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LONG-TERM CARE FINANCING

Growing Demand and Cost of Services Are Straining Federal and State Budgets

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Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today as you discuss the anticipated growing demand and associated costs for long-term care services, which will be driven largely by the aging baby boom generation, and the challenges that increased demand will bring for federal and state budgets. Earlier this year, we issued a report entitled *21st Century Challenges: Reexamining the Base of the Federal Government* to provide policymakers with a comprehensive compendium of those areas throughout government that could be considered ripe for reexamination and review based on our past work and institutional knowledge.[1] In that report, we presented illustrative questions for policymakers to consider as they carry out their responsibilities. These questions examined major areas of the budget and federal operations including discretionary and mandatory spending, and tax policies and programs. One prominent question that we raised in that report and that will be the focus of my comments today is "What options are there for rethinking the federal, state, and private insurance roles in financing long-term care?"

In general, the aging of the baby boom generation will lead to a sharp growth in federal entitlement spending that, absent meaningful reforms, will represent an unsustainable burden on future generations. As the estimated 76 million baby boomers born between 1946 and 1964 become elderly, Medicare, Medicaid, and Social Security will nearly double as a share of the economy by 2035. We have been able to sustain these entitlements in the past with low depression-era birth rates and a large postwar workforce. However, absent substantive reform of entitlement programs, a rapid escalation of federal spending for Social Security, Medicare, and Medicaid is virtually certain to overwhelm the rest of the federal budget.

Most attention has been focused on the need for Social Security and Medicare reform in order to maintain their viability and ability to meet programmatic commitments. By 2017, Social Security's cash income (tax revenue) is projected to fall below program expenses. At that time, Social Security will join Medicare's Hospital Insurance Trust Fund, whose outlays exceeded cash revenues in 2004, as having a cash flow deficit. While these are important issues, a broader focus should also include

[1]GAO, *21st Century Challenges: Reexamining the Base of the Federal Government*, GAO-05-325SP (Washington, D.C.: February 2005).

Medicaid, particularly as it involves financing long-term care. Long-term care includes an array of health, personal care, and supportive services provided to persons with physical or mental disabilities. It relies heavily on financing by public payers, especially Medicaid, and has significant implications for state budgets as well as the federal budget.

My remarks today will focus on (1) the pressure that entitlement spending for Medicare, Medicaid, and Social Security is expected to exert on the federal budget in coming decades; (2) how the aging of the baby boomers will increase the demand for long-term care services; and (3) how these trends will affect the current and future financing of long-term care services, particularly in federal and state budgets. I will also highlight several considerations for any possible reforms of long-term care financing. My comments are based on prior GAO work, particularly a 2002 testimony by the Comptroller General.[2] We updated prior GAO work by including more recent data from GAO's budget simulation model, the Centers for Medicare & Medicaid Services, and the U.S. Census Bureau as well as the literature. We conducted our work to update this earlier testimony from February through April 2005 in accordance with generally accepted government auditing standards.

In summary, it is clear that, taken together, Medicare, Medicaid, and Social Security represent an unsustainable burden on future generations. Increased demand for long-term care, which will be driven in part by the aging baby boom generation, will contribute further to federal and state budget burdens. Estimates suggest the number of disabled elderly who cannot perform basic activities of daily living without assistance may as much as double from 2000 through 2040. Current problems with the provision and financing of long-term care could be exacerbated by the swelling numbers of the baby-boom generation needing care. These problems include whether individuals with disabilities receive adequate services, the potential for families to face financially catastrophic long-term care costs, and the burdens and social costs that heavy reliance on unpaid care from family members and other informal caregivers create coupled with possibly fewer caregivers available in coming generations. Long-term care spending from all public and private sources, which was about $183 billion for persons of all ages in 2003, will increase dramatically in the coming decades as the baby boom generation ages. Spending on

[2]GAO, *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*, GAO-02-544T (Washington, D.C.: March 21, 2002).

long-term care services just for the elderly is estimated to increase from 2000 by more than two-and-a-half times by 2040 and could nearly quadruple in constant dollars to $379 billion by 2050, according to some estimates. Without fundamental financing changes, Medicaid—which pays over one-third of long-term care expenditures for the elderly—can be expected to remain one of the largest funding sources, straining both federal and state governments.

In considering options for reforming long-term care financing in light of these anticipated demands for assistance and budgeting stresses, it is important to keep in mind that long-term care is not just about health care. It also comprises a variety of services an aged and/or disabled person requires to maintain quality of life—including housing, transportation, nutrition, and social support to help maintain independent living. Given the challenges in providing and paying for these myriad and growing needs, several considerations for shaping reform proposals include:

- determining societal responsibilities;
- considering the potential role of social insurance in financing;
- encouraging personal preparedness;
- recognizing the benefits, burdens, and costs of informal caregiving;
- assessing the balance of state and federal responsibilities to ensure adequate and equitable satisfaction of needs;
- adopting effective and efficient implementation and administration of reforms; and
- developing financially sustainable public commitments.

