The Elderly and Functional Dependency: A Policy Statement (1977)

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INSTITUTE OF MEDICINE

A POLICY STATEMENT

THE ELDERLY AND FUNCTIONAL DEPENDENCY

June 1977

National Academy of Sciences
Washington, D.C.

INSTITUTE OF MEDICINE

A POLICY STATEMENT

THE ELDERLY AND FUNCTIONAL DEPENDENCY

Final Report

June 1977

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NOTICE

The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the Councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the Committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

The Institute of Medicine was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of appropriate professions in the examination of policy matters pertaining to the health of the public. In this, the Institute acts under both the Academy's 1863 Congressional charter responsibility to be an adviser to the Federal Government, and its own initiative in identifying issues of medical care, research, and education.

2101 Constitution Avenue, N.W., Washington, D.C. 20418

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INSTITUTE OF MEDICINE
OFFICE OF THE PRESIDENT

Mr. Arthur S. Flemming
U. S. Commissioner on Aging
Administration on Aging
Department of Health, Education,
and Welfare
Washington, D.C. 20201

Dear Mr. Flemming:

I am pleased to present to the Administration on Aging a policy statement prepared by the Institute of Medicine, National Academy of Sciences, under grant number 90-A-777. That grant was initially awarded to support the conduct of an Anglo-American conference on care of the elderly. It was later modified to support, in addition, this policy analysis.

The conference brought together British and American experts in geriatrics and gerontology, providers of health care and social services, program administrators, public officials and representatives of the elderly population to discuss the problems associated with functional dependency among the elderly and methods for addressing these problems.

The purpose of the policy analysis was to assess the findings of the conference and to make recommendations for U.S. policy affecting the functionally dependent elderly. A summary of the conference was prepared as part of this policy analysis.

I shall be pleased to discuss this report in greater detail with you.

Sincerely,

David Hamburg

David A. Hamburg, M.D.
President
Institute of Medicine

NATIONAL ACADEMY OF SCIENCES
2101 CONSTITUTION AVENUE
WASHINGTON, D. C. 20418

INSTITUTE OF MEDICINE
OFFICE OF THE PRESIDENT

Robert N. Butler, M.D.
Director
National Institute on Aging
National Institutes of Health
Bethesda, Maryland 20014

Dear Dr. Butler:

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INSTITUTE OF MEDICINE

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PREFACE

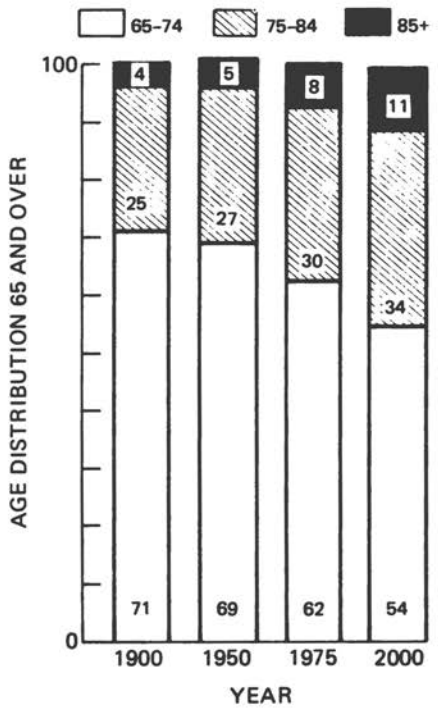
Functional dependency among the elderly is emerging as a critical challenge to our society. The functionally dependent elderly are those individuals over 65 whose illnesses, impairments, or social problems have become disabling, reducing their ability to carry out independently the customary activities of daily life.

The number of functionally dependent elderly persons in the United States has been estimated at between three and four million. [1] It is difficult to be precise in describing this segment of the population, largely because refined data on functional status are not currently available.

Although adult functional dependency does not entirely respect the boundaries of chronological age, it is most prevalent in those age 75 and over. This is important because the 75-and-over group is the fastest growing segment of the U.S. population. Since 1900, the proportion of persons 75 and over, within the entire elderly population over 65, has increased from 29 percent to 38 percent (see figure 1) and is expected to reach 45 percent of the elderly population by 2000. Even more dramatic has been the increase in the age 85-and-over population--from four percent in 1900, to eight percent today, to a projected 11 percent in 2000. [2]

In addition to being very old, the functionally dependent elderly are likely to have substantial limitations in physical performance, to be sick, to be socially isolated, to utilize health services at a higher rate than the rest of the population, and to have limited income and assets.

FIGURE 1
The Percentage of the Very Old Among the Elderly is Increasing*



Note* Figure rounded to nearest total percentage.

SOURCE: Bureau of Census, *Current Population Reports*, Series P. 23, No. 59, May 1976.

