Community health decisions: An analysis of a grassroots venture into citizen participation in health care policy prioritization issues

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Community health decisions: An analysis of a grassroots venture into citizen participation in health care policy prioritization issues

Bonnée-Nichols, Michele, M.A.
University of Nevada, Las Vegas, 1990

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COMMUNITY HEALTH DECISIONS: AN ANALYSIS OF A GRASSROOTS VENTURE INTO CITIZEN PARTICIPATION IN HEALTH CARE POLICY PRIORITIZATION ISSUES

by

Michele Bonneé-Nichols

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Arts

in

Ethics and Policy Studies

Institute for Ethics and Policy Studies
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May 1990
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ABSTRACT

Health care policy making has been largely a closed system in which policy making experts, special interest groups, and politicians have joined forces to decide what was best for the health care of the American people. On a national level, government public health programs, such as Medicare and Medicaid, demonstrate that the closed system of health care policy making was shortsighted. This system may neither be the best, nor the only method of obtaining health care policy that would reflect the best interests of the American people.

The long-range effects of the two governmental policies mentioned above, along with the ever-increasing base of medical technology, have contributed to raising our national debt to trillions of dollars, and left our country with a population at risk of erosion, deterioration, and mortgaging people's health. The "medical commons" are being stretched to their limits. Critical issues including allocation of health care resources and rationing of scarce health resources are emerging upon the horizon of the public policy agenda. With this comes the question, who should decide what is best for society?

These critical forms of social consequence warrant a discussion of health care planning that includes the citizenry for whom the health care policies are intended. Already, a citizen-based grassroots venture known as "Community Health Decisions"
is emerging in several states. The project was initiated in Oregon which set out toward a goal of consensus building of its grassroots population on bioethical health care issues, via forums, small group and town hall meetings.

A similar consensus-building program may be applicable in Nevada. With a rising population of retirees, single parents, and transient unemployed, health care issues for these groups are growing. In addition, an estimated 45,000 people or 30% of the population of Nevada join 40 million other Americans who fall into the health insurance gap because they are not eligible for public or private health insurance.

This move back to the basics of grassroots civic participation in the political arena warrants a review of the literature to ascertain how public participation works in today's society. It would appear that we could learn more from the declared values on health care by the individual citizens than from governmental policy analysts who may be overly biased by interest group or political pressures, and therefore, perhaps far removed from the values of the people they should serve.
Many long hours went into the preparation of this project analysis. Without the assistance of many fine people, it would not have been possible to obtain the literature or documents that added so much to the information contained within the paper. I am grateful to each one.

Most specifically, I would like to express my appreciation to Craig Walton, Ph.D. who chaired my committee and who is responsible above all others in providing me the opportunity to be one of the first candidates to graduate out of The Institute for Ethics and Policy Studies at the University of Nevada, Las Vegas. Dr. Walton's time and dedication to the institute has made my years in the program unmeasureably profitable in knowledge from which I hope, through practical wisdom, I can share with others.

To my committee members, David Berry, Ph.D., Joseph Fry, Ph.D., and Satish Sharma, Ph.D. I owe my gratitude. I was fortunate not only to have each on my committee, but to have been privileged to be a student in their classes as well. Their contribution to my project has been very beneficial and much appreciated.

For all the hours I spent at the computer or at school, I owe my family a great deal. To Nick, Rich, Bryan, and Scott, I would like to say, "Thank you" for putting up with many nights of "on your own" or quick meals and for patience in these last weeks of completing this project. To my mother and father for a belief in me that never doubted, I am lovingly indebted.
Special thanks to Brian Hines, former Executive Director and Publicist for Oregon Health Decisions and Mark Gibson of Oregon Senate President John Kitzhaber’s office for their contribution of invaluable literature for this study. I also thank Judy Hutchison, Project Director of Colorado Speaks Out On Health, a community health decisions project, for her assistance and allowance to reprint their organization’s questionnaire.
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INTRODUCTION

For most of the twentieth century, health care policy making has been a closed system in which the policy making experts and special interest groups joined forces with the politically elite to decide what was best for the people. In so doing, our pluralistic system has become imbalanced.

In speaking generally as to whether the public is represented in policy making, recent (1984) studies have revealed that ...“in a massive classification of 7,000 groups located in Washington, 45% were corporations, 17.9% were trade associations, 6.5% were professional associations. Only 5% were organizations representing people who had few political resources.” (Meier 1987, 191) More specifically, in an extensive review of health planning literature it became evident that participation was high among physicians and health care planners but not among health care consumers. (Checkoway 1984, 300)

Those who ostensibly represent public opinion, special interest group leaders and elected officials, may not perceive the consumer's interests in the same way that the target group perceives them. When misinterpretation occurs, it can lead to misrepresentation no matter how well intentioned or non-maleficent the group leader might be. Over the
last twenty-five years one governmental venture into health care
left us with Medicaid, the public policy meant to provide access to all poor
not covered under insurance programs. Yet, it has failed to reach its goal.
High technology and scientific advancements have created bioethical issues
never before faced by the government or the citizens it serves. Health
policy planning did not foresee the consequences of poor insight into
long-range effects of Medicaid and Medicare. In the wake of this and other
public health care policy decisions made through this relatively closed
system, America has been left with a population at risk of erosion,
deterioration and mortgaging of its people's health.

These consequences to society warrant a discussion on health care
policy planning and decision making. Do we as a society continue on with
the trust in our traditional representative approach to policy decisions
that have led to these societal consequences or return to the principle of
citizen participation in the health care policy arena? Are our
representatives truly representing societal values and opinions?

This paper will explore this issue through the literature by first
looking at how public policy has traditionally been planned and decided and
to what degree, if any, citizen participation has played a role. Secondly,
this will be followed by an historical overview of health care planning in
the United States, and thirdly, a chapter on an example of public policy in
the making, Medicaid. Fourth, having recently been criticized, the Nevada
health planning process warrants a discussion of its policies and
procedures. Fifth, a discussion of the societal consequences resulting
from formerly set public health policy will provide an entrance into a
discussion of the innovative civic participation of the Oregon Community
known as Oregon Health Decisions. Oregon has embarked on an exemplary
grassroots venture into citizen participation in health care prioritization
issues. Sixth, the critical analysis with constructive conclusions drawn
at the end will complete the project.

The paper follows the discussion as outlined above and in so doing
brings the health care crisis into focus and brings to light bioethical
issues at their very core. Autonomy of personal decision making,
universal access to health care, allocation of resources, humane cost
containment, and allocation of scarce health care resources are discussed.
These are among the critical issues that face a political process in
need of revision.

Statement of the Problem

Pluralists argue that democratic societies are organized into many
diverse interest groups which pervade all socioeconomic strata, and that
this network of pressure groups prevent any one elite group from
overreaching its legitimate bounds. Health care policy is set within a
pluralist society, yet it has become unbalanced. Elite, interest groups,
policy analysts, and policymakers are responsible for the policy making
agenda for society, yet leave little room for public choice influence in
their policy planning and decision making. This traditional
policy making has prevented society from having its values and views
placed into the policy making process. The current process of policy
making helped to make a health care crisis. Citizens need to speak up and be heard to bring the pluralist representation in balance and decide what priorities they feel should be considered in health care policy making. (Williams 1988, 461)

Purpose of this Paper

The purpose of this study is to provide the reader with an informational base from which to become aware of some of the critical health care issues facing society today, and to suggest alternatives toward how that society can play a decisive role in the planning and development of the policies under which it must live and ultimately die. It is not the purpose of this writer to condemn the representative political system that America has adopted. Instead, it is suggested that the system is in need of repair because of flaws within its process. Perhaps also, it is due to the policy makers’ lost philosophy of striving to obtain a goal toward public service through a reflective representation of their constituents. In order to bring in balance that which is imbalanced, the political system, as we know it, needs to do some introspective analysis of its policy making process.

Following this Introspection, a proposal might be considered in which the citizens of America could be brought into the health policy making process through their communities. The idea of this is not new. However, traditionally individuals are only asked to participate as “consumers,” a people allegedly interested only in commodities and how best they can acquire them. Policy makers almost take on the role of
salesmen out to sell a product. In the whole of policy making, consumerism is stressed, and little or none is said about citizenship and how members of society should be encouraged to participate in the policy prioritization process in health care. The general policy making process appears not to define an ideal of citizenship, but instead labels the public only as consumers, constituents, voters, or worse, as “the masses.”

Public discussions in a forum-like atmosphere may enlighten policy makers as to the real values society holds on any given issue and in turn foster a revitalized ideal of citizenship. Certainly in our technocratic and scientific age, it is not unthinkable to assume citizens are not prepared to discuss these highly complex issues. However, it is possible to engender qualified discussions within an atmosphere of education and openness shared between policy makers, citizens, and legislators. It can be done and it is being done. This paper will discuss some innovative experiments.

In Greek history, Solon, the chief magistrate of the Republic during its closing years was credited with great prudence as he contained a crisis facing the people. A division over the constitution was threatened and no one could have handled the situation more appropriately. Had any of the contending orders gained absolute supremacy over the others, chaos would have resulted. About this Solon writes,

To the mass of people I gave the power they needed,
Neither degrading them, nor giving them too much rein;
For those who already possessed great power and wealth
I saw to it that their interests were not harmed.
I stood guard with a broad shield before both parties
And prevented either from triumphing unjustly.
(Bookchin 1987, 69)
It is a wise government that can create an environment that fosters citizen participation to its greatest potential, yet balance it within the current pluralistic political system of today. To accomplish this goal, citizen, policy expert, and politician alike must recognize the value of grassroots participation in policy making.

Operating Assumptions for this Paper

There are premises that the writer holds going into this study of grassroots citizen participation in the health care policy making process. Crediting The Citizens’ Committee on Biomedical Ethics, Inc., the following are given as operating assumptions:

* Cultural, legal, and technological changes have created an acute need for the ordinary citizen to be involved actively in the public discussion of medical-ethical issues.

* Information and education are prerequisites for an intelligent public discussion of such issues if it is to be sensitive to the needs of a pluralistic society.

* Public discussion, to be more effective, should initially take place at the community level so that subsequent public policy reflects the interests and values of the general public.

* Public discussion, to be fully effective, should eventually take place between the ordinary citizen and the health care professional, lawyer, ethicist, and public policy maker.

* The increased awareness of, and education in, medical-ethical issues which results from such public discussion would help individuals and families to make prudent plans for, and wise decisions in, the provision of medical care.
Public discussion of this kind avoids the need for legislation, either as constraints on patients and their families or as an additional regulation of the health care profession, as it seeks reasonable public policies on health care. (Strong 1988, 2-3)

Questions to Consider

1. Could an inclusive, democratic process of citizen education and involvement move beyond the politics of special interest group horse-trading and logrolling?

2. Could such a process achieve a greater sense of civic responsibility concerning complex matters of ethical principle and professional practice?

3. Can forums, small group and town hall meetings succeed in bringing technical issues to the public and in turn serve to provide the mechanism from which a consensus could be reached that represents all cross-sections of society?

Description of Terms

Allocation of resources to apportion shares or divide up assets; in this case to set apart or distribute money toward specific types of health care services or it can refer to the distribution of health care services to the population.

American Health Decisions or AHD. A newly formed national organization that acts as a clearinghouse for local or state community health decisions projects.

Autonomy: existing or acting independently, moral independence, self-directing freedom. In this paper the word refers to individual's
rights to decide issues and act upon them accordingly.

**Community Health Decisions or CHD:** Local or state organizations that seek to educate and obtain a consensus of the grassroots citizens on issues involving health care and bioethical decision making.

**cost-shifting:** the process of passing the costs of health care services for the uninsured and therefore, uncompensated poor between providers, physicians, insurance companies, and the public.

**democratization:** the process of creating a political unit that views the common people as being the political authority; a government in which the supreme power is vested in the people and exercised by them directly or indirectly through a system of representation.

**Oregon Health Decisions or OHD:** A state organization that is the forerunner of the Community Health Decisions Project and model for subsequent projects.

**pluralism:** a state of society in which members of diverse ethnic, racial, religious, or social groups maintain an autonomous participation in and development of their traditional culture or special interest within the confines of a common civilization.

**rationing of scarce health care resources** the limited supply of resources and therefore, can refer either to the apportionment of health care resources to a selected population only, not available to all, or only a limited amount of pre-selected services are available to a population.

**urbanization:** In this paper to be differentiated from citification and follows Murray Bookchin's definition as found in his book, The Rise of
Urbanization and the Decline of Citizenship: refers to a form of social cannibalism, with no comparable parallel in the past, that replaces rural culture and all its rich traditional forms with the mass media and technocratic values.
Chapter 1

POLICY MAKING: THE PLANNERS AND DECIDERS, DO AMERICAN'S TRULY HAVE A REPRESENTATIVE TYPE OF GOVERNMENT?

Who plans and decides health care policy? Basically, the answer depends upon whose arena you are in. There are the national health care, state health care, and local health care arenas.

On all three levels, the health care policy planning and making process is not unique from other policy development, except by the nature of issue content. The actual process follows a similar set of steps. Also in complement to one another, federal, state, and local policy development agencies are influenced by specific categories of people. On any given policy issue, there will be specialists in the content area that will act as consultants for the issue at hand, be it health care, nuclear energy, or sanitation.

So it may be safe to say that if a discussion is suitable for federal public policy-planning and decision-making, it may suffice for what happens on the state and local planning and decision making levels. The primary difference may be seen in the numbers of people who are affected by the policy and whether or not access to policy-planners and makers is any more expeditious on the local levels.

The discussion in this chapter will follow the federal process of public policy development. The first step is to understand the process of
public policy planning and decision making. It follows a systematic set of steps. Briefly, Thomas Dye describes these steps as:

* the identification of policy problems through public demands for government action;

* the formulation of policy proposals through the initiation and development of policy proposals by policy-planning organizations, interest groups, government bureaucracies, and the President and Congress;

* the legitimation of policies through political actions by parties, interest groups, the President, and Congress;

* the implementation of policies through organized bureaucracies, public expenditures, and the activities of executive agencies;

* the evaluation of policies by government agencies themselves, outside consultants, the press, and the public. (1987, 324)

The actors in each of these steps are many and hold diverse positions. But, who actually influences policy making the most? Is it equal among all groups? Probably not. The discussion over the influence of one factor, public opinion, has long been debated. Thomas Dye, in his book, Understanding Public Policy, quoted Edmund Burke, who:

believed democratic representatives should serve the interest of the people but not necessarily conform to their will in deciding questions of public policy. In contrast, other democratic theorists have evaluated the success of democratic institutions by whether or not they facilitate popular control over public policy. (1987, 325)

For Burke, representatives must interpret, even over-ride public opinion if they believe it is wrong. Whether public opinion would or should not be over-ridden may never be decided unanimously. However,
whether or not public opinion actually does have an independent, important influence over public policy can be addressed.

In his book, Public Opinion and American Democracy, V.O. Key (1967) states:

Government, as we have seen, attempts to mold public opinion toward support of the programs and policies it espouses. Given that endeavor, perfect congruence between public policy and public opinion could be government of public opinion rather than government by public opinion. (422-23)

Key feels that public opinion has some independent effect on public policy, but he is unable to provide direct evidence of it. To this issue, he says:

Discussion of public opinion often loses persuasiveness as it deals with the critical question of how public opinion and governmental action are linked. The democratic theorist founds his doctrines on the assumption that an interplay occurs between mass opinion and government. When he seeks to delineate that interaction and to demonstrate the precise bearing of the opinions of private citizens on official decision, he encounters almost insurmountable obstacles. In despair he may conclude that the supposition that public opinion enjoys weight in public decision is a myth and nothing more, albeit a myth that strengthens a regime so long as people believe it. (1967,411)

Many political scientists believe public policy shapes public opinion more than public opinion shapes public policy. This viewpoint is based upon the assumption that most citizens have little to no opinion on most policy questions. Secondly, public opinion tends to change on a frequent basis, many times as a result of news events precipitated by political leaders. Thirdly, the communication lines available to decision-makers are not as accessible to the public, and thus many decision-makers do not have a clear picture of public opinion.

Interestingly, the real actors in the policy making arena are
newsmakers, interest group leaders, and other influential persons, and not ordinary citizens. This is because the former are the people who readily access the channels of communication to the decision-makers.

Often, decision-makers respond to influential newsmakers and news stories with an assumption that the media express public opinion. This view is promoted by the media themselves, as they believe they are truly expressing the public opinion. Often, the news media confuse their own opinions and the public's as one. In a cyclic manner, the media reports their opinion as the public opinion, which in turn is accepted by the listener (public citizen) as being the opinion of the masses.

Public opinion polls are used to acquire public opinion on specific issues. However, herein lies another example of discrepancy in reporting public opinion. Pollsters often ask respondents questions they have never thought about until they read the poll. Few people are willing to admit they have no opinion and so feel obligated to answer in some way. Unfortunately, this can make polls very unpredictable and certainly fallible. One study estimates that less than 20% of the public holds meaningful, consistent opinions on most issues, even though two-thirds or more will respond to questions asked in a survey. (Dye 1987, 327)

Another problem with polls is that if a pollster desires a particular approval or disapproval of an issue, the poll can be worded in such a way as to elicit mass response in the desired direction. In Erikson and Luttbeg's (1973) American Public Opinion, a majority of respondents (52 'yes'-39 'no') in a California poll agreed with the statement: "Professors in state supported institutions should have freedom to speak and teach the
truth as they see it." However, a majority of respondents (by the same 52-39 ratio) also agreed with the statement: "Professors who advocate controversial ideas or speak out against official policy have no place in a state-supported college or university."(38) However, in defense of opinion polls, those that are repeated over time and use the same wording or ask the same questions, are more reliable indicators of public opinion than a one-shot poll.

Another difficulty in getting public opinion to the decision-makers is that communication to them is often biased. Very few citizens write or call their congressmen and certainly fewer dine and socialize with them. Most communication to decision-makers comes from newpersons, organized group leaders, influential constituents, wealthy political contributors, and personal friends. Often these people and their congressmen have common views shared among themselves. Generally, the persons who initiate communication with decision-makers are more educated and affluent than the average citizen.

In a careful study of the relationship between mass opinion and Congressional voting on public issues, very low correlations between voting records of members of Congress and the attitudes of their constituents were found on social welfare issues. Even lower correlations were found between the two subjects on foreign policy issues. (Miller and Stokes 1963, 66-72)

Who Decides What Will be Decided?

With these constraints in mind, let us now turn to the actual process of policy-planning and decision-making, to discover who is
instrumental at each level in the process. This may provide us insight into what role, if any, public participation may play.

V.O. Key, while deliberating over the impact of mass opinion on public policy, determined that persons referred to variously as "the political elite, the political activists, the leadership echelon, or the influentials," may be the true shapers of public policy. Key describes the following:

The longer one frets with the puzzle of how democratic regimes manage to function, the more plausible it appears that a substantial part of the explanation is to be found in the motives that activate the leadership echelon, the values that it holds, the rules of the political game to which it adheres, in the expectation which it entertains about its own status in society, and perhaps in some of the objective circumstances, both material and institutional, in which it functions. (1967, 537)

With the apparent lack of real evidence in literature to support popular opinion preferences in public policy, it is reasonable to investigate the possibility of elite opinion preferences on such policy planning.

Thomas Dye reveals that the literature supports the claim that elite preferences are more likely to be in accord with public policy than are mass preferences. However, this does not prove that policies are determined by elite preferences. It may just indicate that government officials are only acting rationally in response to events and conditions, and well-educated informed elites understand the governmental actions better than the masses. Yet, it could also mean that the correspondence between elite opinion and public policy is an indication that elite preference shapes public policy. (1987, 329)

Dye demonstrates this in his description of the relationship between elite and mass opinion and the Vietnam War. Early in the conflict,
well-educated Americans supported the war more than less-educated Americans. The masses, in general, had more doubts of the war than the elites. In response, President Johnson made the policy decision to escalate and sent more combat troops to Vietnam. By 1968, elite opinion had split, and presidential hopefuls only guardedly supported the Johnson policy. By 1969, nearly two out of three well-educated Americans believed it was a mistake for America to be involved in Vietnam. Mass opposition had grown stronger against the policy as well. But, it had not shifted nearly as much as the elite opinion had. Interestingly, the greatest shift in opinion on the Vietnam War occurred among college-educated groups, the groups from which the elite are drawn. These made the largest swing from greatest support of the war in 1966 to the greatest opposition in 1969. Only after the elite had come to oppose escalation did President Nixon reverse the policy by removing combat troops from Vietnam. (1987, 329-330)

It might be of benefit to go back to the beginning of the policy process then, and see who it is that influences which issues should even become policy issues.

Identifying Policy Issues—The Process in the Planning

In the policy-making process, problems of society, like national health care insurance or nuclear waste need to be defined and alternative solutions need to be suggested. This is known as "agenda setting." It is crucial to have problems defined or they do not ever become policy issues. Therefore, the power to decide what will be a policy issue is tantamount to the policy-making process. This decision is probably more important than deciding what the solutions will be.
Political tactics have been employed by influential persons, organized interest groups, policy-planning organizations, political candidates and government officials, and importantly, the mass media. These tactics are at the hub of agenda setting.

Another political tactic is the preventing of issues from becoming policy considerations. This may result when dominant elites act openly or covertly to suppress an issue because they consider it potentially detrimental to their interests. This "non-decision-making" can also occur when political candidates, officeholders, or administrative officials, anticipate that elites will not favor a particular idea and so the idea is dropped at the agenda setting time. The political system's make-up may also cause certain areas of bias within that system that have "a set of predominant values, beliefs, rituals, and institutional procedures...that operate systematically and consistently to the benefit of others." (Bachrack 1979, 43)

Schattschneider (1961) describes this in the following way:

The business or upper class bias of the pressure system shows up everywhere...The data raise a serious question about the validity of the proposition that special interest groups are a universal form of political organization reflecting all interests. (31)

In speaking of representing all interests, one group appears to promote their views as a reflection of public choice. In so doing, the mass media have become the major source of information for the majority of Americans. In particular, television reaches more people than does any other form of media: newspapers, radio, or journals. The private corporations who own the three major networks (ABC, NBC, CBS) dominate television news and entertainment despite the addition of cable and satellite programming. The people officiating these corporate networks
are few, but mighty in their power. About them, Nicholas Johanson, a
member of the Federal Communications Commission and self-professed
liberal, has this to say.

The networks in particular...are probably now beyond the check of
any institution in our society. The President, the Congress of the
United States, the FCC, the foundations, and universities are
reluctant even to get involved. I think they may now be so powerful
that they're beyond the check of anyone. (Epstein 1975, 6)

The power of television is not so much the persuading of viewers to
take one or the other side of an issue. Rather, its power lies in its setting
the agenda for decision-making. Systematic research has shown that issues
which receive the greatest media attention are likely to be seen as
important by voters. The three main networks feel they are a mirror of
reality and therefore a mirror of society. Yet, this is not the case when
newsmen decide what the news will be, how it will be presented, and how it
will be interpreted. As David Brinkley said, "News is what I say it is. Its
something worth knowing by my standards." (TV Guide, April 11, 1964)

Policymaking Process

After the agenda setting decides the issues that are to be
considered for policy, the ball rolls into another court. Policy-planning
organizations become the central coordinating points in the policy-making
process. These organizations combine the leadership of corporate and
financial institutions, the foundations, the mass media, the leading
intellectuals, and influential figures in the government. Relevant
research by credible agencies is reviewed. An attempt is made to reach a
consensus about what action should be taken on national problems under
study. Their goal is to develop action recommendations to resolve national
problems. The resulting policy recommendations are then forwarded to the
mass media, federal executive agencies, and the Congress. The purpose is

to lay the groundwork for making the policy into law. The results of elite
decision-making and consensus-building will then be reflected in the
actions of the elected officials—"the proximate policy-makers."

The proximate policy-makers are the President, Congress, federal
agencies, congressional committees, White House Staff, and interest
groups. The phrase "proximate policy-maker," is derived from the
political scientist, Charles E. Lindbloom (1968), who uses the term to
distinguish between citizens and elected officials. He says that, "except in
small political systems that can be run by something like a New England
town meeting, not all citizens can be the immediate, or proximate makers
of policy. They yield the immediate (or proximate) task of decision to a
small minority." (30)

The activities of these proximate policy-makers have been the
central focus of political science. Yet, really they are the final phase of a
much more complex process. Policy-making is a process of bargaining,
competition, persuasion, and compromise among interest groups and
government officials. Although some of this occurs in the final phase of
policy-making, most has been accomplished in the way of policy direction
long before coming into the proximate policy-maker's hands. The decisions
of these final phase policy makers are then more the means and less the
ends of public policy determination. (Dye 1987, 340)

Policy Innovation

How ready the government is to adopt new programs and policies is
known as policy innovation. On any governmental level, wealth,
urbanization and education are associated with policy innovation. First,
income enables a state, a city, a town, the luxury of experimentation. Low incomes cover the policy field with hurdles that prevent policy makers from raising monies to pay for new programs or policies. Whereas, high incomes provide tax resources necessary to begin new undertakings.

Second, urbanization involves social changes and implies concentration of creative resources in large metropolitan areas. Rural areas do not normally change so rapidly, and as a result, are less adaptable and sympathetic to innovation. Third, education plays a vital role in facilitating innovation by encouraging people to be more aware, more receptive to change, and perhaps more demanding of creative innovation.

Certainly party competition and voter participation affect policy innovation. In an environment with a frequent turn-over of state party control, new administration causes more policy innovations. This can only occur as a result of political participation both by candidates who seek imaginative programs and voters who actively take part in the election process.

Even the decision making milieu itself, viewed as professionalism of legislature and bureaucracy, can affect policy innovation. Dye defines professionalism to include "acceptance of professional reference groups as sources of information, standards, and norms." (1987, 344) It is an atmosphere in which the legislator or bureaucrat seeks to build a professional reputation that transpires his own state, motivated constantly by new ideas and a pursuit of innovation for the purpose of distinction in a chosen field. An opposing side may cautiously argue that the motivation of the professional representative could be that the proposal of innovation may be to expand his or her own authority or "empire building." Of the
above mentioned contributing factors, "professionalism" appears to be the most direct source of policy innovation. Professionals know more about program developments elsewhere through professional meetings, journals and newsletters. They have a more cosmopolitan perspective.

Second to "professionalism," education and participation are next as strongly linked in a causal fashion to innovation. This relationship appears to support the pluralist contention that an educated and active constituency can have an impact on public policy. In summary, policy innovation primarily emphasizes professionalism in legislature and bureaucracies, and an educated and politically active population.

