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10. Ethics: The Quality of Life

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ETHICS: THE QUALITY OF LIFE

The quality of life for the elderly is something we all wish to improve; yet, there is wide disagreement on how this is to be done. In this chapter, the contributing authors address themselves to this question, and although they differ as to the means, there is an implied consensus on the end sought. Broadly speaking, the authors indicate that a quality life is one in which the individual considers himself and is considered by others to have not only a past but a meaningful future over which he has control. Furthermore, it is a life in which the individual is able to retain, wherever applicable and whenever possible, his connection to the activities of the family, the community and the work force. However agreement on goals does not extend to agreement on strategy. This chapter presents two views, two possibilities for an improved system of long term care for the elderly. First, there is an examination of long term care delivery under federal control and then a consideration of delivery under a state controlled system.

ETHICS AND FEDERAL CONTROL OF THE QUALITY OF LIFE

Aging is not an end, it is the beginning of another segment, another passage in our lives. We must begin to realize that the elderly have a right to live this last segment to its fullest. The Federal Government must guarantee this right. Ethically and morally it is the only choice we can make. No part of life should be feared: life should be held, turned over, examined and enjoyed to the fullest. The elderly deserve this choice. Sharon R. Curtin, in her book, Nobody Ever Died of Old Age, states, "If we could change the picture we have of old people and view life as more of a continuous circle...perhaps we could learn to view old people as human beings with a future as well as a past."¹

The present system of Medicaid fails, in many states, to cover those services which are necessary to improve the quality of life for the elderly.
Under the present medicaid system, states may decide eligibility requirements and what levels and types of services to provide. Stephen Loebs in an article on Medicaid states that presently, "dominant political ideology and attitudes... held by legislators and governmental bureaucrats were the chief determinants of the responses to the optional choices in the medicaid program."² What has developed is a separate Medicaid program in each individual state that is often not sensitive to the needs of the elderly.

Long Term Care, one aspect of Medicaid, seems to have become synonomous with institutional care, whether in hospitals or in nursing homes. The very nature of institutionalization often is in direct conflict with quality life; by fostering dependence, it removes dignity and the need to feel wanted and needed from the lives of the elderly at a time when it is most important.

The following analysis was written to examine the prejudicial status that our fears of aging and dying have incorporated into the treatment of the elderly, and to show the lack of dignity allowed the elderly even in their dying. There are alternatives to the present long term care situation but they demand that first we redefine the very term. For purposes of this analysis, long term care will be defined as those medical services which, when guaranteed to all Americans 65 and over, will maximize their opportunities for independent quality living. The states have not accomplished this and under the pressures of rising costs, there is very little proof that the condition will improve in the future. The Federal Government must intervene if an equitable and satisfactory system of medical care for the elderly is to be established. The 1976 Moreland Commission report concluded that the fragmentation of the present Medicaid system was due to the lack of a comprehensive government program.

More important, it stated that what is required "is a new federal program which would help guard all forms of institutional long-term care and....would concentrate on financing more informal and non-institutional means of meeting the
Old Age -- The Feared Frontier

Americans are notorious for their hatred of age. They compulsively buy new things, erect new structures, construct newness into their lives. We are bombarded in every aspect of our lives with advertisements promising happiness through age retarding, youth perpetuating methods -- the face lifts, wrinkle creams, hair dyes, energy tonics. America has become a society which worships the image of youth, attempts to deny age, and refuses to accept death. It is no wonder that this notion surrounds our treatment of the elderly. They have become a flaw, a financially burdensome blemish on our youth cult, and we hide them away in nursing homes, hospitals and domiciliary facilities where we can comfortably ignore their existence -- a reminder of our own mortality. We find them slow, old fashioned, over-the-hill, senile, and in so many ways, irritating. And underlying our irritation is the fearful fact that they will one day move over and allow us, the young, to take their places. How dare they get older! How dare they die! For in their aging and eventual death, each of us is pushed closer to the front of the line. And so we ignore, deny, and resent. In fact, as author Robert Butler points out, "we are so preoccupied with defending ourselves from the reality of death that we ignore the fact that human beings are alive until they are actually dead. At best the living old are treated as if they are already dead."4

