



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:

## THE U.S. EXAMPLE

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# HOME AND COMMUNITY-BASED CARE: The U.S. Example

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# ABSTRACT

In 1985 there were about 5.5 million functionally disabled elderly persons (65+) in the United States (U.S.) living in the community and an additional 1.3 million in nursing homes. By 2020, these figures are expected to almost double to 10.1 million and 2.5 million respectively. The long-term care system (LTC) in the U.S. is large and complex. Fundamentally, it consists of: (a) informal care, provided voluntarily by one's family, friends, neighbors, and community organizations; (b) home and community based care, covering formal (paid) services provided in one's own home or other community based settings; and (c) nursing homes, which provide specialized medical, nursing, and social services in an institutional setting. Home- and community-based care includes a variety of services and financing streams, including (a) Medicare home health care, (b) Medicaid home health services, (c) Medicaid home- and community-based services, (d) programs and services under the *Older Americans Act*, (e) state sponsored social services funded by the Social Services Block Grant, (f) Supplemental Security Income payments, and (g) a range of supportive, housing arrangements. Data on the LTC system are available from several key sources: national surveys, administrative records, inventories, state and local data systems, and demonstration programs. The LTC system remains decentralized. The frail elderly want dignity and independence in the latter years, plus access to needed services and an acceptable quality of life. In policy terms, their caregivers and the taxpaying public continue to struggle to find the appropriate mix of public and private support to meet the needs of the LTC population.

This paper focusses on the elderly of the United States (U.S.): those aged 65+, who are the primary users of long-term care (LTC). LTC 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. LTC, is used mainly by the disabled elderly and by such non-elderly persons as the developmentally disabled or the mentally ill.

Although LTC has been treated in the literature largely as an institutional issue, this paper focusses on home- and community-based care. It deals with an overview of LTC in the U.S., followed by the evolution of and trends in home- and community-based care and their sources. A summary of home-care arrangements is followed by a description of the type of data available on the functionally impaired elderly and their use of such care. Although 1985 is used as the baseline year, in order to present complete data comparable to those of the other countries represented in this journal issue, updated information is provided wherever possible.

## **Functionally Impaired Elderly Population**

Drawing from Manton's (1989) analysis of the National 1984 Long-Term Care Survey, there were about 5.5 million functionally disabled persons aged 65+ living in the community in 1985 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. By 2060 they should have almost tripled to 15.2 million 65+ disabled in the community and more than tripled to 4.5 million in nursing homes.

There were about 1.1 million people aged 85+ who were functionally disabled and living in the community in 1985. An additional 593,000 lived in nursing homes. By 2020, the community-dwelling group is expected to have increased 2.5 times to 2.6 million and the nursing home group to 1.4 million. By 2060 these figures will have doubled again to 5.5 million and 2.9 million respectively. (For a more detailed examination of the demography of the elderly in the U.S., see Van Nostrand, 1996, this issue.)

These estimates rely on a broad definition of functional disability. They include persons who received active human assistance or 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.

# LONG-TERM CARE: AN OVERVIEW

The LTC system in the U.S. is large and complex. It consists fundamentally of (a) informal care, (b) formal home- and community-based care (including home health care), and (c) institutional (mainly 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. In 1982, an estimated 78 percent of functionally impaired elderly persons living in the community relied exclusively on such care (Rivlin, Wiener, Hanley, & Spence, 1987). Informal care remains the backbone of the U.S. LTC system.

Home- and community-based care refers to formal services provided in home- or community-based settings and covered by either private or public funds. Nursing homes provide specialized medical, nursing, and social services in an institutional setting. As Van Nostrand (1996, this issue) has discussed, nursing homes consume the largest fraction of LTC dollars. 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.

There is no single funding source for LTC. From a financing perspective, the LTC system is supported by public funds, out-of-pocket expenditures, and, to a growing degree, private LTC 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 LTC (U.S. House of Representatives, 1990).

The five major federal programs are Medicare, Medicaid, Social Services Block Grant, *Older Americans Act*, and Supplemental Security Income (SSI). Total annual LTC spending in the U.S. from all sources, public and private, is estimated at approximately \$108 billion. Nursing home care consumes about 80 percent and home- and community-based care 20 percent of this amount (U.S. Department of Health and Human Services, 1994).

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

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

Home care of the functionally disabled elderly is not new. The Boston Dispensary established the nation's first home nursing program in the 1790s, organized and administered by lay persons. It was during this period that Visiting Nurse Associations emerged. Later, in 1947, Dr. E.M. Bluestone founded a hospital-based home-care program at Monte Fiore Hospital in New York City (Spiegel, 1987). But it took the passage of Medicare and Medicaid in 1965 to give real impetus to home health care and its expansion in the succeeding decades.

## **Medicare Home Health Care**

Medicare is a federal health insurance program with a uniform eligibility and benefit structure throughout the U.S. 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 care rather than LTC.

