BUDGET
ISSUE PAPER

Long-Term Care for the Elderly and Disabled

February
1977

(Reprinted August 1977)

Congressional Budget Office
Congress of the United States
Washington, D.C.

LONG-TERM CARE

FOR THE ELDERLY AND DISABLED

The Congress of the United States
Congressional Budget Office

For sale by the Superintendent of Documents, U.S. Government Printing Office
Washington, D.C. 20402 - Price $1.60

NOTES

All years in this report refer to fiscal years unless otherwise stated.

Details of tables may not add to totals due to rounding.

PREFACE

The 95th Congress may consider expanding the federal role in financing health care services. Expansion could take the form of a national health insurance plan covering all persons for a broad range of services, or it could involve selective extensions of coverage. The decision whether to extend coverage--and if so how--will be based on various considerations. Among these are the nature and severity of needs so far not met by public or private programs and the total and federal budget costs of various options.

One area of expansion being considered by the Congress is long-term care. Perhaps because long-term care includes social services in addition to health services, it has been excluded from most national health insurance proposals. Long-term care is, nevertheless, the major cause of catastrophic expenses among the elderly. This budget issue paper examines the extent of need for long-term care, the degree to which the demand for services is met by current public programs, and some alternative means of satisfying demand and organizing services. A technical background paper, Long-Term Care: Actuarial Cost Estimates, provides detailed information on the existing supply of long-term care services and the cost of the options discussed in this paper. A second budget issue paper, Catastrophic Health Insurance, explores that subject in greater detail.

This report was prepared by Maureen S. Baltay of the Human Resources Division of the Congressional Budget Office, under the supervision of Stanley S. Wallack and C. William Fischer. The author wishes to acknowledge the valuable assistance of Gordon R. Trapnell, consulting actuary who prepared the cost estimates, and Joshua Wiener, formerly with the Human Resources Division. Special thanks are extended to Judith LaVor of the Department of Health, Education, and Welfare for her continuing advice and assistance and to Janet Kline and Sharon House of the Congressional Research Service, Library of Congress, for their helpful comments.

The paper was prepared for publication under the supervision of Johanna Zacharias. Toni Wright typed the manuscript.

In accordance with CBO's mandate to provide objective and impartial analyses of budget issues, this report contains no recommendations.

Alice M. Rivlin
Director

February 1977

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SUMMARY

Long-term care refers to health and social services provided to chronically disabled, usually elderly, persons. Federal, state, and local governments spent $5.7 to $5.8 billion on long-term care in 1975. Of this, $3.1 billion or 56 percent was federal spending. Private expenditures for long-term care totaled $5.9 to $7.7 billion. These costs will continue to grow as a result of the aging of the population, increased utilization of services, and inflation. This combination of factors is expected to increase total long-term care spending from $11.7 to $13.4 billion in 1975 to $25.8 to $31.0 billion in 1980. Federal spending under existing programs would be $7.2 to $7.6 billion in 1980.

The presence of a chronic condition such as arthritis or diabetes is one indicator of a potential long-term care patient, but it is not a sole or sufficient determinant of need. Functional impairment or the need for assistance in activities of daily living such as eating and bathing is a better gauge. Despite a wide variation in estimates of the functionally disabled from several national studies, the relatively high rate of functional disability among the elderly is clear. While 1.2 to 3.9 percent of the population aged 18-64 is estimated to be functionally disabled, between 11.8 and 16.8 percent of the elderly population is estimated to be functionally disabled. Given the incidence of functional disability, the total potential demand for long-term care is estimated to increase from 5.5 to 9.9 million persons in 1975 to 6.3 to 11.1 million in 1980 and to 7.4 to 12.5 million in 1985.

Long-term care services needed range from frequently required highly skilled nursing and therapy that must be provided in a nursing home to occasional visits by a homemaker/home health aide or social worker. Of the 5.5 to 9.9 million persons functionally disabled in 1975, only 1.9 to 2.7 million received long-term care under government programs. Medicaid, the federal-state health program for the poor, is the principal source (77 percent) of government financing of long-term care. To a lesser degree,

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long-term care services are financed under medicare, the Veterans Administration, the Supplemental Security Income program, and Title XX social services. Perhaps 3 to 6.7 million persons receive basic long-term care services from their families but nothing is known about its quality or adequacy. An estimated 800,000 to 1.4 million disabled may receive no form of long-term care.

Public programs disproportionately support nursing home care. Less than 10 percent of public funds are for home-based services. This has certain consequences. While many disabled receive no long-term care, there is evidence that 20 to 40 percent of the nursing home population could be cared for at less intensive levels were adequate community-based care available. If all services were readily available, the distribution of the disabled and elderly among levels of care would be quite different from its present distribution. As seen in the following table, there is a large unmet demand for sheltered living arrangements, congregate housing, and home health care.

LONG-TERM CARE ESTIMATED SUPPLY AND POTENTIAL NEED, For Calendar Year 1976, Adults in Millions

Type of Treatment	Estimated Potential Need	Estimated Supply
Nursing Home Care: Skilled Care	0.7	0.9
Intermediate Care	0.6	0.4
Personal Care Homes, Sheltered Living Arrangements, and Congregate Housing	1.5 - 1.9	0.3 - 0.8
Home Health Care and Day Care	1.7 - 2.7	0.3 - 0.5
Informal Family Care Only or No Care	1.0 - 4.0	3.6 - 7.2

SOURCE: CBO estimates.

Over half of nursing home care costs in 1975 were paid from private sources. Forty-four percent were paid out-of-pocket rather than by insurance or philanthropy. Nursing home care is the principal cause of catastrophic expenses among the aged. The average annual cost of a nursing home stay in 1975 was an estimated $7,300, whereas 48 percent of elderly families and 70 percent of the disabled have incomes below $7,000 a year. Thirty-five percent of the families of the disabled have incomes below $3,000.

Many families not on welfare and therefore ineligible for medicaid deplete their resources in providing or purchasing long-term care for their elderly relatives. Only by "spending down" to income levels that make them eligible for medicaid payments do they in effect get government assistance for long-term care. This impoverishment of the disabled is suggested by the fact that 69 percent of nursing home residents have incomes of under $3,000 and that over 47 percent of nursing home patients whose costs are paid by medicaid were not initially poor by state definitions but depleted their resources and became qualified as "medically needy."

Some alternatives to present programs may be considered which attempt to deal with the problems of insufficient community-based services, inadequate organization of services, and disability-induced impoverishment. In evaluating the options, little evidence can be offered as to the quality or cost of long-term care provided informally by families. It is therefore difficult to estimate the demand for professional services that would be induced if government financial support of long-term care were to increase. Moreover, no set of financial incentives will readily change the patterns of behavior, social values, or preferences surrounding the care of the aged and disabled.

The three general types of options addressed here reflect different policy approaches with different budget impacts. No one option is intended to describe a specific legislative proposal although several bills introduced in the last Congress would fall into one option category or another. The general approaches are:

A. Modification of existing programs - to revise certain legal or regulatory provisions that restrict the supply of noninstitutional services under the current system.

B. Long-term care insurance - to create a long-term care entitlement that would eliminate financial need as a basis for eligibility and replace much private spending with federal spending.

C. Comprehensive long-term care grant - to funnel all long-term care funds determined by appropriation through a single agency that would be responsible for giving appropriate service to individuals who need it.

Under Option A, the medicare home health benefit would be liberalized, and a minimum level of home-based services would be mandated under medicaid rather than left to the discretion of the states. While these changes would expand noninstitutional services to those eligible for medicare and medicaid, they would in no way expand the number of people covered under these programs. The incremental federal cost of Option A would be $0.9 to $1.6 billion in 1980, $1.8 to $3.9 billion in 1982, and $3.2 to $11.1 billion in 1985 if the federal government were to absorb the additional state cost of providing a minimum level of home care.

Option B would provide universal coverage of long-term care of the highest risk populations through an entitlement program for all aged and disabled. The services covered would include nursing home care, personal care homes, congregate housing, foster care, home health care, homemaker and social services, and adult day care. Such a social insurance program would be financed principally by the federal government, although the states could pay some portion of program costs.

Actual program costs would be a function of the rate at which demand for covered services materialized and was satisfied. Satisfaction of demand in turn would depend upon the rate of increase in the supply of services. Availability of services would be a limiting factor and, in the early years of operation, would be the principal con-

straint on program costs. Demand for long-term care services under an entitlement program is potentially very large because the estimated need is great. The incremental federal cost of Option B is estimated to be $11 to $14 billion in 1980, $17 to $23 billion in 1982, and $28 to $50 billion in 1985.

Because the entitlement program under Option B is potentially very expensive, Option C is offered as a possible way of unifying long-term care programs but controlling growth in spending through appropriations. Option C would combine medicaid long-term care funds and Title XX social services into a comprehensive long-term care grant financed 60 percent by the federal government and 40 percent by the states. As a condition of receiving grants, states would establish community long-term care centers: independent semi-public agencies responsible for identifying the aged and disabled in the area and assessing their needs, certifying providers, authorizing levels of care, and monitoring the quality of services. The centers would be the sole channel of federal long-term care funds.

While not as extensive a proposal as Option B, Option C offers the opportunity for various patterns of care to develop at state and local initiative. The diversity permitted might provide the experience and data to show which approaches are most desirable. The cost of Option C would depend upon the federal funds appropriated for the program. As a practical matter it would probably have to cost at least as much as Option A to make the program attractive to the states, provide for the development of additional long-term care resources, and cover the cost of setting up the local long-term care centers. Therefore, the minimum additional federal cost of Option C would be $1 to $2 billion in 1980, $2 to $4 billion in 1982, and $3 to $12 billion in 1985. At the other extreme, the cost of Option C could run as high as Option B because the need for services is great and the pressure to increase appropriations could be substantial.

The first of the following tables shows the total cost of long-term care under existing programs and under the options compared to potential demand for services. The second table indicates the estimated incremental federal cost under each option.

ESTIMATED TOTAL COST UNDER EXISTING PROGRAMS AND UNDER OPTIONS COMPARED TO ESTIMATED POTENTIAL DEMAND FOR SERVICES, by Fiscal Years, in Billions of Dollars

	1980	1982	1985
Potential Demand	32-47	42-60	60-87
Existing Federal Programs	7-8	9-10	15-17
Option A a/	8-9	11-14	18-28
Option B a/	20-23	29-36	47-73
Option C a/ b/	8-9	11-14	18-28

a/ Fiscal year 1979 is the first year of operation.

b/ Minimum cost. Maximum is the same as Option B.

ESTIMATED INCREMENTAL FEDERAL COST UNDER OPTIONS A, B, AND C, by Fiscal Years, in Billions of Dollars

	1980	1982	1985
Option A a/	0.9-1.6	1.8-3.9	3.2-11.1
Option B	11.0-14.0	17.0-23.0	28.0-50.0
Option C b/	1.0-2.0	2.0-4.0	3.0-12.0

a/ If federal government absorbs the incremental cost of making medicaid home health benefits mandatory.

b/ Minimum cost. Maximum is the same as Option B.

INTRODUCTION

Long-term care services to the chronically disabled and elderly are a concern of legislators and administrators at all levels of government. Major causes of this concern are the expected growth in the cost of government programs, quality of care in nursing homes, and the over-institutionalization of the disabled and elderly.

Federal, state, and local governments spent $5.7 to $5.8 billion for long-term care in 1975. Of this, $3.1 billion or 56 percent was federal spending. Nursing home and other institutional care accounted for $5.2 billion, which is roughly 200 percent more than in 1970.