The lengthening of life expectancy and the growth in our over 65 population has largely been due to advancements in our medical technology. Estimates place the over 65 population at 25% of the American population by the year 2000.5 America's technological progress has created a segment of the population for which we are unprepared; "for whom survival is possible but satisfaction in living elusive."6 It is true that 81% of those over 65 remain independent,
95% live in the community and at any one time only 5% are in institutional care. However, these figures appear to be radically changing as more of the elderly begin to find it financially, medically, or mentally impossible to maintain their independence. Their choice, often reluctantly, is a nursing home. A 1966 study of the characteristics of one home for the aged showed that 45% entered because of their own mental or physical impairment, 23% because of the death or impairment of a spouse, 7% because of poor neighborhoods, loneliness or relationship problems, and 23% because of the death or severe illness of their adult child. This is substantiated by a 1971 study done by Brandeis University's Levinson Gerontological Policy Institute of 100 patients in nursing homes. Of these, 37 needed full time skilled nursing care, 26 needed minimal supervised living, 23 could get along at home with periodic home visits by nurses and 14 needed nothing. Sixty-three per cent of these 100 patients could technically survive without the confines of a nursing home. The Brandeis researchers concluded from their study that "large numbers of disabled are forced into nursing homes...simply because public programs could not give attention to alternative ways of meeting their needs outside of institutions." Much of this "forcing" is done because of the following attitudes which perpetuate unfair myths about old age.

- The Myth of Disengagement which holds that the elderly prefer to live alone or perhaps only with their peers.
- The Myth of Senility which often lumps anxiety and depression into the category of senility and holds that all old people grow forgetful, confused, and have reduced attention spans.
- The Myth of Unproductivity which perpetrates the belief that age and unproductivity and synonymous.

It is these attitudes which perpetuate the belief that the elderly cannot adequately care for themselves that often leads them or their families to choose
dependence over independence -- the "old age home" over their own. Edith Stern wrote in her article "Buried Alive", that "Unlike some primitive tribes, we do not kill off our aged and infirm. We bury them alive in institutions."\(^{12}\)

**The Loss of Quality Life**

All humans get old; in effect, we are all sentenced to die. We have a beginning and an end with death the final point in the continuum. The old cliché that reads that it is not whether we win or lose, but how we play the game that is important. The manner in which we allow the elderly to play out the "game of life" becomes important. Existing data indicate that the opportunities for quality life for the elderly has declined significantly:

- In 1971 over 10 million elderly live on less than $75 per week.
- Thirty per cent of the elderly live in substandard housing.
- Social Security penalizes the old by reducing their income checks as soon as they earn more than $2,400 a year.
- 3.4 million elderly persons live in poverty with an annual household income of less than $3,500.\(^{13}\)

Yet, in spite of these conditions, we expect the elderly to maintain both their physical and mental health. The World Health Organization's Charter states that health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. Robert Butler wrote in *Why Survive* that health meant the "capacity to thrive rather than simply survive."\(^{14}\)

As Americans, we need to establish as a priority the personal right to quality life which is far more important than biological survival. In order to prioritize, we must dispell one of the most distorting mythos of old age -- the myth of senility. We must begin to realize that the elderly as they exist today are plagued by enormous stress that leads to depression, anxiety,
psychosomatic illnesses, and irritability. That grief for the many losses that the elderly suffer -- loss of friends and relatives and ultimately the loss of one's own life -- bring apathy and emptiness. Often alone, the elderly find themselves unable to survive independently. They become dependent pawns, handing their lives over to death or institutionalization. Twenty-five per cent of all known suicides occur in the 65 and over population; until recently, 25% of annual state hospital admissions were 65 and over; and 5% of the elderly are confined to nursing homes, hospitals, or other institutional care.  

Misuse of Hospitals

Are hospitals and nursing homes able to provide quality life to the elderly? Hospitals historically were organized as centers for healing, curing, and restoring individuals to health; they were not organized around dying. Hospital staff are trained in restorative care, not in the care of the aged or dying. A 1973-74 survey of over 100 medical schools in the United States shows that 87% offered no geriatric specialty and did not plan on adding one; 74% lacked apprenticeship in nursing homes; and 53% offered no opportunity for contact with nursing home patients.  