Medicare benefits are provided under two parts: Part A, Hospital Insurance and Part B, Supplementary Medical Insurance. Although most Medicare recipients receive benefits under fee-for-service arrangements, approximately 10 percent of Medicare beneficiaries are enrolled in managed care plans. Under current law, Medicare home health benefits under either part are targeted at persons recovering from an acute illness. The beneficiary must be homebound and services must be ordered and reviewed periodically by a physician.

Medicare expenditures were about \$70 billion in 1985, \$105 billion in 1990, and about \$178 billion in 1995. The growth of the elderly population and changes in Medicare have led to dramatic increases in the costs of home health care. Medicare home health expenditures grew from \$2.1 billion in 1988 to \$15.2 billion in 1995, utilizing 8.7 percent of total Medicare payments in 1995, compared to 2.8 percent a decade earlier. Thus, Medicare home health benefits increased by 76 percent from 1985 to 1990 and by 438 percent between 1990 and 1995 (U.S. House of Representatives, 1994).

## **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, or meet certain other criteria for need. 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: (a) home health care, (b) personal care, and (c) home- and community-based waiver services.

## **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 that Medicare is a social insurance program for the elderly.

Although Medicare home health care is intended as an acute-care benefit, Medicaid home health care is available to some patients with chronic care needs. In contrast to some optional services, these services are a mandatory part of each state's Medicaid plan, to be provided to Medicaid-eligible individuals who are entitled to nursing home care (Congressional Research Service, 1988). In 1985, Medicaid payments for home-health services were \$1.1 billion or 3 percent of all Medicaid payments. Of this amount, \$639 million or 57 percent was spent on behalf of the elderly. In 1993, Medicaid payments for home health services for the elderly were 2.4 billion, representing 42 percent of all Medicaid home health payments and more than a threefold increase over, the 1985 figures (U.S. Health Care Financing Administration, 1995).

## **Medicaid Personal Care Services**

At their option, states may also provide personal care services as part of their Medicaid plans. These are semi-skilled or non-skilled services, such as assistance with bathing, dressing, and toileting, which are prescribed by a physician under the recipient's plan of care and provided to functionally impaired elderly persons living at home. As of January, 1991, 31 states utilized this option.

In 1987, about \$1.2 billion was spent under Medicaid for personal care. About 80 percent of this amount was accounted for by New York. By 1995, this amount had grown to \$2.9 billion, while New York's share of the total had dropped to 61 percent, as other states made use of this option.

## **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. In 1986, Medicaid expenditures for the disabled elderly under Section 2176 were \$164 million and served 78,600 elderly beneficiaries (Congressional Research Service, 1988). In 1995, the total home- and community-based expenditure under Medicaid was \$4.7 billion. Because such services were not covered under the regular state Medicaid plan, States must apply for a waiver from the federal Health Care Financing Administration. By 1995, 48 states had done so.

*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, the states agree to set an overall spending cap on their LTC expenditures. This waiver has been used thus far only by the State of 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 of waiver programs, pertaining only to home- and community-based care (as opposed to nursing home care) and drawn from a single program, Medicaid, illustrate the complexity of the LTC system in the U.S. Even within this single public program, there are different, eligibility criteria, various combinations of services, and multiple sources of funding for home- and community-based care.

# OTHER SOURCES OF HOME- AND COMMUNITY-BASED CARE

## Older Americans Act

The *Older Americans Act* of 1965 established a "network" on aging, consisting of a federal Administration on Aging (AoA), state Agencies on Aging, and local Area Agencies on Aging (AAA). Nationally, there are 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 re-assurance and friendly visiting, chore services, education, training, escort service, and legal assistance. Approximately seven million persons received such services in 1994 at a cost of \$306 million. Ombudsperson services and, for the first time in 1990, elder abuse prevention services were also authorized, and cost \$4.5 million. In 1994, an estimated 127 million *congregate meals* were served to 2.3 million people at congregate sites at a cost of \$375 million. In addition, 113 million *meals* were provided to 877,500 homebound elderly at a cost of \$94 million (Mathematica Policy Research, Inc., 1996). Funding for *in-home services* to the frail elderly first became available in 1988. By 1994 the cost was \$9 million. The total budget for AoA programs in 1995 was \$876 million.

Persons aged 60+ are eligible for services under the *Older Americans Act*. 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.

## 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*), which in 1995, allotted \$2.8 billion 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, in order to prevent or reduce inappropriate institutional care.

## 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. In 1994 there were 6.3 million SSI beneficiaries, of whom about 1.3 million were 65+, and eligible based upon economic need only; an additional 0.7 million were blind or disabled elderly. In 1995, total expenditures amounted to \$25.9 billion, of which \$22.2 billion were federal and \$3.7 billion were federally administered state supplemental benefits.

In 1994, the regular federal SSI benefit was \$446 a month for an individual and \$687 for a couple, and this amount was supplemented by most governments. 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.

