



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy

# HOME AND COMMUNITY- BASED CARE IN THE USA

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Robert F. Clark, D.P.A.

Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services

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## **A. INTRODUCTION**

Long term care refers to a wide range of medical, social and personal care services that are needed by individuals who are functionally impaired. Such impairment may result from injury, chronic illness or some other physical or mental condition. Long term care is used mainly by the disabled elderly and such non-elderly persons as the developmentally disabled or the mentally ill.

This paper focuses on the elderly, aged 65 and over, who are the primary users of long term care in the USA. It examines their use of long term care services, particularly home and community based care. It describes the kinds of data available on the functionally impaired elderly and their use of such care.

## **B. FUNCTIONALLY IMPAIRED ELDERLY POPULATION**

The most reliable indicator of the need for long term care is the presence of functional impairment. A significant number of elderly persons have functional impairments, as measured by the Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) or cognitive impairments. Such persons are candidates for LTC services, whether provided formally or informally.

In 1985, there were about 5.5 million functionally disabled elderly persons aged 65 and over living in the community and an additional 1.3 million in nursing homes. Each of these figures is expected to almost double by the year 2020 to 10.1 million and 2.5 million respectively.

There were about 1.1 million of the oldest old, i.e. persons aged 85 and over, who were functionally disabled and living in the community in 1985. An additional 600,000 lived in nursing homes. By 2020, the community-dwelling group is expected to grow 2.5 times to 2.6 million and the nursing home group similarly to 1.4 million.

These estimates rely on a broad definition of functional disability. They include persons who received active human assistance, standby assistance or used an assistive device. Obviously, a more restrictive definition (e.g. one covering only persons who received active human assistance) would lower these estimates.

<b>TABLE 1. THE FUNCTIONALLY DISABLED POPULATION: 1985-2060</b>						
<b>Year</b>	<b>In Community</b>				<b>In Nursing Home</b>	<b>Total</b>
	<b>1+ IADL Limitations</b>	<b>1-2 ADL Limitations</b>	<b>3-4 ADL Limitations</b>	<b>Subtotal</b>		
<b>Age 65+</b>						
1985	1,965	1,826	1,673	5,466	1,310	6,776
2000	2,522	2,401	2,240	7,163	1,863	9,026
2020	3,592	3,360	3,176	10,131	2,547	12,678
2060	5,160	5,135	4,929	15,223	4,517	19,740
<b>Age 85+</b>						
1985	282	407	417	1,106	593	1,699
2000	465	668	692	1,826	970	2,796
2020	663	947	983	2,593	1,363	3,956
2060	1,434	2,035	2,117	5,585	2,884	8,469
Figures in thousands.						
Source: Adapted from K. Manton, Milbank Quarterly, 1989 using data from the National Long Term Care Survey.						

## **C. LONG TERM CARE: OVERVIEW**

The long term care system in the USA is large and complex. It consists fundamentally of: (a) informal care; (b) home and community based care (including home health care); and (c) nursing home care.

Informal care is care provided voluntarily by one's immediate family (e.g. spouse or adult child), other relatives, friends, neighbors and community service organizations. It is estimated that about three quarters of functionally impaired elderly persons living in the community rely exclusively on such care (Rivlin A. and Wiener, J., 1988).

Home and community based care refers to formal services provided in home or community-based settings and paid for from either private or public funds. For every person in a nursing home, there are an estimated three persons with similar disabilities living in the community. To the extent that the needs of these persons are met, informal care and formal home and community based care are the means.

Nursing homes provide specialized medical, nursing and social services in an institutional setting. As discussed in Joan Van Nostrand's paper, nursing homes consume the largest fraction of long term care dollars.

There is no single funding source for long term care. From a financing perspective, the LTC system is supported by public funds, out-of-pocket expenditures, and, to a growing degree, private long term care insurance. Public funds may be

federal, state or local in origin. The complexity of the system is suggested by the fact that over 80 separate federal programs provide income support, housing assistance or supportive services to persons needing long term care (U.S. House of Representatives, 1990:254).

The five major federal programs are Medicare, Medicaid, Social Services Block Grant, Older Americans Act and Supplemental Security Income (SSI). Total long term care spending annually in the USA from all sources, public and private, is estimated at approximately \$50 billion. Nursing home care consumes about 80% and home and community based care 20% of this amount.

Medicaid, a joint federal-state program, is the largest public source of funds, accounting for about 40 % of all long term care spending. The remaining amount is accounted for by Medicare and other public programs, private long term care insurance and out-of-pocket expenditures.