Background

Long-term care includes many types of services needed when a person has a physical or mental disability. Individuals needing long-term care have varying degrees of difficulty in performing some activities of daily living without assistance, such as bathing, dressing, toileting, eating, and moving from one location to another. They may also have trouble with instrumental activities of daily living, which include such tasks as preparing food, housekeeping, and handling finances. They may have a mental impairment, such as Alzheimer's disease, that necessitates assistance with tasks such as taking medications or supervision to avoid harming themselves or others. Although a chronic physical or mental disability may occur at any age, the older an individual becomes, the more likely a disability will develop or worsen.

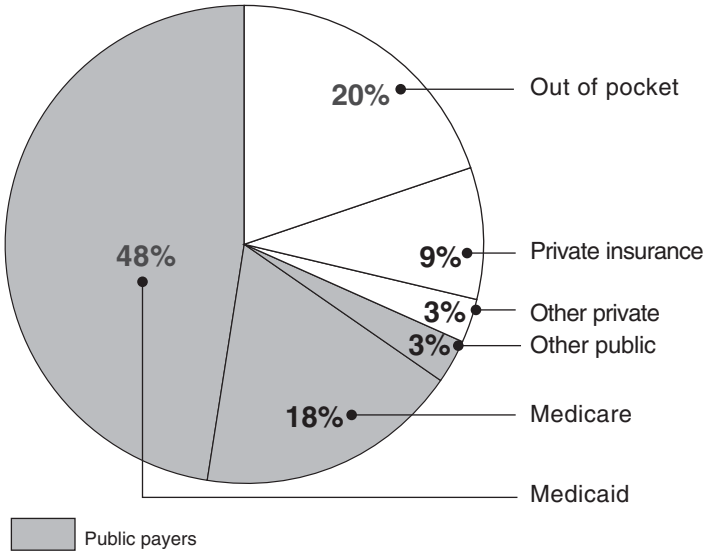
According to the 1999 National Long-Term Care Survey, approximately 7 million elderly had some sort of disability in 1999, including about 1 million needing assistance with at least five activities of daily living.[3] Assistance takes place in many forms and settings, including institutional care in nursing homes or assisted living facilities, and home care services. Further, many disabled individuals rely exclusively on unpaid care from family members or other informal caregivers.

Nationally, spending from all public and private sources for long-term care for all ages totaled about $183 billion in 2003, accounting for about 13 percent of all health care expenditures.[4] About 69 percent of expenditures for long-term care services were paid for by public programs, primarily Medicaid and Medicare. Individuals financed about 20 percent of these expenditures out of pocket and, less often, private insurers paid for long-term care. Moreover, these expenditures did not include the extensive reliance on unpaid long-term care provided by family members and other informal caregivers. Figure 1 shows the major sources financing these expenditures.

[3]See Kenneth G. Manton and XiLiang Gu, "Changes in the Prevalence of Chronic Disability in the United States Black and NonBlack Population Above Age 65 from 1982 to 1999," *Proceedings of the National Academy of Sciences of the United States of America*, vol. 98, no. 11, (2001). The National Long-Term Care Survey was conducted in 1982, 1984, 1989, 1994, 1999, and 2004, but the 2004 results are not yet available.

[4]Based on our analysis of data from the Office of the Actuary of the Centers for Medicare & Medicaid Services and The MEDSTAT Group. These figures include long-term care for all people, regardless of age.

Figure 1: Funding Sources for Long-Term Care, 2003



Source: GAO analysis of 2003 data from the Centers for Medicare & Medicaid Services and The MEDSTAT Group.

Notes: Amounts do not include unpaid care provided by family members or other informal caregivers. Percentages do not add to 100 percent due to rounding.

Medicaid, the joint federal-state health-financing program for low-income individuals, continues to be the largest funding source for long-term care. Medicaid provides coverage for poor persons and for many individuals who have become nearly impoverished by "spending down" their assets to cover the high costs of their long-term care. For example, many elderly persons become eligible for Medicaid as a result of depleting their assets to pay for nursing home care that Medicare does not cover. In 2003, Medicaid paid 48 percent (about $87 billion) of total long-term care expenditures. States share responsibility with the federal government for Medicaid, paying on average approximately 43 percent of total Medicaid costs in fiscal year 2002.[5] Eligibility for Medicaid-covered long-term care services varies widely among states. Spending also varies across states—for example, in fiscal year 2000, Medicaid per capita long-term care expenditures ranged from $73 per year in Nevada to $680 per year in New York. For the national average, about 57 percent of Medicaid long-term

[5]The federal share of Medicaid funding varies by state and is based on a state's per capita income in relation to the national per capita income. By statute, the federal share of Medicaid expenditures across individual states may range from 50 to 83 percent. 42 U.S.C. § 1396 d (b) (2000).

care spending in 2002 was for the elderly. In 2003, nursing home expenditures dominated Medicaid long-term care expenditures, accounting for about 47 percent of its long-term care spending. Home care expenditures make up a growing share of Medicaid long-term care spending as many states use the flexibility available within the Medicaid program to provide long-term care services in home- and community-based settings.[6] From 2000 through 2003, home and personal care expenditures grew at an average annual rate of 15.9 percent compared with 4.0 percent for nursing facility spending. Expenditures for Medicaid home- and community-based services for long-term care almost doubled from 1998 to 2003—from about $10 billion to about $19 billion.