Deaths in a hospital are often viewed as a failure and a cause for anxiety for the staff. As a result, dying patients often become "targets of super human, futile efforts at resuscitation and maintenance (as in the Quinlan case) or shunted off into the farthest room and ignored as much as possible." In Miami not long ago, two elderly men -- critically ill, homeless, penniless -- were put into wheelchairs to sit in a jammed aisle of a hospital until nursing home space could be found for them. Both men died in those chairs, and it was hours before anyone even noticed they were dead. One man had been sitting in his chair for three days and the other for two.  

Section I of the "Principles of Medical Ethics" drawn up in 1973 by the American Medical Association reads
that "The Principal objective of the medical profession is to render service to humanity with full respect for the dignity of man." One need not ask if death in a wheelchair is dignifying or if using hospitals as "holding tanks" is providing quality life.

Nursing Homes -- The Human Warehouses

In spite of the movement to improve the quality of care provided by nursing homes, they will remain in the eyes of the elderly often nothing more than "warehouses". To the old, they are the last stop before death and viewed with a mixture of fear and hostility. "All old people -- without exception -- believe that the move to an institution is the prelude to death....a decisive change in living arrangements, the last change he will experience before he dies."¹⁹

Beyond this, nursing homes often fail to provide the most necessary ingredient, comprehensive medical care. Although Federally required, many states do not effectively enforce the use of a principal physician or medical director. Often, attending physicians' visits involve very little other than glancing at charts, thereby denying the patients quality care. The Moreland Report cited that "a common complaint which the Commission has heard....is that physician visits are often perfunctory."²⁰

The most fearful aspect of nursing homes is that they rob the elderly of every last shred of independence. They are reduced to the status of infants, totally dependent, at first involuntarily and then, finally, voluntarily. In Nobody Ever Died of Old Age, Curtin describes the treatment she encountered in various nursing homes. She found that the attendants often treated the elderly "as if they were infants, unhearing, uncaring, unable to speak or communicate in any way. The patients were uniformly called honey or dearie or sweetie -- or sometimes naughty girl if they soiled their beds -- just as one tends to
call children by pet names.... The bodies were kept clean, fed, powdered, combed, and clothed. They were as infants, without modesty or sex or privacy."

**Death, the Untouchable State**

Growing old, and all that aging entails is terribly lonely. The elderly are talked to and visited and tolerated partly out of guilt, partly out of a sense of responsibility. Perhaps the greatest loneliness comes from the elderly having to fear and grieve for their own death alone. There are very few people that will sit and listen to talk of dying. It is still a taboo; a macabre topic to be avoided. In our need to deny death's existence, we attempt to remove ourselves from its presence. On one hand, we react to death by "abandonment of the dying -- for they symbolize what we want to avoid. To abandon is to isolate. To isolate is to degrade, dehumanize. The final result -- an excruciating loneliness at the end of life." On the other hand, we use every technological method to postpone death through heroic means, methods used to sustain life when there is no hope of restoring the life to a health state. Our technology can often hide the actual time of death by continuing life through machines. The cost of postponing death not only is costly monetarily, but also it denies the dying the right to a dignified death -- the final phase in a quality life. We overlook the basic fact that the quality of life rather than the quantity of living should be the priority.

Passive euthanasia, unlike mercy killing, is the act of allowing a patient to die naturally rather than using heroic means of sustaining life. There are those who would say that any form of euthanasia is unethical. But it is fear of failure and guilt that often prompts doctors and families to continue heroic measures thus convincing themselves that everything humanly possible was attempted. Isn't it much more unethical to allow an individual to die alone and isolated, to rob him in the end of the familiar human companionship
of family and friends?

Hospices and Home Care -- Acceptable Alternatives

In an attempt to deal with death, the concept of hospices was developed. A hospice is an inpatient facility designed specifically to make dying as comfortable an experience as possible and the hospices idea has begun to take hold in the United States. Along with the hospice has come a new emphasis on home care and the right of the individual to know when he is dying thereby giving him control over the last segment of his life. The emphasis on home care is the result of studies that indicate that people prefer to die at home.

