A bout 13 million Americans need the help of another person with basic tasks of daily living. For these individuals and their families, the need for long-term care often causes substantial financial difficulties and other burdens. In contrast to acute medical care, most nursing home and home-based long-term care services are not covered by Medicare or private health insurance. As a result, people needing long-term care often face high out-of-pocket expenses for this care, as well as for prescription drugs and coinsurance payments for acute medical services. While Medicaid provides safety net coverage for nursing home services and, to a lesser degree, home care services, people must first exhaust their financial resources to become eligible for the program.

The long-term care initiative proposed by the President would provide financial and other assistance for people needing long-term care and their families and would help other people plan for such needs. The initiative’s main element is a new tax credit of up to $1,000 for eligible people with long-term care needs, their spouses, and certain caregivers. The other three parts of the initiative would create a new program offering information, counseling, and respite services to caregivers; establish optional private long-term care insurance coverage for federal employees; and provide information to Medicare beneficiaries to help them choose among their options for obtaining and financing long-term care services. The White House estimates that the cost of the initiative would be $6.2 billion over five years, of which nearly 90 percent would be for the tax credit.

BACKGROUND: LONG-TERM CARE NEEDS, CARE ARRANGEMENTS, AND FINANCING

Long-term care refers to a broad range of services for people who, because of a chronic illness or disability, need assistance with activities of daily living (ADLs). Needs vary widely among this population. About 2.2 million of those adults living in the community, for example, need personal assistance with three or more of five ADLs—bathing, eating, dressing, getting in and out of chairs or bed, and using the toilet.

Another 9.2 million elderly people need help with one or two ADLs or with additional tasks necessary to maintain independence, referred to as instrumental activities of daily living (IADLs), such as meal preparation, shopping, money management, using the telephone, and doing housework. Long-term care may also include therapeutic treatment and management of chronic conditions.

The population with long-term care needs is diverse with respect to age, care arrangements, and functional status. Of the 13 million people with such needs, about 56 percent are at least 65 years old, and 44 percent are under age 65 (Figure 1). Among both the elderly and nonelderly populations, most people with long-term care needs live in the community. The nursing home population is significantly

Continued on page 2
older, however, than the community long-term care population: among nursing home residents, fewer than one of 10 is under age 65 and nearly half are 85 years old or older, while about 46 percent of the community-based long-term care population are under age 65.\(^2\)

Although a sizable proportion of the long-term care population is under age 65, the likelihood of needing long-term care is much greater in the older population. The likelihood of nursing home residency is also considerably higher among the elderly. Fewer than 3 percent of people under age 65 need long-term care, and less than one-tenth of 1 percent are nursing home residents.\(^4\) In contrast, 22 percent of the elderly need long-term care, and about 4 percent reside in nursing homes. Furthermore, among the elderly, the proportion of people with severe functional limitations increases dramatically with age. For example, the proportion of people who live in the community and need personal assistance with 3 or more ADLs, or who live in a nursing home, rises from 2 percent of people ages 65–74 to 27 percent of those age 85 and older (Figure 2).

People with long-term care needs are more likely to have low incomes than others. Among people age 50 and older, for example, 43 percent of those with limitations in two or more of five ADLs have incomes below 150 percent of the poverty level, compared with 18 percent of those without ADL or IADL limitations or other disabilities (Figure 3).

### Caregivers

Most community residents with long-term care needs receive unpaid informal care either as their sole form of assistance or in combination with paid care. In fact, even among elderly community residents with chronic, severe limitations, about half rely solely on unpaid help. In 1994, about 50 percent of community residents with limitations in three or more ADLs relied only on unpaid help, 47 percent relied on a combination of unpaid and paid assistance, and 4 percent relied only on paid help.\(^5\)

Nursing home residents, too, often receive assistance on some ADLs from family members.

