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Long-Term Care: What Direction for Public Policy?

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Summary

Options to improve the financing and delivery of long-term care have been a concern for Congress for some time. National spending for long-term care was almost $160 billion in 2002, representing about 12% of all personal health care expenditures. Almost half of this spending was from the federal-state Medicaid program, primarily for care in institutions, while 20% came from families and individuals. Some people face large expenses for which public assistance is unavoidable. The need for long-term care is expected to grow substantially in the future. While the magnitude cannot be predicted with certainty, total public and private spending for long-term care for the elderly alone could double from 2000 to 2025, even assuming no expansion of public benefits. How these added costs would be financed is unclear.

Issues for Congress include: how to pay for these escalating expenses; how to apportion costs among individuals and families and the public sector; how to help people get the services they want and can afford; and whether there are effective private sector options for financing care. Although Congress at times has considered broad-scale reform, it has primarily made incremental changes to current programs. Policy directions suggested in the past range from additional incentives for private insurance to broader social insurance protection, as well as expansion of home and community-based services and assistance to caregivers.

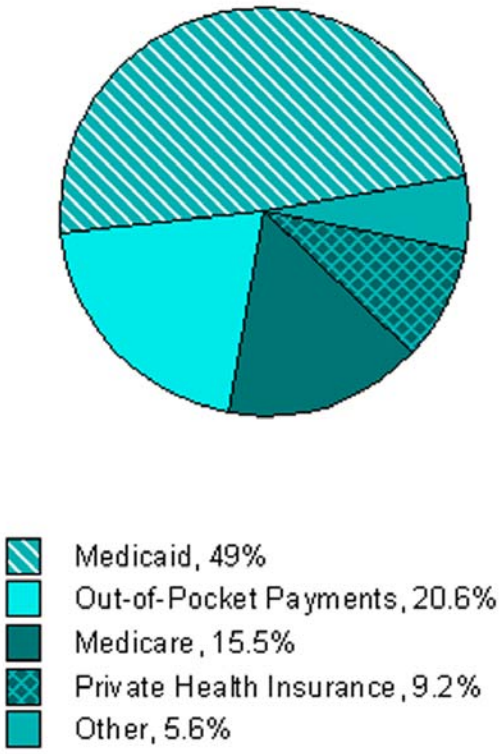
A Growing Need

The need for long-term care — supportive and health services for persons who have diminished capacity for self-care — is expected to grow significantly in coming decades.[1] Almost two-thirds of the people receiving long-term care are over 65, an age group expected to double by 2030. Even faster growth rates are anticipated for people over 85,

[1] The need for long-term care is measured principally by assessing the assistance others must provide with respect to activities of daily living (ADLs). ADLs usually include bathing, dressing, eating, toileting, continence, and transferring from a bed or a chair.

the age group most likely to need care. Demand for long-term care is expected to grow substantially in the future due to increases in longevity, the aging of the baby boom population, and legal actions requiring states to expand home and community-based services to persons currently waiting for publically funded services.

Figure 1. Long-Term Care Spending 2002, $157 billion



Source: CRS calculations based on data from CMS, Office of the Actuary. Does not include spending for hospital-based home health or nursing home care; does not include value of informal care.

Long-term care is already costly. In 2002, $157 billion was spent on long-term care services for persons of all ages, with almost one-half expended through the federal-state Medicaid program. **(Fig. 1).** One-fifth of spending was paid by individuals and families out of their own pockets; Medicare and private health insurance paid for about 16% and 9%, respectively. The $157 billion does not include the cost of informal caregiving provided by families.

While the need for care will climb in the future, whether it will grow as rapidly as the number of elderly is less certain. The prevalence of disability among the

elderly has been declining over the last 20 years.[2] If this trend continues, the elderly of the future may be healthier, which may reduce their need for care. Even so, improvements in the age-specific disability rates need to be sufficiently large to offset projected large increases of persons who are older. Whatever the rate of growth, increases in aggregate demand will likely drive up prices for care, though it might also result in more efficient ways of providing services. While future need is difficult to predict, total public and private spending for long-term care for the elderly could double from 2000 to 2025, even assuming no expansion of public benefits.[3]

How these added costs will be financed is unclear. If economic productivity steadily increases, the nation may have additional resources to spend on long-term care, at least in the aggregate. However, because the population aged 65 and older is growing faster than younger population, the ability of families to provide care and of workers to finance it will be lessened. The shrinking worker/retiree ratio will make it difficult to maintain Social Security and Medicare benefits at current levels, let alone expand other programs for the elderly.

This dilemma — looming costs but uncertain financing — is not news to policymakers. The demographic trends have been apparent for some time, as evident in the long debate over the future of Social Security and Medicare. While their import for long-term care has received less attention, reports of the congressionally-mandated Pepper Commission (the U.S. Bipartisan Commission on Comprehensive Health Care, 1990) called attention to them more than a decade ago.

