Social policy and long-term care of the aged

Allan Kaufman

Current governmental policy regarding long-term care of the elderly relies heavily on a medical-model approach that stresses institutionalization. Because institutionalization has severe negative effects on older people, this policy must be redirected to encourage development of viable alternative programs and to support the traditional role of families in caring for their dependent aged members.

Allan Kaufman, MSW, is a doctoral student, School of Social Work, Florida State University, Tallahassee. He was formerly Associate Administrator, River Garden Hebrew Home for the Aged, Jacksonville, Florida.

DEFINING LONG-TERM CARE

The first problem encountered in an examination of long-term care is that of definition. What constitutes long-term care? Who are the recipients of such care? Where are long-term care services provided? The concept of long-term care implies the existence of a chronic condition for which a person receives care over an extended period of time. The term also implies irreversibility, so that restoration of the individual's ability to care for himself or herself completely is usually not seen as a goal. Recipients of long-term care receive services from other people who respond to a particular set of needs that the recipient is not capable of meeting alone. The provision of long-term care is not restricted to any particular location, although many persons think of long-term care as synonymous with institutionalization. Although most institutionalized aged and handicapped persons receive long-term care services, other people also receive similar types of services in noninstitutional settings such as their own homes or the homes of relatives.

She goes on to point out that these services may focus on prevention, rehabilitation, maintenance, and delay of further deterioration, and they include some emphasis on maximizing the "life satisfaction" of the individual.

In general, long-term care services for all groups are geared toward helping the recipients successfully master the activities required for daily living while improving their personal satisfaction and the quality of their lives. The scope and range of this assistance is as varied as the needs of the persons served and may include such diverse services as sophisticated medical support to treat life-threatening, chronic health conditions and assistance with the daily needs of food, shelter, companionship, and supervision. Persons needing long-term care services may require care that can be defined as "to-
"Persons other than the aged themselves are often left to articulate the needs of this group and draw attention to the social problems and issues affecting them."

tal" care or may only need assistance with those aspects of daily living that they are not able to handle for themselves.

Current statistics place the population of persons aged 65 and over in this country at approximately 22 million, or about 10 percent of the total population. Projections for the next 50 years predict that the percentage of the elderly in the total population will grow to about 14.6 percent, or approximately 43 million persons, by the year 2020. At present, about 5 percent of all persons 65 years and older reside in some type of institution that provides long-term care services. In raw figures, this comes to somewhat over 1 million persons. If this 5 percent rate of institutionalization is maintained, by the year 2020 approximately 2,150,000 persons over age 65 will be in need of institutional beds.

However, these figures do not give a true picture of the growing need for all types of long-term care services. Most persons who receive long-term care do not reside in institutions. It would appear that the number of elderly receiving long-term care services outside institutions may be several times the number of those residing in institutional settings. Hard data on this subject are almost nonexistent, so an accurate assessment of the situation is difficult. Shanahan et al. estimate that approximately 8 percent of the population over 65 years of age who live at home are either bedfast or housebound. Adding this to the percentage of the aged who are institutionalized produces a figure of 13 percent, or almost 3 million persons 65 years of age and older who may currently be receiving some type of long-term care services. Undoubtedly, numerous other persons in this age group who may not suffer the same degree of disability also require some type of supportive care that could be classified as long

term in nature. Considering that the above figures are conservative estimates and that the likelihood that future advances in medical science will help extend the life span, the magnitude of the problem of continuing to provide long-term care services for the elderly population is significant.

CURRENT POLICY

At present, the federal government’s major policy regarding long-term care has been to tie the provision of these services to the country’s medical care system. Many difficulties are inherent in this approach, not the least of which is the consistent lack of interest or enthusiasm the medical profession has shown for the chronic medical problems of elderly persons. The emphasis of modern medicine has been on the concept of "cure." However, given the chronic, irreversible nature of the health problems of many older persons, cure is usually out of the question, and at present, the full restoration of a patient’s facilities and abilities appears beyond the scope of medical science. The goal of complete medical recovery is thus replaced by a goal of partial rehabilitation, by helping the patient to live within the limitations of his illness, and facilitating the patient’s comfort. The contribution of such services to national productivity are miniscule. . . . Patients receiving care for chronic conditions may never return to the work force and geriatric patients have passed the normal age for retirement from the labor force. A narrow economic cost benefit analysis would therefore conclude that as society’s investment in long-term care services cannot be financially recouped, long-term care services are not economically viable as long as other needs, such as pediatric and short-term care, exist, whose servicing would yield a greater economic payoff.