The Congressional Budget Office has estimated that private spending for long-term care totaled $5.9 to $7.7 billion in 1975, but this does not include the estimated dollar value of services provided by family members.

Spending from all sources will continue to grow as a result of the aging of the population, increased utilization of services, and price increases. This combination of factors is expected to increase total long-term care spending from $11.7 to $13.4 billion in 1975 to $25.8 to $31.0 billion by 1980. Federal spending under existing programs would be $7.2 to $7.6 billion in 1980. 1/

Despite the magnitude of investment in long-term care, there is evidence that many individuals needing such care do not receive it either through formal programs of institutional or community-based services or informally from families or friends. There is also evidence that many persons are given intensive institutional care who either need lower levels of institutional care or who might be better off in less formal community settings. This misplacement of patients results partly from fragmentation of funding sources and heavy public support of nursing home care.

1/ Long-Term Care: Actuarial Cost Estimates, Congressional Budget Office, February 1977.

An examination of the structure of long-term care programs and the characteristics of potential recipients suggest some alternative approaches to present programs and policies that would address current concerns.

CHAPTER I BACKGROUND -- PRESENT SUPPLY VERSUS POTENTIAL NEED

LONG-TERM CARE: WHAT IS IT?

Long-term care is a series of services provided to chronically ill and disabled persons over an extended period of time. Chronic conditions are often gradual in onset and of lifetime duration. Unlike acute illnesses, which occur suddenly and are usually resolved in a relatively short period of time, chronic illnesses are difficult to treat medically except to maintain status quo or effect some functional improvement. Long-term care services are therefore concerned more with controlling the effects of disease than with treating the disease itself.

Disability without hope of recovery creates a host of other problems, including sometimes fear, isolation, and impoverishment. Coping with these problems demands a fluctuating and complex package of services that varies over time in frequency, duration, and intensity with the degree of medical, social, or other help required. The need ranges from unskilled basic services to skilled, medically-oriented ones. The basic services are:

- Homemaker services--cooking, shopping, housekeeping, laundry, home management.
- Chore services--less frequent tasks related to home maintenance, lawn care.
- Social services--guidance in social or emotional problems; advice in financial and legal matters; friendly visiting; transportation.

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The health-related services are:

- o Nutrition and health education.
- o Personal care services--bathing, toileting, feeding, assistance in walking, exercise, medication.
- o Occupational therapy--medically-directed activities to promote the restoration of useful function.

The skilled services are:

- o Physical and speech therapy--use of physical or chemical agents and devices to relieve pain, restore function, and prevent loss of use of a part of the body or of speech and writing.
- o Skilled nursing--administration of medicine, changing of catheter and dressings, evaluation of condition.

These services may be provided in private residences or in institutional settings. (See Appendix A for more detailed definitions of terms.)

WHO NEEDS IT?

Long-term care as defined in this paper refers to services to persons with chronic physical disease or disability. The long-term needs of the mentally retarded and mentally ill--a group almost equal in magnitude to the physically disabled--are not included. Long-term care of the mentally ill and retarded involves considerations similar to those involved in the care of the physically disabled, including the lifetime nature of treatment and the appropriateness of institutional versus noninstitutional treatment. However, many of the services required by the mentally ill and retarded are different and historically have been administered through separate delivery systems by a separate class of professionals. The distinctions found in most

legislation between acute care, psychiatric care, and long-term care of the disabled will therefore be retained here, although they are made more for the sake of administrative simplicity than for conceptual purity.

With the exclusion of the mentally ill and retarded, the group most likely to require long-term care as a result of physical disability is the elderly. They have the highest incidence of chronic illness, disability, and functional impairment, although other individuals suffer from these on a less predictable basis.

The Institutionalized Population

The mere fact of institutionalization usually indicates the need for some degree of long-term care. As shown in Table 1, an estimated 1.6 million persons were in non-psychiatric long-term care facilities in calendar year 1976. 1/ Eighty-four percent of institutionalized persons are in nursing homes. The aged comprise 89 percent of the nursing home population.

1/ Cross-sectional census data tend to undercount the number of persons who spent some time during the year in a nursing home. In a study of metropolitan Detroit, Kastenbaum and Candy found 23 percent of the aged deaths occur in nursing homes and other extended care facilities. As part of a larger study of black and white nursing home patients in Alabama, Wershow found that as many as 44 percent of nursing home deaths occur within a month after admission and would not necessarily be picked up in a census count. (R.S. Kastenbaum and S. Candy, "The Four Percent Fallacy: A Methodological and Empirical Critique of Extended Care Facility Program Statistics," Aging and Human Development, 4:15-21, 1973. Harold J. Wershow, "The Four Percent Fallacy: Some Further Evidence and Policy Implications," The Gerontologist, Pt. I, 16:52-55, 1976.)

Table 1. ESTIMATED POPULATION IN LONG-TERM NONPSYCHIATRIC FACILITIES, CALENDAR YEAR 1976, in Thousands

Type of Facility	Average Residents
Chronic Disease and TB Hospitals a/	35
Nursing Homes: Skilled Nursing Facilities	935
Intermediate Care Facilities	365
Personal Care and Domiciliary Care Facilities	200
Facilities for the Deaf and Blind and the Physically Handicapped	25
Total estimated residents	1,560

SOURCE: Derived from unpublished data from the National Center for Health Statistics Master Facility File, the 1973-1974 Nursing Home Survey, and Social Security Administration Office of the Actuary population projections, and Preliminary Estimate of the Cost of Catastrophic Illness in Long-Term Institutions, Abt Associates, Inc., 1976, unpublished. For further detail see Long-Term Care: Actuarial Cost Estimates, Congressional Budget Office, February 1977.

a/ Includes only those not receiving active treatment or diagnosis of an illness.

The Noninstitutionalized Functionally Disabled

The majority of disabled persons are not in nursing homes or other long-term care institutions. Most are living in the community. However, estimates of this population vary widely because of a marked lack of consensus on definitions of disability and the associated need for long-term care services.

The presence of a chronic condition such as arthritis or diabetes is one indicator of a potential long-term care patient, but it is not a sufficient or sole determinant of the need for long-term care. Functional impairment or the need for assistance in the activities of daily living and in moving about is a better gauge of need for long-term care services. Persons who are functionally disabled are often bedridden, need help with dressing and bathing, or need help moving around outside the home. Table 2 shows the estimates of functional disability from four surveys of the noninstitutionalized population. Because each study has used a different definition of disability, an attempt has been made to identify the most severe cases and to align the groups that are most similar in level of impairment. Individuals with limited or moderate impairment have not been included in the table.

Despite the variation in estimates among studies, the relatively high rate of functional disability among the elderly is clear. While 1.2 to 3.9 percent of the population age 18-64 is functionally disabled, 11.8 to 16.8 percent of the elderly population is estimated to be disabled to some degree. 2/

The Potential Demand for Long-Term Care

The institutionalized population is expected to increase over the next several years principally because of the increase in the number of persons over age 65, and a continuing growth in their rate of nursing home use. Eighty-nine percent of current nursing home residents are elderly, 74 percent are over age 75, and 70 percent are female. Females over age 75 have the highest rate of institutionalization, and this group will have increased by 25 percent between 1970 and 1980. The total elderly population will have increased 22 percent over the same period. As a result, the nursing home population is estimated to number roughly 1.8 million in 1980 compared to 0.7 million in 1970. The total institutionalized population is estimated to be 2.1 million in 1980. (See Table 3.)

2/ There are substantial differences in the rate of disability among the elderly. Nagi found that persons over the age of 75 were three times as likely to need personal care assistance as those between the ages of 65 and 74.

Table 2. NATIONAL ESTIMATES OF FUNCTIONAL DISABILITY BY PERCENT OF ADULTS

Age Group	Study	Lesser Disability a/	Greater Disability b/	Total Percent Disabled
18-64	SSA (1974) c/	1.9	2.0	3.9
	SSA (1972) d/	1.8	1.6	3.4
	Nagi (1972) e/	2.0	0.8	2.8
	NCHS (1972) f/	0.6	0.6	1.2
65+	Nagi	11.1	5.7	16.8
	NCHS	6.7	5.2	11.8
Percent of All Adults	Nagi	3.6	1.7	5.3
	NCHS	1.4	1.2	2.7

a/ Definitions: SSA - severe functional loss
Nagi - mobility and personal care assistance needed
NCHS - needs help in getting around

b/ Definitions: SSA - functionally dependent
Nagi - needs assisted living and has severe limitations in physical and emotional performance
NCHS - confined to the house

c/ Unpublished preliminary estimates from the 1974 Social Security Survey of the Disabled.

d/ Social Security Administration, Social Security Bulletin, Volume 39, No. 10, October 1976.

e/ Nagi, Saad Z., "An Epidemiology of Adulthood Disability in the United States," Mershon Center, Ohio State University, mimeo, 1975.

f/ U.S. Department of Health, Education, and Welfare, National Center for Health Statistics, Limitations of Activities and Mobility and Due to Chronic Conditions, United States - 1972, Series 10, Number 96, U.S. Government Printing Office, Washington, D. C., November 1974.

There is no reason to believe that rates of disability among the noninstitutionalized will increase. One must assume that the wide variation among survey estimates of the proportion of the population disabled is due to differences in definition or survey technique and not to real shifts in actual rates of impairment. If the range of disability rates from the national surveys is applied to projections of the population, the noninstitutionalized functionally disabled population would be expected to increase from its estimated range of 3.9 - 8.3 million persons in 1975 to 4.2 - 9 million in 1980 and to 4.5 - 9.6 million in 1985. (See Table 3.)

The total potential demand for long-term care is therefore estimated to increase from 5.5 - 9.9 million persons in 1975 to 6.3 - 11.1 million in 1980 and to 7.4 - 12.5 million in 1985.

WHO PROVIDES IT?

Most of the disabled receive long-term care services --of unknown quality--from families and friends, with little assistance from public programs. Under public programs, 56 percent of the financing for long-term care is provided by the federal government and an estimated 44 percent by state and local governments. Ninety percent of financing under these programs is for nursing home care. Public support of long-term care services in the home is minimal and fragmented among several programs.

Medicaid

The medicaid program is the main source of government financing of long-term care. It is a federal-state matching program for the poor. To be eligible, one's income must fall below levels set by the states. Medicaid spending for nursing homes totaled $4.3 billion in 1975. Care in skilled nursing facilities (SNFs) is a mandated basic medicaid service for all eligible individuals over 21 years of age. Care in intermediate care facilities (ICFs) is optional to the states, but in fact every participating state pays for ICF care. In 19 states, nursing homes account for the bulk of medicaid expenditures.

Table 3. RANGE OF POTENTIAL DEMAND FOR LONG-TERM CARE, Adults in Millions a/

Category	Age 18-64			Age 65 and Over			All Adults		
	1975	1980	1985	1975	1980	1985	1975	1980	1985
The Institutionalized	0.2	0.3	0.4	1.4	1.8	2.6	1.6	2.1	3.0
The Noninstitutionalized Functionally Disabled:									
Low Estimate b/	1.4	1.5	1.6	2.5	2.7	2.8	3.9	4.2	4.5
High Estimate c/	4.7	5.1	5.5	3.6	3.9	4.1	8.3	9.0	9.6
Total Potential Demand							5.5 to 9.9	6.3 to 11.1	7.4 to 12.5

a/ Population projections from Francisco Bayo and Richard S. Foster, "Actuarial Study Number 74," Office of the Actuary, Social Security Administration, June 1975.

b/ NCHS estimates of total percent disabled applied to SSA projections of the noninstitutionalized population.

c/ SSA 1974 estimates of the total percent of the under 65 population disabled and Nagi estimates of the total percent of the elderly disabled applied to SSA projections of the noninstitutionalized population.

