

LONG-TERM CARE

AARP ISSUE BRIEF

BACKGROUND

There is no comprehensive system of long-term care (LTC) or long-term services and support (LTSS) in this country. Yet millions of older adults currently or in the future will receive or provide LTSS. Currently, there is a lack of affordable public and private financing options for individuals to pay for the services they need to help them with basic activities—such as eating, bathing, and dressing. Planning ahead can help with paying for services and give individuals more choices, but financing options are limited, and quality is inconsistent. LTC is not generally covered by private health insurance or Medicare. While private LTC insurance and some public programs pay for some LTSS, these services are most commonly provided by family caregivers or paid for out-of-pocket until individuals impoverish themselves and become eligible for Medicaid. In fact, the estimated economic value of family caregiving was about \$375 billion in 2007. This unpaid care is the backbone of LTC in this country. Yet family caregivers are not receiving adequate support—such as information, education, training, and respite care—to help them with their caregiving roles and enable their loved ones to remain at home, potentially delaying or preventing more costly institutional care.

Medicaid is the largest payer of LTSS in this country, yet it has a bias toward institutional settings, rather than home- and community-based settings, where individuals prefer to receive services and where services can often be provided at lower cost. For example, a recent AARP report found that, nationally, 75 percent of Medicaid LTC spending for older people and adults with physical disabilities paid for institutional services, with only 25 percent going to home- and community-based services (HCBS). Yet among individuals age 50 and older, 89 percent say they want to remain in their homes for as long as possible. In addition, Medicaid is available to only those who have low incomes and limited assets or who face catastrophic costs.

Individuals with multiple chronic conditions often see many providers, take numerous medications, and receive services in multiple settings. Care coordination and communication across providers and settings with the individual and their caregiver is critical, can improve health care quality and outcomes, and potentially save money. Ensuring quality of care and quality of life across all settings is vital and requires improved oversight and an adequate, stable, and well-trained workforce at all levels.

Much progress and innovation on LTC has occurred at the state level, but there are important steps that the federal government can take to help consumers and their families, expand HCBS, improve quality across all settings, strengthen the LTC workforce, and provide better LTC financing tools. Any LTC solution should involve the shared responsibility of government, individuals, and the private sector. Action is needed now so that consumers have more choices, do not impoverish themselves to get the services they need, and so that a strong infrastructure and system is in place to provide assistance to the growing number of older adults and younger people with disabilities who need LTSS. Congress should also consider improvements to LTSS in the context of health care reform.

LEGISLATIVE AND REGULATORY ACTION

- Home- and Community-Based Services: Expand HCBS by enacting legislation such as the Empowered at Home Act (S. 3327/ H.R. 7212);
- Chronic Care Coordination: Enact legislation to improve chronic care coordination for those with multiple chronic conditions, such as the Independence at Home Act (S. 3613/H.R. 7114);

- Family Caregiving: Enact legislation to support family caregivers, such as establishing a Medicaid family caregiver assessment demonstration program to help determine the needs of and get supports to primary family caregivers;
- Nursing Home Quality: Enact legislation to increase accountability and transparency and improve nursing home quality, such as the Nursing Home Transparency and Improvement Act (S. 2641);
- Workforce: Ensure a workforce that meets the needs of an aging population by enacting legislation, such as the Caring for an Aging America Act (S. 2708/ H.R. 6337);
- Elder Abuse and Quality: Enact legislation to improve the prevention, detection, and response to elder abuse, such as the Elder Justice Act (S. 1070/ H.R. 1783);
- Quality: Build on a successful pilot program on LTC employee background checks by enacting legislation, such as the Patient Safety and Abuse Prevention Act (S. 1577);
- Nursing Home Arbitration: Protect the rights of nursing home residents and their families by enacting legislation, such as the Fairness in Nursing Home Arbitration Act (S. 2838/ H.R. 6126); and
- Long-Term Care Insurance: Improve private LTC insurance consumer protections and affordability, such as by enacting the Long-Term Care Affordability and Security Act (S. 2337/ H.R. 3363).

On the regulatory front, the new Administration must revise or rescind six harmful Medicaid regulations that Congress put under a moratorium until April 1, 2009. Of particular concern to AARP is the regulation on case management that would impede efforts to get people out of institutions and into HCBS. Other regulatory priorities include revisions to Deficit Reduction Act rules for:

- Asset transfers: To ensure that people who wish to help family members or charities and are not trying to cheat the system are not penalized; and
- Home equity and Medicaid LTC eligibility so people can get the long-term care that they need.

THE COST OF DOING NOTHING

Failure to address LTC issues at the federal level will mean a continued patchwork approach in which: choices are limited and of inconsistent quality; people must impoverish themselves to obtain and may not be able to find the services they need; government frequently pays more for services people do not want; there is a shortage of LTC workers; and, family caregivers are strained and overwhelmed.