A 1996 survey found that an estimated 22 million people provided unpaid help with personal needs or household chores to a relative or friend who was at least 50 years old.\(^6\) The type and amount of care provided varied widely. About 12 percent—or an estimated 2.6 million people—provided full-time care (more than 40 hours per week) that included assisting with at least two ADLs, such as bathing and dressing. In contrast, about one-fourth of these caregivers provided the lightest level of assistance—up to eight hours of help per week with activities such as household chores, but no assistance with basic personal care activities. The survey found that caregivers of people age 50 and older are predominantly female (73%), a majority work full-time outside the home (52%), and a significant proportion has income below $25,000 (32%). About 41 percent of these caregivers have children under age 18 living in their household.

### Financing of Long-Term Care

Although most people needing long-term care are community residents, the majority of long-term care spending is for nursing home care. In 1997, nursing home care accounted for 72 percent of $115 billion in national spending for long-term care.\(^7\) Medicaid is the largest source of long-term care financing, followed by private out-of-pocket spending. Medicaid paid for 38 percent of total spending for nursing home and home care in 1997, covering 48 percent of nursing home spending and 15 percent of home care spending (Figure 4). Medicare played a far smaller role, paying for one-fifth of nursing home and home care spending.\(^8\)

Out-of-pocket costs of long-term care users and their families constituted 28 percent of nursing home and home care spending in 1997. Almost one-third of nursing home spending was paid for out-of-pocket, as was

Continued on page 5
Figure 1
The Long-Term Care Population, 1996

- Age 18-64
  - Under Age 18: 0.4 million
  - Under Age 65: 0.1 million
- Age 65 and Older
  - Living in the Community: 6.0 million
  - Nursing Home Residents: 1.5 million
  - Total = 13.4 Million


Figure 2
Percentage of Elderly People with Long-Term Care Needs, by Age and Functional Status, 1994

* Based on people who received help or needed supervision or cueing with the following activities of daily living (ADLs): bathing, dressing, eating, getting in and out of bed or chairs, and using the toilet; or instrumental activities of daily living (IADLs): preparing meals, shopping, managing money, using the telephone, doing heavy housework, and doing light housework.

Note: Nursing home residency based on 1996 data.

Figure 3
Income Distribution of Community Residents Age 50 and Older, by Functional Status, 1994

* Based on the following activities of daily living (ADLs): bathing, dressing, eating, getting in and out of bed or chairs, and using the toilet.
** People with no limitations in ADLs or instrumental activities of daily living (IADLs), or other disabilities.

Figure 4
National Spending for Nursing Home and Home Care, by Payer, 1997

Note: Based on spending for services from free-standing nursing homes and home health agencies only; data are not available for spending on services of hospital-based facilities and agencies.
more than one-fifth of home care spending. Long-term care costs can be catastrophic; for example, in 1993, an estimated 36 percent of all elderly nursing home residents—and 72 percent of those with lengths of stay of at least one year—spent 40 percent or more of their total income and nonhousing assets for nursing home care.

Private insurance, which consists of both medical insurance and long-term care insurance, plays only a small role in financing long-term care. In 1997, only 7 percent of long-term care spending was paid for by private insurance, constituting 5 percent of nursing home expenditures and 11 percent of home care expenditures. While long-term care insurance plays a small role in the current financing of such care, the number of people purchasing this insurance has been growing. A recent study estimates that 6 to 7 percent of the elderly currently have long-term care policies.\(^{11}\)

These estimates of national spending for long-term care do not include the value of caregivers’ time or the indirect costs of caregivers. Estimates of the value of caregiving vary widely because of uncertainty about both the amount of caregiving and what value to assign to an hour of such care. Although one recent study estimated the value of informal caregiving at $196 billion in 1997 (based on an assumption that caregiving time is valued at about $8 an hour, midway between minimum wage and the average rate for home health aides), other research has yielded a considerably lower estimate of $45 billion to $94 billion per year.\(^{12}\) Such estimates of the direct value of caregiving do not include the indirect costs caregivers incur when they reduce their work hours or give up jobs. Of those caregivers who were working or had ever worked and were caring for people age 50 and older, more than half reported that they had made adjustments in their work—such as changing their schedule, taking time off, working fewer hours, or quitting—because of their caregiving responsibilities.\(^{13}\) More than 6 percent chose early retirement or gave up work entirely.