Chapter Summary

This chapter discussion of policy planning and decision-making follows a process in which specific steps are followed: 1) identification of problems or "agenda setting," 2) formulating policy proposals, 3) legitimating policies, 4) implementing policies, and 5) policy innovation. Within this context each step has within it certain actors who play the major roles. We have learned that the elite, the media, policy analysts or experts, pressure or interest groups, legislators, and the public all have influence in the policy making process. Yet, the question arises as to whether the contributions of each of these groups are balanced within the policy making political system.

Adapted from Dye's views, the discussion brings forth some general suppositions about the impact of political processes on policy content and the people who participate in the system.

1) It is difficult to assess the independent effect of public opinion on public policy. Although mass opinion and public policy may be in
accordance with one another, one can not be certain which of the two influenced the other more.

2) There has been evidence that public policy conforms more to elite and less to mass opinion.

3) "Agenda setting" does not occur spontaneously. Influential persons organized interest groups, policy planning organizations, the mass media, political candidates, and government officials are responsible for tactics that either bring to the surface issues to be decided or suppress issues though a process known as non-decision making.

4) The mass media, particularly the three major networks play a major role in setting the decision-making agenda by deciding what will be "news."

5) The President, Congress, executive agencies, or those known as "proximate policy makers," attract the most media and public attention, but nongovernmental leaders, interest groups, foundations, policy planning organizations and the mass media may have already set the policy agenda and selected the major policy goals. The proximate policy makers tend to center around the means, rather than the ends of public policy.

6) Policy innovation or the readiness of government to adopt new programs and policies is influenced by urbanization, education, and wealth. More specifically, policy innovation appears to be mostly linked to professionalism in legislatures and bureaucracies, and an educated and politically active population. (1987, 346-347)

The question remains, is rule by an educated elite to be preferred to rule by the uneducated masses? There is an ongoing discussion between
elitists and the exponents of representative and/or participatory democracy. In the next chapter more specific attention will be given to policy planning in the public health care arena. Within this context planning agents sought to benefit most members of society primarily taking into consideration the costs involved. Citizens, always referred to as "consumers," were included but only marginally in most planning processes. Following a historical overview of planning periods over the twentieth century, planning strategies will be discussed.
Chapter II

AN OVERVIEW OF HEALTH PLANNING IN THE UNITED STATES

Descriptively, we live in a very pluralistic society. One can imagine that planning and setting policy for a population with multiplistic views on any given issue is difficult at best. As the previous chapter indicates, only a select few control most of the policy decisions made in this country. In attempting to benefit the greatest numbers of people within that society, politicians have adopted the principle of utilitarianism when planning positive public policy outcomes.

The utilitarian principle states that the "greatest good for the greatest number," should be the guiding force behind policy goals. (Mill 1939, 895-948) However, is it always the best principle to follow in planning health care policies? It is a question from which many other questions have emerged as a result of past planning for health programs. What are we to do with the left-over population of people who receive inadequate health care service delivery who are left untouched by the policy goals altogether? Those who are responsible for policy goals and policy planning for health care may need to take a serious look at defining the problems associated with the model(s) they have followed previously.

Overall health policy, according to Thomas Dye (1987), a historian, primarily follows the political rational model approach as a base and includes four fundamental steps. 1) delineation of problems and objectives, 2) formulation and valuation of alternative means of attaining
objectives. 3) implementation of chosen means, and 4) evaluation of processes and outcomes. (166)

When these steps are carried out on an individual level it results in rational behavior. When a group performs the steps, we call the process planning. In contrast, regulation of health care refers to the means by which one group of people (government agency, council, etc.) implement behavior guidelines to another group (i.e. health care consumers).

Social and economic changes resulting from an increase in the population and high technology have made the health care network a very complex system. The need for planning therefore becomes necessary in order to meet the present health care dilemmas and to address potential concerns and provide viable solutions for the future.

The planning process is quite different from country to country, depending primarily upon their philosophical and traditional administrative functions. Socialist countries own and operate almost all of the social and economic institutions. Planning then is centralized in national governments or decentralized in local governments in a comprehensive manner.

Liberal democratic welfare states have taken specific economical areas and placed them under their own governmental wing. Planning is accomplished by encompassing all the economic decisions and activities within each sector of the state.

In the United States, capitalism places planning decisions upon the private sector. Corporations and private associations accompany the greatest amount of society's planning activities via mutual accommodation, contractual agreements and other private means. Governments primarily focus their planning on public fiscal and monetary policy implementation.
provision of public goods, and the management of public services.

Planning without a means to intervene leads to futility. Techniques of forecasting and modeling are of extreme importance in private industry. They are important in the public sector too, and must stand the test of public accountability. Therefore public planning and regulation are subject to evaluation of their means and processes as well as their outcomes.

With these means and processes in view, a turn to the past might serve to give us a better insight as to how health planning has emerged and what has happened in its course through U.S. history.

Historical Review

Except for public health program planning, any formal national approach to health planning was negligible until the 1960’s. However, there were a few programs that influenced one common thought and paved the way.

The history of health services planning can be divided into three distinct periods based on the locality of the planning and the degree of comprehensiveness. The first period of health services planning ran from the 1930’s to World War II. The second period began following World War II, leaving the third period in the 1960s. A fourth period might be added to include the 1980s. Each had a specific focus.

The first planning period, 1930-World War II: Beginning with the first period in the 1930’s, two forces came together as a result of the emergence of U.S. health services planning. Organizational foundations of health planning in local voluntaristic groups and the idea of a regionalized health services system that remained the ideal upon which comprehensive health planning is focused, both shaped the formation and objectives of planning until its decline in the 1980’s.
Prior to the 1940's, health planning was primarily the responsibility of local community efforts aimed toward coordination of services in municipal public health and welfare departments and hospitals. The focus was centered upon the indigent as opposed to focusing on the health service industry as a whole. The first attempt to reform the health service industry came with the 1930 founding of the Hospital Council of Greater New York. As a direct result of the overcrowding of municipal hospitals and a depletion of the census in voluntaristic hospitals during the Depression Era, prominent citizens had initiated a survey of hospitals and recommended the establishment of a permanent planning body. In time, a few other cities followed New York's example. Financing for these programs came from philanthropic donations which were applied toward non-governmental planning agencies whose boards were primarily made up of influential citizens. Planning concentrated on estimating the number of hospital beds needed in a community.

The formation of the Hospital Council was a result of a national health care conference held by leading physicians, social scientists, public health practitioners and the lay public. The concept of health services planning came about in 1927 when the Committee on the Costs of Medical Care was formed. This committee recommended the establishment of local and state agencies to conduct research and plans for coordinating health services. The concept of regionalization was initialized and divided functions among the hospitals, clinics and medical personnel based upon integrated levels of specialization and intensity of services. Choices of the sites of care and placement of patients were to be categorized by levels of services needed.
The rationale for health services planning in the 1930's and early 1940's was rooted in social values. Planning was considered a voluntary endeavor in which leading citizens and health care providers applied their business savvy to achieve the greatest efficiency and improved health care. Regionalization seemed to offer the best alternative for the provision of health services to the nation's small towns and rural areas.

The second planning period, World War II-1960: With the advent of World War II, the American people experienced many social, political, scientific and technological changes which all contributed to the United States taking the lead in health care development. These developments led the way into the second period of health care planning. Attention began to concentrate at first on health care financing, leading to the formation of the first health insurance plan, "Blue Cross and Blue Shield." This was the era in which the principle of health care as a "right" was accepted and superceded the traditional health care as a "privilege."

Health services planning, as a result, was an issue to be placed on the public agenda. Planning agencies throughout the country were suggested and encouraged to discuss the coordination of construction of hospitals and subsidy programs. Having suffered the effects of the Depression and then W.W.II, hospital facilities were sorely in need of large-scale improvement. Either hospitals sat in areas from which segments of the population had moved away from (rural to city), or the equipment was obsolete, the facilities could not take on the increased population, or rising construction costs prohibited the private sector's ability to build or make improvements.

Congress responded with its passage of the Hill-Burton Act of 1946 (Hospital Survey and Construction Act-PL79-725). The program's main
focus was funding towards eliminating shortages of hospitals, especially in rural settings. Funds were made available to build or improve rural hospitals, and with this provision, physicians responded in order to provide admits to those hospitals. As the need for more beds decreased in time, PL79-725 was amended on several occasions to provide funds for hospital modernization and replacement and later for neighborhood health centers and emergency rooms.

Each state's program was administered through an agency of the state's government assisted by an advisory Health Planning Council. Few if any real or well-defined guidelines or resources were given to assist planners when asked to award grants to specific provider applicants. Those who were ineligible or who did not apply did not fall within the agency's scope of control. However, the Hill-Burton Act did encourage planning of hospital facilities and dealing with difficult problems of defining and estimating population's needs for hospital beds. By 1970, shortages of hospital beds was not so much the concern as was the oversupply of them. The Hill-Burton Act was phased out. In 1974, those remaining elements of health planning in Hill-Burton became enmeshed within a new legislative measure, The National Health Planning and Resources Development Act.

The third planning period, 1960-1980: However, before the 1970 acts came into existence, a third period of health care planning would have its day. During the 1960s, especially during the Johnson Administration, an abundance of federal programs came into effect under less traditional federalism. The usual mechanisms of public liability, election and executive appointment, were bypassed causing new accountability mechanisms to be necessary. Political and consumer movements of that
time mandated the choice that called for the "maximum feasible participation." Accountability involved two main emphases: 1) broadly based representation of statutorily identified categories of people on governing boards of planning and regulatory agencies and 2) the extension of standing before regulatory bodies to virtually all citizens. (Williams 1988, 379).

Health care became fully ingrained in the interest of the public, primarily because it was considered among life's necessities. With the rising costs of health care beginning to sharply increase, the threat to individuals and families abilities to secure adequate health care became a major issue.

Late in the sixties, ignorance of the complexity of medical care was assumed to preclude the consumers from making informed choices among providers and treatment modalities. Widespread insurance coverage served to blind many consumers' interest in seeking lower-priced services and promoted providers a lack of concern over cost control. There was an underlying competitive force which discouraged providers from offering lower prices for service. No one, insurers, insurees, providers, or employers paid any real attention to the mounting costs.

Despite this, the health care industry had little public control. What existing health planning and regulation had been accomplished by the health care providers was essentially closed to the public. By the 1960s these market failures had skyrocketed so much that they finally became public issues demanding public reform. However, public reform was scattered between federal and state control and left a wide variability in measures adopted.
During this period, another health planning measure was to have its day. The Regional Medical Programs Act. In 1965, Congress reacted to the variance in quality health services provided by medical teaching centers and community-based practitioners. There seemed to be little or no communication between the two disciplines. An amendment to the Public Health Service Act, resulted and proposed:

...to encourage and assist in the establishment of regional cooperative arrangements among medical schools, research institutions, and hospitals, for research and training (including continuing education) and related demonstrations of patient care. (Hilleboe 1971, 1:137)

The amendment was influenced by an earlier report by the President's Commission on Heart Disease, Cancer, and Stroke. The commission had proposed that regional centers be formed from which advanced technology could be channeled out to communities, from research and training institutions and where services could be delivered and community-based physicians be informed of new treatment modalities via continuing education. This enactment came at a time when the American Medical Association had battled against the earlier proposal for national health insurance that ultimately came to a compromise with the passage of Medicare/Medicaid. They were no less on the battle field to this amendment. The resulting act then did not have the teeth of the original proposal. The AMA succeeded in amending the bill to omit the services provision authorities and gave the program primarily a grants-in-aid focus. This alleviated the physicians' fears of governmental health centers competing with their own private practices. The program could coordinate services, but not interfere with existing patterns of health services delivery. (Williams 1988, 383)
The Regional Medical Programs Act was designed to influence...

...the coordination and integration of health services through a voluntary, pluralistic mechanism that decentralized decision making directly from the federal government to the 56 RAG's (56 regional advisory groups), which were dominated by the interests of providers, particularly by those of the medical schools and teaching hospitals. (Williams 1988, 383)

The successes of the program were its influences on continuing education for physicians and ancillary staff training. Eventually with the passage of the Partnership for Health Amendments of 1967 came a more concentrated effort toward comprehensive health services. The Regional Medical Programs survived until 1974 when it, like Hill-Burton, became enmeshed within the National Health Planning and Resources Development Act.

Hill-Burton had focused primarily on construction of and planning for facilities, while the Regional Medical Programs centered on specific diseases, at least initially. One year after the Regional Medical Programs Act, more comprehensive health planning, including environmental and personal health services, became the issue.

The new act was entitled The Comprehensive Health Planning Program (CHP). Planning became entrenched within the context of health planning agencies and their councils, and active planning and implementation responsibilities were highlighted. But caution to not interfere with prevalent patterns of medical practices were once again apparent. Unfortunately, this constraint and the absence of any real regulatory authority over health services institutions left the councils without authority to implement the health plans they devised.

CHP was to focus its program on establishing a cooperative effort among the federal and state governments and local areas rather than a
federal-to-local decentralization. The Partnership for Health Amendments of 1967 encouraged the maximal participation. CHP (a) agencies were to be made up of councils with not less than 51% of consumer members. CHP (b) agencies were to be voluntary corporations with similar consumer membership. (Williams 1988, 385)

In his text, Introduction to Health Services, Stephen Williams offers this overview of CHP agencies.

It is generally agreed that CHP agencies were unable to accomplish all of their intended aims. Empirical data on improvements in health levels, health care costs, and the like attributable to CHP planning are virtually nonexistent. However, observations accumulated since 1967 on the organization and process of planning in various sites suggest that CHP was structurally, fiscally, and politically unable to bring about the changes required to significantly affect major trends to the costs, quality, and accessibility of health services. Few statewide or areawide agencies were able to develop long-range plans, most lacked the resources needed to gather information to develop them, and none had the power to enforce compliance with their recommendations. As a result, CHP agencies existed on the fringes of the major forces that shape the nation's health services industry. They attempted to plan in a turbulent and recalcitrant environment, while the power to act remained in the hands of institutions and associations that represented their memberships and provided local funds. (Williams 1988, 385)

CHPs survived until President Nixon, in his attempts to alter failing programs, proposed the "National Health Care Improvement Act of 1970." This was designed to bring the Regional Medical Programs and the CHP Program under one authority. This too failed and both programs remained separate and ineffective until the 1974 National Health Planning and Resources Development Act (PL93-641).

PL93-641 exercised the greatest influence on health planning and regulation until the early 1980's, and its impact has continued to the present. State and local governments were given more authoritative functions. Under this act, planning agencies known as Health Systems
Agencies (HSA) were to be formed at local governmental levels. On the state level, two organizations, the State Health Planning and Development Agencies (SHPDA) and the State Health Coordinating Council (SHCC) were initiated. SHPDA was responsible in the oversight of the HSAs. SHCC was to be made up of representatives of HSAs and other members appointed by the governor of each state.

The purpose of the State Health Coordinating Council was to advise the governor of each state and set policy for planning and regulation of goals. The main focus of SHPDA and the HSA was to develop short and long-term plans which were to be developed through information gathering, to provide specific measurable performance objectives were constructed for accessibility, availability, acceptability, quality, and costs in health care service delivery.

These elements became part of the comprehensive plans, which were to be called Health Systems Plans. Other types of plans the SHPDA and HSA agencies were responsible for were known as the Health Facilities Plan, which would focused attention on personal health services providers, and Annual Implementation Plans which emphasized short-range, action-oriented strategies needed to effect the changes desired.

The major difference between the National Health Planning and Resources Development Act of 1974 and previous planning programs was its regulatory strength. Although this was the positive grain from which the success of PL93-641 grew, the regulatory authority component was the element that created the most upheaval at every level of the system. More than ever before, the federal government specifically, the Secretary of Health and Human Services, took a stronger role. Their responsibilities included oversight in regional planning sites, structures of planning...
agencies and their governing boards, formats and contents of
area and state plans, and the provision of Certificate of Need (CON) laws.

The governors of the states were unhappy with having to relinquish
their power. Many of the grassroots population feared the loss of
consensus-oriented planning into the hands of governors and federal
officials.

On this controversy, Williams (1988) writes,

These conflicting views, apparent in the hearings preceding enactment
of PL93-641, gave rise to numerous lawsuits challenging various
features of the program. Several state governors who found portions
of their states being joined in HSA’s with portions of other states
challenged the Department’s designations of Health Services Areas.
Some entered with the AMA and other parties into suits alleging that
the law’s CON provisions violated constitutional guarantees of states’
rights by coercing (through the threat of terminating particular
federal health subsidies) states to enact such regulatory programs.
Still others challenged the compositional requirements of HSAs and
SHCCs. (390)

Despite these initial controversies, the new program was begun in
most states without too many problems. HSAs were comprised of many of
the staff members who had formed the CHP (b) agencies and the staff of the
former CHP (a) agencies became the personnel staffing SHPDAs. CON laws
in most states were modified, but continued to satisfy federal guidelines.

Three problems restricted the new act’s successful
progress: 1) funding was very limited in view of the act’s extensive
planning mandates; 2) commitment to comprehensive public planning was
negligible in most state and local group planning boards, and 3) the
idealism of comprehensive planning in such a complex and turbulent
environment, such as was seen in the health services industry,
overwhelmed the capabilities of the planner’s theories and techniques
proposed to solve the dilemmas in the industry. Unfortunately, the plans
produced reflected those inadequacies and did not have much impact.
While the program under PL93-641 was being initialized, the national health insurance discussion was again in the public eye and Congress was discussing new alternatives to public planning and command-control regulation. Cost containment was the focus, but the national health insurance issue gained some prominence under Senator Edward Kennedy and other supporters. Still some argued that market-preserving regulation and rollback of market-distorting subsidies should be considered over command-control regulatory measures. The debate over national health insurance lessened, but the discussion of alternate regulatory concepts continued.

When the Reagan Administration began, it opposed command-control regulation. Programs containing this kind of language were set for repeal. The strong stance of some congressional advocates of command-control blocked the repeal of PL93-641. However, the Reagan Administration countered by cutting any funding to this and similar programs in its annual budget proposal. By the mid 80s, Congress finally relinquished the program's authorities and allowed it to expire. Some states repealed their CON laws and discontinued their PL93-641 agencies, while others resumed their planning and regulation as if the law were still in place.

During this same time frame the courts had removed the protection of health care providers, (especially hospitals), against antitrust prosecution. The market-preserving advocates suggested that health services industry be free of any regulation by anticompetitive legislation and public subsidies that distorted health care markets. This led the way for tax subsidies like those allowing the "purchase of too much shallow insurance and correspondingly, fostered the economically devastating disregard for costs among providers and consumers alike." (Williams 1988, 391)
At present, federally mandated health care systems planning is non-existent except for the continued programs under the National Health Planning And Resources Development Act's influence. Each planning period had its emphasis and each used a particular model or models of strategy in order to best develop the plans from which programs and policies emerged to solve the health care problems of the time.

The following section will address four strategic models of planning used under the Comprehensive Health Program. The intent of the next section is to show the advantages and disadvantages of the varying models upon health planning and resultant successes in addressing the health needs of the population for which the health plan is being developed.

The Planning Models Used

There are various models or strategies that planners might use as a resource from which to develop their health care plans. The following discussion will focus on four of these strategies that were used during the Comprehensive Health Programs Era. They are: 1) the rational strategy, 2) the incremental strategy, 3) the mixed-scanning strategy, and 4) the radical strategy. Except where otherwise noted, this next section is from the interpretation of David Berry, Ph.D of health planning strategies.

A social rational policy is one that achieves maximum societal gain. It therefore fits into the philosophical framework of the utilitarian by achieving the greatest good for the greatest number. Maximum social gain then should be “policies which result in gains to society which exceed costs by the greatest amount, and should refrain from policies if costs are not exceeded by gains.” (Dye 1987, 31)
Referring to Appendix 1 of this study, one can see the steps involved in a rational decision making system. As Step 2 requires the establishment of complete inventory of other values and of resources with weights, "rationalism" should then involve calculation of all social, political, and economic values in its attempt to achieve the maximum social gain.

Therefore, Dye tells us that according to the rational model, health planners and policymakers must 1) know all the society's value preferences and their relative weights; 2) know all the policy alternatives available, 3) know all the consequences of each policy alternative; 4) calculate the ratio of benefits to costs for each policy alternative; and 5) select the most efficient policy alternative. (1987,32)

The rational model is a positivist strategy that bases its methodology on scientific, proven and therefore, factual elements. It is a means-ends type of analysis. First, Thomas Dye believes the rational model is the basis for setting health care policy. But to the exclusive use of the rational model, Mr. Dye claims ten flaws in its character:

1) There are not societal benefits that are usually agreed upon, but only benefits to specific groups and individuals, many of which are conflicting.

2) The many conflicting benefits and costs cannot be compared or weighted; for example, it is impossible to compare or weigh the value of individual dignity against a tax increase.

3) Policy makers are not motivated to make decisions on the basis of societal goals, but instead try to maximize their own rewards-power,
status, reelection, money, etc.

4) Policy makers are not motivated to maximize net social gain, but merely to satisfy demands for progress; they do not search until they find "the one best way" but halt their search when they find an alternative that "will work."

5) Large investments in existing programs and policies ("sunk costs") prevent policy makers from reconsidering alternatives foreclosed by previous decisions.

6) There are innumerable barriers to collecting all the information required to know all possible policy alternatives and the consequences of each alternative, including the cost of information gathering, the availability of the information, and the time involved in its collection.

7) Neither the predictive capacities of the social and behavioral sciences nor the predictive capacities of the physical and biological sciences are sufficiently advanced to enable policy makers to understand the full benefits or costs of each policy alternative.

8) Policy makers, even with the most advanced computerized analytical techniques, do not have sufficient intelligence to calculate accurately costs and benefits when a large number of diverse political, social, economic, and cultural values are at stake.

9) Uncertainty about the consequences of various policy alternatives compels policy makers to stick as closely as possible to previous policies to reduce the likelihood of disturbing, unanticipated consequences.

10) The segmentalized nature of policy making in large bureaucracies makes it difficult to coordinate decision making so that the input of all the various specialists is brought to bear at the point of decision. (1987, 35)
Second, unlike the rational strategy, the incremental model is based on normative strategy that seeks to define values and their relationship to the issue at hand. Since man has a limited intellectual and cognitive capacity, only the interrelationship of facts and values can best benefit health care planning. Incrementalism is a conservative model that uses existing programs as a base, and concentrates on new programs and policies that increase, decrease, or modify those programs for the benefit of society.

In David Berry's interpretation of the strategies, Charles Lindblom is quoted on his feelings toward incremental policy planning and decision making as a "safer" approach. He says. Psychologically and sociologically speaking decision makers can sometimes bring themselves to make changes easily and quickly only because the changes are incremental and are not fraught with great risk of error or political conflict. In a society, for example that is a rapidly changing society, one can argue that it can change as fast as it does only because it avoids big controversies over change. (157)

Further Mr. Lindblom believes decision makers do not annually:
1) review the whole range of existing and proposed policies, 2) identify societal goals, 3) research the cost-benefit ratios of alternative policies in achieving these goals, 4) rank-order preferences for each policy alternative in terms of maximum net benefits, and then 5) make a selection based on all relevant information. He believes that in reality, the constraints of time, information, and cost prevent policy makers from identifying the full range of policy alternatives and their consequences. The incremental model therefore, recognizes the impractical nature of "rational-comprehensive" policy making. (Dye 1978,36)

Yehezkel Dror sees incrementalism as anything but the safe model that Mr. Lindblom believes it to be. He states:

..an ideological reinforcement of pro-inertia and anti-innovation forces present in all human organizations...If it is accepted uncritically, it can be dangerous since it offers a "scientific" rationalization for inertia and conservatism, can easily prove itself
through self-fulfilling prophecy and can thus block essential improvements. (Berry 1974, 349)

Unlike the rational strategy, the incremental focus is on the present. Very little thought is given to the future. The danger is that failure to address comprehensive analysis as seen in the rational planning strategy and to deal only with the small changes, may end up in monumental error. Costs in public and economic consequence could soar far above any of the costs that might be incurred, in time or money, to analyze the issue more comprehensively.

Yet, there is a good side to the incremental model. Incrementalism, or the "step lightly and cautiously" strategy, can be a step by step process for a community in which health care planning would be more acceptable. Moving for major and complete change, as the rational decision making strategy might require, may result in the complete rejection of the plan by the very population it sought to serve.

For the smaller and rural settings, where health services have primarily been in an in-patient acute care and solo practice environment, physicians and other providers are not anxious to move into an organizational pattern that may be an extreme removal from the control they have in their present environment. Writing at a time when Health Maintenance Organizations (HMO's) were just on the horizon, David Berry exemplified this well in describing how the Health Maintenance Organization (HMO) concept specifically the "Kaiser Model," might affect the rural provider groups. He says:

Physicians and other providers thus become rather cautious when they are pushed to jump from present organizational patterns in an organizational form in which physicians are salaried; are expected to
work in groups; are asked to link into a system of screening, health education, hospitals, extended care facilities, out-patient services, and home health services; are asked to consider the costs of their recommendations; are asked to be responsible for health as well as the illness of patients; and are asked to justify their actions and accept priorities established by a board highly influenced by consumers. (Berry 1974, 350)

It would seem that it might serve planners better to work in stages toward goal oriented and incremental strategies in order to solve immediate problems and while simultaneously gathering data for planning the long-term, future goals.

(3) Another strategy, the mixed-scanning strategy model, also fits a normative model (inclusive of values). Amitai Etzioni distinguishes between fundamental and incremental decision making. Fundamental decisions are made by exploring the main alternatives leading to goal formation, but would not be as detailed as the rationlist. Incremental decision making is made within the context set by fundamental decisions and reviews. (389-390).

Mixed-scanning on the other hand, is essentially taking "informational glances" at a community and its health statistics over current months in order to gain insight as to what type of health services might best benefit that particular community. Three guidelines cited as the degree of scanning needed are: cost resulting from missing data, costs of additional scanning determination, and time required for further scanning. (Berry 1974, 352) An example of this might be seen in a health center where unusual or sudden changes in morbidity or mortality reports would alert health officials to further investigate a certain disease or condition.

(4) A fourth strategy health planners use is known as radicalism. Politically, radicalism is usually viewed as an extremist position with no intermediate viewpoints offered. Societal ideology and conscience
provide the behavioral impetus the health planner might exhibit and would result in dynamic changes in health care services in any given community. What would be considered radical is relative to each community. Radical planning emphasizes decentralization, an ecologic ethic, and utilizes the tool of evolutionary social experimentation. Basic to this evolutionary experimentation is a synthesis of consciousness and action. (Berry 1974, 354).

Although traditional approaches to planning, which lean toward a centralization approach are inadequate, there may be even greater inadequacies and margins of error with decentralization which leave communities "doing their own thing." Dr. Berry quotes Etzioni's observations.

