Quality of Life in Allocating Health Care Resources

principles adopted by the
Citizens Health Care Parliament
September 23-24, 1988
Portland, Oregon

Oregon Health Decisions

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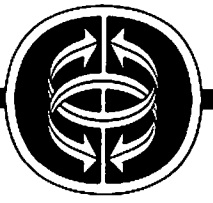

The problem...

Health care in Oregon and the nation faces critical choices. Many attempts have been made to cut health care costs, but spending in this area by both government and the private sector continues to increase much faster than growth in the general economy. Left unchecked, the burden of rising expenditures for private health insurance and public programs such as Medicare and Medicaid will lead to a growing inability of low- and middle-income Americans to receive health care, and siphon off tax dollars that could be used for other pressing social needs.

The real tragedy is that even though this country spends a far greater percentage of its gross national product for health services than does any other nation, this has not bought us either markedly improved access to health services or better health. The United States infant mortality rate ranks 19th among industrialized nations, and 37 million people do not have private or public health insurance.

Such anomalies in our health care system are becoming too painful to ignore. More money fails to bring more health. Wonderful advances in medical science are announced, but cannot be afforded by the people they are intended to help. While some Americans receive the best health care in the world, others get no care at all.

Oregon faces the same problems as the nation. In 1987 the state legislature ceased funding organ transplants, other than kidneys and corneas, for Medicaid clients. Money for these services was used to improve access to basic health care for many people. The widespread attention given this decision has opened up to public view the broad problem of health care resource allocation. As painful as the organ transplant controversy has been to both legislators and the people of Oregon, it has forced citizens to address the resource allocation problem forthrightly.

And steps toward a solution

In 1987 Oregon Health Decisions, a private non-profit organization dedicated to citizen education and action on ethical issues in health care, undertook an ambitious project—*Oregon Health Priorities for the 1990s*—aimed at the problem of how to fairly allocate limited health care resources. A democratic process was developed for involving citizens in setting health priorities.

Nearly 600 citizens at nineteen meetings throughout the state went through the process. Surveys completed at those meetings revealed that preventive care for infants, children and adults were three of the top five priorities—the other two being long-term care for the elderly and critical care for children.

In the meetings, the surveys became a gateway to a more basic question: *why* do people value a particular health service over another? Discussions about the balance in health services between length and quality of life led to the development of draft public policy principles for health care resource allocation. In September 1988 these principles were debated, amended and approved by delegates to a Citizens Health Care Parliament.

These 50 delegates were drawn from three sources: people who participated in the community meetings (24), appointments made by county commissions (15) and representatives of citizen groups with an interest in health issues (11). After a day and a half of intense discussion, the delegates agreed upon fifteen public policy principles which are intended to be guideposts for the state legislature, insurance companies, and others concerned with health care resource allocation.

PRINCIPLES FOR HEALTH CARE RESOURCE ALLOCATION

Adopted by the 1988 Citizens Health Care Parliament September 23-24, 1988 in Portland, Oregon

Purpose of health services

(1) The responsibility of government in providing health care resources is to improve the overall quality of life of people by acting within the limits of available financial and other resources.

(2) Overall quality of life is a result of many factors, health being only one of these. Others include the economic, political, cultural, environmental, aesthetic and spiritual aspects of a person's existence.

(3) Health-related quality of life includes physical, mental, social, cognitive and self-care functions, as well as a perception of pain and sense of well-being.

(4) Allocations for health care have a claim on government resources only to the extent that no alternative use of those resources would produce a greater increase in the overall quality of life of people.

(5) Health care activities should be undertaken to increase the length of life and/or the health-related quality of life during one's life span.

(6) Quality of life should be one of the ethical standards when allocating health care resources involving insurance or government funds.

Why priorities need to be set

(7) Every person is entitled to receive adequate health care.

(8) It is necessary to set priorities in health care, so long as health care demands and needs exceed society's capacity, or willingness, to pay for them. Thus an "adequate" level of care may be something less than "optimal" care.