Few medical schools or schools of nursing have significant programs in geriatric medicine, and many physicians and nurses are ill-equipped to treat the chronic ailments of older people. Institutionalized older persons and their families complain about the lack of concern shown by some members of the medical establishment, and these complaints are supported by research findings that point to a generalized lack of interest on the part of the medical profession in caring for sick aged persons in institutions. Evidence of this attitude may also be seen in the relative scarcity of research conducted by the medical profession on the prevention of chronic illness and in the lack of emphasis placed on rehabilitative programs for older persons inside and outside institutional settings. In this light, it seems ironic that long-term care is, for the most part, currently tied to a medical model of service delivery.

The major federal legislation reflecting this approach to long-term care is P.L. 89-97, the Medicare and Medicaid provisions of the Social Security Act. By providing third-party payments to institutions for long-term care services to the aged, this legislation emphasized an institutional, medical-model approach to the provision of such services. This direction in social policy has serious consequences for both those in need of long-term care services and those who receive them.

This approach forces the institutionalization of those aged who need long-term care but who lack a family support network to provide it, lack sufficient funds to purchase it, or lack the ability to deal with and negotiate the various systems involved in dispensing such care in a community setting. Once an individual enters an institution providing long-term care services, that person is subject to all the negative effects of institutionalization. Institutional care tends to promote feelings of dependence, passivity, and inactivity in residents. The sense of de-personalization, along with the regimentation and lack of privacy found in these facilities, can have devastating consequences for the residents.

Shore has been critical of the way...
the medical-model approach to policy affects the institutions themselves and their ability to provide high-quality care for the residents:

The medical model maintains the centrality of the physician and follows the supposition that care is provided in the hospital or in the post-hospital extended care facility when ordered or directed by a physician. This model views care essentially and fundamentally as acute care followed by short-term or convalescent stay. Thus, long-term care, the major characteristic of which is chronicity, is inappropriately modeled after short-term care, whose major factor is acuteness.

An important consequence of this approach is that financial payment to the institution under the Medicaid program is based on the amount of medical care required by individuals in the facility. The highest level of payment is made for those patients requiring the highest level of services, that is, skilled care. If a resident shows improvement in level of functioning and therefore requires less sophisticated care, the institution faces the possibility of receiving less money for the continued care of that individual. This tends to act as a disincentive for the provision of rehabilitative programs and services and tends to foster an approach to care that encourages illness and dependence.

Another serious economic consequence of the medical-model approach concerns patterns of staffing and costs of nonmedical services. Long-term care institutions must maintain a costly level of medical staff, whether or not all residents of the facility require their services. Also, personnel and programs that provide for the psychosocial needs and well-being of institutionalized residents, such as recreational and social work services, have little impact on the cost-reimbursement formula under the Medicaid program. Therefore, a long-term care facility is faced with significant costs in maintaining the required level of medical staffing and technology, while efforts to improve the quality of institutional life for residents are not supported by the current policy approach.

Medicaid’s “spend down” requirement, which necessitates an almost complete depletion of an individual’s financial resources in order to become eligible for Medicaid coverage for institutional care, bankrupts those persons who have moderate resources when they enter a long-term care facility and remain there for some time. When an individual’s resources are depleted, the option of leaving the institution becomes unrealistic, even if rehabilitation returns that person to a level of functioning that would enable him or her to live in the community. Once the resources are gone and the person has given up a home and furnishings, where can he or she go?

