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Long-Term Care: What Direction for Public Policy?

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Summary

The need for long-term care is expected to grow substantially in the future. While need cannot be predicted with certainty, total public and private spending for long-term care for the elderly could double from 2000 to 2025, even assuming no expansion of benefits. How these added costs would be financed is unclear.

More than $140 billion was spent on long-term care services in FY2000, representing over 12% of total U.S. personal health care expenditures. Increases in life expectancy and the impact of the aging of the Baby Boom population will dramatically affect future demand for services. Long-term care policy in the United States is based primarily on Medicaid, which finances 47% of public and private spending. Medicaid long-term care spending almost tripled during the 1990s, straining state budgets. Many people indicate that the Medicaid financing system is biased toward institutional care. Families and individuals finance about 22% of total spending on long-term care.

Issues for Congress include: how to pay for these escalating expenses; how to apportion costs among the public and private sectors; and how to help people get the long-term care benefits they both want and can afford. Although Congress has considered broad-scale reform in the past, it has primarily made incremental changes to current programs. Different directions have been suggested for long-term care policy, including additional incentives for private insurance, expanded home and community-based services, and broader social insurance protection.

A Growing Need

The need for long-term care — supportive services and health services for persons who have diminished capacity for self-care — is expected to grow significantly in coming decades.[1] Two-thirds of the people receiving long-term care are over 65, an age group

[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.

expected to double by 2030. After 2030, even faster growth rates are anticipated for people over 85, the age group most likely to need care.

Long-term care is already costly. In FY2000, $140.7 billion was spent on long-term care services for persons of all ages. Of this sum, Medicaid and Medicare provided $85.2 billion (60.5%), largely for care in institutions. Private health and long-term care insurance provided $15 billion (10.7%), while individuals needing care and their families paid $31.3 billion (22.2%) from their own income and assets.[2] The $140.7 billion does not include the cost of informal caregiving provided by families. One study estimated that the economic value of these services can range from $140 billion to as much as $389 billion.[3]

While the need for long-term care will surely 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.[4] If this trend continues, the elderly of the future may be healthier, which may reduce their need for care. On the other hand, increased life expectancy of the total population could result in more people needing services. 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 and, for some, less satisfactory care. 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 benefits.[5]

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, financing options may diminish because the ratio of people ages 18-64 to those 65 and over is projected to fall from 4.6 in 2000 to 2.7 in 2030, leaving far fewer workers to support the retired population. 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) and other bodies called attention to them more than a decade ago.

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[2] Center for Medicare and Medicaid Services (CMS)). The remaining 6.6% of expenditures included spending for state and local general assistance and veterans' benefits for nursing home and home care services.

[3] Arno, Peter S., Carol Levine, and Margaret M. Memott. *The Economic Value of Informal Caregiving*. *Health Affairs.* Mar./Apr. 1999, p. 182-188.

[4] Manton, Kenneth G. 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.

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

Current Policy

Medicaid is the primary payor for long-term care; in 2001, it paid $ 75.3 billion for care in institutions ($53.1 billion) and in home and community-based settings ($22.2 billion), an increase of 155% since 1990. Medicaid provides coverage for nursing home care and intermediate care facilities for the mentally retarded (ICFs/MR) and a wide range of home and community-based care for persons of all ages who meet stringent income, asset, and categorical eligibility tests. Many people qualify for Medicaid after depleting their assets and income by paying for nursing home care. In 2000, *Medicare* financed $18.7 billion for a limited range of services. It provides medically necessary, part-time skilled nursing and rehabilitation therapy services at home, and up to 100 days of skilled nursing facility care following hospitalization for individuals who need full-time skilled nursing care. Other programs such as the Older Americans Act and the Social Services Block Grant (SSBG) program support limited home and community-based services.

Congress has adopted a series of incremental changes that provide additional forms of assistance and protections for people needing care. These incremental changes have added to long-term care policy in the following ways:

- *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 2001, $14.4 billion was spent for these services for persons (primarily those with mental retardation and developmental disabilities) who meet state income and asset tests and functional eligibility criteria.

