CHAPTER ONE

Long Term Care: Definition, Demand, Cost, and Financing

by Nelda McCall

During the last 50 years, dramatic changes have taken place in the way our nation cares for the elderly and the disabled. Once the exclusive province of the family, long term care has developed into a system primarily supported by public money and focused on reimbursement for institutional care, the most expensive and most restrictive care setting. As the U.S. population ages, the development of a more flexible and efficient long term care system—as well as more rational and equitable ways to finance it—will become an increasingly important public policy issue.

This chapter provides background on the issue of long term care financing, documenting the services that constitute long term care, discussing the demand for these services, and highlighting their cost and financing. It concludes with reflections on how these forces have come together to make the issue of long term care financing critically important for future public policy.

Defining Long Term Care

Long term care refers to a continuum of medical and social services designed to support the needs of people living with chronic health problems that affect their ability to perform everyday activities. Long term care services include traditional medical services, social services, and housing. The goals of long term care are much more complicated and considerably more difficult to measure than the goals of acute medical care. While the primary goal of acute care is to return an individual to a previous functioning level, long term care aims to prevent deterioration and promote social adjustment to stages of decline.

Long term or chronic care includes a much broader range of services than acute care, emphasizing social as well as medical services. While acute care is usually confined to specialty providers, the providers of long term care
are more wide ranging. They include traditional medical providers such as physicians and hospitals, formal community caregivers such as home care agencies, facility providers such as nursing homes and assisted living facilities, and informal caregivers such as friends or family members.

Below are described services that are included in these three main types of long term care: community care, institutional care, and informal care (Figure 1.1).

**Community Care**

The most common types of community care are home health care, adult day care, and hospice care.

*Home Health Care.* Home health care is provided to those recovering from an acute hospitalization (called subacute care) as well as to those with more chronic long term care needs. Home care may involve a wide variety of medical and social services and providers, depending on the patient’s needs. These services include skilled nursing care provided by registered or licensed practical nurses (LPNs); physical, speech, and occupational therapies; professional services provided by social workers, dieticians, case managers, nutritionists, and audiologists; home health aide services; and personal care, meals, and home-based personal support services such as help with homemaking and chores.

Home health agencies numbered approximately 20,000 in 1998, and their average visit cost was $75 in 1997 (NAHC 1999a). A total of 9,513 of these agencies, or about half, were certified to provide care through
the Medicare program. The number of Medicare-certified home health agencies has decreased in the last few years, likely in response to the more restrictive Medicare payments for home health services and the planned implementation of a home health prospective payment system (GAO 1999). Home health agencies that do not provide skilled nursing care are not eligible for Medicare certification. Many home care services such as meals, transportation, and other assistance are provided through state, community, and religious organizations that are not federally certified.

The 1996 National Home and Hospice Survey reported 7.8 million home health discharges in 1996. The most common diagnoses for home health patients were circulatory conditions (primarily heart disease and hypertension), endocrine diseases (primarily diabetes), and musculoskeletal and respiratory system problems (Haupt 1998). Data from the 1994 Home Care and Hospice Survey found that of those home care patients receiving services, more than four in five (81 percent) had received skilled nursing services during the previous 30 days; more than one in five (21 percent) had received physical, occupational, or speech therapy; more than half (57 percent) had received personal care; and almost one-quarter (23 percent) had received homemaker or companion services (Dey 1996).

**Adult Day Care.** Adult day care programs provide a variety of support services for impaired adults (mainly the elderly) in a protective setting during the day. According to data from Partners in Caregiving, more than half of adult day care programs offer medical services and rehabilitation therapy; more than three-fourths have nursing services, personal care services, and transportation; and more than 90 percent provide social services, meals, and recreational therapy/activities (Partners in Caregiving 1995). Most of the 4,000 adult day centers operate during normal business hours. A few provide care in the evenings and on weekends. Using data from a personal communication with the National Adult Day Services Association, an estimated 4,000 or more adult day health centers in the United States serve approximately 88,000 adults (Holguin 1999). Another source indicates about 150,000 seniors a day can be accommodated in current adult day centers (Harling Communications 1999). Ninety percent are nonprofit and affiliated with larger organizations such as nursing homes, medical centers, or senior organizations. Adult day care costs can range from several dollars to $185 per day (National Adult Day Services Association 1999) and were estimated by the American Health Care Association (AHCA) to be an average of $45 per day (AHCA 1999a).

**Hospice Care.** In addition to medical services, hospices provide supportive emotional and spiritual services to terminally ill patients and their families.
These services usually involve an interdisciplinary team that includes a physician, a nurse or nurse’s aide, a social worker, a member of the clergy, and volunteers. Team members provide medical services, social services, and respite care for the patient and family. In 1999, approximately 3,200 hospices were operating in the United States, of which 80 percent were Medicare certified (NHO 1999). According to data from the 1995 National Hospice Organization (NHO) Survey, 65 percent of hospice patients had Medicare as their source of payment, representing an average of 74 percent of their revenue. To be eligible for hospice services under Medicare, the terminally ill patient must be diagnosed as having six months or less to live. In 1998, hospices served approximately 540,000 patients (NHO 1999). More than 70 percent of all hospice patients have cancer, but other common diagnoses include AIDS, diseases of the nervous and sense organs including Alzheimer’s and Parkinson’s, meningitis, diseases of the circulatory system such as heart disease, and diseases of the respiratory system (Haupt 1998). The average length of stay was 51 days in 1998 with a median of 25 days (NHO 1999).

Hospice providers are of various types and include freestanding hospitals, home care agency–based hospices, hospital-based hospices, and skilled nursing facility (SNF) hospice care. The majority of hospices are divisions of corporations other than hospices. Of the $1.9 billion spent on Medicare hospice care in 1997, most (55 percent) of the hospice outlays went to freestanding facilities, 27 percent went to agency-based care, 17 percent went to hospital-based care, and 1 percent to SNF-based hospice care (NAHC 1999b). Medicare per diem rates for hospice care in 1997 were $94.17 for home care and $418.93 for inpatient care (NHO 1999).