Besides helping the terminally ill to die in dignity and understanding, indications are that the hospice concept can eventually lead to cost containment. Lower rates exist because of low overhead resulting from a reduced range of services, emphasis on home care and less emphasis on technology and hardware. A 1972 study by Cardinal Ritter Institute in St. Louis compared home care costs for 140 terminally ill patients for a four month period against the estimated costs of alternative methods of care. The results showed:

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<td>Nursing Home</td>
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<td>Home with last two weeks in hospital</td>
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Quality Through Opportunities

When planning for the aging, especially in the area of health, we need to maximize the rights to freedom of choice for the elderly while emphasizing quality life. In order to do this, we need to recognize the needs of the elderly. It is not the government's responsibility, whether local, state, or
federal to guarantee health but rather to guarantee that the opportunities for a healthy, quality life is available. The elderly, who must exist on fixed incomes without the hope of increasing those incomes through additional work, must be guaranteed needed services which will enable them to continue their independence in a dignified way. As Lyndon B. Johnson once states, "A basic goal of an enlightened society must be to provide opportunities which enable older people to keep and strengthen their independence and dignity."

Under the present medicaid system, the states maintain flexibility in determining who is eligible, the types and levels of medical services for which financing is available, and the levels of reimbursement for providers of medical services. Under this system, it is estimated that as many as 8,000,000 people below the poverty line are not eligible for Medicaid. Since as previously stated, 3.4 million elderly persons live in poverty, one may assume that a large portion of the elderly are not receiving adequate care. Although states are required to include many services, certain services such as drugs, eyeglasses and dental services are left to the discretion of individual states.

Aging, by its very nature, means that there are certain biological changes in the body. Basically, the body degenerates. The states have been negligent in providing services needed by the elderly, and it is the duty of the Federal Government to provide these services. Since these services cannot be considered luxuries but necessities, they should be completely funded by the Federal Government. Under this definition of a Federal takeover of the medicaid system for long term health care of the elderly, care of the elderly would be a component separated from health care services for those not elderly. For purposes of this paper, the program will be called Medicel or Medical Care for the Elderly. Under a Medicel system there would be two funding components.
Component 1: Medical Services -- 100% Federal Funding:

These services are those which are preventive in nature and are necessary for the elderly to (1) maintain independence, (2) obtain and retain quality living and (3) enable the elderly to remain in their own homes or the homes of family members. These services would include:

1. Diagnostic and clinical screening (i.e. for glaucoma or diabetes)
2. Lab tests
3. Daytime non-residential care at geriatric hospitals
4. Rental of hospital equipment such as beds, wheelchairs, walkers, etc.
5. Physical rehabilitation therapy, non-residential
6. Homemaker, friendly visitor, home delivered meals, and other home services
7. Counseling services in mental health and family needs including psychiatric out-patient services
8. Immunizations
9. All forms of dental services
10. Prescribed drugs
11. Prosthetic devices
12. Eyeglasses and optometrist services
13. Podiatrist services
14. Hearing aids and audiologist services
15. General doctor visits
16. Home hospice care
17. Emergency room hospital services

Component 2: Medical Services under 70% Federal Funding/30% State Funding:

These services would be the most costly services but would not include heroic measures.

1. Private duty nursing care
2. Nursing home care
3. Mental institutional care
4. Residential hospital care
5. Residential hospice care

Under the Medicel system the elderly would be guaranteed medical services emphasizing home care. Besides being a cost containment system, it is aimed at increasing the quality life of the elderly by increasing the amount of income they will be able to spend on services other than health care. Congressman Edward Koch of New York once estimated that keeping a person on home care would cost $2,000 to $6,500 as opposed to $15,000 to $20,000 in a nursing home. It is essential that the elderly be guaranteed the opportunity to remain at home because "Many elderly persons even if chronically ill want to remain at home (but) need assistance in....homemaker home health aid."26