## **D. HOME AND COMMUNITY-BASED CARE: EVOLUTION AND TRENDS**

Care of the functionally disabled elderly at home is not new. The Boston Dispensary established the nation's first home care program in the 1790s. "In the late 1800s, home nursing services were organized and administered by lay persons" (Spiegel, 1987:2). During this period Visiting Nurse Associations emerged. Dr. E.M. Bluestone founded a hospital-based home care program at Montefiore Hospital, New York City in 1947 (Spiegel, 1987:3).

The passage of Medicare and Medicaid in 1965 gave impetus to the expansion of home health care in the succeeding decades.

## **E. MEDICARE HOME HEALTH CARE**

Medicare is a federal health insurance program with a uniform eligibility and benefit structure throughout the United States. The program covers most persons entitled to Social Security benefits, persons under age 65 entitled to disability benefits and some persons with end-stage renal disease. Medicare covers primarily acute rather than long term care.

Medicare benefits are provided under two parts: Part A--Hospital Insurance and Part B- Supplementary Medical Insurance. Under current law, Medicare home health benefits under either part are targeted at persons recovering from an acute illness. The beneficiary must be home-bound and services must be ordered and reviewed periodically by a physician.



TABLE 2. MEDICARE HOME HEALTH BENEFIT PAYMENTS					
Fiscal Year	In Community			Percent Change	HH as % of All Medicare
	Part A	Part B	Total		
1985	\$2,119	\$53	\$2,172	---	3.1
1990	3,400	73	3,473	60.0	3.2
1995 est.	5,246	85	5,331	53.5	3.0

Figures in millions.

Source: U.S. House of Representatives, 1991 Green Book.

Medicare expenditures were about \$70 billion in FY 1985, \$105 billion in FY 1990 and will be about \$178 billion in FY 1995. Home health expenditures have remained at about 3 % of all Medicare expenditures in recent years.

## F. MEDICAID HOME AND COMMUNITY-BASED CARE

Medicaid is a federal-state matching entitlement program providing medical assistance to low income persons who are aged, blind, disabled, members of families with dependent children and certain other needy persons. Within federal guidelines, each State designs and administers its own program. There is considerable variation from State to State in persons covered, benefits included and amounts of payment for services.

Medicaid finances home and community-based care under three coverage options: (1) home health care; (2) personal care; and (3) home and community-based waiver services.

### 1. Medicaid Home Health Services

Medicaid-financed home health services are usually the same set of services as those authorized under the Medicare home health benefit and are provided by Medicare-certified home health agencies. The differences lie in the fact that Medicaid is a welfare program for low income persons regardless of age and Medicare is a social insurance program for the elderly.

While Medicare home health care is intended as acute care, Medicaid home health care can be used by patients with chronic care needs. Furthermore, these services are a mandatory part of each state's Medicaid plan (in contrast to some services which are optional) and must be provided to individuals entitled to nursing home care (Congressional Research Service, 1988:95).

In Fiscal Year 1986, Medicaid payments for home health services were \$1.35 billion (3% of all Medicaid payments) on behalf of 593,000 beneficiaries. Of this amount, \$766,000 (56.7%) was spent on behalf of the elderly.

<b>TABLE 3. MEDICARE HOME HEALTH VENDOR PAYMENTS</b>				
	<b>Total</b>	<b>Percent of Total</b>	<b>Aged</b>	<b>Percent of Total</b>
<b>FY 1985</b>				
1985	\$37,508.0	100.0	\$14,096.0	100.0
1990	1,120.0	3.0	639.0	1.7
<b>FY 1989</b>				
All Medicaid	\$54,368.6	100.0	\$18,558.3	100.0
Home Health	2,571.0	4.7	1,440.5	7.8
Figures in millions.				
Source: Health Care Financing Review: 1990 Supplement.				

Medicaid payments for home health services for the elderly represent about 56% (1440.5/2571.0) of all Medicaid home health payments. They also amount to about two-fifths of Medicare home health payments (1440.5/3473.0).

## **2. Medicaid Personal Care Services**

At their option, states may also provide personal care services as part of their Medicaid plans. As of January 1990, 30 states did so. These are semi-skilled or non-skilled services, such as assistance with bathing, dressing and toileting, that are prescribed by a physician under the recipient's plan of care and provided to functionally impaired elderly persons living at home.

In Fiscal Year 1989, about \$1.2 billion was spent under Medicaid for personal care. However, about 80% of this amount was accounted for by New York and an additional 15% by five other states--Arkansas, Massachusetts, Michigan, Texas and Oklahoma.