Home health services became a covered service for every participating state in 1970, but the program cannot be considered truly national in scope since 70 percent of the payments are in New York, which has the most liberal package. Medicaid home health care expenditures were only $70 million in 1975, 1.6 percent of medicaid long-term care expenditures.

Medicare

Medicare, the health insurance program for the aged, is not a major source of financing for long-term care. Medicare benefits are considered adjuncts to the acute care hospital system and are not designed for long-term chronic care. Only 100 days of skilled nursing care per benefit period is covered and must be preceded by at least three days of hospitalization. Medicare nursing home expenditures were $255 million in fiscal year 1975 and represent only 5 percent of federal nursing home payments and 2 percent of total medicare expenditures.

Medicare also covers up to 100 home health care visits per spell of illness under Hospital Insurance (HI, or Part A) and 100 visits per year under Supplementary Medical Insurance (SMI, or Part B). Like nursing home care, home health care under medicare is designed to be an acute care rather than chronic care benefit. Total medicare home health expenditures were $185 million in fiscal year 1975. They constituted 1 percent of total medicare expenditures and 42 percent of medicare long-term care.

Veterans' Programs

The Veterans Administration directly provides long-term care to veterans in nursing homes and domiciliary care facilities (room, board, and general supervision but no medical services). VA also contracts for community nursing home care, and contributes to the cost of caring for veterans in state institutions. It also gives cash allowances to disabled pensioners who need aid and attendance at home, although it is not known whether these supplementary payments are in fact used to purchase such assistance. In 1975, VA spent $240 million for institutional care, $234 million in cash payments to veterans needing aid and attendance, and $5 million for health care in the home.

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Supplemental Security Income Program

Supplemental Security Income (SSI) is fundamentally a federal-state-local cash grant program to the needy aged, blind, and disabled, but it indirectly finances domiciliary care facilities (DCFs). Under SSI, states may grant a supplemental payment to individuals residing in domiciliary care facilities. Initial data on this relatively new program indicate state expenditure of roughly $40 million in supplementary payments in 1975. 3/

Title XX of the Social Security Act

Title XX of the Social Security Act provides funds to the states for social services for recipients of income-tested cash payments programs (Aid to Families with Dependent Children, SSI) and other low-income individuals. No actual data are available for 1976, its first year of operation. Under the predecessor social services program, $101 million was spent in 1975 on homemaker and chore services, day care, and foster care. These may be considered elements of long-term care but probably only an estimated $66 million was spent on these services for the disabled.

Titles III and VII of the Older Americans Act

Titles III and VII of the Older Americans Act provide funds to states for nutrition and social services for the elderly. While there are no income limitations for recipients, most service projects are located in low-income areas. The entire amount available under Titles III and VII in 1975 was $232 million. Most of the services and meals provided could not properly be considered long-term care, although they could be considered support services if packaged with health services.

3/ Derived from unpublished data from the Office of Research and Statistics, Social Security Administration.

Private Sources

Over half of long-term care costs are paid for privately. Eighty-eight percent of payments from private sources are out-of-pocket because there is little private insurance coverage of long-term care. 4/ It is not known how much is spent on the care of the disabled and elderly by their families and friends in the home, although most of the disabled receive long-term care services in this manner.

Table 4 shows estimated expenditures for long-term care by source of funds and Table 5 indicates the distribution of public funds between nursing home care and non-institutional care.

4/ Long-Term Care: Actuarial Cost Estimates, Congressional Budget Office, February 1977.

Table 4. ESTIMATED EXPENDITURES FOR LONG-TERM CARE a/ BY SOURCE OF FUNDS FOR FISCAL YEARS 1973 AND 1975

	1973 (In Billions of Dollars)	1975 (In Billions of Dollars)	Percent Increase
Public			
Medicaid	2.88	4.40	53
Federal	(1.56)	(2.42)	--
State and Local	(1.32)	(1.98)	--
Medicare b/	0.26	0.44	68
Veterans' Programs c/	0.17	0.24	42
Supplemental Security Income- State Supplement	--	0.04	--
Social Services (Title XX)	--	0.07	--
Other State and Local Programs d/	0.41-0.46	0.53-0.57	26
Subtotal, Public	3.72-3.77	5.72-5.76	--
Private d/ e/			
Out-of-pocket	3.90-4.86	5.20-6.75	--
Insurance	0.36	0.42	--
Other	0.20-0.34	0.32-0.50	--
Subtotal, Private	4.46-5.56	5.94-7.67	35
Total	8.18-9.34	11.66-13.43	--

Table 4 - footnotes

a/ Excludes hospitals, facilities for mentally-related conditions, and physicians' services.

b/ Reimbursements based on an interim rate inflated to adjust for final settlement.

c/ Excludes cash payments to pensioners in need of aid and attendance.

d/ For further detail, see Long-Term Care: Actuarial Cost Estimates, Congressional Budget Office, February 1977.

e/ Out-of-pocket expenditures, philanthropy, and private insurance. Excludes care provided by families and friends.

Table 5. ESTIMATED PUBLIC SUPPORT OF INSTITUTIONAL VERSUS HOME-BASED CARE, FOR FISCAL YEARS 1973-1975, In Millions of Dollars

Program	1973	1974	1975
Medicaid			
Institutional care	2,854	3,383	4,330
Home care	25	31	70
Medicare			
Institutional care	190	232	255
Home care	71	106	185
Veterans Administration			
Institutional care	168	188	240
Home care	a/	1	5
SSI Supplemental Payments	--	--	40
Social Services	--	--	66
Other State and Local Programs			
Institutional Care	228-285	260-320	300-340
Home care	180	200	230
Subtotal, Institutional Care	3,440-3,497	4,063-4,123	5,165-5,205
Subtotal, Home-Based Care	276	338	556
Total Public Support	3,716-3,773	4,401-4,461	5,721-5,761
Percent of Total	7.4	7.7	9.7

a/ Less than $500,000.

GAPS IN COVERAGE

There is evidence that many of the 5 to 10 million adults who might have needed some form of long-term care in 1975 were not receiving it.

An annual average of 1.6 million people were receiving care in institutions in calendar year 1976. Medicaid financed home health care for 150,000 people. Under medicare, home health bills were approved for an estimated 431,000 persons--not necessarily different individuals from those in the medicaid program. 1/ Given medicare regulations, these home health expenses are more properly considered acute care than chronic care. VA funded or provided care for 30,550 veterans in domiciliaries and provided home health services to 1500 veterans. Supplemental state SSI payments were made to 107,000 people in domiciliaries or other supervised living arrangements. 2/ Based upon the number of domiciliary and foster home residents receiving supplemental SSI payments, it is estimated that perhaps a total of 75,000 to 635,000 people are in sheltered living arrangements or in congregate housing. 3/ Under the social services programs, an estimated 36,000 disabled adults received day care; that is, rehabilitation and social services at a center during the day.

1/ Social Security Administration. Based on a 40 percent sample of 1974 bills.

2/ Unpublished data from the Office of Research and Statistics, Social Security Administration.

3/ Long-Term Care: Actuarial Cost Estimates, Congressional Budget Office, February 1977.

Since the recipients of noninstitutional care under federal programs may receive services under more than one program and the degree of overlap is unknown, a range of individuals estimated to be served is shown in Table 6.

Table 6. LONG-TERM CARE ESTIMATED SUPPLY AND POTENTIAL DEMAND, FOR CALENDAR YEAR 1976, Adults in Millions

Source	Estimated Potential Demand	Estimated Number Served
Potential Demand	5.5-9.9	
Estimated Supply		
Chronic hospitals and facilities for the deaf, blind, and disabled		0.1
Nursing home care (ICF & SNF)		1.3
Personal care or domiciliary care		0.2
Sheltered living arrangements		0.1-0.6
Home care and day care		0.3-0.5 a/
Estimated Total Number Served Under Government Programs		1.9-2.7 a/
Estimated Informal Care by Families		3.0-6.7 b/
Estimated Number Receiving No Care		0.8-1.4 c/

SOURCE: CBO estimates.

a/ Function of range of overlap of persons receiving possible duplicate treatment under medicare and medicaid.

b/ Estimates of the disabled population living with others in private residences, congregate housing, or sheltered living arrangements. These persons may also receive home care under public programs.

c/ Estimated disabled living alone less number receiving home care if home care is assumed to be evenly divided between those living alone and those living with others.

Informal basic care is provided to a large degree by the families and friends of the disabled. According to the NCHS survey of the disabled cited earlier, 88 percent of the functionally disabled between 18 and 64 and 70 percent of the elderly disabled live with others. Presumably these other individuals provide whatever assistance is required by the disabled in the way of shopping, cooking, or personal care, although they cannot provide specialized health care. The remaining 30 percent of the elderly disabled and 12 percent of the disabled age 18-64 live alone. If they are not among those receiving home-based services funded under a public program or do not have relatives nearby to provide assistance, they probably receive no care.

In summary, of the 5.5 to 9.9 million functionally disabled, only 1.9 to 2.7 million persons can be identified as receiving assistance under formal programs. Of these, 1.6 million are in institutions and 75,000 to 635,000 are in other sheltered living arrangements. Home health agencies serve up to 500,000 people under medicare and medicaid, but some of these people are probably also receiving help from relatives and not all can be considered to be receiving long-term care. In order to estimate the total number of persons receiving services, it is assumed that the noninstitutionalized disabled living with others are receiving basic services from their families. Under this assumption, an estimated 3 to 6.7 million disabled are receiving some form of informal care. This group may also be receiving home care or may reside in congregate housing so that it is impossible to estimate how many are receiving only informal family care. Moreover, nothing is known about the quality or adequacy of such family services. Similarly, it is assumed that those living alone receive no family care but receive half the home health care under medicare and medicaid (a simplistic and possibly optimistic assumption). Under this assumption, an estimated 800,000 to 1.4 million disabled may receive no form of long-term care.

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INEFFICIENT USE OF EXISTING RESOURCES

At the same time that a substantial number of persons receive no apparent long-term care, a number of persons in Skilled Nursing Facilities (SNFs) and Intermediate Care Facilities (ICFs) either do not need the presumably high level or degree of care provided or could be maintained at home if adequate home care services were available.

Appendix B summarizes fourteen studies of the appropriateness of placement in nursing homes. The studies, done at various times, range widely in their estimates of inappropriate placement. The wide range is due to a number of factors:

- o variation inherent in subjective judgments of what level of disability requires institutionalization;
- o the absence of generally agreed upon criteria for institutionalization at particular levels;
- o use of strict medical necessity versus feasibility of de-institutionalization as criteria; and
- o differences in the sophistication of the patient assessment and placement mechanism in each location or in succeeding years.

Despite these shortcomings, some generalizations can be made. Given the clustering of study results, it is possible to assume conservatively that 10 to 20 percent of SNF patients and 20 to 40 percent of ICF residents are receiving unnecessarily high levels of care. It is likely, however, that most of the persons inappropriately placed at the SNF level still need some form of institutional care. For example, a survey by the Office of Long Term Care of the Department of Health, Education, and Welfare found that 13 percent of all SNF medicaid and medicare patients were completely ambulatory and might be considered at too high a level of care, yet fully half of these patients needed help in bathing and might be considered candidates for ICF care.4/

4/ Office of Long Term Care, Long-Term Care Facility Improvement Study: Introductory Report, DHEW Pub. No. (OS) 76-50021, Rockville, Maryland, July 1975.