- *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 $136 million for FY2002.

- *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.

Medicaid and Medicare and other smaller social service programs provide a variety of assistance and protections that help families with diverse needs. Nonetheless, advocates for people needing care express a number of concerns about current policy. Medicaid eligibility and services depend in part on state policy and financial support, resulting in disparate service patterns and eligibility criteria across states. Many states are concerned about their ability to continue support for Medicaid long-term care services because of the current fiscal crisis facing most states, and, in the long-term, states will face rising costs as increasing numbers of persons turn age 65. Medicaid waiver programs for home and community-based services tend to be relatively small. 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 and pay for that coverage.

A second concern is that, while most people needing long-term care receive services in their homes or community-based settings, most public funding goes for institutional care. About 18% of the people over age 18 who receive services reside in nursing homes. Yet, in 2001 Medicaid spent almost 71% of its total long-term spending for institutional care. While nursing home residents typically need more services than people receiving care at home, many advocates argue that state and federal 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 inconsistent.

Most long-term care is provided by families that 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, which are subject to federal standards and regular inspections. 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 families pay for care? When should they pay – only when care is needed, or through lifetime saving and/or insurance? Should families needing 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 2 decades. By taking small steps, Congress could support what seems to be working and avoid costly commitments that limit future options. 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. Thus, 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 family caregivers. Long-term care is expensive, particularly for prolonged periods, and few families can afford to pay costs out of current income. A year in a nursing home typically costs about $60,000. Some families are forced to spend down assets quickly, becoming eligible for Medicaid. If families could save more, these problems might be alleviated, at least for those with the means to save. Policies to encourage saving might include authorizing tax-advantaged long-term care savings accounts, perhaps in conjunction with medical savings accounts, and permitting more flexible, tax-advantaged withdrawals from pensions and individual retirement

arrangements. However, tax-advantaged 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 many families. The number of policies sold increased steadily during the last decade, reflecting growing consumer interest and more governmental oversight. However, long-term care insurance can be expensive if purchased in 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 President Bush proposed in his FY2003 budget. 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, for example, 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 these costs or purchase insurance. Perhaps people could be educated about the need for long-term care, notwithstanding tendencies to discount risks that occur late in life.

Expanded home and community-based care. Most long-term care is provided informally in the home or the community, not in nursing homes. Moreover, the home is where most people want to stay, even with significant physical limitations. While family care is usually preferred by persons needing services, it 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. Recent proposals to recognize these burdens and costs in the tax code include a credit for caregiving, as President Clinton proposed in his last several budgets, or an additional personal exemption, as President Bush proposed in his FY2003 budget.

Some argue that home and community-based care merits increased public financial 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. Home and community-based care is not an entitlement and is primarily supported through waivers of Medicaid law granted by DHHS. Another option might be to establish a grant program to states for this purpose, as President Clinton once proposed. However, either approach might result in more people receiving public support than at present, thus increasing federal costs.

Broaden social insurance. Current policy already provides limited social insurance for long-term care, as described above. Medicaid's coverage of long-term care might be expanded, for example, 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 Medicaid state optional programs, such as for working disabled under the Ticket To Work program). However, policymakers may be more concerned about preserving, rather than expanding, long-term care benefits.

Medicaid expansion may be limited by sharply rising health care costs and the harsh fiscal constraints state governments face. Medicare expansion may be limited because of competing initiatives, such as improved prescription drug coverage, as well as by rising health care costs.

Even if long-term care benefits were not expanded under these programs, policy-makers might take into account how both programs, as well as Social Security, 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. 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.

Some argue that a new social insurance program is needed for 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). One concern might be that, if the 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.

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 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 expand the federal commitment for nursing home and home and community-based care, cost-sharing by individuals, and incentives for private insurance. Social insurance would cover home and community-based care and the first 3 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 tax-advantaged private long-term care insurance.