Facility Care

Facility care includes nursing home care and various kinds of supportive housing. Services provided include nursing care, personal care services, and room and board.

Nursing Homes. Nursing homes provide institutional care for people recovering from an acute illness or for those whose chronic needs require skilled nursing care, significant assistance with activities of daily living (ADLs) such as bathing, toileting, or transferring, or both. In 1997 approximately 17,000 nursing homes were in operation, with 1.8 million beds and 1.6 million people in residence. Seventy-eight percent of the nursing home facilities and 84 percent of the nursing home beds were dually certified for Medicare and Medicaid; 5 percent of the facilities and 3 percent of the beds were certified for Medicare only; and 14 percent of the facilities...
and 10 percent of the beds were certified for Medicaid only. Only 2.7 percent of the nursing home beds were not Medicare or Medicaid certified (Gabrel 2000).

The Medical Expenditure Panel Survey (MEPS) Nursing Home Component (NHC) found approximately 66 percent of nursing homes were private for-profit, 26 percent were private nonprofit, and 8 percent were owned by the federal, state, or local government in 1996. It also found that the majority (53 percent) of nursing homes were owned by a multifacility chain, with the remainder independently owned or operated (Rhoades, Potter, and Krauss 1998).

Data from the same MEPS survey analyzed in a report by Krauss and Altman (1998) found the vast majority (71 percent) of the 1.56 million nursing home residents were women and approximately half the residents were age 85 or over. Eighty-three percent of residents required help with three or more ADLs and almost half (48 percent) had dementia. The next most common diagnoses were heart disease (46 percent), hypertension (37 percent), arthritis (24 percent), and cerebrovascular accidents (21 percent). More than 20 percent of residents had depression. AHCA (1999a) estimates an average daily nursing home care cost at $112 per day, or just over $40,000 per year. Others have estimated the annual cost in excess of $40,000 (U. S. House of Representatives 1998; gao 1998), at $46,000 in 1995 (Wiener and Stevenson 1998), and at approximately $51,000 in 1997 (HCFA 1999).

An analysis of nursing home trends between 1987 and 1996 based on 1987 data from the National Medical Expenditure Survey (NMES) Institutional Population Component (IPC) and 1996 data from the MEPS NHC found significant changes in the nursing home market and characteristics of the nursing home population. While the number of nursing homes and beds increased almost 20 percent from 1987 to 1996, the elderly population has grown faster such that the number of nursing home beds per person 75 years and over has decreased 17 percent, from 141 to 117 per thousand people. Nursing homes are also caring for an older and sicker population. In 1987, 49 percent of the residents were over 85 years of age; 56 percent were over 85 years of age in 1996. In 1987, 72 percent of residents had three or more ADL limitations; in 1996, the figure had jumped to 83 percent (Rhoades and Krauss 1999).

Supportive Housing. Supportive housing is designed to provide group living, assistance with daily personal care, and protective oversight for people with long term care needs. The major types of supportive housing are board and care homes, assisted living facilities, adult foster care homes, continuing care retirement communities, and congregate housing.
Board and care homes offer medical supervision, help with ADLs, meals, and housekeeping. These facilities are diverse, but all emphasize homelike environments. Residents include older people with physical frailties, those with developmental disabilities, and the chronically mentally ill. Typically, board and care are provided in a family setting for four to ten residents. Some homes specialize in caring for a particular type of resident, such as someone with Alzheimer’s disease. A study for the American Association of Retired Persons (AARP) estimated that in 1993, approximately 500,000 residents were being served in some 32,000 board and care homes. Costs were estimated to range from $500 to $3,000 per month, with about half of residents publicly funded (Blanchette 1997).

Assisted living facilities offer private rooms or apartments, meals, housekeeping services, assistance with ADLs, social activities, and 24-hour oversight. The philosophy of assisted living emphasizes personal autonomy and privacy. These facilities are primarily composed of frail elders and emphasize independence, homelike settings, and the ability to age in place. They typically are more expensive than board and care homes, have more residents per facility, and offer a wider range of supportive services. Assisted living facilities generally provide assistance with medication administration and arrange for skilled nursing care.

According to data from the National Center for Assisted Living (NCAL 1999), in 1998 approximately 1.2 million people were living in 28,000 assisted living residences in the United States. Because of variations across states in the definition of assisted living facilities, other sources (AARP 1999) have put the number of residents at 600,000 in 25,000 to 30,000 facilities.

A mailed survey by PricewaterhouseCoopers (1998) for the Assisted Living Federation of America (ALFA) of 402 facilities found that the typical resident is an 83-year-old woman needing assistance with three ADLs. Forty-seven percent of the residents had cognitive impairments. Their average income was $31,000. More than half came to the facility from their private residence, and 13 percent came from a nursing home. Their average length of stay was 26 months. Forty-four percent of the discharges were to nursing homes, and 26 percent died. Two industry surveys (NCAL 1998; PricewaterhouseCoopers 1998) estimated the average cost per month at approximately $2,000. Reimbursement is generally out-of-pocket, although 22 states (AARP 1999) do provide some Medicaid support, and some private insurance policies do provide coverage.

Adult foster care offers a community-based living arrangement with 24-hour supervision, personal care, and room and board. Adult foster care facilities, like board and care homes, are usually small, offer a family-oriented approach, and have less emphasis on privacy than assisted living.
facilities. They provide support services similar to board and care homes but usually not as extensive as in assisted living. Adult foster care costs were estimated to be $600 to $1,500 per month, with about half of the residents publicly supported (Blanchette 1997).

Continuing care retirement communities (CCRCs) typically guarantee residents a continuum of care, usually at one site, ranging from housing only to skilled nursing facilities. A 1997 GAO report estimated that 350,000 residents were living in approximately 1,200 CCRCs in the United States. In about one-third of these communities, residents were guaranteed lifetime care, with the CCRC assuming the financial risk for providing necessary long term care services. As a result, these CCRCs have strong incentives to promote healthy lifestyles and to provide preventive care. Most CCRC residents are affluent. CCRCs typically require a substantial financial contribution in the form of an entry fee, as well as monthly payments. The 1997 GAO survey of 11 CCRCs reported entry fees ranging from $34,000 to $44,000 and monthly fees ranging from $1,400 to $4,300.

