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## LD 488 – An Act to Improve Home-based and Community-Based Care in the Maine Care Program

AARP is pleased to support this bill on behalf of our 230,000 members in Maine. We recognize that there are extraordinary challenges ahead facing this committee, indeed this state and country. With that said, we would like to suggest that there are significant opportunities on the horizon if we are bold enough to look past the immediate problems and face the future with our eyes wide open.

Maine is the oldest state in the nation. Maine must improve on our Long-term Services and Supports system if we are going to be a state where people are able to age in place safely and securely. We must begin now. It is time to raise expectations for LTSS performance in Maine and we must move to become a state in which older people and people with disabilities are given meaningful choices, have access to affordable, coordinated services, a high quality of life and care, and support for family caregivers regardless what part of the state they live in.

LTSS encompass a broad range of assistance needed by people of all ages who have physical or mental impairments and have lost or never acquired the ability to function independently. LTSS include help with performing self-care activities and household tasks, habilitation and rehabilitation, adult day services, case management, social services, assistive technology, home modification, some medical care, and services to help people with disabilities maintain employment. They are provided in the home, in assisted living and other supportive housing settings, in nursing homes and elsewhere. Many people with disabilities prefer the term “long-term services and supports,” rather than “long-term care,” because the term “care” may imply dependence and seem paternalistic.

The current system for providing and funding LTSS in Maine is largely uncoordinated, fragmented, and costly. Most services are provided by unpaid family caregivers. Surveys indicate that most people who need LTSS strongly prefer to remain in their homes, especially if less than 24-hour help is needed. When they need or want to move to receive services, people strongly prefer to live in an assisted living residence or other residential setting, rather than a nursing home. In fact, demand for institutional services is predicted to grow very slowly.

Despite large increases in the older population, the number of people in nursing homes has remained about the same. Further declines are likely in the near future as the result of increased service options available to older people with disabilities, the growth of home care and assisted living, increased use of technology, and increased public funding for home- and community-based services.

However because of the high cost of services; lack of private, affordable financing options; and limited public funding, people often do not have access to the service options they prefer. Others cannot find the services they need and prefer or are not aware of what is available.

Medicare provides only modest funding through limited coverage of short stays for rehabilitative care in nursing homes and some home health care services. And so the major public financing for LTSS comes through the federally and state-funded Medicaid program. But Medicaid’s stringent financial

eligibility criteria require people to exhaust most of their assets and income to qualify for coverage. Programs to assist unpaid family caregivers are limited, even though they provide the lion's share of LTSS.

Private long-term care insurance is too costly for many older Maine people and may be unavailable to some individuals because of medical underwriting; people with preexisting health conditions, for example, will not qualify for coverage. Consumers who purchase private insurance cannot always predict their future needs accurately. As a result, their policy may not provide the services they need or want at the time they attempt to use benefits.

Yet the number of people needing LTSS is expected to rise after 2021, when the oldest baby boomers begin to turn 75, and will continue to rise until at least 2050, when all of the boomers reach late old age.

Given that most people with LTSS needs receive services from family caregivers, it is important to look at changing demographics. As the population most likely to need services (age 75+) increases, those in the primary caregiving years (40-54) are remaining relatively stable. The result is a dwindling supply of potential caregivers.

To address this rising demand, Maine needs a comprehensive state LTSS policy. Without it, programs operate individually and fail to achieve the best outcomes for people with health care and LTSS needs. For too long LTSS have lacked a holistic focus—one that helps individuals overcome the full range of obstacles to living in the least restrictive setting possible and maximizes their potential for self-determination.

A comprehensive, person-centered LTSS policy would both serve the needs of individuals and allow efficiencies in public spending. A system that starts with the needs of the individual would address medical, housing, and mobility needs, which could help prevent unnecessary use of institutions and keep people in their homes and communities.

For an LTSS system to be effective, people must be able to access easily an array of affordable choices of services in a variety of settings. This array of services should be high quality and maximize consumers' ability to maintain control over what services they receive and who provides them. Critical to this is the development of state systems that allow people to access a robust range of information and assistance in understanding what services are available and how they might pay for them. Most states are developing Aging and Disability Resource Centers (ADRCs) to be a single source of information and assistance about the full range of services available to people with disabilities, regardless of income or type of disability. A critical function of ADRCs is conflict-free care management services. Care managers who are well-versed in all area services should be available to potential beneficiaries and their families. In order to be "conflict-free," care managers must act without self-interest or financial reward with regard to the services they recommend.

Thank you for the opportunity to address the issues that are raised in this important legislation. AARP stands ready to work with you, the department and all stakeholders who share the view that Maine can be the best state in the country to age in place. We have attached our basic LTSS principles with this testimony for your reference.

John Hennessy  
March 7, 2013

## AARP LTSS PRINCIPLES

The following principles for long-term services and supports (LTSS) are designed to guide the association's efforts to bring about comprehensive reform that includes a public LTSS program and a system of quality assurance and improvement in every setting in which LTSS are delivered. These principles do not address every issue relating to LTSS, but they do provide criteria for evaluating and comparing reform proposals. They also serve to guide the association as it participates in the public debate about LTSS reform at the federal and state levels.