Comparatively less is known about the status of residents of ICFs, but it is believed that a substantial percentage of these residents could reasonably be cared for at home or in sheltered living arrangements. The Monroe County Health Council estimated that 74 percent of ICF residents were inappropriately placed in 1969-1970 and 35 percent in 1974-1975. 5/ 6/

Few of the studies attempted a systematic evaluation of the level of care needed. The Massachusetts study estimated that of the patients in nursing homes in 1969, 37 percent needed skilled nursing care, 23 percent intermediate care or home nursing, and 26 percent supervised or sheltered living arrangements; 14 percent were considered capable of living independently. 7/ The 1964 study of the elderly in Monroe County, New York, which sampled the entire noninstitutionalized elderly population in addition to the elderly patients in hospitals and other institutions, concluded that 24 percent of the elderly nursing home population and 62 percent of the hospitalized elderly were inappropriately placed. This resulted, however, in a net drop in estimated skilled nursing bed requirement of only 22 percent and an increase of 3 percent in intermediate care requirements. Some portion of the inappropriately placed group needed a lower level of institutional care, but roughly 10 percent of the noninstitutionalized elderly in fact needed institutional care. 8/

5/ Monroe County Health Council, Survey of the Need for Inpatient Beds in Monroe County, 1969-1970, Rochester, New York, 1970.

6/ Monroe County Health Council, Survey of the Need for Inpatient Beds in Monroe County, 1974-1975, Rochester, New York, 1975.

7/ Massachusetts Department of Public Health study cited in Robert Morris, Alternatives to Nursing Home Care: A Proposal, prepared for use by the Special Committee on Aging, U.S. Senate, Washington, D.C., Government Printing Office, October 1971.

8/ Robert L. Berg and others, "Assessing the Health Care Needs of the Aged," Health Services Research, 5:36-59, 1970.

This last observation is quite significant. Considering that from 3 to 5 percent of the total noninstitutionalized population (12 to 17 percent of the elderly) have levels of disability so high that they are bedridden or require assistance in the most basic functions of daily living, it is easy to see that beds presently occupied by those not needing nursing home care can readily be filled by others. Table 7 roughly illustrates estimated supply and potential need (i.e., demand adjusted for appropriate placement) in calendar year 1976. The figures can be expected to increase significantly over time, but they illustrate the basic mismatch of services with requirements.

Table 7. LONG-TERM CARE ESTIMATED SUPPLY AND POTENTIAL NEED, FOR CALENDAR YEAR 1976, Adults in Millions

Type of Treatment		Estimated Potential Need a/	Estimated Supply
Nursing Home Care:	SNF	0.7	0.9
	ICF	0.6	0.4
Personal Care Homes, Sheltered Living Arrangements, and Congregate Housing		1.5-1.9	0.3-0.8
Home Health Care and Day Care		1.7-2.7	0.3-0.5
Informal Family Care Only or No Care		1.0-4.0	3.6-7.2

SOURCE: CBO estimates.

a/ Derived in the following manner: descriptive levels of disability (e.g., cannot bathe) assigned to probably appropriate levels of care based upon Nagi (national), Greenberg (Minnesota), and Berg (New York) studies cited earlier. Estimates of the incidence of disability adjusted to correspond to national distribution of disability levels. National need then calculated on basis of SSA population projections.

As it is difficult to determine the number of disabled, it is impossible to determine accurately the care needs of the disabled population. Therefore, the numbers in the table should not be taken as absolute values but as indicators of need. They show theoretically correct initial placement based on estimated clinical need if supply were adequate and if people could be shifted from their present care situations into more appropriate ones--including from the community into a nursing home.

Short-term shifts of people out of institutions are not feasible because many inappropriately placed nursing home patients have broken their ties with the community and become psychologically, if not physically, dependent upon the nursing home for support. Moreover, nursing home administrators may be reluctant to replace easy care patients with others from the community who require more services. 9/

Even if alternative resources were available, de-institutionalization might not be economically feasible, depending upon the intensity and frequency of services required by the patient and the cost of home care versus institutional care in a particular region. As Table 8 illustrates, home care can be as expensive per unit of service as nursing home care. In addition, a study of nursing home patients in Minnesota showed that the home care hours required by people who could be de-institutionalized varied from eight hours to 75 hours a month. Although 18 percent of the patients could have been de-institutionalized on the basis of medical need, for only half of these or 9 percent of the total would it have been less costly than

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9/ Some suggest that nursing home administrators are more likely to accept or retain only those residents who do not require personal care assistance. J.T. Gentry and V.R. Curlin, "The Illinois Long Term Care Classification Instrument: Use Experience within the New York City Medicaid Program," New York City Department of Health, mimeo, May 8, 1975, and John W. Davis and Marilyn J. Gibbin, "An Areawide Examination of Nursing Home Use, Misuse and Nonuse," American Journal of Public Health, Vol. 61, No. 6, June 1971.

nursing home care. 10/ (For a further discussion of the cost-effectiveness of home care, see Appendix C.)

Table 8. COMPARATIVE UNIT COST OF NURSING HOME CARE AND HOME HEALTH CARE, 1972, in Percents

Cost	Proportion of Nursing Homes with Cost Per Resident Day of a/	Proportion of Home Health Agencies with Cost Per b/ Nursing Visit of	Therapist Visit of
Less than $10	23	15	12
$10 to $14.99	36	47	64
$15 to $19.99	23	24	16
$20 and over	18	13	7

a/ National Center for Health Statistics, 1973-1974 National Nursing Home Survey.

b/ Estimated from data supplied by the Council of Home Health Agencies and Community Health Services, National League of Nursing.

10/ Jay Greenberg, "The Costs of In-Home Services," in A Planning Study of Services to Noninstitutionalized Older Persons in Minnesota, Governor's Council on Aging, State of Minnesota, Minneapolis, Minnesota, 1974.

THE FINANCIAL BURDEN

Over half of nursing home care costs in 1975 were paid from private sources. Eighty-eight percent of this was paid for out-of-pocket rather than by insurance or philanthropy. According to an analysis by the Congressional Budget Office of the incidence and cost of catastrophic illness, nursing home care is the principal cause of catastrophic expenses among the aged. 11/ If a length of stay of three months is selected as the threshold of a catastrophic event, an estimated 1.6 million people incurred catastrophic nursing home costs of $9 billion in 1975, only a portion of which was defrayed by public health programs. 12/

The families of the disabled are even less able to bear the cost of long-term care than the public at large. The average annual cost of a nursing home stay in 1975 was an estimated $7,300. Roughly 70 percent of the disabled and 73 percent of the disabled elderly have family income of less than $7,000 a year. Seventy-six percent of the institutionalized population have incomes below this level, in striking contrast to the distribution of income among all families. Only 22 percent of all families have incomes below $7,000, although 48 percent of elderly families have incomes below this level, presumably as a result of retirement from the labor force. Table 9 illustrates these disparities in greater detail. Note that family income refers to the income of the immediate household and not to the income of children or relatives in their own households. Income also excludes the value of assets such as a house, which might affect the overall economic position of the family.

11/ For further discussion of catastrophic illness, see Catastrophic Health Insurance, Budget Issue Paper, Congressional Budget Office, January 1977.

12/ Estimate based upon the number of patients treated during the year, not average annual census.

Medicare covers only a fraction of nursing home costs, so long nursing home stays tend to impoverish the disabled and make welfare support inevitable. In fact, 47.5 percent of nursing home patients whose costs are paid by medicaid in 1974 were not initially poor by state definitions but depleted their resources and qualified as "medically needy."

Table 9. COMPARISON OF FAMILY INCOME DISTRIBUTION AMONG ALL FAMILIES, THE DISABLED, AND THE INSTITUTIONALIZED

Family Income	Percent Distribution				
	Families a/		Functionally Disabled b/		Institution-alized c/
	All	65+	All	65+	All
Less than $3,000	5.3	8.3	38.2	43.2	68.7
$3,000-4,999	7.8	20.0	18.9	18.6	5.4
5,000-6,999	8.9	19.4	10.8	11.2	1.7
7,000-9,999	13.8	19.0	7.9	7.2	0.6
10,000-14,999	24.4	17.3	9.0	6.8	0.4
15,000 and over	39.8	16.0	5.5	6.9	0.7
Unknown	--	--	9.8	6.1	22.5
	100.0	100.0	100.0	100.0	100.0

a/ Money Income in 1974 of Families and Persons in the United States, U.S. Bureau of Census, Series P-60, No. 101, January 1976.

b/ Limitation of Activity and Mobility Due to Chronic Conditions, United States - 1972, HEW, National Center for Health Statistics, Series 10, No. 96, November 1974.

c/ Long-Term Care Facility Improvement Study, HEW, Public Health Service, Office of Nursing Home Affairs, July 1975.

CHAPTER III BEHIND THE INADEQUACIES OF LONG-TERM CARE

Perhaps the single largest factor behind the lack of adequate or appropriate long-term care for a large number of the chronically disabled is the general lack of formal alternatives to institutional care. Once it is determined that a person is incapable of living at home without some form of additional support or health care, the question of whether he or she will remain in the community depends upon the existence of social (usually family) support, the adequacy of financial resources, and the availability of noninstitutional health and social services. Unfortunately, many of the elderly are poor and either have no spouse or relative at all or no relative living near enough to assist them in basic services. In other cases, the families of the elderly may be unwilling or unable to provide assistance. The modern, mobile nuclear family is not always inclined to maintain an elderly relative at home, and the increasing participation of women in the labor force further reduces the likelihood that adult married women will remain at home to care for an aged parent. 1/ If there is no social support provided by the family or no formally provided care in the home, the alternatives are a nursing home, in which long-term care services are heavily subsidized by the government, or no care.

1/ Barry R. Chiswick, "The Demand for Nursing Home Care: An Analysis of the Substitution Between Institutional and Noninstitutional Care," National Bureau of Economic Research, September 25, 1975.

Generally, older persons do not prefer nursing home care. To many, institutionalization represents rejection by family and friends, loss of independence, isolation, and separation from society. 2/ One interpretation of the fact that a large number of deaths occur soon after institutionalization is that the elderly or their families wait until the last possible moment to enter a nursing home. 3/ Moreover, many nursing homes, particularly those funded by medicaid, are not considered to be of high quality. The Office of Long Term Care (HEW) found, for example, that most patients in skilled nursing facilities needing specialized rehabilitative services did not receive them: 70 percent of those needing physical therapy and 90 percent of those needing occupational and speech therapy did not receive it. 4/

2/ Several studies are cited in Philip W. Brickner and others, "Home Maintenance for the Home-Bound Aged," The Gerontologist, Vol. 16, No. 1, Pt. 1, 1976: W.G. Bell, "Community care for the elderly: An alternative to institutionalization," 13:349-354, 1973; M.P. Lawton, "Social ecology and the health of older people," American Journal of Public Health, 64:257-60, 1974; M.P. Lawton, B. Liebowitz, and H. Charon, "Physical structure of the behavior of senile patients following ward remodeling," Aging and Human Development, 1:231-39, 1970; M.A. Lieberman, "Institutionalization of the aged: Effects of behavior," Journal of Gerontology, 24:330-40, 1969; E.W. Markson, G.S. Levitz, and M. Gognalons-Caillard, "The elderly and the community: Identifying unmet needs," Journal of Gerontology, 28:503-09, 1973.