Congregate housing arrangements offer fewer services than other types of supportive housing. Typically they include separate apartments for residents and the ability to purchase hotel-like services such as housekeeping, meals, and transportation. Personal care services and supervision are generally not included nor available. Monthly charges ranged from $700 to $1,500 and are usually paid with private funds (Blanchette 1997).

Informal Caregiving

The informal care provided to the disabled by friends, family, or community organizations is in many ways the most important component of our long term care system. The value of this care is hard to estimate because of the unavailability of good data. The Office of Assistant Secretary, Department of Health and Human Services (DHHS 1998) estimated the value of donated care at $45 billion to $94 billion per year.

Arno, Levin, and Memmott (1999) estimated the economic value of informal unpaid caregiving at an even higher number—$196 billion (their midrange estimate; the low estimate was $115 billion and the high estimate was $288 billion) in 1997. To arrive at this estimate they drew from a variety of national data sets: the Survey on Income and Program Participation (SIPP), the National Survey of Families and Households (NSFH), the National Health Interview Survey (NHIS), and the National Long Term Care Survey (NLTCS). The $196 billion estimate is double the amount spent on nursing home care and more than six times the amount spent on formal home health care. The percentage of all home care that is informal care calculated from the study by Arno and colleagues is even higher than
the 80 percent estimated by the National Family Caregivers Association (NFCA 1999).

Unpaid caregivers are disproportionately women family members or friends whose responsibilities often place them under considerable strain. The midrange estimate of Arno, Levin, and Memmott (1999) calculates their number at 26 million. The National Family Caregiver Survey (National Alliance for Caregiving and AARP 1997) found caregivers spent an average of 18 hours per week in that role. Although some states have begun to provide limited financial support for family caregivers through their Medicaid programs, informal care is largely uncompensated. Caregivers often have little training or support and routinely experience significant stress in their own physical and mental health.

Long Term Care Services—Their Past and Future

Other than informal care given by family and friends, long term care services have been dominated by institutional care delivered in nursing homes. Beginning in the 1980s, the use of professional home care services for the chronically impaired increased dramatically, both through the expansion of the publicly supported Medicare and Medicaid programs and through expanded coverage in private health insurance. The last few years have seen increased investment in assisted living and other alternate care such as congregate housing, adult foster care, and board and care homes. These investments make available an expanded range of long term care services.

A key challenge for the delivery of care to those needing long term care is how to coordinate or integrate acute care services with long term care services. In this integration of care conflict often arises between the “medical” model, which focuses on treatment of the client's medical needs, and the “social” model, which focuses on provision of services for the client's social and personal needs. The future holds promise for a more holistic, integrated view of healthcare delivery that will coordinate the delivery of care across services, take a more flexible approach to coverage, and have mechanisms to facilitate the management of preventive and acute care services within a defined system of long term care. Interest is increasing in the role that capitated managed care might be able to play in promoting service integration, as the incentives of a capitated delivery system are consistent with its goals (Knickman and McCall 1986).

Movement is also being seen toward more aggressive consumer involvement in healthcare. The baby boom generation, soon to join the ranks of the aged, will demand more involvement in the selection of long term care services, providers, and care settings than earlier, less educated generations.
This group will fuel the demand for long term care services, as discussed in the next section of this chapter.

**Demand for Long Term Care**

Estimating demand for long term care needs is complicated because it involves consideration of the prevalence of medical diagnoses and of limitations in functional abilities. Individuals need long term care when trauma or a chronic condition limits their ability to perform independently those personal activities necessary to daily living. One common way of measuring the level of disability is by assessing an individual's ability to perform specifically defined ADLs and instrumental activities of daily living (IADLs). ADL measures include such tasks as eating, dressing, bathing, walking, transferring, and using the toilet. IADLs relate to the ability to perform household chores and to participate in social activity, measuring such tasks as preparing meals, doing light housework, keeping track of money or bills, using the telephone, and going outside the house.

The estimate of individuals with functional limitations in a population has differed across data sources as individual analysts use different definitions of limitation, different specific ADL and IADL measures, and different thresholds for the number of ADL and IADL impairments to define a functional limitation. Komisar, Lambrew, and Feder (1996) attempted to define the type of personal assistance that would be characterized as long term care.\(^2\) Their estimate of the number of individuals with functional limitations in 1995 was 10.6 million, with 4.8 million under 65 years of age and 5.8 million over 65 years of age (Table 1.1). For the under-65 group, the prevalence of disabilities was estimated to be 2.1 percent; 4.6 million people were community residents with functional limitations, and 229,000 were nursing home residents. For the 65-and-over population, the prevalence of disabilities was estimated to be 17 percent; 4.1 million were community residents with functional limitations and 1.7 million were nursing home residents. Other estimates of the percent of those 65 years and older with disabilities were between 16 and 21 percent (Siegel 1996; McNeil 1997; Manton, Corder, and Stallard 1997).

Disability is dramatically related to age as seen by the more than eightfold difference in the prevalence of disability between those under 65 and those 65 and older (Komisar, Lambrew, and Feder 1996). Given this relationship, the projected acceleration of aging of the U. S. population is of special concern.

The number of elderly and their percentage of the total population will grow dramatically as a result of the aging of the baby boomers, those people born between 1946 and 1964. The U. S. Census Bureau estimates
Table 1.1: Position Estimates of Demand for Long Term Care, 1995

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Prevalence Rate (%)</th>
<th>Number with Disabilities (in millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>4.0</td>
<td>10.6</td>
</tr>
<tr>
<td>Under 65</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Noninstitutionalized</td>
<td>2.0</td>
<td>4.8</td>
</tr>
<tr>
<td>Institutionalized</td>
<td>100.0*</td>
<td>0.2</td>
</tr>
<tr>
<td>65 and over</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Noninstitutionalized</td>
<td>12.8</td>
<td>4.1</td>
</tr>
<tr>
<td>Institutionalized</td>
<td>100.0*</td>
<td>1.7</td>
</tr>
</tbody>
</table>

Source: Komisar, Lambrew, and Feder (1996).
* Calculated from data in Komisar, Lambrew, and Feder (1996). Significant digits given in the estimates do not permit calculations of the exact number, which is a little less than 100%.