...there is a great deal of "skewed" pluralism in this country, (U.S.A.), in which many of the decisions and plans are made by "local" elites, which are more partisan, exploitative, and change-resistant than any national ones and which often are in conflict, rather than in harmony with each other. ...progress in the "present" society is often found in the national, not local, political arena (for instance it is here the defense budget could be cut in half with endless ramifications for thousands of localities and all citizens) ...(Berry 1974, 354)

Summing up the four models, the rational strategy studies all alternatives to produce the plan, where incrementalism would only look at specific problematic areas, but leave data analysis to the interest groups. The mixed-scanning strategy overviews the health picture to cite problem areas that stand out and seek alternatives, but not to the degree of rational strategy. The radical strategy is the most non-traditional of the four and is what its name implies. It is an extremist tool used to solve a specific health problem that works for a specific community or group. Where the first three are traditional models used to pull together resources under an umbrella of centralization, the radical strategist goes his own way and performs whatever is felt to be needed to take care of the problem.
During the time of the Comprehensive Health Planning Act (CHP), a documented plan was mandated by federal guidelines. Therefore, planning became the process that was intended to produce the "plan" or product. Using the rational model approach, the plan would be to include long-range goals, be as comprehensive as possible, and impacts of social planning upon health were to be considered. This process included cost-benefit ratios, transportation considerations, and population differences, and became a very time-consuming process. The methodology of decision making was then based on comprehensive analysis of all these components. 

By contrast, the incremental strategy spent little time on data analysis, borrowed many of its ideas from the established plans from other communities, and gave little attention to the interrelationships within the health system or to the impact of general social planning for its health care planning. The methodology used was of a marginal analysis base. Therefore, this process would likely take little time to produce a plan.

Mixed-scanning would be a more time consuming project than incremental decision making, but probably less time consuming than the rational strategy approach. Goals would be established but with more of a focus on specific areas associated with incremental strategy than the depth of analysis the rational approach would follow. Its methodology was based in extensive analysis with a fair degree of comprehensive consideration of alternatives.

The means to an end was the methodology used by the radical strategist who would concern himself more with major changes sought in addressing the areas mandated by the CHP Act. Time spent in planning would be moderate within the context of the radical strategy model.
Community Involvement In Planning With Each Planning Strategy

Certain of the models emphasized consensus building more than others. Within the context of the rational strategy model, the emphasis on community relations was related primarily to how many technical experts one could have its boards and on the stabilization of values. The community citizenry would be encouraged to discuss all aspects of the general planning document. But once the document was approved, the community involvement would be discouraged except for its inclusion in the delivery of the means.

In the incremental strategy, consensus building was of major importance in order to assure that the multiple interests of a community were represented. Therefore, committee membership had a fair representation of the community.

In the mixed-scanning strategy environment, public awareness of the decisions to be made and the alternatives available to achieve the goals would be stressed. The radical strategy model would be most characterized by its conflict with the traditionalist views toward health agencies of CHPs.

But what came out of these strategies used during the CHP Era (and the resultant plans from the other planning periods as well)? The next section will be devoted to the resulting policies of each period and their consequences, good and bad, on society.

What Came Out Of The Planning Periods? Health Care Policies Developed

As health care planning became an issue on the public agenda, the federal government established itself as a subsidizer. Small controllable project grants, formula grants, and later capitation grants were made available through the Hill-Burton Act. Most of the time the federal government set up a matching funds system. They were largely
successful and did not strain federal resources.

This subsidization program influenced supply with its major theme of building capacity during the programs to emerge from 1945 through the 1960s. The positive context from which it worked was, "More is better," while the normative context from which it evolved was to attack inequities between diseases and regions. During this time the economy was in a steady growth period with low inflation and little or no deficit. The major programs to emerge during this time frame were the National Institute of Health (NIH), Hill-Burton, and Manpower training. The effectiveness was evident in the production of greater supply of facilities. As training subsidies were available, health care providers filled the newly built or renovated health service facilities.

From 1965-1970, the objective of the planning period was to influence demand. Overcoming financial and other barriers to access were approached therefore, with a demand-side strategy in order to attack inequities between the classes. The economic picture was one of strong growth, still with low inflation and little or no deficit. Politically there was a more partisan, ideological and group conflict than the previous period had shown. The major theme of this era was to build access and its resultant major programs were Medicare and Medicaid. Although both policies effected access to health care for millions, there is evidence to suggest that health was not improved because of an increase in access to health services. More about this will be discussed in Chapter III.

By 1970, the objective turned toward influencing organization of the health care system to correct faulty incentives and thereby meet the needs more efficiently. Economically, the picture was of a more moderate, slow growth period in which high inflation and moderate deficits prevailed. The
political context was of a more rationalizing nature with the attitude to do something, to challenge, yet to allow the status quo to remain. The major theme of this time was to build markets and the major programs to emerge were Health Maintenance Organizations and Alternative Delivery Systems in Medicaid.

Two years later and still prevalent, the period of regulation with the main objective of influencing behavior came onto the scene. The analytic context was to assert public controls and the normative context was to curb waste and redistribute resources. The economic context was erratic growth and inflation with high deficits. Politically the goals were to eliminate waste, limit losses, control providers. The major theme was to build controls and the resultant programs were: Professional Standards Review Organizations, Peer Review Organizations, Health Systems Agencies, 1122/Certificate of Need, and Rate-setting/Prospective Payment System (PPS). (Brown 1987, 456-457) In this way, implementation of policy began to be addressed. No longer were health care providers to have full rein on setting costs and services without some oversight regulations.

**Chapter Summary**

The major emphasis in public policy planning is to address issues such that they can best benefit the greatest numbers in society. The health care system provides planning in just such an environment. Within this context certain federal planning statutes came into being that would affect citizen participation in the policy planning stages more than others. During one planning period especially, four planning strategies were employed that also affected consumer participation in general and effected consumers differently within each process. The following areas are important points of the chapter on health planning.
1) Overall health policy is derived from the rational model which: a) delineates problems and objectives, b) formulates and evaluates alternative means of attaining objectives, c) implements a chosen means, and d) evaluates processes and outcomes.

2) Planning without a means to intervene is futile. As important as techniques and modeling are to private industry, it is as vital to the public sector. Therefore, public planning and regulation should be made accountable of the means and processes as well as the outcomes.

3) Formal national health planning was negligible until the 1960's. Prior to this time influential members of society and philanthropic groups played the major roles of health services planning in their own communities. After World War II federal programs such as the Hill-Burton Act provided subsidization in order to eliminate shortages of hospitals, primarily in rural areas. Later modernization and replacement of outdated hospitals, the building of neighborhood clinics and emergency rooms were funded under this amended act.

4) In the 1960s, influenced by the Johnson Administration with its accent on creating a better society by providing more opportunities to the poor, civil rights issues emerged. Within this environment health planning became a national issue. This resulted in political and consumer movements that called for "maximum feasible participation." The Comprehensive Health Planning Act created an atmosphere that called for consumer participation in health planning. During the CHP period certain strategies were used. The rational, incremental, mixed-scanning, and radical strategies all called for some degree of consumer participation. Each took varying time frames to accomplish their goals and consumers were called upon to participate. However, although each planning model
affected consumer participation in general, citizens were affected differently within each process. Citizens were used mainly to rubber stamp plans already decided. In some cases hearings were open to the public for input during planning stages, yet these open forums were poorly attended.

5) In the late 1960s a pervasive blindness began to affect the foresight of health care providers and consumers to consequences of certain policy. First, the widespread health insurance coverage of the majority of consumers, and the competitive environment of providers blocked either group from seeing the rising health care costs. Second, members of society began to fall out of the policy goals and were left in the system in a category known as uncompensated care. Cost-shifting of monies lost over the uncompensated population, began to be displaced from physician to hospital, then hospital to insurance companies, and insurance companies to the consumers. Because of a growing crisis patient "dumping" began to occur. Private and corporate owned health facilities no longer felt obligated to assume the costs for the uninsured and therefore, uncompensated and so refused care to this category of people. This forced these individuals to find a facility who would take them, usually a publically run institution (e.g. county hospitals).

What we have created is a situation of crisis. We are attempting to provide all kinds of health care to all people. If we were discussing society's distribution of natural resources, we would naturally desire to divide those resources equitably. Policy directives then would center on the sharing of those resources within a common boundary of commodities available. If those resources became scarce, policy would look at rationing of the scarce assets within the common bounds of society. One federal health policy, legislated during the CHP Era, attempted to
give access to health care to all poor who were not covered under some form of health care insurance. It was clearly the result of an incremental strategy to achieve this goal. Primarily to this policy, Medicaid, and to Medicare, we owe the consequences we now face in the health care crisis and that has stretched the "medical commons" too thin to provide unlimited health care to all. The next chapter will show federal health policy in the making and describe the consequences. It is the long term outcomes that should be considered and that seem to be so alien to the federal health care policy planning arena.
Chapter III

FEDERAL FINANCING FOR HEALTH CARE: MEDICAID
DID IT SOLVE THE HEALTHCARE PROBLEMS FOR THE POOR?

How did Medicaid come to be? Many historians have considered Medicaid as an afterthought to Medicare. Specifically, the Medicaid program (Title IX, 1965) was an extension of another program begun in 1950. The Kerr-Mills program introduced the concept of federal-state financing. As in Medicaid, the federal government set mandatory, categorical requirements under Kerr-Mills, but restricted them to the aged population in a program known as Medical Assistance for the Aged (MAA). Medicaid extended this to categories that covered the non-aged, Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI) recipients, while assuming all aged persons 65 years or older would be covered under Medicare.

Categorical eligibility on the state level was set by the individual state's own poverty income levels. In the Medicaid program, certain mandatory basic services were to be provided including some institutional and some non-institutional care services. Optional services could be provided as well. Overall, very little guidance or regulation was done from the federal side. Therefore, the major difference between the Kerr-Mills and Medicaid programs was the extension of mandatory eligibility and federal sharing to welfare recipients who were not aged and who had previously been the sole responsibility of the states.
Medicaid also provided federal matching funds for the medically needy who were not eligible for welfare. An original objective of Medicaid was to induce states to extend eligibility to all persons with income below a certain amount, regardless of whether their incomes were low enough or their situations special enough to qualify them for welfare. This objective was dropped early on.

In reimbursement considerations, Medicaid generally followed Medicare's cost-based standards. Mandatory covered services like hospital care, physicians services, diagnostic services, family planning consults, and nursing home care in a Skilled Nursing Institution (SNI), later screening and treatment of children, could not be subject for copayment or deductible.

On the other hand, optional care, i.e. Intermediate Care Facilities (ICF's), dental care, drugs, eyeglasses, etc. were allowed copayment options. Hospital and physicians services for the medically indigent also allowed for copayments.

Who are the populations served by Medicaid?

The largest group of Medicaid recipients consists of dependent children under the age of twenty-one. Yet, they are the least costly per recipient. Dependent children and their adult parents comprise 65% of Medicaid recipients, but are only responsible for about 28% of Medicaid expenditures. The largest share (37.5%) goes for services to the elderly, primarily long-term nursing home costs. The disabled category, which includes the terminally ill under age 65 and the mentally retarded (MR's), and low-income persons with work-related disabilities, include less than 13% of recipients, but account for about 30% of Medicaid payments. (Table I)
Among services rendered, the largest share of Medicaid payments (73%) goes toward institutional care (acute care hospitals, mental hospitals, nursing homes, and Intermediate Care Facilities-Mentally Retarded {ICF-MRs}.). Per user, Medicaid payments are largest in mental hospitals and ICF-MRs because stays are frequently long. Nursing home services are only somewhat less, since elderly recipients normally have some income and must spend down nearly all of it to become eligible for Medicaid to pay.

This left only a limited population who were covered under Medicaid. Because of the constraints of the federal categories (AFDC and SSI programs), only those deemed eligible could receive Medicaid coverage.

**Who Took The Responsibility For Implementing Medicaid**

Although a federally based policy, the states were given the job of implementing the program. Because of the states virtual autonomy in setting their own poverty income levels, many people were excluded from the Medicaid program even though they were categorically sound. Or, if income was insufficient to meet the state's poverty income eligibility, perhaps they were not categorically eligible. (i.e. A two parent family with children meeting the income level for poverty would not be eligible for the AFDC program {1 parent only with children}, and therefore would not be enrolled in Medicaid).

Also, if the accounting perspective that monitors income levels is done on a monthly basis, one might see two individuals with an identical yearly income at poverty level. Yet, only one receives Medicaid coverage. Why? If income is monitored monthly, one individual may receive below
the poverty income level for one or more months of the year and be eligible. Whereas, the other individual who may make a steady monthly income for all months, may find himself without any health care coverage under Medicaid directly due to his higher than poverty level "monthly" income. (Table II)

A Look At The Medicaid Era

Throughout the current century, the U.S. has seen a steady rise in the population of poor people. Associated with "crisis only" health care and poor environmental conditions, the poor have increased health care problems over the non-poor. The black poor have higher mortality rates than the white poor. (Figure 1)

Many of the poor do not work, work for employers who do not provide group health care insurance, and often cannot afford private insurance. This all leads to the unavailability of access to health care for millions of Americans. The goal of Medicaid has been to provide medical assistance to those whose income and resources are insufficient to meet the cost of necessary medical services. The practical objectives of the Medicaid program were 1) to provide access to health care for a poor population who otherwise could not afford it, and 2) to provide health care services that would assumably improve the health care status of the population receiving those services.

Of these two objectives, the first would be met to some degree, while the second is quite questionable as to its success. Looking at the issues from a legislative view opens the discussion of the real effect of Medicaid on society.

Three points are crucial. First, that Medicaid did not affect all the poor; it was categorical. Secondly, there was no standardization of defined
medical services from state to state. Third, each state was given its own ruling choices as to what income and resources should be used to determine eligibility of a recipient within the categories.

In analyzing this health program's impact on society, one must take a look at the federal and state government's roles, and the effect of their measures on the individual, in order to understand the effect on society as a whole.

In Government. What Happened?: The Federal Arena

From 1960 through the early 1970's, the federal expenditures were highest in the area of national defense, while welfare and health programs lagged behind. Yet, by 1975 (following the end of the Vietnam War), the federal expenditure had almost tripled in welfare and health, while the national defense budget increased only slightly. Thus, the emphasis of the fiscal budget has remained focused on welfare/health programs spending at about one and one-half times above the national defense spending. (Table III)

In 1985, within that budget, the percentage of the U.S. GNP devoted to health has been steadily rising to near 11%, while the percent of the U.S. GNP devoted to Medicare/Medicaid was about 3% during that same year. Also during that year a comparison of the consumer price index with health expenditures shows a much higher percentage in the health expenditures (Table IV)

This is an important reference, as health care spending had increases sharply only in recent times. H. Tristram Engelhardt, Jr. M.D., reports the following health care expenditure percentage increases in his lecture on "The Constraints of Scarcity." In 1929, 3.5% of the GNP was spent on health care costs, 1940: 4.0% (only an increase

When Medicaid came into being, the federal treasury was in a good state of affairs. The federal deficit was low and no one really took a very long-term look at the future cost demands of health care on the budget. So, up until the Reagan years, no cost constraints or budgetary cuts were made.

Also, during the twenty-five years that Medicaid has been in effect, the monies have been increased in areas never originally intended for the Medicaid program. Long term care has been extended to cover not only the disabled and mentally ill/retarded, but a category of people not originally accounted for. This group is the elderly population in nursing homes.

Medicare was to cover all individuals 65 years and older. But one loophole in the Medicare reimbursement coverage has served to be a monumental expenditure for Medicaid. Medicare only pays the first 100 days of nursing home care. Whereas most patients in a nursing home are over sixty-five years and most stay longer than 100 days (most until the end of their life), Medicaid can and often does take over the costs when the individual spends down his lifetime savings and therefore becomes medically needy, meeting eligibility standards for the Medicaid program.

Fraudulent manipulation by providers, as well as recipients have also caused unnecessary increased expenditures for the government. In an issue of 50 Plus (1988), we read that individual physicians have been known to bill for services never rendered or bill for non-existent patients. Providers of medical supplies have increased costs to recipients
over and above the real value of the supplies in order to get a greater reimbursement from Medicare/Medicaid. Deceit on applications enable recipients to get onto the Medicaid rolls who do not belong there and thus increase costs for services they are not eligible for or could pay for themselves.

All of the resultant increases in health care spending have mandated that the costs need to be looked at closer in order to save the program and continue to service the people who need it. And because most of what occurs in the federal government's arena is cost related via budgetary cuts, the states react. When cost cuts have been made, state eligibility requirements tend to become more rigid.

In The State Arena

In the state governments, the effects of budgetary cutbacks mean less matching funds. Less federal matching funds mean more state funds have to be utilized to keep the Medicaid program going. For many this is difficult if not impossible.

In response, the states elevate their minimal poverty income levels and/or cut services in order to keep the program going. In the process many thousands of recipients are deprived of any health care access at all, public or private. Ultimately, the medically indigent individual is affected.

The Individual Plight

The literature seems to agree that there is very little in the studies to indicate the poor have enjoyed better health directly or indirectly as a result of Medicaid. One exceptional group is the Infant group: "The rates of fetal deaths, neonatal deaths, infant deaths, and maternal deaths all declined by larger percentages in the period 1965-1970 than in
the preceding five years.” (Orannemann, 1983, 17) However, with statistics favoring Medicaid’s contribution, many other contributing variables have been cited as being present during the same time frame. Increased technology and specialty care units for neonates may also have played an instrumental role in the favorable statistics. Fertility rates decreased in the late 1960’s, the economic well-being of the poor (especially blacks) brought about by social changes in the same decade, and the Great Society programs of which Medicaid was only a part, also were possible catalysts in decreasing infant mortality rates.

For the individual, by federal regulation the restriction of categorical eligibility caused only specific poor persons to be covered. These were mothers and their dependent children who were automatically enrolled in Medicaid if they were accepted into the AFDC program. Also, SSI recipients are covered under the Medicaid program, although in some states a separate application is required. In some states, not all, other medically indigent persons can optionally be covered under Medicaid’s matching funds. (Table V)

This left only a categorical few covered for health care under Medicaid. What was not foreseen was the population of poor that would evolve into a gap between public and private insurance coverage.

What is Our Legacy?

We have a long road ahead of us in trying to eliminate the national deficit, to which Medicaid annually plays the number one role in fueling the fire. Quality of care is a major issue. Where there is a tendency to control costs, and this is necessary, there is a tendency to cut programs and those who staff them. In doing so, we may be cutting the budget at the expense of depleting access to health care or the quality of that health
care when accessed. Yet access and quality both are essential components to the provision of real health care for an individual.

Rationing of care and allocation of scarce resources are the major issues of the day when discussing health care policy revisions. Yet, once again the Federal policy makers are advocating allocation of more money. This would only fuel the unnecessary, waste of medical services that are already on the medical commons. Access to health care is paramount, but access to what kind of health care is just as important. Whatever policy is adopted, a restructured Medicaid, or a comprehensive national health care insurance, Federal, and or State run, a solution will have to be addressed if we are to survive the individual and social consequences growing in our country as a result of uncompensated health care.

The next section will give us an assessment of the social consequences we have been left with and insight into how we have come to find ourselves in a health care crisis.

What Have Been The Societal Consequences?

State Senator John Kitzhaber, M.D., in a 1988 address to the California Medical Association says, "In the past ten years, 800,000 women and children have been squeezed off Medicaid, and the program, which used to cover 65% of the poor, today covers less than 38%." (712) Widening the gap further between public and private health care insurance coverage are those working class families who make just over the poverty income level, yet not enough to afford private health insurance, uncovered by an employer group health care insurance plan. These people are increasing by the thousands.

Kitzhaber continues by telling us that today this gap is not narrow; it contains 37-40 million Americans. They generate 75% of the
uncompensated care costs. These are not the downtrodden poor. These are working men and women forced into high tech, service-oriented jobs. But in many cases they are the leftovers from the manufacture-oriented era, or the minimally educated, skill-leveled workers. So, the jobs they hold are low paying, non-union and therefore without the fringe benefits of health care coverage. (712)

For the poor individual, health care will always be different for them than for the rich. The wealthy can buy every service, test and treatment they desire. It is also difficult to change public attitude, because the public is made up of individuals each with his or her own values and bias. Where the primary goal of the Medicare/Medicaid programs was to access health care to all Americans, thus ending the two-tier system, it has failed miserably.

The real world of health care finds a poor individual on Medicaid waiting in crowded waiting rooms, rushed through services, and inadequate tests and probably treated differently than the private, group-insured or out-of-pocket payor. However, with the boom of HMO's and physician fears of malpractice allegations, the middle class, privately-insured person is beginning to experience similar situations.

Despite this, the Medicaid program has opened the door of access for millions of poor who would have otherwise been without it. But the question arises as to whether this access has served its purpose in bettering the health of these recipients.

The literature seems to agree that Medicaid has played an instrumental role in paying for intensive neonatal care with costs that range from $20,000 to above $200,000 per recipient. Fetal deaths, neonatal deaths, infant deaths, and maternal deaths have declined during
the first five years Medicaid had been enforced. Yet, there are other variables that may have played the primary role—increased technology and specialty care units also appeared during that same time frame.

So, what is the social impasse? Senator Kitzhaber dramatically emphasizes the social consequences. The people left in the health care insurance gap, as Medicaid's uncovered and therefore, uncompensated, result in an erosion to our commitment to universal access. The millions who have fallen off the roles, or who do not fit the categories, or who do not fit any governmental criteria, yet remain medically needy, are not getting the health care Medicaid promised.

Because there is a physician surplus (left over from the supply side strategy of pre-Medicaid years) and because care for this uncompensated group is not subsidized, we have been left with a very competitive, market driven system in the provider community. Since market systems are not designed to foster social responsibility, no one is competing for the poor clientele. Public clinics are closing and private hospitals have dumped patients from one facility to the next, from physician to hospital, and even from physician to physician.

Kitzhaber reminds us,

...our ability to deliver on the principle of universal access has depended on cost shifting and the willingness of the business community and the government to subsidize the cost of care for the poor. While there is still supposedly a commitment to universal access, we are seeing a progressive shifting of the responsibility to pick up the cost. And, today, if a person does not have insurance coverage and does not have money, that person is increasingly likely to lose access to the health care system, either because providers will not accept any additional indigent patients or the patient delays treatment because of an inability to pay for it. (Kitzhaber, 1988, 712)

This leads to the second social consequence of a very real and measurable deterioration of health for a growing number of Americans.
Kitzhaber continues:

Of 40,000 neonatal deaths per year from complications of low birth weight (a common problem with neonates of mothers who receive no pre-natal care), two-thirds of their mothers received no adequate pre-natal care. Of the American poor, 40% are children. Only a third of them are covered by Medicaid; their other two thirds are in the gap and are losing access to basic preventive services. (Kitzhaber, 1988, 713)

Case by case, the evidence is strong. People are dying that do not have to die. A simple visit to the doctor could have saved their life or prevented the problem all together.

The third and most serious social consequence is that we are mortgaging our own future. Much, if not all the health care insurance the aged have is provided by Social Security payments (Medicare), and Social Security is running on the fuel of monies provided by the current working force. Remembering this, as the present working force ages and becomes eligible for Social Security coverage, we will turn the legacy over to a yet younger generation. As mentioned, this younger generation includes the 40% of poor children, two thirds of whom are “in the gap,” with no health insurance coverage. Sharing the gap of uncompensated individuals are the millions of young working Americans facing a $170 billion debt to foreign governments and a $3 trillion national debt. How are these people going to fuel the future for their elders in view of a $10 trillion unfunded liability (the difference between what we expect them to make and what we are planning to take out of their paychecks to pay for Medicare, Social Security, and federal pensions)? (Kitzhaber, 1988, 172-713) Since this younger generation is made up of the two-thirds of the 40% poor children mentioned above, who are uncovered for health care, and the millions of young working Americans also caught in the uncompensated health care gap, we are in serious trouble. P.G. Peterson,
writing in the October, 1987 issue of The Atlantic Monthly states, "In the past ten years, American workers have averaged a $3,100 increase per capita in personal consumption and only ninety-five dollars of that has been paid for by increases in what each one produces. The remaining $2,150 has been paid for by cuts in domestic spending and investment by foreign debt."

Kitzhaber (1988) warns us of this unfolding drama in a statement made before the California Medical Association House of Delegates:

We are asking this group of people to be more productive than anyone in the history of this country and to probably take a reduction in their standard of living. Having asked them that, we are crippling them going in by denying them access to the basic health care services they need to be healthy, productive members of the workforce. You cannot have an increase in productivity unless your workforce is healthy and well-educated." (173)

We are asking them to do what we all refused to do. We have failed to recognize that the "medical commons," like the grazing field for animals, can only take so much personal consumption and still be balanced in what it makes available. Kitzhaber (1988) sees three realities as solutions to the health care crisis. Society must recognize that 1) resources are limited, 2) a better definition of adequate or basic health care is needed, and 3) rationing of health care resources is inevitable.

What Do We Do? Scrap or Restructure Medicaid?

Unanimously, the literature favors restructuring Medicaid with many optional proposals to do so. What follows have been the most discussed proposals.

One of the most prominent is that of full federalization of the Medicaid program. The advantages of this proposal are that a uniform set of services and eligibility standards could be set for all states to follow.
This would end the disparities and inequities now apparent with the individual states.

States remain deadlocked over their own views of what welfare should be and their fiscal capabilities are as varied. So to federalize the Medicaid Program would meet with opposition on those issues alone. Also, there is a problem of political strategy. Many who favor federalizing Medicaid are also committed to comprehensive national health insurance and fear that to reform Medicaid would remove a major argument for broader reform.

Another proposed option is to remove the financial burden of long term care from Medicaid and transfer it to Medicare. Suggestions have been made to split Medicaid coverage so that routine care would become fully federal and long term care would become a state responsibility, supported at first by a block grant to be phased out by 1991. Because of the unpredictable and uncontrollable costs in long term care, the states vehemently oppose this idea.

Other policy analysts favor building in incentives for informal care giving at home: new residential options, social health maintenance organizations, public mandating of private long-term care benefits which would not easily fit into the Medicare framework and might be better promoted by demonstrations and experiments in the fifty states.