How to set health priorities

(9) Setting priorities and allocating resources in health care should be done explicitly and openly, taking careful account of the values of a broad spectrum of the Oregon populace. Value judgments should be obtained in such a way that the needs and concerns of minority populations are not undervalued.

(10) Both efficiency and equity should be considered in allocating health care resources. Efficiency means that the greatest amount of appropriate and effective health benefits for the greatest number of persons are provided with a given amount of money. Equity means that all persons have an equal opportunity to receive available health services.

(11) Allocation of health care resources should be based, in part, on a scale of public attitudes that quantifies the tradeoff between length-of-life and quality-of-life.

(12) In general, a high priority health care activity is one where the personal and social health benefits/cost ratio is high.

Who sets what priorities

(13) The values of the general public should guide planning decisions which affect the allocation of health care resources. As a rule, choices among available alternative treatments should be made by the patient, in consultation with health care providers.

(14) Planning or policy decisions in health care should rest on value judgments made by the general public and those who represent the public, and on factual judgments made by appropriate experts.

(15) Private decision-makers, including third-party payors and health care providers, have a responsibility to oversee the allocation of health care resources to assure their use is consistent with the values of the general public.

PURPOSE OF HEALTH SERVICES

1

The responsibility of government in providing health care resources is to improve the overall quality of life of people by acting within the limits of available financial and other resources.

This first principle addresses a basic question: why does government exist? And more specifically, why is government involved in providing and paying for health services? The short answer to both questions is that people live not only as individuals, but as members of a community. Thus governments should serve us by using public resources in ways that improve our quality of life beyond what we could accomplish by acting on our own.

Obviously there are limits to those resources available to government. Tax revenues rise and fall with the economy and changing political philosophies. Domestic and international problems repeatedly exceed the capacity of federal, state and local governments to deal with them. So the notion of limits is central to the issue of health care resource allocation. How does government use its limited dollars to most improve the health-related quality of life of people?

2

Overall quality of life is a result of many factors, health being only one of these. Others include the economic, political, cultural, environmental, aesthetic and spiritual aspects of a person's existence.

There are many things which give pleasure and meaning to our existence. These differ for each person, so government leaders have the difficult job of assessing what contributes most to the aggregate quality of life of the citizens for whom they are responsible.

While it may seem that health should be preeminent in this regard, consider this. What if a group of people were in perfect health, but their community had no police? Or no schools? Or no parks? Or no museums? Would they be willing to be a bit less healthy to have these things? Probably.

On the other hand, there is quite a bit of truth to the saying, "when you have your health, you have everything." For most of us, life seems pretty dismal when suffering even from a common cold. And obviously one must be living to have any quality of life at all. So to the extent that health services forestall death and aid people to function normally, they contribute substantially to our overall quality of life.

3

Health-related quality of life includes physical, mental, social, cognitive and self-care functions, as well as a perception of pain and sense of well-being.

No single definition of "health-related quality of life" is possible, for this concept must be approached from several directions, each providing a different perspective on what a fully-lived life means. This principle views health-related quality of life as encompassing seven areas of functioning and perception.

When this concept is brought down to practical terms, each area must be described in detail for quality of life to be objectively measured. For example, scales have been developed to assess how well people can care for themselves: dressing, eating, bathing, shopping and so on. Thus the effect of health services on both this and the other dimensions of health-related quality of life can be evaluated reliably on a "before and after" basis.

Health services, of course, are intended to affect directly only the *health-related* quality of life. *Overall* quality of life includes additional dimensions cited in Principle 2, such as economic and environmental factors. These other factors certainly impact people's health, but are largely outside the domain of the health care system.

4

Allocations for health care have a claim on government resources only to the extent that no alternative use of those resources would produce a greater increase in the overall quality of life of people.

How large a slice of the government budget pie should health services receive? This principle provides the answer—at least in theory. Funding should go to health care only to the extent that this produces a greater increase in people's overall quality of life than would funding some other government service. Thus the benefits of health programs must be assessed carefully against other societal needs.