Conclusion

The challenge that must be faced in providing an equitable medical program for the elderly is to guarantee maximum necessary services while not financially incapacitating the states or the Federal Government. The proposed Medicel system does this. It guarantees services through Component I while continuing some state flexibility under Component 2. The emphasis of the program is on quality living at home. Since most sources speak of the elderly as the 65 and over population, this would be the soul eligibility requirement. Regardless of race, creed or color, all persons over 65 would have the opportunity to obtain necessary medical care. The states, because of their varying ideologies have been unable to guarantee this. As previously shown, this has caused a large segment of our population to exist in poverty, riddled with fear and anxiety. The elderly have a right to live a healthy, dignified, and independent life. The Federal Government has the responsibility to guarantee opportunities to do so. Zorba the Greek once said that "death is not the trouble, life is the trouble."27 The elderly must have access to a life with as few troubles as possible.
STATE CONTROL OF THE QUALITY OF LIFE

Who shall take care of me in 2020? It is in the ethical issues concerning Medicaid-funded long term care (LTC) that the force and even pathos of this question is most apparent. Ethics, by definition, deals with what is good and bad and with moral duty and obligation. Many of the contributors to this book are just beginning to have their lives directly affected by ethical questions relating to Medicaid-funded LTC.

Do we place our parents in nursing homes? Do we acknowledge the wish of terminally ill parents or spouses that no heroic measures be used to prevent death? Can we guarantee the aged a quality life and still retain the quality of our own lives? Is there such a thing as freedom of choice when it comes to health care?

Perhaps the best way to understand the implications of the problem for the year 2020 is to look at the facts in the year 1979:

- Sixty percent of those people receiving Medicaid are either elderly or physically disabled.
- Current projections indicate that Medicaid will cost $22.3 billion dollars by 1980.
- The fastest growing population in the U.S. is the over 75 group.
- Three-fourths of all older people have a chronic illness.
- Forty-seven percent of older people have some limitation in activities of daily life.
- Thirty-eight percent of older people have some significant impairment in their ability to function.
- Chronic brain syndrome or senile dementia which has a prevalence of three percent during the age space of 60 through 69 increases by more than sixfold to age 90, where it reaches a prevalence rate of
approximately twenty percent.

- Estimates for mental and emotional disorders among the aged run from a low of fifteen to a high of approximately thirty percent in the 65+ age group.

- Nursing home bed utilization doubles with every decade of life past the 60's.28

The facts point to an increasing population of older people who will continue to drain resources. As the situation worsens, we will be forced to address a growing number of ethical concerns and decide what are the most humane solutions to our problems.

The ethical problems surrounding Medicaid funded LTC are complex and subject to great regional variation. In order to rationally recognize the problem and come up with solutions, the states must retain the ability to make policy and differently interpret the ethical problems faced by its citizens. The goal of this paper is to examine how state initiated and controlled policies will promote the quality of life of those in LTC in a manner that is superior to all other alternatives.

In order to accomplish this goal, the paper shall look at the importance of state diversity specifically concerning ethical issues: why states are in a better position to obtain community input and convert these inputs into a policy that will be supported by its citizens and why states are in a better position with regard to humane policy innovation which will insure the quality of life of its citizens.

Two issues which reflect the problems of Medicaid-funded LTC shall be discussed within the context of the status quo argument. These are the right to a quality life and the right to freedom of choice, specifically in relation to the euthanasia question.
What is a Federal Takeover?

In this chapter, it has been noted that a federal takeover of Medicaid-funded LTC would be composed of three elements: 1) 100 percent federal funding of those services which are preventative in nature and necessary for the elderly to maintain independence and quality living while remaining in the homes; 2) no federal funding of heroic measures, and 3) 70 percent federal funding/30 percent state funding of nursing homes and hospitals.

The fallacies of this model center around the belief that the federal government can determine what the citizens of this country want in terms of LTC and then enforce these standards in a uniform way. The model also fails to address the question of the controversy over and complexity of such terms as "quality living" and "heroic measures". In addition, the federal takeover model neglects the history of the states in humane policy innovation in numerous social areas including medical care and treatment of the aged.

State Diversity

Daniel J. Elazar in American Federalism: A View From The States presents a picture of a diversified United States whose cultural, political and ethnic makeup varies from state to state and region to region. He divides the country into three cultural bases: moralist, individualist and traditionalist.