3/ Harold J. Wershow, "The Four Percent Fallacy: Some Further Evidence and Policy Implications," The Gerontologist, Pt. I, 16:52-55, 1976.

4/ Office of Long Term Care, Long-Term Care Facility Improvement Study: Introductory Report, HEW, Public Health Service, DHEW Pub. No. (OS) 76-50021, Rockville, Maryland, July 1975.

IMPACT OF GOVERNMENT PROGRAMS ON THE SUPPLY OF SERVICES

Although the issues involving family structure are important in the provision of long-term care for the elderly, it is difficult for government programs to address them directly. There are, however, specific limitations in federal laws and regulations governing federal and federal-state matching programs that have prevented the widespread use of community-based long-term care.

Medicare's Home Health Program

Medicare's home health benefit has remained small because of (1) statutory limitations in the target population, the type of services that are reimbursable, and the conditions of participation for home health agencies; and (2) strict regulatory interpretation of the statute.

The home health care benefit under medicare is concentrated on skilled services for the acutely ill as opposed to health-related or basic services for the chronically disabled. The medicare benefit is limited to a maximum of 100 home health visits under hospital insurance (Part A) and 100 visits under supplementary medical insurance (Part B). If Part A visits are exhausted, Part B visits may be applied up to a maximum under both Parts of 200 visits per episode of illness. Only 2 percent of Part A and 1.4 percent of Part B beneficiaries exceed the maximum number of visits because strict regulations ensure that reimbursement is terminated well before the limit is reached. 5/

Because Part A is designed principally to shorten hospital stays and return a patient to normal function within a short time, home health benefits under Part A are available only to persons who are homebound and who have been hospitalized for at least three days. (Part B does

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5/ General Accounting Office, Home Health Care Benefits Under Medicare and Medicaid, B-164031(3), July 9, 1974.

not require prior hospitalization but does have a deductible; only 30 percent of home health expenditures are under Part B.) Home health care is authorized only if a physician certifies that the patient needs nursing care, physical therapy, or speech therapy to recover or to avoid a sudden adverse change in condition. If a patient's condition is stable or becomes stable--as is the case with many of the chronically disabled and terminally ill--home health services are not covered. On the other hand, skilled nursing home care may be authorized for services "which are necessary to prevent deterioration of the patient's condition and sustain the patient's current capacities even when full recovery or medical improvement is not imminent" (emphasis added). 6/ This again illustrates the implicit priority given institutional care under current federal programs.

Although the needs of the chronically disabled (as well as the acutely ill) include both personal care services and homemaker services, housekeeping and food service arrangements such as "meals-on-wheels" are specifically excluded from coverage. While home health aides under the supervision of a nurse may provide some homemaker services, they are restricted to the performance of those that are incidental and do not substantially increase the amount of time spent by the home health aide. When the patient reaches the point at which he no longer needs skilled services (nursing, physical, or speech therapy), health-related support services (that is, home health aides services) are also withdrawn.

Finally, services must be "intermittent" or "part time" to be covered by medicare. These terms are not clearly defined in the law but the Social Security Administration (SSA) guidelines set a few hours a day several times a week as the norm. For home health aide visits, claims exceeding 20 hours a week are usually denied. Concentrated visits (that is, not intermittent) or occasional visits are not permitted.

6/ Social Security Amendments of 1972, Report of the Senate Committee on Finance, Senate Report No. 92-1230, September 26, 1972, p. 284.

Participation of home health agencies is limited by licensing and service requirements. By statute, a home health agency must provide skilled nursing care and one other therapeutic service (physical therapy, speech therapy, occupational therapy, medical social services, or home health aide services). While intended to ensure the provision of a comprehensive range of services, this requirement has prevented some 500 to 700 agencies from participating in medicare. Many of these agencies are located in rural areas where there is a shortage of skilled personnel. Proprietary home health agencies are also excluded from participation if they do not meet state licensing requirements. Since only seventeen states have such licensing procedures, no agency in the other states can receive reimbursement, even if all federal care standards are met. Proprietary agencies are often the only home health care providers that offer 24-hour and weekend care.

Limitations in the Medicaid Home Health Care Benefit

The medicaid program is more liberal than medicare by statute and regulation. Services need not be performed by a skilled individual and may include personal care services in a recipient's home rendered by an individual, not a member of the family, who is qualified to provide such services. Long-term maintenance of the disabled is therefore possible.

In practice, medicaid is as oriented to skilled services as medicare. Medicaid expenditures for home care remain very small, despite the fact that it has been a required service since July 1, 1970. As with other aspects of the medicaid program, the states are given wide discretion as to the content and administration of their programs, and services vary considerably from state to state. In an effort to control the rising costs of medicaid, at least 15 states have adopted the medicare restrictions. Other states have established reimbursement rates that are significantly lower than medicare rates.

State fears about the cost of a noninstitutional long-term care program may be well founded. Adoption of medicare home care standards guarantees a limit on days of care. Total costs may therefore be limited even though the per visit cost of skilled services is high. Maintenance care under medicaid might be less costly per unit of services because it would involve a higher proportion of basic and health-related services but it is likely to be of longer duration. Moreover, home-based services are far more difficult to monitor than nursing home care because they are decentralized.

Sufficient evidence does not exist to say with certainty that maintenance home care would be less or more expensive than the present system. 7/ (See Appendix C.)

7/ For further discussion see Judith LaVor and Marié Callender, "Home Health Cost Effectiveness: What Are We Measuring?" Medical Care, Vol. 14, No. 10, October 1976. Other studies in this area are of home care as an alternative to hospitalization, not to nursing home care. For a full review of some of the best known studies, see "Appendix 3: Excerpts from Reports of Functioning Home Health Service Programs," in Home Health Services in the United States, A Report to the Special Committee on Aging, U.S. Senate, Washington, D.C., Government Printing Office, 1972; New Perspectives in Health Care for Older Americans: Recommendations and Policy Directions, Report by the Subcommittee on Health and Long Term Care of the Select Committee on Aging, U.S. House of Representatives, Washington, D.C., G.P.O., January 1976.
For detailed discussions of the methodological problems, see William Pollack, Modeling the Costs of Federal Long-Term Care Programs: Issues and Problems, Working Paper 0975-06, Washington, D.C., The Urban Institute, July 8, 1974; Charles H. Brooks, "A Critical Review of Four Home Care Cost-Benefit Analyses," In Metropolitan Health Planning Corporation, Toward a Coordinated System for the Provision of Home Health Services in Cuyahoga, Geauga, Lake and Medina Counties, State of Ohio, Cleveland, Ohio, 1975; and Jay Greenberg, "Part Two: The Costs of In-Home Services," in Nancy Anderson, The Governor's Citizens Council on Aging, the State of Minnesota, A Planning Study of Services to Noninstitutionalized Older Persons in Minnesota, Minneapolis, Minnesota, 1974.

This uncertainty, combined with the strong possibility that even with a generous noninstitutional service program the elderly might ultimately have to be institutionalized, reinforces the conservative inclinations of the states.

Unexploited Potential of Housing Programs

Congregate housing is a concept that can provide an alternative residence and semi-independent lifestyle for older people. It has been defined as

> "a residential environment which includes services such as meals, housekeeping, health, personal hygiene, and transportation, which are required to assist impaired, but not ill, elderly tenants to maintain or return to a semi-independent lifestyle and avoid institutionalization as they grow older." 8/

The Department of Housing and Urban Development (HUD) operates several programs that provide assistance for congregate housing. These include: (1) Section 202 financing for construction or rehabilitation of housing for the elderly and handicapped; (2) Section 231 mortgage insurance for rental housing for the elderly; and (3) specific authority for congregate housing in the 1970 Housing and Urban Development Act. Nevertheless, HUD can identify only 22,560 units of congregate housing funded under these authorities. 9/

CBO estimates that a total of 75,000 to 635,000 units of congregate housing or rooms in foster homes exist, whereas an estimated 1.3 to 1.7 million persons could conceivably benefit from such living arrangements. 10/ Reasons for the limited number of units may include disinterest on the part of private developers and absence of guarantees by state and local service agencies to provide meals and other services.

8/ U.S. Senate Special Committee on Aging, Congregate Housing for Older Adults, Senate Report 94-478, 94th Congress, 1st Session, Washington, GPO, November 1975. Quoted in The Impact of Federal Housing Programs on the Elderly by Susan Dovell, Congressional Research Service, HD 7106D, 76-156E, August 19, 1976.

9/ "Federally-Assisted Congregate Housing Developments for the Elderly," HUD, mimeo, January 1976.

10/ Long-Term Care: Actuarial Cost Estimates, Congressional Budget Office, February 1977.

MANAGEMENT AND ORGANIZATION PROBLEMS - THE OFFSHOOTS OF FRAGMENTED FUNDING

The efforts of government agencies (principally state and local health and welfare departments) to ensure that patients are placed at appropriate levels of care have been plagued by (1) fragmentation of responsibility at the local level, which parallels the fragmented responsibility at the federal level; and (2) lack of adequate placement criteria and assessment mechanisms.

Lack of Coordination

In general, the elderly face a bewildering array of fragmented long-term care services and financing arrangements. In few communities is there a centralized, unified coordination, referral, and placement agency. This should not be surprising in view of the fact that, at the federal level, the Social and Rehabilitation Service, the Social Security Administration, the Public Health Service, the Administration on Aging, and the Department of Housing and Urban Development all run programs that could fall under the heading of long-term care.

Often community-based care of an elderly person is not considered because it takes more effort to devise a home care schedule than to place the person in a nursing home. To provide home care, it might be necessary to obtain income assistance from the welfare department, homemaker services from a Title XX funded social services program, and health care from the Visiting Nurse Association (VNA), with each agency insisting on its own review of the patient's eligibility. If one element of the "package" should fall through, the patient could not remain at home. Hospital discharge planners, under pressure to free a bed, generally cannot wait long enough to spend as much time as it would take to find alternatives to a nursing home. 11/

11/ For further discussion of the difficulties of both coordination and placement see: Helen Kistin and Robert Morris, "Alternatives to Institutional Care for the Elderly and Disabled," The Gerontologist, Summer 1972, and New York State Moreland Act Commission on Nursing Homes and Residential Facilities, Assessment and Placement: Anything Goes, New York City, March 1976.

Lack of Adequate Placement Criteria and Assessment Mechanisms

There is no set of criteria matching levels and combinations of disability with appropriate types of institutional or noninstitutional treatment. Probably the most comprehensive national effort to develop clearly defined and uniform criteria was performed under the auspices of HEW. A manual is published for the information and use of providers and managers but its use is not required in patient placement. 12/ In any event, there is little review of placement decisions prior to institutionalization. Most placement review is done under the ex post facto utilization review system required as a condition of participation in both medicare and medicaid. Post-placement review efforts have not been successful to date because of fear that the relocation of an elderly patient will cause "transfer trauma," or because of opposition by relatives, administrative inadequacies, or the lack of alternative services. 13/

While publicly-financed programs have imperfect placement and patient assessment mechanisms, there is no mechanism required in any state to ensure that privately-financed patients are placed at the appropriate levels of care.

12/ Patient Classification for Long-Term Care: Users Manual, National Center for Health Services Research, DHEW Publication No. HRA-75-3107, November 1974.

13/ Investigations of transfers in New York State in 1975 found that (1) patients and relatives were not notified of impending transfers; (2) old medical records were used to determine appropriate levels of care; (3) transfers were not supervised adequately either by health department or social services personnel who were only rarely present at the appropriate time; (4) patients were transferred to locations remote from relatives without knowledge of what the new facility would be like; (5) patients were sent to new facilities without complete records and all personal possessions; and (6) little or no attempt was made to inform patients and relatives of their rights to appeal decisions in "fair hearings" in cases in which the contemplated transfer was to a lower level of care.

