



Home and Community-Based Services

Introduction

As individuals age, and chronic conditions increase, the need for long-term care services grows. Long-term care refers to a broad range of services, paid and unpaid and provided in a variety of settings, for persons who need assistance with daily activities due to a physical or mental limitation. The availability of formal or informal support and services, an individual's needs and preferences and the ability to finance needed services all play a part in determining the setting in which an individual will receive long-term care services. According to a recent General Accounting Office (GAO) report, of the almost six million adults age 65 and over with long-term care needs, only 20 percent receive care services in a nursing home or other institutional setting, with the remaining 80 percent receiving assistance at home and in the community. Home and community-based care, which allows individuals to maintain their independence and age with dignity in the comfort of their own homes, in familiar neighborhoods and communities, is overwhelmingly the preferred choice of older adults, as well as individuals with disabilities.

Our federal policies do not adequately recognize that the most cost-effective form of long-term care is provided through home and community-based services. These services are currently provided through a fragmented and inconsistent array of federal, state, local, and private support services paid for through public and private financing. Moreover, despite the substantial role that family caregivers play in providing long-term care, the United States lacks a coherent set of policies to assist informal caregivers. Demographic changes, the aging of the 77 million baby-boomers, and increasing longevity will intensify current delivery and financing difficulties.

The 1999 Supreme Court *Olmstead v. L.C.* decision has accelerated the shift of national policy toward home and community-based services. In *Olmstead*, the Court ruled that the unnecessary segregation of individuals in long-term care facilities constitutes discrimination under the Americans with Disabilities Act (ADA). States are required, when it is appropriate and reasonable to do so, to serve individuals with disabilities in community settings rather than in institutions. The Court directed each state to develop a comprehensive, effective working plan to place qualified individuals in less restrictive settings and to assure that people come off waiting lists at a reasonable pace.

Olmstead affects those at risk of institutionalization as well as those currently institutionalized. Therefore, any reform efforts brought on by the decision must involve changes not only to the long-term provision of public health services (primarily Medicaid) but also to housing, transportation and other fundamental support services that are essential to fully integrate individuals with disabilities into least restrictive settings.

Executive Summary

A comprehensive national policy that shifts the focus and funding of long-term care to community-based services is essential to meet the needs and address the desires of America's aging population. Independence, dignity and choice are strongly held values by all Americans, and individuals with physical or cognitive limitations and impairments are no exception. By shifting national policies toward home and community-based services, the quality of life of older adults will improve, taxpayers will be spared the cost of premature and expensive institutional care, and our nation's core values will be honored.

A sound home and community-based system of long-term care provides a coordinated and broad range of services that address the medical, social and environmental needs of the individual. n4a believes the following principles must be adhered to for a home and community-based system to best meet the needs of those it serves, including the not-too-distant future needs of the baby boomer generation.

Reform Medicaid

Medicaid, the largest public program financing long-term care, has an inherent bias toward institutionalization. Congress established the home and community-based service waiver in 1981 to attempt to reduce this bias. The Medicaid waiver program gives states the option to apply for waivers to fund home and community-based services for people who meet Medicaid eligibility requirements for nursing home care. A recent study by the Assistant Secretary for Planning and Evaluation with the U.S. Department of Health and Human Services found that average spending on the aged and disabled under the Medicaid home and community-based waiver saved money – providing for an individual under the waiver program costs \$5,820 a year compared to \$29,112 for nursing home care. Even so, nursing home care remains a basic service under Medicaid, while states still face a burdensome waiver process to offer home and community-based services.

Build Upon the Successes of the Older Americans Act

The Older Americans Act (OAA) has been the foundation of services for older adults throughout the country since its enactment in 1965 and forms the nucleus of a national system of home and community-based services. OAA funds, and the services they make possible, are augmented by leveraging state and local government funding, as well as private sector, foundation, participant and volunteer contributions. OAA funding has not kept pace with inflation or the growing population of individuals eligible for services. Significant increases in federal appropriations are crucial to assure the availability of services and programs that enhance the ability of older Americans to live with maximum independence.