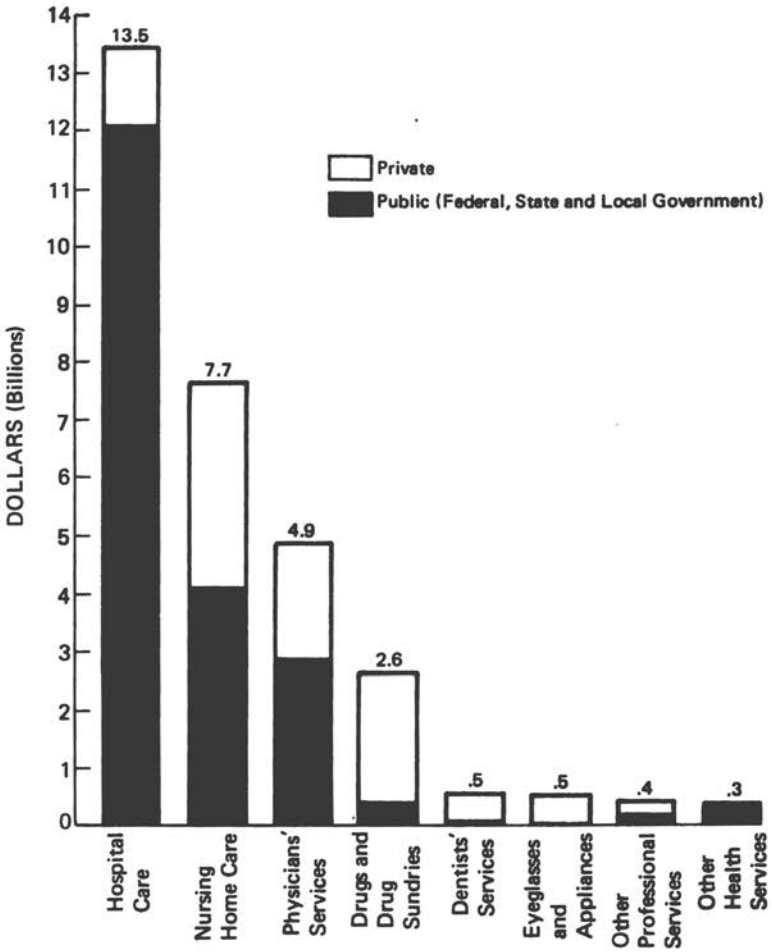
A recent study of physical performance in adults indicated that 42.4 percent of individuals 75 and over had substantial limitations in such activities as walking, climbing, and bending, whereas only 19.8 percent of those 65-74 were so encumbered. [3] Other factors likely to engender dependency--such as poor health and social isolation--also are statistically more likely to be a problem for those 75 and over. Compared with the 65 and over population as a whole, those 75 and over have a greater burden of chronic conditions or impairments. [4]

Marital and residential status are two indicators of degree of social isolation. Both widowhood and institutionalization are, not surprisingly, more frequent among the group age 75 and over. Approximately 42 percent of females 65-74 are widowed, whereas 69 percent of those 75 and over are widowed. Although males over 75 are much more likely to be widowed than those 65-74, elderly women are far more likely to be without a spouse than elderly men. [5] Residence in long-term care institutions increases from 2.1 percent in the 65-74 age group to 7.1 percent among persons 75-84, to 19.3 percent among those age 85 and over. [6] The nursing home population is composed primarily of very old people--83 percent are 75 and over and 43 percent are 85 and over. [7]

Elderly people use two to three times as many health services per person as those under 65. [8] Public funds are the largest single source of payment for health care provided to the elderly (see figure 2). [9] Expenditures on health care for the elderly were approximately $30 billion in 1975. [10] As the number of persons 75 and over increases, utilization and expenditures can be expected to increase as well.

Persons 75 and over have fewer personal and financial resources with which to meet the burdens of dependency than those age 65-74. They are more likely to have children who are themselves approaching old age. They are more likely to be living alone. [11] Since friends and relatives, including spouses, provide most support services to elderly individuals, the loss of that support has important implications for public policy. [12] In the absence of friends or family to provide supportive care, services must be obtained from

FIGURE 2
Expenditures for Health Care for the Elderly (1975)



SOURCE: Division of Health Insurance Studies, Office of Research and Statistics.

public and private agencies, frequently at great personal expense. However, the financial resources required to purchase necessary health and social services are often severely constrained for this segment of the population. The median income for families where the head of the household is 65 and over is about half that for families where the head of the household is 64 or under. [13] Those over 75 years of age have an even lower median income. [14]

There are valid economic as well as humanitarian reasons for public concern with the functionally dependent elderly. It is in the interest of society as well as the elderly individual to prevent the development of unnecessary dependency or minimize its impact once functional capacity has declined. Meeting the challenge of dependency requires a concentration of society's efforts on those who are at high risk of becoming dependent, such as the recently widowed, in addition to individuals who already are dependent on others for care. It was with these concerns in mind, and with the knowledge that both the United States and the United Kingdom are facing the challenge imposed by increasing functional dependency among the elderly, that the Institute of Medicine convened an Anglo-American Conference In May 1976 to discuss the nature and causes of the problem as well as possible responses. A summary of the 1976 conference is contained in the appendix to this report.

FUNCTIONAL DEPENDENCY AMONG THE ELDERLY: IDENTIFICATION OF POLICY INITIATIVES

The 1976 Anglo-American Conference on Care of the Elderly examined many issues related to the development, management, and possible prevention of functional dependency among the elderly. A number of conference participants subsequently expressed interest in specifying the implications of these issues for public policy. The Institute of Medicine responded by appointing the Committee on Care of the Elderly to review the conference papers, identify important areas of concern, and make recommendations for changes in United States policy affecting the functionally dependent elderly. Although the conference proceedings constitute the principal basis for the recommendations made in this report, other sources of information that became available since the Anglo-American Conference also were reviewed and considered.

The committee approached its task by selecting from among the issues raised at the conference those which could be most effectively addressed by a committee of the Institute of Medicine. The committee focused its efforts on a consideration of the psychosocial and health factors that appear to have a role in the development of functional dependency among the elderly.

The committee recognizes that adequate income, decent housing, and suitable transportation are essential to efforts that deal with functional dependency among the elderly. Those factors were not examined in detail at the Anglo-American Conference. Because they pertain to a far broader segment of the population than that of concern here, they are not discussed in this report.

In making its recommendations, the committee was guided by two basic principles that emerged from the Anglo-American Conference: 1) the care of the elderly should be directed toward maintenance of maximum possible functional and social independence; 2) health care and social services should be provided in a manner that preserves the dignity of the elderly individual and provides opportunities for personal choice.

The committee believes that the maintenance of functional independence is an important goal for public policies affecting the elderly. Several papers presented at the Anglo-American Conference challenged the popular notion that substantial and progressive decline in mental and physical function are an inevitable part of the aging process. [15] Although some decline is likely, many elderly individuals retain complete functional capacity until shortly before their death. For those individuals who are functionally disabled, the rate of decline may be substantially decreased or its extent minimized through early detection and appropriate assistance.

The promotion of independence requires vigorous application of preventive health measures, including education about nutrition and healthful behavior during early, middle, and later life. It also necessitates improving our ability to identify environmental, genetic and social risk factors in the development of functional dependency. Individuals at high risk due to such factors as compulsory retirement, widowhood, and social isolation must be provided with necessary supportive services.