Other significant long-term care financing sources include:

- Individuals' out-of-pocket payments, the second largest source of long-term care expenditures, accounted for 20 percent (about $38 billion) of total expenditures in 2003. The vast majority (82 percent) of these payments were used for nursing home care.

- Medicare spending accounted for 18 percent (about $33 billion) of total long-term care expenditures in 2003. While Medicare primarily covers acute care, it also pays for limited stays in post-acute skilled nursing care facilities and home health care.

- Private insurance, which includes both traditional health insurance and long-term care insurance,[7] accounted for 9 percent (about $16 billion) of long-term care expenditures in 2003.

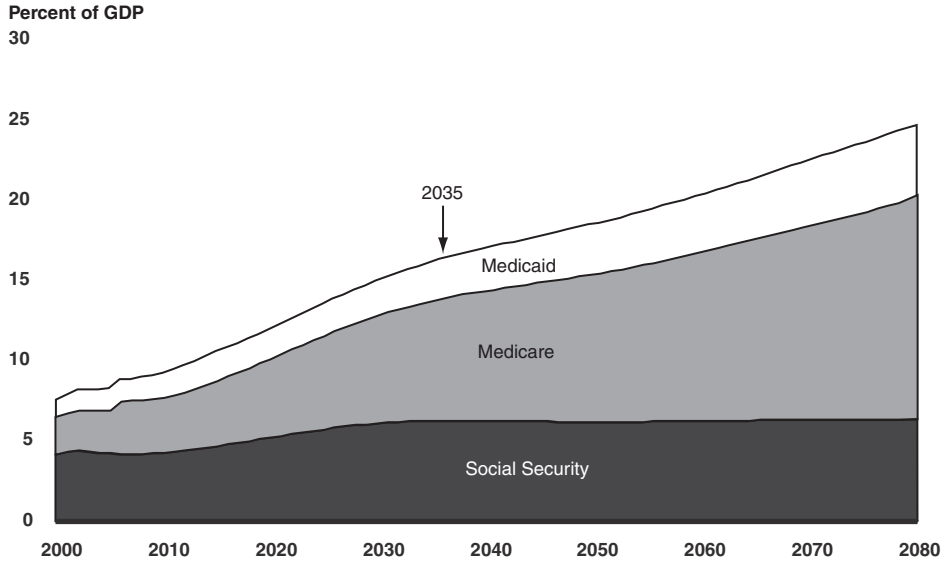
[6]Through Medicaid home- and community-based services, states cover a wide variety of nonmedical and social services and supports that allow people to remain in the community. These services include personal care, personal call devices, homemakers' assistance, chore assistance, adult day health care, and other services that are demonstrated as cost-effective and necessary to avoid institutionalization. In their home- and community-based services programs, however, states often limit eligibility or the scope of services in order to control costs.

[7]Private long-term care insurance commonly includes policies that provide coverage for at least 12 months of necessary services—as demonstrated by an inability to perform a certain number of activities of daily living—provided in settings other than acute-care hospital units.

Absent Reform, Spending for Medicaid, Medicare, and Social Security Will Put Unsustainable Pressure on the Federal Budget

Before focusing on the increased burden that long-term care will place on federal and state budgets, it is important to look at the broader budgetary context. As we look ahead we face an unprecedented demographic challenge with the aging of the baby boom generation. As the share of the population 65 and over climbs, federal spending on the elderly will absorb a larger and ultimately unsustainable share of the federal budget and economic resources. Federal spending for Medicaid, Medicare, and Social Security is expected to surge—nearly doubling by 2035—as people live longer and spend more time in retirement. In addition, advances in medical technology are likely to keep pushing up the cost of health care. Moreover, the baby boomers will be followed by relatively fewer workers to support them in retirement, prompting a relatively smaller employment base from which to finance these higher costs. Based on CBO's long-term Medicaid estimates, the federal share of Medicaid as a percent of GDP will grow from today's 1.5 percent to 2.6 percent in 2035 and reach 4.8 percent in 2080. Under the 2005 Medicare trustees' intermediate estimates, Medicare will almost triple as a share of gross domestic product (GDP) between now and 2035 (from 2.7 percent to 7.5 percent) and reach 13.8 percent of GDP in 2080. Under the Social Security trustees' intermediate estimates, Social Security spending will grow as a share of GDP from 4.3 percent today to 6.3 percent in 2035, reaching 6.4 percent in 2080. (See fig. 2.) Combined, in 2080 almost one-quarter of GDP will be devoted to federal spending for these three programs alone.

Figure 2: Federal Spending for Medicaid, Medicare, and Social Security as a Percentage of GDP, 2000 through 2080



Source: GAO analysis based on data from the Office of the Chief Actuary, Social Security Administration; Office of the Actuary, Centers for Medicare & Medicaid Services; and the Congressional Budget Office.