Education, transportation, corrections, economic development, defense—each budget sector at the state or federal level contributes to the quality of life of citizens along with health services. Deciding how to allocate dollars among these areas is a complex and difficult task, which unfortunately is exacerbated by a lack of solid information about either the effectiveness of government programs, or the degree to which those programs are valued by people. At present, judging the extent to which policy-makers act in accord with this principle is difficult.

5

Health care activities should be undertaken to increase the length of life and/or the health-related quality of life during one's life span.

The broad goals of health care are two-fold: to preserve life and to enhance the nature of that life. Quantity and quality are intertwined in human existence, but separable to some extent. At one extreme, modern health care makes it possible to keep people alive in a persistent vegetative state. While their heart beats and lungs fill with air, never again will their brain serve them as thinking, feeling, communicating persons. Health care has increased their length of life, but not its quality.

At the other extreme, some medical services make people feel or look better (cosmetic surgery, for example) without affecting their longevity or basic health status. Alleviating symptoms of anxiety, or poison oak, similarly impacts the health-related quality of life—but seldom its quantity. Much of health care falls in between these extremes. To some extent health services often improve both the quality of our life, and our short- or long-term chances for living. It is important to keep these intertwined potential benefits in mind when assessing the value of health services.

6

Quality of life should be one of the ethical standards when allocating health care resources involving insurance or government funds.

Since enhancing quality of life is a prime goal of health services, this should be one of the most important criteria used to allocate health care dollars. For it is imperative to use limited societal resources so they do the most good for people. Health care that does not demonstrably improve quality of life is ineffective and inefficient, and should be reduced to a minimum. The only way to accomplish this is to focus on the value of the benefits which health services bring to people. This principle calls on those entrusted with community health dollars—insurance companies and government—to assure that services produce "the most health for the buck."

Personal funds are not mentioned in the principle because different ethical standards apply to the use of individual versus communal funds. Living as they do in a free country, people have a right to spend their own money in any legal way they choose, even for health services which provide little or no benefit. However, funds pooled for the benefit of many people must be spent more carefully, since dollars allocated for one person are not available for another. While it may seem unfair that the rich are able to obtain health services not available to insured workers or the poor, this is a basic feature of the American free enterprise system, and occurs worldwide, even in countries with national health plans.

WHY PRIORITIES NEED TO BE SET

7

Every person is entitled to receive adequate health care.

This principle clearly indicates that the goal of priority-setting is not to *limit* health care benefits, but to assure that as many of those benefits as possible are *made available* to people. Resource allocation becomes a concern only when there is a societal obligation to provide the service to be allocated. There is no public outcry about the maldistribution of diamond rings in homes across America, since this is not considered to be a basic human need. Only those who can afford a diamond ring are able to have one. On the other hand, society views basic education much differently. Every child is entitled to tax-financed schooling through high school—which is considered the boundary of "adequate" education.

Currently health care policy in this nation is a combination of free-market financing and a lip-service commitment to universal access. We tend to speak as if all people should be able to receive adequate health care just as they receive basic education, but typically we organize and pay for health services as if they were non-essential luxuries like diamond rings. This principle calls on society to reconcile words and actions. If we truly believe that adequate health care is as necessary as basic education, ways must be found to provide such care to every person in this state and nation.

8

It is necessary to set priorities in health care, so long as health care demands and needs exceed society's capacity, or willingness, to pay for them. Thus an "adequate" level of care may be something less than "optimal" care.

Health services do not have a blank check from society, though it may seem that way to businesses, private citizens and government officials trying to keep up with rising health care costs. These costs are increasing much faster than growth in the overall economy. Thus health spending is draining resources from both industry and government that could be used for other purposes.

However, there is no one "right" level of health care spending, just as there is no fixed definition of adequate health care. Availability of dollars for health services, and the services themselves, will fluctuate depending on such factors as economic conditions, consumer preferences, competing social needs and medical advances.