CHAPTER IV POLICY OPTIONS FOR LONG-TERM CARE

Despite the inadequacy of long-term care data and the uncertainty surrounding judgments of appropriate treatment, several problems do consistently emerge:

1. A significant number of the noninstitutionalized population need but do not receive long-term care. At the same time, many people are receiving too high a level of care in medically-oriented nursing homes because they cannot get affordable long-term care services or sheltered living arrangements in the community.

2. Existing formal long-term services are provided in such a rigid manner by so many different agencies that it is difficult if not impossible to construct an appropriate, cost-effective, and flexible package of community-based services for many who need them.

3. Most public financing of long-term care is channeled through welfare programs. Families provide basic long-term care services until the disabled require skilled health care or until they have used up all their resources to purchase care and become eligible for medicaid.

Innumerable options can be developed in the long-term care area. While none can specifically address the question of proper placement in the absence of agreed upon criteria, some may reduce incentives to institutionalize inappropriately and to provide coverage for persons receiving no care. At the same time, since family and community care arrangements are appropriate for most of the disabled most of the time, the options might attempt to minimize the extent to which government-provided care would be substituted for private care. It should be noted, however, that no set of financial incentives will necessarily change the patterns of behavior, social values, or preferences surrounding the care of the aged and disabled.

The three general types of options addressed here reflect different policy approaches, with different budget impacts. No one option is intended to describe a specific legislative proposal, although several bills introduced in the last Congress would fall into one option category or another. The general approaches are:

- o Modification of existing programs - to revise certain legal or regulatory provisions that restrict the supply of noninstitutional services under the current system.

- o Long-term care insurance - to create a long-term care entitlement that would eliminate financial need as a basis for eligibility and replace much private spending with federal spending.

- o Comprehensive long-term care grant - to funnel all long-term care funds determined by appropriation through a single agency that would be responsible for giving appropriate services to individuals who need it.

The estimated effect of each option on three policy criteria will be considered:

Supply and distribution of services. What portion of the population would be covered; will new services be generated?

Management and organization of services. Would misplacement be reduced; would appropriate packages of services be provided? Is there an incentive for innovation and cost-effectiveness?

Financial responsibilities: federal, state, and private. What would be the federal and state cost; to what degree would publicly-provided formal care substitute for appropriate informal family care?

The alternatives are necessarily expressed in terms of general aims and policies. Since an operating program is the net result of its authorizing legislation and the accompanying regulations and administrative decisions that apply the precepts to specific situations, program costs may not be estimated with great confidence. Therefore, estimates are given in terms of ranges within which the cost of a program fulfilling the expressed aims might lie. Detailed program specifications and procedures used to estimate costs are contained in Long-Term Care: Actuarial Cost Estimates, a CBO technical background paper.

OPTION A. MODIFICATION OF EXISTING PROGRAMS

Medicare

The medicare modification would liberalize coverage of home health services while retaining the link to treatment of an injury or an acute illness. The liberalization might be accomplished by eliminating the requirement that patients be homebound and expanding the definition of skilled services to include nutritionist services and occupational therapy. Homemaker services under the supervision of a nurse could also be permitted after skilled services were no longer necessary.

In order to increase the supply of home health services as well as benefits, home health agencies offering only skilled nursing might be permitted to receive reimbursement under medicare if there were insufficient numbers of other skilled personnel in the area. The licensing requirement for proprietary agencies could also be dropped if a faster increase in the supply of services were desired.

Medicaid

Medicaid could similarly be altered by requiring that all states provide at least the acute home health services covered under medicare--including those in Option A. Moreover, the mandatory services could be expanded to include basic social services and others required to maintain a sick or incapacitated person at home if that were more economical than institutionalization.

Option A is one way to expand home care, correcting some of the deficiencies in the present programs. Nevertheless, while expanding noninstitutional services for those generally eligible for medicare and medicaid, the modifications would in no way expand the overall number of people covered under these programs. This is especially significant in the medicaid program, in which eligibility is determined by the states. For example, states have the option of limiting the medicaid coverage of SSI recipients by requiring that they meet any more restrictive eligibility standard that was in effect in the state on January 1, 1972, prior to the implementation of the SSI program. Fifteen states currently apply a more restrictive standard, and many aged, blind, and disabled SSI recipients in those states may be ineligible for medicaid and would therefore not benefit from liberalization of medicaid services.

The degree to which an increase in the supply of home-based services would be generated would depend greatly upon the financial attractiveness of home care to potential providers. While there is no evidence that proprietary agencies provide poorer quality services than voluntary agencies, some observers believe that these agencies would maintain a profitable operation by selecting the patients who are least sick and thus require fewer resources. Quality control would be quite important but quality of home care is more difficult to monitor than nursing home care because its delivery is as dispersed as the population receiving it.

Another factor affecting a potential increase in supply of services is the willingness and ability of the states to absorb the costs associated with a mandatory set of benefits. In the absence of any financial relief, the states would possibly offset the increased costs of home care by further limiting medicaid eligibility. One way to avoid this would be for the federal government to absorb the additional state costs by devising a different matching formula for the home care portion of medicaid.

Similarly, there is an alternative to financing the medicare services discussed. Under the present scheme, Part A benefits are paid by a payroll tax and Part B benefits are paid from general tax revenues and monthly premiums. Home health care under Part A must be preceeded by hospitalization; benefits under Part B are accompanied by deductible

and copayment requirements. An alternative is to combine Part A and Part B home health services into a new Part C, which would have no hospitalization requirement and no deductible, but would require a uniform $2 per visit co-payment for all covered services. All persons covered for Part A would also be covered for Part C.

Under present financing, increases would be funded primarily from general revenues because Option A changes affect Part B benefits. Under the alternative, a payroll tax increase would probably be required.

The costs of Option A under the present financing arrangements are presented in Table 10. The additional federal cost would be $0.8 to $1.5 billion in 1980. If the federal government were to absorb all the costs, the increment would be $0.9 to $1.6 billion in 1980, $1.8 to $3.9 billion in 1982, and $3.2 to $11.1 billion in 1985.

Table 10. COST OF OPTION A, by Fiscal Years, in Billions of Dollars

Total Program Cost	Present Financing System		
	Medicare	Medicaid	Total
1980 a/	1.3 - 2.2	0.4 - 0.6	1.6 - 2.8
1982	2.2 - 4.6	0.6 - 1.2	2.8 - 5.8
1985	3.7 - 11.7	1.0 - 3.1	4.7 - 14.8
Incremental Federal Cost	**Medicare**	**Medicaid**	**Total**
1980 a/	0.7 - 1.4	0.1	0.8 - 1.5
1982	1.5 - 3.4	0.1 - 0.3	1.6 - 3.7
1985	2.7 - 9.6	0.3 - 0.8	3.0 - 10.4

a/ Fiscal year 1979 is the first year of the program.

OPTION B. LONG-TERM CARE INSURANCE

Option B would include the medicare changes in Option A and would attempt to provide universal coverage for nonpsychiatric long-term care through an entitlement program for all aged and disabled. Services would be provided to help maintain the disabled in an independent setting or to prevent the need for a higher level of institutional care. The services could include:

- skilled nursing and intermediate care facilities;
- personal care homes;
- congregate housing;
- foster care;
- home health care (all services designed in Option A);
- home care (homemaker, personal care, social, and nutrition services); and
- adult day care.

Determinations of eligibility would be made through community long-term care centers (as described in Option C). All persons found to need care would have to be served at the lowest level on the basis of medical condition, taking into account the capacity of other family members or persons residing with the patient to provide personal care and basic services or financial assistance.

Such a social insurance program would be financed principally by the federal government, although the states could pay some portion of program costs. In order to preserve the family as the principal source of basic services and to provide incentives for economical use of services, a system of copayments might be devised. The copayments --especially for home-based services--could be set high enough so that the free services of families and friends would be an attractive option. However, to minimize the exclusion of low-income disabled, all individuals who fall below minimum income levels and who have been certified to need noninstitutional services could receive supplementary cash benefits to assist them in meeting the copayment requirements.

An option such as this would provide entitlement to a full range of long-term care services for the highest-risk population groups--the aged and the disabled. Because it would be a national program with uniform eligibility standards, the variation in services and eligibility under the medicaid program would be minimized. The quality of institutional care would also potentially increase since nursing homes now funded by medicaid would be reimbursed at higher levels. Moreover, the administration of benefits through local long term care centers would centralize funding of services and permit the packaging of services fitted to individual requirements. Judgments of appropriate services would be made locally, where knowledge of the individual's social and financial, as well as health, condition is more likely. These judgments would still be hampered by a lack of agreed upon criteria for placement, however, so services provided from one area to another would still be conditioned by often subjective perceptions of need.

The ultimate cost of Option B would depend on the definition of need and the judgments made in the certification process. Potential demand for services would become actual demand depending on subjective perceptions of what is desirable as opposed to what is undesirable. The elimination of the welfare aspect of long-term care services may make the services more attractive to those who are offended by the idea of "going on welfare" to receive care. On the other hand, a change in financial incentives will not necessarily change family or social values, or encourage the elderly to give up their homes or buy personal services from strangers.

Actual program costs would be a function of the rate at which demand materialized and was satisfied, and this in turn depends upon the rate of increase in the supply of services. Availability of services would be a limiting factor and, in the early years of operation, would be the principle constraint on program costs. Demand for services under an entitlement program is potentially very large because the estimated need is great.

Table 11 shows the estimated cost of Option B compared to the cost if all those eligible for services demanded them and if the supply were adequate to satisfy that demand.

Table 11. ESTIMATED COST OF OPTION B COMPARED TO COST IF SUPPLY WERE NOT LIMITED, by Fiscal Years, in Billions of Dollars

	1980	1982	1985
Option B Total Program Cost: a/			
If Unlimited Supply and 100% Participation	32-47	42-60	60-87
Under Probable Supply b/	20-23	29-36	47-73
Federal Spending under Existing Programs	7-8	9-10	15-17
Incremental Federal Costs b/	11-14	17-23	28-50

a/ Fiscal year 1979 first year of program.

b/ Low estimate based on low estimate of demand and slower rate of growth in supply. High estimate based on high estimate of demand and faster rate of growth in supply.

The estimated cost of Option B would be $20 to $23 billion in 1980 and $47 to $73 billion in 1985, assuming that 1979 was the first year of operation. If the national supply of services were adequate and if all eligible persons were to participate immediately, the costs would be $32 to $47 billion in 1980, and $60 to $87 billion in 1985. As illustrated in Table 12, the principal element of total government cost is institutional care. The level of institutional care is not, however, substantially different from that under existing programs.

Table 12. DISTRIBUTION OF TOTAL OPTION B COST AMONG SERVICES, by Fiscal Years, in Billions of Dollars

Service	1980	1982	1985
Institutional Care	17.6	24.5	36.9
Sheltered Living and Congregate Housing	0.2-1.8	0.4-3.4	1.7-7.1
Home-based Services	1.7-3.1	3.1-7.4	7.6-27.1
Administration	0.5-0.6	0.7-0.9	1.1-1.8
Total	20.0 - 23.0	29.0 - 36.0	47.0 - 73.0

Because the long-term care insurance program would replace medicaid long-term care expenditures and some medicare and VA spending, the incremental federal cost of Option B would be somewhat less than the estimated total program cost. It would cost an additional $11 to $14 billion in 1980 and $28 to $50 billion in 1985. As shown in Table 13, institutional care is also the major component of incremental federal spending because the federal government would absorb most of state medicaid expenditures. How-

ever, no additional institutional services would be generated as a result of Option B. Additional federal spending for congregate housing and home-based care would be associated with a substantial increase in these services.