The moralist cultures, which are located primarily in the upper middle west and Oregon, welcome the initiation of new programs for the good of the community. "By virtue of its fundamental outlook, states Elazar, "the moralist political culture creates a greater commitment to active government intervention into the economic and social life of the community. At the same time, the strong commitment to communitarianism characteristic of that political culture tends to channel the interest in government intervention into highly localistic paths so that a willingness to encourage local government inter-
vention to set public standards does not necessarily reflect a commitment and willingness to allow outside governments equal opportunity to intervene."

The individualist culture is strongest in the western states of Nevada and Wyoming and views bureaucracy as a potential fetter of private affairs. "Since the individualistic political culture emphasizes the centrality of private concerns, it places a premium on limiting community intervention -- whether governmental or nongovernmental -- into private activities to the minimum necessary to keep the marketplace in proper working order."30

Traditionalism, which is concentrated most heavily in the South, opposes all government interventions except those necessary to maintain the existing power structure and would accept new programs only if they were necessary for the maintenance of the status quo. "Good government in that political culture involves the maintenance and encouragement of traditional patterns and if necessary, their adjustment to changing conditions with the least possible upset."31

It is interesting to compare the chart developed by Dr. Stephen Loebs of Ohio State University documenting the variation among states in the provision of Medicaid-funded services (Figure 1) to the map illustrating Elazar's findings (Figure 2). For example, the southern states, with a predominantly traditionalist culture, provide only federally mandated services to their populations. On the other hand, the moralist cultures of Kansas and Washington provide benefits to four out of the five categories. In general, those states with the greatest amount of traditionalist culture provide services to the least number of categories. Those with a moralist culture provide the greatest number of services.

There are several exceptions to this generalization. Hawaii, for instance, provides aid to the maximum number of categories yet has both an individualist and traditionalist culture. This may indicate the difficulty in making
Title XIX States Classified by Groups Eligible for Medical Vendor Payments
Under Medicaid, January 1, 1970

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Key

I. Federal Cost Sharing in Medical Expenditures and Administrative Expenditures

A = Categorically Related Needy
B = Categorically Related Medically Needy
C = Medically Needy Under 21 Years

II. No Federal Cost Sharing in Medical Expenditures (Cost Sharing in Administrative Expenditures)

D = General Assistance Recipients
E = Medically Needy Between 21 and 64 Years

Source: U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Services;
Assistance Payments Administration and Medical Services Administration, "Characteristics of State Medical Assistance Programs Under Title XIX of the Social Security Act."

FIGURE 2
generalizations about the states, therefore, supporting the argument that a federal takeover is unrealistic because of state diversity and exceptions.

Research by other scholars supports Elazar's thesis that extensive variation exists among the states today. Sociologists Norval Glenn and J.S. Simmons conclude that regional differences are sharper than in the past in questions dealing with morals, political issues, international relations, and racial and ethnic minorities. Political scientist Ira Shransky adds that "officials of leading states within each region are likely to generate their own innovations or take cues from leaders in other regions. The follow-the-regional leader communications network that prevails among most states helps to isolate their officials from direct national influence and permits the development of regional approaches to new programs -- even when such programs are sponsored and regulated by Federal Agencies."33

The Difficulty With Definitions

Even if the states had uniform political, cultural and ethical values, the problem of defining controversial and complex concepts exists to such a degree that a blanket federal policy at this time is unsuitable. For example, it is difficult to determine a definition for euthanasia which is specific enough to protect against misuse yet general enough to form a policy.

Theologian Paul Ramsey describes this difficulty in his analysis of the California Natural Death Act, the first state or federal law allowing for patients refusal of heroic measures:

Any careful reader of the directive will see at once that it contains several quite ambiguous expressions. Among theses are "incurable", "terminal condition", "life-sustaining procedure", "artificially prolong the moment of death"; how these relate to "my death is imminent"; and the bearing of "whether or not life-sustaining procedures are utilized," whatever was the prognosis meant by those earlier expressions.
Before any policy can be made on euthanasia whether by a state or national
government, the concept must be digested by the public and understood by the
individual. The technology which has brought this issue to the public eye is
relatively new. There must be time for the implications of our new technology
to be examined by both policy makers and the general public. Slowly, America's
conception of death is changing. In the last ten years, there has been a
distinct switch in philosophy from a life-at-all costs approach to a right-to-
die ethic. As Ramsey notes, "We have come a long way in exploring what it
means for individuals and groups to be responsible in making decisions regarding
death and dying in the day of the biological revolution. There is much more
openness in discussing the tragic decisions which sometimes must be made if
individuals are to be responsible for their own life histories. In fact,
'death with dignity' has become something of a movement; the 'right to die' has
become an almost faddish slogan."35