A further effect of the government’s linkage of long-term care almost exclusively to Medicare and Medicaid legislation has been the relative lack of official encouragement for the development of alternatives to institutionalization. Recent research has shown that a variety of alternative programs could provide effective long-term care for certain aged persons while enabling them to continue to reside in their own homes, the homes of relatives or friends, or some noninstitutional community setting. These programs utilize several supportive approaches, such as day care, foster care, homemaking and housekeeping services, nutritional programs, social service programs, and home health care programs. They have been demonstrated to be less costly than institutional care and to be capable of providing long-term care services that are more individually geared to the specific needs of the clients. In addition to delaying or completely obviating the need to institutionalize certain disabled older persons, these programs tend to stress preventive and rehabilitative efforts, which promote the independence and self-direction of the persons served rather than their dependence. The importance of developing such alternative programs becomes even more evident in light of the widespread opinion that many older persons are inappropriately institutionalized simply because of the lack of viable, community-based alternative long-term care services and programs. In view of the recent trends in the fields of mental health, mental retardation, and child welfare toward such noninstitutional, community-based services, the lack of a significant federal policy to encourage similar efforts in the area of long-term care services for the aged is most disturbing.

**EFFECTS ON FAMILIES**

A discussion of long-term care and its implications for social policy must include a consideration of the effects of a comprehensive policy—or lack of it—on the families of the elderly. As noted earlier, although 5 percent of persons over 65 years of age are institutionalized and receive some type of long-term care services, several times that number receive such services while continuing to reside in noninstitutional community settings. The important role that many families play in providing some help with these services engenders concern about the manner in which these families are affected by policy on long-term care.

Until the middle of this century, several prominent social scientists theorized that some of the more traditional functions of the extended family were being replaced in Western society by other institutions. This shift was seen as a functional adaptation of the family to the growth of mass, complex, industrialized society. These theorists saw the structure of the three- and four-generation extended family giving way and being replaced by a new dominant family structure: the two-generation nuclear family. This new form was viewed as more efficient and effective for the economic needs of modern society, which required both geographic and occupational mobility. One consequence attributed to this change in family structure was the apparent shift of the traditional “caring” functions of the extended family to certain social welfare institutions of the larger society. Older persons were viewed as isolated from and abandoned by their families, no longer able to rely on the help of family members when the need for long-term care arose.

Over the past twenty years, a considerable body of research has modified this view of the relationship between
This research has demonstrated that although most elderly persons do live apart from their children, family ties are usually maintained. An extended-family helping network usually exists, ready to provide some assistance to older persons when the need arises. Not only do older persons receive assistance from family members, but they often provide assistance themselves to other family members when it is needed.

Atchley discusses studies of the institutionalized aged that show that older persons without a family and without a spouse run a greater risk of institutionalization than do those who are married or have children.

A key factor in institutionalization appears to be the residential setting and family system. Older people in nursing and personal care homes tend not to have a spouse or children. They tend also to have lived alone. Indications are that many older people are able to avoid institutionalization if they have relatives to help care for them and adequate financial resources. In fact, breakdowns in this support system appear to be the primary cause of institutionalization among older people.

In an important study done in England, Moroney examined the question of how social policy on the provision of long-term care services affected the family and the extended-kin helping system. The findings and recommendations reported in his work are relevant to consideration of the same question in this country. Moroney found the family to be the most significant source of long-term care services for its dependent members. In his view, existing governmental policy regarding long-term care services fell into two broad categories: services that substituted for care provided by families and services geared to supporting, helping, and enhancing the family in its efforts. He found that support for the caring function of the family was a stated social policy goal of the English social welfare system. However, the programs that were developed tended to be crisis-oriented and geared toward replacing families that were unable or unwilling to care for dependent members rather than providing support to help families maintain their caring role.

Moroney pointed out the negative consequences of such an approach, both for families and for the larger society. By not providing adequate support and assistance to families that were overburdened by the care certain members needed, this policy subjected these families to stresses and strains that threatened the fabric and quality of individual members' lives. If significantly large numbers of such families gave up their caring functions and requested the state to assume this role in its entirety, serious economic consequences would result for an already troubled economy.