Current policy emphasizes the provision of "skilled" institutional care. By institutional care the committee does not mean apartment buildings, or housing developments restricted to elderly individuals, or congregate living facilities, but rather institutions, including skilled nursing facilities, in which intensive services are delivered. Many individuals require and benefit from such intensive institutional care. However, the lack of alternative types of care can result in inappropriate utilization of high-intensity services. Gerontological studies have emphasized the role of unnecessary services in the development of dependency. [16] If individuals are divested of responsibility for performing certain daily tasks,

such as food preparation or personal hygiene, their abilities diminish rapidly in these and other areas of function. One speaker at the conference distinguished between the effects of providing appropriate and inappropriate services on functional independence. [17] Unnecessary services foster dependency, whereas services appropriate for individual needs promote independence. Care of the functionally dependent elderly should be organized so that a variety of services are available and that the level of intensity of those services can be varied as needed.

Preservation of personal dignity is a basic aim of our society. But all too often the provision of services to an elderly person is accompanied by a narrowing of individual choices normally available, or even by precluding the individual from making decisions about basic aspects of daily living such as place of residence or food preferences. The preservation of individual dignity requires that choices be available to the elderly person in arranging for appropriate care. Evidence strongly suggests that when choices are available, the elderly individual makes the most appropriate decision. [18]

Early gerontological research suggested that "disengagement" from life is a normal part of the aging process. [19] Most gerontologists now dispute that theory, and contend that disengagement is imposed on the elderly by such factors as physical immobility, poverty, and social isolation. [20] Policies that preclude the opportunity for choice among care options, or that fail to recognize the right of individuals to make decisions affecting the quality of their lives, are more likely to produce apathy, hasten disengagement, and accelerate dependency. In most cases, elderly individuals are capable of making necessary decisions regarding such major changes in their lives as being moved to an institution for needed care.

The committee decided that the Anglo-American Conference raised important questions in five areas to which policy initiatives could be directed. These areas are: 1) the provision of long-term care, 2) prevention of functional decline, 3) coordination and planning of services, 4) education, and 5) research. The committee presents its findings and recommendations for each of these areas in the sections that follow.

LONG-TERM CARE: RECOMMENDATIONS

The care of functionally dependent elderly persons requires a different orientation toward patient outcomes than prevails in care of acute illness or trauma. The health and social problems that afflict older individuals are predominantly chronic and cannot be "cured." [21] The care required for chronic conditions is long term. Long-term care is directed toward the management of loss of function with the dual objectives of regaining and maintaining the maximum ability to function and preventing or delaying additional decline.

Historically, federal health policy for the elderly has been directed toward meeting their acute care needs. Coverage for nursing home care under Medicare, for example, is limited to 100 days, contingent upon prior hospitalization of at least three days duration. Most people, however, remain in nursing homes for substantially longer periods of time. The National Nursing Home Survey of 1973-74 indicated that 61.3 percent of nursing home residents had been in the home for one year or more. [22] Home health care coverage under Part A and Part B of Medicare is limited to 200 visits. Such limitations reflect the fact that Medicare was created as an acute care program. The Medicaid program, on the other hand, covers long-term care services. However, Medicaid benefits are restricted to persons who are either eligible for one of the categorical welfare programs, poor enough to qualify as "medically indigent," or deplete their assets to the point at which they qualify as medically indigent. In the view of the committee, the elderly should not be forced to

deplete their assets in order to obtain access to long-term care because elderly persons are in no position to replace assets.

The committee believes that a fundamental change in federal policy for care of the elderly is required to better meet the needs of functionally dependent old people and their families. The committee therefore recommends that:

> The federal government should reimburse for long-term care provided to the functionally dependent elderly. Long-term care should include both health and social services and should provide for choices between institutional and home-based care. Eligibility for federal reimbursement of long-term care should be based on a comprehensive assessment process.

Although it would be premature to formulate and recommend a long-term care program for immediate adoption, the committee believes that its statement of a tentative plan might encourage public debate on the issue. The committee concurs that fundamental changes in policy for care of the elderly can be achieved only through federal financing. The enactment of the Medicare program established a precedent for a strong federal role in payment for care of the elderly. The committee's proposal would "round out" the role of the federal government by extending this involvement to long-term care. The committee believes that other demands on state financial resources are severe, constraints on revenue raising within states too restrictive, and needs of the elderly too universal to recommend state financing for such a program. A long-term care program could be financed either as part of a national health insurance plan, an extension of the Medicare program, a new program supported through general revenues, or by a combination of general revenues and voluntary premiums. It is the committee's view that states and localities should retain key roles in administering the provisions of the program.

The program should include four main elements: 1) an assessment procedure, both to determine initial eligibility and to monitor appropriateness of care over time; 2) long-term care institutions that provide a range of services varying in intensity, so that

transfers between institutions can be kept to a minimum; 3) a defined minimum of home-based support services such as home health care, adult day care, and homemaker services, in a community so that choices between institutions and non-institutional care are available; and 4) the provision of financial support to develop new services, particularly those oriented toward maintenance of elderly persons in their homes, in communities where services are insufficient to meet the needs identified in the assessment process. The committee feels that a long-term care program should become operative in a given community only when it can be demonstrated that an assessment procedure meeting standards of acceptability, a basic package of home-based support services such as home health care and adult day care, and adequate supply of approved long-term insitutional care all exist. The assessment process and the availability of home-based support services are essential factors in the committee's endorsement of a federally financed long-term care program.