### THE PROPOSED LONG-TERM CARE INITIATIVE

The President’s proposed long-term care initiative consists of four parts. Two of them—an income tax credit and a new Family Caregiver Support Program—recognize the burdens of people who currently need long-term care and the family members who assist them. The other two parts—private long-term care insurance for federal employees and information for Medicare enrollees—are primarily aimed at helping people plan for the possibility of long-term care expenses in the future.

#### The Tax Credit

The proposal would establish a tax credit of up to $1,000 for each person with substantial long-term care needs, beginning in calendar year 2000. Eligibility for the credit would be based on specified criteria indicating a significant need for long-term care and would not depend on incurred expenses or use of services. Taxpayers would be eligible for the credit if they have physician-certified long-term care needs lasting at least six months, as defined for the credit; have a spouse with long-term care needs; or can claim a person with such needs as a dependent under specified rules. (See the sidebar on page 6 for more details.)

The value of the credit would depend on a person’s taxable income. In general, the credit would not be refundable, so the total credit received could not exceed a person’s tax liability. (As an exception, the credit would be refundable under certain circumstances for taxpayers with three or more dependents.) The credit would phase out at higher income levels. Specifically, a taxpayer’s total “family care credit”—which would be the sum of any long-term care tax credit and child tax credit amounts—would be reduced by $50 for every $1,000 that adjusted gross income (AGI) exceeded $75,000 for single taxpayers, or $110,000 for couples filing jointly.\(^{14}\)

Continued on page 7.
Eligibility Criteria for the Proposed Long-Term Care Tax Credit

Three groups are eligible for the tax credit: people with significant long-term care needs, spouses of people with significant long-term care needs, and caregivers of people who have significant long-term care needs and meet criteria establishing dependence (as defined for the credit).

People with Significant Long-Term Care Needs and Their Spouses
The President’s proposed long-term care initiative defines people with significant long-term care needs as those in the following groups:

- People age 6 and older who are unable, without substantial assistance from another person, to perform at least three of six specified activities of daily living (ADLs) because of a loss in functional capacity. The six ADLs are bathing, dressing, eating, using the toilet, transferring, and continence management.

- People age 6 and older with severe cognitive impairments who require substantial supervision for their health and safety, and are unable without substantial assistance to perform at least one ADL or are unable to engage in age-appropriate activities.

- Children at least 2 years old and less than 6 years old who are unable to perform without substantial assistance at least two of three specified ADLs (eating, transferring, and mobility), and children under 2 years old who require a skilled practitioner if their parents or guardians are absent, or who require specific durable medical equipment, such as a respirator, because of a severe health condition.

A person must have eligible long-term care needs for a period of at least 6 months and have their eligibility certified annually by a physician.

Caregivers of Dependents with Significant Long-Term Care Needs
A person would be eligible for the credit as a caregiver if the care recipient has significant long-term care needs, as defined above, and:

- The care recipient gets more than half of his or her support from the caregiver (or more than half from the caregiver and others combined, and more than 10 percent from the caregiver); lives with the caregiver for more than half the tax year and is a close relative (an ancestor or descendant of the caregiver or the caregiver’s spouse); or lives with the caregiver for the entire year and is not a close relative; and

- The care recipient has gross income of less than the sum of the exemption amount, the standard deduction, and the additional deduction for the elderly and blind if applicable to the individual (for example, gross income of less than $8,100 in 1999 for a single elderly person). Social Security benefits are generally excluded from gross income for people with low or moderate incomes.

Only one person (or couple) can receive the credit as a caregiver of a given individual.

Source: Georgetown University Institute for Health Care Research and Policy, based on S.10, introduced on January 19, 1999.
The examples in the sidebar below illustrate the income ranges in which elderly people would begin to benefit from the credit. (The following amounts would differ for nonelderly people because they are allowed a smaller deduction in determining taxable income.)

- Among single elderly people, those with AGI of $8,100 or less ($14,400 or less for elderly couples) would not have a tax liability and would therefore receive no credit. For people with low or moderate incomes, Social Security benefits are usually not included in taxable income, so many people with total income (including Social Security) above these AGI levels would not receive the credit. Thus, a single elderly person receiving average Social Security income would benefit from the credit if his or her total income were greater than $17,100; similarly, an elderly couple receiving average Social Security benefits would be eligible if their total income were greater than $28,700.