Table 1.2: Estimates of Aging of the U. S. Population

<table>
<thead>
<tr>
<th>Year</th>
<th>Number (in millions)</th>
<th>Percentage of Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those over 65 years of age in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>34.3</td>
<td>12.7</td>
</tr>
<tr>
<td>2000</td>
<td>34.7</td>
<td>12.6</td>
</tr>
<tr>
<td>2010</td>
<td>39.4</td>
<td>13.2</td>
</tr>
<tr>
<td>2020</td>
<td>53.2</td>
<td>16.5</td>
</tr>
<tr>
<td>2030</td>
<td>69.4</td>
<td>20.0</td>
</tr>
<tr>
<td>2040</td>
<td>75.2</td>
<td>20.3</td>
</tr>
<tr>
<td>2050</td>
<td>78.9</td>
<td>20.0</td>
</tr>
<tr>
<td>Those over 85 years of age in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>4.0</td>
<td>1.5</td>
</tr>
<tr>
<td>2000</td>
<td>4.3</td>
<td>1.6</td>
</tr>
<tr>
<td>2010</td>
<td>5.7</td>
<td>1.9</td>
</tr>
<tr>
<td>2020</td>
<td>6.5</td>
<td>2.0</td>
</tr>
<tr>
<td>2030</td>
<td>8.5</td>
<td>2.4</td>
</tr>
<tr>
<td>2040</td>
<td>13.6</td>
<td>3.7</td>
</tr>
<tr>
<td>2050</td>
<td>18.2</td>
<td>4.6</td>
</tr>
</tbody>
</table>

that in 1998 34.3 million persons in the United States, or 12.7 percent of the total population, were over the age of 65 (U. S. Bureau of the Census 1996). Because of the relatively small number of children born during the Depression, the growth of the older population was relatively slow during the 1990s. However, between 2010 and 2030, when the baby boomers join the ranks of the elderly, the older population is expected to double.

The Census Bureau makes projections based on low, middle, and high assumptions of the fertility rate, life expectancy, and net immigration. Estimates using Census Bureau “middle series” estimates are shown in Table 1.2. Approximately 39.4 million people will be over 65 years of age in 2010, representing 13.2 percent of the population. Twenty years later, in 2030, the elderly population is estimated to swell to 69.4 million—20 percent of all Americans. By 2050, an estimated 78.9 million Americans will be over 65 years of age, and their proportion of the total population will be 20 percent (U. S. Bureau of the Census 1996).

What is perhaps even more interesting is that because of declining mortality rates, a sharp increase is projected in the number of the oldest old, those over 85 years of age. In 1998, 4 million individuals were in this age group; by 2030, the number of elderly over 85 will more than double to 8.5 million. By 2050, an estimated 18.2 million Americans will be over age 85 (U. S. Bureau of the Census 1996).

Estimates of the number of impaired individuals depend on assumptions made about how the age-specific prevalence of disability will change over time among this population. A 1999 Congressional Budget Office (CBO) projection of the number of elderly disabled assumed a 1.1 percent annual decline in the prevalence of disability from 2000 to 2040 (Hagen 1999). NLTCS data (Manton, Corder, and Stallard 1997) indicate prevalence of disability fell 1.1 percent per year between 1982 and 1989 and 1.5 percent per year from 1989 to 1994. Manton and colleagues found the disability rate had decreased from 25 percent in 1982 to 21 percent in 1994. These historical trends, which were projected to continue, combined with the increased educational attainment of the population were used to justify the assumption of a 1.1 percent annual decline.

The CBO estimate thus showed a disability prevalence rate for those 65 years and older that declined from 24.6 percent in 2000 to 17.4 percent in 2030 and to 15.6 percent in 2040. Despite this decrease in the prevalence of disability, the number of disabled elderly was projected to increase from 8.8 million (out of a total population of those 65 years of age and over of 35.7 million) in 2000 to 12.3 million (out of a total population 65 years of age and over of 71.0 million) in 2030 and 12.1 million (out of a total population 65 years of age or older of 77.9 million) in 2040.
As for the under-65 population, estimating disability prevalence is even more difficult because of the smaller amount of data than those available for the elderly. Improvements in technology, however, will increase success in sustaining people with serious injuries, who will likely live with long term permanent disabilities, thus increasing the incidence of nonelderly needing long term care.

To summarize, estimating the number of disabled people who will require long term care services is difficult. Projections must consider the impact of population increases and prospective changes in medical diagnoses, medical treatment, healthcare delivery, lifestyle, and behavior patterns. Future generations of the elderly and disabled are likely to be different—better educated, more health conscious—than today’s population. One view would argue that there will be an increased life span but no change in the onset of illness, requiring more long term care as more people live long enough to develop disabling conditions. The opposite position would argue that improved treatments for or prevention of disabling conditions would lessen long term care needs independent of death rates. However, even under optimistic scenarios, the overall demand for long term care will still rise significantly because of the large increase in the number of elderly. The cost of this care and its future incidence is discussed in the next section.

**Spending for Long Term Care**

Spending for healthcare in this country is estimated yearly by source of funding by the Office of the Actuary in HCFA. Although these are the most reliable and most often quoted numbers available to measure these expenditures, the estimates are limited by the availability of data, especially for services paid by sources outside the government. Of special note is the estimation of the amount spent by private insurance. Estimates of total private expenditures for healthcare are derived by subtracting all public sources of funding from independently derived service expenditure totals. Private expenditures are then split between out-of-pocket, private insurance, and nonpatient revenue using data from government surveys and from trade associations. Because of the difficulties of identifying long term care insurance specifically in these surveys, problems may arise in estimating private insurance payments for long term care services, which would lead to underreporting of the amount of long term care expenditures covered by private insurance.