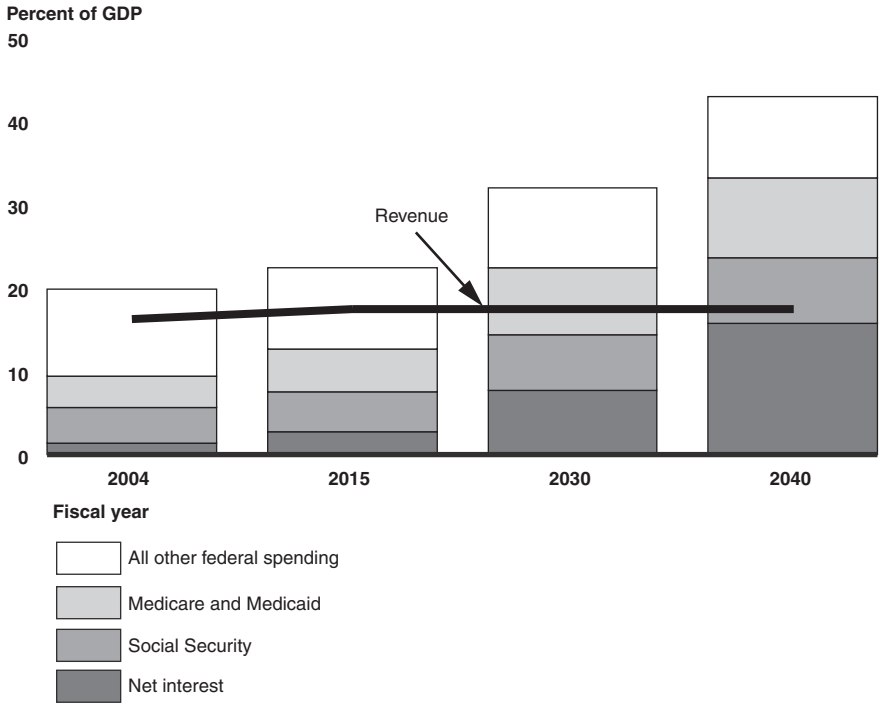
Notes: Medicaid spending includes federal, but not state, expenditures.

Social Security and Medicare projections based on the intermediate assumptions of the 2005 Trustees' Reports. Medicaid projections based on the Congressional Budget Office's (CBO) January 2005 short-term Medicaid estimates and the CBO's December 2003 long-term Medicaid projections under midrange assumptions.

To move into the future with no changes in federal health and retirement programs is to envision a very different role for the federal government. Our long-term budget simulations serve to illustrate the increasing constraints on federal budgetary flexibility that will be driven by entitlement spending growth. Assume, for example, that all expiring tax provisions are extended, revenue remains constant thereafter as a share of GDP, and discretionary spending keeps pace with the economy. Under these conditions, by 2040 federal revenues may be adequate to pay little more than interest on the federal debt.[8] (See fig. 3.)

[8]For additional discussion of our budget simulations, see GAO, *Our Nation's Fiscal Outlook: The Federal Government's Long-Term Budget Imbalance*, at http://www.gao.gov/special.pubs/longterm/longterm.html.

Figure 3: Composition of Federal Spending as a Share of GDP Assuming Discretionary Spending Grows with GDP after 2004 and All Expiring Tax Provisions Are Extended



Source: GAO's March 2005 analysis.

Notes: Although the revenue projections assume that expiring tax provisions are extended, federal revenue as a share of GDP increases through 2015 due to (1) taxpayers paying higher marginal tax rates as the economy grows (referred to as "real bracket creep"), (2) more taxpayers becoming subject to the alternative minimum tax, and (3) increased revenue from tax-deferred retirement accounts. After 2015, the analysis assumes that revenue as a share of GDP is held constant. For additional information on our budget simulations, see GAO, *Our Nation's Fiscal Outlook: The Federal Government's Long-Term Budget Imbalance,* at http://www.gao.gov/special.pubs/longterm/longterm.html.

Beginning about 2010, the share of the population that is age 65 or older will begin to climb, with profound implications for our society, our economy, and the financial condition of these entitlement programs. In particular, both Social Security and the Hospital Insurance portion of Medicare are largely financed as pay-as-you-go systems in which current workers' payroll taxes pay current retirees' benefits. Therefore, these programs are directly affected by the relative size of populations of covered workers and beneficiaries. Historically, this relationship has been favorable. In the near future, however, the overall worker-to-retiree ratio will change in ways that threaten the financial solvency and sustainability of these entitlement programs. In 2000, there were 4.8 working-age

persons (20 to 64 years) per elderly person, but by 2030, this ratio is projected to decline to 2.9.[9] This decline in the overall worker-to-retiree ratio will be due to both the surge in retirees brought about by the aging baby boom generation as well as falling fertility rates, which translate into relatively fewer workers in the near future.