At present we have no policy to guide how we spend health care dollars. We are spending a lot in one area and not enough in others. There has been no attempt to prioritize the spending needs. Once again Senator Kitzhaber intervenes and shares an analogy to explain our present policy:

That is like having someone in charge of a corporate truck fleet who adopts a policy that the oil in the trucks will not be changed until the engine blocks melt. The trucks won't be maintained but will be
serviced only when there is a major breakdown. I doubt if you would endorse this policy for your car, nor would you employ anyone who did, but that is exactly how we spend health care dollars in this country. Rather than spending money on prenatal care, we spend it on neonatal intensive care. Rather than treating hypertension, we treat people who have had strokes. We are rationing by default, unguided by any social policy. It is inequitable, inefficient, and we are wasting millions of dollars and thousands of lives. (Kitzhaber, 1988, 714)

In Oregon the legislature is moving to address this and other inequities caused by previous federal health care policy. To do so requires a waiver from Congress as part of the legislation calls for a change in categories in order to reach more Oregonians not covered under Medicaid's requirements and a proposed change in the basic health care services now mandated under federal statutes.

In conclusion, federal health financing was created in 1965 with the intent to first, finance all elderly (Medicare) and second, to cover all other medically needy individuals (Medicaid). Medicaid's goals were twofold: 1) to access health care to the poor and 2) in the provision of access, better the health of its recipients.

Chapter Summary

There are salient points to consider in the discussion of Medicaid.

1) Federal guidelines mandated only that adherence to certain categories and the specification of a health care package must be accepted by the states if they were to adopt the program and receive federal subsidization. All other implementation guidelines were ambivalent and left the states to interpret within the framework of their own circumstances. One example was in setting eligibility by income. States could decide how they wanted to define poverty level in order for the individual to become eligible for coverage under Medicaid.
2) Problems resulted when the categories failed to cover many people who fell outside their bounds. The categories had been set to the existing Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI) recipients. Persons meeting the poverty level eligibility might be left uncovered because of categorical ineligibility (e.g. a single person with no children or a two parent family with children). Although a health care service package was federally mandated, states could offer more if they wanted. This left great variance between the states in health service offerings to Medicaid recipients.

3) Although there was evidence that infant morbidity and mortality was positively affected during the early implementation years of Medicaid, other variables may have played an instrumental role. During the 1960s a general improvement in the living conditions for the poor resulting from the Civil Rights movements may have been a factor. Also, this was a time of increasing technology and scientific advancement and neonatal intensive care units contributed to the better health of American infants. However, in no other population do we see evidence of a real dramatic improvement of health due to access to health care services.

4) Three flaws in the character of Medicaid led way to the health crisis for the uninsured that we now experience. a) Medicaid did not affect all the poor; it was categorical b) there was no standardization of defined medical services from state to state above the basic package, and c) each state was given its own ruling choice as to what income and resources should be used to determine eligibility of a recipient within the categories.

5) Three long-term consequences have resulted. They are: a) an erosion to our commitment to universal access. Those individuals who don't fit the categories or who are ineligible because of exceeding the
poverty level, are not getting the health care promised by Medicaid. b) a measurable deterioration of health for a growing number of Americans. Those who do not fit onto public or private insurance programs are not seeking or are not receiving health care when needed. These individuals make up a sicker population and some die for lack of proper or any care. Finally, c) a mortgaging of our society where a sicker generation of people is made to face a ten billion dollar deficit (foreign and national debt combined) and fuel the economy not only for themselves but for the elderly generation through social security taxes.

6) Proposals to solve the dilemma are many. The most discussed are related to a complete restructuring of Medicaid which includes: a) full federal financing that would bring eligibility into an equitable stance, b) sharing of financing between states and federal government through redistribution of funds to specific services, c) transferring long-term financing from Medicaid to Medicare, d) provision of incentives for informal health care services like home health care and, e) a national health insurance program. The issues are as varied as the solutions. In any arena, the past has not included the citizenry to a great degree other than to affect them through approving a pre-set plan or by policy outcome.

in Nevada, health policy has been planned and carried out within federal guidelines. Although demonstrating a good economic background due to the gambling industry, the state has not fared as well in the health industry. Nevada's Medicaid program is rated as one of the ten worse states as measured by eligibility requirements, service offerings, and costs to participants. Nevada has an estimated 45,000 individuals not covered by any health insurance. (Las Vegas SUN, 1989) The next chapter
will take a closer look at the health care climate in Nevada and pay special attention to its planning process.
Chapter IV

NEVADA HEALTH PLANNING

Nevada’s demographics

Nevadans are a people concentrated in urban areas or spread far and wide throughout rural or "frontier" towns. Although Nevada is considered by the United States Bureau of Census standards to be an urban state because 86% of its population reside in three major metropolitan areas: Las Vegas (Clark County), Reno (Washoe County), and Carson City, the remaining 14% reside in the outlying counties that comprise an area of 95,696 square miles.

Two trends of major significance in Nevada’s population stand out. They are: 1) the steady growth in total population forecast through the year 2000 and 2) the steadily increasing percentage of elderly in the total population. These population shifts will influence the type and kind of health care services that will be required in future years. (Draft of NHP, 1989)

Nevada is unique for its tourism. Every week of the year sees thousands of out-of-state people crossing the California, Utah, or Arizona border to enter the gambling capital of the country. So on any given day of the week, the population of Nevada can grow tremendously. During these times, motor vehicle accidents, heart attacks, or any other unforeseen illness can occur to a non-resident. The demand for emergency health services may and often are increased.

In addition, the resident population of Nevada has grown so that presently it is rated as number one for most rapid growth in the United
States. To demonstrate this tremendous growth pattern, the following describes a comparison of the age group composition of Nevada's population for 1970, 1980, and forecasts for 1990 and the year 2000.

The proportion of elderly, sixty-five years and older, was 30,968 or 6.3% of the population in 1970. In 1980 that figure grew to 65,757 or 8.2% of the population. The estimates for 1990 and 2000 respectively are, 131,580 (11.1% of population) and 189,880 (12.5% of the population). This means the total elderly population will have grown more than six times over the 1970 level by the year 2000. This is a group of people known to suffer from chronic conditions, most physical, some psychological.

Nevada has gone through other changes in age related groups. In 1970 there were 488,738 people. By 1980 the population had increased to 800,508, a 63.8% increase over 1970. The forecast for 1990 is 1,185,700 which would be a 48% increase over 1980. The estimated population for the year 2000 is 1,519,120, an increase of 28.1% over 1990. From 1970 to the year 2000 then would mean a population 3.5 times greater than three decades prior. This increase in the population will have a profound effect on the amount and distribution of health resources including facilities and manpower to deliver them.

Economic factors are such that Nevada will need to supply resources not just for its own citizens, but for the tourists who come for recreation. The possibility of stretching the resources too thin are present now. Rural or frontier areas are threatened with shutdown for lack of manpower and funds.

Another unique feature of Nevada is the dominance of for-profit hospitals. In 1987 the legislature felt obligated to create a regulatory
Statute (AB 289) as a strong hospital cost containment measure. This was implemented after 1986 profits from billed charges exceeded the ratio of income to operating expenses and resulted in more than the allowable maximum value in major corporate owned facilities primarily located in Clark County.

**Traditional Public Health Planning Process in Nevada**

From 1971 when local state health planning began until the present, Nevada has been guided from the federal level. Planning was shaped around the federal guidelines primarily because of the funding available. Individual regions were not free to develop along their own lines, but instead followed uniform measures. One such measure was tied to the Certificate of Need (CON) program which regulated health care facilities. According to Nevada planners, policy action influencing legislation was to maximize reimbursement and yet achieve the most benefits.

The next section is from an educational/informational packet included in the proposed revisions for the current Nevada Health Plan. An example of a plan development methodology that was used in an earlier Nevada State Health Plan is as follows. The criteria for the selection of the methodology included an allowance for maximum input and decision making by health providers and consumers, and the focus of the plan was to be on health services. The methodology was studied and approved by the Comprehensive Health Planning Advisory Council and an Interagency Review Committee comprised of representatives from state agencies affected by the plan, prior to implementation of the methodology.

Health issues for study were identified and assigned to Health
Issues Committees. Each committee was designed to have eight to twelve health providers and consumers and two Comprehensive Health Plan Advisory Council members. The membership structure was to reflect the socioeconomic, ethnic, and geographic make-up of Nevada as much as possible. The task of each committee was to develop one chapter of the plan by:

- studying assigned health issues
- adding or deleting health issues as the study dictated
- identifying the health needs.
- identifying the strengths and weaknesses of current health services to meet the needs.
- developing goals and short and long-term recommendations for each health issue
- assigning priorities for each health issue.

Three sources of information were utilized by the committee members: 1) position papers, 2) information collected by the committee members and, 3) data and information collected by the CHP staff. The main source of information was provided by the authors of position papers or papers developed by the staff based upon interview with health experts. The authors were requested to write upon an assigned topic meeting the following criteria:

a) documentation by graphs, charts, illustration and the source when possible.

b) provision of a description of the area in terms of practicing professionals in Nevada, services rendered, type and number of the Nevada population serviced, current and future need for services.
c) statement of strengths and weaknesses of the current health care delivery system in providing adequate health care to the Nevada population as it relates to the given area. Statement of what is the current trend and what is likely to be if the present trend continues.

d) statement of what health factors or health related factors have a bearing on the stated problems.

e) identify and evaluate alternative recommendations which will improve the health care delivery of the specialty area and the health care delivery system in general giving economic implications of the recommendations and alternatives and reasons for the position taken.

f. Rate the issue as very high, high, moderate or low-priority after comparing the issue objectively with other issues in the health field.

In response, the State Comprehensive Health Planning Agency (SHPDA) solicited papers from 220 persons and fifty organizations. Ninety-five papers were submitted and most authors met with the committees to discuss their area of expertise. Priorities were assigned to the issues by committee members. Upon the completion of this task, two members of each of the health issues committees met within the context of a Priorities Committee and determined the overall rating of health issues contained in the plan. The staff of CHP then developed a draft chapter for the committee that was in turn approved by the respective committees and the CHP Advisory Council for public review.

Approximately 500 copies of the drafts were given to health providers, consumers and representatives of all public and private agencies named in the drafts. Persons were invited to submit recommendations for changes in writing or voice them at public review.
meetings held in twelve communities in Nevada. Two hundred Nevadans participated. In addition, twenty-three representatives of state agencies submitted recommendations either in writing or at one of two Interagency Review Meetings.

Recommendations obtained during public review were compiled and submitted to a subcommittee of the CHP Advisory Council. The members then deliberated upon each recommendation and modified the chapters in accordance with recommendations. Approximately 80% of the public review recommendations were incorporated into the final drafts. Final drafts were written by the CHP staff and submitted to the Advisory Council who gave final approval for publication.

Although, some of the agencies involved in the methodology described above are no longer in existence, Nevada has held onto the State Health Plan Development Agency and the State Health Coordinating Council. At present the SHCC, who is responsible for development of the State Health Plan (SHP), is in the process of revising and updating Nevada's policies.

Current Health Planning in Nevada

On September 14, 1989, the first public hearing on the currently recommended plan was held. Only one public comment was given in which a spokeswoman for a Reno hospital made critical remarks to the past planning. According to a local newspaper the previous plans met with much criticism. The chief complaints were that the past plan was outdated, arbitrary and inaccurate. L. Scott Mayne, acting administrator of the Health Resources and Cost Review Division was quoted as saying, "The plan should be creating policy and leading the state, not reacting to what the Legislature does." (Carson City Nevada Appeal, October, 19, 1989)
Mr. Mayne said interest in health care planning declined in Nevada when the state lost federal funding for this activity in 1986. Since that time little attention was paid to updated technologies and disease developments and the plan wasn't followed through with annually.

During this time a growing number of Nevadans were falling out of the health care insurance boundaries. An estimated 45,000 or 30% of the population of Nevada lack health insurance. Nevada's Medicaid, the program that would normally insure all persons who would not fall under private or group insurance provided by employers and those who fell into the medically needy category, recently went under revue. The following will detail how Nevada fared in a 1987 study of state Medicaid programs.

**Nevada Medicaid**

At the local level, Nevada had a poor showing in a 1987 study entitled, "Poor Health Care For Poor Americans: A Ranking of State Medicaid Programs." (Erdman 1987, 187-189) Nevada was ranked as the eighth worst in the nation out of fifty states and one province. Out of 350 points possible, Nevada received 167 points. State Medicaid programs were compared in five major categories: eligibility, services, providers, quality, and reimbursement criteria.

What did the researchers of the study have to say about Nevada?

Nevada's Medicaid Program exemplifies the most key indicators of a program incapable of serving those in need: extremely low AFDC income cut-offs; a limited or nonexistent medically needy program; the exclusion of important optional groups; limits on basic mandatory services, cut corners in virtually every area of service coverage; and other barriers to care such as copayments or low availability of providers. The program has the fifth worst eligibility policies in the nation and the ninth worst reimbursement policies...Nevada Medicaid has some good points: good coverage of rehabilitative services relatively high physician fees, and the most serious effort of any state to protect Medicaid patients from dangerous and ineffective drugs. (Erdman 1987, 187)
In most states recipients of SSI automatically are eligible for Medicaid. In Nevada SSI recipients are required to file a separate application. At the time of the 1987 study, Nevada excluded from coverage some major optional groups: two-parent families in which the parents are unemployed, some categories of children who are poor enough to qualify for Medicaid, but whose family structure disqualifies them, most aged and disabled people receiving state payments called SSP that supplement SSI but do not receive SSI, and others.

Under services, Nevada does well in rehabilitative services and regular home care (home health, personal care, and private duty), and community-based services (physical, occupational and speech and hearing therapy, prosthetic devices, and substance abuse treatment). These are the good service areas. The bad news is that mental health services are disastrously inadequate. In-patient psychiatric care and psychologist services for those under twenty one are not covered; psychiatrist, clinic, and outpatient mental health visits are limited to two per month. Other services not covered are abortions (except in life endangerment), over-the-counter drugs, and preventive, diagnostic and screening services. Strict limitations exist on adult dental care, drug prescriptions, and well-child screening visits.

The worst aspect of Nevada's Medicaid program is the tremendous copayment burden it imposes on the program enrollees. Out of pocket payments range from one dollar to three dollars for a visit, equipment use, or transportation fees. For any recipient entering an Intermediate Care Facility (ICF), Intermediate Care Facility for the Mentally Retarded (ICF-MR), or any recipient over sixty-five receiving inpatient
psychiatric care, and any recipient over twenty-one receiving skilled nursing home care is required to contribute half of the first day's payment. Like most other states, Nevada does little to monitor and control quality of Medicaid care other than in controlling drug prescribing and protection of patients from dangerous, ineffective and misused drugs.

In a recent (1989) interview with the Chief Health Officer of the Clark County Health District, Otto Ravenholt stated that all Nevadans are guaranteed emergency health care. But for preventative or basic health needs many may be left without health care services. One population is sorely lacking any security of health care. This group is the mentally ill. The health care system is greatly in need of restructure in our local community. Those who seek mental health care through emergency and primary health care centers easily fall out because referral mechanisms are lacking within these centers.

Nevada's Health Plan For The Future

The present guidelines for health planning in Nevada have been issued by Governor Bob Miller and propose four goals for Nevada: 1) access to health care 2) quality of health care 3) affordable health care, and 4) Public health. In a letter made for release to the council, Governor Miller made the following remarks concerning his proposals:

The citizens of Nevada should have universal access to necessary basic medical services in their communities. The state of Nevada should make the best possible effort to assure its citizens that medical personnel, equipment, and facilities are the highest quality. Cost should not be a barrier to obtaining necessary health care. ...Nevada has an obligation to keep health care costs affordable and to assist those citizens who cannot pay for necessary medical services. ...Citizens should be protected from injury and communicable disease and information should be made available to them. (Miller 1989)

In view of the issues facing Nevadans, as written by Governor
Miller in his proposals, it is evident that there are problems that need to be addressed and that it might benefit the State Health Coordinating Council to have the grassroots views on these issues. Questions of universal access, quality of care, costs, and public health all bring forward bioethical issues. Who will have the final say as to whether life support measures should be implemented; the family, the courts, the doctors, or the patient? Questions of autonomy in one's own health care is at issue. Who will decide who can receive a certain type of care? If universal access is accomplished, what will that access be to? Will all Nevadans be provided all types of care? Or, if the care is defined, who will define it? Who is to prioritize the health care needs of Nevadans? Will Nevada be willing to pay the bill for the estimated 45,000 uninsured? Not all of those individuals may be eligible for Medicaid coverage. If they are not, who will pay for them if there is to be universal access? For public health in general and to the people with AIDS (PWAs) more specifically, who will protect their interests and at the same time the health interests of others?

These and so many other questions need to be addressed. Is it appropriate for citizens to have their views heard when the decisions will affect them personally? If the answer is yes, will that occur under the most current State Health Plan process.

According to the draft of by-laws and revisions for the 1988-1992 State Plan, it would appear SHCC will follow the same procedure as described previously for the state. To date, only providers appear to have responded to issues addressed in the newly drafted plan.

The legal basis that the plan exists upon is from the 1971
legislature which enacted NRS 439A which established a Comprehensive Health Planning Advisory Council which had the authority to develop a State Health Plan (SHP) and to regulate growth of health care facilities through the CON program. Nevada was one of the earliest states to enact such a statute. The current form of NRS 439A (1989) vests the responsibility for CON decisions in the Director of the Nevada State Department of Human Resources. Within that department, the Division of Health Resources and Cost Review (HRCR) is the agency which conducts the reviews of projects under CON statutes. The current statute also provides for a seven member State Health Coordinating Council having the duties of reviewing the SHP at least biennially and making recommendations for any necessary revisions.

The process of developing the SHP is complex and involves a working relationship between the SHCC and HRCR. Upon completion of the draft, and following public review, the staff presents the document together with comments received during public review to the SHCC for final modification and adoption. Upon review and approval by the Governor, the document becomes the Nevada State Health Plan.

The 1989 By-laws draft presented at the SHCC meeting of November 17, 1989, says that representation on the committee must not be less than seven or more than fifteen. No less than fifty percent nor more than sixty percent of the membership is represented by consumers. All members are appointed by the Governor. (Article 2.1, Section 2 and Article 3.1, Section 3)

A public information sub-committee has been chosen and the guidelines written for them are as shown in the 1989 approved draft of the
Nevada SHCC By-laws. The excerpt seems to imply that citizens will be made aware only if the sub-committee feels the issues are necessary to be publicized. It reads:

There shall be a Public Information Committee which shall include the Chairman of the SHCC, the Chairman of the Plan Development and appointed by the SHCC Chairman. The Public Information Committee shall advise the Council and the Department as to the need of the public, including consumer and provider entities, in obtaining information regarding the organization, purpose, activities and functions, current or proposed, of the Council. (Section 3.3 Public Information Committee-PIC)

Because of these trends and the inherent demand for specific types of health care services that tend to be sought by a poor population and with the rising numbers of uninsured, it is of vital importance that we hit the health care crisis head on before it becomes monumental in Nevada. With this in mind, Nevada is not unlike another state, Oregon, who faced similar problems. One perceptive physician created an innovative method of including the citizenry in health care prioritization issues, much like Nevadans are facing today. The next chapter will discuss Oregon Health Decisions and a concept that has become known as the Community Health Decisions Projects.

Chapter Summary

1) Nevada was one of the first states to implement health planning under federal guidelines during the Comprehensive Health Planning era. Health planning in this state has followed the traditional process of relying upon experts to create policy proposals. Fitting into the picture only slightly are the citizens of the community. Once again, the public is referred to as consumers and given access to the governmental health planners primarily through public hearings. Although it is mentioned that
consumers are given copies of the plan, there is no real explanation of how they can become involved in the planning process.

2) Nevada ranked as eighth worst in the nation out of fifty states and one province. States were ranked on eligibility, service offerings, reimbursement criteria, providers, and quality of services. Nevada does well to regulate drugs, especially to the elderly, but does little for another Medicaid recipient group, the mentally ill. An estimated 45,000 people remain uninsured and uncovered for medical care in Nevada. This will add to the burden of the Nevada Medicaid program which already suffers from faults previously mentioned.

3) By the year 2000, the growing population is estimated to have increased over six and one half times what it was in 1970. There has been a tremendous increase in elderly residents. These people suffer from chronic diseases more than any other age group. The general population will continue to sharply increase. Added to this rapid growth pattern, the state sees thousands of out-of-state vacationers weekly. This places tremendous priority on emergency service availability for the visitors as well as for on-going primary and acute care health services for the resident population.

Oregon is addressing the critical health care issues discussed in this chapter. In that state it was decided that "universal access" would be re-defined to open eligibility to everyone not now covered under some type of health insurance. Access to health care is being identified more specifically. Oregon Health Decisions is setting a precedent in obtaining a consensus on these health care issues.
COMMUNITY HEALTH DECISIONS: A GRASSROOTS VENTURE INTO CITIZEN PARTICIPATION IN HEALTH CARE POLICY PRIORITIZATION ISSUES

In 1984, the Board of Trustees of The Prudential Foundation, together with The Hastings Center, made a decision that may well have started a new dimension in health planning and policymaking in America. The Prudential Foundation approved a two-year $250,000 program to support community-based bioethics decision making.

A short historical overview of The Prudential Foundation might help to put this project decision in perspective. The Foundation is a philanthropic program that allocates extensive resources to socially responsive activities. It both initiates and funds programs aimed at assisting varieties of organizations in new and creative ways. Yearly, hundreds of grants are awarded to programs and organizations throughout the United States. Grants are awarded in five program areas with priority given to health education and urban and community development.

The Prudential Foundation supports the development of health policy and the solution of critical health issues. It is upon this stage that the "Community Health Decisions" (CHD) concept began to emerge. Prudential initially responded to a request by the Hastings Center, a non-profit research and educational organization which primarily focuses on ethical issues in medicine, biology, and the behavioral sciences. Within this framework, Hastings had begun discussions on how a public participatory
program of evaluating bioethical issues could be started.

In response to its nationally distributed Request For Proposals, The Hastings Center, in collaboration with The Prudential Foundation, received approximately forty project proposals from non-profit organizations in thirty states.

The Funding Of Oregon Health Decisions

In order to get an idea of the funders' viewpoint, I decided to call the major source of funding for OHD, The Prudential Foundation. I spoke with Rick Matthews, the Program Director. I asked Mr. Matthews to give me a little background as to how Prudential got involved in the program and what guidelines if any were given the OHD group; and what compensation was required in giving OHD the funding money.

The question dealing with guidelines coming from Prudential, was answered very simply. Since OHD was already in progress when their grant proposal came through, Prudential was very flexible and did not stipulate any real guidelines.

In response to my inquiry on compensation, he only said that it was important that OHD could show that they could reach all parts of the state, even those very sparsely populated, hard to reach areas, thus showing they were able to reach most of the state population and therefore have a clearly representative view of a wide variety of people.

Mr. Matthews went on to say, that they did expect OHD to reach the goals they themselves had set, which were to educate the population in the areas of bioethics and derive a consensus. Prudential was so pleased with the results that it decided to extend the funding two more years to Oregon Health Decisions and the five other projects that were initially funded with OHD.
Oregon is the focus of this overview of a CHD project, because it was the first state to begin a health care priorities consensus venture at the grassroots level. Oregon began a state grassroots movement toward resolving health problems, based on four principles—1) personal autonomy, 2) equity of access, 3) prevention of illness, and 4) humane cost containment. By grassroots, I refer to CHD's premise that the project be citizen-based in order to develop statewide awareness of specific bioethical dilemmas.

Why Oregon Health Decisions?

We have explored the traditional health care policy making process to better understand what contributing factors were present to bring about Oregon’s revolutionary project. With reference to the governmental process, Oregon does not function differently than federal or other state policy making processes described earlier in this paper. However, the political environment in Oregon does have its own inherent characteristics. So to give us better insight into why Oregon started such a program, an overview of Oregon’s geographical, cultural, and political environment would service the reader well here.

Summarizing from Brian Hine’s (1985) guide to community action on bioethics, we can get an overview of Oregon. Oregon’s geography is most attractive and stimulating, ranging west to east from the Pacific coastline, to the fertile Willamette Valley, to the forest and high peaks of the Cascades, to the vast dry plateaus and deserts of eastern Oregon. Almost half of Oregon’s 2.6 million people are clustered in the northwest corner of the state in the Portland metropolitan area, with most of the rest living in a fairly narrow corridor of mid-sized cities (Salem, Corvallis, Eugene,
Roseburg, Medford) ranging down the Willamette Valley. Eastern Oregon is very sparsely populated, having about 14% of the state's people and 70% of the land area. Less than 4% of Oregonians are black or of Spanish origin. Thus the population is considerably more homogeneous than the nation as a whole.

Although difficult to encapsulate, the political leaning of the state is generally conservative, yet yields such independent-minded politicians as former governor Tom McCall, former Senator Wayne Morse, Senators Mark Hatfield and Bob Packwood, and Portland Mayor Bud Clark. Oregonians fiercely protect their freedom from government regulation, but passed the nation's first "bottle bill" and tough land use planning laws. Both politically and environmentally it is one of the cleanest states in the nation. Political "scandals," which make the front page in Oregon, probably would receive only a shrug of the shoulders in most other states. Both local and state government are marked by an almost naive and pioneer-like faith that "people can make the difference."

Although sounding a little ideal, there are a few other facts to be noted. Many parts of Oregon have chronically high unemployment due to the state's economic dependence on lumbering and wood products. Housing is one of the first areas of the national economy to suffer from recession and one of the last to recover. It is said that "when the economy sniffs, Oregon sneezes." High tech firms are being wooed with some success to the Portland area, but thus far they have not replaced the jobs lost in wood products. Coupled with the state's reliance on property and income taxes for government funding, this makes for lean state, county and city budgets.

Oregon's Medicaid program, for example, reportedly has been one of
the most restrictive in the nation, even with the expanded funding mentioned earlier. (Note: Even with this comment, Oregon was rated #9 in the same overall Medicaid Rating Study of 1987 that rated Nevada as number forty-four out of fifty states and one province). (Table VI)

Much could be said about the special qualities of Oregon that influenced the OHD project, but the essential point to be made is that Oregon Health Decisions was developed in an environment which give a particular shape to the direction taken by the project. Organizers of the grassroots bioethics projects have been encouraged by this project through its model, but advise others to remain acutely aware of their own state's equally particular political, cultural, and demographic/geographic make-up. (Hines 1985, 12-13)

Since Oregon's population is spread widely, and many are in rural, frontier areas, people power was essential to get the word out about OHD, its issues, and the its small group and town hall meetings. As it turned out, this was also true for the metropolitan areas, although the problem identified in the cities' was that not enough media were emphasized and not enough time was given for advertisement of OHD and its purposes and meetings. Therefore, the volunteers in these highly populated areas often felt overwhelmed.