One other technical issue regarding the data reported below needs to be considered. The personal healthcare data in the National Health Expenditure estimates is commonly reported in nine categories: hospital care, physician services, dental services, other professional services, home
health care, drugs and other medical nondurables, vision products and other medical durables, nursing home care, and other personal healthcare. Long term care services are routinely reported as home health care plus nursing home care. However, other personal healthcare includes home- and community-based services delivered under the Medicaid program. In the numbers presented in the following sections, home- and community-based service expenditures are included in long term care expenditures.

1997 Spending

**Personal Health Care Expenditures.** Figure 1.2 shows the distribution of all personal healthcare expenditures by major categories. National estimates of nursing home and home health care expenditures in 1997 indicate that together these two services make up 12 percent of all personal healthcare spending. When spending for Medicaid’s home- and community-based waiver program is added (Lazenby 1999a), the long term care share of personal healthcare expenditures increases by $8.2 billion, raising the long term care expenditures share estimate to 13 percent.

![Figure 1.2: Long Term Care Spending Relative to All Personal Healthcare Expenditures, 1997](image)

**Figure 1.2:** Long Term Care Spending Relative to All Personal Healthcare Expenditures, 1997

Sources: Braden et al. (1998); Lazenby (1999a).

Note: Besides nursing home and home care cost, long term care includes Medicaid home- and community-based waiver services.
Note that these national expenditure estimates do not include any other personal healthcare expenditures that are paid for out-of-pocket or by private insurance. In addition, no estimates in the national expenditures are made for informal care provided.

**Long Term Care Expenditures.** Table 1.3 breaks down the 1997 long term care expenditures by funding source. Home- and community-based services are included in Table 1.3, but data are available only for those services funded by the Medicaid program. Almost $83 billion was spent on nursing home care and $32 billion on home care. Medicaid paid for almost half (48 percent) of all nursing home care, other public sources (primarily Medicare and the Veterans Administration) paid another 15 percent, and 31 percent was supported out-of-pocket. Out-of-pocket support includes Social Security income received by nursing home residents. These amounts account for an estimated 49 percent of the out-of-pocket nursing home expenditures or 15 percent of all nursing home expenditures in 1997. Private sources of funding thus are estimated to pay approximately 23 percent of nursing home expenditures—16 percent from patients and their families, 5 percent from private insurance, and 2 percent from other private sources.

Medicare funded 40 percent of all home care expenditures in 1997, with 15 percent paid by Medicaid. Twenty-two percent of home care was paid out-of-pocket and 11 percent by private insurance.

**Trends in Long Term Care Expenditures, 1970–1997**

Below we examine the trends in expenditure by main type of service, by source of payment, and by the percentage contribution of each source.

<table>
<thead>
<tr>
<th>Table 1.3: Personal Healthcare Expenditures for Long Term Care by Funding Source, 1997 (in Billions)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nursing Home</strong></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Total Expenditures</td>
</tr>
<tr>
<td>Medicaid</td>
</tr>
<tr>
<td>Medicare</td>
</tr>
<tr>
<td>Other public</td>
</tr>
<tr>
<td>Out-of-pocket</td>
</tr>
<tr>
<td>Private insurance</td>
</tr>
<tr>
<td>Other private</td>
</tr>
</tbody>
</table>

Sources: Braden et al. (1998); Lazenby (1999a).
Note: N/A = not available.
*These services include Medicaid home- and community-based services.
Figure 1.3: Long Term Care Spending by Service Type

1970
TOTAL = $4.4 billion
- Home Care: 5%
- Nursing Home: 95%

1979
TOTAL = $17.2 billion
- Home Care: 11%
- Nursing Home: 89%

1988
TOTAL = $48.8 billion
- HCBS: 1%
- Home Care: 17%
- Nursing Home: 82%

1997
TOTAL = $123.3 billion
- HCBS: 7%
- Home Care: 26%
- Nursing Home: 67%

Sources: Braden et al. (1998); HCFA (1998); Lazenby (1999a).
HCBS: Medicaid home- and community-based waiver services.

By Type of Service. Figure 1.3 shows spending by major service for four years, each nine years apart: 1970, 1979, 1988, and 1997. The data for 1979 reflect spending preimplementation of the Medicaid Home- and Community-Based Waiver Program of 1981 [1915(c) of the Social Security Act]; 1988 was the year of the settlement of the Duggan v. Bowen lawsuit that liberalized the conditions under which Medicare would pay for home care services.

Expenditures on nursing home and home care have increased dramatically, from $4.4 billion in 1970 to more than $115 billion in 1997. Expenditures on home health care also increased from a negligible amount in
1970, $0.2 billion, to $32.3 billion in 1997. If home- and community-based waivers and other long term care Medicaid expenditures are added, the 1997 totals are $123.3 billion in 1997 and $48.8 billion in 1988. The 1970 and 1979 numbers are not affected because the home- and community-based waiver program was not in existence until 1981.

By Source of Payment. Table 1.4 shows the distribution of nursing home and home care expenditures by source of expenditures (Braden, Cowan, Lazenby, et al. 1998; HCFA 1998; Lazenby 1999a). Over time, nursing home services have increasingly been paid for by public funds, while the percentage paid out-of-pocket has decreased. Public support increased from 41 percent in 1970 to 62 percent in 1997 primarily because of an increase in Medicaid support between 1970 and 1979 from 22 to 51 percent and an increase in Medicare support from 2 to 12 percent between 1988 and 1997.

| Table 1.4: Amount and Distribution of Nursing Home and Home Health Care Expenditures by Source of Payment |
| --- | --- | --- | --- |
| **Nursing home** | | | |
| Total expenditures (in billions) | $4.2 | $15.3 | $39.8 | $82.8 |
| Medicaid | 22% | 51% | 46% | 48% |
| Medicare | 3 | 2 | 2 | 12 |
| Other public | 16† | 2 | 2 | 2 |
| Out-of-pocket | 53 | 41 | 44 | 31 |
| Private insurance | 0 | 1 | 4 | 5 |
| Other private | 5 | 3 | 2 | 2 |
| **Home health and HCBS*** | | | |
| Total expenditures (in billions) | $0.2 | $1.9 | $9.0 | $40.5 |
| Medicaid | 7% | 13% | 22% | 32% |
| Medicare | 27 | 29 | 18 | 32 |
| Other public | 0 | 0 | 0 | 0 |
| Out-of-pocket | 12 | 20 | 28 | 17 |
| Private insurance | 4 | 16 | 16 | 9 |
| Other private | 50 | 22 | 16 | 10 |

*This includes Medicaid home- and community-based waiver services of 0.6 billion in 1988 and 8.2 billion in 1997. Data provided by HCFA (Lazenby 1999a).