Social Security's projected cost increases are due predominantly to the burgeoning retiree population. Even with the increase in the Social Security eligibility age to 67, these entitlement costs are anticipated to increase dramatically in the coming decades as a larger share of the population becomes eligible for Social Security, and if, as expected, average longevity increases.

As the baby boom generation retires and the Medicare-eligible population swells, the imbalance between outlays and revenues will increase dramatically. Medicare growth rates reflect not only a rapidly increasing beneficiary population, but also the escalation of health care costs at rates well exceeding general rates of inflation. While advances in science and technology have greatly expanded the capabilities of medical science, disproportionate increases in the use of health services have been fueled by the lack of effective means to channel patients into consuming, and providers into offering, only appropriate services. In fiscal year 2004, Medicare spending grew by 8.5 percent and is up 9.9 percent for the first 6 months of fiscal year 2005.[10] The implementation of the Medicare outpatient drug benefit in January 2006 will further increase Medicare spending in future years.

To obtain a more complete picture of the future health care entitlement burden, especially as it relates to long-term care, we must also acknowledge and discuss the important role of Medicaid. In 2003, approximately 69 percent of all Medicaid dollars was dedicated to services for the elderly and people with disabilities. Medicaid is the second largest and fastest growing item in overall state spending. At the February 2005 National Governors Association meeting, governors reported that states

[9]The specific ratios for the programs differ because of differences in the respective covered populations. Specifically, for Social Security, the ratio of covered workers to beneficiaries in 2005 is estimated to be 3.3. Under the 2005 Trustees' intermediate estimates, this ratio is projected to decline to 2.1 by 2035. For Medicare Hospital Insurance, the ratio was estimated to be 3.9 for 2005 and was projected to decline to 2.3 by 2035 under the 2005 Trustees' intermediate estimates.

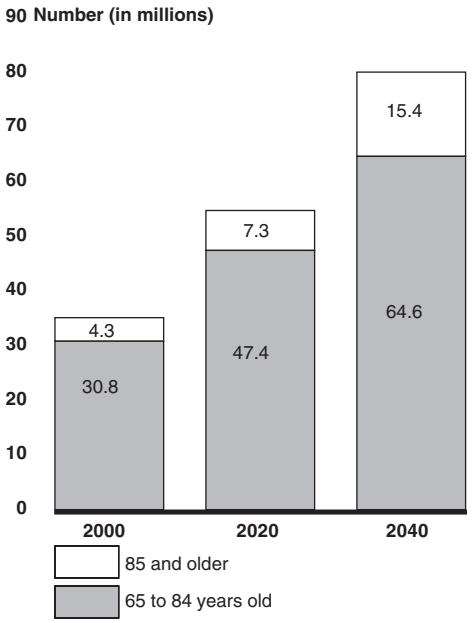
[10]See CBO, *Monthly Budget Review* for November 4, 2004, and April 6, 2005.

are faced with proposing cuts in their Medicaid programs. Over the longer term, the increase in the number of elderly will add considerably to the strain on federal and state budgets as governments struggle to finance increased Medicaid spending. In addition, this strain on state Medicaid budgets may be exacerbated by fluctuations in the business cycle. State revenues decline during economic downturns, while the needs of the disabled for assistance remain constant.

Baby Boom Generation Will Greatly Expand Demand for Long-Term Care

In coming decades, the sheer number of aging baby boomers will swell the number of elderly with disabilities and the need for services. These overwhelming numbers offset the slight reductions in the prevalence of disability among the elderly reported in recent years. In 2000, individuals aged 65 or older numbered 35.1 million people—12.4 percent of our nation's total population. By 2020, that percentage will increase by nearly one-third to 16.3 percent—one in six Americans—and will represent nearly 20 million more elderly than there were in 2000. By 2040, the number of elderly aged 85 years and older—the age group most likely to need long-term care services—is projected to increase more than 250 percent from 4.3 million in 2000 to 15.4 million (see fig. 4).

Figure 4: Elderly Population, 2000 through 2040



Sources: U.S. Census Bureau, *Annual Estimates of the Population by Sex and Five-Year Age Groups for the United States: April 1, 2000 to July 1, 2003 (NC-EST2003-01)* (June 2004), and *U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin* (Mar. 2004).

It is difficult to precisely predict the future increase in the number of the elderly with disabilities, given the counterbalancing trends of an increase in the total number of elderly and a possible continued decrease in the prevalence of disability. The number of elderly with disabilities remained fairly constant from 1982 through 1999 while the percentage of those with disabilities fell between 1 and 2 percent a year from 1984 through 1999. Possible factors contributing to this decreased prevalence of disability include improved health care, improved socioeconomic status, and better health behaviors. The positive benefits of the decreased prevalence of disability, however, will be overwhelmed by the sheer numbers of aged baby boomers. The total number of disabled elderly is projected to increase, with estimates varying from an increase of one-third to twice the current level, or as high as 12.1 million by 2040.