Table 13. DISTRIBUTION OF INCREMENTAL FEDERAL COST OF OPTION B AMONG SERVICES, by Fiscal Years, in Billions of Dollars

Service	1980	1982	1985
Institutional Care	9.6	13.7	20.2
Sheltered Living and Congregate Housing	0.1-1.7	0.3-3.1	1.5-6.4
Home-based Services	1.0-1.9	2.1-5.5	5.9-22.5
Administration	0.3	0.4-0.6	0.7-1.2
Total	11.0 - 14.0	17.0 - 23.0	28.0 - 50.0

Estimates of the potential number of people needing services compared to the persons served under Option B are shown in Table 14. The differences between the number of people served and need during the period 1980 to 1985 are due both to anticipated lags in the supply of congregate housing and home-based services and to lags in participation in the program.

Table 14. AVERAGE NUMBER OF PEOPLE SERVED UNDER OPTION B COMPARED TO NEED AND BASE PROGRAMS, by Fiscal Years, Adults in Millions

	Nursing Homes	Personal Care Homes and Sheltered Living Arrangements	Home-based Services
Existing Programs:			
1975-1976	1.3	0.3 - 0.8	0.2 - 0.4
1980	1.7	0.4 - 1.0	0.4 - 0.5
1985	2.5	0.5 - 1.3	0.6 - 0.9
Estimated Need:			
1975-1976	1.3	1.5 - 1.9	3.0 - 4.4 c/
1980	1.7	1.6 - 2.1	3.3 - 4.8 c/
1985	2.0	1.8 - 2.4	3.5 - 5.2 c/
Option B a/ b/			
1980	1.7	0.4 - 1.1	0.5 - 0.7
1985	2.0	1.0 - 2.2	1.6 - 3.6

a/ Fiscal year 1979 first year of program.

b/ Low estimate based on low demand and slower rate of growth in supply. High estimate based on high estimate of demand and faster rate of growth in supply.

c/ Includes residents of congregate housing who require home health services.

OPTION C. COMPREHENSIVE LONG-TERM CARE GRANT

Because the entitlement program under Option B is expensive, Option C is offered as a possible way of unifying long-term care funds but controlling growth through appropriations.

Option C would include the Option A changes in medicare but would combine medicaid long-term care funds and funds for Title XX social services to the aged and disabled in a comprehensive long-term care grant. Under the grant, each state would be eligible to receive a share of federal funds, based on the number of aged and disabled persons in the state, their income distribution relative to the local cost of living and local cost of long-term care services, and current federal funds received for long-term care. The states would have to match the federal grant so that the average cost-sharing would be 60 percent federal and 40 percent state--a somewhat higher federal share than under medicaid. No state would receive a grant lower than it currently receives for medicaid and Title XX long-term care services adjusted for inflation.

As a condition of receiving grants, states would have to establish community long-term care centers which would be the sole channel of federal long-term care funds. These independent semi-public agencies would be responsible for cataloging available resources in their geographic areas, identifying the aged and disabled population and assessing their needs, certifying providers, authorizing levels of care for individuals, and monitoring the quality of services delivered. The local centers would be allocated funds by the states on the basis of state-approved plans for cost-effective treatment of persons in need of service. Minimum eligibility for services could be set by the federal government at those individuals now covered under present state programs. Services provided could be, at a minimum, those under Option A.

The program would be phased in over three years to give the states with varying degrees of long-term care experience time to establish the local centers and upgrade their services. A special supplemental fund might be created by the federal government to finance development of resources.

Like Option B, Option C would provide an administrative focus for long-term care services at the local level. It would also eliminate the divisions between health and social services that are necessitated by current financing arrangements and establish a uniform set of services to be covered. It would not, however, be an entitlement program and the

number of people served could be limited by appropriations. A fixed budget and state monitoring of treatment plans should induce the centers to assess carefully individual care requirements and to authorize the lowest-cost care consistent with quality. On the other hand, if federal funds were not adequate and states did not provide supplemental funds, many people needing services would not be able to get them through public programs, although more would be untreated under present law.

While not as extensive a proposal as Option B, Option C offers certain administrative advantages. A social insurance program (Option B) will, over time, accumulate a detailed set of uniform service criteria and detailed regulations to be applied nationally. Long-term care centers could become simply extensions of the federal bureaucracy, with functions analogous to that of insurance carriers under medicare. The existing pattern of care--the professionals, institutions, organizations, and administrative agencies--vary greatly across the country and even within the same city or county. It will be difficult to capture these variations with a detailed set of national regulations. Moreover, the level of understanding of what types of programs, organizations, and services will be most effective and efficient is very limited. The diversity of approaches to long-term care permitted under Option C might provide the data to show which approaches are most desirable.

Because there is very little organized long-term care at present, a comprehensive, organized system of long-term care services will be a fundamental change. Flexibility in this development is essential in order to learn from mistakes and to adapt to the problems brought about by change. This flexibility is much easier to obtain in local programs, in which the ease of communication necessary to study problems and initiate changes is greater.

A wide variety of programs are possible within Option C, depending on the extent of the increase in available federal funds. As a practical matter, the program would have to cost at least as much as the sum of (1) present federal appropriations for long-term medical and social services, (2) the additional cost of Option A, and (3) the special appropriation for resource development, including the cost

of setting up long-term care centers in all states. Therefore, the minimum additional federal cost of Option C would be $1 to $2 billion in 1980, $2 to $4 billion in 1982, and $3 to $12 billion in 1985. At the other extreme, the cost could run as high as that of Option B because the need for services is so great that there would be substantial pressure to increase appropriation levels.

APPENDIXES

APPENDIX A: DEFINITION OF TERMS

1. Domiciliary Care Facility (DCF): a nonmedical residential institution providing room, board, laundry, some form of personal care, and, in some cases, recreational and social services. Most commonly licensed by state departments of social services, these facilities usually are not allowed to provide medical care as part of the direct services of the institution. They are not eligible for reimbursement through either medicaid or medicare, but in several states they do receive public funds through special state supplements to the Supplemental Security Income (SSI) program.

2. Home Health Agency: an agency that provides home health care. To be certified under medicare an agency must provide skilled nursing services and at least one additional therapeutic service (physical, speech or occupational therapy, medical social services, or home health aide services) in the home. Under medicare, home health services must be provided by a certified home health agency. Under medicaid, states may, but do not have to, restrict coverage to services rendered by certified home health agencies.

3. Home Health Aide Services: same as personal care services; they may be provided by an aide under the supervision of a professional nurse, or a physical, speech, or occupational therapist. In addition, they may include homemaking services such as shopping, meal preparation, some light housekeeping.

4. Home Health Care: health services rendered to an individual as needed in the home. Such services are provided to aged, disabled, or sick or convalescent individuals who do not need institutional care. The services may be provided by a visiting nurse association (VNA), home health agency, hospital, or other organized community group. Services may include nursing services, speech, physical, occupational and rehabilitation therapy, homemaker services, and social services.

5. Homemaker Services: Environmental services such as cooking, shopping for food, housekeeping, home management tasks.

6. Intermediate Care Facility (ICF): an institution recognized under the medical program which is licensed under state law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care or treatment that a hospital or skilled nursing facility is designed to provide, but who because of their mental or physical condition require care and services (above the level of room and board) that can be made available to them only through institutional facilities. The distribution between "health-related care and services" and "room and board" has often proven difficult to make, but is important because ICFs are subject to quite different regulation and coverage than institutions that do not provide health-related care and services.

7. Medical Social Services: physician-directed services provided by social workers in order to deal with health-related social and emotional problems.

8. Occupational Therapy Services: medically directed treatment of physically and/or mentally disabled individuals by means of constructive activities designed and adapted by a professionally qualified therapist to promote the restoration of useful function.

9. Personal Care Services: bathing, toileting, feeding; assistance with ambulation; assistance with prescribed exercises and medication; physical supervision, as of elderly persons whose movements are unsure; teaching and emotional support tasks such as showing a newly blinded person how to handle daily living tasks; showing a mother ways to cope with a disabled child. These services may be provided by a home health aide.

10. Physical Therapy Services: the use of physical agents, biomechanical and neurophysiological principles, and assistive devices in relieving pain, restoring maximum function, and preventing disability following disease, injury, or loss of a part of the body.

11. Skilled Nursing Services: nursing services that must be furnished by or under the direct supervision of a licensed nurse; e.g., administration of prescribed medications that cannot be self-administered, the changing of indwelling catheters, the application of dressings involving prescription medications and aseptic techniques, and, in certain cases, skilled nursing observation and evaluation.

12. Skilled Nursing Facility (SNF): under medicare and medicaid, an institution (or a distinct part of an institution) that has in effect a transfer agreement with one or more participating hospitals and that: (1) is primarily engaged in providing skilled nursing care and related services for patients who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled or sick persons; (2) has formal policies developed with the advice of a group of professional personnel including one or more physicians and one or more registered nurses, to govern the skilled nursing care and related medical or other services it provides; (3) has a physician, a registered professional nurse, or a medical staff responsible for the execution of such policies; (4) has a requirement that the health care of every patient be under the supervision of a physician, and provides for having a physician available to furnish necessary medical care in case of an emergency; (5) maintains medical records on all patients; (6) provides 24-hour nursing service and has at least one registered professional nurse employed full time. Effective October 30, 1972, the 1972 Amendments permit the Secretary of HEW, to the extent that this provision may be deemed to require that any skilled nursing facility engage the services of a registered professional nurse for more than 40 hours a week, to waive the requirement if he finds that certain conditions are met; (7) provides appropriate methods and procedures for the dispensing and administering of drugs and biologicals; (8) has in effect a utilization review plan that meets the requirements of the law; (9) in the case of an institution in any state in which state or applicable local law provides for the licensing of institutions of this nature, is licensed pursuant to such law, or is approved by the agency of the state or locality responsible for licensing institutions of this nature as meeting the standards established for such licensing; (10) has in effect an overall plan and budget, including an annual operating budget and a three-year

capital expenditures plan; (11) effective July 1, 1973, supplies full and complete information to the Secretary as to the identity of each person having (directly or indirectly) an ownership interest of 10 percent or more in the facility; in the case of a skilled nursing facility organized as a corporation, of each officer and director of the corporation; and in the case of a skilled nursing facility organized as a partnership, of each partner; and promptly reports any changes that would affect the current accuracy of the information so required to be supplied; (12) effective July 1, 1973, cooperates in an effective program that provides for a regular program of independent medical review of the patients in the facility to the extent required by the programs in which the facility participates (including medical evaluation of each patient's need for skilled nursing facility care); (13) effective July 1, 1973, meets such provisions of the Life Safety Code as are applicable to nursing homes; except that the Secretary may waive, for such periods as he deems appropriate, specific provisions of the Code that if rigidly applied would result in unreasonable hardship for a nursing home, but only if such waiver will not adversely affect the health and safety of the patients (except, the provisions of the Code will not apply in any state if the Secretary finds that in the state there is in effect a fire and safety code imposed by state law that adequately protects patients in nursing facilities); and (14) meets any other conditions relating to the health and safety of individuals who are furnished services in such institution or relating to the physical facilities thereof as the Secretary may find necessary. Effective October 30, 1972, the Secretary is prohibited from requiring, as a condition of participation, that a skilled nursing facility furnish medical social services to its patients. However, when these services are provided, it is expected that they conform to recognized standards (see Section 1861 of the Social Security Act).