Historically, elected and appointed officials had made the decisions and set policies for statewide health services and monetary allocations for its population. More recently, citizens asked whether they leave it up to their elected appointed officials to represent the values of citizens when deciding health-related budgetary and legal issues? And, if so, how do these officials come to understand these values?
Oregon was the first state to answer "no" to the first of these questions, and to organize and initiate a health priority grassroots venture in 1982. But the story began earlier for Oregon. During the economic recession of 1980, thousands of Oregonians were out of work and therefore lost health insurance coverage. This not only decreased the working force, but served to increase the rolls of the medically indigent as well.

Searching for policy initiatives, the Oregon Health Council convened the Governor's Conference on Health Care for the Medically Poor. The conference brought to light severe bioethical dilemmas about allocation of limited resources. For example, who should receive health care services under limited federal health care dollars, a possible recipient of an organ transplant or a mother in need of prenatal care? Should unlimited health care services be available to all, publicly insured as well as privately insured individuals? This ethical dilemma as well as others became issues to which one person or one group of people could not provide an answer. It was decided to appoint a task force to develop public awareness and consensus on bioethical issues.

Prior to the 1982 conference, Dr. Ralph Crawshaw chaired Oregon's Statewide Health Coordinating Council, the body responsible for the national health planning act for melding plans developed by the state's three health systems agencies into a State Health Plan. Dr. Crawshaw proposed that the Council redirect some of its time to examining the serious problems of the medically poor, those people not eligible and therefore not covered by Medicare or Medicaid and who lack the money to buy private health care insurance.
Since funding for what came to be known as the Governor's Conference had to be raised from private sources, a non-profit corporation was formed by the Council. The State Health Planning and Development Agency provided the lead staffing. Drawing upon the deliberations of about sixty concerned Oregonians who were formed into panels, a number of resolutions aimed at improving access to health care for the medically poor were passed at the 1982 Governor's Conference. One resolutions led to the formation of a Coalition for the Medically Needy that in turn became successful in lobbying the state legislature to participate in Medicaid's optional "medically needy" program.

Another related resolution suggested that long term attention be paid to the medically needy and other bioethical health care issues which planted the seed of Oregon Health Decisions. Introduced by the panel of ethicists (primarily religious leaders), it said that a task force should be appointed to study biomedical ethical problems related to contemporary health care practices. These problems included rationing of services to the medically poor, legal and ethical issues associated with the use of high technology life-support systems, and the allocation of scarce public dollars among health programs. Quoting from the conference's final report:

Up to now, isolated segments of society typically have assumed, or been given, the responsibility for searching for answers to such bioethical questions: the courts, legislature, religious bodies, government bureaucrats, etc. The task force called for by the conference would be a first attempt to have the full cross-section of the citizenry examine bioethical health care issues. (Hines, 1985, 11)

When the conference steering committee convened to decide how to activate the recommendations, Dr. Crawshaw agreed to implement the
bioethics task force resolution. His efforts eventually culminated in Oregon Health Decisions (OHD). Though the effort was founded philosophically on the need for grassroots citizen participation in making bioethical decisions, in reality without the active support of physicians, hospitals, nurses, and the health insurance industry, it is unlikely that a viable community effort could have been effective.

Oregon Health Decisions operated with two unpaid staff, three paid staff, three semi-paid staff and a host of volunteers. The project director and deputy project director were both physicians who received no pay for their many hours of work. Dr. Ralph Crawshaw was the resident visionary of OHD. A fine speaker and writer, he excelled in communicating the need for the project to the media and professional groups. Dr. Caroline Lobitz was a self-described "practitioner of civic medicine," and was instrumental in assisting Dr. Crawshaw with fund-raising efforts and other duties.

The executive director, Michael Garland, was associate professor of Public Health Preventive Medicine at the Oregon Health Sciences University with a doctorate in theology. Expert in the scholarly dimension of bioethics, he also was in charge of the practical management tasks: revenues and expenses, setting up steering committee meetings and reporting to the board. The publicist, Brian Hines, prepared press releases and other informational materials and responded to inquiries from both the media and the general public. For the majority of literature review of OHD, it is to Mr. Hines this paper owes most of its references.

Three others, Lauretta Slaughter, Kathleen Howard, and Deborah Dunn, represented Oregon's three health systems agencies. They were the
link between the Oregon Health Decisions steering committee and local community representatives in their area and most of their efforts were subsidized by the health systems agencies. The volunteer community representatives, who were to become the means by which OHD contacted Oregonians at the most local level, were chosen by these regional liaisons.

Advisory committees provided valuable support to the steering committee. The project director saw a need to formally involve physicians, nurses, attorneys and the clergy with the project, above and beyond their participation in the community meetings. Medical, nursing, legal and religious advisory committees were established with members drawn from well-respected leaders in their professions. These committees met on an ad hoc basis to comment on report drafts and develop input from their colleagues on the whole OHD process. The nursing and religious advisory committees prepared position papers reflecting their unique perspective on bioethical issues. Committee members made special contributions during the drafting of the recommendations when the need to consider the perspective of professional groups was needed.

Brian Hines (1985) feels that managing the project should be viewed less as a well-structured process in which community knowledge of bioethics is manufactured, and more as an artistic venture that created wisdom. The intention was not to downplay the importance of careful planning at the outset of a community-based bioethics project, but to recognize that just as an artist continually modifies his or her creative image while paints are actually applied to the canvas, so will the project soon take on a life of its own that transcends the organizers' initial conception. (16)
Carrying Out Community Education and Discussion Activities

All the organizing, staffing, budgeting, and fund raising led up to the strategic goal of this community based bioethics effort to bring the delivery of health care services more in line with broadly-held citizen values. It was important for the tactical activities undertaken by the project to be in harmony with a set of guiding principles established early on. The staff of OHD began by setting down several assumptions that constituted the philosophical underpinnings of the project. They are reproduced here:

1. If we are to find long term solutions to our problems with high cost medical care, access to care, charity care (cost shifting) and potential dehumanization, the problems must be faced and understood by the local communities that experience the problems.

2. An informed public, concerned health professionals, and wise restrained government are all necessary to open, prudent discourse on health decisions.

3. Increased public awareness of the critical health decisions all families must make in the coming decades calls for a special educational effort endorsed and fostered by state and community leaders.

4. The proper development of a community forum on health decisions must include full consideration of the moral constraints of our culture as well as the financial constraints of our economy.

5. Concerted efforts must be made to reinforce the individual/patient and his family as the central consideration in all health decisions concerning the care of patients - not government priorities nor professional goals.
6. Legislation should be avoided to pursuing community consensus on health decisions, particularly any additional legal constraints on patients and their families, or additional government regulation of health professions.

7. The necessary advancement of medical science is best pursued through developed public understanding of the costs and purposes of medical science, scientists, and the supporting scientific industries. (Hines, 1985, 19)

Mr. Hines further states the processes that were to be used by the project to engage the public in an examination of bioethical problems. These principles evolved gradually during the planning phase of OHD and were never written, but are summarized by Hines (1985) as follows:

* Citizen involvement with the project should take place at the most local and personal level. The overall community of concern is the state of Oregon.

* People should be allowed to discuss concerns with the health care system in their own terms, and not forced to translate their “language of human suffering” into professional pedantics.

* No constraint should be placed on the issues that could be raised by the public at community meetings, though an effort should be made to focus discussion on key bioethical dilemmas facing the county, state and nation.

* Positive action, as opposed to mere talk, is the ultimate goal. (Hines, 1985, 19-20)

With these assumptions and principles in mind, OHD decided to use the health planning network in a three-stage process. The first step would
be a training conference for community leaders from throughout the state. During the second stage, these volunteer representatives would work with their communities by means of workshops, symposia, and town hall meetings to develop understanding of, and consensus on, the ethical problems in health care of most concern to the community. In the third stage, representatives were to convene for formal debate and voting on proposed health policy recommendations that emerged during the stage two discussions. Approved recommendations would be the basis for a policy statement on ethical questions in health care to be promulgated by the Oregon Health Council.

The initial project took two and a quarter years from the first informal discussions among a few interested people to the issuance of the final report. The first stage of the process began with an initial training conference which had a two-fold purpose: First, to orient the volunteers who would be organizing the meetings in their local areas; second, to begin the project with discrete and well-publicized events that would help make both the public and the health care community aware of OHD. Local representatives were recruited by the health systems agency staff who served as regional liaisons for the project. Each agency was asked to choose approximately ten citizens who were interested in bioethics issues and actively involved with their community.

The resulting thirty-two community representatives were a mixed lot of concerned citizens. They included six nurses, three clergy, two social workers, a physician, chiropractor, economist and attorney. There was a county commissioner, rancher, adult educator, hospital oncology planner, county medical society director and hospice director. Twenty
volunteers were women and twelve men. They came from all over Oregon, from towns of several hundred people and metropolitan areas of several hundred thousand.

Four experts were invited to address the OHD representatives and staff on various aspects of bioethics and to participate in small group discussions. Alexander Capron, LL.B. (attorney), Joanne Lynn, M.D. (physician), Gerald Winslow, PhD. (Professor of Religion), Ross Anthony, Ph.D. (economist). Capron and Lynn had been director and deputy director, respectively, of the President's Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research, which had recently published a set of reports.

Groups toured a neonatal intensive care unit, a hospice, and a hospital children's center where severely handicapped children, some brain dead, were cared for. These units brought home the reality behind the discussion for those volunteers and staff who did not work in the health care field.

Sessions were closed to the public, but all four Portland television stations covered the meeting, as did major area newspapers. Also, production of a twenty-six minute videotape based upon footage of conference addresses and small-group discussions was contracted for. So Oregon Health Decisions was publicized and off to a good start.

As the second step of the process had begun, the small group meetings, which were the heart of the OHD project, now began. While there were a variety of state and national seminars, conferences, task forces, blue ribbon committees and the like pertaining to both individual and societal bioethical issues in health care, the goal of OHD was to
introduce two new elements in health to these largely professionally oriented exercises. OHD wanted to bring discussions of bioethical issues to the level of the general public and to make those citizen meetings part of a process that would lead to action instead of only talk. This action would take the form of legislative recommendations for health policy.

This was the challenge facing the thirty-two volunteers as they left the conference and returned to their communities. During October and November of 1983 they met with their area health systems agency staff, the project's regional liaisons, and planned how to bring OHD to the people.

**Small-Group Meetings**

In November a "Small Group and Town Hall Meeting Information Packet" was distributed to the representatives, though some had already begun organizing meetings on their own. Although there were some variations among the approximately 300 meetings that took place in every corner of the state during the OHD process, most followed the general guidelines outlined in the packet.

The following scenario serves to describe a typical town meeting agenda. The group leader would describe the Oregon Health Decisions organization and give a brief overview of the issues being addressed by the project. Then the videotape, "Oregon Health Decisions: Choices and Costs in Health Care," often would be shown, (ten or twenty-six minute versions allowed for adapting to short and long meetings). Another tool used was an opinion survey containing twelve closed-ended questions pertaining to specific bioethical issues, and several open-ended questions where respondents could indicate additional issues with which they might be personally concerned. Although the original survey for OHD was
unavailable in time for this writing, another survey from a similar project, Colorado Speaks Out On Health, molded from OHD, is included in the appendix. (Appendix 2)

Since the initial use of this type of survey, that was only intended as a discussion starter and not a Gallup poll, it was decided by OHD staff that fewer people would feel the survey was biased and more people would respond to a more open-ended questionnaire.

OHD representatives attended meetings of the local Lion’s Club, Rotary, Chamber of Commerce, senior center, ministerial, medical and bar associations. They spoke with college classes and church congregations, at hospital staff meetings, professional conferences, and seminars.

Depending on the group composition, discussions would center around very personal, emotional stories, often with considerable anger as to how a wife or husband was treated by a perceived callous physician or hospital staff during his or her last days. Such tales often involved the use of expensive life-prolonging technology which apparently did little for the patient and left the survivors with a horrendous hospital bill and unresolved feelings. This led to discussions of autonomy in the patient’s rights to refuse care.

Groups of physicians, naturally enough, would talk in a different vein, venting their frustrations with government regulations intruding into the doctor-patient relationship or the inadequacies of state funding for Medicaid clients. Clergy would discuss their involvement with parishioners faced with death or serious disease and how health care could better support them at this time when the veil between the material and spiritual worlds grows so thin. Public health workers voiced their
annoyance at the short shrift preventive programs get when health dollars are divvied up. Such issues as the individual versus the societal contract, the right to die and allocation of scarce resources would result.

Because no constraint was placed on the issues that could be put on the table at the small-group meetings, an incredible variety of concerns were raised. The moderator, who generally was a community representative or project staff member, would try to distinguish common themes that ran through the remarks of participants and eventually got the group to reach a consensus on their top three concerns. At well run meetings there was a sense then of closure, of a feeling that some order had been brought to the many and varied problems raised by attendees.

One lesson learned was that there was an apparent inverse relationship between the size of the community and the ease with which citizens could be engaged in the OHD process. People in small towns seem more apt to be "belongers" than are urban dwellers. They appear more likely members of organizations, church fraternities, or women's groups. There appeared to be a stronger sense of community between residents in rural and semi-rural areas, which made it much easier to attract them to this grassroots effort. By contrast, the Portland metropolitan area was difficult to crack, partially because the representatives were perplexed and overwhelmed by the task of conducting small-group meetings in a complex metropolis of a million people.

**Town Hall Meetings**

Town Hall meetings were the culmination of the hundreds of small-group sessions. During March 1984, seventeen were held throughout the state. Their purpose was to:
* allow interested citizens who had not participated in one of the small-group meetings a final opportunity to express their views;

* summarize the conclusions reached by project representatives through the small group process and permit people to comment on the validity of that assessment of local sentiment; and

* provide another arena for general community education and consciousness raising concerning bioethical issues. (Hines, 1985, 25)

Attendance ranged from sixteen to sixty people, with an average around forty. The town hall meetings, that were expected to be the rousing crescendo to the first stage of the process, were the biggest disappointment in the Oregon bioethics project.

It appeared it was better to be a part of pre-existing groups for presentations than to call people out of their homes. One reason given was simple: the general public is interested in discussions of bioethics, but not at the cost of leaving hearth and home on a raw March evening. But all in all, even these less well-attended meetings added up to the 5000 Oregonians (1 out of every 500 Oregonians) who were reached across the state.

Though scattered Oregon Health Decisions meetings continued to be conducted for several more months (mostly by invitation), the town hall meetings marked the end of the project's initial active community involvement phase. The next task was to make sense out of the 300 meetings that had been held between October 1983 and March 1984. Local representatives were asked to prepare a summary of their town hall meetings, since those sessions were intended in part to encapsulate the views of area citizens.
However, the primary source of information from which statewide conclusions were drawn was the 5000 surveys completed by most participants at the small group meetings. Many of the results were interesting if not intriguing. Only five percent, for instance, disagreed with the statements that "patient's rights to choose or refuse treatment need to be safeguarded more adequately" and "all children should have access to preventive health measures regardless of their parents' ability to pay."

Thirty-five percent agreed and forty percent disagreed with the statement that "those not able to pay for medical care should be limited in the medical care they do receive at public expense." Similarly, forty percent agreed and thirty percent disagreed that "every person should have guaranteed access to any available life-prolonging interventions." (Hines, 1985, 26) Although these are not scientifically precise polling results, they do indicate a decided lack of public agreement concerning the need to ration health care services.

The richest sources of information for analysis were the open-ended questions and general comments contained on the back side of the survey forms. A great many people took the time to set down their views and concerns. The Executive Director and his wife, a social scientist, took on the job of compiling this information and insuring that the citizens' values were presented in a pure form as much as possible.

In July 1984, Oregon Health Decisions released "Ethics and Health Care Choices-A Report from Oregon Communities." The report cited five areas where there was general agreement among the 5000 participants in the small-group meetings. The five areas are reported here:
(1) THE DIGNITY AND AUTONOMY OF SICK AND DYING PATIENTS NEEDS BETTER PROTECTION. Patients may not be aware of the legal means available to them (such as "living wills") to have their treatment decisions carried out by physicians and hospitals. Doctors and nurses need to do a better job of sharing information with patients about their illness and the treatment options open to them. Both health providers and patients should come to view death less as an enemy to be fought at all costs, and more as a natural companion to life.

(2) MUCH GREATER EMPHASIS SHOULD BE PLACED ON DISEASE PREVENTION AND HEALTH PROMOTION. Economic incentives such as health insurance discounts for non-smokers and drinkers should be used to reward healthy lifestyles. Health education could be made much more effective in preventing such problems as venereal disease, injuries and deaths caused by drunken driving and other unsafe vehicle practices, and illness resulting from toxic substances to households and workplaces. Health professionals should place more emphasis on disease prevention and health promotion in their work with people.

(3) EVERYONE SHOULD HAVE ACCESS TO AN ADEQUATE LEVEL OF HEALTH CARE. Oregonians must reach specific agreement on what "adequate" means, then insure that everyone in the state is able to obtain at least that level of health care. Particular attention must be paid to the needs of children and pregnant women. Elderly and rural residents have special needs that must be addressed. Compassion, however, must be balanced with prudence and a recognition that the individual bears primary responsibility for maintaining his or her own health.
(4) HEALTH CARE COSTS MUST BE BROUGHT UNDER CONTROL.
Efforts must be intensified to reduce waste and inefficiency to Oregon's health care system. It is a disgrace that many millions of dollars are going down the drain due to unnecessary hospitalizations, excessive diagnostic tests and useless treatments when funds are lacking to provide genuinely needed care for so many of our poor and elderly. Both regulatory and competitive approaches to cost containment should be carefully evaluated.

(5) RATIONING AND ALLOCATION DECISIONS MUST BE MADE FAIRLY AND OPENLY. Currently the "luck of the draw" determines whether the most vulnerable citizens of Oregon get necessary health care: whether their local hospital is accepting people who can't pay, whether their community is willing to raise money for a $150,000 heart transplant. Better ways must be found to decide who gets what kinds of health care, so that the burdens of ill health and limited funds do not fall unjustly on a narrow band of society. Both local communities and state government need to assure that allocation within and among the publicly-funded programs are driven more by clear social choice than by budgetary crisis management. (Hines, 1985, 25-26)

Drafting proposed resolutions was another subject altogether. Relating the information, Mr. Hines (1985) describes this aspect of the project as being one of the weakest aspects of the initial OHD process. Few resolutions were written by community participants and the few that were written (mostly by health care worker participants) were non-specific. Another negative was that the time between the end of the first phase of the project and the arrival of the Citizens Health Care Parliament was very short, leaving little time to write the resolutions to be presented to the
However, with time running out, the delegates were able to write up their contributions to the draft resolutions. In all, seventy-six resolutions were presented at the Citizens Health Care Parliament. The original thirty-two community representatives, general public, and staff members all contributed to those seventy-six resolutions.

Four staff and an advisory committee member took on the responsibility of reviewing proposed resolutions pertaining to each of the five content areas: "autonomy and dignity," "prevention of disease," "access, justice and social welfare," "cost control," and "allocation for fairness." Attempts were made to clarify the language of ambiguous proposals and combine those which were clearly redundant.

From the beginning the steering committee had planned a final conference to tie together the grassroots, statewide implications of the project. But the exact nature of the conference was really not decided until mid-summer 1984. It was discussed then that the conference purpose was not so much to solve discrete and time-limited problems, but more to reform some of the most basic processes by which health policies were formed and health services delivered. So gradually the notion of something akin to the Constitutional Convention of 1787 took hold. The constitution for the parliament would be laid out as "health" in nature, not political, and the rights and responsibilities of parties would be defined in a health care environment.

Sixty-five delegates were invited to the parliament: thirty community representatives who led the project's grassroots phase; twelve Oregon Health Decisions advisory committee members (three each from the
nursing, medical, religious and legal committees); and twenty-three additional community representatives named by the regional Health Systems Agency boards. For one and one-half days delegates broke into small groups and diligently worked in the five areas of concern.

At the conclusion of the two-day meeting, which accepted public input right on through, the second evening was devoted to an intensive review of the resolutions. After all was said and done, the delegates broke into five reference committees, each dedicated to the five main concerns stated above, (autonomy and dignity, disease prevention and access) and decided the resolutions that would be brought before the full parliament.

Thirty-four resolutions had been deleted and twelve more incorporated by the time they reached the parliament as a whole. Each committee ranked the proposals with which it had dealt, into a priority order. Work had ensued throughout the night and into the early hours of the morning. When the parliament convened at 8:00 A.M. on the last morning, it followed Robert's Rules of Order with the Director of the Project, Ralph Crawshaw chairing. The first resolution considered called for the acceptance of a statement of "Ethical Principles for Health Decisions." These principles are reproduced in the appendix. (Appendix 4)

In turn, the five chairpersons were introduced to present their committee's highest priority resolution. Each proposal received considerable debate and many were amended repeatedly. By the end of the final day all but a few of the proposed resolutions were approved. It was observed that one could not fail to be inspired by the sight of attorneys, nurses, physicians, elected officials, public health
workers, clergy and college professors coming together as equal representatives of 2.6 million Oregonians, almost totally laying aside parochial special interests in favor of the broad public interest. (Hines, 1985, 31)

A compilation of final resolutions passed by the parliament was prepared and distributed within several weeks. This report was entitled "Society Must Decide: Ethics and Health Care Choices in Oregon." (Appendix 5)

Linking the Gap Between Consensus Gathering and Legislative Action

The foundation of efforts to implement resolutions passed by the parliament was laid months prior to the conference. An implementation committee chairperson was recruited and attended the parliament as an observer. Within ten days of the conference, the implementation committee began its work. In addition to the chairperson who was an attorney, the other core members included one individual appointed by each of the health systems agencies in Oregon, two R.N.s, and an M.D. The project director, deputy project director, executive director and publicist for OHD were adjunct members.

From the implementation committee came specific follow-up projects to two resolutions. The first resolution was in line with the autonomy and dignity area, which states that legal reforms should occur "which allow health care providers, without risk of criminal and civic liability, to follow patient's wishes to forego life-sustaining interventions." Oregon's first "living will" or "right to die" legislation was enacted as a result of this committee's action.

Brian Hines shares the second major implementation
project which is presently being pursued by OHD. "This project, as opposed to the first implementation resolution which involved individual bioethics, involves the area of societal bioethics. Once again, the goal would be to define through an open process of community debate and consensus-building the boundaries of adequate health care. The top parliament priority in the Allocation for Fairness area asks the Oregon legislature "to create a special task force which will establish an ongoing process for defining 'adequate' health care, and that this process shall evolve as the basis for apportioning health care resources." (1985, 25)

A concrete example of the pressing need to define the boundaries of adequate care came as requests besieged the Oregon legislature's House Human Resources committee to both expand primary care services for the medically poor and fund organ transplants. How does a legislator choose between basic health care for many and exotic care for a few?

Staff of OHD had proposed to the legislative leadership that a comprehensive review be undertaken of publicly-funded health programs in the state to insure that state dollars are spent on health services in a manner consistent with the values of Oregonians. First, an inclusive audit of how these funds are being used in preventive, treatment, research and educational programs would be conducted. The intent would be to produce an easily understandable overview with many charts and graphs of the current state of affairs.

Again the proposal involved the holding of another series of grassroots meetings focused on defining the boundaries of adequate health care and the desired use of state health dollars. Here the gap between ethics and economics would be bridged by framing budget decisions in the
language of human values. The assumption underlying both this approach and the entire OHD process is that the values of the general public should form the basic outlines within which specific health policies are formed. Thus after strategic goals for state-supported programs had been elicited through a community involvement phase, the legislature would hold a more technical series of hearings at which state health programs would be viewed afresh in the light of citizen values and priorities.

Oregon Health Decisions remains alive and active. Their purpose is not to be identified with any special interest, dogma, ideology or political persuasion. This distinguishes them from other groups which take a focused, strident, adversarial approach to advocate what they view as the "public interest." In OHD's definition, physicians, hospital, insurance companies, pharmaceutical firms and other providers are just as much a part of the "public" as is the rancher, Rotary club member, homemaker and senior citizen. The views and concerns of health care providers must be blended with the values of the general citizenry to develop genuinely enlightened positions on bioethical issues.

In his review of the ongoing OHD project, Mr. Hines sums up the critical importance of the grassroots venture as follows:

"One of the important tenets of Oregon Health Decisions is that we lack not good ideas, but the will to put them into action. Doers are needed more than thinkers. While other social problems may be resolved through elitist technocratic and bureaucratic approaches, ethical problems in health care patiently require the development of a social consensus before legislators and other policy makers will find the courage to act. Because the problems are ultimately rooted in human suffering, the solutions must grow from a solid base of grassroots support. To establish this foundation of a concerned, informed, committed citizenry is Oregon Health Decisions reason for being. This is the wellspring from which lasting change in the health care system will come, not from pronouncement of leaders — no matter how "on the mark" the latter may be. (1985, 28)"
As a result of public health policy outcomes, Oregon began a democratization process that was innovative in light of today's traditional health policy planning system. Because of an economic crisis involving a depressed lumber industry, thousands of Oregonians found themselves out of work and uncovered by health care insurance. Suddenly the medically needy population had grown raising the Medicaid enrollment. Still others found themselves without any coverage at all because they did not meet eligibility requirements of Medicaid. This crisis led to a group of astute individuals who recognized that a great many ethical issues were emerging from the health care crisis and that the grassroots citizens should be participants in planning health care policy. The following points discussed here describe a concept that has spread to at least sixteen other communities and has become known as Community Health Decisions.

**Chapter Summary**

1) Community Health Decisions contains the belief that the grassroots individuals should have their views voiced, but are often kept from this through a policy making process often hostile or at least, foreign to them. Through an educational atmosphere, a mechanism involving volunteerism and commitment, as well as a methodology which includes small-group and town hall meetings, participation of a cross-section of citizens can be reached within the state. A consensus is compiled from surveys and comments participants make and then brought forward into parliamentary proceedings that are culminated into resolutions. It was felt that the process should not stop there but seek to bring the resolutions to the legislature for consideration in deciding policy issues. In Oregon the resolutions fell into five categories. They are:
a) autonomy and dignity, b) prevention of disease, c) access and justice, d) cost control and, e) allocation for fairness.

2) Policy directives have resulted in the legalization of Advance Directives, Durable Power of Attorney, and Living Wills. These directives place the citizen as the final authority in deciding whether personal health care measures will be accepted. The implementation of extra-ordinary life support systems is one example of a situation in which a patient may want to exercise his or her autonomy via the use of one of the above legal formats.

3) Most recently (Summer, 1989) two bills have been enacted that will enable Oregon to set a precedent in health care. Oregon has just completed a process in which the citizenry met to discuss prioritization of health care services that would be included in a basic health services package offered to Medicaid and employer financed health insurance recipients. Oregon has revamped the Medicaid guidelines and extended federal categories to include anyone who falls below the federal poverty level, or who are medically needy and not covered under another health care insurance program. For this, Oregon is seeking a waiver from Congress so that if approved they can receive subsidization. What makes this a precedent setting case is that both categories and service package offerings are being changed from those federally mandated under Medicaid. To create the health services package, Oregonians are involved with OHD in town hall meetings to discuss what health care priorities individuals feel are important for inclusion in the package.

