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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, straining both public and private financial resources. Many analysts argue that the current system fails to meet the needs of many people with long-term care needs because of its reliance on institutional care and on informal caregivers who bear most of the burden of care, as well as uneven availability of home and community-based services. Currently, federal programs provide some fragmentary protection against the costs of long-term care.

A myriad of long-term care issues has drawn congressional attention for more than two decades. These have ranged from debate about large scale reform, such as new or expanded social insurance, to consideration of incremental changes to existing programs and tax policies. The 107th Congress may reexamine broad approaches to alter public and private financing of long-term care. Alternatively, Congress may continue an incremental approach, without major federal involvement, leaving state governments to develop strategies within existing federal and state funding constraints. This report will not be updated.

Introduction

The need for long-term care – supportive and health services for persons who have lost the capacity for self-care – is expected to grow substantially in the future, straining both public and private financial resources. About $133.8 billion was spent on long-term care services for persons of all ages in FY1999, representing 12.7% of total U.S. personal health care expenditures. Of that total, federal and state governments spent 57.5%, and consumers paid 24.6% out of their own pockets. Estimates indicate that total spending for long-term care for the elderly alone could more than double from 2000 to 2025,[1] and could increase still further as a result of the aging of the "baby boom" generation.

[1] U.S. Department of Health and Human Services (DHHS), Health Care Financing Administration (HCFA), 2000, and The Lewin Group, Inc., 2000.

A myriad of long-term care issues has drawn congressional attention for more than two decades. These have ranged from debate about large scale reform, such as new or expanded social insurance, to consideration of incremental changes to existing programs and to tax policies. Many analysts argue that the current system fails to meet the needs of many people with long-term care needs because of its reliance on institutional care and the sometimes poor quality of such care; heavy reliance on informal caregivers who bear most of the burden of care; and uneven availability of home and community-based services which most people prefer over care in institutions.

Previous Congresses did not reach any consensus on what policy directions to take. A key element of debate is what, if any, changes should be made in public financing of long-term care. While federal and state governments spend an enormous amount on long-term care, spending is primarily for institutional care through the Medicaid program. Many advocates have championed major expansion of home- and community-based care. Some believe that the federal government should assume the major role in expanding access to services through a new or expanded entitlement program. Others believe that costs of a new entitlement program would be prohibitive and that private sector approaches through insurance and changes in tax policy should be pursued. Some believe that a hybrid of public and private sector strategies should take place.

Previous Congresses pursued an incremental strategy to change long-term care policy. One of the most significant expansions occurred over 20 years ago when Congress passed legislation to allow waivers of Medicaid law to encourage states to offer a range of home- and community-based services for persons who would otherwise be institutionalized. In FY2000, spending on waiver services reached $12 billion. More recently, the 106th Congress approved legislation to expand services to family caregivers under the Older Americans Act, and a plan to provide federal civilian personnel with options to purchase long-term care insurance.

Congressional interest in long-term care is expected to accelerate in the near future due to concern about the aging of the "baby boom" generation (the first of whom will turn 65 in 2011) and increasing life spans of those who reach old age. Advances in medicine may allow the survival of people of all ages who experience illness or disability.

Background

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness, frailty, or a disabling condition. Need for long-term care services is measured by assessing the need for assistance from others in performing basic types of daily activities, referred to as activities of daily living (ADLs) and instrumental activities of daily living (IADLs).[2] About 9 million persons over age 18 receive long-term care assistance. Most of these persons – 3.9 million persons age 65 and older, and 3.4 million persons age 18-64 – receive care in home- and community-

[2] ADLs include bathing, dressing, toileting, transferring from a bed or a chair, eating, and getting around inside the home; IADLs include such things as meal preparation, managing money, taking medications, grocery shopping, and transportation.

based settings, *not* in nursing homes. Only about 1.6 million persons reside in nursing homes.[3]

Currently, federal programs provide some fragmentary protection against the costs of long-term care. *Medicare* pays for medically necessary, part-time skilled nursing and rehabilitation therapy services at home; it also pays for up to 100 days of care in a skilled nursing facility following hospitalization for individuals who need full-time skilled nursing care. Medicare does not cover long-term care services for persons with chronic care needs or who require only assistance with ADLs. *Medicaid* provides coverage for nursing home care and a wide range of home- and community-based services for persons of all ages who meet income, asset, and categorical eligibility criteria prescribed by federal and state law. Many people qualify for Medicaid benefits by depleting most of their assets and income to pay for care. Other federal programs, such as the *Social Services Block Grant (SSBG)* program, the *Older Americans Act*, and state supplements to *Supplemental Security Income (SSI)*, authorize a range of home- and community-based services for persons with long-term care needs. Benefits for these programs, except Medicare, vary widely by state.