13. Speech Therapy Services: treatment of defects and diseases of the voice, of speech, and of spoken and written languages.

SOURCE: A Discursive Dictionary of Health Care, Subcommittee on Health and the Environment, Committee on Interstate and Foreign Commerce, U.S. House of Representatives, February 1976.

APPENDIX B

Table B-1. SUMMARY OF STUDIES OF INAPPROPRIATE UTILIZATION OF NURSING HOMES

Study	Percent of Patients Inappropriately Placed a/
Gainsborough County, Florida 1970 (Bell b/)	20-30
Durham, North Carolina (Burton, et al. c/)	6
Minnesota, 1973-74 (Miller et al. d/)	8 (SNF)
Minnesota, 1974 (Greenberg e/)	18 (SNF)
Massachusetts, 1969 (Massachusetts Department of Public Health f/)	40-63
Massachusetts, 1974 (Beattie & Jordan g/)	26 (SNF)
New York City, 1975 (Gentry and Curlin h/)	65-76 (SNF)
Western New York State, 1967-69 (Davis and Gibbin i/)	27
Rochester, New York, 1964 (Berg, et al. j/)	48 SNF 21 ICF
Rochester, New York, 1969-70 (Monroe County Health Council k/)	48 SNF 74 ICF

Table B-1 (continued)

Study	Percent of Patients Inappropriately Placed a/
Rochester, New York, 1973 (Zimmer l/)	13 SNF 17 ICF
Rochester, New York, 1974-74 (Monroe County Health Council m/)	10 SNF 35 ICF
National, 1973-74 (National Center for Health Statistics n/)	18-22 (Independent on feeding, continence, dressing, movement, and bathing)
National, 1974 (Office of Long Term Care, HEW o/)	7-13 (7% do not need help in bathing; 13% are fully ambulatory and able to walk outdoors at will)

a/ Percentages refer to generic category of "nursing home" unless otherwise specifically indicated. SNF refers to Skilled Nursing Facility, ICF to Intermediate Care Facility.

b/ William G. Bell, Community Care for the Elderly: An Alternative to Institutionalization, Florida Department of Health and Rehabilitation Services, June 1971, cited in Burton D. Dunlop, Long-Term Care: Need versus Utilization, Working Paper 0975-05, Urban Institute, May 22, 1974, revised April 15, 1975.

c/ Richard M. Burton, William W. Damon, David C. Dellinger, Douglas J. Erickson and David W. Peterson, "Nursing Home Cost and Care: An Investigation of Alternatives," Durham, North Carolina, Center for the Study of Aging and Human Development, Duke University Medical Center, mimeo, July 8, 1974.

Table B-1 (continued)

d/ Winston R. Miller, Sandra J. Hurley, and Elaine Wharton, "External Peer Review of Skilled Nursing Care in Minnesota," American Journal of Public Health, 66:278-83, 1976.

e/ Jay Greenberg, "The Costs of In-Home Services," in Nancy Anderson, A Planning Study of Services to Non-institutionalized Older Persons in Minnesota, Governor's Council on Aging, State of Minnesota, Minneapolis, Minnesota, 1974. Patients believed to be potential candidates for home care.

f/ Massachusetts Department of Public Health studies cited in Robert Morris, Alternatives to Nursing Home Care: A Proposal, prepared for use by the Special Committee on Aging, United States Senate, Washington, D.C., U.S. Government Printing Office, October 1971.

g/ Robert T. Beattie and Harmon S. Jordan, "A Preliminary Analysis of a Survey of Massachusetts Hospital Patients Who Were Ready for Discharge and Awaiting Placement in Other Facilities," Massachusetts' Department of Health, mimeo, April 11, 1975.

h/ John T. Gentry and Victor R. Curlin, "The Illinois Long Term Care Classification Instrument: Use Experience Within the New York City Medicaid Program," Medical Section, Bureau of Health Care Services, New York City Department of Health, May 8, 1975. Nonrandom sample of five SNFs.

i/ John W. Davis and Marilyn J. Gibbin, "An Areawide Examination of Nursing Home Use, Misuse and Nonuse," American Journal of Public Health, 61:1146-1155, 1971.

j/ Robert L. Berg, Francis E. Browning, John G. Hill, and Walter Wenkert, "Assessing the Health Care Needs of the Aged," Health Services Research, 5:36-59, 1970.

Table B-1 (continued)

k/ Monroe County Health Council, Survey of the Need for Inpatient Beds in Monroe County, 1969-1970, Rochester, New York, 1970, cited in T. Franklin Williams et al. "Appropriate Placement of the Chronically Ill and Aged," Journal of the American Medical Association, December 10, 1973.

l/ James G. Zimmer, "Characteristics of Patients and Care Provided in Health-Related and Skilled Nursing Facilities," Medical Care, 13:992-1010, 1975.

m/ Monroe County Health Council, Survey of the Need for Inpatient Beds in Monroe County, 1974-1975, Rochester, New York, 1975.

n/ National Center for Health Statistics 1973-74 National Nursing Home Survey data analyzed in: Applied Management Sciences, "Analysis of Incentive Reimbursement System for Health Care and Long Term Care Services Provided to the Elderly and Long Term Disabled: Development and Validation of a Patient Assessment Index," Interim Report No. 3, Contract No. HEW-100-76,0029, Silver Spring, Maryland, January 15, 1976.

o/ Office of Long Term Care, Long-Term Care Facility Improvements Study: Introductory Report, U.S. Department of Health, Education, and Welfare, Public Health Service, HEW Publication No. (OS) 76-50021, Rockville, Maryland, July 1975.

APPENDIX C

COST-EFFECTIVENESS OF HOME-BASED CARE

The claim is often made that an expanded home care program would be less costly than the current organization of long-term care because it would substantially reduce the use of nursing home care by substituting home care, which has a lower cost per day. Evaluating the proposition that expanded home care would reduce the use of nursing homes raises substantial methodological difficulties and adequate research does not exist to produce a definitive answer. Unfortunately, the most widely cited studies in this area are of home care as an alternative to hospitalization rather than to nursing home care. This makes this usefulness very limited.

A few localized studies suggest that home care can prevent institutionalization. Using the number of home health starts per 1,000 medicare beneficiaries as his measure, Dunlop, in a multiordinate analysis of 1970 nursing home utilization, found that increases in home health care were associated with decreases in the utilization of nursing care homes and related facilities. 1/ In a study of 245 patients in a New York City program for the homebound aged, Brickner and others reported that after 24 months, 23 patients improved to the extent that they were no longer homebound, 116 remained stabilized under the program's continuing care, and 40 patients were in institutions, either a hospital or nursing home. Relying solely on clinical judgment, the authors estimate that 85 of the patients would have required institutional care and 25 of

1/ Burton Dunlop, Determinants of Long Term Care Facility Utilization by the Elderly: An Empirical Analysis, Working Paper 963-35, Washington, D.C., The Urban Institute, revised March 1, 1976.

the patients would have died without the program. 2/ A one-year study by the Benjamin Rose Institute in Cleveland of 50 elderly patients receiving home health aide service after hospitalization indicates that the service group had significantly fewer days in and admissions to long-term institutions. 3/ They also appeared to be significantly more contented. Finally, Bryant and others reported on a small study of home care provided to stroke victims who had been discharged from the hospital. This ex post facto study contrasted data from the group that had received home care and a mixed group who received either physical therapy only, or no after care. 4/ After a nine-month follow up, two home care and nine control patients were in nursing homes; 22 home care and eight control patients were living at home. However, close examination of the study indicates that the experimental and control groups were probably not well matched according to severity of illness.

2/ Philip W. Brickner, James F. Maneski, Gloria Rich, Sister Teresita Duque, Laura Starita, Richard LaRocco, Thomas Flannery, and Steven Werlin, "Home Maintenance for the Home-Bound Aged: A Pilot Program in New York City," The Gerontologist, Part I, 16:25-29, 1976.

3/ Margaret Neilson, M. Blenkner, M. Bloom, T. Downs, and H. Beggs, "A Controlled Study of Home Health Aid Services," American Journal of Public Health, 62:1094-1101, 1972. Cited in Critical Evaluation of Reported Research Involving Alternatives to Institutionalization and Cost/Efficiency-Effectiveness, Evaluation of Personal Care Organizations and Other In-Home Alternatives to Nursing Home Care for the Elderly and Long Term Disabled, American Management Sciences, Contract No. HEW-OS-74-294, Silver Spring, Maryland, April 30, 1975.

4/ N.H. Bryant, L. Candland, and R. Loewenstein, "Comparison of Care and Cost Outcomes for Stroke Patients, With and Without Home Care," Stroke, 5:54-59, 1974.

Few studies are available to support the proposition that home care is less costly than nursing home care. Again, the most widely cited home care studies concerning cost savings are of short-term acutely ill patients. Conceptually, any chronically disabled person can be maintained at home if enough resources are expended. Further, it appears reasonable to assume that the cost of services is related to the level of the patient's disability. If this is the case, the problem is to establish some break-even point at which economies of scale in nursing homes make it more expensive to maintain a person at home than in an institution. Brickner and others in their study of a program for the homebound in New York City claim considerable cost savings, but their claims are based solely on physician estimates of "probable" institutionalization. In addition, they estimate only one-year savings, but not the counterbalancing costs of several years of possible home care maintenance.

In a study in Durham, North Carolina, Burton and others estimated that for approximately 87 percent of the patients in nursing homes the only suitable alternatives were economically infeasible, costing approximately four times the cost of nursing homes. For the other 13 percent, alternatives outside the nursing home were possible, but there would be no great reduction in costs. 5/

In what remains by far the most sophisticated cost study in the field, Greenberg disaggregated a Minnesota target population into four disability levels and two living arrangements (living alone and living with others) on the assumption that home care costs would vary on these

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5/ Richard M. Burton, William W. Damon, David D. Dellinger, Douglas Erickson, and David W. Peterson, "Nursing Home Cost and Care: An Investigation of Alternatives," Durham, North Carolina, Center for the Study of Aging and Human Development, Duke University Medical Center, mimeo, July 8, 1974.

dimensions. 6/ Costs were measured in terms of total costs and included room and board. Only for the worst disability level (an individual whose medical condition is stable or changing in a predictable way, for example, declining or terminal; who is moderately confused, and who needs complete help with personal care and/or at least one person to help with ambulation) was home care as expensive or more expensive than nursing home care. An individual living alone with a medically stable condition, having some difficulty in ambulation, and requiring moderate assistance with bathing, dressing or toileting would have home care costs equivalent to institutional care. All other levels of disability and living arrangements were cheaper under home care. Greenberg estimated that 9 percent of the 1974 Minnesota skilled nursing facility patient population could be cared for at home with cost savings.

Despite evidence of possible savings from deinstitutionalizing some present nursing home residents, the number of the noninstitutionalized disabled who are bedridden or need personal care assistance is so great that patients removed from nursing homes would be quickly replaced. Moreover, home health services, if not limited to those who had first been institutionalized, would be demanded and needed by so many of the noninstitutionalized disabled that there would be a net increase in expenditures.

6/ Jay Greenberg, "The Costs of In-Home Services," in the Governor's Citizens Council on Aging, A Planning Study of Services to Noninstitutionalized Older Persons in Minnesota, Minneapolis, Minnesota, 1974.

U. S. GOVERNMENT PRINTING OFFICE : 1977 O - 94-835