The increased number of disabled elderly will exacerbate current problems in the provision and financing of long-term care services. For example, in 2000 it was reported that approximately one in five adults with long-term care needs and living in the community reported an inability to receive needed care, such as assistance in toileting or eating, often with

adverse consequences.[11] In addition, disabled elderly may lack family support or the financial means to purchase medical services. Long-term care costs can be financially catastrophic for families. Services, such as nursing home care, are very expensive; while costs can vary widely, a year in a nursing home typically costs more than $50,000, and in some locations can be considerably more. Because of financial constraints, many elderly rely heavily on unpaid caregivers, usually family members and friends; overall, the majority of care received in the community is unpaid. However, in coming decades, fewer elderly may have the option of unpaid care because a smaller proportion may have a spouse, adult child, or sibling to provide it. By 2020, the number of elderly who will be living alone with no living children or siblings is estimated to reach 1.2 million, almost twice the number without family support in 1990.[12] In addition, geographic dispersion of families may further reduce the number of unpaid caregivers available to elderly baby boomers.

Spending for Long-Term Care for Elderly Anticipated to Increase Sharply

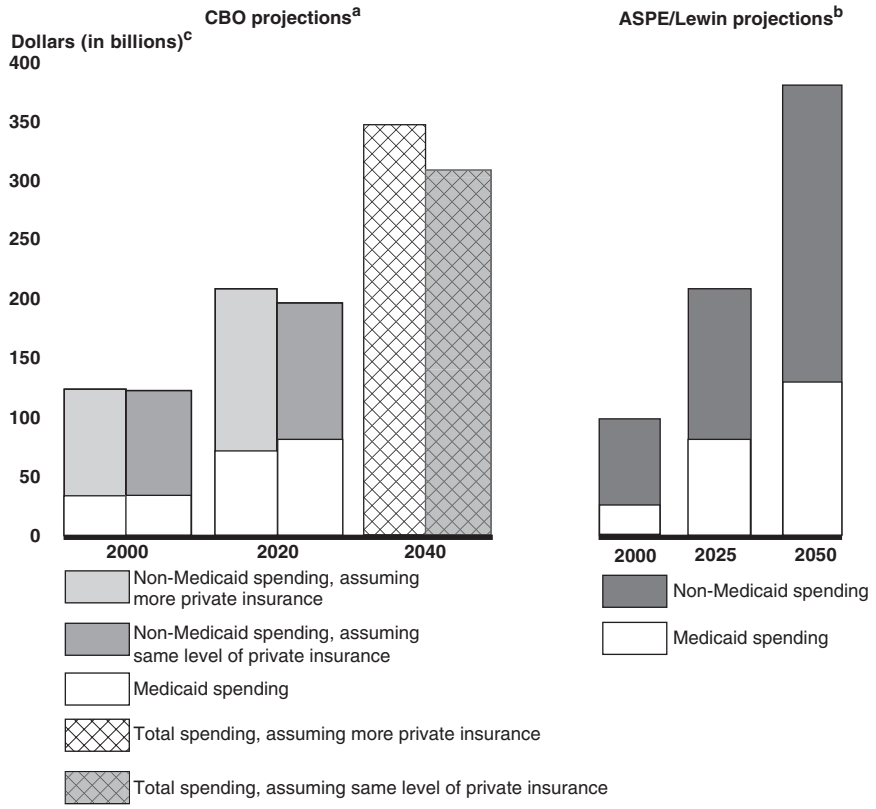
Public and private spending on long-term care was about $183 billion for persons of all ages in 2003. CBO projected in 1999 that long-term care spending for the elderly could increase by more than two-and-a-half times from 2000 to 2040. A 2001 study projected that these expenditures could quadruple from 2000 through 2050, reaching $379 billion in 2050.[13] (See fig. 5.) Estimates of future spending are imprecise, however, due to the uncertain effect of several important factors, including how many elderly will need assistance, the types of care they will use, and the availability of public and private sources of payment for care. Absent significant changes in the availability of public and private payment sources, however, future spending is expected to continue to rely heavily on public payers, particularly Medicaid, which estimates indicate paid about 35 percent of long-term care expenditures for the elderly in 2004.

[11]Judith Feder et al., "Long-Term Care in the United States: An Overview," *Health Affairs*, May/June 2000, pp. 40-56.

[12]"Aging into the 21st Century," prepared by Jacob Siegel for the Administration on Aging, U.S. Department of Health and Human Services, May 1996.

[13]Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services, who contracted with The Lewin Group, as published in Urban Institute, "Long-Term Care: Consumers, Providers, and Financing, A Chart Book" (Washington, D.C.: March 2001).

Figure 5: Long-Term Care Expenditures for the Elderly, 2000 through 2050



Sources: CBO, "Projections of Expenditures for Long-Term Care Services for the Elderly" (Washington, D.C.: March 1999) and ASPE/Lewin, published in Urban Institute, "Long-Term Care: Consumers, Providers, and Financing, A Chart Book" (Washington, D.C.: March 2001), with additional information provided by ASPE on projected Medicaid spending.

[a]CBO did not separately report spending by Medicaid or any other financing source as a portion of the total estimated long-term care expenditures for the elderly for years later than 2020.

[b]ASPE/Lewin did not report separate estimates for different assumptions about the role of private insurance.