Current Policy

Public support for long-term care occurs through a number of programs and policies. *Medicaid* pays the largest amount, about $83.8 billion in FY2003 (from both federal and state sources), over two-thirds of which was for services in institutions and the balance for services in home and community-based settings. Medicaid spending for long-term care almost doubled from FY1993 to FY2003. Medicaid has strict financial eligibility tests, but people can qualify for assistance after depleting their income and assets paying for nursing home care. *Medicare* financed $24.3 billion in 2002 for medically necessary, part-time skilled nursing and rehabilitation therapy services at home, and for up to 100 days of skilled nursing facility care following hospitalizations for individuals who need full-time skilled nursing care. Other federal programs such as the *Older Americans Act* and the *Social Services Block Grant* support home and community-based services.

Congress has also adopted a number of incremental changes that provide additional forms of assistance and protections for people needing care:

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[2] Kenneth G. Manton, and XiLiang Gu. *Changes in the Prevalence of Chronic Disability in the United States, Black and Nonblack Population above 65 from 1982 to 1999.* Proceedings of the National Academy of Sciences, May 22, 2001.

[3] The Lewin Group, Inc., *The Long-Term Care Financing Model*, for Dept. of Health and Human Services, 2000.

- *Home and community-based care*. In 1981, Congress gave authority to the Secretary of the Department of Health and Human Services (DHHS) to waive certain provisions of Medicaid law allowing states to provide a wide range of home and community-based services for persons with disabilities of all ages. In 2003, Medicaid spent $18.6 billion for these services, primarily for people with mental retardation and developmental disabilities.

- *Services to family caregivers*. In 2000, Congress authorized a new state grant program under the Older Americans Act to assist family caregivers. The program is funded at $163 million for FY2005.

- *Long-term care insurance*. In 1996, Congress clarified the tax treatment of long-term care insurance and allowed taxpayers who itemize a limited deduction for premiums. In 2000, it established a voluntary long-term care insurance program for federal employees, retirees, and family members as an example for other employers.

Advocates for people needing care express a number of concerns about current federal policy. Medicaid eligibility and services depend in part on state policies and financial support, resulting in disparate service patterns and eligibility criteria across the Nation. While most people needing long-term care receive services in their homes or community based settings, most Medicaid funding goes for institutional care. While nursing home residents typically need more services than people receiving care at home, many advocates argue that federal Medicaid policies have an institutional bias. Some states have made significant strides to develop home and community-based care, but service availability across and within states is uneven. In addition, states are concerned about their ability to continue support for Medicaid long-term care services as the population ages. Other programs administered by states, such as the Older Americans Act and the SSBG, vary widely in scope. Long-term care insurance helps only those who elect coverage.

Most long-term care is provided by families who receive little or no public assistance. Almost 60% of persons age 65 and older receiving care at home or in the community rely exclusively on unpaid caregivers, primarily spouses and children; only 7% rely exclusively on paid services. Family members — predominantly women — who provide care frequently experience enormous strain.

Finally, advocates point to persistent quality problems, most evident in nursing homes. Problems may also occur in smaller assisted-living facilities, group homes and home care. Quality problems are partly attributable to shortages of trained personnel.

What Future Direction?

The growing need for long-term care and concerns about current policy raise important questions about how services might be organized and financed in the future. What role should the federal and state governments play? To what extent should

individuals and families pay for care? When should they pay — only when care is needed, or through lifetime saving or payments for insurance? Are there effective private sector options for financing care? Should families providing care receive tax relief or grant assistance? Who should provide care, and in what settings? What standards are desirable, and how can these be assured?

As it considers these questions, Congress might continue making incremental policy changes like those of the past two decades. On the other hand, incremental changes may not be sufficient to prepare for the large increase in future needs. Demand for care may rise so sharply that programs currently in place will not be adequately financed. Larger, more comprehensive change may be needed.

Whether small or large steps are taken, Congress might consider the different directions described below in developing long-term care policy. None of these directions need be exclusive, and all might be combined to some degree. But the approaches differ in objectives, as well as in degree and type of government involvement.

Assistance to families. Long-term care is expensive, particularly for prolonged periods, and few families can afford to pay costs out of current income. On average, a year's nursing home charges can range from $60,000 to $70,000. Some families are forced to spend down assets quickly, becoming eligible for Medicaid. If families could save more over their lifetimes, these problems might be alleviated, at least for those with the means to save. Policies to encourage saving might include encouraging use of recently authorized Health Savings Accounts or permitting more flexible, tax-advantaged withdrawals from pensions and individual retirement arrangements. However, savings accounts typically do little to help taxpayers with lower incomes, and their effectiveness in encouraging new savings has been questioned in some economic studies.