The key is assuring that the most important services always receive top priority in funding so long as health care demands or needs exceed available dollars. This is the only way to guarantee that health programs supported by pooled funds (insurance premiums or taxes) are administered fairly. People must not be denied health services that offer substantial benefits when less effective services *are* being provided.

HOW TO SET HEALTH PRIORITIES

9

Setting priorities and allocating resources in health care should be done explicitly and openly, taking careful account of the values of a broad spectrum of the Oregon populace. Value judgments should be obtained in such a way that the needs and concerns of minority populations are not undervalued.

Do health insurance companies often ask their individual policy-holders what services they want in a benefit package? Has the state or federal government done much to involve citizens in deciding the content of publicly-funded health programs? No. Of course, throughout society there often is a wide gulf between people and the institutions which attempt to serve them, but the life and death nature of health services makes it especially important to bring about direct citizen involvement in this area.

What is indicated is a shift toward "strong democracy". Citizens should be expected to do more than simply select representatives who make decisions for them. This is weak democracy. *Strong* democracy involves citizens directly in practical policy choices.

Elected officials and government administrators are servants of the public will, not masters of it. Policy-makers are held accountable for their health care resource allocation decisions—accountable both for making decisions explicitly and openly, and for founding them on widespread citizen values. This admittedly is a lofty goal, requiring the creation of new mechanisms for citizen participation, yet it offers the best hope for making lasting improvements in our nation's health care system.

10

Both efficiency and equity should be considered in allocating health care resources. Efficiency means that the greatest amount of appropriate and effective health benefits for the greatest amount of persons are provided with a given amount of money. Equity means that all persons have an equal opportunity to receive available health services.

Efficiency speaks more to the mind, and equity more to the heart. Efficiency says, "Work to produce the most cost-effective health services. Make every dollar count." Equity says, "Strive to make health services available to everyone. Don't leave anyone out." Together they provide a sound framework for setting health priorities. The difficulty lies in giving each its proper emphasis.

To better understand this dilemma, consider basic education. If our goal was to raise the overall level of education among children in the most cost-effective manner, then expensive special programs for those with learning problems would be eliminated. For money spent on them likely would produce more "educatedness" if spread out among the general school-age population. Fortunately, we are willing to tolerate some inefficiency so children with unique needs are not left out of the educational system.

Another aspect of the efficiency/equity issue can be seen when identified individual lives are at stake. Rescuers will spend vast amounts of money to save a person trapped in a well when logic argues that more lives could have been saved if that same money were spent differently. The point seems to be that whatever our minds decide, our hearts must be able to live with.

11

Allocation of health resources should be based, in part, on a scale of public attitudes that quantifies the tradeoff between length of life and quality of life.

The need for such a scale derives from Principle 4, which states that health care activities should increase the length and/or quality of life, and Principle 10—which says that cost-effectiveness should be one of the considerations in allocating health care resources. How does one assess the overall effectiveness of a health service when the potential benefits, length of life and quality of life, are so disparate? The former is a matter of years, the latter a matter of how well those years are lived.

Health researchers have developed a method of combining these benefits into a single measure of effectiveness. This approach is based on the fact that almost everyone would be willing to tradeoff some portion of their *length* of life for an increased *quality* of life. For example, one person might feel, "I'd rather have three years of good health when I can do what I want, than five years bedridden with constant pain."

One term for the measure that results from this concept is a "quality-adjusted life year". It is based on a scale that adjusts the chronological length of life for the quality of that life. This scale must be developed from surveys of the general public, for only they can tell policy-makers what value life and health has for them.

12

In general, a high priority health care activity is one where the personal and social health benefits/cost ratio is high.

Some people object to the use of quantitative methods in determining health care priorities because this seems akin to putting a price on life. However, assessing the benefits and costs of various health services in accord with these principles simply results in an ordering of those services by their effectiveness in improving people's health. The benefits—increased length and quality of life—are expressed in just those terms, not in dollars. No price is put on life.

