, while eligibility is being determined, Medicaid funds are available to pay for HCBS. Otherwise, a consumer might be forced to enter a nursing home to receive needed services for which a Medicaid entitlement exists.

8. To obtain a copy of the first annual report on the legislation, see www.state.nj.us/health/senior/documents/idc_report_108.pdf.

9. Reduction in beds per 1,000 people age 65 and older is a goal of benchmark 4.

10. For an in-depth description of Minnesota’s LTC goals, see www.dhs.state.mn.us/main/groups/aging/documents/pub/dhs16_142277.pdf.

11. Approved slots for PASSPORT in SFY 2006 were 34,957; the average daily program census was 26,000.


13. Of the 12 counties that had nursing homes, six had met or exceeded the 40/60 goal in 2006.

AARP

AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. AARP does not endorse candidates for public office or make contributions to either political campaigns or candidates. We produce AARP The Magazine, the definitive voice for 50+ Americans and the world’s largest-circulation magazine with over 33 million readers; AARP Bulletin, the go-to news source for AARP’s 40 million members and Americans 50+; AARP Segunda Juventud, the only bilingual U.S. publication dedicated exclusively to the 50+ Hispanic community; and our website, AARP.org. AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

NCSL

The National Conference of State Legislatures (NCSL) is the bipartisan organization that serves the legislators and staffs of the states, commonwealths and territories. It provides research, technical assistance and opportunities for policymakers to exchange ideas on the most pressing state issues and is an effective and respected advocate for the interests of the states in the American federal system.

ABOUT THE PROJECT

The National Conference of State Legislatures (NCSL) and AARP are collaborating on an 18-month project to bring together state legislators, staff and volunteers to identify long-term care issues and challenges. Through a series of issue briefs and policy statements, as well as forums and webinars, this collaboration—The Long-Term Care Reform Leadership Project—will provide lawmakers with the information needed to develop sound statewide policies.