Scientists and moralists such as Ramsey caution against treading too
hastily into these complex areas and making decisions by crisis. The moral
and ethical consequences of euthanasia, especially in the cases of active
crime of those presumed to be hopelessly ill or disabled, are far-reaching.
Will active euthanasia, for example, become a method to reduce expenditures?
Will governments use euthanasia as an excuse for genocide? What will happen
to the moral framework of this country if we legislate killing? Are we on
the verge of declaring war on the aged?

Leo Alexander's analysis of the medical practices and attitudes of German
physicians before and after the reign of Nazism in Germany presents a chilling
picture of what can happen when consequences are ignored and definitions are
not distinct. He writes that the outlook of German physicians that lead to
their cooperating in what became a policy of mass murders, "started with the
acceptance of that attitude, basic in the euthanasia movement, that there is
such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to include the socially unproductive, the radically unwanted, and finally all non-Germans. But it is important to realize that the infinitely small wedged-like level from which this entire trend of mind received its impetus was the attitude toward the nonrehabilitable sick.36

At the present time, there are at least 49 death-with-dignity bills pending in 36 state legislatures. State governments, through the pressures placed upon them by their citizens, are beginning the slow process of determining policy for their areas. This decision-making process should remain at the state level.

The State As Policy Makers

As the issues involved with Medicaid-funded LTC grow increasingly complex and controversial, can the states answer the challenge? Historically, the answer has been "yes" with the states often responding to problems within their communities with innovativeness and sensibility.

Terry Sanford, ex-governor of North Carolina, describes the states as "laboratories of democracy." He quotes for support Supreme Court Justice Louis D. Brandeis who said, "It is one of the happy incidents of the federal system that a single courageous state may, if its citizens choose, serve as a laboratory and try novel social and economic experiments without risk to the rest of the country."

To cite just a few examples of state initiative in social issues:
- Mental Health. Kentucky's innovative training programs, Illinois' regional state-hospital clinics, and Maryland's community based programs have provided impetus for national programs.
- Education. States invented community colleges, pioneered in the use of instructional technology and pushed for universal education and consolidated high schools.\textsuperscript{37}

- Abortion. 23 states considered changes in their abortion laws before the Federal courts took any decisive stand.\textsuperscript{39}

State policy is often a reaction to the values considered important by its citizens. Oregon, for example, discourages economic development because its population has observed the problems caused by the influx of new settlers in its neighboring states of California and Washington. Minnesota protects itself against organized crime by a combination of strict legislation against betting, a vigilant judicial system and the attitude of its citizens.

The concept of citizen determination of state policy is important to remember before adopting a judgmental attitude about those states which provide benefits to only certain segments of their populations. Alabama, which provides services only to the categorically related needy, is often cited as an example of neglect in the social services and medical areas. In discussing what he describes as the "maligned states," Ira Sharansky concludes:

"Alabama is another low-income state that shows unusual support for some public assistance. The state's economy is poor, and its population takes a conservative view toward the support of people who do not provide for their own needs. However, the recipients of old age assistance do relatively well. The figures show payments to 'pensioners' -- as the old age recipients are labeled in Alabama -- rank closest to the national average. This class of the Alabama population receives the benefits of a program that is consciously mislabeled as a "pension program"; the rates and eligibility requirements are considerably more liberal than those applied to other welfare programs; and the state has responded quickly to new Federal grants in behalf of the elderly.\textsuperscript{40}

(A discussion of what states are presently doing to provide better Medicaid funded LTC can be found in the "Levels of Care" and "Standards of Care" chapters of this book).
Is A Quality Life Possible?