- Among elderly single people, those with AGI greater than $8,100 and less than $14,750 would receive a credit of less than $1,000, as would elderly couples with AGI greater than $14,400 and less than $21,050.

### Calculating the Proposed Long-Term Care Tax Credit: Illustrative Examples, 1999

<table>
<thead>
<tr>
<th>Income</th>
<th>Single Elderly Person</th>
<th>Elderly Couple*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example 1</td>
<td>Example 2</td>
<td>Example 3</td>
</tr>
<tr>
<td>Social Security</td>
<td>$9,000</td>
<td>$14,300</td>
</tr>
<tr>
<td>Other Income</td>
<td>8,100</td>
<td>14,400</td>
</tr>
<tr>
<td>Total Income</td>
<td>17,100</td>
<td>28,700</td>
</tr>
<tr>
<td>Adjusted Gross Income (AGI)</td>
<td>8,100</td>
<td>14,750</td>
</tr>
<tr>
<td>Exemptions and Deductions</td>
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<td>-8,100</td>
</tr>
<tr>
<td>Taxable Income</td>
<td>0</td>
<td>6,650</td>
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<tr>
<td>Tax Liability Under Current Law</td>
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<td>1,000</td>
</tr>
<tr>
<td>Proposed Tax Credit</td>
<td>0</td>
<td>1,000</td>
</tr>
</tbody>
</table>

*Assumes couples file jointly and only one person meets eligibility criteria for the credit.

Note: Amounts are rounded to nearest $10.

- For single persons, amount in the examples is based on the average monthly benefit of non-disabled widows and widowers age 65 and older of June 1998, adjusted to 1999 and annualized. For couples, the amount in the examples is similarly computed based on the sum of the average monthly benefit of retired workers age 65 and older and the average monthly benefit of retired workers’ spouses age 65 and older.

- Assumes all other income is taxable.

- Uses 1999 amounts: exemption amount is $2,750 per person; standard deduction is $4,300 for single individuals and $7,200 for married couples; and additional deduction for the elderly is $1,050 for single individuals and $1,700 for married couples.

A full credit of $1,000 would be received by single elderly persons with AGI from $14,750 to $75,000, and by elderly couples with AGI from $21,050 to $110,000.

The White House estimates that the credit would assist about 2 million people with substantial long-term care needs or their relatives. Most community residents with this level of need live with their spouse or others; therefore, caregivers would constitute a significant proportion of people eligible for the credit. The White House projects that the tax credit would cost $5.5 billion over five years.

**Other Assistance to Caregivers**

The initiative would also establish a Family Caregiver Support Program to provide supportive information and services to families caring for elderly individuals with long-term care needs. The support would consist of information on local resources for caregivers, counseling, and training. The program would also provide respite services that allow caregivers a break from their care responsibilities, plus supplemental services on a limited basis to complement the care they provide. States would be required to give priority to elderly individuals and families with the greatest social and economic needs.

The program would be funded with federal grants to state units on aging, which in turn would distribute funds to local agencies. States would be required to match the federal grants. Federal funding for the program would be $125 million in fiscal year 2000, an increase of about 14 percent over what proposed spending would be in that year without the new program. Proposed funding would be $625 million over five years.

**Optional Long-Term Care Insurance for Federal Employees**

Under the proposal, the U.S. Office of Personnel Management (OPM) could offer federal employees, retirees, and eligible family members (spouses, former spouses who are entitled to annuities, parents, and parents-in-law) the opportunity to purchase private long-term care insurance at negotiated group rates. OPM would require compliance with federal tax qualification rules and the newest standards set forth by the National Association of Insurance Commissioners, which include standards restricting premium increases and also require insurers to offer benefits to individuals whose coverage lapses because of certain premium increases (a “contingent nonforfeiture” benefit). OPM would also require participating companies to be licensed by all states.

