

CHAPTER 1

A CALL TO ACTION

Over 12 million Americans of all ages with functional impairments today rely on personal assistance and other long-term services and supports (LTSS) in their home and community or in an institution to perform daily activities to maintain their quality of living and, when possible, their independence. Most of them receive services and supports from dedicated caregivers that enable them to cope with their cognitive or physical limitations with dignity. The services and supports they receive are provided by family or friends who provide unpaid assistance out of love and commitment and by paid caregivers who have chosen to earn their living in an intensely personal caring profession.

LTSS are essential but costly for individuals with cognitive and functional limitations and their families. Family caregivers sacrifice other family and work responsibilities and bear a financial and emotional burden that can be overwhelming. Paid services and supports are expensive, and when received over an extended period of time, can be financially catastrophic. Individuals and families rarely have sufficient resources (either savings or private insurance) to pay for an extended period of LTSS. Medicaid provides a critical safety net those with few resources or who have exhausted nearly all of their resources paying for care. More than half of the cost of LTSS today is financed by the federal and state government through the Medicaid program.

LTSS have improved substantially in recent decades. Yet problems remain for individuals and families who need care, notwithstanding the commitment and dedication of thousands of paid and family caregivers providing loving and quality services. Paid services and supports are highly fragmented and difficult for individuals and family caregivers to access; they lack the focus and coordination across agencies and providers necessary to ensure the best outcomes for the person and family, and they are provided in ways that can be expensive and inefficient. The needs for LTSS and the costs of paid LTSS must be addressed in the context of the financial pressures for many American families and the fiscal challenges, including population aging and high health care costs, that face our Nation.

A dramatic projected increase in the need for LTSS in coming decades will confront significant constraints in the resources available to provide LTSS. Aging Baby Boomers will grow the numbers of older Americans with physical and cognitive limitations. At the same time, fewer family caregivers combined with more limited personal financial resources to pay for caregiving due to declines in savings rates, retirement asset accumulation, and private insurance purchase, will place increasing pressure on the Medicaid program and the federal and state budgets that

fund it. Governments will have to balance growing LTSS needs with education, public health and safety, and other priorities.

New approaches are needed to bring LTSS care integration, technology, and innovative workforce strategies together to reduce the overall cost of achieving better health and well-being outcomes for individuals and their families. Many persons living with disabilities are able and want to participate in the workforce. Changes are needed to support them so they can receive the LTSS they need. Creative financing efforts are needed to affordably insure the risk of needing LTSS and encourage higher levels of savings. A more accessible and sustainable Medicaid is needed to assure its continued role in guaranteeing the availability of LTSS for individuals and families with few resources to provide for themselves.

Now is the time to put these new approaches and efforts in place if the coming generations of Americans are going to have access to the array of LTSS they will need to remain independent themselves or to assure the safety and well-being of a loved one with substantial physical or cognitive limitations. The need is great. The time to act is now.

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