## **3. Medicaid Home and Community-Based Care**

Medicaid home and community-based care services were first authorized under Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981. Such services typically include case management, personal care, homemaker and chore services, and respite care. In general, they are designed to assist elderly persons who otherwise would occupy a nursing home bed. Since such services were not covered under the regular state Medicaid plan, states had to apply for a waiver. By 1989, 36 states had done so.

In Fiscal Year 1986, Medicaid expenditures for the disabled elderly under Section 2176 were \$164 million and served 78,600 elderly beneficiaries (Congressional Research Service, 1988:162).

OBRA 1987 established a second home and community-based waiver program under Section 1915(d). This waiver provision exempts states from serving only persons who otherwise would be in a nursing home. In return, states agree to set an overall spending cap on their long term care expenditures. This waiver has been used by only one state, Oregon.

Under OBRA 1990, states may elect to provide home and community-based services at their option under the state Medicaid plan. However, this new provision establishes an overall spending cap for each state and for Medicaid overall. This source of funding is independent of the Medicaid Section 2176 waiver program under which States may request a waiver from normal Medicaid requirements in order to provide home and community-based care.

These examples, pertaining only to home and community-based care (not nursing home care) and drawn from a single program, Medicaid, illustrate the complexity of the USA's long term care system. Even within this single public program, there are different combinations of services and multiple sources of funding for home and community-based care.

## **G. OTHER SOURCES OF HOME AND COMMUNITY-BASED CARE**

### **1. Older Americans Act**

The Older Americans Act of 1965 established a "network" on aging, consisting of a federal Administration on Aging, State Agencies on Aging and local Area Agencies on Aging. In Fiscal Year 1989 there were 670 AAAs. A variety of services is provided to the elderly under Title III, including: (a) supportive services and senior centers; (b) congregate nutrition services; (c) home-delivered meals; and (d) in-home services for the frail elderly.

Supportive services include transportation, housekeeping, telephone reassurance and friendly visiting, chore services, education, training, escort service and legal assistance. In FY 1989, approximately 7.1 million persons received such services. Ombudsman services and, for the first time in FY 1990, elder abuse prevention services are also authorized.

Over 144 million congregate meals were served to older persons and their spouses. An additional 99.6 million meals were provided to the homebound elderly.

Funding for in-home services to the frail elderly first became available in FY 1988 and over 91,00 persons were served in FY 1989.

<b>TABLE 4. OAA TITLE III FUNDING: FISCAL YEAR 1991</b>	
Supportive Services	\$290,818
Ombudsman/Elder Abuse Prevention	5,367*
Congregate Nutrition	361,083
Home-Delivered Meals	87,831
U.S. Department of Agriculture Commodities	149,897
In-Home Services for Frail Elderly	6,831
<b>TOTAL</b>	<b>\$901,827</b>
Figures in thousands.	
* Includes \$1 million for planned White House Conference on Aging.	
Source: U.S. Senate, Special Committee on Aging, 1990(1):361.	

Services under the Older Americans Act are available to all elderly persons aged 60 and over. There is no means test, although under law there is a requirement to emphasize the needs of low income minority elderly. Over the past decade, there has been an expansion of case management and other supportive services to the frail elderly.

## **2. Social Services Block Grant**

The principal source of federal funding for state social service programs is the Social Services Block Grant (Title XX of the Social Security Act). In Fiscal Year 1989, \$2.7 billion were allotted to the states. Within general statutory limits, each state can determine what services to provide, who is eligible for these services and how funds are distributed among state agencies. Social services aimed at assisting elderly persons with self-care needs may be provided.

States are not required to report the number of elderly recipients of services or expenditures on behalf of the elderly. Most states provide homemaker and chore services, as well as adult protective and emergency services for their elderly citizens.

## **3. Supplemental Security Income**

The U.S. Social Security Administration administers the Supplemental Security Income (SSI) program for needy aged, blind and disabled persons. SSI benefits are financed from general revenues. As of June 1989, there were 4.5 million SSI beneficiaries, of whom about 2.0 million were aged 65 and over. In Fiscal Year 1989, total benefits paid amounted to \$14.3 billion, of which \$11.4 billion were federal and \$2.9 billion were federally-administered state supplemental benefits.

In 1990, the regular federal SSI benefit was \$386 a month for an individual and \$579 for a couple. Most states supplement this amount. All but seven states provide supplements aimed at covering the additional costs of housing for the frail elderly, mentally ill, or developmentally disabled in board and care homes or similar group living arrangements.