Direct parallels exist between what Moroney found in England and the social policy affecting long-term care services in this country. Because the federal government has chosen a policy that supports long-term care services for the aged mainly through the Medicaid program, long-term care in institutions remains the primary alternative to the family's provision of such care. This policy essentially replaces the family rather than supports the family's caring functions. Programs devised as alternatives to institutionalization have demonstrated their ability to use existing extended-kin helping networks, thereby supporting these systems rather than replacing them. The federal government, however, has shown relatively little interest or enthusiasm in supporting such programs.

RECOMMENDATIONS

A major concern for a significant number of elderly persons in this society is how to satisfy long-term care needs. The present social welfare policy of the federal government ties the provision of long-term care services to a medical-model approach by linking federal economic assistance for such services to the Medicaid program. This approach has resulted in an almost exclusive emphasis on institutionalization as the means of obtaining long-term care services for aged persons whose families are unable or unwilling to provide this care. Such a policy had severe negative economic and social consequences for the aged persons in need of such services; it also has negative consequences for the families of these individuals.

Ways must be found to develop significant program alternatives for long-term care that offer quality care while providing real choices for aged persons and their families. Efforts must be made to avoid the unnecessary institutionalization of older persons and to help those currently residing unnecessarily in long-term care facilities to leave those institutions. Attention must also be focused on ways of deinstitutionalizing the institutionalized themselves so that the negative effects of institutionalization on older persons can be mitigated. The medical profession must make a concerted effort to develop a specialization in geriatric medicine and to develop significant approaches and programs aimed at the prevention of chronic illness in older persons and the rehabilitation of persons already affected by such conditions.

The federal government must address itself to the task of developing a comprehensive policy toward the entire issue of long-term care for the aged. A significant part of this effort must be research to determine the true dimensions of the problem and to gain a fuller understanding of how the difficulties of obtaining long-term care affect the families of older persons. Finally, a comprehensive federal policy directed at the problems and issues involved in long-term care must address itself to supporting and strengthening families so that they can be encouraged to continue and improve the types of care that they can give to their aged family members.

NOTES AND REFERENCES


Toward Emotional Well-Being During the Crisis of Cancer

In this helpful and humane book, Dr. Robert Canter explores the emotional impact of cancer for not only lessening the anxiety of cancer, but for using a time of crisis as an opportunity for self-confrontation. "It is commended to medical, nursing, ministerial and other associated health care students."-American Journal of Psychiatry

paperback CN742, $3.95

AND A TIME TO LIVE Robert Chernin Cantor

Toward Emotional Well-Being During the Crisis of Cancer

In this helpful and humane book, Dr. Robert Canter explores the emotional impact of cancer on patients, family, friends, nurses, and physicians—and presents strategies and perspectives for not only lessening the anxiety of cancer, but for using a time of crisis as an opportunity for self-confrontation. "It is commended to medical, nursing, ministerial and other associated health care students."—American Journal of Psychiatry

daytime care

paperback CN746, $3.95

A DEATH OF ONE'S OWN Gerda Lerner

In April of 1972 Gerda Lerner learned that her husband of thirty-two years had an incurable brain tumor. He was determined, with her support, to die a "death of his own," and despite the problems of his increasing disability and the pressures of his wife's full-time teaching, he remained at home. Eighteen months later he died. A Death of One's Own is Gerda Lerner's personal account of their struggle together to face his dying.

daytime care

paperback CN741, $3.95

SECRETS IN THE FAMILY Lily Pincus & Christopher Dare

"Secrets in the Family is a psychodynamic approach to the unconscious beliefs, longings and incestuous fantasies that shape family relationships. Engrossing!"—Boston Globe

"...a thorough exploration of the profound emotional costs and benefits of growing up as a member of one family and of becoming a founding member (as most people do) of another."—Psychology Today

paperback CN669, $3.95

KAUFMAN / Long-term Care Needs

887

Harper & Row
10 E. 53rd St., New York 10022

Four important new paperbacks...