While only a small proportion of those receiving long-term care services reside in nursing homes, public spending for such care, primarily through Medicaid, is disproportionately high. In 2000, of total Medicaid spending on long-term care ($67.7 billion), 73% was for institutional care; only 27% was for home- and community-based care which most people prefer. While some states have made significant strides to develop home- and community-based care,[4] service availability across and within states is variable.

Despite substantial public spending for long-term care, families provide the bulk of long-term care services. Almost 60% of persons age 65 and older receiving long-term care assistance in the community rely exclusively on unpaid caregivers, primarily spouses and children; only 7% rely exclusively on paid services. Similarly, over 70% of persons age 18-64 receiving long-term care assistance in the community rely exclusively on unpaid caregivers; only 6% rely exclusively on paid services. Research has documented the enormous strain family members – predominantly women – face in their caregiving responsibilities.

Persons with long-term care needs face significant uncovered liability for long-term care. Paying for nursing home care – averaging more than $40,000 per year – can impoverish most families. Private long-term care insurance coverage, while growing, is still quite small relative to the potential universe of need.

The aging of the population will increase the demand for long-term care services. Estimates predict that the number of elderly using home care services will increase by one-

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[3] 1994 National Health Interview Survey, Disability Supplement (NHIS-DS) from Spector, William, et. al. *Characteristics of Long-Term Care Users*. Prepared for the Institute of Medicine, 1998.For more information on long-term care data, see *Long-Term Care Chart Book: Persons Served, Payors, and Spending*. CRS Congressional Distribution Memo CD00122, May 5, 2000.

[4] One study estimated that state spending for home- and community-based services for the elderly was more than $1.2 billion. American Association of Retired Persons, *Taking Care of their Own: State-Funded Home- and Community-Based Care Programs for Older Persons. Washington, 1997.*

third by 2020; the number using institutional care will increase by an almost equal amount. The rate of increase is expected to accelerate with the aging of the large "baby boom" generation.

Broad Policy Directions

The 107th Congress may reexamine broad approaches to alter public and private financing of long-term care. Alternatively, Congress may continue to pursue an incremental approach, without major federal involvement, leaving state governments to develop strategies within existing federal and state funding constraints. Congress may focus on other specific issues, such as improvement in quality of institutional care and long-term care labor force issues, among others. Broad policy approaches advanced in the past have included proposals for social insurance coverage of long-term care costs, expanded public commitment for home and community-based care, incentives for private financing, and combinations of these, among others.

Social Insurance Approach. Some analysts argue that access to long-term care could be made affordable to all persons in need through social insurance. Such an approach could also resolve issues of uneven coverage of home- and community-based care that exist under Medicaid and multiple state programs. Social insurance schemes have been adopted by many nations as a way to offer universal insurance against major financial risks that all their residents face, but that only a few can afford to insure against on their own. These systems are usually financed by some combination of contributions from insured individuals, their employers, and taxpayers generally. Participation is usually compulsory. Thus, the "contributions" are in actuality taxes – payroll taxes and mandatory allocations of general government revenue – set at the levels necessary to finance expected costs.

In the United States, the social insurance concept has been used to protect most Americans against: loss of income in old age, loss of family income because of the death of the breadwinner, loss of income because of permanent and total disability, loss of income while temporarily unemployed, and the costs of health care for hard-to-insure populations (the aged and disabled). At least two countries have recently begun to finance long-term care services as part of their social insurance systems. Germany added mandatory long-term care insurance to its social insurance system in 1995. Japan, with one of the most rapidly aging populations in the world, instituted broad social insurance coverage in 2000.

If the United States were to use social insurance to make long-term care services more affordable, one way would be to expand coverage through Medicare or to create a new entitlement. While such an approach may address issues of equity across income groups and provide universal coverage, it would be costly and there could be resistance to the increased taxes that would be necessary to finance it. Additionally, careful study would be needed to determine how to mesh a new entitlement program with the private long-term care insurance market.

Expanded Public Commitment for Home and Community-based Programs. Because of cost concerns, some have proposed limiting new federal benefits to home- and community-based care. Options include block grants to states for home care services, or

amending existing state-administered programs to expand home- and community-based care. For example, in 1993, President Clinton proposed capped grants to states for home- and community-based care for severely disabled persons, regardless of age and income. By FY2003, federal grants to states would have been $38 billion with required state matching of another $7.3 billion.