Of course, legislators and other policymakers must then decide to what extent they wish to fund the prioritized health services. Since cost-effectiveness methods can only point to what health services will bring the most benefits to people at the lowest cost, decision makers must use their own judgment in determining the value of health care in relation to other social and economic needs. Cost-effectiveness analysis supports resource allocation decisions; it does not make them. Yet by determining the costs and benefits of health services in an explicit and open manner, better decisions should result.

13

The values of the general public should guide planning decisions which affect the allocation of health care resources. As a rule, choices among available alternative treatments should be made by the patient, in consultation with health care providers.

Underlying this principle is a recognition that the relationship between patients and health care providers is based on mutual trust, and must be preserved. Physicians, nurses and other health professionals should not be responsible for making the public policy resource allocation choices that determine what services are available to their patients. These are planning decisions which must be made by government and insurance companies in consultation with experts, and guided by the values of the general public who both provide the funding for, and are served by, the health programs.

Once those planning decisions are made, then eligible patients have the right to choose among available alternative services—naturally in close consultation with health care providers. The key word is *available*. A treatment cannot be selected if it is a service not provided by the health program. To some this may seem heartless and bureaucratic, but the alternative is worse: having no citizen control over the health care system. And when a service that produces minimal health benefits is cut back, another service that offers *more* benefits can be provided. Unfortunately, media and public attention tends to focus on particular, easily identified patients who are denied a low priority treatment, rather than the many unidentified people who consequently receive care.

14

Planning or policy decisions in health care should rest on value judgments made by the general public and those who represent the public, and on factual judgments made by appropriate experts.

The general public (including those who represent the public, such as legislators) and experts each have separate and distinct roles in making planning decisions that affect the allocation of health care resources.

The general public knows best what they expect of health services. Everyone understands what it means to be healthy or ill, and how much they value good health. For example, the question of how much pain and disability one would be willing to tolerate in exchange for several added months of life often arises in the care of terminally ill patients. Being a value judgment without a "right" answer, guidance on such issues must come from those who are living and dying—the public at large.

On the other hand, experts have an important role in providing policymakers with factual information concerning the benefits of specific health services. Physicians can estimate how a particular treatment typically will change the length and/or quality of a patient's life. When this information is weighed against the value the general public places on those health benefits, a sound planning decision can be made about the treatment's priority.

15

Private decision-makers, including third-party payors and health care providers, have a responsibility to oversee the allocation of health care resources to assure their use is consistent with the values of the general public.

Along with government, private decision-makers who administer pooled funds provided by individuals, organizations and businesses have an obligation to assure that their allocations of health care resources are consonant with public values. Furthermore, health care providers have such a responsibility. This may be a new concept, for physicians customarily have viewed that it is both an ethical duty, and a legal obligation, to offer their patients all potentially beneficial health services.

Yet, is a physician obliged to offer treatment options which are not available as a result of explicit and informed public policy decisions? Does this further an ethical health care system, or undermine it? Should health care providers be legally liable for the failure to provide a health service to clients of government or private health insurance programs, if that service is not included as a program benefit ?

These are difficult questions, but they must be faced squarely and discussed openly. Bold and creative solutions to the resource allocation dilemmas that face this state and nation must be sought. These principles have been established by the Citizens Health Care Parliament in that American spirit.

Checklist for policy-makers

Key concepts embedded in these principles provide a checklist for policy-makers. When facing a resource allocation decision involving a particular health service, they should ask these questions:

❑ *How many people are expected to benefit from the service?*

❑ *What areas of health-related quality of life will be most impacted by the service?*

- *physical*
- *mental*
- *social*
- *cognitive*
- *self-care*
- *perception of pain*
- *sense of well-being*

❑ *To what extent will the service increase people's health-related quality of life?*

❑ *To what extent will the service increase people's length of life?*

❑ *What will be the combined impact on recipients of this service when both length of life and quality of life are considered?*

❑ *What are the immediate and long-term costs of providing the service?*

❑ *What other health or non-health services are competing for the funds at stake?*

❑ *How do the benefits and costs of these other services compare?*

❑ *To what extent does the service promote equity in the distribution of health care?*

❑ *How specific and objective have been the data provided to address the questions above?*

DELEGATES
Citizens Health Care Parliament
September 23-24, 1988 • Portland, Oregon

Note: right-hand column shows delegate affiliation. No entry indicates community meeting attender. "___ County" indicates county commission appointee. Others were representives of indicated health-related organizations.