When a person enters a hospital or nursing home, where a major part of the bill is paid by Medicaid, the SSI benefit is reduced to a personal needs allowance of \$30 a month.

<b>TABLE 5. SSI RECIPIENTS: SELECTED YEARS</b>				
<b>Year</b>	<b>Total</b>	<b>Aged Only</b>	<b>Blind or Disabled</b>	
			<b>Total</b>	<b>65 and Older</b>
1975	4.3	2.3	2.0	0.2
1980	4.1	1.8	2.3	0.4
1985	4.1	1.5	2.6	0.5
1989	4.6	1.4	3.2	0.6

Figures in millions.

Source: Social Security Administration.

## **H. HOME HEALTH CARE: SUMMARY**

The following table summarizes spending on home health care in 1985.

Data (unpublished) from the 1984 National Long Term Care Survey indicate that 7.3% of the functionally disabled elderly living in the community used home health care services in the month prior to the survey. The rate of use rose with age with 5.1 % of those aged 65-74 using home health care, 7.5% of those aged 75-84 and 11.7% of those aged 85 and over.

TABLE 6. HOME HEALTH CARE BY PAYMENT SOURCE (1985)		
Payment Source	Expenditures	Percent
Medicaid		
- Federal	\$0.6	7.0
- State	0.5	5.0
Medicare	2.3	25.0
VA, Older Americans Act Social Services Block Grant	0.6	7.0
State	0.5	5.0
Out-of-Pocket Payments	3.7	41.0
Private Insurance/Other	0.9	10.0
TOTAL	\$9.1	100.0
Dollar figures in billions.		
Source: U.S. General Accounting Office, 1988.		

## I. SUPPORTIVE HOUSING

Long term care involves housing, personal care and, where needed, skilled nursing care. Besides one's own home and the nursing home, a variety of supportive housing arrangements for the frail elderly has grown up in recent years. These include Continuing Care Retirement Communities (CCRC), board and care homes, and various forms of subsidized housing.

### 1. Continuing Care Retirement Communities

CCRCs, sometimes called life care communities, provide under contract housing, personal care, nursing care and other social and recreation services to their residents. Residents pay an entrance fee and a monthly fee for these benefits. "There are approximately 700-800 continuing care retirement communities with an estimated 230,000 residents..." (U.S. Senate, Special Committee on Aging, 1990:325). Median entrance fees range from \$33,000 to \$70,000 and median monthly fees from \$700 to \$1000. The average age of residents is about 75.

### 2. Board and Care Homes

Board and care homes are non-medical community-based facilities that provide protective oversight and personal care for their residents, who in the main are disabled elderly, mentally ill and developmentally disabled. While CCRC residents come from middle and upper middle income groups, board and care residents are more often low income.

Frequently, residents receive SSI checks, which they turn over to board and care owner/operators in return for services. Alternatively, e.g. when the resident is cognitively impaired, checks may be sent directly to the owner/operators who act as representative

payees. While hard data are lacking, there may be as many as 50,000 to 75,000 board and care homes nationally, serving approximately one million disabled persons.

### **3. Other Supportive Housing Arrangements**

At the federal level there are several programs that provide supportive housing to the frail elderly. The Department of Housing and Urban Development (HUD) administers the Section 202 program, under which subsidies are provided for the building and managing of, rental housing for the elderly. The number of frail elderly in these projects has been growing, due to the phenomenon of residents "aging in place".

The low income elderly among others also may take advantage of HUD's Low Rent Public Housing Program, which includes 1.4 million units and houses 3.5 million persons. HUD's Section 8 Rental Assistance Program provides subsidies to landlords on behalf of tenants with incomes too low to afford private market housing.

The U.S. Department of Agriculture's Farmer's Home Administration (FmHA) administers several programs that benefit low income rural residents, including the elderly, under several sections of the Housing Act of 1949 as amended.

There are an estimated 105,000 persons aged 65 and over with a limitation in at least one ADL living in government-assisted housing (Struyk, R., et al., 1989:30).

A number of supportive housing programs have been initiated at the state level, such as Maryland's Sheltered Housing Program, the Massachusetts' Congregate Public Housing Program, New York's Enriched Housing Program and Oregon's Assistive Living Program.

The linkage between housing and long term care is evident as residents age in place and increasingly require more personal care and nursing services. Traditional lines of demarcation between housing and long term care are breaking down.

Besides the existing arrangements, many new models of housing with supportive services for the frail elderly are being developed and tested. These include the Supportive Services Program in Senior Housing sponsored by the Robert Wood Johnson Foundation, the National Demonstration of Congregate Housing for the Elderly in Rural Areas developed jointly by the Administration on Aging and the Farmers' Home Administration and the Life Care Home model developed at Brandeis University.