In view of the uncertainties associated with the costs of a federally supported long-term care program for all persons 65 and over, the committee suggests that initially the program should be restricted to those persons 75 and over. Some committee members feel it is inappropriate to use age as the criterion for eligibility and would prefer that the assessment process be the sole determinant of program eligibility. However, the majority of the committee believes that until more is known about the extent of functional dependency among the elderly, some initial restrictions on eligibility are necessary. [23]

Long-term care includes a variety of health and social services. These services fall into three general categories: 1) basic--such as homemaker assistance, chore services, or social services, 2) health-related--such as nutrition and personal care, and 3) skilled health and medical--such as physician services, nursing, and rehabilitation therapies. The committee believes that the full range of long-term care services should be available to the functionally dependent elderly. Reimbursement should be provided for all such care whether delivered in an institution or as an adjunct to maintaining an individual within the community.

At present, reimbursement for long-term care favors services provided within skilled institutional settings, such as chronic disease hospitals and skilled nursing facilities, over home-based care or less intensive institutional care. The needs of functionally dependent elderly individuals, however, vary widely. Some individuals are in need of skilled institutional services, but others may require only the sheltered environment provided by congregate living facilities, health or social services provided within their place of residence, or adult day care. Deficiencies in reimbursement for these alternative services can prevent certain individuals from receiving them and can foster inappropriate utilization of those services for which reimbursement is available. [24]

Perhaps the greatest deficiency in current reimbursement for long-term care is for in-home services. Restrictions under Medicare and Medicaid have severely limited public expenditures for such services. In 1973, for example, reimbursement for in-home services accounted for less than one percent of combined Medicare and Medicaid expenditures. [25]

A fundamental source of home-based care is the family. It is a popular misconception that elderly individuals are abandoned by their families and institutionalized prematurely. Current evidence indicates that as much as 80 percent of the supportive care received by elderly individuals living in the community is provided by family members. [26] A decision to place an elderly relative in an institution is usually made only as a last resort, due to the exhaustion of family resources--financial, physical, and emotional. [27] Participation of family members and friends in the care of functionally dependent old persons could be encouraged through a variety of methods including tax credits or deductions, payments to those who do not file income tax returns, and short-term institutionalization of the elderly person in order to give respite to the family.

The committee recognizes that services designed to keep dependent elderly persons in their own homes can never totally supplant institutional services for all individuals. For a significant number of individuals, there is no choice but institutional care. These individuals

require total care--from feeding to round-the-clock monitoring--thus making services provided in the home or on a daily basis outside the home extremely expensive and highly impractical. For others, however, home-based services such as day care or home health care, may obviate or greatly postpone the need for institutional care.

Increased reimbursement of basic home-based services, such as home health care and adult day care, and homemaker services, is often urged for reasons of cost containment, the argument being that money is saved by substituting less intensive services for more expensive institutional care. The committee believes that the cost of home care on an individual basis could be less than comparable services provided in an institutional setting if appropriate controls on utilization are developed.

Although the committee members doubt that the provision of home or day care services can be justified solely on grounds of cost savings, [28] they believe that there is a humanistic value in maintaining individuals in their own homes. When that is feasible, and reflects the wishes of the individuals involved, it is the opinion of the committee that home care should be provided even in the absence of demonstrable cost savings. Concern about the costs of home care can be addressed by limiting reimbursement for all home-based services in a given case to the per diem cost of the appropriate level of institutional care as determined through an assessment of functional status.

A major problem in the expansion of government support of long-term care for the elderly is the limited supply of non-institutional providers. [29] This problem was an important concern of the committee because a federally sponsored long-term care program that fails to ensure the availability of noninstitutional providers could result in a disproportionate increase in the number of institutionalized elderly persons. As a means for addressing this problem, the committee recommends that as part of an overall program for long-term care:

> Federal financial support should be provided to develop long-term care services provided either in the home or as an adjunct to maintaining a dependent elderly individual within the community.

The provision of start-up support for non-institutional providers would address shortages in the supply of services such as home care or adult day care. The committee believes that such support is a necessary aspect of developing a long-term care program. In the long run, reimbursement for non-institutional services once established should maintain the necessary supply.

In addition to shortages in the supply of certain types of services, speakers at the Anglo-American Conference cited inappropriate utilization of services as a major problem in long-term care. [30] As indicated previously, appropriate utilization plays a critical role in the promotion of maximum possible independence. [31] The Congressional Budget Office report on Long-Term Care for the Elderly and Disabled points to the lack of adequate functional assessment methods as a major factor in inappropriate utilization. [32]

Functional assessment has been defined as "any systematic attempt to measure objectively the level at which a person is functioning, in any of a variety of areas such as physical health, quality of self-maintenance, quality of role activity, intellectual status, social activity, attitude toward the world and self, and emotional status." [33] Assessment of an individual's functional capacity and health status is important in the identification of individuals who are already functionally dependent as well as those who are at high risk of becoming dependent. It is an essential part of long-term care because it should assure that the services received are appropriate in type, frequency, and duration for individual needs.

The value of some form of assessment in long-term care is widely recognized. [34] Ideally, functional assessment should be a multidisciplinary process engaging physicians, nurses, and social workers. Financial constraints on a long-term care program and shortages of manpower in certain areas may preclude participation by all three types of personnel. However, the committee believes that a complete assessment should be based on several sources of information including nursing, social, psychological, and medical data. The committee is not prepared to designate a particular type of health or social service provider as most appropriate for conducting functional assessments. Until assessment

methods are more developed, the committee would prefer to encourage flexibility and testing of different types of personnel in this role.

An initial assessment should take into account individual and family preferences about living arrangements and should include counseling for the individual and family members. Periodic follow-up assessments also should be conducted. During an assessment, the elderly person should be given the option of identifying a relative, friend, or representative of a service agency who can serve as an advocate. The committee believes that an advocate could play an important role in assuring the quality and appropriateness of long-term care. The advocate should be encouraged to report changes in circumstance or lapse in care to the appropriate agencies or service providers.

The committee believes that a functional assessment can and should serve as the "gateway" to long-term care consisting of both health and social services. Once services are certified as necessary through an assessment process, financial considerations should not prevent functionally dependent elderly persons from receiving those services. It is the committee's view that an assessment process should replace an inventory of income and assets as the test of eligibility for services.