4) Several assumptions and principles underpin the CHD projects which influence and promote the citizens in educational processes that in
turn provide an open and prudent discourse with concerned health professionals and a wise and restrained government. This increased public awareness of critical health issues has brought the grassroots into the political arena. As a result this has led to a realization that long term solutions to the problems of high cost medical care, access to care, charity care (cost shifting) and potential dehumanization must be faced and understood by the local communities that experience the problems.

Now stepping back, this assessment and the previous chapter discussions gives us an opportunity to review objectively the community bioethics concept in light of our present day representative government.
Chapter II

A CRITICAL ANALYSIS

From Polis to Urbanization: A Look to the Past to Ensure the Future

To provide the reader a conceptual framework to serve as a base from which the Community Health Decisions Project has arisen, let us turn first to Dorothy Nelkin (1977) as she describes the civic participation that is referred to as democratization. She states that:

1) Democratization requires participation at an early stage of the policy process; 2) regardless of their technical nature, political conflict and ambiguity are basic realities of technological decisions; 3) if political participation is to be effective, there must be means to improve public understanding of science; 4) participatory efforts are faced with difficult problems of defining "legitimate" interests; and 5) the forms of participation will vary according to the values that a society wishes to maximize. (Nelkin 95)

Yet, the underpinnings of democratization are societal values and societal values come from within the individual citizens who make up that society. So for a moment we shall take a look into the far past and seek advice from Aristotle, the Greek philosopher and then return to Ms. Nelkin's modern day democratic model in order to put CHD to the test.

Aristotle felt that a virtuous life, a life of human well-being, could not be lived in a society that failed to apply practical reasoning "because of an excessive or even exclusive reliance on technical reasoning." (Tong 1987, 43) Aristotle believes in man's virtue or possible excellence and the promotion of civic life—man being friends in action. "Friends in action" is equivalent to civic participation in all
Its forms. Therefore, the true conceptual model from which the civic participation described in this paper originates is from the Athenian ideal of citizenship.

Unfortunately, recent social history has viewed its citizens as members of a politically schizophrenic society of mixed actions at both ends of the extremes. Within this shaky framework, individuals tend to be apathetic to issues of a civic nature or, if verbally espousing interest on a given issue, fail to act together to resolve the issue.

Somehow "politics" has taken on an American definition of governmental function left to a few. It has left some with the perception of an unethical body of elites who hold power over the people, guiding their lives through policies the people have no real say in making. 'Politics' cause most Americans to envision rhetorical figures campaigning continuously from election to election, doing what they must to attain the next rung on the way up the political power ladder. Politicians seem to have little time to take into consideration the public's views, and even less value is given if that public opinion gets in the way of a political position. Our present society has come to associate politics with "oppression, manipulation, cunning and seductiveness. It is a system in which people are controlled." (Bookchin 1987, 32)

Bookchin (1987) tells us, "Politics as a phenomenon distinguishable from the state and from social life initially appears in the extant writings of Aristotle, perhaps the most Hellenic of the Greek social theorists and philosophers." (33) Aristotle's view of the polis or city is that of human association at that level. He believed that politics was action between people who engaged in the interpersonal moral activity of
community-making. There was no elite rule or unethical activity.

Until recent times, professional systems of governance and violence co-existed with richly articulated community forms at the base of society; “city neighborhoods in the world’s few large urban areas, self contained towns and villages, a network of extended kinship ties, a great variety of vocational, mutual aid, and fraternal groups,” far from the reach of a centralized state authority. (Bookchin 1987, 34)

To Aristotle we owe the theory of Athenian democracy and “mixed polity,” which was anything but a professionalized system of governance organized strictly for social control. It was a system, notable for “its high level of consciousness, civicism commitment, and esthetics.” (Bookchin 1987, 35) Within this political body, economic distinctions existed through all material resources from the wealthy to the poor, yet, Aristotle explained that wide gaps would destroy the community.

Summing up what Aristotle believed to be the qualifications for the ideal polis, Bookchin (1987) quotes Aristotle’s conclusions “that the best limiting principle for a polis is the largest expansion of the population with a view to self-sufficiency that can be taken in at one view.” (36)

Unlike modern theorists who debate the essence of a community based upon logistical, democratic and esthetic grounds, Aristotle argues human scale on ethical, biological and historical grounds. An ethical pragmatism pervades his view of human consociation.

Politics in Aristotle’s view is inseparable from its ethical context. “A polis however, is more than a community or koinonia."
It is a koinonia that has reached the ideal form of a shared commonality of purpose among men whose self-realization is the "good life." (1987, 37) The "good life," as Aristotle would describe it, includes material self-sufficiency but more than mere survival. It does not mean an appetite for goods that takes man to the edge of excessive desires, clouding his ethical and intellectual clarity. Man, unlike other animals, has reason and speech. Yet these abilities alone do not guarantee that man will reach the fulfillment of his potential. Aristotle believed that institutions were necessary to provide man the means for achieving human self-fulfillment. Bookchin further describes Aristotle's view that:

"a body of ethics must exist that gives the required institutions substance as well as form; a wealth of social activities must be cultivated in the civic center or agora of the polis, the gymnasium, and in the theater as well as the popular assembly and courts to nourish interactions and discourse; a mode of character development and education, both of which are combined in the Greek word paideia must be at work to enrich the interactions among men and thereby foster the growth of ethical and intellectual insight." (1987, 37)

Bookchin sums up the best ordered polis as Aristotle saw it as:

"...structured around a system of governance where the most ethically and materially meritorious stratum of the population manages the polis's affairs in the interests of all. The "polity" or "meritocracy," as it has been called is an ethical union that simultaneously yields the "good life" in moral and material sense. Politics consists of the practical reason (phronesis) and action (praxis) that enters into such a felicitous koinonia (1987, 39-40)

Therefore, the true meaning of politics, from its original Greek root, is people-oriented. It is an action of citizens within the polis, the city, seeking a consensus through education and discussion on issues that affect the society.
To further enlighten us about the Greek citizen ideal, Bookchin describes that what united citizens of the *polis* was the cultural conception of personal development—*paideia*. *Paideia* is translated into English as education. But to the Greeks this word meant considerably more. The education of a young man involved a "deeply formative and life-long process whose end result made him an asset to the *polis*, to friends and family, and induced him to live up to the community's highest ethical ideals." (59) The German world, *bildung*, with its combined meanings of character development, growth, enculturation, and a well-rounded education in knowledge and skills, more appropriately denotes what Greeks meant by *paideia* than any word we have in English." (Bookchin 1987, 59)

The expression of this word then denotes a creative integration of the individual into his environment, a balance that demands a critical mind with a wide-ranging sense of duty. The Greek world, *areté*, which originally described a warrior for his prowess and valor, was extended to mean good ability, virtue, or excellence of one's capacities in all aspects of life. *Paideia* and *areté* are linked not as a means to an end, but as a unified process of civic and self-development.

Excellence in public life was as crucial to an Athenian's character development as excellence in his personal life. The polis was not only a treasured end in itself; it was the "school" in which the citizen's highest virtues were formed and found expression. Politics, in turn, was not only concerned with administering the affairs of the polis but also with educating the citizen as a public being who developed the competence to act in the public interest. *Paideia*, in effect, was a form of civic schooling as well as personal training. It rooted civic commitment in independence of mind, philia, and a deep sense of individual responsibility. (Bookchin 1987, 58)

In recorded history we have no structure comparable to the Athenian
democracy model. The closest modifications have been the popular assemblies such as the New England town meeting and the Parisian revolutionary sections of 1793-94 that appeared over time. The Swiss Confederation is one of the few among many incomplete examples where popular control formed the underpinnings of an on-going political system. "Athens, however, is unique historically in that the polis fostered a degree of citizen participation not only in the decision making activities of the assembly but in the everyday politics of the agora that impelled its admirers over the ages to regard it with uncritical adulation as evidence of a "pure" democracy. (Bookchin 1987, 40)

From here then, I will launch an analysis of our present day civic participatory democracy, or lack of it, in a pluralistic society during a time of dominating "statecraft" or centralized politics. Can we ever hope to achieve the virtues of character necessary to become good citizens who care about one another and are willing to come together to discuss and evaluate the highly complex health care issues facing society today?

An Analysis of Health Planning

In respect to other areas of concentration, the federal government's role in the health care system is relatively recent. Although health care planning was done earlier, before the federal government made its entrance into the field, most was accomplished by private, state and local perogatives. Only since about 1945, has the government played a vital role in health care planning, with its most sizeable influence beginning only since 1965. Although federal health planning was divided into three, possibly four time periods, in essence, the health policies coming out of those planning sessions resulted in only two policy evolution periods.
The first policy period lasted from twenty to twenty-five years and concentrated on the wisdom of adding new commitments to the federal agenda. Equity was the heart of the period’s public philosophy, so politics generated the major subsidy programs that supported providers in building the system’s capacity and financing entitlements that built new access to that system among consumers. This was known as the breakthrough era.

The next fifteen to twenty years marked the political system’s conviction that policies had become overloaded by public and private partisan groups and a sense of stagnation and loss of purpose and coherence in federal policy. From the resultant debates, a movement was generated toward reorganization which attempted to improve current policy and contain costs by a market-oriented strategy and regulatory programs, which sought to build new governmental controls into the system. Efficiency was the primary goal.

The overall historical picture portrays a governmental intervention into a very complex, highly technological, and erratic environment, the health care system. Although the planning proposals of the Hill-Burton, Regional Medical Programs, Comprehensive Health Programs, and National Health Planning and Resources Programs, emphasized the problems of the time, little or no foresight of possible results from the policies seemed to be evident.

The consequences of these past programs have left us trying to bail out water as fast as it is coming into the boat. We seem to have little time for addressing the problems. Our health planning measures have resulted in producing policies that are stalemated, deadlocked, and incremental at best.
Major revisions if not total restructure of planning and policy proposals need to be addressed. Although, incremental revisions can be successful, care should be taken not to overuse and abuse this strategy or additional costs and problems may far outweigh the costs or problems of an entirely new program. The Bipartisan Commission on Health Care, which is called the "Pepper Commission" exemplifies this. Eighty-six billion dollars under this proposal, would be needed to fix the health care crisis. Yet the health care system presently costs more than $550 billion a year. Adding to the dilemma, this recommendation still does nothing for the ten percent of our population left uninsured. (Las Vegas Review Journal, March 25 1990, 1C) In its report, the Commission failed to suggest how the funds for the programs are to be raised.

The answer to this may be that re-allocation of government funds from other major areas may be transferred to health care. But then what are the consequences? If we borrow from education there will be cut-backs to another major American system. Already schools and supplies are becoming scarce as monies grow less. There needs to be some real thought given to more judicious allocation of funds inclusive of overseeing where the dollars are going and if they are doing what they were intended to do. Perhaps waste and inappropriate spending can be curtailed. If the government was more careful in its spending habits, we might find a reserve of unused funds that could be used for other needed areas. Looking ahead rather than for the short term only (as evidenced in the past) is what is needed to be included in the health planning strategy.

Each of the strategy models discussed in this paper in relation to the
Comprehensive Health Planning: rational, incremental, mixed-scanning, and radical, all have a definite place that can be useful in planning health care today. No one strategy is good for every situation and there should be options from which to draw in a given environment. However, since the health care system seems to have problems that are universal in nature, federal health planning should remain comprehensive and seek to address national issues. Perhaps there can still be room for governmental or non-governmental health planning agencies which can deal with problems unique to a particular locality—a region, state, community.

There is no current federally legislated health planning act being funded and supported. The last health planning action taken by the federal government was the Health Planning and Resources Development Amendments of 1979 which extended the 1974 National Health Planning and Resources Development Act for another three years and amended the State CON requirements.

It is apparent then that someone needs to guide the planning of health care from a national perspective. Some (including Nevada), but not all states have continued on with the principles set by the 1974 Act, PL93-641. So, (1) we have basically returned to health care planning on a localized level. Although some might conclude this local effort may succeed in addressing local needs, another view exists. But, (2) others feel this local effort with its multiplicity of economical and social contexts will decentralize health care and with all probability continue to drive the inequities of health care services further into negative societal consequences. Number two is debatable in light of the OHD experiences. They are dealing with the inequities of federal policy guidelines and making
provision that all citizens will be covered for health care.

We can learn from the past and the past tells us that planning has failed mainly from the perspective of not having the regulatory teeth to implement the plans successfully. Either this or lack of funding has been the downfall. It might prove fruitful if we can devise a plan of action and give it the support needed to see it through. Whether this is on a local or federal level is yet to be seen, but it must be done. If not, we will continue to see the chaotic turmoil of the health care system grow into a monster no one will tame. The societal and economic outcomes are with us now, but the future growth of these consequences could be more devastating than we can imagine if more strategic plans are not implemented.

Perhaps the government or outlying private groups are out in the field now experimenting with this idea. We can only hope it to be so. Oregon and several other states are certainly among those who are.

An Experiment to improve Access. Medicaid: Was There Insight Into The Future?

As an attempt to meet the social contract in which all citizens would have access to quality health care, Medicaid was at least a start. Still, there were some problems going into the program as well as some acquired along the way. Clearly there were faults on both the federal and state sides. First, the federal faults were 1) too much flexibility in the program design, which led to gross inequities in benefits from state to state; 2) linking Medicaid eligibility to eligibility for cash assistance programs, such as AFDC, excluded millions who could not pay for adequate medical care themselves; 3) states that needed Medicaid money the most
usually got the least; and 4) about one-third of Medicaid funds cover nursing home care for the poor or near-poor elderly, not an original intention of Medicaid; which all leads to a decreased access of poor population to primary and acute care services. The state faults were: 1) unjustly wide variation in eligibility criteria; 2) unjust variations in payment rates; 3) unjust variation in scope of services; and 4) lack of control over quality of care.

Those who have benefited most from the program are the direct recipients, those who have enjoyed open access to health care. But what was missed was the anticipation of those millions who would fall into the gap between private and public insurance coverage. As a result, the three major consequences discussed earlier have affected the society of which these individuals are a major part. (1) The consequences of erosion in our commitment to universal access is growing as our health provider community becomes more market-oriented. (2) Certainly of vital concern is a deterioration in the health of those who are financially barricaded from access to basic health care and suffer the consequence of severe health problems, worse yet, needless and early death.

Finally, (3) there are the rising health costs and monetary budget increases that have left our younger society with a legacy of spending a working lifetime subsidizing the costs of health care and retirement for the older generation. Compounding the problem is the fact that we are handicapping this younger generation with an environment of deficits; deficits in health care, productivity, and standards of living. We are indeed mortgaging our future.

Policy decisions should have embodied and reflected long term goals.
Barring this, intermittent, short term evaluations should have been made along the way. Instead Dye saw a very different picture. He quotes from *Practical Program Evaluation*:

The most impressive finding about the evaluation of social programs in the federal government is that substantial work in this field has been almost nonexistent.

Few significant studies have been undertaken. Most of those carried out have been poorly conceived. Many small studies around the country have been carried out with such lack of uniformity of design and objective that the results rarely are comparable or responsive to the questions facing policy makers.

There is nothing akin to a comprehensive federal evaluation system. Even within agencies, orderly and integrated evaluation operations have not been established. Funding has been low. Staffing has been worse, forcing undue reliance on outside contractors by agencies that lack the in-house capacity to monitor contract work. The most clear-cut evidence of the primitive state of federal self-evaluation lies in the widespread failure of agencies even to spell out program objectives. Unless goals are precisely stated, there is no standard against which to measure whether the direction of a program or its rate of progress is satisfactory. (1987, 350)

Policy decisions are needed that will address these vital issues. Policy analysts on the governmental level have several proposals for restructuring the Medicaid program to meet the needs of society. Full federalization of the program making income eligibility and service offerings uniform across the U.S. has been one suggested option. Included in this proposal are several options: federal/state sharing of services, shifting cost of long-term care to Medicare or state levels, federal/state/local sharing of cost responsibilities, home equities, and beneficiary/federal/state sharing. However, to date no program proposal has met with overwhelming positive response. Each has its advantages and disadvantages, but none has passed the talking stage.

One innovative approach has come from the state level. Not only has discussion on the important health issues evolved, but action has been
taken. Community Health Decisions Projects are sprouting up over many states. These programs are beginning work on the specific areas of prevention of disease, access and justice, cost control, and allocation for fairness. The difference in these policy decision proposals are that they come from the grassroots society. The community individuals making up community and state societies are having their say in setting the health care policy agenda.

An Analysis of Community Health Decisions.
A Civic Participatory Experience

This has been a very healthy approach to the problem the poor face today. Each state has its own fiscal capabilities and each holds its own view on welfare and health care issues. By prioritizing the values of its own citizens, policy decisions can be effected that benefit the greater portion of that society. Keeping their health care spending focused on the prioritized areas, mostly preventive health care, is saving millions of dollars.

How this reduces legislative regulatory acts is addressed in most cost/beneficial-cost/effective models designed to reach the greatest number of society’s members. This is a difficult, but not impossible task. For those who would find themselves in the minority of individuals who might fall into another gap left from prioritizing services, enough funds will most likely be left over from what is saved on preventive medical care and its resulting, anticipated better health to its recipients.

From this preventive health maintenance viewpoint, a cycle of benefits can be seen: preventive health care leads to better health and less demand for unlimited health services. Also there would be less need for inappropriate “crisis” care, that so often is sought by
non-emergency patients who feel emergency rooms and clinics are the only place they can get any type of health care. The emergency doctor becomes their primary physician. The need for crisis intervention would lessen because individuals would apply preventive health care measures which in turn would presumably give them better health. If better health is enjoyed, a lesser population feels it necessary to flood the emergency rooms and clinics for basic health care services.

Seeking crisis intervention would only be initiated in a true emergency situation. Emergency services result in high costs which lead to more dollars spent in the health care budget. More judicious and appropriate use of these high technological and expensive facilities would result in more monies saved and thus available to provide services to both preventive and acute care services. As this cycle is perpetuated, the government would truly meet its original practical goal of providing access to all who need it and to better their health in the process.

How Do Policy Analysts View Citizen Participation?

The CHD projects have taken this approach and would probably meet with a positive general reaction. Yet, in reality, interest groups and policy analysts have not always favored suggestions from the grassroots citizenry. In an attempt to provide a critical analysis of the Community Health Decisions grassroots citizen participation concept and in particular, the Oregon Health Decisions Project, it is clear from the outset that there might be questions about this popular democratic involvement of citizen participation in the health care delivery policy decision making arena.
First, one might ask how receptive have policy analysts and policy makers traditionally been to citizen participation in the general political arena, and second, how do policy analysts view citizen participation in the actual policy decision making process?

First, citizen participation in public policy making has been met with mixed feelings among policy analysts. Rosemarie Tong (1986) provides a good overview of both sides of the question of whether popular democracy or representative democracy is better at the policy making planning and decision making levels.

How our government has evolved and the emphasis placed on its function has differed over time. The world in ancient times saw little difference between ethics and politics. There were no distinct political institutions that decided the standards. The standard that was set for man's goodness was the same for the goodness of society. Plato listed virtues for man as wisdom, courage, temperance, and justice and these were the same virtues desired for the city as a whole. Aristotle felt that a virtuous life could not be lived in a society that failed to apply practical reasoning "because of an excessive or even exclusive reliance on technical reasoning," as we noted earlier. (Tong 1986, 43)

Aristotle defines technical reasoning as the process of thinking used by a doctor to produce health, a builder to construct a house, or a musician to play a lute. Technical reasoning is not just a familiarity of experience without depth of insight into the full picture of universal application; and it is not just a theoretical knowledge without practical experience of application. (Tong 1986, 43)

In her discussion of Aristotle's view on technical reasoning, Tong
(1986) says,

The aim of technical reasoning is to control things—to mold matter to serve human purposes—the aim of practical reasoning is to liberate persons, to let them engage in those activities that will serve their best interests. (44)

Hobbes and others in the early modern period emphasized that man regards himself as a controlling subject rather than a controllable object. On the other hand, B.F. Skinner blames this tradition for asserting man's autonomy, and claims it was the precursor to the problems now besetting mankind. He believes we would be much better off in a disciplined environment where we are uniform in our desires and drop our thirst individually to do what we want, when we want, and how we want. (Tong, 1986, 45)

This Skinnerism tears at the concept of man's possible moral and intellectual virtue and the promotion of persons being friends in action. It promotes the raising of an elite group to a scientific and technical pedestal from which all knowledge is passed downward to the masses to make their lives 'better.' Many would say this is what our present American society has become, a technically, scientifically managed political machine.

In America, much of this trend is relatively new. It was not until the rise of scientific technology early in this century that Americans feared a loss of national freedom unless the “true experts,” the scientists, were given free rein to plan and make decisions. World War II and Hiroshima, as well as Sputnik helped convince the public that it knew little and scientists knew much. Americans began to lean on experts to decide issues that ostensibly had become too varied and complex for the average citizen to follow.
Experts are defined as individuals (not elected representatives) with specialized knowledge and experience in any given area. They are seen in the form of policy analyst, subject-area specialists, or policy advisers. Each of these roles is heavily involved in policy development. However, each is a role of a technician, not a value evaluator. Yet all too often these experts recessively include value determination in policy development, as often the technical and value aspect are difficult to separate.

By the 1960's, in part as a result of television American citizens realized that expert rule was not utopia. Americans began to see the flaws, the immoralities, the deceptions, and began to question the relinquishing of responsibility for themselves to these experts.

To date, most attempts at reforms to increase public participation have been intended to expand information to the public and to communicate information about public preferences to decision-makers. To a lesser degree, some have attempted to open the administrative process in order to allow public representatives to take active roles in policy development. (Tong, p. 50) Two legislative acts that have opened the door for an increase in the public information base are the Administrative Procedures Act and the Freedom of Information Act.

The Administrative Procedures Act requires all federal agencies to make available, via the Federal Register, any proposed regulations and to solicit public comment. The Federal Register is a 60,000 page-per-year publication and few citizens have the resources, access, or expertise to get the document much less utilize it. It is in most city libraries, but we usually do not consult it. The Freedom of Information Act has also had as
little impact on the public participation forum. Eight of nine exemption clauses seem to unnecessarily keep information from the public. Three of the nine arise out of concern to protect private property, "trade secrets." Yet, they have been used by the Food and Drug Administration to close meetings in which safety and effectiveness of certain drugs were discussed on the grounds that relevant information classified as "trade secrets" were involved.

Yet, both acts have led the way for citizen involvement on advisory boards, national commissions, and institutional review boards. Although the numbers of citizens participating have increased, many of these citizens are members of organized interest groups. There is then the question as to whether these citizens represent the public at large or just that of their interest group? (Tong 1986, 51) Or, is it the case that the mixture of all interest groups guarantees an overall fair picture of that larger public?

In Europe, public participation experiments have been fairly successful. In her book, Technological Decisions, Dorothy Nelkin follows the increase in public demand for participation in European countries. In Sweden, study circles, long a tradition for the Swedes, were used to develop political democracy. Usually non-technical issues were discussed, but more recently the circles have focused on more technically oriented issues. Energy issues became the topic geared to educate the public. Eighty thousand Swedes attended a minimum ten hour session in which groups met and discussed questions concerning the high energy demand in the Western World, comparative economic costs and benefits of different energy sources, and the political and ethical problems posed by a reliance
on nuclear energy as opposed to coal, oil, or gas. (Tong 1986, 51) Results of the group consensus were sent to each of the other groups and out to the public. No real swing in opinion on nuclear policy resulted, but as a result of a more insightful public, the government implemented a more cautious nuclear policy than it might have otherwise.

There is a tendency in public policy innovation, to initiate policy first and then "educate" the public toward a "rubber stamp" approval of it. It should rather be a presumption that in order to reflect social priorities, policy-makers should consult the people during the formation process of policy intentions and objectives. (Nelkin 1977, 95) How else can the value determinations of the people be prioritized at the level they might consider as legitimate concerning costs, benefits, and risks?

There are times when public discussion is not and cannot be possible. In perilous times when decision-making requires split-second timing, a participatory discussion would be ludicrous. But, in non-perilous times and on issues not needing to be decided for immediate national security, public discussion and participation is warranted and necessary. As Aristotle's mean between extremes theory might suggest in this context, a middle ground between allowing only the brightest to speak or allowing everyone to speak on a given issue must be reached. This mean would prevent elite dominance that promotes their policy thoughts about the "masses," and also prevent so much public discussion as to bring the policy-making process to a halt.

Experts may set up an "us against them" regime. The experts' loyalty would then set its truth in its own way, the public in their own way. Can the two join? Or, do the experts become as the media so often do, a mirror of what they interpret to be the mass society's viewpoint on
any given issue?

For those who have difficulty with accepting the expert rule, one might be inclined to turn toward the interest groups as being representative of public opinion and interests. But often these groups have their own experts who in turn are loyal to those groups whose bias can bar the way to showing the facts in an open and valid way. The tendency leans toward showing facts only inasmuch as they support the group's claims.

Are all interests truly represented then? Public interest groups are certainly needed as they play a vital role in getting the opinion of the people to the policy-makers. They more easily fit into the political channels of communication to these policy developers, and they are accepted more easily by them since the group leaders often understand the political system better than the average citizen.

Groups that have had success in the political policy-making arena are many, and include the Consumer Advocacy (Nader) groups and Common Cause, as well as environmental groups such as The Sierra Club and the National Wildlife Federation. These groups give the impression that the public is well represented in the broad spectrum of policy issues. As recent studies have indicated, this impression may be false.

One of these studies was done by Kay Scholzman (1987) who reports that in a massive classification of 7,000 groups located in Washington D.C., 45.7% of these groups were corporations, 17.9% were trade associations, 6.5% were foreign corporations, and 6.9% were professional associations. Only 5% were organizations that represented people having few political resources. (1013) Robert Salisbury (1984) found a similar
dominance of these favored institutions among the lobbyist forces. (75)

In 1977, the dominance of business organizations among the interest groups was furthered by the bureaucratic and legislative decision-making procedures. Almost half of the fifty largest financial and one hundred fifty largest non-financial corporations were represented on federal government advisory boards.