## Supportive Housing

LTC 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), assisted living facilities, board-and-care homes, and various forms of subsidized housing.

*Continuing-Care Retirement Communities (CCRCs)*, sometimes called life-care communities, offer a long-term to lifetime continuum of care. A CCRC usually has a contractual arrangement with its residents under which they are guaranteed housing, supportive services, and access to nursing care and other health care for an extended period, usually the rest of their lives. Typically, residents pay an entrance fee and a monthly fee for these benefits, although in recent years other CCRC models (e.g., rental only, equity-based) have emerged. There are approximately 1100 CCRCs nationally. Median entrance fees range from \$35,000 to \$200,000 and median monthly fees from \$600 to \$2000. (American Association of Homes and Services for the Elderly and Ernest & Young, 1991). The average age of residents is approximately 81 years.

*Assisted living* refers to residential settings that combine housing, personal assistance, and other supporting services to elderly persons with physical or cognitive limitations. These facilities, which cater primarily, to a private, paying market, are thought to offer greater privacy, autonomy, and dignity to residents in their living and service arrangements than are typically provided in settings like nursing homes or board-and-care homes (Kane & Wilson, 1993). The assisted living industry is growing rapidly. A growing number of states (notably Oregon and Washington) provide public support for assisted living as an alternative to more costly nursing home care.

*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 from low income groups.

Frequently, residents receive SSI checks, which they turn over to board-and-care owner-operators in return for services. Alternatively, if, for example, the resident is cognitively impaired, checks may be sent directly to the owner-operators, who act as representative payees. There are approximately 34,000 licensed board-and-care homes nationally, serving approximately 613,000 disabled persons, of whom 73 percent are elderly (Clark, Turek-Brezina, Chu, & Hawes, 1994).

*Other supportive housing arrangements:* At the federal level, public programs for elderly housing have encountered the phenomenon of residents "aging in place". As a result, housing agencies have begun to address the long-term and chronic care needs of their residents. 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, with the concomitant need for supportive services.

The low-income elderly, among others, can also 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.

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 et al., 1989). 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. Furthermore, 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 Assisted Living Program.

In the aggregate, the number of frail elderly persons served under these programs is relatively small. However, the linkage between housing and LTC is becoming ever more evident as residents age in place and increasingly require more personal care and nursing services. Traditional lines of demarcation between housing and LTC 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-at-Home model, developed at Brandeis University.

# DATA SOURCES AND DATA NEEDS

Data on the LTC system in the U.S. are available from national surveys, administrative data, and other data sources (inventories, state and local data systems, and demonstrations). Coverage of nursing home care in data systems is more comprehensive than is coverage of home and community care, because the latter is more diffuse and the former absorbs the largest share of public funds.

## Surveys

A number of national surveys yield data on the functionally disabled elderly population and their use of LTC services, most of which are available to outside researchers in the form of public use data files. Wiener et al. (1990) cite the following surveys that have been published since 1982 and the results of which are readily available: (a) National Long Term Care Surveys (1982, 1984, 1989, 1994); (b) New Beneficiary Survey (1982, 1989); (c) National Health and Nutrition Examination Survey (NHANES) I Epidemiologic Followup Study; (d) Survey of Income and Program Participation (SIPP) -- Disability Module; (e) National Health Interview Survey-Supplement on Aging and Longitudinal Study of Aging (1984-1986); (f) National Nursing Home Survey (1985); (g) National Mortality Followback Survey (1986, 1993); and (h) National Medical Expenditure Survey (1987). (The italicized years in this list refer to surveys administered after the publication of the Wiener et al. [1990] article.) In addition, 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.

## Administrative Data

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

Administrative records have the advantage of being centralized and of being policy-relevant, as they cover persons who meet the program's eligibility criteria. Unfortunately, they 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. SSA supplements its administrative records periodically with surveys such as the New Beneficiary Survey.

HCFA maintains claims files on Medicare beneficiaries that can be linked to other data or, respondents to national surveys. Through co-operative arrangements with the states, the agency has also developed the Medicaid Management Information System (MMIS). In 1991, HCFA inaugurated the Medicare Current Beneficiary Survey, which is administered to a sample of Medicare beneficiaries on an ongoing basis.

## **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 conducted the 1991 National Health Provider Inventory (NHPI), which is a comprehensive national listing of LTC 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 LTC population that shows funding sources and transitions from one setting to another. Massachusetts has sponsored surveys of home- and community-based service 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 extensive set of public use data files released from the National Long Term Care Channelling Demonstration, which was conducted by the U.S. Department of Health and Human Services from 1981 to 1986.

# CONCLUSION

Over the past decade, there has been significant growth in LTC data bases. Over the same period, however, there have been major shifts within the LTC system itself. As Gilford (1988) has said:

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.

The three follow-up 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 modelling the processes of change, projecting future needs, and documenting the outcomes of care.

Finally, the entire LTC 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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