Much has been done to develop instruments and procedures to assess functional status, and several prototype processes now exist. [35] Nevertheless, the committee believes that questions remain regarding the scope and specificity of the instruments, appropriate times for assessment, and degree of training required for persons conducting the assessment. The potential contribution of an assessment process to the prevention of premature functional loss also is uncertain. Another concern of the committee is a potential conflict of interest if assessments are conducted by a long-term care provider. The committee therefore recommends that:

> Procedures and instruments for assessing the functional status of elderly persons should be refined. Questions regarding timing of assessments, training of assessment personnel, reliability and effectiveness of assessment, and the locus of

authority for the conduct of the assessment must be addressed in refining assessment procedures. Uniform minimum standards for the conduct of functional assessments which address such factors as the scope and frequency of assessment and qualifications of assessment personnel should be developed.

The quality of services provided to the elderly was an important concern of conference participants and committee members. Regulation of long-term institutional care is extensive. It includes state and local regulations for licensure as well as requirements for certification under federal programs. However, recent reports have indicated that there are serious deficiencies in the quality of long-term care, particularly nursing home care. [36]

The committee believes that the current regulatory process for long-term care is deficient in several respects. Although they recognize the need to ensure the safety of long-term care facilities, committee members feel that regulation of long-term care is disproportionately oriented to physical safety. [37] For many individuals, long-term care facilities are residences as well as treatment situations. Factors that contribute to the quality of life, such as social and recreational services, are not adequately addressed by the regulatory process.

To the extent that regulation addresses factors other than physical safety, it tends to concentrate almost exclusively on easily measurable aspects of facility operations or structure, such as licensure and qualifications of personnel, number of nurses per shift, and number of square feet per bed. [38] The committee questions the assumption that these factors ensure high quality performance by institutional providers.

In this report the committee concludes that a comprehensive set of long-term care services, including home-based care, is required to meet the needs of the dependent elderly. At present, attention to the quality of non-institutional services such as adult day care and home health care is minimal. [39] However, if reimbursement for non-institutional care is increased consistent with the committee's recommendation, methods to assure the quality of such

care and to prevent fraud and abuse must be developed. The multiplicity of home-based long-term care providers, as well as the spatial separation of the recipients of home-based care, pose serious problems for monitoring the quality of care and for minimizing provider fraud.

With these problems in mind the committee recommends that:

> Standards governing factors such as patient comfort, physical safety, social and recreational services, and medical and nursing care should be designed to accommodate the inclusion of a broad set of providers. Standards should focus to the extent possible, on actual provider performance. Consideration should be given to the development of "targeted" utilization review and quality assurance techniques for monitoring home-based care.

Under targeted utilization review and quality assurance, periodic examination of a small sample of cases would be substituted for continuous case-by-case review. It is a more practical approach where there are large numbers of providers and where recipients of care are geographically dispersed. Although the committee did not develop a detailed quality assurance program for home-based care this is a worthwhile task for other groups to pursue.

PREVENTION: RECOMMENDATIONS

Functional dependency is not an inevitable consequence of the aging process. It is possible to distinguish in theory between primary aging, or senescence, and secondary aging, or senility. [40] Primary aging is caused by biological processes inherent in the organism, whereas secondary aging results from disability associated with trauma or disease. Although secondary aging is more directly related to environmental factors and health behavior, even primary aging can be influenced by these external factors. Many factors that affect the development of dependency, such as nutrition, building design, and accessibility of public transportation, have been identified. The burdens of functional dependency could be lessened by focusing on these factors.

Considerable evidence exists on the antecedents of major chronic illnesses and disability. Associations between certain behaviors, such as cigarette smoking and malignant neoplasms or cardiovascular disease, are well documented. [41] Similarly, alcohol abuse, poor dietary patterns, and vitamin deficiencies are known behavioral precursors to disabling conditions. [42] In addition, there is mounting evidence that the development and control of chronic disabling conditions are related to major changes in life-style and stress-producing events that tax the adaptative capacities of populations at risk. [43]

In spite of documentation that suggests potential social and individual benefits to be derived from preventive practices, most adult health care programs do not emphasize prevention and health maintenance

activities. [44] Some progress has already been made in identifying the goals of preventive practice among the elderly. [45] Good preventive practice includes measures to reduce the occurrence of disease through minimization of exposure to known antecedents of disease, early detection and intervention in presymptomatic disease, and minimization of the effects of disease and trauma once they have occurred. The committee believes it is important to supplement the long-term care program outlined in the previous section with programs aimed at preventing dependency or minimizing its extent beginning in the younger years of life. The committee, therefore, recommends that:

> Demonstration projects should be initiated to determine the effectiveness of specific preventive services and programs for the elderly, such as screening for chronic disease, pre-retirement counseling and nutrition education. These projects should be aimed at avoiding the occurrence or minimizing the extent of functional dependency.

New demonstration projects should be directed toward identifying individuals at high risk of developing functional dependency and determining the specific preventive services that are most effective. One approach to identification of persons at risk is to isolate times of extreme stress such as retirement, death of a spouse, or the onset of a chronic disease. Preventive services for those who are not yet functionally dependent also should be encouraged in demonstration projects. The importance of individual behavior and way of life in the development of some of the antecedents to functional dependency suggests that demonstration projects should include a strong education component to acquaint elderly individuals and their families with what they can do to maintain their own health and their ability to function independently.

COORDINATION AND PLANNING OF SERVICES: RECOMMENDATIONS

Coordination, planning, and integration in the delivery of health and social services to the elderly is widely recognized as a goal for social policy. However, papers and discussion at the Anglo-American Conference pointed out that neither the United Kingdom nor the United States has achieved a great deal of success in this endeavor. Conference participants referred several times to fragmentation in the delivery of services to the elderly and its consequences. Papers by Conable, [46] Maddox, [47] and Krause [48] dealt specifically with these concerns and suggested ways to encourage greater continuity of care.

