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Issue Brief

In Pursuit of Long-Term Care: Ensuring Access, Coverage, Quality

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Introduction

Providing accessible, affordable, and high-quality long-term care services to an aging population presents a growing challenge to long-term care providers. As the oldest members of the baby boom generation approach retirement, federal and state policymakers are exploring policies to care for the increasing number of elderly and to finance expanding long-term care needs. Other concerns include how to provide an adequate mix of institutional care and home and community-based services and how to monitor the quality of services delivered in these settings.

The Growing Need for Long-Term Care

Long-term care refers to a wide range of supportive, medical, personal, and social services for people limited in their ability to function independently and to perform everyday activities, whether due to injury, chronic illness, or aging.[1] Currently, more than 12 million people, 6.6 million of whom are elderly, receive long-term care assistance.[2] Of elderly long-term care recipients, 1.5 million reside in an institution such as a nursing home and the remainder receive care in their homes or communities. Compared with the rest of the population, long-term care users are disproportionately female, low income, and very old, and they live alone or with a relative other than a spouse. In general, the requirement for long-term care services is measured by the need for assistance in performing basic activities of daily living (ADLs), such as eating, bathing, and dressing, and instrumental activities of daily living (IADLs) necessary for maintaining independence, such as preparing meals and shopping.[3]

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The likelihood of needing long-term care increases with age, and the elderly population is growing. Population aging reflects high birthrates between 1946 and 1964, improvements in medical care, and a longer life expectancy. The U.S. Census Bureau estimates that the over-65 population will grow from 36 million (about 13 percent of the population) in 2000 to 78 million (20 percent) in 2040.[4] People age 85 and older constitute the fastest-growing population, projected to increase from four million (11 percent of the elderly) in 2000 to 14.5 million (18.6 percent of the elderly) in 2040.[5] Estimating the magnitude of future demand for long-term care is difficult. The number of elderly is expected to increase, but the prevalence of disability among the elderly has decreased by 1 percent or more per year for several decades.[6] This could offset some of the overall increase in demand for long-term care.

Meeting the Demand for Long-Term Care

While future demand for long-term care services may exceed supply, providers have difficulty meeting even current need. Despite all of the long-term care options available, many older people face significant barriers to obtaining these services. Medicaid is targeted to the poorest population, but many who are not very poor cannot afford paid help. A variety of public and private agencies provide long-term care services and this fragmentation can impede access. Changes in family structure, such as smaller and more geographically dispersed families, can limit the pool of potential informal caregivers. People without informal caregivers often are forced to leave their homes and seek institutional care. Most elderly and disabled people say they prefer to remain at home rather than move into nursing homes, but many families cannot provide the appropriate level of informal care or cannot afford formal home health care. Due in part to these access barriers, one in five elderly persons with long-term care needs living in the community reports an inability to get appropriate care.[7] People with unmet needs are disproportionately severely impaired, living alone, and poor or near-poor.

The anticipated need for institutional and community-based long-term care services may be greater than states' ability to pay for it. Recent federal policy changes in Medicare's home health payment methodology led to service reductions that force many beneficiaries to seek private, state, and Medicaid-funded alternatives to supplement or replace their Medicare home health services.[8] States largely control who gets what services under Medicaid by determining eligibility levels, establishing limits on total enrollment, targeting programs to selected areas and population groups, and regulating the supply of nursing home beds. These different choices produce a large cross-state variation in Medicaid long-term care spending and disparities in access to Medicaid-funded long-term care services.[9]

Private long-term care insurance can reduce potential catastrophic financial losses for the elderly and relieve some of the financial pressure on public long-term care programs. In a recent survey of the noninstitutionalized elderly, over half of private long-term care insurance claimants said that without their policy they could not afford their current level of services, would have to consume fewer hours of paid care, and would seek institutional alternatives to their home health care arrangements.[10] Yet, challenges to expanding the long-term care insurance market persist. Only a small number of employers sponsor group coverage and take-up rates are low, with less than 10 percent of eligible employees purchasing coverage.[11] The affordability of long-term care insurance is a key factor in the decision to purchase and retain a policy. A recent study estimates that coverage is affordable for only 10 to 20 percent of the elderly, which could explain why less than 10 percent of the elderly overall have purchased long-term care insurance.[12] Unfamiliarity with long-term care policies, uncertainty about the value of coverage relative to the premium, and underestimation of the need for long-term care insurance also may deter people from purchasing a private policy.