Not only is there a heavy concentration of non-consumers in interest groups, but documentation reveals that bias plays a strong role within the interest group process. In several instances, researchers have found instances that public policy did not have all interests represented. One researcher believed “that cooptation and one agency/one interest politics is the dominant form of politics in the United States.” (Meier 1987, 191)

Individual citizen participation can occur in several ways. From voting to membership in a political organization, an individual can play a part in political actions. Yet, one study reveals that in reality, 31% of the population performs no political acts, and 22% perform only one act (usually voting for the President). When acts are more involved, up to 77% of the population does not participate in any political activities or only one activity. (Verba 1972, 34)

Another view is from those who believe there is little or no room for citizen participation in the policy-making process. John Byrne (1981) comments on this idea as it relates to cost benefit analysis, which is a primary analytical model used in health care policy-making.

The world of cost-benefit analysis has no need of a participative citizenry. The processes of public decision-making depend in this world upon the identification of objective values. It is only with their identification that rational solutions can be found. To involve
the citizenry in the process of identifying values could only result in the contamination of the process, for all they can offer are subjective assessments of their idiosyncratic circumstances. To operate effectively, the world of cost-benefit analysis must be insulated from and pre-emptive of the participation of its citizens. (204-205)

Byrne feels the citizen is treated by policy analysts and policymakers as a mere consumer who has no substantial contribution to offer, much less a place in policy-making. He further adds:

Citizens {are supposed to} decide whether and to what degree they are satisfied with the products of governance, but they have no responsibility for the production of governance or even overseeing its production. Indeed, the expectation is that citizens have no substantial interests in such matters. (1981, 205)

In many political situations, Mr. Byrne may not be off the mark. Unfortunately, this attitude of the policy experts may be self-confirming, that is, it may increase the typical citizen’s sense of ignorance and powerlessness. When this happens, the citizen then becomes alienated or apathetic. The experts, who are very vocal and whom they and the media make visible to the community, foster the citizen’s dependence to allow those “in the know” to make the crucial decisions. This dependence is more true in the case of the citizen who is virtually unthreatened with any loss and is comfortable in material accumulation and the pursuit of “lifestyle.” The result is a consumer model for policy-making, rather than a citizenship model.

For the apathetic citizen, Aaron Wildavsky (1979) argues their case by saying it is the responsibility of policy analysts to make the policy-planning and decision stages more interesting and conducive to citizen participation. He suggests that policy experts make themselves available through forums to stimulate discussion. (252) Although no one could expect every citizen to become expert on every issue, each would find
his or her own pet issue(s) to act upon. Waldavsky believes citizens should become amateur experts on issues of interest to them by investigating and acquiring all the information they can.

Tong, in her discussion of the role of the expert in a democratic society, supports citizen participation and states that,

In a democratic, pluralistic society, ethics progresses by means of conversation and by means of a mutual search for the human good. To exclude the citizenry from policy discussions is not only to subvert the democratic process, but to evade moral dialogue. Thus, whatever else policy experts may do, they should devise mechanisms that will enhance citizen participation. (1986,59)

A further obligation of policy analysts and experts is to remember for whom and why they are developing policy. Although each expert may be working for a specific client; the government or private enterprise, each has a responsibility toward third parties. Third parties are those people who will be affected, for better or for worse, by the policy decisions the experts will shape, but who did not contract with the policy expert to do that job.

One cannot then separate the political world and the individuals, who make up the citizenry of that political world. It should be their decision, based upon the highest standards, as to how their world should be run. Those high standards should be set upon the base of personal and private ethics and the virtues expected in policy experts. If public discussion, followed by education on a given issue is allowed, a consensus of opinions could more legitimately be used for value determinations on societal issues. There would then be no reason for political elites or interest groups dominating the policy making process.

Once again, referring back to the first section where a conceptual model is provided, I reintroduce Dorothy Nelkin's
democratization approach as further support for the CHD concept. The program steps serve not only as a guideline for policy analysts/experts, but also for policy makers as well. I offer this now as a critique of the CHD concept and OHD Project.

The first step of Ms. Nelkin's program states that democratization requires participation at an early stage of the policy process. So often health care policies have been decided first, and then in the aftermath, education about the decided policy is offered to the people in seeking their "rubber stamp" approval. Unless policy analysts are aware of the society's values and priorities, there is little chance and therefore little guarantee of them accurately weighing the costs, benefits, and risks in the same way the people themselves would.

The second step recognizes that the political conflict and moral ambiguity are basic realities of technological decisions. Better information and education on an issue do not necessarily resolve all controversial viewpoints. This is certainly the case with CHD as many issues discussed are and probably never will be unanimously favored or negated. But as in most decision-making the majority consensus determines how society's values are prioritized. This process also takes into account the deliberative process and critical thinking so important in Aristotle's analysis of citizens and community life.

Now, in any given area of health decision making, disagreement caused by the policy decisions may be inevitable, and Dorothy Nelkin's second guideline in her public participation program mentions this. But that is not the fault of or in any way a contraindicating factor in OHD or any community health decisions project. After all, OHD simply acts as the vehicle through which the citizenry can express their values and
views on a given health care issue. In turn, the policy makers can have realistic access to citizen’s views at the grassroots core in order to represent them more truthfully. The difference is that in one case the misfortune is unintended or unforeseen, while in the other case the deliberative process allows those who suffer such adversity to be heard and at best, to receive better attention or an equitable treatment.

In the third step, there must be means to improve public understanding of science. Unless we want to divide our country into a two-class structure, with one segment as the intelligent and the other as the ignorant, there should be devised a way to educate people not only during school years, but thereafter. The media of our age are excellent means to reach the public wherever they live. This does not guarantee freedom from bias, but the Public Broadcasting System, newspapers, journals, debates among local officials and national figures, and radio are all means to educate people. OHD has used these forms of the media, plus sending out facilitators to draw the public into an educational program that allows for public discussion of health issues. So Aristotle’s paideia may be adapted to modern times.

The literature I have perused has remained central in theme and constant in content and has presented a balanced, impartial overview of the OHD project and reporting. Educational meeting facilitators had received training in how to say just enough to get the ball rolling. Education on certain issues was mainly via video and handout material with discussion, so that the material presented in one meeting in one part of the state was identical to that presented in another part of the state. So much as humanly possible, OHD stayed with this concept.
The fourth step presumes participatory efforts are faced with difficult problems of defining "legitimate interests." It is important therefore, that each citizen realize the importance of an issue from a humane perspective, and not legitimate policy only if it directly relates to the individual himself. Although many of the survey questions placed before the citizens of Oregon may not have pertained to every individual, an attempt was made to allow everyone to see how one might deal with an issue if it was directly to involve him or her.

The fifth and final step is to recognize that the forms of participation a society fosters will vary according to the values it wishes to maximize. Our present day society or current policy analysts within it, value the "benefit" of efficiency and therefore sees citizen participation as a cost to be weighed against that benefit. Although the benefit of efficiency is quite necessary in times of peril, that mandate that a decision be made quickly, it is not apparent that the cost of a slower process of involving citizens in decision making is a contradiction to that benefit.

During the entire century, government policy makers increased health care services supply in order to provide access. Many policy makers assessed that if one has access to health care still one will presumably have better health. So for decades legislators responded to policies that accented high technology research and equipment, increased medical schools and health care facilities, and medical education. Monies were poured into these areas so much that America became the most medically advanced country. Yet, under this rational policy approach, there was little evidence, except in the case of infant mortality, of improved health among the poor population receiving health care under public policy programs.
The flaws mentioned previously have created cost containment problems and questions of general access to adequate care. And what of the health care decisions individuals face as a result of our advanced medical technology? Who answers the questions about life support procedures? Who decides who lives, who dies? Is it the doctor, the nurse, the courts, or legislators? And when health care must be rationed, {and it already is,} who decides what services will be cut and who should receive or be denied the rationed health care?

It only makes sense that we as the individuals who make up the society and who endure the consequences of the health care policies enacted should be the ones setting the guidelines under which the particular policy decisions will be made.

I really did not read into the OHD project any blatant or underlying attempt to overthrow the traditional government process in developing policies. What I do perceive is a real movement toward bringing the citizenry's values and views into focus so that the policy experts and legislators will truly be able to represent those values in their policy decisions. And I was under the impression that that was what our representative political system was all about.

So, who better than the people themselves to decide the matters they would have to live with? Yet, in the age of wide spread populations and the plurality of people with varying general and medical educational backgrounds, how does one reach a consensus on a given issue? Oregon Health Decisions conceived a well executed plan to address this problem, and has executed it well.

And what of the continuing saga of Oregon Health Decisions? Where have they gone from their initial project's final report? Originally set to
shut down after their two year project's end, it was unanimously decided that there was much too much at stake to leave the project just when resolutions sat waiting to be set in motion. Much had been revealed about the citizens' views that had not been resolved and needed further exploration.

Advance directives and Durable Power of Attorney have become familiar terms to many Oregonians who might never have heard of them in their lifetimes had OHD not come into the picture. In the legislature a bill addressing recognition of Power of Attorney in health care as legally binding was placed before the elected representatives. All this came about as a result of the educational consensus building efforts of the OHD project.

Currently, the OHD is seeking its 1990 goal of acquiring access to adequate health care for all citizens and with that defining just what adequate health care consists of. This leads to the third set of questions concerning the OHD project itself. (The survey and results for 'Oregon Health Care Priorities for the 1990's" is included in the appendix)

Analyzing the community health decisions concept at its core, in which people empowerment is highlighted through education and consensus building, I find little fault. This would appear to follow Aristotle's model of citizenry and Dorothy Nelkin's model for democratization in the technological and scientific age.

Returning to the literature, I looked to see what has gone on since the end of the initial two year project. OHD is going strong in implementing the resolutions it sought. Taking some of these resolutions as guidelines, the project staff is seeking to present them to the legislation. This has caused quite a controversial stir in some health circles. In the legislation at present are two bills that would grant
access to basic health care services to all Oregon citizens. One bill hits explicit rationing at its core. It has arisen as a result of the consensus of Oregonians participating in the Oregon Health Decisions Project who decided they would rather see health care monies go to the people covered neither by public nor private health care policy.

Bioethical awareness in Oregon has definitely been affected significantly as a result of Oregon Health Decisions. The Oregon Medical Association appropriated $30,000 for continuing bioethical education for the state's physicians. The Association of Oregon Hospitals and others have been stimulated into forming hospital ethics committees. State political leaders have sought consultation with members of Oregon Health Decisions on proposed legislation.

The media, including national television, reported in depth on the process as well as the issues and goals while publicly acknowledging its ethical responsibility in properly reporting health news. The Multnomah Medical Society has sponsored reforms in Oregon's Natural Death Act, in addition to following up many of the resolutions, while the Board of Directors is considering how to continue OHD's implementation process. Most important, the citizens have clearly declared their wish to control personal medical-decision making while affirming a commitment to move beyond bioethics and to engage in genuine evaluation of rationing, allocation of resources, and cost containment in Oregon. (Crawshaw 1986, 248)

One last question I would ask is, are the areas in which a consensus is being obtained through OHD different than would have been the consensus of the policy experts and policy makers without the help of the citizenry project? This is difficult to answer. However, it may be
addressed through Oregon's political history. Prior to OHD, little was done to change health care policy other than by incremental increases or decreases in funding. And the more recent increases had originally occurred as a result of OHD's predecessor, the Governor's Conference for the Medically Poor.

The real testing ground is yet to come. What might be successful on a community or statewide level, may not be on a national level. After all, it is there that the policy experts perhaps feel there is more to lose and are more subject to political affiliations, governmental constraints, moral psychology that leans toward an appetite for prestige and power, conformation of a specific organization and its values and bias and monetary or other gain. Yet, it is upon the Federal waters that the health care policy ship sailed astray and ran aground in a sea of out of control spending resulting from lack of any real goals and a lack of any real benefit besides cost effectiveness in its public health care policies. Perhaps, it is just this historical backdrop that will cause the Federal government to turn an open ear to its citizenry. If we as citizens speak a little louder, in an educated manner through a process like Oregon's, maybe we will be heard after all. And with that in mind, American Health Decisions (AHD) is on the horizon.

With its mission statement and purposes nearly identical to the community health decisions projects like Oregon Health Decisions, AHD would seek to become a national clearinghouse for CHD projects and their citizen consensus on issues. In October 1988, representatives from ten states with CHD projects came together to form American Health Decisions. The organization will seek to explore the possibility of acquiring a national consensus on health care issues, for
presentation to the national policy makers.

It is plausible that certain issues in health care, such as access of every citizen to basic health care services, could be obtained through a national consensus gathering education and survey program. Other issues such as how local and state dollars can be allocated to scarce health care services are best left to the citizenry of that local or state area. Populations of elderly in states like Maine, probably do not value funding of services in prenatal preventive care, but would value eyeglasses and preventive and management health care for specific chronic disease processes like Alzheimer's, or Chronic Obstructive Lung Disease. In Oregon, where a larger population of younger adults reside, prenatal care is a priority. I am not sure that we could reach a nationwide consensus on those issues.

Yet, on a state level, the open democratic process of citizen participation may well have made its way back into an environment that had given way to the thought that the country had gotten too big to listen to its citizens, and where the masses thought they were too spread out or too uneducated in the sciences to speak up and be heard anymore.

What kind of relationship can we hope to foster between the federal and state levels? There will be questions of equity. Who will provide for a state population that suffers an economic catastrophe? Oregon faced a depressed economy before from a drop in the lumber industry. What if this happens again? Will the federal government be expected to step in and pay for all of the citizens who will join the welfare roles from loss of income? And what should be the oversight mechanism the federal government would employ to regulate the states? Or should there even be regulatory measures taken at all by the federal government? Perhaps
there are answers that can be agreed upon by both federal and state parties. A catastrophe fund, likened to the fund set up for natural disasters, could be available for states who might suffer an economic depression. An emergency medical pool, likened to the emerging medical insurance risk pools may be an alternative for individual states who may find a sudden rise of people needing health coverage due to a local catastrophe.

And what conclusion can we reach on the Community Health Decisions Project and its venture into a community bioethics movement? The following closing comments are offered.
Chapter III

CONCLUSIONS

Internally, the OHD project has had some flaws; but any new venture that involves a pluralistic and widely dispersed people will have flaws. Yet, the flaws appear minor and the OHD project has been successful in achieving their original goals. They not only have reached the intended population, but were able to obtain a consensus on given issues, have taken them to parliamentary proceedings and placed the resolutions in a priority list.

From here, the implementation phase took over and succeeded in bringing those priorities to the attention of the law makers. The results have been mentioned above. From a review of the literature as well as discussions with members of the OHD, I feel they have faithfully pursued their mission statement of desiring first education of the citizenry and then their input through an unbiased environment.

Earlier in this paper, general surveys and polls were assessed, revealing that they may be invalid for a number of reasons including: 1) biased due to presentation or wording of questions; 2) one-time polling without education as to the nature of the survey or its content; and 3) asking questions that solicit a particular response. By contrast, the survey used for OHD and other community health decisions projects were given after the participants heard a short introductory statement on the project's intent, viewed a film, and held discussions. All sessions in all
parts of the state used the same format, same information, same survey. Although OHD intended the survey to be an educated opinion poll rather than a scientific research tool, this process gave more validity to the outcome of values and priorities set down by the citizens.

From a more global view, the overall approach of the Oregon community health decisions project was based on the conviction that citizens are responsible for their society. In this particular case, they are responsible for addressing the problems of health care systems which form an integral part of a humane society. It is the conviction of the OHD project that these problems are too important to be left to hospitals, physicians, policy analysts, legislators, or the courts alone. In a national, as well as a world-wide perspective, this civic participation is plausible on many issues, but certainly none is so personal and life or death decisive as is the setting of health care priorities.

Medical-ethical issues will receive more adequate attention when, together with professionals, the users determine how health care systems can work to honor the values of individual autonomy, justice, dignity, compassion, and fairness, as well as medical benefit. The OHD affirms the right and responsibility of citizens to insist that their ethical values and preferences shape health care policies relating to actual medical treatment and the allocation of resources. One major outcome of this broad-based discussion would be the determination of the boundaries of adequate health care to which every citizen might claim a right.

The OHD project's orientation is to remain neutral and to be committed to fair civic dialogue. This in turn develops a base of
community support, creates open forums for community discussion (critical thinking), and finally, encourages movement from enhanced understanding to joint constructive action. Applying the Athenian model of citizenship, we would see both *phronesis* (practical reason) and *praxis* (action) as Aristotle conceived them. The significance of this is that Americans would be able to become co-makers of the health care policies affecting them, both to their moral and their medical benefit.

Although, so far as can be determined, each of the fourteen other projects in the community bioethics movement has followed a similar pattern of programs and activities as Oregon, each adapts to their program the particular social, cultural, and political circumstances of its own state or local area. Some projects focus primarily on informing and educating the public on ethical issues in health care, while others (like Oregon), combine their educational mission with activities designed to represent citizen opinion.

Perhaps civic participation is not viewed as necessary by citizens or politicians on all policy issues. One might think it ludicrous to form a consensus on the dispersion of utilities decisions mainly because a societal consensus already exists. When we turn on the switch we want our lamp to light up and when the garbage can is put out full in the morning, we expect to find it empty in the afternoon. How electricity is produced or where the trash goes to is not as yet so vital a concern for most people.

Utility policies thus revolve primarily around technological concerns—the most efficient means to produce a well-defined product. The desired end is a given, whereas in health services the product
is never clear. "Health" is difficult to define exactly, not to mention "quality of life." The relative efficiency of hydroelectric generators versus coal-fired plants in producing kilowatts of electricity can be measured precisely. Whether healthier hearts are more likely to be produced from hypertension screening programs or advances in open-heart surgery is a very open question. And obviously the process of providing health care services is difficult to separate from the outcomes desired. We not only want our treatments to make us well, we want to be treated humanely, fairly, with dignity and respect.

So these special characteristics of American health care, - the lack of a societal consensus regarding the goals of the health care system, not to mention the desired means to attain these goals,-create a need for a grassroots approach to policy making which is much less crucial in other sectors of public policy. The perspectives of health services academics, researchers, and philosophers must be tested in the fire of citizen moral deliberation before being cast into the mold of public policy. The first phase of the OHD process was intended to develop a set of broad value statements which would serve as a "litmus test" for subsequent specific recommendations. This was accomplished.

The literature supports the community health decision's concept. The reason for this may not be so obscure. Most of the literature concerning CHD is available through the project workers or supporters. However, there is certainly enough literature on the side of citizen participation in policy planning from political scientists to support the project as well.

The two common strands that I have seen running through other
community health decision projects with Oregon Health Decisions as their model, are, first, the goals of reaching a population, (be it a town, city, state, or nation) with education on bioethical issues; and second, facilitating discussions and then taking the resulting consensus to the policy makers. In Oregon these goals have been met successfully.

On a small scale, Oregon has led the way to what might become a major social revolution in health care planning and decision making on a national level. With American Health Decisions in its infancy, it may provide the real testing ground for how the community health decisions concept may influence the entire American society. Can the American people reach a consensus on given health care issues? Will the Federal arena be as receptive as the state arena has been?

These are questions that only time will answer as the American Health Decisions project materializes. However, it does seem plausible to me that the ultimate goal of having a national CHD "parliament" representing grassroots values can be accomplished. The major concern is whether an organization can possibly represent such a pluralistic society and accomplish this without bias or self-interest of its own.

In fact, from the literature I have reviewed on five other projects similar in nature to OHD, each has shown remarkably similar areas of concern and resolutions desired. American Health Decisions seeks to represent community health decisions projects by acting as a clearinghouse for these state community health decision projects. Its own mission statement and purposes are identical to Oregon Health Decisions so their intent to remain unbiased as much as humanly possible is believable.
Will the federal political arena be as receptive to these citizen participatory decision making efforts? Oregon is the first state to explore the border between precedent-setting, on one side, and over-stepping their responsibilities under federal guidelines, on the other. Oregon presently is requesting a waiver from Congress to change federal mandates for Medicaid categories and health service offerings in order that the state might implement their 1989 "Basic Health Services Act." From a summary attached to a packet inclusive of Oregon Senate Bills 27 and 935 (Oregon's Basic Health Care Services Act), which assures all Oregonians access to adequate health care, this statement was made:

We recognize that while the Oregon Basic Health Services Act will begin to realistically address the problems of access and cost in our health care system, this is not an issue that can ultimately be solved on a state by state basis. It needs a national solution. Oregon has pioneered the way in terms of honestly facing the issue of limits; of forcing society to make explicit resource allocation decisions; and in terms of developing a conscious and equitable public policy to guarantee access to the health care system. We have broad based public and professional support for the program within our own state but face stiff opposition in Congress to our request for a waiver. Part of this opposition stems from a lack of understanding about our program; part of it stems from the honest concerns that always accompany a new approach to a problem; part of it stems from special interest politics; and part of it, quite simply, stems from a refusal to recognize the limits facing our society in the 1990's. Whether or not we are granted our waiver in this session of Congress, we will continue to press the national debate. [from a packet sent from the office of Senator John Kitzhaber, Oregon Senate President]

Our country was built on grassroots citizenship, town hall meetings and consensus gathering. It has only been within a relatively short time that our technology and scientific advances have brought on the urbanization and bureaucratization that led to an unrepresentative type of governance. In a few words, we are only seeking to go back to the "basics" of allowing society's citizens to place their values up for consideration.
The Federal government has a history of setting policies, especially public welfare and health care policies and then dumping the program implementation into the arms of the states. As stated before, this has certainly caused some problems in the state arena as the federal guidelines have often been very ambiguous.

However, this time the consensus decision making is coming from the states and then making its way to the federal arena. If the states can pull together a consensus on any given issue, that should be a pretty powerful lobbying force. Oregon will not stand alone. Other states (Colorado, California, Washington, Vermont, Maine) which have adopted the CHD project as their own are preparing their own state legislators for similar bills. I think it will be only a matter of time before the Congress will have to lend their support.

But OHD and any of the other state projects like it will rise or fall based on the very thing that binds the community health decisions projects together - people. Without their involvement, often in a voluntary capacity, we go back to the policy-making mill as it has been, a few deciding for the many, setting policy aimed at cost/benefit ratios that only look at economic values and probably create more chaos in the long run.

Community Health Decisions is opening the door for many who never considered an active political role in health care or any other area for that matter. As each citizen is educated, one can feel he or she is better prepared to analyze and make decisions with which each can live.

In the health care field, by legal and ethical initiatives, we must provide patients with informed consent before performing a procedure. It
seems only fitting that with the development of health policy that will affect every citizen, that opportunity should be given people to be educated and allowed to contribute their opinions on policy priorities. Many people are involved in public policy outcomes either through payment of taxes or indirectly through the policy directives which may prevent them from receiving certain health care services.

Oregon has been persistent in their goals and serves as an example to other states and the nation as a whole. They have exemplified to us all that society has the right and therefore the responsibility to decide what is ultimately going to determine its fate. It most assuredly involves life or death decision making for many society members; and in fact, it involves decision making that will ultimately determine the fate of the health of the entire American society. On that premise alone, only its citizenry has the right to choose the priority guidelines for those decisions.

What of the plausibility of having such a project as CHD in Nevada? Interestingly, Nevada and Oregon have much in common geographically and demographically. In view of the lack of civic participation in the planning stages of the Nevada's Health Plan (1988-1992), and in view of the letter from Governor Robert Miller to prioritize both access to health care and to a good quality of health care, the State Health Coordinating Council seems to be lacking in plans to include the citizens in making the moral evaluations upon which these priorities will be based. From the evidence shared earlier in this paper, it is insinuated that the citizen's role in Nevada's health planning agenda, is only used to give a "rubber stamp" approval.
From my own experience, I do not see how present state guidelines foster citizen participation in Nevada's health planning. I found it difficult trying even to find the people responsible for setting up the health care planning for Nevada. Many of the people in the Department of Human Resources, although very cordial, were not sure to whom they needed to refer me. Herb Pevney of the SHCC committee was very helpful in giving me a historical picture of Nevada health planning, but the council as a whole is not available to the general public, except for poorly-attended public hearings.

Upon visiting one recent public hearing of Nevada's SHCC, I noted that all the attendees in the audience were health care provider representatives. I also saw that consumer membership on the Nevada SHCC is primarily represented by retired or other citizens associated with the provider community. As example, one member is the wife of a public health district administrator, another member is a former administrator of a long term care facility.

I am not suggesting that these people are any less consumers than Joe Businessman, but they are probably more vulnerable to bias and accessibility for "favor" voting. This is not to say they are guilty of this, they are just more vulnerable to it than an average citizen. Therefore, I am not convinced that this Council is any different than most governmental health care councils or committees which include consumers. This seems to agree with the study quoted earlier in this paper denoting that most "consumer" representatives are in some relationship to the health care professionals field. (Page 1 of this paper)

In all due respect to the Nevada SHCC, I would propose that they
include the citizens in a much more expanded role in the planning of the health care policies for Nevadans. Allowing the grassroots citizenry to assist in setting health care priorities by placing their values into the policy making process, can only enhance and verify societal concerns to the policy planners. It is my suggestion that the Nevada SHCC make a study of the Community Health Decisions Projects with an emphasis on Oregon. In coordination with the existing public and governmental agencies, a statewide citizens task force intended to look at bioethical medical issues facing Nevadans today would be most advantageous. Perhaps then, Nevada will join other states like Oregon in becoming the pioneers who change the health care policy setting agenda for a better health care future for our citizens.

In Oregon, the OHD project was created within the State Health Coordinating Council. In Colorado, four hospitals formed a joint venture and initiated "Colorado Speaks Out On Health." There is no evidence that any one type of approach is better than another. The most important factor is that the individuals who make up the main board and its committees are dedicated to the philosophy that it is of paramount importance to allow the values of the citizens to be expressed and discussed in health policy prioritization issues.

In accordance with this attitude it is vital to perceive the role of citizenship as active participation in a process that is enmeshed in an educational environment. Within this setting then citizenship can be nurtured and individuals can be empowered to discuss highly complex issues. The critical health issues facing Nevada today, warrant such a discussion from the very people who will live by the eventual policy
directives. Since very important issues (universal access, quality of care, and more) are on the agenda assigned to the State Health Plan developers, it seems fitting that Nevada's SHCC might want to lend its good offices to start such a community health decisions venture in Nevada.

To implement a citizens participatory program in health care planning brings with it a proposal to Nevadans as well. As citizens, not mere consumers, we have the privilege and responsibility to exercise our citizenship. One way in which each individual can activate this duty is to participate in policy planning that directly affects the person and his or her society in community action. This process, whether it takes place in a health care planning environment or otherwise, needs development and nurturing. To conclude I would once again turn to Murray Bookchin (1987) for my final remarks and for some guidance to each citizen, policy planner, and legislator involved in the policy making process. Bookchin says:

The development of citizenship, in effect, must become an art, not merely an education-and creative art in the esthetic sense that appeals to the deeply human desire for self-expression in a meaningful spiritual community. It must be a personal art in which every citizen is fully aware of the fact that his or her community entrusts its destiny to his or her moral probity, loyalty, and rationality. The very essence of state power and statecraft today is that the "citizen" is an incompetent being, indeed infantile and normally untrustworthy...