The lack of an integrated system for the delivery of health and social services to the elderly is a function of differences in the nature of the services and type of providers involved and of the overall pluralistic approach to the delivery of health and social services in this country. Health and social services--public and private--are delivered by specialized providers and are organized as well as financed along categorical program lines. The importance of the contributions made by many professional and volunteer groups to the well-being of the dependent elderly should not be underestimated. Nonetheless, the committee believes that a pluralistic approach, although it provides valuable options in service delivery, imposes certain costs on both the elderly individual and society.

One component of pluralism in the delivery of health and social services is specialization. Specialization means that each of several different providers is trained to deliver expert services at a specific point along the

entire spectrum of care. Medical specialists are trained to treat certain diseases or trauma. Social service professionals concentrate on other aspects such as the social and emotional difficulties of individuals. Nurses manage yet another range of concerns.

The multiple health and social problems of functionally dependent elderly persons call upon all of these specialized providers for care. Interrelationships among the problems faced by elderly individuals make coordinated and comprehensive care critical to the success of interventions designed to meet their needs. Unfortunately, specialization can mean that responsibility for comprehensive patient care is divided among several specialists rather than vested in a single individual. When such responsibility is divided, the probability of gaps or duplication in services increases.

Pluralism and specialization in the delivery of services often mean that elderly individuals are forced to seek the assistance of several providers or programs in order to obtain a necessary complement of services. Limitations in functional capacity, confusion engendered by differences in eligibility requirements for services, and limitations in the scope of services offered by some programs make the arrangement of a care program very difficult for many elderly individuals. [49] Pluralistic delivery patterns and excessive specialization can become barriers to the receipt of necessary services. In order to address these problems, the committee recommends that:

> A single agency should be identified to coordinate the delivery of health and social services to the dependent elderly at the community level.

It is the consensus of the committee that coordination is more than planning. Coordination involves those activities necessary to bring about cooperation among diverse providers of services. The committee believes that although the responsibility for effecting coordination in the delivery of services need not be vested in the same organization in every community, it should not be divided among several organizations within a single community. The committee further believes that the organization selected for the role of coordinator should

exercise more than a planning function. It should have the authority necessary to effect communication and programmatic cooperation among providers of health and social services but should stop short of actually delivering services.

Area Agencies on Aging (AAAs) are a promising step toward encouraging cooperation and communication. AAAs were established in 1973 as part of Title III of the Older Americans Act. [50] AAAs are charged with "the establishment of a comprehensive and coordinated system for the delivery of social services" in their respective planning areas. [51] Social services are defined to include any service "necessary for the general welfare of older persons." [52] Examples of such services include:

- assistance to older persons designed to prevent institutionalization, including home health services
- legal and other counseling
- programs of regular physical activity and exercise
- programs to provide adequate transportation
- programs to help older persons in obtaining adequate housing. [53]

AAAs are responsible for assessing need for services, identifying gaps and duplication in the delivery of services, and entering into agreements with providers to deliver services.

Since 1974, 507 AAAs have been designated and are in early stages of development and operation. [54] No systematic evaluation of their performance has been conducted because most agencies are quite new. The growth in the number of AAAs and their progress in developing coordinated systems for the delivery of services to the elderly should be monitored. Because the ability to coordinate can depend in large measure upon available financial and personnel resources, it is important to determine whether funding is adequate to maintain appropriate staffing and to support the initiatives required to attain coordination. Working relationships between AAAs and Health Systems Agencies (HSAs) [55] should be encouraged, given the congruence of a number of

their functions. In communities without AAAs, or in which AAAs have experienced difficulty in operating, an attempt should be made to identify other organizations that could assume the coordinating role.

The committee recognizes that each population group in the community with special needs has tended to establish its own special advocacy agency--e.g., mental health councils, child health councils. Multiple special interest agencies can become divisive forces in the development and operation of health and social service delivery systems within the community. Thus it is important to keep in mind that the primary goal of an agency such as the committee recommends should be to promote coordination of services for the elderly rather than to develop age segregated health and social services. However, the committee believes that a separate approach for coordinating services for the elderly is a necessary first step in assuring recognition of the needs and problems of this segment of the population.

EDUCATION: RECOMMENDATIONS

The number of individuals age 65 and over in the U.S. has increased from about 3 million in 1900 to almost 23 million today. [56] This increase is attributable to a number of factors, including control of many communicable diseases and improvements in nutrition, sanitation, and medical technology. The major contribution of these factors has been the reduction of premature death. The increase in the number of elderly persons has brought with it not only the benefits of longer life, but also the burdens of chronic disease. The care of older individuals, particularly those with chronic and disabling ailments, accounts for an increasingly important part of the work of health and social service professionals.

Despite striking demographic changes during this century, attention to the care of the elderly (geriatrics) and the study of the aging process (gerontology) in U.S. educational programs for health and social services personnel has remained minimal. [57] Curricula in medical and nursing schools continue to emphasize detection, treatment and cure of acute conditions rather than chronic and disabling health problems. Diagnostic criteria and treatment regimens are established in relation to populations that are not aged. Elderly individuals, because of physiological and other changes, often exhibit "unusual" responses to drug therapies or fail to manifest "classic" symptomatology when afflicted with certain diseases. [58] They are also likely to have multiple and interrelated health and social problems thereby making detection and treatment extremely complex. [59]

Accordingly, the committee recommends that:

> Basic information on the aging process and on the special characteristics and needs of the elderly should be included in the education of all health and social services personnel.

The Anglo-American Conference highlighted the importance of including knowledge about the aging process and the special characteristics of the dependent elderly in the education and training of professionals who provide care to the elderly population. Several factors underlie the committee's recommendation for changes in education to reflect the needs of the elderly. These include the increase in the number of elderly individuals, the magnitude of public expenditures devoted to providing health and social services for the elderly, and a desire to ensure that the care delivered is of good quality and appropriate to their problems.

In order to reach all care providers, information on aging and care of elderly individuals should be included in continuing and in-service educational programs as well as undergraduate professional education. One way to ensure that appropriate attention is directed to the problem of the elderly would be to include material on geriatrics and gerontology in licensure examinations for all health and social services personnel.