Participating employees and retirees would pay the full cost of premiums. However, the proposal includes $15 million to fund OPM’s administration of the program over five years.

**Information for Medicare Beneficiaries**

The initiative also seeks to improve the private long-term care insurance market by educating potential purchasers. It would provide $10 million in fiscal year 2000 for a program, administered by the Health Care Financing Administration and other parts of the Department of Health and Human Services, aimed at informing Medicare beneficiaries and their families about their options for long-term care services and financing. One of its main goals would be to make beneficiaries aware that Medicare provides only limited long-term care benefits. The program would also provide information on long-term care coverage under Medicaid, options for long-term care services including home- and community-based services, and key components of private long-term care insurance coverage.

**EVALUATING THE PROPOSAL**

The initiative would provide welcome assistance to many families affected by the need for long-term care and would help others plan for the possibility of such needs in the future. The initiative does not, however,
address the broad current and future issue of how to provide and equitably finance long-term care.

**Tax Credit and Caregiver Support Program**

Both the tax credit and the new Family Caregiver Support Program would make federal funds available to people who are currently in need of long-term care services and their families. By focusing on those with substantial care needs, the credit effectively targets individuals and families with financial and other burdens. However, the initiative would leave significant gaps both with respect to who could receive the credit and the extent to which the credit amount would assist those eligible for it.

The tax credit would provide up to $1,000 for approximately 2 million people who either have significant long-term care needs or share a household with or provide substantial financial support to someone with such needs. The tax credit is targeted to people with the greatest needs for long-term care, most of whom also have significant medical needs. By not requiring that people use formal long-term care services to be eligible, the credit recognizes the other financial burdens faced both by people with long-term care needs and by family members who help support them. For example, people with long-term care needs might use the credit to help pay for prescription drugs or other out-of-pocket health care expenses, or to pay for some formal home care services. Similarly, the credit could help family members offset some of the direct and indirect expenses they incur in caregiving.

The effect of the credit would be limited, however, by the level and nature of its income requirements. Because it generally would not be refundable, many people with low incomes would be ineligible. Those with incomes below poverty would usually be ineligible, and many people with incomes from 100 to 200 percent of the poverty threshold would not qualify because their Social Security income is not taxed. Furthermore, eligibility for the credit would depend not only on level of income but on source of income, because people can have different tax liabilities depending on the proportion of their income contributed by Social Security.

Although many people with incomes too low to qualify for the credit have Medicaid coverage for their long-term care needs, many others—especially those living in the community—do not. For example, among adults with long-term care needs living in the community, 54 percent with incomes below the poverty level, and 21 percent with incomes from 100 to 200 percent of the poverty level, had Medicaid coverage in 1994. Medicaid coverage is probably somewhat higher for community residents with the greatest long-term care needs who may qualify for optional benefits available in most states. It is also higher for nursing home residents: in 1996, two-thirds of nursing home residents were covered by Medicaid.

Moreover, even among those who are eligible, the credit would not prevent the impoverishment of numerous people with substantial care needs. For those facing nursing home costs, the credit would be quickly absorbed. Annual nursing home expenditures averaged about $40,000 in 1995, but varied significantly with location; for example, nursing homes in New York state charge an average of $73,000 annually. Moreover, the credit would not alleviate the uncertainty about future long-term care expenses and the risk of catastrophic expenses. One study estimated that of people turning age 65 in 1995, 39 percent would use nursing home care at some time in their lives, and 20 percent would use such care for more than one year.

The Family Caregiver Support Program would help reduce some of the problems experienced by family caregivers. In contrast to most programs supported by state units on aging, which mainly assist people with long-term care needs, the FCS program funds services that family caregivers could use even when loved ones do not require long-term care services. The FCS program also funds services that would be available to people in the community either before or after a need for long-term care services. In 1995, federal funds to support state programs grew to $257 million, which funded about 160 programs, with typical expenditures of about $500,000 per state. The assistance the programs provided included care management, respite care, and transportation and homemaker services.
term care needs directly through such activities as home-delivered meals, congregate meals, and personal care services, the new funds would be targeted primarily to supportive services for caregivers. However, the state grants would be small relative to needs and would therefore be modest in their effects.