Enhance Support for Family Caregivers

The majority of people of all ages with chronic disabling conditions rely on family members or friends as their primary source of care. Nearly one out of every four households (23 percent or 22.4 million households) is involved in caregiving to persons age 50 or older. Among older adults with long-term care needs, nearly 95 percent receive some or all of their care from informal caregivers who often suffer emotional, physical and financial hardships as a result of caregiving. Furthermore, cultural and demographic changes are reducing the pool of available caregivers just as the baby boomer generation approaches retirement age. The National Family Caregiver Support Program, enacted in 2000 as part of the Older Americans Act reauthorization, and numerous state programs provide support services for caregivers, but current federal funding is insufficient to meet caregiver needs.

Link Affordable Housing with Needed Support Services

Housing security is critical to the health and well being of older adults. The home and community-based system will not succeed without the provision of affordable and accessible housing for older adults. Greater coordination needs to occur between housing and service providers to guarantee that support services, such as meals, personal assistance and housekeeping, as well as health services, are readily available and easily obtainable. While policy initiatives are underway to increase existing assisted living facilities stock, convert existing public housing into accessible housing, and provide increased coordination of support and housing services, progress has been slow and more commitment to these efforts by policymakers is needed.

Develop Systems to Help Older Adults Retain Mobility

Mobility is essential for an individual to live at home and in the community. Transportation provides necessary access to medical care, shopping for daily essentials and the ability to participate in cultural, recreational and religious activities. Feelings of isolation and loss have been reported among older adults who can no longer use personal automobiles. Public policy must focus on the provision of safe, reliable and convenient alternative means of transportation for those for whom driving is no longer an option, as well as on efforts to help older adults retain their licenses and cars for as long as possible.

Design Responsive Mental Health Services

Good mental health is fundamental to the well being of older adults and has a major impact on quality of life and optimal functioning. Yet, as the U.S. Surgeon General's 1999 report on mental health points out, too many older adults struggle with mental disorders that compromise their ability to participate fully in life. Older adults underutilize mental health services, for both social and systemic reasons, and care professionals and social services personnel frequently fail to recognize the signs and symptoms of mental illness. Service gaps, lack of collaboration among service agencies, and shortages of trained personnel also contribute to a poorly functioning mental health service system. Policymakers must work toward resolving current challenges in the design and delivery of mental health services that affect quality of life for the older population.

Expand Nutrition and Wellness Programs

Good nutrition and daily physical activity both play important roles in preventing or forestalling the onset of chronic conditions as well as reducing the effects of existing conditions. Nutrition programs such as congregate and home-delivered meals, provided through the Older Americans Act and other government programs, not only improve participants' dietary intake but also provide a social outlet for older adults at risk of isolation. Unfortunately, long waiting lists for these meals programs exist throughout the country. And while fewer structured programs exist to promote physical activity, the social, economic and health benefits of daily exercise must be recognized. Greater emphasis needs to be placed on the development and expansion of programs that promote sound nutrition and increased physical activity at the federal, state and local level.

Increase Efforts to Prevent Elder Abuse and Neglect

The dependence on others for care and assistance whether at home or in a facility leaves older adults, especially the most frail, vulnerable to abuse, neglect and exploitation. Adult protective services are designed to reduce the incidence of abuse and neglect and are essential to making it possible for older adults to remain safely in their homes and communities. Many older adult victims do not report abuse and many cases are not prosecuted. Staffing shortages, poor training and heavy caseloads contribute to unsatisfactory protective services. Greater outreach and educational efforts and increased collaboration among service providers at the federal, state and local level are important measures that can be taken to prevent and decrease all types of elder abuse.

Collaborate on Solutions to Workforce Shortages

At a time when an increasing percentage of the population needs direct care services, our nation is facing a serious shortage of workers in this industry. Paraprofessional personnel shortages can be attributed to, among other things, low pay, inadequate employee benefits including lack of health insurance, insufficient training and minimal chance for career advancement. Moreover, health care agencies have a hard time maintaining employees due primarily to poor reimbursement rates from both public (Medicare, Medicaid) and private providers. Furthermore, the care that is provided by these workers is undervalued by society. Policymakers need to work collaboratively with workers unions, service providers and consumers to recruit and retain a stable, reliable workforce.