Nearly all municipalities have been fragmented by differences in economic status, pitting poor, middle, and wealthy classes against each other often to the ruin of municipal freedom itself...
The municipalist conception of citizenship, polis, assumes precisely the opposite. Every citizen is regarded as competent to participate directly in the "affairs of the state," indeed what is more important, encouraged to do so. Every means is provided, whether esthetic or institutional to foster participation in full and see it as an educative and ethical process that turns the citizen's latent competence into an actual reality. (259-160, italics mine)

I believe that people can rise above the constraints of urbanization and be heard again. Oregon believed in a grassroots participatory concept
and they put it to work in an age of scientific and technological dominance. The machines that prolong a vegetative state may one day lay dormant, and society may have long since surpassed what science and technology brought our way. We will hopefully have realized that we went too far, too fast, and demanded too much. And when we came to our senses, we were able to sit down as friends in action to decide a non-excessive means to share equitably the "medical commons" so that we all could have access to health care when needed.
APPENDIX ONE
INPUT

All resources needed for pure-rationality process

All data needed for pure-rationality process

1. Establishment of complete set of operational goals with weights

2. Establishment of complete inventory of other values and of resources with weights.

3. Preparation of complete set of alternative policies

4. Preparation of complete set of predictions of benefits and costs for each alternative

5. Calculating net expectancy for each alternative

A rational model of decision system

Source: Dye, Thomas, Understanding Public Policy, Prentice Hall, Inc. New Jers
4. Preparation of complete set of predictions of benefits and costs for each alternative.

5. Calculation of net expectation for each alternative.

6. Comparison of net expectations and identification of alternative(s) with highest net expectations.

OUTPUT

Pure-rational: policy

ions system
APPENDIX TWO
Instructions: Please check the appropriate line, or circle the number which best describes your answer. Try to answer the questions from a realistic perspective; consider these true situations, not as you might wish them to be.

Please Note: Many questions do not give you as much information as you would like. Rarely, in critical care cases, do physicians, patients, or family members have all the facts. Please try to answer as best you can with the information given.

For the Purpose of this Questionnaire, Our Definition of Critical Care is: Conditions in which:

a) a severe illness or injury threatens life, or severely lowers the quality of life,
b) a crisis demands intense treatment over a short period of time to protect life, limb, or major organs, or,
c) survival depends on use of life-sustaining measures, whether or not there is a crisis.

COMMENTS: We welcome your comments. Please use last page of questionnaire.
1. **Questions**

1. If I had an illness and there was little or no hope of cure, I would want to know the truth.

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2. If I become permanently unconscious and couldn’t eat normally, I would want my life maintained with artificial feedings.

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3. My physician has the duty to follow my wishes as a patient, even if he or she disagrees with me.

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4. If a serious disease, known to be terminal, has caused my heart to stop beating, I would want my doctor to try to revive me.

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5. I would want my life maintained by a breathing machine (respirator) even if there was little hope of my ever breathing on my own again. (Assuming I would remain mentally alert.)

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6. Major organ transplants are a worthwhile investment of health care dollars.

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7. There is a critical shortage of donor organs. I would support a law that assumes all suitable bodies are donors unless the next of kin refuses or the deceased left written instructions to the contrary.

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8. Medical preparations are necessary prior to the death of an organ donor. If a dying member of my family had left no instructions, I would want to be approached before their death for permission to use their organs for transplantation.

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9. Age is an important consideration in determining who should receive an organ transplant.

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10. If I had a newborn infant in intensive care, I would want the doctors to do everything they could to treat it, even if the child might survive with severe handicaps.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

11. As a parent, I would want the right to refuse treatment for my newborn infant if he or she is likely to survive with severe handicaps.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

12. As a parent I would want the right to refuse life-sustaining treatment for my handicapped newborn infant if he or she would be a serious burden on my family.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

13. Expensive life saving technology should be denied when a person lacks the ability to pay.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

14. I would be willing to have taxes raised to the point where no person would be refused critical care because of inability to pay.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

15. Expected quality of life should be a consideration when deciding whether someone is to be treated with critical care technology.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
16. Have you heard of the "Living Will?" (1) Yes (2) No

17. Do you have a "Living Will?" (1) Yes (2) No

18. Have you heard of a "Durable Power of Attorney?" (1) Yes (2) No

19. Do you have a "Durable Power of Attorney?" (1) Yes (2) No

20. A hospital that provides critical care should not be allowed to refuse treatment to a patient on the basis of inability to pay.
   
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

21. If a hospital becomes overwhelmed with patients who cannot pay, public funds from taxes should be made available to cover the cost of care.
   
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

22. All employers should be required to provide a minimum level of health insurance for their employees.
   
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

23. In a shortage situation, an individual who has money should be given priority over someone who does not.
   
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

24. I would support the decision to withdraw or withhold food and fluids from a member of my family if he or she refused them.
   
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

25. There are some lifesaving medical treatments that are so ordinary, usual, and basic that they should be provided by tax support to everyone, regardless of their ability to pay.
   
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

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26. There are lifesaving treatments which are so costly, unusual, and extraordinary that they should be restricted to those people who can afford to pay.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

27. If a family planned to institutionalize a newborn because of permanent handicaps, the financial burden upon society ought to be a consideration in deciding whether or not to undertake lifesaving treatment.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

**THIS STATEMENT APPLIES TO QUESTIONS 28 through 30:**

Colorado has a law which allows adults to appoint someone, in advance of a crisis, to make health care decisions for them if they become ill and unable to communicate.

28. Such a document should include the patient's wishes either to be an organ donor or to refuse to be an organ donor.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

29. Such a document should allow a person to decide whether to be fed artificially or to be permitted to die, if he or she would ever become permanently unconscious.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

30. Such a document should include the patient's wishes to permit or prohibit an autopsy.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

31. I would not want members of my family to be allowed to change my instructions concerning organ donation, withholding food or fluids, and autopsy instructions.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>No strong feelings one way or another</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
II. Demographic Information

1. Age ________

2. Sex: (1) Male ________ (2) Female ________

3. Marital Status:
   (1) Married
   (2) Single, Never Married
   (3) Single, Divorced
   (4) Single, Widowed

4. Number In Household (Permanent residents who rely on your financial support) ______

5. Biological Parent Living:
   (a.) Mother (1) Yes (2) No ______

   (b.) Father (1) Yes (2) No ______

6. Religious Affiliation
   (1) Protestant
   (2) Catholic
   (3) Jewish
   (4) Moslem
   (5) Latter Day Saints
   (6) Other

7. Educational Level (Check highest level finished)
   (1) High School/Vocational Diploma
   (2) College, 2 years
   (3) College, 4 years
   (4) Master's degree
   (5) Doctorate or Professional Degree

8. Combined Household Income Level (Check appropriate level)
   (1) under $5,500
   (2) $5,501-$11,000
   (3) $11,001-$25,000
   (4) $25,001-$50,000
   (5) $50,001-$75,000
   (6) $75,001 and over

9. Ethnic Background (Check one)
   (1) Black
   (2) White
   (3) Native American
   (4) Hispanic
   (5) Asian
   (6) Other

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10. Occupation:
   (1) Professional
   (2) Technical
   (3) Managerial/Administrator
   (4) Sales
   (5) Clerical
   (6) Craftsman/Foreman
   (7) Laborer (except Farm)
   (8) Farm Work
   (9) Service Work
   (10) Transport Equipment Worker
   (11) Operator (except transport)
   (12) Not employed outside the home
   (13) Student
   (14) Other

11. Please check which activities you participated in within the past two years:
   (1) Voted in political election, (any local or general election)
   (2) Put campaign sign in yard
   (3) Contributed to political campaign
   (4) Campaigned for a candidate
   (5) Hosted a campaign fund-raiser
   (6) No political activity

12. Have you personally faced a critical care situation with a family member, friend, or yourself?
   (1) Yes
   (2) No
   If so, who required critical care?
   (1) You
   (2) Parent
   (3) Spouse
   (4) Child
   (5) Other

13. In what city do you live? (Please write out)

14. What is your zip code?

15. Are you covered by Health/Medical insurance? (please check one)
   (1) Medicare
   (2) Employer's Plan
   (3) State or Local Government Plan
   (4) Military
   (5) Personal Insurance
   (6) Other
   (7) None

16. Have you completed this questionnaire before?
   Yes ________, No ________

17. Which hospital would you use if you needed to be admitted for care?
APPENDIX THREE
Oregon Health Priorities for the 1990s

Citizen Survey

Part 1. Background information

1. Where do you live? Name of Town: __________________________
   Name of County: __________________________

2. Age: ______

3. Sex: Male___ Female___

4. Do you work in the health care field? Yes___ No___

5. Education (check highest level finished):
   ___ High school/vocational diploma
   ___ College, 2 years
   ___ College, 4 years
   ___ Master's degree
   ___ Doctorate or professional degree

6. Political leaning (check which best describes you):
   ___ Politically conservative
   ___ Politically middle of the road
   ___ Politically liberal

Part 2. Overall state government priorities

The table below shows how the Oregon state government dollar currently is split among six areas (and an “all other” category). After reading which major programs are in each area, please put an “X” in one of the boxes on each line of the table according to whether you would like to have more money, the same amount of money, or less money spent in that area. Similarly, on the TOTAL line indicate whether there should be more taxes, the same amount of taxes, or less taxes to pay for all of these state government programs.

<table>
<thead>
<tr>
<th>Current</th>
<th>Desired</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>More $</td>
</tr>
<tr>
<td>Economic development and consumer services</td>
<td>8 e</td>
</tr>
<tr>
<td>Education</td>
<td>29 e</td>
</tr>
<tr>
<td>Health services</td>
<td>13 e</td>
</tr>
<tr>
<td>Human resources—non health-related</td>
<td>19 e</td>
</tr>
<tr>
<td>Natural resources</td>
<td>5 e</td>
</tr>
<tr>
<td>Transportation</td>
<td>10 e</td>
</tr>
<tr>
<td>All other areas</td>
<td>16 e</td>
</tr>
<tr>
<td>TOTAL State government spending</td>
<td>$ 1.00</td>
</tr>
</tbody>
</table>

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Part 3. Oregon health priorities

(1) Shown below are 16 “building blocks” for this state’s health care system. Please indicate what priority you would give to each of the blocks. Use these rules and guidelines:

- Assume that these priorities apply to all Oregonians, and that it is the role of government to assure that the highest-priority health services are available to everyone in the state.
- Put a “1” in the five blocks which you feel are the highest priorities.
- Put a “2” in the six blocks which you feel are the medium priorities.
- Put a “3” in the five blocks which you feel are the lowest priorities.
- Assume that the health care provided in each block is effective.
- Assume that your highest priorities would be first in line for newly available state government health care dollars, and that if cuts need to be made in government programs, they would be made first in your lowest priorities.
- Refer to a separate sheet for brief descriptions of the building blocks.
- Don’t be concerned if you think that you lack enough information to assign these priorities. Trust your feelings and personal experience.

<table>
<thead>
<tr>
<th>LIFE CYCLE</th>
<th>Infants</th>
<th>Children</th>
<th>Adults</th>
<th>Elderly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long term</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short term</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preventive</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(2) Looking specifically at one of the types of “Critical” health care, should Oregon state government pay for heart, liver, pancreas and bone marrow transplants for Medicaid clients?

- [ ] Yes
- [ ] No
- [ ] Don’t know

We welcome your additional comments.

How satisfied are you with the manner in which the meeting was conducted?

- [ ] Very satisfied
- [ ] Somewhat satisfied
- [ ] Not at all satisfied

What comments do you have on the issues that were discussed at this meeting?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
Oregon Health Priorities for the 1990s
Overall Results of Town Hall meetings
February—June 1988
(Percentages may not add to 100% due to rounding)

Number completing survey: 560

Part 1. Background Information
Ages:
- Under 25: 5%
- 25-44: 48%
- 45-64: 31%
- 65 and over: 13%

Sex:
- Male: 35%
- Female: 64%

Work in health care:
- Yes: 56%
- No: 41%

Political leaning:
- Conservative: 20%
- Middle of the road: 47%
- Liberal: 29%

Part 2. Overall state government priorities
Desired spending of the state government dollar:

<table>
<thead>
<tr>
<th>Area</th>
<th>More $</th>
<th>Same $</th>
<th>Less $</th>
<th>NR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Economic development &amp; consumer services</td>
<td>15%</td>
<td>53%</td>
<td>25%</td>
<td>7%</td>
</tr>
<tr>
<td>Education</td>
<td>51%</td>
<td>35%</td>
<td>9%</td>
<td>5%</td>
</tr>
<tr>
<td>Health services</td>
<td>69%</td>
<td>24%</td>
<td>3%</td>
<td>4%</td>
</tr>
<tr>
<td>Human resources—non health</td>
<td>31%</td>
<td>41%</td>
<td>23%</td>
<td>6%</td>
</tr>
<tr>
<td>Natural resources</td>
<td>27%</td>
<td>58%</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>Transportation</td>
<td>12%</td>
<td>57%</td>
<td>26%</td>
<td>6%</td>
</tr>
<tr>
<td>All other areas</td>
<td>2%</td>
<td>39%</td>
<td>51%</td>
<td>8%</td>
</tr>
<tr>
<td>TOTAL state government spending</td>
<td>33%</td>
<td>34%</td>
<td>7%</td>
<td>26%</td>
</tr>
</tbody>
</table>

Part 3. Oregon health priorities
(1) Priorities given to 16 "building blocks" for this state's health care system

<table>
<thead>
<tr>
<th>Life Cycle</th>
<th>Infants</th>
<th>Children</th>
<th>Adults</th>
<th>Elderly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical</td>
<td>Medium</td>
<td>HIGH</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>Health</td>
<td>Long term</td>
<td>Low</td>
<td>Low</td>
<td>Medium</td>
</tr>
<tr>
<td>Care</td>
<td>Short term</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
</tr>
<tr>
<td>Preventive</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>Low</td>
</tr>
</tbody>
</table>

(2) Looking specifically at one of the types of "Critical" health care, should Oregon state government pay for heart, liver, pancreas and bone-marrow transplants for Medicaid clients?
- Yes: 20%
- No: 41%
- Don't know: 32%

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APPENDIX FOUR
STATEMENT OF ETHICAL PRINCIPLES FOR HEALTH DECISIONS OF CITIZENS HEALTH CARE PARLIAMENT, 1984

* The pursuit of good health is a basic right and responsibility of every individual.

* Individuals are entitled to full information and liberty needed to decide on their own behalf about the use or refusal of available health services.

* When necessary, the authority to decide about using or refusing health services should pass from the individual to the individual's family and others closely involved in the individual's life; only as a last resort should the government make these decisions.

* Since the health of a nation's people is a top priority, society is responsible for organizing and financing a system of services, education, research and technological development to prevent disease, promote health and provide care to the sick and injured.

* Given limited resources, society should decide what constitutes the adequate level of health services that should be guaranteed to all.

* Community consensus should guide policies for allocating resources to health and controlling health care costs, and where necessary for rationing health care services.
A SUMMARY OF THE FINAL RESOLUTIONS FROM THE OREGON HEALTH DECISION'S CITIZENS HEALTH CARE PARLIAMENT

1. Autonomy and Dignity: Americans are facing a new range of life or death decisions where patient freedom, costs of care, quality of life and perceived liability make choices exceedingly difficult. Citizens fear they will lose control over decisions affecting their own lives should they become dependent on the health care system. Providers of health care increasingly fear litigation from unhappy patients and families. Third-party payors feel pressure from their constituents to stem the flow of resources into high-tech interventions that merely prolong dying. Providers and users of health care need to develop new customs and new legal forms relevant to this new technological reality. Recommended actions include:

- accomplish legal reforms that will broaden the scope of options in terminal care;
- conduct educational programs to alert the general public to existing legal supports for autonomy;
- form and evaluate institutional ethics committees in hospitals, nursing homes and communities;
- support, stimulate and publicize community-based programs that provide social and spiritual support for the terminally ill and their families;
- increase public and private third-party payment for hospice and other home care alternatives.

2. Prevention of Disease: Preventing disease makes better economic and ethical sense than trying to cure it. Disease prevention today, however, often involves individual life-styles not readily controlled by legislation. Thus, in addition to recognized public health measures, innovative ideas discouraging unhealthy behavior and promoting health need to be implemented in the health care system. Recommended actions include,

- intensify support for educational efforts aimed at the general public and at the school age population;
- explicitly include prevention in health policy concepts of "adequate" health care while increasing general access to health promotion and disease prevention programs;
- use taxes and other economic incentives to discourage injurious behavior and promote healthier life-styles;
- maintain adequate research about control of environmental hazards.

3. Access and Justice: Although most of our citizens have access to medical and hospital needs through private insurance or public programs, there remain gaps in the system that are ethically unacceptable. Recommended actions include,

- use appropriate quality-of-life criteria in individual and health policy statements;
- remove obstacles that keep children and pregnant women from receiving appropriate health care;
- develop a statewide insurance program to include those presently unsponsored for health care;
- remedy problems of physical access to health services;
- use cost-effectiveness data to set limits for care in high cost cases;
- encourage the mass media to report societal as well as individual aspects of dramatic health care stories.

4. Cost Control. Since health care spending is a major component of America's economic output, efficient use of collective revenue sources is a major task for socially just public policy. Recommended actions include,

- reform malpractice liability laws;
* develop guidelines for the prudent introduction of new procedures and technologies to be paid for by the third-party payors.
* maintain a system-wide perspective when devising specific cost-containment programs;
* use cost-benefit information to set priorities and payment policies for publicly financed health services;
* dedicate a portion of alcohol and tobacco tax receipts for county-based health programs.

5. Allocation for Fairness. Uses of public money should reflect the values of the communities whose funds are being spent. Society must decide what should be the adequate level of health care it will guarantee to all its members. Recommended actions include,
* create a legislative task force to define "adequate health care" through a process involving widespread public participation;
* use the definition of "adequate health care" to guide resource allocation for health including broadened coverage for the medically needy;
* increase funding for research on effective prevention;
* encourage third-party payors to cover a wider variety of alternative institutional, community-based and home-based health care services;
* stimulate active community participation in allocation decisions;
* discourage use of political influence to secure high-cost care in individual cases;
* encourage regional philanthropic foundations to support projects for determining community values related to health care.

TABLE 1
MEDICAID RECIPIENTS AND PAYMENTS BY ELIGIBILITY CATEGORY,
FISCAL YEAR 1980

<table>
<thead>
<tr>
<th>Basis of Eligibility</th>
<th>Recipients</th>
<th>Payments</th>
<th>Average Payment per Recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (thousands)</td>
<td>Percentage of total</td>
<td>Dollars (millions)</td>
</tr>
<tr>
<td>Age 65 or over</td>
<td>3,420</td>
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<tr>
<td>Blindness</td>
<td>92</td>
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<tr>
<td>Permanent and total disability</td>
<td>2,727</td>
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<td>7,004</td>
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<tr>
<td>Dependent children under twenty-one</td>
<td>9,283</td>
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<tr>
<td>Adults in families with dependent children</td>
<td>4,784</td>
<td>22.1</td>
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<tr>
<td>Other</td>
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<tr>
<td>Total</td>
<td>21,617 ²</td>
<td>100.0⁴</td>
<td>23,253</td>
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</table>

a. Payments are Medicaid vendor payments made to providers of service for care rendered to eligible individuals. Amounts include both state and federal share.
b. Categories do not add to totals because of a small number of recipients who are in more than one category during the year.
c. Detail does not add to total because of rounding.

In States which use a one month accounting period for categorically needy adults, persons with fluctuating income may be continuously eligible for SSI benefits but not for Medicaid. The following example illustrates this problem.

State X uses SSI criteria but requires a separate application for Medicaid and uses a monthly accounting period. Ms. Goldburg receives $200 in January, $200 in February, and $50 in March, while her neighbor, Ms. Wilson, receives $150 each of the three months. Both are eligible for SSI payments but Ms. Goldburg is not eligible for Medicaid in January or February, while Ms. Wilson is eligible in all three months.

<table>
<thead>
<tr>
<th>Month</th>
<th>Ms. Goldburg</th>
<th></th>
<th>Ms. Wilson</th>
<th></th>
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<tr>
<td></td>
<td>Income</td>
<td>Grant</td>
<td>Medicaid</td>
<td>Income</td>
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<tr>
<td>January</td>
<td>$200</td>
<td>$47.80</td>
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<tr>
<td>February</td>
<td>$200</td>
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<tr>
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<td>50</td>
<td>47.80</td>
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<tr>
<td>Total</td>
<td>$450</td>
<td>$147.40</td>
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# TABLE 3

Federal Expenditures Over Two Decades

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<td>251.3</td>
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<td><strong>118.4</strong></td>
<td><strong>196.6</strong></td>
<td><strong>326.2</strong></td>
<td><strong>579.5</strong></td>
<td><strong>757.5</strong></td>
<td><strong>945.3</strong></td>
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PERCENTAGE DISTRIBUTION

|                      |                      | National Defense | 49.0 | 40.6 | 40.0 | 29.2 | 29.4 | 29.2 | 25.7 |
|                      |                      | Welfare and Health | 20.7 | 23.2 | 26.8 | 41.8 | 43.3 | 44.9 | 44.0 |
|                      |                      | Veterans         | 5.9  | 4.8  | 4.4  | 5.7  | 3.7  | 3.2  | 2.6  |
|                      |                      | Education and Training | 1.1  | 1.8  | 4.4  | 4.9  | 5.3  | 2.9  | 3.1  |
|                      |                      | Commerce and Housing | 1.7  | 1.0  | 1.1  | 1.7  | 1.3  | 2.4  |      |
|                      |                      | Transportation   | 4.4  | 4.7  | 3.6  | 3.2  | 3.6  | 2.3  | 2.7  |
|                      |                      | Environment, Resources | 1.7  | 2.1  | 1.6  | 2.2  | 2.9  | 1.3  | 1.4  |
|                      |                      | Energy           | .5   | .6   | .5   | .7   | 1.1  | 6   |      |
|                      |                      | Community Development | 2   | 9.1  | 1.2  | 1.1  | 1.7  | 9   | 2    |
|                      |                      | Agriculture      | 2.8  | 3.3  | 2.6  | 5   | 3   | 8   | 2.7  |
|                      |                      | Interest         | 9.0  | 6.6  | 9.3  | 3.5  | 11.1 | 14.3 | 13.7 |
|                      |                      | Revenue Sharing  | 2.2  | 2.3  | 2.2  | 2.2  | 1.1  | .6  | 1.7  |
|                      |                      | International Affairs | 3.3  | 4.4  | 2.2  | 2.1  | 2.1  | 1.8  | 1.7  |
|                      |                      | Science and Space | 7.4  | 4.3  | 2.3  | 1.2  | 1.0  | 1.0  | 3.2  |
|                      |                      | General Government | 1.1  | 1.3  | 1.0  | 1.0  | 1.0  | 1.0  | 1.0  |
|                      |                      | Justice          | .4   | .4   | 5   | 3   | 8   | 6   |      |

*Figures do not total correctly because of offsetting receipts from various programs.

Table 4

* Percent of U.S. GNP devoted to health

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<td>11.0</td>
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Long-term trend

Percent of U.S. GNP devoted to Medicare and Medicaid

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<tr>
<td>%</td>
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</table>

Long-term trend

Percent rise in health expenditures versus consumer price index

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<tbody>
<tr>
<td>%</td>
<td>8.0</td>
<td>10.0</td>
<td>12.0</td>
<td>14.0</td>
<td>16.0</td>
<td>16.0</td>
<td>16.0</td>
<td>16.0</td>
<td>16.0</td>
<td>16.0</td>
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</table>

### Legend: CN = Categorically Needy

<table>
<thead>
<tr>
<th>Optional Services in State Medicaid Programs</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Eligibility</th>
<th>Categorical Need</th>
<th>Services Covered</th>
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<td>Medicare</td>
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<tr>
<td>Medicaid</td>
<td>Yes, No HMO or Medicare</td>
<td>Yes</td>
</tr>
<tr>
<td>SSI</td>
<td>Yes, No HMO or Medicare</td>
<td>Yes</td>
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</tbody>
</table>

**Basic Required Medicaid Services**

- Skilled nursing facility services and home health services for individuals 21 and over.
- Early and periodic screening, immunization, and intervention for individuals under 21.
- Family planning services and supplies.
- Psychosocial services.
- Nursing and auxiliary services.

**Optional Services in State Medicaid Programs**

<table>
<thead>
<tr>
<th>State</th>
<th>Eligible for Ages 60 and Over in Nursing Home Placement</th>
</tr>
</thead>
</table>

**Eligibility**

- Eligibility is determined by the State Medicaid office.

**Note:** Services and limits vary from State to State. This table is a general overview and should be consulted with the State Medicaid agency for specific details.

---

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<table>
<thead>
<tr>
<th>Service Category</th>
<th>Specific Service</th>
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<td>Urgent Hospital Services</td>
<td>A. Urgent Hospital Services</td>
</tr>
<tr>
<td>Emergency Hospital Services</td>
<td>B. Emergency Hospital Services</td>
</tr>
<tr>
<td>Intermediate Care Facility Services</td>
<td>C. Intermediate Care Facility Services</td>
</tr>
<tr>
<td>Short Term Nursing Facility Services</td>
<td>D. Short Term Nursing Facility Services</td>
</tr>
<tr>
<td>Outpatient Psychiatric Services</td>
<td>E. Outpatient Psychiatric Services</td>
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<tr>
<td>Chronic Disease Management Services</td>
<td>F. Chronic Disease Management Services</td>
</tr>
<tr>
<td>Case Management Services</td>
<td>G. Case Management Services</td>
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<td>Management Services</td>
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<td>Personal Care Services</td>
<td>I. Personal Care Services</td>
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<tr>
<td>Transportation Services</td>
<td>J. Transportation Services</td>
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<tr>
<td>Other Preventive Services</td>
<td>K. Other Preventive Services</td>
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<td>Preventive Services</td>
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<td>M. Diagnostic Services</td>
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<td>Screening Services</td>
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<td>Preventive Services</td>
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Note: The table above represents a list of services that may be covered by Medicaid in various states, with categories such as urgent hospital services, intermediate care facility services, and other preventive services.

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Source: Erdman, Karen and Sidney Wolfe, Poor Health Care For Poor Americans: A Ranking of State Medicaid Programs, 1987

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FIGURES
FIGURE 1

[Diagram showing infant mortality rates by race from 1950 to 1990. The graph indicates a decrease in mortality rates over time for both black and white populations.]

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