**The design and delivery of all LTSS should promote consumer independence, choice, dignity, autonomy, and privacy. The federal, state, and local governments should recognize and support consumer choices to the maximum extent possible.**

Consumers have the right to decide on and direct the LTSS they receive, unless it is determined that they are unable to do so.

**Public LTSS should give meaningful support to families and friends who provide them.**

Both existing LTSS programs and any new national program should support—not necessarily replace—the care that families and friends currently give. Families and friends need access to assistance so they are not unreasonably burdened and can continue to provide care. This assistance should include respite care, adult day services, programs that help individuals pay relatives and friends who provide care, and other types of help financed through such means as tax incentives.

**Access to a comprehensive range of LTSS should be guaranteed to all who need them, regardless of age or income.**

LTSS programs should base eligibility on a person's physical and cognitive or other mental functioning and on the types of assistance a person needs. Uniform assessments should determine whether a person meets the eligibility criteria for a program and what type and level of services a person requires. Furthermore, financial and functional eligibility should be determined in a timely manner.

LTSS programs should be easy to access and affordable. Consumers and their families should have access to information about the full range of LTSS programs and services that are available to meet their needs. Conflict-free counseling and information should be available to assist families and individuals in choosing the LTSS that align with their preferences. Single points of entry in each state should facilitate system navigation. Services should be affordable for people with moderate and higher incomes and a safety net should be available for those who cannot afford services.

Services should include in-home assistance, community services, a full range of supportive housing options, institutional care, rehabilitative services, and other enabling services, as well as assistive devices and home modifications. Services should be responsive to the needs of the individual and be provided in the least restrictive setting appropriate and should enhance the ability of people of all ages and incomes to participate as fully as possible in all aspects of community living. Wherever possible, consumers should have the opportunity to direct their own services, if that is their preference.

**The federal and state governments must ensure the delivery of high-quality LTSS.**

The maintenance of quality of life is a critical component of LTSS quality and should include measures of consumer satisfaction. Federal and state governments should protect consumers' health and safety by swiftly and vigorously applying sanctions to enforce laws and regulations against nursing homes and providers of home and community-based care. Governments should explore additional methods of protecting people from abuse and ensuring the quality of LTSS, such as incentives to encourage providers to seek continual service improvements.

Services should be organized to promote effective transitions between levels and types of care. LTSS should be effectively coordinated or integrated with health-related services and social supports.

**Provider payments should be adequate.**

Payment to LTSS providers must be reasonable and offer appropriate incentives to deliver high-quality services and supports, including incentives to attract and retain qualified workers and pay them a fair wage and benefits. Reimbursement systems for home, community, and institutional services must respond to clients' needs, promote delivery of quality care, and recognize service outcomes.

**The rights of LTSS consumers should be protected.**

Consumers should have the right to timely information concerning care, including access to their medical records; to meet with advocates; and to express grievances without fear of reprisal. Anyone receiving services from any provider should have a private right of action in court to pursue grievances. Residents of nursing homes, assisted living facilities, or other residential alternatives, should be protected from undue hardship when they are transferred in the event of a facility closing or other circumstance. In addition, the rights of vulnerable persons who need assistance in times of disaster to remain free from harm should be safeguarded.

**LTSS consumers have a right to privacy.**

Consumers, regardless of their source of payment, should not have to share rooms or bathrooms unless they choose to do so. When consumers share rooms, providers must take steps to protect privacy with visual and auditory barriers. Consumers in all LTSS settings should have private areas for visitation, security protections for personal property, and access to private telephones.

**LTSS programs should receive adequate public financing through a social insurance program.**

Under social insurance programs like Social Security and Medicare, individuals pay into the system and are then entitled to benefits when they need them. If the cost is spread across the entire population, universal protection can be affordable and equitable. The US should use its resources to finance an LTSS program through taxes, which would go into a trust fund. Revenue sources could include payroll or other taxes, modest premiums, or other cost-sharing mechanisms.

**Implementation of any comprehensive public program must ensure orderly development of the new system.**

Development of an LTSS infrastructure that will permit the delivery of a comprehensive range of home, community, and institutional services should accompany expanded services. Health care and direct services workers, social workers, case managers, and other needed personnel should be included.

**Private-sector insurance should supplement public LTSS financing.**

A new public program must provide a solid foundation for consumer protection on which the private sector can build. The private sector could supplement the public program with insurance products, which—much like Medigap policies—would cover copayments, deductibles, and services the public program does not provide. Any private-sector approach (e.g., long-term care insurance) should be subject to strong standards that protect consumers from inadequate products and deceptive marketing practices. In addition individuals with insurance

or private funds should not receive preferential treatment in being admitted to nursing homes and supportive housing.

**Public LTSS programs should include cost-containment mechanisms.**

Cost containment could focus on measures to combat fraud, waste, and abuse; promote efficiency in service delivery; tie the amount of benefits to disability levels; and phase in the scope of the public benefit over time. Cost containment should not reduce access to adequate and affordable services and supports.

March 7, 2013