The Changing Nature of Long-Term Care Services

Long-term care can be provided in a variety of settings. Although the 17,000 nursing homes in the U.S. may be thought of as the predominant setting for long-term care, most elderly who need care live in noninstitutional settings. In 2000, 4.5 percent of the elderly population (approximately 1.5 million) resided in nursing homes, compared with 5.1 percent in 1995.[13] The majority (87 percent) of long-term care recipients resided in the community and received informal (unpaid) care from family and friends.

Home and community-based alternatives to nursing home care include assisted living facilities, home health care, adult day care, and hospice care. States reported a total of 13,537 licensed home health care agencies in 1998, an increase of 326 percent from 1989.[14] Three factors fueled this growth: consumer preferences for home care over nursing home care, policy changes, and pressures on state Medicaid budgets to reduce levels of institutionalization.

In 1999, every state provided home and community long-term care services through Medicaid. The Medicaid Home and Community-Based Service (HCBS) 1915(c) waiver program allows states to fund these services at a cost no higher than that of institutional care for people who meet Medicaid eligibility requirements for nursing home care. States can provide services not usually covered by the Medicaid program, including case management, home health care, adult day care, and respite care, if these services are required to prevent institutionalization. States can design and operate multiple waiver programs and tailor services to best meet the needs of the population they wish to serve. By 1998, the number of Medicaid recipients who received home health or community-based services was similar to the number of Medicaid recipients receiving nursing facility services.[15] Currently, 242 HCBS waiver programs operate in every state except Arizona and serve 262,000 people.[16]

Community-based long-term care has assumed new urgency since the U. S. Supreme Court's 1999 decision in L.C. & E.W. vs. Olmstead. The Court ruled that under the Americans with Disabilities Act (ADA), states must serve people with disabilities (including the elderly) in the setting most appropriate to their needs, whether institutional or community-based. The Olmstead decision means that the disabled should not be institutionalized if they can be served more appropriately in a less restrictive community setting. As a result of this ruling, states may need to accelerate efforts to provide community-based long-term care services to the elderly.[17]

Long-Term Care Financing

Long-term care is expensive, with costs for a year in a nursing home costs averaging $55,000.[18] The system of financing care is characterized by a limited private insurance market covering few elderly and comprehensive public coverage available only to the poor. In FY1999, spending on long-term care for persons of all ages was $133.8 billion, almost 13 percent of total personal health spending; it is expected to rise to $207 billion by 2020.[19] Institutional care comprised 67 percent of FY1999 spending, and the remainder was targeted to home and community-based services.

Through Medicaid and Medicare, the government is the single largest payer of long-term care costs. Medicaid, the largest public source of funding, accounted for 45 percent of all long-term care spending, 46 percent of nursing home revenues, and 38 percent of home care revenues in 1998. Of the $68 billion spent by Medicaid on long-term care in FY2000, 73 percent financed institutional care.[20] The program covers the cost of care for two-thirds of nursing home residents. Medicare finances 16 percent of long-term care overall, 12 percent of nursing home care, and 27 percent of all home health care. Medicare coverage of long-term care is limited because it is tied to the need for skilled services subsequent to a hospital discharge. Other sources of public funding for long-term care include the Social Services Block Grant, the Older Americans Act of 1965 (OAA), and state supplements to Supplemental Security Income (SSI). These programs, administered by states, provide a range of home and community-based services to various groups, including those with low incomes and people aged 60 and over.