† In 1970 this was primarily (14% of the 16%) non–Title XIX federal and state funding.

Sources: Braden et al. (1998); HCFA (1998); Lazenby (1999a).
Table 1.5: Percentage of Nursing Home Expenditures Supported by Social Security Income (in Millions)

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Social Security income</td>
<td>$996</td>
<td>$4,565</td>
<td>$8,078</td>
<td>$12,692</td>
</tr>
<tr>
<td>Nursing home expenditures</td>
<td>4,867</td>
<td>19,989</td>
<td>42,789</td>
<td>82,774</td>
</tr>
<tr>
<td>Percentage</td>
<td>20.5%</td>
<td>22.8%</td>
<td>18.9%</td>
<td>15.3%</td>
</tr>
</tbody>
</table>

Sources: Lazenby and Letsch (1990); Lazenby (1999b).

*1980 data are presented instead of 1979 because data for 1979 were not available.

In 1970, total out-of-pocket payments were a majority of the nursing home expenditures (53 percent). However, a portion of these out-of-pocket expenditures is supported by Social Security payments to nursing home residents; the estimated amount is shown in Table 1.5 for 1970, 1980, 1988, and 1997. As shown in this table, Social Security income is a substantial contributor to financing long term care.

Over this same time period, private insurance payment of nursing home costs rose from virtually no coverage in 1970 to supporting 5 percent of all expenditures in 1997. Other private sources of revenue decreased from 5 to 2 percent of expenditures.

Primary payment sources for home care also have changed substantially over time. In 1970, half of all home care was supported by private third-party payers (not including private health insurance), primarily philanthropic organizations. Public funds paid for only a little more than one-third (34 percent) of all home care, with 27 percent paid for by Medicare and 7 percent by Medicaid. The Medicaid share increased to 13 percent by 1979 and stabilized at the 15 to 16 percent range between 1988 and 1997. After the Duggan v. Bowen court decision in 1988, Medicare percentage contribution for home healthcare increased substantially. From 1988 to 1996, Medicare expenditures increased from $2 billion to $17 billion, an average annual increase of 31 percent per year (MedPAC 1998). These Medicare increases drove the overall home care expenditure increases in the period from 1990 to 1997, making it one of the fastest growing components of National Health Expenditures (Braden, Cowan, Lazenby, et al. 1998).

By 1997, only 10 percent of home care was funded by private sources other than insurance. Sixty-four percent of all home care expenditures were covered by public programs—32 percent by Medicare and 32 percent by Medicaid. Only 17 percent of home care expenditures were funded out-of-pocket in 1997. Private insurance coverage of home care also rose from only 4 percent in 1970 to 9 percent in 1997.
Percentage Contributions by Source. The percentage of total long term care expenditures by different payment sources has shifted substantially in the last 30 years. Figure 1.4 shows the percentage of expenditures by source of funds in four years: 1970, 1979, 1988, and 1997. From 1970 to 1979, Medicaid coverage increased substantially, from 22 percent of expenditures to 46 percent, and stabilized at 42 percent of expenditures. Medicare percentages remained at about the same level, 5 percent, until after 1988 when they increased dramatically to 19 percent. Other public and private sources have reduced their percentage of contributions over time. Other public sources decreased from 15 to 2 percent by 1979 and stabilized at that rate through 1997. Other private sources began at the level of support of 7 percent of expenditures and stabilized at a rate 4 to 5 percent of expenditures through
the three later years observed. Private insurance support started from a low of one percent in 1970 and increased to 6 percent of expenditures by 1997.

Future Spending

Estimates of resources to be spent in the future and the funding sources’ respective contributions are difficult to project. Not only do the incidences of need discussed earlier in this chapter need to be considered, but assumptions need to be made about the rules of eligibility and coverage for public programs and the amount of private health insurance coverage that will be in place to support consumer expenditures. Some of the factors that could affect the availability of public funding, the support likely to be available from private sources, and some recent CBO projections of long term care expenditures and financing sources are examined below.

Rules of Eligibility and Coverage for Public Programs. Recent changes in federal legislation will likely affect availability of Medicare financing for home care services, including the new home health payment system legislated in the Balanced Budget Act (BBA) of 1997. This legislation puts in place an interim payment system that limits amounts that can be reimbursed per visit and per beneficiary and legislates enactment of a prospective payment system. This new capitated payment system will undoubtedly affect the percentage of long term care home health costs supported by Medicare as the Medicare home care payment is shifted from a cost-based system to a case-mix adjusted prospective payment system. Whether this will result in cost shifting to the Medicaid program or to increased out-of-pocket expenditures is being studied (Center for Home Care Policy and Research 1998). Other changes of this type as well as more radical changes are possible in publicly financed programs.

Considerable interest and debate has arisen on the use of legal means to attain eligibility to Medicaid. Some commentators believe it is a substantial problem that, with the assistance of elder law attorneys, results in easily transferring income and assets to achieve Medicaid eligibility (Moses 1999; Walker, Gruman, and Robison 1999). Others think it is not an important issue and that tightening of asset transfer rules will not substantially affect Medicaid revenues (Wiener 1996). The amount of Medicaid dollars spent in the future is dependent on whether Congress takes more aggressive steps to limit the ability of Medicaid beneficiaries to divest assets and on which of these viewpoints proves more accurate.