**Long-Term Care Insurance for Federal Employees and Medicare Information**

With respect to addressing future needs for long-term care, the initiative would provide a model for a private long-term care insurance market and information to educate Medicare beneficiaries about long-term care services and insurance. The initiative would therefore be useful in improving consumer protections and knowledge. Neither the initiative nor private long-term care insurance, however, fully addresses the broad question of how to adequately and equitably finance long-term care now and in the future.

The proposed long-term care insurance program for federal employees and retirees could help the federal government and private purchasers better understand the potential role of private long-term care insurance in covering the population’s long-term care needs. It could serve as a model program in at least two ways. First, the program could explore the role of employer-sponsored long-term care insurance. Features of this approach include facilitating the purchase of insurance by deducting the premium directly from the participants’ pay or annuity and obtaining group rates for coverage that could be an estimated 15 to 20 percent lower than rates in the individual market.21 Employer-sponsored coverage also has the attribute of providing a forum for the sale of long-term care insurance to a diverse range of individuals, some of whom may need long-term care services soon and others who will not. As employees and retirees begin to benefit from this coverage, their experiences could enable OPM to observe the advantages and disadvantages of different product offerings and, as a result, suggest changes in the products offered to employees.

Second, the long-term care insurance program would provide a model of high-quality insurance coverage. OPM could design a high-quality benefit package and assure that it contains sufficient consumer protections. In administering the program, OPM would also have the flexibility to recommend changes that respond to developments in the long-term care market, thereby reducing the risk of enrollees locking themselves into coverage for modes of care that may be out-of-date by the time benefits are needed.

The insurance option would, however, reach a limited number of people. The initiative would not provide federal employees with financial support for the cost of premiums. At this point, the extent to which federal employees would participate is unknown. By combining the insurance program with the broader education program about public program coverage and other resources for long-term care, the initiative would begin to provide Americans with the tools to learn about and plan for their current and future long-term care needs. However, while Medicare beneficiaries and their families may become more informed, many will still have scant resources available to address them.

**The Proposed Initiative and Policy Toward Long-Term Care**

Taken together, the components of the proposed long-term care initiative would provide some valuable financial and other relief to some individuals with long-term care needs and their caregivers, and would promote better understanding and operation of the private long-term care insurance market. Both types of public policy could contribute to an individual’s and society’s ability to cope with long-term care needs. However, neither aspect of the initiative is, or
claims to be, a solution to the widely recognized and growing inadequacies in financing long-term care. Only insurance can reduce the uncertainty and risk associated with long-term care needs, and private insurance, even if well-regulated, is likely to reach only a portion of the growing population of people who need long-term care services. Both now and in the future, better public financial support is essential to assuring access to care and to providing adequate protection against the financial risk of requiring extensive long-term care. Further policy initiatives are needed to address this most fundamental long-term care problem.

NOTES

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1 Most parts of the initiative are included in S.10, the Health Protection and Assistance for Older Americans Act of 1999, introduced on January 19, 1999. The description of the initiative in this policy brief is based on the bill and on White House, “Background: President Clinton’s Long-Term Care Initiative,” unpublished, January 4, 1999.


4 Figure 1 and population estimates from the U.S. Census Bureau at website http://www.census.gov/population/estimates/nation/infile2-1.txt (accessed March 1, 1999).


8 Because much of the nursing home and home health care paid for by Medicare is not long-term care but rather “post-acute” care, such as rehabilitative, skilled nursing, and other services needed for a relatively short period of time, the national health expenditures data presented here probably overstate Medicare’s role in paying for long-term care and underestimate Medicaid’s role.


10 Congressional Budget Office, “Projections of Expenditures for Long-Term Care Services for the Elderly,” CBO Memorandum, March 1999.


14 Thus, for households with one person who had substantial long-term care needs, and no children, the credit would phase out at AGI of $95,000 for single taxpayers and $130,000 for couples filing jointly. The maximum income levels would be higher for taxpayers claiming a long-term care tax credit for two or more people, or who additionally claimed a child tax credit ($500 in 1999) for one or more children.