The largest source of private financing and the second largest source of funding overall is individual out-of-pocket contributions, which financed 27 percent of long-term care and one-fifth of home care spending in 1998. In 1993, an estimated 36 percent of all nursing home residents, and 75 percent of those with lengths of stay of at least one year, spent 40 percent or more of their total income and nonhousing assets on nursing home care.[21] Private long-term care insurance currently finances less than 10 percent of long-term care (about $14 billion), constituting 5 percent of nursing home spending and 11 percent of home care spending.[22] Long-term care insurance is available for purchase in the individual market and as a voluntary group policy option through some employers. Approximately 4.1 million persons had policies in 1998, compared with 1.7 million in 1992.[23]

Ensuring the Quality of Long-Term Care Services

In 1986, the Institute of Medicine (IOM) released a report that documented widespread quality of care problems in nursing homes.[24] The report resulted in the passage of nursing home reform legislation as part of the Omnibus Budget Reconciliation Act of 1987. Research has shown that the percentage of Medicare and Medicaid patients in a nursing home is an important factor in quality. Nursing homes have historically considered Medicaid reimbursement rates to be low and prefer private pay patients. In 2001, the IOM released a more comprehensive report on the quality of long-term care that identified problem areas and offered recommendations for quality improvements to federal and state policymakers.[25]

Federal and state governments share responsibility for regulating long-term care quality. The Centers for Medicare and Medicaid Services (CMS) sets standards for nursing homes, which must comply to receive Medicare and Medicaid funds. By law, nursing homes are inspected annually and can be fined up to $10,000 for each serious incident that threatens residents' health and safety. Recently, CMS implemented new quality enforcement regulations, such as new enforcement tools; strengthened federal oversight of state nursing home inspections and nursing home health and safety standards; introduced more effective, more consistent, and less predictable state inspections; and launched initiatives to help consumers make informed choices about nursing facilities.[26] Since 1998, the proportion of deficiencies resulting in harm to nursing home residents has decreased by 35 percent.[27] Yet, concerns about the quality of nursing home care persist. Recent reports indicate that about 25 percent of all nursing homes continue to have serious deficiencies.[28] Research into federal and state regulation has raised questions about its effectiveness in promoting the quality of institutional long-term care.[29]

Questions about the effectiveness of state and federal regulatory policies extend beyond nursing homes to alternative long-term care settings, such as home and community-based services and residential care facilities. States attempt to ensure quality of care in HCBS waiver programs through monitoring activities, consumer complaint programs, and licensing, certification, and regulatory requirements.[30] However, little is known about the quality of home and community-based services and care provided by home health agencies.[31] Challenges to ensuring the quality of noninstitutional care include the difficulty of monitoring home and community-based services, where recipients are dispersed and the delivery of care is less visible; states' inexperience in regulating noninstitutional care; and the difficulty of measuring quality when professional disagreement exists about quality standards.

Enhancing the Long-Term Care Workforce

Providing high-quality long-term care requires an adequately trained and skilled workforce. Registered nurses, licensed practical nurses, nursing aides, and home health aides represent the largest component of the paid long-term care workforce. The quality of care often depends on their performance, but professional standards vary across states and long-term care settings. Research suggests that inadequate staffing levels may be related to problems with the quality of nursing home care.[32] Low wages and the difficulty of the work hinder hiring and retaining qualified long-term care workers, leading to high turnover and staff shortages. One nursing home-based initiative, Wellspring Innovative Solutions, Inc. in Wisconsin, strives to improve nursing home quality by improving clinical practice and reducing staff turnover.[33] Based on the idea that the individual worker is fundamental to quality improvement, the Wellspring model empowers all nursing home staff to make decisions that affect quality of resident care.

Given current staff shortages, the future demand for long-term care services will likely outstrip the supply of qualified workers to provide such services. Improving the workforce could be difficult without increased resources. Higher payment does not ensure high quality, but payment rates can be too low to support adequate quality. Generally, little is known about the effect of reimbursement on quality of care in nursing homes, and even less about its effect on home and community-based services. In its most recent report, the IOM called for more research into the relationship between quality and costs of long-term care and how the method of payment, independent of its level, affects quality. The IOM also suggested that wages, benefits, and working conditions should be improved to recruit and retain a skilled workforce.