Long-term care insurance might be the better solution for some families. The number of policies sold increased during the last decade, reflecting growing consumer interest and more governmental oversight. However, long-term care insurance can be expensive if purchased at or near retirement (premiums generally are based upon the age when policies are acquired), and many find it a difficult product to evaluate. More families might obtain the insurance if taxpayers were allowed to deduct premium costs (whether or not they itemize), as some have proposed. Some argue that the cost of the tax deduction to the federal treasury would be offset by future Medicaid savings, but such offsets are speculative.

Encouraging families to finance more of their own long-term care through tax incentives is appealing to those who prefer not to expand government programs. It would likely save some public costs as well, though some object that public subsidies to encourage savings or insurance may largely help families preserve assets, not pay for care. The principal issue with this approach is whether families will actually anticipate the costs they might incur and save enough to cover them or purchase insurance. Some families, particularly those with lower incomes, may be unable to save enough even for short periods of care. Many believe that consumers should be educated about the need to plan for long-term care as they age.

Expanded home and community-based care. Most long-term care is provided informally in the home or the community, not in institutions. Moreover, the home is where most people want to stay, even if they have significant physical limitations. However, home care can be burdensome for family caregivers if needed for a prolonged period of time for highly impaired individuals. There also are significant economic costs to caregivers who must curtail their own employment. Proposals to recognize these burdens and costs in the tax code have included giving caregiving families a tax credit or an additional personal exemption.

Some argue that home and community-based care merits increased public program assistance. One option would be to give this care the same access to Medicaid funding as nursing homes now have. Nursing home care is an entitlement under Medicaid for persons who meet state financial and functional eligibility criteria while home and community-based care is primarily supported through Medicaid waivers of granted by DHHS. Another option might be to establish a new grant program to states or add funding for existing grant programs. However, these approaches might result in more people receiving public support than at present, thus increasing federal costs.

Broaden social insurance. Current policy provides limited social insurance for some long-term care services. Some argue that a new social insurance program is needed to cover long-term care expenses. Models include systems adopted in Germany in 1995 and Japan in 2000. One advantage of social insurance dedicated to long-term care would be that coverage could be universal (at least for those who met a basic eligibility test, such as that for Medicare). On the other hand, if insurance were funded through a payroll tax, the trust fund could be inadequate to provide benefits to those already near old age. Another concern might be that social insurance would reduce the likelihood that families would save or buy private insurance.

One advocacy group, Citizens for Long-Term Care, argues that need for long-term care is insurable and should be considered as part of reforms in Social Security and Medicare financing.[4] Even if long-term care benefits were not expanded under these programs, policymakers might take into account how both programs affect people who need long-term care. Medicare payments for health care, for example, have significant indirect effects on families' ability to pay for long-term care; without health care coverage individuals would have less income and assets to pay for long-term care. Similarly, long-term care costs affect perceptions of the adequacy of Social Security benefits.

Medicaid's coverage of long-term care might be expanded by extending coverage to people who have higher income or more assets than current tests allow and requiring persons to pay premiums and cost-sharing (as is the case in certain state optional Medicaid programs, such as for working persons with disabilities under the Ticket to Work program). However, policymakers may be more concerned about containing, rather than expanding, long-term care benefits. Medicaid expansion may be limited by sharply rising health care costs and the fiscal constraints state

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[4] Citizens for Long-Term Care, *Defining Common Ground: Long Term Care Financing Reform in 2001*. Washington, D.C.

governments face. Medicare expansion may be limited because of rising health care costs and the recently authorized prescription drug coverage.

Hybrid strategies. Some observers argue that long-term care policy should include a mixture of the approaches outlined above, combining some aspects of incentives for private financing as well as public financing. Hybrid strategies might build on current programs and initiatives, expanding some and strengthening others. One rationale for hybrid strategies is that they can better respond to the diverse needs and circumstances of people who need care — for example, those with varying income and assets and impairment levels, and those with and without informal caregivers. Another rationale is that it may be easier to reach consensus for a combination of strategies than for one approach. However, hybrid strategies may have internal conflicts — incentives for one program may be undermined by incentives for others, and coordination of programs may be a continual problem.

One hybrid strategy proposed by the 1990 Pepper Commission was to combine an expanded federal commitment for nursing home and home and community-based care with cost-sharing by individuals and incentives for private insurance. Social insurance would cover home and community-based care and the first three months of nursing home care, with cost-sharing from individuals based on ability to pay. For longer nursing home stays, the Commission recommended a floor of asset protection ($30,000 for individuals and $60,000 for couples, excluding homes, in 1990 dollars). Persons wanting additional asset and income protection could purchase private long-term care insurance.