Federal legislators have made efforts over the last 20 years to discourage Medicaid estate planning, beginning with the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, which restricted transfer of assets and
authorized estate recoveries. The most recent effort to criminalize attorney participation in certain types of estate planning came with the BBA of 1997. None of these efforts seems to have been successful in stemming estate planning activities. To the extent that a piece of federal legislation can be passed that will effectively criminalize Medicaid estate planning or otherwise provide incentives to consumers to plan for long term care costs, the distributions of financing sources could be altered substantially in the future.

Another wild card in estimating future costs is the extent to which nursing homes as we know them will continue to be supported with public dollars. Clearly institutional care will shift to include other housing-like alternatives. In addition, some policy analysts have recommended removing room and board from publicly supported programs (Kane 1999). Nursing home bankruptcies and reorganizations are widely rumored today (Appleby 1999; California Healthcare Foundation 1999) as Medicaid reimbursement drives the dollars available to the nursing home industry. At the same time, the heavy focus of federal and state regulations on ensuring the structure and process of the care delivered further increase nursing home costs. Reforms in any of these areas could have profound effects on future nursing home costs and who will pay them.

Support by Private Sources. The amount of long term care insurance and the use of other financial vehicles to support long term care costs in the future are other unknowns that affect estimates of both the total costs and their incidence by funding source. Long term care insurance in the last 30 years has increased its participation in the payment of long term care costs from less than one percent to about 6 percent of expenditures. The number of individuals covered by long term care policies has increased from 1.7 million in 1992 to 2.9 million in 1997 (NAIC 1998). The concept behind insurance is to pool the risk of having a relatively low incidence of a catastrophic event across a large number of people. Private insurance prices the risk by estimating the probability of the event occurring, the cost of its occurrence, and the premium stream necessary for sufficient reserves to support insurance payouts. Long term care seems to be a service for which private insurance might be appropriate.

Insurers were initially reluctant to enter the market and, when they did, tended to price their products conservatively. Twenty years ago, long term care insurance was not thought to be a very good product (McCall, Rice, and Hall 1983). Adverse selection (i.e., the people who buy insurance are more likely to use it) and moral hazard (i.e., people will use more services when they have insurance) were thought to be major problems. If incidence rates and costs for the average person are used as estimates for pricing policies
and if adverse selection and moral hazard exist, adequate monetary reserves will not be set aside by the companies to support the long term care use of those who insure. This scenario has historically been the dilemma for private insurers. If they price their policies too high, only those who are likely to be sickest will purchase them. Thus the failure of the market becomes a self-fulfilling prophecy.

Also contributing to the apparent market failure of long term care insurance is the population's lack of awareness of their risk of needing nursing home care. Analysis of the 1977 NMES found that fewer than 40 percent of Medicare beneficiaries knew whether their policies covered nursing home care (Cafferata 1984), and a study of 1,650 randomly selected Medicare beneficiaries in 1982 in six states found only a little more than one-third of the beneficiaries (36 percent) correctly knew that Medicare did not cover all the costs for a six-month nursing home stay (McCall, Rice, and Sangl 1986). By the 1990s substantially more beneficiaries knew about the limitations of Medicare. A study conducted in 1995/96 indicated that among a random sample of 1,050 people 55 to 75 years of age in four states only 23 percent believed that Medicare provided sufficient coverage for long term care (McCall et al. 1997).

Although knowledge about financing sources has increased, two recent studies of individuals over 55 indicated a continued lack of knowledge of the risk of needing long term care services. Although data from MEPS indicate that 40 percent of Americans will need long term care (AHCPR 1996), only 39 percent in one study (Cohen and Kumar 1997) and 42 percent in the other (McCall et al. 1997) thought their chances of needing long term care services were greater than 25 percent. Only 21 percent (Cohen and Kumar 1997) and 32 percent (McCall et al. 1997) had considered buying long term care insurance. Even more troubling are surveys including younger adults demonstrating the same pattern of lack of knowledge. A survey of 1,000 adults in 1998 conducted by the National Council on Aging (NCOA) and the John Hancock Mutual Life Insurance Company found that 70 percent were not able to pass a ten-question quiz on basic facts about long term care (i.e., who provides care, what care options are available, and who pays). They also found 73 percent incorrectly responded that Medicare is the primary funding source for older persons’ long term care needs (NCOA 1998).

Another study, commissioned by AHCA (1999b), of 800 adults 34 to 52 years of age also indicated baby boomers are not adequately prepared for long term care needs. Eighty percent indicated they did not know how long term care is paid for. More than two-thirds (68 percent) said they were not financially prepared for long term care should they need it in retirement, and half had not given any thought to how they would pay for long term care needs. Twenty-seven percent thought they were covered by long term care
insurance although only a small percentage of the 6 percent of individuals with such coverage are boomers (AHCA 1999b).

Thus, despite some recent improvements in the perception of their risk of needing and their ability to pay for long term care, people have not in great numbers looked to private insurance to fill these needs. One reason may be a continuing lack of willingness to plan for the risks of long term care, but another might stem from the unsettled nature of the market, where both insurance products and the delivery system are changing.

CBO Projections of Future Financing. Recent projections of future long term care expenditures for the elderly, prepared by the CBO in March 1999, project an increase in inflation-adjusted expenditures for nursing home and home health services of 2.6 percent per year, from $123.1 billion in 2000 to $207.3 in 2020 and $346.1 in 2040 (Hagen 1999). It should be noted that these estimates exclude home- and community-based services provided under waivers by the Medicaid program as well as services provided in assisted living facilities and adult day care centers, both of which are likely to be more important components of long term care in the future. Even the current Medicaid home- and community-based waiver program is excluded from these estimates. (Note the home- and community-based waiver program’s estimates are included in the data presented earlier in this chapter.)

The CBO estimate includes an assumption of decreased prevalence of disability of 1.1 percent per year and an increase in private insurance spending during the years 2000 to 2020. The distribution of total expenditures by payment source for 2000 to 2020 are given in Table 1.6 for the CBO projection and for an alternative CBO projection that assumes no increase in private insurance coverage.