A state's fiscal response to the needs of its aged is only one indicator of its concern for the quality of life of its elderly. It can be argued that no matter how generous the state and federal government are with medical benefits, quality life will always elude some of the aged because of their view of Medicaid as a "handout." If a major determinant of quality life is a feeling of self-respect and independence, the concept of Medicaid itself may work against the elderly. Alabama has been one of the few states to make a conscious effort to preserve the pride of the aged by deliberately naming its program "Old Age Pensioners," therefore removing the welfare onus from the recipients.

The attitude of a community toward its aged may not be reflected in how much of its tax dollars support Medicaid. In some states, especially those with a traditionalist culture, the norm is for members of society to take care of their own. (See the section on non-whites and Medicaid-funded LTC for an examination of ethnic groups and their view on aging).

Sociologists John Lozier and Ronald Althouse document this occurrence in rural West Virginia and conclude:

What is required for successful old age is the continued existence of community or neighborhood systems which can recognize and store credit for the performance of an individual over a whole lifetime and which enforce the obligation of juniors to provide reciprocity. Without such a system, the help that is provided to an elder robs him of his dignity, for there is no recognition that this is his due, and not a form of charity.

Just as it is important to destroy the myth of the aged as serene human beings going gently into the night, it is also important not to paint a picture of utter despair among the aged. In many parts of this country, the nuclear family does expand to include an elderly parent who needs LTC. The rise of the Grey Panthers and the extension of retirement age until 70 are indicators of a growing militancy in the elderly population which may result in increased political power. Attitudes toward aging, like attitudes toward death, are changing.
As the fabric of our society changes, so must the individual change. L.F. Jarvile, in his investigation of aging suggests that, "It always comes as a surprise to younger people that many older adults experience life's high satisfactions. The finding of social science research reports that life satisfaction is not unduly low in the aged; and many older adults report greater satisfaction at their present late stage of living than do young adults. The evidence suggests that most older adults have not grown old, sick, poor, and lonely. Indeed, they are more concerned with opportunities for learning and experiencing life than the young are prepared to believe."^43

Quality life for Medicaid funded LTC patients will increase when public pressure within the states comes to bear on the issue. Variation of the quality of life among states and communities will always remain, and this variation will provide the flexibility needed for an aging population to coexist with a young population.

The ethical problems concerning quality life are as difficult as those of euthanasia and need the same careful thought. Should we allocate our money to the study of aging or childhood diseases? What price do we want to pay to guarantee the aged quality life? Are we looking for something that money can not buy? If allocating resources is not the answer, how do we integrate the aged population into society in a way that promises a better life for all?

Conclusion

This paper has shown that we are faced with difficult and complex ethical problems in relation to Medicaid funded LTC. The solution to these problems is not waving the magic wand of a federal takeover, but rather in careful examination and innovative solutions at the individual, community and state level in cooperation with the federal government.
The United States is a country with a diverse population which has led to innovative ideas and programs. To superimpose a federal system upon the states in the area of health care for the aged would neither consider the different values within and among the states nor provide for the priorities set by taxpayers. The states would probably, if history can predict, synthesize a federal program for their own use, therefore both defeating the purpose of a federal takeover and voiding the responsibility of the community and the state to its people.

In addition, the changes that have occurred through the advent of new technology and social services need more examination before decisions can be made. The changing attitudes of Americans toward death and aging will bring about the most far-reaching improvements in LTC. When we finally learn to live with death and the aging process, we will have conquered most of our problems.

The challenge of today and the years until 2020 is to use diversity and flexibility as our strength.
FOOTNOTES


5 Ibid.

6 Ibid., p. xii

7 Ibid., p. 7


9 Butler, Why Survive, p. 268.

10 Ibid.

11 Ibid., p. 8-9.


13 Butler, Why Survive, p. 3.

14 Ibid., p. 225.

15 Ibid., pp. 227-228.


17 Ibid, p. 159.

18 Ibid., p. 8.


26 Ibid., p. 159.

27 Ibid., p. 242.


30 Ibid., p. 94.

31 Ibid., p. 99.


33 Ibid., p. 37.


36 Ibid., p. 553.


39 Elazar, American Federalism, p. 12.
FOOTNOTES

40 Sharkansky, The Maligned States, p. 44.

41 Ibid., p. 45.


43 Jarvik, Aging Into the 21st Century, p. 553.