The role of the physician in caring for the elderly is a much debated issue. In the United Kingdom, and in a few other European countries, geriatrics has emerged as a medical specialty. [60] The committee is not prepared to recommend that a specialty of medical geriatrics or departments of geriatrics within medical schools should be developed in the United States. Nevertheless, the committee is convinced that physicians and other health and social services personnel should be equipped to deal with the special problems of the elderly. A number of methods are available for accomplishing that end, including the establishment of electives in geriatrics and the integration of information on aging into existing clinical training and didactic curricula. At present, all possible options should continue to be explored. The committee believes it is important for most providers of primary health care to develop skill in geriatric care and an appreciation of the necessity for a

coordinated multidisciplinary approach to caring for the elderly.

The success of programs designed to inculcate knowledge about aging and care of the elderly rests on the availability of teachers, researchers, and leaders in geriatrics and gerontology. Currently, development of faculty and research personnel in aging is limited. The National Institute on Aging called attention to deficiencies in the supply of research personnel in a recent report on research priorities. [61] The committee recommends that:

> Teaching and research competence in geriatrics and gerontology should be encouraged through both public and private support.

The committee believes that strong faculty and research groups in a number of different settings across the country would assure sufficient numbers of teachers, investigators, and leaders in geriatrics and gerontology. Consideration should be given to expanding the role of existing university programs in gerontology so that they will be able to assume greater responsibility in developing the necessary numbers and types of personnel. The committee feels that these programs could play an active role in providing technical assistance and advice to community leaders and directors of programs designed to serve the elderly. The expansion of university programs in gerontology should be conditioned upon demonstrated willingness to serve as a resource to the community. The identification of alternative models to university-based centers for training and research in aging also should receive attention.

RESEARCH: RECOMMENDATIONS

Some aspects of the aging process have long been the subjects of investigation by biomedical and behavioral scientists. Major research findings on aging have been summarized by Birren and Schaie, [62] Riley, et al, [63] Binstock and Shanas, [64] Finch and Hayflick, [65] Busse, [66] and Exton-Smith. [67] Although these findings have improved understanding of both the scientific and humanistic dimensions of the aging process, many areas of uncertainty remain for future study. For example, distinctions between those changes that are an inherent part of the aging process [68] and those that result from disease, trauma, or other environmental insults remain largely theoretical. [69] Research is now underway to learn more about the processes that are part of "normal" aging, to elucidate environmental factors that influence aging, and to determine the effectiveness of preventive strategies in forestalling premature functional decline.

At the Anglo-American Conference four areas of research were identified as especially promising for further development: 1) bio-physiologic regulatory systems, 2) the role of stress, 3) the epidemiology of aging, and 4) the organization and delivery of health and social services to the elderly.

The role of bio-physiologic regulatory systems in aging--such as the central and autonomic nervous systems, the endocrine system, and the immune system--was discussed by several conference participants. Such systems change with age, but there is disagreement on the magnitude and direction of the changes. It is known, for example, that both brain weight and number

of neurons in the brain decrease with age. [70] Eisdorfer, however, has indicated that substantial cognitive loss is not a part of "normal" aging. [71] Evidence on the critical role that changes in the immune system play in aging has been summarized by Birren and Renner. [72] The immune system becomes less efficient in recognizing and eliminating antigenic substances and becomes more likely to reject parts of the body as "foreign" with advanced age. Increased incidence of autoimmune disorders among the aged is the basis for this observation. [73] Elderly individuals also experience a decreased ability to adjust to temperature changes. [74] Alteration in the function of the endocrine system with age appears to be a critical factor in aging, mainly because many body functions depend upon hormonal regulation. [75]

The committee believes that changes in bio-physiologic regulatory systems like the central nervous system may play a key role in the development of functional dependency among the elderly. The high prevalence of complex disorders afflicting the central nervous system, such as senile dementia, merits much further study. [76] As the population groups 75 and over and 85 and over increase, the prevalence of senile dementia can be expected to increase as well, unless it is a cohort phenomenon. The costs of such disorders in terms of individual suffering, family disruption, and expenditures for care, are compelling reasons for concern about their etiology. [77] Recent research findings challenge the assertion that senile dementia is a normal part of the aging process. [78] It is also important to be able to differentiate between dementias and conditions such as normal pressure hydrocephalus, which mimic senile dementia but are reversible. [79] Accordingly, the committee recommends that:

> Age-related changes in bio-physiologic regulatory systems should be given high priority in research on aging.

The importance of stress in the development of functional dependency among the elderly was emphasized at the conference. [80] Research findings indicate that physical, psychosocial, and environmental stress can bring about confusion, disorientation, and

depression, as well as physical illness in individuals of all ages. [81] It is possible that psychosocial stress, particularly in middle aged individuals, is contributing to high mortality from stress-associated diseases, especially cardiovascular disease [82] and to the differential in male/female life expectancies in the United States. Stress is a special problem among the elderly for two reasons. First, elderly individuals appear to have a diminished ability to cope with stress. [83] Second, the frequency of high-stress events, such as death of family members and friends, increases in the later years.

Progress has been made in identifying some of the major physical, psychosocial, and environmental stresses which increase the risk of developing functional dependency. Further research is needed to expand and validate the list of risk factors as well as to develop techniques for the reduction of stress and the minimization of its consequences. The committee recommends that:

> Research on psychosocial and biological stress, particularly as it relates to the development of functional dependency among the elderly, should be expanded.

The utility of currently available demographic and epidemiologic data on older people is limited by the fact that most of these data refer to all persons age 65 and over. Data on the health and socio-economic status of subgroups within this population are largely unavailable. The growth in the overall size of the population age 65 and over, the growth in the 75-84 and 85 and over age groups, and the heterogeneity of the elderly population necessitate greater availability of subgroup data.

There have been few epidemiologic studies of chronic or disabling conditions that are highly prevalent among the elderly, particularly among those 75 and over. Such studies could make substantial contributions to our understanding of the aging process. For example, it has been suggested that the high prevalence of senile dementia among those age 75 and over today may result from a common feature of the life experience of the present

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together in a single facility are also worthy of attention.