Under the primary CBO projection, private insurance coverage would increase from 4 percent of expenditures in 2000 to 10 percent in 2010 and 17 percent in 2020. Medicare expenditures would remain relatively stable at 24 percent to 25 percent. Medicaid expenditures would increase from 35 percent to 42 percent and later decline to 37 percent in 2020, while out-of-pocket increases would decrease from 35 percent to 22 percent in 2010 and to 21 percent in 2020.

Under the alternate projection that assumes no increase in private insurance, Medicare expenditures as a proportion of total expenditures would increase from 24 percent to 27 percent in both 2010 and 2020. Medicaid expenditures would increase from 36 percent to 47 percent in 2010 and decrease to 45 percent in 2020. Out-of-pocket expenses would decrease—but not as substantially as under the primary projection—from 38 percent to 25 percent in 2010 and would increase to 27 percent in 2020.
Table 1.6: cbo Projections of the Amount and Distribution of Nursing Home and Home Care Expenditures for the Elderly by Source of Payment, 2000, 2010, and 2020

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th>2010</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>With an Increase in Private Insurance</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total expenditure (in billions)</td>
<td>$123.1</td>
<td>$160.7</td>
<td>$207.3</td>
</tr>
<tr>
<td>Medicare</td>
<td>24%</td>
<td>25%</td>
<td>24%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>35</td>
<td>42</td>
<td>37</td>
</tr>
<tr>
<td>Private insurance</td>
<td>4</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td>Out-of-pocket</td>
<td>35</td>
<td>22</td>
<td>21</td>
</tr>
<tr>
<td>Other payer</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Without an Increase in Private Insurance</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total expenditures (in billions)</td>
<td>$120.7</td>
<td>$153.8</td>
<td>$195.1</td>
</tr>
<tr>
<td>Medicare</td>
<td>24%</td>
<td>27%</td>
<td>27%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>36</td>
<td>47</td>
<td>45</td>
</tr>
<tr>
<td>Out-of-pocket</td>
<td>38</td>
<td>25</td>
<td>27</td>
</tr>
<tr>
<td>Other payer</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>


Total expenditures are also assumed to be smaller in the alternate projection because of insurance-induced demand for services. The total expenditure estimate in 2020 for the primary projection is $207.3 billion as compared to $195.1 billion for the projection, assuming no increase in insurance coverage. Overall, the Medicare and Medicaid programs are projected to expand $14.5 billion more in 2020 under the alternate scenario than under the projection that assumes an increase in private insurance coverage.

**Conclusion**

While in the past long term care in the United States has been heavily biased toward nursing homes, we now have an increasing array of services to support aging and disabled Americans in the future. Some of these will be less costly than full institutional care, but larger numbers of elderly and disabled individuals will use them.

Long term care expenditures can be expected to grow significantly to meet this demand. While the baby boom generation is likely to be better educated and more financially secure than previous generations of the aged,
whether they have factored financing for long term care into their retirement planning is not clear. Current financing is dominated by public funds, and current growth rates in the economy are not likely to support public funding at the current percentage levels, much less the substantially increased ones projected, even with increases in private health insurance coverage.

These imperatives suggest that finding new ways of financing and delivering long term care services need to be considered today. Yet such efforts often become engulfed in ideological debates about whether a social insurance or a private insurance approach is best (Meiners 1996; Rivlin and Wiener 1988). This debate centers on a conflict of values and beliefs about the appropriate role of the federal government in the financing and provision of social services.

As the Partnership for Long Term Care moves beyond its initial implementation, it is appropriate to reflect on what we have learned and what clues the Partnership may give us to help solve the puzzle of financing long term care. We need to learn from the experience of the Partnership and begin to articulate future policy directions for long term care financing.

Although most policy analysts agree that we are facing substantial problems with respect to long term care financing, these problems will occur farther in the future than the more immediate solvency problems faced by the Medicare program and the Social Security system. Our lack of success in achieving consensus on these reforms does not augur well for political solutions in the near future for long term care financing.

How can we stimulate public policy in the next few years to confront the issues surrounding services, demand, and financing and begin reasoned discussions about what needs to be done? The purpose of this book is to raise some of these issues and to develop the framework for a policy debate that can lead to creative solutions.

NOTES

1. This number is estimated by HCFA’s National Health Statistics Group based on total revenues to freestanding facilities. It is not adjusted for level of care or region and is meant to provide an estimate for the national average cost of a one-year stay in a nursing home.

2. They defined an ADL impairment as receiving help from another person and an IADL limitation as not performing the activity. Five ADLs (bathing, dressing, getting into and out of bed or a chair, using the toilet, and eating) and five IADLs (using the telephone, doing light housework, preparing own meals, shopping for personal items, and managing money) were considered. Difficulty with one or more ADL or IADL was considered a functional impairment.
3. Laguna Research Associates calculation using methodology supplied by Helen Lazenby (1999b), the HCFA health insurance specialist who did the estimates for the earlier years (Lazenby and Letsch 1990). This estimate assumes that 91.3 percent (i.e., the percentage of nursing home residents on Medicare from the 1996 National Expenditure Survey) of nursing home residents receive Social Security. The amounts of Social Security income that will by legislation go directly to the nursing home for Medicaid-eligible beneficiaries eligible for Social Security using the same methodology would be estimated at $10.5 billion, or 41 percent of the $25.7 billion total out-of-pocket costs. The percentage of out-of-pocket expenditures that was accounted for by monthly Social Security benefits was estimated at between 36 and 56 percent from 1960 to 1989 (Lazenby and Letsch 1990).

4. If non–Title XIX federal and state expenditures are added to Medicaid, the change in the 1970 figure would be from 38 to 51 percent.

5. These numbers, summarized from the reports submitted to NAIC by insurers, are thought to be generally problematic because of the lack of standard definitions of terms used. NAIC notes in its 1997 Long Term Care Experience Report that the declines in the number of policies in force reported in 1995 and 1996 are largely due to incorrect reporting. Therefore, although they are the only national data available, this suggests NAIC data should be interpreted with caution.

REFERENCES


Who Will Pay for Long Term Care?
Health and Human Services, Administration on Aging, National Aging Information Center.