Deborah Abramovitz	Tigard	
Bea Brock	Lakeview	Lake County
Katherine Broderick	Portland	Multnomah County
Sue Cameron	Tillamook	
Dorin Daniels	Ontario	
Sister del Rey	Bend	
Ellen Dennis	Salem	Human Rights Coalition
Karla Dickinson	Portland	
Katherine Eaton	Eugene	Lane County
Kathy Ellis	Tillamook	
Tom Gallagher	Portland	Human Services Coalition
Bill Gordon	Portland	United Seniors
Don Green	Joseph	Wallowa County
Jan Hamilton	Eugene	
Harold Hazelrigg	Lincoln City	
Ann Helm	Lafayette	
Lynn Huntington	Sisters	Deschutes County
Sandy Huston	Medford	Jackson County
Craig Irwin	Portland	Oregon Transplant Project
Julie James	Bend	Oregon Health Council
Thomas Johnson	Dallas	Polk County
Marjorie Killingsworth	Fossil	Wheeler County
Joyce Lear	Milwaukie	
Harry Lewis	Grants Pass	Josephine County
David Lindley	Baker	Baker County
Louise Magun	Portland	
Debra McFadden	Medford	
Marianne McGee	Milwaukie	Clackamas County
Norma McMillin	Newport	Lincoln County
June McMurdo	Corvallis	Benton County
Evelyn Miller	Portland	Human Rights Coalition
Richard Milsom	Portland	
Linda Modrell	Philomath	
David Olson	Portland	NW Foundation for Children

Betty Perkins	Ontario	
Rev. Wayne Pew	Lake Oswego	
Rep. Bob Pickard	Bend	
Ellen Pinney	Salem	Health Action Campaign
Marijo Poujade	Salem	Marion County
Charlotte Ramsey	Medford	Oregon Fair Share
Nan Rittall	Salem	
Hector Roche	Portland	
Terry Ann Rogers	Portland	Human Services Coalition
Carole Romm	Portland	
Lauretta Slaughter	Hillsboro	Black Health Coalition
Robert Smith	Eugene	
Christa Sprinkle	Portland	
Ian Timm	Salem	
Judith Tuerck	Aloha	
Jean Vercouteren	The Dalles	Wasco County

STEERING COMMITTEE

Oregon Health Priorities for the 1990s project

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Robert Adam	Portland	Intracorp
Barry Anderson	Portland	Portland State University
Hersh Crawford	Salem	Adult and Family Services Div.
Ralph Crawshaw	Portland	Physician in private practice
Jim Davis	Salem	State Council for Senior Citizens
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Vicki Gates	Salem	Dept. of Human Resources
Richard Gingrich	Portland	Physician in private practice
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Mike McCracken	Salem	Office of Health Policy
Terry Ann Rogers	Portland	Human Services Coalition
Barney Speight	Portland	Health Maintenance of Oregon
Alan Yordy	Eugene	Sacred Heart General Hospital

PROJECT STAFF

Ralph Crawshaw	Portland	Project director
Brian Hines	Salem	Lead staff
Mark Gibson	Salem	Legislative liaison
Peter Wotton	Eugene	Regional coordination
Joan Krahmer	Hillsboro	Admin. support/public relations
Adrienne Green	Portland	Admin. support/public relations

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This report was written and designed by Brian Hines.

Oregon Health Decisions

Address and phone

Oregon Health Decisions
921 SW Washington, Suite 723
Portland, OR 97205

(503) 241-0744
(800) 422-4805, in Oregon only

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