[c]Projections are in constant dollars.

One factor that will affect spending is how many elderly will need assistance. As noted earlier, even with continued decreases in the prevalence of disability, aging baby boomers are expected to have a disproportionate effect on the demand for long-term care. Another factor influencing projected long-term care spending is the type of care that the baby boom generation will use. Per capita expenditures for nursing home care greatly exceed those for care provided in other settings. Since the 1990s, there have been increases in the use of paid home care as well as in assisted living facilities, a relatively newer and developing type of housing.

It is unclear what effect continued growth in paid home care, assisted living facilities, or other care alternatives may have on future expenditures. Any increase in the availability of home care may reduce the average cost per disabled person, but the effect could be offset if there is an increase in the use of paid home care by persons currently not receiving these services.

Changes in the availability of public and private sources to pay for care will also affect expenditures. Private long-term care insurance has been viewed as a possible means of reducing catastrophic financial risk for the elderly needing long-term care and relieving some of the financial burden currently falling on public long-term care programs. Increases in private insurance may lower public expenditures but raise spending overall because insurance increases individuals' financial resources when they become disabled and allows the purchase of additional services. The number of policies in force remains relatively small despite improvements in policy offerings and the tax deductibility of premiums. However, as we have previously testified, questions about the affordability of long-term care policies and the value of the coverage relative to the premiums charged have posed barriers to more widespread purchase of these policies.[14] Further, many baby boomers continue to assume they will never need such coverage or mistakenly believe that Medicare or their own private health insurance will provide comprehensive coverage for the services they need. If private long-term care insurance is expected to play a larger role in financing future generations' long-term care needs, consumers need to be better informed about the costs of long-term care, the likelihood that they may need these services, and the limits of coverage through public programs and private health insurance.

With or without increases in the availability of private insurance, Medicaid and Medicare are expected to continue to pay for the majority of long-term care services for the elderly in the future. Without fundamental financing changes, Medicaid can be expected to remain one of the largest funding sources for long-term care services for aging baby boomers, with Medicaid expenditures for long-term care for the elderly reaching as high as $132 billion by 2050. As noted earlier, this increasing burden will strain both federal and state governments.

[14]GAO, *Long-Term Care: Baby Boom Generation Increases Challenge of Financing Needed Services*, GAO-01-563T (Washington, D.C.: Mar. 27, 2001) and *Long-Term Care Insurance: Better Information Critical to Prospective Purchasers*, GAO/T-HEHS-00-196 (Washington, D.C.: Sept. 13, 2000).

Considerations for Reforming Long-Term Care Financing

Given the anticipated increase in demand for long-term care services resulting from the aging of the baby boom generation, the concerns about the availability of services, and the expected further stress on federal and state budgets and individuals' financial resources, some policymakers and advocates have called for long-term care financing reforms. Indeed, we identified options for rethinking the federal, state, and private insurance roles in financing long-term care as one of the key questions that our nation needs to face as it addresses 21st century challenges.[15] The Comptroller General previously testified in 2002 on several considerations for policymakers to keep in mind when considering reforms for long-term care financing, and these considerations remain relevant today.

At the outset, it is important to recognize that long-term care services are not just another set of traditional health care services. Meeting acute and chronic health care needs is an important element of caring for aging and disabled individuals. Long-term care, however, encompasses services related to maintaining quality of life, preserving individual dignity, and satisfying preferences in lifestyle for someone with a disability severe enough to require the assistance of others in everyday activities. Some long-term care services are akin to other health care services, such as personal assistance with activities of daily living or monitoring or supervision to cope with the effect of dementia. Other aspects of long-term care, such as housing, nutrition, and transportation are services that all of us consume daily but become an integral part of long-term care for a person with a disability. Disabilities can affect housing needs, nutritional needs, or transportation needs. But, what is more important is that where one wants to live or what activities one wants to pursue also affects how needed services can be provided. Providing personal assistance in a congregate setting such as a nursing home or assisted living facility may satisfy more of an individual's needs, be more efficient, and involve more direct supervision to ensure better quality than when caregivers travel to individuals' homes to serve them one on one. Yet, those options may conflict with a person's preference to live at home and maintain autonomy in determining his or her daily activities.

Keeping in mind that policies need to take account of the differences involved in long-term care, there are several issues that policymakers may wish to consider as they address long-term care financing reforms. These include:

[15]GAO, *21st Century Challenges: Reexamining the Base of the Federal Government.*

- **Determining societal responsibilities**. A fundamental question is how much the choices of how long-term care needs are met should depend upon an individual's own resources or whether society should supplement those resources to broaden the range of choices. For a person without a disability requiring long-term care, where to live and what activities to pursue are lifestyle choices based on individual preferences and resources. However, for someone with a disability, those lifestyle choices affect the costs of long-term care services. The individual's own resources—including financial resources and the availability of family or other informal supports—may not be sufficient to preserve some of their choices and also obtain needed long-term care services.