Delivering Long-Term Care

Broad policy approaches advanced to ensure the accessibility and affordability of long-term care include enhanced social insurance coverage of long-term care and stronger tax incentives for private financing. Policymakers have proposed expanding coverage of long-term care services for chronically dependent individuals through Medicare, by expanding Part A coverage of nursing facility services and providing for coverage of home care services under Part B. Alternatives for improving the current system include expanding the supply of home and community-based services, promoting the purchase of private long-term care insurance policies, developing programs that support informal family caregiving, and integrating acute and long-term care services.

Over the last decade, state Medicaid spending has shifted toward home and community-based care as a result of expanded Home and Community-Based Service waiver programs. These services accounted for 16.6 percent of all Medicaid long-term care services in 1999, compared with 4.4 percent in 1990.[34] CMS also provides resources, known as Real Choice Systems Change Grants, to help states develop long-term care systems that emphasize home and community-based alternatives to institutional care. Congress appropriated $50 million to CMS in FY2001 for this initiative.[35]

Recent congressional initiatives aim to increase the use of private insurance by providing a tax deduction for the cost of long-term care insurance, allowing long-term care insurance in employer cafeteria plans, and expanding public-private partnership programs that combine private insurance benefits and the Medicaid program. Starting in 2002, federal employees will be able to purchase long-term care insurance through the Federal Employees Health Benefits Program. Eligible individuals who opt to purchase insurance would be responsible for 100 percent of the cost of the premiums. The federal Office of Personnel Management (OPM) estimates that 20 million people will be eligible for coverage under the program, and that between 300,000 and 600,000 eligible employees will purchase coverage.[36] Tax incentives are another mechanism to increase insurance coverage. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provided for favorable tax treatment of long-term care insurance premiums, and as of August 2000, 23 states provide either tax credits or tax deductions to individuals or employers who purchase insurance.[37]

Encouraging and supporting family caregiving is another strategy to improve the system. In 2000, Congress enacted the National Family Caregiver Support Program as part of the Older Americans Act Amendments of 2000 (P.L. 106-501). The program is intended to provide information, assistance, and respite care services to family caregivers. Respite care offers a temporary break from caregiving responsibilities. These services and supports may delay or prevent the need for institutionalization. The FY2001 appropriation for the program is $125 million. Both Congress and the Administration support proposals to give tax credits to family long-term caregivers.

Better integration of care services, programs, and funding could increase access and improve the quality and efficiency of care. An example of such integration is the Program of All-Inclusive Care for the Elderly (PACE). PACE projects include a full range of acute and long-term care services, including all Medicare and Medicaid services made available by a state, to Medicaid-eligible individuals. PACE services are generally offered in an adult day care setting, and can permit recipients to live at home rather than be institutionalized. PACE projects receive a fixed monthly payment per enrollee from Medicare and Medicaid.[38] Currently, 25 PACE sites operate in four states, with plans for projects in an additional 10 states. Another example of integrated services and financing is the Medicare/Medicaid Integration Program (MMIP), sponsored by the Robert Wood Johnson Foundation.[39] MMIP projects, underway in 13 states, target the elderly population dually eligible for Medicare and Medicaid. The projects integrate Medicaid's long-term care services with Medicare acute services through managed care arrangements. However, despite their promise, integrated service and financing arrangements, including PACE and other similar models, serve a very limited population. As of June 1997, enrollment in PACE projects had reached 3,524 people after seven years of operation in 11 sites.[40]

Conclusion

An improved system of public and private financial support could ensure that all elderly and dis-

abled Americans have access to quality long-term care. To satisfy demand, several steps could be considered to improve the current system, including:

- Orient federal programs and reimbursement toward home and community-based services;
- Remedy quality deficiencies in institutional care;
- Improve the monitoring and measuring of home and community-based service quality;
- Increase the supply of skilled long-term care workers;
- Provide enhanced support to informal caregivers; and
- Reduce variation in the availability of home and community-based services across states.

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