Another approach that has received attention in recent Congresses include proposals to amend the Medicaid program to require states to make certain home care services, such as personal attendant services, available to eligible persons who would otherwise require institutional care. The intent of these proposals is to place Medicaid funding for home- and community-based services on a level playing field with its spending for nursing homes. Versions of this proposal were introduced in the 105th Congress as H.R. 2020 (Gingrich) and in the 106th Congress as S.1935 (Harkin)/H.R. 4416 (Danny K. Davis). This approach is costly in part because of its potential liberalization of Medicaid eligibility; the Congressional Budget Office (CBO) estimated that the cost of H.R. 2020 could have reached $10 to $20 billion per year.

Private Financing. Family and other informal caregiving – the predominant care option – can be burdensome, particularly for prolonged care. However, it allows people who need care to remain at home or in community settings with their families. The principal economic cost of family caregiving is the foregone earnings of caregivers who have to curtail or give up paid employment. Recently there have been proposals to recognize caregiver burden and costs in proposed tax policy changes. These include proposals for tax credits (e.g., President Clinton's proposal for a $3,000 credit in the FY2001 budget), an additional personal exemption (e.g., the Taxpayer Refund and Relief Act of 1999, vetoed by President Clinton), or a new $10,000 deduction not limited to itemizers (e.g., H.R. 5542, which was incorporated in legislation the House passed at the end of the 106th Congress, but was not enacted). Current law already allows a small tax credit for taxpayers who pay others to provide household care so they can be employed.

The principal financing issue for individuals and families is whether they can anticipate costs and take appropriate steps to meet them. Most families cannot pay nursing home costs for prolonged periods, at least not without selling their homes and/or depleting other assets, but many might be able to save more than they now do for potential long-term care costs. Options might include establishing new tax-advantaged savings accounts for long-term care. Other possibilities include expanding pension and individual retirement arrangements to include long-term care options. Tax-advantaged savings arrangements do little to help taxpayers with lower incomes, however, and their effectiveness in encouraging new savings has been questioned.

Long-term care insurance may be the solution for some families. While some taxpayers who itemize can deduct premiums for qualified policies, proposals have been made for tax credits or deductions that would be generally available to all taxpayers with a tax liability. In the 106th Congress, the House and Senate passed legislation that would have allowed deductions for long-term care insurance. Tax benefits for long-term care insurance might reduce Medicaid costs later on, but whether the savings would pay for the benefits remains unclear. Some have questioned whether families should be encouraged to obtain policies they might not be able to afford. In addition, the cost for insurance is quite high for older persons.

Joint Public-Private Strategies. Some analysts have argued that what is needed is a strategy that would combine public and private financing approaches. For example, they argue that many individuals cannot afford the entire cost of care themselves, but could pay for a portion of such costs. An example of such an approach was contained in the 1990 U.S. Bipartisan Commission on Comprehensive Health Care (the Pepper Commission) which recommended expanded federal commitment for nursing home and home- and community-based care, cost-sharing by individuals, and incentives for private insurance. The Commission recommended social insurance for home- and community-based care and for the first 3 months of nursing home care regardless of income, but with cost-sharing from individuals based on ability to pay. For persons with longer nursing home stays, the Commission recommended a floor of asset protection ($30,000 for individuals and $60,000 for couples, excluding homes). Persons wanting additional asset and income protection could purchase private long-term care insurance, with certain recommended tax incentives for private insurance.

Other Issues

In the short term, there are several continuing concerns.

Quality of Nursing Home Care. Despite significant federal spending on nursing home care, and even with enactment of major reform of nursing home quality of care requirements in 1987, oversight and enforcement of nursing home standards continue to draw attention. Recent General Accounting Office (GAO) reviews showed that more than one quarter of nursing homes surveyed had deficiencies that caused actual harm to residents or placed them at risk of death or serious injury. In September 2000, the Clinton Administration proposed a $1 billion, 5-year initiative to improve nursing home quality. Among other things, it would have established a program to address nursing home staffing and training issues. Other parts of the proposal would have established immediate penalties for nursing homes that endanger patient safety, and would have provided public information on nursing home staffing levels.

Personnel Needs. Directly related to quality issues is concern about recruitment, training, and retention of nurses and nursing aides in nursing homes and home care settings. Nursing aides and homemaker/home health aides, who provide the bulk of care across many long-term care settings, generally receive low wages and limited, if any, benefits, and have little opportunity for upward mobility, but nonetheless carry out emotionally and physically challenging tasks. As a result, long-term care jobs are characterized by high turnover presenting challenges for long-term care administrators. he aging of the population will intensify the demand for long-term care personnel. One DHHS study estimated that the projected demand for registered nurses and nursing aides will increase by 44% and 47% respectively from 2000 to 2020. Over the same time period, the need for nurses and aides in home health agencies is projected to increase by 44% and 48%, respectively.