The committee recognizes the dangers and limitations of directed research. The recommendations included in this section are intended to call attention to areas of research in which there appears to be relatively high probability for progress at this time, and direct applicability to current needs. These recommendations should not be construed as limiting or discouraging other investigatory efforts relating to the needs of the dependent elderly.

To Here

APPENDIX

CONFERENCE SUMMARY

The Anglo-American Conference was held at the National Academy of Sciences on May 17-19, 1976. A full account of conference discussion is presented in Care of the Elderly: Meeting the Challenge of Dependency published in 1977 by Academic Press in London and Grune and Stratton in New York. The objectives of the conference were threefold:

1) to delineate the special problems of those elderly persons who require or are at risk of requiring supportive health, personal, and social services;

2) to compare approaches in the United Kingdom and the United States toward care of the elderly and the prevention and minimization of functional dependency; and,

3) to assess the social policy implications of current or anticipated social responses to the special problems of the dependent elderly.

These objectives grew out of the realization by the sponsors that the populations of all Western industrialized societies have aged substantially in the past several decades and that inadequate action is being taken, particularly in the United States, to ensure that the health and social needs of elderly persons will be met.

The conference brought together experts in geriatrics and gerontology, providers of medical care and social services, legislative staff members, and

representatives of the elderly to discuss the problems associated with functional dependency in old age and methods for resolving these problems. The first day of the conference was directed to defining functional dependency--what it is, who it affects, and why it is an important health and social problem. Detailed presentations on demographic changes in both the United States and United Kingdom highlighted projected increases in the proportion of the elderly in the next century. [84] In both nations the number of those 85 and over is increasing at a faster rate than any other segment of the population. [85] This group is composed primarily of women, most of them widowed. [86] Although the rate of institutionalization in long-term care facilities is highest among those 75 and over, the bulk of this group in both nations continue to live outside institutions. [87]

Several papers presented during the first day of the conference examined the consequences of the aging process on the functional status of individuals. Speakers discussed changes in visual, auditory, and taste perceptions, diminution in the size and strength of voluntary muscles, decline in basic metabolic rate, changes in patterns of electroencephalographic activity, and disturbances in sleeping habits. [88] One presentation emphasized the significance of decline in the functioning of the autonomic nervous system, which affects the response to changes in temperature; changes in postural balance, which increase the probability of falls; and alteration in the quality of bone tissue, which increases the probability of fracture when falls do occur. [89] Theoretical distinctions were drawn between primary aging, which refers to senescence--inherent and predictable deterioration of numerous biological processes--and secondary aging, the senility that results from trauma or disease. [90]

The effects of aging on the mental and emotional well-being of the elderly were emphasized in both the papers and discussion. [91] Speakers pointed to the importance of mental health problems in bringing about dependency. Senile dementia was cited as the most devastating and least recognized condition leading to breakdown in the elderly. [92] Presentations on the origins and nature of functional dependency were concluded by an analysis of the role of factors such as relocation and

institutionalization in the development of dependency among the elderly. [93] The same presentation stressed the need for societal recognition of the legitimacy of dependency among the elderly. [94]

Commentary on the first day's discussion noted the primary role of the family in the provision of care [95] and cautioned against an overprotective approach to the avoidance of environmental hazards that could lead to an increase in immobility and decline in the quality of life. [96]

During the second day of the conference speakers discussed institutional care, community and home care, the integration of health and social services, the role of the physician, advances in and prospects for research, and training of personnel. A speaker from the United States pointed out that the United Kingdom has a national policy of making it possible, through the provision of a network of social and medical services, for the dependent elderly to stay in their own homes or in other community housing as long as possible. In the United States there is no national policy of providing such support services. [97] Instead, long-term care is provided largely in proprietary nursing homes. When institutional care for the elderly is indicated in the United Kingdom, it is provided by special geriatric hospitals and geriatric beds in general hospitals. [98] About five percent of those over 65 in the United States are institutionalized for long-term care and about three to four percent in the United Kingdom. [99] This discrepancy, though significant, was felt to be surprisingly small in view of the differences of orientation toward care in the two nations. [100]

A United States speaker pointed to the pre-eminence of the "medical model" in the organization and delivery of long-term care in this country. He criticized United States medicine for its emphasis on "cure" rather than maintenance of function or prevention of further decline [101] and proposed a "psycho-social" model, including supportive social services in an integrated system of care, to supplant the medical model.

Presentations by geriatricians from Great Britain demonstrated that the British define geriatrics to include the whole spectrum of health and social services

with the physician assuming the role of coordinator and manager. [102] Speakers described the training of geriatricians--a training that stresses the inculcation of appropriate attitudes as well as skills. [103]

A comprehensive paper on aging research in the U.S. highlighted bio-physiologic regulatory systems (particularly the central nervous system) and stress as areas with considerable promise. [104] Major developments in U.K. research on aging were outlined in a presentation whose conclusions were that research is fragmented and that there is a paucity of data on conditions peculiar to the elderly. [105]

The third day of the conference took up possibilities for future action. The keynote speaker from the United States expressed a strong dissatisfaction with the direction of current U.S. policy affecting the functionally dependent elderly. He focused on the lack of coordination in federal and local programs, expressing the belief that complexity in the provision of services often leads persons to look to a highly visible institution, such as a nursing home, for the care they need. [106] He proposed the establishment of a network of community long-term care centers to coordinate and direct the provision of services to the elderly. In contrast, the speaker from the United Kingdom strongly supported current policy for care of the elderly in that nation: "the use of hospital facilities only where necessary, and then intensively, with the object of restoring the patient to the best level of function he can reach in a residential situation usually in his own home, failing that in a residential group home, and only in a hospital ward as a last resort." [107] He suggested that the capacity to care for the elderly within the community be strengthened through increased support of specialized housing for the elderly, and social services and by adequate cash allowances.

Commentary on these presentations included suggestions for changes in current public policies regarding health and social services, income, retirement, and use of voluntary services. These suggestions were considered by the committee in formulating recommendations.

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