  Societal responsibilities may include maintaining a safety net to meet individual needs for assistance. However, the safety net may not provide a full range of choices in how those needs are met. Persons who require assistance multiple times a day and lack family members to provide some share of this assistance may not be able to have their needs met in their own homes. The costs of meeting such extensive needs may mean that sufficient public support is available only in settings such as assisted living facilities or nursing homes. More extensive public support may be extended, but decisions to do so should carefully consider affordability in the context of competing demands for our nation's resources.

- **Considering the potential role of social insurance in financing**. Government's role in many situations has extended beyond providing a safety net. Sometimes this extended government role has been a result of efficiencies in having government undertake a function, or in other cases this role has been a policy choice. Some proposals have recommended either voluntary or mandatory social insurance to provide long-term care assistance to broad groups of beneficiaries. In evaluating such proposals, careful attention needs to be paid to the limitations and conditions under which services will be provided. In addition, who will be eligible and how such a program will be financed are critical choices. As in establishing a safety net, it is imperative that any option under consideration be thoroughly assessed for its affordability over the longer term.

- **Encouraging personal preparedness**. Becoming disabled is a risk. Not everyone will experience disability during his or her lifetime and even fewer persons will experience a severe disability requiring extensive assistance. This is the classic situation in which having insurance to provide additional resources to deal with a possible disability may be better than relying on personally saving for an event that may never occur. Insurance allows both persons who eventually will become disabled and those who will not to use more of their economic resources during their

lifetime and to avoid having to put those resources aside for the possibility that they may become disabled.

The public sector has at least two important potential roles in encouraging personal preparedness. One is to adequately educate people about the current divisions between personal and societal responsibilities. Only if the limits of public support are clear will individuals be likely to take steps to prepare for a possible disability. Currently, one of the factors contributing to the lack of preparation for long-term care among the elderly is a widespread misunderstanding about what services Medicare will cover. Another public sector role may be to assure the availability of sound private long-term care insurance policies and possibly to create incentives for their purchase. Progress has been made in improving the value of insurance policies through state insurance regulation and through strengthening the requirements for policies qualifying for favorable tax treatment enacted by the Health Insurance Portability and Accountability Act of 1996.[16] Furthermore, since 2002 the federal government has offered long-term care insurance to federal employees, military personnel, retirees, and their families, providing the largest offering of long-term care insurance. While the federal government's program is still very new, other employers and policymakers will likely be carefully watching the federal government's experience in offering long-term care insurance. Long-term care insurance remains an evolving product, and given the flux in how long-term care services are delivered, it is important to monitor whether long-term care insurance regulations need adjustments to ensure that consumers receive fair value for their premium dollars.

- **Recognizing the benefits, burdens, and costs of informal caregiving**. Family and other informal caregivers play a critical role in supplying the bulk of long-term care to disabled persons. Effective policy must create incentives and supports for enabling informal caregivers to continue providing assistance. Further, care should be taken to avoid creating incentives that result in informal care being inappropriately supplanted by formal paid services. At the same time, it is important to recognize the physical, emotional, and social burdens that providing care impose on the caregiver and its economic costs to the caregiver and to society. Caregiving may create needs in caregivers themselves that require respite or other relief services. In addition, caregiving can conflict with caregivers' employment, creating economic losses for caregivers and society. Such

[16]Pub. L. No. 104-191, §§ 321-327, 110 Stat. 1936, 2054-2067.

losses in productivity will become even more important in the coming decades as the proportion of the population that is working-age declines.

- **Assessing the balance of federal and state responsibilities to ensure adequate and equitable satisfaction of needs**. Reforms in long-term care financing may require reevaluating the traditional federal and state financing roles to better ensure an equitable distribution of public support for individuals with disabilities. The variation across states in Medicaid spending per capita on long-term care is in part reflective of differences among states in generosity of services as well as their fiscal capacity. Given these differences, having states assume primary responsibility for financing long-term care subjects individuals to different levels of support depending on where they live. In addition, because state revenues are sensitive to the business cycle and states generally must have balanced budgets, their services become vulnerable during economic downturns.

- **Adopting effective and efficient implementation and administration of reforms**. Proposed reforms to better meet the increasing demand for long-term care within budget constraints will be successful only if they are administratively feasible, effectively reach targeted populations and unmet needs, and efficiently provide needed services at minimum cost while complementing already available services and financing sources.

- **Developing financially sustainable public commitments**. Finally, as noted earlier, absent reform, existing federal entitlement commitments for Medicaid, Medicare, and Social Security will represent an increasing and potentially unsustainable share of the economy. States, too, are concerned about their budgetary commitments for long-term care through their share of the Medicaid program. Before committing to any additional public role in financing long-term care, it is imperative to provide reasonable assurance that revenues will be available to fund its future costs.

Mr. Chairman, this completes my prepared statement. I would be happy to respond to any questions you or other members of the subcommittee may have at this time.

Contact and Acknowledgments

For future contacts regarding this testimony, please call Kathryn G. Allen at (202) 512-7118. Other individuals who made key contributions include John Dicken, Linda F. Baker, Laura Sutton Elsberg, James R. McTigue, and Joseph Petko.

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