## **J. DATA SOURCES AND DATA NEEDS**

Data on the long term care system in the USA are available from several main sources: surveys, administrative data, and other data sources (inventories, state and local data systems, and demonstrations). Coverage of nursing home care is more

comprehensive than coverage of home and community care, because the latter is more diffuse and the former absorbs the largest share of public funds.

## **1. Surveys**

A number of national surveys yield data on the functionally disabled elderly population and their use of long term care services. Current surveys whose data are available include:

- National Long Term Care Surveys (1982, 1984, 1989)
- New Beneficiary Survey (1982, 1989)
- National Health and Nutrition Examination Survey (NHANES) I Epidemiologic Followup Study
- Survey of Income and Program Participation (SIPP)--Disability Module
- National Health Interview Survey--Supplement on Aging and Longitudinal Study of Aging (1984-1986)
- National Nursing Home Survey (1985)
- National Mortality Followback Survey (1986)
- National Medical Expenditure Survey--Household and Institutional Components (1987).

See Wiener, et al. (1990).

The decennial Census of the U.S. population provides baseline data for the elderly as well as other population subgroups. It is supplemented annually by the Current Population Survey.

## **2. Administrative Data**

Administrative records on the functionally disabled elderly are available through the Social Security Administration (SSA) and the Health Care Financing Administration (HCFA), both of which are components of the U.S. Department of Health and Human Services.

Administrative records have the advantage of being centralized and of being policy-relevant, since they cover persons who meet the program's eligibility criteria. They, of course, miss non-beneficiaries. Furthermore, because they are maintained for purposes of program administration, they often lack data about an individual's abilities, disabilities and other characteristics that do not pertain to program eligibility.

Within SSA, there are administrative data on the beneficiaries of two programs, viz., the Old Age, Survivors and Disability Insurance (OASDI) program and the Supplemental Security Income (SSI) Program.

OASDI serves persons with substantial work histories and their dependents, while SSI, as described above, targets low income persons.



HCFA maintains records on Medicare beneficiaries through its Medicare Automated Data Retrieval System (MADRS). Through cooperative arrangements with States, the agency has also developed the Medicaid Management Information System (MMIS).

SSA supplements its administrative records periodically with surveys such as the New Beneficiary Survey. In 1991, HCFA is inaugurating the Current Beneficiary Survey, which will be administered on an ongoing basis.

### **3. Other Data Sources**

Data on the functionally impaired elderly can often be found by accessing specialized inventories. For example, the National Center for Health Statistics is conducting the 1991 National Health Provider Inventory (NHPI), which is a comprehensive national listing of long term care providers (nursing homes, board and care homes, home health agencies and hospices). Such inventories often include data on the characteristics of their resident populations such as the frail elderly.

State and local governments maintain their own data bases. For example, Connecticut has an extensive longitudinal file on its long term care population that shows transitions from one setting to another and funding sources. Massachusetts has sponsored surveys of home and community based services for its frail elderly population.

While not nationally representative, data from federally-funded research and demonstration programs can be used to examine in depth the characteristics, service use patterns and expenditures of their participants. A prominent example is the public use files from the National Long Term Care Channeling Demonstration, which was conducted from 1981 to 1986.

## **K. CONCLUSION**

Over the past decade, there has been significant growth in long term care data bases. Over the same period, however, there have been major shifts within the long term care system itself.

"To project the need for long term care, data are required for a relatively long period on changes in the characteristics of the elderly population, their use of services, and the nature of their support system, as well as changes in the system both formal and informal" (Gilford, 1988:15).

The three followup waves to the 1985 National Nursing Home Survey, the Longitudinal Study of Aging and the National Long Term Care Surveys form the core of such longitudinal survey data.

More such longitudinal data are needed to describe the transitions of the elderly from one state to another, where "state" can refer to health, functional status, longevity, service use or payment source. Such longitudinal data are vital to model the processes of change, project future needs, and document the outcomes of care.

Finally, the entire long term care system needs to be examined in terms of the degree to which it produces desirable outcomes for the frail elderly, their caregivers and the taxpayers. For the frail elderly, these outcomes include the maintenance of dignity and independence in their latter years, access to needed services and an acceptable quality of life.

For their caregivers, there must be an appropriate mix of formal and informal care and of public and private support. The nation's taxpayers, whose average age is rising, are not likely to quarrel with such a system.

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